

Exploring Pediatric Healthcare Initiatives of Non-Governmental Organizations in Low-and  
Middle-Income Countries

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**Thesis Abstract**

**Objective:** To explore and describe how healthcare non-governmental organizations provide and evaluate programs and services that result in positive and sustainable health outcomes in children and adolescents living in low-and middle-income countries and to better understand the role of nursing within these organizations.

**Scoping Review:** A scoping review informed by the Arksey & O'Malley framework was completed to explore the research on the delivery of pediatric health services by non-governmental organizations in low-and middle-income countries.

**Qualitative Study:** Semi-structured interviews were conducted to share the voices and experiences of stakeholders working in the field of NGO practice to provide clarity, further insight and depth to the results from the scoping review and broaden the understanding of the role of nursing on this topic.

**Conclusions:** Despite variability in practice and a multitude of competing priorities, outcome evaluation is growing within the field of pediatric NGO practice, and progress is being made towards evaluation of broader health outcomes besides unidimensional health indicators or outputs. Nurses can play a significant role in improving pediatric NGO program development and evaluation practices and are well positioned to be global health leaders who can influence policy and practice for the achievement of positive and sustainable health outcomes in children and adolescents in low-and middle-income countries.

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### List of Abbreviations

#### Abbreviation

ARV	Antiretroviral
ART	Antiretroviral Therapy
CD4	Cluster of Differentiation 4
CHART-SF	Craig Handicap Assessment Recording Technique Short Form
FMA-Kids	Functional Mobility Assessment-Kids
GNI	Gross National Income
HIV	Human Immunodeficiency Virus
ICNPO	International Classification of Non-Profit Organizations
IMCI	Integrated Management of Childhood Illness
LMIC	Low-and Middle-Income Country
MDG	Millennium Development Goals
MNCH	Maternal, Newborn and Child Health
NGO	Non-Governmental Organization
PAHO	Pan American Health Organization
PICOT	Population, Intervention, Comparison of Interest, Outcome, Time Frame
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PRESS	Peer Review of Electronic Search Strategies
SDGs	Sustainable Development Goals
STM	Short-Term Mission
TB	Tuberculosis
UNAIDS	Joint United Nations Program on HIV and AIDS

UNICEF	United Nations International Emergency Children's Fund
VoIP	Voice over Internet Protocol
WANGO	World Association of Non-governmental Organizations
WHO	World Health Organization
WHOQL-BREF	World Health Organization Quality of Life Questionnaire

## **Chapter 1**

### **Introduction & Literature Review**

## Exploring Pediatric Healthcare Initiatives of Non-Governmental Organizations in Low-and Middle-Income Countries

The World Health Organization (WHO) strongly endorses health as a fundamental human right and believes that the attainment of the highest possible level of health is an important world-wide social goal (World Health Organization, 1978). The right to health is inclusive, must be provided without any discrimination, must be scientifically and medically appropriate, and of good quality, regardless of the setting (United Nations Office of the High Commissioner for Human Rights, 2008). Globally, vast health inequalities exist, and vulnerable populations such as children and adolescents living in low-and middle-income countries (LMICs) suffer from the unequal distribution of resources and social determinants of health (Houweling & Kunst, 2010). Health service provision by non-governmental organizations (NGOs) has increased in LMICs in recent years to assist with meeting the needs of these vulnerable populations and to compensate for inadequacies in national health programs (Lorgen, 1998; Lurie, 2012). While they play a valuable role in health service delivery and contribute to health systems and strategies worldwide, NGOs may focus on their own goals and objectives according to donor requirements and overlook certain health needs of the community or inefficiently deliver care (Chaudhry, 2016; Druetz, 2018; Piotrowicz & Cianciara, 2013). In an era where evidence-based practice and financial accountability are drivers of healthcare, it is appropriate to examine whether NGOs providing health services to children and adolescents in LMIC's, operate in a way that transparently link positive health outcomes with program implementation and spending. Understanding how NGOs provide quality healthcare that results in desirable health outcomes is imperative, as all healthcare NGOs need to be held accountable for the impact and outcomes of their work.

### **Non-governmental Organizations: Definition and History**

Since the 1990s, NGOs have flourished within the development and global health arenas (Lurie, 2012). They are a diverse sector, with an estimated 10 million NGOs worldwide, including more than 40,000 international NGOs and thousands of local NGOs participating in health and development work in any single country (Nonprofit Action, 2015; Weintraub et al., 2011). NGOs are defined as non-profit, non-public, voluntary organizations outside direct state control, that pursue activities to relieve suffering, promote interests of the poor, protect the environment or undertake community development (Hecht & Tanzi, 1994; Nonprofit Action, 2015). The term NGO is often used interchangeably with other terms such as non-profit organization, voluntary organization, third sector organization, charitable organization, faith-based organization, and many more (Piotrowicz & Cianciara, 2013). It has been argued that “NGO”, is an umbrella term which includes all of these listed organizations, however, no firm consensus has been reached on the matter (Piotrowicz & Cianciara, 2013).

Areas of NGO activity are classified into twelve categories according to the *International Classification of Non Profit Organizations (ICNPO)* which include: culture and recreation; education and research; social services; environment; development and housing; law; advocacy and politics; philanthropic intermediaries and voluntarism promotion; international; religion; business and professional associations and unions; and health (Piotrowicz & Cianciara, 2013). Historically, NGO involvement in health care began due to the perceived failure of state led development in the era of the 1970s and 1980s (Chaudhry, 2016). During this time, NGOs provided new approaches to address poverty and health inequalities, and delivered programs and projects in partnership with communities to provide care and empower poor, vulnerable, and

marginalized populations (Chaudhry, 2016). Since then, NGOs have been an integral part of providing health care throughout the world (Chaudhry, 2016).

**NGO's within the health system.** Health systems are defined as the combination of resources, organization, financing and management that culminate in the delivery of health services to a population, with the purposes of promoting, restoring and maintaining health (Piotrowicz & Cianciara, 2013; Roemer, 1993). Due to a variety of reasons, such as lack of infrastructure, resources or low-economic or war-torn states, many countries lack strong government-led health care programs (Ejaz, Shaikh, & Rizvi, 2011). As such, the delivery of health services in LMICs are often the responsibility of a variety of organizations, including the private, for-profit, public, non-governmental, and faith-based sectors (Weintraub et al., 2011). NGOs act as one entity within the greater health system with widely varied activities that include programs and initiatives related to health promotion, disease prevention, service delivery, health advocacy, education, and training (Piotrowicz & Cianciara, 2013). Small NGOs often partner with larger international agencies such as United Nations (UN), WHO, Pan American Health Organization (PAHO), and United Nations International Children's Emergency Fund (UNICEF) to implement their programs and achieve their desired goals and mandates (Chaudhry, 2016). Although the value of NGOs operating within the global health sector is evident, they do not function without criticism and concern over performance, evaluation, sustainability, and accountability of their programs (Bozzo, 2000; Chaudhry, 2016; Kareithi & Lund, 2012; Sarriot, Winch, Ryan, Edison, et al., 2004).

**Accountability.** NGOs are first and foremost accountable to their donors, not to the general public or a country's government (Lorgen, 1998). As a result, accountability of NGO programs is not always to their beneficiaries and the quality of services they receive, but to the



sources of NGO program funding (Biermann, Eckhardt, Carljord, Falk, & Forsberg, 2016). Although donor accountability should not be overlooked, NGOs delivering health services should also be held accountable to safe, ethical, and standardized practice.

Organizations such as The World Association of Non-Governmental Organizations (WANGO) provide guidance for accountability in NGO practice, however, NGOs must choose to subscribe or pay to be a member of these types of associations (World Association of Non-governmental Organizations, 2018). The self-regulatory activities which involve the adoption of codes of rules and ethics are then implemented, but only to a small extent (Piotrowicz & Cianciara, 2013). Other organizations such as WHO and PAHO model best practices for international and global health and are highly regarded for their work within the global health and NGO communities. Although NGOs may adopt the guidelines and health delivery models demonstrated by these organizations, the lack of a mandatory overarching governing body in addition to the donor focused accountability, creates concern for ineffective program implementation, unsafe or inadequate delivery of health services, and improper evaluation of program outcomes.

**Evaluation of programs and services.** Healthcare NGOs face many challenges for program implementation and facilitation. Limited resources due to small operating budgets and volunteer, unskilled staff, can negatively affect the efficiency and quality of services provided (Biermann, Eckhardt, Carljord, Falk, & Forsberg, 2016; Piotrowicz & Cianciara, 2013). Just as many countries struggle with providing strong government led health programs, LMICs struggle with the coordination, monitoring, and evaluation of the numerous health organizations operating within them (Weintraub et al., 2011). NGOs themselves, are also frequently unable to properly evaluate their programs due to financial, resource or capacity constraints (Bozzo, 2000). When

evaluations are conducted, they often focus on meeting evaluation criteria mandated by donors (Bozzo, 2000; Palumbo, 2017). Although resources exist to assist in the evaluation of programs, there are multiple barriers that impede their use and the process is not consistent or standardized (Bozzo, 2000).

### **Global Pediatric Health**

Evidence has shown that in general, poor health is directly related to an individual's socioeconomic position (Commission on Social Determinants of Health, 2008). Socioeconomic position in combination with the other social determinants of health in an LMIC context, results in the unequal distribution of health, health care, and health outcomes (Davis & Chapa, 2015; Houweling & Kunst, 2010). Social determinants of health are defined by the conditions in which people are born, grow, live, work, and age (Commission on Social Determinants of Health, 2008), which are further shaped by the distribution of money, power, and resources at global, national, and local levels (Bhutta & Black, 2013). Some of the most important determinants of health for children and adolescents are environments in which malnutrition and exposure to disease pathogens are prevalent (Houweling & Kunst, 2010). These circumstances are directly influenced by issues such as quality of water and sanitation, housing conditions, hygiene behavior, and other practices related to child care (Houweling & Kunst, 2010). Maternal factors also contribute to inequalities in childhood mortality, such as high fertility rates and high rates of teenage pregnancies in lower socio-economic groups (Houweling & Kunst, 2010). Furthermore, the use of health services is much lower among poorer and less educated groups within LMICs due to lack of adequate access to care and inequalities in health service delivery, making maternity care, childhood vaccination, and medical treatment of childhood illness ongoing challenges for children and adolescents in this context (Houweling & Kunst, 2010).

**Millennium development goals & child mortality.** The reduction of child mortality in LMICs has been an ongoing global goal due to the staggering statistics on death rates in children under five years of age in the 1990's and 2000's (Houweling & Kunst, 2010). Since the implementation of the Millennium Development Goals (MDGs) by the United Nations, there has been a reduction in global under-five child mortality by 48%, associated with evidence-based health interventions and multi-sectoral socioeconomic improvements (Cohen, Murray, Jack, Arscott-mills, & Verardi, 2017). While it is clear that much has been accomplished to reduce preventable deaths of children under five years of age (Sarriot, Winch, Ryan, Bowie, et al., 2004), there are still considerable advancements to be made to continue to improve the health of pediatric populations in LMICs. Priority has been given to a narrow spectrum of the pediatric age range and much of the literature has focused on programs and interventions that address maternal, newborn and under five year old child health issues, which are specific to women, reproduction, and early childhood (Bhutta & Black, 2013; Corsi & Subramanian, 2014). As a result, health interventions and improvements for older children and adolescents in LMICs have been virtually un-represented.

**Health indicators and outcomes.** Infant and child mortality rates are used as the most important indicator of health, nutrition and the overall social and economic development of a population (Corsi & Subramanian, 2014). Additionally, health outcomes have been historically defined by negative indicators such as death, disease and disability (Mitchell et al., 1997). While these indicators and outcomes provide a general overview of population health status, a shift has recently occurred to focus on more positive outcomes such as improved health status, functional ability, and perceived quality of life (Mitchell et al., 1997). The WHO definition of health emphasizes that health is more than just the absence of disease, but also includes components of

physical, mental and social well-being (World Health Organization, 1948). Therefore, positive indicators and outcomes need to be included in the evaluation strategies for child and adolescent health globally, to better reflect the holistic and complex nature of health and well-being.

### **Summary**

The background information presented summarizes the history and trends in NGO practice as well as the pediatric health situation in LMICs. The challenges identified for NGO program evaluation, coupled with the use of negative health outcomes and indicators for pediatric health evaluation, generates increased concern for insufficient NGO healthcare provision for children and adolescents in LMICs. The following literature review was conducted to determine the current research evidence supporting pediatric health initiatives of NGOs in LMICs, further investigate the priority issues for pediatric health and NGO evaluation, and identify the gaps in the current research.

## **Literature Review**

### **Pediatric Health in LMICs**

Pediatric health improvements in LMICs have been clearly linked to increased socioeconomic status and better maternal healthcare practices (Claeson & Waldman, 2000; Cohen, Murray, Jack, Arscott-mills, & Verardi, 2017). However, specific health interventions such as routine vaccinations and improved diagnosis and treatment of pediatric illness also have the ability to rapidly increase the progress of pediatric health in LMICs, even in the midst of slow economic development (World Health Organization Commission on Macroeconomics and Health. Working Group 5 & World Health Organization, 2002). Childhood vaccinations are among the most effective and cost-effective public health interventions available, yet, vaccine-preventable diseases were responsible for 14% of the burden of disease from mortality and

morbidity globally in 2015 (Phillips, Dieleman, Lim, & Shearer, 2017). A study by Tao et al. (2013), which analyzed the vaccination coverage in LMICs between 1986 and 2009, identified that coverage was actually lower than previously reported (Tao, Petzold, & Forsberg, 2013). In 2009, coverage of all essential vaccines was under 80% in LMICs with the exception of tuberculosis coverage which achieved 97% (Tao et al., 2013). As of 2017, 71 countries had yet to achieve the Global Vaccine Action Plan target of 90% or greater coverage of Diphtheria, Tetanus and Polio (United Nations International Children's Emergency Fund, 2018). Other vaccine preventable diseases such as rotavirus and streptococcus pneumoniae have been reported as the leading causes of diarrhea and severe pneumonia in the pediatric population of LMICs (Fischer Walker et al., 2013). In the year 2013, both lower respiratory infections and diarrhea were the leading causes of death in younger and older children in these contexts (Europe PMC Funders Group, 2016; Zar, Madhi, Aston, & Gordon, 2013).

A systematic review by Lamberti, Fischer Walker & Black (2012), which evaluated diarrhea morbidity to understand the impact of diarrhea on disability, estimated the diarrheal duration and severity outcomes for different age categories in LMICs. It was identified that in children under five years of age, moderate and severe episodes of diarrhea accounted for a large proportion (35.2%) of the overall diarrhea burden (Lamberti, Fischer Walker, & Black, 2012). Results showed that for children under five years of age, on average, mild episodes lasted 4.3 days, whereas severe episodes lasted 8.4 days and caused dehydration in 84.6% of cases (Lamberti et al., 2012). While the study estimated that the burden of disease was much lower in older children, it also identified that there was a significant lack of research reporting diarrheal outcomes for children aged 5-15 years (Lamberti et al., 2012). Thus, further arguing that the health of older children and adolescents is underreported in the LMIC literature.

**Adolescent health.** With the improvements in under five year old child mortality, the population of adolescents in LMICs is increasing (Lassi, Salam, Das, Wazny, & Bhutta, 2015). It is estimated that almost one sixth of the world's population are in the adolescent age category and that almost 90% live in LMICs (United Nations Department of Economic and Social Affairs Population Division, 2017). As a result, adolescent health has become a new concern within the global health agenda, as health in this population is essential to the growth and transformation of the future of LMICs (United Nations, 2015). A mixed methods synthesis study completed by Nagata, Hathi, Ferguson, Michele, & Ross, (2018), categorized the priority adolescent health research in LMICs within the three agendas of the United Nations Global Strategy (Survive, Thrive and Transform). Within the “survive” agenda, research was focused on the most effective prevention, monitoring and treatment strategies for communicable and non-communicable diseases (Nagata et al., 2018). The “thrive” agenda, focused on leveraging key communication channels to promote healthy behavior, while the “transform” agenda, explored the impact of non-health sectors on adolescent health (Nagata et al., 2018). Ultimately, the study identified that the need to integrate health services to meet the unique needs of adolescents was a top priority (Nagata et al., 2018). These results were intended to stimulate further research for adolescent health in LMICs (Nagata et al., 2018), and demonstrate the importance of improving health in this specific age bracket of LMICs.

**Non-communicable illness and chronic disease.** Health services in LMICs have historically focused on the treatment of acute and infectious diseases, however, the burden of non-communicable and chronic diseases is increasing (Beran, Zar, Perrin, Menezes, & Burney, 2015). Children and adolescents living in LMICs are suffering from more chronic conditions such as asthma, malnutrition, musculoskeletal conditions, cancer, and human immunodeficiency

virus (HIV) (Beran et al., 2015; Boerma et al., 2016; Gupta, Rivera-luna, Ribeiro, & Howard, 2014). While these illnesses have an impact on mortality rates, they also have a significant impact on quality of life. Pediatric cancer diagnosis accounts for approximately 200,000 cases per year worldwide (Rodriguez-galindo, Friedrich, & Morrissey, 2013). Eighty percent of these cases occur in LMICs and account for 90% of pediatric cancer related deaths (Rodriguez-galindo et al., 2013). A systematic review that analyzed viral suppression rates among children started on anti-retroviral therapy for HIV in LMICs, determined that viral suppression rates were poorer than previously found, at 60-75% in most analyses (Boerma et al., 2016). A cross-sectional survey that measured the global prevalence and severity of asthma symptoms in children, reported that although countries with lower income tended to have lower overall prevalence of asthma for younger and older age groups, the prevalence of symptoms of severe asthma was higher in lower income countries, especially in older children (Lai et al., 2009). As the emphasis of positive health outcomes is not necessarily the absence of disease, focus on improving quality of life or management and improvement of disease symptoms will contribute to better health and well-being in this specific group of children and adolescents. To achieve this, understanding how to deliver health services that contribute to these outcomes is vital.

**Pediatric surgery.** Pediatric surgery has also become a priority as an essential and cost-effective public health intervention that contributes to the improvement of pediatric health in LMICs (Torborg et al., 2018). However, many countries are not meeting the targets outlined by the WHO for the standards of essential surgery (Walker, Obua, Mouton, Ttendo, & Wilson, 2010). As an example, Walker et al. (2010), identified that in 2007-2008 the annual surgical rate for children 14 years old and younger in South-Western Uganda, was 180 operations per 100,000 and that most of these were emergency procedures. In addition to low surgical rates, the lack of

available human and material resources contributed to poor surgical outcomes (Livingston, Dacruz, Pemberton, Ozgediz, & Poenaru, 2015; Torborg et al., 2018). A prospective cohort study that evaluated the short-term outcomes of pediatric cardiac surgery in Indonesia, found that the incidence of complications was as high as 81%, and that one-fifth of these complications were major (Murni et al., 2019). Similarly, a prospective, observational cohort study of pediatric surgical patients in South Africa identified that 1 in 10 pediatric patients suffered a postoperative complication and that the most common complications were infective in nature. That study recognized that the risks for poor surgical outcomes are different in LMICs than in higher income countries and recommended that strategies be developed to target improved pediatric surgical outcomes in these contexts (Torborg et al., 2018).

**Summary.** Specific programs such as the Integrated Management of Childhood Illness (IMCI) developed by WHO and UNICEF, have resulted in substantial progress for addressing priority illnesses and further decreasing infant and child mortality (Picken et al., 2018). However, greater support is needed to address pediatric surgical needs as well as extend curative and preventive care to the well child, the child with long-term health needs and children older than five years of age (Picken et al., 2018). The results of the studies reviewed support this claim and make clear that there are still substantial gains to be made in the improvement of health service delivery and health outcomes of children and adolescents in LMICs, even in the presence of declining mortality rates (Sarriot, Winch, Ryan, Edison, et al., 2004; Zar et al., 2013). In addition to morbidity and mortality, pediatric health in LMICs is defined in the academic literature by indicators such as surgery rates and lack of coverage or access to essential services. While this knowledge is important for monitoring trends and identifying priority pediatric health



issues, measuring the health of the pediatric population of LMICs should also include dimensions of positive health outcomes such as quality of life or improved health status.

### **NGO Involvement in Pediatric Health in LMICs**

NGOs are frontline implementers of effective pediatric health interventions, and have a significant presence within health systems in LMICs (Sarriot, Winch, Ryan, Bowie, et al., 2004). A literature review by Magalhães Costa, Silveira da Silva, & Bonan (2011) that assessed the participation of NGOs in child healthcare by identifying and classifying their activities, found that NGO involvement in pediatric health is in the early stages from a research perspective, and further study is warranted. Their study was not specific to the context of LMICs and thus it is unclear the degree to which their findings are fully relatable. Studies exist specific to NGO involvement in pediatric surgical initiatives in LMICs, as evidenced from newer studies by Nyugen et al. (2014) and Shrime, Sleemi & Ambereen (2015). Nguyen et al. (2014), identified in their study that 80 NGOs supported cardiovascular programs for children in 92 LMICs and that the largest outreach efforts were in South and Central America, Africa and Europe. NGOs in this study provided services specific to education and diagnostics in addition to surgical interventions (Nguyen et al., 2014). The systematic review by Shrime, Sleemi & Ambereen (2015), classified the platforms for surgical delivery in LMICs and reviewed their effectiveness, sustainability, cost-effectiveness, and role in training. The study reported a vast array of NGOs providing surgical care in LMICs and determined that short-term surgical missions were the method most utilized for delivery of surgical services (Shrime et al., 2015). The study by Walker et al. (2010) supports these findings, reporting that mission or NGO hospitals accounted for more than 55% of the pediatric operations in South-Western Uganda in the year 2007-2008, with 80% of the 140 cleft lip and palate operations performed by externally funded surgeons. Although the

contribution of NGOs in pediatric surgical service delivery in LMICs is evidenced in the literature, there is a gap in the amount of research available, especially specific to the contribution NGOs are making to pediatric medical initiatives in LMICs. In addition to this gap, there is no clear understanding of whether any standardized process exists for NGOs providing pediatric medical or surgical health services to strategically evaluate their programs for positive and sustainable health outcomes.

**Evaluation.** Research on NGO performance is growing due to stricter official aid requirements and concerns from NGO practitioners, governments, citizens, donors, policymakers, and academics (Kareithi & Lund, 2012). However, this growth in research is relatively new (Kareithi & Lund, 2012), and much of the focus is on NGO performance in the development sector, not the health sector. Additionally, evaluation reports and studies on NGO performance are not being published and reviews are kept confidential as a result of fear that negative results will lead to the removal of program funding (Fenn, 2012; Kareithi & Lund, 2012). Yet, the availability of academic research on evaluation strategies and frameworks suggests that the knowledge around the importance of NGO evaluation is increasing and that resources are readily available for utilization, even in the health sector (Bach-Mortensen & Montgomery, 2018; Bell & Aggleton, 2012; Bozzo, 2000; Ebrahim & Rangan, 2014; Fenn, 2012; Khandker, Koolwal, & Hussain, 2010). However, caution needs to be taken when utilizing these frameworks or evaluation strategies, as many program evaluations are based on the measurement of proxy health outcomes (e.g. number of vaccinations), and do not necessarily measure actual health impacts (Kareithi & Lund, 2012). The study by Berti, Mildon, Siekmans, Main et al. (2010), clarified the difference between performance evaluation (evaluating provision, utilization and coverage) and impact evaluation (evaluating health outcomes and

behaviors), however, also identified that performance and impact evaluation designs are less rigorous than plausibility evaluations or probability evaluations. The different categories of evaluation strategies available indicate the complexity of simply choosing one particular method, in addition to the multiple other barriers that contribute to the prevention of their use.

**Sustainability.** Sustainability of programs is a common topic in the development literature (Dwyer, 2010; Nabifwo & Kimutai, 2017). Program sustainability is often measured by the maintenance of program activities or the continuation of services to a certain number of people (Scheirer, Hartling, & Hagerman, 2008), and does not always incorporate quality of health interventions. One framework was identified in the literature for use by NGOs in primary health care and community-based projects to measure the sustainability of child health programs. That framework systematically places health interventions within a sustainability perspective, which then guides program and management decisions (Sarriot, Winch, Ryan, Bowie, et al., 2004). It emphasizes that sustainable health outcomes are only part of the conditions needed for sustainability of programs and that capacity building is to be viewed as an essential piece in improving pediatric health in these contexts (Sarriot, Winch, Ryan, Bowie, et al., 2004). While it is clear that a link exists between sustainability of programs and sustainability of health outcomes, it is unclear if NGOs are using these types of sustainability frameworks in the evaluation of their programs and interventions.

### **Theoretical Framework**

Humanitarian endeavors are often driven by altruistic motives with the intent of positively impacting individuals or communities who are suffering from the unequal distribution of wealth and resources (Berry, 2014). Global health is filled with illustrations of unintended and often harmful consequences of programs (Kleinman, 2010), as good intentions in humanitarian

focused environments can lead to the misconception that any healthcare is good healthcare, regardless of the quality of services it provides (Maki, Qualls, White, Kleefield, & Crone, 2008).

Robert Merton's theory of unanticipated consequences of purposive action, proposes that all social interventions have unintended consequences and that these interventions should be thoroughly investigated with attention to context and evidence before implementation (Allen-Scott, Hatfield, & McIntyre, 2014; Merton, 1936). The underlying assumptions of the theory speak to the production of unanticipated consequences from ignorance, error, values, immediate interest, and self-defeating prophecy (Allen-Scott et al., 2014). Self-defeating prophecy can elicit behaviors that produce the opposite results of what was assumed or predicted (Bushman, Baumeister, & Stack, 1999), such as the expectation or prediction that as long as healthcare services are provided, even if they are substandard, it is better than providing no healthcare at all. Because the assumption is made, the opposite occurs, which inherently creates the potential for unintended consequences such as negative health outcomes (e.g. drug resistance caused by improper drug dosing and administration). The theory is relevant and informs the proposed study, as it questions the interests and values of the stakeholders and funders of NGOs, challenging them to thoroughly address the components of their programs and assess the potential consequences of their well-intended actions. The desire to limit consequences should guide and inform the delivery of health services that contribute to sustainable and positive health outcomes (Allen-Scott et al., 2014).

