THE EFFECTS OF DISRUPTIONS IN CARE ON WELLBEING IN ORPHANS

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ABSTRACT

Christine Lynn Gray: The Effects of Disruptions in Care on Wellbeing in Orphans (Under the direction of Brian W. Pence)

Caring for the world's more than 150 million orphans and separated children (OSC) is a global priority. Current polices advocate deinstitutionalization, but recent evidence from low-and middle-income countries (LMICs) shows similar outcomes in institution-based and family-based care settings. We used data from the longitudinal POFO cohort of OSC from five LMICs to examine the effects of transitioning OSC from institution-based care to family-based care on incident abuse, emotional difficulties, and cognitive functioning among institution-based OSC. We characterized the familial adult structure among family-based OSC, and assessed associations between changes in that structure and wellbeing outcomes.

Among the 1,194 institution-based OSC in Aim 1, we found a small effect of transitioning from institution-based care to family-based care on incident abuse (risk ratio (RR): 1.2, 95% confidence interval (CI):0.58, 2.43; risk difference (RD): 0.01; 95% CI: -0.03, 0.05), a slight decrease in cognitive functioning (mean difference: -0.96; 95% CI: -2.17, 0.25) and a slight increase in emotional difficulties (mean difference: 0.24; 95% CI:-0.91, 1.39). For the 1,357 family-based OSC in Aim 2, up to 61.2% reported living with a mother, 12.9% with a father, and 45.4% with a grandmother during follow-up. Approximately 60% experienced at least 1 change in their familial adult structure over follow-up. Cumulative changes in the structure were not associated with incident abuse or cognitive functioning, but more changes were associated with a small increase in emotional difficulties (1 change: mean difference 0.23,

95% CI:-0.33, 0.79; 2 changes: mean difference: 0.57, 95% CI: 0.00, 1.16; ≥3 changes: mean difference: 0.73, 95% CI: 0.18, 1.29).

Global deinstitutionalization policies may not confer the presumed benefits of reductions in abuse and improved cognitive functioning, but the disruption may increase emotional difficulties. Changes in the adult familial structure for family-based OSC are not uncommon, and are associated with emotional difficulties.

This work is de	edicated to my p of education, i	parents, Kathy on the control of the	and Webster G nking, hard we	Gray, who taugh ork, and good h	t their children v umor.	values

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LIST OF ABBREVIATIONS

AIDS acquired immunodeficiency syndrome

CI confidence interval

DAG directed acyclic graph

GEE generalized estimating equations

HIV human immunodeficiency virus

IPW inverse probability weighting

IPCW inverse probability of censoring weight

IPOW inverse probability of observation weight

IPTW inverse probability of treatment weight

IRB institutional review board

LEC Life Events Checklist

LMIC low- and middle-income countries

MI multiple imputation

MSM marginal structural model

OSC orphaned or separated child

POFO Positive Outcomes for Orphans study

PTSD posttraumatic stress disorder

RD risk difference

RR risk ratio

SD standard deviation

SE standard error

SDQ Strengths and Difficulties Questionnaire

STI sexually transmitted infection

UNC University of North Carolina at Chapel Hill

UN United Nations

UNCRC United Nations Convention on the Rights of the Child

UNICEF United Nations Children's Fund

US United States

WWI World War I

WWII World War II

CHAPTER 1: STATEMENT OF SPECIFIC AIMS

1.1 Rationale

More than 150 million children worldwide have lost one or both parents, including 17 million orphaned by AIDS; additional millions are separated. The number of orphans and separated children (OSC) is increasing, particularly in areas such as sub-Saharan Africa and South Asia that have been disproportionately affected by the HIV/AIDS epidemic. OSC are vulnerable to substantial adversity including food insecurity², emotional and cognitive deprivation, stigma, exposure to traumatic events, and sexual risk behaviors resulting in HIV or other sexually transmitted infections (STIs).

As world leaders struggle to provide care for OSC, the appropriateness of institutional care has become a central question in international aid policy. Early studies describing institutional care of orphans documented severe abuse and neglect as well as decreased cognition among neglected infants.^{3,4,9} Although these studies were limited by small sample sizes, selective focus on destitute Romanian orphanages, and inability to make comparisons across settings, their impact has been far-reaching: International aid policies surrounding care for OSC are structured to minimize time in institutional settings or to eliminate institutions all together.¹⁰⁻¹³

More recent comparisons between the experiences of orphans cared for in institutions and in family-based settings revealed no overall differences between OSC in the two settings in physical growth, traumatic experiences, or cognitive, behavioral or emotional functioning. 14-17

These studies suggest that child characteristics and caregiving quality influence child outcomes more strongly than the simple dichotomization of institutional versus family-based care. The

findings imply that the global effort to eliminate institutional care settings may be removing a viable – and in some cases protective – placement option for the world's 150 million orphans. Yet, a recent *Lancet* review called for worldwide deinstitutionalization. ¹⁸

Despite the call for deinstitutionalization, it is unclear whether a transition to family-based care confers a benefit on key health outcomes, or whether family-based care offers a more stable care structure for OSC already in the family-based setting in low- and middle-income countries (LMIC). Families and communities in resource-poor settings are increasingly economically constrained, creating potential for less stable environments in terms of caregiving structure in the household and added tension for the child as caregiver burden increases. ¹⁹⁻²¹ The caregiving environment for orphans in family-based care in LMIC is not well-understood. The gaps in knowledge include understanding a) with which adult family members OSC are living, (b) the extent to which that familial adult structure is stable over time, and c) whether any instability in the familial adult structure is associated with long-term outcomes for the OSC.

As OSC age into adolescence and young adulthood, outcomes that have received comparatively little research attention assume increased importance. Exposure to sexual and physical abuse may put OSC at risk of a range of negative physical and mental health outcomes. Reduced cognitive function may restrict future wage-earning potential and general functioning as an adult. Emotional difficulties can increase risk of substance abuse, earlier sexual debut and multiple partnerships that may increase HIV or STI risk. Stability is considered essential for child development. Understanding how disruptions in care such as transitioning from an institution to family or shifts in the familial adult household structure may affect incident abuse, cognitive function, and emotional wellbeing are important for making decisions on orphan care.

The Positive Outcomes for Orphans study (POFO) is a longitudinal study conducted over nine years at six geographically, politically, and culturally diverse sites in five low-and-middle income countries (Cambodia, India, Ethiopia, Kenya, and Tanzania). Statistically representative samples of 1,480 family-dwelling OSC and 1,357 institution-dwelling OSC ages 6-12 at baseline were identified using two-stage random sampling. This research uses POFO data to 1) examine the effects of transitioning from institutional to family-based care on abuse, cognitive functioning, and emotional wellbeing; and 2) describe the familial adult household caregiving structure for family-based OSC, including stability in that household adult caregiving structure over time, and examine whether instability in the household structure is associated with the same outcomes.

1.2 Specific Aims

Aim 1: Estimate the total effect of transitioning from institutions to family-based settings on 1) incident abuse 2) cognitive functioning, and 3) emotional wellbeing. Rationale: Current policy is oriented toward moving children from institutions to family-based settings as quickly as possible. However, the transition itself is a major life adjustment that includes change in location, primary caregiver, and sibling structure, among other alterations to everyday life; the effects of transition are unknown. Hypotheses: Compared to children who remain in institutional-based care, those who transition to family-based care will experience higher incidence of abuse, lower cognitive functioning, and more emotional difficulties.

Aim 2: Characterize the familial adult household structure among family-based OSC, including stability over time, and examine the association between changes in that structure and 1) incident abuse, 2) cognitive functioning, and 3) emotional wellbeing.

Rationale: Little is understood about the familial adult caregiving environment into which family-based OSC are placed, the extent to which that adult familial structure is stable over time,

and how cumulative changes in that structure impact OSC wellbeing. Better understanding can facilitate more effective development and targeting of interventions to improve OSC outcomes. *Hypothesis*: Changes in the familial adult household structure, are associated with incident abuse, decreased cognitive functioning, and decline in emotional wellbeing.

Care for orphans is a major concern for leaders worldwide, particularly in areas greatly affected by the HIV/AIDS epidemic such as sub-Saharan Africa and South Asia. Current policy efforts to limit or eliminate institutional care are not supported by recent evidence, and the caregiving environment for orphans placed in family-based care is not well understood. Questions that may be consequential for OSC care, especially as they age into adolescence and young adulthood, remain unanswered. The high prevalence of abuse, concerns about diminished cognitive functioning, and vulnerability to emotional difficulties in this population warrant better understanding of the effects of care disruptions on these outcomes.

CHAPTER 2: BACKGROUND AND SIGNIFICANCE

2.1 Historical Context

Orphanages (here, used interchangeably with institution-based care) have been a feature of societies dating back at least hundreds of years, but their role in care for vulnerable children today is perhaps best understood through contextualization of the 20th century. Formalization of the rights of children began to take shape in the early 1900s. Reforms emerging from the atrocities of World War I (WWI) and the establishment of the League of Nations (1919, forerunner of the United Nations (UN))^{30,31} following the war included attention on protection-based rights for children. In 1924, the Geneva Declaration of the Rights of the Child was adopted, providing explicit international focus on responsibilities toward children.³² With World War II (WWII), the numbers of orphans and displaced persons increased dramatically, prompting additional global collaborations focused on children, including what we know today as the United Nations Children's Fund (UNICEF).³³ In 1989, the Convention on the Rights of the Child (UNCRC) treaty was adopted by the UN General Assembly; it specifies child rights including the right to life, to a name and national identity, and to a relationship with their parents.³⁴ The 196 signatories to the treaty are bound to it by international law.

In short, the 20th century marked a period of global affirmation that children had specific rights and that adults in general, and world leaders in particular, had a responsibility to protect children's rights. In the background of these efforts to protect children were geopolitical and economic realities that created the need for orphanages. Devastation and migration resulting from WWII, the ensuing Cold War, and civil wars and refugee crises in different parts of the

world left millions of children in need of care during the second half of the 20th century; that need persists today.

The discovery of the severe deprivation occurring in Romanian orphanages during the fall of the communist Ceausescu regime in 1989 put a spotlight on the inhuman conditions to which those children were subjected and garnered worldwide attention.³⁵ The regime had a pronatalist policy that outlawed abortion and contraception, and monitored and questioned women who were not conceiving; families could not support all of their children and placed them in state-run orphanages that were over-crowded and poorly managed.³⁶ The visceral images of malnourished children and infants in rows of cribs, unstimulated and barely alive, prompted widespread condemnation of institution-based care and a global response to place the children in adoptive families.^{35,37}

During the same period (1980s – 1990s), the AIDS crisis was emerging and wreaking havoc in low-and middle-income countries (LMICs), especially in sub-Saharan Africa. Already impoverished families were faced with disproportionate loss of life of adults in their productive years and additional economic instability. 38-40 The AIDS crisis both exacerbated and called attention to a growing population of orphans in LMICs. Even for children who had a remaining parent, that parent may also have been quite sick from HIV or otherwise unable to adequately care for the children in the household. This reality motivated UNICEF and other aid organizations to define children in these settings as orphans if they were "single" orphans (loss of one parent) or "double" orphans (loss of both parents) as a means of underscoring their needs. 41

2.2 Current Status and Critical Outcomes for Orphans in LMICs

The number of orphans and separated children (OSC) worldwide is substantial and disproportionately affects LMICs. In 2009, over 150 million children worldwide had been

orphaned by the death of one or both parents, including over 17 million AIDS orphans.¹ Millions more had been separated from or abandoned by their families,¹ occurrences which are often the result of poverty, war, or internal displacement.⁴² Leaders and policymakers need evidence-based strategies to provide OSC with quality care that provides a foundation for a healthy life trajectory.

