Prevalence of Major Limb Loss (MLL) in Post conflict Acholi sub-region of Northern Uganda: Cross sectional study

Pamela Atim[1], Constantine S Loum[1], Tom R Okello[3] , Samuel M Magada[1,2], Walter Onen Yagos[1], Peter Abelle[1,2], Emmanuel B Moro[1], Jonathan Huck[4], Anthony Redmond,[4] Mahesh Nirmalan[4]

[1] Faculty of Medicine Gulu University, Gulu, Uganda;
[2] Gulu Regional Referral Orthopaedic Workshop, Gulu, Uganda;
[3] Faculty of Medicine, University of Lira, Uganda;
[4] University of Manchester, Manchester, United Kingdom.

Corresponding author:

Professor Mahesh Nirmalan.
Faculty of Biology, Medicine and Health
Room 1.002
Core Technology Facility
Grafton Street, Manchester
United Kingdom
Tel: 0161 276 2904
Mob: 00447545803210
Email: m.nirmalan@manchester.ac.uk

Abstract

Background: Awareness of residual disabilities amongst people living in countries recovering from prolonged armed conflicts and their socio-economic consequences is increasing. Robust data on the prevalence of such disabilities are important for planning cost effective health services. This study outlines the first community-based prevalence study of Major Limb Loss (MLL) in the Acholi sub region of Northern Uganda. The generic lessons learnt are relevant to many other post-conflict societies in Asia and Africa.

Methods: A cross sectional survey using random cluster sampling was conducted across 8,000 households in eight districts, of which 7,864 were suitable for analysis. The households were sampled randomly using a high-resolution population model generated using a combination of census data and artificial intelligence. Data were collected using semi-structured questionnaires administered by trained staff, and results were statistically analysed to identify patterns.

Results: Data obtained from 7,864 households demonstrated that 47.9% (3,763) of households contained people with disabilities, and 3.0%, (237) of households contained people living with MLL. Of those exhibiting disabilities, the most common types were physical disabilities affecting mobility and other conditions limiting vision or hearing. Our analysis suggests that MLL sufferers are disproportionately male, older and less well educated than the general population. Using the identified prevalence rate of MLL (0.6%) and an estimated population value for the Acholi Sub-Region of 1.9 million, we estimate that there are approximately 11,400 MLL sufferers in the region who require long-term rehabilitation services.

Conclusions: This is the first large scale study on the prevalence of MLL following the Ugandan civil war - known for extreme forms of violence, cruelty and mutilation. Our study demonstrates the magnitude of the problem still faced by the affected people, almost 15 years after the end of large scale combat, and the relative paucity of rehabilitation services to meet their needs. Suitable alternative health policy frameworks are required to address these relatively invisible needs.

Background

The physical and mental wellbeing of people living in parts of the world that are recovering from prolonged armed conflicts is receiving increasing attention [1,2]. It is known that victims who suffer major disabilities are prone to developing a wide range of secondary health problems as a result of chronic inactivity, social isolation, unemployment, under employment, discrimination and marginalisation. For example, a study of landmine victims in Northern Sri Lanka showed that a large proportion of victims lost their earning capacity as a result of their injuries [3]. Furthermore, the prevalence of post-traumatic stress disorder (72%), acute stress reaction (73%), anxiety disorders (80%) and depression (73%) amongst the victims was significantly greater than in the general population living in the affected areas [3]. In a similar prevalence study amongst veterans returning to predominantly low-income minority New York city neighbourhoods, misuse of alcohol, prescription drugs or recreational drugs was found to be significantly greater than in the general population at 28%, 18%, and 32%, respectively [4]. An increased prevalence of non-communicable diseases (NCDs) amongst victims of war injuries is also well-recognised [5]. These residual issues, attributable to the direct or indirect consequences of the conflict, have a serious impact on quality of life, criminal behaviour, social cohesiveness, productivity and wellbeing. Most importantly, they increase the chances of these communities slipping back into conflict, and thereby trapping many of these already impoverished countries in recurrent cycles of violence and poverty.

The availability of quantifiable data obtained through robust prevalence studies is an essential driver of health service planning in any post-conflict situation and has received special attention in some post-conflict countries such as Sri Lanka [6]. For example, a prospective community based survey across three districts in the Northern Province of Sri Lanka demonstrated a very high prevalence of physical disabilities affecting mobility (approximately 30%) [6]. Findings of this formal survey confirmed the informal assessments by key stakeholders that had already drawn attention to the possibility of a very high disease/injury burden in the immediate post-conflict period in Sri Lanka as the war came to an end in 2009. The availability of data through such formal and informal surveys was instrumental in the introduction of a wide range of rehabilitation services in Northern Sri Lanka. A comprehensive outreach prosthetic limb service established by the '*Meththa Foundation UK*' – a UK based Registered Charity run by the Sri Lankan diaspora of all ethnicities[7,8], and similar services provided by other state and voluntary organizations (e.g: *Jaffna Jaipur Centre for disability rehabilitation [9])*, are examples of positive outcomes that resulted from extensive public engagement activities, backed by objective data obtained through systematic prevalence studies, in post-war Sri Lanka. However, such an organised approach has not been evident in many other post-conflict countries, with perhaps even greater levels of poverty, and more pressing health needs. In this context, the prolonged war between the Ugandan Government forces and the Lord's Resistant Army (LRA) provides an important case study.

The Ugandan civil war was never officially declared, and so it is not easy to determine the precise moments at which it began or ended [10], even though the period 1986-2005 (20 years) is generally accepted as the duration of the conflict [11]. One of the most striking elements of this conflict was the brutality and apparent arbitrariness of the LRA violence, with no evidence of any clear cause for which they were fighting or any final goals [12,13]. Another prominent characteristic of the conflict was the "*brazen disregard for human rights and international humanitarian law*" [10,13], including the mutilation and summary execution of non-combatants; mass rape; the abduction of children and adults for as foot soldiers, sex slaves and porters; the rounding up of civilians into camps, thought to have accounted for 1.2 million people by 2003; and large-scale massacres at Atiak (1995), Karuma (1996), Acholpi (1996) and Lokung-Palabeck (1997) [10]. Of all of these acts, the one that has become particularly associated with the memory of the LRA is that of mutilation. LRA practices included severing lips, ears, noses, fingers, hands and legs; as well as more elaborate approaches such as sewing eyes shut and padlocking lips together [12]. Victims would often be forced to 'consent' to the mutilation by being silent throughout the process on pain of death [12]. Such acts of mutilation were intended to be highly visible and symbolic, allowing mutilation to be used as a method of communication and control over the population [12]. Ears and lips, for example, were cut off as a signal to beware of informing on the LRA, whereas bicycle riders would have their legs cut off in order to control the number of bicycles travelling between population centres and so inhibit communication amongst the local population, whilst providing a highly visible warning to anyone else who may wish to cycle [12].

It is estimated that over 100,000 people were abducted or mutilated by the LRA (and other combatants) during this conflict [14]. The extensive media coverage associated with this conflict triggered large-scale operations by relief agencies such as the United Nations (UN), World Food Programme (WFP), International Committee of the Red Cross (ICRC) and several other smaller International Non-Governmental Organisations (INGOs). The health needs of the population during the conflict were met largely by these voluntary agencies, as the already limited local health infrastructure was destroyed by war [14]. However, many NGOs provided rehabilitative services only to those with war injuries, leaving those with other disabilities un-treated due to limited resources. The involvement of these agencies has however been gradually scaled down since 2005 when the war ended and with this shift in focus, the role of providing for the health needs of the population moved into the hands of the Ugandan Government.

Uganda has several challenges to overcome in the face of widespread disability. Despite the formation of positive government policy with respect to disabled people, it suffers from differing statistics and of definitions of disability, both of which make targeting interventions difficult [15,16]. Data on disability type and prevalence are also scarce, mostly existing only at the national level, with no understanding of spatial variations of prevalence within Uganda [15]. Such detailed local data are of particular importance in a country where a prolonged and violent conflict was concentrated in the remote Northern region, which is where data collection is likely to be worst. In order to try and meet the increasing demands for research, services and personnel in the health sector in the Northern Region, the Ugandan Government established the Gulu Medical Faculty in Northern Uganda in 2004 and strengthened a network of hospitals and community-based health organizations who, despite a severe lack of funding, are currently facing up to these challenges. There is widespread recognition within these agencies that rational planning of rehabilitation services needs to be underpinned by appropriate prevalence studies so that the responses are appropriate, proportionate and cost effective. This manuscript outlines a partnership between the Gulu University, Uganda and the University of Manchester, UK leading to the first ever prevalence study in relation to Major Limb Loss (MLL) in the Region in order to aid this process.