### **Thesis Objective**

The background information presented and review of the literature is an overview of the issues surrounding pediatric health in LMICs (mortality and morbidity rates, surgical outcomes, focus of children under five years of age, chronic pediatric conditions etc.) and offers some

clarity as to the services currently implemented (vaccination rates, short term surgical missions, IMCI). However, a clear understanding of how NGOs providing pediatric healthcare in LMICs ensure that their interventions and health services directly result in positive and sustainable health outcomes, despite available evaluation strategies and frameworks, is lacking. Therefore, the purpose of the research was to:

1. Identify and describe the existing types of programs and services NGOs are providing to children and adolescents in LMICs.
2. Identify and describe the types of health outcomes pediatric NGOs are reporting.
3. Identify and describe NGO's outcomes related to sustainability.
4. Determine the pattern of NGO outcome reporting over time.
5. Explore stakeholders' thoughts and experience regarding pediatric NGO healthcare delivery and outcome evaluation in LMICs.
6. Explore the role of nurses within pediatric NGOs and their ability to contribute to the achievement of positive health outcomes in these contexts.

A scoping review with stakeholder engagement was completed to review the extent, range and nature of research activity, to identify knowledge gaps within the existing literature and to share the voices and experiences of NGO stakeholders on this topic (Levac, Colquhoun, & O'Brien, 2010).

### **Research Questions**

1. What is known in the published peer reviewed research literature about the delivery of pediatric healthcare services by NGOs in LMICs for positive and sustainable health outcomes in children and adolescents?

2. How do stakeholders describe the evaluation of NGO programs and what are their experiences with the achievement of positive and sustainable health outcomes in children and adolescents living in LMICs?
3. What is the role of nurses working with pediatric NGOs and how can they contribute to the achievement of positive health outcomes in children and adolescents in LMICs?

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**Chapter 2**  
**Methodology**

## Method

Synthesis studies are a form of research that connects evidence through the process of knowledge integration (Wyborn et al., 2018). Unlike primary research studies which collect raw evidence as a means to answer specific research questions, synthesis research collects, examines, and interprets the findings from a collection of primary research on a similar topic (Suri, 2013). The value of synthesis studies are that they produce new knowledge by making connections between or among primary research evidence that may not have been previously identified (Suri, 2013). Specific methods have been developed for this form of research, the most common being a systematic review (Grant & Booth, 2009).

A systematic review seeks to answer a specific research question by collecting all empirical evidence that fits a pre-selected eligibility criterion (Higgins et al., 2019). It has been referred to as the best known type of review, adhering to guidelines provided by organizations such as the Cochrane Collaboration, Campbell Collaboration or the NHS Centre for Reviews and Dissemination (Grant & Booth, 2009). However, systematic reviews are known to be limited to providing insights about effectiveness instead of answering more complex research questions (Grant & Booth, 2009). A scoping study or scoping review is an alternative method for synthesis research. Its purpose is to identify all relevant literature on a specific topic, regardless of study design (Arksey & O'Malley, 2005), and is useful for addressing exploratory research questions (Colquhoun et al., 2014). As the purpose of the research was to explore what is known in the existing published peer reviewed literature about pediatric healthcare initiatives provided by NGO's in LMICs and their contribution to positive and sustainable health outcomes, a scoping review was the most appropriate method to answer the exploratory research question.

Considering the limited availability of academic NGO research, the scoping methodology ensured that all categories of studies and types of literature on the topic were reviewed.

The scoping review for this study was completed using the methodological framework established by Arksey & O'Malley (2005). Their framework is designed to determine key concepts, main sources, and types of research in complex areas as well as in new fields of research (Arksey & O'Malley, 2005). Arksey & O'Malley (2005), identify four possible reasons for conducting a scoping study, three of which were relevant to the present research study. As the growth of NGO research is relatively new, scholars have called for further and more thorough research on NGO performance (Kareithi & Lund, 2012). A preliminary review of the literature revealed minimal research on healthcare initiatives by NGOs in LMICs specific to positive and sustainable health outcomes in children. Therefore, the scoping review was beneficial for 1) thoroughly assessing the potential size and scope of the available research, by examining the extent, range and nature of research activity; 2) summarizing and disseminating research findings; and 3) identifying gaps in the existing literature (Arksey & O'Malley, 2005; Grant & Booth, 2009).

Scoping reviews share several characteristics with systematic reviews, as they are systematic, transparent, and replicable (Grant & Booth, 2009). However, they are criticized for limitations in rigor, and hold the potential for bias due to the short duration of the review process (Grant & Booth, 2009). Scoping reviews typically do not include a quality assessment of studies, which is reported to limit the ability to use the findings of the review to inform practice or policy (Grant & Booth, 2009). Recommendations to enhance Arksey & O'Malley's framework are published by authors Daudt, Van Mossel, & Scott (2013) and Levac, Colquhain & O'Brien (2010), who suggest that additional steps should be taken for conducting a quality assessment of

studies as well as ensuring that two researchers independently review the abstracts and full texts for study selection. These steps were included in the study design to enhance the methodological rigor and reliability of the review, and allowed for improved transparency in the research process, permitting further use of study findings.

Additionally, both Daudt et al. (2013) and Levac et al. (2010), suggest including the optional sixth step in the original Arksey and O'Malley scoping review framework to incorporate a consultation stage with stakeholders. Stakeholders contribute to additional sources of information, perspectives, meaning, and applicability to a scoping study, which also adds to the methodological rigor (Daudt et al., 2013; Levac et al., 2010). Given that the study focus was specific to positive and sustainable health outcomes of pediatric healthcare NGO initiatives in LMIC's, stakeholders from existing healthcare NGOs currently operating in LMIC's were consulted for increased relevance of the review.

### **Design**

The scoping review was primarily informed by Arksey and O'Malley (2005). The modifications proposed by Daudt et al. (2013) and Levac et al. (2010) were also adopted, including consultation with stakeholders, quality assessment of included studies, and the use of two independent reviewers for study selection.

### **Scoping Review Framework**

The scoping review framework guiding this study involved six stages. They included:

1. Identifying the research question
2. Identifying relevant studies
3. Study selection
4. Charting the data

5. Collating, summarizing and reporting the results
6. Consultation with Stakeholders

**Stage 1: Identifying the research question.** The first stage of the framework was to clearly define the research question (Colquhoun et al., 2014). Arksey & O'Malley (2005), state that it is necessary to consider which aspects of the research question are important, such as the target population, interventions or outcomes. Although the question should be kept broad in nature, adequate clarity of concepts is required to properly guide the scope of the review (Levac et al., 2010). To ensure that these criteria were met, the research question was formulated using the PICOT tool, a guide for constructing evidence-based practice questions for health research (Polit & Beck, 2012). The acronym PICOT, stands for population (P), intervention (I), comparison of interest (C), outcome (O) and time frame (T) (Fineout-Overhold & Johnston, 2005). Depending on the nature of the research question, the "C" and the "T" components of the tool are not always applicable (Polit & Beck, 2012). As the research question for this study was exploratory in nature and did not include a comparison or specific time frame, the "C" and "T" sections were not used. The PICOT strategy is outlined below, and each concept is defined to ensure a clear understanding of the components of the research question. The main concepts within the research were identified as pediatrics, non-governmental organizations, and low-and middle-income countries. As a scoping review is considered to be an iterative process, the question and concepts were refined as increasing familiarity with the literature occurred (Arksey & O'Malley, 2005).

P (Patient): Children and adolescents (pediatrics) living in LMICs

I (Intervention): Programs/interventions delivered by a healthcare NGO

C (Comparison): n/a

O (Outcome): Health outcomes

T (Time Frame): n/a

***Definition of main concepts.***

*Pediatrics.* An age group from birth to adolescence. The term pediatrics is used to describe a specialty within healthcare and is stated to be concerned with maintaining health and providing medical care to children (Kastner, Wilczynski, Walker-dilks, & Mckibbon, 2006).

*Healthcare NGO.* Any non-profit, non-public, voluntary organization outside direct state control, pursuing activities related to health promotion, disease prevention, service delivery, health advocacy, education or training (Hecht & Tanzi, 1994; Piotrowicz & Cianciara, 2013).

*Low-and middle-income country.* A country with a gross national income (GNI) per capita of \$12,055 or less: includes those classified by low-income (GNI per capita = < \$1025), lower-middle income (GNI per capita = \$1026 - \$3995) and upper-middle income economies (GNI per capita = \$3996 - \$12 375) (The World Bank, 2017).

***Definitions of additional terms in the research question.***

*Healthcare services.* Healthcare services include a wide range of medical, surgical, social or psychological services, nursing care, health education or training, immunizations, and disease prevention (Chaudhry, 2016), that primarily focus on improving health. It should consider the whole spectrum of care from promotion and prevention, diagnostic, rehabilitation, and palliative care, as well as self-care, home care, community care, primary care, long-term care, and hospital care (World Health Organization, 2019).

*Health Outcomes.* The World Health Organization defines a health outcome as “A change in the health status of an individual, group or population which is attributable to a planned intervention or series of interventions, regardless of whether such an intervention was

intended to change a health status” (World Health Organization, 1998, p. 10). Health outcomes are normally assessed using health indicators. Health indicators are defined by the WHO as “a characteristic of an individual, population, or environment which is subject to a measurement (directly or indirectly) and can be used to describe one or more aspects of the health of an individual or population (quality, quantity and time)” (World Health Organization, 1998, p. 9). An example of a health indicator is absence of communicable disease for which an individual has been vaccinated. A positive health outcome is the result of an intervention contributing to good or improved health and a negative health outcomes is the result of an intervention contributing to worsened or ill health (World Health Organization, 1998, 2020).

**Stage 2: Identifying relevant studies.** The search strategy was established according to the purposes of the research and research question, to identify the existing relevant primary research on the topic. It was developed in consultation with a library scientist and peer reviewed using Peer Review of Electronic Search Strategies (PRESS) (Mcgowan et al., 2016).

The search was executed in Medline (via OVID), CINAHL, CAB Direct, Nursing & Allied Health (via ProQuest), and PAIS Index (via ProQuest) databases. There was no limit set to year of publication, but one limit was added to exclude studies published in languages other than English. Reference lists of each included study were further reviewed for any other additional studies that met criteria. One additional study that was not captured in the search, but met inclusion criteria through a hand search, was also identified and included.

**Stage 3: Study selection.** In keeping with recommendations of Arksey & O’Malley (2005), a two-step study selection procedure was used. Two reviewers independently applied the inclusion and exclusion criteria to all citations and full texts gathered from the systematic literature search (Levac et al., 2010). Step one was conducted at the title and abstract level based

on the set inclusion and exclusion criteria. Citations selected for inclusion from the first step then underwent step two, which involved the full text review of selected articles (Arksey & O'Malley, 2005). Prior to commencing initial screening (step one) at the title and abstract level, both reviewers met and discussed the purpose of the study, reviewed the set inclusion/exclusion criteria, main concepts and research question, and orientated themselves to the online software (*Covidence*) which was used for the organization and tracking of the scoping review. When clarification was needed during the selection period, the reviewers corresponded by email or text message. Disagreements between reviewers were resolved by a third member of the research team (primary investigator's thesis supervisor). The web-based software platform *Covidence*, was used to support citation screening and full text screening.

The preferred reporting items for systematic reviews and meta-analyses (PRISMA) flow diagram (Appendix A) was used to report the number of citations identified, screened, excluded, assessed for eligibility, and included for synthesis (Moher et al., 2009). Following the iterative nature of the scoping review process, the exclusion criteria were revised after the first round of screening to further exclude studies in the full-text screening round if either the term outcome, impact or sustainability were not stated in the aim/purpose of the research or within the research question to eliminate studies that did not address the main questions of this scoping review. Studies were included if they were primary research studies (qualitative, quantitative or mixed-methods study designs), specific to patients within the pediatric age range of birth to 18 years of age, conducted in an LMIC, specific to NGOs (including organizations that identify as non-profit organizations, charities and faith-based organizations), focused on health service delivery, and were relevant to any or all of the following; program implementation, health outcomes, health impacts, health interventions, sustainability, capacity building, evaluation, monitoring,



performance, community engagement or health prevention strategies (e.g., immunizations). Studies were excluded if they were not primary research studies (e.g., reviews, book chapter, discussion papers, news), published in a language other than English, dissertations or theses, focused only on adult populations, specific to maternal health (including pregnancy), conducted in high income countries, focused on health promotion (education etc.), nutrition or nutritional interventions, focused on WHO recommendations/policies implemented or tested in government or private healthcare contexts, specific to programs that were government and NGO collaborations, did not separate pediatric data from adult data when both were included, focused only on epidemiologic trends or used NGO programs as the comparison for an intervention.

**Stage 4: Charting the data.** Stage four of the framework involved the documentation of relevant information extracted from the primary articles that met inclusion/exclusion criteria (Arksey & O'Malley, 2005). 'Charting', is referred to as the narrative summary report of the findings, including the interpretation and categorization of the data into key findings (Arksey & O'Malley, 2005). The framework suggests the use of a descriptive-analytical method as a means of collecting information from each of the studies (Arksey & O'Malley, 2005). Data extraction was done using an extraction table created specifically for the review. The table was completed by the primary investigator and independently checked by a second reviewer for accuracy. The following components were extracted for each study including; author(s), year of publication, country, NGO, study design, research question/purpose, population/sample, data collection, main results/findings specific to pediatric health outcomes.

A quality assessment of studies was also completed to determine the strengths and weaknesses of each study using a framework by Caldwell, Henshaw, & Taylor (2011). This framework provided a list of criteria for evaluating qualitative, quantitative and mixed methods

research, and was useful for determining the quality and applicability of the studies included (Caldwell et al., 2011). The questions posed within the framework guided the examination of different aspects of the studies to help determine the dependability of the results (Twycross, Forgeron, & Williams, 2015). Studies were not excluded based on their methodological weaknesses, but the results of the application of the framework for each study were included in the data extraction table to provide a detailed understanding of the strengths and weaknesses of the available research.

**Stage 5: Collating, summarizing, and reporting the results.** The fifth stage of the scoping study was to present an overview of all the material reviewed using an analytic framework or thematic construction technique (Arksey & O'Malley, 2005). In addition to presenting the findings in narrative format, Levac et al. (2005), suggest that researchers should also discuss the implications of the findings in relation to the purpose of the review and implications for future research, practice and policy (Colquhoun et al., 2014). Daudt et al. (2013), emphasize the importance of a clear and consistent approach during this stage. The collated data for the following study characteristics were summarized and reported on, including; date published, study design, categories of age groups, representation of LMICs by location and income status, representation of NGOs by individual organization, types of health services or health programs delivered, and data collection methods used. Health outcomes were extracted across studies and classified as positive, negative or unchanged outcomes and then grouped into categories of similar outcome types. Data analysis involved descriptive quantitative measures including counts, frequencies and percentages. The pattern of outcome reporting over time was determined by graphing the total number of outcomes reported throughout the period of published works collected as well as graphing the number of health outcome types by year of study publication.

**Stage 6: Stakeholder involvement.** Although stakeholder involvement is an optional stage within the framework, multiple authors (Arksey & O'Malley, 2005; Levac et al., 2010; Daudt et al., 2013), endorse the inclusion of stage six as a valuable and essential component of the scoping study methodology. Weintraub et al. (2011), highlight the importance of engaging stakeholders to create a link between healthcare providers and researchers, and argue that this link is vital to the study of global health delivery. Heeding these suggestions, stage six was included in the protocol of this study.

Levac et al. (2010), recommend that the purpose of the consultation should be clearly established and that the “type of stakeholders to consult, how data will be collected, analyzed, reported, and integrated into the overall study outcome” (p.7), should be clearly communicated. Stakeholders were recruited using specific criteria pertinent to the topic of interest, with the purpose of drawing from their knowledge and experience, not only to validate research findings but also to ensure that the findings were relevant to work happening in the field of practice (Weintraub et al., 2011). Additionally, the role of nurses working within these organizations was explored to understand how nurses can facilitate and contribute to the achievement of positive and sustainable health outcomes for children and adolescents in LMICs. This portion of the framework was conducted as a separate qualitative descriptive study.

***Study design.*** Qualitative descriptive studies are beneficial for developing an understanding of a certain phenomenon or process as well as to discover perspectives of those directly involved (Bradshaw, Atkinson, & Doody, 2017). Due to the lack of research specific to evaluation and outcome reporting heard from the voices of those affiliated with NGOs providing pediatric health services in LMICs, a qualitative descriptive design (Sandelowski, 2000), was

chosen as the methodology for engaging stakeholders in order to capture their knowledge and experiences on the topic.

***Stakeholder/participant sample selection.*** Purposive sampling was used to recruit four stakeholders. As there are no set rules for sample size in qualitative research (Polit & Beck, 2012), and the fact that this research topic has not been explored extensively before, a small number of purposely selected participants provided a rich data set that was appropriate for the aims of the study.

Individuals affiliated with an NGO providing pediatric health services in LMICs were invited to participate. Recruitment was done using existing professional networks of the primary investigator and research team. The research team acted as gatekeepers during professional engagements and forums where potential participants were present. Potential participants were given a letter of invitation (Appendix B) or a recruitment card (Appendix C) and instructed to contact the primary investigator if they required further information or were interested in participating in the study. One NGO was contacted via email to request further direction on engaging with potentially interested participants.

***Stakeholder eligibility.***

Participants were eligible to participate if they were involved as a donor, founder, board member, program coordinator, employee or volunteer of an NGO providing pediatric healthcare services in a LMIC. Participants in any of these roles were also eligible if the NGO they were affiliated with was intending to implement a program targeted at pediatric health service delivery in a LMIC, however, none were recruited that met that criteria.

***Data collection.*** Participants were first asked to review the preliminary scoping review findings and then take part in a one-on-one semi-structured interview. The interviews were

scheduled according to the available times agreed upon by the researcher and each individual stakeholder. The preliminary findings were electronically sent to the stakeholder for review after the interview was scheduled to allow them an opportunity to prepare for the discussion of the findings.

Semi-structured interviews were conducted with each stakeholder using Skype, a Voice over Internet Protocol (VoIP) technology. Although VoIP technologies such as Skype and Facetime are questioned as appropriate methods of collecting data in qualitative research (Lo Iacono, Symonds, & Brown, 2016), these technologies allowed for the primary investigator to conduct the interviews with the stakeholders from their distant or international settings. While Lo Iacono et al. (2016), recognize that VoIP mediated interviews should not completely replace face to face interactions, it is deemed an appropriate alternative and valuable tool for researchers to conduct interviews with participants who live outside the direct research area. Other added benefits to using VoIP technology include the ability to have visual feedback throughout the interview and the establishment of a more relaxed rapport, as both the interviewer and interviewee are often participating in the interview from the comfort of their own home or office space (Deakin & Wakefield, 2014; Hamilton, 2014).

A semi-structured interview guide (Appendix D) was used to direct the interviews which was informed by the preliminary scoping review results. The interviews were audio recorded and field notes were written by the interviewer. The audio recordings were then transcribed by a professional transcriptionist with the names and identifying information of each participant removed at the time of transcription.

***Data analysis.*** An inductive content analysis approach was used to analyze the data with the intent of combining and interpreting responses into a comprehensive and general

understanding of the knowledge gathered (Elo & Kyngäs, 2008). A qualitative content analysis approach systematically organizes and interprets narrative data and allows researchers to improve their understanding of the information and identify important themes, categories or critical processes (Elo & Kyngäs, 2008; Polit & Beck, 2012). The flexibility of the inductive qualitative content analysis method was complementary to the iterative nature of the scoping review framework (Elo & Kyngäs, 2008).

Each audio file was listened to simultaneously while the transcript was read so that the researcher immersed themselves in the data, ensured accuracy of transcription, and had a clear understanding of the content (Elo & Kyngäs, 2008). Only manifest content (concrete data as opposed to underlying meanings of the data) were used for data analysis as the aim of the research was to validate and enhance the knowledge from the scoping review and not to find hidden meanings or to interpret the nature of responses (Elo & Kyngäs, 2008). Open coding, category creation, and data abstraction were the three methods used to organize the data, find similarities and themes, and then create categories and subcategories based on the findings (Elo & Kyngäs, 2008). Additionally, meetings with the research team were used to ensure that the categories were grounded in the data.

*Open coding.* Open coding of the transcripts was done by reading through each individual transcript and highlighting and identifying words and texts (codes) that described all aspects of the content (Elo & Kyngäs, 2008). After the first two transcripts had been read and coded, a document was created to transcribe and organize the codes into categories. This provided guidance in the coding of the remaining two interviews. New codes found in the subsequent interviews were added to the list as they were found.

*Categories.* Initial categories were created during the coding of the interviews. These categories were then grouped into higher order headings to reduce the number of individual categories by combining similar and different concepts (Elo & Kyngäs, 2008). The categories were reviewed with the primary investigator's thesis supervisor before further analysis.

*Data abstraction.* Abstraction was done by compiling the data to provide an understanding of how the data fit together into main categories which described the overall content and meanings found (Elo & Kyngäs, 2008). This was done through discussion of the categorized data with the thesis supervisor and members of the thesis committee.

*Trustworthiness & Rigor.* To ensure research quality and trustworthiness, the four principles outlined by Lincoln & Guba (1994), were considered throughout the research process. Credibility (establishing confidence in the truth of the findings), dependability (stability of data over time), and confirmability (objectively representing the data provided by participants) was ensured by debriefing with members of the research team to review and explore various aspects of the data collected (Polit & Beck, 2012). This assisted in maintaining objectivity, consistency and believability in the data patterns and findings (Polit & Beck, 2012). Thick description of the context of the research was used to improve transferability (applicability of data to other contexts) by following specific inclusion criteria for participants, utilizing a semi-structured interview questionnaire for data collection, clearly conveying the methods of data analysis, as well as representing the voices of the stakeholders with verbatim quotes (Polit & Beck, 2012).

*Ethics.* Ethics approval was obtained through the Research Ethics Board (REB) at the University of Ottawa in Ottawa, Ontario prior to any data collection. Stakeholders were respected by seeking their free, informed, and ongoing consent throughout the research process (Canadian Institutes of Health Research, 2010). Stakeholders were provided with a detailed

consent form outlining the purposes of the scoping review (Appendix E; Appendix F), inherent risks and benefits to their involvement and the assurance of privacy and confidentiality. If feasible, written consent was obtained prior to the beginning of each interview. When written consent was not feasible, verbal consent was obtained at the beginning of the interview prior to data collection.

***Confidentiality.*** The stakeholders received assurance from the researcher that the information shared would remain strictly confidential, and that the contents would only be used for the current study. They were assured that their name/role and position as well as the NGO/organization they were affiliated with would not be shared publicly or revealed in any publications or presentations. Each stakeholder was given an anonymous code that was not reflective of their personal information to link them to their data.

Interview transcripts and recordings were stored and secured using encryption techniques and password protected on the university server for five years after the completion of the study. The transcriptionist was also required to sign a confidentiality agreement before proceeding with transcription of the audio recordings (Appendix G).

***Benefits and risks.*** The study was determined by the REB to be of minimal risk to the stakeholders. Participants were asked to answer questions and share opinions specific to the NGO that they were personally or professionally affiliated with. This could have caused uneasiness or discomfort in the participants who may have felt that their answers negatively reflected on the NGO or their mission/mandate. Stakeholders received assurance prior to the interview that there was no obligation to answer questions if they felt uncomfortable doing so. They also were assured that every effort would be made to minimize any risk by keeping interview responses confidential.



Both the written and verbal consents were used to make participants aware that no monetary compensation was being offered for participation and that the benefits of participating included increasing the relevance of the research and advancing the link between research and practice. Additionally, it was communicated that their participation would help provide clarity to the current field of pediatric healthcare provided by NGOs in LMICs and contribute to the body of evidence-based research that promotes quality healthcare for children and adolescents in LMICs.

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### Chapter 3

## Exploring Pediatric Healthcare Initiatives of Non-Governmental Organizations in Low-and Middle-Income Countries: A Scoping Review

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**Abstract**

*Objective.* To explore the research on the delivery of health services by non-governmental organizations in low-and middle-income countries to better understand how they evaluate and contribute to positive and sustainable health outcomes in children and adolescents. *Methods.* A scoping review was completed to identify the available research on the topic. A two-step study selection procedure was used. Two reviewers independently applied the inclusion and exclusion criteria to all citations and full texts. Data extraction was completed by the primary investigator and independently checked for accuracy by a second reviewer using a study specific extraction form. *Results.* Of the 5742 studies, 17 met criteria, including quantitative and mixed method designs, representing 10 different non-governmental organizations with programs in 33 low-and middle-income countries. Health outcomes were reported 89 times across the studies. Fifty-six different outcomes were identified in total, of which 24 were positive, 27 were negative and five were unchanged. *Conclusions.* Widespread variation between non-governmental organization practice exists, however, comprehensive outcome evaluation is growing. Further emphasis should be given to adolescent specific research and more robust measurement of quality of life outcomes.

**Keywords:** pediatric(s), non-governmental organizations (NGOs), low-and middle-income countries (LMICs), health outcomes

## Introduction

Health inequities affect millions of people on a global scale, however, children and adolescents living in low-and middle-income countries (LMICs), especially those living in remote and poor areas, bear the burden of being on the bottom of the socioeconomic scale and social gradient of health.<sup>1,2</sup> Statistics from the early 2000's indicated that globally, over nine million children per year died before their fifth birthday and almost all of these deaths occurred in LMICs.<sup>1</sup> Appropriately, the set of eight Millennium Development Goals (MDGs) established by the United Nations to be achieved by 2015, included the goal for a two-thirds reduction in the under-five year old child mortality rate.<sup>1,3</sup> Reports from these goals have shown that between the years 1990 and 2015, global under-five child mortality declined by 48%.<sup>4</sup> This rapid mortality decline in the context of LMICs is associated with evidence-based health interventions such as skilled birth attendance, increased coverage of immunizations, and multi-sectorial socioeconomic improvements.<sup>4</sup> Although the MDGs have contributed to the prioritization of pediatric health in the last 20 years, focus has been given to a narrow spectrum of the pediatric age range of children five years and younger. Additionally, this population bracket is grouped into a larger category that includes maternal and newborn health (MNCH). As a result, much of the published literature has focused on programs and interventions that address MNCH issues,<sup>5,6</sup> leaving an understanding of the health outcomes of older children and adolescents under-represented.

