

Perspectives of Health
In Rwandan Child Headed Households

by

Michelle Henriette Hardy
B.A., University of Victoria, 2007

A Thesis Submitted in Partial Fulfillment
of the Requirements for the Degree of

MASTER OF ARTS

in the Department of Anthropology

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Supervisory Committee

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ABSTRACT

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This thesis focuses on the perceptions and experiences of Rwandan children living in rural child headed households regarding malaria, and how these perceptions and experiences compare to their other health concerns. Despite the attention given to malaria by the international community and the Rwandan government, and the numerous studies that have documented the material and socioeconomic poverty that characterizes the lives of child headed households, Rwandan children's perspectives regarding their health have rarely been elicited. Through the use of drawing activities and semi-structured interviews with 37 children between the ages of six to eighteen years, living in 14 child headed households, I explore how poverty shapes their understandings, experiences and responses to malaria, and the variation in these perceptions and experiences based on age and gender. Malaria, although a concern for the children, is simply one of many challenges they face in a context characterised by poverty, and structured risk to poor health outcomes. These barriers, along with the other health concerns expressed by the children, receive little attention from informal and organised networks of support, which results in the children bearing a disproportionate burden of social suffering. Insight into structural violence is gained through interviews with NGOs who have or are currently working with child headed households. These interviews illustrate how larger socio-political and economic forces shape the lived reality of the children. Additionally, interviews with community members who offer support to the children illustrate how social ideologies affect local level perceptions and responses to child headed households.

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CHAPTER ONE: INTRODUCTION



Figure 1.1 Rwandan Rural Landscape. Photo: Michelle Hardy August 2008

1.1 Research Topic

There are an estimated 290,000 children in Rwanda who have been orphaned because of civil unrest, genocide and AIDS, and who are living without an adult caregiver (UNICEF 2006:36). The country has neither the infrastructure nor the resources to provide care for these children; consequently, there are approximately 42,000 households headed by children (UNICEF). In addition, malaria transmission is increasing in Rwanda, due to increased chloroquine resistance, higher population density and movement, and an increase in breeding areas for mosquitoes due to changes in human economic activities (President's Malaria Initiative 2007:6-7). My research, based on qualitative methodology, examines the health concerns among children living in child headed households (CHH) in rural Rwanda. In particular, the research examines the children's perspectives of malaria and some issues affecting their understanding and susceptibility, as well as access to treatment and support.

1.2 Context

Children in CHH in rural Rwanda face a number of health challenges from preventable or treatable diseases, including malaria and HIV/AIDS. Although there is a plethora of literature on research among children regarding HIV/AIDS, malaria in

Rwanda has not received as much attention. Furthermore, although many of the children in CHH are orphans due to AIDS, malaria remains the principal cause of morbidity and death in Rwanda, and is responsible for close to 50% of hospital outpatient services (President's Malaria Initiative 2007; Rwanda Development Gateway 2007). Although some of the children within CHH may be at risk to HIV/AIDS due to sexual activity, sexual exploitation, or may already be HIV positive, all members of CHH are confronted with the daily threat of malaria. In fact, the majority of Rwandan children experience a malaria episode at least once per year, which incapacitates them for an average of eight days (President's Malaria Initiative 2007:8). A case study conducted in 2005 that focused on households that did have an adult caregiver indicated that only 12.3% of children received treatment for malaria, and under 6% were given the recommended drug. Prevention in the form of insecticide treated bed nets is low, because few children use them (President's Malaria Initiative 2007:7-8). As is common in development work, intervention has focused on inadequate resources and lack of education regarding transmission and treatment. Current interventions in Rwanda include mosquito bed net distribution, educating the public on treating the nets with insecticide and providing subsidized medical treatment through community based services (President's Malaria Initiative 2007; Rwanda Development Gateway 2007; UNICEF 2004).

1.3 Research Objective

The objective of this research is to examine perspectives of malaria among rural Rwandan children in CHH, and situate these perspectives among their other health concerns. Critical theory informs my approach, and in particular, literature on structural violence (Farmer 1999; 2005), social suffering (Kleinman et al. 1997), anthropological interest in children (Scheper-Hughes and Sargent 1998; Schwartzman 2001; Stephens

1995) and feminist standpoint theory (Haraway 1997; Harding 2004). These theoretical paradigms allow for a critical examination of the role of society in shaping the reality of children in CHH, as well as offering insight into the agency of children in transforming their lived experience. Specifically, based upon interviews with children in CHH, I analyse the children's ideas about malaria and their experiences of the disease.

Interviews with non-governmental organisations (NGOs) addressing health concerns among CHH provide an opportunity to analyse whether children's ideas are considered in program delivery, as well as the type of support available to the children. Community members who are neighbours of CHH were also interviewed in order to analyse how the social location of CHH affects the children's experiences of malaria, as well as providing an understanding of the support networks available to the children. The information collected from these interviews illustrates the societal structures that contribute to the poor health outcomes of the CHH as well as providing insight into the agency of children and the sources of support they have to address their health concerns.

1.4 Research Questions

The following research questions provide the framework for this project.

- What are the perceptions and experiences of children living in child headed households regarding malaria, and how do these perceptions and experiences compare to their other health concerns?
- How does poverty shape the children's understanding, experience and response to malaria, and how do these understandings, experiences and responses vary according to age and gender?

- To what extent do local NGO health programs working in rural areas in the South Province¹ draw upon and incorporate children's perspectives and concerns about malaria?
- What are the perceptions of community members of child headed households, and how do they respond to those households that live in their community?

1.5 Literature Review

I have found little ethnographic research specifically focusing on vulnerable children and health in Rwanda. Most information on the vulnerability of orphans living in CHH in Rwanda is found in studies affiliated with development organisations or funding agencies, although there are some descriptive studies published in peer-reviewed journals. These studies broadly examine educational, economic, health, and psychosocial measures of the well-being of the orphans, with the intent of improving development initiatives aimed at assisting the CHH. The relevant literature that I have accessed regarding health-care among vulnerable children is summarized under the following topics: (1) the health of orphans in child headed households, (2) current interventions with CHH, and (3) impoverished children's perspectives on illness and disease causation.

1.5.1 The Health of Orphans in Child Headed Households

1.5.1.1 Poverty

Rwanda has been characterised as “both the least urbanized and the poorest country in the world” (Sommers 2006:84). Eighty-six percent of Rwanda's population relies on subsistence agriculture, and lives in poverty (Sommers 2006:84). Several studies by development organisations demonstrate that orphans living in CHH are particularly vulnerable and at risk to poor health outcomes. All these studies stated that

¹ The actual name given to one of Rwanda's provinces.

most Rwandan CHH live in extreme poverty (ACORD 2001:2; Boris et al. 2006:592-594; Veale et al. 2001:iii). A nation-wide study involving 1% of the CHH in Rwanda (ACORD 2001:2) indicated that most orphans rely primarily on subsistence agriculture. Many of these households own less than one hectare of land or no land at all, forcing some of them to work as labourers. In Uganda, a country with similar impoverished conditions, after parental deaths the health of orphans often deteriorates due to poor nutrition and increased workloads (Oleke et al. 2006:281-282). This study points out that economic constraints appear to underlie the vulnerability of orphans in almost every respect. Poverty inhibits people from integrating orphans into their households through adoption or fostering, it places enormous workloads on CHH, it leads to discrimination and neglect, it exacerbates conflicts over property ownership, it leads to sexual exploitation of female orphans, it results in inadequate food and clothing, and it limits the orphan's access to schooling. Studies in Rwanda indicate that the CHH lack financial means to access health treatment, even though they are often sick due to malnutrition and overwork (ACORD 2001:5; Human Rights Watch 2003). In the nation-wide ACORD study, children surveyed stated that health was the third most important issue for them, after food and clothing needs (ACORD 2001:3).

1.5.1.2 Age

A number of studies examined differential health outcomes among children based on age. Boris et al. (2006) found that children in CHH under the age of five are particularly vulnerable to poor health outcomes. The operational plan of the President's Malaria Initiative (2007:7-8), funded by USAID, indicates that malaria is the leading cause of death for children under the age of five in Rwanda. Other studies, while not based in Rwanda, provide information from which to draw inferences about the particular

vulnerability of young children in CHH. Research done in northern Uganda among CHH found that young children were often left at home with little to eat while their older siblings spent their days working in the fields (Oleke et al. 2006:275). Literature also indicates that young children's health is at risk simply because they may not yet have acquired knowledge on how to maintain good health. In a study examining children's understandings of health and illness in South Africa, nine-year old children were able to identify objective symptoms of illness and to articulate preventative measures for illness, while five year old children were not able to do so (Peltzer and Promtussananon 2003). Besides lacking health knowledge, young children may practice limited preventative measures for infectious disease. In a randomized controlled trial in western Kenya on permethrin-treated bed net use, children under five years of age tended not to use bed nets (Alaii et al. 2003). The vulnerability of young children and the degree to which they are dependent on their older siblings is evident.

There are also other ways in which age may affect health outcomes. Based on my own experience in Rwanda, the age of the head of the household at the time of parental death or absence influences how much these older children have learned about caring for their younger siblings. This is then evident in the health outcomes of the younger siblings. Literature also states that it is the head of the household, the oldest child, who is most likely to drop out of school to support their younger siblings (ACORD 2001:5; Veale et al. 2001:xv). Therefore, the younger school-aged siblings usually have more of a chance to stay in school where they may have access to health education. These children also report that they are able to form friendships there, gaining a support network (Veale et al. 2001:xv). The results of these studies indicate that research on the

health of CHH needs to take into consideration the age composition of the household and access to different sources of information on health and supportive relationships.

1.5.1.3 Gender

A number of studies investigate the vulnerability of female children and consistently indicate that their health is particularly precarious. Female orphans are susceptible to sexual abuse by male community members (ACORD 2001; Human Rights Watch 2003; Oleke et al. 2006; Snider and Dawes 2006; Veale et al. 2001). Consequently, these girls may then be confronted with health challenges related to sexual and reproductive health in a context that often does not provide accessible and adequate health care. Studies in other low-income contexts have examined how gender inequalities lead to higher mortality of female children (Arokiasamy 2004; Hill and Upchurch 1995). Research in the northern and north-central regions of India indicate that girls experience neglect through decreased access to immunization, which increases with successive female births (Arokiasamy 2004). To date I have found limited literature on the dynamics of gender inequalities among siblings in CHH. However, one study conducted among 89 households in Rwanda indicated that young orphans with a male head of the household were less likely to have received adequate immunization (Boris et al. 2006:597). The study suggested that this might be because young men are not traditionally the primary caregivers of younger children in Rwanda. In addition, from my own experience in Rwanda and from current literature, there are some social practices that favour boys over girls (Boris et al. 2006:587; de Lame 2005:39-40). CHH may follow these same patterns in their interactions at home, which may result in unequal health outcomes.

1.5.1.4 Community Support

Due to the high prevalence of orphans in Rwanda, a number of studies have examined the local community response to these children. Many of the studies have indicated that the CHH are marginalized from community structures and from protective adult and family care systems (ACORD 2001; Veale et al. 2001), and have discussed the resulting implications for the children's health (Snider and Dawes 2006; Thurman et al. 2006). One study concluded that social marginalization results in decreased access to community based knowledge of illness causation, practical assistance, and mentoring that is needed for the CHH's physical, mental and psychological well-being (Snider and Dawes 2006:26-29). However, it did not acknowledge that marginalization is a multidimensional construct, making it difficult to measure. Another study was more explicit in how marginalization was determined (Thurman et al. 2006). This study used a social marginalization scale that included six items, which the children responded to on a five-point scale (strongly agree-disagree using pictorials) of felt and enacted stigma. Over 85% of CHH in the study reported feeling rejected by their communities in some way (Thurman et al. 2006:221-222, 226).²

Much of the literature provided analysis on the underlying reasons for social stigma against Rwandan orphans. Although the country has remained relatively peaceful since the 1994 genocide, post-conflict social relations indicate the prevalence of distrust and suspicion in communities, dissuading people from assisting the CHH (Thurman et al. 2006:226; Veale et al 2001: xiii). Furthermore, the particular reasons underlying the

² The studies that discussed marginalisation are pointing to the children's lack of community support. While some studies might attempt to measure marginalisation by studying the density and reach of children's social networks, Broadhead et al. (1983:529) state that the quantity of contacts or friends is not significantly related to well-being. Rather, the quality of social support is a stronger predictor of health outcomes. Furthermore, Cook et al. (2003:93) state that children in high-risk environments are able to cope with stress more effectively when they have a significant relationship with one or more nurturing and helpful adults.

death of the children's parents contribute to the extreme marginalization the children report. Social stigma surrounding AIDS is still prevalent in Africa. Those children who have lost their parents due to AIDS, or who have a surviving parent in prison on charges of genocide, experience a greater amount of marginalization (Snider and Dawes 2006:26; Veale et al 2001:xii). As children have been left on their own, they have developed new coping strategies to deal with their numerous challenges. Although the literature does not give examples of these strategies, the research states that the strategies are contrary to traditional views on children, and consequently place the children in conflict with social norms and values (Veale et al 2001:xi). Lastly, due to the civil war and genocide in Rwanda, community and extended family structures have been decimated, resulting in a lack of community capacity to support the CHH (Veale et al 2001:xi). This capacity is also limited by the level of poverty within Rwanda and has resulted in people placing the responsibility for the CHH on NGOs or on local authorities (ACORD 2001:2).

1.5.2 Current Interventions with CHH

Like many other low-income countries, Rwanda does not have the economic resources to provide welfare policies for the poor. Rwandan policy on CHH indicates the nation's awareness of the vulnerability of the orphans, and cites the country's commitment to implementing laws and policies so that orphans are assured access to health services (MINALOC 2003). However, this document acknowledges the lack of economic and logistical resources to implement these policies and states that non-governmental, community-based and faith-based organizations in Rwanda should continue to provide support for CHH. A public Rwandan database that provides the contact information of aid organisations in the country lists close to three hundred of them (Rwandan Development Gateway 2004). In fact, much of the research on Rwandan

CHH or programs aimed at assisting them has been funded by multilateral or bilateral agencies such as UNICEF, WHO and USAID. There is a plethora of literature outlining programs and health care initiatives for Rwandan CHH funded by these donors (ACORD 2001; CAREa; Human Rights Watch 2003; President's Malaria Initiative 2007; Roll Back Malaria Initiative; Thurman et al. 2006; UNICEF 2004, 2007; Veal et al. 2001; WHO 2004a, 2004b, 2005). However, the literature coming from these organisations reflects the interests of the donors, and presents data that justifies their program interests. These NGOs do not appear to do research on children's concerns that might be outside of the organisation's program interests.

A study conducted by World Vision and UNICEF in 1998 illustrates the significance of the NGO presence in the lives of Rwandan CHH (cited in Veale et al. 2001:10-11). During a social mapping exercise done with CHH, children indicated that NGOs were their largest source of support. UNICEF (2007) states that NGOs are continuing to increase their programs in order to provide essential protection to children who have been affected by AIDS in Africa. However, findings from one study indicated that although NGO intervention seems to have the potential for strengthening the coping capacities of CHH, the sustainability of their programs is doubtful (Luzze 2002). In addition, this study suggested that NGO presence weakened community philanthropic initiatives towards CHH. Some NGOs working directly with CHH do attempt to draw from local community support through their adult-mentorship program (CAREb; FHI 2001). However, their literature does not indicate whether the adult volunteers receive

incentives,³ and although CARE states that the mentorship is sustainable after the CARE program leaves the area, so far I have not been able to find research that supports this.

Some NGOs in Rwanda are focusing on prevention and treatment of malaria, responding to studies indicating that fewer than 13% of children use insecticide treated bed nets, and even fewer receive treatment (President's Malaria Initiative 2007:7-8). There is also some evidence within the literature that NGOs in Africa are soliciting children's perspectives on AIDS (Henderson 2006:309; Manyau 1998:69-75; Singhal and Howard 2003; UN 2003). However, it appears that the majority of initiatives focused on health care or malaria prevention in Rwanda (President's Malaria Initiative 2007; Rwanda Development Gateway 2007; UNICEF 2004; WHO 2004a) do not solicit children's perspectives; they simply want to make intervention available. The focus of aid organisations is on implementing biomedical interventions without analysis of local beliefs and practices. As a result, these interventions might not be effective, because they do not take into consideration what the children consider are barriers to their health, and their particular vulnerability.

1.5.3 Impoverished Children's Perspectives on Illness & Disease Causation

Currently, I have not found literature that focuses specifically on Rwandan children's perspectives on health or disease. Although there is some focus on children's perspectives regarding health in North America and England, there has been little published research done on impoverished children's perspectives on their health and illness causation. Mitchell (2006a) worked with poor children in an urban neighbourhood in the Philippines, who face a complex and precarious landscape similar to that of the CHH in Rwanda. These children are also confronted with multigenerational

³ However, when I worked in Rwanda from 1999-2002, adult mentors received incentives in the form of such items as hoes and cooking implements.

poverty, chronic hunger and social marginalization. Using creative, child-centered approaches such as photo-elicitation, drawing and body mapping to access the children's ideas about their body, illness and health, the study details how the children drew from the dominant biomedical discourse taught in school, but merged this knowledge with their own feelings and experience of poverty, as well as other culturally significant explanations about health and illness. For example, the children linked their health concerns to their impoverished neighbourhood strewn with garbage, and to the local beliefs of dangerous spirits that roamed through their community. A similar finding was outlined in a study based in western Kenya among Luo children (Geissler 1998). The Luo children drew from socially construed and biomedical notions when depicting ideas about worms in the body. This literature is of relevance to this study on CHH in Rwanda because it illustrates how children's ideas about health are drawn from various domains of knowledge in order to give meaning to their health experiences. To supplement the limited work detailing impoverished children's ideas about illness, some inferences may be drawn from work with adults. One study (Green 1999) uses a number of case studies from various countries in Africa to illustrate the variety of perspectives on malaria infection. These perspectives draw from biomedical theories as well as local interpretations of germs, pollution and environmental dangers. Another research project in Ghana (Ahorlu et al. 1997) examining malaria prevention and treatment found that the words for "fever" and "malaria" represented the same thing and were used interchangeably. Although people identified the major symptoms of malaria, ideas of malaria transmission were variable. This literature portrays the value of accessing Rwandan children's knowledge of malaria in order to understand how it intersects with biomedical notions of malaria conveyed through NGOs and schools. Furthermore, in

order to understand the CHH's perspectives on health and illness causation, I wanted to find out how their perspectives are "shaped by their lived experience of place, material organisation of social life, by history, as well as by local meanings, social relationships and the corporeality of their own bodies" (Mitchell 2006a:337).

Children's and adults' perspectives on health may be different, and these differences might indicate whether the children actually benefit from health care initiatives (Mitchell 2006a:332). The research project based among urban children in the Philippines (Mitchell 2006a) points out that the children in the study talked about health concerns that adults deemed as inconsequential such as cut knees, sore stomachs, and toothaches. In fact, children did not mention national public health concerns of tuberculosis, dengue fever, or AIDS (Mitchell 2006a:358). Consequently, because children's health concerns do not reflect those of adults or the national health initiatives, children have to figure out how to deal with their health concerns on their own. This has direct implications for work among CHH in Rwanda. It suggests that national and local level initiatives aimed at health care and infectious disease among CHH in Rwanda might be overlooking the health concerns of the children. However, the lack of children's observations on infectious disease, such as malaria, does not negate the necessity or the urgency of dealing with it.

Although children's perspectives are rarely solicited, they are valuable and are important for health care initiatives (Robottom and Colquhoun 1992). Children's involvement in making decisions that affect their health outcomes may lead to improved interventions (Ivan-Smith and Johnson 1998; Obeng 1998; Otaala 1998). Many current interventions are based on notions of self-care, and independent responsibility for health. However, for many impoverished children, this is often difficult to achieve due to their

subservient positions and insufficient diets (Mitchell 2006a:365). Literature from an ethnographic based study on children from low-income families living in an inner-city neighbourhood in Canada discussed the tension that children might experience when they view their social environment as inhibiting good health outcomes (Irwin et al. 2006). For example, many of the children in this study stated that physical activity led to good health outcomes. However, these children said they felt unsafe in their community and would not play outside, or the researchers noted that the children simply had little opportunity to get outside. A careful examination of children's perspectives illustrates their vulnerability and the factors that limit their capacity to avoid illness or injury (Mitchell 2006a:366).

Initiatives that consider children's perspectives demonstrate an appreciation of the voice of children, and for their value and worth as contributing members to society. It also allows for identification of those factors that inhibit the children from good health outcomes and provides a greater understanding of the social and material world of the children. For example, NGO initiatives that deliver broadly implemented malaria prevention programs may not consider how local beliefs, combined with an impoverished home environment, inhibit CHH from using a mosquito net. A child-based study on illness causation can highlight the complex relationship between knowledge and context, the interplay of particular realities and ascribed meaning.

1.6 Conceptual Framework

This thesis draws from anthropological theories that seek to understand the underlying structures that lead to disproportionate suffering among vulnerable population groups. Drawing from the domain of critical theory, I situate the children's own ideas about illness causation within societal structures that result in social suffering. Of

particular relevance to my research is the work of Paul Farmer (1999; 2005), who implicates these structures in unequal health outcomes for the poor. I also rely on literature that explores how individual problems are linked with different forms of social suffering (Kleinman et al. 1997). My research draws from anthropological interest in children (James et al. 1998; Scheper-Hughes and Sargent 1998; Schwartzman 2001; Stephens 1995) and research on children's perspectives about their health and illness causation (Geissler 1998; Irwin et al. 2006; Mitchell 2006a). In addition, feminist standpoint theory (Haraway 1997; Harding 2004) guides my understanding of the social position and the distinct perspective of CHH and the children within these households.

Critical theory is a tradition that originated in the Frankfurt School and derives from Max Horkheimer, Theodor Adorno, and Herbert Marcuse's philosophical and social analysis of the work of Marx, Kant, Hegel, and Weber. The three were influenced by the devastations of World War I and by the empirical practices of American social science research, which they challenged along with orthodox Marxism (Kincheloe & McLaren 2000:279-280). Unlike positivism, which emphasizes the validity and reliability of data and measurement, critical theory recognizes historical situatedness and the social construction of experience (Lincoln & Guba 2000:170). Critical theory considers reality to be shaped by social, political, cultural, economic, ethnic and gender factors (Guba & Lincoln 1998:203). These factors influence the way that society is organised, to the detriment of some members of society. Critical theory points out how powerful societal structures result in injustice and inequality (Kincheloe and McLaren 2000; Lincoln and Guba 2000; Singer et al. 1998). For example, neo-liberal economics has restricted access to malaria prevention and treatment to those who can afford it. This has resulted in the

eradication of malaria in the western hemisphere and higher incidences of malaria in low-income contexts like Rwanda (Farmer 1999:40-42; Holtz and Kachur 2004).

Critical theory within medical anthropology has informed Paul Farmer's (1999; 2005) approach to health and inequality. He has examined how social structures and the policies and practices of economic, political, legal, religious and social institutions result in structural violence. Structural violence (Galtung 1969) refers to the systematic and unequal distribution of resources by social structures or social institutions based on factors such as ethnicity, gender or socioeconomic status (Farmer 1999). The ensuing economic and health disparities lead to reduced life spans for those prevented from meeting their basic needs. The resulting individual and collective distress is referred to as social suffering (Kleinman et al. 1997:ix).

The critical theory approach is especially valuable in my own research as it provides a means to examine how social structures inhibit collective and individual agency, leading to social suffering and preventing CHH from accessing resources to maintain or improve their health and reduce disease. Specifically, it provides the framework from which to examine how the health outcomes of CHH and their perceptions of malaria are associated with a society fractured by ethnic tension and extreme poverty (Thurman et al. 2006; Veale et al. 2001). The ongoing ethnic tension in Rwanda is the result of a number of factors, such as the historical colonial experience that gave power to certain ethnic groups, as well as the inability of the Rwandan nation to overcome the impact of colonization after independence (Mamdani 2001). Although the nation has remained relatively peaceful since the 1994 genocide, ethnic tension has resulted in societal distrust, leading to a lack of communal involvement in the care of CHH (Thurman et al. 2006; Veale et al. 2001). The health challenges of the children

within CHH and Rwandan social problems are intertwined - “suffering is a social experience” (Kleinman et al. 1997:ix).

The main concepts that emerge from these approaches include a concern with issues of power and inequality (Guba & Lincoln 1998:211; Kincheloe & McLaren 2000:281). Power, the ability to either constrain or propel human action, is a basic component of human existence (Wolf 1999). On a global scale, hegemonic control is evident in the neo-colonial practices of capitalist nations toward the African continent. African nations, such as Rwanda, are managed according to the development agendas of neo-liberal economics and multilateral agencies such as the United Nations and the World Bank (Lins Ribeiro 2006:368; see also Crewe and Harrison 1998; Uvin 1998). These funding agencies determine what type of aid is offered to low-income countries and how aid money is to be spent (Nolan 2002:60), often resulting in sporadic and unequal assistance to CHH (Veale et al. 2001:xiv). The local and specific effects of power frame my research. In particular, my research identifies structural inequalities such as poverty, unequal access to resources, and gender discrimination, and their effects on children’s perspectives on malaria, their experiences of the disease, as well as access to support and care. In addition, I examine how power is manifested in perspectives on childhood, resulting in neglect of the particular health concerns of children in CHH.

Studies on childhood in anthropology have pointed out how the institution of childhood varies across societies, as does the meaning attached to childhood (James and Prout 1990:3-4, 7). My research draws upon current anthropological perspectives on children when examining the agency of children within CHH. Childhood studies within anthropology have recognised that children are not passive victims to various forms of domination; rather, they are actively involved in resisting and manipulating power

(Caputo 2001). This recognition grew out of historical perspectives that had focused on the “social developing child” (James et al. 1998:178). Children had been of interest in research because they represented future adults within society. However, their participation and contribution as children within society was disregarded (Caputo 2001:179). Emergent anthropological studies on children have been instrumental in highlighting children’s creativity and competency as social actors in numerous social and cultural contexts, and have reframed theoretical discourse on childhood (Caputo 2001:179; see also James et al. 1998; Schwartzman 2001; Scheper-Hughes and Sargent 1998; Stephens 1995). This current perspective has legitimized children and childhood as subjects worthy of analysis. Like other members of their society, children are affected by and participate within the “global political-economic structures and everyday practices embedded in the micro-level interactions of local cultures” (Scheper-Hughes and Sargent 1998:2). Ethnicity, gender and class, as well as the larger societal processes of colonialism, economics and politics, shape and construct childhood (Stephens 1995:4-7). This approach situates children’s perspectives on illness causation within larger historical, social, and material contexts,⁴ which have influenced both their ideas and the varied responses to these ideas. The children’s thoughts and ideas about illness causation, and in particular malaria, reflect their lived experience in a context of poverty where they are increasingly responsible for carrying “the costs of social reproduction under global capitalism” (Katz 2004:182; see also Mitchell 2006a).

Feminist standpoint theory (Haraway 1997; Harding 2004) provides a theoretical framework from which to examine the positionality of households within society and children within the household. Donna Haraway (1997:304, n. 32) describes standpoints

⁴ The information pertaining to the historical, social and material contexts are drawn from a literature review.

as “cognitive-emotional-political achievements, crafted out of located social-historical-bodily experience - itself always constituted through fraught, noninnocent, discursive, material, collective practices.” Standpoint theory affirms the unique perspective of the individual, which is shaped by their particular place in society. CHH, marginalised and subordinate within their communities due to societal stigma (Thurman et al. 2006; Veale et al. 2001), offer a particular vantage point from which to comment. In addition, households may include hierarchies based on age and gender differences, leading to differential health outcomes within the household (Helleiner 1999:33; see also Barrett et al. 2006:201; UNICEF 2004:1). Therefore, the differentially situated knowledges of the children within the households offer distinctive and valuable comments on illness causation, that contrast with adult-oriented ideas. Those in positions of power may not see the factors that contribute to the children’s particular experience of malaria. Although Sandra Harding (2004), a proponent of standpoint theory, believes that the lives of the marginalized can provide a more objective view than the perspective of those in positions of power, children in powerless positions may echo the voice of the powerful. Their voice may simply replicate the dominant discourse (Gaventa and Cornwall 2004:326). Insight is required in listening to the children, and in recognizing what contributes to their perspective.⁵

Feminist standpoint theory also recognizes that the researcher’s social experience shapes their knowledge and perspective. I acknowledge my own position and that which informs my critical gaze. As a student within anthropology, I am still growing in my awareness of the wide anthropological horizon that serves to inform my theoretical

⁵ Although a critical theory approach would seek to empower CHH by assisting them in a critical examination of local and macro-level social structures of power (Kincheloe & McLaren 2000:283), due to the limited scope of my research, I did not focus on attempting to transform the critical consciousness of my research participants.

orientation and enrich my understanding and analysis. I am also aware, as I reflect back on the situations, positions, and perspectives of the children within CHH in Rwanda, that my privileged position as a white North American from a middle-class background brought a variety of biases and blinders into this research project. However, I draw inspiration from Virginia L. Oleson (2000:229), who points out that our “cultural self” (Scheper-Hughes 1992), is not always a problematic issue, but rather can serve as a resource in guiding research design, data gathering and analysis. As a practical example of this, due to my previous experience in development work in Rwanda from 1999-2002, I am acutely aware of the power differential that still exists in Rwanda, evident in the interactions between people from affluent contexts, such as myself, and Rwandans. However, this experience in Rwanda has also enriched my critical understanding of the political nature of development work, and the enormous power Europe and North America have over the health outcomes of some of the world’s most vulnerable population groups. It is also for this reason that I am drawn to critical theory’s analysis and challenge of dominant power holders.

1.7 Terminology

This research project centers on children’s perceptions and experiences in regards to malaria, and compares them to their other health concerns. In the literature reviewed for this thesis, malaria is commonly referred to as a “disease.” An ecological or biomedical perspective considers disease to be one possible outcome of the interaction between a host and a pathogen or germ (Brown 1998b:77). The biomedical perspective is that malaria is contracted through mosquitoes that are carrying the parasite (Sherman 2006). However, cultural definitions of disease vary. In this research I explore what the children attribute as the causes of malaria or their other health concerns. This then allows

for examination of the larger political-economic processes, as well as the local level factors that influence these perspectives.

Additionally, I examine what the children say about their illness experiences. I use “illness” in association with “being sick.” “Disease” and “illness” are commonly distinguished, with “illness” representing an individual’s perceptions and experiences of sickness or disease (Brown 1998a:108). I rely on illness as a means to incorporate the social dimensions of being sick into discussions with the research participants.

Lastly, in order to define health, I draw upon the World Health Organization’s (WHO 2009) definition, which states that “health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” This definition suggests that well-being is characterized by physical and psychosocial aspects, and not simply the absence of disease. However, I am aware that the research participants may define health differently. For example, they might include worries about their future, such as getting a job. Openness to their interpretations allows for deeper understanding of their ideas about health and illness.

1.8 Significance

The importance of this research lies in its ability to contribute to literature on the vulnerability of impoverished children through its analysis of the specific factors that affect the health outcomes of members within a particular group of marginalized children. With its specific focus on rural CHH in Rwanda, this thesis builds on existing literature that identifies how poverty specifically restricts these children’s access to knowledge-based resources and prevention measures for malaria. In addition, although there has been some research on how patterns of vulnerability, such as age and gender, affect health outcomes of children, there has been little research on how these factors are

manifested in the health outcomes within households headed by children. This research builds on existing literature on the particular vulnerability of younger orphans through examination of what children over six years of age report, and what older orphans say about the health of their younger siblings. Additionally, my research points out how social patterns regarding gender restrict or enable access to health care and other forms of support for the CHH.

Literature from many NGOs detailing their interventions aimed at CHH in Rwanda suggests they offer generalised programs. Whether these programs effectively address the health concerns of all the children in the household is addressed in Chapters Four and Five. This research contributes to the existing literature by examining how effective the interventions are in terms of addressing the health concerns of the children and the barriers that affect their health. Analysis of the information gained from interviews with NGOs regarding their funding sources, and the influence of these bilateral and multilateral donors on program direction and parameters, contributes to discussions on the influence of neo-liberal economics to the health outcomes of the children, as well as if the health programs encourage sustainable community support networks. In addition, considering that CHH are situated in a context where they may be isolated from community support, the interviews with community members provide insight into how Rwandan ideas about children or gender help or hinder CHH's practices around malaria. This has implications for the development and improvement of current interventions that are focused on addressing the children's health needs by identifying those factors that contribute to the depth of poverty, stigma and the higher burden of illness in CHH.

Lastly, in a context where impoverished CHH are responsible for their own well-being, this research indicates how children are acquiring health knowledge. The CHH represent a new social grouping in a society that habitually cared for extended family members (Cook et al. 2003:89). Some CHH are faced with marginalization from their communities and relatives. My research into the children's sources of support indicates that new types of social relationships are being formed. In addition, by utilising a child-based approach that elicits the perspective of CHH, this study allows for a new way to understand health issues by providing analysis of the children's own health concerns, their health care strategies and their conceptions of illness causation. My previous experience in Rwanda and literature examining ideas about malaria in Africa (Ahorlu et al. 1997) indicate that "fever" and malaria represent the same thing, and are often used interchangeably. This may be based on a particular understanding of the cause(s) of the disease that was explored within the research process. Research into children's ideas and definitions of malaria builds upon Ahorlu et al.'s (1997) research and provides additional insight into the particular ways that they identify their ailments and how this terminology corresponds to that used by NGOs. This is of particular relevance in determining how much of a concern malaria is to the children compared to their other health concerns, and if their health concerns are being addressed. In addition, analysis of the children's perspectives indicates how their knowledge about malaria and prevention measures differs from or overlaps with the biomedical-based approach adopted by NGOs in their health programs, and whether CHH benefit from initiatives to improve their wellbeing.

1.9 Overview of Thesis

In Chapter Two, *Methods*, I describe the area where this research was conducted, discuss issues with using a translator and how these were dealt with, and describe the

methods used in recruitment of the research participants. I discuss the methodological approach that characterises this research project - qualitative critical inquiry, which draws upon grounded theory. I describe the surveys and open-ended, semi-structured interviews that were used to gather data with the three different groups of participants: CHH, NGOs and community members. Lastly, I outline the methods that were used to analyse the surveys and the narrative data.

Chapter Three, *Household Characteristics*, outlines the findings from the household surveys conducted with the CHH. The results serve to characterise the poverty found within the sample. I include photographs and narratives, drawn from my observations and interactions with various households, to provide snapshots of particular characteristics of these CHH. This chapter serves to introduce the households and illustrates the barriers to the children's health seeking behaviour.

Chapter Four, *NGO and Community Perceptions and Responses to Child Headed Households*, discusses the research findings from the interviews with the NGOs and the community members. The thematic emphasis serves to illustrate the large scale and the local-level perceptions of CHH and the various responses to this social group in rural Rwanda.

Chapter Five, *Children's Perspectives*, is a presentation of research findings from the interviews with the CHH. The results are organised around the first two research questions, focussing on what the children said about malaria, how poverty shapes their ideas and experiences, and the influence of age and gender. Within each category, I identify the themes that emerged from the data.

In Chapter Six, *Analysis*, I discuss the findings from the interviews with the CHH, NGOs, and the community members. Using a critical theoretical framework to guide the

discussion, I draw from the body of existing literature and the relevant theories, to support the argument that I present.

Chapter Seven, *Conclusion*, provides a summary of the project's results and discussion. I include a synopsis of the important findings and suggest how the findings of this research can contribute to the literature, as well as to various efforts aimed at assisting children living in CHH.

CHAPTER TWO: METHODS



Figure 2.1 Interview Activities at Household E.⁶ Photo: Michelle Hardy July 2008

In this chapter, I begin by providing a descriptive overview of the research area in which this project took place. Next, I discuss issues regarding the use of a translator and how I dealt with these concerns. I then describe recruitment of the CHH, NGOs and community members, and provide a brief description of the characteristics of each group. I move on to discuss and justify the methods that were used when conducting research with each group. The methods are derived from the critical framework on which this research is based and include household surveys and semi-structured ethnographic interviews. Lastly, I include an overview of the methods I used to analyze the resulting data.

2.1 Research Area

Rwanda is a small country in East-Central Africa, burdened with a conflict-ridden history of colonialism, ethnic divide, extreme poverty, infectious disease, and chronic malnutrition. The densely populated country relies primarily on subsistence agriculture

⁶ I gave the households letters to identify them in my field notes. See Appendix 1 for a brief description of each household.

(Sommers 2006:84), and perhaps is best known for the genocide that occurred over a span of 100 days in 1994. Today, Rwanda continues to rely heavily on food imports, outside aid, and the services from NGOs (de Lame 2005). However, after 14 years of relative stability, Rwanda is rapidly gaining a reputation as a safe tourist destination. A Rwandan brochure for tourists claims that Kigali, the capital, is “among the safest and friendliest of African capitals” (Rwanda Tour Guide Map). The capital serves as a base for foreigners dropping in for day excursions to the Virunga Mountains to view the mountain gorillas. Kigali is also the hub for the large number of NGOs based in Rwanda. Many of the city’s restaurants and shops cater to the expatriate population, at prices far beyond what the average Rwandan could afford.⁷ Beyond Kigali’s boundaries, and the city streets packed with vehicles bearing the logos of the multitude of NGOs, is where the majority of Rwanda’s population resides.

Rwanda’s population of 8.3 million inhabits an area just over 26,338 sq. km (Encyclopedia of the Nations 2007). Rwanda is commonly referred to as “the land of a thousand hills” or the “Switzerland of Africa” due to its hilly terrain. There are few villages in Rwanda, and the houses in the rural areas are scattered over the hillsides (de Lame 2005:12-13) among crops of bananas, maize and sorghum. It is in the rural areas outside of Kigali that the majority of Rwanda’s population lives (Sommers 2006:84), relying primarily on farming and raising some livestock. There is little land for grazing, and until recently, those with livestock would scatter them over the hillsides (de Lame 2005:126). A recent law forbids this, and people are now required to keep their livestock tied up, cutting grass themselves for feed. Rural households grow most of what they consume, such as sorghum, beans, potatoes, and bananas (de Lame 2005:249; Edge

⁷ A 1993 USAID study (cited in Uvin 1998:117) reported that 90 percent of the rural population (which accounts for 86 percent of the total population) was living below the poverty line.

2008:80). However, what is produced is not enough to adequately feed the household, nor does it provide the cash required by the state and its administration for such services as health care or education. Land scarcity has led people to grow crops that are consumed locally, and that can be easily sold at the local market. Therefore, although some of these crops, especially sorghum and bananas, may be considered cash crops, they rarely leave the local economy. Some families have been able to maintain coffee groves, which are harvested once a year. The limited sale of these crops brings in a little extra cash, which may be used to pay school fees or health coverage (de Lame 2005:42, 249-250).

The rural area is of particular interest to this study, not only because the majority of the population lives there, but because children living in rural areas are more likely to suffer from poor health due to geographic isolation, distance from health care centers and other forms of support, as well as their level of poverty.⁸ This research was conducted in the rural area outside one of the towns in the South Province of Rwanda. The South Province of Rwanda, composed of eight political districts, is 5701 sq. km, and has a population over two million, fifty-eight thousand people. The altitude of this mountainous region ranges from 1500 to 2800 m (Republic of Rwanda Southern Province 2007). Like other parts of the country, the region has two rainy seasons and average temperatures ranging from 16 to 26 degrees Celsius (Rwanda Tour Guide Map).

My previous work experience in the South Province was a significant factor in why I chose to conduct research with CHH living in the rural areas in this province. I

⁸ Depending on how poverty is measured, poverty may be more acute in urban areas, as people do not have access to land to grow food, and food is more expensive to buy. For those in rural areas, the minimum size of land to feed a family of five is 0.7 hectare (National Agricultural Commission cited in Uvin 1998:113). Due to land scarcity in Rwanda, many CHH own less than a hectare of land, or no land at all (ACORD 2001:2). Children in CHH in the research sample were asked during the household survey if they have enough land to grow food to provide for the household. Their responses are discussed at the end of this chapter and in chapter three.

have contacts in this area both among NGOs and among the Rwandan population, as well as a familiarity with the region. Additionally, although I do not have specific statistics on the number of orphans in this area, from my own work experience in this particular area from 1999-2002 I knew there had been a high number of CHH in the area.