Methods

Study setting

This study was conducted in all the eight districts of Acholi sub region of Northern Uganda (Agago, Amuru, Gulu, Kitgum, Lamwo, Nwoya, Omoro and Pader). The region is approximately 28,500 km^2 (or 11,000 square miles) in area[17], and the total population of this area is hard to determine accurately, in part due to the on-going movement of people/refugees across the Democratic Republic of Congo (DRC) and South-Sudan borders. The best available estimate based on the 2014 census is approximately 1.9 million people, even though it is generally accepted that this is likely to be an underestimation[17]. The population distribution for the region is shown in Figure 1 (Obtained from Facebook Laboratories 2019[18–21]).

Figure 1. The 'High Resolution Settlement Layer' Population Density model of the Acholi Sub-Region (Obtained from Facebook Laboratories 2019 [18–21]).

Participants and procedures

The Ugandan National Population and Housing Census 2014[22] defines a household as a group of persons who normally live and eat together. This census report states that 99% of the Ugandan population were enumerated in private households (the remaining 1% were enumerated in hotels, institutions or are homeless) and the mean household size of 4.7 persons/household has remained stable for the past four decades despite growth in the population [22]. Our study therefore is based on a survey of household heads who were randomly selected from across the entire region.

Between July and September 2018, we conducted a cross-sectional survey of 7948 households in all of the eight districts. Participants were identified using random cluster sampling, whereby 100 clusters were randomly selected for analysis in each of the eight districts. Each cluster consisted of 10 households consisting of a group of individual huts containing an extended family unit. In the absence of up-to-date maps or data on the distribution of the population in the region, we utilised the High resolution settlement layer datasets [18–21] which was produced in 2015 through collaboration between the World Bank and the Connectivity Lab at Facebook as part of an on-going programme that seeks to provide internet access to regions that do not currently have adequate provision. These datasets [18–21] provides estimated values of population density as a continuous raster surface of *c*.30m^2 (1 arc-second[1]) cells. Values were calculated using high-resolution satellite imagery and a combination of computer vision and machine learning techniques in order to detect buildings and combine this information with census data in order to determine a population estimate. In order to perform the cluster sampling operation, all cells containing non-zero values in the HRSL dataset were converted to point locations using a Python Script [23], and then a stratified random sample of 800 'cluster locations' (100 within each of the 8 Districts within the Acholi Sub-Region) were selected from these points using the 'Random Selection' functionality in QGIS version 3.12 [24]. The results of the cluster sampling exercise were output to an interactive HTML file designed to help field researchers locate the cluster accurately. Each entry in the HTML file contained an unique ID for each cluster, the name of the district within which it is located, its coordinates in the WGS84 coordinate reference system (compatible with GPS receivers) and links to access maps of the cluster location in the form of a static satellite image; an interactive Google Map and an interactive OpenStreetMap that were enhanced by volunteer mappers engaged by our team as part of this project[8] ; and a seamless, digitised version of historic maps of the region produced in the 1960's by the British Directorate of Overseas Surveys . These were essential prerequisites to gain access to people living in some of the most remote parts of Northern Uganda by the study teams and the innovative approach used in this study to access these remote populations in unmapped parts of the world has previously been described by our group [8]. The selected sample cluster locations are illustrated in Figure 2.

Figure 2. Locations of the 8,000 randomly selected sample locations, with an indication of the straight-line distance to the Gulu Referral Orthopaedic Workshop (GROW) at the Gulu Referral

[1] *1 arc-second* is 1/3600 of a degree of latitude or longitude. Whilst the precise area of these cells will vary across the surface of the Earth (as the width of a degree of longitude decreases as one moves from the equator towards the poles), the distance in Uganda is approximately 30m^2.

Hospital – which is the only health facility providing basic rehabilitation services in this entire region.

Data collection and analysis:

Data was collected using two pre-tested semi-structured questionnaires (Appendix 1&2), one for heads of households (HoH), designed to identify the presence of any disabled people within the household and the nature of the disability; and a follow-up one for MLL sufferers, designed to gather further information about their experiences as a disabled person. Trained Research Assistants administered both questionnaires and all participants provided informed written consent prior to being interviewed. Interviews were conducted in the local language (Acholi) and translated into English for analysis. The local village administration officer (known as the Local Council one, 'LC1') was given prior notice of the research team's visit to any given cluster and was incorporated within the visiting research teams in order to reassure the local communities. Data were analysed using the Python programming language [25]. The scripts used are available at the following site [26].

Data from the questionnaires were used in order to help determine the prevalence of disability and MLL within the selected households. In order to avoid the challenges associated with inconsistent definitions of disability in Uganda [15], we adopted the definition of 'disability' provided by the Uganda Persons with Disabilities (PWDs) Act of 2006: *"a substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environmental barriers resulting in limited participation"*[27]. For purposes of the survey MLL was defined as loss of a limb above the Ankle (lower limb) or Wrist joints (Upper limbs). Socio-Demographic patterns amongst MLL sufferers were analysed using the Chi-squared (χ^2) goodness of fit statistic in order to determine the probability that the distribution of values seen in the sample might have been drawn from the 'expected' distribution of values, which is determined by scaling the distribution of values drawn from the UBOS 2014 Census [28,29] or the UBOS 2018 Mid-Year Population Projection survey [28,29].

Spatial autocorrelation (analysis of the distribution of MLL incidence across the region) took place using the Moran's *I* statistic [30], which assesses the degree to which similar values in a dataset correspond with similar locations, therefore identifying the degree of clustering of similar data across the whole dataset. This ‘global’ analysis is complemented by a Local Indicators of Spatial Association (LISA) analysis, in which the *Local Moran’s I* statistic [31] is calculated in order to decompose the global autocorrelation into local clusters of similar values (e.g. a high value surrounded by several other high values) and outliers (e.g. a high value surrounded by otherwise low values). Significance levels (*p* values) generated from both the Moran’s *I* and *Local Moran’s I* analyses are simulated ‘pseudo-significance’ values, generated using 9999 permutations of the analysis.

Results

Prevalence of self-reported disabilities and MLL:

Of the 8,000 planned 7,864 surveys were completed and the data were available for further analysis following manual review of all completed questionnaires. The mean age was 43 (SD: 15.3), and just under half of them (45%) were female. The questionnaire used for the interviews with the household heads is shown in Appendix 1 and the extracted summary of relevant demographic data are shown in Table 1. People with disabilities were identified in 47.9%, (3,763/7,864) of households. The overall number of individual disabilities reported was 3,943, with 180 participants having multiple disabilities. The most common types of disability reported by the household heads were: those affecting mobility 54% (2032/3763), major conditions affecting vision that limits their ability to work 18% (666/3763) and major conditions affecting hearing that limits communication 14% (512/3763). The main causes of disability were disease 53% (2010/3763), trauma 20.0% (751/3763), birth defects 15% (552/3763) and war (6.7%) (Table 2).

Table 1: Socio-demographic characteristics of Household Heads (HoH)

Variable	Frequencies (N=7,864)	Percent (%)
Gender		
Male	4,351	55.3
Female	3,513	44.7
Age[1]		
0-19	108	1.4
20-39	3599	45.8
40-59	2872	36.5
60+	1279	16.3
Tribe		
Acholi	7,393	94.0
Lango	78	1.0
Others	393	5.0
Religion		
Catholic	5,595	71.2
Protestant	1,801	22.9
Muslim	88	1.1
Pentecostal	328	4.2
Others	52	0.7
Highest level of Education[2]		
No formal education	1,814	23.1
Primary	4,336	55.1
Secondary	1,271	16.2
Tertiary	443	5.6
Occupation		
No formal occupation	6,929	88.1
Formal occupation	935	11.9
Place of residence		
Urban	966	12.3
Rural	6,898	87.7

1. Age data was not available for 6 questionnaires that were included in the analysis

2 This refers to the highest level of education attended, not necessarily completed.

Table 2: Proportion of disabilities by person, cause and type

Variable	Frequencies (N=3,763*)	Percent (%)
Cause of disability		
Disease	2,010	53.4
Birth defects	552	14.7
Trauma	751	20.0
Domestic violence	57	1.5
War injury	254	6.7
Others	139	3.7
Type of disability		
Major Visual	666	17.7
Major Hearing/speak disability	512	13.6
Mobility/physical	2,032	54.0
Mental	417	11.1
Chronic disease	70	1.9
Others	66	1.7

* Types of disability and aetiology reported by Household Heads

Of the 3763 households, 237 included a subject with major limb loss (MLL), of which approximately 55% had lost lower limbs, 40 % upper limbs, and 2% both upper and lower limbs (Table 3). We were able to gather data directly from 181 (76%) of these MLL sufferers in order to better understand their characteristics and experiences using an additional questionnaire (Appendix 2). The mean age of MLL sufferers was 44, approximately two thirds (66.5%) were male and almost all of them (95.2%) belonged to the Acholi tribe. The main causes of limb loss and the levels of amputations are illustrated in table 3 and Figure 3. It is seen that war injuries is the most frequent cause of MLL in the region, accounting for 116 of 237 cases (48.9%).