Infant and child mortality rates are used as the most important indicator of health and overall social and economic development of a population.<sup>6</sup> Additionally, health outcomes are historically defined by death, disease, disability, discomfort, and dissatisfaction.<sup>7</sup> While, these outcomes and indicators are appropriate for the era of MDG achievement when under five-year



old child mortality was at the highest priority, there has been a shift in recent years towards evaluation of more positive health outcomes such as improved health status, functional ability and perceived quality of life.<sup>7</sup> Even though the prevention of under five year old child mortality is still a target in the post-MDG era, the newly established Sustainable Development Goals (SDGs) with targets for the year 2030, further recognize the importance of ensuring healthy lives and promoting well-being for all at all ages.<sup>8</sup> With this in mind, it is now time for the global health sector to focus on the entire pediatric age spectrum and to broaden health evaluation beyond mortality rates and negative health indicators.

Non-governmental organizations (NGOs) have a significant presence within health systems in LMICs and provide services that are increasingly utilized to fill gaps in government health programs.<sup>9–11</sup> While their contribution to health service delivery is often apparent, NGOs may focus on their own programs and goals, and neglect to engage with the greater health agendas in the contexts in which they work.<sup>12</sup> In an era where evidence-based practice and financial accountability are drivers of healthcare, it is appropriate to examine whether NGOs providing health services to children and adolescents in LMICs operate in a way that transparently links positive health outcomes with program implementation and spending. Because there are no mandatory governing bodies monitoring their agendas, it is imperative that NGOs are accountable not only financially to their donors, but also to the populations they serve for the impact and outcomes of their work.

Healthcare NGOs can face many challenges for proper monitoring of outcomes and evaluation of programs due to small operating budgets, limited resources, and unskilled staff.<sup>13</sup> When evaluations are feasible, the focus is generally on reporting metrics (e.g. number of patients treated) rather than outcomes demonstrating effectiveness (e.g. improved viral

suppression rates in HIV positive individuals) and are completed to appease the program requirements mandated by donors.<sup>13,14</sup> Since the activities of each NGO vary by their country of operation, services provided, and populations served, standardization of these processes is a challenge.

NGO involvement in LMIC pediatric health initiatives is in the early stages from a research perspective.<sup>15</sup> Studies exist specific to NGO involvement in pediatric surgical programs operating in LMICs, as evidenced from studies by Nyugen et al<sup>16</sup> and Shrime et al<sup>17</sup>. The survey conducted by Nguyen et al<sup>16</sup> identified eighty NGOs supporting cardiovascular programs for children in ninety-two different LMICs through the use of outreach missions. In their systematic review, Shrime et al<sup>17</sup> classified the platforms for surgical delivery in LMICs and reviewed their effectiveness, sustainability, cost-effectiveness and role in training. The results of these studies indicate that there are a vast array of NGOs providing surgical care in LMICs and that short-term missions are the method most frequently utilized for delivery of surgical services.<sup>16,17</sup> While these research studies contribute to the knowledge of pediatric surgical service delivery in LMICs by NGOs, there remains a gap in the amount of research known to be available and thus, further synthesis of pediatric medical services provided by NGOs in LMICs. In addition to this gap, there is no clear understanding of whether a standardized process exists for NGOs providing pediatric medical or surgical health services to evaluate their programs for positive and sustainable health outcomes.

Children and adolescents are a vulnerable and valued population who are greatly affected by socioeconomic status, social determinants of health, inequities and inequalities of healthcare availability and delivery. Understanding how healthcare NGOs contribute to positive health outcomes in children and adolescents who live in LMICs is instrumental in ensuring the delivery

of quality healthcare that is evidence-based, financially accountable, and falls in line with the goals and objectives for global health in the coming years. The purpose of this study was to synthesize peer-reviewed, empirical research about the delivery and evaluation of pediatric health services by NGOs in LMICs. The specific objectives were: 1) to identify and describe the existing types of programs and services NGOs are providing to children and adolescents in LMICs, 2) to identify and describe the types of health outcomes pediatric NGOs are reporting, 3) to identify and describe NGO's outcomes related to sustainability, and 4) to determine the pattern of NGO outcome reporting over time.

## **Methods**

### ***Design***

This was a scoping review as articulated by Arksey and O'Malley<sup>18</sup>. A scoping review is useful for addressing exploratory research questions by identifying all relevant literature on a specific topic, regardless of study design.<sup>18,19</sup> Considering the limited availability of empirical pediatric NGO research and the heterogenous nature of NGO programs, a scoping review was most appropriate to assess the potential size and scope of the available research; summarize and analyze research findings; and identify gaps in the existing literature.<sup>18,20</sup>

***Stage 1: Identifying the research question.*** The research question and eligibility criteria were formulated using PICOT, a guide for constructing evidence-based practice questions for health research.<sup>21</sup> Since the research question for this study was exploratory in nature and did not include a comparison or specific time frame, the "C" and "T" sections of the tool were not used. The PICOT strategy is outlined in Table 1, and each concept is defined to ensure a clear understanding of the components of the research question.

Research Question: What is known in the published peer reviewed literature about the delivery of pediatric healthcare services by NGOs in LMICs for positive and sustainable health outcomes in children and adolescents?

*Insert Table 1 Here*

**Stage 2: Identifying relevant studies.** The search strategy was developed in consultation with a library scientist to identify all relevant research on the topic. The initial MEDLINE search was peer reviewed using Peer Review of Electronic Search Strategies (PRESS)<sup>22</sup> prior to translation into CINAHL, CAB Direct, Nursing & Allied Health (via ProQuest) and PAIS Index (via ProQuest) databases. The search was limited to English-language studies; however, no other limits were placed on the strategy. Reference lists of each included study were further reviewed for any other relevant studies. One additional study that was not captured in the search, but met inclusion criteria through a hand search, was also included.

**Stage 3: Study selection.** A two-step study selection procedure was used, with two reviewers independently applying the inclusion and exclusion criteria to all citations obtained from the systematic literature search.<sup>23</sup> Step one was conducted at the title and abstract level. The citations selected from step one then underwent step two, which involved full text review.<sup>18</sup> Disagreements between reviewers were resolved by a third member of the research team. The web-based software platform *Covidence*, was used to support both citation screening and full text screening. Only primary research studies (qualitative, quantitative or mixed-methods study designs) published in English were included. The inclusion and exclusion criteria are outlined in Table 1. See the PRISMA (Figure 1) for the number of citations identified, screened, excluded, assessed for eligibility and included for evaluation.<sup>24</sup>

*Insert Figure 1 Here*

*Stage 4: Charting the data.* Data extraction was done using an extraction table created for the review. The table was completed by the primary investigator and independently checked by a second reviewer for accuracy. The following components were extracted for each study in Table 2; author(s), year of publication, country, NGO, study design, research question/purpose, population/sample, data collection, main results/findings specific to pediatric health outcomes. A quality assessment of studies was completed to determine the strengths and weaknesses of each study using a framework by Caldwell et al.<sup>25</sup> This framework provides a list of criteria for evaluating qualitative, quantitative and mixed methods research.<sup>25</sup> The results of the application of this framework are reported in the last column in Table 2.

*Stage 5: Collating, summarizing, and reporting the results.* The results were organized according to the objectives of the scoping review and data extraction table fields. The collated data for the following study characteristics were summarized and reported on, including; date published, study design, categories of age groups, representation of LMICs by location and income status, representation of NGOs by individual organization, types of health services or health programs delivered, and data collection methods used. Health outcomes were extracted across studies and classified as positive, negative or unchanged outcomes and then grouped into categories of similar outcome types. Data analysis involved descriptive quantitative measures including counts, frequencies and percentages. The pattern of outcome reporting over time was determined by graphing the total number of outcomes reported throughout the period of published works collected as well as graphing the number of outcome types reported by year of study publication.

*Insert Table 2 Here*

## **Results**

### ***Study Details***

A total of 17 studies published between 1999-2016 were included in the review. They comprised both quantitative studies (n=15, 88%) and mixed methods studies (n=2, 12%). Of the 15 quantitative studies, the predominate study design was cross-sectional (n=8, 47%), followed by retrospective record (e.g. chart) reviews (n=4, 24%), and cohort studies (group of individuals studied with data collected at different intervals over time<sup>21</sup>) (n=3, 18%) (Table 3). Categories of age groups included children (n=6, 35%), adolescents (n=1, 6%), children and adolescents (n=6, 35%), and all ages (n=4, 24%) (data for children and adolescents reported separately from adults) (Table 4).

*Insert Table 3 and Table 4 Here*

### ***Representation of LMICs***

Fifteen studies reported on NGO interventions/programs delivered in 33 different LMIC's. The mapped global distribution of these countries is shown in Figure 2. The remaining two studies reported on data collected in an additional 36 LMIC's, but these countries were not listed. The majority of the identified countries were located on the continents of Africa (n=19, 58%) and Asia (n=13, 39%), with only one country located on the continent of South America (n=1, 3%) (Table 5). In terms of economic status, 52% (n=17) of the identified countries were classified as lower-middle income, 42%(n=14) as low-income and 6%(n=2) as upper-middle income (Table 5).

*Insert Figure 2 and Table 5 Here*

### ***Representation of NGOs***

The interventions/programs of 10 different NGOs were evaluated across the 17 studies. One study did not identify a specific organization but instead referred to a network of NGOs that

contributed to a health program being examined.<sup>26</sup> The names of the NGOs involved in the network were not specified. Interventions by Médecins Sans Frontières were most commonly studied (n=4, 24%), followed by Operation Smile (n=3, 18%) and Walk for Life (n=2, 12%) (Table 6).

*Insert Table 6 Here*

### ***Representation of Health Services***

Several types of health services were represented, including medicine (n=7 studies, 41%), surgery (n=7 studies, 41%), mental health (n=1 study, 6%), program implementation (n=1 study, 6%) and mobility device provision (n=1 study, 6%) (Table 7). The most common health interventions were cleft lip/palate repair (n=4 studies, 24%), clubfoot treatment (n=2 studies, 12%) and anti-retroviral therapy (ART) (n=2 studies, 12%) (Table 7).

*Insert Table 7 Here*

### ***Data Collection Methods***

Data used to report on the study outcomes were collected using a range of methods. Open ended or semi-structured interviews were used for data collection in 24% (n=4) of the studies.<sup>26-30</sup> A survey or questionnaire was used for data collection in 24% (n=4) of the studies.<sup>26,31</sup> Two studies (12%) used study specific, data collection tools, both evaluating outcomes related to surgical interventions within the peri-operative setting.<sup>32,33</sup> Direct observations or examinations by a clinician were used in 35% (n=6) of the studies, either as a single method of data collection or in combination with other methods.<sup>26-28,34,35</sup> Two studies (n=2, 12%) had an unclear description of data collection methods, including one study that did not report any method of data collection, and another which only specified that data were collected using patient monitoring data (n=1, 6%).<sup>36,37</sup> For the chart review studies, the authors extracted data pertinent

to the outcome of interest directly from the health record and/or chart reviewed (n=4, 27%).<sup>34,38-</sup>

40

### *Health Outcomes*

The studies reported a relatively equal mix of time points at which outcomes were measured, including short-term (e.g. immediately post-intervention) (n=5 studies), medium-term (e.g. 6 months to 2-years post-intervention) (n=7 studies) and long-term outcomes (e.g. >2 years post-intervention) (n=5 studies) (Table 8). Six studies (35%) reported both positive and negative health outcomes, five studies (29%) reported only negative health outcomes, and two studies (12%) reported only positive health outcomes. Two studies (12%), reported positive, negative and unchanged outcomes and two studies (12%) reported positive and unchanged outcomes. Outcomes were reported 89 times across the 17 studies. Fifty-six different outcomes were identified in total, of which 24 were positive, 27 were negative, and five were unchanged.

#### *Insert Table 8 Here*

Six categories of positive health outcomes were identified, including; 1) successful intervention/cure rates; 2) reduction of symptoms or improving clinical signs (e.g. improving CD4 count); 3) satisfaction with care or results of treatment; 4) physical improvement (e.g. improved mobility, facial appearance, increase in weight, improved speech etc.); 5) social improvement (e.g. ability to play with friends unimpeded); and 6) improved prevalence rate after treatment. Four categories of negative health outcomes were identified, including; 1) death; 2) complications/adverse events (e.g. return to OR, infection post-op, GI intolerance etc.); 3) default from treatment or loss to follow-up; and 4) relapse or recurrence (e.g. stricture recurrence). The most common category of positive health outcome reported across studies was physical improvement (n=5, 29% of studies). The most common category of negative health



outcome reported across studies were death (n=9, 53% of studies) and complications/adverse events (n=9, 53% of studies) (Table 9).

*Insert Table 9 Here*

### ***Outcome Evaluation Techniques***

Most of the described outcomes were evaluated quantitatively and reported as frequencies, percentages, proportions, means or standard deviations. Inferential statistics were used across 15 studies primarily to draw comparisons between outcomes, groups and patient demographics, however, three studies used inferential statistics to report outcomes. The study by Gonzales, Dearden & Jimenez<sup>31</sup> evaluated the point prevalence of diarrhea within four treatment groups using Chi-square analysis. The study by Ngondi et al<sup>26</sup> evaluated the change and percent reduction in active trachoma and unclean faces using 95% Confidence intervals. Lastly, the study by Toro, Eke & Pearlman<sup>41</sup> evaluated satisfaction with means of mobility between the treatment group and comparison group using Fisher's exact test and Mann-Whitney U test.

The two mixed methods studies, both focused on evaluating NGO programs that repaired cleft lip and palates, reported positive outcomes which were identified within the themes of their qualitative analyses. These themes included improved appearance, improved school attendance, ability to play with friends unimpeded, improved speech, improved eating, improved social benefits (e.g. less teasing) and simply, a repaired cleft.<sup>28,30</sup> Only one negative outcome, discussed as the report of negative features associated with surgery (e.g. fear of pain or death, travel costs), was identified through qualitative analysis in the Sharp et al.<sup>30</sup> study.

Three validated tools were used to assess outcomes across three studies. The Bangla Clubfoot Assessment tool<sup>42</sup> evaluated six positive outcomes in the Evans et al.<sup>27</sup> and Perveen et al. 29 studies including, brace use, ability to walk, run, squat and manage steps appropriately, and

parental satisfaction. The Functional Mobility Assessment – Kids (FMA-Kids)<sup>43,44</sup> and Craig Handicap Assessment Recording Technique Short Form (CHART-SF)<sup>45</sup> assessed outcomes in the Toro, Eke & Pearlman<sup>41</sup> study, and resulted in the report of positive outcomes including increased satisfaction with mobility as well as a higher mobility domain for children with proxies who received a wheelchair, compared to children with proxies in the waitlist group. The Evans et al<sup>27</sup> study also utilized the Bhaskar tool<sup>46</sup> to evaluate relapse in children after clubfoot treatment, however, it is unclear if this tool has been validated.

### ***Sustainability***

Sustainability of interventions or programs was infrequently mentioned in the studies. Mirabel et al<sup>39</sup>, in their study on pediatric cardiac surgery programs in Cambodia and Mozambique, briefly suggested in their conclusion that capacity building aimed at improving program delivery, in addition to local political support, would assist in improving healthcare systems. Myung et al<sup>40</sup>, reported that further data needs to be collected to evaluate the long-term sustainability of their program for directly observed anti-retroviral therapy in HIV infected children. Perveen et al<sup>29</sup> stated that the purpose of their study was to evaluate the long-term outcomes in their clubfeet program to build on their assessment of project sustainability previously identified in their short-term results. However, except for the study by Gonzales et al<sup>31</sup>, which focused on health outcomes of a multi-sectoral development program, the studies included in this scoping review, despite the inclusion criteria, focused heavily on treatment and management of symptoms with immediate or sustained outcomes, and did not primarily focus on capacity building or improving infrastructure and current health systems in LMIC contexts.

### ***Outcome Reporting Over Time***

Over time, the overall reporting of outcomes by NGOs increased, however year-to-year variability was evident (Figures 3 and 4). Specifically, in the earliest publications (1999-2007), an average of n=3 outcomes were reported per year and in the most recent publications (2008-2016), an average of n=7 outcomes were reported per year. The evaluation of broader health outcomes beyond death, complications, physical or clinical improvement (e.g. improved school attendance, improved ability to play with friends) were reported in the more recent years of publications (2008-2016) (Figure 4).

*Insert Figure 3 and Figure 4*

## **Discussion**

This scoping review sought to explore the available academic research on the delivery of pediatric health services by NGOs in LMICs to further understand how healthcare NGOs are evaluating and contributing to positive and sustainable health outcomes in children and adolescents. Review of the studies included suggests that while there is very little consistency in data collection and outcome evaluation, this work is growing within the field of NGO practice in LMICs (Figures 3, 4 and 5). The increased evaluation of health outcomes over time as well as the types of outcomes evaluated (e.g. satisfaction of care, improved ability to play with friends etc.) suggests that NGOs are considering a broader spectrum of outcome types when evaluating their programs, rather than solely assessing and reporting on morbidity, mortality or numbers treated. These types of outcomes are useful not only for delineating between effective interventions, ineffective interventions and areas for improvement, but shows that NGOs are more robustly evaluating outcomes related to the complex health needs of children and adolescents in LMICs.

### ***Qualitative Research Methods for Outcome Evaluation***

The under-representation of qualitative research methods in the included studies highlights the need for the advancement of research methods in NGO outcome evaluation. Rich data on health outcomes were gathered through the research done by Fell et al.<sup>28</sup> and Sharp et al.<sup>30</sup>, and assisted in a deeper understanding of the experiences of the participants in the studies. Many authors and researchers discuss the benefits of both mixed methods and qualitative research, as they contribute to an improved understanding of the human and social experience, provide insight on issues like barriers to care, as well as both positive and negative patient views and experiences.<sup>47-50</sup> Polit & Beck<sup>21</sup> discuss that although outcomes research has been primarily focused on quantitative design approaches, the complexities of outcomes research is evolving to allow for more novel methodologic approaches in this area. Even relatively straightforward outcome research in LMICs could be considered complex due to context, and thus would benefit from a qualitative component. As previously discussed, multiple barriers exist for NGOs when evaluating program outcomes due to competing priorities, lack of financial capability, untrained staff, etc.<sup>13</sup> Perhaps further education on the benefits of qualitative methods for outcome evaluation would encourage NGOs to collect data in this manner, as these approaches allow for insights that quantitative approaches alone do not provide <sup>47</sup>. Qualitative research in this field, would help to further understand how the participants' experiences relate or contribute to the achievement of positive, negative or unchanged outcomes in children and adolescents in LIMC.

### ***Evaluation of Quality of Life***

Although the evaluation of broader health outcomes has increased over time and the types of health outcomes reported reflect some aspects of quality of life measurement, specific evaluation of quality of life was done minimally across the studies. Toro et al<sup>41</sup>, were the only researchers who stated an intended purpose to evaluate quality of life as a specific outcome in

their study. Although they utilized a validated tool (World Health Organization Quality of Life-BREF scales<sup>51</sup>) to measure this outcome, it was only used for quality of life assessment in adult participants, resulting in no actual measurement of quality of life for children or adolescents in the study.<sup>41</sup> The authors did measure outcomes that reflect components of quality of life (e.g. improved mobility, improved participation in society) using other tools such as the FMA-Kids,<sup>43,44</sup> and CHART-SF<sup>45</sup> which resulted in statistically significant results for improvement in satisfaction with mobility for children with proxies ( $p < 0.001$ ,  $r = 0.50$ ,  $\beta = 0.99$ ) and a decrease in mobility for children with proxies in the waitlist group in comparison to the wheelchair group. Although the results did not show any statistically significant results for improved participation in society, the study showed that wheelchair provision can improve certain aspects of quality of life in this population (mobility). Unfortunately, the FMA-Kids and CHART-SF tools did not completely measure or address the multiple domains included in a comprehensive quality of life assessment.

The study by Sharp et al<sup>30</sup>, assessed the long-term outcomes of cleft lip and palate repair by Operation Smile's programs using a study specific survey and questionnaire titled "Quality of Life After Cleft Palate Repair".<sup>30</sup> The results included a report of positive outcomes experienced and perceived as important by children and adolescents such as improved speech, improved eating, improved social benefit and improved appearance.<sup>30</sup> Additionally, three other studies reported outcomes that suggested improvement in quality of life for either the child or family unit.<sup>27-30</sup> The two studies that evaluated the interventions provided by the NGO Walk for Life, reported outcomes of parental satisfaction in addition to improvements in physical functioning for the child such as the ability to walk, run and manage steps independently.<sup>27,29</sup> The study by Fell et al<sup>28</sup>, which assessed Project Harar's impact of cleft lip and palate repair, reported

qualitative themes that conveyed improvements in quality of life such as improvement in appearance, ability to play with friends unimpeded, as well as better school attendance. While these outcomes were certainly linked to or reflected improvement in quality of life, the studies within this review lacked robust validated measurement of quality of life as a primary outcome.

Further work is therefore needed on the comprehensive measurement of pediatric quality of life as an outcome of NGO programs/interventions, as health is not unidimensional. Pediatric quality of life measures assess the wider impact that health interventions have on a child or adolescent's well-being and is seen as an essential health outcome.<sup>52,53</sup> Understanding how interventions impact pediatric quality of life is important, as the WHO endorses that health is not just the absence of disease but rather a state of complete physical, mental and social well-being.<sup>54</sup> Thus, for NGOs, a more holistic approach to pediatric quality of life would improve performance measurement, inform quality improvement, and determine best areas for financial investment.<sup>52</sup> Therefore, it is imperative that more robust assessments of quality of life are accounted for when determining whether NGO programs are positively impacting the populations they serve.

At minimum, instruments measuring pediatric health related quality of life must include physical, mental and social health dimensions, and incorporate the role of school functioning.<sup>53</sup> A study by Mabugu et al<sup>52</sup> which assessed the methodological challenges for quality of life estimation in low-income countries for children, identified eight different scales that can be used to measure pediatric quality of life. Although the study concluded that the use of these tools in low-income settings should be done cautiously with consideration of context-specific factors,<sup>52</sup> the variety of tools identified within the study reiterates that many are available for use. Unfortunately, it is unclear why any of these tools were not utilized for the pediatric participants in the Toro et al<sup>41</sup> study or why quality of life was not mentioned by any of the other researchers.

After consideration of context-specific factors as Mabugu et al<sup>52</sup> suggests, these instruments could be useful to further report on the effectiveness of NGO interventions as well as add depth to the meaning of their outcome results. Proper measurement of quality of life could also be an indicator of long-term health improvements and sustainable outcomes of interventions which was identified as lacking within the included studies.

### ***Adolescent Research***

While a number of the studies included participants within the adolescent age bracket (children and adolescents, all ages), there was a lack of studies specific to adolescents alone. This was expected given that research priorities have been focused on maternal, newborn and under five years of age population health in recent years. The only study specific to adolescents was the Isaakidis et al<sup>55</sup> study, which presented the intermediate outcomes of HIV infected adolescents receiving anti-TB treatment by the NGO Médecins Sans Frontières in India.

According to UNAIDS 2019 estimates,<sup>56</sup> approximately 1.6 million adolescents between the ages of 10-19 are living with HIV globally. Yet, adolescents still lack adequate access to HIV and other health services, even though they have been recognized as a critical age group requiring care through this time of development and transition into adulthood.<sup>57</sup> Issues highlighted within the Isaakidis et al<sup>55</sup> study mirror those discussed in the adolescent HIV literature, including higher rates of loss to follow-up, poor treatment adherence and increased need for psychosocial support compared to the adult HIV population in LMICs.<sup>58,59</sup> Barriers such as these contribute to undesirable outcomes such as death and loss from treatment, as reported in the Isaakidis et al<sup>55</sup> study, suggesting that research focused on adolescent populations needs to capture the effects of barriers to care for this age group and strategies to address them in order to improve adolescent health outcomes in LMICs. Armstrong et al<sup>57</sup> suggests that improved

understanding of how to best provide care to the adolescent population is needed to inform innovative and targeted interventions to improve health outcomes. One of the priorities highlighted by the WHO and Collaborative Initiative for Pediatric HIV Education and Research is to gather further evidence on the management of coinfections among adolescents with HIV, especially those with advanced disease.<sup>57</sup> Isaakidis et al<sup>55</sup> suggest that active case-finding, direct referrals to treatment centers, targeted adherence counseling and social support around life events could improve the outcomes in their study, but also highlighted that research on problem solving and improved decision making around interventions is also needed.

The fourteen targets for adolescent health and development outlined in the sustainable development goals reiterate the message that further research, policy development and program modification is needed for this population.<sup>60</sup> The lack of studies focusing on outcomes in adolescents within this review supports the need for continued focus and effort among these targets. Healthcare professionals working in LMICs have a profound ability to be active participants in assisting adolescents with the management of their health needs and contribute to improved positive outcomes for those living with illness. Not only can healthcare professionals contribute to research initiatives, and policy development, they can be available to adolescents at the point of care to assist with effective initiatives such as active case finding, referral to supportive services, counseling, and social support.

### ***Limitations***

Despite contributing to a better understanding of the research by NGOs providing pediatric healthcare in LMICs, this scoping review has several limitations. Five academic databases were used for the systematic search, however the studies found may not represent a complete collection of the literature available on this topic. NGO publications may be more



widely available in grey literature forums or websites, meaning that there is potential for available research on the topic to not have been included. However, the purpose of this scoping review was to locate and analyze the published peer reviewed research studies, as they are more readily available to the wider scholarly community and clinicians interested in this field.

