Surviving Gun Violence with Spinal Cord injury in Guatemala

A thesis submitted in fulfilment of the requirements for the degree of
Master of Applied Science

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Candidate Statement

I, Rebecca Peters, certify that this thesis does not contain material, without the appropriate acknowledgement, that has been accepted for the award of any other degree at The University of Sydney, or any other educational institution. I also certify that this thesis does not contain, without the appropriate acknowledgement, any material previously published or written by another person. This thesis is wholly my own work, and to the best of my knowledge, appropriate acknowledgement is given where material previously published by others is cited therein.

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Date: 8th March 2020

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Contents

Abstract

This thesis explores the lived experience of members of a little-studied group, the survivors of gun violence. Although gun violence is a topic of intense interest and discussion around the world, the focus tends to be on mortality, with little consideration given to people who are shot and do not die.

The Guatemalan wheelchair NGO Transitions reports that, among adults, the single most common reason for needing a wheelchair is spinal cord injury (SCI) caused by gunshot. This suggests a very serious impact of gun violence in terms of disability and its accompanying challenges in a low-resource context like Guatemala. The study set out to investigate the phenomenon of living with SCI caused by gunshot.

No scholarly research, whether quantitative or qualitative, has been published on people who survive being shot in Guatemala. Violence is ranked by the World Health Organization as the third leading cause of spinal cord injury, but it is barely mentioned in global reviews of SCI research. This is because the low- and middle-income countries most affected by violence do not tend to be included in global reviews. However, a search of the Latin American literature reveals gunshot to be the primary cause of SCI in some studies from Honduras, Brazil and Colombia. This may also be true in Guatemala, which is similar to these three countries in terms of crime and violence. Meanwhile, the published qualitative research on the experience of gunshot survivors is mostly limited to studies of current or former gang members in the US, a context very different from Guatemala.

In order to gain a deep understanding of the experience of people who are shot and survive with SCI, this study took a qualitative approach, based on semi-structured interviews and thematic content analysis. The participants' experiences are analysed in terms of six themes: hospital and health, justice, economic impact, family, religious faith, and disability identity and wellbeing.

The findings highlight the serious impact of poverty on health and mobility, the common experience of severe and preventable secondary health problems, as well as the key role of family support and religious faith in these survivors' lives.

This research contributes to an understanding of the immediate and long-term impacts of gun violence, and the need for improved policies and services for crime victims and people with spinal cord injury in Guatemala. The recommendations could inform policy (eg crime victims assistance), programs (eg education for SCI patients, their families and health workers), and public awareness in Guatemala. Further research is recommended into the experience of gun violence survivors and their families as well as the economic impact of gun violence. Better data collection is recommended in areas including gun deaths, non-fatal injuries, circumstances of shooting, types of weapons used, police investigations, prosecutions and convictions.

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Acronyms, abbreviations, and official names in Spanish

AIHW Australian Institute of Health and Welfare

CDC US Centers for Disease Control and Prevention

CEH *Comisión para el Esclarecimiento Histórico* (Guatemalan Commission for Historical Clarification)

CIA Central Intelligence Agency

CICIG *Comisión Internacional contra la Impunidad en Guatemala* (International Commission Against Impunity in Guatemala)

CONADI *Consejo Nacional para la Atención de las Personas con Discapacidad* (National Council for Support of People with Disabilities)

CRPD United Nations Convention on the Right of Persons with Disabilities 2006

DALY Disability adjusted life year

DFAT Australian Department of Foreign Affairs and Trade

ECLAC Economic Commission for Latin America and the Caribbean

ENDIS *Encuesta Nacional de Discapacidad* (2016 Guatemala National Disability Study)

ENPEVI *Encuesta Nacional de Percepción de Seguridad Pública y Victimización* (2018 Guatemalan National Crime Victimisation Survey)

GBD Global Burden of Disease study of the World Health Organization

GDP Gross Domestic Product

HEUNI European Union Institute for Crime Prevention and Control

HREC Human Research Ethics Committee

IADB Inter-American Development Bank

IANSA International Action Network on Small Arms

ICED International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine

ICESCR International Covenant on Economic, Social and Cultural Rights 1966

ICF International Classification of Functioning, Disability and Health (World Health Organization)

ICG International Crisis Group

IGSS *Instituto Guatemalteco de Seguro Social* (Guatemalan Social Security Institute)

IHME Institute for Health Metrics and Evaluation

ILO International Labour Organization

INE *Instituto Nacional de Estadística Guatemala* (Guatemalan National Statistics Institute)

LB *Latino Barómetro* (Latin American Democracy Barometer)

LILACS Latin American and Caribbean Literature in Health Sciences

MMW Minimum monthly wage

MP *Ministerio Público* (Guatemalan Attorney General's Department)

MS-13 *Mara Salvatrucha* (Criminal gang originating in Los Angeles, US, in 1970s and 1980s)

MSPAS Ministerio de Salud Pública y Asistencia Social (Guatemalan Ministry of Health)

MTPS *Ministerio de Trabajo y Previsión Social* (Ministry of Work and Social Planning)

MVA Motor vehicle accidents

NGO Non-government organisation

NTSCI Non-traumatic spinal cord injury

OAV *Oficina de Atención a la Víctima* **(**Office of Victim Support, Guatemalan Ministry of Justice)

PCF Participant Consent Form

PDH *Procurador de los Derechos Humanos* (Office of the Human Rights Advocate)

PIS Participant Information Statement

PNC *Policía Nacional Civil* (Guatemalan National Police)

PTSD Post-traumatic stress disorder

Q *Quetzal* (the currency of Guatemala)

SAS Small Arms Survey

SCI Spinal cord injury

SGV Surviving Gun Violence Project

SOSEP *Secretaría de Obras Sociales de la Esposa del Presidente* (Social Work Office, a Guatemalan government agency)

TSCI Traumatic spinal cord injury

TSI Traumatic spinal injury

UN United Nations

UK United Kingdom of Great Britain and Northern Ireland

UNDP United Nations Development Program

UNGA United Nations General Assembly

UNHCR United Nations High Commissioner for Human Rights

UNICEF United Nations Children's Fund

UNODC United Nations Office of Drugs and Crime

US United States of America

UTI Urinary Tract Infection

WHO World Health Organization

YLD Years Lived with Disability

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Chapter 1 Introduction

This is a story about gun violence in Guatemala, one of the world's lowest ranking countries in terms of human development but one of the highest in violence. Gun violence in Guatemala is usually measured in homicides, with gunshots claiming 3000-4000 lives each year. However, that figure only represents around half of the people who are shot. For every Guatemalan who dies by gunshot, another is wounded but survives because the bullet missed a vital organ, the distance to hospital was short, or just out of sheer luck. No information is available on those survivors. The present study set out to fill part of this knowledge gap.

This chapter outlines the background to the research, identifies the research problem, states the aim and the research question, and briefly describes the research design. Lastly it recounts the motivation for the study and comments on its significance.

1.1 Background

Guatemala is one of the world's poorest countries in terms of human development (UNDP 2019a) and inequality (World Bank 2019a). Nearly 60% of the population lives below the poverty line of US$3.20/ day (Banco de Guatemala 2019a). There is no general disability pension or unemployment benefit, and no crime victim compensation. Governance and public services are undermined by corruption and organised crime, and impunity is rife, with 90% of homicides going unpunished (CICIG 2019). The underfunded health system is, by the government's own admission, in crisis (MSPAS 2016). Added into this volatile environment are large quantities of guns and very active criminal gangs (World Bank 2010), resulting in one of the world's highest homicide rates. Guatemala is one of six countries that together account for 50% of all the world's gun deaths (Naghavi et al 2018).

In discussions about gun violence, the focus on counting the dead tends to overshadow the fact that many people are shot and survive. As with any form of injury, only the most severe cases end in death. No information is available on the number or severity of non-fatal firearm injuries occurring each year in Guatemala. However, the NGO wheelchair provider Transitions reports that, among adults, the single most common reason for needing a wheelchair is spinal cord injury (SCI) as a result of a gunshot wound. This suggests that gun violence is a major cause of SCI, at least among poor Guatemalans seeking a wheelchair from a charity; and in turn raises the question: if large numbers of Guatemalans are incurring SCI by gunshot, what are their lives like?

Conditions for people with disabilities in Guatemala are challenging. The country has ratified the Convention on the Rights of People with Disabilities (CRPD), but the UN Committee on the CRPD has criticised the failure to implement the Convention (Committee on the Rights of Persons with Disabilities 2016). Almost one-third of households include at least one person with a disability, according to the 2016 ENDIS national disability study (ICED 2017). ENDIS found that people with disabilities have more serious health problems

and more difficulty in finding work than their non-disabled counterparts, especially if they have significant physical functional limitations such as SCI. Two thirds of people who need a wheelchair do not have one (ICED 2017).

1.2 Statement of the problem

No scholarly research, whether quantitative or qualitative, has been published on people who survive gunshot wounds in Guatemala. In fact, very little is available anywhere in the world. Although violence is ranked by the World Health Organization (WHO) as the third leading cause of spinal cord injury (Bickenbach 2013), it is barely mentioned in global reviews of SCI research (Kumar et al 2018; Rahimi-Movaghar et al 2013; Jazayeri et al 2015; Singh et al 2014). This is likely because the global reviews tend not to include Latin America, where gun violence is most concentrated, according to WHO's Global Burden of Disease (GBD) study published by the Institute for Health Metrics and Evaluation (IHME 2017). The only Latin American country included in global reviews is Brazil, where gunshot is said to cause 27-37% of SCI (Cripps et al 2011).

The qualitative published research on the experience of people who have survived being shot is mostly limited to studies of current or former gang members in the US (Hoffman 2004; Kroll et al 2003; Patton et al 2019, Ostrander 2008). This context is very different from Guatemala.

1.3 Aim and research question

The aim of the study was to understand the lived experience of Guatemalans who have been shot and survived with a spinal cord injury. A gunshot (or several) can force dramatic changes in a person's life, transforming them into a crime victim, a person with a disability, an unemployed person, sometimes an isolated person who cannot leave their home. In principle, they should turn for support to institutions of the state, but government institutions in Guatemala are inadequate and mistrusted. The study sought not only to describe the problems confronting gun violence survivors, but also their solutions, sources of support and processes of transformation and adaptation.

The research question is: What are the health, human rights, economic and social consequences for Guatemalans who acquire spinal cord injuries by gunshot?

1.4 Research design

In order to gain a deep understanding of the survivors' experience, the study took a qualitative approach, based on semi-structured interviews and thematic content analysis. Potential candidates for participation were selected from the database of people who have received wheelchairs from Transitions (convenience sampling), However, the selection was also purposive in that only adults with a spinal cord injury from gunshots, living within two hours by car from Antigua, were chosen as potential participants.

Participants were interviewed not only about what had happened, but also how they felt about events or what those events meant to them. The questions covered domains such as family, use of government services,

hospital admission and coming home. Their answers to interview questions were generally lengthy stretches of narrative. These were analysed in terms of six themes: hospital and health, justice, economic impact, family, religious faith and disability identity and wellbeing. The findings are presented as thematic chapters, with the life story of each participant included in the Appendices.

1.5 Motivation

This study arises from my involvement with NGO projects related to gun violence over many years. I have been working on prevention for nearly three decades;[1] and in 2011, as part of the Surviving Gun Violence Project (SGV), I began to focus on people who have been shot and survived, often with severe disabilities. I visited Guatemala and El Salvador to interview survivors for SGV's book (Buchanan 2014). This ground-breaking publication is the first attempt to pull together knowledge and ideas on non-fatal gun violence from multiple thematic and geographic perspectives. My chapter outlined some of the health and economic challenges faced by survivors in Guatemala and described the minimal support services available to them.

I subsequently returned several times to visit Asociación Transiciones, a Guatemalan wheelchair NGO whose work involves many survivors. Transiciones (known in English as Transitions) is both a disabled people's organisation (DPO) and a disability service provider. Its staff, who are wheelchairs users themselves, manufacture over 300 wheelchairs each year at a small factory in Antigua Guatemala, about 1.5 hours' drive from the capital, Guatemala City. Transitions' clients are mainly poor people who would not otherwise be able to obtain a wheelchair.

The executive director of Transitions, Alex Gálvez, is a gunshot survivor with paraplegia whom I have known for 20 years through IANSA, the global civil society movement against gun violence. Our many conversations about engaging survivors in advocacy have helped me to understand more clearly how disability arises from the interaction of impairment with environmental and social barriers (WHO 2013). If people with SCI are overwhelmed by infections because of poor healthcare and lack of information, or if they cannot leave their homes because they have no wheelchair or their neighbourhood is not wheelchair-friendly, then attending a rally or an advocacy training session is not only impossible but unimaginable. The voices of survivors will not be heard in the movement against gun violence unless systemic barriers to participation are removed or at least eroded. As part of the effort to remove those barriers, I have been increasingly involved with Transitions since 2013, and began volunteering there in 2015.

As every good advocate knows, a vital tool for achieving change is information about the problem. The absence of information on gun violence survivors made it difficult to portray this as a policy or program gap, rather than simply a sad personal story for an individual like Alex. Frustration at the lack of information available on survivors in Guatemala (and elsewhere) eventually developed into a proposal for this study.

[1] My work in this area has been recognised with the Australian Human Rights medal and the Order of Australia (AO).

1.6 Significance

The significance of the research is that it begins to fill the information gaps about non-fatal gun violence and about spinal cord injury in Guatemala. The results also may be of interest in other developing countries, where generally there is very little research on the lived experience of people with SCI, even less on any aspect of non-fatal gun violence, and absolutely nothing on the interaction of the two topics.

My intention in undertaking the research was to generate information that could be used by advocates and campaigners. The results may be helpful for disability rights campaigners as well as policymakers and service providers in health and justice. The results should also give gun control advocates an additional argument to deploy as to the consequences of gun violence and why the proliferation of guns must be reined in. Painting a detailed picture of life with a severe disability, and all the ramifications this entails, can bring a new dimension to our discussions with policymakers and politicians. I hope that by making gun violence survivors visible, the study might also inspire other survivors to become involved in advocacy or activism.

In addition, the study provides a list of practical recommendations that would be helpful to gunshot survivors with SCI, others with SCI or other mobility impairments, and survivors of crime generally.

1.7 Overview of the thesis

The thesis contains 12 chapters, including six (Chapters 5–10) presenting the findings. The full profiles of the participants are in the Appendices.

Chapter 1 has introduced the rationale, purpose and significance of the study, as well as setting out the research question and briefly outlining the method.

Chapter 2 reviews the literature which informs and justifies my study. My research interest is situated at the intersection of three themes: living with spinal cord injury, non-fatal gun violence and Guatemala. This is unexplored territory in the scientific literature, but fortunately a modest amount of information is available from areas conceptually or geographically nearby. The chapter first reviews the quantitative literature touching on the role of gunshot as a cause of SCI globally and in Latin America. Next it considers qualitative studies on the lived experience of gunshot survivors, mainly involving former gang members in US rehabilitation centres. Lastly it summarises the two important investigations that have been conducted on disability in Guatemala.

Chapter 3 covers the study design and methodology. I chose a qualitative approach to gain a deep understanding of the personal experience of a small number of gunshot survivors with spinal cord injuries. The chapter outlines the development of interview questions, selection and recruitment, the interview process and data analysis based on thematic content. It explains the structure adopted for presentation of the findings: six chapters, each on a theme, with the life stories of the six participants included as Appendices. Reading the

Appendices is strongly recommended in order to appreciate the context of comments cited in the finding chapters. As a back-up, a profile paragraph on each participant is included in this chapter.

Chapter 4 provides background information on Guatemala and its challenges in terms of crime, poverty, the health care system and disability rights. Since Guatemala is the most religious country in Latin America, this dimension is also described.

Chapter 5 is the first of the six Findings chapters, each with a different thematic focus. The focus of Chapter 5 is Hospital and Health. It presents the participants' experiences in hospital and rehabilitation, finding out they had SCI, struggles with secondary health conditions such as pressure ulcers and urinary tract infections, and mental health.

Chapter 6 puts the focus on Justice, including interactions with law enforcement agencies, behaviour of the police, attitudes toward impunity and the stigma attached to gun violence victimisation.

Chapter 7 deals with the Economic Impact of acquiring a spinal cord injury by gunshot. The impact, which is felt by the entire family, includes reductions in household income as well as increases in costs.

Chapter 8 considers the Family dimension, including family as a source of support for people who acquire a spinal cord injury as well as the effect on couple relationships.

Chapter 9 explores the role of Religious Faith in the participants' lives. In the absence of legal justice, religious faith helps the survivors to come to terms with what has happened to them.

Chapter 10 is the final Findings chapter, with a focus on Disability Identity and Wellbeing. This chapter considers the participants' attitudes toward disability and experiences of discrimination, as well as analysing the factors that enabled one participant to declare that being a wheelchair user did not create any serious problems for her.

Chapter 11 discusses the findings in relation to previous research on surviving gun violence and living with SCI.

Chapter 12 contains brief conclusions and a list of recommendations to reduce barriers to inclusion for gunshot survivors with SCI in Guatemala.

Chapter 2 Literature Review

2.1 Gun violence as a cause of spinal cord injury

A literature search of PubMed, Google Scholar and the Latin American health sciences database LILACS was undertaken in English as well as Spanish and Portuguese, the dominant languages of Latin America. Since Latin America is the region with the highest concentration of gun deaths (Naghavi et al 2018), it seemed likely that researchers there might have studied non-fatal shootings too. Most articles in English on non-fatal gun violence are clinical studies on wound ballistics, surgical case reports, or analyses of injury patterns among gunshot patients admitted to US Emergency Departments. The articles in Spanish and Portuguese are overwhelmingly surgical studies, especially from military hospitals in Colombia and Mexico, plus some unpublished theses from medical and allied health sciences which are defined as grey literature.

The first section of this literature review considers a quantitative question: what proportion of spinal cord injuries are caused by gunshot; or the related question, how often does gun violence produce a spinal cord injury? Guatemalan health professionals maintain that gunshot is the primary cause of SCI, but information to confirm this is lacking. This review looks first at the global literature, then specifically at Guatemala, followed by literature from other countries in Latin America which, like Guatemala, have very high rates of homicide. (Some studies focus specifically on traumatic spinal cord injury (TSCI), as opposed to non-traumatic SCI (NTSCI) which is caused by diseases or tumours. Other studies consider spinal cord injury in general, without distinguishing between TSCI and NTSCI. Spinal cord injury by gunshot is traumatic SCI, but I did not restrict my search to the TSCI literature.)

The second section of the review considers the existing qualitative literature on the lived experience of people who have survived being shot, whether or not they have a spinal cord injury.

The third section is about disability generally in Guatemala.

2.1.1 SCI by gunshot in global reviews

The World Health Organization's (WHO) report on spinal cord injury (Bickenbach et al 2013) provides a comprehensive overview on SCI internationally, summarising the information available at that time on epidemiology, services, policies and interventions. The report ranks violence as the third leading cause of traumatic spinal cord injury (TSCI), behind motor vehicle accidents (MVA) and falls. The violence category includes gun violence and other types of assault, as well as self-inflicted injury and war.[2] WHO notes that the prevalence of TSCI caused by violence varies dramatically, from 60% in Afghanistan to 4% on average in Europe and 2% in Canada and Australia. After Afghanistan, the report identifies the countries with the highest

[2]The task of quantifying gun violence is complicated by the fact that it overlaps categories in WHO's ICD-10 injury classification system. Firearm injuries are mostly classified as violence (intentional self-harm, assault, legal interventions or operations of war), but some are categorised as accidents, and some as events of undetermined intent (WHO 2016).

prevalence rates as Brazil (42%), Turkey (25%) and South Africa (21%).[3] In relation to SCI caused by firearms, the report only mentions two locations: Sub-Saharan Africa, which is said to have the highest rate of violence-related SCI at 38% of all cases;[4] and the United States (US), where gunshot is said to account for 11% of all SCI, rising to 28% in some population groups.[5] No figures for Guatemala are provided in the report.

Despite WHO saying it is the third leading cause of TSCI, violence receives only passing mention in global systematic reviews of incidence or prevalence of spinal cord injury. This omission may be because such reviews tend to include little or no information from Latin America, the most violent region internationally as measured by homicide numbers and rates in the WHO's Global Burden of Disease (GBD) study published by the Institute for Health Metrics and Evaluation (IHME 2017). Brazil is the only Latin American country that appears in international reviews; its health system seems to have a data collection capacity that smaller countries lack.

The most recent global review by Kumar et al (2018) focussed on the larger category of traumatic spinal injury (TSI), of which around one-third are spinal cord injuries (SCI). The authors considered 102 studies in a systematic review and 19 studies in a meta-analysis, with articles from 32 mostly high-income countries. Violence as a cause of TSI was especially high in South Africa, Mexico, Brazil, and Botswana. Guns were not mentioned.

The systematic review of traumatic spinal cord injury (TSCI) in developing countries by Rahimi-Movaghar et al (2013) covered 64 studies from 28 countries. The authors note that Brazil and South Africa have high rates of SCI by violence, and that gunshot has taken over from stabbing as a cause of SCI in South Africa.

A global systematic review of TSCI by Jazayeri et al (2015) found 133 resources (articles, books etc) from 41 mainly high-income countries, and does not mention violence at all. Another global review by Singh et al (2014) includes no studies from Latin America or Africa, but mentions violence as causing 28% of SCI in Jordan and 21% in the Southern US state of Alabama.

A literature review by Cripps et al (2011) is the only one to make more than a brief reference to violence as a cause of TSCI. This study, part of a mapping project by the International Spinal Cord Society, reviewed 377

[3] The conclusions about the proportion of SCI caused by violence in these countries were reached on the basis of very limited information. The source for Afghanistan is a study by the ICRC based on two towns (Deconinck 2003); for Brazil it is a study of 106 paediatric SCI patients in one hospital over six years (Costacurta et al 2010), and for South Africa a study of 101 patients in one hospital over 1 year (Frielingsdorf & Dunn 2007). The average figure for Europe comes from a study of 380 patients in one Italian hospital over 18 years (Scivoletto et al 2011). This highlights the international shortcomings in data collection and the need for national SCI registers.

[4] Sub-Saharan Africa in this case refers to just two countries, South Africa and Zimbabwe.

[5] The information in WHO (2013) on SCI by gunshot in the US is somewhat confused. The studies cited (Devivo & Chen 2011, Devivo & Vogel 2004) are about SCI caused by violence in general, not specifically by gunshot. In fact the proportion of SCI caused by firearms in the US is 5-8% overall, and 14-18% in the age group 16-24 (Jain et al 2015).

records, including some unpublished material, giving preference to recent studies containing national statistics. The Cripps review found that violence causes 15% of SCI in the US (almost all of it by gunshot); and that unintentional gunshots cause 15% of SCI in Greenland (due to hunting accidents), and 26% in Jordan (due mainly to celebratory shooting in the air).[6] The only Latin American country included was again Brazil, where gunshot caused 27-37% of SCI. In South Africa 35-40% of SCI was caused by gunshot. This study was updated by Lee et al (2014), but the update contained no further insights on violence or gunshot as a cause of SCI.

The main conclusion to be drawn from the global reviews (as noted by the authors of all of them) is that more information is needed on SCI in developing countries. In the next section of this literature review, I gather together the modest amount of additional information available on gunshot and SCI in Latin America.

2.1.2 SCI by gunshot in Latin America

This section of the literature review begins with what is known about gunshot as a cause of disability or SCI in Guatemala. It then considers research from other countries which, like Guatemala, have very high rates of gun violence, or at least of firearm mortality.

According to the Global Burden of Disease (GBD) study, Guatemala's firearm mortality rate in 2016 was 32.3 deaths by gunshot per 100,000 inhabitants, or nearly 10 times the global age-standardised rate of 3.4/100,000 (IHME 2017). Countries considered to be quite violent have rates in the 7-12 range, such as South Africa (6.9), the US (10.6) or Iraq (11.1). However, a group of Latin American countries top the scale, with rates surpassing 19 gun deaths per 100,000, or 5.5 times the global rate. These countries include El Salvador (39.2) and Honduras (22.5) in Central America; and Brazil (19.4), Colombia (25.9) and Venezuela (38.7) in South America.

I have included these countries in my literature review because information is lacking on Guatemala; but countries that share some of its social and cultural characteristics (as well as its high firearms mortality) may have a similar injury profile to Guatemala. If gun violence is a major contributor to SCI in these countries, the same might be true in Guatemala.

None of these countries has a national SCI register, so the studies available are limited to a single city and often a single institution. Nor do any of the studies provide information on the circumstances of the shootings that led to disability, for example robberies vs domestic violence shootings.

[6] In relation to Jordan, Cripps et al (2011) cited the finding by Otom et al (1997) that 26% of SCI were caused by gunshots, nearly all unintentional. The global review by Singh et al (2014) cites the same Otom study, but attributes 28% of SCI in Jordan to 'violence'.

Guatemala

I have been told that gunshot is the primary cause of spinal cord injury in Guatemala by Dr Luis Gonzalez, head of physical medicine at the Von Ahn National Rehabilitation Hospital (Personal communication, 12 August 2015); and by Dr Sergio Castillo, head of traumatology at the Roosevelt General Hospital (Personal communication, 7 December 2011). However, no data have been published to confirm or disprove this claim. Mortality figures from the GBD study show that gunshot is the country's largest cause of fatal injury, outnumbering MVA, falls, industrial accidents and other causes of injury death (IHME 2017). It seems reasonable to assume that guns would also be a significant cause of serious non-fatal injury.