Table 3: Characterizing limb loss (reported by head of households)

Variable	Frequencies (N=237)	Percent (%)
Gender		
Male	153	64.6
Female	84	35.4
Tribe		
Acholi	227	95.8
Langi	06	2.5
Others	04	1.7
Level of the limb loss		
Below elbow joint	60	25.3
Above elbow joint	43	18.1
Below knee joint	47	19.8
Above knee joint	87	36.8

Figure 3: Frequencies of MLL causes in the Acholi sub-region

Of the 176 MLL sufferers who gave us information relating to their access to healthcare over the past 6 months; 80 (45.5%) had no access to assistive devices (prosthetic limbs, crutches etc.); 82 (46.6%) had no access to any rehabilitative services; and 16 (9.1%) had no access to any kind of healthcare whatsoever. Of those who have received a device, verbal feedback indicated that many did not use them due to them being badly fitted (in some cases the device was second hand, with no attempt whatsoever to fit them to the individual), heavy, non-articulated, or broken.

Spatial Analysis of MLL Sufferers

Figure 4: Locations (by parish) of the 158 MLL sufferers for which valid location data was available, demonstrating a spread of MLL across the whole region.

The distribution of these MLL sufferers is illustrated in Figure 4, illustrating the incidence of MLL across all parts of the region. Data in Figure 4 are shown as counts of MLL sufferers at parish level, rather than as individual point locations due to an issue in the data collection process as only 57 locations were correctly recorded, whereas 167 parish names were correctly recorded. This distribution was examined for spatial autocorrelation (clustering of MLL incidence) using Moran's *I* statistic and this analysis showed that the simulated probability that MLL incidences are randomly distributed throughout the Acholi Sub-Region is $p=0.231$. However, whilst there is not a global pattern of spatial clustering, a LISA analysis showed (Figure 5) that there are significant local clusters around the town of Kitgum ($p=0.003$ and $p=0.039$) and positive outliers surrounding the town of Gulu ($p<0.0001$ in both cases), both of which evidence increased rebel activity in the areas surrounding the two largest urban areas in the region. There are also positive clusters in remote rural areas of the Kitgum ($p=0.0407$ and $p=0.0305$) and Amuru ($p=0.0478$ and $p=0.0456$ and $p=0.0393$) districts. It should be noted that this LISA analysis will be affected by the relatively sparse distribution of the sample locations, meaning that some patterns that are not evident or are insignificant in this analysis might be revealed in a larger (or even a different) sample. Nevertheless, this analysis is useful to help us identify that there are concentrations of values in both urban and rural areas of the Acholi Sub-Region.

Figure 5: LISA analysis of clusters and outliers of MLL cases from our sample (by parish) calculated to the significance level $p=0.05$ (simulated p based on 9999 iterations).

Figure 6 illustrates the observed distribution of distances for the 158 MLL sufferers for whom parish location was successfully recorded, alongside the expected distribution (created by scaling the distribution of distances of the 8,000 sample locations). The distances were calculated from the respective parish centre to the Gulu Referral Orthopaedic Workshop (GROW) which is the only facility available in the region where prosthetic limb services may be accessed by the affected subjects. Whilst the mean and standard distribution of the two distributions are similar (mean: 68.73km; SD: 40.34km expected; mean: 63.67km; SD: 39.66km for MLL sufferers), the χ^2 goodness of fit statistic indicates that the probability of the distribution of values having been drawn from the expected distribution is very small (p=0.01).

This main difference between the distributions comprise unexpectedly high values in the 0-20km and 80-100km distance bands. These are likely explained by the presence of the two large towns in the region (Gulu, in which the clinic is located; and Kitgum, c.90km north east of the clinic). LRA violence was known to be concentrated around these areas of higher population density (see Figure 1), and these areas have also seen recent increases in the prevalence of modern tarmac roads, which are leading to greater traffic speeds and so more serious accidents. This is also supported by the above LISA analysis (Figure 5), which identified statistically significant clusters and outliers of high MLL values in the areas surrounding both population centres.

Figure 6: A comparison of the distribution of distances from the Gulu Referral Orthopaedic Workshop (GROW) for the 149 MLL sufferers for which location information was recorded, and expected values (derived from the 8,000 random samples from across the Acholi Sub-Region).

The large positive differences between the observed and expected distributions in the 0-20km bands are likely explained by the presence of the only settlements of significant size in the region: Gulu, which is the largest town in the region (and the location of the clinic); and Kitgum, the second-largest, about 90km north east of Gulu (Figure 1). Many rural residents fled to the towns during the LRA insurgency which, along with their importance as key hubs in a very limited transport infrastructure, made the towns and their surrounds a target for violence during the LRA insurgency. Kitgum experienced a disproportionately high level of violence during the LRA insurgency (this can be seen in Figure 4, with the highest MLL value located in Kitgum). Recently, towns such as these have seen the development of modern tarmac roads and the increasing availability of motor vehicles (mostly motorbikes), which has led to a substantial increase in road traffic accidents.

Socio-Demographic Analysis of MLL Sufferers

The gender, age, and education of MLL sufferers was compared with underlying population distributions using the χ^2 goodness of fit statistic, in order to identify any socio-demographic trends amongst those who are disabled. This analysis suggested that MLL sufferers in the Acholi Sub-Region are disproportionately male, older and less well educated than would be expected from the respective underlying population distributions.

167 of the sample of 237 ML sufferers (70%) provided information relating to their gender. Figure 7 illustrates the observed gender distribution (from the MLL sufferer's questionnaire) against the expected distribution, which were calculated by scaling the distribution of genders from the 2014 census figures from Acholi Sub-Region (http://catalog.data.ug/dataset/2014-census-data). The χ^2 goodness of fit statistic illustrates that there is a disproportionate prevalence of males amongst our sample of MLL sufferers, with the probability of the observed distribution of values having been drawn from the expected distribution extremely small (p=3.1×10^{-6}). This is likely due to males having been more likely to have been injured in the LRA insurgency, as well as being more likely to have been working in the fields, where they may pick up injuries from remnant land mines or accidents caused during manual labour.

Figure 7: Comparison of the observed distribution of gender amongst 167 MLL sufferers with the expected distribution based upon the 2014 census.

167 of the sample of 237 ML sufferers (70%) provided information about their age. Figure 8 illustrates the observed (mean: 44.66; SD: 17.71) and expected (mean: 20.39; SD: 17.24) distribution of ages between the 167 MLL sufferers and the underlying population, calculated from the 2018 UBOS Mid-Year Population Projection (https://www.ubos.org/explore-statistics/statistical-datasets/6133/.) Once again, these illustrate a substantial difference between the observed and

expected distributions, with the sample of MLL sufferers typically much older than expected. The χ^2 goodness of fit statistic indicates that the probability of the distribution of observed values having been drawn from the expected population distribution is vanishingly small (p=1.3×10^{-67}). It is likely that this has been affected by the LRA insurgency ending in around 2005, meaning that the very young will have experienced a reduced (though not necessarily entirely diminished) effect of the conflict, and are less likely to have been involved in fighting or otherwise become injured (e.g. during an attack or through standing on a landmine) due to the conflict. Those who lived through the conflict will also have likely experienced periods of reduced access to healthcare; meaning that less severe injuries might have resulted in MLL that could otherwise have been treated. It is also perhaps less likely that very young people will be involved in road traffic incidents (as they cannot drive and travel less frequently), or develop some chronic diseases such as type-2 diabetes (which typically present later in life).

Figure 8: Comparison of the observed distribution of age amongst 167 MLL sufferers with the expected distribution based upon the UBOS 2018 Mid-Year Population Projection.

166 of the sample of 237 ML sufferers (70%) provided information about their educational attainment. Figure 9 illustrates the observed and expected distribution of educational attainment between the 171 MLL sufferers and the underlying population, calculated from the 2014 census for the Acholi Sub-Region [29]. Once again, these illustrate a substantial difference between the observed and expected distributions, with the sample of MLL sufferers typically less well educated than expected. The χ^2 goodness of fit statistic indicates that the probability of the distribution of observed values having been drawn from the expected population distribution is again vanishingly small (p=8.9×10^{-73}). There is likely a dual causation this statistic, with those who are disabled less likely to be able to afford or access education; whereas those with lower levels education are more likely to be in situations where they might become injured, such as engaging in manual labour, or working in fields where they might become injured by remnant land mines.

Figure 9: Comparison of the observed distribution of educational attainment amongst 166 MLL sufferers with the expected distribution based upon the 2014 census.

MLL Prevalence Estimate

Based upon the mean household size of 4.7 [22] , the total estimated size of the sampled population is 36,961 individuals, of which 237 suffered from MLL. Because the sample was randomised, we can scale this up to the population of the Acholi Sub-Region using a population estimate of 1.9 million people. Based upon this, we estimate that there are 12,183 MLL sufferers in the Acholi Sub Region (c.0.6% of the population), which is the first formal estimate of MLL prevalence in the region. The study also found that people with MLL are spread across the entire region (Figure 4) and that large numbers of those living with disability have never had any access to prosthetic or rehabilitation services since losing their limbs. Similarly, based upon our findings we can estimate that there are 190,509 with physical disabilities other than MLL in the region (c.10% of the population), many of whom once again have had little or no access to medical or rehabilitation services.