Studies published in a language other than English may also contribute to the findings but were not included in the review due to the language limitations placed on the search. One study that met criteria was included after a hand search of an NGO website was completed but was not identified via the systematic search. This was due to the fact that the MeSH term used to identify the organization in the study was ‘national health programs/economics’, which was not a keyword or MeSH heading determined appropriate in the search strategy used for this scoping review. Therefore, further studies may have been missed if they were inappropriately classified by the databases.

Although a framework was used to evaluate individual studies’ strengths and limitations (see Table 2), the results of this evaluation were not utilized to draw conclusions regarding the inclusion of a study in this review as the intent of a scoping review is to have an understanding of the research in the field, not to make recommendations on treatments themselves.

## **Conclusion**

Findings from this scoping review highlight a number of gaps in research and practice. The results emphasize numerous variations between NGO practice for children and adolescents receiving care in LMICs. Not only is there a lack of research available regarding the work of pediatric NGOs globally, there is also widespread diversity between how outcomes are evaluated and reported. Progress has occurred towards an increased report of more comprehensive health outcomes beyond morbidity and mortality. However, there is still significant room for growth in

this area, including the use of validated tools that capture data for a holistic quality of life measure. The use of qualitative or mixed methods research needs to be further utilized in NGOs' research to better understand the complex context in which interventions are delivered, as well as processes and life experiences of children and adolescents. Finally, additional emphasis and priority needs to be given to research specific to adolescents due to the complex nature of their needs and barriers to achieving positive health outcomes in this population. Healthcare professionals are well situated within programs of many NGOs globally to advocate for and be involved in these changes to improve care and health outcomes in the pediatric population of LMICs.

**Declaration of Conflicting Interests**

The authors declare that there is no conflict of interest.

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**Table 1. PICOT Strategy**

PICOT	Formulation	Definition of Terms	Inclusion Criteria	Exclusion Criteria
P (Population)	Pediatric patients living in LMIC(s)	<i>Pediatrics:</i> Age group from birth to adolescence. The term pediatric is referred to as a specialty within healthcare stated to be concerned with maintaining health and providing medical care to children. <sup>61 61</sup> <i>LMIC(s):</i> Countries with a GNI per capita of \$12,055 or less. Includes countries classified by low-income (GNI per capita = < \$1025), lower-middle income (GNI per capita = \$1026 - \$3995) and upper-middle income economies (GNI per capita = \$3996 - \$12 375). <sup>62</sup>	<ul style="list-style-type: none"> <li>• Age range of participants from birth-18 years of age</li> <li>• Age of participants &gt;18 years of age but identified as adolescents by individual study definitions</li> <li>• Research conducted in a LMIC</li> </ul>	<ul style="list-style-type: none"> <li>• Adult participants only</li> <li>• No separation between pediatric data and adult data when both populations included</li> <li>• Specific to maternal health, including pregnancy</li> <li>• Research conducted in high-income countries</li> </ul>
I (Intervention)	Programs/ service(s) delivered by healthcare NGO(s)	<i>Healthcare NGO(s):</i> Any non-profit, non-public, voluntary organization outside direct state control, pursuing activities related to health promotion, disease prevention, service delivery, health advocacy, education or training <sup>63,64</sup> <i>Healthcare services:</i> The range of medical, surgical, social or psychological services, nursing care, health education or training, immunizations and disease prevention that primarily focus on improving health <sup>12</sup> , including the spectrum of care from promotion and prevention, diagnostic, rehabilitation and palliative care, self-care, home care, community care, primary care, long-term care and hospital care. <sup>65</sup> *Healthcare intervention will be used interchangeably with healthcare service	<p>Program/intervention by an organization identified as:</p> <ul style="list-style-type: none"> <li>• Non-governmental</li> <li>• Non-profit</li> <li>• Charity</li> <li>• Faith-based</li> </ul> <p>Health service delivery relevant to any/all of the following:</p> <ul style="list-style-type: none"> <li>• Program implementation</li> <li>• Health outcomes or impacts</li> <li>• Sustainability</li> <li>• Capacity building</li> <li>• Evaluation</li> <li>• Monitoring</li> <li>• Performance</li> <li>• Illness prevention (e.g. immunizations)</li> </ul>	<ul style="list-style-type: none"> <li>• Health promotion (e.g. education)</li> <li>• Nutrition or nutritional interventions</li> <li>• WHO recommendations/policies implemented or tested in government or private healthcare contexts</li> <li>• Government and NGO collaborations</li> <li>• Epidemiology studies focused on only trends</li> <li>• NGO programs used as the comparison for an intervention</li> </ul>
O (Outcome)	Health Outcomes	<i>Health outcomes:</i> A change in the health status of an individual, group or population as a result of an intervention. <sup>66</sup> <i>Positive health outcome:</i> The result of an intervention contributing to good or improved health. <sup>66,67</sup> <i>Negative health outcome:</i> The result of an intervention contributing to worsened or ill health. <sup>66,67</sup>	<ul style="list-style-type: none"> <li>• Positive health outcomes (e.g. clinical improvement, improved school attendance, cure)</li> <li>• Negative health outcomes (e.g. death, complications)</li> </ul>	<ul style="list-style-type: none"> <li>• Either outcome(s), impact or sustainability not stated in aim/purpose of the research or within the research question</li> </ul>

Abbreviations: LMIC=Low-and middle-income country; GNI=Gross national income; NGO=Non-governmental organizations; WHO=World Health Organization



**Table 2.** Data extraction table of included studies.

Author, Year of Publication, Country, NGO, Study design	Research question/Purpose	Population/Sample	Data collection	Main results/Findings	Strengths/Limitations
Contini et al <sup>36</sup> (2009)  Sierra Leone  “Emergency”- <i>Italian NGO hospital</i>  Cross-sectional	To evaluate the clinical outcomes, safety and efficacy of late caustic stricture dilatation in children compared to results of timely dilatations	56 children <15 years of age with alkaline caustic ingestion  Group 1: 25 Children with a late dilatation (>6 weeks having arrived at the hospital after ingestion) Mean age= 5 +/- 2.5 years  Group 2: 31 children with a timely dilatation (<6weeks after injury) Mean age= 5 +/- 4 years	Data collection measures not reported (possible chart review)  Methods section includes description of participants as well as treatment process/procedures	Group 1: Late dilatation <ul style="list-style-type: none"> <li>• 91.6% (n=22) successful clinical outcome</li> <li>• 16% (n=4) perforations</li> <li>• 72.7%(n=16) stricture recurrence x 1</li> <li>• 31.8% (n=7) stricture recurrence x 2</li> <li>• 12% (n=3) developed subcutaneous emphysema</li> <li>• 4% (n=1) died</li> </ul> Group 2: Early dilatation <ul style="list-style-type: none"> <li>• 96.7% (n=30) successful clinical outcome</li> <li>• 30% (n=9) stricture recurrence x1</li> <li>• 3.3% (n=1) stricture recurrence x 2</li> <li>• 3.2% (n=1) died</li> </ul> Odds ratio for stricture recurrence in Group 1 compared to Group 2= 7.93 (95% C.I. 2.23-28.15)  Overall: Higher recurrence rate and higher risk of perforation expected after late treatment ( $p= 0.0008$ )	Strengths: <ul style="list-style-type: none"> <li>• Study carried out over 2-year period</li> </ul> Weaknesses: <ul style="list-style-type: none"> <li>• Study design and data collection methods not clearly outlined</li> <li>• No identification of alpha or power to determine statistical significance</li> <li>• No report of ethical considerations</li> <li>• Limited generalizability</li> </ul>

<p>Evans et al<sup>27</sup> (2016) <i>Walk for Life</i> Bangladesh Cross-sectional</p>	<p>To review the outcomes of Bangladeshi children with congenital clubfoot deformity 4 years after undergoing Ponseti method for club foot correction</p>	<p>99 parents and children who started congenital club foot treatment  n= 72 males n= 27 females  Mean age at 4-year assessment = 5.01 years (S.D. = 0.94)  Age at first corrective cast: 0-3 months (n=31) 4-12 months (n=26) 1-2 years (n=28) 2-3 years (n=14)  Mean age of first corrective case = 1.01 years (range 0.20-2.40)</p>	<p>Bangla clubfoot assessment tool to evaluate treatment outcomes  Domains: • Parent satisfaction • Gait and function • Clinical examination  Data collection methods: • Face-to-face interviews with parents • Patient examination by the researcher</p>	<p>Gait and Function: • 40.4% (n=40) continued brace use • 59.6% (n=59) no brace use • 98.9% (n=98) able to walk • 98.9% (n=98) able to run • 84.8% (n=84) able to squat fully • 95.9% (n=95) able to manage steps independently  Parental Satisfaction: • Mean score = 84% Clinical Examination: • 13.1% (n=13) showed signs of relapse Lost to follow up: • n=48 (32.6%)  • Satisfaction positively correlated with children having straight feet (<math>\rho=0.703, p&lt;0.001</math>) and children being able to wear normal shoes (Spearman <math>\rho=0.907, p&lt;0.001</math>)  • Satisfaction negatively correlated with children unable to manage stairs (<math>\rho=-0.862, p&lt;0.001</math>)  Overall: Relapse rate was low, parent satisfaction was high, but those with children needing further treatment were less satisfied</p>	<p>Strengths: • Sample adequately reflected population • Outcomes evaluated using validated tools • Statistical evaluation and significance levels determined a priori  Weaknesses: • Study design not identified • Potential bias in data collection (local examiner not blinded) • Sample from one large WFL clinic (not generalizable) • No comparison groups • 48 cases lost to follow-up • Parental satisfaction not clearly defined</p>
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<p>Fell et al<sup>28</sup> (2014)</p> <p>Ethiopia</p> <p><i>Project Harar</i> (in partnership with Smile Train and Transforming Faces)</p> <p>Mixed Methods</p>	<p>To conduct a quality assessment of the impact (change to the life of a person) of a single surgical intervention in patient's treated by Project Harar's program.</p> <p>To highlight aspects of care for improvement.</p>	<p>356 individuals with isolated cleft lip operated on at least 6 months previously</p> <p>Ages of participants: 0-7 years (infants) n=120 7-20 years (school age) n=169 &gt;20 years (adults) n=67</p> <p>n=221 Males n=135 Females</p>	<p>Evaluation completed by a single independent clinician not involved in surgeries.</p> <ul style="list-style-type: none"> <li>• Self-report</li> <li>• Parent/guardian report for children too young to be questioned (no age reported)</li> </ul> <p>Semi-structured interview questions:</p> <ul style="list-style-type: none"> <li>• Demographics</li> <li>• Pre-operative feelings/motivation for treatment</li> <li>• Post-operative changes</li> <li>• School attendance, employment &amp; marriage, pre &amp; post operatively</li> <li>• Functional ability to speak, eat and hear pre &amp; post operatively</li> <li>• Satisfaction with care provided and outcome of treatment</li> </ul> <p>Observed: Lips examined for wound dehiscence, full-face photos obtained and matched to pre-operative photos</p>	<p>Qualitative data themes:</p> <ul style="list-style-type: none"> <li>• Post-operatively patients/parents most frequently reported improvements in <ul style="list-style-type: none"> <li>▪ Appearance</li> <li>▪ School attendance</li> <li>▪ Ability to play with friends unimpeded</li> </ul> </li> </ul> <p>Quantitative Outcomes:</p> <ul style="list-style-type: none"> <li>• Breast-feeding/eating problems occurred in 38% (n=135) of patients pre-operatively but resolved in all but 1 patient post-operatively</li> <li>• Proportion of school attendance increased from 46% to 79% (n=134) post-operatively</li> </ul> <p>Observed outcomes (pediatric and adult data combined):</p> <ul style="list-style-type: none"> <li>• 97% (n=346) no complications</li> <li>• 3% (n=10) lip repair complication</li> </ul> <p>Overall: Follow-up can be achieved, and patients reported a positive impact following surgical intervention</p>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>• Quantitative &amp; qualitative data collected</li> <li>• Statistical analysis with descriptive and non-parametric tests with statistical significance set as <math>p &lt; 0.001</math></li> </ul> <p>Weaknesses:</p> <ul style="list-style-type: none"> <li>• No specific study design identified</li> <li>• No comparison group</li> <li>• Potential for socially desirable responses</li> <li>• Only a proportion of Project Harar's patients interviewed (patients with poor outcomes may not have participated)</li> <li>• Missing data for some: Details regarding original cleft defect and operative treatment</li> <li>• Some pediatric and adult data not separated</li> </ul>
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<p>Fisher et al<sup>32</sup> (2001)</p>	<p>To develop a profile of anesthetic practices.</p>	<p>n=5256 patients who underwent general anesthesia during procedures for cleft palate and/or lip repair</p>	<p>Anesthesia provider and PACU nurse completed perioperative events log</p>	<p>Complications</p> <ul style="list-style-type: none"> <li>• 5% (n= 263) airway complications (3.4 times greater risk in children under age 5, 95% C.I. 2.6-4.6; p &lt;0.05)</li> </ul>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>• Large sample size</li> <li>• 57 study sites increase generalizability</li> </ul>
<p>18 countries – not specified</p>	<p>To evaluate how to develop quality assurance mechanisms by studying anesthetic techniques &amp; outcomes.</p>	<p>Overall age range: 3 months – 63 years</p>	<p>Data recorded:</p> <ul style="list-style-type: none"> <li>• Demographics</li> <li>• Anesthesia techniques</li> <li>• Selected adverse anesthesia events (laryngospasm, bronchospasm, upper airway obstruction, croup, arrhythmias, bradycardia, hypotension)</li> <li>• Selected PACU events</li> </ul>	<ul style="list-style-type: none"> <li>• 3.3% (n=175) one or more airway difficulties in PACU</li> <li>• 2.2% (n=114) delayed transfer to ward due to excess sedation or pain</li> <li>• 1.8% (n=92) delayed transfer to ward due to agitation</li> <li>• 1.7% (n=89) delayed transfer to ward due to excess bleeding</li> <li>• 1.5% (n=77) delayed transfer to ward due to cardiovascular complications</li> <li>• 1.8% (n=95) significant morbidity</li> <li>• 0.9% (n=45) return to OR</li> <li>• 0.5% (n=25) cancellation of surgery after induction</li> <li>• 0.02% (n=1) death</li> </ul>	<p>Weaknesses:</p> <ul style="list-style-type: none"> <li>• Authors report potential for underreporting of mild or moderate events</li> <li>• Study design reported but does not meet definition of “cohort analysis” used for the present study analysis</li> </ul>
<p><i>Operation Smile</i></p>		<p>Median age: 5 years (25<sup>th</sup>-75<sup>th</sup> percentiles: 2-9 years)</p>	<p>Age categories:</p> <ul style="list-style-type: none"> <li>• Less than 2 years</li> <li>• 2-4 years</li> <li>• 5-9 years</li> <li>• 10-14 years</li> <li>• 15-19 years</li> <li>• 20 years and older</li> </ul>	<p>Overall: Complications more common in younger children. Feasible to track adverse perioperative events.</p>	
<p>Cross-sectional</p>					