Communication that I received from a local NGO working in the area while I was planning my research (personal communication,⁹ December 3, 2007) confirmed that there was still a high number of CHH in the area. I was based in a town centrally located in the province, which allowed me easy access to rural areas where literature (MARA ARMA 2002; President's Malaria Initiative 2007:7) indicated there was a prevalence of malaria. The town was also a convenient location for the many NGOs who work with rural CHH. Preliminary research and conversations with some of the NGOs prior to my departure for Rwanda indicated that they were addressing health issues such as HIV/AIDS and malaria, as well as primary health care.

2.2 Translator

Kinyarwanda is the national language of Rwanda, although French, and more recently, English, have been adopted as official languages and are taught in elementary and secondary school. From my previous experience in Rwanda I knew that people living in rural areas would primarily speak Kinyarwanda, and therefore I would need a translator for my interviews with CHH and community members. Finding a translator turned out to be a little more difficult than I had originally assumed. This was in part because of the nature of my research, which was situated in the rural areas of Rwanda. Most people who were available to translate were situated in the capital, Kigali. My first

⁹ Name withheld to ensure anonymity.

translator relocated herself from Kigali to the area I was in until she found a permanent job in Kigali. The second translator was from the area I was situated in.

Due to the on-going ethnic tension that permeates the Rwandan landscape, I was aware that the ethnicity of the translator might present a barrier in my interactions with research participants. However, there were no overt indications that it affected the research in the interviews with the children, community members or NGO staff.¹⁰

I was also aware that the gender of the translator might inhibit self-disclosure on the part of the children in CHH. In particular, I was sensitive to the older CHH, who might not feel comfortable discussing certain topics related to health in the presence of someone of the opposite sex. Unintentionally, it worked out that I was able to work with my female translator for most of the interviews with the households that were predominantly female, and with my male translator for those that were predominately male, or where there was an even split of males and females.

Having played “broken telephone” as a child, I am very aware that much is lost when messages are transmitted from one person to another. When these messages are additionally translated from one language to another, more may be lost. The issue of the accuracy of translation, and of translating the children’s words verbatim, was an ongoing concern. I tried to address this through repetition of questions at different points of the interview, phrased in different ways, and coming back to points I was unclear on in subsequent interviews. Accuracy of translation increased as the translator and myself became familiar with the children’s discourse. For example, I was able to identify to my second translator that I wanted him to distinguish between the word “fly” and the word “mosquito” when he translated for me. Initially, I caught myself addressing the

¹⁰ I only used my Rwandan translator one time with a NGO staff person.

translator, rather than speaking directly to the child. When I spoke to the translator, they would tend to generalise the child's statements and say "she said" or "he said", rather than translating verbatim. I found that this improved when I clarified that I wanted the children's words to be translated verbatim, and as I learned to address everything directly to the person I was interviewing.

Lastly, I was aware that the presence of yet another adult in the interview process with the children might add to the children's discomfort. However, both translators exhibited strong interpersonal skills in their interactions with the children, which assisted in this area.

2.3 Participants and Recruitment

2.3.1 Child Headed Households (CHH)

The primary focus of this research is to examine what children in CHH are saying about their health and about malaria. Research was conducted among fourteen CHH, with children and youth¹¹ between the ages of six to eighteen years.¹² In total, I talked to thirty-seven children. This sample size allowed me enough time with each child to talk with them about the details of their lives and their particular health concerns. The broad age range provided opportunity to examine the different understandings of malaria or health concerns of the children that may be related to age. There was only one child in a household who was younger than six years of age, and no questions were directed at him. However, his older sister did refer to him when she talked about health concerns within the household. In addition, I did find that some of the children close to six years of age

¹¹ For the sake of continuity (since the children and youth are commonly identified as children or CHH by community members and NGOs), I will refer to them as children throughout this thesis.

¹² Rwandan law defines a child as someone under 18 years of age (Onesphore Karuho, personal communication, October 9, 2006). At 18 years of age a person can vote, however, a person must be 21 years of age to get married.

were reluctant to talk to me. Some information was gained by asking their older siblings about the health of their younger brothers and sisters. As noted in the literature review, children below the age of five years are particularly vulnerable to malaria. This is one reason why I was interested in learning about the health of these younger children, in order to find out if malaria was a concern for them. Furthermore, young children in CHH are often susceptible to malnourishment due to neglect by older siblings. Literature had also indicated that children between the ages of nine and twelve years of age may still be attending school where they may have access to sources of information on malaria and health. These children, because of their contacts at school, may also have a broader social support network than their older siblings who spend their days cultivating in the fields. Therefore, interviewing this broad age range allowed me to examine variation within the household in regards to access to food, sources of information on health, and support networks.

I used purposeful sampling (Maxwell 2005:88-89) when recruiting the CHH.

Initially I had planned on selecting households

- of double orphans (no adult caregiver in home),
- where the oldest child is 18 years of age or younger,
- with gender diversity in the household, and
- who have participated in a NGO malaria intervention program.

This would allow me to gain information on how children were addressing their health concerns without an adult caregiver, as well as an opportunity to examine their perceptions of NGO assistance and community levels of support. The gender diversity would allow me to examine gender differences within the household in regards to ideas about malaria and particular health concerns. The NGO criterion allowed me to make

referrals to the NGO (with the consent of the children) in the event that there were immediate shelter or health needs of the CHH. Additionally, I planned to examine the types of health programs the NGOs offer, therefore, recruiting CHH who have participated in their programs would result in data applicable to this research.

Originally, the CHH were to be recruited with the assistance of two NGOs with whom I was in contact and who were working with CHH in the research area. However, when I arrived in Rwanda, I discovered that one of the NGOs was no longer running a program focused on CHH. The other NGO was still working with CHH, but the CHH were participants in a larger program aimed at orphans and vulnerable children (OVCs). Unless I moved my research area to another part of Rwanda where the NGO reported that there was a large number of CHH, I would have to change my criteria.¹³ Since I was limited by time, and considering I had a number of contacts and familiarity with the area that I had planned to conduct research in, I decided to remain there, and change my criteria. I recruited households

- of double orphans (no adult caregiver in home),
- where the oldest child is 18 years of age or younger, and
- who have contact with an NGO.

I did not look for households with gender diversity, since there were only a limited number of households meeting this criterion. Although I found some households with gender diversity, I chose to focus on gender across households, rather than within households. Of the fourteen households I interviewed, girls headed eleven of them. Six

¹³ Additionally, I found that the data provided from the NGO on household members of CHH in their program did not accurately reflect who was living in the CHH. Therefore, I was sceptical about the accuracy of the data that they had on households in the other part of Rwanda, and doubted I would be able to meet my original research criteria. It would have taken a considerable amount of time to relocate to this other area, initiate contact with the CHH there, and check the data that the NGO had on the households by visiting each one.

of these households had one male member, while the other five households were all female. The three households headed by boys had no female members.

The reason for the higher proportion of households headed by girls may be explained in various ways.¹⁴ Two of the households headed by girls in this sample did have an elder brother living elsewhere. Additionally, an NGO program manager who has worked with CHH for ten years noted that female-headed homes tend to portray more unity and cohesiveness, compared to male-headed households. An interview with a community member supports this point. She was commenting on a household of male orphans living near her (not in the research sample), saying that they leave the home and return sporadically. Apparently, boys from rural areas will often go to Kigali to attempt to find employment there, and then return home and recruit other boys to join them. In Rwandan society, women are discouraged from loitering in public areas. This may discourage girls from leaving the home without a set place to go. All these factors illustrate how it might be more common for households headed by boys to disperse, rather than to remain as a collective within a home. Among the household members, the household compositions included siblings and half-brothers or sisters, and in two households, there were boys who were cousins of the other siblings in the household.

Besides the change in the gender criterion, I also made some changes to the NGO criterion. I chose households that had not necessarily participated in an NGO health program since I was limited in what households were available through the NGOs I was in contact with. This shift allowed me to examine where the children were learning about health and compare the responses of those children who had participated in a NGO health program with those who had not.

¹⁴ Research done by Boris et al. (2006:592) with CHH found similar gender characteristics in their sample.

Although one of the NGOs which had offered to assist me with recruitment was not running a program focused on CHH, they still had other programs with CHH as participants. This NGO, as well as the second NGO who was working directly with CHH, notified the CHH in their programs and asked the children if they were interested in participating in my research project. If the children expressed interest, they arranged a time for the children to meet me and hear more about the research project. All the children who were asked initially if they wanted to participate in the research project were interested in hearing more about it. It was difficult to have to tell some of the households that they did not meet my criteria. This occurred quite frequently, as I found that the data that the NGOs supplied me with did not reflect the actual household composition. In some cases, I also found that the children were actually living with an adult caregiver. This might have been because the adult caregivers did not live with them consistently.

I and my translator (Appendix 2 and Appendix 3) explained the research to those households that did meet my criteria by following a standardized script (Appendix 4) translated into Kinyarwanda.¹⁵ I found that all the children were interested in participating, and once they indicated this to me, they either signed the consent form, or gave their verbal consent.¹⁶

Children were compensated for their participation in the study once the interviews were over. This was done in consultation with the NGOs I was in contact with, in order

¹⁵ All documents that needed to be translated into Kinyarwanda were translated by a native Kinyarwanda speaker, and then verified by another native speaker. Discrepancies were resolved by a third native speaker. All recruitment and interviews activities took place in Kinyarwanda, with a translator. Appendix 4 and Appendix 5 detail what was said to the children regarding the goals of the research, confidentiality, participation, the consent process, etc.

¹⁶ A copy of the consent form was left with each of the households who had signed a form. Their verbal consent was recorded with a digital audio storage device upon the consent of the child, and was also written in my field notes.

to find out what is appropriate. The compensation was comparable to what previous researchers (Boris et al. 2006:590) have done when compensating CHH for their participation in research. They provided the children with a package of household items. I provided the children with similar items: matches, hygiene items, cassava flour, rice, and beans, as well as paper and crayons. Additionally, I provided the children with a snack on each of the household visits, except for the first visit, during which the research was explained.

2.3.2 Non-Governmental Organizations (NGOs)

The second group that I had planned on interviewing were the directors, program directors and program staff of NGOs who offered malaria related health care assistance to CHH. Since there were few NGOs that had health programs that exclusively focused on CHH, I broadened my criteria to include NGOs who had CHH participants in a program that included a health component. In the early 1990s there were over 250 NGOs working in Rwanda (Uvin 1998:48), and today the number remains as high (Rwanda Development Gateway 2004). There are different types of NGOs in Rwanda, such as faith-based, those focused on specific populations, nationally run, etc. Many of these organisations worked with CHH after the 1994 genocide, when the plight of orphans living without adult caregivers received international attention. Since funding has shifted to other issues, NGOs are no longer focusing solely on CHH, and instead integrate them into their other programs, offering various forms of assistance, including health care. Some of these NGOs work now with OVCs, and the CHH are only one category of vulnerable children that they provide support for. The NGOs sometimes work in partnership with adults in the children's community whom the CHH have a relationship with, and whom the children have asked to be their adult mentor (CAREb; FHI 2001). There is concern,

however, that the influx of NGOs through which aid is funnelled has negatively affected health care systems and exacerbated social inequality (Pfeiffer 2004:44-45).

In order to examine the role that NGOs have in the health concerns and care of CHH, I conducted research with four NGOs. With one NGO, I had the opportunity to interview the regional director, the health program specialist, as well as program staff. This provided me with a cross section of perspectives within one NGO. In the other three NGOs my interviews were with management level staff. I relied on purposeful sampling (Maxwell 2005:88-89) to ensure that this research project accessed various approaches to malaria intervention used by NGOs working with CHH in rural areas. Some of the NGOs were faith-based, some of which had a global scope, and others were locally run NGOs. Three of the organisations either had worked or still worked directly with CHH, creating programs specifically for them. The fourth NGO incorporated the CHH into their programs, as did one of the NGOs who had previously run a CHH program. Each NGO had a health component to their programs.

NGOs were recruited with the assistance of two NGOs that were working in the area I conducted research, and that were familiar with the program focus of different organisations. The NGOs were recruited through a letter of information (Appendix 7) that was addressed to the country director or program director of the organisation in Rwanda. The letter, in English, contained the goals of the research and the nature of the interviews. English is one of the national languages in Rwanda, and is widely spoken among NGOs. Therefore, I had planned to conduct all recruitment and interviews by myself in English. However, two of the people I interviewed, although they spoke English, chose to be interviewed in French. Another participant chose to be interviewed in Kinyarwanda. Therefore, those interviews were conducted with the assistance of a

translator. All the interviews were held in the NGO office, with the exception of two interviews, which were held at the guesthouse where I was staying.

All the people that were interviewed were familiar with the programs available to the CHH by that NGO, and with the content of the health messages within the program. Each interview took approximately one and a half hours in duration.¹⁷ All the NGOs contacted consented to participate in the research project, and all agreed to a digital recording of the interview. Once I transcribed the interview, the participant verified the transcript and emailed back to me any required changes. Once the interview transcript met their approval, a thank you email was sent to them.

2.3.3 Community Members

The third group I interviewed consisted of adult neighbours of various CHH who participated in this study. Although it would appear that children in CHH are dependent on community support with the absence of an adult caregiver in the home, literature states that they are often marginalised from their communities (Thurman et al. 2006:226; Veale et al 2001: xiii). This has led to the emergence of new social support networks.¹⁸ Interviews with community members provided insight into this reported marginalisation. It also provided the opportunity to examine how poverty, stigma and the higher burden of illness lead to the marginalisation of CHH in Rwanda, as well as identifying other issues that surround discrimination. Neighbours commented on the type of support they gave, which illustrated the children's particular vulnerability as well as providing some information on the factors that shape children's ideas of malaria. The community's

¹⁷ Prior to the start of the interviews, any questions the interviewee had prior to consenting to participate were answered. The NGO staff members were told that their responses would remain confidential and that they would be free to refuse to respond to any questions and/or end the interview at any time without any consequences. All the interviewees completed and signed the consent form (Appendix 8), and received a copy to keep for personal reference.

¹⁸ For example, during my experience working with CHH in Rwanda, it was evident that there were strong ties being built among the children of nearby CHH.

perspective on CHH also indicated other issues that both helped and hindered the children's health care practices. In addition, interviewing community members allowed for insight into local level concepts on poverty, age and gender and situated the children's knowledge and experiences of malaria in these understandings. As there was neither the time nor the resources to interview everyone in the community, I interviewed neighbours of nine of the households. Purposeful sampling (Maxwell 2005:88-89) allowed me to recruit participants who were part of the children's support network, and ensured that I included both males and females. My sample included six women and three men. One community member was a volunteer mentor for a NGO, five were relatives, two were neighbours and one was a volunteer community leader.

The community members were recruited with the assistance of the children in the CHH. At the end of the fourth interview with a CHH, I asked one of the children if I might interview an adult community member that they had identified during the course of the interview as someone who was part of their support network. All the children were in agreement, and written or verbal consent was obtained from the child (Appendix 6). In addition, I asked the child if they would be willing to ask this community member if they might be interested in participating in the study. If the child preferred, I asked the community member myself. All the community members were in agreement. I then went to the neighbour's home or in some cases the community member came to talk to me at the children's house.¹⁹ The research project was explained to the community member and my Rwandese translator read the letter of information (Appendix 9), since the literacy levels of the community members were unknown. Communication was in Kinyarwanda, as it is the language that people in rural areas learn at birth, and are most

¹⁹ No reference to the information that the children shared was disclosed to the community members.

fluent in. Once the community member had verified that they were still interested in participating in the research, a time was set up for the interview. The interviews were approximately one hour in length, and all the interviews except for two were done in the homes of the community members. These two community members elected to be interviewed at the home of the CHH that they were in contact with.²⁰ Community members were compensated for their participation in the study once the interview was over. This was done in consultation with the NGOs I am in contact with, in order to find out what would be appropriate. I gave each community member rice and sugar.

2.4 Methods

This research is founded on the premise that the perspectives and experiences of individuals are socially constructed. Research methods that rely on qualitative approaches, such as semi-structured interviews, provide insight into the subjective meanings, the ambivalences, ambiguities, confusions and firmly held beliefs (O'Reilly 2005:114). A qualitative approach is flexible, allowing for a mixture of methods to be used in order to provide focus to the interview, as well as ensuring that the participants are able to freely express themselves beyond the research question (O'Reilly 2005:116-117). This reflects my critical framework, which strives to understand the participant's "negotiated way of life" (Fontana and Frey 2000:668). For example, the household survey I used with the CHH provided insight into the constraints facing the children, as well as their avenues for health care. In the semi-structured interviews, the questions

²⁰ The children from the household were not in the same room as the community member during the interview. Appendix 9 and Appendix 10 detail what was said to the community members regarding the goals of the research, confidentiality, participation, the consent process, etc. A copy of the consent form (Appendix 10) translated into Kinyarwanda was left with each participant. Their verbal consent was recorded with a digital audio storage device upon their consent, and was also written in my field notes.

were based on an attentiveness to issues of power and inequality, in order to understand the influence of social, political and economic factors.

2.4.1 Child Headed Households (CHH)

I made at least five visits to each of the fourteen households of children.²¹ All the visits, except the first, included data collection. Situating the research in the household was suitable for this research as it is a familiar place for the children (Greig et al. 2007:137) and provided a wealth of contextual information on the home environment.

The visits can be summarised as follows:

1 st visit: 30 minutes	Introductions and explanation of research project to the household
2 nd visit: 45 minutes	Obtaining consent from children, observations and questions about livelihood and work load
3 rd visit: 1 hour	Household survey
4 th visit: 1 ½ to 2 hours	Semi-structured interviews through drawing activities
5 th visit: 1 ½ to 2 hours	Semi-structured interviews through showing and drawing activities

The first visit with the CHH involved introductions of myself and the translator to the children, as well as explaining the research goals. This visit was to occur with a staff person from the NGO that the children are connected with. In a few cases, the NGO had arranged to meet the children at a central location, where the NGO staff person introduced me. The research was appropriately explained to the children by clearly detailing what their participation in the project would entail, the time commitment required, and the confidentiality of information (Hill 2005:69). If the children were interested in participating, I returned for the second visit, which began with the introductions and explanation of the research project, as I had not yet met all the children

²¹ In some cases, I found that not all the children were home at the arranged date and time of our appointment. In these cases, I either interviewed the children that were home, and returned to interview the remaining children at a convenient time for them, or else I returned again to the home at an agreed upon time to interview all the children.

living in the household.²² Time was spent responding to the children's questions. It was often during this visit that I found out if there was something that would eliminate a household from the research. If the household met my research criteria, and if the children expressed interest in participating in the research,²³ a subsequent visit was arranged.

The second visit was spent answering any further questions the children had. The children often asked questions about the nature of the drawing activities, about who else was participating in the project,²⁴ and about the photograph of the household I had promised to leave with them. After answering their questions, and once the children confirmed their interest in participating in the study, I proceeded with obtaining their written or verbal consent. Once this was completed, the remainder of the visit was used for rapport building and observations. The children were invited to show me around their home and property. Not only did this provide opportunity to engage with the children and ask them some informal questions (Appendix 11), it also allowed for observation of their lived reality in terms of their daily workload and subsistence practices. In addition, it provided opportunity for naturalistic observations of the children's social interactions, their real-life experiences and their reactions to these experiences (Dunn 2005:87). Although this second visit is a source of data, it was disruptive of the children's daily routine and did not necessarily reflect their day-to-day interactions. However, during this time, I collected field notes and used this information in my analysis.

²² In all cases, it was the eldest child who had come to the central location and who had met me. These children were affiliated with the NGO, and the other household members were not necessarily participating in the NGO activities.

²³ All the children agreed to participate.

²⁴ I did not disclose any names of any of the other research participants.

The third visit with the household involved conducting a household survey (Appendix 12). The survey questions were initially asked to the oldest child in the household and included some fixed response options in order to obtain basic descriptive tallies. However, as other household members began to feel at ease in our presence, I would direct questions to them as well. The survey allowed for the collection of precise details (O'Reilly 2005:119), provided information on household composition, education, available resources, subsistence practices, association with NGOs, and how the household came to be headed by children. Using proxy measures, characteristics of household poverty were noted, providing additional insight into the constraints on children's agency as well as their resiliency and creativity in adverse situations.

The fourth visit with the CHH focused on children's explanations and ideas regarding their susceptibility to malaria and other illnesses, as well as their access to care and treatment when they are sick. The children were asked to draw a picture of themselves when they were sick and when they were healthy. The completed pictures were used with open-ended questions (Appendix 13) to solicit the children's ideas. Open-ended questions allow for a range of responses and enable the participants to interpret the questions in ways that are meaningful or relevant to them (O'Reilly 2005:120). Approximately 20 minutes was spent with each child, asking them questions based on their drawings.

This approach is based on the view that children are capable of acting with intention and are persons of value. Rather than simply considering children as future adults, this research is interested in the children's present perspectives and their lived experiences (Greene and Hill 2005:3). Initially I planned to rely heavily on drawing as a method to encourage children to express what they know and experience about illness

and health. Drawing has been successfully used in other research with children in resource poor areas (Geissler 1998; Mitchell 2006a). It is a method that does not require the researcher's sustained presence. For example, while the children were drawing, I would ask their permission to look around their house. This gave me the opportunity record my observations of what was going on in the household. In addition, drawing may provide some freedom and empowerment to the child in being able to express their ideas and concerns to others and it is something that many children enjoy doing (Mitchell 2006b:62). However, I soon became aware that not all the children in the CHH were comfortable with drawing. Although the majority of the children did participate in the drawing activities, for some of them, drawing was associated with school. In Rwanda, children are taught that there are correct ways to draw objects. Some of the children were nervous that they would not be able to express themselves "correctly" to me through drawing. As a researcher, I represented another authority figure. Furthermore, some children who had not had much access to schooling would tell me that they did not know how to draw. However, after hearing that I was not looking for "correct" depictions of their health, some of these children did decide to draw, and appeared to enjoy it. Other children chose to respond to my interview questions directly, without drawing. A few children showed me things around their home rather than drawing them. Due to the various responses I got from the children regarding drawing, the drawings became primarily a tool to elicit the children's perspectives. Therefore, the drawings are viewed as a method within this research project, and not as a source of material. Consequently, there is little discussion on the children's drawings in this thesis, although a few of them are used to illustrate points that the children made.²⁵

²⁵ Photographs were taken of the drawings and the drawings were left with each child.

The last visit to the household followed a similar methodology to the fourth visit and focused on gathering data on the children's explanations and ideas regarding their health, illness and malaria. Children were asked to point out things in/around their house that make them sick or keep them healthy or to draw things that make them sick, and other things that help them stay healthy. Based on what the children indicated through showing or drawing, the children were encouraged to talk about their ideas through open-ended questions (Appendix 14).

2.4.2 Non-Governmental Organizations (NGOs)

I used semi-structured interviews with the NGO representatives to ensure that I made efficient use of the participant's time. I expected that they would be available for only one interview, although I asked them if I might return if I had subsequent questions. A semi-structured interview involves detailing the topics to be covered before hand, and listing possible questions (Appendix 15) that are open enough to elicit discussion but cover the research topics (Bernard 2002:205). The questions included the types of health programs that are accessible to CHH, the involvement of CHH in program design, and whether the NGO relies on community involvement in their programs. By using a semi-structured interview, I was able to ensure that the topics pertinent to this research were addressed, while allowing the participants and myself to follow new leads that arose in the discussion. Lastly, as a middle-ground approach between structured and unstructured approaches, a semi-structured interview allowed me to compare data between NGOs, and to focus the interview on the particular approach a NGO carried out that was unique to their organisation (Maxwell 2005:80). This was particularly evident when talking with one program staff member who provided a unique perspective on a program of which

CHH were a part, detailing how vulnerable the children were to hierarchies of power within the organisational structure of the program.

2.4.3 Community Members

Interviews with the community members followed a similar approach to that described above with the NGOs, and for the same reasons. Questions had been prepared that were used to guide the interview process (Appendix 16) and addressed the local community's perspectives on CHH, the relationships between community members and CHH, and the social discourse on malaria, poverty, age and gender. However, as mentioned above, the semi-structured interview also allowed the participants the opportunity to expand on their responses and for the interview to focus on new areas of insight that arose in the course of the discussion (Bernard 2002:202, Maxwell 2005:80). This occurred on several occasions, allowing the participants to talk about current issues affecting the health and welfare of the CHH in the area.

2.5 Methods of Analysis

Data from the household survey and interviews was recorded using field notes, and data from the interviews was also recorded using a digital recording (all the participants consented to recorded interviews). Translation occurred during the interviews with the assistance of a translator fluent in Kinyarwanda. Field notes were transcribed by myself as soon as possible after the interview, supplemented by the audio recordings (further clarification of the translation was obtained as required).

In order to describe poverty within the households, I drew upon Boris et al.'s (2006) methods to structure the household survey, using specific material items as indirect measures of economic status. Data collected during the household survey were tabulated and summarized with descriptive statistics and percentages. These included,

for example, the number of boys and girls per household, the average age within the household, the age range, the age of the eldest child and the number of children within the household (Appendix 12). I compared my results to those of Boris et al. (2006), and I also made comparisons within my sample in order to characterise the poverty within my sample. The results are discussed in the next chapter.

Initially, the analytical categories used to organise the data from the interviews were based on the themes that I had identified from my literature review. However, I have both added to and changed these categories throughout my fieldwork and analysis (O'Reilly 2005:186), working inductively and being attentive to what the children prioritised. This reflects the grounded theory approach where analysis leads to theory (O'Reilly 2005:201) and the identification of new themes. Themes are groupings of recurring or similar ideas that are in the data. They may include indigenous concepts, categories of linked concepts, metaphors and analogies, similarities or differences within data, etc. (Ryan and Bernard 2003:86-94). I had initially identified themes, such as "body size" or "bodily cleanliness", as emerging from responses to the questions about health. In fact, only a few of the children talked about body size as an indication of health, while many did indeed talk about personal hygiene. For the questions about being sick, I had identified initial themes such as "time of the year" or "rainy season." These themes were evident in the data, but there were also more nuanced responses that detailed the time of the day (morning versus afternoon) in relation to when they might get sick (from exposure to the strong afternoon sun). I had thought that themes drawn from the questions on who does or does not assist the children when they are sick would be centered on the qualities of the person. However, no such themes were evident in the children's responses. Some themes emerged based on what was noticeably absent in the

responses from the CHH, such as the theme for seeking external help when sick.

Children rarely talked about asking for help outside of the household when they were sick. Further discussion on the themes that emerged from the interviews with the children is found in Chapter Five.

The data obtained from the interviews were examined from a critical theoretical perspective. This provides a means to examine how social structures inhibit collective and individual agency, leading to social suffering and preventing CHH from accessing resources to maintain or improve their health and reduce disease. A full exploration and analysis of the data is presented in Chapter Six. There, I move beyond the preliminary themes to thinking critically about issues such as the children's differential knowledge of malaria, how NGOs' funding parameters constrain the assistance they offer CHH, and how Rwandan ideas about gender both constrain and enable children's capacity to engage in health care.

2.6 Chapter Summary

In research projects like this one, the reliance on translation means that the responses of the participants may be constrained due to issues associated with the ethnicity or gender of the translator. Power imbalances associated with the presence of adults may also serve to decrease the comfort level and openness of children. Furthermore, translation may not be accurate due to techniques used, or unfamiliarity with the particular translation issues in the language. Efforts were made to remain cognizant of these issues and to address them.

The open-ended nature and semi-structured format of the interviews with the CHH, NGO staff and the community members was particularly helpful because it provided opportunity for the participants to interpret questions in a way that was

meaningful to them. In addition, it provided me with the flexibility to focus the interview on topics that were relevant to the interviewee.

The methods used in this research project provided me with descriptive statistics and qualitative data, which enabled me to rely on a thematic analysis of the results. The results of the household survey conducted with the CHH are given in the next chapter, along with descriptive observations of some of the households and photographs taken during the research project. Discussion on the themes that emerged from the interviews with the community members and NGO staff members is found in Chapter Four. Chapter Five covers the themes that emerged from the interviews with the children.

CHAPTER THREE: HOUSEHOLD CHARACTERISTICS



Figure 3.1 Household M. Photo: Michelle Hardy. July 2008

In this chapter, I describe the households in my research project by drawing from the findings from the household survey. The descriptive data is organised under the following categories: household demographics, education, material indicators of poverty, livelihood and land, and health care coverage. At the end of each category, I provide a descriptive narrative on a household derived from my field notes, supplemented with a photograph. These verbal and pictorial snapshots introduce some of the households and further illustrate the household characteristics.

3.1 Household Survey

During my third visit to each CHH, I used a household survey to ask the children about the demographic and economic aspects of their households. This survey was based

in part on a survey used by Boris et al. (2006) who also conducted research among Rwandan CHH. I asked the children questions regarding the relationship between the household members, how household chores were divided up, the number of years they had lived without an adult caregiver, the material items they owned, and the crops that they grew (Appendix 12). The survey provided a structured context from which to begin to explore the children's lives and to begin their participation in the project. By using similar proxies as Boris et al.'s (2006) to characterise poverty within CHH, I am able to compare my findings with published work. Additionally, it allows me to examine the effects of poverty on the households, and identify some of the constraints on the children's health seeking behaviour.

3.1.1 Household Demographics

Table 1 and Table 2 summarise the demographic data of the 14 households interviewed. Significantly, there were over three times as many girls (78.6%) as boys (21.4%) heading the households. The majority of the household heads (85.7%) were either 17 or 18 years old, with the rest being either 15 or 16 years old. Approximately 43% of the heads had taken responsibility of their households for four or more years, which meant that some children had taken on the burden of responsibility for the household when they were as young as 13 years of age. Half of the children reported being the head of the household for a shorter period (1-3 years), including the two youngest household heads (15-16 years old). Only one household head had assumed responsibility for their siblings within the year preceding the household survey. The

majority of the youth in my sample were orphans due to parental death from an unspecified sickness or from AIDS.²⁶

The highest number of children (45.8%) were in the 14-16 year age range, and the number decreased in each lower age range, to one (4.2%) at 0-3 years of age. None of the non-heads in this sample were children of the heads. Most (58.3%) were siblings, 29.2% were half sisters or brothers, and the remainder (12.5%) were cousins.

On my third visit to Household Q, I join Chantal²⁷ (17), Jeanine (15), Margerite (12), Thérèse (9) and Celestin (6) in the main room of their three-room house. Roof tiles almost fill the room, and we seat ourselves knee to knee on the mats and benches that fill the available space. The family has been waiting for a year for their new home to be built,²⁸ and the tiles are stored inside for safekeeping. Unlike some of the other children in the sample, all five of the children enjoy the drawing activities and their colourful pictures soon cover the walls of the room. On this visit, Chantal, the oldest, begins to tell me about her parents as she sits beside me, drawing. “When my parents were still together, it was good. They could work, they had lots of energy, they were strong, they had unity.” Then she tells me that “it is difficult to dig (cultivate) when you are young.” She draws a fireplace with no cooking pot on it, and tells me that she was nine years old when her mother died. There was no food to eat, so she had to learn how to start cultivating so that she and her sister could grow things to eat. “Jeanine was seven years old. She had to carry heavy things. It was difficult for her.” I ask about her father, and she tells me that he had died before her mother, in the genocide. Her mother had then married her brother-in-law, and had given birth to the youngest three children with him. However, she had contracted AIDS, and she died giving birth to Celestin. After their mother’s death, their stepfather remarried, and had two more children, who live with him and his new wife. Chantal tells me “He is a drunkard; he likes drinking. He does not help us.” None of these five children lives with him, and they do not see him very often (Fieldnotes).

²⁶ It is difficult to give an exact percentage. For example, in one case the father was shot, and the mother died from AIDS. However, in 12 of the 14 households, at least one parent died from an unspecified sickness or from AIDS.

²⁷ Pseudonyms are used throughout the thesis to ensure anonymity.

²⁸ An NGO financed the construction, but the builder walked away with the money.



Figure 3.2 Some of the children from Household Q participating in drawing activities. The roof tiles are on the right. Photo: Michelle Hardy. August 2008.

Table 1. Household Demographics of CHH - Children ages 3-18 (n=38)²⁹

	#	%
Gender		
Male	15	39.5
Female	23	60.5
Age		
0-3	1	2.6
4-6	2	5.3
7-10	4	10.5
11-13	6	15.8
14-16	13	34.2
17-19	12	31.6
Number of Children in Households (n=14)		
2	8	57.1
3	3	21.4
4	2	14.3
5	1	7.1

²⁹ Although I only interviewed children between the ages of six and eighteen years of age, there was one three-year-old male in a CHH that is counted in this table. Other than this child, there were no other children below the age of six years in the sample.

Table 2. Sociodemographic Characteristics of Households

	#	%
<u>Heads (n=14)</u>		
Gender		
Male	3	21.4
Female	11	78.6
Age		
15-16	2	14.3
17-18	12	85.7
Years Head of Household (approx)		
0-1	1	7.1
2-3	7	50.0
4-5	4	28.6
6-7	2	14.3
Currently Enrolled in School		
Yes (all girls)	3	21.4
No	11	78.6
Last Class Attended		
Primary 1 – Primary 3	5	35.7
Primary 4 – Primary 6	8	57.1
Secondary	1	7.1
<u>Non-Heads (n=24)</u>		
Gender		
Male	12	50.0
Female	12	50.0
Age		
0-3	1	4.2
4-6	2	8.3
7-10	4	16.7
11-13	6	25.0
14-16	11	45.8
Relationship to Head of Households		
Sibling	14	58.3
Half sister/half brother	7	29.2
Cousin	3	12.5
School Aged Children (6 -18 years)		
Enrolled in School		
In Male-Headed Households (n=6)		
Yes (all boys)	1	16.7
No (all boys)	5	83.3
In Female-Headed Households (n=17)		
Yes (both boys and girls)	13	76.5
No (all girls)	4	23.5

3.1.2 Education

Although all the household heads in my research had attended primary school at some point, it was apparent that it was difficult for them to stay in school after they assumed responsibility for the household. Of the 14 households in the sample, only three (21.4%) of the eldest children were attending school. All were girls, and all three of these households were receiving support such as food, assistance with chores, and childcare, from relatives or neighbours. One of the three heads was attending secondary school. Her school fees were being paid for by a local NGO, but she had recently been told that they would not be paying for the following year. Of the 11 heads of household who were not in school, ten of them had left school either the year of a parental death or the year after, or the year a caregiver left. Although more female heads had completed primary school, due to limitations in the sample it is difficult to determine if there is a relationship between age or sex of the head of household and years of education.

In comparison, I found that non-heads of household were more likely to be in school. Of the school-aged non-heads³⁰ within the sample, 64% of them were attending primary school. However, school attendance varied strongly with the gender of the household head. In households headed by girls, 81% of non-heads were in school, compared to 20% in households headed by boys. Of the three households headed by boys, only one boy attended school. In contrast, in the eleven households headed by girls, there were only three households where younger, school-aged children were not attending school. Girls in Rwandan society are socialised to care for their younger siblings, so the higher number of younger children in school in households headed by girls may be because of the attentiveness of the female head.

³⁰ This does not include one six year old, as there was no nursery school in her area for her to attend.

There are four siblings in Household P, but the paternal grandparents have taken the 11-year-old boy to live with them, so I never meet him. Claudine is the oldest. She is 15-years-old. Florence and Gregoire are six and three years old. Both their parents died of AIDS, the father in 2005 and the mother last year. Claudine tells me that they were sick for a long time, and that she had to go to the hospital to take care of them. Claudine is in the third grade at school; most of the other children in her class are nine or ten years old. While she is at school, a neighbour keeps her eye on Florence and Gregoire. On one of the visits, Florence tells me about all the Kinyarwanda medicine she knows. Urumuva is for malaria, and mukubayoka helps you when you have worms. If a bee stings you, a green plant called isogo will help (Fieldnotes).



Figure 3.3 Claudine and Florence sharing a snack before we begin the interview activities. Photo: Michelle Hardy. August 2008

3.1.3 Material Indicators of Poverty

On my first visit to the households, I was struck by the impoverished conditions that the children lived in, although there was obvious variation in their housing conditions and the amount of furniture they owned. All the children were living in sun-dried mud brick houses with either dirt or brick floors. Most of the houses had belonged to their parents or a relative, but some had been built by the community or an NGO for the children. One family was living in a house that still belonged to an uncle, and

consequently their long-term occupancy of the house was tenuous.³¹ Half of the children lived in compounds that included the main house, a building for domestic animals, and a kitchen, all surrounded by a fenced enclosure.³² This was similar to other houses in rural areas. The other houses in the sample consisted of just one building. Doors were made of wood, sometimes covered with metal sheeting, and windows were open, except for wooden shutters. Outside doors into the enclosure or into the house always had a padlock, and the window shutters could be latched from the inside. None of the houses had electricity or running water. Furnishings in the houses ranged from two grass mats and nothing else, to benches with backs, tables, sturdy wooden beds and mattresses. Normally two to three children would share a sleeping mat or a bed.

Some of the living conditions of the CHH are represented in Table 3. These conditions are very similar to those in the sample of Boris et al. (2006). Over 70% of the households in my research had a latrine, made from sun-dried mud bricks, with logs covering the opening in the floor. Households that did not have a latrine, or had a latrine in very poor condition, were all households headed by girls. Almost 60% of the households relied on a petrol lamp for light, although often the children would tell me they had no petrol to fill it. Two households (14.3%) showed me an LED lamp they had engineered by wiring the bulb to batteries wrapped in banana tree fibre. Approximately 35% of the households had no light source, other than cooking fires.

³¹ In fact, just prior to leaving Rwanda, I heard that another relative who wanted to use the house had chased out the children living in the house. The children had split up and were living with different community members.

³² Most of the time the latrine was situated outside the enclosure.

Table 3. Indicators of Poverty within CHH (n=14)

Items Identified with Household	#	%
Toilet		
Latrine	10	71.4
Light Source		
Petrol Lamp	8	57.1
Batteries powered LED light	2 (1 also has a Petrol Lamp)	14.3
None	5	35.7
Household Items		
Mattress	7	50.0
Blanket	12	85.7
Bed	8	57.1
Mosquito Net	8	57.1
Mosquito Net Hanging Up	4	28.6
Stove	5	35.7
Brazier (charcoal)	1	7.1
Table	8	57.1
Radio	5	35.7
Domestic Animals		
Cows	3	21.4
Goats	2	14.3
Pigs	5	35.7
Chickens	3	21.4
Rabbits	4	28.6
Guinea Pigs	2	14.3
Livelihood (income/subsistence)		
Farming	9	64.2
Market	3	21.4
Brickyard	1	7.1
None	1	7.1
Land Size (Hectares)		
0.00 – 0.29	12	85.7
0.60 – 0.89	2	14.3
Approximate Household Income		
\$ 0 (CAD/month)	4	28.6
1-3	3	21.4
7-9	2	14.3
10-12	3	21.4
13-16	1	7.1
17-19	1	7.1
Individual Items		
Clothing & Shoes (n=38)		
Shoes	37	97.4
Spare set of clothes	38	100.0

Boris et al. (2006:592) also used other indirect measures of economic status, asking only the head of the household if they owned a mattress, blanket, shoes, and/or spare clothing. I have expanded on this by including all household members, and including other household items, amount of land, and income per month. Note that some items are collectively owned, while others are owned by individual household members. In 50% of the households in my research sample, there was at least one mattress in the household, and 57% of the households owned at least one bed. Some of the beds had been made by the children, by using branches to make a bed frame. Although 57% of the households owned a mosquito net, I found that only half of those households had it hanging up. Most of the children cooked over a fire built between three rocks, on which they balanced a cooking pot. Almost 36% of the households had a simple wood-burning stove, which was a brick rectangular structure that had either one or two openings at the top for pots. One household had a brazier, a small charcoal stove, which they rarely used because they could not afford to buy charcoal. All the households cooked indoors, and consequently, the walls of the houses were blackened with soot. This practice is possibly linked to the persistent cough I noticed that many of the children had.