Discussion

This study was conducted in the entire Acholi sub-region in Northern Uganda and covered all 8 districts. The aim of the study was to provide the first detailed prevalence study of MLL and other physical disabilities in the region, as well as provide a socio-demographic characterisation for MLL sufferers, in order to support the provision of medical care and rehabilitation services to one of the most impoverished parts of the world where such services are most needed. The end of the war almost 15 years ago has not brought the relief people of this region deserve and addressing the needs of the disabled victims in the region deserves the attention of all concerned. We have identified that approximately 0.6% of the population (>12,000 people) in the region suffer with MLL, and approximately 10% of the population (>190,500 people) with other physical disabilities.

Of the 3763 individuals with physical disabilities, 2032 (54%) had mobility-related issues, 237 (12%) of which had MLL. The causes for impaired mobility in the remaining 88% of subjects were multi-factorial, including birth defects, unhealed ulcers, discharging wound, sinuses from osteomyelitis, spinal injuries, and congenital malformations such as spina bifida, chronic osteomyelitis, residual foreign bodies and chronic neuralgia. Many of these issues are easily treated by simple surgical interventions available in adjoining district hospitals such as the Gulu Referral Hospital. However, such conditions remain untreated, thereby adding considerably to the disease burden in the region. Our study has demonstrated that the level of provision for MLL sufferers is currently inadequate. Ambulation with a suitable prosthesis is the ultimate goal of rehabilitation for a person with MLL, and recipients of a suitable prosthesis have reported significant health benefits [32,33]. However, difficulties in accessing such services are well recognized in Africa and in other LMICs. The relatively low priority given to less visible chronic health needs such as rehabilitation services during budget setting is very apparent in these countries, and Uganda (Northern Uganda in particular) is no exception to this pattern [34]. In this context, prevalence studies are essential tools to highlight the magnitude of the problem and its potential impact on wellbeing and productivity, in order to influence health policy.

The distance analysis presented above shows that victims in Northern Uganda need to travel very long distances to access prosthetic limb services at GROW. These services are relatively expensive to set up and maintain and consequently it is not possible for the Ministry of Health to open more centres across the region. As part of the current study, we have set up an outreach prosthetic limb service operating out from GROW based on a Hub-spoke model. This service has been successful in identifying many of these victims and referring them to the appropriate authorities for further management. This outreach service has in 2019 provided 52 prosthetic limbs to 51 patients (one bilateral) whose stumps were healthy and suitable for rapid interventions through the provision of prosthetic limbs. Our outreach clinics have also identified many victims with complex stump-related conditions (protruding bony spikes, infected sinuses, neuromas etc.) that require further corrective surgery before a prosthetic limb can be fitted. These outreach clinics were modelled on a similar approach adopted in Post-war Sri Lanka [7], which is designed to give remote villages access to rehabilitation services without the prohibitive requirement for them to travel long distances from their communities. As part of this project, two Ugandan prosthetic technicians completed a three-month training period at the prosthetic clinics in Sri Lanka, establishing an important South-South collaboration in post-conflict rehabilitation. Initial impressions of these outreach clinics are very favourable, with a very high level of patient satisfaction in both Sri Lanka and in Uganda (unpublished observations: MN, JH, SM and EM). Further formal studies are required to evaluate the acceptability, suitability and cost-effectiveness of outreach rehabilitation services in order to support their adoption in other post-conflict locations in the world.

The Acholi sub-region is a very remote part of the world. Despite considerable improvements in the road networks due to post-war reconstruction, access to many of the rural population remains limited. In this context, planning and implementing a robust field study presents many difficulties. Given that the conflict with the LRA was predominantly focused in rural areas, many of the disabled victims are likely to be living in rural and hard to access communities, meaning that hospital-based studies are not well placed to fully understand the magnitude of the problem. We have therefore employed novel datasets and bespoke maps of this area to identify clusters and to guide our field workers. Our production of maps of the region continues, with volunteers from both the UK and from Uganda undertaking remote and in-field (respectively) mapping activities on a regular basis [8]. The map data that we collect is made open access through OpenstreetMap [35] and bespoke paper maps are made freely available to all stakeholders, including future researchers and aid workers.

The preponderance of lower limb loss over upper limb amputations from combat areas has been reported previously. For example *Bendinelli* in 2009 reported that almost 50% of civilian adults who sustained blast injuries in Cambodia had lower limb injuries [36]. As a result, most prosthetic limb services in post conflict LMICs (including Cambodia, Uganda and Sri Lanka) have focused on lower limb prostheses. Our study revealed that approximately 40% of those with MLL had lost upper limbs, with 2% having lost both upper and lower limbs. Blast injuries from the ground upwards are likely to affect lower limbs more than upper limbs; but amputation of both upper and lower limbs was a widely practiced punishment by the LRA, which along with gunshot wounds is likely to account for this relatively high proportion of upper limb loss in our study population. The question of rehabilitation for these upper limb amputees is compounded by the near absence of upper limb prosthetic limb services in the entire region. The majority of amputees (95.8%) were from the Acholi tribe, reflecting the predominance of the Acholi people (94%) in this region. In approximately 50% of cases the cause of the limb loss was related to war trauma and a further 20% of cases were due to road traffic collisions or industrial/work place incidents. The proportion of patients with non-war related amputations is likely to rise further with the development of a modern road network as part of the post-war development in Uganda. Unfortunately, the development of this road network is not matched by road safety regulations or acute trauma services and hence this problem is set to grow even further.

Limitations in methodology:

The expected distributions for gender and educational levels were based upon data for the Acholi Sub-Region, taken from the 2014 census. We must assume that these distributions (rather than individual values) have not changed significantly in the 4 years between the publication of the census and the data collection, and we are reliant upon the quality of the census data. The expected distribution for age was based upon the UBOS Mid-Year Population Projection for 2018, which is a modelled extrapolation from the 2014 census. This is a national dataset (values are not given at regional, sub-regional or district level), and so we must assume that the underlying model is robust, and that the population distribution of the Acholi Sub-Region is not significantly different to the national population distribution. The risks associated with all three of these expected distributions are mitigated somewhat by the extremely low probabilities of the values in our dataset being drawn from the expected distribution.

The HRSL dataset is describes estimated population density, rather than individual buildings. There is also a possibility that this dataset might perform less well in rural than urban settings (as there are fewer buildings available in a more-sparse distribution, which can make populated areas harder to detect). However, two training visits to the area by the study team (JH and MN) and validation by visual inspection against satellite imagery showed that population patterns in the dataset do correlate well with the location of buildings and huts in rural areas and, in the absence of a better alternative, this tool was deemed sufficient for the production of a random sample. Nevertheless, more detailed maps and population data would permit more precise estimates of population to be undertaken, and increase the robustness of this sampling strategy.

Some errors were made in the survey data collection, meaning that precise locations were only collected correctly for 49 of the 171 MLL sufferers. This was addressed by aggregating MLL sufferers to parish level, for which data were available for 158 of the 171 MLL sufferers. As a result, this has had a very minor impact upon the analysis, and does not affect the quality of the conclusions.

Conclusions and recommendations:

The prevalence of all forms of disability and MLL in the Sub Acholi region is approximately 10% and 0.6% respectively, giving an estimated 190,000 people with physical disabilities in the region, of which an estimated 11,400 suffer from MLL and require long term access to prosthetic limb services. The current level of service provision is not capable of meeting this need, and will have a significant impact on individual wellbeing and the productivity of the region. Suitable policy frameworks are needed urgently to support budgetary planning for a more equitable distribution of health care resources to meet the needs of the less visible, but equally important, living with chronic health needs such as MLL.