The only Guatemala reference to disability caused by guns is in an unpublished thesis by Rustrian (2018) involving people in the social security system or IGSS. (See Chapter 4 – Guatemalan Context for a description of IGSS, which provides healthcare and some welfare benefits to 18% of the workforce.[7]) For her master's degree in medicine, Rustrian sought to quantify the role of violence in the impairments of 286 people who applied for an IGSS disability pension during two months in 2017. Through analysis of case files, she found that 34 applicants had a spinal cord injury, and 16 of these (47%) were caused by violence. Violence had also caused 41% of lower limb amputations, 31% of "loss of lower limb function", 21 % of visual impairments, and 14% of traumatic brain injuries. Of all the impairments caused by violence, 51% were from gunshots.

El Salvador

No published research is available on the causes of spinal cord injury or the outcomes of shootings in El Salvador.

Honduras

Chang and Zelaya (2007) conducted a prospective, descriptive study of 46 people with SCI referred to a rehabilitation centre in the Honduran capital, Tegucigalpa, over 13 months in 2005-2006. The age range was 7 to 78 (mean age 35), 80% of participants were male, and 80% came from urban areas. Of the 46 cases, 67% were traumatic SCI and 33% were non-traumatic. Gunshot was found to be the cause of 58% of TSCI and 39% of total SCI, well ahead of the second cause, falls.

Another Honduran study, by Yacoub et al (2006), used patient records from Tegucigalpa's only public Emergency Department to study all 1592 patients admitted for injuries (intentional or unintentional) during the year 2001. Gunshot wounds accounted for a remarkable 40% of all admissions. Of all the patients with permanent "sequelae", namely loss of an organ or limb or SCI, 69% had been shot.

[7] IGSS beneficiaries are mainly people who work for large companies and government departments, so they are much better off economically than the population as a whole. Gun violence in Guatemala is concentrated in poor neighbourhoods, so people with IGSS would tend to be less likely to be shot than people who are less well off.

Brazil

Several studies on spinal cord injury come from Brazil, the largest country in Latin America (population 209 million) and the country with the most gun deaths in the world: 43,000 in 2016 (IHME 2017).

In the city of Sao Paulo, Blanes et al (2009) profiled 52 men and eight women who had lived with traumatic SCI for between six months and 17 years. A questionnaire assessing clinical and sociodemographic characteristics revealed that gunshot was the cause of SCI in 63% of participants, followed by MVA (20%).

Also in Sao Paulo, Costacurta et al (2010) analysed clinical records on 196 children with SCI (under age 16, 63% boys) admitted to a rehabilitation centre between 2002 and 2008. Gunshot was the largest single cause, accounting for 43% of traumatic SCI and 22% of SCI overall, MVA (20% of overall) and tumours (18%).

In the city of Natal, which ranks fourth in the world for homicide rates (Seguridad, Justicia y Paz 2018), Coura et al (2013) studied self-care abilities by administering oral questionnaires to 73 adults with SCI (85% male, mean age 25, mean time since injury just under 13 years). Gunshot was the leading cause of their injuries, accounting for 48% of all SCI, ahead of MVA (19%).

Another study in Natal considered lifestyle and health conditions (eg smoking) in 47 adults (95% men) with SCI, using a questionnaire administered at home (Franca et al 2014). The leading case of SCI was gunshot (32%) followed by falls (28%).

These four studies in two Brazilian cities put gunshot first as a cause of SCI, but other studies rank it lower. Bellucci et al (2015) conducted a cross-sectional study of 348 people (85% male) with TSCI contacted via a rehabilitation centre in Sao Paulo in 2012, using a questionnaire and clinical evaluation of injury severity. Overall, gunshot was the third cause of SCI (21.5%), after MVA and falls.

A systematic review of 15 Brazilian studies (Botelho et al 2014) found substantial variation in SCI incidence and aetiology, depending on local social, geographic and architectural characteristics. For example, falls from rooftops predominate in cities where recreational areas are typically located on top of buildings. Gunshot as a cause ranged from 5% to 27% of spinal cord injuries. The review predated the two Natal studies cited here, but also did not include the two Sao Paulo studies I have cited. Notably the review was based on the LILAC database, which is less comprehensive than mainstream scientific databases. The authors concluded that the main causes of SCI in Brazil are motor vehicle accidents and falls.

Colombia

Certain cities in Colombia also see frequent spinal cord injuries by gunshot. In Cali, the country's most violent city, Angulo et al (2013) tracked the admission routes of all 30 adults arriving at the University Hospital with traumatic SCI during four months of 2007-2008. The main cause of injury was gunshot (43%) followed by MVA (33%).

In Medellin, a retrospective cohort study by Carvajal et al (2015) examined the records of all 68 people admitted to a tertiary hospital with SCI, finding that 57% were from gunshots and 32% from MVA.

Another study in Medellin evaluated an outpatient SCI program (Lugo et al 2007). Of the 42 patients who completed the 18-month program between 1999 and 2001, 62% had been shot, 14% had suffered falls and only 12% MVA.

In the smaller city of Manizales, Henao and Perez (2011) conducted a descriptive, correlational study of the health and functioning of 45 adults with SCI in 2009-2010. The participants came from hospitals, rehabilitation centres and disability organisations as well as private individuals. Gunshot was the cause of 44% of SCI, followed by MVA (20%)

Venezuela

The scientific literature contains one study on spinal cord injury in Venezuela. The cross-sectional study by Robles et al (2012) analysed medical records for 64 patients with traumatic SCI at rehabilitation centres in the state of Anzoátegui in 2008-2010. The main cause of injury was gunshot (50%) followed by MVA (27%).

Table 1 summarises the results related to firearm injuries in the studies cited above. These 13 studies from five countries suggest that gunshots may cause around 40% of spinal cord injuries in Latin American contexts severely affected by gun violence. This lends credence to the statement that gunshot is the primary cause of SCI in Guatemala.

Table 1: Gunshot as a cause of SCI in studies from high-homicide countries in Latin America

Authors	Country	Year	Sample	Gunshot as cause
Chang & Zelaya	Honduras	2007	46	58% of TSCI, 39% of all SCI
Yacoub et al	Honduras	2007	1592	40% of injury admissions to hospital, 69% of permanent impairments
Lugo et al	Colombia	2007	42	62% of all SCI
Blanes et al	Brazil	2009	60	63% of TSCI
Costacurta et al	Brazil	2010	196 children	43% of TSCI, 22% of all SCI
Henao & Perez	Colombia	2011	45	44% of all SCI
Robles et al	Venezuela	2012	64	50% of TSCI
Coura et al	Brazil	2013	73	48% of all SCI
Angulo et al	Colombia	2013	30	43% of TSCI
Carvajal et al	Colombia	2015	68	57% of all SCI
Bellucci et al	Brazil	2015	348	21.5% of TSCI
Franca et al	Brazil	2018	47	32% of all SCI
Rustrian (unpublished thesis)	Guatemala	2018	34	47% of SCI by violence

2.2 The experience of gun violence survivors

This section of the literature review examines the existing research on the experience of people who are shot and survive. It begins by considering what is known from Latin America, starting with Guatemala. It then moves to the US, home of most of the scientific literature on the topic.

2.2.1 Surviving gun violence in Latin America

The Latin American literature revealed one published study from Mexico. Alvarez and Sugiyama (2010) conducted in-depth interviews with two men (gunshot survivors) and two women (non-gunshot) who had lived with SCI for an average of four years. The published article focussed only on experiences in hospital. The participants reported a lack of compassion or sensitivity from hospital personnel who treated them "not as a person but as a pathology". The devastating announcement that they would never walk again was delivered without any information or advice about what they *would* be able to do. One doctor was recalled saying, "You're never going to get better, on the contrary, you're going to get worse and worse." Participants also complained about clinical standards, for example that nothing was done to prevent pressure ulcers in hospital.

The Brazilian grey literature contains an unpublished master's thesis in nursing by Bega (2017), based on semi-structured interviews with 23 people aged 23 to 58 who had lived with SCI between three and 33 years, including eight gunshot survivors (seven men and one woman). The participants were recruited through local health centres and the disabled sports association in the small southern city of Maringa. Eighteen of the 23 were living on disability or retirement pensions, since Brazil has a near-universal social security system. No comments about financial difficulties are cited in the study. The average family income was four minimum wages, and 18 of the 23 participants owned cars. No reference is made to experiences specific to the gunshot survivors as opposed to the other participants. However, the study offers insights on life with a spinal cord injury, including dismay caused by dependency; health problems such as pressure ulcers, urinary tract infections, pain and spasms; friends from pre-injury days drifting away; and strengthening bonds with family members. Sources of support were primarily family, followed by friends, God, the church and local health centres which provided incontinence supplies and medication, as well as support groups and other assistance.

The story of Wellington, a young Brazilian paralysed by a stray bullet in Rio de Janeiro, is included in the Surviving Gun Violence collection (Szabó & Viceconti 2014). His mother recounts how the family, having been given no instructions, became overwhelmed by the challenges of caring for a person with pressure ulcers and a colostomy. Wellington describes his frustration over his education and his plans for life being cut short. He also recalls the reaction of police, who suspected him of being a criminal rather than a victim. When he awoke in hospital, he found that he was handcuffed to the bed with a police officer standing over him.

Another study from the grey literature is by Amnesty International Venezuela, examining the impact of gun violence in a poor district of the capital, Caracas (Rangel & Santos 2011). The researchers interviewed four primary survivors (those wounded) as well as secondary survivors (family members) of nine people who had been shot dead. Both groups of survivors mentioned the stigma associated with gun violence: for example,

emergency department staff hanging back when a gunshot patient is brought in, out of fear that the patient may be a gang member. The families of those who died encountered the stigma in their dealings with police, coroners, and even undertakers who refused to do funerals for gunshot victims. The consequences of shootings included loss of household income, the risk of further attacks, and the need to restrain male family members from seeking revenge. However, the participants also reported community and family solidarity.

2.2.2 Surviving gun violence in the United States

The only scholarly research on the post-hospital experience of people with spinal cord injuries from gunshots is a handful of qualitative studies from the United States (US). In these studies, most of the participants were young men involved in large or small ways with illegal activity, as gang members, drug sellers or just "hustling on the street." A significant focus was on how being shot changed their relationship with criminal activity and criminal identity. The fact that the literature is limited to studies of gang members may both reflect and reinforce the link in the popular imagination between getting shot and being a criminal. This belief gives rise to the stigma reported by Wellington in Brazil (Szabó & Viceconti 2014) and by Venezuelan survivors (Rangel and Santos 2011). The context is very different in the present Guatemalan study, whose participants have no connection with criminal activity despite residing in dangerous neighbourhoods of Guatemala City.

Hoffman (2004) conducted a study over the period 1990-1999 at two hospital-based youth violence prevention programs, in Los Angeles and Boston. The study involved in-depth interviews, observation, continued dialogue, and case studies as well as journal entries and autobiographical statements by the 20 participants. These were young people from violent neighbourhoods (including some ex-gang members) who had been shot or stabbed, and who were considered at risk for further victimisation or perpetration of violence. All had previous hospital admissions for gunshot or other violent injuries, and half had a spinal cord injury from gunshot.

Hoffman's study sought to understand the pathways in and out of violence, ie what factors had led to becoming involved in violence and what factors had enabled or obstructed disengagement from it. Because violence was so normalised in gang members' lives, some participants had expected that sooner or later they would be shot and killed or left with a disability. On admission to hospital, some survivors had lied to the medical staff and police about what had occurred, because they distrusted the establishment and feared retaliation by their attackers. All had some knowledge of who was responsible for shooting them, but they saw the criminal justice system as corrupt and uncaring, so did not consider that the police might be of any assistance. However, they all encountered helpful health professionals, generally a social worker or counsellor, who helped them come to terms with what had happened. Many participants observed that being shot had a transformative effect on their lives, awakening a desire to be more responsible, improve their communities and protect other young people from violence. Despite the US being a wealthy country, they faced challenges on returning home to impoverished, violent neighbourhoods with inaccessible housing and transport, broken footpaths, high unemployment, and a lack of information about assistance or opportunities available.

An earlier study by Kroll et al (2003) was based on in-depth interviews at a rehabilitation centre in Washington DC with 22 male and three female gunshot survivors with SCI. The survivors were mostly African-Americans aged 20-40, and an unspecified proportion were involved in "street life". The study aimed to identify factors that hindered or facilitated coping with SCI, as well as the rehabilitative needs of survivors. Like Hoffman's subjects, some of these participants said being shot was a wake-up call to change their lives; but since their neighbourhoods were as violent as ever, they remained in danger. Their relationships with family were mostly unchanged, but as with Bega's (2017) Brazilian participants, friends from before had drifted away. Most of the survivors were in paid work before being shot, but none had a job afterwards except in hospital-based peer mentoring programs. The study concluded that the coping process involves a combination of personal, social, environmental and economic factors, and noted a lack of economic resources, vocational counselling, and community-based support for inclusion.

Another Chicago study of gunshot survivors with SCI (Ostrander 2008) is less relevant to the current Guatemalan research because the 11 African-American male participants were all perpetrators of violence before becoming victims. This study focussed on how being shot had affected their sense of self and identity. The participants did not want to integrate disability into their identity because they felt their image as men was diminished. Coming from the hypermasculine culture of gangs, and accustomed to dominating their environment, they found it difficult to accept becoming dependent on others. They were preoccupied with what they had lost, rather than adjusting to their new life.

The most recent study involved in-depth interviews with nine male and one female African American gunshot patients, including an unspecified number with spinal cord injuries, at a trauma centre in Chicago (Patton et al 2019). The study focused on experiences in hospital and immediately after discharge. Concerns expressed by participants included: feeling stigmatised in hospital because of stereotyping of gunshot victims; staff being too busy to pay attention or provide information; being unable to afford pain medication after discharge; excessive questioning and suspicion toward them by police; transport difficulties for wheelchair users in returning to hospital for follow up appointments or rehabilitation; anxiety about being attacked again; and the absence of counselling or mental health support for themselves and their families.

In summary, the limited literature on the lived experience of gunshot survivors from Latin America and the US paints a picture that varies with context. However, some recurring elements include suspicion toward survivors by health workers and police, mistrust of authorities by the survivors, loss of independence, physical pain, inaccessible transport and environments, and economic pressure. These concerns transcend the divide between developing countries and the highly developed United States.

2.2.3 The health professionals' perspective

In addition to the articles on survivors' experience, the US scientific literature contains two studies on the views of rehabilitation staff toward people who acquired SCI by gunshot. Devlieger and Balcazar (2010) conducted semi-structured interviews with 16 professionals in Washington DC and Chicago. They noted that

the health staff were highly professional and strongly focussed on their patients achieving bodily self-sufficiency (eg bowel and bladder control). However, they tended to see gunshot survivors differently from other SCI patients. The (mostly white) staff perceived a wide cultural gap between themselves and gunshot survivors, who were mainly minorities coming from environments characterised by poverty and danger, where people live day-by-day rather than following plans, therapeutic or otherwise. The authors observed that this cultural difference may manifest as mistrust of hospital staff by survivors and non-compliance with the rehabilitation regime. They noted that this in turn can affect the attitudes of staff, who may have lower expectations of what gunshot survivors can achieve in rehabilitation; and may tolerate the development of secondary complications in order to teach the survivor to take more responsibility for their health.

In the study by Kroll (2008), 11 health professionals were interviewed about obstacles to rehabilitation for gunshot survivors at a large rehabilitation centre in Washington DC. Compared with other SCI patients, gunshot survivors were believed by health professionals to have less support at home, less access to services and to be less able to pay for necessities such as modifications to make their homes wheelchair accessible. As a result, many young survivors end up living in nursing homes. In addition, the lack of coordination with community services, lack of trust and lack of staff understanding of the survivors' home environments were seen as undermining rehabilitation, discharge and transition back to the community.

Both these studies indicate that the gunshot survivors' mistrust of authority is recognised by health workers. The cultural gap described by Devlieger and Balcazar may contribute to the stigma perceived by survivors. The health workers interviewed did not say that they assumed gunshot survivors to be criminals and therefore less deserving of conscientious care than other SCI patients. However, they admitted that the survivors' chaotic home environments (which could be a proxy for "criminal") affected their treatment.

A limitation of the US survivor studies is that they have a narrow focus either thematically (eg gang membership) or in terms of time (eg hospital admission and shortly after discharge). Thus they do not cover the broader experience of living daily with SCI, or the evolution of the survivors' thinking over years. Typically, excerpts from interviews are only aggregated under thematic headings, so it is difficult to get a sense of each person's life circumstances before and after their injury. Also, since the participants were recruited through rehabilitation centres, most had lived with SCI for only a few years. On the other hand, the Brazilian study by Bega (2017) describes life with SCI more fully but does not address the particularities of gunshot survivors at all.

2.3 Disability in Guatemala

No information is available on the number of people with spinal cord injuries in Guatemala, much less the proportion of those injuries that are caused by gun violence. Attempts to measure the prevalence of disability have evolved since the 1994 general census, which asked respondents whether they were blind, deaf, deaf-mute, mentally retarded or had impairments in one or more limbs or in "the whole body". On this basis, 1% of the population was estimated to have a disability (INE 1996). The 2002 census used similar questions, but

inquired about disability in the section on households, rather than individual characteristics. Thus 7% of households were estimated to include someone with a disability (INE 2003).

In 2005 the Inter-American Development Bank funded the first national survey on disability. This survey continued to ask respondents whether they had specific disabilities, but framed the results as a mixture of functional (eg visual, auditory) and biological (eg musculoskeletal, neurological) categories. Importantly, this survey also addressed access to health services, use of assistive devices, educational attainment, employment, income, and types of housing. The 2005 disability prevalence was estimated at 4.2% (INE 2005).

In 2016 the second national disability survey, known as ENDIS, was carried out by the International Centre for Evidence in Disability at the London School of Hygiene and Tropical Medicine, in conjunction with Guatemala's National Council on Support for People with Disabilities or CONADI (ICED 2017).[8] Instead of asking respondents to identify as having a specific disability, ENDIS adopted the WHO International Classification of Functioning, Disability and Health (ICF). This conceptual framework recognises that disability is not simply a biological impairment. Rather it arises from the interaction of impairment with environmental and social barriers, resulting in limitations on activities and restrictions on societal participation, and depending heavily on the environmental and individual context (WHO 2013).

The ENDIS survey had both quantitative and qualitative elements: a population-based survey to estimate disability prevalence; a case-control study to compare the experience of people with and without disability on socio-economic, health and other variables; and a qualitative study of disability and poverty in rural areas.

The survey team assessed 13,073 people living in 3095 households across the country, using the Washington Group Extended Question Set on Functioning, which are guided by the ICF. These questions are based on the functional domains of seeing, hearing, walking, upper body strength, communication, cognition, self-care, depression and anxiety, eg "Do you have difficulty walking 100 meters on level ground …?" (Washington Group on Disability Statistics 2011). In the Guatemalan survey, any respondent reporting difficulty was also screened clinically in the relevant domain.

On this basis, ENDIS estimated that 10.2% of Guatemalans have a disability (ICED 2017). This is twice the rate in the 2005 survey, confirming Mont's (2007) observation that surveys based on the functional approach yield much higher prevalence than those asking people to adopt the often-stigmatised disability identity. Nearly 31% of households contained a person with a disability. The most common significant limitations were in the domains of anxiety and depression (reported by 9.3% of adults with disabilities) and mobility (reported by 8%). Around 3% of people with disabilities said they used a wheelchair, and twice that number said they needed a wheelchair but did not have one. Awareness of rehabilitation services was relatively low. Around 7% of disabilities were caused by violence and a further 1% by war, but these were not disaggregated by

[8] ENDIS was funded by UNICEF and CBM, the international disability NGO.

functional domain. Compared with the general population, people with disabilities were significantly more likely to be poorer, less educated, older, female and unmarried.

In the case control study, 707 people identified as having a disability were age- and sex-matched with 467 controls (among older respondents, cases outnumbered controls). Interviews revealed that adults with disabilities had less stable livelihood opportunities and were significantly less likely to have worked in the previous week (23%), compared to adults without disabilities (47%). The likelihood of work was particularly low among people with significant physical functional limitations (for example, mobility). Compared with controls, people with disabilities had poorer quality of life scores, were more likely to have serious health problems, were more likely to report being disrespected in health facilities; and had more difficulty understanding health information (ICED 2017).

The qualitative study for ENDIS was undertaken by social science researcher Shaun Grech, who interviewed 27 adults in four rural areas, exploring their perspectives on disability and the social, political, and economic dimensions (Grech 2016). The respondents told stories of hardship caused by structural inequality, deprivation, isolation and infrastructural barriers. However, they did not always encounter "systematic stigmatisation of disabled people," and some noted that others' attitudes became more positive over time.

Grech is also the author of the only book on disability in Guatemala, an ethnographic study based on interviews over the course of 11 years with 80 people living with a range of physical, sensory and intellectual disabilities in poor rural communities (Grech 2015).[9] The participants included an unspecified number of people with spinal cord injuries and at least one gunshot survivor. The author draws on the participants' narratives about their health, work and families, as well as their experiences of using health and other services. However, its broad approach, encompassing all types of disabilities, precludes identifying the particularities of a specific group such as people with SCI by gunshot. The focus on rural communities means that disability from gunshots does not feature prominently, since gun violence is concentrated in urban areas and especially in Guatemala City, where 40% of all shootings occur (Viceministerio de Prevención de la Violencia y el Delito 2019a).

2.4 Conclusion

Gun violence occurs on a spectrum. A few millimetres or a few minutes is all that differentiates a homicide victim from a survivor with a serious disability. Yet homicide is the subject of many thousands of studies and reports (not to mention novels and films), while non-fatal shootings have received barely any attention from the research, policy or advocacy communities (Buchanan 2014).

[9] Grech also interviewed 35 family members, 27 other community members and 35 other informants including health workers, government officials and NGO representatives.

One reason for the dearth of research on the experience of survivors may be that no one knows the extent or nature of the phenomenon of non-fatal gun violence. Are there many survivors or not? What proportion are left with a serious impairment? What are the circumstances of their shootings? In the absence of quantitative data to identify the size, location or characteristics of the population affected, it is perhaps understandable that researchers have not recognised this as an area of investigation.

The US research on gang members, and the Guatemalan research on people with disabilities in rural areas, provide clues that may resonate with the participants in the current study. However, unlike the Americans, the participants in my study have no criminal connections and no disability benefit to fall back on. Unlike their compatriots in distant rural villages, these participants live in urban areas where violence is rife, but government services are concentrated, so that in principle they should have access to the facilities and support they need.

To date there has been no exploration of the experience of ordinary people who survive being shot with a serious disability in Guatemala or other countries in the world's most violent region. To the best of my knowledge, this study is the first step toward filling that information gap. The next chapter outlines the method I used for my qualitative study.

Chapter 3 Method

3.1 Introduction

This study investigates the under-researched phenomenon of non-fatal gun violence resulting in spinal cord injury. The research question was: What are the health, human rights, economic and social consequences for Guatemalans with SCI caused by gunshot? Importantly, the study sought not only to describe the problems confronting gun violence survivors, but also their solutions, sources of support and processes of transformation and adaptation – all aspects of human experience that are best described qualitatively.

In this chapter I outline the methodological approach taken to examine this research question. I describe my choice to use qualitative methods in order to gain a deep understanding of the personal experience of a small number of gunshot survivors with SCI. I then describe how the data collection and analysis were carried out, through semi-structured interviews and thematic content analysis.

A note on terminology: In general usage, the term 'survivor' is often applied to both primary survivors who have been shot, and secondary survivors who have been traumatised, for example the family members of a person who has been shot dead. In this study, survivors are people who have been shot.

3.2 Research setting

The phrase 'survivors of gun violence' covers a wide range of individuals who have been shot, from people suffering superficial flesh wounds to those who acquire a significant spinal cord or brain injury. The delineation of the participant population for this study (survivors with paraplegia) was influenced by my circumstances as a volunteer with Asociación Transiciones, also known by the English name Transitions, as a disability organisation in the town of Antigua Guatemala.

There is no public provision of wheelchairs in Guatemala, and as noted earlier, the National Disability Survey revealed that most people who need a wheelchair do not have one (ICED 2017). The lack of a wheelchair can condemn a person to years of isolation at home; or they may save up to buy a hospital-style transport chair which is not suitable for independent living. Transitions helps to fill this gap by manufacturing robust, high-quality wheelchairs that are suitable for Guatemalan conditions and personalised to suit each user's needs and abilities. The factory crew is made up of wheelchair users affected by SCI, polio or other disabling conditions, and the executive director is a gunshot survivor with paraplegia. Each year Transitions serves about 350 clients, mostly poor people who make a token payment. However, the quality of the wheelchairs also attracts affluent clients from Guatemala's upper classes, who pay up to US$450 for a chair. Among adult clients, the most common reason for needing a wheelchair is a spinal cord injury caused by gunshot; while among children it is cerebral palsy. Thus the database of wheelchair recipients contains contact details of many gun violence survivors with SCI. The availability of this pool of potential participants led to the research focus being defined specifically on gunshot survivors with paraplegia. (Transitions sees far fewer gunshot survivors

with quadriplegia, because the NGO makes manual wheelchairs designed for users who can propel themselves.) Transitions facilitated the study by recruiting participants from its database.