LMICs in particular have disproportionate numbers of orphans and separated children (OSC), due in part to the HIV/AIDS epidemic. ⁴³ Much of the attention in recent years on OSC has been a function of the AIDS epidemic, and has prompted leaders to put substantial funding into addressing the needs of orphans and vulnerable children through the President's Emergency Plan for AIDS Relief (PEPFAR), ^{43,44} with attention not only on providing direct materials, but also on systems of care. ^{45,46} However, while the overall conclusion of a 2013 Institute of Medicine evaluation of PEPFAR was to recommend continued funding, ⁴⁷ separate studies have indicated that quality data on evidence-based strategies for systems of care for OSC are still needed. ^{48,49}

OSC experience substantial adversity, making them vulnerable to a range of negative experiences, including food insecurity, ^{2,50} stigma and discrimination, ⁵ and increased exposure to potentially traumatic events beyond parental death, such as physical or sexual abuse, family violence, or war. ⁶ Each of these in turn contribute to poor longer-term outcomes including decreased educational attainment, ⁵¹ psychological distress, ⁶ and, in some countries, increased HIV. ^{7,52}

As OSC age into adolescence and early adulthood, outcomes such as maltreatment, cognitive functioning, and emotional wellbeing become important indicators of overall health and wellbeing. Understanding how to achieve a healthy overall trajectory for OSC maturing

through adolescence and into early adulthood requires consideration of outcomes that cut across multiple domains of health. Maltreatment, increased emotional difficulties, and low age-adjusted cognitive functioning each contribute to a broader, overarching trajectory for OSC. Sexual and physical maltreatment can put OSC at risk for a range of negative health outcomes, including anxiety, depression, and behaviors associated with increased risk of HIV and other STIs. 6,22,53-55 Emotional regulation is necessary for long-term mental health stability; emotional difficulties are associated with poor mental health sequelae and lagged cognitive development. 24,56 Reduced cognitive function is likely to restrict general functioning as an adult, as well as future wage-earning potential, either directly or through lower educational attainment. 23,24

Key features of child development, including attachment and stability, are critically important for long-term positive outcomes. The importance to child development of secure attachment and a stable nurturing environment has been well described, 57,58 as have the consequences of the absence of that nurture and attachment. 4,59-63 Studies of severe deprivation during infancy in institutional care have contributed to understanding the long-term effects of early deprivation, including inability to sustain attention, poor working memory, and lack of inhibitory control and behavior regulation. A recent study reviewing both evidence from animal models and observational data on humans presented a hypothesis describing plausible biologic mechanisms for the negative effects of early deprivation on behavioral development in later adolescence. 8

2.3 Emerging Evidence for Orphan Care in LMICs

Many existing articles on OSC in institution-based care have documented severe abuse and neglect, concluding that institution-based care is not viable.^{4,9,69-75} However, those studies are primarily limited to Romania, where poverty and governmental impositions on families resulted in severe deprivation conditions.⁷⁶ A meta-analysis comparing institution-dwelling OSC

to family-dwelling OSC found lower IQ among institution-dwelling OSC; however the results did not hold for three of the four countries ranking low on the Human Development Index (HDI), a commonly used global measure of health, education and standard of living.⁷⁷

Furthermore, recent studies designed to compare OSC across care settings in LMIC have reported no differences between those in institution-based care and those in family-based care on multiple outcomes, cognitive functioning, physical growth, or emotional or behavioral. ^{14-16,78,79} Studies from the randomly sampled, longitudinal POFO cohort of OSC in five LMICs have also shown that trauma, including physical and sexual abuse, is highly prevalent in both institutional and family-based care; annual incidence of abuse is higher in family-based care (19.4%) than in institution-based care (12.9%). ¹⁷

A study in Kenya used the UN Convention on the Rights of the Child framework to understand the extent to which institution-based care and family-based care aligned with protecting children's rights. ⁸⁰ The researchers evaluated specific articles from the framework, such as the right to information; the right to health; the right to protection from abuse or exploitation; the right to know and be cared for by one's parents; and the right to education. Children were sampled from both institutions, many of which were charitable children's institution (CCIs), and families. Important needs for improvement were identified in both settings, but OSC in CCIs had more basic needs met, higher standard of living, and greater access to books. Corporal punishment was more prevalent in family-based care. ⁸⁰ A separate study in China similarly found that AIDS orphans living in orphanages reported a higher standard of living and better support than those living with families. ⁸¹

Reliance on family-based care has created substantial caregiver burden in resource-poor settings. In many LMICs, family-based caregiving often takes the form of child-headed

households, or results in placement with caregivers who do not have the resources to properly care for the orphaned child; case studies have described that such instances of inadequate care can result in failure to achieve educational aspirations, exploitation and even child trafficking. Exploitation and even child trafficking. Furthermore, several studies have documented substantial caregiver burden in LMICs when caregivers do not have the resources to support an additional child, including reduced economic security, missed work, poorer heath, and stress. These factors can create added household tension and, for the orphaned child, a sense that he or she is unwanted.

2.4 The Importance of Studying Disruptions in Care

As described above, the ability to form proper attachment has consequences into adulthood; children with secure attachment formation are able to forge relationships and effectively engage social supports.⁸⁴ A key aspect of facilitating secure attachment is to create stability in a child's care. Disruptions in care can threaten the security of the caregiving structure and have lasting impact. Certainly, in cases of maltreatment (e.g., neglect, physical or sexual abuse), disruption is beneficial, and with the right relationship supports, coping with some adversity helps children learn adaptation and regulation.⁸⁵

However, evidence suggests that in general, disruptions are negatively experienced as a departure from stability, and that instability can occur in several domains, including residential and family instability. ⁸⁶ Much of the existing literature is from the United States (US), but it indicates that disruptions can include residential moves as well as transitions in familial structure, both of which have been associated with worse behavioral, emotional and cognitive outcomes. ⁸⁷⁻⁹²

2.5 Limitations of Existing Studies

Existing studies of OSC transitioning from institution-based to family-based care are limited by selection bias and lack of generalizability to LMIC. The Bucharest Early Intervention

Project (BEIP) was a randomized trial of Romanian orphans living in orphanages known for severe abuse and neglect. Children were randomly assigned to remain in institutional care or moved to foster care; an additional never-institutionalized group was also followed. Results from the trial showed worse cognitive development, physical growth, emotional functioning, attachment, and neural development among the children who remained in the severely deprived and abusive institutions compared to those moved to foster care or those who were never institutionalized. 63,93-101

The English and Romanian Adoptees (ERA) study similarly examined outcomes of children reared in Romanian orphanages (described as ranging from "poor to abysmal")⁴ but adopted into families in the United Kingdom (UK). To control for the possible effects of adoption, the comparison group was UK children adopted into UK families. Several studies of this population showed that cognitive outcomes, attachment formations, and neurological imaging were worse in the Romanian adoptees who experienced severe institutional deprivation than the UK adoptees who did not, and that longer duration of deprivation yielded worse outcomes.^{4,74,102-107}

Both the BEIP trial and the ERA study were seminal in their documentation of the effects of early deprivation, as well as in the possibility for improvement when young children were placed into better care. However, neither reflected the heterogeneity of institutions, nor of families, making conclusions limited to Romanian children who entered orphanages known for severe deprivation as infants.

2.6 Current Policy and Gaps in Knowledge

Transitions from institution-based care to family-based care have not been studied in LMICs. However, current policy views institution-based care as a last resort, and advocacy to close institution-based care worldwide is increasing. A key objective of the 2012 U.S.

Government Action Plan for Children in Adversity: Framework for International Assistance is to "put families first" by reducing the number of children in institutions. ¹⁰⁸ In 2014, the Children in Families First (CHIFF) Act, which formalizes implementation of the Action Plan for Children in Adversity, was passed by the U.S. Congress to encourage family-based care. ¹¹ A recent *Lancet* review summarizing studies of institutionalized children concluded that: "With a robust evidence base to guide transformations, political will and social organisation are now needed to overcome remaining barriers to deinstitutionalization." ¹⁸ However, the studies cited in the review relied heavily on the BEIP and ERA cohorts referenced above, as well as government reports that were not peer-reviewed; the review did not discuss the emerging evidence that OSC in institution-based care in LMICs are not worse off than their counterparts in family-based care. The review also did not address the abuse that occurs in family-based settings, or how to protect against child-headed households, homelessness, or child trafficking that may result if the safety net of institution-based care is eliminated.

Furthermore, family-based care in LMICs is not well-characterized. Existing studies have described how families are economically constrained and increasingly overwhelmed by caregiving duties for disproportionate numbers of orphans. What remains unknown is how many OSC in LMICs are living with adult familial relations or the extent to which that caregiving structure is stable over time.

Understanding the effects of transitions from institution-based to family-based care on OSC wellbeing, as well as better characterizing family-based care, its stability, and the association of cumulative changes in the familial adult structure with OSC wellbeing, can provide important context for leaders and policy makers charged with protecting these vulnerable children.

2.7 Summary

Care for OSC is an urgent need, especially for countries disproportionately affected by AIDS, war, and other emerging crises (e.g., Ebola) that deplete resources while simultaneously increasing the number of OSC. Current policy is to use institutional care as a last resort 11,109 and to move children out of institutional care if at all possible, despite a growing body of evidence from LMICs that OSC in institution-based care are not worse off than OSC in family-based care. 14-16,78,79 Moreover, the move itself from one setting to another is a disruption that may negatively impact wellbeing outcomes. Knowing whether the move itself from institution-based care to family-based care has a positive or negative effect on key outcomes will help inform the appropriateness of current policy, and has the potential to broaden policymakers' perspective on viable care options for OSC. Furthermore, better characterizing the family-based care environment and assessing the stability of the familial adult structure with respect to OSC wellbeing will provide additional context for potential policies and interventions on OSC care.

CHAPTER 3: RESEARCH DESIGN AND METHODS

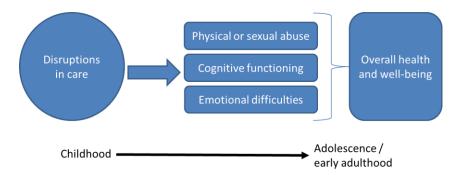
3.1 Overview

The overall goal of this research was to examine the role of disruptions in care on key adolescent indicators of health and well-being among orphans and separated children (OSC) in low- and middle-income countries (LMIC). Longitudinal data from the Positive Outcomes for Orphans (POFO) cohort study were used to estimate effects of care disruptions on three outcomes of interest: 1) incident abuse, 2) emotional wellbeing, and 3) cognitive functioning.

First, the effect of transitioning from institution-based care to family-based care on each outcome among institution-dwelling OSC was estimated (Aim 1). Second, the familial adult household structure was characterized among the family-based OSC and assessed for changes over time; those changes were related to each outcome (Aim 2).

Broadly, this study was conceptualized as an examination of outcomes that reflect multiple domains of health and wellbeing for OSC who are in adolescence or early adulthood. The examined outcomes are considered critical markers for a trajectory toward long-term wellbeing. In particular, disruptions in care during childhood and early adolescence were theorized to affect each of these outcomes in adolescence and early adulthood. Figure 3.1 depicts the overall conceptual framework for this study.

Figure 3.1 Conceptual model for the overall study



More specifically, the central hyptheses of this study were that both transition from institution-based care to family-based care (Aim 1) and instability in the familial adult household caregiving structure (Aim 2) adversely impact each of the outcomes of interest: physical or sexual abuse, emotional wellbeing, and cognitive functioning.

3.2 Parent Study Data Source

The Positive Outcomes for Orphans (POFO) study data were collected longitudinally for approximately 7 years of follow-up. Study enrollment took place between May, 2006 and February, 2008, depending on study site. Children ages 6–12 at baseline were enrolled based on their caregiving setting, institution-based or family-based care, using a two-stage sampling design at each of six study sites: Battambang District, Cambodia; Addis Ababa, Ethiopia; Hyderabad, India; Nagaland, India; Bungoma District, Kenya; and Kilimanjaro Region, Tanzania (Figure 3.2).

Figure 3.2 Map of POFO study sites



For the institution-dwelling sample, all institutions in each of the six regions were enumerated, excluding institutions dedicated to street children, adoption, or children with special needs. ¹⁴ The comprehensive list was randomized and institutions were sequentially approached until 250 OSC were enrolled, with a maximum of 20 children ages 6–12 randomly selected from any institution. In three sites, the maximum limit of 20 children per institution was removed to ensure the targeted total enrollment. In total, children from 83 institutions ranging in size from five to over 250 children were included in the study.

Family-dwelling OSC were identified by first dividing each geographic region into 50 clusters defined by geographic and administrative boundaries. Five age-eligible children in each cluster were identified through random selection of households based on available community lists or through house-to-house census to achieve the target of 250 family-dwelling OSC in each region. If more than one age-eligible child was in the home, the child whose first name came first alphabetically was selected.