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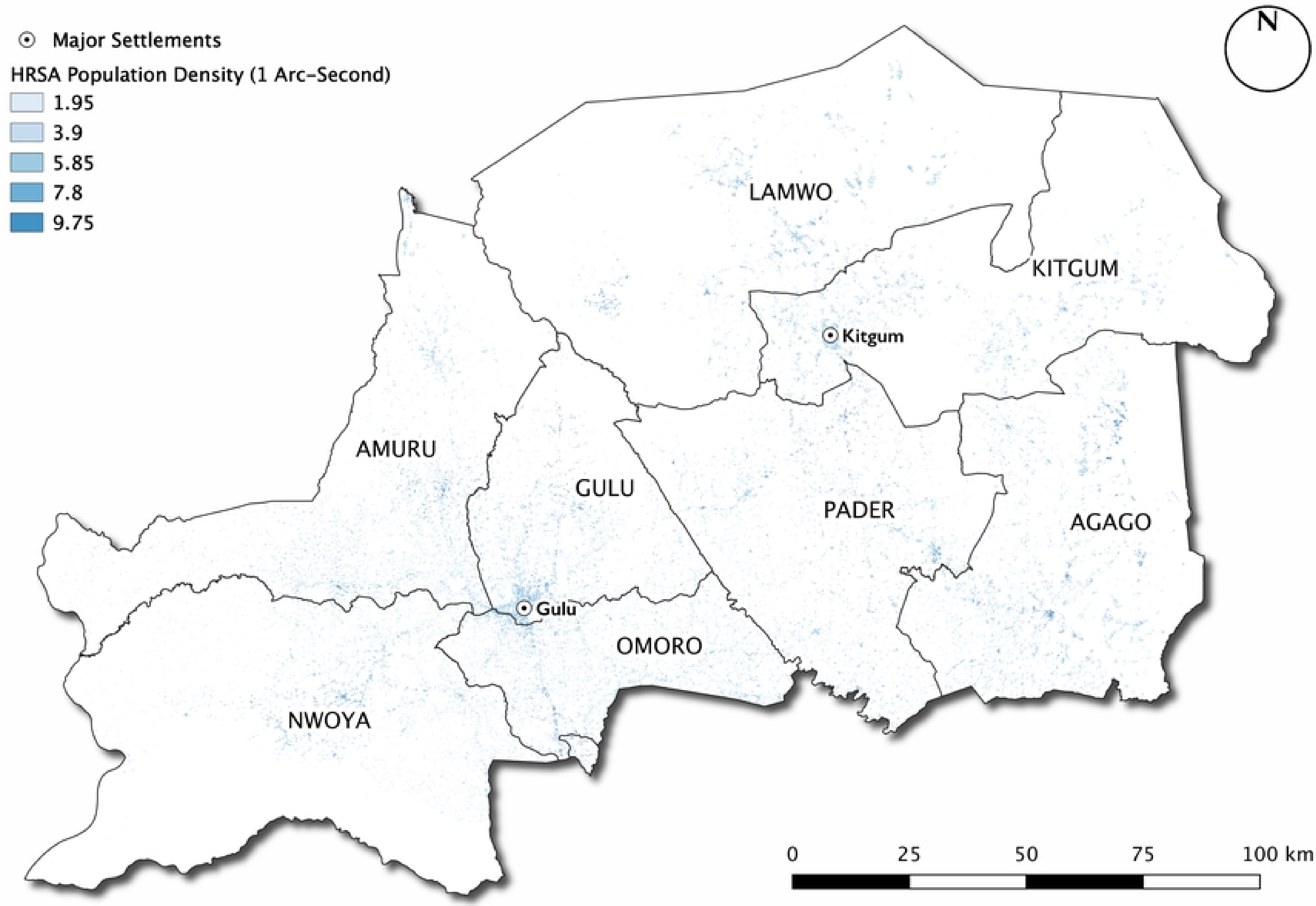


Major Settlements
HRSA Population Density (1 Arc-Second)
1.95
3.9
5.85
7.8
9.75
N
LAMWO
KITGUM
Kitgum