I have been volunteering with Transitions since 2015, having known the organisation and its executive director Alex Gálvez for many years. Alex, a gunshot survivor with paraplegia, brought Transitions into the International Action Network on Small Arms (IANSA), when I was IANSA's director.

3.3 Qualitative methods

As previously mentioned, Guatemala has one of the highest homicide rates on earth (IHME 2017), but basic epidemiological data are lacking on the number of people who are shot and survive, or the nature and distribution of their injuries. Even if that quantitative information were available, it would not help in understanding the experiences of survivors of gun violence who live with SCI. A qualitative approach, based on interviews, was anticipated to enable a broader exploration, not only of the physical consequences of gunshots, but also the social, emotional and economic impacts on people whose bodies are damaged by bullets, in their specific context and over time (Marshall & Rossman 2011).

For that reason a qualitative research design was chosen to explore the experiences of survivors of gun violence in Guatemala.

3.3.1 Semi-structured interviews

The qualitative research design relies on semi-structured interviews to discover each participant's lived experience of being a gunshot survivor with a spinal cord injury – eliciting not only the facts of but also their meaning (Kvale 2007). Interviews accommodate the telling of complex life stories in the participants' own words, in a way that survey questions do not (Riessman 2008). Interviews were chosen over focus groups because topics like violence and incontinence might be too sensitive for participants to discuss in a group, and because of the logistical difficulties of trying to gather the participants in one place. The interviews were conducted in Spanish, using an interview schedule as a guide but diverging from it, either slightly (via probe questions) or significantly (when participants shifted topics in the course of their answers). Semi-structured interviews accommodate such diversions in a way that structured interviews do not, and are thus a suitable method for understanding in-depth experiences (Minichiello et al 2008). Most of the participants gave lengthy answers, often complete with back-story, so that their interviews lasted over an hour and came to resemble narrative accounts.

In one case additional information was provided informally to supplement the interview. One participant, Kimberly (all participants agreed to be identified by their real first names), was unable to answer questions about household income and expenditure before she was shot, since she was only 12 years old at the time. Her mother, who had accompanied her to Transitions on the day of the interview, provided this information informally afterwards.

3.3.2 Development of interview questions

The aim of the interviews was to generate a detailed picture of life for people in poor neighbourhoods of Guatemala City who have been shot and survived with a spinal cord injury. The study sought to understand the experiences of survivors including the challenges they faced, their sources of support and strategies for overcoming challenges, and how they felt about their present situation and the future.

The interview schedule (included in Appendix I and described briefly below) began chronologically and then proceeded thematically. The early chronological sections, beginning by asking about life before being shot, were chosen to enable the participants to tell their stories rather than simply answering questions, establishing rapport and trust in the interviewing process (Minichiello et al 2008).

Reminiscence helped to put the participants at ease in this very personal conversation with a stranger. The historical line of questioning illuminated the family background, dynamics and factors that influenced each participant's personality and decisions. Painting a picture of the life that was interrupted by gun violence provided the context which is crucial to understanding the phenomenon under study.

- Section 1 contains basic demographics and factual questions on family composition, occupation, and area of residence.
- Section 2 begins, "Tell me about your life before you were shot, where did you grow up?" This section elicited information and memories of childhood and young adulthood.
- Section 3 begins, "Tell me about the day when you were shot," including questions about what they saw, heard and felt.
- Section 4 is the aftermath, including what participants remembered about the trip to hospital.
- Section 5 is the hospital experience, including, as far as they knew, what injuries they had and what treatment they received; conditions in hospital, and what they understood about their SCI.
- Section 6 deals with homecoming: hospital discharge, the trip back home and how it felt to be back. This section also asks how the participants obtained their first wheelchair.

After the chronological section came a change of pace with the Washington Group Extended Set of Questions on Functioning[10] (Washington Group on Disability Statistics 2011), which are designed to estimate disability prevalence and provide comparable data for disability studies in different countries. I included this following the example of the National Disability Survey ENDIS, and because severity of impairment could impact

[10] Available at http://www.washingtongroup-disability.com/washington-group-question-sets/extended-set-of-disability-questions/. The questions use the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) as a conceptual model.

responses in other sections. The questions can be completed in writing, but all participants preferred to be asked verbally, with me recording their answers.

- Section 7 was the Washington Group Questions. I then asked how their level of functioning had changed since being injured, followed by questions about their experience of rehabilitation.

The thematic sections of the interview schedule were chosen based on my knowledge of important aspects of life in Guatemala, my previous experience of interviewing survivors (Peters 2014), and my observations of the daily lives of survivors who are members of Transitions; as well as on the small number of studies in the international literature which deal with living with a spinal cord injury discussed in Section 2.2, Chapter 2. For example, experience with police is a key topic for crime victims (Patton et al 2019), as is disability for people with spinal cord injuries (Kroll 2003; Bega 2017; Clifton et al 2018).

- Section 8 asks about the participants' health before they were injured and now, whether they have had health problems secondary to their SCI and how they manage those problems; questions about mental health and mental health support.
- Section 9 deals with family, relationships, household roles and activities, any how these may have change after the shooting. It also covers financial questions on household income and expenditure.
- Section 10 covers the impact on education and work, the experience of looking for work, and what would make it possible to get a job or continue with education.
- Section 11 asks about experience of any government or non-government services and other sources of potential or actual support.
- Section 12 focuses on the legal system, including interactions with police and what they know about the legal disposition of their case.
- Section 13 is about religious belief, whether faith helps them to understand their shooting and whether their faith has changed over time.
- Section 14 covers identity, how the participants see themselves and how they believe others see them, whether they know other people with disabilities, experiences of discrimination, whether they have ever felt that it was better to lie about how they acquired a spinal cord injury, and finally hopes and ambitions for the future.

3.3.3 Data Collection

To answer my research question, I needed to interview Guatemalans who had acquired a spinal cord injury as a result of being shot. I discussed the study with Alex Gálvez, who was keen to lend the organisation's support. He felt the study could provide insights to benefit not only gunshot survivors, but also the broader population of Guatemalans with a range of mobility impairments represented by the clients who come to Transitions for wheelchairs.

3.3.4 Ethics

Ethics approval No 2017/803 was gained from the University of Sydney Human Research Ethics Committee (HREC) on 27 November 2017, subject to special conditions (Appendix H). These related to certified translation of the Participant Information Statement (PIS) and Participant Consent Form (PCF), explanation in the PIS and PCF of the possibility of the study results being used for public awareness, and acknowledgement by the Head of School of the degree of risk involved in travelling to Guatemala. During the ethics application process a Safety Protocol was developed to minimise the risks in conducting research in a country where DFAT's travel advice is generally Yellow: Exercise a high degree of caution. The Safety Protocol involved providing the University with my emergency contacts in Guatemala, agreeing to conduct all interviews in the Transitions offices, explaining the conditions in the town of Antigua, maintaining close contact with my supervisor and registering with the Australian embassy in Mexico, which covers Guatemala.

The PIS and PCF were developed to ensure that participants understood and felt comfortable with the study purpose and process. The Ethics Committee was concerned about potential vulnerability of the participants in relation to a foreign interviewer. To manage any imbalance of power, initial contact was made by a Transitions staff member who is also a gunshot survivor with paraplegia (see below); and the PIS stated that I was not in a position to influence, either positively or negatively, the respondents' relationship with Transitions or any other aspect of their lives, and that their responses would not affect the services they may receive in the future from Transitions. The PCF asked participants to specify whether they would be happy to be identified by their first name or remain anonymous, and whether they would be happy for their stories and/or photos to be used later in materials for public awareness. The English versions of the PIS and PCF are included in Appendices J and K.

The Ethics Committee did not require the use of a translator for the interviews, because I am fully bilingual and very familiar with local Guatemalan social norms and customs. The main cultural divide I anticipated between the participants and myself was that they were likely to be religious, whereas I am not religious at all. However, I am respectful of other people's beliefs and living in such a religious society has given me a good understanding of the predominantly Christian beliefs which strongly influence Guatemalan society.

There were no anticipated longer-term risks to the survivors participating in this study. Allowing for the possibility that participants might feel distress or discomfort when talking about their violent victimisation, the PIS included the contact details of a clinical psychologist who had agreed to speak to them if they desired. They were informed that there would be no benefit to them personally from participating, but that there could be a public benefit in the possibility that the study results may help to secure better services for people with spinal cord injuries and greater understanding of the challenges facing people who have been shot.

3.4 Selection and recruitment

Recruitment was conducted via Transitions. Candidates were selected from the database of people who had received a manual wheelchair from Transitions since records began being kept in 2014.

Potential participants were people aged over 18 who had paraplegia as a result of a gunshot injury and were living within roughly a two-hour drive from Antigua, which would encompass the far reaches of the capital, Guatemala City. I knew that most candidates would be men, reflecting the predominance of males among shooting victims in Guatemala (Viceministerio de Prevención de la Violencia y el Delito 2019a) and in the world (IHME 2017).) I expected that most candidates would be in the capital, since it has by far the highest concentration of gun violence – with only 20% of the country's population, it sees nearly 40% of gun homicides. Guatemala City is also the location of around half of all Transitions clients.[11]

In addition, I was hoping for a degree of diversity among the candidates in terms of circumstances of shooting (eg domestic violence, gang shooting), as well as length of time since being shot.

About 25 potential candidates were initially identified, but around half were unable to be contacted. This was to be expected, because phone numbers in Guatemala are constantly changing, due to phone extortion, theft of mobile phones or discontinuation due to failure to maintain a credit balance. In some cases contact was made via Facebook.

To avoid any possibility of the survivors feeling intimidated into participation by a foreigner, the Transitions receptionist served as the channel of communication for potential participants. He made the initial contact by telephone, using a script which I provided to explain the research. He rang each potential participant, explained the project, answered any questions and invited them to participate. I also provided a written invitation, Participant Information Sheet (PIS) and Participant Consent Forum (PCF). If a candidate expressed interest in participating, the receptionist went through these documents on the phone with them. Most of the participants do not have email, so they received the actual documents when they came to Transitions to be interviewed.

Eight candidates agreed to take part in the study, but logistical and family difficulties prevented two them travelling to Antigua. Descriptions of all participants are provided at the end of this chapter.

The first phase of the selection process involved convenience sampling, with selection being made from the database of people who have received wheelchairs from Transitions. However, the selection was also purposive in that only adults with a spinal cord injury from gunshots, living within two hours by car from Antigua, were chosen as potential participants. I did end up with diversity in relation to types of shooting and time since shooting, but this was by chance rather than by selection. Two of my participants have lived with paraplegia more than half their lives, enabling them to reflect on the evolution of their attitudes, understanding and capacities over time.

[11] The location of Transitions in Antigua came about because Alex Gálvez and his colleagues who set up the organisation in the 1990 had met through the Catholic charity hospital in Antigua where they were all long-term patients.

Convenience and purposive sampling are both non-probabilistic sampling methods, and therefore not generalisable to the population as a whole. However, qualitative research does not aim to be representative of the whole population. Rather the aim is to gain a deep understanding of a phenomenon in a particular context, in this case living with SCI caused by gun violence and having a wheelchair provided by Transitions. Non-probabilistic sampling is most appropriate as it offers depth and contextual richness to achieve that goal (Llewellyn et al 1999).

It would have been far more difficult to recruit participants in the absence of a database at an NGO like Transitions, because there are no channels of communication for identifying or contacting survivors with spinal cord injuries in Guatemala. (In fact, when asked whether they know other gunshot survivors with SCI, most of the participants only mentioned members of Transitions.) Another benefit of using the Transitions database was that participants would likely feel more comfortable coming to be interviewed in a safe space with supportive personnel, at a familiar location where they knew that SCI and gun violence would not be topics arousing curiosity or suspicion.

3.4.1 Consent

Participants were informed by the Transitions receptionist that their participation was strictly voluntary and would not affect the way they were treated or the provisions of services by Transitions. They were informed that the Australian researcher was a volunteer at Transitions with no involvement or authority in decisions about who received services from the NGO. They were informed that they did not need to answer any questions they did not feel like answering, they could change or delete any or all of their answers afterwards, and they were free to discontinue participation at any time, without prejudice. They were also informed that if they wished their name could be used; or alternatively they would not be identified.

One of the participants, Flory, already knew me because I had involved her in four previous activities: a meeting to discuss forming a network of gunshot survivors, an advocacy event for the Global Week of Action Against Gun Violence, a photo exhibition on women with disabilities and violence, and an interview with a journalist writing a magazine article about my work at Transitions. This prior connection doubtless boosted her interest in participating in the study. Also, Flory lives in a location so inaccessible that she generally only leaves home around once a year, because she must be carried up a cliff. Thus she is always keen on opportunities to be involved in projects which can justify the effort, especially for a trip out of town to Antigua. One of the other potential participants, Manuel, had met me before but did not recall the event. It had been soon after he was injured, when he was an inpatient at the Von Ahn National Rehabilitation Hospital, and I had accompanied Transitions staff to the hospital to discuss providing wheelchairs to patients there. At that time Manuel was still so shocked that he was unable to speak or make eye contact with us.

Potential participants were invited to come to Transitions, a familiar location because they had received their wheelchairs there. Travel costs by taxi or private car (usually around US$30) were paid on the spot. All participants signed the consent forms, indicating that they also consented to the use of their story, their real names and images in potential later activities such as media outreach or public awareness.

3.5 Interview process

The study was conducted through semi-structured in-depth interviews with each survivor, conducted face-to-face at a table in an office at Transitions, following their reading of the PIS, having any questions answered and signing the PIC. Although participants had been offered the chance to have friends or family present during the interview, only one (Manuel) took up the offer. He was accompanied by a friend.

The interviews were conducted in Spanish, the first language of all the participants. The focus was on the participants' own memories, impressions, beliefs and understanding of what had occurred to them and how their community and society had responded.

I had a printed list of open-ended questions divided into content areas, but the participants' answers frequently involved background stories which caused diversions from the original schedule. For example, questions about health almost inevitably led to information about relationships with family members who assisted with health care. The interviews, lasting being an hour and 90 minutes, were free flowing, containing specific insights into the experience of each participant but also a core of comparable qualitative data, as I made sure to cover all the content areas in each interview, though not necessarily in the same order. The only structured section of the interview was the Washington Group Extended Set of Questions on Functioning.

The interviews were audio recorded on a pocket recorder and transcribed by a professional transcriptionist with whom I have worked on previous projects (Peters 2014, Peters & Carrera 2014). The interviews were conducted over a period of several months in 2018, so I was able to review the transcripts of the early interviews before interviewing the later participants. I reviewed the transcripts whilst listening to the tapes in order to check accuracy and make corrections (eg medical terms which the transcriptionist had not recognised). The transcripts were in Spanish, a language in which I work professionally. I translated them into English so I could share them with my supervisors. The participants were given their transcripts to keep, but none came back with comments or questions. This may have been because they considered the transcripts to be less important that the eventual report would be, or because reading long documents does not come easily to them.

3.6 Data analysis

The transcriptions were subjected to thematic analysis, following the six-step process outlined in Braun and Clarke (2006). This process was considered appropriate to ensure systematic and reflexive consideration of the quantum of data in the transcripts which reflected the diversity of the participants in current age, family circumstances, gender, circumstance of shooting age and age at the time.

Phase 1: *Familiarisation with the data*. I read and reread the original Spanish transcripts carefully, while simultaneously listening to the interviews. I was listening for transcription errors, but also for intonation, emotion and significant nonverbal cues such as pauses, faltering, emphasis, uncertainty or irony. Absorbing

this additional information was crucial to understanding fully each person's narrative in preparation for analysis; but also in order to produce a faithful English translation for my supervisors to read. I made notes on these para-linguistic features as well as some salient recurring topics before translating the transcripts to English. I tried to translate the tone and feel of the interview as well as the words, while still attempting to maintain objectivity and not injecting more emotion into the English than was in the original verbalisation. This required me to be very aware of and contain or 'bracket' my own potential biases. For example, accounts of poor performance by police evoked a sense of outrage in me, but the participants did not imbue that part of their story with more emotion than other parts.

As each translation was finished, I shared them with my supervisors and then began again the process of familiarisation by reading and rereading. Since I planned to write my thesis in English, I would be using the English versions of the transcripts for analysis. Because I had listened several times to the original interviews, I could still hear the participants' voices as I analysed the English texts.

Phase 2: Generating initial codes. I used coloured highlighting and pens to identify patterns and features of interest, including substantive topics (eg loss of income), key points in time (eg the moment when they were shot), recurring expressions (eg 'thanks be to God'), notable linguistic markers (eg referring to self in third person), statements of self-image (eg 'I'm the sort of person who'), euphemisms for one's disability (eg 'my condition'), intense emotion (eg tearfulness). Some of the substantive topics were broad (eg relationships) while others were very specific (eg bullets remaining in the body). Many items of data had two or three codes, for example, a story about church members assisting Jairo financially was tagged as economic, religious and sources of support. Although my interview schedule had been organised in 14 sections, I did not begin with a list of codes; rather I named them as I observed them in the text using the inductive process described above. Eventually I had dozens of codes, some very specific (eg masculinity) and others quite broad (eg sources of support / optimism).

Phase 3: Searching for themes. I used scissors to cut the printed transcripts into blocks according to their codes, then sticky-taped the similarly coloured blocks together into short or long strings. I used three printouts of the transcripts to accommodate items of data that had more than one code, such as Jairo's story about assistance from church members. I then grouped together the shorter strings that bore some relevance to each other, forming a set of larger possible themes. Thus the items coded as pressure sores, pain, hospital experiences and medication became part of the Health themes (later renamed as Hospital and Health). Some items became part of two or three themes, for example items about costs incurred in hospital were part of the Money theme (later renamed as Economic Impact), as well as the Hospital and Health theme.

Phase 4: Reviewing themes. This phase required checking whether the themes made sense when compared with the coded data, noting how themes relate. I still had quite a lot of potential themes, some concrete (eg Guns, Wheelchairs, Work, Transport) and some more abstract (eg Opportunities, Restrictions, Stigma, Fun). I also was weighing the balance of themes: I hoped to end up with a set of themes that reflected the overall dynamics or emphases in my conversations with the survivors. For example, numerically I had the most themes and sub-themes related to health, yet it did not feel as though health had dominated our conversations

in those same proportions. On further examining the data it was apparent that although there were many comments about health, the longer passages of reflection were on other topics such as family or financial worries.

Phase 5: Defining and naming themes. At this stage I decided on a set of five themes that largely represented the balance of the content of the interviews and offered significant insights into the participants' experience of surviving gunshot. The themes were:

- **Hospital and Health**, which included codes for hospital experiences, rehabilitation, secondary conditions such as pressure ulcers, mental health, toileting, pain, maintenance of good health. Hospital stories dominate this theme, because the participants' concept of health mainly centres on how long it has been since their last readmission for infections.
- The **Justice** theme represented what I had originally thought of as the legal sector, until I realised how little contact the participants had with the legal system. In fact, their experience as crime victims is characterised by a total absence of legal or formal justice. However, most of my participants did not feel outraged or dissatisfied, thanks to their inner resources, religious faith and cultural expectations (or lack thereof). This is the only theme that did not emerge naturally in the participants' accounts of their experience: they raised the topics of health, financial pressure, family etc on their own, but no one mentioned police until I asked them about it.
- **Economic Impact**. This theme, which replaced Work and Money, encompasses the financial impact on the entire household, since that is how the participants framed their remarks. The main impact is loss of income (measured in terms of the prevailing minimum monthly wage at the time of the shooting); but also the economic burden of expenses resulting from living with SCI.
- The theme of **Family** is fundamentally important, not only because of culture and affection, but also, for the participants, out of necessity. Since there is little or no support available from government or non-government sources, family is essentially the only source of practical support in daily life. However, the data include references to family as a source of stress as well as support.
- **Religious Faith.** I had not originally expected that this would emerge so strongly as a theme, but all the participants (to a lesser extent in the case of Manuel, the youngest and shyest) stressed their relationship with God as a significant presence in their lives after being shot.

All these themes featured in all the interviews, which take the form of narratives interspersed with my questions derived from the semi-structured schedule. However, some themes were more strongly associated with certain participants than others. This led me to think about assigning one participant to each theme, or one theme as a particular slant on each participant's story. I very much wanted to honour the participants by telling the full story of each person, rather than atomising them into a collection of disembodied thematic quotes as so often occurs in the qualitative studies with which I am familiar. However, telling each person's story in all its multidimensional complexity would lead to repetition, perhaps boredom, and still leave me with the task of highlighting the thematic content in their stories to analyse.

Writing the participant profiles or life stories involved two different types of information extracted from the interviews. First the facts as recounted by the participant: (fairly) objective information on background, relationships and events, to establish the context and chronology of each person's life. Second: the subjective lived experience, including sensory and emotional details, reasoning, reflection, insights and meanings from each participant's perspective. I wrote the profiles first, each with a thematic emphasis, and then brought in the comments made by the other participants on that same theme. Some of these comments had already been included in the focus participant's profile, and others had waited patiently in their sticky-taped thematic strings to find their niche in the text of the thesis.

The disadvantage of this structure was that it took up more space than a traditional straight thematic analysis from which the individuals have disappeared. I quickly reached the word limit for a Masters thesis and was thus in a quandary as to what to do. I resolved the dilemma by moving the life stories (the first section of each Findings chapter) to Appendices A through F. This "amputation" left my Findings chapters depersonalised and looking more like the traditional aggregations of thematic quotes that I had hoped to avoid. I became aware through this process of the tension felt by qualitative researchers as format parameters conflict with the desire to give voice to each participant. A potential solution to ensure that individual narratives remain intact is via monographs or books about personal experiences of spinal cord injury, such as Shane Clifton's autobiographical *Husbands Should Not Break* (Clifton 2015a).

Assigning themes for five participants was easy, but it was less straightforward for my sixth participant, Kimberly. She has a very different trajectory from the others: her family was better off before the shooting and she is now a university student, whereas the other participants have only a few years of schooling. In the end I paired her with topics related directly to disability such as discrimination, wheelchairs, disability rights and identity. (She was the only participant who understood the question when I asked whether she identifies as a person with a disability. The others thought I was asking whether they considered themselves inferior to other people.) Thus my sixth theme became Disability Identity and Wellbeing.

Phase 6: Producing the findings. During this final phase of analysis and reporting my analyses I wrote the six findings chapters, each retaining thematic emphasis as follows:

- Hospital and Health – Jairo
- Justice – Kevin
- Economic Impact – Manuel
- Family – Flory
- Religious Faith – Byron
- Disability Identity and Wellbeing – Kimberly

To assist the reader in distinguishing the voices in the Findings chapters, I have provided a profile paragraph for each participant in Section 3.7 below. However, I strongly encourage taking time out to visit Appendices

A through F to read their stories– for the sake of clarity, but also for the pleasure of meeting these six Guatemalans who have shared their experiences with honesty and courage. Engaging with the participants individually in their context will help to situate their accounts of their experience in each thematic domain.

3.7 The Participants

The participants were six Guatemalans who acquired spinal cord injuries as a result of being shot. The four men and two women were aged between 18 and 40. The age of the participants when they were injured ranged from 12 to 26. Time elapsed since acquisition of the injury ranged from two to 23 years. None of the participants had any prior involvement with crime. All participants speak Spanish as their first language, and all said they did not have a cognitive impairment. Five of the six were shot in the capital, Guatemala City, and one was shot in a coastal town several hours' drive away. At the time of interview all participants were living in Guatemala City.

The participants were shot between one and 12 times, in circumstances of robbery, sexual rivalry, extortion, domestic violence, mistaken identity by gang members, and (probably) a gang initiation ritual. Three were shot in attacks in which other people died from gunshot wounds. Five participants have paraplegia, with no use of their legs but full use of their hands and arms. The remaining participant (Manuel) has quadriparesis with limited use of only one arm and hand.

Jairo

Jairo, a taxi driver, was shot seven times 14 years ago by a group of men who stole his taxi. He was 25 years old, divorced with two young daughters. After a month in hospital he was discharged with pressure ulcers which became infected and worsened steadily for eight years. He was saved from death by a surgeon who operated to repair the sores without charge. Jairo's life has been deeply affected by gun violence, which has killed his brother, sister and mother. He is now raising the children of his murdered sister, supporting the family by taking in sewing and clothing repairs.

Kevin

Kevin was shot three years ago at age 19 by the ex-boyfriend of a woman he was dating. He lived on the Caribbean coast but was transferred to Guatemala City for treatment. He spent a year in hospital before leaving with severe pressure sores, and now rents a room near the hospital with a care assistant coming daily. Although he knows who shot him, Kevin did not inform the police out of fear of retaliation. Because gunshot victims are commonly suspected of being criminals, he often says he acquired his spinal cord injury in a motorbike accident.

Manuel

Manuel was shot four years ago at age 14, while working as a bus assistant. Guatemalan buses are common targets for extortionists who kill drivers, including Manuel's boss, for not paying their "quota". When he was first injured, he could only move his eyes; but several months in rehabilitation enabled him to recover partial use of one hand. The shooting cost his family not only his income but also his mother's, as she stopped work to be his carer. The family of four lives in one rented room with not enough space for him to navigate in his manual wheelchair.