Besides the items that were collectively used by the household, each of the household members also owned their own clothing and shoes.³³ Only one child did not own a pair of shoes, but they all had spare sets of clothing. Heads of household owned on average more spare sets of clothing and shoes compared to the younger household members. The obvious difference in individual possessions is linked to control of household resources. This is a theme that will be more fully explored in Chapter Five.

³³ Although I sometimes saw children wearing each others' clothes or shoes on different visits to the household.

It is our first visit to Household H, where Angelique (17), Béatrice (15), Désiree (13) and Jean-David (11) live. My translator and I are welcomed into the main room of the house, the only building that the children own. In the corner of the dimly lit room is a pile of dirt, and beside it on the floor is a woven grass mat. Against one wall is a small bench. There is nothing else. We stand around, rather awkwardly, until my translator takes the initiative, and slips off her shoes and sits down on the mat. I follow suit, then everyone else joins us, and we begin to explain the research project. Our subsequent interviews always begin with the six of us huddled on the mat, but we go into another room to do the interviews, where there is another mat to sit on and a few clothes slung over a cord strung across the room. The other room of the house is the kitchen. There are a few buckets, some pots, an oil can, thermoses, and three rocks on which to rest the cooking pot. Sometimes there is some firewood. On our third visit to the house, the children tell us that someone stole their cabbages from the field. They were going to pick them and sell them on the market, but when Angelique went down to the field, they were gone. They do not own the field; a neighbour lends it to them. Angelique usually cultivates alone during the week, while the other three are at school. Sometimes, however, they are home, and they help her. Sometimes their teachers send them home because they do not have school uniforms, or enough school supplies. Eventually they call them back, and tell them they can return. However, nothing has changed - they still do not have school uniforms, or enough school supplies (Fieldnotes).

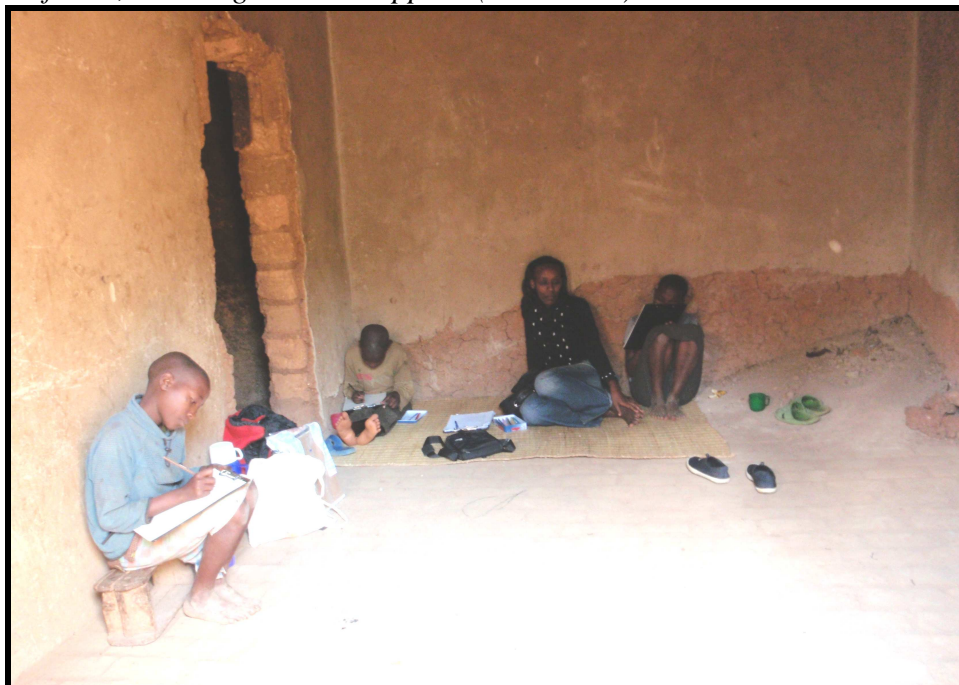


Figure 3.4 Some of the children from Household H with my translator, doing the drawing activities. Photo: Michelle Hardy. July 2008

3.1.4 Livelihood and Land

Almost two-thirds of the households in this sample (64.2%) relied exclusively on farming to feed themselves and to gain some income. However, there were households who relied more on selling produce³⁴ in local markets (21.4%), and one who supplemented their cultivating with waged work at a local brickyard. The remaining household relied almost exclusively for food on an older sibling who lived next door, as both household members were in school, and had little opportunity to cultivate on the small piece of land they owned. The children had very little land on which to farm. All but two of the households cultivated on less than 0.29 hectare (2900 square meters) of land.³⁵ The remaining households cultivated on land between 0.60 and 0.89 hectare. Most of the children had inherited land from their parents, and the rest borrowed land from relatives or community members. Households headed by girls tended to own less land than those headed by boys, 0.17 hectare on average compared to 0.42 hectare.

During the household survey, I asked each household if they had enough land to grow food to provide for the household and a surplus to sell. Of the 14 households, only three (21.4%) told me that they sometimes sold produce when they had a surplus. I noticed that land size appeared to be a significant factor in the number of different types of vegetables and fruit that were grown. The two households with larger pieces of land grew a larger variety of produce on their land. All the families were growing sweet potatoes, a food staple that was prominent in the children's comments about their health.

I also noted that there was an inverse relationship between the amount of land cultivated by a household, and the amount of income the household as a collective earned

³⁴ It is important to note that this is not surplus produce from their land, but rather produce that they bought or picked and then resold for a profit.

³⁵ As noted in Chapter Two, the minimum size of land to feed a family of five living in a rural area, is 0.7 hectare (National Agricultural Commission cited in Uvin 1998:113).

per month. On average, households with under 0.29 hectare of land made close to \$7 CAD per month, whereas those with over 0.60 hectare of land made \$5 CAD per month.³⁶ It was apparent that a lack of land-based resources meant some CHH had to engage in other income generating activities. All the heads in households earning incomes over \$1 CAD per month were not in school. These households earned on average \$8 CAD per month in contrast to those households with heads in school who earned on average \$0.33 CAD per month. There were no apparent trends concerning level of income and gender of household heads.

Cows are prestige items in Rwanda, and the government has recently started up a campaign to ensure that each family in Rwanda owns at least one cow. The cows are meant to be kept stabled so that their manure can be collected to fertilize land, and because there is little grazing land available. Of the 14 households, only 21% had a cow. One household had two cows. A few of the households owned goats, pigs, chickens, rabbits or guinea pigs. Manure from the goats and pigs is also collected for the fields. Piglets are sold at the market for a profit when fully grown, as are rabbits and guinea pigs. Eggs from the chickens are sometimes sold as well.

After a thirty-minute hike from the main road down the hillside, along a track that winds its way through cassava³⁷ fields and around banana groves on its way toward the river, we eventually reach Household M. My translator and I wait outside the compound, which is made up of the main house, a kitchen, a stall for animals, and a mud-brick fence, until Vincent (16) eventually comes home and welcomes us inside. In one corner of the compound, I notice a neatly stacked pile of roof tiles. Just then, Vincent's 18-year-old brother Raymond arrives. He and the boys' cousin, Serge (16), who lives with them, have been cultivating in the fields. That is when I notice that the cow that had been in the stall on our last visit is no longer there. Instead, there is a calf and a pig, munching on the

³⁶ Income level is approximate, as figures were informally gathered from the children. What is interesting is how household income was spent (individuals versus household) and the priorities evident in spending. This is covered in Chapter Five.

³⁷ Root vegetable commonly eaten in Rwanda, which has little nutritional value.

grass that Vincent had cut for them. Raymond tells us that he had brought the other cow to market the week before and sold it. With the money, he had been able to buy the calf, the pig and the roof tiles. The three boys planned to put the tiles up on the animal stall before the rainy season began. When we go back the following week, the job is done (Fieldnotes).



Figure 3.5 Raymond and the roof tiles. Photo: Michelle Hardy. July 2008

3.1.5 Health Care Coverage

The government in Rwanda has recently initiated national medical insurance for those people who are not employed or do not have insurance through their place of employment. Upon the recommendation of one NGO, I added a question to the household survey regarding the national medical insurance, known as *mutuelle de santé* (or simply *mutuelle*) in Rwanda. Health insurance is typically bought in December, and is activated the following January. Families are encouraged to purchase insurance for all household members. In fact, I was told by one person that it was impossible to buy insurance for one family member; all household members had to be covered at the same time. However, if this was the rule, it was not always followed. *Mutuelle* costs 1000 RWF (\$2 CAD) per person per year, and the enrolment fees must be accompanied by a photo, which is valid for one year. The photo can be purchased in town for an additional

\$2 CAD. With *mutuelle*, a person has to pay approximately 200 RWF (\$0.40 CAD) for treatment and medicine for malaria at a health clinic.³⁸ However, *mutuelle* does not cover specialised treatment at a hospital.

I found that those households in my sample that were closest to a health center were more likely to have *mutuelle*. Of the five households with *mutuelle*, three had received it from the local government,³⁹ one had bought it, and the other household did not state how they had acquired it. Health centers tend to be situated near town centers, or near government offices. Therefore, it may be that those children living closer to government services would be more visible, and more likely to receive assistance. In addition, those living in closer proximity to a health center may be more likely to consider buying insurance, because the walk to receive treatment when sick would not be as daunting.

Bernadette (17) and Filaline⁴⁰ from Household F live in their uncle's house as he is currently living in Tanzania. A few meters away is another aunt and uncle's house. The girls tell me that they do not have a good relationship with them, and they rarely talk to each other. The girls say that they are worried, because their relatives want the house, and they have nowhere else to live. They farm on a small plot of land that they inherited from their grandmother after she died. Sometimes Bernadette sells tomatoes on the market, and Filaline might go down to the local brickyard to earn some money. Together, they may earn 1,000 to 1,500 RWF (\$2 - \$3 CAD) per week. Bernadette tells me that sometimes people come to their house at night and knock on their door. Consequently, a neighbour has sent her eighteen-year-old daughter to come and sleep in one of the rooms to keep them company. Bernadette has medical insurance. A neighbour was given free insurance for her family from the government because of her volunteer work in Gacaca (Rwandan community court system focused on those accused of involvement in the 1994 genocide). There was room for one more person on the family health insurance, so Bernadette was included as one of her dependents.

³⁸ Without insurance, the amount that children paid for malaria treatment ranged from 800 to 8000 RWF (\$1.74 to 17.40 CAD).

³⁹ One of the three households had received health insurance from a neighbour, as outlined below.

⁴⁰ Age unknown. She is approximately 15 years of age, based on the year her mother died.

Sometimes when Filaline is sick, she uses her older sister's health insurance in order to access treatment and medicine (Fieldnotes).



Figure 3.6 Household F owns one of these strips of land. Photo: Michelle Hardy. July 2008

3.2 Chapter Summary

The children's precarious position and their vulnerability was immediately apparent to me based on my initial observations of the households. My observations were verified and expanded upon by the children, as they responded to the questions from the household survey. The CHH have little access to food, and few opportunities to earn cash. Notably, the small size of their land holdings both restricts their diet and requires that they engage in additional income-generating activities such as market selling or waged work. However, they have little or no opportunity to save money in order to respond to illnesses. For many, the government medical insurance system is beyond their economic means.

Significantly, the results from the survey also indicated to me that there was differential access to resources within my sample. The high number of households headed by girls in the sample, a trend also noted in Boris et al.'s (2006) study, suggested that there is unequal access to opportunities outside of subsistence agriculture for CHH based on gender. NGO staff and community members verified this, when they later

explained to me that Rwandan men have greater access to the public domain (discussed in the next chapter). Furthermore, households headed by girls had significantly less access to land-based and material resources, as well as animals.

Lastly, it was apparent that those households that lived closer to town had greater access to resources, such as health insurance, as well as more opportunities to engage in waged labour. This theme of passive exclusion (Sen 2000)⁴¹ reappeared in the children's comments in subsequent interviews, and it also appeared in discussions with NGO staff regarding establishing program parameters and criteria for beneficiaries.

The following chapter focuses on two key possible means of support for CHH in rural Rwanda. First are the NGOs, who have been identified as crucial means of support for CHH by the international and national community. Second are the community members that the CHH self-identified as sources of support. However, as the discussion will indicate, these avenues of support are by no means easily accessible for the CHH, nor is the support that they offer comprehensive.

⁴¹ Although there may be no deliberate intention on the part of the government or NGOs to exclude people in rural areas from access to town-based resources, passive exclusion occurs when there is no acknowledgment of this implicit barrier.

CHAPTER FOUR: NGO AND COMMUNITY PERCEPTIONS AND RESPONSES TO CHILD HEADED HOUSEHOLDS



Figure 4.1 Collette, the cousin of Household K. Photo: Michelle Hardy. July 2008

This chapter focuses on the interviews conducted with NGO staff and a number of community members actively involved with CHH. The interviews provide insight into the perspectives that aid organisations and communities have of CHH, as well as the type of support available to CHH by community members. The responses of the NGO staff illustrate the extent that NGOs draw upon and incorporate children's perspectives and concerns in their health programming, as well as the impact of international and national policies on the lives of CHH. The conversations with the community members provide insight into rural community life in which CHH are situated, and the social challenges and ideologies that influence the type of support CHH receive from their communities.

4.1 NGOs

There are a plethora of NGOs in Rwanda. Some are faith-based, receiving much of their funding from religious organisations and private donations. However, some of the faith-based and secular organisations have a global scope and have autonomous chapters in different countries. There are also some indigenous NGOs, with few ties to Western donors. The four NGOs in this sample included faith-based and those with autonomous chapters in different countries. Two of the NGOs focused on people affected by HIV/AIDS and integrated CHH into these programs. One NGO used to run a program for CHH, and was now focusing on providing support for *Nkundabanas*. *Nkundabana* is Kinyarwanda for “someone who loves children.” NGOs have adopted this term for the volunteers in their program who mentor the CHH. *Nkundabanas* receive training from the NGO on mentoring the children and assisting them in income generating activities. The fourth organisation focused on orphans and other vulnerable children (OVCs), including CHH. I interviewed staff from each of the four NGOs, and three different levels of staff: one country director, who was also the Great Lakes⁴² regional director, four management level staff (representing each NGO), and one staff member, who was involved in program delivery. My primary purpose was not to get an overview of NGO programs working with CHH, but to understand the extent that the NGOs drew upon the CHH’s concerns about malaria in their health programs, and what factors influenced the NGOs’ ability to do so. To ensure confidentiality, I have numbered the NGOs and given pseudonyms to the staff.

⁴² This refers to the area encompassing Rwanda, Democratic Republic of Congo, Uganda and Burundi.

4.1.1 National Governance and NGO Coordination

Assistance to CHH in the form of NGO programs is situated in a political arena that is influenced by global and national relations. After the genocide in 1994, there was an influx of aid organisations into Rwanda and the eastern part of the Democratic Republic of the Congo. Ferguson (2006) notes that in areas of crisis and conflict, when states are no longer exercising bureaucratic control, aid organisations often take over governance in many sectors. While many development agencies remain active in Rwanda, today they are more coordinated by and accountable to the Rwandan government. The comments from the country director of NGO 4 illustrate some underlying tension as their organisation struggles to work alongside a government that is slowly regaining its governing power.

Michelle: How are your plans of action received by the districts? Are they open to your ideas, or are they saying “we want this and this”?

Wayne: *They try. For example, yesterday we were in a meeting with the Ministry of Local Government. They are initiating a new program, which they call Vision 2020 Umurenge. They want us to commit by next week which sector we are going to support. As if I have the budget latitude to make that decision between now and next week. Give me a break!*

Michelle: But are they telling you what kind of activities or what kind of programming they want, or are they open to what you offer?

Wayne: *Mostly, they have accepted the reality that we are who we are, and that they have to coordinate. So they do try to limit that. But we have not experienced nearly as much of that in the past as we have now that we are trying to work with the government. In the East, I still get some of that in meetings, where they have their list of expectations, and want to know why we have not funded to a greater degree.*

4.1.2 NGO Funding

The political arena in which NGOs are situated includes numerous funding agencies, whose agendas influence NGO programming. Among the four NGOs in my sample, three received most of their funding through NOs (national offices of the NGO, usually in Western nations) and ecumenical NGOs based in Europe and in North

America. The NOs solicit funding from private donors and from their respective government programs, such as the Canadian International Development Agency (CIDA). The funding for these three NGOs ranged from US \$1 million to US \$3 million over a three-year period. The other NGO had a smaller budget (US \$500,000 over three years) and relied mainly on private donors, who receive periodic updates on sponsored families.

Funding has a significant impact on program length and focus. Most of the NGOs ran three-year programs, based on contracts they had with donors. After three years, the NGO could reapply for new funding, but this funding had different criteria. NGO 1 had run a three-year program, working directly with CHH. When they applied for new funding, the donors stipulated that they had to focus on strengthening community support of CHH, so now they were focusing on assisting *Nkundabana* initiatives with CHH. The OVC program of NGO 3 also ran for three years. At the time of my research they were waiting for donor approval of new funding to continue to work with the same group of children (and perhaps some new households), but offering different forms of support. The donors wanted to see progress, which meant that NGOs had to change their programs to meet that expectation.

Sometimes internal fractures in an NGO can also affect funding and programming. After the genocide, NGO 4 had been funded by a Western nation to run CHH programs. When that government decided that CHH no longer required assistance, donors from Asian nations continued the funding. A recent split between the Asian and Euro American offices of NGO 4 ended this funding and the program closed early in 2008. As a result of the increasingly limited funding, and increased Rwandan government control, NGO 4 had to change their program direction, and was no longer focusing on CHH.

Small NGOs are particularly vulnerable to funding changes and, because of their dependency on NOs to solicit funding, they are constrained by what the NOs want done.

Michelle: Do you find that NOs have a realistic perspective on what is going on here and what needs to get done?

Wayne: *No, not a clue. They have a fantasized version that is laundered by their interests.*

Michelle: And it is impacted by where they get funding from.

Wayne: *But they also come here on short visits and take back partially informed perspectives that they use to project out for their planning.*

Consequently, programs do not necessarily reflect the needs in a particular context, but rather the donors' poorly informed perceptions.

4.1.3 Program Design

The need to “sell” a program in order to get funding was apparent in the interviews with program managers. Most of them focused on the success of their programs, although the manager from NGO 4 openly discussed the constraints that funding placed on program design and implementation.

Michelle: How do you determine the focus of your health programming? Is it primarily funding?

Heather: *Yes, on funding opportunity. In my year here, I focused a lot on networking with other NGOs, because that, I think, is one of the best avenues to access funding. How do we choose? It's sad to say – funding is the determining factor.*

Michelle: And the funding itself depends on what the donors determine is the hot topic – or need?

Heather: *Exactly.*

Besides funding constraints, program design is influenced by the national government's health care agenda. This was noted by the manager from NGO 2.

Sabine: For the health programs, usually, we cannot do more than what has been set. There is a whole health policy at the national level and we have only done what is in accord with the policy. We can't do anything special. We do everything in accord with the national health policy. If they say family planning, then it's that. If they say it's vaccination of children, then it's that, we are going to encourage that. For the HIV-positive, it is supporting poor people to achieve country policy.

Alphonsene represented NGO 3, which worked with CHH within a program aimed at orphans and other vulnerable children (OVCs). Funded by an American ecumenical NGO, this NGO had more autonomy in program design and the children's perspectives were taken into consideration.

Michelle: How do you determine what you will talk about in your health programs? For example, why did you choose to talk about reproductive health, HIV/AIDS, malaria and the other diseases?

Alphonsene: Maybe it is because of experience. Since we live in the community, we know what sicknesses are normally seen in the community. When you first come to Rwanda, you cannot talk about other things without talking about malaria, because statistics show that people are still dying from malaria. Maybe it is reducing, because of mutuelle insurance, but malaria is something that you can have. A big percentage of children are sick. You can call a meeting and you can find that some are sick and are absent. You ask what they have and they say they are in the hospital. You then ask what are they suffering from, and you find out that it is malaria. So you see it is something that we can talk about. We work also with young people, and they are sexually active. They need to be educated on sex, they need to be educated on reproductive health – how they can protect themselves from sexually transmitted diseases, how not to get pregnant. This is something – maybe we did not do any research to know exactly what they need, but sometimes we talk with the children, when we meet for the second or third meeting. We ask them what topics they want to talk about. So they always say project design (for income generating projects), that is the first one, and also they want to talk about HIV/AIDS – because they know it is a serious disease, and they want to talk about reproductive health, because they do not know how their body functions. Those are the top three choices. So we may choose the topics depending on what the children want, but also from observations of the community as we live in the same community.

When I asked what they did if the children were not interested in talking about malaria, Alphonsene said that they still included it in the program, since the government encourages it.

Involvement of CHH in program design, implementation and evaluation was varied. In programs that focused on CHH, such as the program run by NGO 3 or the one that was run by NGO 1, the CHH had the most involvement. Besides identifying what program components they wanted covered, CHH assisted with monitoring each other.

They visited each other's homes and evaluated their peers on whether or not they were following the health training that they had learned. However, the staff did all program evaluation.

The involvement of CHH in the programming of NGO 3 is partially due to the limited number of staff and volunteers, as well as other resources. Many children lived in geographically isolated areas, and significant staffing and logistical resources were required just to reach them. To reduce the demand on these resources, as well as to combat isolation, the CHH were placed in working groups of 10-15 children. These children met together on a regular basis with a *Nkundabana*, sometimes working on each other's land one day a week. Three or four children were chosen from the working group to receive training from the NGO, and then, along with a *Nkundabana*, they were supposed to pass it along to the other members of their group.⁴³ Consequently, the NGO staff may have very limited or no contact with the CHH.⁴⁴

4.1.4 Beneficiaries and Program Components

The beneficiaries of NGO programs were chosen in conjunction with government personnel in the area and local community members. NGO 3's criteria for including CHH in their OVC program included: under 21 years of age, double orphans, and no adult caregiver. In another CHH program, the criteria were a household head under 18 years, and many children living in impoverished circumstances. As noted above, reaching the CHH in rural areas is difficult, due to distance, hilly terrain, road conditions (or lack of roads), and the lack of access to motorised transport. NGOs are normally

⁴³ This reliance on peer education and volunteers is evident in other NGO programs. NGO 4 uses it in transmitting health messages, relying on a care team model. One person is trained in health care, and then is expected to go and transmit the health messages on to a group of ten others.

⁴⁴ During recruitment of CHH for my research, many NGO staff who introduced me to beneficiaries in their programs had not met the CHH before, and did not know where they lived.

situated in Kigali, though some have a few offices in town centers. One NGO based their program location on where they could find community volunteers. Within a selected household, age hierarchy played a role in determining which child could participate in a program. Normally, only one child per CHH was in a program, and the program managers said that it was usually the head of the household.

Program components were quite standardized, including nutritional or food supplements for the first year, counselling, income generating activities, payment for school supplies (but not bonuses for teachers), school uniforms, and fees for secondary or vocational school (for a limited time period). All the NGOs paid for health insurance, either until the children could pay it themselves, or on a sliding scale, decreasing their support over three years.⁴⁵

Health training was an aspect of all the programs run by the NGOs. Most focused on nutrition, hygiene, malaria, STDs, and HIV/AIDS, as well as the distribution of mosquito nets, *sirap*⁴⁶ to disinfect water, and worm medicine. As one of many issues addressed by NGOs, programming regarding malaria was standardized.

Sabine: Here we can simply use impregnated mosquito nets for the beds, and get rid of the bushes, and avoid stagnant water. That's the three. And also to get treatment promptly.

The nets that are distributed are LLITNs,⁴⁷ intended to last five years. Only one staff member noted that the nets may not last that long, and that if they found the situation was bad in the household, they would give the household another one. However, she said that they tried to teach the people to buy them for themselves, rather than constantly giving them new ones.

⁴⁵ Some of the CHH had received insurance at one point from an NGO. However, none of the CHH in my sample who currently had insurance, had received it from an NGO.

⁴⁶ *Sirap* (syrup) refers to a water purification product that is sold in small bottles at pharmacies.

⁴⁷ Long lasting insecticide treated bed nets

4.1.5 Program Delivery

One of the NGO staff I interviewed was a program staff member who worked directly with beneficiaries from NGO 4. The conversation with Eulade not only illustrated what occurs in NGO program delivery, but it also indicated how marginalised CHH are from the structured support offered by NGOs, and the lack of attention NGOs give to them. Eulade was monitoring various income generating projects associated with churches. The beneficiaries in the programs were people living with AIDS, orphans because of AIDS, and other vulnerable and poor people. Groups of beneficiaries organized themselves into “associations” and chose an income-generating project. For example, one association in which there were some CHH from my sample chose to start a sewing project.⁴⁸ A significant theme evident in the interview was that intended beneficiaries of the income generating activities were not getting help. The program started four months late because of issues associated with funding and management. Improper program management meant that the beneficiary criteria were not applied consistently and some associations never began because people used financial resources for themselves.

I was particularly interested in the CHH, and whether or not they benefited from being integrated into a program.

Eulade: In Rwandan culture they do not like to tell the truth. When I visited that group (the sewing association), all the children told me that everything was okay, no one said that there were any problems, or asked for help. They told me that everything was okay.

In fact, a few weeks into the training, at least six members of CHH who were in the association were told that they could not start their training until the next session. The

⁴⁸ As the following discussion illustrates, this is not represented in the previous chapter because none of the CHH had actually participated in the association.

association ran out of money and never informed the children. Finally, one girl asked her neighbour, who had been in the first sewing course, and she was told that she and the others would have to pay if they wanted to receive training, since there was no money. This illustrates the particular vulnerability of CHH, and how little voice they have, not only in Rwandan society, but in programs from which they are supposed to benefit.



Figure 4.2 I saw Albertine, Charlotte and Bernadette one day after the course of interviews with them was finished. They had finally started their sewing training in the NGO program.
Photo: Michelle Hardy. September 2008

Eulade explained to me why the children had not come to him and talked to him about these barriers.

Eulade: People do not want to get in any problems with anyone who has authority over them. For example, I asked those in the sewing association if everything was okay. Because the leaders were there, they said everything was okay. But if I went outside and asked them how things were going, they would be more free to tell the truth to me, because the leaders were not around. In Kinyarwanda they say that “different arms cannot greet each other.” I went to the sewing association, and there were the girls (CHH members) who had not yet started sewing. But they were ashamed to tell me that. They just told me that everything was okay.

Michelle: Why are people afraid of their leaders?

Eulade: They are afraid of them because they see that the leaders can solve their problems. For example, if there is someone living in the rural areas, and if a person from the town comes to visit, the person in the rural area may ask this town person for help. The person from the town has the power to help them or not.

The CHH's attempts at economic stability are thwarted due to societal hierarchies of power, played out even in NGO programs. These hierarchies are based on poverty and unequal access to resources.

4.1.6 Barriers to Health Care

Some NGO staff are aware of the barriers CHH face regarding malaria prevention.

Onesphore (NGO 1 Program Manager): The children have the smaller houses, which contain smaller rooms, so using mosquito nets can sometimes be impossible because they are missing the appropriate bed or it (the net) can also be burned because some children sleep in the same room where they cook meals. It means that the bedroom can play the role of kitchen also.

What was striking was that there was minimal discussion on program efforts aimed at addressing these challenges. Most programs focused on delivering the standardized program components and health messages, and empowering children through income generating projects, but did not address the barriers that constrained the children from meeting their needs.

A few NGO staff noted the vulnerability of the household members due to age and the age hierarchies within the households, as well as the different characteristics of the households based on the gender of the household head.

Sabine: These orphans, they can't practice income generating activities – because they are still young. First of all, it's the lack of responsibility, without doubt. They are little; they have to go to school. Maybe the head of the household works alone. They can't be at the same level as a family that has a father and a mother and two grown children that can work. You don't have the same results.

Michelle: What about in the households – what are their challenges in not following your instructions in hygiene or mosquito nets?

Alphonsene: The level of understanding is also a barrier. They also said that sometimes the head of the household is trained and doesn't share with the siblings. They can't do everything in the house. In addition, if they don't share with the siblings, then they will not know the information, and

not know for instance, that they should clean their rooms. Also they said that they think mainly about fulfilling the first needs – to get something to eat, to go to the hospital when they are sick. Other things are secondary.

Sabine: I think the biggest need of a family of orphans is a leader, a person in charge. The burden of this responsibility is much greater than their capacity - physical, intellectual, moral, all that. So, in my opinion, this family has a special need. But for others, when the head of the household, for example, is 16... We have lots of experience, we have families where the head is 21, for example, from 18 to 21. They are at the age of majority. They are mature. And everything is different if it is a boy or a girl.

Michelle: How is it different?

Sabine: We have lots of experience when the head is a girl, when the leader of a household of orphans is a girl, all the members are together, all the members are united. No one leaves the family. But when it is a boy - to the winds, all the members for themselves. I have lots of experience. I have worked in this program for 10 years. Every time the head of the household is a boy, we have had problems. They have no solidarity. Everyone is for his side. The family is completely disorganised and they do not succeed.

A broader perspective on barriers to health care was given by one manager from NGO 4, a Swiss-trained nurse. Heather acknowledged the constraints to children's health that are beyond their control. Basic things such as clean water and nutritious food are difficult to obtain. Due to geographic isolation, accessing care at a health center may require a day (to walk there, access treatment and come home). People may be hesitant to go because of the time commitment involved, and because the symptoms of malaria are non-specific.⁴⁹ She also noted that malaria can be difficult to diagnose, and sometimes people receive treatment they do not need. They come to the health center with a fever, and are immediately given malaria medication or antibiotics without a proper examination, because the staff are familiar with the usual things they see.

The shifting interests and agendas of the international community and the national government lead to constant changes in NGO programming and beneficiary criteria.

⁴⁹ They include flu like symptoms; body aches, fever, headache, nausea and vomiting.

Furthermore, the desire for progress, or the need to demonstrate to donors that funding is making a difference, means that assistance to CHH is often cut short. NGOs grapple with selling their programs to donors, appeasing government health care agendas, and integrating vulnerable CHH into programs with limited resources, all in the midst of an environment that presents challenging logistical constraints. As a result, children's perspectives and concerns about malaria frequently have little consequence.

4.2 Community Members

There was a great deal of diversity in my sample of community members whom the children had identified as sources of support.⁵⁰ Of the nine people interviewed, one was involved in local leadership within the community, another was a *Nkundabana* for an NGO, some were relatives who live close by, and others were neighbours of the children. The interviews revealed that the role and status of the community member, as well as their gender, influenced their perspective and response to the CHH. Other themes touch on societal tension and social ideas about age and gender that influence societal attitudes and responses to CHH.

4.2.1 Local Community Leader

One of the members that I interviewed was a volunteer leader of an *umudugudu*.⁵¹ Claudine, a head of a household of three orphans, had referred to him as someone who had given her and her siblings health insurance. His perspective on the household, and the type of support he gave to the household, illustrated local government strategies

⁵⁰ Some of the community members were identified by all the children in the household, while in other cases, only one child identified the community member. This was often the case when the community member's support was through structured or formalised avenues. For example, if a community member was a volunteer for an NGO, or involved in local level governance, it was usually the oldest child that had the most contact with them.

⁵¹ *Umudugudus* are a collection of 50 houses, governed by locally elected unpaid leaders.

directed at the poor and vulnerable in communities. He emphasized the formalized community structures that were supposed to offer support to the CHH.

Michelle: Does anyone teach them (Claudine and her younger siblings) how to take care of their health, how to take care of their body, to make sure they do not get sick?

Christophe: In the umudugudu committee leadership, there is one that is responsible for the welfare of the community. He teaches them to take care of themselves, to leave bad habits, so they may go to school and leave bad things.

Michelle: How does the *umudugudu* help them?

*Christophe: We prevent ourselves from backbiting⁵² them, so they will not be traumatized. When it is time for cultivating, we prepare umuganda,⁵³ and people go and cultivate for them. Another thing is putting them on the list of the poor, so when they get any help. They get *mutuelle*. And if there is any food from the high leadership, they can easily be the first to receive the food.*

Michelle: So the poor in your *umudugudu* receive *mutuelle* for free?

*Christophe: Yes, free – no price. The criteria we follow is that we start with the orphans, then we start with those who don't produce: widows, old women and old men. We have a limit; we can only give out 23 *mutuelle* cards.*

In spite of local government efforts to provide health insurance for vulnerable groups, there was only one other household in the sample who had received health insurance from the local government. A few households had received health insurance from an NGO until that assistance was phased out. Nine households did not have *mutuelle*. It may be that because some children were enrolled in NGO programs, the local government assumed that the NGO would be providing *mutuelle* for the children.

4.2.2 NGO Community Volunteer

One community member I interviewed was a volunteer *Nkundabana* for an NGO that was working with OVCs. Epiphanie worked with 39 households, including two in my sample, Household A and Household B, although only Household A referred to her as

⁵² “Backbiting” was a term that came up often in the conversations with the children in reference to community responses. The children would use it to describe the malicious talk of the community about them.

⁵³ Community work projects.

a source of support. Marie-Claire, the head of Household A, frequently referred to Epiphanie as someone who gave her practical assistance. Epiphanie had taught her how to grow vegetables, and she assisted her around the house. In fact, Epiphanie was at every interview that I had with Marie-Claire and her brother Alexandre. When I went to interview Epiphanie at her home, Marie-Claire was sitting in her living room. In contrast, the other household for whom Epiphanie was a mentor never talked about her. Epiphanie told me that she did not interact much with this other household, because they received assistance from an elder brother who was living beside them.

Epiphanie's role as an NGO volunteer gave her a particular vantage point on community interactions with CHH and perceptions of orphaned children. Epiphanie described the tension that exists between some children and their relatives due to distrust and beliefs about the relative's involvement in the parent's death. In Marie-Claire and Alexandre's family, when their mother had died, the children and their father blamed the family for charming her. Charming, according to Epiphanie, involves demons and evil spirits that cause someone to die. When the father of the children died, the relatives had nothing to do with the children.

Epiphanie: Their relatives don't like them. Their grandmother doesn't like them, she doesn't care. One day Alexandre was beaten by some people, and I went to report this to the leaders, and the family did not do anything.

Epiphanie talked about other influences on community attitudes to the CHH. She suggested that stigma associated with AIDS was an underlying reason for why communities ostracize those CHH whose parents had died from AIDS.

Epiphanie: They become like cast people. Some people think they have AIDS, and they are taken out of the community and they don't want to come near them. It is ignorance. People do not understand that AIDS is a sickness like any other sickness. They throw them away, they don't like them.

This was in contrast to what another community member said about stigma associated with HIV/AIDS. Esperance was a neighbour of another household, Bernadette and Filaline.

Esperance: Yes, AIDS is a problem. There are many children who are orphaned because of AIDS. When someone gets AIDS they teach them to go to the hospital to get medicine. Before, we did not go near their house – those with AIDS – because we did not know how we could catch AIDS and we thought you could get it in any way. But now we know that you can get AIDS from sexual relations, so now we go and visit and we are friendly with those people.

The variation in the two responses illustrates the complexity of societal perspectives (and perhaps the reality of two different communities with differential access to health training). Epiphanie's comments illustrate an attitude in Rwanda that may slowly be disappearing due to heightened efforts on the part of the national and international community to provide education about AIDS in Rwanda. This may result in decreased marginalisation of CHH.

Epiphanie also identified the age of a child in a CHH as a factor that influences community support. She noted that relatives were both more prone to assist children when they were young and more likely to take advantage of them. She used the children from Household B as an example.

Epiphanie: Like Marceline's family.⁵⁴ They only gave her a small piece of land. They did not give them a big portion of land. They use the land of the girl freely, they do not contribute to her, they use the land themselves. So when she gets married, she has little.

⁵⁴ Her elder siblings are married and have moved out of the house.

4.2.3 Relatives

In my sample of community members, there were five relatives identified as sources of practical support or advice. One was a family patriarch,⁵⁵ the oldest paternal male relative alive, and the uncle of the household of boys. Three relatives were paternal or maternal aunts, all of whom were single mothers. The last relative was an older cousin. Again, in the conversations I had with these relatives, it was evident that their particular place in society and in relation to the children influenced their perspectives and the assistance they gave the CHH.

4.2.3.1 *Family Patriarch*

Remy was the paternal uncle of Philippe and Leonard, and was identified by Philippe as a support. It was not clear to me how he was related to the other two boys in the household, Thierry and Edward.⁵⁶ However, Thierry and Edward also said they admired Remy because he came and gave them advice. Remy was the eldest man of a number of relatives who lived on the same hill.⁵⁷ The two older boys were trying to pay off debts incurred by their father during the genocide, and were selling off family land to gain some disposable income. This had created tension between the boys and their older siblings who had since married and moved out of the house. The uncle gave advice regarding the land and mediated between the boys and their older siblings.

As this situation exemplifies, repercussions from the 1994 genocide are played out in the lives of the CHH. Remy identified the challenges facing these CHH as a result.

⁵⁵ In pre-colonial times there were stronger lineage relations, with the male head of a lineage controlling access to land (de Lame 2005). Today, families tend to be more individualistic, but lineage relations persist. The head of a patrilineal group is the father of brothers, or his successor whom he designated before his death. Households belonging to the same lineage usually live near one another, unless one member has acquired land outside of the succession process. Lineages typically have a two to three-generation history (de Lame 2005:129-130).

⁵⁶ It was unclear to me if these two were maternal or paternal cousins of the older boys.

⁵⁷ Remy's deceased brother was the father of Philippe and Leonard. Remy's children, as well as his nephews and nieces had begun to marry, and family land was being divided up.

Remy: The problem that they are facing is that there are many in the house, and they don't have enough food. The other thing is that people come and attack them and say "your father destroyed this and these things, we need payments for them." You can never say that you don't have anything when you have land, a cow. However, you need these things to live, you can't sell them. It is a challenge. In most cases, they charge them the animals their father ate, or the tiles he took. But in most cases, it is the animals that he ate.

Another challenge that Remy identified had to do with the impact of the new inheritance law in Rwanda, which now includes females as beneficiaries of land.

Remy: The land remaining is for the two boys (Philippe and Leonard) and three girls. The older brothers have already their share – because they are married, they got their land already. They could not marry without getting their land. We will try and divide the land into small pieces, even if someone gets 20 cm. We will do it. That is what the government wants. The government says now, even if a girl is married, she must get a part of her inheritance that is the law of the government. It must be equal. They say that boys and girls should be the same.

Other community members identified the issue of land scarcity in Rwanda, and it emerged in the discussions with the CHH. It is a significant issue that contributed to the tension in families and in local communities.

4.2.3.2 Aunts

The three aunts in the sample, Grace, Mechthilde, and Rachel, were all single mothers. Two of the women were widowed, and the other, a mother of two children, was dependent on her parents, and lived with them. As single mothers, all the women were vulnerable members of Rwandan society. One told me that she was in conflict with others in her community because they wanted her to return to the area of her birth so they could take her land. Additionally, the aunts were responsible for the care of their children and the household, as well as trying to earn a living. Each of these women displayed compassionate insight into the lives of the CHH. All were identified by the children as providing them with practical support when they were sick, and in assisting

them with their basic needs. All the women lived in close proximity to the children, and saw them on a regular basis.

The perceptions that these three women had of CHH underscore the poverty faced by children. They were deeply aware of the extreme lack in the children's lives.

Grace: The biggest problem that they have is the standard of living. There are four things that they struggle with. They need clothes, they need medical insurance, they need to have a house and food, and they need someone to be near them to advise them and to encourage them. This is the same struggle for all children without parents.

Mechthilde: It is to be poor, and you do not have true ideas. Because of poverty, they worry. I know that they want many things. Sometimes they tell me that they have no field to cultivate, or no money to pay someone to cultivate their fields.

Rachel: There are two problems, their well-being, getting food and clothes, and another problem is getting school fees.

Each of the three women talked about the practical support that they gave to the children.

Their responses reflected what the children had told me about the type of assistance they received from their aunts.