Additionally, 50 non-OSC from each site were sampled as a qualitative referent group. The non-OSC were identified using the same geographic clusters as the family-based care sample; one household with non-OSC was randomly selected from each of the 50 clusters. These non-OSC were used as a qualitative referent for understanding the adult familial structure and changes in that structure among family-based OSC in Aim 2.

3.3 Study Population Characteristics

The full POFO cohort consists of 2,837 OSC (1,481 family-based and 1,356 institution-based OSC) and 300 non-OSC. Table 3.1 reflects the distribution of key characteristics (site, gender, and POFO enrollment) in the in the full POFO sample of institution-based OSC and the distribution among those included in Aim 1. Those included in Aim 1 had approximately the same distribution across sites as the full sample of institution-based OSC; the maximum difference was 2% in Hyderabad and Tanzania. The gender distribution varied by only 1%, and the age at POFO enrollment only varied by a maximum of 1% at each age.

Table 3.1 Characteristics of family-based OSC and non-OSC in the full POFO cohort and in the Aim 1 study sample

	DOEO A! 1					
		OFO	Aim 1			
	Institution-		Institution-			
	Based		Based			
		SC	OSC			
	(N=1)	1,356)	(N=1	l ,194)		
Characteristic	N	%	N	%		
Site						
Cambodia	156	12%	129	11%		
Ethiopia	250	18%	201	17%		
Hyderabad,						
India	250	18%	233	20%		
Kenya	250	18%	230	19%		
Nagaland,						
India	202	15%	165	14%		
Tanzania	248	18%	236	20%		
Gender						
Male	762	56%	684	57%		
Female	594	44%	510	43%		
Age at						
Enrollment						
in POFO						
6	150	11%	109	9%		
7	197	15%	168	14%		
8	215	16%	180	15%		
9	233	17%	204	17%		
10	275	20%	253	21%		
11	161	12%	159	13%		
12	125	9%	121	10%		

Table 3.2 reflects the distribution of key characteristics (site, gender, and POFO enrollment) of family-based OSC and non-OSC in the full POFO sample and in Aim 2. For family-based OSC, the maximum difference in site distribution was in Kenya, which was only 14% of the Aim 2 sample compared to 17% of the full POFO family-based OSC sample. That trend held for the non-OSC; the Aim 2 sample had 15% while the full POFO non-OSC sample had 17%. For both family-based OSC and non-OSC, the gender and age at POFO enrollment distributions were nearly identical between the full POFO sample and the Aim 2 study sample.

Table 3.2 Characteristics of family-based OSC and non-OSC in the full POFO cohort and in the Aim 2 study sample

	POFO Family-			m 2 nily-					
	Based			Based		POFO		Aim 2	
	O	SC	OSC		Non-OSC		Non-OSC		
	(N=1)	1,481)	(N=1,359)		(N=300)		(N=	271)	
Characteristic	N	%	N	%	N	%	N	%	
Site									
Cambodia	250	17%	238	18%	50	17%	48	18%	
Ethiopia	251	17%	227	17%	49	16%	40	15%	
Hyderabad	250	17%	250	18%	50	17%	50	18%	
Kenya	250	17%	193	14%	50	17%	40	15%	
Nagaland	229	15%	219	16%	50	17%	49	18%	
Tanzania	251	17%	232	17%	51	17%	44	16%	
Gender									
Male	777	52%	713	52%	154	51%	138	51%	
Female	704	48%	646	48%	146	49%	133	49%	
Age at									
Enrollment									
in POFO									
6	190	13%	169	12%	35	12%	31	11%	
7	222	15%	205	15%	61	20%	53	20%	
8	241	16%	221	16%	54	18%	46	17%	
9	233	16%	218	16%	62	21%	60	22%	
10	270	18%	250	18%	53	18%	49	18%	
11	212	14%	194	14%	27	9%	24	9%	
12	113	8%	102	8%	8	3%	8	3%	

3.4 Measures

A comprehensive self-report survey was administered to each child through in-person interviews at baseline and every six months for the first 36 months of follow-up. Four additional rounds of follow-up occurred approximately annually thereafter. Orphan wellbeing measures, including the incident abuse, cognitive functioning, and emotional difficulties outcomes in this study, were only conducted at baseline and annually throughout follow-up, for a total of eight measurements (baseline plus seven follow-up interviews).

3.4.1 Outcome definitions and assessment

As OSC age into adolescence and early adulthood, outcomes that signal long-term wellbeing become increasingly important. This dissertation examined three main outcomes that reflect domains of physical, intellectual, and emotional wellbeing: physical or sexual abuse, cognitive functioning, and emotional difficulties. Each outcome was assessed with respect to each of the exposures represented in Aims 1 and 2.

For the abuse and emotional difficulties outcomes, only children who were at least 10 years old at the time of a given interview were administered these questions. The exclusion of children under 10 was based on both pilot testing and IRB recommendations. ¹⁴ Thus, older children provided information on experiences of abuse and emotional difficulties starting at baseline, whereas younger children only started once they reached age 10. Cognitive functioning was measured regardless of age.

Physical or sexual abuse was measured at baseline and annually at an additional seven follow-up visits using 17 items from the Life Events Checklist (LEC). The LEC is an instrument developed by the National Center for Posttraumatic Stress Disorder to assist with detection of posttraumatic stress disorder (PTSD). The LEC was selected based on its wide use in a multitude of cultural settings and prior research along with its measurement of events predictive of anxiety, depression, and PTSD Children in the POFO study were asked about 17 "things I have seen and heard"; at each assessment they indicated whether the event had ever happened, and if it had happened, whether the event had happened in the last year, and whether the event happened once or more than once.

Among the 17 items assessed are four items that specifically address physical or sexual abuse: 1) "Been hit, kicked, or beaten at home", 2) "Been hit, kicked, or beaten by other children", 3)"Someone touched my private sexual parts when I did not want them to" and 4) "I

20

was raped or sexually molested." For this research, the outcome of interest was whether or not the child was abused either physical or sexually. The outcome was defined to match that of prior studies: the four items were collapsed into a single dichotomous variable indicating whether or not the child experienced any of the four possible abuses. 6,78,114,115

Both lifetime prevalence and annual incidence are captured in the LEC trauma questions. For both aims, incident abuse is the outcome of interest. Specifically, the abuse outcome was defined as experiencing (or not) any of the four types of abuse in the past year.

Cognitive functioning was measured at baseline and annually at an additional seven follow-up visits using the Market List. The Market List is a culturally adapted version of the California Verbal Learning Test (CVLT); memory and verbal learning are tested through recitation of items commonly seen in local markets. During administration of the Market List, an interviewer reads a list of 15 items from categories that match the CVLT: items a child eats, wears, or plays with. The child repeats back as many items as possible, and is scored from 0 to 15 based on the number of items recalled. Three trials of this test were administered and the average of those three scores was used as the continuous outcome variable to represent cognitive functioning. A higher score indicates better cognitive functioning.

During initial rounds of data collection, the Kaufman Assessment Battery for Children II (KABC-II) was also used.¹¹⁷ However, it was not used in later rounds, and an evaluation of both measures in the POFO population indicated that both could be used successfully in the LMIC setting.¹¹⁸ To fully leverage all rounds of data collection for this outcome, the Market List was used for both aims.

Emotional wellbeing, assessed as emotional difficulties, was measured at baseline and at an additional seven follow-up visits using the Strengths and Difficulties Questionnaire (SDQ).

The SDQ is a 25-item assessment tool used to evaluate the child's emotional and behavioral wellbeing, and pro-social behavior. The child is asked five questions in each of five domains (emotional symptoms, conduct problems, hyperactivity/inattention, peer relationships, and pro-social behavior) to self-report whether the statement presented is "not true," "somewhat true," or "certainly true." For scoring purposes, answers to the first four scales (20 questions) are assigned values of 0, 1, or 2 to contribute to a Total Difficulties score ranging from 0-40. 119-125 The Total Difficulties score was used as a continuous outcome variable to represent emotional wellbeing. A higher score indicates more difficulties and poorer wellbeing.

3.4.2 Covariate definitions and assessment

Several covariates were considered in one or both aims.

Site: Each of the six study sites (Cambodia, Ethiopia, Hyderabad, Kenya, Nagaland, and Tanzania) reflects a different culture, including different social norms and expectations, family and community structures, etc. Site is a time-fixed, nominal categorical variable that contributed to defining inclusion in the POFO cohort; it can be controlled as part of the survey sampling design or by indicator terms.

Gender: At baseline, each child's gender was recorded as male or female. Gender is a time-fixed binary variable used to control for the differential experience of males and females.

Age: Age (in months) was established at baseline and current age is calculated at each assessment using the baseline age and interview date. Baseline age is used as a time-fixed variable to control for expected differences in experience or functioning based on age. While age increases annually and is thus time-varying, it increases by the same unit for each child at each time point, essentially reflecting time, which was controlled separately.

Time: Time was measured in years, corresponding to the annual rounds of data collection.

Parental status: While orphaning (loss of one or both parents) is a defining criterion for inclusion into the POFO OSC cohort, parental death varies by child. OSC may have one, both, or neither parents deceased. The "neither" category exists for children who are permanently separated from one or both parents due to abandonment or other severe circumstances such as war or refugee crises, with no expectation of reunification. In that case, the parent may not be dead or death status may be unknown or unconfirmed.

Educational attainment: Educational attainment was measured at each round of data collection. To be meaningfully related to the child's expected attainment given his or her age, grade-for-age was calculated by assigning a value of 0 if the child was at the appropriate grade-for-age, and positive or negative values corresponding to the number of years ahead of or behind target, respectively. Educational attainment is a time-varying continuous variable that represents socioeconomic opportunity and is a predictor of future social, economic, and health outcomes.

History of physical or sexual abuse: As described in the outcomes above, abuse is measured using the LEC and assessed at baseline and annually during follow-up. As a covariate, abuse was assessed dichotomously as having ever experienced physical or sexual abuse. It was considered a time-varying binary variable.

Past emotional difficulties: The Market List, as described in 3.3, was also used to control for prior experience of emotional difficulties. It was used as a time-varying continuous variable.

Child health status: At each round of data collection, children were asked to rate their health status on a five-point scale ranging from "very good" to "very poor." This question is based on Short Form 36 health survey. 126 This time-varying ordinal variable was assessed as both a continuous and categorical variable to control for the child's general health.

3.4.3 Exposure overview

Each aim was defined by a unique exposure and examined with respect to each of the three outcomes; complete exposure definitions are detailed within each aim in subsequent sections (3.4 and 3.5). In brief, the Aim 1 exposure was defined as the transition from institution-based care to family-based care. For Aim 2, exposure was defined as cumulative changes in the familial adult household caregiving structure. The Aim 2 analysis included novel descriptive characterization of the family members with whom family-based OSC are living.

3.5 Aim 1 Methods

3.5.1 Inclusion and exclusion criteria

In Aim 1, the study population was the institution-based OSC. The analytic samples for each outcome in Aim 1 were slightly different. Children were excluded from interviews about abuse and emotional difficulties until they reached 10 years of age. For all outcomes, children were excluded if there was no data on abuse history during follow-up because abuse history was considered an important confounder for all outcomes.

Because incident abuse could not be observed until one year after baseline, and had an age restriction, the number of children eligible for this outcome during follow-up was smaller than other outcomes (N=1,152). The analytic sample assessing emotional difficulties (N=1,193) excluded children on whom there was no data for abuse history or no data for emotional difficulties; these two exclusions were almost entirely overlapping due to the common age restriction. Cognitive functioning was measured regardless of age, but emotional difficulties and history of abuse were considered important confounders of this association. Like the emotional difficulties outcome, the analytic sample for cognitive functioning excluded children on whom abuse history and emotional difficulties were never observed. Because cognitive functioning was

assessed as change from baseline, children on whom there was no baseline measure of cognitive functioning were also excluded; the analytic sample for cognitive functioning was N=1,180.

3.5.2 Exposure assessment and definition

The exposure for Aim 1 was transition from institution-based care to family-based care. At each round of data collection, interviewers documented where children were currently living and whether that location was an institution or the "community," which meant family-based care. In a very few cases, children may have spent part of the year in boarding school. Generally, those in boarding school were institution-based OSC whose education was supported by the institution. Since they were institution-based when not at school, they were classified as institution-based. For the purposes of this analysis, children were classified dichotomously at each round as being "institution-based" or "family-based."