Flory

Flory was shot 23 years ago at age 17 by her boyfriend, a security guard, as the culmination of a pattern of domestic violence. The boyfriend lied to cover up his culpability, and for months Flory did not reveal the truth. Despite doing several training courses though her church, Flory has never been able to get a job. She now lives with her sister's family in a house built illegally partway down a cliff in a very dangerous part of Guatemala City. The location is so inaccessible that Flory must be carried up the cliff in order to reach the street; as a result she hardly ever leaves home. However, she feels valued in the family which makes her happy.

Byron

Byron was shot eight years ago at age 26 by teenage gang members who mistook him for their intended target (the gang later apologised). With 12 bullets in his body, he asked God to let him live so that he could be a better father to his son. He had previously been in formal employment with a good salary and benefits, but his old employer refused to take him back as a wheelchair user. He supports his family by begging on a busy street, a dangerous occupation in which he has been run over several times.

Kimberly

Kimberly was a 12-year-old schoolgirl when she was shot 11 years ago from a passing car, probably as part of a gang initiation. She struggled with secondary health problems until she had the good fortune to be sponsored by a Hollywood film star to travel to the US for rehabilitation. As with Manuel, Kimberly's mother had to give up work to care for her. She continued in school and today is completing an IT degree online. She believes technology will enable her to circumvent the limitations imposed by her spinal cord injury and have a professional IT career.

Chapter 4 Context – Guatemala

Prior to the presentation of findings, this chapter provides background information on Guatemala, its history and the major dimensions of society that affect the lives of the participants in this study, as residents of poor neighbourhoods in Guatemala City who have acquired a spinal cord injury as a result of being shot. These dimensions include poverty, gun violence, criminal justice, religion, healthcare, and disability rights.

Guatemala is a developing nation in Central America (Figure 1). It is a semi-tropical country whose jungles and mountainous terrain make parts of the interior difficult to reach by road.

Figure 1: Map of Central America

Guatemala has the largest population in Central America and the youngest in Latin America.[12] According to the 2018 census, around 45% of the 14.9 million inhabitants are under age 19 (Instituto Nacional de Estadística (INE) 2019a). The country is divided into 22 provinces or departments, and just over half the population (54%) lives in cities or towns. The only large city is the capital, Guatemala City (population 3 million) and there are 10 other cities with populations over 100,000 (INE 2019b).[13]

Guatemala is a multicultural society where 42% of people identify as indigenous (INE 2019a), and the remainder mostly as *ladino*, a mix of European and indigenous descent. The official language is Spanish, but nearly 30% of the population speaks one of 24 indigenous languages[14] as a mother tongue (INE 2016). About half the population leaves school at the end of primary.

Traditionally dependent on coffee, sugar and banana exports, the economy diversified during the 20th century to include mining, garment manufacturing and the services sector (especially tourism), which now accounts for 65% of economic activity (Central Intelligence Agency 2017). A very large number of Guatemalans live

[12] Central America comprises seven countries: Belize, Costa Rica, El Salvador, Guatemala, Honduras, Nicaragua, and Panama. South America consists of 12 countries: Argentina, Bolivia, Brazil, Chile, Colombia, Ecuador, Guyana, Paraguay, Peru, Uruguay, Surinam and Venezuela, plus t French Guiana, an overseas department of France. Latin America is Central and South America plus Mexico, the US territory of Puerto Rico, and the Caribbean nations of Cuba, Dominican Republic and Haiti.

[13] The 2018 census was the first to find more Guatemalans living in urban than in rural areas.

[14] Guatemala has 22 Mayan languages – Achi', Akateco, Awakateco, Chalchiteco, Ch'orti', Chuj, Itza', Ixil, Jacalteco, Kaqchikel, K'iche', Mam, Mopan, Poqomam, Poqomchi', Q'anjob'al, Q'eqchi', Sakapulteco, Sipakapense, Tektiteko, Tz'utujil, and Uspanteko – plus two non-Mayan languages, Xinka and Garífuna (Mamo 2020).

legally or illegally in the US, with estimates ranging from 1 million (Navas 2017) to 3.5 million (Diario de Centro América 2018). Around 12% of GDP comes from remittances, money earned in the US and sent home (Banco de Guatemala 2019c). This is more than the total tax collected each year by the government (Banco de Guatemala 2019b). International development assistance or foreign aid accounts for 0.05% of GDP, ranking Guatemala 100th out of the 130 aid-receiving countries (World Bank 2019b).

4.1 History and Governance

Guatemala was the home of the Mayan empire from 200 BC until the Spanish conquest in the 16th century, when it became the epicentre of Spain's Central American colony. Under colonial rule the Mayan people were displaced, expropriated, Christianised and enslaved, producing commodities for international export (Lovell 1988).

After independence in 1821 the country was ruled for a century mainly by dictators friendly toward the United States. The United Fruit Company established huge banana plantations, and by the 1940s owned about 16% of the country's arable land. In 1952, to prevent planned land reform that threatened US business interests, the Truman administration began planning a coup two years later which toppled the Guatemalan government and launched another repressive military dictatorship (Schlesinger and Kinzer 1982).

A guerrilla resistance emerged, and 1960 saw the start of 36 years of genocidal civil war in which over 200,000 civilians were killed, more than 600 villages razed, and more than a million people displaced (Comisión para el Esclarecimiento Histórico 1999). Physical impairment resulting from the war has not been the subject of research, but the collective trauma is reflected in high rates of depression, anxiety, sleep problems and post-traumatic stress disorder (PTSD) among Guatemalans (Herrera and Ferraz 2005).

The 1996 peace agreement replaced the military regime with formal democracy, but power brokers from the old regime were able to limit the effect of the reforms and minimise accountability mechanisms (Cruz 2015). The same officials who ran the old state institutions were put in charge of new ones, and nearly 60% of the new civil police officers came directly from the old military police (Spence 2004). Former military leaders assumed high posts in the government and private sector, supporting politicians who passed laws providing impunity for crimes committed during the war. The political and economic elites seized the opportunity to ensure that the new Guatemala prioritised the market over the state (Cruz 2015); and as a result the government serves largely as a tool to advance private interests rather than the public good (Insight Crime 2017).

Limiting the role of the state created a favourable environment not only for legal business activity but also for criminal enterprises. The drug cartels moving cocaine from Colombia to the US rerouted their product overland to avoid interdiction at sea. They protect their business by financing political candidates and by bribing police, judges and other officials. Local security for the cartels is provided by international gangs or

maras (Serrano-Berthet & Lopez 2011), which also run their own local extortion and money laundering rings (Global Initiative Against Transnational Organized Crime 2019).[15] With criminals infiltrating government institutions including the judiciary and the National Congress, impunity is rampant: the indicator most often cited is that 90% of homicides go unpunished (Comisión Internacional Contra la Impunidad en Guatemala (CICIG) 2015).[16] Commentators have warned of the risk of Guatemala becoming a failed state (Isaacs and Montenegro 2019).

In 2008 the UN created a special agency, the International Commission Against Impunity in Guatemala or CICIG. CICIG uncovered corruption in the health system, customs, prisons, the Congress, the judiciary, and the executive branch of government, revealing the influence of drug traffickers, money launderers and businesses providing kickbacks to public officials in return for overvalued state contracts. Its investigations led to prosecution of officials including the past president and vice president of Guatemala (CICIG 2019). However, in mid-2019 the sitting president closed down CICIG, after the agency decided to investigate his own family and associates (Boyle 2019). The closure of CICIG has increased political and legal instability, emboldened the old guard and raised fears of retaliation against individuals who supported the campaign against corruption (Abbott 2019).

4.2 Poverty and inequality

On his 2017 visit to Guatemala the UN High Commissioner for Human Rights, Zeid Ra'ad Al Hussein, lamented the gap between the rich and the poor, which includes people with disabilities:

> There are two realities in Guatemala. For a small minority, Guatemala is a functioning, modern country where economic and political power is concentrated; for the rest of the population, in particular for women, indigenous peoples, Afro-descendants, migrants and *persons with disabilities*, [my italics] it is a country in which they have faced a lifetime of discrimination, marginalization, and the pernicious effects of corruption and impunity. (United Nations Office of the High Commissioner for Human Rights 2017)

Guatemala was considered a lower-middle income country by the World Bank until 2018, when it was reclassified as upper-middle income because per capita Gross National Income exceeded US$3895 (World Bank 2018). However, this label belies the poverty affecting the population. More than 59% of Guatemalans live below the poverty line of US$3.20/day, including 23% in extreme poverty on less than US$1.90/day (Banco de Guatemala 2019a). On the Human Development Index, which measures human development in

[15] The *maras* were created by the deportation of Latino gang members coming out of US prisons. Hundreds of thousands were repatriated to Central America, including members of two rival Los Angeles gangs, the *Mara Salvatrucha* or MS-13 and the *Calle 18*. These *maras*, renowned for their brutality, have become the dominant street gangs in Guatemala.

[16] To put this figure into context, the ratio of solved to unsolved homicides in Australia is exactly the opposite: about 90% of homicides in Australia are solved (Bryant and Bricknell 2017, Bricknell 2019).

terms of health, education and income, Guatemala ranks equal 126th (with Nicaragua) out of 189 nations (UNDP 2019a). In the Americas, only Honduras and Haiti rank lower.

How is it possible for a country recently re-classified as upper-middle income to have almost two-thirds of its population living below the poverty line? The answer lies in inequality. Based on the World Bank's Gini index, Guatemala is the 17th most unequal country in the world (World Bank 2019a).[17] The Gini index measures how equally or unequally income is distributed throughout a country's population. The richest 10% of Guatemalans receive 47% of the income, while the poorest 10% receive just 1% (Economic Commission for Latin America and the Caribbean 2014).

Inequality has been intensified by the limited role of the state. Taxes are low and easily evaded, which suits the wealthy. The country's tax revenue of 11% of GDP is the lowest in Latin America (regional average 23.5%) and one of the lowest in the world (global average 24.5%) (World Bank 2019c). With low tax revenues constraining the government's capacity to provide essential services, Guatemala's public spending of 9.7% of GDP is almost the lowest in the world (average 16.0%).

4.2.1 Income and social protection

There are two categories of official minimum monthly wage (MMW) in Guatemala, one for the general workforce and a lower one for workers in *maquilas* or clothing factories. In 2018 the general MMW was 2992 quetzals (Q2992) or US$409, while the *maquila* rate was Q2758 or US$376 (Acuerdo Gubernativo No 297-2017). However, the minimum wage is a legal requirement in name alone: 70% of workers earn less than the official minimum (Prado Sanchez 2017). The minimum wage is itself recognised as inadequate to support a family, since it falls 16% short of the cost of the Q3552 (US$461) food basket considered necessary to provide the minimum monthly caloric intake for a household of 4.77 people (INE 2018).

Almost 70% of Guatemalan workers are employed informally (INE 2019c), without entitlements like the minimum wage, time off for holidays or illness, or designated working hours. Average monthly income in the informal sector is US$212, about half the official general MMW. Informality is highest in rural areas, but even in Guatemala City, 44% of workers are informal. The high rate of informal employment and low wages mean that Guatemala has the worst working conditions in Latin America (Inter-American Development Bank 2019).

Conditions are much better for the 30% of Guatemalan workers employed in the formal sector, which includes government agencies and large companies. The average monthly formal income is US$453, or US$44 more than the general MMW (INE 2019c). Guatemala City is the only part of the country where more people are employed formally than informally.

[17] The World Bank also refers to the "two Guatemalas" in describing the country's inequality (World Bank 2017).

Some Latin American countries have disability quotas for the public service (Incluyenme n.d.), but Guatemala is not among them. Guatemalans with disabilities, if they are working, are likely to be among the 70% of workers who are in the poorly paid informal sector. This is obliquely supported by a finding in the National Disability Survey ENDIS (see below under Disability) that people with disabilities are more likely to have a job in rural areas (where nearly all employment is informal) than in urban areas (ICED 2017).

A big advantage for some workers in the formal sector is the opportunity to pay into the social security system, known as IGSS. By law, all employers with three or more workers must affiliate them with IGSS (Acuerdo Gubernativo 85-2003). However, in practice just over half of formal sector employees (18% of the total workforce) are affiliated (Instituto Guatemalteco de Seguro Social (IGSS) 2019).

IGSS membership brings two very significant benefits relevant to people who become disabled. First, members who have paid into IGSS for the minimum required period can receive health care in the IGSS health system, whose hospitals and facilities are better resourced than the public health system (see below under Healthcare). Members' spouses and their children up to age seven also have this health benefit. The qualifying period for pensions ranges from 36 to 240 months of paying into the system through the employer. Members are entitled to use IGSS health for the rest of their lives, even if they move to a job in the informal sector and no longer pay into IGSS (IGSS 2019c).

The second benefit of IGSS is a contributory social security scheme providing financial support to members who are temporarily or permanently unable to work because of illness or disability. The determination as to whether the member is unable to work is made by an internal panel; and once the ability to work is recovered, the disability pension ceases. IGSS also provides a retirement pension to members who stop work after age 60, and a widows' benefit for partners of IGSS members who die (IGSS 2019b). In a society with no workers compensation, government disability or age pension, this scheme is a vital safety net for people who experience long term disability such as gunshot survivors with spinal cord injuries – but only if they are among the 18% of workers whose employers provide access to IGSS.

4.3 Guns and violence

4.3.1 Gun proliferation

Guatemala, El Salvador and Honduras are collectively known as the Northern Triangle of Central America. As well as sharing some historical and cultural similarities, the three countries face common economic, ecological, social and political challenges, including the proliferation of firearms. The flood of guns results from multiple factors: outdated and permissive legal frameworks; weak enforcement mechanisms; failure to disarm ex-combatants after the wars; organised trafficking of weapons, either in transit or for the local market; small-scale cross-border trafficking by individuals; theft of firearms from legal owners; theft and diversion from poorly managed state arsenals and inadequately regulated private security companies; as well as production of craft or home-made weapons (De Leon-Escribano 2006). The largest source of guns seized from criminals is the United States (Parsons & Vargas 2018).

Guatemala's peace accords identified gun control as a post-war priority (Acuerdo Sobre Fortalecimiento del Poder Civil y Función del Ejército en una Sociedad Democrática 1996). The country is also bound by international and regional agreements on firearms, including the Arms Trade Treaty (2013); UN Programme of Action on Small Arms (2000); Firearms Protocol of the UN Convention on Transnational Organized Crime (2000); Central American Code of Conduct on the Transfer of Arms, Ammunition, Explosives and Other Related Material (2005); and Inter-American Convention Against the Illicit Manufacturing of and Trafficking in Firearms, Ammunition, Explosives, and Other Related Materials (1997).

However, gun ownership is encouraged by the post-war national constitution, which enshrines a right to keep and carry guns, subject to regulation (Article 38) (Constitución Política de la República de Guatemala 1985).[18] The post-war Law on Weapons and Ammunition is fairly permissive, with no mechanism to limit the accumulation of large numbers of guns by individuals (Decreto 15-2009, Ley de Armas y Municiones). Legal loopholes enable the licit and illicit markets to overlap; for example, large quantities of legally purchased ammunition are easily transferred to illegal owners of guns (Rojas & Sánchez 2017). Attempts to strengthen regulation and enforcement have been strongly resisted by vested interests and their allies within the state (De Leon-Escribano 2011).

Demand for guns is high among state agencies, private security companies, criminals and ordinary civilians. On average in 2019, 116 new guns were registered by individuals each day, an increase of 21% on the previous year (Chumil 2020). The firearm most commonly sold in Guatemala, and the most often recovered from crime, is the 9mm semi-automatic pistol (Chavez 2019; De Leon Wantland 2019).

4.3.2 Gun violence

Homicide is the third leading cause of death in Guatemala, after cardiovascular disease and respiratory infections. In 2016 more than 5800 Guatemalans were murdered, according to the WHO's GBD study (IHME 2017). On this basis the homicide rate was 36/100,000. Of those homicides, 75% were by firearms, an average of 14 people shot dead each day. Gunshots caused 38% of all injury deaths in the country, outnumbering every other category of injury death. The impact falls heavily on the young: gunshot is the leading cause of death in the age groups 14-19 and 20-24, and the second leading cause in the age group 9-14.[19] Guatemala is one of six nations that together account for 50% of all gun deaths in the world (Naghavi et al 2018).[20]

WHO obtains the data for its GBD study primarily from health sources in each country. Another international agency, the UN Office on Drugs and Crime, produces the Global Study on Homicide based primarily on data

[18] Guatemala, Mexico and the US are the three countries in the world whose constitutions mention gun ownership.

[19] By comparison, in Australia the homicide rate is less than 1/100,000 and gunshots (mainly self-inflicted) account for 2% of injury deaths (Australian Bureau of Statistics 2019.)

[20] The others are Brazil, the US, Mexico, Colombia and Venezuela. This includes firearm homicides, suicides and unintentional shooting deaths, although in Latin America most gun deaths are homicides.

from police sources (UNODC 2019).[21] For the year 2016, the GBD figures on the number and rate of homicides in Guatemala are substantially higher than UNODC's. The difference comes to nearly 1300 deaths and nearly nine points on the homicide rate (Table 2).

Table 2: Number and rate of homicides in Guatemala 2016, WHO Global Burden of Disease (GBD) vs UNODC Global Study on Homicide

Agency	GBD	UNODC	Difference between the sources
Source in-country	health	police	
Total homicides	5806	4520	1286 homicides
Total homicide rate / 100,000	36	27.3	8.7/100,000
Gun homicides	4430		

According to HEUNI, the UN's European crime research institute, disparities between health and police statistics on homicide are common, with the divergence being largest in developing countries (Malby 2010). This example illustrates the difficulty of obtaining reliable statistics even on fatal injuries, much less on non-fatal injuries where data collection is even more challenging.

No data are available from the Guatemalan health system on non-fatal shootings; but the Vice-ministry of Crime Prevention publishes statistics on criminal injuries from the Guatemalan National Police, which is known by the acronym PNC. In 2018 the PNC recorded 5766 shooting victims, of whom 3100 died and 2666 survived (Viceministerio de Prevención de la Violencia y el Delito 2019a). This means slightly under half of all shooting victims recorded by police survived, an average of seven per day.[22]

How does Guatemala's gunshot survival rate compare with other similar countries? The only international study on firearm injury lethality is by Alvazzi del Frate and De Martino (2013) at the Small Arms Survey in Geneva. They found a general paucity of information across the world on non-fatal shootings, but noted that in Brazil, Colombia and Mexico, about 70% of gunshot victims die and 30% survive. The researchers posited that in countries like those three (and Guatemala), which have very high rates of gun violence, gunshot victims are less likely to survive their injuries; whereas in countries with lower rates of overall gun violence the chances of survival are higher. On this basis they estimated an average global case fatality rate for

[21] The Global Study on Homicide ranks Guatemala 9th in the world for homicide rates. Immediate neighbours El Salvador, Honduras and Belize are also in the top 10, making the northern part of Central America the world's most homicidal subregion. The top 10 includes four others in the Americas – Jamaica, Bahamas, Brazil, Saint Lucia, Dominica – plus South Africa (UNODC 2019). The GBD and Global Homicide Study also differ on numbers and rates for other countries, but the two sources are in general agreement on the group of countries which rank highest for homicide.

[22] This contrasts strongly with the US and Australia, where two-thirds of people with suffer gunshot wounds survive (CDC 2016, AIHW 2017). Two important factors must be taken into account in this comparison: (a) the US and Australian survival rates are based on health rather than police data; and (b) the largest proportion of US and Australian non-fatal gunshot injuries arise from unintentional shootings, a category for which there is no information in Guatemala. The Guatemalan data refer specifically to intentional assaults, which prove lethal far more often than unintentional shootings do. In addition, US and Australian survival rates may be bolstered by superior emergency medical care.

intentional shootings (excluding war injuries) of 48% – in other words, there is one survivor for every person killed. The Guatemalan rate of 46% from PNC statistics is consistent with this estimate. However, the PNC number may be an underestimate, given the low level of police performance generally and the tendency by Guatemalans to not report crimes. These issues are discussed below under Section 4.4 – Criminal Justice.

According to Alvazzi del Frate and De Martino (2013), between 500,000 and 750,000 people around the world may survive non-war shooting injuries every year. However, no information is available on the health or disability consequences of those shootings.

The Global Burden of Disease study ranks violence as the second cause of premature death in Guatemala. Major causes of death are generally also significant causes of Years Lived with Disability or YLD. However, since such a large proportion of victims die, violence does not feature among the top 10 causes of YLD in Guatemala (IHME 2017).

No analyses are available on the circumstances of gun violence in Guatemala, for example what proportion of incidents are associated with gangs, domestic violence or robberies; or what proportion occur at home, on the street or in a workplace. The Office of the Human Rights Advocate (PDH) has identified public transport as being an especially dangerous place, and reports transport shootings (based on media monitoring) in its annual human rights report. During 2018, at least 200 people were shot dead on public transport (PDH 2019).

4.4 Criminal justice

In addition to its extraordinary homicide toll, Guatemala suffers from high rates of robbery, kidnapping, domestic violence, and activities associated with gangs and criminal networks such as extortion, money laundering, corruption and trafficking in drugs, people and weapons (UNODC 2012). In the 2018 national victimisation survey or ENPEVI, 16% Guatemalans (one in every six) said they had been victims of crime in the previous year, with the highest rate (25%) in the capital (Viceministerio de Prevención de la Violencia y el Delito 2019b). However, 77% of crimes were not reported to the police. Nationally, the main reason cited was the victim's belief that the authorities would not do anything about it.

The perception of reporting as pointless is justified by the high criminal impunity mentioned earlier, and by a 2006 study of the justice system by the former Argentine prosecutor Ricardo Mendaña. He pointed to a lack of professionalism, resources and training; sometimes corruption; and a culture of bureaucratic form-filling:

> Investigations continue to be bureaucratic. Priority is accorded to process rather than to results … The reality generally shows us that "what should be a creative activity has become a routine activity, a mere accumulation, more or less mechanical, of papers that transcribe records." (Mendaña 2007)

The ENPEVI victimisation survey highlights another reason for not reporting crime, or for not sharing information that could assist the police investigation: fear of reprisal by the criminal perpetrator. This was the most common reason for not reporting in some departments with very high homicide rates. Keeping quiet is a

protective strategy: the victims hope to avoid provoking the perpetrators into further attacks. Without information, criminal investigation cannot proceed and impunity escalates.

The failure by victims to report, and failure by police to investigate, also means that crime victims miss out on a modest support program that exists within the Ministry of Justice. There is no system of victims' compensation, but a small Office for Victim Support can arrange legal, medical, psychological and other assistance. However, a victim does not qualify for support if there is no investigation, arrest or prosecution (Instrucción General No 10-2008). This means that only a minority of victims ever receive support.

4.5 Religion

Guatemala is the most religious country in Latin America, according to the 2014 Pew Survey on Religion. Over 99% of Guatemalans believe in God, and the country ranks first in the region in terms of weekly church attendance (74%), daily prayer (62%), belief in miracles (97%), and belief that God grants material wealth and good health to Christians who have enough faith (90%) (Pew Research Centre 2014). In 2014 half of Guatemalans identified as Catholic, 41% as Protestant (mainly evangelical) and 6% as religiously unaffiliated.

The notion of disability as divine punishment for sins or errors is often woven into religious belief, both Christian and Mayan (Sanson and Felix 2013). The faults may have been committed by the person with a disability or by members of their family, or may be the original sin carried within the whole human race (Grech 2015). The Shadow Report by civil society to the UN Committee on CRPD cited this belief as an obstacle to advancement of human rights and inclusion for Guatemalans with disabilities (Comisión Informe Alternativo de la CDPD Guatemala 2015). Even if disability is not seen specifically as punishment, it is commonly seen as part of God's plan for the individual (Grech 2015). This acceptance can make it easier to bear the harsh consequences of living with disability, especially for poor people who cannot afford services or products to mitigate those consequences.

The strength of Guatemalans' religious faith is even more notable when contrasted with their lack of faith in government. The 2018 Latin American Democracy Barometer survey asked people in all Latin American countries about confidence in a variety of institutions (Corporación Latinobarómetro 2018). In Guatemala, church is the only institution that has the confidence of more than half the population. Over 70% of people have confidence in a church, as opposed to the army (33%), police (25%), judiciary (22%), the Congress (17%) or political parties (11%). Confidence in government overall (15%) was the fourth lowest in a region where state institutions are generally poorly regarded. This lack of confidence is reflected in alienation from the system of government: only 50% of Guatemalans (the lowest in Latin America) agreed that "Democracy has its problems but is still the best system of government". One third of Guatemalans said it makes no difference whether the government is a democracy or not.

4.6 Healthcare system

Guatemala's constitution guarantees the right to health (Constitución Política de la República de Guatemala 1985), and the statutory Health Code declares that "the provision of health services to all the Guatemalan people is guaranteed to be free" (Decreto No 90-97, Código de Salud, Art 4). However, like other essential services, the health system is chronically underfunded. Government spending on health comes to just 2.1% of GDP, the lowest in Central America and almost the lowest in Latin America (World Bank 2019d). The Ministry of Health admits that 52% of all health expenditure is paid out-of-pocket by patients themselves (Ministerio de Salud Pública y Asistencia Social (MSPAS) 2017). This puts an onerous burden on poor people with chronic health needs, such as those with spinal cord injuries.