Rachel: I help them in different ways. If they come from school, and they don't have any food, I give them food to eat. I give them water if they don't have water. Or on Sundays, when they do not have firewood, I go with them to collect firewood so that they won't be lonely, and so they won't say "If we had someone to help us, I could do it quickly."

Mechthilde: I see them every day. When they fall sick, I come to visit them; I cook porridge for them, so that they will feel better. When their parents died, I tried to teach them how to cultivate. They would come to my house, and cultivate, and I would come to their house to cultivate.

However, one of the women told me how her own poverty and circumstances constrained her in the type of support that she could give to her nieces, Cesarie and Yvette.

Grace: Sometimes they do not have enough food, or ask for advice about a problem. Cesarie works at the market, and many times she has no money, and many times she comes here and says she has no money. She came here asking me for 1,000 RWF (\$2 CAD) today, and I didn't have any to give her. She left and she was furious. Generally, I help with food. But when they have visitors, like boys, they come to me and ask me for advice, because they know their behaviour. If they have problem with

wood, I give them some wood to cook with, or when they have conflict between themselves, I try to help them to resolve it together to unite them. Food is the biggest problem I help them with. I may have sweet potatoes in the field, and I give some to them. Or perhaps they come here and there is food, and they eat them, and it is finished, and so we have none.

This theme of lack and the difficulty in sharing what little one has with CHH may be a significant barrier to community assistance of CHH. As a local level community leader, Christophe was aware of the widespread challenge of poverty.

Michelle: What do you think is the biggest problem for households like Claudine's who have no adult living in them?

Christophe: The problem of hunger. Clothes and hunger. They cannot work for themselves. They don't know how to cultivate. They just go there and there is no good harvest, because they are children. That is why they have a lot of hunger. They don't have the energy to cultivate what can feed them, and community members don't usually give them food because they themselves have a problem of food. They have many children, and if they give them something, their own children have nothing to eat the next day. All that is a result of producing so many children that you cannot take care of them.

Widespread poverty may result in communities projecting the responsibility of CHH onto relatives, or associating assistance with charitable acts done by "Christians," as one community member told me. Others see the training of the children as the responsibility of the government.

Michelle: Now that their parents are gone, who teaches the children how to cultivate?

Thomas: They have an older married sister who sometimes helps them, and there are Christians, who are members of the Catholic church who sometimes come and help them, even us, sometimes we help them by advising them.

Michelle: Does anyone in the community teach the children how to grow their crops?

Epiphanie: (An NGO) used to teach them with an agronome (person in charge of agriculture for the region).

Michelle: No one in the community comes and teaches them?

Epiphanie: There is an agronome from the sector office, and other specialists in the sector. They usually have communal meetings and people below 17 years of age are taught how to cultivate.

4.2.3.3 Cousin

Over the course of the interview with Collette, a cousin of Valency and Athanase, the theme of obligation became apparent. Collette explained why she had moved in for a few years with her cousins and then back to her brother's house.

Collette: At their mother's death, my mother ordered me to move in with them, as a member of their family to help them. Their brother (who has since moved out of the house, and lives in Kigali) was in Primary Six (last year of elementary school), so it was hard for him to care for them.

Michelle: So you lived there for four years. Why did you come home?

Collette: I lived there while my mother was still alive. After she died, I came back here because there was no one living in the house, no one to cultivate. My brother was living here, but sometimes he goes to work.

It was apparent that her mother had felt an obligation to care for her niece and nephews who were orphaned, and so she had instructed her daughter to move in with the children. However, once the mother died, Collette moved back home, where her brother was living. Not all family members feel the same sense of obligation to care for their orphaned relatives.

When talking about barriers to health, Collette identified the children's psychological well-being, linking it to the loss of their parents. This theme was also evident in other interviews that I had with community members.

Collette: Anything that you do for them, they are not happy because they do not have their own mother. That is what I observed, because when they meet with something, they say it would be better to have our mother. For me, to have a mother, it is very good, otherwise when you have a problem or a question, you don't have anyone to talk to, no one to give you advice.

Michelle: What do you think are the main problems facing these children?

Epiphanie: The children usually have constant problems. They are not usually happy; they are sad. The biggest problem they have now is feeling lonely. They taught us (the NGO for whom she volunteers) that those not going to school should go back to school. Poverty, and not having enough food to eat.

When I asked Collette what Valency and Athanase needed to learn about their health, she identified AIDS and malaria. Some of the other community members said

that malaria was not a significant problem, claiming that preventative measures had helped in alleviating malaria in Rwanda. Others talked about how the environment and the rainy season provided a healthy habitat for mosquitoes, and how malnutrition meant that people were more susceptible to malaria.

Thomas: Yes, it (malaria) is here. But there are preventative measures that have been taken. Supa nets (mosquito nets) have been distributed, clearing bushes has been advised, draining water, it is now improving, so there is less malaria.

Esperance: Many people suffer from malaria here because we have many forests and the food is not enough and it is bad. People eat sweet potatoes without vegetables. It means that you are weak and you get no vitamins, so you can get malaria easily, you cannot fight the sickness.

Remy: Yes, it (malaria) is a problem, but it has decreased because of supa nets. But it is a problem when it rains, there is a lot of malaria.

In contrast to the diversity of responses about malaria, the majority of the community members said that AIDS was an issue in Rwanda. The awareness of this issue within their communities illustrates how much attention the disease has received nationally.

4.2.4 Neighbours

One community member whom Household I had identified as someone who gave them advice had been a friend of the children's parents. He was retired from his job as a cook in a secondary school, and was obviously wealthier than many others in his community. His house had glass in the windows and brightly painted shutters, as well as LED lights in each of the rooms hooked up to a battery. Although he said that he sometimes assisted Gilbert, the youngest, with school supplies, he talked mainly about the advice he gave to Laetitia, the oldest in the household.

Thomas: What we can advise them most about is AIDS. They should prevent themselves from bad behaviour, especially fornication, and they can then prevent themselves from AIDS. Especially that young girl. She can easily get an unwanted pregnancy. Even if she gets sick, the AIDS can

pass through it. Other things are minor, but those are the important things they must learn.

The underlying idea was that if the children followed the health care instructions that were widely disseminated, they would not get sick.



Figure 4.3 Thomas, during the interview in his home. Photo: Michelle Hardy August 2008

The theme of self-care was apparent in many conversations with the community members – self-care in accessing treatment, and that health care was the responsibility of the individual. Community members rarely said that they went to the children’s house to help them when they were sick, or that they accompanied them to get treatment.

Michelle: What should children do to stay healthy?

Epiphanie: Maintaining their health and their body weight, following the government orders – the government is sensitizing people to construct shelves to put their plates on, that can prevent their utensils from getting dirty, and to build beds, so they sleep on a bed. And even using a mosquito net – it can prevent them from getting sick.

Grace: I tell them to prevent themselves from having sex, not to use a razor, or get injections and not to go get private injections. I learned this from the radio, from school and from training on AIDS. People get worms by not drinking potable water, eating food that is not well cooked, especially meat. To use unwashed plates, to eat without washing hands, and to not wash what I am going to cook.

This idea of being responsible for one's own health did not mean that the community members were unaware of the challenges facing the children. More likely, they were repeating what they had heard at community health training or at health centers prior to treatment. When I closely questioned the community members about whether or not the children were able to implement the health care instructions, they did identify specific challenges, associated with the children's impoverished environments.

Michelle: But what about the mosquito net? Do the children use them?

Epiphanie: Some have them. Most of them got old, even mine is now torn. They last a year and a half. They then get torn in the middle. They (the NGO) had given us some insecticide to treat the net, and told us that if you treat it with the insecticide it would last five years. But that is not true. The insects get there and they do not die.

Michelle: Are they able to provide enough food for themselves?

Rachel: No.

Michelle: So where do they get food then?

Rachel: They divide the quantity of food that they have for each meal, because they do not have the food in the garden. For example, food that would be for one day, they divide it, and use it over two days.

Michelle: Does anyone give them food from around here?

Rachel: No one gives them food.

Michelle: Can you tell me some practical things that children should do so that they do not get sick?

Rachel: Cleanliness, good feeding and drinking clean water. Nothing else.

Michelle: Is there clean water to get here?

Rachel: We fetch from the pipe. But when you have left the water for some time, there are microbes in it.

Michelle: So what are you supposed to do?

Rachel: You can boil it.

Michelle: Do you boil your water?

Rachel: No, we don't boil it.

Michelle: Do the children boil their water?

Rachel: No.

Michelle: Why not?

Rachel: There are few containers to put the water in.

Esperance was a neighbour whom Household F had identified as a source of support. Esperance seemed to be particularly aware of the vulnerability of the girls in

CHH who were living in her area, and noted that the constraints of their circumstances had prompted them to engage in health-risk behaviour.

Esperance: Sometimes when she (Filaline) does not have enough money, she goes to engage in prostitution to make money in town. In general, something that causes a girl like that to go to town and to make money through prostitution, is because of a lack of money. She is living badly at home, there is nothing to eat at home, so she prefers to go where she can find money. It is a bad life here in Rwanda.

Esperance was trying to expand her soap-making business. She was interested in hiring the girls from the CHH in order to give them an alternative way of making money.

Although none of the girls had disclosed to me that they were involved in the sex-trade, they might have considered it a viable source of income, considering their economic constraints. Epiphanie had also noted the vulnerability of girls in CHH.

Epiphanie: After the war, there was a big problem of unwanted pregnancies from the children I care for. Like now, I have four girls who are pregnant. Boys come and deceive them and they get pregnant. They get pregnant and produce, and the fathers of the children, they don't care for the children. Except for one, he admitted that he is the father, because they reported and it was proved that he was the father of the child.

Vulnerability due to gender and the particular constraints placed on women was very apparent in the conversations that I had with the women in the sample.

Esperance: The man is the leader of the house. The woman cooks, she makes the husband's bed, she sweeps. The man controls the house. If necessary here in Rwanda, a woman can work to get money to buy clothes for her husband. Girls must cook, wash dishes, girls sweep and wash clothes. The boys get firewood, and both children get water.

Epiphanie: Every umudugudu has a person in charge of health. So once a month, they come together and they learn about prevention of sickness and about health. Especially, it is the men who come, and women remain at home. Women like doing housework and they don't have time to come to the meeting. It is because they are very busy doing the work and some of their husbands don't allow them to come. They tell them to stay at home while they go. They (women) don't have the liberty that they want.

Epiphanie's comments illustrate the limited opportunities there are for women, and how their household roles isolate them from interaction in the community. In contrast, men are free to walk around, according to another community member.

What I found interesting were the gendered perspectives of the community members. The men in my sample offered very different perspectives on gender roles in Rwanda. Their comments mainly centered on the discourse of development: Rwanda was now a developed nation, so there was no more inequality.

Thomas: Before, it was different, girls did different things. Now they do the same thing. It changed since the government came into power. It started in 1994. Now in Rwanda, there is equality in gender, men and women are the same, especially in the law. Before, there was segregation, where men and women did their own things, but now they are the same. They are equal. Even in the umudugudu, even in inheritance, they have to inherit the same things from the parents.

Remy: Before the law, they were different, but now they have the same. Because now there is development as knowledge, a girl can do the same things that a boy does. But before, a girl could not do the same things as what a boy did. Before, girls could not go to school, they could not have a say, or have a word that people would give them value or agree. But now, they go to school, they even have words to talk, they can even be leaders, but before they couldn't, that is why even the law has changed.

Women hold positions in political governance in Rwanda, but in rural households they are still considered to be under the authority of the male head (if there is one). Rwanda is certainly making great strides to promote positive changes, but the women's vantage points offer a perspective on the present day constraints on rural Rwandan women. Consequently, girls in CHH live in a social milieu that offers conflicting messages about their role and position in society and in the household. These messages both encourage and constrain them in their decision-making and in their health seeking initiatives.

4.3 Chapter Summary

NGOs and community members represent formal and informal means of support for CHH. My research into the extent that NGOs draw upon CHH's perspectives and concerns about malaria in their programs found that this is not a priority for NGOs. The current practice of integrating CHH into programs with other beneficiaries also meant that the children are further constrained from expressing their particular constraints. In the interviews, NGO personnel focused on the constraints that they were under that impacted their program focus and the approaches that they used in health intervention. Malaria represents only one health topic that some NGOs cover, and underlying determinants are rarely addressed. NGO staff said little about the malaria component in their programs, because it was not a primary focus for any of them, and because they relied on standardized approaches to malaria intervention.

My focus on community members' perceptions of CHH and their response to CHH in their communities indicated that community members see children as responsible for their own health care. Although some members acknowledged the particular barriers facing CHH, many of the community members were constrained by their own impoverished conditions in their ability to offer practical help. Additionally, the hierarchical nature of community life in Rwanda, social tensions due to repercussions from the genocide, and land scarcity affect community response to orphans. Consequently, some members identified NGOs as being responsible for CHH. Moreover, rural Rwandan perceptions on age and gender affect community perceptions on the vulnerability of CHH.

The perspectives of both the NGO staff and the community members, as well as the discussion from the previous chapter on household characteristics, provide a

contextualised backdrop from which to understand the children's experiences and perspectives on health and illness. The following chapter centers on the CHH's perspectives about malaria and their other health concerns, and examines the influence of poverty, age and gender on their understandings, experiences and responses.

CHAPTER FIVE: CHILDREN'S PERSPECTIVES



Figure 5.1 Left: Yvette, 14 Her drawing of what she does when she is sick (top) and when she is healthy (bottom). Photo: Michelle Hardy July 2008

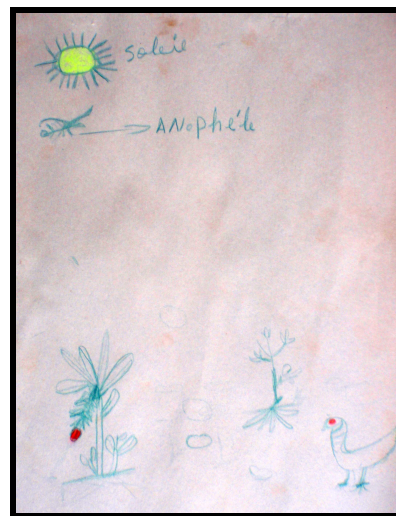


Figure 5.2 Right: Vincent 16, His drawing of the things that make him sick (top), and keep him healthy (bottom). Photo: Michelle Hardy July 2008

This chapter centers on the perspectives of the children in CHH who participated in the research, and presents their responses in relation to the first two research questions of this project. The chapter begins by outlining the children's perspectives and experiences of malaria in relation to their other health concerns. I then examine how insufficient access to resources shapes the children's understanding, experience and response to malaria. Economic and social poverty is a lived reality for each of the households of orphans and it influences their susceptibility to malaria as well as their ability to initiate preventative measures and access treatment. Lastly, I focus on the influence of age hierarchies and sanctioned gender domains and roles, as evident in the children's understandings, experiences and response to malaria.

5.1 Children's Perspectives on Malaria

This section of the chapter provides an overview of what the children said about their experiences of being ill with malaria, the current education on malaria that

influences children's perceptions, what children identified as the causes of malaria, and the prevention methods and the treatment options they identified for malaria. Their responses are compared to their comments about their other health concerns. The significance of malaria in their responses needs to be considered with the understanding that the children were aware that I was particularly interested in malaria. Additionally, while doing the drawing activities and responding to my questions about malaria, children may have associated me, a white westerner, with an NGO.⁵⁸ Consequently, their responses may be somewhat biased toward what they had been taught in formal trainings versus what they experienced or had learned through informal knowledge transfer.

5.1.1 Illness Experiences

When I asked the children to identify their illnesses, almost all identified malaria. Most of them distinguished malaria from other health concerns by noting the differences in the length of an illness episode, symptoms, and treatment choices. There was a great deal of variation in their responses to my question "how often do you get malaria?" The frequency ranged from chronic malaria to rare occurrences of the illness. However, very few children said that they got malaria a lot.

*Even yesterday I was sick from malaria, but now I am improving.
Alexandre, 15*

It has been three years since I had it. Claudine, 15

Children usually said that when they were sick with malaria, they had it for one to two weeks, although a few of them said they were sick with it for three weeks to a month. They also differentiated their experience of malaria from their other illness experiences.

⁵⁸ This appeared to be the case when, during the drawing activities, some of the children would tell me they did not know how to draw. A British teacher who was doing teacher training in Rwanda told me that there is a strong emphasis on the "right" way to write and draw in school. Children are expected to produce writing and images that satisfy the criteria sanctioned by the teacher.

When you are sick from malaria you feel weak, you don't eat, you don't drink, you feel so weak. It is different (from other illnesses), because you can get a cough and walk and do everything when you are sick from a cough. But when you are suffering from malaria, you cannot do anything. Yvette, 14

When you feel worms –you feel them in your belly. But with malaria, you are weak, you feel cold, and you are sick all over the body. Désiree, 13

Children tended to identify malaria as a serious threat to their health; only a few considered malaria less threatening than other illnesses.

Leonard: With throat infections, you sit in the sun and stay in bed, but malaria is not the same, because malaria you can relax outside.

Michelle: Which one is more serious?

Leonard: Throat infections.

Sometimes in the interviews, as evident in the following discussion with Yvette, the children would use “malaria” interchangeably with “being sick.” I also noticed this in some of the conversations I had with community members.

Yvette: What can cause me to get sick from malaria – not being clean, sleeping where there is no mosquito net, it can cause me to get sick.

Michelle: So if you are umwanda (dirty), you can get malaria?

Yvette: It depends on the dirtiness. It can cause you malaria or not.

Michelle: Is it the same type of malaria that you can get from being bitten by a mosquito?

Yvette: No. Malaria that is caused by mosquitoes you must go to the hospital. But the one caused by dirt, you can easily take herbs and get well.

Michelle: When you get malaria from dirt – do you feel as sick as you do when you get malaria from mosquitoes?

Yvette: When you have malaria that is caused by mosquitoes – you vomit yellow things, when you get malaria from being unclean, you feel weak and don't have an appetite. But it is the same thing as the malaria that is caused by the mosquito.

When using “malaria” in exchange for “being sick” children would usually identify other vectors besides mosquitoes, but when talking about malaria, they usually identified mosquitoes as the cause.

Importantly, children told me that they suffered from other health complaints more often than they did from malaria. These complaints included headaches, stomach aches,⁵⁹ sore throats, coughs and influenza. Less frequently, children also said they suffered from sore body parts, abscesses, stomach ulcers, sore eyes, cracked skin, or rashes. However, when they had malaria, they said they tended to be sick longer than they were with these other illnesses.

When I asked the children to identify what they were worried about in relation to their health, their answers were broad, including daily and future concerns that had to do with their social, psychological and physical needs. These concerns included where they would work in the future, how they would divide up their land, their lack of food, and concerns for their safety. A few referred to malaria and AIDS. The breadth of their answers may reflect the fact that in Kinyarwanda the same word, *ubuzima*, is used for “health” and “life.” Although I tried to clarify the question, I wanted the children to feel free to interpret it as they wished.

Not only were few children explicitly worried about malaria, but somewhat surprisingly, even fewer children cited AIDS⁶⁰ as a central concern. In spite of the high probability that many of the children’s parents had died from AIDS,⁶¹ most children only said they were worried about AIDS if I asked them directly. Commonly they said they

⁵⁹ I found it surprising that the girls never talked to me about reproductive health issues, e.g. menstruation.

⁶⁰ I purposely asked the children about AIDS in the interviews because I wanted to compare the children’s answers about malaria with a health topic that was currently being addressed in Rwanda. See Appendix 14.

⁶¹ Some children disclosed that their parents had died from AIDS, others said that they had been sick when they died. Sometimes the community member whom I interviewed in association with the household would tell me that the parents had died from AIDS. Most of the children had probably not been tested for HIV/AIDS. One girl did disclose that she had recently been tested, and that she was negative. Her younger sister was HIV+ and was taking anti-retroviral medication. There are mixed messages in Rwanda regarding the cost of AIDS testing. It is supposed to be free, but one NGO who worked directly with CHH thought that there were costs involved. Rather than asking the children directly if they were HIV+, I asked them about prevention, and if they were able to prevent themselves from contracting HIV.

were worried about it because they knew that people with AIDS “died badly,” and that there was no cure for AIDS.

5.1.2 Malaria Education

The children’s responses to my questions about malaria prevention, cause and treatment clearly reflected the prominent place of malaria in the national health agenda and the health instruction they receive at school, through NGO training, and through community health training. Although children talked about informal teaching occurring through peers or siblings, when talking about training on malaria, they most frequently identified a government institution or supported initiative, or an NGO as the source of their knowledge.

One avenue of training on malaria occurs at local health centers, where people go to access biomedical treatment for malaria. There, health training is given each morning, primarily on AIDS, TB and malaria. I observed one such lesson at a local health center. At 8 am, there were a number of people already gathered at the health center. People tend to arrive early, in hopes of getting an appointment that day. Before they could receive their treatment, everyone was told to sit on rows of concrete benches while the daily health message was given. That morning, the talk was on malaria, and the prevention messages that I had heard from research participants were repeated: clear bushes from around the house to stop mosquitoes, get rid of stagnant water, use mosquito nets, and shut windows to stop mosquitoes from entering the house in the evenings. It was also emphasized that it is mosquitoes that cause malaria.

In school, children are taught the same messages about causation and prevention of malaria. One research participant, a sixteen-year-old boy in his fourth year of primary

school, showed me one of his notebooks. Neatly copied down in French⁶² with red and blue ink were the prevention messages of clearing bushes and sleeping under a mosquito net. He had also listed the danger of stagnant water, which encourages the breeding of mosquitoes – in particular the *Anophele* mosquito that causes malaria.

Regardless of their access to formal education, children were well versed in biomedical⁶³ notions of cause, prevention and treatment choice for malaria. Importantly, the information on malaria that they shared was predominately recited or intellectualized knowledge, evident in the standardised list of causes, prevention methods and treatment. I differentiate intellectualized knowledge from experiential knowledge, which is gained through personal experience of sickness.

5.1.3 Discourse on Causation

When the children were asked to identify what caused malaria, many of them identified being bitten by mosquitoes.

Mosquitoes come and bite me and cause me to get sick from malaria.
Marie-Claire, 18

These are mosquitoes, when they bite you, you catch malaria. Athanase, 8

However, very few of the children commented on other symptoms of mosquito bites, such as feeling itchy around the bite. Children most frequently cited school as their source of knowledge about malaria. Less frequently, they referred to training at a health center, community health training, or radio programs.

⁶² In Rwanda, school lessons are abruptly switched to French in the fourth year. Lessons are written on the board, and if the children have notebooks and pens, they are copied down in their books. Up until that point, children are taught in Kinyarwanda, the local language, with some French lessons being taught. However, when I tried to talk to this boy in French or to other children who were in Primary Four or higher, the most that they could do was to respond by greeting me and telling me their name. The one notable exception to this was a seventeen-year-old girl who was in her second year of secondary school. She was able to communicate more in French and in English with me.

⁶³ Biomedical refers to “the tradition of scientific, biologically oriented methods of diagnosis and cure” (Brown 1998a:108). It is a medical system associated with Western cultures.

In school they told us that the female Anopheles mosquito is the one that causes malaria. I don't know what it looks like, but when it bites you, you get malaria. Gilbert, 11

All mosquitoes don't cause malaria, it is one mosquito called Anopheles that causes malaria. At the health center and on the radio they talk about it. Yvette, 14

The standardized or intellectualized knowledge also emerged in the children's ideas about causes of AIDS. However, a different sort of knowledge, a more diverse, experiential knowledge, emerged in their talk about health topics less likely to be covered by government services or NGOs, such as sore throats or sore body parts. When talking about the causes of these other concerns, the prominent theme was the environment. The children talked about the weather, sunshine, rain, and dirt as making them sick. Another theme that was apparent was their life conditions. The children talked about food issues that caused them to get sick, or their working conditions. What is common to all these things is that the children have little control over them.

5.1.4 Prevention Messages

Children most commonly identified mosquito nets, the cornerstone of government and NGO messages, as a means of prevention for malaria. Sometimes they did so because I asked them specifically about mosquito nets if they did not initiate it themselves in the interview. Children also identified the other prevention messages that I had heard at the health center. In reference to clearing bushes, a number of children explained that mosquitoes habitually stay in the bushes, and if the bushes are near the house, the mosquitoes can easily come in and bite them. Although most children said that they were able to clear the bushes around their house, I noticed that shrubs often surrounded their houses. The children also talked about clearing stagnant water from around the house, explaining that mosquitoes breed in the water, or that water encouraged

the presence of mosquitoes. To deal with this problem, the children said they tried to build channels to drain the stagnant water, or they dumped their wastewater in the bushes away from the house. The few times that it rained when I was visiting households, there was water everywhere, and it seemed that it would be very difficult to ensure that stagnant water could drain.⁶⁴



Figure 5.3 Bushes and the rain water collecting outside Household I.
Photo: Michelle Hardy August 2008

Some of the children also said they needed to shut the doors and windows of their house at dusk (6 pm)⁶⁵ to prevent mosquitoes from entering. We were never at the children's houses at dusk, so I could not observe them shutting their doors and windows. However, the children usually cooked inside, so I imagine that they would prefer to have access to whatever outside light there might be,⁶⁶ as well as ventilation for their cooking

⁶⁴ According to the lab technicians at a few health centers, the number of malaria cases seen at the centers increases during the two rainy seasons.

⁶⁵ Because Rwanda is situated near the equator, sunset and sunrise are at approximately the same time every day.

⁶⁶ Very few of the children who owned a petrol lamp had the fuel for it.

fires. Only a few children listed non-standard preventative measures for malaria such as good hygiene, keeping a clean house, and boiling drinking water.



Figure 5.4 Household P's bed and mosquito net. Photo: Michelle Hardy. August 2008

Although mosquito nets were described as a key prevention method, only four of the fourteen households had a mosquito net up.⁶⁷ Four other households had nets, but they were not hung up.⁶⁸ Those children with mosquito nets usually did not comment on treating them with insecticide unless I asked them about it. It was not something that they appeared to do on a regular basis. This may be because current malaria prevention initiatives in Rwanda are promoting the distribution or sale of nets that have already been treated (long lasting insecticide treated bed nets - LLITNs). However, on one of my visits, the head of a household described to me how she had treated the mosquito net that she and her brother used to own.

When you have a mosquito net, you put it in a basin full of clean water, and if you have the insecticide called Karisha, then you mix it with the

⁶⁷ This gave eight of the thirty-seven children in the sample protection from the mosquitoes while sleeping. Most of the siblings shared a bed or a mat to sleep on, although in two of the cases where there were mosquito nets that were not hung up, there was more than one bed in the household.

⁶⁸ The children's responses regarding mosquito nets will be discussed in the following sections.

water, and after you put in the mosquito net, and afterwards you dry it where there is no sunshine, because the sun removes the capacity of the insecticide to work. Then you dry it, and when it is dry, you put it back on the bed. Marie-Claire, 18

Insecticide for treating mosquito nets is available in town for 100 RWF, or 23 cents CAD, but not all households could afford that. One brand of insecticide includes an insecticide tablet that has to be diluted in water, a plastic bag in which to put the tablet and water, and plastic gloves. The detailed instructions are in French and English (languages that only those who have completed secondary school would know), although there are pictorial instructions as well. The package gives several warnings of the toxicity of the insecticide.⁶⁹ When Marie-Claire treated her net, she told me she did not have gloves, so she covered her hands with paper bags. I asked her where she had learned to treat her net.

It's the Nkundabana who taught me to do that, and she took me to some training, where I was told how to build a bed, using mud and sticks. There, malaria cannot easily attack you. Marie-Claire, 18

For health concerns other than malaria, school textbooks stressed the need to boil water for drinking, eat nutritious food, practice good hygiene, and maintain a clean house and dishes. These sanctioned health messages were evident in some of the conversations I had with the children. However, they much less frequently talked about preventative measures that were not on the national health care agenda. When they did, their words reflect knowledge that was acquired through other avenues, such as personal experience, or from interactions with others in their community.

When there is a lot of sun, it causes you to get gapfura – it's a sickness in the head. You feel that the head is so heavy, and the eyes are swelling. I usually get sick of it in the dry season. I try not to be in the sun after 11 am. I come home. At noon the sun is strong. Leonard, 16

⁶⁹ Household Q had previously used an LLITN. They complained of waking up with sore and swollen eyes and faces. They said they thought it was because of the insecticide.

5.1.5 Treatment Options

The local health arena in rural Rwanda is pluralistic, including local remedies, Kinyarwanda medicine, and biomedicine. Local remedies represent knowledge shared within the community. Kinyarwanda medicine involves the use of plants and herbs for various ailments, and people either treat themselves, or receive treatment from people who are known in the community as Kinyarwanda healers. Biomedicine is available at pharmacies, health centers and hospitals. Although the children identified all these treatment options in relation to their various health complaints, they most commonly identified biomedicine as their treatment choice when I asked them what they did when they had malaria.

I go to the health center to get medicine. It takes one hour to walk when you are sick. Kanobana, 16

Much like the messages associated with the cause of malaria and prevention methods, the message of going to the health center for treatment of malaria is strongly articulated through government-sponsored institutions and NGOs. It is taught at school, at the health centers, and by local level health promoters. It is a discourse that most children, whether they are in school or not, will frequently hear and readily express when asked about their treatment choice. However, it is uncertain whether or not they do access the treatment they need through the health centers or if they were simply reciting what they have been told to do.

The children's understanding of the biomedical treatment for malaria varied. One boy was on malaria medication at the time of the interview, and when I asked what it was, he told me he did not know. This was understandable because the tablets were folded up in a small piece of paper with the prescription written illegibly across one side.

A few of the children were able to tell me the type of medicine they took for malaria, while others described the regime.

Michelle: What do they give you at the health center when you have malaria?

Filaline: They give me amodiaquine. They gave me 15 pills, I took them morning, noon and evening. I finished the tablets, and then after some days I was well.



Figure 5.5 Béata's drawing of herself taking medicine she got from the health center when she was sick with malaria. The package of tablets is at the center. Photo: Michelle Hardy. July 2008

The dominance of the biomedical discourse in association with malaria treatment is evident in the lack of other treatment choices identified by the children. A few children said that they would initially treat malaria with Kinyarwanda medicine, but if they did not get better, they would then go to the health center. One girl told me that she used to take Kinyarwanda medicine for malaria,⁷⁰ but she was told at the hospital to stop doing that because Kinyarwanda medicine inhibits biomedical treatment from working well. Very few children said that they would go to a pharmacy to buy medication for malaria on their own, rather than going to a health center for testing and treatment. There were also a few who stated that they would wait and see if they got better on their own.

⁷⁰ Children identified plants called *giterezo*, *umuravumba* and *umubitizi ibishiswa bya barakatsi* as Kinyarwanda medicine that they used for malaria, which they said helped them get better.

In contrast to the prominence of biomedical treatment for malaria, the children drew from a variety of other treatment options for their other health complaints. This reflects not only the children's ability to determine their treatment options based on a number of variables, but also the focus of the national health care agenda. However, in spite of the lack of national attention to health concerns other than malaria, AIDS, and TB, people are still encouraged to access biomedicine instead of local or Kinyarwanda medicine. For example, some children that suffered from sore throats commonly sought assistance from a local practitioner who would rub their inner throat with a leaf wrapped around their finger. As the following exchange illustrates, some children said that they knew that they should go to a local health center instead.

Michelle: You said you got a throat infection – what did you do when you got it?

Vincent: There is someone from our neighbours, who helped me with it.

Michelle: What did they do?

Vincent: They rubbed my throat. He protected himself with something on his finger, and he used it to rub. Something like blood came out.

Michelle: Did it help?

Vincent: Yes.

Michelle: Did you have to pay him?

Vincent: Something.

Michelle: How did you know that he could do that?

Vincent: My neighbours told me to go to this man. Many people go to him, and he tests you. If he finds that you have a throat infection, then he can help you. But if it is not, he cannot help you. Many people go to him. However, the authorities told him to stop. They told him if they catch him doing it, he will be imprisoned.

Michelle: Why?

Vincent: Because many people went to him free, and they did not want to go to the hospital and the Rwandan government said everyone must go to the hospital where they can be tested well.

In spite of this strong emphasis on biomedicine, there was also the perception that some ailments could not be cured at the health center. This was evident a little further along in the same interview with Vincent. This exchange also illustrates the interplay of sanctioned health responses with community level knowledge.

Michelle: You also told me that you got poisoned before – can you tell me about that?

Vincent: I don't know who gave it to me, but I felt bad, and I went to a man, who is dead now, who helped me.

Michelle: What did he do?

Vincent: He took a razor and cut my skin on my arm and drank the blood and then he spit on the floor, and he took water and then spat on the floor again. Then he took some herbs and rubbed them onto my skin, and then he went home.

Michelle: How did you know that you had been poisoned?

Vincent: My neighbours said that I was poisoned and said to see the man, if not, to go to the hospital.

Michelle: Did it help when the man cut you?

Vincent: Yes.

Michelle: Did you go to the hospital afterwards?

Vincent: No.

Michelle: Why did you not go to the hospital?

Vincent: Because they cannot heal people who have been poisoned.

Children also said that health centers could not treat swellings, abscesses, or burns.

Children marshalled diverse treatment resources to deal with their range of health problems beyond malaria.

Michelle: When you have a headache what do you do?

Yvette: Sometimes I take Kinyarwanda medicine and I get well.

Michelle: What do you do when you get a cough?

Rosine: I take lemons, I wash them and chew them.

Michelle: What do you do when you have influenza?

Leonard: I mix salt with water, (on a banana leaf) and put it in my nose.

Michelle: What did you do when you got the abscess?

Augustine: I went to my neighbour and he squeezed it.

Cesarie: In the morning I can't see.

Michelle: So what do you do?

Cesarie: They told me to bathe with water from the grass in the morning.

Michelle: Who told you that?

Cesarie: I don't remember – many people say that.

Michelle: Does it help?

Cesarie: You can see a bit, but it continues.

Many of the children would treat themselves, having learned to identify herbal remedies from relatives, peers or community members. Other children would rely on a relative or a community member to assist them.

For children living in CHH in Rwanda, malaria is a familiar illness, one that they hear about quite frequently from government-sponsored initiatives, and often experience directly, but it is not their main health concern. Their responses to my questions illustrate recited knowledge, based on the formal training that they have received about malaria and about other concerns on the national health care agenda, such as HIV/AIDS. In contrast, what the children say about their other health concerns reflects experiential knowledge, illustrating that the children are given less information and support regarding these other ailments. However, the measures that they take in response to these health concerns, although not sanctioned, are more accessible to them.

5.2 Insufficient Access to Resources

The following section examines the economic and social barriers to children's understanding and response to malaria, and how poverty shapes their experience of the disease. Although the data is mainly derived from the children's narrative responses given in the last two visits to their household, it builds upon the indicators of poverty based on the household survey that were examined in Chapter Three.

5.2.1 Economic Scarcity

Schooling is one avenue through which children learn about malaria, as well as methods of prevention and treatment. It also represents access to a social network, which may be instrumental to health and well-being. However, access to schooling is constrained by economic poverty. Although primary education is technically free in Rwanda, children in CHH experience various forms of passive exclusion (Sen 2000). There are a number of hidden costs associated with education, including school uniforms (approximately \$11 CAD), supplies (approximately \$4), and teacher bonuses

(approximately \$3 CAD), which are sometimes paid directly into the teacher's pockets.⁷¹ Some households struggle with covering the costs of uniforms and school supplies. One household reported that the teacher regularly sent them home when they came to school without school uniforms or the required school supplies. They would stay home until the teacher finally sent a message saying they were allowed to return. In another family, the two younger girls told me that their teachers had told them they could not start the new term because the girls' oldest sister had not given them money to pay overdue bonuses.

A lack of money was also the most frequent reason children gave for not being able to carry out certain preventative measures for malaria that they had been taught and for other sicknesses, as well as the main barrier for accessing biomedical treatment. For example, thirteen of the fourteen households told me that they currently or previously owned a mosquito net. Three of these households had bought a net, and ten had been given a net by the hospital or an NGO. At the time of the research, six households did not own a net, four were using nets, and four others owned but did use the net. Among the six households who did not currently own a net, five of them had owned one, but they no longer had it, because it had gotten old, torn or accidentally burned. The children in these households identified their lack of economic means as inhibiting them from purchasing a new one. A mosquito net costs approximately 500 RWF (\$1 CAD).

These days we are getting sick from malaria because we do not have a mosquito net. We don't have the money to buy one. Alexandre, 15

Economic scarcity meant that the children had to prioritise and choose where they would spend their resources. In Household D, Cesarie and Yvette had told me that they could not buy a mosquito net because they did not have the money. During another

⁷¹ Teachers' salaries are augmented by bonuses that are approximately \$1 CAD per child per term (three terms/year). Each primary school handles payment of the bonuses differently.

interview when we were talking about why the girls did not have health insurance, Cesarie told me that they had “very many needs, especially food.” Evidence of other priorities could be seen on the windowsill in the room where we did the interviews. It was usually full of assorted jars of creams and hair products. In another room, the walls were covered with clothing hanging on nails. This was different from many of the other households, where the children were often wearing the same clothes on each of the visits I made to their households.

In spite of economic scarcity, the children showed resiliency and ingenuity in accessing treatment for malaria. Most of the children told me that they would go to a health center if they got sick with malaria. Some of the households in the sample had health insurance, which allowed them to access this option. For those children without health insurance, their initiative in making choices and making sense of their situation was obvious. One 16-year-old girl, Marceline, told me that she walked four hours to the *centre de santé* by herself when she last had malaria. She sold her rabbit to get the 800 RWF (\$1.60 CAD) she needed for medicine.

Some children would try other treatment options before going to a health center because they did not have the money to pay for malaria treatment.

Michelle: Have you got malaria since you have lived here in this house?

Thierry: Yes, I got it. When I got it, it was easier to get traditional medicine (Kinyarwanda medicine), to pick it, than to go to the pharmacy, because I did not have the money, and I wasn't that sick.

Michelle: Do you ever go to the health center when you have malaria?

Jean-David: When I am sick, Angelique (his older sister) goes and collects medicine (Kinyarwanda medicine) and I get well. But when I spend a month and a half not getting well, that is when I go to the hospital.

Living with few available economic assets, children struggle to find treatment that they can afford. I asked Jean-David's older sister Angelique where she gets the money to pay

for her brother's treatment. She told me that when she brings her younger brother to the health center, sometimes they charge them a lot of money, and other times they "forgive" them, and charge them 1,000 RWF (\$2 CAD). When they charge them a lot of money, they sell some vegetables in order to get the cash to pay for treatment.

Although the government is attempting to regulate pharmacies and health centers, medication can still be purchased in partial dosages if a client cannot afford the full regime all at once. Consequently, children may not be getting the full dosage that they require, and the malaria parasite can build resistance to malaria treatment.

Laetitia: I remember I went there, and I paid 1,000 RWF (\$2 CAD). And they told me that I needed more money, but because I didn't have enough money, they gave me less medicine. That was last year. It was at a health center for out patient care. I got medicine for one week or more, I think – I can't remember... It is difficult to get a taxi (public transport) to go there, so I walk. If I walk fast, and am not sick, it takes two hours, but when I am sick, it takes three hours.

5.2.2 Material Poverty

In addition to the significant lack of economic resources, insufficient basic needs also inhibit the health care practices of children living in CHH in Rwanda. The children are surrounded by material poverty, evident in the impoverished conditions of their households. Their houses have dirt floors, leaky roofs, crowded sleeping accommodation, minimal bedding, no running water, few cooking utensils, no ventilation for cooking fires, no electricity, no screens on the windows, and unhygienic latrines.

The effect of impoverished conditions on the prevention of malaria was significant. The mosquito net given to Cesarie by an NGO was torn and unusable after three years. Like the other children, she lived in a house that did not have screens, and if she wanted ventilation while cooking over a fire indoors at night, she would have to open

a window. She had had a particularly bad bout of malaria previously and had been sick for a month, yet she was very aware of her inability to protect herself.