AMURU
GULU
PADER
AGAGO
Gulu
OMORO
NWOYA
0
25
50
75
100 km

Figure 1

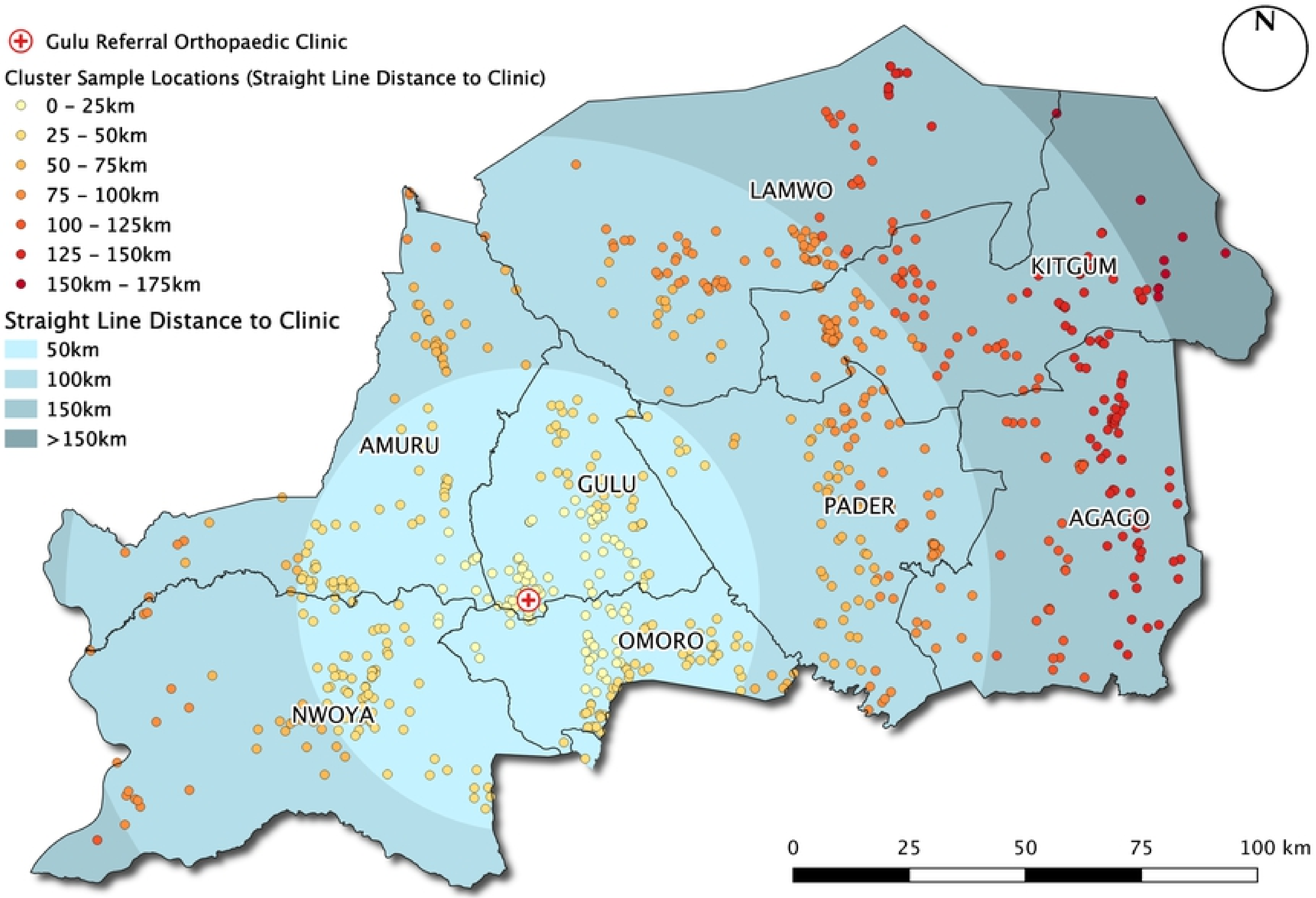
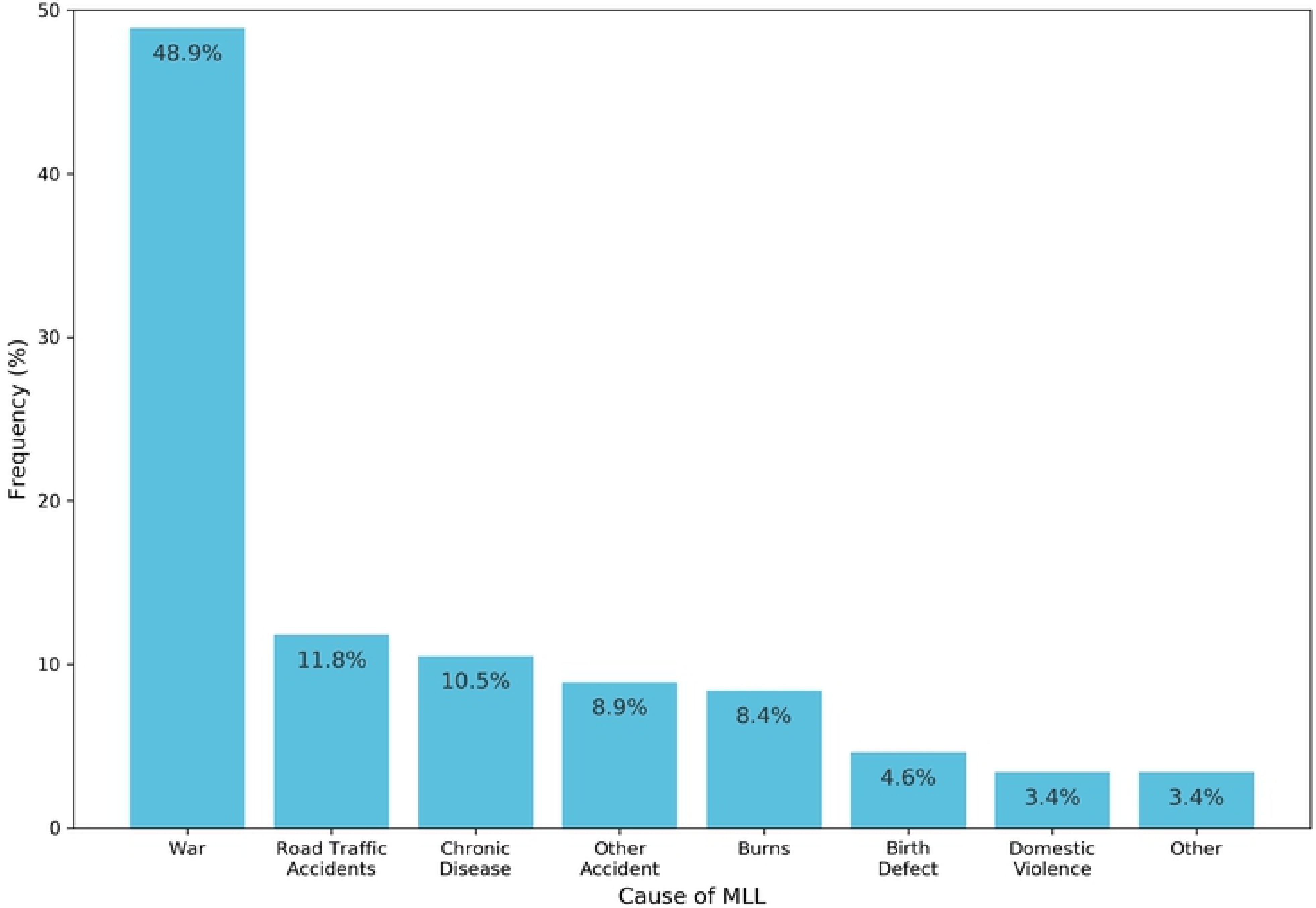
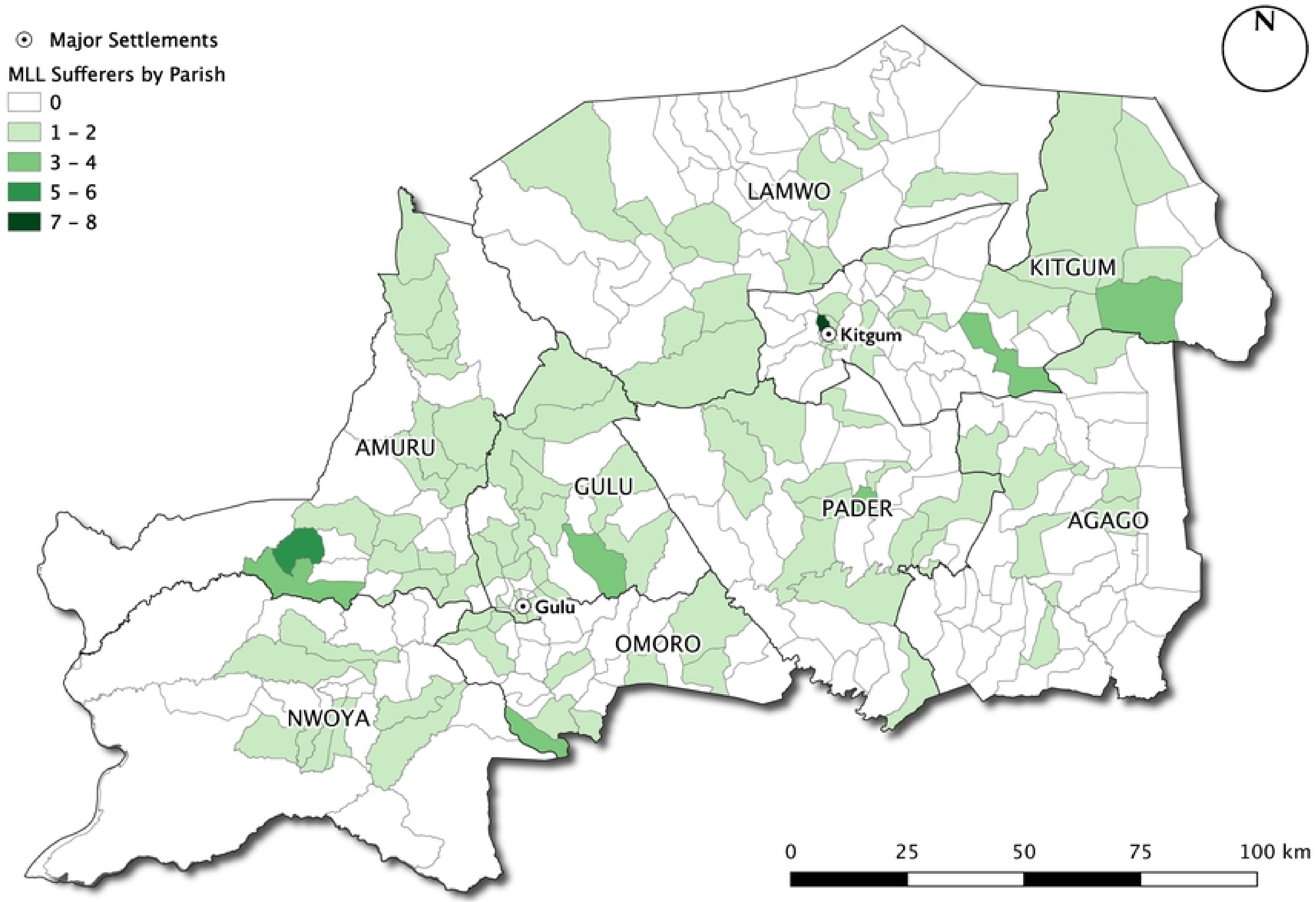