The exposure was coded as a binary variable (0=not exposed, still in institution-based care; 1= exposed, transitioned to community/family-based care). We defined the transition exposure as "once exposed, always exposed." Therefore, once a child had moved to the community, they were coded as "1" for subsequent rounds of follow-up. Many children were transitioned because institutions were closed in response to pressure to support family-based care. Based on anecdotal evidence from study site coordinators, there was no expectation that any children later returned to institution-based care. The data supported these observations; we did not find evidence of children returning to institution-based care from family-based care.

Because OSC could be naturally aging out of institution-based care, we assigned a maximum age at which OSC could "transition." We used a cut-point of age 16 (<16 = eligible for transition; ≥ 16 = not eligible for transition) as our primary age threshold of interest because 16 is a common age at which OSC in the POFO sites may start transitioning to work or marriage.

3.5.3 Analytic approach

For Aim 1, the objective was to estimate the average causal effect of transition to family-based care on each of the three outcomes (incident abuse, cognitive functioning, and emotional wellbeing) among OSC who were in institutional-based care at study enrollment. There were very few transitions in type of care among family-dwelling OSC, i.e., OSC in the POFO cohort did not typically move from family care to an institution.

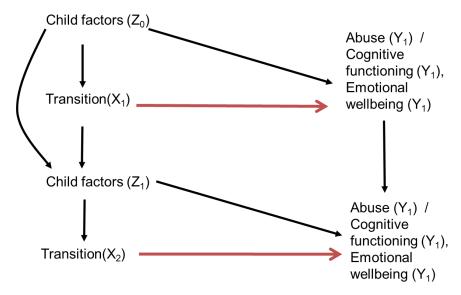
Because the data are observational, rather than collected through randomized assignment of treatment (exposure), causal interpretation is limited. In particular, causal inference requires meeting identifying assumptions of exchangeability (no unmeasured confounding), positivity (probability of exposure is greater than 0 and less than 1 at every level of modeled confounders), and consistency (treatment variation irrelevance). However, with careful design and analysis, conclusions will be similar to those reached via experiment. 128

We used a directed acyclic graph (DAG) to assess potential confounding and identified the following possible confounders for the emotional difficulties and cognitive functioning outcomes: study site, baseline age, gender, parental status, history of abuse, prior emotional difficulties, child health, and educational attainment. We identified the same confounders with the exception of prior emotional difficulties for the incident abuse outcome.

The longitudinal nature of this aim enabled repeated assessments of each of the three outcomes such that the child's dynamic outcomes over the course of study could inform the final effect estimates. Several of these variables were time-varying: history of abuse, prior emotional difficulties, child health, and educational attainment. Time-varying factors such as child health status and emotional difficulties could affect susceptibility to abuse or lower cognitive functioning, as well as the probability of subsequent exposure to disruptions in care; such factors

may also be determined by prior disruptions in care. A simplified DAG illustrating the timevarying confounding is presented in Figure 3.3.

Figure 3.3 Simplified Directed Acyclic Graph depicting time-varying confounding



Marginal structural models (MSMs) are a class of models often used to control for time-varying confounding, a situation that arises when a confounder affects the outcome as well as subsequent exposure, and prior exposure affects subsequent levels of the confounder. Standard adjustment fails in the presence of time-varying confounding because the time-updated exposure history represented in subsequent values of the confounder is blocked, preventing estimation of the total exposure effect; this failure to capture the total effect is analogous to controlling for a mediator. With MSMs, the association between confounders and exposure is removed, generally through a parametric or nonparametric approach to standardization, and the marginal probability of exposure is related to the outcome to estimate average treatment effects.

Specifically, inverse probability of treatment weighting (IPTW) is increasingly used to facilitate bias control through standardization in observational studies, often as an estimator for parameters in MSMs. ¹³¹⁻¹³³ The IPTW estimator enables creation of a "pseudo-population" in which observations are weighted, based on specified observed covariates, so as to achieve

balance in covariates across levels of the exposure. Effectively, the newly created pseudo-population is standardized to have the same covariate distribution in both the exposed and unexposed, thus adjusting for confounding (of measured variables). The weights are calculated as the inverse probability of exposure to upweight observations in which the predicted probability of having the observed exposure is low and down-weight the observations in which the predicted probability of having the observed exposure is high. Often, weights are stabilized by the marginal probability of exposure.

Overall retention in POFO has been quite high, with 82% and 78% participants remaining in the study at 36-month and 90-month follow-up, respectively. However, missing data points for multiple the visits in the longitudinal analyses exceeded a reasonable threshold (10%) for producing unbiased estimates if the data is not missing completely at random (MCAR). Complete case analysis, which only uses observations with complete information on variables included in the analysis, is a common approach for handling missing data because it is simple and is the default for most statistical packages. However, this approach requires an assumption that data are MCAR; otherwise estimates will likely be biased. Prior studies in other adolescent populations suggest that loss to follow-up is higher among sub-populations at greater risk of poor outcomes such as abuse, risk behaviors and educational achievement, suggesting that attrition in this study was unlikely to be MCAR.

To address missing data, we used inverse weights. The inverse probability weighting (IPW) approach to handling missing data only uses complete cases (rather than all observations, as multiple imputation does) but re-weights the complete cases such that they represent the original sample. We used two types of weights: inverse probability of observation weights (IPOW) to account for missed visits and inverse probability of censoring weights (IPCW) to

account for loss-to-follow-up. We considered a child lost to follow-up if they missed more than 2 consecutive visits, or if they were reported to have died.

Sampling weights that account for the complex study design and selection into the POFO cohort were incorporated into the final weights, which reflected the product of the IPTW, IPOW, IPCW, and the sampling weights. The exposure variable was lagged from the incident abuse outcome to ensure the changes occurred before the abuse, which reflected the prior year before the interview at which it was reported.

For the final marginal models, we used generalized estimating equations (GEEs), which enable estimation of parameters even when there is correlation between observations, as is the case with repeated measures on children. We used an autoregressive correlation structure, though GEEs are robust to misspecification of the correlation structure, unlike the alternative mixed model regression. As is common practice in application of the GEEs, the Huber-White sandwich estimator for robust standard errors was used.

For the incident abuse outcome, we estimated a weighted GEE with robust variance, binomial distribution and log link to account for repeated binary outcome observations to estimate risk ratios (RRs); a Poisson distribution was used if convergence was not achieved. The same approach with a binomial error term and identity link was used to estimate risk differences (RDs). For the cognitive functioning and emotional difficulties outcomes, a weighted GEE with robust variance, a normal error distribution, and identify link was used to estimate mean differences. In alignment with standard convention and expectation, all estimates used a 95% confidence interval (CI).

3.6 Aim 2 Methods

3.6.1 Inclusion and exclusion criteria

For Aim 2, the population was family-based OSC; we also assessed the non-OSC in family-based care as a comparison. In Aim 2, the exposure of interest was the familial adult household caregiving structure. Questions about the household composition were not asked until the second year of the study. Therefore, the analytic baseline for this aim was year 2 of the overall study, rather than enrollment date. We restricted Aim 2 analyses to family-based OSC (N=1,359) and non-OSC (N=271) who were observed at year 2; we observed them for an additional 6 rounds of follow-up until the end of the study.

As with Aim 1, only children who were at least 10 years old at the time of interview were asked about abuse or about their emotional difficulties. For Aim 2, the analytic samples for both incident abuse and cognitive functioning were the same (N=1,356) and the sample for cognitive functioning was the complete 1,359 available at analytic baseline since there was no age restriction. For each outcome, the non-OSC sample was the same (N=271).

3.6.2 Exposure assessment and definition

In Aim 2, we first characterized the adult familial household structure. This was based on a series of questions in which children were asked "Of the adults and children in your household, how many are your [mother, father, stepmother, stepfather, grandmother, grandfather]?" Children were also asked about non-relatives, but because we could not distinguish between adults and children, we could not assess nonrelatives as part of the adult household caregiving structure. Therefore, we limited the assessment to the six adult familial relations that were specified (father, stepmother, stepfather, grandmother, grandfather).

The question of interest was the stability of that adult caregiving structure and its relation to outcomes over time. Therefore, the Aim 2 exposure for analyses was cumulative change in

the familial adult household structures, which was related to the three wellbeing outcomes to examine associations.

The exposure was calculated in three steps. In step 1, we assessed "change" since last interview for each of the sex adult relations. If the children reported differently than the prior round in terms of the presence or absence of the particular relation, we coded the change as a 1; if status of that relation was the same, change was coded as a 0. Because the overall stability of the adult household structure was the question of interest, we treated both "gains" and "losses" equally; both were considered changes.

In Step 2, we summed the number of changes experienced across all six relations for each time point. Therefore, the maximum possible changes for any child at one time point was six. Finally, in Step 3, the number of changes was accumulated over time for each child, creating the "cumulative change" variable. Therefore, at each time point, the cumulative change variable reflected the total number of changes in the adult household caregiving structure since analytic baseline.

Each family member was treated equally because the importance of any particular relation may be variable by child, and while parents are assumed to have greater importance, there was no established metric for weighting or quantifying the value of one relation over another.

3.6.3 Analytic approach

As with Aim 1, we controlled for several potential confounders identified with a DAG: study site, baseline age, gender, parental status, history of abuse, and educational attainment.

Missingness exceeded 10% and MCAR could not be assumed. To address missing data for Aim 2, we used multiple imputation (MI), which enables leveraging of the information that is observed on incomplete cases. In Aim 2, there was more missingness on the exposure metric

than other variables, which would have resulted in loss of available information had another approach been selected. In MI, missing values are filled in by sampling from a probability distribution of the missing value conditional on specified observed covariates. This process is repeated over several imputed datasets and the final estimate is a mean of the imputed datasets, along with a standard error incorporating variability across datasets; the imputed information is incorporated into the final outcome model. 149

For this analysis, the Markov Chain Monte Carlo (MCMC) data augmentation algorithm in Stata was used to create 10 imputation datasets. MI datasets were created separately for each outcome because each had different inputs into the imputation.

The cumulative change exposure was categorized into four categories: 0 changes (referent), 1 change, 2 changes, and 3 or more changes to explicitly observe how numbers of changes were related to the outcomes. As with Aim 1, the exposure was lagged from the incident abuse outcome to ensure it temporally preceded the outcome.

GEEs with an autoregressive correlation structure and robust variance estimator were used to estimate associations between cumulative change in the familial adult household caregiving structure and each of the three outcomes. 147,148 Incident abuse was estimated using a Poisson regression model to estimate RRs and 95% CIs. Cognitive functioning and total difficulties were estimated with linear models and reported as mean differences and 95% CIs. Associations were estimated using the imputation structure which uses Rubin's rules to estimate standard errors. 150,151

CHAPTER 4: MARGINAL STRUCTURAL MODELS TO ESTIMATE EFFECTS OF TRANSITIONING FROM INSTITUTIONAL CARE TO FAMILY CARE ON WELLBEING OF ORPHANS IN LOW-AND MIDDLE-INCOME COUNTRIES

4.1 Introduction

Orphans and separated children (OSC) are among the world's most vulnerable populations. Their orphan status puts them at increased risk of food insecurity, ^{2,50} stigma and discrimination, ⁵ traumatic experiences, ^{6,17} psychological distress, ⁶ lower educational attainment, ⁵¹ and in some countries, diseases such as HIV. ^{7,52} Globally, the number of children orphaned by the death of one or both parents exceeds 150 million; ¹⁵² still more are separated from their parents through circumstances of abandonment, poverty, war, or internal displacement. ⁴² Protecting the human rights of children is a global imperative, formalized by the Convention of the Rights of the Child. ³⁴ However, placing these children in a care setting that will provide them basic needs, protect them from abuse and neglect, and nurture their development toward a positive life trajectory is a challenge for leaders, policymakers, and caregivers worldwide.

The two most common settings for OSC are family-based care and institution-based care. Family-based care can include the remaining parent, another relative, or placement with another family of non-relatives through official or unofficial fostering or adoption. Institution-based care can range from a small group home of children from a few different families raised by a non-biologically related caregiver to a larger facility of several hundred children. While orphanages often conjure images of Oliver Twist, there is wide variability in the size, structure, and quality of caregiving across institutions.