What can protect me from malaria, like a mosquito? How can you protect yourself? I feel that there is nothing (I can do). Even when you sleep under a mosquito net, when you are walking in the morning, it can bite you. When you are seated in the evening, even when you are coming home in the evening, it can bite you. Cesarie, 17



Figure 5.6 Household Q's Kitchen. Photo: Michelle Hardy. August 2008

Other children referred indirectly to their impoverished home environment when they described how their nets were damaged, or why they did not have their nets hanging up. Sleeping quarters in the children's homes are not always separated from areas in the household that are used for other purposes. In one household, the net had got torn on some firewood that had been stacked in the corner. In Household Q, the five children actually said there was nowhere to hang up their two nets that was not in the way of their daily activities. The room that they used for sleeping, which was approximately 2.5 m²,

doubled as a storage area. Every morning they had to roll up their mat and mattress so that they would have space for food preparation and so they could pull out the kitchen utensils and other items they needed for the day. In another household, the mosquito net was burned when a petrol lamp was knocked onto it.

5.2.3 Insufficient Food and Clean Water

A significant theme evident in the children's discussions about their health was their lack of nutritious food and clean water. Malnourishment and chronic diarrhea result in a weak immune system, leading to a lower resistance against malaria and other illnesses.⁷² After malaria, one of the most common health complaints that the children cited was stomach aches, and another one was headaches. Both could be the result of malnourishment and unpurified water. Children said that if they had food, they ate two cooked meals a day, usually at noon and in the evening. They did not usually drink anything with their meals, and they did not eat snacks between meals. When I asked the children if they had enough food to eat, the children gave different answers. Some talked about being hungry, and others said that they usually had enough to eat.

All the time I am hungry, I have no energy. I do not have enough food to support myself. It is not the reason why I get malaria, but if I ate at the right time, and ate without being so burdened, and if I eat well, I will fight the sicknesses. When we don't have enough food, we eat what we have, what we don't have, we don't eat, so we don't eat. Marie-Claire, 18
We have enough food. Florence, 6

Most of the children grew what they ate. Their diet consisted primarily of sweet potatoes. It is a crop that can be grown all year in Rwanda, in both the dry and rainy

⁷² Lack of nutritious food and clean water affects overall health. Level of health is a significant factor in building and maintaining the immune system, which affects susceptibility to malaria (Dr. Terry Pearson, personal communication, November 8, 2007). From my observations, malnourishment was a significant issue for the children in the sample. It clearly had resulted in stunted growth. I had the opportunity to talk with Dr. Sara Stulac, a pediatrician working in Rwanda. She told me that malnutrition is a bigger issue than is realized in Rwanda. It results in stunting, developmental delay, and massive cognitive and physical development issues (Dr. Sara Stulac, personal communication, September 17, 2008).

seasons. The children also ate cassava, a staple starch that fills the stomach but has little nutritional value. Sometimes the children would be cooking *matoke* when I visited them, a type of banana similar to plantain. If the children had it, they might also add a green vegetable, like *dodo* or cabbage to one of the dishes.⁷³



Figure 5.7 Mealtime at Household J – eating cassava. Photo: Michelle Hardy August 2008

Many of the children talked about their steady diet of sweet potatoes throughout the dry season, and about the lack of variety in their diet. One boy explained the choices he had to make regarding what he could afford to purchase at the market. He had to decide between what was nutritious, what was affordable and what would last a long time without going bad.

If we eat sweet potatoes and beans – we eat them for a long time, without changing our diet, and they don't contain many vitamins, that is why he (his brother, Kanobana) gets sick. If we change our food, we only eat cassava. It is always the same. To get cabbage – it is only by chance, if I find them at the market and they are cheap. But many times I do not buy

⁷³ The diet of rural Rwandans not living in extreme poverty might consist of black beans, cabbage, tomatoes, *dodo*, carrots, avocados, peas, cassava, cassava leaves, *matoke*, sweet potatoes, Irish potatoes, and sometimes fruit, such as pineapple, passion fruit, bananas, and Japanese plums. Meat might be eaten on special occasions.

them because they are expensive, and so we do not usually eat them. When I have money, I want to buy beans (black beans), because they will last a long time, but the vegetables will not. Usually we do not buy fruit, but sometimes at the market, I buy one of them. And also we grow pineapples and sometimes we eat it. But we don't buy fruit. I bought fruit a month ago. But I do not usually buy them because I don't have enough money to buy fruit and to buy beans to bring home. Augustine, 18

A few children associated malnourishment with susceptibility to malaria, however, more often they talked about it in reference to stomach aches.

Michelle: What do you get sick from the most?

Béatrice: Stomach aches.

Michelle: What is it that makes you sick?

Béatrice: Bad feeding – because a person does not eat good things. We usually eat sweet potatoes when we get them. Sometimes they are not ripe, and we eat them too early. Sometimes we are hungry and they are there, and we uproot them before they are ready. When we cook them, especially because it is the only food we usually eat, we get sick. Sometimes we buy cassava flour when we have money.

Béatrice and her family borrow 0.02 hectares from a community member to grow their food. Another member of a family of five children, told me that they had little time to cultivate on their land. They would get up early in the morning, and try to cultivate before rushing off to school.

*When we eat sweet potatoes every day, we get sick. We eat sweet potatoes every day and they give us worms. Because we eat them every day, because it is the only food that we have, so the worms are not happy, they don't enjoy the sweet potatoes, so they eat us. (Get stomach aches)
Margerite, 12*

In addition to being constrained by poverty in their ability to access nutritious food, children also talked about the unpurified water accessed from community taps. In some rural areas, there is a government run organization, ElectroGaz, that purifies water and sells it for approximately 50 RWF (0.07 CAD) for a 25 liter jerry can. Most households, however, got their water from the communal pipes that are connected to underground water sources. Some NGOs have been instrumental in setting up these

pipes throughout rural areas. It does not necessarily take long to walk to the tap (on average 15 minutes), however, it often takes a long time to wait for one's turn to fill up the jerry can, especially in the dry season when the low water pressure reduces the flow to a dribble. The water from the taps is not purified, and health messages sponsored by the government stress boiling water. Although children would frequently recite these health messages, boiling their water was often difficult in the midst of all their other responsibilities of trying to maintain a household, cultivating in the fields, going to school, and caring for younger household members.

Sometimes we take unboiled water because we don't have time to boil it. We are busy with a lot of activities such as cultivating, watering the green vegetables. Albertine, 18

The firewood we have – we use it for cooking, not for boiling water, we do not have enough firewood. Margerite, 12

Due to land scarcity, firewood is a scarce resource and some children had to walk far to get enough firewood for cooking.



Figure 5.8 Margerite collecting water. Photo: Michelle Hardy. August 2008

5.2.4 Access to Health Care

Access to biomedical treatment for CHH is also influenced by proximity to health care centers. Inadequate proximity to health care centers is a form of passive exclusion (Sen 2000) that imposes a burden on impoverished rural populations. Health care centers are normally located near community government offices along or near roads. However, roads do not permeate large areas of Rwanda's hilly terrain, and many rural households are situated far from these centers. Children told me that they had to walk from 30 minutes to 4 hours to get to a health center and none said that they took any form of transportation, such as a bicycle or public taxi. There are some clear distinctions in treatment choices between those children reporting that it took under an hour to walk to a health center (six households) and those that said it took them over an hour to walk to a health center (eight households). For malaria, the majority in each group identified biomedicine as their treatment of choice. However, more children in the group that lived further away from health centers identified other, non-biomedical treatment options. For other health concerns, although both groups were more likely to identify other options besides biomedicine, significantly fewer children in the closer group chose non-biomedical options. Also, as noted in Chapter Three, those households that were closest to a health center were more likely to have health insurance.

5.2.5 Social Support

Although literature had indicated that CHH are marginalised from their communities (ACORD 2001; Veale et al. 2001), I found that the responses from the children regarding social support indicated that social exclusion or inclusion is a relative concept. In other words, children experienced social exclusion and inclusion from particular community groups and at particular times, rather than absolute marginalization.

They also were active participants in some community groups and in this way children sought to establish support for their households.

Most of the children lived in close proximity to their paternal relatives since land was commonly divided up among male siblings.⁷⁴ Of the households that lived close to relatives, five said those relatives provided them with various forms of support. One household, Household B, relied on their older brother, who lived close by with his wife, for food. However, the eldest, Marceline, said that the support was sporadic, and he did not assist her with accessing treatment when she got sick with malaria. In another household, the head of the household frequently referred to her godmother as someone who taught her about health care and other concerns. In addition, an aunt would come to cultivate their land on a weekly basis. In a household of boys, some of them referred to their older uncle, the family's patriarch, as someone they admired and respected. The boys said their uncle gave them advice regarding land issues and debts incurred by the boys' father during the genocide, which the boys were now struggling to pay back. In another household, the boys told me that their aunt would visit them when they were sick and make them porridge. In two other households, children identified relatives who either accompanied them to the health center or provided them with Kinyarwanda medicine when they were sick.

In contrast, there were five households who said they did not receive any assistance from their relatives living close by. Three of these households said that their parents had been in conflict with their relatives before they died.⁷⁵ In the other two

⁷⁴ National inheritance law has changed to bilateral inheritance, to include female descendents. Although Rwandans practice patrilineal descent (de Lame 2005:130), because of land scarcity, land ownership is probably the primary determinant of place of residence for those living in rural areas.

⁷⁵ Although Rwandans live in nuclear families, relatives live in close proximity to each other, and according to one community member, there is frequent family conflict over land use and inheritance, as well as styles or standards of cultivating.

households, although the relatives lived immediately adjacent, their support was infrequent or nonexistent. In one case, the girls complained that the relatives wanted their house and wanted the girls to move out. However, they also said that an uncle would come and check on them when they had malaria and encourage them to take their medication. In the other household, the second wife of the children's deceased father lived next door, but offered the children no support.

Some children identified poverty as a barrier to receiving support from relatives or neighbours.

Michelle: Do you ever not have enough food?
Cesarie: When we get it, there is enough food for us.
 Michelle: What do you do if you do not have enough?
Cesarie: We eat what we have and we just live.
 Michelle: Do you ever go and talk to (her aunt)?
Cesarie: I don't tell anyone, I just keep quiet.
 Michelle: Why don't you tell anyone?
Cesarie: Sometime you can tell someone, they just hear you for nothing, or they just go and back bite⁷⁶ you out.
 Michelle: Why would they back bite you?
Cesarie: It is how people are. There is no person you can trust.
 Michelle: What about (her aunt)?
Cesarie: Sometimes you see that she has nothing, too.
 Michelle: What happens if you do not have enough food in the house, and you want to borrow some from someone, who would you go and ask?
Laetitia: No one can give you food.
 Michelle: Why do your neighbours not lend you some food?
Laetitia: It is the culture here. I don't know if it is in all of Rwanda, as I have not gone to all places. But in this area, neighbours don't give food. You can go and cultivate for someone, and they may give you something to eat. Or you can go and beg, and they give you something to eat. But because we are ashamed, we do not go there.
 Michelle: Why are you ashamed?
Laetitia: They can laugh at me when I go and ask there for food.

As the children's comments illustrate, poverty weakens social support for CHH by constraining available resources such as food and money for health care, and by

⁷⁶As discussed earlier, back bite is a term that I heard used in Rwanda in reference to people talking derisively about someone to others.

stigmatising children who are unable to meet their basic needs. Consequently, it diminishes some children's willingness or ability to ask for help.

5.3 Hierarchies of Age

Examining hierarchies of age among CHH is important to this research because many studies, as well as NGO programs, direct their programming primarily at the head of the household. Conducting research with all the children in a household provided significant insight into household dynamics, and into differential access to knowledge and support connected to age and social position. I examined age using two approaches. Mainly, I distinguish between heads of households and younger children to illustrate the differences in children's perspectives and experiences that may be overlooked when research and NGO support focuses only on the eldest child. In some cases, to identify nuances that may be associated with age, I also compare the responses of children according to age.

5.3.1 Household Hierarchies

Age hierarchy in the household was readily apparent on my first visit with the children. Frequently, it was the eldest child, the head of the household, who would respond to me and speak for the household. Although sometimes it was obvious the younger household members were shy and did not feel comfortable in my presence, this was not the only reason. On one occasion, I had met the second oldest child, a 15-year-old, at her school prior to the first visit with the family. I remember having a conversation with her, and remarking on her efforts to communicate to me in French. However, when I visited her at home, she deferred to her eldest sister who responded to all the questions directed at the entire household.

I made a point of asking the children during the survey to identify the household head. In every case, the eldest child in the household self-identified as the head, and/or the younger children identified the eldest as the head. The children's explanations why that individual was the head of the household were similar: because they were the oldest, because they cared for their younger siblings, or because their parents were dead. Notably, being household head was based on age and came with responsibilities

When children's descriptions about malaria and their other health concerns are situated within the household's age hierarchy, nuances in children's initiatives regarding health care are evident. Age hierarchy either constrains or enables the child in addressing their health concerns, depending on their position in the home. The eldest child takes responsibility for the household and is the household decision maker. This responsibility is both assumed by the household head and ascribed to them by their younger siblings. When I asked 14-year-old Yvette if she was going to the Independence Day celebrations, she replied that she really wanted to go, but it depended on whether or not her 17-year-old sister let her.

When children were talking about prevention, household heads were more likely to list preventative measures that affected the household as a collective. These included clearing bushes, removing stagnant water, keeping the house clean, not drinking dirty water, sleeping in a bed, eating green vegetables, using clean dishes and using a light source. In contrast, fewer of the younger members of the households listed these types of preventative measures – except for shutting windows and doors at night. The non-heads tended to talk more about preventative measures that affected them individually, like using an umbrella or not getting wet in the rain, or keeping away from mosquitoes. This

illustrates the sense of responsibility that the heads had for the household, and the scope of their awareness in terms of health care.

This sense of responsibility could be seen in the awareness that the heads of the household had regarding household possessions. For example, when the children explained why they did not have a mosquito net, household heads were more likely to talk about priorities regarding expenditures for household needs, rather than only stating they did not have the money to buy one, as the younger children did.

Michelle: Why do you not get a mosquito net?

Angelique, head of household: Because I don't have enough money. And when I have money, I need to spend it on buying food, and not on a mosquito net.

Michelle: Why are you not using a mosquito net?

Désiree, Angelique's younger sister: We do not yet have the money to buy one.

It was evident that the heads of the household controlled how money was spent in the household, and thus determined which forms of malaria prevention were available for all household members. Often, there were indications that money was spent on the priorities of the household head, rather than the house as a collective. In some cases, this may have been because the household head was the income earner. For example, in one household of three girls, the eldest, Rosine, sold avocados on the market, while her younger siblings went to school. The girls slept wrapped up in a tarp at night, because they had no mattress or blanket and no mosquito net. At one point between visits to the household, Rosine got her hair braided, a hairstyle that cost her approximately \$2 CAD, double the cost of a mosquito net. Another time, she showed me a new pair of shoes she had bought for herself. Meanwhile, her younger siblings wore the same outfits every time I visited them. As described earlier, her younger sisters were also at risk of being barred from school because the teachers' bonuses were not paid.

The older children were also clearly aware of their younger sibling's health vulnerability and dependency.

Michelle: Do you think that the others (her younger siblings) know the same things as you on how to stay healthy?

Chantal: I think some don't know.

Michelle: Why not?

Chantal: Because some are so young, and they don't yet know.

Michelle: Who is too young still?

Chantal: Celestin and Thérèse. Margerite knows, but she can't do as I can do.

Michelle: Why not?

Chantal: Because we do not have the same level of knowledge and understanding.

Michelle: Where would they learn these things or when will they learn them?

Chantal: They will grow up while knowing them.

Michelle: Will someone teach them?

Chantal: Yes, at school they will teach them, and I will teach them.

Not all heads expressed this sense of responsibility to disseminate health knowledge to younger household members. Age and the level of perceived vulnerability of the younger household members may be significant factors in this, as illustrated in the following example from one household of two boys, Augustine and Kanobana (18 and 16 years old).⁷⁷

Michelle: Does Kanobana do the same things as you to stay healthy – does he try to eat these fruit and vegetables to stay healthy?

Augustine: Yes, he eats them, whenever I eat them.

Michelle: Does he know that mosquitoes and amoebas make him sick?

Augustine: I don't know if he knows about them.

Michelle: Did he not go to the training with you?

Augustine: No. Because we are only two in this house and we both cannot go. He must stay here to do work at home, such as cooking, and watching the goat we have.

⁷⁷ Gender may be important here – that male heads take less responsibility for children in their household. This may be why male-headed households tend to disperse, and why there were few of them in my sample. However, in the two other male-headed households in my sample, the heads were aware of the health and well-being of the younger children. Additionally, in two of the households headed by girls, the heads also took little responsibility for the younger children. For example, in one, the head sometimes left the household for a few weeks at a time.

Michelle: Do you tell him about the things that you have learned, or not?
Augustine: I won't lie to you, I do not tell him. But in the training, if they tell me to buy cabbages and vegetables, then we eat together.

Michelle: Why do you not talk to him about it?

Augustine: When they ordered me to buy vegetables, for staying healthy, if I buy them, we share them. That is why I did not talk to him about it.

Michelle: Does he know what malaria is?

Augustine: He should know that, because he got it.

Michelle: Do you think he knows about how he can catch malaria?

Augustine: He should know that, but I don't know – you have to ask him.

The influence of the older children on the younger children's access to health care was also very evident. Importantly, it was not only the head of the household that showed responsibility for younger children. In one conversation with Rosine's youngest sister, H  l  ne, she said that when Rosine was not around, the middle sister, B  ata, tells her to go and pick the leaves from Japanese plums and chew them for her cough. The eldest in a household of five children, Chantal, was often away since she boarded at secondary school, and would be home only on the holidays and sometimes on the weekends. In her absence, her sister Jeanine would have taken on some of Chantal's responsibilities for the household.

Michelle: When you get malaria Jeanine, do you treat it differently than when Celestin and Th  r  se get malaria?

Jeanine: Yes, because they are young, you have to treat it differently.

Because they don't tell you where they are paining, you must hurry and take them to the hospital.

In contrast, children who are household heads report that they took care of themselves when they were sick, or they would go for treatment on their own. Sometimes, they seemed to be more stoic about their health. At one point in a conversation with Chantal, she noted the differences when she got sick and when her younger brother (the youngest) got sick.

Maybe, me, I can get sick, and I persevere, and he cannot. Celestin can get sick and cry, or he starts saying he wants this and this. But me, when I

get sick, I am the person that is supposed to look for these things, so I cannot say that. Chantal, 17

Certainly, the heads had an enormous amount of responsibility, which, for the most part, they seemed to take quite seriously. The heads of the households were frequently the ones involved in earning an income, and they appeared to be the ones that took on the burdens of whatever misfortunes the house faced. Often, they identified their responsibility and the amount of work they did as the cause of their health concerns. Cesarie, the head of her household, worked at a local market, buying produce and attempting to resell it for a profit.

Michelle: Are there other things that make you sick?

Cesarie: Headache. Sometimes it is caused by sunshine, or very many problems that make you mad. They give you a headache. At the market, I am selling outside in the sun. You feel it, when the sun is shining. You feel it coming slowly by slowly, until you get a headache.

Michelle: Is there something you can do to make sure you don't get a headache?

Cesarie: Protect yourself from the sun. You don't go into the sun. I go out of the sunshine when I get home. When I reach home, I get well.

Michelle: You also said that you get many problems and that sometimes makes you mad. What kind of problems?

Cesarie: Yes, there are many problems. Sometimes I sell things, and I get a loss and I think so much how we are going to live, and I don't have any way through.

Michelle: Are there other things?

Cesarie: When I come home, and I have found that they have stolen from us, and I think of many things and I get a headache.... When I think of very many things, how people have disappointed me, I get a headache. Like when I think of the person who charmed my mother, even other things that are not good.

In contrast to the sense of responsibility expressed by household heads, conversations with the younger children highlighted their dependency on older siblings. The younger children would often say that their older sibling assisted them with accessing treatment, accompanying them to a health center, or getting Kinyarwanda medicine when they were sick. H el ene, the youngest of three, talked about the different

types of treatment that her older sister, Rosine, assisted her with when she was sick.

Michelle: Where did you learn that dirty water gives you worms?

Hélène: Because when I take it, I get worms. I feel it – they shout.

Michelle: What do you do when they shout?

Hélène: Rosine picks medicine for me – herbs. It helps.

Michelle: How do mosquitoes make you sick?

Hélène: If you do not have a supa net, they eat you. You get a rash on your face.

Michelle: Do you get sick from other things from the mosquitoes?

Hélène: Yes, malaria. You get malaria from mosquitoes.

Michelle: What do you do when you have it?

Hélène: Rosine takes me to the hospital.

An eight-year-old boy described to me the attentiveness of his 18-year old sister.

Athanase: Sometimes I sit in a lonely place, and I don't feel good. But when I am playing soccer with the children, I feel better. Many times I sit inside the house, or sit on stones outside, and there I am alone because Valency (his older sister) has to go somewhere.

Michelle: Are you able to find your friends and play soccer so that you feel better?

Athanase: Because Valency knows that if she leaves me alone, I will sit alone here, so before leaving, she tells me to go and look for friends to play soccer with.

A distinct exception to this theme of age-based dependency was in Household J, a household of boys, two brothers and two cousins. One of the cousins was 14 years old, had lived with his grandmother for a number of years before she died, and had learned a lot about Kinyarwanda medicine. When Thierry moved in with his cousins, he continued to rely on that knowledge. He would more often say that he would treat himself with Kinyarwanda medicine rather than receiving help from one of the older boys.⁷⁸

Since the oldest child controlled the decision-making in the home, sometimes the health knowledge of younger siblings may have been thwarted. For example, Kanobana, the younger boy in a household of two, had received a mosquito net from a local NGO,

⁷⁸ Prior to moving into this household, Thierry had also learned about mining for the minerals coltan and cassiterite, which could be found in a local river. He had taught the other boys in the household, and now the household was able to sell ½ a kilo of cassiterite weekly for 1,500 – 2,000 RWF (\$3-4 CAD). (They said coltan was hard to find.)

but it was not hung up. In this particular home, Household L, the boys sleep in separate rooms. Kanobana slept next to the kitchen, under a window that opened directly over the cooking fire. Over the course of the interviews I had with the boys, I had encouraged them to hang up their net. On the fifth visit, Augustine, the eldest, told me that they had decided that the net should be hung in his room, so that it would not get damaged by the smoke from the fire. He showed me the net that he had hung up. It had been hung so that it covered the whole room, and it was hanging four inches above the bed. I took the opportunity to assist Kanobana with re-hanging the net so that it covered the bed and could be tucked in. It was soon evident that he knew how it should be hung, and that he had read the instructions on the back of the package. However, he may have been reluctant to challenge his brother's approach when the net was hung earlier.

In spite of the challenges that younger children face in expressing health care knowledge, some of them talked about the responsibility that they took for their own health care, and in accessing Kinyarwanda medicine. This was commonly expressed when talking about other health concerns besides malaria, and in those households where the head was frequently away (e.g. working at the market, or attending school).

5.3.2 Forms of Social Support

The children's opportunities for social interaction were also age-dependent. When I visited those households with children younger than eight or nine years old, these children were frequently outside playing with their friends. Their chores (collecting water, firewood and grass) also took them outside of the home and into the community and brought them into contact with others, whereas the household chores for heads were mainly centered around the home. While school is frequently viewed as providing

opportunity for socialisation of the younger children, some of them were excluded from their peers.

Other children are rich, they wear good clothes, they have nice books and go for rides in motor cars, and they eat meat. But us, we have poor books and they say that we bring poor books. So when I tell them to choose me (when playing games), they say to me, "Tell your mother to buy you one." They tell me that they will always go in cars, and then they ask me, "Where is your mother, won't she take you in a car?" Margerite, 12

The vulnerability of the younger children may also have prompted people to provide support. In one household, the 15-year-old head went to school, and the younger children, six years and three years, were left on their own, under the watchful eye of a neighbour. During the course of one interview with this household, the younger children were outside while I was talking with the eldest child. At one point, one of the younger children came running in nibbling on a sweet potato given to her by a neighbour. In Household Q, a household of five children, an aunt living close by had informally adopted the youngest sibling when the mother had died at childbirth. Celestin was now six years old and had begun to move back in with his four older sisters. He reported that he frequently slept at home with his sisters, but it varied at which house he ate his meals. His two oldest sisters had been seven and nine when their mother had died, and they had been left on their own. In another household of two, when the 18-year-old had gone to the capital to care for her older brother who was sick, a relative had come to stay in the house with the younger, eight-year-old brother. In Household L, relatives had taken in a three-year-old, and left the 16 and 18 year old.

While heads of households may not appear as vulnerable as their younger siblings and therefore may elicit less support from their community, many of the heads did identify support that they received, and sometimes this was due to their position in the household. For example, one head of a household frequently mentioned a *Nkundabana*

as a supportive mentor who cared for her when she was sick, or helped her to borrow treatment money from neighbours. Another head of a household told me about a church member who, upon hearing about the conditions in which she and her sister lived, began lending her money weekly to buy produce to resell on the market for profit.

5.3.3 Differential Access to Knowledge

As discussed previously, it was evident that all the children were aware of government-sponsored health messages regarding malaria, but they received these messages through different means. Non-household heads were more likely to be in school compared to heads, but older children were more likely to attend community health training than their younger siblings. More often than younger children, heads identified health centers, NGOs and the radio as sources of health knowledge.

Interwoven in the younger children's explanations of the causes of malaria were messages that reflected informal teaching and informal social networks. Six-year old Celestin, who spent part of his day at nursery school and the rest running around outside with his peers, told me that the devil can cause malaria. When I asked him where he learned that the devil causes malaria he replied that "he is a bad man. All the children (told me)." Celestin's ideas about malaria also drew upon his school instruction. This was apparent when he said "a mosquito can find you on the bed and cause you malaria." He had learned that mosquitoes cause malaria in school. Other children also referred to their peers and neighbours as sources of health care knowledge.

Michelle: Why do you get a throat infection from the sun?

Gilbert: I learned this when I got it when I was at school and was in the sun for a long time, a class mate told me that is what it was from. I am supposed to keep from the sun – when I go and come from school it is not hot, it is hot from 1 to 3 pm.

These examples show that children draw upon different domains of knowledge, including their peers, schooling, NGOs, etc., in understanding their health.

The children's descriptions about their experiences of being sick with malaria and their symptoms show some age-based variation. The youngest children, like six-year-old Celestin, told me that they had learned in school that malaria was something very dangerous, and they referred to malaria as a time when they felt very sick.

Michelle: What is malaria?

Celestin: It is a bad sickness. Because when you get sick from it, if you don't get well, you die. I learned that at school.

Michelle: Have you ever had malaria?

Celestin: Yes.

Michelle: How did it feel when you were sick with malaria?

Celestin: You feel like dying.

Michelle: What do you do when you get malaria?

Celestin: Nothing. I get pain in the stomach.

In contrast to older children who were more precise about their symptoms, young children like Celestin would identify few symptoms when they described their experience with malaria. Since they are dependent on their older siblings for access to health care, if they are not able to articulate many symptoms, they may not receive appropriate care.

Some of the older children, depending on their own experience with malaria, did not describe malaria as such a severe illness as the younger children did. Perhaps this was because they were the decision makers in their health experience, and had had the opportunity to express a certain amount of control over their illness experiences. This was apparent in the conversations I had with Philippe, who, at eighteen, was the oldest of four boys in his household.

Michelle: You said that you sometimes get malaria. Do you get it a lot?

Philippe: Yes, I get it around two times per year, and I am sick for three weeks. But if I get medicines, I am sick for maybe two weeks. I usually go and get medicines from the pharmacy – a private one in (town). It is an hour walk. I can get medicine for malaria for 600 RWF (\$1.33 CAD) for 12 to 14 pills that I take for five days for malaria and fever.

Michelle: Do you usually buy medicine for malaria?

Philippe: It depends, when I am feeling very bad I have to buy medicines from the pharmacy. When I do not feel too bad, I stay at home and don't buy the medicines. Most times, I do not buy medicine, and just stay at home.

Philippe had had the opportunity to determine the treatment choice for his experiences with malaria, and had been able to successfully manage it. He did not discount the seriousness of malaria, but did not consider himself as vulnerable as others were to malaria.

Michelle: Do you think that malaria is a serious sickness?

Philippe: Yes, I think that it is serious, but you neglect it because in most cases it kills young children, or pregnant women, because they do not have the capacity to fight against sicknesses, they are not strong enough to fight against diseases.

Michelle: So for someone like you who is strong and healthy, it is not something to be worried about?

Philippe: Yeah, there is nothing that disturbs me, just working.

Michelle: But isn't there some types of malaria that are really serious, that can kill someone like you who is strong?

Philippe: Yes it is there. If you get it, and you are careless and you don't go to the hospital, you can easily die. When you get it, if you immediately go to the hospital – you can be fine. But if you delay, it may be hard to be fine.

Michelle: Can you tell right away, at the beginning when you get malaria if the type you have is not serious, or if it is serious, and that you must go and get medicine?

Philippe: You can know right away (when you first get malaria) that it is serious.

Children's understandings, experience and response to their health were dependent on their age, as well as their particular position in society and in their household. Household heads held the burden of responsibility for the home, a responsibility that gave them privileges in decision making, but also demanded that they care for their own health. Their experience in self-care gave them more opportunity to participate in their treatment choices for malaria. Although younger children's

dependency on household heads and their vulnerability in terms of their health are apparent, their vulnerability also elicits informal community support.

5.4 Gendered Opportunities and Constraints

The public domain in rural Rwanda is male dominated (de Lame 2005:119).

Public domain in rural Rwanda refers to communal gathering places, such as local bars or the local government office. I commonly saw men loitering in public places, leaning together against a bridge while they listened to a soccer match on a radio, or sitting on the grass on the side of the road, drinking beer, but I rarely saw women loitering in public. The exception was at the market, but they were engaged in selling produce.

Private space is also gendered. As one community member told me, in the household, the man “controls” or “leads” the house. He is responsible for the decisions regarding the household. Additionally, as noted in the interviews with the community members, there are significant differences in the chores for which men and women are responsible.

The lack of gender diversity among my household heads limits the amount of data regarding gendered influences, and consequently the conclusions that can be drawn. However, some of the material from the children’s discussions points to significant themes regarding gender and health care, including attentiveness to health, the influence of gender ideologies on health care, and access to resources.

5.4.1 Attentiveness to Health

Attentiveness to the body and to health was a significant theme in the children’s discussions of malaria and health care. Among the boys, there was not the same degree of attentiveness to the body and to health as there was among the girls. This was evident in several ways. First, when describing symptoms of malaria, girls tended to describe

more symptoms than boys. Second, when discussing the frequency of malaria, girls were more precise, specifying the number of times they had had it over the past year, whereas the boys commonly did not.

Malaria, but it is rare. Once per year. Rosine, 17, female
I don't know how often, I can get malaria at any time. It is difficult to figure out. Kanobana, 16, male

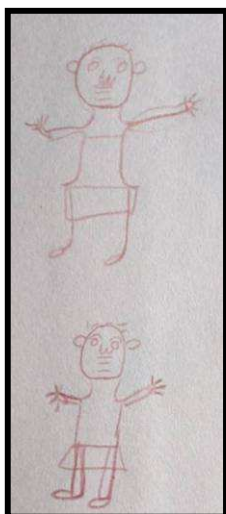
Third, girls described being sick longer compared to boys. When describing the duration of a malaria episode, boys said that they were sick for a week while half of the girls reported they were sick for one week, and the others said from two weeks to one month. There is no indication in the literature on malaria that females are more susceptible to malaria. Furthermore, when I asked the children what made them sick, almost all the boys identified malaria, but the girls did so less often. However, girls tended to identify a greater variety of health complaints compared to boys.

Another indicator of gender-based differences in attentiveness health was attention to body size. From my previous experience working in Rwanda, I knew that body size was sometimes referred to as a sign of wealth and well-being. I assumed that the children might talk about body size as an indicator of health. However, in my discussions with the children, only a few girls noted this, while none of the boys did.

Claudine: When I am sick, I am like this (pointing to her picture), and when I am healthy, I am very fat.
 Michelle: When you are sick, are you fat as well?
Claudine: No, I am very thin.
Margerite: When I am sick, I am very thin. When I am not sick, I am very fat.

The drawings by Claudine and Margerite (Figure 5.9) illustrate similar ideas about body size. The top figure in both drawings is a picture of themselves when they are sick and the bottom figure they identified as themselves when they are healthy. In Claudine's

drawing, her bottom figure has thicker legs, illustrating being fat. In Margerite's



drawing, her bottom figure is much bigger than the figure at the top of the page.

Figure 5.9 Claudine's drawing. Photo: Michelle Hardy. August 2008

5.4.2 Sanctioned Gender Roles

In rural Rwanda, both men and women cultivate in the fields in the morning. However, as Ernestine, a community member, told me, in the afternoons women go home from cultivating, take care of the children, and do the chores around the house. Men, if they have animals, will look for grass to cut for them, or "they will walk around, the way men usually walk." In other words, men have more freedom to move around in public compared to women. Women's afternoon activities are largely centered on the home.

In the households I interviewed that were headed by girls, the boys were responsible for getting water, firewood and grass for the domestic animals. They rarely cooked, did the laundry, washed dishes or cleaned the house. In the households headed by boys, the oldest boy did not cook, or wash dishes, and they rarely cleaned. This was done by younger household members. During a conversation I had with Valency, she explained to me the different roles, and her perceptions of the health consequences of these different roles.⁷⁹

Michelle: Are there things that make girls or boys sick differently?

Valency: *They are not the same because they do not have the same work. Because girls work harder than boys.*

Michelle: Do all girls work harder than boys?

Valency: *Yes.*

⁷⁹ When asked specifically about any differences according to gender in types of sicknesses, the children rarely identified any. Valency was an exception.

Michelle: What kind of work do girls do that boys do not do?

Valency: Girls cook, look for something to use for cooking, they wash clothes, and when you cultivate, the girls plant the seeds. The boys don't know how to do this. The boys look for herbs for domestic animals, they fetch water, collect wood and they cultivate.

Michelle: Who told you that girls work harder than boys?

Valency: I remarked on it myself, because I could see with my eyes that our work during the day is different.

Michelle: Do girls get sick more often because they work harder than boys?

Valency: Yes, because after working hard, they get tired and fall sick.

Further evidence of the impact of gender roles was seen in the children's discussion on prevention for malaria. Although most children recited the three or four biomedical prevention messages, some children added a few other methods of prevention. Among these children, noticeably more girls said that keeping a clean house would prevent malaria. They also identified sleeping in a bed, eating green vegetables, and using clean dishes as preventative measures. In contrast, it was only boys who said that people should not drink dirty water, and that people should try not to get wet in the rain.

Another gendered theme became evident in the children's discussions of their sense of community and community assistance regarding their health concerns. In the sample, girls talked about issues to do with social exclusion in their community.

There is no one else who I can talk to. Because there is no other, there are only these (people at her church). (Not even your neighbours?) No, not my neighbours. No, we don't like talking with many people because with some we have misunderstandings. Like our parents died, some want to take our lands or our gardens. Albertine, 18

When I asked another girl, Rosine, about talking to a community member, she said to me that she did not want me to talk to the neighbours because she had misunderstandings with them, and they do not talk to each other. Significantly, although some boys talked

about not getting help from relatives, no boy talked about societal distrust. One boy even talked pointedly about making connections in the community.

Because I am well known all over here, if they (people in the community) know that I am feeling sick from malaria, they come to see me, and most of them help me. Because I am very kind to them, and I make conversation with them, and they want to see me every day. I show no arrogance to people. If someone wants me to help them, I help them immediately without delay. If someone wants to send me on an errand, I do it right away. Raymond, 18

It is evident that in Rwandan rural society boys have more opportunity to build relationships outside the household, since the public domain is accepting of males, and also because people see them as less competent in caring for the household. In contrast, girls may be more susceptible to isolation, because they have less opportunity to connect with people outside of the family home, and because they are assumed to be capable of doing household chores.

Evidence of varying social opportunities based on gender was seen in the children's drawings and discussion about being healthy. When I asked the children to draw themselves when they were healthy, many boys drew themselves playing soccer.

Michelle: What can you tell me about that makes you healthy?

Gilbert: To make conversation with other children, to practice sport, to play soccer and to eat food that contains all the necessities.

Michelle: So, playing soccer keeps you healthy?

Gilbert: Yes, I know it does. I am able to do it a lot. I do it in the afternoon, and in the evening I am tired then. But I am not too tired to play it in the afternoon after I have worked in the morning (during the school holidays).

Michelle: Does Laetitia (his sister) do the same things as you to stay healthy?

Gilbert: She only talks to her friends, because girls are not able to practice sports. (After some discussion with him about this he continued) I think it is the grown up girls that do not practice sport. The young girls play soccer.

However, girls are not entirely isolated from community interaction. Some talked about involvement in church groups, such as youth groups or choirs.

5.4.3 Unequal Access to Resources

There were some noticeable trends in access to land and animals that differently shaped girls' and boys' ability to care for their health. In the sample of fourteen households, those headed by girls cultivated 0.17 hectare on average, and those headed by boys cultivated 0.42 hectare on average. The impact that this had on the health of the children can be seen in what they identified as barriers to health care. More girls talked about the lack of firewood as inhibiting them from boiling their water. In contrast, boys rarely identified a lack of firewood as an issue. One of the male-headed households showed me an area of their land reserved for growing trees that they were using for firewood. Girls were also more likely to talk about their overall lack of nutritious food, in contrast to boys who might only talk about seasonal barriers to nutritious food.

Two of the three households headed by boys owned cows (providing them with manure to fertilise their fields),⁸⁰ whereas only one out of eleven households headed by a girl had a cow, and she had an older brother living in Kigali who periodically assisted her financially. Besides the cows, the households headed by boys tended to own other animals that were more expensive, including goats and pigs, whose manure could also be used to fertilise their crops. The households headed by girls, if they had animals, owned less expensive ones that did not provide as much fertiliser for their fields - hens, rabbits or guinea pigs.⁸¹ All three of the households headed by boys had a latrine, a light, a mosquito net (not hung up), blankets, a stove and at least one bed, and two of the households also owned a radio. In contrast, in the eleven households headed by girls, just over half had a latrine, less than three-quarters of them had a light, less than half had a

⁸⁰ Rwandan cattle do not give as much milk as western-bred dairy cattle. Only Household K talked of drinking the milk they got from their cow.

⁸¹ The households tried to sell the eggs from the hens, and raised the rabbits and guinea pigs to sell on the market.

mosquito net, two households did not have a blanket, only two households had a stove, four households had a bed, and only three owned a radio (See Table 3).

Due to the limitations in the sample, few significant conclusions regarding gender differences could be drawn. There were no significant trends in the data that indicated that girls had less opportunity to access health information or resources. However, there is indication that gender privileges boys by allowing them freer access to informal social connections and material resources. In contrast, girls' greater attentiveness to their health may result in better preventative measures and health outcomes.

5.5 Chapter Summary

The children's understandings, experiences and responses to malaria indicate that malaria is a significant health concern to the CHH. Every child said they had suffered from malaria at some point. However, malaria represents one of many health concerns to the CHH. When examining their other health concerns, concerns that are also closely connected to their impoverished circumstances, it becomes apparent they receive little attention by government sponsored health training or NGO programs. Furthermore, the significant barriers that impede CHH from implementing preventative measures regarding malaria are rarely addressed in the standardized programming of NGOs. Although efforts are being made to provide impoverished CHH with health insurance, many households do not receive assistance, and as non-biomedical treatment options become increasingly stigmatised, CHH are able to do little in terms of their health care.

The children's comments illustrate how their household and social position, based on age and gender, results in different access to care and support in regards to malaria, and health care in general. For example, younger siblings in the CHH are often entirely dependent on the resources of the eldest child, while household heads make decisions

regarding prevention and access to health care for malaria. In terms of gender, girls, although evidently attentive to health, face particular constraints to accessing social support and land-based resources, and their ability to implement health care practices.