Guatemala actually has five health systems: public, IGSS (social security), military,[23] private,[24] and NGO (Becerril-Montekio 2011). The public system has 44 hospitals across the country, including two large teaching hospitals in the capital, San Juan de Dios and Roosevelt. [25] These two hospitals provide outpatient rehabilitation, and there is also Von Ahn, a dedicated public rehabilitation hospital. Across the country around 400 local primary care clinics and over 1000 small neighbourhood "health posts" provide basic services such as baby health checks and health promotion (MSPAS 2016).

As mentioned earlier, the 18% of workers who belong to IGSS have their own health system. It includes 23 hospitals (one of them a stand-alone rehabilitation hospital) and 97 outpatient facilities, many specialising in areas such as cancer or dialysis (IGSS 2019d).

Both the public and IGSS systems are overseen by the Ministry of Health (MSPAS), which in 2017 drew attention to a significant inequity in the distribution of resources between the public health and IGSS systems. In 2016 spending per user in the public health system was Q185 (US$24), compared with Q839 (US$110) in the IGSS system (MSPAS 2017). IGSS is 50% funded by the government, with the other 50% coming from affiliated employers and employees. The care provided to patients in the two systems reflects the funding disparity. IGSS health care includes provision of all medications and products needed by people with SCI such as incontinence supplies and wheelchairs (IGGS 2019a). By contrast, patients in the public system must buy those supplies as well as items from X-rays to surgical materials (MSPAS 2017).

Public hospitals are overcrowded and understaffed: they treat four times as many patients as IGSS hospitals, with just 1.7 times the number of clinical staff (MSPAS 2016). The Office of the Human Rights Advocate (PDH) raises concerns every year about the poor quality of health care, especially in the public system. In

[23] The military system provides medical and dental services exclusively for members of the police and armed forces.
[24] The private health system includes hospitals, clinics, private surgeries, imaging centres and pathology laboratories. A nascent medical tourism industry provides cosmetic surgery, dentistry and weight loss surgery to overseas visitors.
[25] San Juan de Dios and Roosevelt, with 1000 beds each, consume 44% of the public hospital budget (MSPAS 2017).

2018 PDH said that San Juan de Dios, one of the two major public hospitals in Guatemala City, was suffering "an infrastructure collapse", shortages of medication and supplies, and severe understaffing (PDH 2019).[26]

NGOs (including churches) constitute the fifth health system in Guatemala, because after the civil war the government contracted out basic rural health services to domestic and international NGOs as a way of rapidly scaling up coverage. That program was cancelled in 2014, but many NGOs still operate local centres providing, for example, nutritional support, family planning or zika prevention (O'Brien 2016). In addition, thousands of urban and rural Guatemalans receive health care, especially surgery, from visiting overseas medical teams on short-term mission trips (Roche and Hall-Clifford 2015). NGO health services have been criticised for being self-serving, competing and failing to coordinate, for staff turnover, programmatic discontinuity and lack of sustainability (Roche and Clifford 2015, Becerra et al 2014, Rohloff et al 2011).

4.7 Disability rights

Guatemala's Constitution recognises rights for people with disabilities in terms of rehabilitation (Article 53) and employment (Article 102) (Constitución Política de la República de Guatemala 1985). The country ratified the 2006 UN Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol in 2009 (United Nations Department of Economic and Social Affairs 2006). It had previously ratified other relevant international and regional instruments: the 1983 ILO Convention on Vocational Rehabilitation and Employment (Disabled Persons) (No. 159) and the associated Recommendation (No. 168) (International Labour Organization 1983); the 1999 Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities; (Organization of American States 1999) and the 1988 Protocol of San Salvador, which provides the rights to social security, education and training for people with disabilities (Organization of American States 1988).

In its only report to the UN Committee on the Rights of Persons with Disabilities, the government stated that "Advances have been made in regard to legislation, given that the country now has a legal framework for addressing the issues of persons with disabilities and protecting them in every sphere" (Committee on the Rights of Persons with Disabilities 2013). However, as the Shadow Report from Guatemalan civil society pointed out, the legislation in question had been enacted in 1996, 13 years before ratifying CRPD, and thus could not be claimed as progress since ratification (Comisión Informe Alternativo de la CDPD Guatemala 2015). The law contained no mechanism for enforcement and had not been amended to comply with the CRPD.

Another point raised in the Shadow Report was that the existing Guatemalan law embodies the charity and medical models of disability. These outdated 'deficit' approaches focus on individual impairment, framing the

[26] The IGSS health system provokes fewer complaints, but it has been embroiled in its own scandals. In 2015 a group of IGSS officials was arrested for a corrupt procurement scheme involving kickbacks from suppliers of products, including one that caused the death of patients. The group included the IGSS Board Chair, one of the retired military officials who prospered after the end of the war (Wirz 2015).

person with disability as defective or ill and in need of sympathy and a cure. They have generally been replaced by approaches based on the social model, which posits disability as arising not from individuals' impairments, but from barriers imposed by society which have the effect of excluding and oppressing those individuals.

The UN Committee on the CRPD agreed with the Guatemalan Shadow Report and made numerous recommendations to the government, including revision of the 1996 law, addition of penalties for non-compliance, establishment of complaints mechanisms, and provision of funding for disability organisations (Committee on the Rights of Persons with Disabilities 2016).[27] The Committee noted with concern the growing trend toward voluntarism in Guatemala, recognising a more general problem in health, welfare and human rights whereby the poor must turn to NGOs for the essential services that the State fails to provide.

The 1996 legislation is the Assistance to People with Disabilities Law (Decreto No 135-96, Ley de Atención a las Personas con Discapacidad). In addition to proclaiming the rights to health, education, work, and participation in society, the law declares that the government should facilitate job creation for people with disabilities and make buildings and services accessible. Both government and civil society, it says, should eliminate discriminatory actions or provisions. As the Shadow Report to the UN Committee pointed out, the law is well intentioned but mostly aspirational as it lacks timelines for compliance, sanctions for non-compliance, and a budget. Every year the Office of the Human Rights Advocate reports on the failure to deliver the promises in the law (eg PDH 2019).

An aspect of the law that has been implemented is the creation of the National Council on Support for People with Disabilities or CONADI. This statutory organisation is made up of government officials and NGOs representing people living with different types of disabilities. It is Guatemala's principal voice for people with disabilities, but as a government body its advocacy is constrained: for example, it was CONADI that prepared the official report to the UN Committee describing the government's achievements as significant. CONADI promotes the social model of disability as follows: "The social model considers that the original causes of disability are neither religious nor scientific, but rather are to a large extent social." (CONADI 2017)

CONADI is mainly dedicated to awareness-raising to challenge stereotypes about disability (CONADI 2018), but in 2016 it showed energetic leadership in supporting the development of Initiative 5125, a bill to replace the 1996 legislation with a new law based closely on the CRPD (Registro 5125 2016). Responding to the UN Committee' criticism, the proposed law would include targets and timelines: for example, that public transport operators must make 100% of vehicles wheelchair-accessible within 10 years of the law's adoption. The bill proposed quotas for employment of people with disabilities, and budget allocations for assistive devices such as wheelchairs. Initiative 5125 served as a rallying point for civil society organisations which joined the PDH

[27] A large part of the UN Committee's report dealt with Guatemala's treatment of people with disabilities in institutions, including the country's only public psychiatric hospital which has been at the centre of many scandals. For the purpose of this study, only the points most relevant to people with mobility impairments are mentioned here.

and Office of the UN High Commissioner for Human Rights in strongly supporting the bill. However, the Congress showed little concern about the country's international human rights obligations. A raft of amendments was proposed to remove the targets, timelines and budgets, and in 2017 the bill stalled completely. One prominent conservative legislator declared that "People with disabilities just constitute an expense for the country" (Global Disability Watch 2017).[28]

4.8 Conclusion

Guatemala is a difficult context for anyone who is poor, has a disability or is a victim of crime. For a person with all three features the challenges can be daunting. In the following Chapters 5 through 10, the participants describe those challenges and how they confront them.

The chapters are framed around themes, and each chapter brings in the voices of all the participants on the theme in question. In addition, each survivor's story full story is told (with a thematic slant) in an Appendix, each story containing additional rich detail and thoughtful comment. The reader is strongly encouraged to visit the Appendices and consider reading the full stories in tandem with Chapters 5 through 10, as follows:

• Appendix A: Jairo's story	• Chapter 5 Hospital and Health
• Appendix B: Kevin's story	• Chapter 6 Justice
• Appendix C: Manuel's story	• Chapter 7 Economic Impact
• Appendix D: Flory's story	• Chapter 8 Family
• Appendix E: Byron's story	• Chapter 9 Religious Faith
• Appendix F: Kimberly's story	• Chapter 10 Disability Identity and Wellbeing

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[28] Two years later the legislator was charged with the crime of discriminating against people with disabilities (Ramos 2019); this was a rare application of a provision in the Criminal Code that can punish discriminatory behaviour with a fine and a jail term (Decreto No. 17-73, Código Penal de Guatemala 1973, Article 202bis).

Chapter 5 Hospital and Health

Jairo was shot seven times by thieves who stole his taxi (see Appendix A). The Roosevelt public hospital saved his life, but also gave him an infection that would devastate him for eight years and nearly kill him. During his month-long admission he was not regularly moved or checked for pressure ulcers, and as a result he developed a huge sore on his sacrum. Back home, with incorrect instructions on how to manage the ulcer, it grew to 15cm in diameter, causing dramatic deterioration in his physical and mental health. His mother's tireless search eventually led to Dr C, a public-spirited surgeon who treated him successfully for free. Jairo has since helped other ulcer sufferers by connecting them to Dr C.

5.1 Hospital admission

After being shot, all the participants were taken quickly to the nearest Emergency Department by paramedics, taxi (Manuel) or pick-up truck (Kevin). Length of stay varied widely. Flory was admitted 23 years ago for only five days, while Kevin, who was shot three years ago, spent a year in hospital. Three participants (Kevin, Kimberly, Flory) were admitted to the San Juan de Dios public hospital, while Manuel and Jairo were at Roosevelt, the other large public facility. Byron was taken initially to Roosevelt, but later transferred to the IGSS social security hospital.

In the public hospitals, the participants could see that staff were overloaded, too busy to respond to requests for a glass of water or pain relief. A lack of empathy was also evident. Byron arrived at Roosevelt hospital with 12 bullets in his body:

> [The staff] wanted me to sit on the X-ray machine and I didn't understand why I couldn't sit up, and they said, "Well, do you want to do the X-ray or not?" "Yes, but I can't sit up." "Well, [sounding annoyed] can you, or not?" "I can't." … then they said, "go wash all the blood off him," and … in the bathroom there were three corpses, uncovered, just with labels on the toes. They put me there to wait for someone to finish in the shower, I was right next to the corpses. Then they cleaned the blood off and everything, and took me to Trauma... But the nurses didn't have the slightest compassion or say [be careful,] he's been wounded. No, they kept telling me to turn over, turn on my side, while I – without knowing why – couldn't move my legs at all.

After having surgery, he was taken to a ward where:

> They did not take good care of me. They had me three days in a window where the sun beat on me and I was roasting, and I couldn't move or even reach for the curtain or anything. I said, "Nurse, could you move me from here or close the curtain, I'm burning." "Ok, in a minute," they would say but they never did. I even turned red where the sun was hitting me, but they didn't move me.

Flory felt a similar lack of compassion at San Juan de Dios public hospital:

> I didn't feel that they cared about me at all … I guess it's normal – we're used to the fact that the care in our hospitals is not good. They treat you like you're not important, unfortunately.

Jairo discovered an additional reason for lack of kindness, namely staff prejudice against gunshot survivors (see Appendix A).

Kimberly, who was 12 years old when she was shot, took a less negative view of San Juan de Dios, because her mother stayed with her to ensure her comfort:

> It's a public hospital [so you can't expect much], so my mother took care of me. Basically, they only attended me in the medical area, you could say, giving me medicines and all that, but my mum took care of the rest … She fed me, dressed me.
>
> Q: Did she bring food from home?
>
> Yes, because I didn't want to eat the hospital food.

Kevin had a happier experience, which he attributes to his natural charm:

> For some reason that I don't know, the gift God gave me is [that] from the first impression, people always like me.
>
> Q: So they made an effort to help you?
>
> Yes, all the nurses, I spoke to them nicely, and when I had pain I said, "Give me something for the pain, I can't stand it", [and they did].

This contrasts sharply with the experience of Jairo, Kimberly, Flory and Byron, for whom the lack of pain medication was one of their worst hospital memories.

Like Kimberly, Kevin had a relative staying at the hospital with him – his brother, who made himself at home:

> He was there with me for a year, and he got himself his own nurse!... And once my brother made himself the boyfriend of the nurse it was even better, because they took me out of the big ward to a room with only four beds on the second floor; and then after eight months I moved to the fourth floor where there were only two of us, I had my TV and various amenities.

His brother's relationship with the nurse brought clinical advantages for Kevin's treatment, too:

> I spent a lot of time with fever because ... I was super-infected ... But thank God, we met this nurse, and we got a very expensive antibiotic that wasn't given to everyone in the hospital because they didn't have much of [it] … and about four or five times they gave me a dose of this antibiotic, it was called Imipenem.

5.2 IGSS vs public hospital

The social security hospitals are of a higher standard than the public hospitals, since IGSS is shielded to some extent from the chronic underfunding affecting the public system. One study participant, Byron, was an IGSS contributor through his job before being shot, and thus was entitled to treatment at the IGSS hospital. As

mentioned earlier, he was initially taken to Roosevelt public hospital, which was the closest Emergency Department. After a few days he transferred to IGSS, where staff corrected an error made at the public hospital:

> When I arrived at the [IGSS] hospital the doctors noticed that the tubes I'd had inserted at Roosevelt were positioned wrong. So they took them out and opened another hole – without anaesthesia – on each side of me to put in new tubes.

Byron's experience at IGGS was generally better than the other participants' in the public hospitals. However, he still suffered "a huge amount of pain", and the risk of infection was ever present. He narrowly escaped developing a pressure ulcer: "[The staff] don't turn you over when you need it, not until it's time to turn everyone over at once." However, a nurse noticed the early signs of a sore just in time:

> She said "Look, we'd better move you." She was the only one who really looked after me well. Then others came and grabbed some blankets, they twisted them together and placed me so I wouldn't roll on that side, like to ease the pressure, and then another nurse said, "I'll get you a waterbed, so you'll be cooler." And he got it for me, and I felt better, more comfortable.

On another occasion a nurse turned him over and failed to notice that his catheter tube had bent, so the urine could not escape:

> That gave me a 40° fever and I was shaking, trembling and shaking, because it gave me such tremors that they had to inject me with an antibiotic to get rid of the infection I'd gotten because the urine had returned to my bladder. When they unfolded the hose, it was not just urine that came out, but also blood.

5.3 "You'll never walk again"

Jairo and Manuel were told "You'll never walk again" as soon as they woke up in hospital. Kevin, who was shot in a coastal town, was kept in the dark about his injury in his local hospital, only learning the truth once he was transferred to the capital:

> Over there [at the coast] they didn't want to disappoint me I guess, so they didn't drop the bomb on me all at once. They said, "Look, probably it may be that with therapy later on, you could walk again and when you recover, you will be normal." But when I came here [to San Juan de Dios] they did the exams, the X-rays of my spine and all that: "Look, your injury is complete, now you have to become independent, you have to learn to do everything because you're not going to walk again."

Byron was taken by surprise by "a nurse who suddenly dumped a bucket of cold water on me":

> I'd been there three, four months when I asked the nurse – actually I wasn't talking to her, but to another nurse – why was it that I couldn't move my feet? And she said, "The doctor will explain it." Then the [other] nurse said, "You know, what's going on is that you are dead from the middle of your

> body down," she said just like that, and I just froze at being told a diagnosis like that. [Then I asked] "Why? how?", until the doctors explained that it was because of the gun, the bullet.

Flory was never told directly, but she overheard a doctor speaking to her father while they thought she was sedated:

> Nobody took the trouble to come and tell me the damage that the bullet had caused…. [But] I heard it when the doctor told my dad… that even if I had surgery, I was not going to walk again … And I didn't understand at that moment the magnitude of what the words meant, not to walk again. After a while, a few months, I understood that essentially my life had collapsed – life for me was no longer life if I couldn't walk anymore.

Kimberly learned the news in what she describes as a "paranormal experience" – a vision of a kindly nurse who, she later learned from staff, is often seen by sick children in hospital:

> [The nurse] said, "Look, in a few days, like in about three days, you will be moved to a room, but in that room you'll be the only one that isn't going to be able to walk anymore. Don't feel bad, because there are a lot of kids there and you'll realise they are suffering more than you." And that's how I found out. Nobody bothered to tell me … Maybe because it was very difficult for them, I think that's why.

5.4 Rehabilitation

Four participants spent time as inpatients in dedicated rehabilitation facilities. Manuel and Flory were in the Von Ahn public rehabilitation hospital for eight and 12 months respectively, Byron was at IGSS rehab for 11 months, and Kimberly was at Children's Healthcare of Atlanta in the US for three months. All four spoke highly of their rehab experience, saying the staff seemed committed to achieving the best outcome for each patient. This contrasted markedly with their general hospital experience. Another difference between the two setting: none of the participants was asked to pay for anything during their stay at rehabilitation centres.

Manuel, who has the highest-level injury among the participants, spent just a week in Roosevelt after being shot. On discharge, he says, "the only thing I could move was my eyes." He also had a worsening pressure sore. His mother secured his admission to the Von Ahn rehabilitation centre, which proved transformative: the sore healed and he learned how to avoid recurrences, as well as urinary infections. Now he can sit up, eat and drink, use his phone, pick up small items and partly dress himself. At home he squeezes a rubber ball to build his strength, and his brother helps him to do leg exercises.

Before travelling to the US, Kimberly spent a year in outpatient rehab at San Juan de Dios hospital. She described that experience as "bad, seriously". She attended for five hours a day, during which she mostly recalls being placed on a verticaliser and tilted up to a standing position:

> And they had a red light to warm my legs, that was all they did to me. And on a few occasions, I think they put me on the floor on some, like, carpets and made me drag myself along. That was all they

> taught me there – for one year, it was wasted time, doing nothing … I imagined that they would teach me how to transfer to my wheelchair or something, [but] my expectations were a bit high for them.

Frustrated, she began to figure things out for herself.

> My mum used to dress me, but then I didn't want her to do it so one day I said, "No, don't dress me today." … And that's when I started trying to put on my trousers, put on my blouse and that's how I got better with practice, putting on my shoes and everything.

However, the real breakthrough occurred when Kimberly was sponsored by a Hollywood film star to travel to Atlanta in the US for surgery and intensive rehabilitation at a leading children's hospital.[29] (See her story in Appendix F). After three months she returned to Guatemala with new skills and confidence, plus a wheelchair.

Flory has had the most exposure to rehabilitation. She was referred for outpatient rehab at San Juan de Dios where she had been treated initially, but the travel logistics proved too difficult. Instead, her boyfriend paid for home visits by Dr H, a physiotherapist from the hospital. (The boyfriend was the person who had shot her, although Flory had not told anyone that.) Dr H helped her immensely:

> God loved me very much and gave me someone like [Dr H] ... He taught me how to bathe, how to change myself, how to move from the chair to the bed or from the bed to the chair. He taught me how to sit in any chair that I want to, he taught me to sit on the floor if I want to, he taught me how to cook, how to sweep, how to iron, how to comb my hair, how to do my makeup. He taught me to be a Flory who – well, if I don't do all these things now, it's just because I don't want to [ie because I can't be bothered] [laughing].

Dr H came regularly for four months, until there was no more money to pay him because Flory broke off the relationship with the boyfriend. She then applied successfully to the Von Ahn public rehabilitation hospital. The most important skills she learned in her eight months there were avoiding pressure ulcers and changing her catheter, for which she had previously needed help. At Von Ahn, a nurse taught her to do it herself:

> She taught me because she got angry that I was always bugging her, "Miss, my catheter is blocked, my catheter is blocked!" Then one day she scolded me and said, "I'm going to show you how to put it in." So thank God, because even if in a mean way, but she showed me, and I still do [it myself].

Byron pointed out that the positive atmosphere at rehab can raise unrealistic expectations:

> In there [at rehab] I was working with psychologists, therapists and everything and when it came time to leave [I felt like] everything was marvellous…
>
> But in there everything is flat, everything is accessible ... But the stark reality is that when you come out of there, when you're discharged, that's when the reality hits you.

[29] The identity of Kimberly's benefactor is confidential.

As an example of the stark reality, in rehab Byron had been taught to evacuate his bowels on the toilet; but at home the bathroom door is not wide enough for his wheelchair, so he has to do it sitting on the bed, with the accompanying risk of mess. In addition, supplies such as latex gloves for use during defecation are provided at rehab; but upon going home the patient must buy them at inflated cost in a pharmacy.

Similarly, the participants who attended rehab were taught how to bathe or wash themselves in a bathroom. However, in the inaccessible real world, most of them bathe by sitting outside in a plastic chair while a family member pours bowls of water over them.

5.5 Pressure ulcers

Jairo's was the worst experience of pressure sores or decubitus ulcers, but other participants have also had to deal with this dangerous secondary effect of SCI. Byron's incipient ulcer was detected and prevented by a nurse, while Kimberly, Manuel and Kevin developed full-blown ulcers in hospital. Kimberly recalled:

> They didn't tell us, "You have to keep moving her, you have to change her position" … So I just stayed there, because I had a lot of pain … It hurt to breathe, so I didn't move. Then I got the ulcers.
>
> Q: The nurses and the doctors didn't come to look, they didn't notice?
>
> Only when the ulcers were already there. But since I didn't have any surgery or any [treatment], they became infected and kept getting deeper.

The infected ulcers plagued her for more than a year after her initial hospitalisation, requiring several readmissions. The treatment was ineffective: "they scraped them and made them bigger and they would get infected again." She eventually had surgery to close the ulcers in the US, where she also learned how to prevent recurrences. Now she says she has ulcers "under control".

Flory received a word of advice from a nurse while she was being put into a taxi to go home from hospital:

> [The advice was] "she shouldn't get bumped, try to move her regularly" … basically it was the advice of a nurse who spoke personally, not because it was his job. When he took me to the taxi he told [my family], try to take care of her, move her so she doesn't get sores… He was just a good guy who gave us that advice.

Though she has occasionally had pressure sores since leaving hospital, she says they have been "minimal":

> Now I take care of it with antibiotics or I use baby oil, so that helps me keep my skin soft and avoid ulcers… [You have to] check your feet, don't knock against anything, feel yourself, look in a mirror to see if an ulcer is developing – first it is like a scrape, that's the first thing I look for.

Kevin developed three large ulcers in hospital, where his last five months were solely to treat the ulcers. As they grew steadily worse, he discharged himself against medical advice:

> I thought that if I stayed in hospital I would rot there, because the ulcers were not improving, they just became infected because of the very environment there, the contamination in the whole hospital.

When he was interviewed, two years after release from hospital, Kevin was still in poor health due to the same three ulcers. He said he was improving slowly with the support of a daily care assistant:

> I'm using a lot of honey, a lot of pure honey, antibiotics, we mix them… [She] is very clever and she does it, she makes a mixed antibiotic, throws in omega and honey and a powder that I don't remember the name ... She puts that on me and that has helped a lot to reduce it a bit.
>
> Q: Has anyone said how long the ulcers will take to heal?
>
> I've been told that if I don't do what I have to do, not spend a lot of time in the chair, get up every 15 minutes – if I don't do that, I have been told that two, three years will go by and the ulcers are never going to close up.

Byron learned how to prevent pressure sores during his rehabilitation at IGSS; but nonetheless has had a few because he sits on the ground every day to beg. The worst was on his coccyx:

> [Someone told me]: don't worry, heavy people don't get them, it's just skinny people with no flesh to cushion them. I trusted in that, and when I saw my coccyx, I was frightened… Those are really awful, the coccyx ones, because it's the area where you sweat and you have to be more careful.

He went to the IGSS hospital seeking help with the ulcer but was unable to keep attending for treatment because he couldn't afford the taxi fare of Q35 (US$5) each way. The hospital refused to give him the supplies he would need to treat himself at home. Instead he bought some antiseptic and antibiotics at the pharmacy and the ulcer healed in a month.

5.6 Spasticity

All the participants except Jairo experience spasticity in their legs and feet. Kimberly suffers spasms about five times a day:

> When I get it, my legs jerk really fast or really hard, and then I have to hang onto something because if not, I can fall over.
>
> Q: I see that you're doing something right now, where you sort of lock your leg in your wheelchair. Is that what you do?
>
> Yes… If I react quickly then it goes quickly, but sometimes I just get tired and say "Well, do what you have to do," and let it go, because I get sick of it, but that's all… It [lasts] seconds, a minute at most.
>
> Q: Could you take medication for that?
>
> Well, here in Guatemala I haven't been prescribed anything for it. In the United States they prescribed Baclofen, but here in Guatemala it's not available.

Flory's legs begin to spasm when the pain from the bullet in her back becomes intense:

> There are days when the pain is really very strong. When it hurts, my foot reacts and starts jumping and jumping, and I say that hurts! I start to check [my foot] but I know it's more because of the pain up here.