Current United States (US) policy strongly advocates family-based care and suggests institution-based care should be minimized or eliminated everywhere in the world. 11,108 This position is commonly held 153 and is supported by international organizations such as the United Nations Children's Fund (UNICEF). Advocates for the elimination of institution-based care primarily cite two key studies that document the effects of severe deprivation observed in Romanian orphanages. The Bucharest Early Intervention Project (BEIP) and the English and Romanian Adoptees (ERA) project were seminal in their observations of cognitive decline due to severe deprivation, as well as in their findings that such decline could be arrested or even reversed if a child was moved to an improved set of conditions (i.e., was provided appropriate stimulation and nurturing). However, these findings were based on observations of institutions selected for their severe deprivation; the BEIP and ERA studies were not designed to compare the variety of institution-based and family-based care settings in which OSC around the world live.

Yet, the conclusion of these studies was that the institutional setting per se, rather than neglectful and abusive care that occurred within the specific selected institutions, was the cause of poor outcomes. This conclusion – that all institutions are inherently and irrevocably worse than all families – has persisted despite randomized trials showing that outcomes can be significantly improved with caregiver training, including one in sub-Saharan Africa. 154,155

Furthermore, the largest multi-country study of OSC in low-and middle-income countries (LMIC), has shown that the average experiences of OSC in institution-based care are no different than OSC in family based care, 14,79 which is consistent with findings from other studies in LMICs. 15,16

In LMICs in particular, many families are already economically constrained; taking on additional children presents substantial economic and caregiving burden. ¹⁹⁻²¹ Transitioning children from institutions to family-based care, as is currently advocated, may itself present risks in terms of disrupting potentially beneficial caregiving conditions and potentially placing an orphan in a living situation with fewer resources or other unintended risks.

Our objective is to estimate the effects of transitioning from institution-based care to family-based care among OSC in LMIC. We use the Positive Outcomes for Orphans (POFO) study, the largest randomly sampled, statistically representative cohort of OSC in LMIC, to examine the effect of moving from institution-based care to family-based care is beneficial with respect to multiple indicators of child wellbeing.

4.2 Methods

Study population

The POFO cohort is a representative sample of OSC randomly selected from the OSC living in institution-based and family-based care settings in six study sites: Battambang District, Cambodia; Addis Ababa, Ethiopia; Hyderabad, India; Nagaland, India; Bungoma District, Kenya; and Kilimanjaro Region, Tanzania. In this analysis, we focused on 1,194 children who were in institution-based care at baseline. Study enrollment began in 2006 to 2008, depending on study site, and continued until 2015; OSC were followed for approximately eight years.

POFO participants were identified through a two-stage sampling process. First, institutions caring for OSC were randomly selected from a comprehensive list enumerated through government and community-based organizations, local leaders, and key informants in the study site regions. Second, age-eligible children were randomly selected from within each institution until 250 OSC in each site had been identified. A maximum of 20 children per institution was permitted; that restriction was relaxed in three sites to ensure the 250-child target

was reached.¹⁴ Additional details of the complex sampling design are described in a prior publication.¹⁴

Outcomes

This paper applies a whole-child approach that examines multiple facets of child wellbeing. Specifically, we focused on three outcomes: incident abuse, reported emotional difficulties, and changes in cognitive functioning.

Incident abuse was measured with the Life Events Checklist (LEC), a widely used 17item questionnaire that assesses traumatic experiences. The LEC has been used in culturally diverse settings. The LEC includes 4 questions addressing physical and sexual abuse, in which the participant indicates if they have experienced: 1) unwanted touching of private sexual parts, 2) rape or molestation, 3) being hit, kicked, or beaten at home, or 4) being hit, kicked or beaten by other children. Incident abuse was defined as experiencing of any of these four types of abuse in the past year. We coded incident abuse as a binary variable.

We defined emotional wellbeing using the "Total Difficulties" score from the Strengths and Difficulties Questionnaire (SDQ), a self-report scale that is commonly used across cultural settings to assess child wellbeing. 119-125 We calculated difficulties (rather than strengths) to align with prior studies in this population and common usage of the tool. 21,22,31,32 Children were provided 20 statements and asked to assess the degree to which the statement was true of them. Examples of difficulty items include: "I have many fears; I am easily scared," "I am constantly fidgeting or squirming," and "I get very angry and lose my temper." Children reported whether the statement was "Not true," "Somewhat true," or "Certainly true" of them. Responses were coded as 0, 1, or 2, respectively, and the sum of these values across the 20 items constitutes the

"Total Difficulties" score. The score is a continuous measure ranging from 0 to 40, where higher values reflect worse emotional wellbeing.

We used the Market List to assess cognitive functioning. The Market List is a variation on the California Verbal Learning Test (CVLT) and assesses memory and verbal learning. 116 Children are asked to recite back a 15-item list that is read to them by the interviewer. The Market List is culturally adapted and site-specific, mapping categories from the original CVLT to items familiar to participants from their local markets. The performance of the Market List was evaluated in a prior study in the POFO population, which determined it could be successfully used in non-standard settings. 118 The average of three trials of reading and reciting is calculated as the child's cognitive functioning score, which ranges from 0 to 15. We used change since baseline as our outcome measure.

Based on pilot testing and recommendations from the Institutional Review Board (IRB), questions about traumatic experiences and emotional difficulties were only asked of children at least 10 years of age. Because both of these measures serve as outcomes in this analysis, and are important potential confounders of the cognitive functioning outcome and potential predictors of missed visits and loss-to-follow-up, this analysis is limited to observations occurring after children were at least 10 years old.

Exposure

We defined our exposure as experiencing a transition from institution-based care to family-based care. At each round, interviewers documented whether the child was still living in an institution, or had transitioned to family care. Because children begin to age out of institutional care around age 16, we only counted transitions that occurred before age 16 as

exposures. This exposure was coded as a binary variable (1=moved to family, 0= still in institution).

Covariates

We used several time-fixed covariates: gender (male or female), age at baseline, study site, and orphan type. While all children in this study are orphans, we used indicators to describe whether they were single orphans (one parent deceased), double orphans (both parents deceased, or neither (the parent is not known to be dead, but has either abandoned the child or been permanently separated due to war, poverty or other circumstances).

We also used several time-varying covariates. Self-reported general health was measured at each round on a five-point scale ranging from "Excellent" to "Poor"; the question is commonly used on the Short Form 36 Health Survey. Sumulative history of abuse was measured as a time-updated binary variable reflecting whether or not the child had ever experienced abuse at each point in time, which is a predictor of future abuse and other negative outcomes. Grade-for-age was an indicator of educational achievement measured in number of years above or below target. In this study, the rounds of data collection reflect one-year time intervals. We used a continuous variable for time that indicated number of years since baseline. Statistical analysis

Our goal was to estimate the average treatment effect of transitioning from institution-based care to family-based care on three wellbeing outcomes: incident abuse, emotional wellbeing, and cognitive functioning. To do so, we constructed inverse probability weights to control for potential confounding, potentially informative missed visits, and potentially informative loss-to-follow-up, and estimated treatment effects using marginal structural models. The weighting approach is preferred in this case to traditional multivariable regression models as

it enables appropriate control for time-varying confounders that are influenced by prior exposures. 130,131,141,156

Weight estimation

We estimated inverse probability of treatment weights using potential confounders identified through examination of directed acyclic graphs. For the incident abuse outcome, time-fixed covariates included sex, study site, baseline age, and orphan status. Time-varying covariates included lagged cumulative history of abuse, lagged grade for age, lagged general health, and time. We used the same variables for the emotional wellbeing and cognitive functioning outcomes, but also included the last observed measure of emotional wellbeing as a predictor of both current emotional wellbeing and cognitive functioning.

We differentiated observation ("missed visit") weights from censoring ("lost to follow-up") weights to more precisely account for the variability in types of follow-up and potential selection bias that can occur. We estimated inverse probability of observation weights conditional on not being censored; observation weights were fixed once a subject was censored. Subjects were censored if they missed more than two visits in a row; censoring weights were estimated in the usual fashion. For each outcome, we used the same covariates for observation and censoring weights as were used in the treatment weights.

All weight models used third-order polynomials for continuous covariates. This decision was based on a balance of flexibly modeling covariates while assessing potential positivity concerns as well as the distribution of weights, as is recommended for the construction of weights. We assessed models with linear terms, squared polynomials, splines (cubic and quadratic), categories, and interaction terms for each weight model for each outcome.

All weights were estimated using pooled logistic regression. The denominator models included the covariates specified above. All models were stabilized by the marginal probability of exposure, observation, or censoring for each of the respective weight models. Our final combined weights (the product of the stabilized inverse probability of treatment, observation, and censoring weights) were truncated at the 1st and 99th percentile.

Sampling weights

Finally, we multiplied the combined treatment, observation, and censoring weight by the study-defined sampling weight assigned to each child based on their probability of selection from the source population into the POFO cohort from the target population.²²

Marginal models

We used weighted generalized linear models with a robust standard error to account for clustering within person to estimate the marginal effect of transitioning out of institution-based care on our three outcomes. We treated the exposure as permanent (once exposed, always exposed) for subsequent rounds of observation. For incident abuse, we estimated both relative risk and linear risk models to report the risk ratio (RR) and risk difference (RD). Because incident abuse was assessed over the past year, we lagged exposure to ensure the exposure occurred before period in which abuse could have occurred. For the total difficulties and cognitive functioning outcomes, we estimated mean differences. We report 95% confidence intervals (CI) using robust standard errors for each of the estimates.

This analysis was approved by the IRB at the University of North Carolina at Chapel Hill. The parent POFO study was approved by the Duke University IRB and local IRBs at each of the study sites. Local advisory boards at each site were established, and interviewers were trained on site-specific protocols for reporting concerns or observed abuse. Caregiver consent

and participant assent was ascertained until participants were old enough to provide consent directly. All analyses were conducted using Stata 14.¹⁵⁷

4.3 Results

Among the 1,194 institution-based OSC in this study, more than half (57%) were male and many (39%) had no living parent (Table 4.1). Across the six study sites, the distribution ranged from 11% in Cambodia to 20% in Hyderabad and Tanzania. The age at baseline enrollment ranged from six to 12 years old, consistent with the inclusion criteria for the overall POFO cohort.

A total of 155 (13%) children were transitioned out of institution-based care before age 16. Most transitioned between the ages of 13 and 15 (Figure 4.1).

The distribution of each set of weights for each outcome is included in Table 4.2. For treatment weights, incident abuse had greatest departure from 1 (mean weight: 1.04; range: 0.17, 52.2), but in the final truncated weight the mean was 1.01 (range: 0.14, 9.4). The final truncated weight for emotional wellbeing was 0.94 (range: 0.16, 8.2) and for cognitive functioning was 0.94 (range: 0.15, 9.0).

We observed a slightly elevated risk of abuse in children who transitioned (RR: 1.20, 95% CI: 0.58, 2.43; RD: 0.01, 95% CI: -0.03, 0.05), though the confidence intervals include estimates consistent with protective, null, and adverse effects (Table 4.3). We also observed slight increase in total difficulties (mean difference: 0.24, 95% CI: -0.91, 1.39). The difficulties score ranges from 0 to 40, and the mean score in this population was 8.5, suggesting the observed difference due to transitioning out of the institution is small. The effect of transition on cognitive functioning was more pronounced, with transition resulting in a mean decline of 0.96 (95% CI: -2.17, 0.25).

4.4 Discussion

We found small but negative effects of transitioning orphaned children from institution-based care to family-based care. For each of the wellbeing outcomes we assessed (incident abuse, emotional wellbeing, and cognitive functioning), transition out of institutional care resulted in slightly worse wellbeing: increased abuse, increased difficulties, and decreased cognitive functioning.

Notably, we did not find that transition to family-based care improved OSC wellbeing. These results contribute to a growing body of evidence indicating that institution-based care is not inherently worse than all family-based care. Past studies have documented the detrimental effects of severe deprivation and abuse on cognition and long-term wellbeing. However, those studies used a select sample of orphans in institutions known for their severe abuse and neglect. The institutions in our study were randomly selected, as were the children within them. This means that our estimates reflect the more representative, heterogeneous experience of OSC in institution-based care in LMICs.