<p>Gonzales, Dearden &amp; Jimenez<sup>31</sup>  (1999)  Bolivia  <i>Save the Children US</i>  Cross-Sectional Survey</p>	<p>To investigate if multisectoral development programs have a greater impact on health behaviors &amp; outcomes than health programming alone</p>	<p>n=2552 men, women &amp; children from 499 households</p> <p>4 groups of households with varying levels of access to Save the Children’s program compared:</p> <ul style="list-style-type: none"> <li>• Health programs only (n=792)</li> <li>• Health programming + at least 1 adult female household member participating in credit or post-literacy programs (n= 360)</li> <li>• At least 1 adult female participating in all 3 programs (n= 614)</li> <li>• Households from comparison communities in neighboring provinces with no Save the Children programs (n=786)</li> </ul>	<p>Trained local research assistants conducted survey and questionnaires using study specific tools</p> <p>Data collection:</p> <ul style="list-style-type: none"> <li>• Household-level survey (Sociodemographic data, gender, relations)</li> <li>• Questionnaire for women of reproductive age (education level, literacy, pregnancy history, point prevalence of diarrhea, treatment of diarrhea etc.)</li> <li>• Measure of mid-upper arm circumference of children in the household</li> </ul>	<p>Health Outcomes:</p> <ul style="list-style-type: none"> <li>• Point prevalence of diarrhea similar in all 4 groups (PP=19, 26, 27, 27, <math>X^2=4.0</math>, 3 df)</li> <li>• Children of women participating in all 3 programs had highest mean arm circumference (Age:12-59 months)</li> <li>• Rates of malnutrition for those participating in none of the Save the Children’s programs and those benefiting from health-only programs are only slightly higher (32% &amp; 35% respectively)</li> <li>• Percentage of liveborn children who subsequently died of diarrhea and all other causes was similar for all four groups (14, 12, 11, 13, <math>X^2=3.1</math>, 3 df)</li> </ul> <p>Overall: No association between participation in one or more of Save the Children’s programs and parents’ actions to prevent and treat diarrhea, but children better nourished with mothers participating in all 3 health programs</p>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>• Study design identified</li> <li>• Sample sizes calculated based on alpha level of 0.05, beta level of 0.20</li> <li>• Statistical significance determined at <math>p&lt;0.05</math>, <math>p&lt;0.01</math> and <math>p&lt;0.001</math></li> <li>• Inferential statistics used to compare groups</li> </ul> <p>Weaknesses:</p> <ul style="list-style-type: none"> <li>• Lack of baseline data</li> <li>• Lack of information on length and quality of participation in Save the Children’s programs</li> <li>• Results not generalizable due to potentially uncontrolled variables (e.g. age differences across communities, fidelity of program delivery)</li> <li>• Potential for clustering of data collected due to multiple women interviewed from single households</li> <li>• Potential for recall bias</li> </ul>
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<p>Isaakidis et al<sup>55</sup> (2013) India <i>Médecins Sans Frontières</i> Retrospective Record Review</p>	<p>To present intermediate outcomes of HIV-infected adolescents receiving second-line anti-TB treatment</p>	<p>n=11 adolescents diagnosed with MDR-TB and co-infected with HIV  Ages of participants: 10-19 years  46% (n=5) Male 54% (n=6) Female  Median age = 16 years (IQR: 14-18)</p>	<p>Electronic chart database.  Information collected:  <ul style="list-style-type: none"> <li>• Demographics</li> <li>• HIV status</li> <li>• Anti-retroviral therapy</li> </ul>  Treatment Outcomes:  <ul style="list-style-type: none"> <li>• Treatment completed</li> <li>• Cure</li> <li>• Death</li> <li>• Default (treatment interruption)</li> <li>• Transfer out (referred to alternate facility)</li> <li>• Treatment failure</li> <li>• Alive on treatment</li> </ul> </p>	<p>Favorable treatment outcomes = 36% (n=4)  <ul style="list-style-type: none"> <li>• 9% (n=1) cured</li> <li>• 27% (n=3) on treatment with negative smears and improving clinical signs</li> </ul>  Poor treatment outcomes = 64% (n=7)  <ul style="list-style-type: none"> <li>• 63.6% (n=7) died</li> <li>• 27% (n=3) defaulted treatment</li> <li>• 100% (n=8) experienced adverse events</li> <li>• n=2 required hospital admission</li> <li>• n=2 required discontinuation of the culprit drug</li> </ul>  Overall: Poor treatment outcomes with majority of patients dying or defaulting from therapy</p>	<p>Strengths:  <ul style="list-style-type: none"> <li>• Aim, rationale, study design and results clearly outlined</li> <li>• Study population clearly defined and reflective of the overall population</li> </ul>  Weaknesses:  <ul style="list-style-type: none"> <li>• Small sample size</li> <li>• Results from one program only</li> <li>• Descriptive statistical analysis only (due to sample size)</li> <li>• Not generalizable</li> </ul> </p>
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<p>Lokuge et al<sup>34</sup> (2013)  Democratic Republic of Congo, Iraq, occupied Palestinian territory  <i>Médecins Sans Frontières</i>  Retrospective Record Review</p>	<p>Describe demographic characteristics, mental health complaints (with precipitated/underlying events) of children &amp; adolescents presenting to MSF mental health programs and compare them across three countries  Describe mental health services provided and short-term outcomes in each country</p>	<p>3025 children and adolescents &lt;20 years of age presenting for care in DRC, Iraq and occupied Palestinian Territory  Children &lt;15 years of age (n=1258): 47.1% (n=592) Female 52.9% (n=665) Male  Adolescents 15-19 years of age (n=1767): 68.5% (n=1210) Female 31.5% (n=557) Male</p>	<p>Demographics: Age, gender, country of care  Self-report: Precipitating events associated with presentation, presenting symptoms/complaints, severity of symptoms and functional impairment (rated on scale from 0-10),  Self-report: Report of ongoing self-assessment, care provided and outcomes  Medical provider: Assessment of the status of the presenting complaint.</p>	<p>Reported improvement in presenting complaint following completed treatment:  <ul style="list-style-type: none"> <li>• 99.8% (n=521) in DRC</li> <li>• 98.9% (n=785) in Iraq</li> <li>• 81.9% (n=122) in oPt</li> </ul>  45.7% (n=1382) defaulted/did not complete treatment  Overall: Brief trauma-focused therapy effective in reducing symptoms of trauma experiences but inferences on outcomes limited due to high default rates</p>	<p>Strengths:  <ul style="list-style-type: none"> <li>• Rationale for undertaking research</li> <li>• Large sample size reflective of population being studied</li> </ul>  Weaknesses:  <ul style="list-style-type: none"> <li>• Internal validity of treatment (data collection from 3 different settings with differing approaches to service delivery)</li> <li>• High rates of withdrawal with no follow up data</li> <li>• No reference or control group</li> <li>• Unclear if parents used as proxies for young children reports</li> </ul> </p>
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<p>McQueen et al<sup>38</sup> (2009) 18 developing countries  <i>Operation Smile International</i>  Retrospective Record Review</p>	<p>To evaluate outcomes and data points of surgical cases from 2005-2007  To monitor critical indices during surgical missions essential for quality assurance reviews</p>	<p>n= 8151 surgical interventions  n=2485 Male n=1907 Female  Age groups:  <ul style="list-style-type: none"> <li>• &lt;1 year (M=307, F=190)</li> <li>• 1-7 years old (M=1179, F=802)</li> <li>• &gt;7 years old (M=1005, F=915)</li> </ul>  n=6114 craniofacial corrections/revisions included for further review of characteristics and outcomes</p>	<p>Electronic medical record data reviewed and statistically processed for specific patient information and perioperative complications  Data from EMR:  <ul style="list-style-type: none"> <li>• Age</li> <li>• Weight</li> <li>• Surgical priority</li> <li>• Surgical procedure</li> <li>• Surgical and anesthetic complications</li> </ul>  Each critical incident reviewed and compared to surgical and anesthetic details of the case  Significant anesthesia and surgical complications reviewed and catalogued</p>	<p>Complications (surgical or anesthetic):</p> <ul style="list-style-type: none"> <li>• 30% (n=21) due to anesthesia <ul style="list-style-type: none"> <li>▪ Difficult Intubation n=2</li> <li>▪ Bronchospasm n=5</li> <li>▪ Airway Obstruction n=9</li> <li>▪ Cardiac/respiratory arrest n=5</li> </ul> </li> <li>• 61% (43) due to surgical repair <ul style="list-style-type: none"> <li>▪ Post-op bleeding n=31</li> <li>▪ Return to OR n=6</li> <li>▪ Wound Dehiscence n=3</li> <li>▪ Transfusion n=3</li> </ul> </li> <li>• 9% (n=5) classified as “other” <ul style="list-style-type: none"> <li>▪ Allergic reaction n=3</li> <li>▪ Fever n=1</li> <li>▪ Seizure n=1</li> <li>▪ Death after discharge n=1</li> </ul> </li> <li>• Surgical complications observed significantly more than anesthetic complications (<math>p= 0.006</math>)</li> <li>• Anesthesia complications occurred more often in children &lt;1 year of age (<math>p=0.072</math>)</li> <li>• Surgical and anesthesia complications more frequent in patients with cleft palate correction (<math>p= 0.0004</math>)</li> <li>• Anesthesia and surgical complications more frequent in patients receiving combined palate/lip procedure (<math>p=0.034</math>)</li> <li>• Primary surgery had greater incidence of complications than patients undergoing surgical revision or secondary repair (<math>p=0.0024</math>)</li> </ul> <p>Overall: Complication rates similar to high income contexts. Quality assurance and outcome monitoring is essential and possible for surgical procedures.</p>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>• Large sample size</li> <li>• Multiple sites with standardized data collection</li> <li>• Inferential statistics to determine complication differences</li> </ul> <p>Weaknesses:</p> <ul style="list-style-type: none"> <li>• Purpose of study not clearly defined</li> <li>• No comparison groups</li> <li>• Site specific differences not reported</li> </ul>
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<p>Mirabel et al<sup>39</sup> (2016) Cambodia &amp; Mozambique <i>Chaine de l'Espoir</i> (France) Retrospective Cohort Study</p>	<p>To assess two cardiac surgery programs by assessing:</p> <ul style="list-style-type: none"> <li>• Characteristics</li> <li>• Surgical procedures</li> <li>• Temporal trends</li> <li>• Outcomes</li> </ul>	<p>Patients undergoing open-heart surgery between January 2001 and December 31, 2011</p> <p>Mozambique:</p> <ul style="list-style-type: none"> <li>• Ages 3-18 years old</li> <li>• n=767</li> </ul> <p>n=385 (50.2%) Males n=382 (49.8%) Females</p> <p>Cambodia:</p> <ul style="list-style-type: none"> <li>• Ages 4-14 years old</li> <li>• n= 1332</li> </ul> <p>n=547 (41.2%) Males n=785 (58.8%) Females</p>	<p>Data collected retrospectively:</p> <ul style="list-style-type: none"> <li>• Demographic characteristics</li> <li>• Underlying etiology</li> <li>• Surgical procedure</li> <li>• Distance between place of residence and surgical center</li> <li>• Early post-operative mortality</li> <li>• Use of secondary prophylaxis collected for RHD patients at follow-up</li> </ul> <p>Mozambique:</p> <ul style="list-style-type: none"> <li>• Aristotle basic complexity score computed for patients with CHD</li> </ul> <p>Cambodia:</p> <ul style="list-style-type: none"> <li>• Passive surveillance of surgical patients' (part of standard of care)</li> </ul>	<p>Outcomes:</p> <ul style="list-style-type: none"> <li>• &lt;30-day postop mortality rate 6.10% (n=40) in Mozambique</li> <li>• &lt;30-day postop mortality rate 3.05% (n=18) in Cambodia</li> <li>• 12.26% of patients in Mozambique underwent re-do surgery</li> <li>• 8.18% of patients in Cambodia underwent re-do surgery</li> <li>• Overall mortality did not differ for CHD or RHD in Cambodia (<math>p=0.33</math>) or Mozambique (<math>p=0.25</math>)</li> </ul> <p>Patients lost to follow-up at 30 days</p> <ul style="list-style-type: none"> <li>• Mozambique n=112 (12.60%)</li> <li>• Cambodia n=741 (55.63%)</li> </ul> <p>Overall: Cardiac surgery feasible in LMICs with acceptable mortality rates. Outcomes largely remain unknown due to high numbers of lost to follow-up.</p>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>• Large patient sample</li> <li>• Inferential statistical tests conducted</li> <li>• Results reported clearly</li> <li>• Outcomes measured in Mozambique using standardized tool (C-index for mortality and morbidity 0.70 and 0.67 respectively)</li> </ul> <p>Weaknesses:</p> <ul style="list-style-type: none"> <li>• Reported patient selection bias based on exclusion criteria</li> <li>• Significant number of participant's lost to follow-up</li> </ul>
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<p>Myung et al<sup>40</sup> (2007) Cambodia <i>Maryknoll International Catholic Charity</i>  Retrospective Record Review</p>	<p>To evaluate outcomes and cost of a program providing directly observed antiretroviral therapy to HIV infected children</p>	<p>n= 95 children</p> <ul style="list-style-type: none"> <li>• 1-18 years of age</li> <li>• Documented HIV infection</li> <li>• Living in an orphanage or with families in the community</li> </ul> <p>n=54 Males n=41 Females</p> <p>n=33 orphans living in group homes n=62 living in family setting n= 68 children received 2 or more months of treatment n=33 children received approximately 18 months of treatment Mean age at initiation of treatment 5.5 years (S.D.=2.5 years with a range of 1 to 13 years)</p>	<p>Medical records of children started on directly observed treatment with HAART reviewed</p> <p>CD4 measurements repeated after a mean of 6.2 (+/- 0.7), 12.3 (+/- 0.2) and 18.8 +/- 0.9 months of treatment.</p>	<p>Death:</p> <ul style="list-style-type: none"> <li>• n=22 patients (treatment &lt; 6 months)</li> <li>• n=1 patient (treatment &lt; 15 months)</li> </ul> <p>Adverse reactions from treatment:</p> <ul style="list-style-type: none"> <li>• Skin rashes n=4</li> <li>• Elevated liver enzymes n=5</li> </ul> <p>Unchanged outcome/Treatment failure:</p> <ul style="list-style-type: none"> <li>• No significant rise in CD4 count after 6 months n=1</li> </ul> <p>Increase in mean weight-for-age z scores</p> <ul style="list-style-type: none"> <li>• Baseline (n=95) = -3.8 (SD 2.9)</li> <li>• 6 months (n=95) = -1.7 (SD 2.5) (<math>p&lt;.001</math>)</li> <li>• 12 months (n=68) = -2.4 (SD 1.8) (<math>p&lt;.001</math>)</li> <li>• 18 months (n=33) = -2.2 (SD 1.5) (<math>p&lt;.001</math>)</li> </ul> <p>Improvements in mean absolute CD4 count:</p> <ul style="list-style-type: none"> <li>• Baseline (n=95) = 255 cells/mm<sup>3</sup></li> <li>• 6 months (n=95) = 656 cells/mm<sup>3</sup></li> <li>• 12 months (n=68) = 854 cells/mm<sup>3</sup></li> <li>• 18 months (n=33) = 992 cells/mm<sup>3</sup></li> </ul> <p>Overall: Directly observed treatment with HAART can be feasible and effective.</p>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>• Rationale for research well described</li> <li>• Sample reflective of population</li> </ul> <p>Weaknesses:</p> <ul style="list-style-type: none"> <li>• No report of ethical considerations</li> <li>• Discussion lacks detail and no reference to other studies or programs</li> <li>• Single evaluation of one program</li> </ul>
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<p>Ngondi et al<sup>26</sup> (2006)  South Sudan  <i>Network of unnamed NGOs</i> involved in the delivery of the SAFE intervention  Cross-sectional</p>	<p>To evaluate and quantify the uptake of SAFE interventions  To assess the prevalence of active trachoma signs and unclean faces in children</p>	<p>n= 2365 Children in 1354 households examined at baseline  n=1867 Children in 743 households examined at 3-years  Ages 1-9 years  Baseline Surveys:  <ul style="list-style-type: none"> <li>• 49% (n=1159) Males</li> <li>• 51% (n=1206) Females</li> </ul>                       3-year evaluation:  <ul style="list-style-type: none"> <li>• 51.4%(n=959) Males</li> <li>• 48.6% (n=908) Females</li> </ul> </p>	<ul style="list-style-type: none"> <li>• Baseline survey to detect active trachoma prevalence</li> <li>• Program activities monitored monthly</li> <li>• Program data, interviews and observations used to measure coverage and uptake of SAFE</li> <li>• Heads of sampled households interviewed (carers responded on behalf of children)</li> <li>• Trachoma grading done by 8 examiners skilled in the use of the grading system</li> </ul>	<p>Prevalence decrease post-treatment:</p> <p>Kiech Kuon</p> <ul style="list-style-type: none"> <li>• TF = 2% (-10 to 12)</li> <li>• TI = 35% (23 to 45)</li> <li>• Active trachoma=10% (3 to 17)</li> <li>• Unclean faces = 10% (-3 to 23)</li> </ul> <p>Katigiri</p> <ul style="list-style-type: none"> <li>• TF=92% (87 to 96)</li> <li>• TI=98% (93 to 100)</li> <li>• Active trachoma=92% (88 to 96)</li> <li>• Unclean faces= 87% (78 to 94)</li> </ul> <p>Padak</p> <ul style="list-style-type: none"> <li>• TF=28% (14 to 41)</li> <li>• TI=90% (84 to 90)</li> <li>• Active trachoma=37% (25 to 48)</li> <li>• Unclean faces=16% (7 to 25)</li> </ul> <p>Tali</p> <ul style="list-style-type: none"> <li>• TF=91% (86 to 95)</li> <li>• TI=100% (98 to 100)</li> <li>• Active trachoma=92% (88 to 95)</li> <li>• Unclean faces=38% (22 to 52)</li> </ul> <p>Overall: All intervention areas showed a decrease in TF, TI and unclean faces.</p>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>• Grading of trachoma standardized with interobserver agreement greater than 80%</li> <li>• Robust statistical analysis with double entry clerks and comparisons for consistency</li> <li>• Power and level of significance used and reported</li> <li>• Rigorously implemented non-experimental study</li> </ul> <p>Weaknesses:</p> <ul style="list-style-type: none"> <li>• Timing of 3-year evaluation surveys coincided with annual mass distribution of azithromycin in some locations (likely affected decrease in prevalence in these areas)</li> </ul>
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<p>Perveen et al<sup>29</sup> (2014) Bangladesh <i>Walk for Life</i> Cross-sectional “Clinical audit”</p>	<p>To review physical and functional outcomes of children after 2 years of treatment for congenital clubfoot deformity using the Ponseti method</p>	<p>n=400 Children and parents of children less than 3 years old with clubfoot  n=269 Males n=131 Females  Typical clubfeet: 79% Bilateral clubfeet: 55%</p>	<p>Principle researcher collected data using:</p> <ul style="list-style-type: none"> <li>• Face-to-face interviews with parents</li> <li>• Examination of patients at each clinic</li> </ul> <p>Bangla Clubfoot assessment tool used to evaluate treatment outcomes including:</p> <ul style="list-style-type: none"> <li>• Parental satisfaction</li> <li>• Gait</li> <li>• Clinical assessment (ability to walk, run, use stairs)</li> <li>• Objective assessment of heel position and ankle range</li> </ul>	<ul style="list-style-type: none"> <li>• Mean Bangla clubfoot score = 9.66/11 (87%)</li> <li>• 100% (n=400) parental satisfaction</li> <li>• 95.5% (n= 382) able to run</li> <li>• 93.3% (n=373) able to squat</li> <li>• 93% (n=372) able to manage steps independently</li> <li>• Ability to squat was positively correlated with fewer corrective casts, good and continued brace use, non varus heel position, good ankle range of motion, good Bangla clubfoot scores and ability to walk</li> </ul> <p>Overall: High functional scores after treatment, very high parent satisfaction.</p>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>• Data collection done using validated assessment tool with an intraclass correlation of 0.93, indicating very good reliability and Cronbach alpha scores of 0.87 and 0.89.</li> <li>• Large sample reflective of population</li> </ul> <p>Weaknesses:</p> <ul style="list-style-type: none"> <li>• No comparison groups</li> <li>• Self-reported systematic bias by including only the 10 largest clinics for sampling</li> <li>• Local examiner not a blinded assessor</li> <li>• 35% missing data and those with incomplete database records excluded which may affect generalizability</li> </ul>
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<p>Sauvageot et al<sup>37</sup>  (2010)  Benin, Burkina Faso, Cameroon, Republic of Congo, Cote d'Ivoire, Democratic Republic of the Congo, Guinea, Kenya, Liberia, Malawi, Mozambique, Nigeria, Uganda, Zambia, Zimbabwe, Myanmar (Burma), Cambodia, China, India, Laos</p>	<p>To describe medium-term outcomes for children receiving ART in resource- limited countries</p>	<p>n=3936 HIV-infected children &lt;5 years old n=1855 Female n= 2081 Male  Africa n=3537 (89.8%) Age Groups &lt; 12 months n=307 12-35 months n=1818 36-59 months n= 1412  Asia n= 399 (10.1%) Age Groups &lt;12 months n= 28 12-35 months n=153 36-59 months n= 218</p>	<p>Surveillance data collected and entered into Fuchia monitoring software  Variables  <ul style="list-style-type: none"> <li>• Gender</li> <li>• Age</li> <li>• Previous ARV agents</li> <li>• Current ARV agents</li> <li>• Visit dates</li> <li>• WHO clinical stage</li> <li>• Previous and current clinical events</li> <li>• Drug Intolerance</li> <li>• CD4+ cell count</li> <li>• CD4+ cell proportions</li> <li>• Weight</li> <li>• Height</li> </ul> </p>	<p>At time of analysis:  <ul style="list-style-type: none"> <li>• 6.3% (n=249) died</li> <li>• 10.3% (n=407) lost to follow-up</li> <li>• 7.8% (n=305) transferred out</li> <li>• 0.10% (n=4) unclear outcomes</li> </ul> <p>Within first 6 months of ART, toxicities were more frequent in Asia than in Africa (0.93 vs 0.97; log rank test, P&lt; .001).</p> <p>Severe drug-related adverse events after 6 months n= 39 children (n=30 in Africa and n=9 in Asia).</p> <p>Overall: ART for children &lt;5 years of age is feasible, with encouraging clinical outcomes.</p> </p>	<p>Strengths:  <ul style="list-style-type: none"> <li>• Inferential statistics utilized for data analysis comparing outcomes and probabilities</li> <li>• 48 study sites increase generalizability</li> </ul> <p>Weaknesses:  <ul style="list-style-type: none"> <li>• Variation in program delivery between multiple countries not accounted for</li> </ul> </p> </p>
<p><i>Médecins Sans Frontières – 48 programs from 20 countries</i></p>					
<p>Cross-sectional</p>					

<p>Schmeller &amp; Dzikus35 (2001) Kenya <i>Doctors in Aid of Children with Skin Diseases in Africa</i> (German) Longitudinal Cohort Study</p>	<p>To assess the impact of a dermatology project in which children in schools and nurseries were treated for dermatitis, bacterial skin infections, dermatophytosis and scabies by community health workers</p>	<p>Children aged 3-17 years old in 13 schools and nurseries  Years of examination: 1993 (n=5780) 1995 (n=4358) 1999(4961)</p>	<ul style="list-style-type: none"> <li>• 3-5 trained community health workers (CHW) in each sublocation visited one school each week to provide medications for treatment of skin conditions (instructions also given for household)</li> <li>• All schools visited 2-4 times per year</li> <li>• 4961 students re-examined after 5-year period of regular visits from CHW's</li> <li>• Prevalence rates of skin diseases collected in 1993 and 1999 and compared</li> </ul>	<p>Prevalence of bacterial infections:</p> <ul style="list-style-type: none"> <li>• 12.7% in 1993</li> <li>• 11.3% in 1999</li> </ul> <p>Number of tropical ulcers:</p> <ul style="list-style-type: none"> <li>• 1.2% (n=72) in 1993</li> <li>• 0.1% (n=7) in 1999</li> </ul> <p>Prevalence of impetigo:</p> <ul style="list-style-type: none"> <li>• 0.9% in 1993</li> <li>• 1.6% in 1999</li> </ul> <p>Prevalence of fungal infections:</p> <ul style="list-style-type: none"> <li>• 10.1% in 1993</li> <li>• 13.9% in 1999 (p&lt;.05)</li> </ul> <p>Prevalence of tinea capitis:</p> <ul style="list-style-type: none"> <li>• 7.8% in 1993</li> <li>• 9.9% in 1999</li> </ul> <p>Prevalence of Pityriasis versicolor:</p> <ul style="list-style-type: none"> <li>• 0.9% in 1993</li> <li>• 2.9% in 1999</li> </ul> <p>Prevalence of Kerion Celsi:</p> <ul style="list-style-type: none"> <li>• 0.1% in 1993</li> <li>• 0.1% in 1999</li> </ul> <p>Prevalence of scabies:</p> <ul style="list-style-type: none"> <li>• 8.0% in 1993</li> <li>• 8.3% in 1999</li> </ul> <p>Prevalence of dermatitis:</p> <ul style="list-style-type: none"> <li>• 0.7% in 1993</li> <li>• 0.7% in 1999</li> </ul> <p>Overall: Prevalence rates did not decrease significantly except for tropical ulcers</p>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>• Large study sample</li> <li>• Substantial time of study with multiple comparison opportunities over 6 years</li> </ul> <p>Weaknesses:</p> <ul style="list-style-type: none"> <li>• No control for comparison group</li> <li>• No ethical considerations reported</li> <li>• Only descriptive statistics of prevalence rates reported</li> </ul>
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<p>Sharp et al<sup>30</sup> (2008) Philippines <i>Operation Smile</i> + any additional visiting surgical mission group Mixed Methods</p>	<p>To establish if feasible to conduct long-term outcomes research in developing economy country (specifically the Philippines)  To describe primary outcomes perceived as important by recipients of oral cleft surgery</p>	<p>n=54 patients and caregivers of patients who received surgery for cleft lip and/or palate  Age range of surgery recipients = 2-22 years (Mean 7.7 years)  63% (n=34) Male 37% (n=20) Female Caregivers (n=53):</p> <ul style="list-style-type: none"> <li>• 63% mothers</li> <li>• 12% fathers</li> <li>• 8.5% aunt or uncle</li> <li>• 3% grandmother</li> <li>• 2% sibling</li> </ul> <p>n=21 &gt;7 years of age invited to give responses in addition to caregiver responses</p> <p>Demographics:</p> <ul style="list-style-type: none"> <li>• 100% (n=54) cleft palate</li> <li>• 37% (n=20) left unilateral cleft lip &amp; palate</li> <li>• 20% (n=11) right unilateral cleft lip &amp; palate</li> <li>• 22% (n=12) bilateral cleft lip &amp; palate</li> <li>• 19% (n=10) cleft palate only</li> </ul>	<p>Self-report</p> <ul style="list-style-type: none"> <li>• Demographics (age, cleft type, date of surgery)</li> <li>• Responses to open-ended questions</li> <li>• Study created Likert type scale asking for change since surgery across functional domains (5-point scale)</li> </ul> <p>Interviews conducted in local dialect by research interviewer and guide &amp; then transcribed and translated into English</p> <ul style="list-style-type: none"> <li>• n=75 interviews conducted representing n=53 caregivers and n=22 children</li> </ul>	<p>Open ended questions:</p> <p><i>What can others expect about surgery?</i></p> <ul style="list-style-type: none"> <li>• 99% (n=74) would encourage others to pursue surgery</li> <li>• 17% affordable or free</li> <li>• 19% improved speech</li> <li>• 17% cleft will be closed</li> <li>• 9% improved appearance</li> <li>• 8% improved social benefits</li> <li>• 8% (n=6) negative features</li> </ul> <p><i>How has life changed?</i></p> <ul style="list-style-type: none"> <li>• 55% of patients and 51% of caregivers reported improved speech</li> <li>• 31% reported improved eating and decreased nasal leakage</li> <li>• 10% patients and 16% caregivers reported improved social benefits/reduced teasing</li> <li>• 10% patients and 4% caregivers reported improved appearance</li> <li>• 25% reported cleft closed</li> <li>• Improved eating statistically significant (p&lt;.05)</li> </ul> <p><i>Most important change?</i></p> <ul style="list-style-type: none"> <li>• 49% of caregivers, 68% of patients reported improved speech</li> <li>• 26% of patients, 24% of caregivers reported improved appearance</li> <li>• 19% of caregivers, 11% of patients reported social benefits and decreased teasing</li> <li>• 21% of patients reported cleft closed</li> <li>• 30% caregivers noted improved eating (p&lt;0.05)</li> </ul> <p>Scaled Estimates of Change and Overall:</p> <ul style="list-style-type: none"> <li>• Nearly all patients and caregivers rated all functional outcomes as “a lot better” after surgery</li> </ul>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>• Qualitative &amp; quantitative data collected</li> <li>• Self-report of outcomes on 5-point scale allowed opportunity to respond with balanced positive and negative options reducing bias for either positive or negative responses</li> <li>• Results clearly presented in the report</li> </ul> <p>Weaknesses :</p> <ul style="list-style-type: none"> <li>• Limitations of data collection (interviews recorded in local dialect translated/transcribed into English, terms reflected clinical knowledge of interviewer/translator, caregiver responses possibly influenced children and vice-versa, answers may reflect social bias)</li> <li>• No comparison groups</li> <li>• Data collection tool designed for study, not validated</li> </ul>
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<p>Toro, Eke &amp; Pearlman<sup>41</sup> (2016)</p>	<p>To investigate the impact of UCP's wheelchair provision services</p>	<p>n=344 children, children with caregivers, adults and adults with caregivers</p>	<p>Questionnaires conducted by 5 data collectors:  <ul style="list-style-type: none"> <li>• Baseline</li> <li>• 6-month follow-up</li> </ul> </p>	<ul style="list-style-type: none"> <li>• Satisfaction with means of mobility (FMA-kids) significantly improved in children with proxies who received a wheelchair compared to the waiting list (<math>p &lt; 0.001</math>)</li> </ul>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>• Multiple validated tools used</li> <li>• Inferential statistical evaluation with power calculation and level of significance set a priori</li> </ul>
<p>Indonesia <i>United Cerebral Palsy Wheels for Humanity (UCP)</i></p>	<p>To investigate how wheelchairs, provided to individuals with mobility impairments, improve one's participation in society, quality of life, wheelchair skills, wheelchair maintenance and satisfaction with mobility compared to a control group.</p>	<p>Only pediatric results reported here:            49% (n=153) children or children with proxies  <ul style="list-style-type: none"> <li>• n=167 participants on the waiting list</li> <li>• n=142 received a wheelchair</li> </ul> </p>	<p>Data collected/tools used for pediatric participants:  <ul style="list-style-type: none"> <li>• Demographics</li> <li>• Functional Mobility Assessment kids (FMA-kids)</li> <li>• Craig Handicap and Assessment Recording Technique Short Form</li> <li>• Wheelchair Assessment Checklist</li> <li>• Wheelchair Skills Test Questionnaire (WST-Q)</li> <li>• Wheelchair technology</li> </ul> </p>	<ul style="list-style-type: none"> <li>• Children with proxies in waitlist group reported significant decrease in mobility domain (CHART) compared to children with proxies in wheelchair group (<math>p = 0.023</math>)</li> <li>• No significant difference in number of children enrolled in school between baseline and follow-up for both the waitlist and the wheelchair group</li> </ul>	<ul style="list-style-type: none"> <li>• Rationale and aim of research well described</li> </ul>
<p>Cohort Study</p>		<p>Children  <ul style="list-style-type: none"> <li>• 83% (n=5) Male Mean age = 11.3 +/- 3.3 (S.D.)</li> <li>• 17% (n=1) Female Mean age = 7.4</li> </ul> <p>Children with Proxies  <ul style="list-style-type: none"> <li>• 61.2% (n=90) Male Mean age = 10.3 +/- 3.7 (S.D.)</li> <li>• 38.8% (n=57) Female Mean age = 10.4 +/- 6.4 (S.D.)</li> </ul> </p> </p>		<p>Overall: Provision of fitted wheelchairs resulted in greater satisfaction with mobility for children with proxies.</p>	<p>Weaknesses:</p> <ul style="list-style-type: none"> <li>• Child only group had small sample size (n=6)</li> <li>• ++ missing data for questionnaires with no clarification of how data was managed</li> <li>• Convenience sample</li> <li>• Accuracy &amp; reliability of translated questionnaires unknown</li> </ul>



<p>Trudeau et al<sup>33</sup> (2015)</p> <p>20 MSF-OCP locations: South Sudan, Yemen, Syria, Gaza, Pakistan, Nigeria, Central African Republic, Democratic Republic of the Congo, Philippines</p> <p><i>Médecins Sans Frontières – Operational Centre Paris</i></p> <p>Cross-Sectional (retrospective)</p>	<p>To describe the range of surgical indications and procedures provided in MSF operated missions in LMIC.</p> <p>To better characterize the needs and outcomes in pediatric surgery performed by NGOs in LMIC.</p>	<p>n=59 928 surgical interventions performed</p> <p>Only pediatric results reported here:</p> <p>n=22593 pediatric surgical interventions recorded by MSF-OCP during this period</p> <p>30.1% (n=18 040) Preteen patients &lt;13 years old</p> <ul style="list-style-type: none"> <li>• 30.1% (n=10 093) Males</li> <li>• 43.9% (n=7903) Females</li> </ul> <p>7.6% (n=4571) Teenage patients aged 13-17 years old</p> <ul style="list-style-type: none"> <li>• 54.3% (n=2479) Males</li> <li>• 45.7% (n=2083) Females</li> </ul>	<p>Prospective data collected on surgical interventions following a predetermined classification system</p> <p>Categories included:</p> <ul style="list-style-type: none"> <li>• Mechanism of injury</li> <li>• Type of intervention</li> <li>• Perioperative outcome (alive or dead)</li> </ul> <p>Data not collected beyond the recovery room</p>	<p>Descriptive Results</p> <ul style="list-style-type: none"> <li>• Preteen mortality rate 0.07% (n=12)</li> <li>• Teenager mortality rate 0.15% (n=6)</li> </ul> <p>Inferential Results</p> <ul style="list-style-type: none"> <li>• Both preteen and teenager mortality rates lower than adult rates (0.22%, n=73) (P= .001, X<sub>2</sub> analysis)</li> <li>• The difference in mortality rate for major and minor surgery statistically significant for Preteens (p=&lt;.001)</li> <li>• American Society of Anesthesia classification significantly related to outcome (P&lt;.001)</li> <li>• Perioperative mortality rose sharply as ASA classification increased with rates of 9.6% and 92.3% for ASA classifications of 4 and 5 respectively</li> </ul> <p>Overall: Further work is needed to assess long-term outcomes of surgery cases to determine effectiveness of surgery programs.</p>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>• Large sample size</li> <li>• Prospective data collected using a predetermined classification system</li> <li>• Descriptive statistics for types of surgeries and inferential statistics for mortality rates amongst groups</li> <li>• Results reported clearly</li> </ul> <p>Weaknesses:</p> <ul style="list-style-type: none"> <li>• Study design identified but does not meet definition of “cohort study” used for present analysis</li> <li>• Not generalizable to other contexts</li> </ul>
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Abbreviations: S.D.=Standard Deviation; PACU=Post Anesthesia Care Unit; C.I.=Confidence Interval; PP=Point Prevalence; X<sub>2</sub>=Chi-squared test; df= degrees of freedom; HIV=Human Immunodeficiency Virus; MDR-TB=Multi-drug resistant tuberculosis; EMR=Electronic medical record; IQR=Inter-quartile range; RHD=Rheumatic Heart Disease; CHD=Congenital heart disease; TF=Trachomatous inflammation-follicular; TI=Trachomatous inflammation-intense; ART=Anti-retroviral therapy; ARV=antiretroviral CHW=Community Health Worker; WST-Q=Wheelchair Skills Test Questionnaire; MSF-OCP=Médecins sans frontiers-Operational Centre Paris; Spearman’s Correlation=rho; SAFE=surgery, antibiotics, facial cleanliness, and environmental change

**Table 3.** Summary of research designs.

Design Type	n (%)	Reference
Cross-sectional	8 (47%)	Contini et al (2009) Evans et al (2016) Fisher et al (2001) Gonzales, Dearden & Jimenez (1999) Ngondi et al (2006) Perveen et al (2014) Sauvageot et al (2010) Trudeau et al (2015)
Retrospective Record Review	4 (24%)	Isaakidis et al (2013) Lokuge et al (2013) McQueen et al (2009) Myung et al (2007)
Cohort Studies	3 (18%)	Mirabel et al (2016) Schmeller & Dzikus (2001) Toro, Eke & Pearlman (2016)
Mixed Methods	2 (12%)	Fell et al (2014) Sharp et al (2008)