Manuel has frequent spasms (including during the interview) but said they do not cause pain: "In fact it helps me, it feels good because it stretches my leg out which feels good, and then I sleep well."

Byron has learned to recognise repeated leg spasms as an indicator of an incipient urinary tract infection. A few years after being shot he was hit by a car and taken to Emergency:

> Arriving at the hospital, I had spasms. They should know what spasms are. [They said] ok let's check to see if his legs are broken, they checked me and my legs were twitching, my legs jumping. "Stay still," the doctor scolded me, "Stay still!" Then a nurse came and said, "No doctor, excuse me, those are spasms." "Oh, I thought he just wouldn't let me examine him." So there are doctors who don't know about spasms.

Kevin, the only participant who attended no formal rehabilitation program at all, has had surgery to reduce the contracture which deformed his legs into a bent shape, so that he is not able to lie flat. He has frequent spasticity in his left foot and knee. The spasms themselves do not hurt, but they can cause his back to twist which does cause pain.

5.7 Urinary tract infections (UTIs)

All the study participants use indwelling catheters, and all have had to deal with serious urinary tract infections. None were taught how to change their catheter before leaving hospital, which meant they depended on someone else to change it every week or two.

For Flory, ignorance about catheterisation could have proved fatal. After being shot she was discharged from hospital wearing an indwelling catheter which she assumed was a permanent fixture, since no one had mentioned changing it. Nor had she been told of the danger of dehydration. She soon became gravely ill; the doctor who came to the house diagnosed a severe UTI and told her the catheter needed to be replaced every week or two. He taught Flory's sister to change the catheter, and months later in rehab she learned to do it herself. She still gets an infection once or twice a year, "because I stop drinking water or I drink a lot of Coke or a lot of coffee, out of carelessness. But I look after myself and I recover."

Nowadays only Manuel (who has limited use of one arm) and Kevin still rely on assistance to change their catheters. The others taught themselves or learned in rehab.

In the 13 years since Kimberly was shot, she has been readmitted to hospital many times for UTIs, usually for two to three weeks. She tries to prevent infection by drinking water and eating citrus fruit. Manuel returns to

hospital once or twice a year because “my catheter gets blocked”, which he blames on too much coffee and soft drinks. The last time he went into hospital, he developed a pressure sore – a problem he does not have at home.

Byron is entitled to be treated at the IGSS hospital but has never been readmitted there for a UTI. Instead he is offered outpatient appointments, sometimes months in the future, forcing him to seek another option. He usually goes to a private doctor who sends him to a private laboratory for tests, then prescribes an antibiotic which he buys at a pharmacy. One of the benefits of belonging to IGSS should be that medication and supplies such as catheters are provided free. However, in Byron’s experience IGSS is often out of stock, forcing patients to buy their supplies from commercial outlets. Byron also takes Pregabalin or Lyrica every day for his back pain, but IGSS only provides enough medication for a few days at a time. He cannot afford the transport to keep returning for additional medication, so buys this medication privately as well.

5.8 Bullets in the body

Four of the participants still have bullets in their bodies. Jairo and Byron were shot multiple times and had surgery to remove some bullets, but others were left due to the risks of extraction. Kevin was shot twice; one bullet was removed from his stomach and one remains in his back. Flory was shot just once, but the bullet lodged “between my ribs and my liver.” Asked whether it bothers her to know the bullet is inside her, she replied:

> It's not the knowledge that bothers me, it’s that it hurts me a lot… I’m in pain day and night. Sometimes the pain is more intense, especially if there is a moon effect or a change. It affects me a lot, and when it’s cold it affects me more, so I try to keep covered with something warm because of the pain. The pain is perennial, it’s hurting me now, but I have learned to live with it – not to ignore it, because there are times it can’t be ignored. It’s very strong.

She has discussed the pain with doctors but was told “There’s no reason why that should hurt, you’re imagining it. It’s all in your head, you’ve gotten the idea that it hurts.”

Despite saying the knowledge of the bullet’s presence does not bother her, she assigns meaning to the pain:

> It is something that reminds me that I made a mistake that cost me a lot, it cost me a high price to fall in love with someone who was not worth it, at least for me, maybe for someone else but not for me. He wasn’t the person I hoped, and I paid a high price.

Byron was initially left with four bullets inside him, but two worked their way to the surface and were removed. (“It hurts more when they take out a bullet that when it enters.”) The remaining two cause him severe pain in his lower back:

> Sometimes it stops me and I have to count to 10 to relax, relax… in the lumbar area the pain is really severe, and sometimes it irritates me, it puts me in a bad mood. Someone will speak to me and POW, I explode.

Kevin, Jairo and Byron said they had been shot with 9mm bullets, and Byron's second shooter fired a .45 calibre pistol. Manuel, Kimberly and Flory did not know what guns were used against them, although Flory's visual description corresponds to a 9mm semi-automatic pistol. As mentioned earlier, this is the gun most commonly sold in Guatemala.

5.9 Mental health

All the study participants reported their current mental health as good; though all said they had felt depressed or despairing, especially in the early months or years of living with a spinal cord injury. None of the participants said they had taken any mental health medication.

Leaving hospital was difficult for most participants. As Kimberly said, coming home made her feel bad:

> Because it wasn't the same, it wasn't the same anymore … Firstly because I couldn't go to school, it was like being – I had to be rehabilitated, it was a different rhythm of life, I didn't feel the same. It was like I began to lose my sense of what home meant for me, because home for me had meant fun – but afterwards it was lying there all day watching TV, and that was it.

Flory had been living with her boyfriend when he shot her. On her discharge from hospital, they both went to live at her parents' house:

> Arriving home was the most difficult, realising that my life had changed completely. [It was] was a very heavy moment, it was like drinking a glass of bitter vinegar and saying, what am I doing here? [The boyfriend] carried me inside and I looked at him and thought, now what? There was nowhere to go, what course was I going to take? They all had their lives and could continue as usual, but not me.

Kevin, the most recently injured participant, said he still gets depressed: "Sometimes I cry a lot and I can't control my sobs." He attributes his sadness to feeling alone, missing his hometown and his family:

> For example, recently my grandmother came for my birthday... Since she left, I hadn't left the house until yesterday I went out in the neighbourhood. But when I spend days inside is when I get depressed. But when I see people I know and they talk to me, they revive me a bit, they talk to me kindly, they treat me well, that helps me to not think about depression, not be a little depressed, not think so much about my family, that I want to be close to them.

He talks with God as a mental health strategy: "I start talking to God, and wonder if I'm crazy, because I talk to Him as if He were there with me, and He would listen to me and answer me."

Byron became so depressed that he attempted suicide twice, driven to desperation by physical pain and financial worry. The second attempt brought admission to the psychiatric ward:

> Ugh, it was an unforgettable experience, because there are people who are out of their tree... people who scream because they have a screw loose, who stand in front of you and scream. And I was

> "Dang!" so scared, so they put me in a room on my own, because I was afraid and said, "Please double bolt the door so nobody can get in here!"

After one night he negotiated his discharge by convincing the psychiatrist that he was not mentally ill:

> When you go to your session you tell them the exact date, day and time, and they'll say, "This guy is fine," and out you go.

He was offered follow-up counselling but could not afford the taxi fare to the hospital for the appointments. He was eventually rescued from depression by a friend who told him to focus on finding a way to bring in some money. (Money remains the main cause of stress for most participants.)

Most participants said they had suffered nightmares, flashbacks, fear or anxiety in the early day after being shot. However, these have reduced with time, as Kimberly explained:

> The truth is I don't worry about it. It's not like I go out on the street and look around feeling worried. No, I don't have that fear. In the beginning I did have it, like a firecracker or something would scare me a lot, but not now. I've learned to overcome that situation… Sometimes I have dreams about someone shooting me or something and it's a bit – I wake up scared, but I say, it's over now, I got over it once, and it's just a dream.

Kevin often thinks about his shooting and feels afraid, even though he knows his assailant is no longer alive. (He was shot by a romantic rival who has since been murdered.) Kevin and Flory became visibly emotional remembering their shootings. More than the other participants, these two speculated during their interviews about what they might have done differently to avoid being shot.

Flory had access to a psychologist when she was in the Von Ahn hospital, but didn't talk to him because she didn't trust him enough to tell the true story of her shooting by her boyfriend:

> Back then I was afraid to talk about what had happened to me…. To be judged, to be criticised, to be labelled as an idiot, because I was so young and had already got together with a man … Out of shame, that's why.

Kevin wished he could get some mental health support:

> I would like to talk with a psychologist, I've never spoken to a psychologist, but I feel, yes... I sometimes think, sometimes I remember the past, I remember the things I did before, how much fun I had, when I was getting up to mischief or playing with friends, or in the disco. And a part of the trauma is erectile dysfunction… [That] has traumatised me.

He has a new girlfriend and was the only participant to comment on SCI affecting his sex life. Byron said he and his wife have learned to work around it. The other participants are all single and not sexually active. Manuel and Kimberly believe their injuries will not prevent them from finding romantic partners in the future.

Chapter 6 Justice

Kevin was riding his motorcycle late at night when he was shot by his girlfriend's ex-partner (see Appendix B). The shooter had earlier threatened him, and Kevin thought they might end up in a fight; instead, the man attempted to kill him. Kevin has never been interviewed by police about his shooting: in the immediate aftermath he was too unwell, and neither he nor the police followed up afterwards. His reluctance to talk to police stemmed initially from fear of retribution by the shooter. The shooter has since died, but Kevin remains afraid of attacks by the dead man's friends.

Kevin's experience of the justice system was generally similar to of those of the other participants. Most thought there had been little or no investigation into their shootings, and none was aware of any arrest having been made. Despite this, most of the participants did not demand justice or even cooperate with police, for fear of making a bad situation worse.

6.1 Absence of criminal investigation

Guatemalan police are required by law to investigate serious crimes including attempted homicide and criminal injuries (Decreto No 51-92, Código Procesal Penal, Art 24, 112). However, five of the six study participants said little or no effort had been made to investigate their attacks or apprehend the perpetrators.

In Flory's case, the shooter (her boyfriend) accompanied her to the hospital where he claimed she had been shot in a robbery at a local bakery. A police officer at the hospital heard the bakery story but never asked Flory to explain what had happened. Like Kevin, Flory made no effort herself to bring about an investigation. However, she considers that the police should have investigated the bakery story, since a cursory inquiry would have revealed that no such robbery had occurred.

Jairo was interviewed briefly in hospital by police about the theft of his taxi, but it seemed that they were investigating him as a criminal, rather than as a victim: "they thought I was involved in something." Despite following up afterwards, he never received any information about progress, and he believes the police did not actually investigate the theft of his car or the attempt on his life.

In contrast, Manuel felt more positive about the authorities. His case was an extortion shooting on a bus, a type of crime often in the news, with its own section in the annual report of the Office of the Human Rights Advocate (eg PDH 2016, pp. 55-57). Detectives spent about 10 minutes showing him photos to see if he recognised his attacker:

> I think they made an effort … They showed me some photos of people they had [previously] detained … There were photos of guys from the neighbourhood whom I knew, but they hadn't done anything to me.

The detectives were friendly, and he felt that they wanted to help him:

They said, “If we get the guy, we’ll get some money off him and give it to you.” Like to help me.

Q: Do you think they meant that seriously?

I don’t know because I never heard back from them.

Manuel thought his attacker might be found, because the detectives told him that security cameras had captured images of both the shooter and an accomplice. He never heard back from the detectives, but he did think that an investigation had occurred. His case may have received higher investigative priority because it was a bus shooting, or because of the bus driver being murdered as well as the attempt on Manuel’s life.

Flory and Kimberly speculated that they were not interviewed by police because they were minors at the time, aged 17 and 12 respectively. Instead, the police spoke to Flory’s boyfriend (not realising he was the shooter) and to Kimberly’s mother. On the other hand, Manuel was interviewed, despite being only 14. It may be that police are inconsistent in their approach to underage victims; or perhaps the policy has changed, since Manuel was shot more recently.

6.2 Reluctance to cooperate with police

Three study participants – Flory, Kevin and Byron – knew the identity of their shooters (or in Byron’s case the gang boss who ordered the shooting), but they chose not to inform the police. Flory’s low self-worth and passivity kept her from turning in her boyfriend, but Kevin and Byron kept quiet out of fear of reprisals.

Byron was shot in error by young gang members who mistook him for the target they had been sent to kill. The gang leader, someone Byron had known since childhood, apparently felt bad about the error. On arrival by ambulance at the hospital, Byron was approached by a woman offering him an apology and an envelope containing Q2000 (US$260) as an inducement to silence. He refused the money, but still complied with the gang’s gag order when the police spoke to him:

A detective came on the third day [in hospital] and took my statement. The only thing I told them was that it was just an ordinary street crime …

Q: You told him it was a random street crime … but by the time the detective arrived, you had already received an apology and been offered Q2000. So in fact you did have some information that could have helped them find the shooters?

Exactly.

Q: But you didn’t share that information?

I didn’t share it.

Q: Do you think they realised that you knew a bit more than what you were saying?

Yes, but since we’ve often seen that the police are involved with those same [criminals], you can do more harm to yourself and those around you. So better not, just say “street crime” and leave it at that.

Byron not only concealed the gang leader's identity, but also told police he did not want them to investigate:

> The detective asked, "Are you sure [you don't want us to investigate]? Because we can investigate and send people to prison." But on that point, people going to prison, that's impossible! Because – unless you're a member of Congress or something where they would pursue the investigation to the end, sure! But not for [someone like me] ... It's only if you're a powerful person that the investigation would go forward.

Kimberly had no idea who had shot her, but even at age 12 she felt it was safer if the police did not investigate:

> I told my mother, "No," because the situation here in Guatemala is dangerous and we don't know what those people are like, or who they were, so I thought, "Why take the risk?" ...
>
> Q: Did you think they could hurt another member of your family?
>
> If they knew we were investigating or something like that, I think so… And here in Guatemala, when they do investigate, the police are so corrupt and all that, so better leave it. Anyway, the damage is done and nobody is going to pay for that.

Kimberly was the only participant to mention the notion of "paying for" the "damage done". Her comment was made in an explanatory, matter-of-fact tone, without bitterness. Like the other participants, she had no expectation that the state would provide any kind of redress, satisfaction or support for her as a victim.

Manuel did cooperate by telling the police what little he remembered of his shooting on the bus. However, he never followed up to ask about the outcome. He said he might have, if someone had pushed him:

> But I didn't have anybody to say to me, "Let's go and ask what's happening [with the investigation]." The truth is … whether they caught the guy or not, it doesn't matter to me.
>
> Q: It makes no difference to your life?
>
> No, in fact if they did get him, I think they [the extortion gang] might even have come after me again, like, "That's the guy who told on us." So it's better to leave it as is.

This comment from Manuel shows that, although he did cooperate with the authorities, he shared the other participants' apprehension about a potential revenge attack arising from the investigation.

The fear of revenge attacks for telling tales seems justified by Byron's experience. Toward the end of his hospital stay, the gang boss who had ordered the shooting came to see him, accompanied by two bodyguards. The gangsters did not speak to Byron: "They just looked at me, then turned around and left." Byron believes the visit was a warning that he should not try to seek justice "for the accident that happened, for the mistake."

Jairo, who was shot by car thieves, was the only participant whose sense of justice led him to push for an investigation:

> In fact, I went to see what they were doing about the investigation, but [they said], “Well, we didn’t find anything, so let's just say case closed and leave it at that.”
>
> Q: Where did you go?
>
> The Public Prosecutor, the police, they didn’t investigate anything. And that is what kind of bothers me, there’s nobody – you don’t feel protected by the authorities.

6.3 Stigma associated with gun violence

The stigmatisation of gunshot survivors as presumed criminals was experienced by most of the male participants. Kevin was viewed with suspicion in the San Juan de Dios hospital because he was a gunshot patient and had a tattoo. He was accused of being a gang member by a police officer:

> [My tattoo] is nothing to do with gangs, but here in the hospital there was an officer who hassled me a lot. I was [on a stretcher] on my way to get an X-ray… [The officer] lifted up my shirt and saw my tattoo, he lifted my shirt and asked what gang I was from… And my brother was alongside me, “What’s the matter with you?" ... I said, "Do you see a number or something that identifies me as a gang member?[30] Don’t be like that, we are not all criminals here."

As mentioned earlier, Jairo encountered the stigma among doctors in hospital, but also among members of his church who glared at him:

> And I had to ask them, “Why are you looking at me that way?”
>
> “Well, brother, it’s just that we don’t know what happened to you, why are you like this [ie in a wheelchair]?”
>
> So I told them, “Because my car was stolen.”
>
> “Oh, we thought it was because you were a gang member or a thief.” After that, their manner of dealing with me changed.

As a result of this stigma, Byron and Kevin routinely attribute their SCI to a more benign cause, namely a motor vehicle accident. Byron explained:

> Because sometimes people … ask, “What happened to you?” And you can see they’re the type of person who BOOM, if you mention it was a gun, they get scared – and if they see you again, they don’t want to know you. So it’s better to say it was a car accident, because people are scared.

[30] The two major crime gangs in Central America are known by numbers, MS-13 and Calle 18, and gang tattoos often incorporate 13 or 18 in their designs (International Crisis Group 2017).

6.4 Was justice done?

As far as the study participants know, no one has been prosecuted for the attacks that nearly killed them. They handle this apparent lack of justice with equanimity (or fatalism). Byron has the satisfaction of knowing that his two young gunmen, plus the boss who ordered the shooting, have been punished for other crimes:

> It doesn't bother me because if I have learned something in life… it's that everything good or bad that you do has its reward. Like in their case, the two who shot me, both of them are dead… They are dead for different reasons, the lives they led… I saw it in the newspaper, someone told me, "Look, so-and-so, they dropped a motorcycle on his head because he was stealing, or he was extorting," and the other one was set on fire in a prison in Escuintla. And my friend who I grew up with, the one who sent [the shooters], he's in prison in Escuintla, serving a sentence of 50 years.
>
> Q: So in a certain way, do you think there is justice?
>
> There's no justice here on earth from the authorities. But you can't escape the justice of God.

As mentioned above, Kevin's attacker was also later murdered. Manuel imagined that same fate could have befallen the man who killed his boss and left him paralysed:

> Maybe [my attacker] has also been killed, because if you get involved in problems [ie bad activities], well then… I don't think about him, but just as he did something to me, maybe he tried to do the same thing to someone else who would strike back and do something, like kill him.

Jairo was the only one to express anger about inaction in the justice system. However, his feelings about his shooter have evolved over the 13 years since the attack. Initially he was furious and wanted to hunt down his assailant to exact revenge:

> My way of thinking was that as soon as I'm healed, I'm going to start investigating who did this to me, to search and search.

Now he takes a different view:

> We don't know what happened to him, it is possible that someone killed him, or that he was picked up for another crime, or that he escaped justice. Well, sometimes I think about that. If I found him, I think I would forgive him for doing this to me.

Kimberly is similarly forgiving:

> I really can't feel anything, positive or negative because I don't know that person [who shot me]. I just think, what kind of life did they have to end up doing something like this? I try to put myself in their position and say, "Well, we all have reasons why we do things," and I hope that person at some point in his life, if he is still alive, has reconsidered and repented. I don't wish him anything bad, it's fine.

Although the participants have come to terms with what is objectively a lack of justice, most would have wanted their attacker to be arrested if this did not put them in danger. Flory was the exception. Her tolerance of impunity went so far as to be glad that her attacker had not gone to jail:

> I've never asked for justice, I just say, "Well, God allowed it to happen." And I thank God that I didn't accuse him, because I don't know what would have happened, and that is a burden on my conscience that I would not like to carry. I feel free of that weight.

Underlying this degree of acceptance could be Flory's sincere belief that what God has allowed should not be questioned; or her feeling of shame and guilt for becoming involved so young in an unhealthy relationship. She also seems to devalue her own suffering as a survivor of brutal domestic violence before being shot. Rather than identifying as an innocent victim entitled to justice, she feels responsible for how her attacker might suffer if he were obliged to confront the consequences of his crime.

6.5 Attitudes toward firearms

Participants expressed a range of opinions about guns and gun violence. Kevin likes guns, and Byron thought of saving up to buy one, but decided against it because of his own impulsive character: "I'd be risking 25 years in prison, so better not." A soldier at a military barracks near Jairo's house offered to sell him his gun:

> So I went home to get the money and my oldest daughter asked, "Dad, where are you going with that money?" "It's just there's a soldier out there who will sell me a pistol for Q600." "You, Dad? We go to church, what's the matter with you?" "Well, if we were out together sometime and I had to defend you, wouldn't you want me to defend you?" "Sure Dad, but remember that you're a Christian, and a Christian doesn't need a gun." "You're right," [I said].
>
> Q: When you say a Christian doesn't need a gun, what do you mean?
>
> Simply because one is protected by God, that's the real reason.

Kimberly and Byron want stronger gun control, but Jairo disagrees:

> I think [guns] are a matter that cannot be controlled by the authorities, or anything. Because I think our society and our people have lost their values, that's why we are where we are. It's not the authorities that are to blame, it's the family's fault, really the family, because the family has lost it values, it's lost all that, and that's why the situation has become so bad.
>
> Q: But families in other countries have also lost their values, yet they don't have so many homicides…?
>
> Because the system is different! In other countries, something happens and immediately the authorities [are onto it], or if someone does something, they catch them and do justice. But here, people can see for themselves that they shoot you, or me, and everyone just says "Poor thing..." but they don't do anything.

Flory is frightened by gunshots in the neighbourhood:

> That makes me nervous and scared because I know the damage they can cause. It's not fear for myself, but for someone else – because the only thing that can happen to me is to die or something, but someone else could get hurt. So it is scary... if I hear a gunshot or see a gun I start to tremble.

Chapter 7 Economic Impact

When Manuel was shot at age 14, he had already been contributing financially to his family for several years by working as a bus driver's assistant. The driver was murdered in the attack, presumably for not paying extortion money (see Appendix C). Manuel's spinal injury is higher than those of the other study participants, and he has only partial use of one arm. His shooting cost his family two incomes, since he was no longer able to work and his mother quit her job to care for him.

Each participant's economic position varies according to factors including their situation before being shot, sources of income, health, whether they have dependents or perhaps a benefactor, and housing. One thing they all have in common is financial stress. Rent is the major cost for most, except for Jairo whose family owns their home and Flory whose family lives on squatted land. External events also have financial impact. For example, Byron earns his living by begging on the street, and he has been hit by cars several times. Each time he is run over, he is hospitalised and thus unable to work for a period, worsening the financial position of his household.

7.1 Impact on income

As mentioned in Chapter 4 – Guatemalan Context, the country lacks a broad social safety net for poorer people: there is no crime victims' compensation or unemployment benefits, and the limited workers compensation / disability scheme only applies to a minority of the population who belong to social security or IGSS.

This section considers the participants' incomes in relation to Guatemala's minimum monthly wage (MMW), both at the time when they were shot and in 2018 when they were interviewed for the study. The general MMW in 2018 was Q2992 or US$409 (Acuerdo Gubernativo No 297-2017).

Most of the study participants had a combined household income greater than one MMW before acquiring a spinal cord injury. For Byron (age 26 at the time), Jairo (25) and Manuel (14), it meant an abrupt curtailment of the income on which their families depended. Kimberly's shooting at age 12 had the same effect, as her mother was obliged to quit work. These four families saw a reduction in income of about 50%.

Prior to Byron's shooting, he and his wife both worked at a *maquila* or clothing factory. Their combined monthly income was Q4800 (US$600), the equivalent of 2.5 MMWs at that time. Even with two salaries, they were sometimes unable to cover rent and living expenses for themselves and their baby. Still, Byron hoped to save up, buy a piece of land and eventually build a house for his family. Eight years after his shooting they have a second child, his wife is still in her factory job, but their household income has dropped to around Q3900/month (US$510), the equivalent of 1.5 current MMWs. Byron works much harder than before to earn this reduced income, leaving home six days a week to beg at 3am and returning 16 hours later.

Byron was initially fortunate that his old job came with Social Security (IGSS) coverage. After he was shot, he received a one-off IGSS disability payment of Q5000 (US$625) but did not qualify for the ongoing disability pension. His failure to qualify may have been because he underwent rehabilitation at IGSS, and therefore was considered capable of working. Byron also considered himself able to work, but his former employer refused to take him back, leaving him unemployed. Money worries drove him to depression; after his suicide attempts, he swallowed his pride and began to beg. He has learned techniques for improving his takings – for example, passers-by give him more money if he sits cross-legged on the ground instead of in his wheelchair. The price of sitting in this position is that his face is at the same level as the car exhaust pipes, "and when I get home, I pass a wet cloth over my face, it comes out really black from the smoke from the cars."

Recently he revived his dream of a piece of land, and began a savings plan in a jar. There are two versions of the one-quetzal coin in circulation, the new coin being thinner than the old one. Every time Byron receives a new thin coin, he banks it in the jar:

> We started in January and [my family said] "oh, it's not filling up!" [I said] no, don't get worked up about it, just keep putting it in there for the end of the year, and if we get together a decent amount, we'll put it in the bank and start another container, another year, to be able to buy something. A lot of people say, "Buy a motorbike, buy a car" … but my vision is to have somewhere to live, so that my children are not fluttering from one place to another.