In the following chapter, *Analysis*, I draw together the themes that have emerged from the data derived from the interviews with the NGOs, community members and CHH. Critical theory and current literature discussed in Chapter One are used to frame and support the conclusions that I have drawn from the data.

CHAPTER SIX: ANALYSIS



Figure 6.1 A snapshot from Household G – An NGO vehicle, and community members leaving church. Photo: Michelle Hardy. July 2008

The ethnography of social violence implicates the social dynamics of everyday practices as the appropriate site to understand how larger orders of social force come together with micro-contexts of local power to shape human problems in ways resistant to the standard approaches of policies and intervention programs (Kleinman 2000:227).

Building on the interviews with the CHH, NGO staff and community members, this chapter draws from a critical theoretical framework to provide analytical insight into the barriers that exist for CHH in addressing malaria, why these barriers are prevalent, and how they have been established. In particular, I use critical theory to examine how the children's perceptions, understandings and experiences of malaria are shaped by social, political, cultural, economic, ethnic and gender factors (Guba & Lincoln 1998:203). I begin by showing how the particular positions of CHH within rural Rwandan society result in disproportionate social suffering. Social suffering, as it is used within anthropological literature, refers to the individual or collective distress resulting from the processes of political, economic or institutional power (Kleinman et al. 1997). These processes are characterised by structural violence (Galtung 1969), or the systematic and unequal distribution of resources by social structures or institutions, based on factors such as ethnicity, gender or socioeconomic status (Farmer 1999). The concept of structural violence enables me to point out the determinants of the social suffering of CHH, and to

illustrate that their health care is not wholly dependent on their compliance with biomedical health messages, but rather is constrained by these structures that have shaped their impoverished environments. The chapter then concludes by examining the influence of structural processes on the children's agency, their "socioculturally mediated capacity to act" (Ahearn 2001:112), in regards to their health care.⁸²

For rural Rwandan CHH, malaria is just one of their many pressing health concerns. The barriers to health imposed by an impoverished context shaped by structural violence and wracked by social suffering, as well as the social ideologies associated with hierarchies of age and gender, not only shape the children's perceptions, understandings and experience of malaria, but they inhibit community support of CHH. Furthermore, although poverty, inequality, and insufficient health resources are central to the NGO presence in Rwanda, NGOs are also constrained in their ability to identify and respond to the CHH's primary health concerns. Moreover, NGOs are also instrumental in perpetuating inequalities that prevent CHH from receiving required support. Efforts that ignore the contextual factors and socio-economic dynamics that mitigate children's ability to access that treatment and prevention offer "neither protection for individual children nor the potential to transform the relationships of inequality that dominate their lives and produce their suffering" (Mitchell 2006a:367).

6.1 Social Suffering

6.1.1 Patterns of Suffering

Although social suffering is experienced collectively, it is evident in individual lives. Children in rural Rwandan CHH live in a context characterised by the social

⁸² Social suffering, structural violence and agency are deeply interconnected, and although I focus on each in relation to the children's perspectives and experiences of malaria, and in terms of the support given by community members and NGOs, at times it is difficult to fully discuss one without reference to the other.

suffering of poverty, poor health, and limited education. Yet, they experience that suffering in very immediate and individualistic ways that relate, in large part to their positionality within their household and community. Although Kleinman et al. (1997) have written extensively on social suffering, there is little theory on the level of the individual or on children's social suffering. Instead, their work examines politicized forms of suffering, such as that experienced by refugees and victims of torture (Daniel 1997; Asad 1997). In my analysis, I rely on feminist standpoint theory (Haraway 1997; Harding 2004) to examine how the positionality of both CHH and children results in disproportional suffering. As noted in Chapter One, Haraway (1997:304, n. 32) describes standpoints as "cognitive-emotional-political achievements, crafted out of located social-historical-bodily experience - itself always constituted through fraught, non-innocent, discursive, material, collective practices." A full and rich standpoint analysis is beyond the scope of this research project, and instead I use this approach to examine how social suffering refers to more than collective suffering of individuals. Rather, social suffering refers to the ways in which the organisation of society and the place of groups and of individuals within society generates suffering.

The suffering of the children in CHH represents what Kleinman and Kleinman (1991) have identified as "routinized forms of suffering" associated with the poor and vulnerable. This suffering is evident in the impoverished conditions of the CHH and their corresponding hunger, thirst, and ill health. Additionally, the social context of the CHH is characterised by "suffering resulting from extreme conditions" (Kleinman and Kleinman 1991), in particular, due to the years of civil war, the 1994 genocide, and the AIDS epidemic. The political nature of this suffering results in oppression and rejection of marginalized groups of people.

The suffering that children in CHH experience in relation to malaria is evident in their hungry and malnourished bodies, which makes them more susceptible to malaria.

All the time I am hungry, I have no energy. I do not have enough food to support myself. It is not the reason why I get malaria, but if I ate at the right time, and ate without being so burdened, and if I eat well, I will fight the sicknesses. When we don't have enough food, we eat what we have, what we don't have, we don't eat, so we don't eat. Marie-Claire, 18

Furthermore, suffering is evident in the children's anxiety over not being able to prevent themselves from getting malaria.

What can protect me from malaria, like a mosquito? How can you protect yourself? I feel that there is nothing (I can do). Even when you sleep under a mosquito net, when you are walking in the morning, it can bite you. When you are seated in the evening, even when you are coming home in the evening, it can bite you. Cesarie, 17

Suffering is also manifested in the experience of poverty and the enormous effort that is required for the children to access biomedical treatment. This was illustrated in Marcelline's experience the last time she had malaria. She had to walk alone for four hours to the *centre de santé* after she had sold her rabbit to get the money for treatment.

Furthermore, the suffering that the children experience is also evident in relation to their other health concerns as well as their other worries. Some children talked about getting sick from being outside too long in the hot afternoon sun, others talked about the hard work involved in cultivating, resulting in sore backs. Many children talked about the upset stomachs they got from not being able to boil their water, due to a lack of firewood. Children also talked about their anxiety about being thrown out of their homes by relatives who wanted the use of their home.

While these forms of suffering may well be routinized, "not all suffering is equivalent, in spite of pernicious and often self-serving identity politics that suggest otherwise" (Farmer 2005:50). For example, worldwide, women experience sexism, an

ideology that results in an inferior status to men (Farmer 2005:43). Analysis of the suffering of CHH illustrates that it is patterned by gender, age, and household hierarchies. Social ideologies⁸³ based on gender and age influence the children's perceptions and experiences of malaria and result in differential suffering. I observed gendered suffering among households headed by girls, who had less access to land compared to households headed by boys. Girls were also more likely to talk about their general lack of access to food. Furthermore, the girls experienced more social isolation than the boys. The girls talked about feeling ashamed because people would laugh at them if they asked for help with food. In contrast, none of the boys talked about feeling anxious or stressed due to lack of social support from community members. In fact, one boy, Raymond, said that he was so well known in his area that when he had malaria many people came to see him and help him.

There is also evidence of differential experiences of suffering based on age. Some of the young children in the sample were left alone while their elder siblings were working or at school. They had to rely on neighbours for food, or cook for themselves, as one six year old did. Consequently, these children may be more susceptible to malnourishment, and hence poorer health. Additionally, as indicated by other research among young children (Peltzer and Promtussananon 2003), the younger children in the sample were less likely to identify symptoms of malaria. If they are unable to identify how they are feeling to the older household members who make treatment decisions, their sickness experience may be prolonged. The particular vulnerability of young children is supported by other research conducted among CHH in Rwanda (Boris et al. 2006), and in northern Uganda (Oleke et al. 2006:275).

⁸³ Social ideologies are shared beliefs or ideas regarding how life should be organised. These ideologies mediate behaviour, relationships and roles (see Jones and Williams 2004:157).

In contrast to the vulnerability of young children, the household head carries the burden of responsibility for the care of the younger children. This burden is evident in their anxiety over not being able to provide for the younger household members, and in the tension they feel due to the lack of community support. Although there is little in the literature that focuses on the particular suffering of heads due to their responsibilities in households, in my research household heads indicated that they were more susceptible to anxiety and stress, and that they had no one to support them when they were sick and needed assistance. They were also more likely to base their ill health on the greater workload that some carried. For example, some noted the headaches they got from anxiety, or the sore backs from being the only one in their household that cultivated in the fields. Furthermore, heads were more likely to show resiliency, stating that they could not cry like their younger siblings, as they were responsible for the household.

The children's suffering, their bodily experiences of malaria, their concerns about their future and anxieties about their daily needs is systematized by social patterns. These patterns, based on gender and age hierarchies, are cast as "normal" or "natural." For example, the fact that girls stay home and take care of the household and have less opportunity to interact with others in their communities, reflects larger patterns evident in rural Rwandan society. That the head of the household should bear the responsibility for the younger household members is accepted by community members and NGOs. These "practices of casting social experiences as "natural" or "normal" obscure the greatly consequential workings of "power" in social life" (Kleinman et al. 1997:xi). The "naturalized order" of their world represents a form of power that is rarely overtly challenged, because it is central to the way the children constitute themselves as subjects (Foucault and Bourdieu cited in Moore and Sanders 2006:13). This was evident in the

younger children's acceptance of the head of the household's control over household decision-making.

6.1.2 Responses to Suffering

A close examination of the suffering of CHH points out the underlying social determinants of their health, and how the insidious nature of poverty results in a continuous lack of physical, economic and social resources required for health care. Much like other initiatives in Rwanda (President's Malaria Initiative 2007; Rwanda Development Gateway 2007; UNICEF 2004; WHO 2004a), the NGOs that I interviewed did not acknowledge the determinants linked to social ideologies on age and gender. Although there was more discussion about the effects of poverty, the emphasis on mosquito net distribution by NGOs ignores the fact that children live in environments that are breeding grounds for mosquitoes, and that their inadequate housing provides them with little protection. Although some NGOs subsidized the health insurance of the children, they did not take into account that after the program was over, the children still did not have the economic resources to buy their own insurance. Nor did they consider that gendered access to land-based resources may result in a higher number of households headed by girls suffering from hunger and weakened immune systems. Furthermore, the NGOs work with the household heads reinforces the household hierarchy, and although some NGOs indicated that they were aware that knowledge is not necessarily shared with younger children, they did not address this issue in their programs.

The social suffering experienced by the children is exacerbated by the suffering in their impoverished communities. Research conducted after the genocide noted how the position of all children in Rwandan society had changed since 1994 (Cantwell 1997:57). Prior to the genocide, children had been integral to community life. However, due to

widespread community distrust, children have lost their “unifying central place in society” (Cantwell 1997:57). Later research conducted by Andrea Veale (2000:236) on social relations and social support in Rwandan communities indicated that Rwandans see the previous societal norms of collective care and responsibility for children as having changed. In the workshops Veale facilitated, many people stated they felt that their situation, poverty and daily responsibilities prevented them from caring for vulnerable children, such as CHH. People also pointed to the marked rise in societal distrust since the genocide, conflict over land and inheritance, and family restructuring due to the death of some members, all of which resulted in diminished collective support (Veale 2000:236).

Although Cantwell’s (1997) and Veale’s (2000) research offers insight into how community suffering has led to the marginalisation of CHH, it ignores social ideologies that lead to variation in community responses to CHH. While evidence of social marginalisation was evident among the CHH in my research, children’s access to social support was also linked to gender. Households headed by girls were more susceptible to marginalisation, possibly because sanctioned social roles confine them to the household. However, I would also argue that gender affects forms of social support. For example, because girls are associated with household chores and nurturing activities they may not have appeared to need as much assistance as boys. For example, girls that headed households were less likely than boys to say community members assisted them with food preparation when they were sick. Additionally, social perceptions of vulnerability could be seen in the differential access to social support based on age. Younger children evoked more community support than older children, but were also vulnerable to exploitation by relatives, such as appropriation of their land.

Social suffering does not simply refer to the suffering of a collection of individuals. Rather, patterns of suffering reveal positionality, resulting from larger structural forces and social ideologies. The life experiences of the CHH reveal their suffering, and “they tell us what happens to one or many people; but to explain suffering, one must embed individual biography in the larger matrix of culture, history and political economy” (Farmer 1997:272).

6.2 Structural Violence

Analysis of the larger matrix in which the CHH’s biographies are embedded necessitates a geographically broad and historically deep study (Farmer 2005:42) of how global political and economic processes intersect with Rwandan national level policies and result in structured risk of poor health outcomes for CHH in rural Rwanda. Drawing from the literature, I begin by showing how the impoverished conditions in which CHH live and their experience of malaria are linked to global economic policies that also continue to shape the children’s health through the policies’ influence on NGO programming. I then examine the influence of colonialism and its repercussions in relation to land scarcity in Rwanda, which not only results in social tension and constrains social support of CHH, but leaves the CHH with few land-based resources.

6.2.1 Global Policies, Malaria and Poverty

Malaria, like many other diseases, is associated with poverty (Farmer 1999; 2005). Due to poor housing conditions and landscapes overrun with vegetation and water in the rainy seasons, the CHH’s surroundings are breeding grounds for malaria. The children’s lack of access to land-based resources results in a meagre diet, making them more susceptible to the disease, and their lack of economic resources constrains their access to biomedical treatment. The following discussion begins by identifying how

global policies have led to malaria becoming a disease associated with poverty, and then identifies the larger global economic policies that have influenced the prevalence of economic scarcity within Rwanda.

Although malaria is considered a “tropical problem,” it was a major concern in the United States until the early 1900s, and has been found as far north as Canada and Siberia. It was also endemic throughout Europe before it was eradicated (Holtz and Kachur 2004:133, 135). The reduction of poverty in the West brought “improved housing, screened windows, mosquito nets, and access to better treatment for febrile illnesses” (Holtz and Kachur 2004:136). Malaria has now been eradicated in the western hemisphere (Farmer 1999:40-42; Holtz and Kachur 2004), while in sub-Saharan Africa, where the incidence of malaria is the highest, the World Health Organisation (WHO) never attempted to eradicate it. WHO believed that the obstacles to the eradication of malaria were too large to overcome (Holtz and Kachur 2004:136). Neoliberal⁸⁴ economists continue to perpetuate the notion that the location and severity of malaria is primarily related to climate and ecology, not to poverty. However, Farmer (1999:41) argues that the link between high instances of malaria and poverty can be traced back through structural adjustment programs (SAPs)⁸⁵ implemented by the World Bank in the 1980s that exacerbated conditions of poverty in low-income contexts (Gershman and Irwin 2000). Although Rwanda never fully implemented its SAP, they implemented a number of policies with the assistance of aid money that reflected the philosophy of the SAP (Uvin 1998:59). Consequently, like other low-income nations, Rwanda has not had

⁸⁴ Neoliberalism considers the best use of resources to be through market-oriented transactions (Shakow and Irwin 2000:52).

⁸⁵ SAPs were initiated by the World Bank and the IMF to resolve the “Debt Crisis” and meant to stimulate economic growth within low-income nations as well as allow these countries to continue paying the interest on their foreign loans (Gershman and Irwin 2000:20).

the resources to combat malaria. Today, to address the issue of malaria, the American government is implementing the US \$1.2 billion President's Malaria Initiative (PMI) in Rwanda and 14 other nations (PMI 2008).⁸⁶

Global economic governance that favours neoliberal ideologies restricts access to treatment for diseases such as malaria to those who can pay for it. Biomedical malaria treatment is available in Rwanda, but the cost is a significant barrier for the CHH. Some CHH receive free health insurance from the government or an NGO, but NGOs do not supply full coverage for more than a year.

The story of the CHH's impoverished lives, and that of their communities, includes the German and later the Belgian colonisers who arrived in Rwanda in 1916, and who viewed the area as an economic resource.⁸⁷ They imposed "onerous legislation, taxes, and obligatory cash crops to pay these taxes" (Uvin 1998:16). The economy began to be transformed, as agriculturalists were forced to shift from subsistence agriculture to export crops, such as coffee (Robbins 1999:294). Coffee soon became Rwanda's major export commodity. Then, in the 1980s, coffee prices collapsed due to the termination of the International Coffee Agreement, which meant that market forces began to determine the price of coffee. The Rwandan government increased its borrowing in an effort to keep up its spending pattern (Uvin 1998:54). Consequently, the country's foreign debt rose rapidly, exacerbated by another civil war and the resulting demands for emergency food and housing. As the Rwandan government began to funnel economic resources into its military, the nation entered an economic crisis (Uvin 1998:56).

⁸⁶ PMI focuses on four intervention strategies to prevent and treat malaria: insecticide spraying, mosquito nets, medication, and treatment for pregnant women (PMI 2008).

⁸⁷ Eric Wolf (2006) has been instrumental in reminding anthropology that no society was a bounded system without ongoing relationships and involvements prior to European contact. However there is little literature detailing the pre-colonial period, therefore, my analysis begins in the early 1900s.

Rwanda's economic crisis coincided with those of many other Third World nations, which were also in debt and unable to make payments to commercial banks in wealthy nations. The World Bank and the International Monetary Fund took control of resolving the "Debt Crisis" and instructed Rwanda to implement SAPs. As mentioned earlier, Rwanda never fully implemented these programs, but did implement a number of policies that reflected the characteristics of the SAPs. The result was the devaluation of the Rwandan franc. This led to inflation, falling production, and increased poverty (Robbins 1999:296; Schoepf et al. 2000:105; Uvin 1998:58). The education and health care systems broke down, child malnutrition increased, and the incidence of malaria increased, due to the unavailability of medication (Robbins 1999:296). In mid-1993, the World Bank refused to give Rwanda any more funds until the government was able to follow through on the agreed upon commitments (Uvin 1998:91). In 1994, the civil unrest culminated in the genocide. The looting and pillaging that occurred throughout the atrocity reflects the economic tension in Rwanda at the time (Schoepf et al. 2000:103).

Since the genocide, Rwanda has received an influx of international aid in the form of NGOs attempting to mitigate the effects of spiralling poverty. NGOs are sometimes identified as a form of neo-colonialism, because they are a means by which Euro-American governments can continue to exert influence indirectly on impoverished nations (Manji and O'Coill 2002:580). Donor agendas influence which development programs are run and illustrate the issues of power and inequality in development work. These donors direct program parameters by regulating funding to NGOs to certain population groups and certain types of programs, resulting in structural violence. Assistance given by NGOs is dependent on donor interests, and does not necessarily reflect the issues within a particular context. For example, after the 1994 genocide, many

NGOs in Rwanda provided relief assistance to children living in CHH.⁸⁸ Today, there are fewer NGOs with programs focused specifically on CHH. One significant reason for this is the difficulty of getting funding for such programs, because the discourse on those “at-risk” has shifted from CHH to include both orphans and other vulnerable children (OVC).

The health messages disseminated by the NGOs in my research sample center on self-care and personal responsibility for health. Ferguson and Gupta (2002:989) identify these messages as a form of management and control, which ignores the social construction of experience. The international community and the Rwandan government rely on the biomedical discourse as a useful way to legitimize or define what is a disease (Nguyen and Peschard 2003:456), and consequently, what receives attention.

Furthermore, while legitimising biomedicine in Rwanda, the government has also stigmatised non-biomedical therapeutic options, such as Kinyarwanda medicine. With few economic resources to access biomedical care, and home environments that constrain the use of mosquito nets as well as other prevention methods for malaria, children living in CHH may be blamed for behaviour over which they have little control (Mitchell 2006a). They are subjected to health interventions that have been chosen and determined by the State (Nguyen and Peschard 2003:458-459), which have little consequence in their lives because of the barriers that impede their ability to implement them. Ironically, NGOs, which have been afforded the power to alleviate suffering, are themselves perpetrators of structural violence.

6.2.2 The Historic Legacy

Many CHH are attempting to sustain themselves on insufficient land to supply a nutritious diet, let alone grow a surplus and make an income. Similar conditions are

⁸⁸ Based on my own experience working in Rwanda with CHH from 1999-2002.

faced by community members, thereby exacerbating on-going societal tension and resulting in diminished support of CHH. Although this discussion centers on structural factors that have influenced access to land, as seen in the shifts in national governance and the influence of colonial hegemonic practices, admittedly, population density and Rwandan's mountainous topography are determinants as well.

Rwanda's population since 1900-1950 has risen from between one and two million (CePeD 1994 cited in Uvin 1998:186), to 8.3 million (Encyclopedia of the Nations 2007). In part, this has to do with the social value of children; rural families still consider having eight children as the ideal number of offspring (de Lame 2005:413). The current population density in Rwanda is 337 people per sq. km (World Bank 2009). Consequently, even the steepest slopes in Rwanda's hilly terrain "are cultivated, and cultivation is often almost permanent. Rwandan farmers face two main challenges: erosion and exhaustion of soil fertility" (Uvin 1998:189). However, as the following discussion shows, limited access to land based resources is not solely the result of a high population density and fragile ecological resources.

In pre-colonial times, when land scarcity was not an issue, people had more opportunity to move through the hillsides, gaining land through establishing relationships with the head of a lineage, through community distribution, or through shared ownership under corporate lineages (de Lame 2005:252). However, there were geographic regions in Rwanda that were under the Tutsi⁸⁹ monarchy, which were governed under a different system of land control that involved a process of ethnic polarisation.⁹⁰ As the Tutsi

⁸⁹ There are three ethnic groups in Rwanda: Tutsi, Hutu and Twa. The Tutsi are associated with the monarchy that has been abolished.

⁹⁰ I acknowledge that this account is one interpretation of Rwanda's ethnic history. As the focus of this research is not on the ethnic tension within Rwanda, I will not discuss the political question of Rwanda's ethnic history in this thesis. For this interpretation of Rwandan history, Pottier references Webster, J. B., B. A. Ogot and J.-P. Chrétien (1992) *The Great Lakes Region, 1500-1800. In General History of Africa. B.*

monarchy took control over various regions in Rwanda, control over land was taken away from the lineage heads, leaving some with small portions of land of three hectares or less. In response, the lineage heads asked their tenants for more goods and services in exchange for their use of the lineage land (Pottier 2002:184).

This practice of land concentration continues in present day Rwanda (Uvin 1998:112), whereby wealthy farmers whose primary income is gained from government or development work, buy land from poor farmers (Uvin 1998:112). Although Rwandan law forbids the purchase of land by those who own three or more hectares, and requires that all land purchases be authorised by the government, this law is circumvented through various means, including sale on black markets (World Bank 1991b:61; Ministère de l'Intérieur n.d.:10 cited in Uvin:1998:112).

Colonial practices have also influenced tension associated with control of land. Both the German (de Lame 2005:5-6) and then the Belgian colonisers supported the Rwandan monarchy. Colonial authorities used the Rwandan court as a means to establish indirect rule (Pottier 2002:15). Furthermore, in 1959, when the Belgian colonial administrators switched allegiance from the Tutsi to the Hutu ethnic group shortly before granting the country independence, this led to internal tension and civil war, and resulted in 150,000 Tutsi fleeing to Burundi, Uganda and the Congo (Pottier 2002:209). In 1994, the historical colonial influences and the failure of the Rwandan nation to overcome the impact of colonization after independence, culminated in the genocide. Again, much of the population was displaced. The subsequent return of many of these displaced people has placed additional pressure on limited land resources (Pottier 2002:189). Current tension within communities over land ownership is exacerbated by the lack of initiative

on the part of the national government to get involved and set up policies to manage the repatriation (Pottier 2002:190).

The social tension associated with land scarcity was especially evident among the households headed by girls, who not only had less access to land than those households headed by boys, but were more likely to say they had little social support. Until very recently, patrilineal inheritance was practiced in rural Rwanda, and so land was divided up among male descendents. Women who married normally moved onto their husband's property. Most of the CHH in the sample lived in close vicinity to their paternal relatives, and had little contact with their maternal relatives. The paternal relatives may have felt little responsibility for the households headed by girls, because they assumed these girls would move away when they got older, and the girls did not represent the permanence of the lineage. Now, with the imposition of bilateral inheritance, the households headed by girls may represent an additional stress on limited resources, and provoke more tension and animosity from paternal relatives.

Structural violence in Rwanda stems from hegemonic colonial endeavours and global economic policies, which continue to be manifested in NGO programs. Malaria, ethnic tension, lack of resources, and conflict over land are only some of the consequences of these structures and practices that shape the CHH's health seeking behaviour. The following discussion examines how these constraints are manifested in the children's agency.

6.3 Agency

Children's perceptions and experiences of malaria are situated in the shifting space of childhood in Rwanda, resulting from societal fractures brought on by ethnic tension and AIDS, whereby household heads may now be ascribed adult status. While

anthropological studies on children view them as articulate social actors (James 2007:261), and active agents in society (Caputo 2001), their agency and understanding are socially constructed, enabled and constrained. Interviews with the CHH illustrated how structural violence works in a repressive way and how children reproduce the conditions in which they live. Furthermore, although there was differential access to resources among the CHH, they all were situated in a context with inadequate access to public health care and nutritional support, and in a context with little indication of social responsibility or of caring governance. This social and economic poverty influences the children's agency.

The following discussion shows how children's capacity to implement biomedical prevention methods and treatment for malaria and to address their other health concerns has been shaped by a repressed society and by social ideologies of age and gender. I draw upon Laura Ahearn's (2001:113) "ideas of personhood and causality" to identify individual perceptions of agency, and on standpoint theory to examine how positionality affects children's self-conceptions and ideas about what makes them sick. As Jones and Williams (2004:157) point out, behaviour is influenced by social identity, which in turn is based on factors such as sex, age, socioeconomic status, class or ethnicity.

6.3.1 Acceptance of Biomedical Perspective

What I found striking in my conversations with the children in CHH about malaria was that all the children identified mosquitoes as the vector of transmission, that most of them told me that they were able to implement the prevention methods, and that they habitually accessed biomedical treatment when sick. Only a few children questioned the sanctioned prevention messages. Cesarie, for example, pointed out that she was exposed to mosquitoes when she walked home in the evenings, or sat down in

her house. Besides those who were constrained by their lack of resources to access biomedicine, only a few of the older children chose to treat themselves with Kinyarwanda medicine first and see if they got better. This is in stark contrast to what they said about their other health concerns, where children drew from multiple notions to define causality, from environmental determinants and economic scarcity, to relatives or community members who had caused them to get sick by poisoning them or who had caused the death of their parents through “charming.” The children were more likely to tell me that they could not protect themselves from these other health concerns, and they drew upon a variety of treatment options besides biomedicine. In the children’s acceptance of the biomedical discourse on malaria, I see evidence of how structural violence works to place the locus of responsibility for health on the individual.

Structural violence stemming from the processes of colonisation continues to be played out in current political structures of governance, and has led to particular social relationships and patterns of behaviour in Rwandan society. The children’s acceptance of the sanctioned messages on malaria is reflective of the authoritative and repressive society in which they live. From a young age they are taught not only to respect and obey their older household members, but others in their communities (Longman 2007). Additionally, the Rwandan “public administration structure is built in a vertical and all-encompassing model; obedience and respect for authority do seem to be crucial parts of Rwandans’ daily lives” (Uvin 1998:215).⁹¹ Even at the community level, there is evidence of these hierarchies. *Umudugudus*, a collection of 50 houses, are governed by

⁹¹ I did observe that Rwandans were subjugated to a strict code of conduct. For example, during the compulsory monthly *umugandas* (community work projects), police in towns would assign jobs to people who were out in public and not obviously working. However, as Uvin (1998) later cautions, it is important not to adopt a reductionistic perspective on Rwandan behaviour. I saw people breaking these codes, by staying inside and not participating in *umuganda*. Nonetheless, it was rare to hear criticism of the government.

locally elected unpaid leaders. Christophe, the *umudugudu* leader I interviewed, showed me his list of responsibilities. They included “Letting people know and ensure that they follow the program of politics that has been decided by the high leadership.”⁹² Children are immersed in this authoritative climate that gives them little room to engage in critical thinking. In school, they are taught not by engagement, but by rote and repetition. Even at the training session on malaria at a local health center that I attended, the instructor never asked if people had problems implementing prevention for malaria. The CHH involved in NGO programs also have little opportunity to express their concerns about malaria. Although two of the NGOs in the sample said they considered the children’s perspectives when designing the programs, the challenges that confront them with addressing malaria do not have much bearing on the program. Instead, standardized messages are taught that center on self-care or individual responsibility for health.

I heard little from the children in the way of critique of the biomedical perspective. They were reciting what they had been taught, and it was only when the discussion moved away from topics less likely to be covered by community level training or by NGOs, or at school, that the children would draw from their own conceptions and identify barriers. Research among Filipino children living in similar impoverished conditions (Mitchell 2006a) illustrates how children’s ability to follow sanctioned health messages based on personal hygiene is used as a measure of their worth. Furthermore, the Filipino children’s self-blame for illness and injury reproduces the parental view that children’s behaviour and ignorance are to blame for their ill-health and deflects responsibility away from both crumbling societal structures and from impoverished and

⁹² High leadership would refer to those in government positions at the sector, district level or provincial level. Rwanda’s provinces are divided into districts, which in turn are divided into sectors, then cells and then *umudugudus*.

exhausted parents. Rwandan children's assurance that they implemented the sanctioned health messages on malaria may have been passive reproduction of what they had been taught, or a way to earn approval. Importantly, their assurances serve to reproduce the dominant discourse that they are solely responsible for ill-health, and deflects attention from the barriers to health care in their impoverished lives,

6.3.2 Positionality

Children's agency, experiences of malaria, and other illness burdens are influenced by their position within household hierarchies of age. The burden of responsibility upon household heads is linked to Rwandan perceptions of childhood. Rwandans do not necessarily base their definition of childhood on chronological age. Rather, it is dependency on parents or "social maturity" which are the influential factors for being considered a child. Consequently, a 15-year-old who is living on their own may not be considered a child, while a 20-year-old who is still living with their parents may still be considered a child (Cantwell 1997:57). This has obvious repercussions for children living in CHH. For example, unlike NGO staff, community members in my sample never expressed concern about the amount of responsibility that the heads of the households carried, which may have been because they viewed them as adults.

In their interactions within the household, the heads reproduced the social hierarchy in which they were immersed, illustrating that agency emerges "from the social, political, and cultural dynamics of a specified place and time" (Desjarlais cited in Ahearn 2001:113). Decisions about health care at the household level illustrate what Nichter identifies as the "social embeddedness and microhistorical character of therapy management" (2002:83). Consequently, analysis of agency at the household level needs to consider that:

The perception that household members are largely altruistic, that they pool their income and function as a homogenous unit having common goals, has been brought into question... Studies of therapy management provide insights into priority setting within households, the manner in which gender and generation relations influence resource allocation, circumstances that foster competition and cooperation, and processes of negotiation and accommodation as well as resistance and assertion. They also contribute to the anthropology of self and a growing critique of the simplistic way in which cultures and peoples have been described in terms of sociocentric (collectivist) versus individualist motivations and goals (Nichter 2002:82).

Among Rwandan CHH, household heads determined the treatment choice for younger household members who were sick, and determined how household resources would be spent. As the example of Rosine indicated in Chapter Five, some heads prioritised their needs over that of the household. As was evident with Augustine and Kanobana and the hanging of their mosquito net, the head's perspective took precedence over a younger household member's ideas. Furthermore, the heads saw themselves as the decision makers in their own health care. For example, Philippe waited to determine the severity of his bout with malaria before deciding on his treatment choice. Socially sanctioned roles allowed for greater agency among household heads.

Similarly, younger children subscribed to socially sanctioned ways of interacting. However, in their case, it restrained their agency. They deferred to the household heads in decision-making, and were clearly dependent on them for assistance with treatment when they were sick. Consequently, they may be more likely to suffer longer with malaria if their sibling does not seek treatment for them right away. As Jean-David said, if Kinyarwanda medicine does not work, and if he is still sick from malaria after a month and a half, then his older sister will take him for treatment at a health center. In deferring and relying on the household head, there was no indication that the younger children challenged age-based roles. Although discussion on agency (Ahearn 2001) includes the

concept of power in terms of the ability to bring about change and to reconstitute one's social environment, this ignores the larger structural processes that shape these possibilities (Wolf 1999). In contexts characterised by extreme poverty, and societies mired by structural violence, where marginalised populations bear the burden of social suffering, children in powerless positions often reproduce the socially sanctioned roles and discourses (Gaventa and Cornwall 2004:326).

Analysis on gendered perspectives of health care (Sargent and Bretell 1996) also challenges the assumption that the locus of health decision-making rests with the individual. Instead, they also identify both positionality as a starting place for analysis and the need to conceptualise those seeking health care as gendered people, situated in a particular socioeconomic context, who may be constrained or enabled depending on their gender. Among the CHH in my sample, there was a noticeable gendered attentiveness to the body and to health. Girls tended to identify more symptoms associated with malaria, to be more precise about the frequency of their malaria episodes, and to identify more health complaints than did boys. Some girls associated body size with well-being or sickness, while no boys did. These patterns are derived from the Rwandan context in which the girls are situated, which encourages this attentiveness and care. Ethnographic research (de Lame 2005) which discusses Rwandan gender roles indicates that throughout their childhood, girls are taught to care for the household, and as they grow older, they are given more nurturing and caring responsibilities for their younger siblings. Consequently, girls' agency in caring for their health is socially sanctioned and enabled.

Discussions with boys in my sample indicated that they had more opportunity to engage with community members compared to the girls, whose own daily activities were more likely to be centered on the household. Other research among Kenyan children who

also live in a patrilineal society (Wenger 1989) has noted that girls' time from a young age is more structured in contrast to boys. Girls' time is structured by social expectations that they provide for the consumption, production and reproduction needs of the family. Frequently girls would talk about societal distrust and tension, or about being robbed. In contrast, boys in my research talked pointedly about their interactions with people in the community, including organised opportunities to play soccer on a regular basis. Lack of opportunity for girls to interact with other community members can exacerbate notions of social distrust, and prevent opportunities to build connections within one's community. Furthermore, the susceptibility of female orphans to sexual abuse by male community members has been well documented (ACORD 2001; Human Rights Watch 2003; Oleke et al. 2006; Snider and Dawes 2006; Veale et al. 2001). This may also be a source of the girls' anxiety and distrust.

6.3.3 Agency and Community/NGO Support

Structural constraints and social ideologies are also manifested in community responses to CHH. Kleinman et al. (1997:ix) state that social suffering is not only an outcome of political, economic and institutional power, but it also results "from how these forms of power themselves influence responses to social problems." The very presence of NGOs has influenced communal support of CHH. In my interviews with community members, some said that they felt the responsibility for CHH lay with NGOs. Veale (2000:237) remarks that the reliance of Rwandan communities on formal, authoritative and hierarchical forms of social relations inhibits spontaneous and collective communal efforts to interact, or to support children whose family structure is tenuous. Community members may have been prone to only involve themselves in community level initiatives focused on CHH, rather than initiating support on their own. At least one

CHH in my research had their house built during government organized *umugandas* (community work projects).

When the community members talked about the agency of CHH in terms of their health seeking behaviour, their perspectives were noticeably influenced by their own positionality. One community member, who was clearly wealthier than his neighbours, told me that there were no barriers to the CHH's health seeking behaviour. He felt that if the children followed the health messages they were taught, they would not get sick. In contrast, the single mothers, whose own access to basic needs was precarious, were more likely to comment on the barriers confronting CHH. However, none identified the social determinants of ill health, although they talked about how land shortage contributed to the children's poverty, and ability to access nutritious food. Notably, they did not critique the government, but linked the land shortage to the tumultuous history of Rwanda and the resulting repercussions. In part, this is due to the repressive nature of Rwandan society, where there is limited criticism of the government.⁹³ Instead, I often heard the refrain "we are developed now," which suggested that people accepted their responsibilities in this government propagated discourse.⁹⁴

NGOs operating in the communities where the CHH live represent a formalised support structure, and their perspective on the children's agency is evident in their health messages, which focus on individualized responsibility for malaria prevention and treatment. These messages ignore the social determinants of the children's suffering, as well as the structural barriers and social ideologies that influence the CHH's health

⁹³ It was only in private conversation with friends that I heard criticism. One Rwandan who was working for a NGO in Burundi, noted the difference between the two countries. He observed that in Burundi the government allows public criticism of current politics.

⁹⁴ These included such things as bilateral inheritance of land, the sharing of household responsibilities by males and females, ethnic unity, and compulsory rice cultivation among landowners in valleys.

seeking behaviour. Self-care is impossible for the children to achieve due to their subservient positions and insufficient diets (Mitchell 2006a:365). Household heads bear a burden of responsibility far beyond their resources, and young children, with whom the NGOs have little to no contact, are particularly vulnerable to poor health outcomes (see Alaii et al. 2003; Oleke et al. 2006; Peltzer and Promtussananon 2003). Additionally, the brevity of their programs (see Luzze 2002) does not provide a sufficient amount of time to work with children to address the underlying barriers.

The current NGO practice of shuffling CHH into programs with other beneficiaries ignores the particular constraints faced by CHH and the disproportionate burden of social suffering the children bear.⁹⁵ Furthermore, it serves to reproduce social structures that constrain children's agency. Those children involved in the associations managed by NGO 4 were at the bottom rung of the social ladder, and due to social norms around communicating, did not express their concerns or issues to program staff. Those NGO programs that focused on orphans and other vulnerable children put more effort in eliciting the children's comments, but little was done in addressing the underlying barriers facing children that affect their ability to implement health messages. Furthermore, in legitimising the risk of malaria, focusing funding efforts on this disease, and endorsing biomedical approaches to it, NGOs are negating the children's other health concerns. Mitchell (2006a:332) points out that when children's and adults' ideas differ on what health issues need to be addressed, children may not be benefiting from health care. For example, the children would often tell me that they would "leave it" or "sleep" when sick with health concerns other than malaria, or they might draw upon local

⁹⁵ Merging CHH in other beneficiary groups might be a way to show that the country is practicing "good governance" (used by an NGO staff member in reference to the image the Rwandan government is trying to maintain to the international community) and effectively managing the issue of AIDS.

remedies or Kinyarwanda medicine. The children were not benefiting from international or national health care, because these other concerns fell outside of the national and international health care agenda.

6.4 Chapter Summary

The children living in CHH who participated in this research project are situated in a politicised space characterised by poverty, societal distress and hierarchies of power. Consequently, their perceptions and experiences regarding malaria are intersected by divergent cultural projects reflecting various health care ideologies and forms of support. Social, political, cultural, economic, ethnic and gender factors construct, enable and constrain children's agency and interpretations of their health. Understanding children's ideas and experiences regarding malaria serves to illustrate the significance of both larger processes and local constraints in the lives of the children, manifested in their burden of social suffering. This illustrates how "health behaviours are not simply a function of knowledge or beliefs but are also modified and constrained by the social, cultural, economic and political context in which they occur" (Jones and Williams 2004:157).

The particular experience of social suffering born by the CHH, their bodily experiences of malaria, and their concerns and anxieties regarding malaria are systematized and reflect cultural patterns of being, as well as global forces, and the ongoing effects of structural violence. Consequently, their particular standpoints offer the researcher a critical perspective on the interplay of political and socioeconomic forces that lead to structured risk for poor health outcomes.

In the following chapter, I discuss the conclusions drawn from this research project and suggest how the findings of this research can contribute to various efforts aimed at assisting children living in CHH.

CHAPTER SEVEN: CONCLUSION



Figure 7.1 Left: Jeanine, Celestin & Margerite (Household Q) during the drawing activities, Visit 5. Photo: Michelle Hardy August 2008

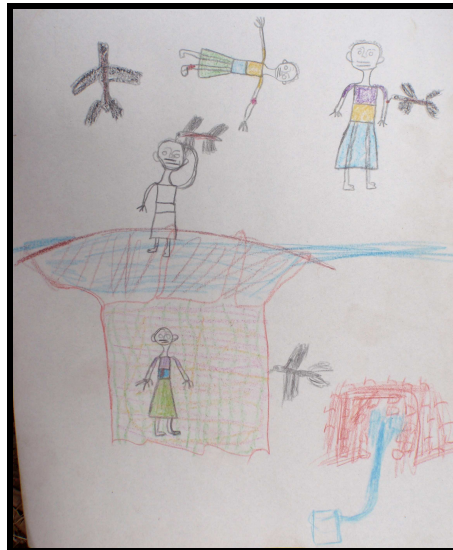


Figure 7.2 Right: Jeanine's drawing. Top: Things that make her sick –falling down, being bitten by mosquitoes. Bottom: Things that keep her healthy – mosquito nets, water from a clean source. Photo: Michelle Hardy. August 2008

...a language of dismay, disappointment, bereavement, and alarm that sounds not at all like the usual terminology of policy and programs may offer a more valid means for describing what is at stake in human experiences of political catastrophe and social structural violence, for professionals as much as for victims/perpetrators, and also may make better sense of how the clash among globalizing discourses and localized social realities so often ends up prolonging personal and collective tragedy (Kleinman et al.1997:xi).