**Table 4.** Categorization of study populations.

Study Population	n (%)	Reference
Children	6 (35%)	Contini et al (2009) Evans et al (2016) McQueen et al (2009) Ngondi et al (2006) Perveen et al (2014) Sauvageot et al (2010)
Adolescents	1 (6%)	Isaakidis et al (2013)
Children & adolescents	6 (35%)	Lokuge et al (2013) Mirabel et al (2016) Myung et al (2007) Schmeller & Dzikus (2001) Sharp et al (2008) Trudeau et al (2015)
All ages (data for children & adolescents separate from adult data)	4 (24%)	Fell et al (2014) Fisher et al (2001) Gonzales, Dearden & Jimenez (1999) Toro, Eke & Pearlman (2016)

**Table 5.** Summary of countries represented.

Countries by Continent	n (%)	Frequency (within studies)	Economic Status
Asia	13 (39%)		
Cambodia		3	Lower-middle
Bangladesh		2	Lower-middle
India		2	Lower-middle
West Bank & Gaza		2	Lower-middle
Philippines		2	Lower-middle
Iraq		1	Upper-middle
Indonesia		1	Lower-middle
Yemen		1	Low
Syria		1	Low
Pakistan		1	Lower-middle
Myanmar		1	Lower-middle
China		1	Upper-middle
Laos		1	Lower-middle
Africa	19 (58%)		
DRC		3	Low
Mozambique		2	Low
South Sudan		2	Low
Kenya		2	Lower-middle
Sierra Leone		1	Low
Ethiopia		1	Low
Nigeria		1	Lower-middle
Central African Republic		1	Low
Benin		1	Low
Burkina Faso		1	Low
Cameroon		1	Lower-middle
Republic of the Congo		1	Lower-middle
Cote d'Ivoire		1	Lower-middle
Guinea		1	Low
Liberia		1	Low
Malawi		1	Low
Uganda		1	Low
Zambia		1	Lower-middle
Zimbabwe		1	Lower-Middle
South America	1 (3%)		
Bolivia		1	Lower-middle

**Table 6.** Representation of NGOs.

NGO	n (%)	Reference
Médecins sans Frontières	4 (24%)	Isaakidis et al (2013) Lokuge et al (2013) Trudeau et al (2015) Sauvageot et al (2010)
Operation Smile	3 (18%)	Fisher et al (2001) McQueen et al (2009) Sharp et al (2008)
Walk for Life	2 (12%)	Evans et al (2016) Perveen et al (2014)
Emergency NGO	1 (6%)	Contini et al (2009)
Project Harar	1 (6%)	Fell et al (2014)
Save the Children US	1 (6%)	Gonzales, Dearden & Jimenez (1999)
Chaine de l'Espoire	1 (6%)	Mirabel et al (2016)
Doctors in Aid of Children with Skin Diseases in Africa	1 (6%)	Schmeller & Dzikus (2001)
Maryknoll	1 (6%)	Myung et al (2007)
United Cerebral Palsy Wheels for Humanity	1 (6%)	Toro, Eke & Pearlman (2016)
Unnamed network of NGOs	1 (6%)	Ngondi et al (2006)

**Table 7.** Summary of health service provision.

Health Service Type	n (%)	Reference
<b>Medical</b>	<b>7 (41%)</b>	
Ponseti method for clubfoot deformity	2	Evans et al (2016) Perveen et al (2014)
ART	2	Myung et al (2007) Sauvageot et al (2010)
TB treatment	1	Isaakidis et al (2013)
SAFE intervention for trachoma	1	Ngondi et al (2006)
Dermatology	1	Schmeller & Dzikus (2001)
<b>Surgical</b>	<b>7 (41%)</b>	
Cleft lip & palate repair	4	Fell et al (2014) Fisher et al (2001) McQueen et al (2009) Sharp et al (2008)
Caustic stricture dilatation	1	Contini et al (2009)
Cardiac Surgery	1	Mirabel et al (2016)
General surgical interventions	1	Trudeau et al (2015)
<b>Mental Health</b>	<b>1 (6%)</b>	
Brief Trauma Focused Therapy		Lokuge et al (2013)
<b>Program Implementation</b>	<b>1 (6%)</b>	
Multi-sectoral Development		Gonzales, Dearden & Jimenez (1999)
<b>Mobility Device Provision</b>	<b>1(6%)</b>	
Wheelchair provision		Toro, Eke & Pearlman (2016)

Abbreviations: TB= tuberculosis; ART=antiretroviral therapy; SAFE=surgery, antibiotics, facial cleanliness and environmental change

**Table 8.** Classification of outcomes reported.

Outcomes	n (%)	Reference
Short-Term	5 (29%)	Contini et al (2009) Fisher et al (2001) Lokuge et al (2013) McQueen et al (2009) Trudeau et al (2015)
Medium-Term	7 (41%)	Fell et al (2014) Isaakidis et al (2013) Myung et al (2007) Perveen et al (2014) Sharp et al (2008) Sauvageot et al (2010) Toro, Eke & Pearlman (2016)
Long-Term	5 (29%)	Evans et al (2016) Gonzales, Dearden & Jimenez (1999) Mirabel et al (2016) Ngondi et al (2006) Schmeller & Dzikus (2001)

**Table 9.** Summary of outcome categories reported by study.

Category	n (%) (studies)	Reference
<b>Negative Outcomes</b>		
Death	9 (53%)	Contini et al (2009), Fisher et al (2001), Gonzales, Dearden & Jimenez (1999), Isaakidis et al (2013), McQueen et al (2009) Mirabel et al (2016), Myung et al (2007) Sauvageot et al (2010), Trudeau et al (2015)
Complications/Adverse events	9 (53%)	Contini et al (2009), Fell et al (2014), Fisher et al (2001), Isaakidis et al (2013), McQueen et al (2009), Mirabel et al (2016), Myung et al (2007), Sauvageot et al (2010), Sharp et al (2008)
Default from treatment/ Loss to follow-up	5 (29%)	Evans et al (2016), Isaakidis et al (2013), Lokuge et al (2013), Mirabel et al (2016), Sauvageot et al (2010)
Relapse/Recurrence	2 (12%)	Contini et al (2009), Mirabel et al (2016)
<b>Positive Outcomes</b>		
Success/cure rates	3 (18%)	Contini et al (2009), Fell et al (2014), Isaakidis et al (2013)
Reduction of symptoms/ Improving Clinical Signs	3 (18%)	Isaakidis et al (2013), Lokuge et al (2013), Myung et al (2007)
Satisfaction	3 (18%)	Evans et al (2016), Perveen et al (2014), Toro, Eke & Pearlman (2016)
Physical improvement (e.g. mobility, ability to speak, facial appearance, weight gain etc.)	5 (29%)	Evans et al (2016), Fell et al (2014), Gonzales, Dearden & Jimenez (1999), Perveen et al (2014), Sharp et al (2008)
Social improvement (e.g. playing with friends, school attendance)	2 (12%)	Fell et al (2014), Sharp et al (2008)
Improved prevalence rate post treatment	2 (12%)	Ngondi et al (2006), Schmeller & Dzikus (2001)
<b>No Change in Outcome</b>		
Unchanged prevalence rate	2 (12%)	Gonzales, Dearden & Jimenez (1999), Schmeller & Dzikus (2001)
Unchanged school attendance	1 (6%)	Toro, Eke & Pearlman (2016)
No improvement in CD4 count	1 (6%)	Myung et al. (2007)



Figure 1. PRISMA diagram.

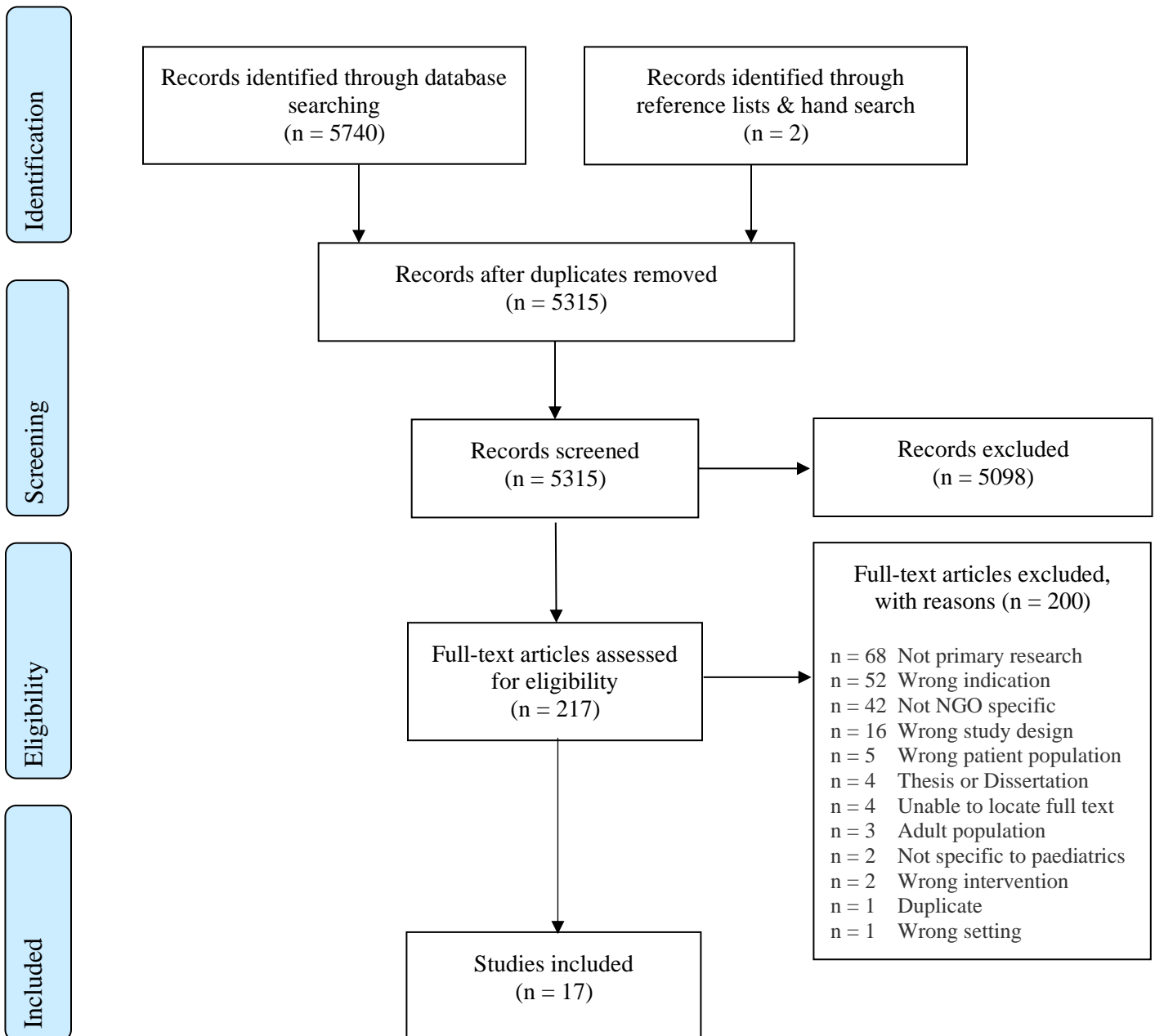
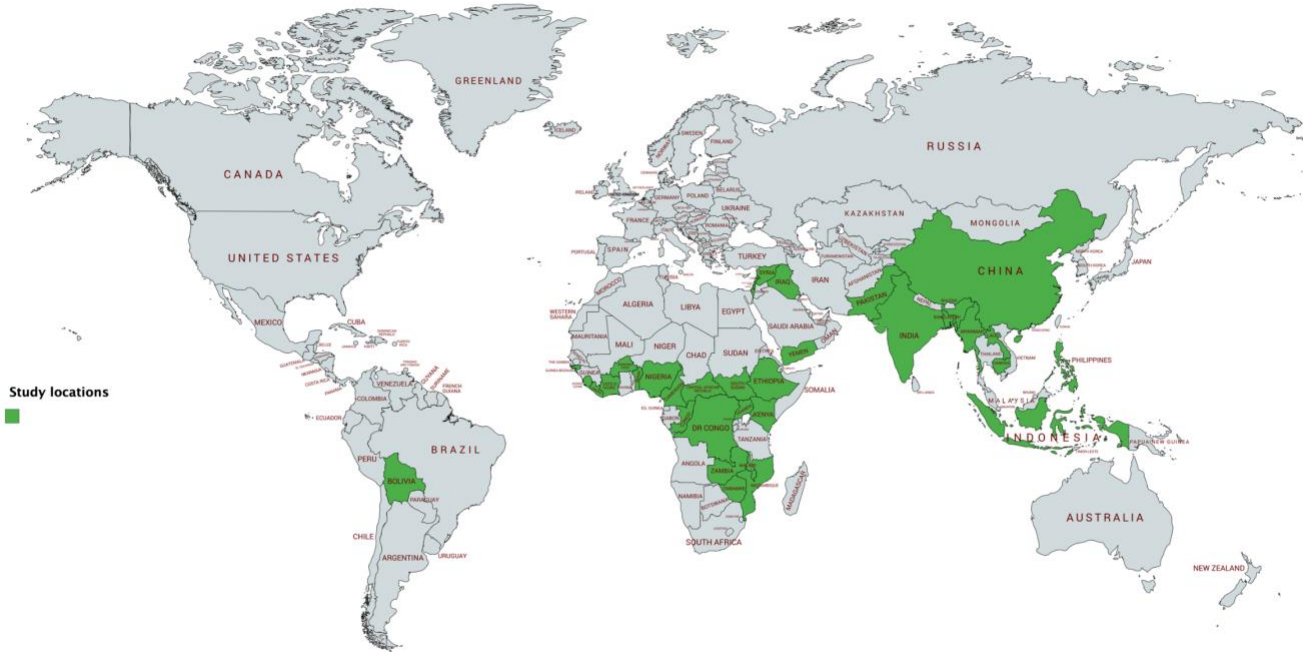
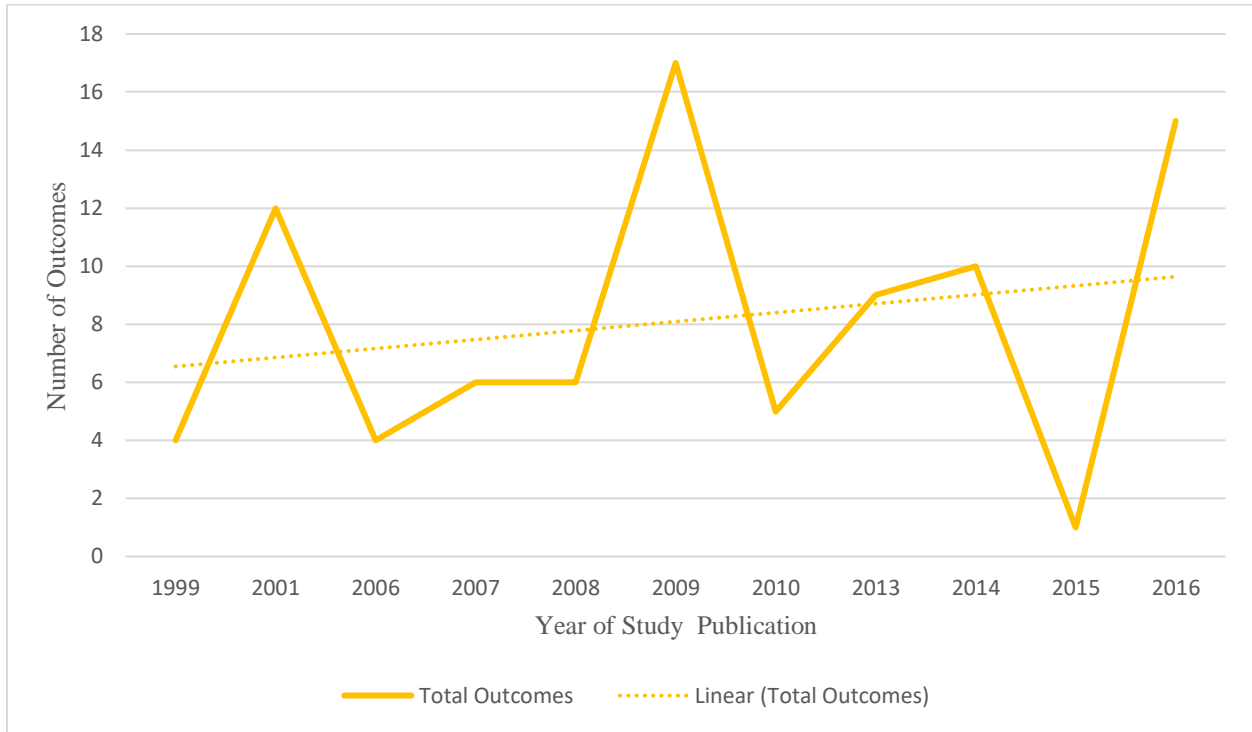


Figure 2. Global distribution of countries represented.

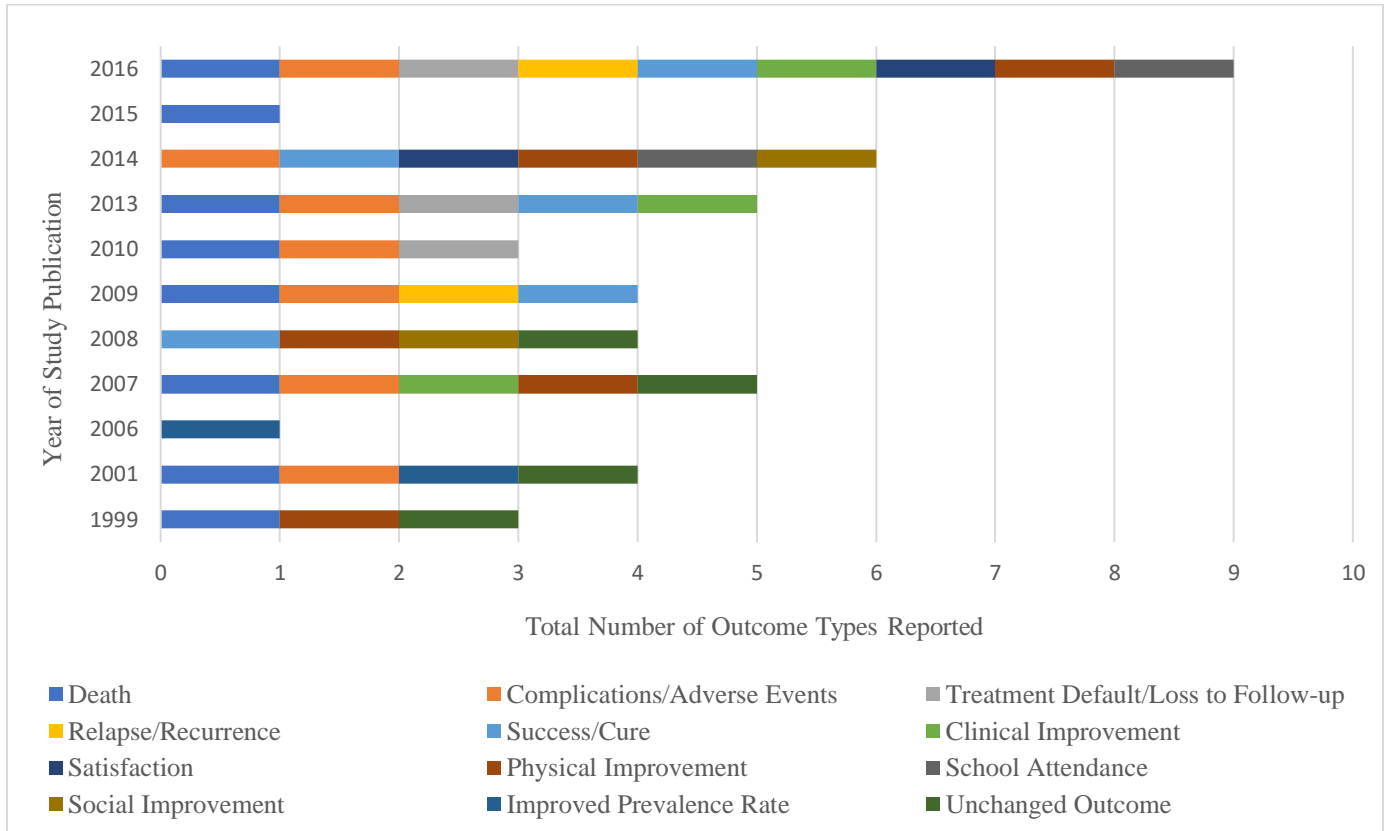


**Figure 3.** Total number of outcomes reported over time by year of study publication.



Note: No studies were published during the years 2000, 2002-2005 or 2011-2012

**Figure 4.** Outcome types reported over time by year of study publication.



Note: No studies were published during the years 2000, 2002-2005 and 2011-2012

## **Chapter 4**

### **Stakeholder Input on NGO Pediatric Healthcare Delivery and Outcome Evaluation in Low-and Middle-Income Countries**

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### Abstract

The purpose of this research brief is to report on stakeholders' thoughts and experiences regarding non-governmental organization pediatric healthcare delivery and outcome evaluation in low-and middle-income countries and to explore the role of nurses working within these organizations. A semi-structured questionnaire was used to interview four participants affiliated with a surgical or humanitarian non-governmental organization providing healthcare to children and/or adolescents in low-and middle-income countries. Qualitative inductive content analysis was used to analyze the data, resulting in the emergence of four main categories; Reflections on the Evidence; Competing Priorities; Ambiguity of Nomenclature; and Nursing Contributions. The results indicate that outcome evaluation is a priority for healthcare non-governmental organizations working in low-and middle-income countries. However, the culture of evaluation for funders and quality improvement processes as well as multiple competing priorities within organizations contributes to a lack of evaluation for research purposes or broader sharing of knowledge. Nurses are leaders within these organizations and can play a key role in improving research and knowledge dissemination. Further research is needed to determine how nurses can best support these endeavors.

**Keywords:** *pediatric, children, adolescents, non-governmental, low-and middle-income countries, health outcomes*

## 1. Introduction

Healthcare non-governmental organizations (NGOs) working in low-and middle-income countries (LMICs) face many challenges with the monitoring and evaluation of their programs due to limited resources, small operating budgets and volunteer, unskilled staff (Biermann et al., 2016; Bozzo, 2000; Piotrowicz & Cianciara, 2013). While the value of NGO programs are often outwardly considered evident, it is important to look critically at their processes and outcomes to ensure that the programs they offer actually contribute positively to the health of those they are trying to help.

Literature specific to evaluation strategies and frameworks suggest that broadly, NGO evaluation is increasing in the health sector (Bach-Mortensen & Montgomery, 2018; Bell & Aggleton, 2012; Bozzo, 2000). However, the lack of available studies on the evaluation of pediatric healthcare initiatives suggests that these strategies and frameworks are not being utilized. The general scope of NGO research for pediatric health initiatives in LMICs is also limited (Magalhães Costa et al., 2011), with existing studies focused on pediatric surgical initiatives such as cardiovascular programs and classification of surgical platforms, causes of pediatric mortality or programs focused on child nutrition (Chanani et al., 2019; Nguyen et al., 2014; Shrima, Sleemi & Ambereen, 2015; van den Boogaard, Manzi, Harries, & Reid, 2012).

In this research brief, we report on the qualitative findings stemming from stakeholder interviews, which occurred as part of a larger scoping review study (Arksey & O'Malley, 2005; Levac et al., 2010; Taylor, Forgeron, Vandyk, Lightfoot, & Finley, 2020). The objectives were: 1) explore stakeholders' thoughts and experiences regarding NGO healthcare delivery and outcome evaluation for children and adolescents in LMICs and 2) explore the role of nurses working with NGOs and their ability to contribute to the achievement of positive health

outcomes for children and adolescents in these contexts. Nurses make up the largest section of the professional health work force globally, however, their roles and experiences working with non-profit or non-governmental organizations in LMIC settings is under-investigated (Dawson, Elliott, & Jackson, 2017; World Health Organization, 2015b). The knowledge gained through this study raises awareness of the topic and sheds light on some of the perspectives of those currently working in the field of pediatric NGO practice in LMICs.

## **2. Materials and Method**

### **2.1. Materials**

#### **2.1.1. Study Design**

A qualitative descriptive design (Sandelowski, 2000) was employed to engage with stakeholders (participants) who were affiliated with NGOs providing pediatric health services in LMICs. Qualitative descriptive studies are beneficial for exploring and creating understanding of a certain phenomenon or process, discovering perspectives of those directly involved, broadening the scope of a narrow or under-researched topic, and is an appropriate qualitative approach compatible with stakeholder engagement as part of a scoping review study (Arksey & O'Malley, 2005; Bradshaw et al., 2017; Neergaard, Olesen, Andersen, & Sondergaard, 2009).

#### **2.1.2. Participants**

Purposive sampling was used to recruit participants. Individuals affiliated with an NGO providing pediatric health services in LMICs were invited to participate. Recruitment was accomplished using existing professional networks of the primary investigator and research team. Potential participants were contacted via email or personally given a recruitment card or letter of invitation and instructed to contact the primary investigator if they were interested in possibly participating.



### **2.1.3. Eligibility Criteria**

Participants were eligible for the study if they were involved as a donor, founder, board member, program coordinator, employee or volunteer of an NGO providing pediatric healthcare services in a LMIC.

## **2.2. Method**

### **2.2.1. Data Collection & Analysis**

Participants were asked to review the preliminary scoping review findings and then take part in a one-on-one semi-structured interview. Interviews were conducted via Skype using a semi-structured interview guide (Appendix A) informed by the preliminary scoping review results. The interviews were audio recorded and later transcribed by a professional transcriptionist. Qualitative inductive content analysis was used to analyze the data. Open coding, category creation, and data abstraction were the three methods used to organize the data, identify themes, and create categories (Elo & Kyngäs, 2008). Meetings with the research team were also conducted to ensure that the categories were grounded in the data.