We used robust epidemiological methods for minimizing bias and making inference on the average treatment effect of transitioning OSC out of institution-based care and into family-based care. In doing so, we controlled for potential bias due to confounding, missed visits, and informative loss-to-follow up. We note that our estimates are imprecise, and as such we examined the sensitivity of our estimates in multiple ways. We assessed adjustments in functional form of measured covariates, using only observation ("missed visit") weights instead of combined observation and censoring weights, and truncation. While the estimate was sensitive to these adjustments, the overall conclusion remained the same: there is little effect of transitioning OSC out of institution-based care, but the effect tends to be negative for their

wellbeing. Inverse probability weighting is sensitive to correct model specification; our estimates may have residual confounding bias.

Abuse and emotional wellbeing rely on self-report data. However, the LEC questionnaire for assessing traumatic experiences and the Strengths and Difficulties Questionnaire assessing total difficulties are commonly used measures across culturally diverse settings. 112,113,119-125 The POFO interviewers underwent substantial training and have gone to great efforts to build a rapport with the children over the course of the study so children were comfortable sharing their experiences. The Market List is interviewer-administered and has been evaluated and used in the POFO population and provides a locally adapted version of the CVLT used in the U.S. 79,118

The POFO cohort represents the largest multi-country cohort of orphaned and separated children available in low-and middle-income countries. The complex sampling design of the POFO cohort provides the most statistically representative sample available on which inference can be made about the target population of orphans in LMICs.

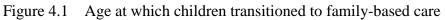
This is the first study to estimate effects of transitions from institution-based care to family-based care using a multi-country cohort randomly sampled to be representative of the orphan population in low- and middle-income countries from which the sample was drawn.

Using methods designed for inference, we found slightly negative effects of transition on orphan wellbeing. Current global policies strongly advocate that children be placed in family-based care rather than institution or group-home care, and this position is supported by calls for political will to eliminate institution-based care as an option. Our results indicate that moving children out of institution-based care into families does not necessarily improve their overall wellbeing. Eliminating institutional care would remove one of the care options available to vulnerable children, but may not confer the assumed benefits.

Table 4.1 Baseline characteristics of institution-based OSC

		Institution-based OSC (N=1,194)	
Characteristic		N	%
Site			
	Cambodia	129	11%
	Ethiopia	201	17%
	Hyderabad	233	20%
	Kenya	230	19%
	Nagaland	165	14%
	Tanzania	236	20%
Gender			
	Male	684	57%
	Female	510	43%
Age at baseline			
	6	109	9%
	7	168	14%
	8	180	15%
	9	204	17%
	10	253	21%
	11	159	13%
	12	121	10%
Orphan Type			
	No parents deceased*	212	18%
	Paternal orphan	118	10%
	Maternal orphan	402	34%
	Double orphan	462	39%

^{*}Children who were abandoned by or separated from a parent due to war or other crises with no expectation of reunion are classified as orphans



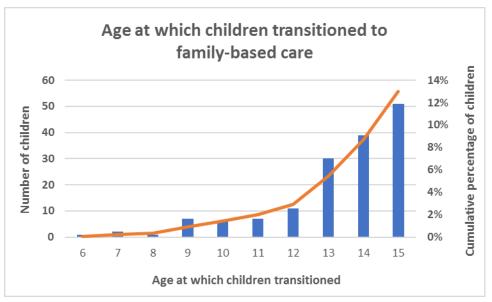


Table 4.2 Distribution of treatment, observation, censoring, and final weights for each outcome

	Treatment	Observation	Censoring	Final Truncated Weight*
Outcome	Mean (Range)	Mean (Range)	Mean (Range)	Mean (Range)
Incident Abuse	1.04 (0.17, 52.2)	1.15 (0.22, 29.5)	0.97 (0.37, 30.6)	1.01 (0.14, 9.4)
Emotional Wellbeing	1 (0.13, 12.9)	1.24 (0.18, 53.4)	0.94 (0.22, 27.7)	0.94 (0.16, 8.2)
Cognitive Functioning	1 (0.11, 10.7)	1.14 (0.18, 53.8)	0.94 (0.22, 25.7)	0.94 (0.15, 9.0)

^{*}The final weight was truncated at the 1st and 99th percentile

Table 4.3 Effects of transitioning from institution-based care to family-based care

Outcome	Estimate	95% CI			
Incident Abuse					
Risk Ratio	1.2	(0.58, 2.43)			
Risk Difference	0.01	(-0.03, 0.05)			
Total Difficulties					
Mean Difference	0.24	(-0.91, 1.39)			
Cognitive Functioning					
Mean Difference	-0.96	(-2.17, 0.25)			

CHAPTER 5: ORPHANS LIVING WITH FAMILY MEMBERS: STABILITY IN THE ADULT FAMILY STRUCTURE AND ASSOCIATIONS WITH ORPHAN WELLBEING

5.1 Introduction

The term "orphan" is defined by international aid organizations, including the United Nations International Children's Emergency Fund (UNICEF), as a child with either one or both parents deceased. As such, orphans may have a living parent, and may even reside with that living parent. As of 2016, the estimate of the world's orphan population was 140 million. Millions more children, called "separated," have been abandoned by or disconnected from one or both parents because of poverty, war, refugee crises, or other internal displacement stemming from civil strife within a country, with no expectation of reunification.

Low- and middle-income countries (LMICs) have disproportionately greater numbers of orphaned and separated children (OSC), in part due to the HIV/AIDS epidemic and its coupling with extreme poverty and civil conflicts. OSC are particularly susceptible to a multitude of adverse outcomes, including food insecurity, stigma, emotional and cognitive deprivation, traumatic events, and risk behaviors that can result in HIV or other sexually transmitted infections. As

These vulnerabilities, compounded by the disproportionate numbers of OSC, make caring for OSC in LMICs particularly challenging. OSC may be living in institution-based care (i.e., orphanages or group homes) or in family-based care (i.e., with a caretaker's family in the family home). Institution-based care is provided by non-relatives; family-based care may or may not involve relatives, including the remaining parent. Family-based care has been advocated in

United States policy,^{11,12} UNICEF reports,^{1,43} and scholarly papers¹⁸ as the only viable option for OSC care.

The emphasis on family-based care may be based on over-simplified assumptions of family-based care. For example, family-based care is generally thought to provide both a more stable and a more loving environment for children, and this paradigm makes sense under ideal conditions (economic stability, ability and desire to raise the child as one's own, absence of abuse, etc.). Increasing economic constraints on families and communities in resource-poor settings may prevent family-based care from being the stable caregiving environment it is assumed to be, and may create added tension for the child as caregiver burden increases. ^{19-21,82,83} More than half of family-based OSC experience abuse by age 13 and annual incidence of abuse is 19% in family-based OSC. ¹⁷

Familial stability has been more well-studied in the United States, and is considered a critical element of child development; transitions in familial structure have been associated with worse behavioral outcomes. R7-89 Understanding the family-based environment in which OSC in LMICs live is essential for identifying the supports requisite for a child's long-term functioning and wellbeing. A critical first step is quantifying how many family-based OSC are living with a remaining parent or relative, the extent to which that adult familial household structure is stable over time, and how changes in that structure relate to orphan wellbeing.

The Positive Outcomes for Orphans study (POFO) is a longitudinal and statistically representative cohort of OSC from six culturally and geographically diverse sites in five LMICS. In this study, we focus on 1,359 OSC in family-based care to characterize the adult family structure in their household, and the extent to which changes in that structure are associated with

three key outcomes that serve as markers of longer-term OSC trajectories: incident abuse, changes in cognitive functioning, and emotional wellbeing.

5.2 Methods

Study population

We used data from the POFO study, a longitudinal cohort of OSC randomly sampled from both family-based care and institution-based care in six study sites: Battambang, Cambodia; Addis Ababa, Ethiopia; Hyderabad and Nagaland, India; Bungoma, Kenya, and Kilimanjaro Region, Tanzania. Children ages 6-12 and their caregivers were enrolled at baseline (May 2006 – February 2008, depending on site), and followed until January 2015 – December 2016, depending on site. For this study, we used an analytic baseline starting at 12 months after enrollment because the exposure of interest was not measured until 12-month follow-up. For the measures in this study, children were interviewed approximately annually for a total of seven rounds of observation.

The complex sampling design has been described elsewhere. ¹⁴ Briefly, family-based children were selected by dividing each study site region into 50 clusters based on administrative and geographic boundaries; five children in each cluster were randomly sampled using available lists or house-to-house census until five households with age-eligible OSC were identified. A qualitative comparison group of non-OSC (one per cluster) was sampled in the same manner and provides context for the experience of non-OSC from the same regions; we include parallel analyses on non-OSC here. The sampling frame was not always known for the family-based children and thus sampling probabilities were not available to construct sampling weights. ¹⁴ Institution-based OSC (not reported in this study on family-based care) were randomly sampled separately.

Exposure: change in the familial adult household structure

The exposure for our analyses is cumulative change in the familial adult household structure. Specifically, we measured whether there was a change (gain or loss) in 6 key adult relations in the household since the last interview, and quantified the accumulation of those changes over time. We used a series of questions asking whether the study participant was living with each of the following adult relations presumed to be part of the caregiving structure: father, mother, stepfather, stepmother, grandfather, grandmother. The questions specifically ask, "Of the adults and children living in your household, how many are your...[mother, father, etc]."

We calculated the exposure in three steps. First, for each of the 6 identified adult relations, we defined "change" as reporting differently than the last interview. Because we were focused on stability of the household structure, we treated both gains and losses as "changes." For example, if a child reported living with their father at time 1 but not at time 2, then we coded "change in father" as a "1" at time 2. Similarly, if a child reported she or he was living with a stepmother at time 3 and again at time 4, then we coded "change in stepmother" as a "0" at time 4. Second, we created a variable for "total changes" that summarized how many of the 6 possible adult changes had been experienced at a given time point, for a maximum of 6 if a change occurred with each relation that round. Third, we created a "cumulative change" variable that accumulated over time to reflect the total number of changes in the familial adult structure the child had experienced up to that point across all 6 adult relations.

The available data did not enable identification of non-relative adults who may have been part of the household structure. Therefore, we did not consider non-relative adults in this analysis. We treated each relation equally, i.e., we did not weight or value, for example, parents over grandparents. To our knowledge, there is no established metric for doing so.

Orphan wellbeing: three distinct outcomes

We identified three outcomes essential to the overall wellbeing of OSC: incident abuse, emotional wellbeing, and cognitive functioning.

Incident abuse was defined using self-reported responses to questions on the Life Events Checklist (LEC), a 17-item inventory of traumatic experiences that has been used in diverse cultural settings. 112,113 The LEC was only administered to children if they were at least 10 years old, based on pilot testing and IRB recommendations. We used the four questions asking whether the participant experienced 1) unwanted touching of private sexual parts, 2) rape or molestation, 3) being hit, kicked, or beaten at home, or 4) being hit, kicked or beaten by other children in the past year. Endorsement of experiencing any of these four events in the past year was coded as "1" for incident abuse for this binary outcome.

Emotional wellbeing was defined using self-reported responses to the Strengths and Difficulties Questionnaire (SDQ). As with the LEC, the SDQ was only administered to children who were at least 10 years old. We focused on the 20 "difficulties" items, which is the most common usage of the SDQ, ^{120,121} and is consistent with prior studies in this population. ^{14,79} These 20 items include questions such as "I am restless; I cannot sit still," "I fight a lot," and "I have many fears; I am easily scared." Each item was evaluated on a three-point scale of "Not true," "Somewhat true," or "Certainly true," and coded as 0, 1, or 2, respectively; total difficulties scores can range from 0 to 40. The final score was a summation of the values across items. A higher score indicates worse emotional wellbeing for this continuous outcome.

Cognitive functioning was defined using the Market List, a culturally adapted, sitespecific version of the California Verbal Learning Test (CVLT)¹¹⁶ in which memory and verbal learning are assessed through recitation of items familiar to study participants in their local

markets. To preserve consistency with the original measure, items were identified from categories used in the CVLT (things a child eats, wears, and plays with). This measure captures short-term memory and attention, and was validated in prior analyses as a measure of learning that could be assessed with fidelity in LMICs. Interviewers read a list of 15 locally familiar market items to the participant, and tested the participant's ability to recall the items. We scored the Market List by averaging the number of items recalled in three trials of an interviewer reading and a participant repeating the 15-item list; mean scores can range from 0 to 15. We used change since analytic baseline as the outcome variable to account for the child's baseline functioning. A higher score indicates better cognitive functioning for this continuous outcome.