Anti-malaria initiatives that focus only on preventative methods and treatment regimes overlook the impact of social factors, such as sociocultural beliefs and practices, and the impact of the political and economic context on children's ability to act on these initiatives. These factors influence perceptions, behaviour, social structure, as well as social responses to the disease (Jones and Williams 2004). In this research project I have shown how the understandings, experiences and responses of children living in CHH in rural Rwanda regarding malaria are influenced by larger structural factors, "cultural values, social roles and institutions, power relations and economic circumstances"

(Nichter 2002:82). It is within this framework that the discussion on children's perceptions and responses to malaria has been situated, as well as their burden of social suffering due to the impact of their resource-poor context and social and household hierarchies.

In this chapter I provide a summary of the theoretical framework and conclusions of the research project, and propose entry points for future research. I then suggest how the findings from this project contribute to current efforts aimed at assisting children living in CHH.

7.1 Theoretical Framework

This research project is founded on the premise articulated by anthropological studies on children (Scheper-Hughes and Sargent 1998), which considers children to be both acted upon and participants within global political-economic structures and micro-level interactions. The CHH are situated in a particular space in Rwandan society, subject to processes that both constrain and enable their health seeking behaviour. For example, younger children are highly dependent on older siblings for health care assistance, and elder children have more opportunity to make their own health care decisions. Importantly, the space in which the CHH are situated, although influenced by historical structures (Stephens 1995:4-7), continues to shift as it is simultaneously transformed from within, and acted upon by large-scale processes, and local level practices. These transformations are evident in the historical colonial influence on access to land, the emergence of CHH as a social category due to the genocide and AIDS, the influence of the international community through the continued presence of NGOs, and in the recent shift to dual inheritance of land.

Although I relied on a critical theoretical approach based on grounded theory, which prioritises the analytical insights that emerge from the data rather than verification of propositions (Emerson et al. 1995:143), my project's approach was framed by the theories of social suffering, structural violence and standpoint theory. For example, my original conception of the framework of social suffering was to use this theoretical construct to examine how social suffering inhibited community responses to CHH. However, the particular burden of social suffering born by the CHH themselves emerged over the course of the research. Using standpoint theory, I was able to analyse the household hierarchies evident in differential access to resources based on age and gender.

My reliance on structural violence provided the basis for my analysis into how international donor interests and the Rwandan government policies on health result in structured risk for CHH. However, my original perspectives on CHH being defined as an "at-risk" group by NGOs were changed over the course of the research, as I noted how they had been shuffled into larger beneficiary groups. Consequently, this research has highlighted how CHH are no longer receiving the targeted assistance that they need. Furthermore, the theoretical concept of structural violence was useful in examining the larger historical processes of colonisation and global economic policies that have exacerbated issues over land and led to deepening poverty within Rwanda.

Lastly, by drawing upon the notion of agency along with standpoint theory, I was able to examine why CHH are not questioning sanctioned knowledge on malaria, nor challenging age or gender based roles, and why the children reproduce the conditions in which they live. Based on what I know about Rwanda, the colonial history, the very recent violence, and the impoverished conditions, it does not surprise me that there is little evidence of resistance among the CHH.

7.2 Conclusions

Based on my research data, I suggest that malaria is familiar to the children, not only because it is an illness that they have experienced, but because it holds a significant position in the nation's discourse on health. Children living in rural CHH are exposed to official health messages on malaria through a number of means: school, NGOs, community health training, and the radio. Therefore, children are well versed in biomedical prevention and treatment for malaria. However, the dominant biomedical discourse intersects with other messages transmitted through less formal networks of exchange, such as the children's peers. This is particularly evident in children's understandings and experiences in relation to their other health concerns.

Malaria, although a health concern for the children in CHH, represents only one of their many concerns. These other concerns are also associated with their impoverished environments, over which they have little control and which receive little attention by government sponsored health initiatives. The underlying themes of "self-care, self-blame and individualized responsibility" (Mitchell 2006a:365) permeate the children's, community members' and NGOs' discourses on health. The national and international community's lack of acknowledgment of the barriers to health care represented by the children's economic and material poverty underlies the structural causes of their suffering.

The analysis of the children's understandings, experiences and responses to malaria points to an unequal distribution of suffering by age and gender. Household hierarchies create both constraints and opportunities for health-seeking behaviour. These hierarchies place the burden of responsibility for the health of the other members on the household head, while younger household members are dependent on the household head

for treatment decisions and assistance. The head has more access to formalised forms of support, while the younger children are more likely to have access to education.

Although very young children are at particular risk to illness, they are regarded as vulnerable by community members and therefore may be more likely to receive community support. Sanctioned gender roles and domains result in girls being more attentive to health care, but constrain their access to the public domain. Gendered variation is also evident in access to land-based resources, even with the restructuring of national laws promoting equal inheritance rights for females. Consequently, sociocultural factors play a significant role in children's experiences and responses to malaria.

NGOs represent an organised means of support for CHH. However, they pay little attention to the children's particular perspectives and concerns about malaria, and contribute little to relieving the impoverishment of CHH. Community support is constrained by social ideologies that frame the perceptions of the vulnerability of CHH, and shaped by social tension associated with land scarcity and widespread poverty. On a positive note, community marginalisation of CHH appears to be decreasing in some areas, concurrently with stigma associated with AIDS.

Some significant limitations affect the implications of these conclusions. First, due to the limited gender diversity in my sample, I can say little about the difference in health outcomes of children based on gender. Second, my status as a white westerner meant that the children most likely viewed themselves as subordinate to me, and therefore, they probably did not disclose the full spectrum of their health concerns, or all the different treatment options they relied on. For example, the girls never talked to me about any reproductive health issues or their vulnerability to sexual exploitation, which

literature suggests is a significant concern for girls. Third, ethnic tension in Rwanda continues to impact social relations. However, because it is such a sensitive issue, and because of the strong government discourse stressing a unified nation, I was unable to examine the impact of ethnicity on children's access to organised and informal support.

7.3 Further Research

The perspectives of the children illustrate how the discourse of individualized responsibility for health overlooks the particular barriers that hinder children's efforts at health care. Poverty impacts children's efforts at implementing health care in multiple ways. It creates an environment that leads to poor health outcomes, and it restricts children from access to biomedicine, while other treatment options are becoming increasingly marginalised due to increased government control. Research into the knowledge transfer of Kinyarwanda medicine might indicate how much access children have to other treatment options.

Patterns of vulnerability are clearly identifiable based on household hierarchies associated with age, and sanctioned gender roles and domains. Although the locus of responsibility for the health of the household is placed on the eldest child, this is an excessive burden. Consequently, health knowledge transmission and assistance to younger children does not always occur. Further research into the factors that influence decision making at the household level would illustrate the priority of household health in comparison to other concerns.

My research indicated that gender based social ideologies restricts girls from avenues of public support, and isolates them in their health seeking behaviour. This leads to questions regarding the high prevalence of female-headed households in Rwanda, and the life-course outcomes of these vulnerable household groupings in comparison to male-

headed households. For example, although none of the girls heading households ever disclosed that they were involved in the sex trade, there were indications that some were. Further research is needed on how limited economic opportunities may lead to higher health risk behaviour for households headed by girls.

As NGO programming shifts away from programs that acknowledge the particular vulnerability of CHH, they are neglecting a social group that will continue to exist as long as HIV/AIDS remains an issue within rural Rwanda. My research highlights what happens when shifting donor interests result in changes in NGO criteria regarding program beneficiaries. CHH have been integrated into other NGO beneficiary profiles, but due to their vulnerable status in Rwandan society, they are hindered from accessing the support initiated by NGOs. Although my research was primarily concerned with whether NGOs solicit the perspectives of CHH in their programs, an anthropological inquiry into NGO assistance would be useful to determine the long-term health impact of NGO assistance on the lives of CHH, and to determine the effectiveness of their health training and other forms of support.

My research supports earlier research (ACORD 2001; Veale et al. 2001) on the social marginalisation of CHH by showing the lack of practical health care support given to CHH. However, the results from my research suggest that there is some social support given to CHH and it varies according to social ideologies associated with age and gender. Further research could look into the impact of NGOs on community initiatives aimed at CHH, and explore community reliance on formal initiatives to assist CHH. This might lead to improvements in how communities are mobilised to support CHH. There is some indication that Rwandans are informally adopting orphaned relatives. It appears that some of these children have differential access to resources compared to other children in

the household. The marginalization of these children from health care resources would also be a significant area for further research.

7.4 Knowledge Transmission

The mayor of one of the districts within the Southern Province where this research was conducted has requested a summary of the findings of this research project. A final report of the findings has been prepared for this office, as well as for those NGOs that participated in the research and indicated they would like a research summary.⁹⁶ Additionally, I have presented the results of this research to the public on two occasions, and I also plan to present at academic conference in Canada. Results of the research may also be submitted to a peer-reviewed journal or shared at an academic presentation.

The following points will be included in the report given to the mayor's office:

- Community support aimed at CHH tends to be given primarily through organized efforts. The support that is given informally is based on perceived vulnerability of CHH, often linked to ideas around age and gender. Households headed by girls are particularly marginalized from community support, and therefore, very vulnerable.
- *Umudugudu* leadership could mobilize community members to address particular issues confronting CHH. For example, CHH living in one sector used brick stoves that required less firewood, while CHH living in other sectors did not. These stoves could be built for those CHH during community *umugandas*.
- Children's health concerns extend beyond those covered in community health training (malaria, TB, AIDS, hygiene, boiling water). The children have no source of support for these needs. Although general health training is offered in

⁹⁶ The reports will be sent upon the completion of the thesis, as they contain recommendations that are included in this document.

the *umudugudu*, could specific training be given to CHH on the needs that they identify?

- Although some children receive health insurance through the *umudugudu* leadership, many CHH are overlooked. This may be because there is an assumption that an NGO is assisting the children. Greater coordination between the *umudugudu* leadership and the NGO needs to occur.

The following points will be included in the report given to the NGOs:

- In order to assist CHH effectively, their perspectives and concerns need to be solicited and used to determine program design. For example, malaria is not the only health concern confronting CHH. Soliciting the children's input will ensure that programs are including their concerns.
- Children's responses to malaria are not simply based on what they have been taught about the disease, but they are also constrained by their impoverished household conditions, lack of economic resources and social support, as well as household hierarchies and gender. Programs should work towards addressing these factors rather than simply teaching children prevention methods on malaria.
- A significant issue that the children identified was a lack of economic resources to buy health insurance or a mosquito net, and eat a nutritious diet. How might NGO programs more effectively assist CHH with income generating projects that will benefit the children over the long-term, not just a three-year program period?
- The practice of only working with the household head should be examined, because knowledge and support is not always effectively transmitted to other children. The household heads need help from the NGO in transmitting that knowledge, and support in their particular responsibilities as household head.

Program efforts need to consider the vulnerability of younger children, and staff and volunteers should also work with these children.

- CHH represent a socially vulnerable group in Rwanda, and merging them into groups with other beneficiaries means that they face a similar social vulnerability within the beneficiary group. CHH are reticent to talk about their needs in these groups. If possible, CHH should not be merged into larger groups, and if they are, greater efforts need to be made to ensure that the children are not hindered from benefiting from program components, and that they are able to express their needs.

REFERENCES

- ACORD: Agency for Cooperation and Research in Development
 2001 Research into the Living Conditions of Children Who are Heads of Households in Rwanda. Electronic document, <http://www.acord.org.uk/r-pubs-Rwanda%20Child-headed%20hhs.PDF>, accessed October 16, 2007.
- Ahearn, Laura
 2001 Language and Agency. *Annual Review of Anthropology* 30:109-137.
- Ahorlu, Collins, Samuel Dunyo, Edwin Afari, Kwadwo Koram, and Francis Nkrumah
 1997 Malaria - Related beliefs and Behaviour in Southern Ghana: Implications for Treatment, Prevention and Control. *Tropical Medicine & International Health* 2 (5):488-499.
- Alaii, Jane A., William A. Hawley, Margarette S. Kolczak, Feiko O. Ter Kuile, John E. Gimnig, John M. Vulule, Amos Odhacha, Aggrey J. Oloo, Bernard L. Nahlen, and Penelope A. Phillips-Howard
 2003 Factors Affecting Use of Permethrin-Treated Bed Nets During a Randomized Controlled Trial in Western Kenya. *American Journal of Tropical Medicine and Hygiene* 68 (4): 2003:137-141.
- Arokiasamy, Perianayagam
 2004 Regional Patterns of Sex Bias and Excess Female Child Mortality in India. *Population* 59 (6):833-864.
- Asad, Talal
 1997 On Torture, or Cruel, Inhuman, and Degrading Treatment. *In Social Suffering*. Arthur Kleinman, Veena Das, and Margaret Lock, eds. Pp. 285-308. Berkeley: University of California Press.
- Barrett, Ronald, Christopher W. Kuzawa, Thomas McDade, and George J. Armelagos
 2006 Emerging and Re-emerging Infectious Diseases: The Third Epidemiologic Transition. *In Health and Healing in Comparative Perspective*. Elizabeth D. Whitaker, ed. Pp. 193-211. Upper Saddle River, NJ: Pearson Education, Inc.
- Bernard, Harvey Russell
 2002 Research Methods in Anthropology: Qualitative and Quantitative Approaches. 3rd Ed. Walnut Creek, CA: AltaMira Press.

- Boris, Neil W., Tonya R. Thurman, Leslie Snider, Erin Spencer, and Lisanne Brown
 2006 Infants and Young Children Living in Youth-headed Households in Rwanda: Implications of Emerging Data. *Infant Mental Health Journal*. 27 (6):584-602.
- Brown, Peter J.
 1998a Belief and Ethnomedical Systems: Conceptual Tools. *In Understanding and Applying Medical Anthropology*. Peter J. Brown, ed. Pp. 108-109. Mountain View, CA: Mayfield Publishing Company.
- Brown, Peter J.
 1998b Culture and Political Ecologies of Disease: Conceptual Tools. *In Understanding and Applying Medical Anthropology*. Peter J. Brown, ed. Pp. 77-78. Mountain View, CA: Mayfield Publishing Company.
- Cantwell, Nigel
 1998 Starting From Zero: The Promotion and Protection of Children's Rights in Post-Genocide Rwanda July 1994-December 1996. Florence, Italy: UNICEF International Child Development Centre.
- Caputo, Virginia
 2001 Telling Stories from the Field: Children and the Politics of Ethnographic Representation. *Anthropologica* XLIII:179-189.
- CARE
 a CARE's Work: Rwanda. Electronic document, <http://www.care.org/careswork/countryprofiles/93.asp>, accessed November 24, 2007.
- CARE
 b Lessons Learned: A Model for Community-Based Care for Orphans and Vulnerable Children. Electronic document, <http://www.crin.org/docs/Rwanda%20Nkundabana.pdf>, accessed October 23, 2007.
- Cook, Alice Skinner, Janet Julia Fritz, and Rose Mwonya
 2003 Understanding the Psychological and Emotional Needs of AIDS Orphans in Africa. *In The Children of Africa Confront AIDS: From Vulnerability to Possibility*. Arvind Singhal, W. Stephen Howard, eds. Pp. 85-104. Athens, OH: Ohio University Press.
- Crewe, Emma and Elizabeth Harrison
 1998 Whose Development? An Ethnography of Aid. London: Zed Books.

de Lame, Danielle

- 2005 *A Hill among a Thousand: Transformations and Ruptures in Rural Rwanda*. Helen Arnold, trans. Madison, WI: The University of Wisconsin Press.

Daniel, E. Valentine

- 1997 *Suffering Nation and Alienation*. In *Social Suffering*. Arthur Kleinman, Veena Das, and Margaret Lock, eds. Pp. 309-358. Berkeley: University of California Press.

Dunn, Judy

- 2005 *Naturalistic Observations of Children and their Families*. In *Researching Children's Experience: Approaches and Methods*. Sheila Green and Diane Hogan, eds. Pp. 87-101. London: Sage Publications.

Edge, Wayne (Comp.)

- 2008 *Global Studies: Africa*. 11th Edition. Dubuque, IA: McGraw-Hill.

Emerson, Robert M., Rachel I. Fretz, and Linda L. Shaw

- 1995 *Writing Ethnographic Fieldnotes*. Chicago: The University of Chicago Press.

Encyclopedia of the Nations

- 2007 *Africa, Rwanda. Location, Size and Extent, and Population*. Electronic document, <http://www.nationsencyclopedia.com/Africa/Rwanda.html>, accessed December 8, 2008.

Farmer, Paul

- 1999 *Infections and Inequalities: The Modern Plagues*. Berkeley: University of California Press.

Farmer, Paul

- 2005 *Pathologies of Power: Health, Human Rights, and the War on the Poor*. Berkeley: University of California Press.

Ferguson, James

- 2006 *Global Shadows: Africa in the Neoliberal World Order*. Durham: Duke University Press.

Ferguson, James and Akhil Gupta

- 2002 *Spatializing States: Toward and Ethnography of Neoliberal Governmentality*. *American Ethnologist* 29 (4):981-1002.

- FHI: Food for the Hungry International
 2001 Child-Headed Household Assistance Program. Electronic document, <http://www.fhi.net/countries/countries.php3?countryid=23>, accessed October 23, 2007
- Fontana, Andrea and James H. Frey
 2000 The Interview: From Structured Questions to Negotiated Text. *In Handbook of Qualitative Research*, 2nd Edition. Norman K. Denzin, Yvonna S. Lincoln, eds. Pp. 645-672. Thousand Oaks, CA: Sage Publications, Inc.
- Galtung, Johan
 1969 Violence, Peace and Peace Research. *Journal of Peace Research* 6 (3):167-191.
- Gaventa, John and Andrea Cornwall
 2004 Power and Knowledge. *In Critical Strategies for Social Research*. William K. Carroll, ed. Pp. 320-333. Toronto: Canadian Scholar's Press, Inc.
- Geissler, P. Wenzel
 1998 'Worms Are Our Life', part 2: Luo Children's Thoughts about Worms and Illness. *Anthropology and Medicine* 5 (2):133-144.
- Gershman, John and Alec Irwin
 2000 Getting a Grip on the Global Economy. *In Dying for Growth: Global Inequality and the Health of the Poor*. Jim Yong Kim, Joyce V. Millen, Alec Irwin, and John Gershman (eds.). Pp. 11-43. Monroe, MA: Common Courage Press.
- Green, Edward C.
 1999 *Indigenous Theories of Contagious Disease*. Walnut Creek, CA: AltaMira Press.
- Greene, Sheila and Malcolm Hill
 2005 Researching Children's Experiences: Methods and Methodological Issues. *In Researching Children's Experience: Approaches and Methods*. Sheila Green and Diane Hogan, eds. Pp. 1-21. London: Sage Publications.
- Greig, Anne, Jayne Taylor, and Tommy MacKay
 2007 *Doing Research with Children*, 2nd edition. London: Sage Publications Ltd

- Guba, Egon G. and Yvonna S. Lincoln
 1998 Competing Paradigms in Qualitative Research. *In* The Landscape of Qualitative Research: Theories and Issues. Norman K. Denzin and Yvonna S. Lincoln, eds. Pp. 195-220. Thousand Oaks, CA: Sage Publications.
- Haraway, Donna
 1997 *Modest_Witness@Second_Millennium. FemaleMan_Meets_OncoMouse: Feminism and Technoscience*. New York: Routledge.
- Harding, Sandra
 2004 *The Feminist Standpoint Theory Reader: Intellectual and Political Controversies*. NY: Routledge.
- Helleiner, Jane
 1999 Toward a Feminist Anthropology. *Atlantis* 24 (1):27-38.
- Henderson, Patricia C.
 2006 South African Aids Orphans: Examining Assumptions around Vulnerability from the Perspective of Rural Children and Youth. *Childhood* 13 (3):303-327.
- Hill, Kenneth and Dawn M. Upchurch
 1995 Gender Differences in Child Health: Evidence from the Demographic and Health Surveys. *Population and Development Review* 21 (1):127-151.
- Hill, Malcolm
 2005 Ethical Considerations in Researching Children's Experiences. *In* Researching Children's Experience: Approaches and Methods. Sheila Green and Diane Hogan, eds. Pp. 61-86. London: Sage Publications.
- Holtz, Timothy and S. Patrick Kachur
 2004 The Reglobalization of Malaria. *In* *Sickness and Wealth: The Corporate Assault on Global Health*. Meredith Fort, Mary Anne Mercer and Oscar Gish, eds. Pp. 131-143. Cambridge, MA: South End Press.
- Human Rights Watch
 2003 Lasting Wounds: Consequences for Genocide and War for Rwanda's Children 15 (6). Electronic document, <http://hrw.org/reports/2003/rwanda0403/rwanda0403.pdf>, accessed October 16, 2007.
- Irwin, L. G., J. L. Johnson, A. Henderson, V. S. Dahinten and C. Hertzman
 2006 Examining How Contexts Shape Young Children's Perspectives of Health. *Child: Care, Health and Development*. 33 (4):353-359.

- Ivan-Smith, Edda and Victoria Johnson
 1998 The Way Forward. *In* *Stepping Forward: Children and Young People's Participation in the Development Process*. Victoria Johnson, Edda Ivan-Smith, Gill Gordon, Pat Pridmore and Patta Scott, eds. Pp. 291-299. London: Intermediate Technology Publications.
- James, Alison
 2007 Giving Voice to Children's Voices: Practices and Problems, Pitfalls and Potentials. *American Anthropologist* 109 (2):261-272.
- James, Allison, Chris Jenks, and Alan Prout
 1998 *Theorizing Childhood*. New York: Teachers College Press.
- James, Allison and Alan Prout
 1990 *Constructing and Reconstructing Childhood: New Directions in the Sociological Study of Childhood*. London: The Falmer Press.
- Jones, Caroline O. H. and Holly A. Williams
 2004 The Social Burden of Malaria: What are We Measuring? *American Journal of Tropical Medicine and Hygiene* 71 (Suppl 2):156-161.
- Katz, Cindi
 2004 *Growing Up Global: Economic Restructuring and Children's Everyday Lives*. Minneapolis: University of Minnesota Press.
- Kincheloe, Joe L. and Peter McLaren
 2000 Rethinking Critical Theory and Qualitative Research. *In* *The Handbook of Qualitative Research – 2nd Edition*. Norman K. Denzin and Yvonna S. Lincoln, eds. Pp. 279-314. Thousand Oaks, CA: Sage Publications, Inc.
- Kleinman, Arthur
 2000 The Violence of Everyday Life: The Multiple Forms and Dynamics of Social Violence. *In* *Violence and Subjectivity*. Veena Das, Arthur Kleinman, Mamphela Ramphele and Pamela Reynolds, eds. Pp. 226-241. Berkeley: University of California Press.
- Kleinman, Arthur, Veena Das, and Margaret Lock, eds.
 1997 *Social Suffering*. Berkeley: University of California Press.
- Kleinman, Arthur and Joan Kleinman
 1991 Suffering and its Professional Transformation: Toward an Ethnography of Interpersonal Experience. *Culture, Medicine, and Psychiatry* 15 (3):275-301.

Lincoln, Yvonna S. and Egon G. Guba

- 2000 Paradigmatic Controversies, Contradictions, and Emerging Confluences. *In* The Handbook of Qualitative Research – 2nd Edition. Norman K. Denzin and Yvonna S. Lincoln, eds. Pp. 163-188. Thousand Oaks, CA: Sage Publications, Inc.

Lins Ribeiro, Gustavo

- 2006 World Anthropologies: Cosmopolitics for a New Global Scenario in Anthropology. *Critique of Anthropology* 26 (4):363-86.

Longman, Timothy

- 2007 Culture of Rwanda. Electronic document, <http://www.everyculture.com/No-Sa/Rwanda.html>, accessed March 18, 2008.

Luzze, Frederick

- 2002 Survival in Child-Headed Households: A Study on the Impact of World Vision Support on Coping Strategies in Child-Headed Households in Kakuuto County. Electronic document, <http://www.crin.org/bcn/details.asp?id=9038&themeID=1002&topicID=1015>, accessed October 17, 2007.

Mamdani, Mahmood

- 2001 When Victims Become Killers: Colonialism, Nativism, and the Genocide in Rwanda. Kampala: Fountain Publishers.

Manji, Firoze and Carl O'Coill

- 2002 The Missionary Position: NGOs and Development in Africa. *International Affairs* 78(3):567-583.

Manyau, Charity

- 1998 Situational Analysis with Children Living in Difficult Circumstances in Zimbabwe using Participatory Rural Appraisal. *In* Stepping Forward: Children and Young People's Participation in the Development Process. Victoria Johnson, Edda Ivan-Smith, Gill Gordon, Pat Pridmore and Patta Scott, eds. Pp. 69-75. London: Intermediate Technology Publications.

MARA ARMA

- 2002 Rwanda: Distribution of Endemic Malaria. Electronic document, <http://www.mara.org.za/>, accessed November 29, 2007.

Maxwell, Joseph A.

- 2005 Qualitative Research Design: An Interactive Approach. 2nd Edition. Thousand Oaks, CA: Sage Publications Inc.

- MINALOC: Ministry of Local Government, Information and Social Affairs
 2003 National Policy for Orphans and Other Vulnerable Children. Electronic document, www.unicef.org/southafrica/SAF_resources_ovcrwanda.doc, accessed Sept. 20, 2007.
- Mitchell, Lisa
 2006a Body and Illness: Considering Visayan Filipino Children's Perspectives within Local and Global Relationships of Inequality. *Medical Anthropology* 25:331-373.
- Mitchell, Lisa
 2006b Child-Centered? Thinking Critically about Children's Drawings as a Visual Research Method. *Visual Anthropology Review* 22 (1):60-73.
- Moore, Henrietta L. and Todd Sanders
 2006 Anthropology and Epistemology. *In Anthropology in Theory: Issues in Epistemology*. Henrietta L. Moore and Todd Sanders, eds. Pp. 1-21.
- Nguyen, Vinh-Kim and Karine Peschard
 2003 Anthropology, Inequality, and Disease: A Review. *Annual Review of Anthropology* 32:447-474.
- Nichter, Mark
 2002 The Social Relations of Therapy Management. *In New Horizons in Medical Anthropology*. Mark Nichter and Margaret Lock, eds. Pp. 81-110. London: Routledge.
- Nolan, Riall
 2002 Development Anthropology: Encounters in the Real World. Boulder, CO: Westview Press.
- Obeng, Christina
 1998 Cultural Relativity in Ghana: Perspectives and Attitudes. *In Stepping Forward: Children and Young People's Participation in the Development Process*. Victoria Johnson, Edda Ivan-Smith, Gill Gordon, Pat Pridmore and Patta Scott, eds. Pp. 132-135. London: Intermediate Technology Publications.
- Oleke, Christopher, Astrid Blystad, Karen Marie Moland, Ole Bjørn Rekdal, and Kristian Heggenhougen
 2006 The Varying Vulnerability of African Orphans: The Case of the Langi, Northern Uganda. *Childhood* 13 (2):267-284.

Oleson, Virginia L.

2000 Femininisms and Qualitative Research At and Into the Millennium. *In* The Handbook of Qualitative Research – 2nd Edition. Norman K. Denzin and Yvonna S. Lincoln, eds. Pp. 215-256. Thousand Oaks, CA: Sage Publications, Inc.

O'Reilly, Karen

2005 *Ethnographic Methods*. London: Routledge.

Otaala, Barnabas

1998 Children's Participation for Research and Programming in Education, Health and Community Development: Selected Experiences in Africa. *In* Stepping Forward: Children and Young People's Participation in the Development Process. Victoria Johnson, Edda Ivan-Smith, Gill Gordon, Pat Pridmore and Patta Scott, eds. Pp. 135 - 142. London: Intermediate Technology Publications.

Peltzer, Karl and S. Promtussananon

2003 Black South African Children's Understanding of Health and Illness: Colds, Chicken Pox, Broken Arms and AIDS. *Child: Care, Health and Development* 29 (5), 385–393.

Pfeiffer, James

2004 International NGOs in the Mozambique Health Sector: The "Velvet Glove" of Privatization. *In* Unhealthy Health Policy: A Critical Anthropological Examination. Arachu Castro and Merrill Singer, eds. Pp. 43-62. Walnut Creek, CA: AltaMira Press.

Pottier, Johan

2002 *Re-Imagining Rwanda: Conflict, Survival and Disinformation in the Late Twentieth Century*. Cambridge: Cambridge University Press.

President's Malaria Initiative

2007 Malaria Operational Plan: Rwanda FY2007. Electronic document, http://www.fightingmalaria.gov/countries/rwanda_mop-fy07.pdf, accessed October 23, 2007.

President's Malaria Initiative (PMI)

2008 Country Profile: Rwanda. Electronic Document, http://www.pmi.gov/countries/profiles/rwanda_profile.pdf, accessed January 13, 2008.

Republic of Rwanda Southern Province

2007 Overview. Electronic document, <http://www.southernprovince.gov.rw/spip.php?article74>, accessed December 8, 2008.

- Robbins, Richard H.
1999 *Global Problems and Culture of Capitalism*. Boston: Allyn and Bacon.
- Robottom, Ian and Derek Colquhoun
1992 Participatory Research, Environmental Health Education and the Politics of Method. *Health Education Research* 7 (4):457-469.
- Roll Back Malaria Initiative (RBM)
East Africa Roll Back Malaria Network (EARN). Electronic document, <http://www.rollbackmalaria.org/aboutus.html>, accessed October 16, 2007.
- Rwanda Development Gateway
2004 RDG-NGOs Database. Electronic document, <http://www.rwandagateway.org/ngos/>, accessed October 23, 2007.
- Rwanda Development Gateway
2007 Campaign Against Malaria Making Gains in Africa. Electronic document, http://www.rwandagateway.org/article.php3?id_article=5322&var_recherche=malaria, accessed October 16, 2007.
- Rwanda Tour Guide Map
Tourist map, no copyright information available.
- Ryan, Gerry and H. Russell Bernard
2003 Techniques to Identify Themes. *Field Methods* 15 (1):85-109.
- Sargent, Carolyn and Caroline Brettell
1996 Introduction: Gender, Medicine, and Health. *In Gender and Health: An International Perspective*. Carolyn F. Sargent and Caroline B. Brettell, eds. Pp. 1-28. Upper Saddle River, NJ: Prentice-Hall, Inc.
- Scheper-Hughes, Nancy
1992 *Death without Weeping: The Violence of Everyday Life in Brazil*. Berkeley: University of California Press.
- Scheper-Hughes, Nancy and Carolyn Sargent, eds.
1998 *Small Wars: The Cultural Politics of Childhood*. Berkeley: University of California Press.
- Schoepf, Brooke G., Claude Schoepf, and Joyce V. Millen
2000 Theoretical Therapies, Remote Remedies: SAPS and the Political Ecology of Poverty and Health in Africa. *In Dying for Growth: Global Inequality and the Health of the Poor*. Jim Yong Kim, Joyce V. Millen, Alec Irwin, and John Gershman, eds. Pp. 91-125. Monroe, MA: Common Courage Press.

Schwartzman, Helen B., ed.

2001 *Children and Anthropology: Perspectives for the 21st Century*. Westport, CT: Bergin & Garvey.

Sen, Amartya

2000 *Social Exclusion: Concept, Application and Scrutiny*. Electronic document, http://www.adb.org/Documents/Books/Social_Exclusion/Social_exclusion.pdf, accessed December 31, 2008.

Shakow, Aaron and Alec Irwin

2000 *Terms Reconsidered: Decoding Development Discourse*. In *Dying for Growth: Global Inequality and the Health of the Poor*. Jim Yong Kim, Joyce V. Millen, Alec Irwin, and John Gershman (eds.). Pp. 44-61. Monroe, MA: Common Courage Press.

Sherman, Irwin W.

2006 *Malaria, Another Fever Plague*. In *The Power of Plagues*. Pp. 135-156. Washington, D.C.: ASM Press.

Singer, Merrill, Freddie Valentín, Hans Baer and Zhongke Jia

1998 *Why Does Juan García Have a Drinking Problem? The Perspective of Critical Medical Anthropology*. In *Understanding and Applying Medical Anthropology*. Peter J. Brown, ed. Pp. 286-302. London: Mayfield Publishing Company.

Singhal, Arvind and W. Stephen Howard (eds.).

2003 *The Children of Africa Confront AIDS: From Vulnerability to Possibility*. Athens, OH: Ohio University Press.

Snider, Leslie M. and Andy Dawes

2006 *Psychosocial Vulnerability and Resilience Measures for National-Level Monitoring of Orphans and Other Vulnerable Children: Recommendations for Revision of the UNICEF Psychological Indicator*. Electronic document, http://www.childinfo.org/tools/docs/PsychosocialMeasures_Final06.pdf, accessed October 25, 2007.

Sommers, Marc

2006 *In the Shadow of Genocide: Rwanda's Youth Challenge*. In *Troublemakers or Peacemakers? Youth and Post-Accord Peace Building*. Siobhán McEvoy-Levy, ed. Pp. 81-97. Notre Dame, IN: University of Notre Dame Press.

Stephens, Sharon, ed.

1995 *Children and the Politics of Culture*. Princeton, NJ: Princeton University Press.

- Thurman, Tonya R., Leslie Snider, Neil Boris, Edward Kalisa, Eleazer Nkunda Mugarira, Joseph Ntaganira, and Lisanne Brown.
2006 Psychosocial Support and Marginalization of Youth-headed Households in Rwanda. *AIDS Care* 18 (3):220-229.
- UN: United Nations
2003 *Young People: Partners in HIV/AIDS Prevention*. New York: United Nations Publication.
- UNICEF
Fact Sheet. Electronic document, http://www.unicef.org/infobycountry/23867_20292.html, accessed November 23, 2007.
- UNICEF
2004 *Malaria: A Major Cause of Child Death and Poverty in Africa*. Electronic document, file:///F:/Anth%20516/Malaria/UNICEF%20report%20on%20Malaria.pdf, accessed September 27, 2007.
- UNICEF
2006 *Africa's Orphaned and Vulnerable Generations: Children Affected by AIDS*. Electronic document, http://www.unicef.org/publications/files/Africas_Orphaned_and_Vulnerable_Generations_Children_Affected_by_AIDS.pdf, accessed November 24, 2007.
- UNICEF
2007 *Children and AIDS: A Stocktaking Report*. Electronic document, [http://www.unicef.org/aids/files/FINAL_STOCKTAKING_REPORT\(1\).pdf](http://www.unicef.org/aids/files/FINAL_STOCKTAKING_REPORT(1).pdf), accessed February 23, 2007.
- Uvin, Peter
1998 *Aiding Violence: The Development Enterprise in Rwanda*. West Hartford, CT: Kumarian Press, Inc.
- Veale, Angela M.
2000 Dilemmas of 'Community' in Post-Emergency Rwanda. *Community, Work and Family* 3 (3):233-239.
- Veale, Angela, Pdraig Quigley, Théoneste Ndibeshye, and Célestin Nyirimihigo
2001 *Struggling to Survive: Orphan and Community Dependent Children in Rwanda*. Ministry of Local Government and Social Affairs and UNICEF. Electronic document, http://www.unicef.org/evaldatabase/files/RWA_2000_001.pdf, accessed September 12, 2007.

Wenger, Martha

1989 Work, Play, and Social Relationships among Children in Giriama Community. *In Children's Social Networks and Social Supports*. Deborah Belle, ed. Pp. 91-115. New York: John Wiley & Sons.

WHO: World Health Organization

2004a Malaria. Electronic document, <http://www.who.int/tdr/diseases/malaria/>, accessed October 16, 2007.

WHO: World Health Organization

2004b Serious Childhood Problems in Countries with Limited Resources: Background Book on Management of the Child with a Serious Infection or Severe Malnutrition. Electronic Document, http://www.who.int/child-adolescent-health/publications/CHILD_HEALTH/ISBN_92_4_156269_2.htm, accessed October 23, 2007.

WHO: World Health Organization

2005 Rwanda: Summary Country Profile for HIV/AIDS Treatment Scale-Up. Electronic document, http://www.who.int/hiv/HIVCP_RWA.pdf, accessed March 21, 2007.

WHO: World Health Organization

2009 About WHO in SEAR: Constitution of the World Health Organization. Electronic document, <http://www.searo.who.int/en/Section898/Section1441.htm>, accessed January 27, 2009.

Wolf, Eric R.

1999 *Envisioning Power: Ideologies of Dominance and Crisis*. Berkeley: University of California Press.

Wolf, Eric R.

2006 Europe and the People without History. *In Anthropology in Theory: Issues in Epistemology*. Henrietta L. Moore and Todd Sanders, eds. Pp. 367-381. Malden MA: Blackwell Publishing.

World Bank

2009 Rwanda: Country Brief. Electronic document, <http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/AFRICAEXT/RWANDAEXTN/0,,menuPK:368714~pagePK:141132~piPK:141107~theSitePK:368651,00.html>, accessed March 8, 2009.

Worrall, Eve, Suprotik Basu and Kara Hanson

2005 Is Malaria a Disease of Poverty? A Review of the Literature. *Tropical Medicine and International Health* 10 (10):1047-1059

APPENDIX 1 HOUSEHOLD COMPOSITION AND ASSOCIATED COMMUNITY MEMBER

The following list provides the household composition of each CHH that participated in the research project. The households are organized alphabetically based on the letter I assigned to them during the household survey. Names of the participants have been changed to ensure anonymity. Also included are the ages and gender of the household members. The first name in each household is the household head. The last name on the list in brackets is the name (pseudonym) of the community member who I interviewed, who was identified by the household as someone who gave them support, along with the role or relationship to the household and their gender.

Household A: Marie-Claire – 18/F, Alexandre – 15/M (Epiphanie – *Nkundabana*/F)

Household B: Marceline – 16/F, Claudette – 7/F

Household D: Cesarie – 17/F, Yvette – 14/F (Grace – Aunt/F)

Household E: Rosine – 17/F, Béata -12/F, Hélène – 8/F

Household F: Bernadette – 17/F, Filaline – age unavailable/F (Esperance–Neighbour/F)

Household G: Albertine – 18/F, Charlotte – 14/F

Household H: Angelique – 17/F, Béatrice – 15/F, Désiree – 13/F, Jean-Davide – 11/M

Household I: Laetitia – 18/F, Gilbert – 11/M (Thomas – Neighbour/M)

Household J: Philippe – 18/M, Leonard – 16/M, Thierry – 14/M, Edward – 12/M
(Remy – Uncle/M)

Household K: Valency – 18/F, Athanase – 8/M (Collette – Cousin/F)

Household L: Augustine – 18/M, Kanobana – 16/M

Household M: Raymond – 18/M, Vincent – 16/M, Serge – 16/M (Mechthilde – Aunt/F)

Household P: Claudine – 15/F, Florence – 6/F, Gregoire – 3/M
(Christophe – Local Leader/M)

Household Q: Chantal – 17/F, Jeanine – 15/F, Margerite – 12/F, Thérèse -9/F,
Celestin – 6/M (Rachel – Aunt/F)

APPENDIX 2 TRANSLATOR CONFIDENTIALITY FORM

Project Title: Perspectives of Health in Child Headed Households

Researcher: Michelle Hardy, MA Candidate, Anthropology, University of Victoria

It is important that all of the information that you translate be kept confidential. Confidentiality is very important in this project. Confidentiality means that any information that you translate from either children or adults cannot be repeated in such a way that the person who contributed the information (words or drawings) can be identified. The participants' real names will not be used with any of the information that is collected.