Gulu Referral Orthopaedic Clinic
Cluster Sample Locations (Straight Line Distance to Clinic)
0 - 25km
25 - 50km
50 - 75km
75 - 100km
100 - 125km
125 - 150km
150km - 175km
Straight Line Distance to Clinic
50km
100km
150km
>150km
N
LAMWO
KITGUM
AMURU
GULU
PADER
AGAGO
OMORO
NWOYA
0
25
50
75
100 km

Figure 2



48.9%
11.8%
10.5%
8.9%
8.4%
4.6%
3.4%
3.4%
50
40
30
20
10
0
Frequency (%)
War
Road Traffic Accidents
Chronic Disease
Other Accident
Burns
Birth Defect
Domestic Violence
Other
Cause of MLL

Figure 3



Major Settlements
MLL Sufferers by Parish
0
1 – 2
3 – 4
5 – 6
7 – 8
N
LAMWO
KITGUM
Kitgum
AMURU
GULU
PADER
AGAGO
Gulu
OMORO
NWOYA
0
25
50
75
100 km

Figure 4

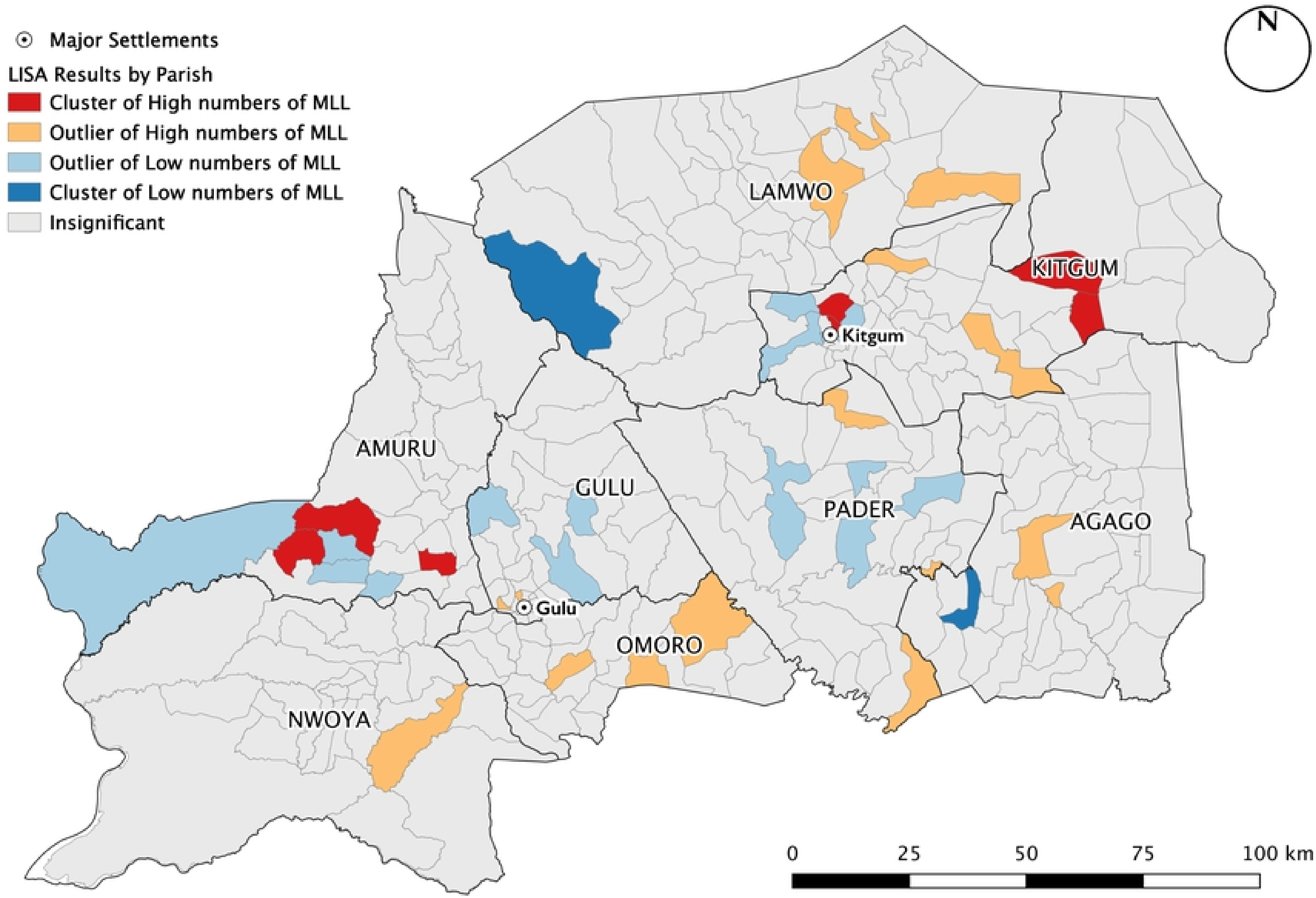
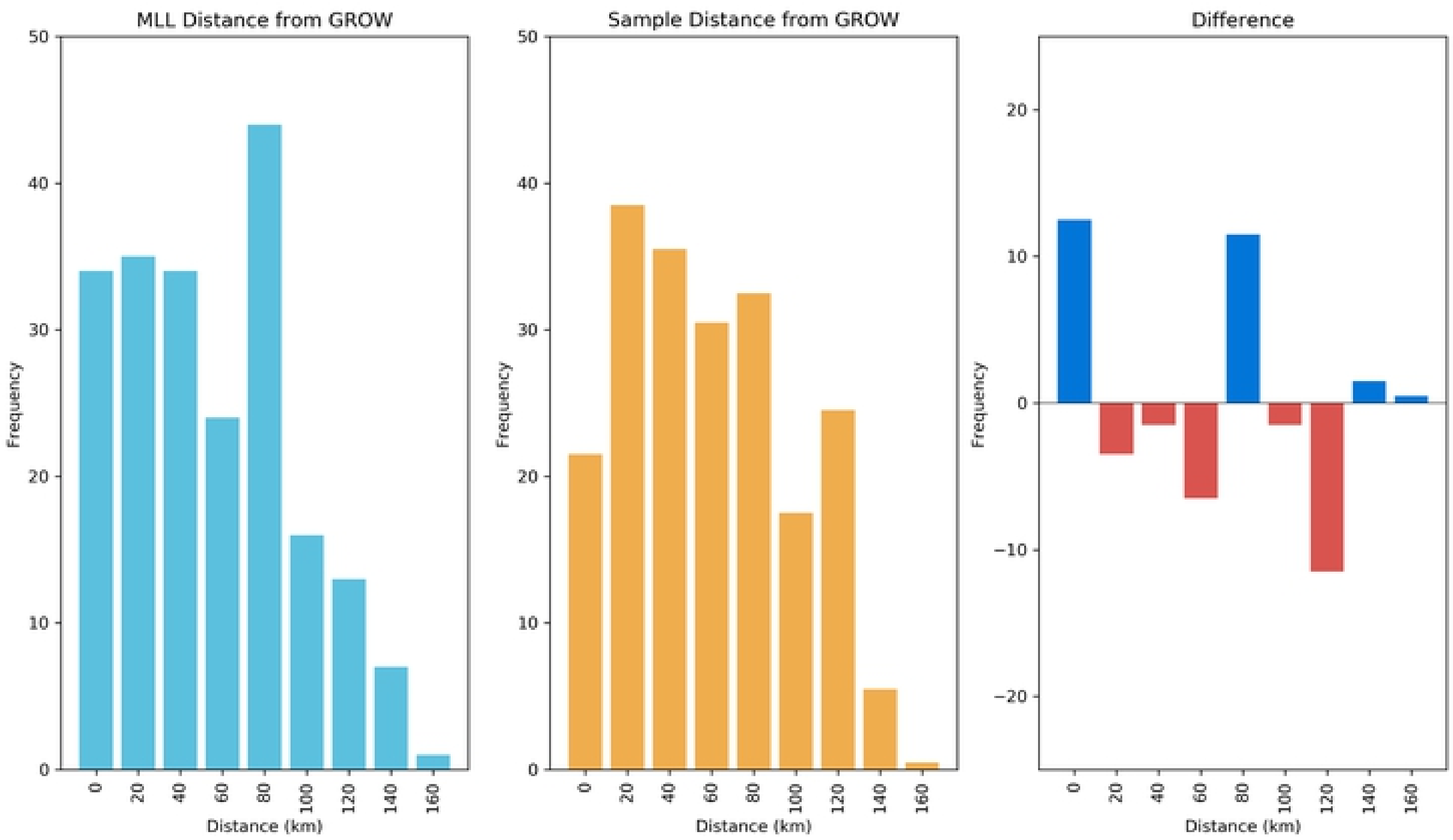

Major Settlements
LISA Results by Parish
Cluster of High numbers of MLL
Outlier of High numbers of MLL
Outlier of Low numbers of MLL
Cluster of Low numbers of MLL
Insignificant
N
LAMWO
KITGUM
Kitgum
AMURU
GULU
PADER
AGAGO
Gulu
OMORO
NWOYA
0
25
50
75
100 km

Figure 5



MLL Distance from GROW
Sample Distance from GROW
Difference
Frequency
Distance (km)
0
10
20
30
40
50
−10
−20
60
80
100
120
140
160

Figure 6

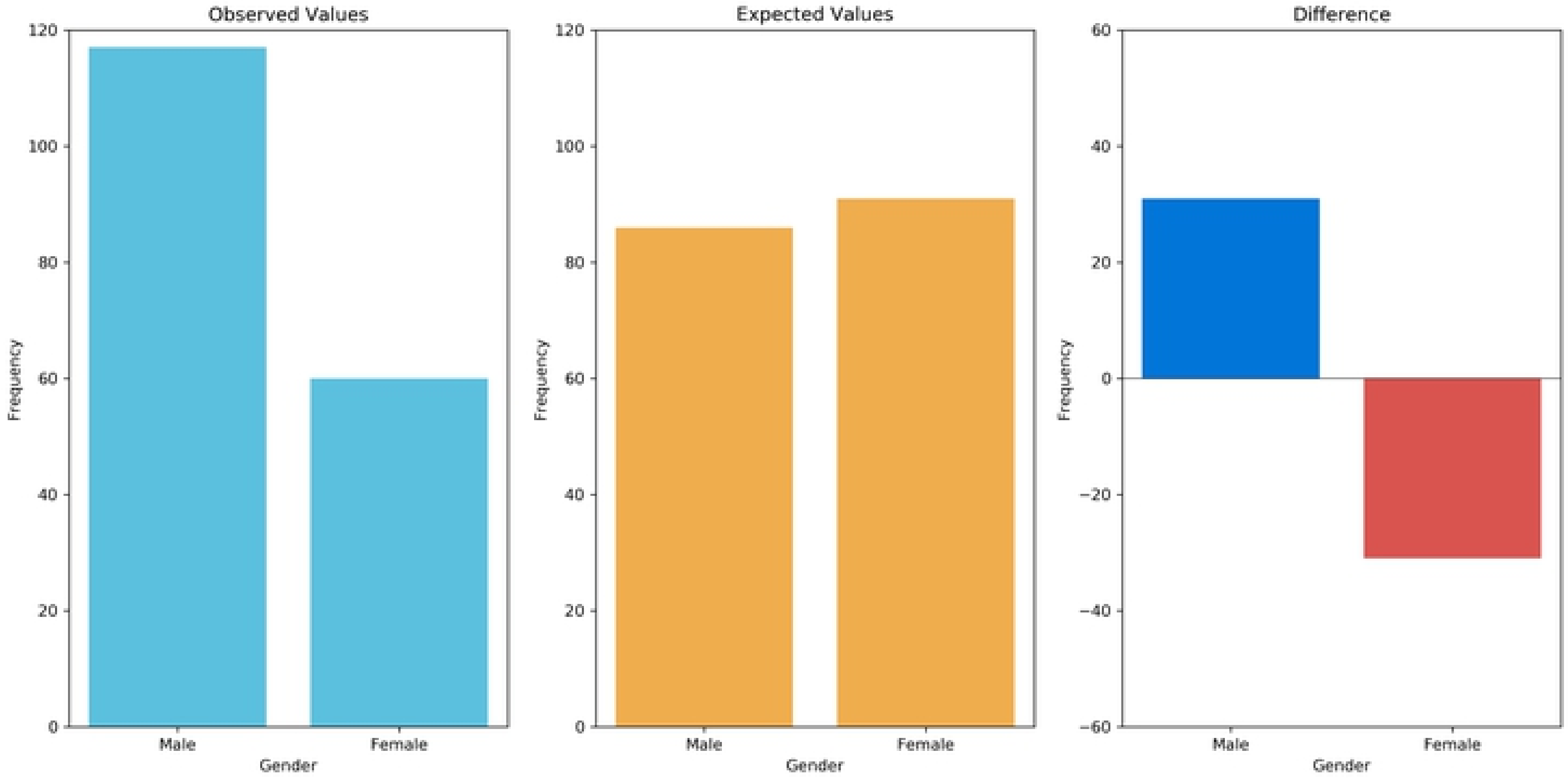

Observed Values
Expected Values
Difference
120
100
80
60
40
20
0
-20
-40
-60
Frequency
Male
Female
Gender