Jairo's monthly income as a taxi driver was about Q4000 (US$524), or 2.8 times the MMW in 2005. He considered this a reasonable income from which he paid child support for his two young daughters. He lived at his mother's house, along with his sister, a single mother of three. After he was shot, his daughters came to stay with him, and the whole household of three adults and five children depended for eight years on Jairo's mother's income of Q3000/month (US$400). During those eight years Jairo was too ill with infected pressure ulcers to work. Later his sister and mother were murdered, so it fell to him to support the four children still at home. Out of necessity he took up sewing, which now earns him about Q2000/month (US$260), or two-thirds of a minimum wage. In his interview, when Jairo was asked about his mental health, he replied that he worries about money. He is sometimes mistaken for a beggar, which annoys him:

> I was flagging down a taxi… and suddenly [a motorist] put his hand [out the window] and [gave me] 50 cents! I started to laugh, and the man saw me looking at him like that and said, "Excuse me if I offended you."
>
> "The truth is you didn't offend me, but you know what offends me?" I said, "If I'm going to give someone something, I'll give him something significant, but I'd be ashamed to give someone 50 cents." …
>
> The man stared at me … "I'm going to pull over and give you a lift. You just taught me a great lesson, brother." [So] he pulled over and drove me home, and we were chatting, "Look, sorry for having offended you," [he said].

> "Listen brother, I'm going to tell you something very special… Look, I'm a child of God, I don't need anyone to give me anything, and if I have money it's because I earn it, I've never wanted to be given anything. Since I was a kid, 13 years old, I've been working and I never asked anyone to give me anything, much less being like this [in a wheelchair]."

Kevin has no dependents and has been shielded from the general poverty in Guatemala because his living costs are subsidised by remittances from his mother, one of the millions of Guatemalans who emigrated to the United States in search of work. Kevin was raised by his grandmother in a coastal town. After being shot he was transferred to the capital for treatment, and health problems have kept him there ever since. This has caused financial hardship for his mother:

> She had two bank accounts [before the shooting]. In one she had Q36,000 (US$4700). The other one was less because she had just opened it, it was about Q8,000 (US$1050). Later they told me one account had been closed because there was nothing there – that was the Q36,000. And then we had to sell a block of land … We had to sell it for Q15,000 (US$2000), to cover my expenses and it is still covering them now.

Kimberly was shot as a schoolchild who was not working, but her injury nonetheless affected the family income dramatically. Her single mother was a manager earning Q5000/month (US$650) or 3.5 MMWs, so the household was relatively comfortable: for example, Kimberly and her two younger brothers went to the movies regularly. This was the highest pre-shooting monthly income reported among the study participants. After Kimberly was shot, her mother had to leave work to look after her. A severance payment lasted a year, but now the family's monthly income is about Q3000 (US$400), or one MMW.[31] The household survives on whatever her mother can buy cheaply and resell – eggs, ice cream, bread, vegetables. She also cleans houses, and Kimberly's father and grandfather contribute occasionally. For Kimberly the reduction in circumstances has been obvious:

> [Now] we have to go without certain things to pay for others. Like going out on the weekend, we can't do that because there are expenses to pay… I remember before, there was nothing we needed. But now it's noticeable.

Kimberly is studying computer science at university, and her financial worries are reduced by her confidence of finding a well-paid job in future. She is also shielded because her mother handles all the family finances.

Flory is another participant who was not earning money when she was injured. At age 17, she was keeping house for her boyfriend – and had served him his dinner just minutes before he shot her. Now aged 40, she lives with and depends financially on her sister's family. In 23 years Flory was never able to get paid work, but recently she began making *guaipes*, industrial cleaning rags that are produced by picking apart fabric offcuts from textile production. She wears a mask to protect against the fine fibres that rise in a cloud around

[31] Kimberly's mother provided this information on household income and costs.

her while she works, sitting on her bed. She earns Q300/month (US$39), or one-tenth of a MMW, and is proud that she buys her own toiletries, living precisely within her means. Although this means she cannot save, "it also means I have no debt."

7.2 Impact on costs

All the participants have additional expenses as a result of acquiring a spinal cord injury. This reflects the research finding of Mitra et al (2017). The direct costs associated with SCI can include medical or rehabilitation expenses, wheelchairs, medication, incontinence supplies, personal assistance and modification of dwellings; as well as the additional cost of services such as transport which is more expensive for a person who uses a wheelchair.

7.2.1 Initial costs in hospital

Although Guatemala's Health Code stipulates that that health care is "guaranteed to be free" (Código de Salud, Decreto No 90-97, Art 4), most of the participants incurred costs for their treatment in public hospitals. Jairo recalls his family having to buy everything he needed 13 years ago at Roosevelt, including food, water, nappies, catheters, medication, MRIs and other scans. The scans should have been free, but "supposedly the machines at the hospital were broken"; so Jairo travelled by ambulance to a private imaging centre where each test cost up to Q700 (US$90). He estimates that his month-long stay at Roosevelt cost him Q15,000 (US$2000), nearly four months of his earnings at that time.

Kevin's experience two years ago at San Juan de Dios was similar, but he recalls it less negatively (perhaps because he was not paying the bill himself). Asked about the cost, he first insisted, "Everything is free, it's a public hospital." A moment later he added a caveat:

> We had to pay for X-rays …Sometimes the equipment doesn't work, and they spend days without X-rays or ultrasound, anything like that. So they send you to another laboratory outside the hospital to get those scans and deliver them to the hospital … The most expensive cost was Q1800 (US$240). Others were Q600 (US$80), Q700 (US$90) – sometimes there were several on one day.

Flory and Kimberly were treated 23 and 13 years ago respectively at San Juan de Dios. Both women were minors at the time. Flory does not recall having to pay anything; though she admits she may not have been aware of costs being incurred. Kimberly, who was only 12 years old, said her mother had to bring her a pillow, bedclothes and food during her two-month admission. However, her mother remembers it slightly differently. Speaking informally (she was not interviewed) Kimberly's mother said she voluntarily brought those items from home to make her daughter feel more comfortable. She did pay Q1500 (US$200) for an MRI (30% of the family's monthly income at the time). Kimberly's subsequent re-admissions for urinary tract infections have often required her mother to venture out to find medications that are out of stock at the hospital. Most recently she spent Q180 (US$23) at a pharmacy on an antibiotic which should have been administered for free in hospital.

Since Byron was covered by IGSS while he was employed, his treatment in the IGSS hospital was free, not only after the initial shooting, but also for subsequent admissions due to injuries. Begging on the footpath at a busy intersection, he has been run over twice by cars and once by a bus, each accident landing him in hospital for a period ranging from days to months. He said he has never incurred costs as an IGSS inpatient.

7.2.2 Costs of living with a spinal cord injury

In addition to the ordinary costs of daily living, most of the study participants said they struggle to cover the additional costs resulting from having a spinal cord injury. These range from consumables like catheters to the excessive cost of taxi transport.

The first cost mentioned was incontinence supplies. All the participants use Foley (indwelling) catheters with urine bags, and sometimes nappies as well. Kimberly's family spends Q500/month (US$65), or 17% of the household income, on these supplies. Manuel, whose impairment is more severe than Kimberly's, spends only Q100 (US$14) per month on these supplies, or 7% of his household's monthly income. (This suggests that Manuel may re-use his supplies more often than Kimberley does.) Flory buys nappies from her meagre income, but luckily a friend (another gunshot survivor) gives her catheters and urine bags. Jairo buys his catheters at a commercial supplier for Q27 (US$3.50) each, including urine bag. He also has a colostomy and usually cannot afford colostomy bags at Q260 (US$35) for a two-week supply, but a friend taught him how to improvise with an ordinary plastic supermarket bag and surgical tape.

Bulk buying would be cheaper, but most of the participants cannot afford to purchase their supplies in quantity. Kevin is the exception, because his mother in the US supports him financially:

> Every three months I spend Q3000 (US$400) on supplies, buying tape, gauze, catheters, colostomy bags, medicine that I need when they prescribe it… Because it was more expensive for my mum, to be asking her for a few things at a time, like to buy one bag – so she said, "You know what, buy a good amount of stuff and tell me how much it is." and Boom! I bought 50 bags, 80 rolls of tape. With the 50 bags, thank God a nurse I met in the hospital sells them for Q10 (US$1.40) per bag, because the cheapest ones cost Q28 (US$3.75) [at the pharmacy].

A common complaint is that even if a user has the money to buy catheters, an unreliable supply means they are often not available. Byron is entitled to receive his catheters free from IGSS. However:

> I spent six months where they didn't have them, until I went to lodge a complaint with the IGSS director and the director got me four catheters, that was all … I change it every fortnight, so I use four in two months. Then I was buying them at the Galeno pharmacy, and the Galeno pharmacy ran out … The pharmacy got to know me by my name, and they began to recognise my phone number because I rang them [so often] and they would answer, "Byron!"
>
> And the gloves – because when you are in rehabilitation, they give you gloves to stimulate yourself to be able to defecate. But when you leave hospital they don't give you anything, so you have to buy them yourself.

Q: Does the catheter come with the bag?

No, separately, it's just the catheter…. Sometimes they have bags at IGSS and sometimes not. Sometimes I find friends to barter, I'll give you bedside bags and you give me leg bags.

Other costs resulting directly from being shot include medical expenses for treatment of pressure sores and urinary tract infections, two recurring problems for the participants. Byron buys a spray for his ulcers at Q120 per bottle (US$17) and uses two or three bottles for each ulcer crisis. A single UTI costs nearly 15% of his household monthly income: about Q500 (US$70) for lab test, doctor's appointment and medication. As an IGSS patient he could get treatment free at the IGSS hospital, but the waiting times are long: "It's better go to a private doctor because it's faster, you get treated faster instead of waiting around for it to get worse."

By visiting a local doctor instead of travelling to the IGSS hospital, Byron also saves on transport. Taxi fares to visit a lab, doctor's surgery or hospital are part of health costs for all the participants, since they are unable to use Guatemala's wheelchair-inaccessible buses. The US$6-10 cost of a taxi can be an insurmountable obstacle to health care and rehabilitation.

Taxi fares (or the lack of accessible transport) were also cited as an impediment to other activities such as going out with friends, playing sport or looking for work. Kimberly has occasionally applied online for a job, and though she has never been invited for an interview, she doubts she could afford to get there if one was offered.

Three of the participants (Byron, Manuel and Kimberly) have moved house since they were shot, in order to reduce their rent. However, Kevin's cost of housing has increased because he now rents in the capital, instead of living rent-free at his grandmother's home on the coast. His monthly costs (paid by his mother in the US) include Q400 (US$52) to rent a room and Q1500 (US$200) for a young woman to provide in-home care. He lamented the burden on his mother:

There have been so-o-o-o many expenses, my poor mother, my mother has gotten sick a lot because of that, she suffers a lot of brain pain [migraine].

Buying a wheelchair represents a very substantial expense in Guatemala, often the equivalent of a month's minimum wage. Byron received his first wheelchair for free from IGSS (after a lot of paperwork), but it was smashed when he was hit by a car. Knowing it would be difficult to get a new chair, as he was loaded into the ambulance he called out to the paramedics to collect the broken pieces:

[I said], bring my wheelchair, because my dad can weld it for me, grab the pieces of my chair! Because it broke into 3 or 4 pieces. And the paramedics brought it and my dad did cobble it together.

The repaired wheelchair was destroyed in the next car accident, and Byron persuaded IGSS to replace it. But after that chair was wrecked in the third accident, IGSS refused to replace it. Byron reluctantly sold the family's prized possession, the dining room set, to buy the next wheelchair second-hand. Just as that chair wore out, he heard about Transitions where he was given a high-quality, personalised model.

The other study participants were given their early wheelchairs by friends, churches or charities; although not always the ideal chair for each person's capacity and condition. Jairo and Flory waited about a year before someone gave them their first chairs. Manuel and Kevin were lucky enough to be included in Transitions wheelchair projects as soon as they came out of hospital, so they never had to contend with having the wrong wheelchairs. This was by sheer coincidence: Transitions contacted the Von Ahn rehabilitation hospital when Manuel happened to be an inpatient there, and Kevin met a woman who knew about Transitions while he was in hospital.

Now all the participants have received appropriate wheelchairs made by Transitions, as well as training to maximise performance and reduce the effort required to use their wheelchairs.

Kevin and Manuel (the two youngest participants) mentioned mobile phone credit as a cost that has increased since they were injured. Mobile phones are a lifeline for wheelchair users vulnerable to boredom, isolation and depression. Kevin spends Q270/month (US$35) on phone credit, whereas "before I was shot, I sometimes didn't even get around to topping up."

Poverty itself also drives up living costs. Byron notes that before he was shot, he and his wife had enough money to go grocery shopping every Saturday at the supermarket, and they saved money by buying groceries in larger sizes. Now they cannot afford transport to the supermarket, and they can only afford to buy the items they need one at a time, in the local shop where prices are higher.

When asked about financial worries, Flory expressed concern about the eventual cost of her own funeral, since she is aware that people with SCI tend to have a shortened lifespan:

> I'm worried about dying and leaving my sister the funeral expense. I think, Oh Lord, help me to save a bit to pay for the funeral home, to pay for this or that for my sister … You pay by instalments. It depends on the service, but I tell my sister that I want the most modest one. I said I don't want the vigil [traditionally held throughout the night]: if I die in the day, I want you to bury me that same day.
>
> I don't want nine days [the mass and family celebration held nine days after a death], I don't want this or that … I tell my sister, I have no one to answer for me, because I don't have children and I don't have a husband who'll pay for it, it is a responsibility that I don't want to leave to you or my nieces. So I'm going to try to pay for my funeral, I tell her… So that worries me, I worry about that.

7.3 Financial assistance

Byron received a one-off payment of US$625 from IGSS after his shooting. Otherwise, none of the participants have received financial assistance from any government or non-government agency, although several have had occasional economic or practical support from private benefactors. The most unlikely case was Kimberly, who was sponsored for travel, treatment and rehabilitation at a leading children's hospital in

the US, thanks to a philanthropic celebrity (see Chapter 10 – Identity and Wellbeing). The connection was made through a US-based friend of a friend of Kimberly's mother.

Flory's first benefactor was a family friend who bought her first wheelchair more than 20 years ago. Nowadays another friend (also a gunshot survivor) gives her catheters and sometimes a few quetzals in cash as well.

As described in Chapter 5 on health, Jairo had the good fortune to meet Dr C, a surgeon in private practice who saved his life. His infected ulcers were so severe that the public hospital had turned him away as too ill for treatment. Dr C happened to hear of Jairo's situation and operated on him without charge. Since then he has treated Kevin and several other gunshot survivors critically ill with ulcers. In addition, he is assisting Jairo financially by sponsoring the education costs for one of Jairo's nephews.

Asked about other sources of financial assistance, Jairo mentions God, citing examples like this one:

> God is the one who has helped me... In fact today when I came here [to be interviewed], I don't have any money and I was worried because I have to pay the electricity and water bills at home, and my friend calls me: "I don't know but God has put it on my heart, I'm going to give you Q150 (US$20), send someone around to collect it."

Jairo has occasionally encountered individuals who said they work with an NGO that might be able to help him in some way. They have asked for his mobile phone number and promised to get in touch, but none ever has.

Chapter 8 Family

Flory, who was shot at 17 by her abusive boyfriend, struggled for years afterwards in a dysfunctional family situation (see Appendix D). She now lives with her sister, brother-in-law and nieces in a wheelchair-inaccessible location where she must be carried up a cliff to reach the street. Although their circumstances are difficult, she feels able to contribute to family life. “That makes me feel satisfied, that they value … the little that I know and that I'm there, and that I’m not in their way.”

Family configurations vary among the study participants. For Manuel and Kimberley, family means mother and brothers; while for Byron it means wife and children. Jairo is bringing up his niece and three nephews, after the murder of his mother and sister. Kevin is closest to his grandmother; when he realised that he had been shot, “The first thing I thought was about my grandmother, how she would react, because whenever bad things happen she became very upset, and I thought [this is] going to kill her.”

8.1 Family as a source of support

Asked about sources of support in their recovery, all participants nominated a female family member first: Flory’s sister, Byron’s wife, Kevin’s grandmother, and Manuel’s, Kimberly’s and Jairo’s mothers. Jairo is the only participant who can bathe himself, because a builder friend modified his bathroom for him. All the other participants depend on a family member or caregiver to bathe them by scooping water over them with a bowl. Similarly, they rely on others to check their skin for signs of pressure sores.

Family members also provide critical support at specific moments of need, such as during the initial hospital admission. Kevin’s brother moved from the coast to stay with him for almost a year in San Juan de Dios Hospital, keeping him company, bringing him food and negotiating concessions from the nurses on his behalf. Jairo’s sister and mother alternated to stay with him during his month at Roosevelt Hospital, bringing him water, washing him regularly and changing his urine and colostomy bags. Kimberly remembers her mother being constantly by her bedside in San Juan de Dios, helping with toileting, advocating for pain relief, bringing her comfortable pillows and tasty food.

(Byron and Jairo also have practical family responsibilities themselves, since they are raising children. Byron and his wife share the housework and sometimes pay someone to look after their children because they both go out to work. Jairo, who is a single parent to his niece and nephews, has taught them to help around the house. His adult daughter does the cooking – not, he insisted, because of his disability, but because she is a better cook.)

8.2 Family as a source of stress

Family dysfunction drove Flory into the relationship where she was shot by her partner, and the same family members made her feel like a burden for years afterwards. Byron also experienced the stress of depending on hostile family members after he was shot. He and his wife and son went to stay with his father because they

could no longer afford their rent, but his stepmother was unkind to them. Unlike Flory, Byron was able to change the situation instead of being stuck. He and his wife found a small room to rent and moved out.

Byron, like Kevin, grew up without his mother, who left to look for work in the US when he was small. (Unlike Kevin's mother, Byron's mother eventually stopped sending remittances and lost contact with her family in Guatemala.) Byron's thoughts turned to her as he and his father lay bleeding, having been shot by a pair of teenage gang members:

> [My dad] said, "We're going to die together." "No Papa," I said, "I still have to see my son grow up, we're not going to die… Hang on, and besides that, I want to see my mum" – because my mum had abandoned us when we were little – "and I shouldn't die without seeing her," I said.

Some years later he obtained his mother's telephone number in the US and rang her. It had been 27 years since she left, and he felt sure she would want to help when she learned what had happened to him. However, he was disappointed:

> It wasn't like we'd hoped… it's been about three years now since we were in contact and I haven't had any help from her.

8.3 Impact on couple relationships

Three of the study participants had partners when they were shot. Flory was shot by her boyfriend and ended the relationship eight months later. Kevin was shot by the ex-boyfriend of his girlfriend. The girlfriend visited him once in hospital; but shortly afterwards returned to the ex-boyfriend who had shot him.

Byron and his partner were not married when he was shot, but they married while he was in the IGSS general hospital. He says their relationship is stronger for the difficulties they have endured, but some other gunshot survivors whom he met in rehabilitation have not been so lucky:

> Some of them are already dead, others have addictions, because their wife left them … It is hard, because – at least me, I have a strong character so sometimes I want things quickly – I want this, and I want it now! Because that's what I was used to … It's sometimes patience that separates people, because someone might have a character where anything annoys them and they fight all the time and everything – so in that situation, women sometimes get bored, they say Damn it, I have to bathe him, I have to do this and that, then they have [relationship] problems, they fight and everything, and she's the only one working and the guy isn't, then another guy comes along, talks to her nicely and next thing you know she's gone.

Acquiring a disability has not affected his role or identity as a man, he says:

> No, that would only be if you were sexist! No, when we're going to decide something, it's decided between two people. And the other issue, it's mental, if I can get my wife to finish, so to speak [have

an orgasm], my body also says that's done, so that's the way it is. Sometimes the erection is there, and she has ... she does it all and when she says "Now!" my body feels like dang, the job is done!

By contrast, Kevin mentioned erectile dysfunction as one of the traumatic consequences of being shot. At age 22 with paraplegia, he takes a far more cautious view of sexual relationships:

> I did sleep around a lot before, I can say that… [But] sometimes I feel I'm not sure if what I feel is real or if I'm kind of disappointed, you could say, with love or women. But yes, love – I am very affectionate when they treat me well, I like to be very affectionate. But the sexual issue, no... let's say there are other things you can do, but no.
>
> Q: Do you think [erectile dysfunction] is more of a problem for you or for a girlfriend?
>
> I think for both of us, yes, because sometimes I think she's annoyed about that, because she really wants to do something nice with me and she can't.

Kimberly and Manuel have never had a partner, but both do not believe their injuries will prevent them from love in the future. Jairo said he is not looking, but he might have had a girlfriend if not for the spinal cord injury:

> Yes, maybe it has affected me, because when you're in a wheelchair, the time comes when ... when it feels like you're not worth much. People see you differently.
>
> Q: Like what people?
>
> I'd say the whole society, and especially if you're a man. Women see it that way, but honestly it doesn't affect me [because I'm not looking for a relationship].

8.4 Closer ties with family

Most participants said that, with the passage of time since they were shot, their relationships with immediate family members improved. For Kimberly and Manuel, the change has been dramatic. Previously, work schedules meant they barely saw their mothers and brothers all day. Kimberly and her brothers were minded by babysitters while their mother worked long hours. As for Manuel:

> Before, I was hardly ever at home, I was always out on the street. I'd get home to sleep and eat, then get up the next day and out to the street again.

Since the mothers in both families had to give up their jobs to care for their injured children, they are home together now most of the time. Spending so much more time together has strengthened their connection; as Manuel put it, "We're a lot more united now."

For Kevin, being shot led to a new relationship with his father, who had left the family when Kevin was a baby. Kevin had better luck than Byron with his long-lost parent:

> Because for 20 years [we weren't in contact], but when this happened – I don't know, maybe out of fear that I might die, he came from the States to talk to me. He came to see me in hospital, and that's how I started to communicate with him.

Jairo has more close family than the other participants, because gun violence has thrown them together. His main relationship for the first eight years after being shot was with his mother, who supported him in the seemingly hopeless battle against pressure ulcers. However, he was also raising five children. They all lived in Jairo's mother's house. At the nine-year mark, just when his ulcers had finally healed, his mother was murdered, and he became head of the household. Then his other sister abandoned her 13-year-old son, leaving Jairo as a single father to six teenagers. Jairo's top priority became ensuring that they all finished high school (he himself had only reached Year 9). By the time he was interviewed for this study, his daughters had graduated and the eldest had her own baby. Jairo brought his infant grandson and one of his nephews to the interview, where it was evident that he is a doting grandfather and proud adoptive father. He recalls that when he was ill, he worried about being a burden:

> But they showed me the opposite, my nephews, that's why I help them a lot and I love them very much, ever since they were little, since they've been with me … They have helped me, in fact they're the reason why I keep going – because my mum's not here, my sister's not here… so that's the reason why I continue.

Byron is conscious of having chosen his family over the friends who used to be important to him:

> Lots of friends [used to say] "Come around to my place", let's go here, let's go there – but not anymore. Now there aren't many [friends] because it's not the same anymore. Before the accident it was "Let's go to a party!" … But now that group is "What's up Byron, come around to my place," "No man, I can't." But it's not just that I can't – I mean, in terms of being able to, I could – but I have two kids now, and also it's bad for me, in the long run it damages me. So [I say] "Maybe next time," like that, but there aren't many now.

His family is his inspiration:

> What makes me happy is to arrive every day, "You're home, Dad!" They give me my hug, my kiss, the three of them, my two children and my wife, and when I leave [at 3am] even my 2½-year-old son wakes up and he says "Bye bye dad!" because he knows I'm going to work to bring him his nappies, so that he won't have to cry. And that motivates me, and I leave happy and come back happy, because I bring them maybe an orange or an apple, they expect that I'll bring them something, and that is my motivation and I feel happy.

Chapter 9 Religious Faith

Byron was shot 12 times by a pair of young gang members in his neighbourhood shop (see Appendix E). He was nominally a Christian before the attack, but now turns to faith every day for strength and comfort. He believes his shooting was part of God's plan to make him lead a better life; and that prayer helped him survive his injuries. He often appeals for divine help and can recount examples of his pleas being answered.

All the study participants identify as Christian, some specifying Evangelical or Catholic. Church attendance varies from six days a week (Jairo) to not at all (Kimberly and Flory). All participants said their faith has helped them come to terms with what happened to them.

9.1 Before the shooting

Like Byron, most of the study participants were irregular churchgoers. Flory now believes that her failure to take God seriously was a factor keeping her in a violent relationship with her boyfriend:

> Actually, I don't think I really had it [faith]. I believed that it was I myself who achieved things or had things … If I'd had God at that time, I would've realised that I did not deserve what was being done to me and I would not have allowed it. But since God was not there at that moment – I mean, He was with me, but I didn't think He was – because I thought I was fine and I knew it all.

Kevin was "a believer, but it was just me with my belief in my mind... I very rarely went to church, to pray and clap there." One of his acquaintances was a taxi driver and part-time pastor who used to bring his car to the service station where Kevin worked:

> He used to see me at work, ever since I started there, and when I was working on his tyres he would talk to me about God. But I'm really stupid, because I didn't realise that God is the only one that's with you, so I would try to serve him quickly because it was boring … Even today that still makes me feel bad, because I think, why didn't I take his advice, all the talks he gave me ...