### **2.2.2. Ethical Considerations**

Ethics approval was obtained through the Research Ethics Board at the University of Ottawa prior to any data collection. Participants were electronically provided with a detailed consent form outlining the purposes of the scoping review, inherent risks and benefits, assurance of privacy and confidentiality, and provided with an opportunity to clarify questions. Either written or verbal consent was obtained prior to the beginning of each interview. The transcribed interview data and field notes were stored and secured using encryption techniques and password protected on the university server.

### **2.2.3 Trustworthiness & Rigor**

To ensure research quality and trustworthiness, the four principles outlined by Lincoln & Guba (1985), were considered throughout the research process. Credibility (establishing confidence in the truth of the findings), dependability (stability of data over time) and confirmability (objectively representing the data provided by participants) was ensured by debriefing with additional members of the research team to review and explore various aspects of the data collected (Polit & Beck, 2012). This assisted in maintaining objectivity, consistency, and believability in the data patterns and findings (Polit & Beck, 2012). Thick description of the context of the research was used to improve transferability (applicability of data to other contexts) by following specific inclusion criteria for participants, utilizing a semi-structured interview questionnaire for data collection, clearly conveying the methods of data analysis as well as representing the voices of the stakeholders with verbatim quotes (Polit & Beck, 2012).

### **3. Results**

Four main categories emerged from the data including; Scoping Review Reflections; Competing Priorities; Ambiguity of Nomenclature; and Nursing Contributions, which are described below.

#### **3.1 Demographics**

Four participants meeting inclusion criteria were interviewed, including two women and two men. All participants had current or recent affiliations with either surgical or humanitarian NGO(s) that provided pediatric health care in diverse LMIC locations spanning multiple continents. The roles of the participants included senior vice president of programs; volunteer; research coordinator; and employee/consultant.

#### **3.2 Reflections on the Evidence**

Participants expressed a sense of surprise regarding the preliminary results of the scoping review. This sense of surprise was largely related to the low number of studies found, considering the broad spectrum of pediatric services that were included in the review and the interview participants' assumed plethora of literature on pediatric programs in LMICs involving NGOs. "I was really surprised that it was that low, in particular, considering that it was pediatric healthcare services broadly and not just surgery" (Participant 1). Surprise was also felt regarding the absence of studies related to trauma and injury, a major cause of mortality in this population in LMICs. One participant commented on the decent representation of countries from a diverse set of geographies compared to how few studies were included. Another participant expressed positive surprise with the reported high incidence of complications within some of the studies, as they did not expect NGOs to publish negative results. Overall, the common thread between the participants was the expectation that more studies would be available and that there would be a wider range of interventions/programs, given the current number of issues facing children and adolescent's health in LMICs.

### **3.3 Competing Priorities**

The interviews exposed that one of the biggest challenges with evaluation and monitoring of outcomes is the constant tension of multiple competing priorities within each organization's structure, culture, and operating environment. As one participant shared,

We have aims and objectives. And the objectives are always measurable, and we plan in advance how we're going to monitor and evaluate our progress. The monitoring and evaluation have to be very closely tied to the aim of the program, because there are so many confounding and competing variables that come into play. (Participant 2)

It was made clear through the discussions with participants that evaluation of programs is a priority for many NGOs, however, the purpose of these evaluations is not necessarily to publish research findings for broader knowledge dissemination, but rather, used for program planning purposes and informing internal processes. This was evidenced by Participant 1 who said, “We have not researched our own data for research purposes, [but rather] for moving our organization forward and making sure that we’re planning correctly”.

The participants reported that the indicators used for internal evaluations can be difficult to measure, are based on the type of NGO program implemented (humanitarian vs. surgical) and can be influenced by external factors such as type of funding (individual vs. institutional) and even the foundational beliefs of the organization itself. Some participants reflected on the importance of NGO’s being accountable to their beneficiaries but expressed challenges in balancing that accountability based on the types of benefactors, as some do not insist on outcome data, while others do.

At the end of the day, let's say that it's a harder accountability to the donor that gives you this \$1 million, than to the people [recipients of NGO care] that are vulnerable and are less in a position of power to ask for. So, it's really a tough balance. (Participant 3)

Although this balance can be difficult to achieve, participants expressed the importance of maintaining accountability and that proper evaluation is further becoming an essential responsibility of NGO’s.

I think it’s-it’s super important that as NGOs we keep ourselves accountable for what we do. That we record our outcomes, that we are not shy or also sharing like the difficult stuff, cause, I think we’ll learn from that. (Participant 4)

There was also a clear distinction between the priorities of the types of NGOs that were represented by participants. Those affiliated with humanitarian NGOs spoke about indicators and evaluation as being the technical part of providing aid and that the priority within these organizations is widely focused on being present and being able to provide care. "...in humanitarian contexts, sometimes just the presence of-of proximity of being there is essential as an act of humanity" (Participant 2). Those affiliated with the surgical NGOs, expressed pride in their endeavours for evaluation and the growing nature of this type of accountability. "We have a number of different mechanisms on quality of treatment. We're extremely proud of our quality assessment systems" (Participant 1).

### **3.4 Ambiguity of Terminology**

Confusion regarding the definition of terms used by NGOs was also a common theme among participants. Participants discussed that many of the terms such as 'impact', 'sustainability' and even 'evaluation', are used differently amongst organizations, potentially leading to misunderstanding. This was reflected by Participant 1 who said, "I think sustainability and impact are kind of still so hard to define. I think the lack of, in my opinion, clear nomenclature around things makes it really hard to compare apples to apples".

The lack of clearly defined terms was echoed by others as making it difficult for even similar types of organizations to standardize or compare their evaluation practices, and thus, share learned knowledge. Participants also discussed the high expectations placed on the term sustainability and how it can be interpreted ideologically, leading to criticism of certain organizations for not being sustainable. As participant 2 expressed, "Sustainable is a loaded word in global health".

### **3.5 Nursing Contributions**

Stakeholders had very positive responses regarding nurses' work with pediatric NGOs in LMICs, especially their contributions to evaluation strategies and positive health outcomes. All participants described nurses as essential to the overall operation of NGO programs due to the types of roles that nurses occupy, especially their leadership within these organizations, and how valuable they are to all aspects of patient care.

Nurses are central to the NGO. They occupy positions from the top to the bottom. They often are in managerial positions, coordination positions, they really-nurses-run the show. In their role as medical team leaders, they can ensure that the clinical guidelines are being followed. They can anticipate the needs, for instance if there's increasing cases of bloody diarrhea or respiratory illnesses. They can identify these trends very quickly and put the appropriate response mechanisms into place. (Participant 2)

Participants discussed how nurses provide holistic care to patients and that they are well qualified to serve many roles, contributing to successful outcomes. Participant 4 shared, "I think the nurses play a huge role in emotional support for patients. I'm sure they're a huge part of our patient outcomes". Participant 1 also expressed that, "They're often the ones providing or the only ones that can provide nutrition to support a patient. They fill so many roles. We really, we really value them". Participant 1 also discussed the importance of strengthening the role of and empowering local nurses working with NGOs to maintain a high standard of practice through capacity building, because nurses are pivotal to ensuring that quality care is delivered.

A huge part of the burden might not only be that they [local nurses] hadn't gotten the skills that they need to identify complications in a post-operative six-month old, for example. But even if they had learned them, sometimes they weren't empowered just due to the

system to act. So, a huge part of our training is to both empower them and to really ensure they have the skills needed to feel that they can competently do their job. (Participant 1)

The interviews also exposed that nurses' ongoing experiences in these contexts can assist in improving program operations and outcomes.

There's a huge qualitative component and the [international] nurses that have done multiple missions can compare from other projects, what has worked, what didn't work, and they can bring that experience, make improvements and learn lessons and convey them to other programs so that things improve. (Participant 2)

Thus, both local and international nurses are key in pediatric NGO healthcare delivery, but the role and resources they require to be more impactful may be different.

#### **4. Discussion**

The views and experiences shared by the participants provide useful insight into some of the cultural underpinnings of NGO practice, and contribute to further understanding of how pediatric healthcare NGOs evaluate and contribute to positive and sustainable health outcomes in LMICs. Discussions with participants suggest that evaluation of program outcomes is a priority for NGOs. However, improving the structure and culture of sharing results of NGO research publications needs to be further cultivated due to the barriers that exist (e.g. ambiguity amongst terms, competing priorities, meeting donor needs). Participants expected a wider range of available research on this topic; however, the majority commented that the purposes of their own evaluations were focused on the improvement of their programs and/or meeting specific program objectives. Interestingly, despite their surprise at the paucity of research literature in the scoping review, the participants in this study could not reconcile this surprise with their report of competing priorities and need to protect future funding through donor appeasement. Although

participants recognized that research on pediatric NGO program outcomes would contribute to global health knowledge, the growth of research to improve sustainable health outcomes of children and adolescents will be slow, unless there is a shift to emphasize its importance and overcome the contributing barriers.

There have been a number of recent publications which have reported the benefits and challenges specifically for global child health partnerships and data sharing amongst international communities (Hate et al., 2015; Jao, Kombe, Mwalukore, Bull, & Parker, 2015; Pisani et al., 2016; Steenhoff et al., 2017). Interestingly, two of the four participants discussed their experiences with these types of initiatives. Data sharing has become increasingly endorsed as a means to make data more widely available within the scientific community (Jao et al., 2015), with benefits such as improved utilization of resources, avoidance in duplication of efforts, creation of international connections and enhancing the generation of evidence and knowledge (Hate et al., 2015; Pisani et al., 2016). While data sharing is categorically different than sharing outcomes and evaluation strategies of NGO programs, the resulting benefits of such initiatives could be similar. Peer reviewed published research may help clarify the definition of terms that participants discussed as ambiguous, and aid in the standardization of pediatric NGO practice by growing the evidence base, avoiding duplication of efforts and improving the utilization of resources. The expert-consensus review presented by Steenhoff et al. (2017), discussed the broad range of organizations participating in global child health partnerships seeking to improve child health globally. The mutual benefits highlighted between organizations include the exchange of knowledge, leveraging of resources and strengthening of research in LMICs (Steenhoff et al., 2017). NGOs are well experienced in creating and maintaining effective partnerships with many sectors (e.g. local communities, ministries of health, etc.) for successful



operations of their programs but could further benefit from global child health partnerships with academic institutions, private foundations or international agencies for enhancing research initiatives. While many NGOs may already be engaged in these types of partnerships, these initiatives need to be further prioritized within NGO communities for improved outcome sharing and knowledge generation for evidence-based practice, especially given the participant's acknowledgment of competing priorities, suggesting that research and publication are not a priority.

Engagement with participants also emphasized the pivotal role of nurses within NGO programs and highlighted their capacity for leadership. Nurses working with pediatric NGO programs are in a position to advocate for the increased sharing of knowledge and evaluation of outcomes through peer reviewed research. Nurses have a strong voice within the health field to advocate for greater transparency and accountability in all global health initiatives (Merry, 2012). Their vast experience and ability to reflect on lessons learned, as discussed by the participants, can not only improve programs at the local level but contribute to research sharing and knowledge dissemination.

## **5. Limitations**

The major limitation of this research was the small number of participants recruited for data collection. The sample does not represent all of the various types of NGOs engaged in pediatric healthcare in LMICs, making transferability of these findings cautionary. While the purpose of the study was to provide additional understanding to the results of a scoping review, which was achieved, further qualitative research on this topic is needed to determine if there are other challenges and facilitators to conducting and publishing research on NGO pediatric healthcare practices in LMICs. This research would be useful to inform strategies to improve the

dissemination of NGO programs and interventions aimed at improving the health of vulnerable children and adolescents.

## **6. Conclusions**

NGOs providing pediatric healthcare are consistently evaluating their programs, but due to competing priorities and the culture of evaluation purposes within NGO practice, their outcomes are not necessarily being shared with the wider NGO, healthcare, and research communities. Initiatives such as data sharing and global child health partnerships may contribute to the broader reporting of program outcomes and improve the culture of research practices for NGOs working in LMICs. Further research is needed to determine how best to equip and empower nurses to engage in pediatric NGO research and knowledge dissemination in LMICs.

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## Appendix A: Semi-Structured Interview Guide

<p><b>Introduction</b></p> <ul style="list-style-type: none"> <li>• Introductions</li> <li>• Background &amp; purpose of the interview</li> </ul>
<p><b>Consent</b></p> <ul style="list-style-type: none"> <li>• If consent not already obtained, allow participant to thoroughly read consent form and sign or give recorded oral consent</li> <li>• Researcher will reiterate that confidentiality and respect for free and ongoing consent will be maintained throughout the interview process</li> </ul>
<p><b>Questions</b></p> <ul style="list-style-type: none"> <li>• Any questions from the participant will be answered before moving forward in the interview</li> </ul>
<p><b>Sample Interview Questions</b></p> <ul style="list-style-type: none"> <li>• You've had a chance to review the preliminary findings of the scoping review. Can you share your thoughts and opinions regarding these findings?</li> <li>• In your experience, how does/did the NGO(s) you are affiliated with evaluate the effectiveness or impact of its program? (ex. Audits, formal evaluations, financial reports, monitoring of clinical outcomes etc.) <i>Probe: How do you decide what data will be collected?</i></li> <li>• How do you define positive and/or sustainable health outcomes? <i>Probe: How is this information presented to donors?</i> <i>Probe: How do you measure these outcomes? (Capacity building? Quality of life?)</i></li> <li>• Is ensuring positive and sustainable health outcomes for children and adolescents a priority to the NGO(s)? If so, how does the NGO(s) ensure that they are providing health services that result in these types of outcomes?</li> <li>• What role do nurses play within the organization? How do they contribute to these types of outcomes?</li> <li>• During program implementation, did the NGO(s) incorporate strategies for ensuring interventions resulted in positive and sustainable health outcomes?</li> <li>• Did/does the NGO(s) incorporate ongoing monitoring of the sustainability of their interventions?</li> <li>• Do you have any further insight as to how NGOs working as a partner within the global health community, can improve the delivery of healthcare services for children and adolescents in LMICs that ensure positive and sustainable health outcomes?</li> <li>• Any other comments?</li> </ul>
<p><b>Conclusion</b></p> <ul style="list-style-type: none"> <li>• Thank you to participant for willingness and participation in the research</li> <li>• Discussion of any further points or remarks</li> <li>• Ensure participant has researcher's information and encourage contact if further comments, questions or concerns.</li> </ul>

**Chapter 5**  
**Integrated Discussion**



## **Introduction**

The purpose of this thesis was to explore and describe how NGOs working in LMICs provide and evaluate their programs and interventions for positive and sustainable health outcomes in children and adolescents. Understanding the contribution of NGOs to positive health outcomes in this population is essential for the delivery of quality healthcare that is evidence-based and financially accountable.

Two studies were completed to meet the thesis objectives. The first study was a scoping review, with the purpose of reviewing the extent, range and nature of research focused on the delivery of pediatric healthcare services by NGOs in LMICs for positive and sustainable health outcomes (Arksey & O'Malley, 2005; Grant & Booth, 2009). The second study utilized a qualitative descriptive design (Sandelowski, 2000) to engage with stakeholders working with NGOs providing pediatric healthcare in LMICs to provide further clarity, insight and depth into the results of the scoping review (Arksey & O'Malley, 2005; Levac et al., 2010). Additionally, the qualitative descriptive study sought to explore the role of nurses working with NGOs and understand how nurses contribute to the achievement of positive and sustainable health outcomes in children and adolescents in LMICs. This chapter summarizes and discusses the results of the two studies and examines how the findings impact nursing practice, research, education and policy development.

### **Study 1: Exploring Pediatric Healthcare Initiatives of NGOs in LMICs for Positive and Sustainable Health Outcomes: A Scoping Review**

A systematic search of the literature and two step study selection procedure resulted in the inclusion of 17 studies in the scoping review. Fifteen of the studies were sourced from five electronic database searches in addition to one study identified from a hand search and one study

from the included studies' reference lists. Data were extracted from the studies and the results were organized, collated, and summarized using descriptive quantitative measures (counts, frequencies and percentages). Outcome reporting over time was determined by graphing the total number of outcomes reported by year of study publication as well as graphing the number of outcome types reported by year of study publication.

The data analysis showed that studies focused on the evaluation of 10 different NGO programs. The most common interventions/programs evaluated were cleft lip/palate repair and clubfoot treatment. Outcomes were reported 89 times, with fifty-six different outcomes reported in total, of which 24 were positive, 27 were negative, and five were unchanged. Similar outcomes were grouped into six categories of positive outcomes and four categories of negative outcomes. The most common negative outcome categories were death and complications/adverse events and the most common positive health outcome categories were physical improvement, reduction of symptoms/improvement in clinical signs, and satisfaction with care.

The overall reporting of outcomes by NGOs increased over time, despite year-to-year variability. Additionally, the evaluation of broader indices of health outcomes that were more inclusive of improved social health (in addition to physical and cognitive health) were found in more recent publications (2008-2016). Evaluation or consideration of sustainability of interventions/programs was lacking within the studies as well as studies specific to adolescent targeted programs or robust measurement of quality of life.

## **Study 2: Stakeholder Input on Pediatric NGO Healthcare Delivery and Outcome Evaluation in Low-and Middle-Income Countries: A Research Brief**

A semi-structured questionnaire informed by the preliminary scoping review results was used to interview four stakeholders (two men and two women) affiliated with either surgical or

humanitarian NGO(s) providing healthcare to children and/or adolescents in LMICs. Qualitative inductive content analysis was used to analyze the data using open coding, category creation, and data abstraction (Elo & Kyngäs, 2008). Four main categories emerged from the interviews including: Reflections on the Evidence; Competing Priorities; Ambiguity of Nomenclature; and Nursing Contributions.

The voices and experiences expressed by the study participants highlighted that outcome evaluation is a priority for healthcare NGOs working in LMICs, however, there are multiple influencing factors that contribute to these processes. The culture of evaluation for the purposes of quality improvement and assurance of continued program funding, as well as the effort of balancing competing priorities, impedes evaluation for the purpose of research dissemination and sharing of outcomes. Additionally, participants discussed the confusion around terms used within research and within NGO structures such as evaluation and sustainability, and that the lack of clear nomenclature makes it difficult to compare outcomes of different programs or develop any form of practice standardization.

The discussions around the roles of nursing within these organizations clearly identified the contribution that nurses have to positive health outcomes for children and adolescents in LMICs. Specifically, nurses are qualified to fill many rolls, and their capacity for leadership within NGOs is instrumental for program operation and improvement in NGO processes.

### **Integrated Discussion**

The findings from the scoping review were encouraging, as the results indicated that outcome evaluation is growing within the field of pediatric NGO practice and progress has been made towards evaluation of health outcomes broader than unidimensional health indicators or outputs. Furthermore, the results contributed to a better understanding of how NGOs provide

pediatric healthcare in LMICs by identifying a small sample of types of NGOs evaluating their programs and the variety of health services currently being delivered. Stakeholder input was helpful to contextualize the findings from the scoping review and provided clarity and insight into a number of the results.

The results of the data analysis from the scoping review, as well as the themes gathered from the qualitative descriptive study emphasized the heterogeneous nature of NGO work in LMICs. The differences noted between the priorities and objectives of the two types of NGOs reflected on during the stakeholder interviews, not only displayed the variability in types of programs implemented, but also revealed the differences in foundational beliefs of different types of organizations. This variability was also evidenced in the scoping review results, as the number of NGOs represented and types of outcomes reported were broad, considering the low number of studies included. It is clear that further research studies with larger sample sizes are needed, as well as studies from additional NGOs to really grasp the differences between similar organizations' (e.g. humanitarian, surgical) care delivery and outcome evaluation. This knowledge is essential not only for comparing the effectiveness of programs, determining gaps in care and identifying where overlap of services exist, but also to determine the value and necessity of standardization of practices.

A number of publications support the standardization of practices for short-term missions (STM), an arm of care delivery in LMICs provided by independent groups (often NGOs), with use of guidelines and models that direct the provision of medical or surgical services (Butler et al., 2018; Suchdev et al., 2007). Interestingly, research on the effectiveness of STMs has indicated that this type of care delivery is more costly and less effective than individual longer-term programs operating in similar contexts (Shrime, Sleemi & Ambereen, 2015). As there are

numerous groups and organizations providing care through the use of STMs worldwide and research has provided appropriate guidelines for the standardization of their practices, the standardization of practices within homogenous groups of NGOs should be achievable, which could result in increased effectiveness of interventions and considerable cost savings compared to STMs. Standardization needs to be evidence-based and include the flexibility to be contextually based, given the variability in LMIC resources and infrastructure (McCormack et al., 2002). This can only be done by further generating knowledge on the impact of pediatric health interventions in the context of LMICs.

Further research is also needed on the cost analyses of programs and interventions, because NGOs need to ensure that they are making appropriate decisions for resource allocation and utilization (Delisle, Roberts, Munro, Jones, & Gyorkos, 2005; World Health Organization, 2003). The benefit of this type of evaluation allows for the shift in resources from cost-ineffective interventions to cost-effective ones, improving efficiency and further contributing to improved health outcomes (World Health Organization, 2003). A number of the studies in the scoping review discussed some element of cost, whether in regard to the limitations placed on diagnostic abilities, performing evaluation after treatment, or specific to the actual monetary cost of an intervention. However, only one study analyzed the long-term cost benefits of their program, and none of the studies compared cost-analyses to other programs or intervention types. This topic was not explored through the stakeholder engagement phase, as any financial dialogue was centered around donor accountability and economic cost burden for patients undergoing treatment. Therefore, further emphasis needs to be placed on this type of evaluation.

Further clarification of terms used by NGOs related to the effectiveness of programs is also needed, as evidenced by the results from the qualitative descriptive study. The lack of

sustainability measured or discussed within the studies in the scoping review could also be a result of the ambiguity of the term, again highlighting the need for a more clearly defined understanding of both program and outcome sustainability and their importance in the evaluation of intervention effectiveness. Measuring pediatric quality of life is a robust outcome that could be beneficial in determining the sustainability of program interventions and effectiveness. The aim of quality of life measurement is to assess a person's well-being and health status beyond limited time specific health indicators (Mabugu et al., 2013), which is more in keeping with the WHO's definition of health (World Health Organization, 1948).

Across the 17 studies in the scoping review, quality of life assessment was not measured for any pediatric population, demonstrating that the evaluation of this type of outcome was not a priority for NGO programs. While the results indicated that NGOs are evaluating outcomes that may reflect improved quality of life (e.g. ability to play with friends, improved school attendance), additional emphasis needs to be placed on the robust measurement of pediatric quality of life using validated tools specific to pediatrics and LMIC contexts. Quality of life measurement has emerged as an important outcome that informs cost-benefit analyses (Mabugu et al., 2013; Varni et al., 2001), which could also be valuable for NGOs in determining whether their interventions are cost-effective and utilized for the largest impact. Overall, it is vital that substantial efforts continue to be placed on improving the delivery of health services and evaluation of NGO interventions for children and adolescents in LMIC settings.

### **Implications for Nursing**

The World Health Organization (WHO) estimates that there are 20.7 million nurses and midwives globally, representing more than 50% of the health workforce globally (World Health Organization, 2016). The role of nursing is critical to the achievement of the sustainable

development goals as advocates, educators, leaders, researchers, and care providers who make a difference in the health of individuals globally through the provision of evidence based high-impact and low-cost interventions (Wilson et al., 2016; World Health Organization, 2016).

Nurses are well situated within the health workforce to advance not only the role of nursing in global health, but also to advocate for changes that improve the health outcomes of vulnerable populations suffering from the unequal distribution of wealth, health and resources. The following sections describe how the current research and nursing profession can contribute to the achievement of these goals through nursing education, clinical practice, research and policy development.

### **Nursing Education**

The increased globalization of our world has contributed to an expanded awareness of global health issues and to diverse practice settings for nurses (Joyce et al., 2017; Wilson et al., 2016). Not only do nurses require an understanding of the wider cultural and social diversities that exist in their local environments, nurses are actively participating in initiatives that aim to provide care and advance the health of individuals in international settings (Leffers & Mitchell, 2010). As such, nursing curriculums need to prepare nurses to engage in global health practice by providing opportunities for learning and skill development to acquire the competencies for global health and interprofessional practice in both local and global settings (Joyce et al., 2017). Global health education in both undergraduate and graduate nursing programs can begin to foster global nurse leaders to look beyond their local health systems, enhance the understanding of health from a wider global perspective and cultivate connections and partnerships within the global health community (Edmonson, Mccarthy, Bc, Adams, & Marshall, 2017). Understanding how health systems function in different countries economic systems will also provide insight

into the issues surrounding care of the most vulnerable populations and expose nurses to the need for effective and evidence-based health interventions in these contexts. Nurses working with NGOs during any point in their career path need to be well informed of the importance of providing quality care in LMIC contexts and advocate for upholding practice standards that result in positive and sustainable health outcomes for children and adolescents receiving healthcare from NGOs.

One of the key issues identified through the qualitative study was the importance of educating and empowering local nurses working with NGOs in LMICs. The scoping study also revealed that all but one of the NGO programs were heavily focused on treatment and management of pediatric clinical symptoms, and none had a primary focus on capacity building initiatives. Therefore, educating nurses on how to engage in capacity building initiatives, as well as teaching them strategies to achieve increased capacity amongst local nurses in LMICs needs to be a priority objective of NGO programs to assist in improving the knowledge and clinical skills of nurses caring for the pediatric patients that NGOs serve. This will not only contribute to improved clinical outcomes, but also empower local nurses to be leaders in their communities for standardized care and evidence-based practice once an NGO is no longer involved or providing care in their communities.

Prioritizing nursing education is imperative for enhancing global nursing leaders (Wakefield, 2018), as well as empowering nurses partnering with NGOs in LMIC settings, both of which contribute to the provision of the highest standard of care for children and adolescents globally.