In each of the three analyses, we controlled for several covariates: gender, age, study site, time, parental death status, and history of abuse. Age in years was calculated by subtracting the interview date from the child's date of birth reported at baseline enrollment. Time is measured in one-year units that correspond with the annual rounds of data collection. While orphaning is a defining characteristic of inclusion in the family-based OSC group, the status of parental deaths is not the same for every child. For example, the child may be a single orphan (one parent remaining) or may have been abandoned or separated (and neither parent is known to be deceased). Therefore, we controlled for parental status ((neither dead (referent), single orphan, both dead). Because more than half of children in this population have experienced abuse by age 13,¹⁷ we controlled for history of abuse. History of abuse was defined by endorsement of any of the four physical or sexual abuse questions on the LEC, but was not subject to the "past-year" requirement of incident abuse. We coded it as a binary variable where "1" indicated ever having

experienced abuse prior to each interview and "0" indicated never having experienced abuse prior to each interview.

Statistical analyses

The exposure, cumulative number of changes over time, was categorized into 4 categories for statistical analyses: 0 changes (referent), 1 change, 2 changes, and 3 or more changes. Associations between the exposure and each of the three outcomes were assessed using generalized estimating equations (GEEs) to account for repeated measures. An autoregressive correlation structure was assumed and robust standard error estimates were used for inference. Associations with incident abuse were estimated using Poisson regression models and reported as risk ratios (RRs) and 95% confidence intervals (CIs). Because incident abuse is defined as "past-year," the exposure was lagged one round to ensure that it was measured prior to the interval for which the abuse was being reported.

The exposure was not lagged for the cognitive functioning or emotional wellbeing outcome models because these outcomes measured the child's state at the time of survey administration, so any reported household changes occurred prior to measurement of the outcome. Associations with the cognitive functioning and emotional wellbeing outcomes were estimated with linear models and reported as mean differences with 95% CIs.

Missing data, due either to incomplete observations or missed visits, were assumed missing at random (MAR), conditional on observed data. ^{163,164} Multiple imputation (MI) was used to account for missing data. In particular, the Markov Chain Monte Carlo (MCMC) data augmentation algorithm in Stata was used to create 10 imputation (complete) data sets for analysis. ¹⁶⁵ Point estimates and standard error estimates from the 10 completed data sets were combined using Rubin's method. ^{150,151}

All analyses were conducted in Stata 14.¹⁵⁷

The POFO study was approved by Institutional Review Boards (IRB) at Duke University and each of the study sites. Caregiver consent and child assent was ascertained at each round until the child was 18 and could consent for themselves. Interviewers were trained in site-specific protocols, which included local advisory boards to which abuse or other difficult situations were reported.

5.3 Results

Among the 1,359 family-based OSC in this study, approximately half (52%) were male, and the distribution across study sites was similar, ranging from 14% to 18% in each site (Table 5.1). More than half (56%) have a deceased father, and 17% have a deceased mother and father. Just under half (44%) were younger than 10 at the analytic baseline. The distributions in the group of 271 non-OSC were similar on these baseline characteristics (Table 5.1).

Familial adult household structure

Among the 6 adult relations identified, mother is the most commonly present member of the household (Table 5.2). At any given time point, 53% to 61% of children reported living with their mother. Presence of a grandmother was also common; at least 25% of children reported living with a grandmother at each round. Fewer reported living with a grandfather (10% to 21%) and still fewer reported living with their father (8% to 13%). Even if a father or mother was not known to be deceased, they could have been permanently removed from the child's life due to abandonment, separation during emergency crises, or other such circumstances; as such, the child may not have been living with the parent even if they are not known to be deceased. Living with stepparents was infrequently reported, less than 5% in most rounds. As expected, most non-OSC were living with both their father (79% to 95%) and mother (87% to 95%); up to 29%

reported a grandmother and up to 20% reported a grandfather in the household over the followup period.

Changes in the familial adult household structure

Approximately 60% of OSC experienced at least 1 change in the adult household structure over 5 years of follow-up (Figure 5.1). The total number of changes ranged from 0 to 11, with a mean of 1.6 and median of 1; nearly 10% experienced at least 5 changes in the familial adults present in the household. Non-OSC experienced a similar range (0 to 10), but somewhat smaller mean (1.4) and median (0); approximately 7% of non-OSC experienced at least 5 changes.

Distribution of outcomes

Among OSC, the average past-year incidence of abuse across all time points was 13%. The total difficulties score ranged from 0 to 31, with a mean of 8.0 and median of 7. The change in cognitive functioning score ranged from -9.7 to 10.7, with a mean of 1.3 and median of 1. Outcomes were similar but slightly lower among non-OSC. The continuous outcomes (total difficulties and cognitive functioning) were normally distributed in both OSC and non-OSC populations.

Associations with wellbeing outcomes

Among OSC, OSC, having 2 changes or ≥3 cumulative changes in the adult household structure was statistically significantly associated with greater total difficulties, and there appeared to be a dose-response with increasing numbers of changes and emotional difficulties (Table 5.3). Cumulative changes were not strongly associated with change in cognitive functioning; estimates showed very slight decline in cognitive score but were close to the null and with confidence intervals that included the null. Having one or two changes in the familial

adult household structure was associated with slight decrease in relative risk of incident abuse, but 2 or more changes was associated with slightly increased risk of abuse; associations were close to null. For non-OSC, overall trends in total difficulties and incident abuse were similar, but having more than 2 changes was slightly associated with increased (rather than decreased) cognitive functioning scores; for all outcomes, estimates were less precise among non-OSC due to the smaller sample size.

5.4 Discussion

We characterized the familial adult household structure of family-based orphans and separated children (OSC) in 5 LMICs. We further assessed the extent to which that structure changes over time and how those changes impact multiple wellbeing outcomes. Importantly, we found that most family-based OSC experienced changes in the presence of familial adults in their household during follow-up, and that those changes were associated with increased emotional difficulties. Changes were not associated with incident abuse or changes in cognitive functioning.

For comparison, we also assessed a small group of non-OSC sampled from the same regions. In general, the adult family structures for non-OSC were somewhat more stable over time, i.e., they experienced slightly fewer changes. The impacts of those changes were similar for total difficulties and incident abuse. The direction of association for change in cognitive functioning was opposite that of OSC for 2 changes and \geq 3 changes. However, the associations are still null, and are much less precise, and thus cannot be interpreted as meaningfully different from the associations in the OSC.

To contextualize our findings, several aspects of orphan care are important to consider. The economic constraints felt by families in LMICs, partly due to AIDS and partly due to war, poverty, and other crises, continue to be substantial. Furthermore, caregiver burden in LMICs

has been documented when caregivers do not have the resources to support an additional child; these factors create added household tension¹⁹⁻²¹ In this study, we were able to take a first step toward characterizing the stability of the familial adult household structure for OSC living in families. This is important in part because family-based care is often advocated as the only viable option for orphan care, ^{11,12,43,152,153} though family-based care for OSC has not been well-characterized in LMICs. Concerns with institution-based care, the alternative to family-based care, often center around instabilities in caregiving structure that are presumed to be stable in family-based care. Here, we have shown that the assumption of a static familial adult household structure in family-based care cannot be made.

Familial stability is considered important for child wellbeing and has been better studied in higher-income settings such as the US, ⁸⁷⁻⁸⁹ but has not been examined among OSC in LMICs. Existing studies have shown that changes, regardless of whether an adult is entering as a member of the household (a "gain") or leaving as a member of the household (a "loss"), the change itself is disruptive to emotional wellbeing. ^{88,89}

We found that more changes increased the emotional difficulties felt by children. Emotional difficulties reflect the degree to which a child is worried, relates poorly to peers, is afraid, and is distracted, among other difficulties. Aside from the immediate negative feelings of fear, worry, distraction, etc., emotional wellbeing is important for later outcomes including educational achievement and adult functioning. 166,167

While we have previously found high incidence of abuse in this population¹⁷ we did not find notable associations between instability (changes) in the adult familial caregiving structure and incident abuse. It is possible that some changes the familial adult household composition remove the threat of abuse, nullifying overall associations. It is also possible that abuse is not

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associated with changes in the adult household structure at the individual or population level. We also did not find associations with cognitive functioning. It is possible that cognitive functioning is generally robust to changes in familial structure changes. The Market List is advantageous in its culturally adaptive features, but may not have been sufficiently sensitive to detect change at this resolution. It may be that some amount of change is unavoidable, but additional research into which changes are particularly detrimental, and whether there are mechanisms for creating stabilizing supports, may shed light on opportunities for intervention.

This study had notable strengths, including six years of longitudinal follow-up on a hardto-reach, vulnerable population of children in LMICs. The relevance of our conclusions is strengthened by the random sampling design of the original POFO cohort. Further, our outcomes were assessed using validated, culturally tailored measures. 112,113,120,124,168-170 Although the Market List was assessed by a well-trained interviewer, the SDQ and LEC were strictly selfreport. However, both have been shown to have good psychometric properties and to be robust in low-resource settings and across cultures, 112,113,120,123,168-170 and interviewers in the POFO study spoke the native language of participants and made substantial efforts to gain rapport over many follow-up visits to ensure honest answers. Incident abuse was measured with a combined outcome for sexual or physical abuse. For consistency with prior analyses in this population^{6,17,114} and as a starting point for understanding how disruptions may be related to abuse, we focused on whether any abuse was associated with changes in the familial adult household structure, but specific types of abuse may have more pronounced associations. To our knowledge, this study is the first to assess stability in the adult household structure is related to wellbeing outcomes among family-based OSC in LMICs.

Potential biases included confounding bias and informative missing data, including loss to follow-up. We controlled for several important predictors of the outcomes as well as potential confounders to mitigate potential confounding bias. Retention for this population over follow-up was very good (84%). Nevertheless, to address possible informative loss to follow-up, we used robust data augmentation methods to multiply impute incomplete observations and missed visits, and pooled standard errors across imputation sets. With this approach, we mitigated the potential bias in conducting a complete case analysis, thus improving validity of our estimates of association.

Our exposure metric is limited in that the survey questions did not directly ask about the caregiving structure but simply identified the relations with whom the children were living. It is reasonable to assume those adults were part of the caregiving structure, but there may have been other important adult figures we could not identify, and additional changes that were not measured. This is particularly true for children living with non-relatives; just as many adults in their household could have shifted, but we could not observe those changes in this analysis. Our analysis assumes equal weight to the available relations because we do not know which relation may be more or less important to any given child. The importance of different relations may be particularly variable in a population of orphans. We focused our analysis on the number of changes in the familial adult household structure as our metric of stability; as such, we did not assign values to "gains" and "losses." While change in the familial structure has been studied in more developed countries such as the U.S,87-89 it has not been examined in family-based care of orphans in LMICs. However, these results reflect average estimates across several LMICs in South Asia and East Africa, and may not be generalizable to other cultures or settings such as Eastern Europe or Latin America.

Ensuring that the world's orphans have care that enables them to become healthy, productive adults is a challenging endeavor. To our knowledge, this study was the first to characterize the familial adult household caregiving structure for family-based OSC in LMICs. We found that many OSC are living with family members, and some with a remaining parent. We showed that the adult household caregiving structure changes a few times over a five-year period for many OSC, and that increased numbers of changes are associated with increased emotional difficulties. Research and programs focused on improving wellbeing in family-based OSC may be enhanced by considering mechanisms that help stabilize the familial adult household caregiving structure.