Even after this research project is finished, you must not discuss specific information from the interviews or the children's activities in any way that will identify participants. It is very important that we maintain confidentiality of the information and the anonymity of the participants.

The participants in this research project will be asked for their voluntary consent. Voluntary consent means that the research participants understand the goals, risks, and benefits of their participation and that they are free to decide if they want to participate or not. Each adult and child who participates in the research project will be asked to give either verbal or written consent.

Do you have any questions? Do you understand why I am asking you to promise to keep the information confidential and the participants anonymous?

If you are ready, I would like you to sign the following statement:

I, _____, will not reveal or discuss any of the information that I translate during this project in any way that reveals the identity of the participants. I will maintain the confidentiality of the information and the anonymity of the participants at all times.

Signed _____

Witness _____

Date _____

A copy of this confidentiality form will be left with you and the researcher will keep a copy.

Your signature below indicates that you have received a copy of this consent form for your own records:

Signature

APPENDIX 3 TRANSLATOR CONSENT FORM

Project Title: Perspectives of Health in Child Headed Households

Researcher: Michelle Hardy, MA Candidate, Anthropology, University of Victoria

During the course of the research, Michelle is taking photos of the children living in the child headed households as well as the community mentors that assist the children. Because you may be present when these photos are taken, you may appear in some of the photos. Michelle would like your permission to use these photos when she writes about her research, or when she does presentations on her research. The photos may appear in written documents such as magazines, journals, books, etc., and may be used in academic, public or private presentations on the research project. Michelle will not use your name when she writes or talks about her research, instead she will use a pseudonym.

Do you have any questions? Do you understand that I am asking your permission to use photos of yourself in my research? I will not be using your real name when I write about the research or when I talk about it.

(Please circle either yes or no)

1. Is it alright for Michelle to use photos in which you appear when she writes about her research or does presentations on her research?

Yes No

Signed _____

Printed Name _____

Witness _____

Printed Name _____

Date _____

A copy of this consent form will be left with you and the researcher will keep a copy.

Your signature below indicates that you have received a copy of this form for your own records:

Signature

APPENDIX 4 SCRIPT DETAILING RESEARCH PROJECT FOR CHH

Project Title: Perspectives of Health in Child Headed Households

Researcher: Michelle Hardy, MA Candidate, Anthropology, University of Victoria

This is Michelle Hardy. She is from Canada. She is a student at a big school called the University of Victoria and she is studying children's health. She would like your help for a project that she is working on for school, and we have come to ask you if you would like to help. My name is (the translator's name), and I will be helping her because she does not know how to speak Kinyarwanda. I will read what she wants to say to you today. You all know (NGO staff person's name: _____) who is working with (name of NGO). They have told us that you are interested in hearing more about this research project. Michelle and I do not work for (the NGO), the project we are doing is not connected to (the NGO). This project has nothing to do with the help you get from (the NGO) or your participation in their programs.

You might have heard about us from the staff working with (the NGO). We are working here in the area outside of the town of (deleted to ensure anonymity) for the next few months of this year. The money for this work that Michelle is doing comes from a part of the Canadian government. Michelle is interested in the health of children who live without an adult over the age of 18 years. Michelle wants to talk with you and other children living in child headed households to find out what you think about your health. She wants to know what things make you sick, what you do when you are sick, if you get help from anyone and what you do to try to be healthy. She also wants to hear from you what you know about malaria, what you do when you get malaria and how you prevent yourself from getting malaria.

If you want to take part, Michelle and I will come and visit you four more times. Each visit will last between one and two hours. Michelle knows that you have work to do, so she will try to come to your house at a time that is good for everyone in the house. When she comes on these visits, Michelle will ask you some questions. Some of these questions will include asking you who lives in your house, if you farm or how you earn money, questions about your parents, and what types of things you own (e.g. if you own a mattress, a mosquito net, a blanket). She might ask you questions such as "what do you think causes malaria?" or "are there things about your health that make you worried?" If it is okay with you, Michelle will record your voice when you answer these questions so she can remember better what you said. Do you have any questions?

On some of our visits, Michelle will ask you to make some drawings. She will bring some crayons and paper for you to do that. Michelle thinks these drawings will be fun for you to do. You will be asked to draw pictures of yourselves when you are sick and when you are healthy. Michelle will also ask you to draw pictures of things that make you sick or keep you healthy. Then Michelle will ask you questions about these drawings, and about the things you get sick from, what happens when you get sick, and

who helps you when you are sick. You can keep the drawings, and if it is okay with you, Michelle will take a photograph of them.

Michelle would also like to take photographs of you during the activities at your home. If you do not want her to, that is okay, we will not take any photos. If you do not mind that we take photographs, we will give you a copy of a photograph of yourself to keep.

The information that you share is very important. Michelle thinks that your ideas about health will show people what your life is like and some of the challenges you face. The things that Michelle learns from you will be written down and shared with people at her school in Canada, and with people who are studying children's health. She might also write something about what she learns that ends up in a magazine or in a book. She may include some of the photographs of the drawings that you did. However, when Michelle talks and writes about this project, she will not use your real names. If you like, you can choose the names that she will use and no one else will be told that you have chosen that name for yourself. As well, she will not use the real name of this area where you live. Michelle might tell (the NGO) what she learned in this project, but she will not tell them the names of the people who told her. However, if she finds out that you have health needs that need to be taken care of right away, or if anyone tells her that they have been hurt by someone, or are thinking of hurting themselves, Michelle will tell this to either (the NGO) staff person, so that they can help you.

If you do not want to participate in the project, that is not a problem. You will still continue to receive help from (the NGO) and can still participate in their programs. You decide if you want to do these things. If you do not want to do any of them, that is okay. Nothing bad will happen. You might also decide you want to do the drawings, but you do not want to talk about them. That is okay too. If you do not want to answer some of the questions, that is not a problem. You can choose which questions you want to answer. If you decide that you do not want to answer any more questions, and that you want to stop participating in the project, that is okay too. Some of the questions you might not want to answer if your brother or sister is around. So if you would rather talk to her with just myself (the translator), that's fine. Or perhaps you might want to have your brother or sister around, that will be fine too. However, whatever you hear your brother or sister say to me, is something that you do not repeat to other people. What they say are their ideas and thoughts, and if they want other people to know these things, they will tell them themselves.

On our last visit Michelle will give you some items for your household as a way to thank you for your time and your help with this project. However, if you would not participate in this study if the gift was not offered, then you should not participate in this study. If you decide at some point to stop answering questions, and not to participate in the interviews, your household will still get a thank you gift. However, if you stop participating in the research project part way through, Michelle will still use the information that you shared with her up to that point when she writes up the results of her project since it will be impossible to figure out exactly what information it was that you

had told her. If you are interested in what she is learning from you, you can ask her at any time. If you have any questions after the research project is over, and Michelle is back in Canada, you can talk with (the NGO) staff person. Do you have any questions?

We will let you think about whether you want to participate in the project. If you do want to participate in the project, you can let (the NGO) staff person know, and Michelle will come back to visit you. Michelle is interested in everyone's ideas in the house, but in particular she wants to talk to the people who are between the ages of six years and eighteen years. So, everyone in the house who is between these ages needs to think about whether they want to participate in the project. This is a decision that each person needs to make, and then you need to decide together as a household if this is something that you will do. Michelle will only talk to households if everyone between the ages of six and eighteen wants to participate in the project.

This is a lot of information. Do you want to ask any questions? Do you understand what we want to do? Do you understand what you would be doing if you take part in this research?

APPENDIX 5 WRITTEN AND VERBAL CONSENT FORM FOR CHILDREN IN CHH (FOR PARTICIPATION IN THE RESEARCH)

Project Title: Perspectives of Health in Child Headed Households

Researcher: Michelle Hardy, MA Candidate, Anthropology, University of Victoria

This research project is interested in what you have to say about your health and in particular what you have to say about malaria. Michelle wants to hear from you why you get sick, what causes the illnesses, what you do when you get sick, if you get help from anyone, and how you stay healthy. Today, if you agree to participate, Michelle wants you to show her around your house and your property. On the next visit she will ask you questions about your household, what you own, if you farm, etc. On the last two visits she will ask you to show her things that make you sick or keep you healthy and have you draw them. As well, she will ask you to draw pictures of yourself when you are sick. She will ask you questions about them and take pictures of them to use in her project. You do not have to answer any of these questions if you do not want to. The things you say will be put together with answers from other children who live in child headed households so no one will know what you said exactly. Michelle will not tell people which things you said or which drawings you did when she shows the picture of them to people. She will not use your name when she talks or writes about this work. If you agree, she will also record the interviews and take pictures of you during some of the activities. She will not tell people your name if she shows the pictures. If you decide part way through the study that you do not want to answer any more questions, Michelle will still use the information that you gave her up until that point in her study because it will be impossible to separate it from the other material that she has. At the end of all the visits to your household, she will give you some items for your household, as a way to thank you for your time and your help with this project. However, if you would not participate in this study if the gift was not offered, then you should not participate in this study.

Michelle will be going back to Canada in September. If you want to talk to someone about this work after she has gone back to Canada, you can contact the staff person at (the NGO) and ask them your question.

Do you have any questions? Can you tell me what this project is about? In what sorts of activities will you be participating? Would you like to take part in this research project? If you do, you can either sign your name, or you can agree out loud. On each visit, we will ask you if you want to continue to participate in the project. You will then need to sign your initials, or say again out loud that you want to participate.

Written Consent:

(Please circle either yes or no)

1. Is it alright for Michelle to take pictures of you?
She would like to show your photo to other people,
and it may be included in what Michelle writes about this research. Yes No

2. Is it alright for Michelle to record your voice?
She and the translator will be the only ones listening to your voice. Yes No

Signing your name here shows Michelle that you want to participate in this study:

Signature

Printed Name

Date: _____

A copy of this consent form will be left with you and a copy will be kept by Michelle. Your signature below means that you have received a copy of this consent form to keep for your own records:

Signature

Written ongoing Consent:

Putting your initials here shows Michelle that you agree to continue to participate in the study for each of the visits she makes to your house:

Visit 3: _____

(Please circle either yes or no)

1. Is it alright for Michelle to take pictures of you?
She would like to show your photo to other people,
and it may be included in what Michelle writes about this research. Yes No
2. Is it alright for Michelle to record your voice?
She and the translator will be the only ones listening to your voice. Yes No

Visit 4: _____

(Please circle either yes or no)

1. Is it alright for Michelle to take pictures of you?
She would like to show your photo to other people,
and it may be included in what Michelle writes about this research. Yes No
2. Is it alright for Michelle to record your voice?
She and the translator will be the only ones listening to your voice. Yes No

Visit 5: _____

(Please circle either yes or no)

1. Is it alright for Michelle to take pictures of you?
She would like to show your photo to other people,
and it may be included in what Michelle writes about this research. Yes No
2. Is it alright for Michelle to record your voice?
She and the translator will be the only ones listening to your voice. Yes No

Verbal consent (for each visit):

If you want to participate today, and you want to tell us out loud, you need to say your name, and that you want to participate in the project Michelle is doing. If it is alright, Michelle will record your voice saying this. If you would rather she did not record your voice, that is not a problem. She will write down that you agreed to participate in her journal. We will also ask you to answer these questions as we ask them to you:

1. Is it alright for Michelle to take pictures of you?
She would like to show your photo to other people, and it may be included in what Michelle writes about this research.
2. Is it alright for Michelle to record your voice?
She and the translator will be the only ones listening to your voice.

**APPENDIX 6 WRITTEN AND VERBAL CONSENT FORM FOR
CHILDREN IN CHH (TO INTERVIEW COMMUNITY
MEMBER IDENTIFIED BY CHILD)**

Project Title: Perspectives of Health in Child Headed Households

Researcher: Michelle Hardy, MA Candidate, Anthropology, University of Victoria

When you were telling Michelle about the people that help you when you are sick, you told Michelle that your neighbour sometimes comes to help you. Michelle would be interested in going to talk to your neighbour and asking them some questions if it is okay with you. Michelle would like to ask them questions about child headed households in Rwanda, about malaria, other illnesses and staying healthy, as well as ideas that people in Rwanda have about children. She will use the information that she learns from your neighbour in the project that she is writing. The information that Michelle learns, and the report that she writes will be shared with other people at her school in Canada, people who do similar projects or who are researching children's health. She may also write what she learns and put it in a magazine or a book, or talk about it when she does a presentation to other people. Michelle will not tell your neighbour anything that you said to her. If you do not want Michelle to talk to your neighbour, it is not a problem. Nothing bad will happen. If you agree to let Michelle interview your neighbour, Michelle needs to get your signature or needs to hear from you that you agree to allow her to interview your neighbour. If you are willing, Michelle would also like you to go and ask your neighbour if they would be interested in participating in the project. Michelle will ask you on our next visit to your home if your neighbour is interested in participating and if they are, she will go and meet them. If you would prefer that Michelle asks your neighbour for their permission, that is okay too.

Would it be alright if Michelle interviews your neighbour (or _____ name of this person if the child had identified them by name in an earlier interview) that you said helped you, and asks them some questions? If it is alright with you, you can either sign your name here, or else you can say out loud and we will record your voice if it is alright with you. If you would rather she did not record your voice, that is not a problem. Michelle will write down that you agreed to allow her to interview your neighbour in her journal. You will need to say your name, and that it would be alright for Michelle to interview your neighbour (or _____ name of person child identified earlier).

Signature

Printed Name

Date: _____

A copy of this consent form will be left with you and a copy will be kept by the researcher. Your signature below means that you have received a copy of this consent form to keep for your own records:

Signature

APPENDIX 7 LETTER OF INFORMATION FOR NGOS

Dear (name of the director of the organisation),

You are invited to participate in a study that is being conducted by myself, Michelle Hardy. I am a Canadian student here in Rwanda conducting research as a requirement for a graduate degree in Anthropology. I am focusing on the perspectives of children in child headed households regarding their health and regarding malaria. I would be interested in interviewing yourself or another staff member who is familiar with your health related programs that are aimed at child headed households. The following letter provides details about the research project.

Project Title: Perspectives of Health in Child Headed Households

Researcher: Michelle Hardy (Master of Arts student)

Supervisor: Dr. Lisa Mitchell

Institution: Department of Anthropology, University of Victoria, Canada

Contact Info: Michelle Hardy: (cell phone number in Rwanda) or mhardy@uvic.ca

Dr. Lisa Mitchell: 01-250-721-6282 or lmm@uvic.ca

What is the study about?

This study will examine the health concerns among children living in child headed households (CHH) in rural Rwanda. In particular, the research will examine the children's perspectives of malaria and some issues affecting their understanding, susceptibility, as well as access to treatment and support. Given that non-governmental organisations (NGOs) in Rwanda are significantly involved in providing for the needs of children in CHH, this study also takes into consideration the health care support that is offered to CHH through NGO programs. Research of this type is important, because it provides insight into the particular needs and challenges of CHH, and how these needs are being met. This research may be useful for those initiatives that focus on providing health care for CHH.

Who is conducting this study?

Michelle Hardy is conducting this study under the supervision of Dr. Lisa Mitchell in the Department of Anthropology at the University of Victoria in British Columbia, Canada. It is part of her thesis research for her Master of Arts degree. Parts of this study may also be published in academic journals or books and used in presentations. This research project has received funding from the Government of Canada's Social Sciences and Humanities Research Council.

Why are you being asked to participate?

You have been invited to participate in this study because the organisation you work for is offering malaria-related health care assistance to CHH. As the director of the organisation, your opinion, or that of someone else within the organisation who is familiar with the health care program, is sought in order to understand what type of health care is available to CHH, how these health care programs are designed, and the sustainability of the programs.

What are you asked to do?

If you or another staff member of this NGO agree to voluntarily participate in this research, your participation will include a single interview with myself; this interview should last no longer than 1 ½ hours, and may take place at your office, if that is convenient for you. In the event that clarification is needed on the responses given during the interview, a subsequent interview may be requested. I will ask a number of questions about the nature of your health care programs, and I would also be interested in examining any available documentation detailing your health care programs. The interview will be audio recorded unless you have an objection to this. In addition, if you are aware of any children participating in this research project, you are asked to keep the children's identity confidential.

What are the risks involved in participating?

While every effort will be made to maintain your anonymity, due to the small sample size it may be possible to associate you or the NGO with the information you share when it is included in the dissemination of results.

Benefits

The potential benefits of your participation in this research include contributing insight into how children's health concerns are being addressed, and what barriers are inhibiting them from accessing health care. In addition, the information you share will indicate if there is a need for other types of initiatives to assist children in their health needs.

What will be done to keep your identity confidential?

All interview notes and recordings will be stored in an access controlled location accessible only to the researcher. Your name or other identifying information associated with you or your organisation will not be used in any publication or presentation that I make.

What rights do you have as a participant?

- Your participation in this research is voluntary.
- You may choose to stop the interview at any time or decline to answer any particular question. If you choose to stop the interview entirely, I will ask for your permission to retain the information that has been given up to that point for use in this research.
- You may request additional information from the researcher or her supervisor before starting the interview or anytime thereafter.
- I will email you a written transcript of the interview for your verification. You are invited to revise, edit, or delete anything that you wish to. Sending it back to me with or without revisions is an indication that you agree with the content of the transcript.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in the following ways. The results gathered from the interview and from any program documentation you share with me will be written up for my thesis dissertation, for class presentations and for conferences. In addition, the material collected from the research may be used in the future in published articles or books and for other presentations.

Therefore, the data collected for this research will not be destroyed. If you are interested in receiving a summary of the results of this study, please let me know.

You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (01-250-472-4545 or ethics@uvic.ca).

Thank you for your consideration. I look forward to the possibility of interviewing you or another staff person of this organisation. I will contact you by telephone within the next week to find out if someone is available for an interview.

Sincerely, Michelle Hardy

APPENDIX 8 CONSENT FORM FOR NGO REPRESENTATIVE

Project Title: Perspectives of Health in Child Headed Households
Researcher: Michelle Hardy (Master of Arts student)
Supervisor: Dr. Lisa Mitchell
Institution: Department of Anthropology, University of Victoria, Canada
Contact Info: Michelle Hardy: (cell phone number in Rwanda) or mhhardy@uvic.ca
Dr. Lisa Mitchell: 01-250-721-6282 or lmm@uvic.ca

What is the study about?

This study will examine the health concerns among children living in child headed households (CHH) in rural Rwanda. In particular, the research will examine the children's perspectives of malaria and some issues affecting their understanding, susceptibility, as well as access to treatment and support. Given that non-governmental organisations (NGOs) in Rwanda are significantly involved in providing for the needs of children in CHH, this study also takes into consideration the health care support that is offered to CHH through NGO programs. Research of this type is important because it provides insight into the particular needs and challenges of CHH, and points out how these needs are being met. This research may be useful for those initiatives that focus on providing health care for CHH.

Who is conducting this study?

Michelle Hardy is conducting this study under the supervision of Dr. Lisa Mitchell in the Department of Anthropology at the University of Victoria in British Columbia, Canada. It is part of her thesis research for her Master of Arts degree. Parts of this study may also be published in academic journals, in books and used in presentations. This research project has received funding from the Government of Canada's Social Sciences and Humanities Research Council.

Why are you being asked to participate?

You have been invited to participate in this study because the organisation you work for is offering malaria-related health care assistance to CHH. As the director of the organisation, your opinion, or that of someone else within the organisation who is familiar with the health care program, is sought in order to understand what type of health care is available to CHH, how these health care programs are designed and the sustainability of the programs.

What are you asked to do?

If you or another staff member of this NGO agree to voluntarily participate in this research, your participation will include a single interview with myself; this interview should last no longer than 1 ½ hours, and may take place at your office, if that is convenient for you. In the event that clarification is needed on the response given during the interview, a subsequent interview may be requested. I will ask a number of questions about the nature of your health care programs, and I would also be interested in examining any available documentation detailing your health care programs. The interview will be audio recorded unless you have any objection to this. In addition, if you

are aware of any children participating in this research project, you are asked to keep the children's identity confidential.

What are the risks involved in participating?

While every effort will be made to maintain your anonymity, due to the small sample size it may be possible to associate you or the NGO with the information you share when it is included in the dissemination of results.

Benefits

The potential benefits of your participation in this research include contributing insight into how children's health concerns are being addressed, and what barriers are inhibiting them from accessing health care. In addition, the information you share will indicate if there is a need for other types of initiatives to assist children in their health needs.

What will be done to keep your identity confidential?

All interview notes and recordings will be stored in an access controlled location accessible only to the researcher. Your name or other identifying information associated with you or your organisation will not be used in any publication or presentation that I make.

What rights do you have as a participant?

- Your participation in this research is voluntary.
- You may choose to stop the interview at any time or decline to answer any particular question. If you choose to stop the interview entirely, I will ask your permission to retain the information that has been given up to that point for use in this research.
- You may request additional information from the researcher or her supervisor before starting the interview or anytime thereafter.
- I will email you a written transcript of the interview for your verification. You are invited to revise, edit, or delete anything that you wish to. Sending it back to me with or without revisions is an indication that you agree with the content of the transcript.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in the following ways. The results gathered from the interview and from any program documentation you share with me will be written up for my thesis dissertation, for class presentations and for conferences. In addition, the material collected from the research may be used in the future in published articles or books and for other presentations. Therefore, the data collected for this research will not be destroyed. If you are interested in receiving a summary of the results of this study, please let me know.

You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (01-250-472-4545 or ethics@uvic.ca).

Your signature indicates that you consent to participate in this study, and that you will keep confidential the identity of any children whom you know are participating in the study.

May I make an audio recording of this interview? YES NO (please indicate by circling)

Printed Name

Signature

Date

Organisation

A copy of this consent form will be left with you and a copy will be kept by the researcher.

Your signature below indicates that you have received a copy of this consent form for your own records:

Signature

Second Interview:

In the event that a follow-up meeting is arranged, your signature below indicates that you consent to participate in a second interview.

May I make an audio recording of this interview? YES NO (please indicate by circling)

Printed Name

Signature

Date

Organisation

In the event of withdrawal partway through the interview:

In the event of withdrawal partway through the interview, your signature below indicates that you agree to allow Michelle to use the data you have provided up to the point of withdrawal.

Printed Name

Signature

Date

Organisation

APPENDIX 9 SCRIPT DETAILING RESEARCH PROJECT FOR COMMUNITY MEMBERS

Project Title: Perspectives of Health in Child Headed Households

Researcher: Michelle Hardy, MA Candidate, Anthropology, University of Victoria

This is Michelle Hardy. She is a student at the University of Victoria in Canada. She has prepared the following outline that describes the project that she is working on for school, so that you can decide if you want to be part of it or not. My name is (the translator's name), and I will be translating for her. I will read what she has prepared for you.

Michelle is here in Rwanda to talk to children who live in child headed households and find out what they are saying about their health and about malaria. She wants to find out what the children's health concerns are, where they are learning about health care, what kind of help they are getting when they are sick and what they say about malaria. She will be in Rwanda until September. She also wants to find out what the community members, such as yourself, have to say about child headed households. Some of the money for this work that Michelle is doing comes from a part of the Canadian government.

Specifically, Michelle wants to hear your thoughts about child headed households in Rwanda and some of the challenges that they face, since you are involved in helping children in child headed households. She wants to ask you questions about how children in these households are learning the skills they need and how people in the community respond to these children. In addition, she would like to ask you some questions about the children's health care, and about malaria and other illnesses. She would also like to learn about Rwandan customs and ideas about age differences and the responsibilities of male and female children.

If you take part in this research, Michelle and I will come back at a time that is convenient to you to ask you questions on those topics at your home. The questions will take about one hour, maybe longer if there is a lot to talk about. If it is alright with you, Michelle will record your voice during the interview. She would be the only one that would listen to it after the interview. With your permission she may also want to take some photographs of you. These pictures might be shown to other people or printed in a report. After the interview, your answers will be put together with other people's answers so that no one can tell which person made which statement. That way, other people will not know what you said.

You do not have to be part of this research. It is your decision. If you decide not to participate, it will not cause any problems or hardships for you or for the children in the child headed households that you are in contact with. You can choose which questions you want to answer. If you decide you do not want to answer any more questions, that is okay. However, if you do stop the interview at any point, Michelle will ask your permission to use the information that you have said up to that point in the interview for her research.

Michelle would like to share what she learns from this work with other people. She will be writing a report for school on what she learns, and she may also write something for a magazine or for a book. The pictures might be used in these reports or in presentations she makes at school or with other people who are interested in this research. However, when she talks and writes about what she learns, or shares the photos, she will not use your name or the name of your community. All the information that Michelle learns from you, which she writes down, the recordings of your voice, and the pictures, will be kept in a secure place.

The information that you share will be useful for people who are interested in helping people like the children in child headed households. It will be useful for them to hear how the community is able to help these children, and what prevents them from helping the children. There are no risks to you for participating in this research. Michelle asks the you do not tell other members in the community that the children in the child headed households are participating in this research project, and that you do not tell other people what you said about the children to other people.

If you want to take part in this research, Michelle will give you (either a monetary gift or household item based on the advice from the NGOs I am in contact with) to compensate you and thank you for your time at the end of the interview. If you stop the interview at any point, and say you do not want to continue, she will still give you the thank you gift. However, if you would not participate in this study if the gift was not offered, then you should not participate in this study.

If you have any questions about this research after the study is over and after Michelle has gone back to Canada, you may talk with the NGO staff person who works in this area.

This is a lot of information. Is there anything you want to ask?

If you are interested in participating in the research Michelle will come back at a time that is convenient for you. At that time, she will see if you have any more questions about the project, and she will get your permission to do the interview. Michelle will then ask you the questions and I will translate.

APPENDIX 10 WRITTEN AND VERBAL CONSENT FORM FOR COMMUNITY MEMBERS

Project Title: Perspectives of Health in Child Headed Households

Researcher: Michelle Hardy, MA Candidate, Anthropology, University of Victoria

This research project is interested in what the health concerns of child in child headed households. However, Michelle wants to find out from you what type of support you or other community members are able to give to the children, what you think are the challenges facing the children living in child headed households, and how they are learning the skills they need. She wants to ask you questions about malaria and other illnesses, as well as questions on Rwandan ideas about boys and girls and age differences. You can choose which questions you want to answer. If you decide you do not want to answer any more questions, that is okay. Michelle will ask for your permission to use the information that you have shared with her up to the point that you decided to stop participating in the study. She will not tell other people that you have talked to her. The things you say will be put together with answers from other community members. Michelle will not tell people which things you said. She will not use your name when she talks or writes about this work. She would also like to record your voice during the interviews and take pictures of you, if that is alright with you. She will be the only one who listens to your voice on the recording. She will not tell people your name if she shows the pictures. At the end of this interview, she will give you (an item or some money depending on the recommendation by the NGO) as a way to thank you for your time and your help with this project. However, if you would not participate in this study if the gift was not offered, then you should not participate in this study. Michelle will be going back to Canada in September. If you want to talk to someone about this work, you can contact the staff person at (the NGO) and ask them your question.

Do you have any questions? Would you like to take part in this research project? If you do, please answer the following questions and sign your name below, or you can say it aloud.

Written Consent:

(Please circle either yes or no)

- | | | | |
|----|--|-----|----|
| 1. | Is it alright for Michelle to take pictures of you?
She would like to show your photo to other people,
and it may be included in what Michelle writes about this research. | Yes | No |
| 2. | Is it alright for Michelle to record your voice?
She and the translator will be the only ones listening to your voice. | Yes | No |
| 3. | Do you agree to not tell other people that the children
you know are participating in a research project? | Yes | No |
| 4. | Do you agree to not tell other people what you
say about the children? | Yes | No |

Signing your name here means that you want to participate in this study:

Signature

Printed Name

Date: _____

A copy of this consent form will be left with you and a copy will be kept by the researcher. Your signature below means that you have received a copy of this consent form to keep for your own records:

Signature: _____

Verbal Consent:

If you want to participate on this visit, and you want to tell us out loud, you need to say your name, and that you want to participate in the project Michelle is doing. Then we will ask you four questions about recording you, taking pictures and about not talking to people about the children participating in the study, as well as what you say about them. If it is alright with you, Michelle will record you saying this. If you would rather she did not record your voice, that is not a problem. She will write down that you agreed to participate in her journal.

1. Is it alright for Michelle to take pictures of you?
She would like to show your photo to other people, and it may be included in what Michelle writes about this research.
2. Is it alright for Michelle to record your voice?
She and the translator will be the only ones listening to your voice.
3. Do you agree to not tell other people that the children are participating in a research project?
4. Do you agree to not tell other people what you say about the children?

In the event of withdrawal partway through the interview:

Written Consent:

If you decide partway through the study that you want to stop answering questions, your signature below means that you agree to allow Michelle to use the information you have provided up to the point that you decided to stop answering questions.

Printed Name

Signature

Date

Verbal Consent:

If you decide partway through the study that you want to stop answering questions, Michelle asks for your permission to use the information you have provided up to the point that you decided to stop answering questions. If you agree, and you want to tell us out loud, you need to say your name, and that you allow Michelle to use the information that you have shared with her up to this point. If it is alright with you, Michelle will record you saying this. If you would rather she did not record your voice, that is not a problem. She will write down that you agreed to let her use the information.

Is it alright for Michelle to use the information that you shared with her up until this point? She would like to use this information in her research project.

APPENDIX 11 SAMPLE QUESTIONS FOR CHH – 2ND VISIT

The following are questions I may ask the children as they show me around their house and property. They are informal questions that will be used to acquire insight into their daily workload, subsistence practices and social interactions.

1. I am interested in where you live. Would it be possible for me to see inside your home?
2. Where do you do the cooking?
3. Is it difficult to find wood for the fire? Where do you collect it from? How far away is that?
4. Where do you get water for your cooking and drinking? How far do you have to go to get it?
5. Do you have crops that you are growing?
6. May I go and look at what you are growing with you?
7. Who works in the field? How did you learn how to grow these crops?

APPENDIX 12 HOUSEHOLD SURVEY FOR CHH

Date: _____

Household #: _____

District: _____ Sector: _____ Cellule: _____

Umudugudu: _____

Household members (circle name of head of household)

	Name	Sex	Age	Relationship to Head of Household	Imm./ Vacc.	Med. Ins.	Birth Cert.
1							
2							
3							
4							
5							
6							
7							

School

	Current class	Attendance				Last class attended	When last attended
1		always	usually	sometimes	rarely		
2		always	usually	sometimes	rarely		
3		always	usually	sometimes	rarely		
4		always	usually	sometimes	rarely		
5		always	usually	sometimes	rarely		
6		always	usually	sometimes	rarely		
7		always	usually	sometimes	rarely		

Work

1. How do you earn money? How much does the household approximately earn?

2. Do you own a plot of land?
Yes/No
Is it big enough to grow food for all of you and to sell some?
Yes/No

3. What do you grow?

4. Who works outside the house?

5. When do you work? When do you start work?

6. When do you eat during the day?
Morning/Noon/Evening

Chores

Chore	Child responsible
Cooking meals	
Fetching water	
Cleaning	
Washing clothes	
Fetching firewood	
Other?	

Household items

Item	Number	Comments
Latrine		
Light		
Mattress		
Mosquito net		Insecticide? Yes/No When treated?
Blanket		
Shoes		
Spare set of clothes		
Radio		
Stove		

Other

7. What do you do with your garbage?
8. Where do you get water? How long does it take to get there?
9. Where do you get firewood? How long does it take to get there?
10. Are / Were you involved in a program with an NGO? Yes/No
11. What type of program was / is it?
12. Does anyone stay home during the day? Yes/No
13. *If young child stays home:* Who looks after [name of child]?
14. May I ask you some questions about your parents? *If the child says yes, the following questions will be asked:* Where are your parents?
15. *If parents died:* Do you know how they died?
16. When did your parents leave / die?
17. Has another family member died recently?
18. Do you have any relatives? Where do they live? When did you last see them?
19. How far is the nearest health clinic or hospital? How much does it cost to get there?
20. Is there a question that you would like to ask me about myself?

House

1. Describe the house (sundried bricks, concrete, walls, dirt floor, etc.)
2. Number of rooms and designations
3. Sleeping arrangements (bed / floor / mattress / mosquito net)
4. Differences from other houses in the same area

APPENDIX 13 INTERVIEW QUESTIONS FOR CHH – 4TH VISIT

Focus: Children's explanations and ideas regarding their susceptibility to illness/malaria and their access to/sources of care and treatment when they are sick.

The children will be asked to draw a picture of themselves when they are sick and when they are healthy. I will use the completed pictures to ask the children individually about their susceptibility to malaria/other illnesses and their access to health care.

Introductory questions

- Can you show me on the picture where you felt sick or where you hurt yourself?
- What happened when you got sick or hurt yourself?
- Have you got sick from other things? What were those things that made you sick?
- How did you feel?

Questions around poverty

- When we were talking about the pictures you drew, you mentioned that you sometimes get a fever/get malaria.
- Do you get (what was identified) very often?
- When do you get it?
- What do you do when you get sick?
- Did someone tell you what you should do if you get malaria? Who? Are you able to do that? Why/why not?
- Did you go to the health clinic? Did they help you? Or -Do you go and tell someone when you got sick? Who did you go to?
- Does someone come and help you when you are sick? Who does? Why not or What do they do?
- Do you take any medicine when you have malaria? Why/why not?
- Where do you get the medicine? What do you take? How long do you take it for?
- Are you ever short on food? What do you do when you do not have enough food? Do you ask anyone for help? Who do you ask? What do they do?

Questions pertaining to age differences

- Does your older/younger brother/sister get (the illness) too?
- For heads of household: do your younger brothers and sisters get sick in different ways? Can you tell me about it?
- What do they do when they get sick? Do you help them? What do you do?
- Do they get help from anyone else? Do they go to the clinic?
- When you get sick, does everyone else get sick too?
- Does your younger brother/sister get malaria more than you? How much more/less? Why do you think that is?
- What do they/you do when they get malaria?
- Who takes care of them when you are away from home and working?

Questions pertaining to gender differences

- When you get sick, does everyone else get sick too?
- Does your brother/sister get (the illness) too?
- Do girls/boys get this more than boys/girls?
- Does your brother or sister get sick in a different way – what do they get?
- What do they do when they get sick?
- Does your brother or sister go to the clinic when they are sick? Or what do you do when they get sick?
- Does your brother or sister get help from anyone when they are sick? From who? What do these people do?
- Does your brother/sister get malaria? How much more/less than you? Why do you think that is?
- What do they/you do when they/you get malaria?
- When you get malaria, do you treat it differently than your brother/sister does when they get malaria?

Questions pertaining to community support

- Who do you ask for help if your younger/older sibling is sick?
- Who do you borrow a hoe from if yours is broken?
- What do you do if your cow/pig/hen is sick?

APPENDIX 14 INTERVIEW QUESTIONS FOR CHH – 5TH VISIT

Focus: Children's explanations and ideas regarding health, illness and malaria
All the children in the household will be invited to draw:

- A picture of things that make them sick.
- A picture of things that keep them healthy.

Those children who do not want to draw, or in addition to drawing, will be invited to show me:

- Things in/around the house that keep them healthy.
- Things in/around the house that make them sick.

As the children finish drawing, or as they show me around the house, I will spend approximately 20 minutes with each child, asking them the following questions:

- Why do these things keep you healthy? Are there other things that keep you healthy?
- How do you feel when you are healthy?
- I noticed you drew / did not draw a picture of a bed net. Do bed nets keep you healthy? How? Or Why or why not?

Questions around poverty

- Do you always do (what the picture they drew of things that keep them healthy depicts)? Why/why not?
- What happens when you do not do (what picture depicts)?
- What causes the (what was identified)?
- Where did you learn that?
- Are there things about your health that make you worried? What are they? Why do they worry you?
- Are you worried about AIDS?
- How do people get AIDS?
- What can you do in order to prevent yourself from getting it?
- Are you able to prevent yourself from getting it?
- Who told you about AIDS? What did they tell you about it?
- What is malaria? How do you get it?
- Do you know anyone who has malaria? What happens when they are sick? How can you tell that it is malaria and not something else?
- Why do people get malaria?
- Where did you learn about malaria? What did they teach you in school or what did the NGO tell you about malaria? What did they tell you that you should do in order not to get it? What did they say? Are you able to do it? Why/why not?
- Are there things you could do to prevent yourself from getting malaria?
- Do you do these things? ...Why not?
- Other questions regarding prevention of malaria (e.g. avoiding mosquito bites, using anti-malarial drugs, vector control – screens, indoor spraying, larval control, and personal protection measures- insecticide-treated bed nets, clothing, sheets at night, etc.

- How do you know when you have malaria?
- Can your malaria come back on its own even if you have not (use child's causal agent)?
- How do you feel when you get malaria?
- How long do you have it?
- Does it feel different than when you get sick with other things? How is it different?

Questions pertaining to age differences

- Does your older/younger brother/sister do the same things as you to stay healthy?
- Does your older/younger brother/sister know about these things that make you healthy? How did they learn them? Or Why don't they know these things?
- How do you know when your younger brother/sister has malaria?
- Does your younger brother/sister know what malaria is? Why not or How did they learn about malaria?
- Do you ever talk to the NGO about your concerns regarding malaria? What do you tell them?

Questions pertaining to gender differences

- Are there things that keep boys healthy and things that keep girls healthy?
- Does your brother/sister do these things? Why or why not?
- Are there things that make girls or boys sick differently?
- When girls have malaria is it different than when boys have malaria? How is it different?
- What causes their (illness)?
- How do you know that?
- For heads of household: do your younger brothers and sisters get sick in different ways? Can you tell me about it?

APPENDIX 15 INTERVIEW QUESTIONS FOR NGOS

Questions pertaining to program parameters and focus of health care programs

- What is your organisation's overall purpose or mandate?
- Can you describe the programs?
- What health needs are the programs primarily addressing?
- Do you pay for health insurance for the children?
- How do you determine the focus of your health programs?
- What do you teach CHH about malaria?
- How do you determine which CHH can be in your program? How long do you work with a group of CHH? How is program duration determined?
- Where does your organisation get funding? Can you give me an idea of your budget?

Questions on the extent the health programs consider children's concerns and lived reality

- Has this program been successful? In what way?
- Do you do evaluation of your programs? Can you describe how it is carried out?
- What barriers inhibit the children from following your program recommendations?

Questions on the children's involvement in program design and evaluation

- How are your health programs designed?
- Are children involved in program planning and evaluation? Why or why not?

Questions pertaining to the NGO's influence on community support of CHH

- Do you elicit community involvement in your programs? Who from the community gets involved? How are they recruited? How are they involved? How does the community remain involved with the CHH once you leave the area?

Other questions

- Is there anything else you want to add that has not been addressed in these questions?
- Is there any material on the health programs that I might be able to examine?

APPENDIX 16 INTERVIEW QUESTIONS FOR COMMUNITY MEMBERS

Questions pertaining to community perspectives/response to CHH

- Do you have some land to farm or where do you work?
- Are there many children without parents at home who are living around here?
- Do you see the children from the CHH near you very often?
- Do you know how their parents died/why they are not living here?
- What do you think is the main problem facing households without adult caregivers?
- Does anyone teach the children about growing crops?
- Does anyone teach the children how to take care of their health? Or
- Who is responsible for teaching the children in CHH now that their parents are gone?
- What do these children need to learn?
- Are you able to teach them anything/help them?
- Is it difficult for you to help them/teach them? Why or why not?
- What do you teach them/help them with?
- Do the children listen to you?
- Do the children ever ask you for assistance?
- Are you able to assist them? In what ways?
- Are the children able to provide enough food for themselves?

Questions pertaining to malaria

- What do you think the children should do to stay healthy?
- Do the children do these things? Why or why not?
- Is malaria a problem here? Why is that?
- Where do people living around here learn about malaria?
- Do they teach children about malaria in school? What do they teach the children?
- Is AIDs a problem for people living around here? Why is that?

Questions about age/gender

- Do you think the children in CHH know how to stay healthy?
- Do you think they know how to prevent themselves from getting malaria?
- Do you have different responsibilities around the house than your husband/wife does? What do you do that they don't do/vice versa?
- Do girl children have different responsibilities than boys?