## **Nursing Research**

The priority of nursing research is to develop reliable and quality evidence on topics and issues central to the nursing profession (Polit & Beck, 2012). As nurses have a vested interest in global health and are essential to NGO program operation and service delivery, the gaps in research identified throughout the studies are significant for nursing practice. The gaps identified include the need for further research on NGO evaluation practices among more homogenous groups of NGOs, efforts to further prioritize research on adolescent healthcare and outcome evaluation in LMICs, further study on the benefits of qualitative research for outcome evaluation as well as improved understanding of how best to equip and empower nurses to engage in pediatric NGO research.

The lack of adolescent specific outcome research available was not explored or better understood through the stakeholder consultation phase, and therefore additional qualitative research is needed to generate knowledge from the experiences of NGO stakeholders. NGOs could benefit from improved knowledge on how they can best care for this population, due to the barriers identified in the Isaakidis, Paryani, Khan, Mansoor, & Manglani (2013) study and supporting research (Armstrong et al., 2018; Auld et al., 2014; Hudelson & Cluver, 2015).

The lack of emphasis on capacity building initiatives in the scoping review studies also highlighted that the needed level of expertise (e.g. nurses, physicians, social workers) to achieve desired outcomes in resource restricted areas remains unknown. Given this finding, the role of nurses in pediatric NGO practice and outcome evaluation was explicitly explored through the consultation stage with stakeholders. Through the qualitative interviews, stakeholders identified that nurses have a profound presence within NGOs to be leaders and advocates for change. This was not surprising given that nurses are leaders and advocates for many vulnerable populations

(International Council of Nurses, 2012). Nurses need to collaborate with NGOs as independent researchers, promote evaluation efforts for research purposes, and disseminate outcomes for improved sharing amongst organizations globally (International Council of Nurses, 2012). Global health nurses need to foster relationships with global partners to advocate for evidence-based practice rooted in quality research studies to create standardized practice (e.g. common definitions for outcomes) for NGO program evaluation. As leaders within organizations, nurses can assist in prioritizing the research agenda of NGOs and advocate for the enhancement of evaluation techniques such as the use of validated tools or qualitative research designs to conduct quality research (World Health Organization, 2016).

### **Nursing Clinical Practice**

The current healthcare environment highly promotes clinical practice that is based in evidence (Edmonson et al., 2017). Evidence-based practice can improve patient health outcomes by increasing the quality of services provided which results in the better use of healthcare resources (Polit & Beck, 2012). Nurses working in global health can address global health issues by utilizing evidence-based practice for prevention, early recognition, intervention and implementation of practices and programs (Edmonson et al., 2017). Quality patient care based in evidence requires practice standards for healthcare professionals (World Health Organization, 2016), which should include nursing practice with unregulated organizations such as NGOs. Clinical practice guidelines, which are adjusted to local context and available resources, can assist nurses in making informed clinical decisions and determine the best options for caring for children and adolescents with certain illnesses, injuries or diseases (Grinspun & Bajnok, 2018).

As nurses are central to NGO programs, best practice guidelines (that take into consideration challenges in LMICs) to support clinical decision making are essential to support

nurses' practice in LMIC contexts. Nurses working with NGOs can be from local or international settings and therefore varied in their knowledge, skills and nursing experience. Implementing and supporting contextually based nursing best practice guidelines will contribute to the standardization of nursing practice and maintain quality of care delivery. Nurses working with NGOs in LMICs contexts would benefit from best practice guidelines on issues such as global nurse leadership, quality of care in resource limited environments, ethical practice in culturally diverse settings, safe and effective nurse staffing in austere environments, and partnership with health systems in lower-income countries.

The implementation of best practice guidelines as well as continued research on the effectiveness of interventions provided to children and adolescents in LMICs by NGOs through outcome evaluation will contribute to knowledge available for nurses to utilize for evidence-based practice and improved clinical decision making.

### **Policy Development**

Historically, nurses involvement in global health policy development has been limited (World Health Organization, 2011). As 2020 has been designated the Year of the Nurse and the Midwife, the International Council of Nurses and *Nursing Now* movement are further promoting the involvement of nurses in national and global health policy (Mitchell, 2020). Not only does nursing science contribute to the body of literature that informs policymakers (Wagner, Fisher, & Pascual, 2018), nurses are well equipped to lead change and influence health policy to shape the global health agenda by policy formulation, identifying issues and solutions with policy implementation, and raising public awareness of healthcare issues (Edmonson et al., 2017; Wichaikhum, Abhicharttibutra, Nantsupawat, Kowitlawakul, & Kunaviktikul, 2020; Wilson et al., 2016).

While nurses should continually be engaging in opportunities to influence policy and advocate for populations most in need, there are a number of ways in which nurses can be involved in policy development specific to the issues identified through the scoping review and qualitative study. Nurses need to advocate for improved regulations for pediatric NGO practice due to the lack of governing bodies that monitor their programs. At minimum, a global electronic database should be created with mandatory registration to track the types of NGO programs operating in different countries. This initiative would provide access to comprehensive information for healthcare personnel wishing to be involved in global initiatives and help determine where and how healthcare services are allocated (Institute of Medicine (US) Committee on Regional Health Data Networks, 1994). It would also allow the opportunity for pediatric NGO collaborations and the pooling of resources and efforts in particular countries providing services for specific populations and health needs, further contributing to sustainability of programs and outcomes (Arhin, Kumi, & Adam, 2018).

Nurses need to advocate for improved practice and evaluation standards of NGOs delivering healthcare to children and adolescents and call for program audits by external evaluators who are not tied to donors or NGO administrators. Additionally, nurses need to be involved in the implementation of existing standards within NGO programs such as the WHO global standards for quality services for adolescents (World Health Organization, 2014). This would assist NGOs in improving program development and service delivery by providing evidence-based strategies for addressing the unique health needs of certain populations (World Health Organization, Organisation for Economic Co-operation and Development, & The World Bank, 2018). Policy development in these areas would initiate the beginnings of some form of standardization amongst similar types of NGOs which would lead to improved allocation of

resources, program delivery and better outcomes for children and adolescents in LMICs (Friedman & Fulton, 2016). Nurses have a significant role to play in designing the clinical and policy responses to these issues, as well as outcome evaluation and effectiveness of health programs and initiatives (International Council of Nurses, 2017).

### **Conclusion**

This thesis describes how NGOs working in LMICs provide health care to children and adolescents and explores how NGOs evaluate their programs for positive and sustainable health outcomes. Additionally, it contributes a better understanding of the role of nurses working with these organizations and their instrumental contribution to the achievement of positive health outcomes and improved care delivery. Although the results indicated that program evaluation is a priority for NGOs, and that evaluation practices have grown and improved over time, the scoping review and stakeholder interviews highlighted numerous gaps in research and practice that need to be prioritized. Addressing these gaps will help to further the work of NGOs in achieving positive and sustainable outcomes in children and adolescents in LMICs which are hindered by the culture of current evaluation practices and competing priorities limiting evaluation and sharing of program outcomes.

Nursing schools need to incorporate global health focused education opportunities in both undergraduate and graduate programs to cultivate global health nurse leaders who can advocate for quality healthcare delivery and outcome evaluation globally. Capacity building needs to be prioritized for NGOs working with local country nurses to improve quality and safety of care provision and empower nurses to become health leaders in their communities. Future research priorities need to focus on NGO evaluation practices among homogenous groups of NGOs, adolescent care and outcome evaluation in LMICs, the benefits of qualitative research, a holistic

approach to assessing quality of life with validated tools for outcome evaluation, as well as equipping and empowering nurses to engage in pediatric NGO research initiatives. Cost-analysis evaluation and reporting should also be prioritized to ensure appropriate resource allocation and program development decision making. The implementation of context based best practice guidelines for nurses working with NGOs in LMIC settings will assist in improving clinical decision making informed by evidence-based practice and foster the culture of evaluation and sharing of program outcomes. Lastly, nurses should be advocating for the standardization of NGO practices, starting with a mandatory electronic database of pediatric NGO programs operating in LMICs and the implementation of existing guidelines outlined by organizations such as the WHO.

This research has direct benefits for pediatric NGO program development and implementation and supports the need for robust evaluation of NGO outcomes. It also contributes to the growing body of literature for global health resources, furthers the NGO research agenda and voice of nurses working and interested in global health. Nurses need to continue to advocate for global equity and support greater transparency and accountability for all global pediatric health initiatives to ensure that children and adolescents living in LMICs are receiving the highest quality of evidence-based healthcare that contributes to positive and sustainable health outcomes and better quality of life (Merry, 2012).

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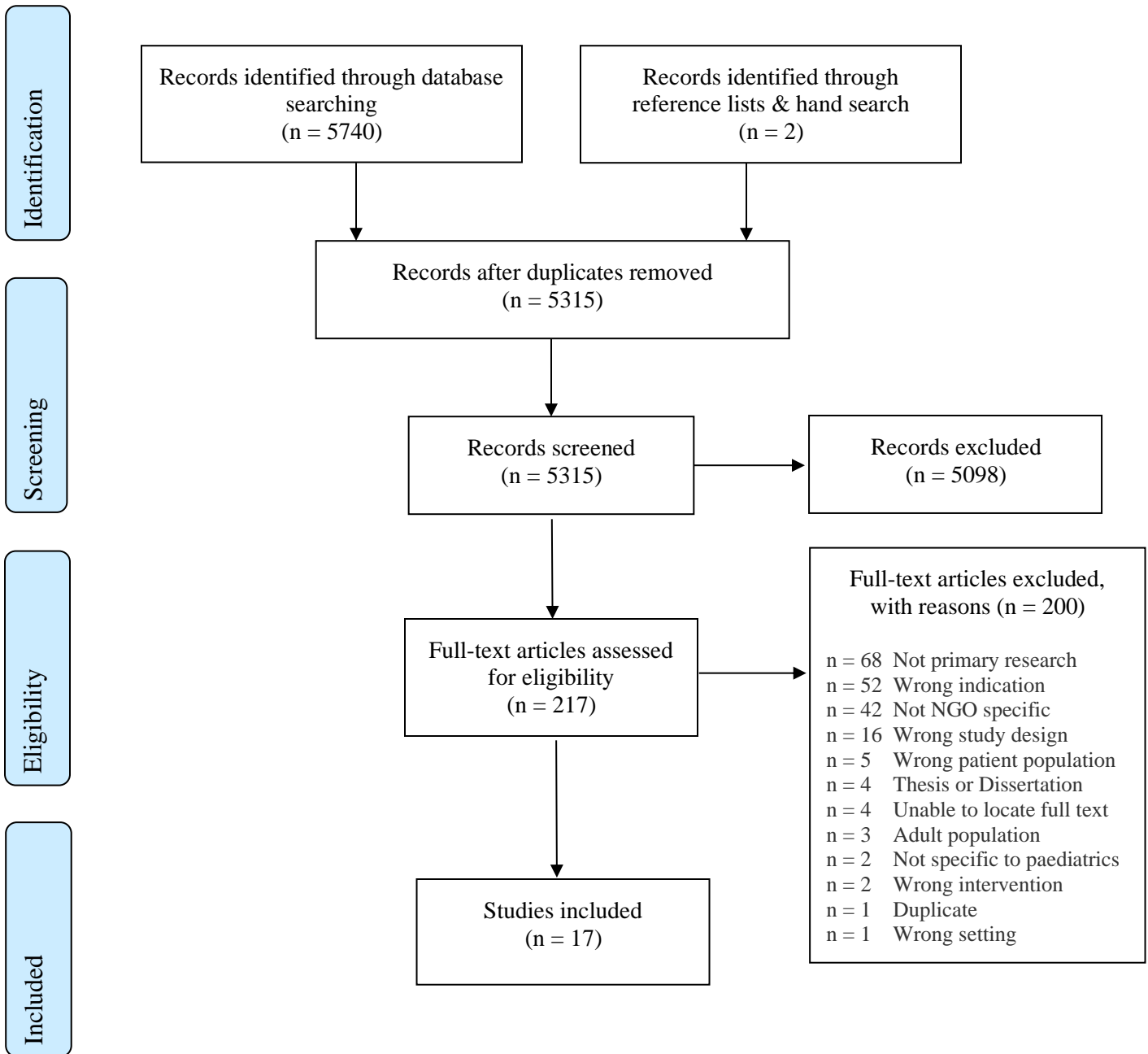
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**Appendices**

**Appendix A: PRISMA Flow Diagram**



## Appendix B: Research Invitation Letter



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Université d'Ottawa  
Faculté des sciences  
de la santé

École des sciences  
infirmières

University of Ottawa  
Faculty of Health  
Sciences

School of Nursing

Dear interested participants,

My name is Jennifer Taylor, and I am a Master of Science in Nursing student at the University of Ottawa. The purpose of this letter is to invite you to participate in the research I have been conducting regarding pediatric health outcomes of healthcare interventions provided by Non-governmental organizations (NGOs) in low-and middle-income countries. As you may know, the existence of academic literature on this topic is somewhat limited. As such, I have embarked on a scoping review to establish what studies currently exist, and to synthesize the findings for a better understanding of how NGOs achieve sustainable and positive health outcomes in this population.

You are being invited to participate, as you are in a position which allows you to offer insight, experience or expertise on this topic as a stakeholder in the field. Stakeholder involvement in this scoping review is an important component that will increase the meaning and applicability of the results, as well as assist in creating a link between providers and researchers.

As a stakeholder, your involvement will be to review the preliminary results of the scoping review and then participate in a one-on-one interview (in person, by phone or by Skype/Facetime), lasting no longer than one hour. You may be asked to engage in a second, short interview (lasting less than 30 min), should any clarification or further discussion on your responses from the first interview be required. Approximately, 6 stakeholders will be asked to participate. Participants will be included on a first come first serve basis.

Participation is completely voluntary, and you may discontinue your participation at any time. If you have questions about the research, you may contact me via email, and I will respond as soon as possible. Thank you for your time and consideration.

Sincerely,

Jennifer Taylor RN, BScN, MScN Student

Thesis Supervisor: Dr. Paula Forgeron

Thesis Committee Members: Dr. Allen Findley & Dr. Amanda Vandyk

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**Appendix C: Recruitment Card****Exploring Pediatric Healthcare Initiatives of NGO's  
in Low-and Middle-Income Countries:  
A Scoping Review****Purpose of Research:**

- Explore how NGO's provide health services that achieve positive and sustainable health outcomes in children and youth living in LMIC's

**Looking for:**

- Stakeholders who can offer insight, experience or expertise on this topic

**Participants will:**

- Review preliminary results of the scoping review
- Participate in one-on-one interviews no more than 1 hour in length either in person, by phone or skype

**Benefits of participating:**

- Assist in validating and building on the reported evidence to offer a higher level of meaning to the results
- Help create a link between researchers and NGO's working in the field, a vital part of the study of global health delivery



Contact: Jennifer Taylor RN BScN, MScN Student

Supervisor: Dr. Paula Forgeron, RN PhD



### Appendix D: Interview Guide

<p><b>Introduction</b></p> <ul style="list-style-type: none"> <li>• Introductions</li> <li>• Background &amp; purpose of the interview</li> </ul>
<p><b>Consent</b></p> <ul style="list-style-type: none"> <li>• If consent not already obtained, allow participant to thoroughly read consent form and sign or give recorded oral consent</li> <li>• Researcher will reiterate that confidentiality and respect for free and ongoing consent will be maintained throughout the interview process</li> </ul>
<p><b>Questions</b></p> <ul style="list-style-type: none"> <li>• Any questions from the participant will be answered before moving forward in the interview</li> </ul>
<p><b>Sample Interview Questions</b></p> <ul style="list-style-type: none"> <li>• You've had a chance to review the preliminary findings of the scoping review. Can you share your thoughts and opinions regarding these findings?</li> <li>• In your experience, how does/did the NGO(s) you are affiliated with evaluate the effectiveness or impact of its program? (ex. Audits, formal evaluations, financial reports, monitoring of clinical outcomes etc.) <i>Probe: How do you decide what data will be collected?</i></li> <li>• How do you define positive and/or sustainable health outcomes? <i>Probe: How is this information presented to donors?</i> <i>Probe: How do you measure these outcomes? (Capacity building? Quality of life?)</i></li> <li>• Is ensuring positive and sustainable health outcomes for children and adolescents a priority to the NGO(s)? If so, how does the NGO(s) ensure that they are providing health services that result in these types of outcomes?</li> <li>• What role do nurses play within the organization? How do they contribute to these types of outcomes?</li> <li>• During program implementation, did the NGO(s) incorporate strategies for ensuring interventions resulted in positive and sustainable health outcomes?</li> <li>• Did/does the NGO(s) incorporate ongoing monitoring of the sustainability of their interventions?</li> <li>• Do you have any further insight as to how NGOs working as a partner within the global health community, can improve the delivery of healthcare services for children and adolescents in LMICs that ensure positive and sustainable health outcomes?</li> <li>• Any other comments?</li> </ul>
<p><b>Conclusion</b></p> <ul style="list-style-type: none"> <li>• Thank you to participant for willingness and participation in the research</li> <li>• Discussion of any further points or remarks</li> <li>• Ensure participant has researcher's information and encourage contact if further comments, questions or concerns.</li> </ul>

## Appendix E: Research Consent Form



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de la santé

École des sciences  
infirmières

University of Ottawa  
Faculty of Health  
Sciences

School of Nursing

**Title of the study:** Exploring Pediatric Healthcare Initiatives of Non-Governmental Organizations in Low-and Middle-income Countries: A Scoping Review

Jennifer Taylor RN - MScN Student  
Supervisor - Dr. Paula Forgeron

School of Nursing, Faculty of Health Sciences, University of Ottawa  
RGN 3051  
451 Smyth Rd.  
Ottawa, ON Canada  
K1H 8M5

**Invitation to Participate:** You are invited to participate in the above-mentioned research study conducted by student researcher Jennifer Taylor and her supervisor Dr. Paula Forgeron.

### Purpose of the Study:

1. Identify and summarize the research that currently exists specific to the delivery of pediatric health services by non-governmental organizations (NGOs) in low-and middle-income countries (LMICs)
2. Explore how NGOs provide health services that directly result in positive and sustainable health outcomes in children and adolescents living in LMICs
3. Understand which strategies could be used to aid the implementation of an NGO into an LMIC setting for positive and sustainable health outcomes in children

**Participation:** You will be asked to participate in a one on one interview lasting no longer than 1 hour in length. The interview will occur either in person, by telephone or by Voice over Internet Protocol technologies such as Skype or Facetime. You will be asked to review the preliminary study findings before your interview occurs. The one-on-one interview will be scheduled to your availability and convenience in coordination with the researcher's availability and convenience. During the interview, you will be asked to share your thoughts and opinions regarding the preliminary study findings, as well as respond to questions specific to program implementation and evaluation of the NGO you are affiliated with. You will also be asked questions about how the NGO you are affiliated with, provides pediatric health services that contribute to positive and sustainable health outcomes. You may be contacted for an additional short discussion within a four-week period after my interview is complete, using the methods previously mentioned, for any clarification or validation of your responses.

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**Risks:** Your participation in this study will entail that you answer questions and share opinions specific to the NGO whom you are personally or professionally affiliated with. This may cause you to feel that you are in conflict of interest due to your investment in the NGO. You may feel that your responses or opinions negatively reflect the organization's program or leadership strategies and may cause you to feel like you are betraying their organizational confidence or not fully supporting the NGO's mission/mandate. You have received assurance from the researcher that every effort will be made to minimize these risks by keeping interview responses confidential.

**Benefits:** Your participation in the study will help increase the relevance of the research and advance the link between research and practice. Additionally, your participation will help provide clarity to the current practice in the field of pediatric healthcare provided by NGOs in LMICs and contribute to the body of evidence-based research that promotes quality healthcare for children and adolescents in LMICs. The findings from the research will be valuable to current and future NGO communities seeking to evaluate the impact of their programs and ensure positive and sustainable health outcomes of their health initiatives.

**Confidentiality and anonymity:** You have received assurance from the researcher that the information you share will remain strictly confidential. You understand that the contents will be used only for the study proposed and that my confidentiality will be protected. You understand that some demographic information will be collected during the research process but under no circumstances will my name or any other identifying information be shared publicly. You understand that the information you provide will be identified by an anonymous code that is not reflective of your personal information.

**Conservation of data:** The data collected, including interview notes and transcripts will be kept in a secure manner. They will be stored and secured using encryption techniques and be password protected on the primary thesis supervisor's secured individual research storage space on the University of Ottawa server. All data will be conserved in a secure location for five years after the study is completed.

**Compensation:** No compensation is being offered for this study.

**Voluntary Participation:** You are under no obligation to participate and if you choose to participate, you can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. Any data collected before my withdrawal will not be included in the study findings and be destroyed anonymously.

**Acceptance:** I, (*name of participant*), agree to participate in the above research study conducted by Jennifer Taylor, MScN Student of the School of Nursing, Faculty of Health Sciences at the University of Ottawa, under the supervision of Dr. Forgeron.

If you have any questions about the study, you may contact the researcher or her supervisor. If you have any questions regarding the ethical conduct of this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5

Tel.: (613) 562-5387

Email: ethics@uottawa.ca

There are two copies of the consent form, one of which is yours to keep.

Participant's signature:        *(Signature)*                      Date: *(Date)*

Researcher's signature:        *(Signature)*                      Date: *(Date)*

Consent form retrieved and modified January 21, 2019 from <http://research.uottawa.ca/ethics/guidelines/consent-process>

## Appendix F: Verbal Consent

This verbal consent is for a research study entitled: *Exploring Pediatric Healthcare Initiatives of Non-governmental Organizations in Low-and Middle-income Countries: A scoping review*.

The purpose of the scoping review is to:

1. Identify and summarize the research that currently exists specific to the delivery of pediatric health services by Non-governmental organizations (NGOs) in low-and middle-income countries (LMICs).
2. Explore how NGOs provide health services that directly result in positive and sustainable health outcomes in children and adolescents living in LMICs.
3. Understand which strategies could be used to aid the implementation of an NGO into an LMIC setting for positive and sustainable health outcomes in children

Your participation in the scoping review will require you to partake in a one-on-one interview with myself, Jennifer Taylor, lasting no longer than 1 hr in length. Additionally, you may be contacted for a short discussion within a four-week period after the initial interview for any clarification or validation of your responses. The interview and subsequent discussion will take place via telephone or videoconferencing using Skype or Facetime and will be audio recorded. It will then be transcribed and analyzed at a later date.

The interview will begin by asking you to share your opinion and thoughts about the preliminary research findings from the initial stages of the scoping review that you have already been asked to review. I will then be asking you questions about the NGO you are representing, related to program implementation, evaluation, sustainability and health outcomes. If you need to stop or skip questions at any time during the interview you may do so. You are not required to share any information that you do not want to. There are no risks to participating, however you will be asked to answer questions and share opinions specific to the NGO whom you are personally or professionally affiliated with. This may potentially cause you to feel that you are negatively reflecting the organization and/or not fully supporting the organization's mission/mandate. There are no direct benefits to participating in the interview, however, the information that you provide will help to increase the relevance of the scoping review, advance the link between research and practice and contribute to the body of evidence-based research that promotes quality healthcare and improved health outcomes for children and adolescents in LMICs.

All of the information you share with me will remain confidential. Your name and identifying factors will be removed from the transcript to protect your identity and will not be revealed in any publications or presentations. The transcript will be assigned a participant identification number that will be used to identify you and your demographics. All documents and transcripts related to the scoping review will be stored on the University of Ottawa's secure server, or computer, and will be password protected and encrypted.

You are under no obligation to continue with the interview, and you may choose to stop the interview at any time. If you decide to leave the interview or remove your participation from the scoping review, the information you have provided will not be included in the research results. The research findings will be used as part of a Master of Science in Nursing thesis and submitted for publication to an academic journal. Your name or identifying features will be removed during the analysis of the data, making you unidentifiable should the research be published.

Do you have any questions?

Can you state and spell your name to record your consent?

This serves as documentation of verbal consent for: (*Participant's Name*)

On this date (DD/MM/YYYY) at (00:00).

Do you (*participant's name*) understand the study, and give voluntary consent to participate?

I, Jennifer Taylor, have made sure, to the best of my abilities, that the participant understands the above research, and that all questions have been answered to the satisfaction of the participant. You have voluntarily verbally consented to participate. A copy of this consent will be mailed to you. If you have any questions about the ethical conduct of this research, you may contact the ethics board. Their contact information will be on the consent form mailed to you.

**Appendix G: Confidentiality Agreement for use with Transcription Services**

Research Study Title: Exploring Pediatric Healthcare Initiatives of Non-governmental Organizations in Low-and Middle-income Countries: A Scoping Review

Jennifer Taylor RN - MScN Student  
Supervisor - Dr. Paula Forgeron  
School of Nursing, Faculty of Health Sciences, University of Ottawa

RGN 3051  
451 Smyth Rd.  
Ottawa, ON Canada  
K1H 8M5

I, (*name of transcriptionist*), agree to maintain full confidentiality of all research data received from the research team related to this research study.

I will hold in strictest confidence the identify of any individual that may be revealed during the transcription of interviews or in any associated documents.

I will not make copies of any audio-recordings, video-recordings, or other research data, unless specifically requested to do so by the researcher.

I will not provide the research data to any third parties without the client's consent.

I will store all study-related data in a safe, secure location as long as they are in my possession. All audio recordings will be stored in an encrypted format.

All data provided or created for purposes of this agreement, including any back-up records, will be returned to the research team or permanently deleted. When I have received confirmation that the transcription work, I performed has been satisfactorily completed, any of the research data that remains with me will be returned to the research team or destroyed, pursuant to the instructions of the research team.

I understand that the University of Ottawa has the right to take legal action against any breach of confidentiality that occurs in my handling of the research data.

Transcribers name (printed):

Transcribers signature:

Date:

*Template retrieved and modified February 5<sup>th</sup>, 2019 from <https://sbsirb.uchicago.edu/page/confidentiality-agreement-transcriptionists-sample>*