Table 5.1 Baseline characteristics of family-based OSC and non-OSC in the study

		nily- sed				
		SC		Non-OSC		
	(N=1)	,359)	(N=	(N=271)		
Characteristic	N	%	N	%		
Site						
Cambodia	238	18%	48	18%		
Ethiopia	227	17%	40	15%		
Hyderabad	250	18%	50	18%		
Kenya	193	14%	40	15%		
Nagaland	219	16%	49	18%		
Tanzania	232	17%	44	16%		
Gender						
Male	713	52%	138	51%		
Female	646	48%	133	49%		
Age at analysis baseline						
7	171	13%	39	14%		
8	211	16%	47	17%		
9	211	16%	45	17%		
10	218	16%	66	24%		
11	255	19%	45	17%		
12	201	15%	20	7%		
13	92	7%	9	3%		
Orphan Type						
No parents deceased*	144	11%	N	N/A		
Paternal orphan	763	56%	N	ſ/A		
Maternal orphan	220	16%	N	N/A		
Double orphan	232	17%	N	N/A		

^{*}Children who were abandoned by or separated from a parent due to war or other crises with no expectation of reunion are classified as orphans

Table 5.2 Percentage of OSC and non-OSC with each type of adult relation in their household, at each time point*

OSC	Dad	Mom	Step- father	Step- mother	Grand- father	Grand- mother
Years since		-				
analytic						
baseline	%	%	%	%	%	%
0	10.5%	53.2%	1.8%	2.5%	13.1%	28.2%
1	7.8%	61.2%	2.4%	3.6%	10.3%	24.7%
2	7.4%	54.1%	2.7%	2.4%	12.6%	28.5%
3	12.9%	54.5%	9.3%	2.9%	21.4%	45.3%
4	10.1%	59.4%	3.8%	3.4%	15.3%	32.6%
5	9.0%	58.9%	6.6%	4.6%	14.2%	30.0%
6	10.1%	58.3%	4.6%	4.0%	13.7%	27.8%
			Step-	Step-	Grand-	Grand-
Non-OSC	Dad	Mom	father	mother	father	mother
Years since analytic						
baseline	%	%	%	%	%	%
0	86.3%	91.9%	0.0%	0.4%	4.4%	12.2%
1	94.6%	94.0%	0.0%	0.0%	5.4%	14.5%
2	91.8%	94.6%	0.8%	1.6%	3.1%	12.5%
3	79.3%	84.7%	2.9%	2.8%	19.7%	29.2%
4	83.9%	90.3%	1.7%	1.7%	10.0%	27.2%
5	81.6%	86.5%	3.9%	3.4%	9.2%	22.1%
6	79.3%	88.9%	2.0%	6.0%	9.6%	23.5%

^{*} Missingness ranges from 0 to 29%, depending on round and relation

Figure 5.1 Cumulative changes experienced over five years of follow-up, OSC and non-OSC

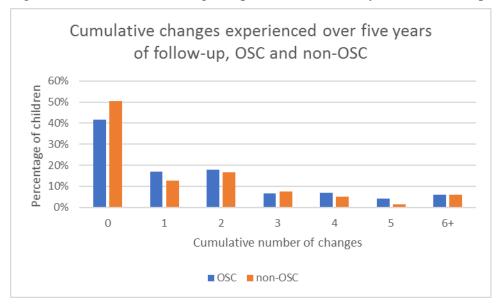


Table 5.3 Associations between cumulative changes in adult household caregiving structure and wellbeing outcomes

osc	(N	l Difficulties N = 1,356)	Cognitive Functioning (N = 1,359)		Incident abuse (N = 1,356)	
Exposure	mean difference, 95% CI		mean difference, 95% CI		RR, 95% CI	
0 changes	ref		ref		ref	
1 change	0.23	(-0.33, 0.79)	-0.07	(-0.40, 0.27)	0.93	(0.57, 1.53)
2 changes	0.57	(0.00, 1.16)	-0.04	(-0.45, 0.37)	0.92	(0.57, 1.49)
≥3 changes	0.73	(0.18, 1.29)	-0.14	(-0.59, 0.30)	1.07	(0.75, 1.54)
Non-OSC	Total Difficulties (N = 271)		Cognitive Functioning $(N = 271)$		Incident abuse (N = 271)	
	mea	n difference,	mean difference,		RR,	
Exposure		95% CI	95% CI		95% CI	
0 changes	ref		ref		ref	
1 change	0.77	(-0.52, 2.06)	-0.16	(-1.03, 0.0.72)	1.07	(0.36, 3.12)
2 changes	0.14	(-1.05, 1.33)	0.32	(-0.52, 1.17)	0.38	(0.06, 2.36)
≥3 changes	0.89	(-0.38, 2.16)	0.53	(-0.36, 1.43)	2.40	(0.90, 6.37)

RR: risk ratio; CI: confidence interval

^aTotal difficulties is a continuous score ranging from 0 to 40, where a higher score indicates worse emotional wellbeing

^bCognitive functioning is a continuous measure ranging from 0 to 15, where a lower score indicates lower functioning

^cIncident abuse is a binary indicator of past-year experience of physical or sexual abuse

CHAPTER 6: DISCUSSION

6.1 Summary of Findings

In Aim 1, we followed 1,194 institution-based OSC from the longitudinal POFO cohort to observe potential transitions to family-based care and examine the effects of those transitions on wellbeing outcomes. Over approximately 8 years of follow-up, 155 OSC (13%) transitioned from institution-based care to family-based care before reaching age 16. We observed a small increase in risk of incident abuse when transitioning from institution-based care to family-based care (risk ratio (RR): 1.2, 95% confidence interval (CI):0.58, 2.43; risk difference (RD): 0.01; 95% CI: -0.03, 0.05). We also observed a slight decrease in cognitive functioning (mean difference: -0.96; 95% CI: -2.17, 0.25) and a slight increase in emotional difficulties (mean difference: 0.24; 95% CI:-0.91, 1.39).

In Aim 2, we followed 1,359 family-based OSC and 271 non-OSC from the longitudinal POFO cohort for nearly 7 years of follow-up. We characterized the adult familial household structure in which family-based OSC and non-OSC are living, and related stability in that structure to wellbeing outcomes. We found that, at any given time, 53% to 61% of family-based OSC are living with their mother. Many also report living with a grandmother, at least 25% at each time point. Only 8% to 13% report living with their father at any time. The numbers among non-OSC were predictably higher: most are living with both their father (79% to 95%) and mother (87% to 95%); up to 29% report a grandmother. Approximately 60% experienced at least 1 change in their caregiving structure over follow-up. We did not observe large associations between cumulative changes in the familial adult caregiving structure and incident abuse or

cognitive functioning. However, we did find increases in emotional difficulties with increasing numbers of changes (1 change: mean difference 0.23, 95% CI:-0.33, 0.79; 2 changes mean difference: 0.57, 95% CI: 0.00, 1.16; ≥3 changes mean difference: 0.73, 95% CI: 0.18, 1.29)).

6.2 Strengths and Limitations

In Aim 1, this study was the first to examine how transitions from institution-based care to family-based care affects orphan wellbeing in LMICs. Furthermore, it was the first study of any kind to examine transitions of OSC from institution-based care to family-based care using a population of OSC that reflects the heterogeneity of institutional experiences. Prior studies were primarily based on Romanian orphanages that were selected for their severe abuse and neglect. As such, these prior studies were not designed to draw contrasts between what orphaned children experience, on average, in institutions, with what they experience, on average, in family placements.

POFO is the largest study of OSC who were randomly sampled from both institutional-based and family-based care in multiple LMIC. Importantly, POFO follows children as they age into adolescence and early adulthood, providing longitudinal information from sub-Saharan African and South Asian regions where data collection is difficult and long-term follow-up through critical developmental periods is often non-existent. This study offers insight into how changes in care affect multiple outcomes that are fundamental to health and wellbeing throughout the life-course.

In Aim 2, this study was the first to quantify the adult relations with which family-based OSC are living. Many OSC are placed with kin, or even live with a remaining parent, but those numbers have not been previously reported using a randomly sampled population across multiple LMICs. Further, the familial adult household structure was evaluated over time to assess how changes in that structure, thought to be critical for OSC development, may relate to wellbeing

outcomes. Again, this was the first study to begin to characterize the stability of family-based care for OSC in LMIC. The findings that changes in the household are common and more changes yield increased difficulties is important in considerations of how to support both OSC and their families and communities.

In both aims, we used sophisticated methods to minimize bias from potential confounding as well as from missing data and loss to follow-up, improving the ability to make inference. However, our estimates were imprecise, and did not show strong effects or associations. Our evaluation of cumulative changes in the adult familial structure (Aim 2 exposure) was particularly limited because the data did not enable direct characterization of the household structure. It is possible, and actually quite likely, that other key adult figures were part of the structure and not captured, which would make our estimate of changes conservative. Furthermore, we could not quantify the relative importance of one adult relation over another. There is no metric to do so, and relative importance likely varies by individual child. An additional level of complexity is that any given relation may be helpful or harmful to the wellbeing of the child. The departure of an abuser is likely beneficial; the departure of someone who supports and protects the child likely has a negative impact.

While we did control for several potential confounders, the possibility of unmeasured confounding remains. In our investigation of the effect of transition from institution-based care to family-based care, it would have been ideal to control for some institution-level characteristics such as size, caregiver-to-child ratio, and financial resources. While some of that information is available at baseline, it is incomplete and unavailable over time. Similarly, our assessment of associations between cumulative adult familial household changes and wellbeing outcomes could be confounded by household financial resources, as well as factors such as the general health of

the adult family members in the household. We did not have this information for each of the relations assessed. The impact of potentially uncontrolled confounding is unknown. In general, our estimates showed small effects and associations that are fairly close to the null; it is possible that any uncontrolled confounding may be biasing our results toward the null.

Our outcome measures have been used and validated in prior studies and other settings, though it is possible that self-reports of abuse or emotional difficulties could bias results. It is likely that abuse would be under-reported, and the impact on effects and associations could be in either direction. The Market List may not have been sufficiently sensitive to detect effects, though it is also possible that cognitive functioning as measured by the Market List is sufficiently stable over time such that only particularly sharp exposures affect it.

6.3 Public Health Relevance and Future Directions

Current policy is predicated on the idea that "children must grow up in permanent, safe, nurturing families in order to develop and thrive" and that "science now proves conclusively that children suffer immediate, lasting, and in many cases irreversible damage from time spent living in institutions or outside of families". This dichotomization may be oversimplified, particularly in LMICs where the number of orphans is disproportionately higher and the family economies are disproportionately more constrained than in higher-income countries. In addition, the role of disruptions in the care setting – change in setting from institutions to families, or change in the adult structure for OSC already in families – had not been previously studied in LMICs to understand the possibly de-stabilizing impact of those disruptions.

We observed that moving OSC out of institutions and into families results in some increase in emotional difficulties. While we did not observe substantial negative effects of transition on incident abuse or in cognitive functioning, it is noteworthy that we also did not see improvements in either outcome. Our findings in the family-based care setting were similar: the

most pronounced results suggested that changes in the adult family household structure were associated with increasing emotional difficulties, and associations with cognitive functioning and incident abuse were much closer to the null.

Overall, our findings suggest that changes in the care setting (transitions from institutions to families or shifts in the family household structure), while posing some impact on emotional health, are likely not the primary drivers of overall OSC wellbeing. These findings are consistent with a growing body of evidence indicating that the setting of care is less important than the quality of care within the setting.

Researchers should continue to strive for and test measures that enable detection of quality caregiving. This can be quite challenging, because existing assessment tools and "checklists" often rely on evaluation of structures, materials, and numbers of children and caregivers rather than the quality of a relationship, which is much harder to assess. The wide variability in caregiving in both family-based and institution-based settings necessitates a much more nuanced understanding of what constitutes quality caregiving, and how different types and aspects of caregiving may be beneficial or harmful depending on individual characteristics of the child. As leaders and policymakers consider how to provide the best possible care for OSC, a much more detailed understanding of quality caregiving will be necessary to promote and improve orphan wellbeing.

6.4 Conclusions

Providing appropriate care options for millions of orphaned children is an incredible task.

Different children have different needs, and policymakers are challenged to consider broad programs and policies that, almost by definition, will not work well for every child. Yet, the wellbeing of children – their physical, emotional, and mental wellbeing – remains global priority,

as evidenced by the ratification of the UN Convention on the Rights of the Child by nearly all countries.

We showed that, on average, disruptions in care have a slightly negative impact on OSC in LMICs, particularly on their emotional wellbeing. Stability is critical for child development, and disruptions in care can threaten that stability. 84-91 However, the effect of a care disruption on any individual child depends on the conditions from which they are coming and the conditions into which they are moving. Focusing on changes to the care setting – whether that means moving children out of institutions or minimizing changes in their adult familial household structure – may not substantially improve overall OSC wellbeing.

An important next step will be understanding the heterogeneity of experiences among OSC in both institution-based and family-based settings, and better measuring the features of caregiving that are most helpful for OSC given their individual experiences. With that, we can hopefully make even more progress toward the global imperative of ensuring the world's children are provided the best possible conditions for optimal wellbeing.

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