Figure 7

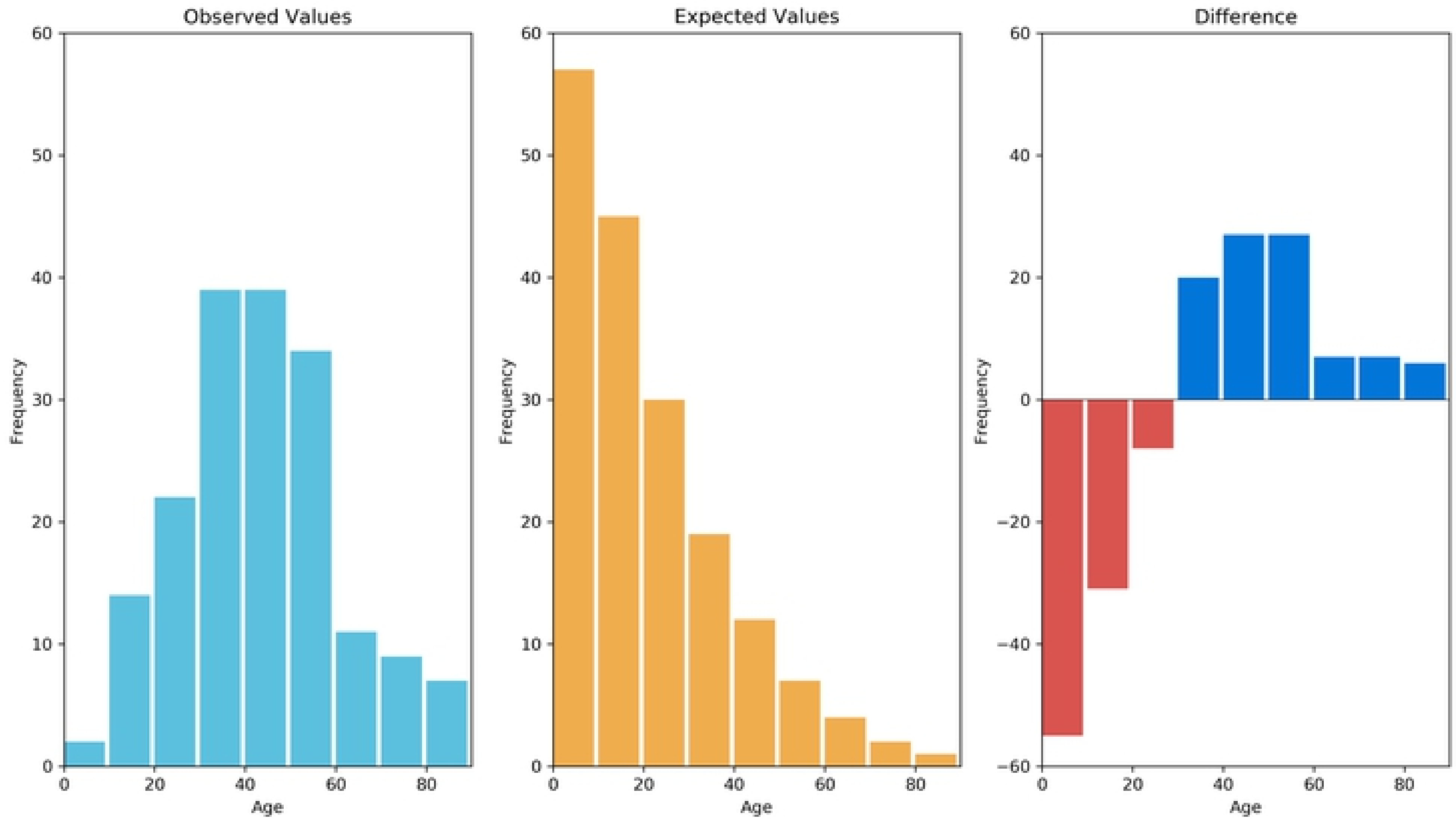

Observed Values
Expected Values
Difference
Frequency
Age
0
10
20
30
40
50
60
−20
−40
−60
80

Figure 8

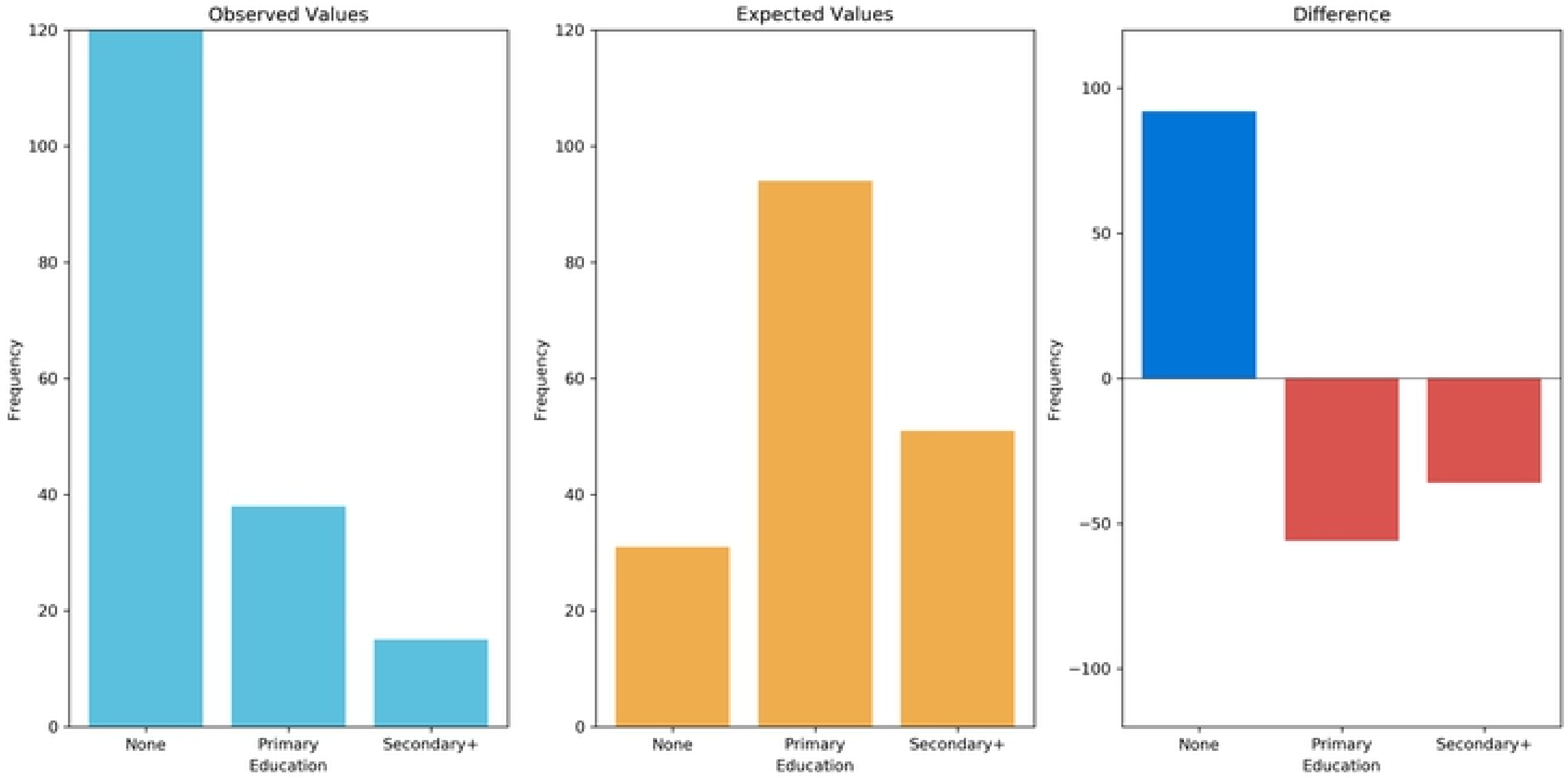

Observed Values
Expected Values
Difference
Frequency
120
100
80
60
40
20
0
50
−50
−100
None
Primary Education
Secondary+

Figure 9