9.2 After the shooting

On the night of Kevin's shooting, the taxi driver / pastor was one of the motorists who gathered around as he lay by the side of the road:

> [The pastor] got there, knelt down and grabbed my hand and told me I was still in time to ask God's forgiveness, if I wanted to go with God.
>
> Q: Did you think you were going to die?
>
> Yes, because of what had happened, I'd been killed! ... and that guy was holding my hand, telling me to ask forgiveness from God.
>
> Q: And did you ask God for forgiveness in that moment?

Yes, I had to do it.

Byron also invoked God in the immediate aftermath of his shooting, asking to be allowed to survive. Kimberly had a visit in hospital from a spirit nurse who urged her to trust in God (and informed her that she would never walk again).

All the participants said their religious faith is stronger now than before they were injured. However, the shift was not immediate. In fact, Flory lost her faith after being shot. She recalls a conversation with the physiotherapist, Dr H:

> "Oh Flory," he said (he is a Christian), "God help you and give you strength because if he left you here [alive], he has his reasons." And I said, "What do you mean? God doesn't exist, Doctor – look how I am! If He did exist, then I would have died, or I would have been left normal [without a disability]." "But this was what you got, trust in God, you have to try hard, it's true that there are lots of things you can't do, but there also is a lot that that you can."

Over the years Flory's thinking changed:

> [I used to think that] if God existed, I wouldn't have ended up in a wheelchair. But I didn't recognise that I had also brought the problem on myself. That is, God gives us opportunities and we are the ones who choose what we want to do.

Kimberly used to go to church as a child, but now believes religions are too prescriptive. She said: "I believe in God, but not religion … I moved away from the church, but not from God."

For the first three years after he was injured, Jairo did not go to church, or even leave the house, because he only had a part-time borrowed wheelchair and because he didn't feel like it. However, a churchgoing friend persuaded him to go, and now he attends church every day except Monday.

9.3 Making sense of what happened

The study participants believe God allowed them to be shot as part of His plan for their lives. Byron thinks the message was to change his unruly ways: "slow down… do something better." Jairo sees a lesson in his shooting: "God allowed things to happen in order to teach me the value of life."

Flory similarly believes a lesson was being taught:

> I think He allowed it, because nothing happens unless God allows it; and this way He allowed me to understand and comprehend that life without Him is not life, that He is the one who decides if we live or die.
>
> Q: So was it like, a lesson?

> To teach me that everything has a time, a reason and a purpose … I am grateful first to God, because He gave me the opportunity to understand that there was a reason why I ended up in a wheelchair and that my life changed, I hope for the good, and to be happy...
>
> Q: But do you feel that God was punishing you ...?
>
> No, at no time have I felt that it is a punishment from God. At times I've complained like Oh Lord, you forgot about me, because look at how I am ... those are moments of depression or sadness, but I've never blamed God or said it was His fault, not at any time.

Flory and Jairo both conflated the question of why God allowed them to be shot with that of why God permitted them to survive:

> (Flory) Because I easily could have died, but I didn't die, I'm still here, so... I learned that without Him I would have died a long time ago.
>
> (Jairo) I think maybe God allowed things to happen to me because otherwise maybe I wouldn't be with my family or I would have died on the spot, and I wouldn't have the opportunity to do the things I'm doing now.

Kevin is also confident there was a reason (albeit still unclear) for his shooting. As the most recently injured participant, he has had less time than the others to consider the question:

> I think everything happens for a purpose and God has everything prepared … I still don't understand what God's purpose is for me, but I know that one day I will understand it and that will be my way of thanking God.
>
> Q: Do you ever feel guilty? Like it was your fault?
>
> The truth is yes, I think so because I had no need to get together with her, with that woman [whose ex-boyfriend shot Kevin]. I had better [options] where they could give me affection, but I don't know what happened. And despite – she was the only one, of all the girls I went with, who had a child – and despite that I still thought about settling down with her, maybe that was my mistake. [Crying]

While accepting that God allowed his shooting, Kevin also credits Him with saving his life:

> From the moment that bullet hit my spine, God was with me. Because if that bullet hadn't hit my spine, if I hadn't fallen, [the shooter] would've hit me, he would've shot me in the head. That fall … was what caused the shots to be diverted to this side here… And from there, God was with me, because I thought I was going to die when I was raising my hand [trying to flag down cars] and I couldn't even scream, and nobody was helping me.

9.4 The silver lining

Kimberly enumerated the benefits that have come about because of her shooting:

> Things happen for a reason. I look at how I was before and how my life could have been, and how I am now, and it's worth it, it's not as bad as I thought.
>
> Q: When you say things happen for a reason, what do you mean?
>
> Well, I mean that God has a purpose in the situation and that he knows what is best. Maybe it's not a very logical thing to say, that it's somehow better to be in a wheelchair, but now at least I can be closer with my mum, with my brothers, I had the opportunity to meet a Hollywood star which I never in my life thought I would do. Bad things have happened, but very good things have happened, I think. Before, I didn't like to study, but now I appreciate studying. Before, I didn't value everyday things and now I give thanks that I can do them. I see things more clearly, I like the person that I am now.

All the other participants also identified elements of a silver lining. Like Kimberly, Kevin likes the person he is now more than his old self:

> Now I think things through before speaking, before acting, not like before. I used to get an idea in my head and instantly – for example, speeding on the motorbike, I liked to go fast on the motorbike, I sped and I didn't care if I passed in between the cars – you should have seen, I nearly killed myself several times.
>
> Q: And endangering other people?
>
> Yes, but not now. If I could go back in time, I wouldn't do anything that would cause danger to other people.

Jairo also considers himself a better person, because his shooting led him eventually into church:

> It changed my way of being, my way of thinking, my way of acting, attending church … I'm not the same person, being inside the church has helped me to raise my family better, to behave better with people, to be more aware.

He admits that his original motivation was purely self-serving:

> My way of thinking was, as soon as I'm healed [from paraplegia] I'm going to start investigating who did this to me, to search and search.
>
> Q: Were you thinking of getting revenge?
>
> Exactly, but after I was in the church, the pastor at the church said, "Hey Jairo, I want to ask you something, what's the reason why you come to church?" "Well pastor, I come to church because I want God to heal me, and then I'm going to leave the church."
>
> Then he said … "I'm going to tell you what God asked me to tell you: when you change your way of thinking, your way of acting and your way of living, He will help you. You might never get up from the wheelchair, because your way of thinking doesn't allow for God to act. So, change your way of thinking and your way of living, and you'll see that everything will change."

> … And one day … I said to the Lord, if you're going to help me that's fine, but I don't want to attend church for utilitarian purposes anymore. Actually, everyone goes to church because they need something from God, but I had been after something else: I wanted to get better and then leave. But… I used to be rude, I used bad language, I was always rude about things, and then [that day…] after I prayed, I no longer had the desire to use bad language.
>
> …Even my friends who knew me before said to me, "You've really changed!" In fact my sister … someone asked her, "If there was a person who you wanted to be like, who would you choose?" … And she stood there and said, "I would want to be like my brother … my brother Jairo." And I was right there, but she said, "it's not because he's here, but because I've seen how his way of being has changed." And I thought, well this is working!

His approach to life is much calmer now – so much so that he now says he would forgive the perpetrators if he ever met them again. He notes that he is also more generous:

> Before, I might have had money and seen a need, but I didn't do anything [to help]. Someone would come to me and [I would make an excuse], "I haven't got any…" But now it's different, because I've gone through very difficult situations, I've had no money, I've reached rock bottom and not had a single quetzal, not even for bread in the morning, that's where I got to. So when I see someone in need saying, "I wonder if you can help…" Sure, of course. I tell my daughter, "Hey, get me about five pounds of sugar, about three pounds of noodles, three pounds of beans, put it in a bag and give it to this person."

Flory credited God with giving her the courage to participate in this study and tell her traumatic story in detail for the first time:

> If I tell my story now, it is because God has allowed me, because touching these themes with anyone, it was like opening an anthill and I would run away. But now God has given me the courage to face my situation by talking about it.

9.5 Better off dead?

Except for Manuel, all the participants at some point felt they would be better off dead than surviving with SCI. Byron was the only one who attempted suicide, but others wondered, as Flory said, "would it have been better to die and not end up like this?" When she was living with her parents:

> "You're so annoying, you're an idiot, look now you're a burden to your mum, or we're tired of being here" … I already felt that I was useless, but they ended up making me feel like why didn't you die, you're in the way, why are you still here? And it's something I always asked, Lord, why didn't I die?

Jairo also felt that he was a burden:

> There came a time when I thought it was better to die, because it was affecting my family, just seeing me so sick [with pressure ulcers] made them worry –

Q: And what was your logic, why did you think it would be better to die?

Not to cause so much trouble for my family… because sometimes my mum would have to stop doing things to take me to the hospital or something. And also, when I needed something, I thought they're busy, I don't want to take up their time.

Kimberly, who was shot at age 12, recalls not caring when she was told in hospital that she might die:

Maybe because of my age, I think, I never really came to terms like, Oh, I'm going to die! For me it was, Well, so what if I die? It was not that important.

Later when she was stuck at home instead of going to school, feeling useless made her depressed:

Seriously, I was about to die and it was not because of the gunshot, it was because I was in depression.

In contrast, Manuel, who has the most severe impairment among the participants, has never regretted surviving:

A guy said that to me, "If someone shoots me one day, it's better that they kill me because I don't want to end up like you" … [but] they might say that now, but then when they see they are in danger of dying – well, even if it's in a wheelchair, I want to live.

For those who wished they had died, recovery from this mindset was assisted by support from family (Kimberly and Byron), from the church community (Jairo), or by talking with God (Kevin and Flory). Flory recounted:

Thinking positively and breathing deeply and saying, Sorry, Lord! [laughter]. Sorry because I'm here for a reason ... Because sometimes I feel that I'm not doing anything … But I know I'm here for some reason, I'll serve as an example for someone, which is what I say to my nieces: pay attention to my example, look at my case so as not to make these mistakes. I try to talk positively to them, so they'll open their eyes and not be dumb like I was.

9.6 Waiting for a miracle

Belief in miracles is very strong in Guatemala (Pew Research Center 2014), and many people can cite examples of prayers being answered in seemingly hopeless circumstances. The most highly prized miracle for people with mobility impairments is being able to walk again, and Manuel's family is still praying for it:

They are still hoping, sometimes my mum says, "You should go to church because God can work a miracle in you so you can walk again..." I'd like to go, but it's hard.

Kimberly has no such expectations:

No, I'm more logical than that, I know I can't walk, I don't expect a miracle. But who knows? But really, it's not among my possibilities.

Flory believes in miracles but does not expect one:

> I know that if God wants to, he can do it, but I'm not obsessed with "Oh please, a miracle Lord." I've accepted my situation, I tell my sister, If God wills it in his time and if not, that's fine, I'm going to try my hardest. And I tell God that I'm going to put up with whatever it is, whatever comes my way as long as he gives me the strength, because without God I'm not going to manage.

Jairo hoped for years that he would "heal":

> Well, in fact that was my goal, that was always my thought, not to stay this way [with paraplegia], but there's a moment when you come to understand that you cannot, honestly you cannot. I'm missing two bones in my back and – although for God nothing is impossible, but humanly I can't. And I've learned to live like this, I've made progress.

Short of his mobility being restored, he (like Byron) can cite many examples of lucky breaks or supernatural assistance received just when he needed it. One example was meeting Dr C, the plastic surgeon who cured his infected pressure ulcers when all hope was lost:

> Within the year I was going to die – supposedly. But since God had other plans, I met this friend [Dr C].

In another example, his nephew's school recently required a special uniform costing Q1500 (US$200), far beyond Jairo's capacity to pay:

> My nephew was worried, he said, "Uncle, if you want, I can drop out of school and go to work so you don't have to spend all this money on me." "Don't worry son, what are you worried about, don't you trust me? If you don't trust me, then you don't trust God. "Sure I do," he said, because I've raised them to trust in God ... And when I got home, a friend phoned me, "Hey, I know you're really busy [but] … I have 3000 [partly manufactured] T-shirts, I want you to attach the sleeves and close the sides … I'll pay you Q2 (US$0.25) for each shirt, that's Q6,000 (US$800)." … And I said to my nephew, "You see, God has already sent work!"

Chapter 10 Disability Identity and Wellbeing

Kimberly's shooting at age 12 could have derailed her future. It interrupted her schooling and plunged her into a struggle with infections and depression (see Appendix F). However, she had the good fortune to be sponsored for rehabilitation in the US, her mother pushed her to stay in school, and she is now studying online for a degree. She hopes to have a digital career, and her friends are mainly online too. Thus the internet enables her to overcome many of the obstacles created by a disabling society.

Kimberly differs from the other study participants in several ways, beginning with her pre-injury socioeconomic status which was higher than the others' (See Chapter 7 – Economic Impact). Her mother's professional position at the time meant that Kimberly's "job" was simply to go to school and advance through the grade levels. She is the only participant not put to work as a child, and the only one who finished high school. Schooling for the others ranged from Year 3 (Byron) to Year 9 (Jairo).

Kevin, who left in Year 5, could also have afforded to stay in school, thanks to the remittances from his mother in the US. However, with no precedent or expectations about schooling in his family, he chose to drop out and work alongside his grandmother. This indicates that finance is not the only factor influencing school retention. The professional position of Kimberly's mother may have produced not only above-average income, but also awareness of tertiary education as a possibility for her children. Kimberly is one of the 5% of all Guatemalans who reach university (INE 2019a); while for Guatemalans with disabilities the figure is under 2% (ICED 2017).

Another difference: Kimberly was a schoolchild when she was shot, so her identity and expectations were likely less established than for the other study participants. (Flory and Manuel were also under 18 when they were shot, but functionally they had already transitioned to adulthood.) The change in Kimberly's life was less radical than for the adults. Like them, she lost mobility and autonomy, but since she was a dependent child, she had less autonomy to lose. Once out of hospital and in possession of a wheelchair, her daily activities (school) were not so different from before. With two to three years' delay, she was able to continue along the path she had originally expected to take. Kimberly has lived longer with a spinal cord injury than without, and her concept of "normality" is based on using a wheelchair. The sense of frustration and loss expressed by other participants was almost absent in her interview; she said being a wheelchair user did not create any serious problems for her.

A third very significant difference was Kimberly's stroke of luck in having three months of high-quality, results-oriented rehabilitation at a US hospital, thanks to her benefactor. Apart from practical skills, the visit to the US gave her a glimpse into another society where it is common for people with mobility impairments to finish school, study at university and pursue a career. The experience helped transform her from dependent on her mother to a purposeful and confident young adult.

10.1 Disability as an identity

Whether to embrace an identity as a person with a disability would generally be an internal individual question, connected to prevailing cultural ideas of identity; but as Kimberly pointed out, in Guatemala (at least for people with visible impairments) this status is officially assigned with the DISABILITY stamp on one's national identification document. Asked whether they identified as a person with a disability, most of the study participants were confused by the question. Perhaps due to her higher level of education, Kimberly understood the concept of "identity", even using the word "label":

> The truth is I've never labelled myself like that, I wouldn't know how to identify myself. I know I was a victim of violence and now I'm a person with a disability, but I don't think of myself in that way, honestly.

In acknowledging that "now I'm a person with a disability", Kimberly was referring to the practical obstacles she faces as a wheelchair user. At the same time, by insisting "but I don't think of myself in that way" she was rejecting disability as an identity. She added that her family also does not assign the disability identity to her:

> They see me the same [as before], it doesn't matter to them.

The last phrase suggests a negative connotation, as though acquiring a disability would normally be expected to "matter" and thus change the way a person is perceived by others.

Other participants also distanced themselves from disability identity. When Kevin was asked whether he considers himself a person with a disability, he replied in terms of how other people treat or do not treat him:

> Well … at least the people in my life, they don't treat me as if I were someone weird in a wheelchair, they treat me as if I were a normal person. And that has helped me to feel good, normally.

Kevin's image of a person with a disability as "weird" and not a "normal person" reflects the stigma attached to the concept of disability in Guatemala. Other participants also used the term "normal" to refer to people without disabilities.

Jairo explained why people do not like to call themselves a person with a disability:

> Well, no one who is in this situation likes it. But it's the situation we're in, and we have to cope.

Flory tried to soften the stigma by describing how she works around her impairment:

> Well, I do describe myself as a person with a disability, but I just mean with some limitations. I mean my limitations will go as far as I permit … If there is a very high step and I can't get down it, then maybe I can get down it by sitting down or looking to find a way to do it…
>
> Q: And how do other people see you? Do you think they see you as less capable than you are?

> Some people, not all of them. For some people I'm a nuisance since I can't even get up on the kerb. I've had that said to me, "you're no use for anything, not even to climb that kerb."
>
> Q: Who said that to you?
>
> Some guy… An obnoxious guy on the street.

Fundamentally, all the participants recognise that they have a disability, but none of them want disability to be their most salient characteristic. Disability identity is forced on them in any case by the government's official practice. Acquiring SCI robbed them of a great deal of agency, and they have worked hard to reduce the extent to which this physical feature governs their daily activities. Like many other people around the world, "they want to be seen as ordinary members of society, free of limitation or classification" (Shakespeare 2014, p. 97).

10.2 Wheelchairs

All the study participants have received wheelchairs from Transitions. For Manuel and Kevin, the two most recently injured, these are the only wheelchairs they have had. Manuel was a patient in the Von Ahn rehabilitation centre when Transitions visited to discuss donating wheelchairs; while Kevin was referred by another NGO immediately on leaving hospital. Manuel received a new wheelchair from Transitions during the study period, replacing the first one which had rusted because the lack of space in his house means the chair is often left outside.

Wheelchair design and quality make an enormous difference to a user's mobility (WHO 2008). Flory, Jairo, Byron and Kimberly struggled for many years with chairs of the wrong size or design. Kimberly returned from the US with a wheelchair which she outgrew, and then her mother bought another chair from a medical supply shop. Flory also had a commercial chair, bought by a family friend (see below). These wheelchairs were too wide and heavy, designed not for independent living but for pushing a patient along the corridors of a hospital. Jairo had no wheelchair at all for a year after his shooting.

Byron is the only participant who received a wheelchair from the government, via IGSS. After finishing his rehabilitation, he lobbied the IGSS administration for a wheelchair:

> It's hard to get them to give you a chair, and then to repair it or to make changes, it takes up to a year and a lot of paperwork. In the long run they give it to you, but it takes a lot of effort.

He has broken several wheelchairs on the flight of steps that he regularly descends on his way to work. Three chairs were wrecked by vehicles running him over. IGSS gave him two wheelchairs during his first four years, but he has had to buy the rest. The last time he was run over, his chair was destroyed and he had to sell the family's dining room set to buy a new one.

Wheelchairs are essential to the participants' mobility and sense of agency or empowerment. However, in the early days of injury, the wheelchair also symbolised impairment and what they had lost. Flory recalled her despair on receiving her first wheelchair as a gift from a family for whom her mother cleaned house:

> [The donor] sent me a letter telling me that it was a gift from him and his family and that he hoped it would help me ... But when I saw the chair come out of the box – if I had wanted to die before, now I wanted the earth to swallow me, because I was confronting my new reality, which was: Flory you cannot walk, you need this to be able to move.

She managed to control her feelings and "tried to put on a happy face, saying thank you it's lovely." However:

> Then they said "Flory, sit in the chair!" But I wished they hadn't said to sit in it, because it was really hard, that moment was very difficult. I said, "I don't want to sit, I want to get up and walk." "Yes, my dear, but you cannot, and you have to accept that now you need this." I took a deep breath and sat down to please them, and when they left, they were happy to see that I was sitting in the chair. But for me it had been very difficult, in that moment I said, if only they knew how much it hurt me to sit there. [Crying]
>
> So that was my first chair… They wanted to make me feel good, but actually nothing could make me feel good.

10.3 Disability community

The Guatemalan disability rights movement is quite limited. The only disability organisation with any public profile is CONADI, the National Council for Assistance for People with Disabilities, which is a government agency (see Chapter 4 – Guatemalan Context). Flory, Byron and Jairo are aware of CONADI's existence; but they consider it to be a closed shop, doing very little for people with disabilities in general. (This opinion is heard often in conversations in the sector, with complaints, for example, that CONADI's office employs mostly people without disabilities.)

Manuel could only name one disability organisation, Transitions. Kevin and Kimberly said they were not familiar with any disability organisations. They did not think to mention Transitions, and Kevin did not think of another organisation, Fundación Sigue Avanzando, which put him in contact with Transitions in the first place. It is possible that they do not think of service providers as "disability organisations". (Transitions plays a hybrid role as service provider and advocacy organisation on behalf of people with disabilities. It also participates regularly in CONADI's activities.)

Most of the participants know two or three other people with mobility impairments, usually met during rehabilitation or via Transitions. The exception is Jairo, who dedicates time as a sort of volunteer networker, connecting people with ulcers to Dr C, the plastic surgeon who saved his life. Jairo is proud of this work but does not see himself as a disability advocate, rather as a person who likes to help others.

Byron revealed an activist bent during his interview. Like all the other participants, he cited the inaccessibility of transportation and public spaces as a major obstacle to participation in society, wishing that Guatemala would be made more wheelchair accessible. Unlike the others, Byron has tried to bring about that change. He lodged a complaint with the Office of the Human Rights Advocate when new suburban buses were brought into service, equipped with turnstiles that block access for wheelchair users. However, such complaints are only taken up by government agencies if they are signed by a large number of people. Byron said that if he had someone to advise him on how to go about it, he would like to "take up the matter and meet with the transport people."

10.4 Discrimination

Kimberly, Manuel and Kevin said they have not encountered disability discrimination. (They did not define being stared at as a form of discrimination.) All three said they have heard of employers discriminating against wheelchair users, but since they are not looking for jobs, they have not yet experienced this. Kevin's experience of discrimination arises more from being a gunshot victim (and suspected criminal) than being a wheelchair user. Byron and Jairo also experienced the stigma related to gunshot.

The older participants cited more serious examples of negative reactions to them as wheelchair users. When Byron returned to his workplace after rehab, his employer refused to rehire him, apparently because of his paraplegia. Flory went door-to-door applying for many clerical jobs during the years when she lived in a house with access to the street. She never heard back from any employer, but does not know whether this was because she used a wheelchair or simply due to her lack of experience. However, she was often treated dismissively, including by able-bodied employees of CONADI where she had gone to request assistance. She saw this as an example of the lack of professionalism that permeates Guatemalan government offices, where employees have often obtained their positions through nepotism and therefore lack commitment to public service.

Jairo observed:

> When you're in a wheelchair, the time comes … when it feels like you're not worth much. People see you differently… in the hospital, on the street, there are people who see you as less than them, without even knowing you.

Chapter 11 Discussion

This chapter discusses the findings that emerged from the interviews with the six survivors, and considers how they relate to the results of previous research.

11.1 Hospital and Health – "We're used to the fact that the care in our hospitals is not good"

The health system saved the lives of the study participants, turning them into survivors rather than six more deaths from gun violence. Beyond that point, their experiences confirmed some of the Office of the Human Rights Advocate's complaints about the dismal state of Guatemalan health care (PDH 2019).

Most participants had negative memories of the public hospitals, due mainly to the poor bedside manner of staff. A few doctors and nurses stood out for their kindness, but generally the participants recalled being treated roughly, without compassion, patience, respect or concern for their comfort. This resonates with the experiences of survivors interviewed in Mexico (Alvarez and Sugiyama 2010) as well as in the better resourced setting of Chicago (Patton et al 2019).

The study did not include examination of hospital records or interviews with clinical staff, so information about what treatment each participant underwent came from their own knowledge and memory. None recalled their treatment being explained; but this does not mean information was not provided, since even in industrialised countries patients have poor recall of information received in hospital (Kessels 2003). Manuel and Kimberly considered that they had not really had any "treatment", since the bullets had gone right through their bodies and therefore did not require removal. (In talking about treatment, removal of bullets was generally seen as the most important procedure conducted in hospital. The perceived threat was the presence of the bullet itself, rather than the damage it causes to organs and structures of the body.)

From the participants' accounts, it appears that clinical standards were low, or at best inconsistent. Although the participants blamed the uncaring attitudes of hospital staff, other possible factors include staff overload and a lack of knowledge and training in, for example, prevention of pressure ulcers. For Kimberly, Jairo and Kevin, ulcers became a life-threatening condition dominating their lives for years. Kimberly's ulcers were brought under control because she had the good luck to be sponsored to visit the US. Jairo was saved from death because, by sheer coincidence, his file caught the eye of a public-spirited plastic surgeon. Kevin was still in danger of succumbing to infections at the time of his interview. On the other hand, at the IGSS general hospital, a nurse noticed an incipient sore on Byron and took preventive action.

Most pressure sores are preventable with proper nursing care (Black et al 2011); and clinical guidelines for prevention have been adopted in many countries. However, the World Health Organization has noted that standards for patient care are applied inconsistently, especially in under-resourced hospital systems (Jha 2008).

In Guatemala, the IGSS rehabilitation hospital has spinal cord injury management guidelines which include prevention of pressure sores (IGSS 2014). Byron was admitted to this hospital four years before these guidelines were adopted, yet he did not develop secondary health problems during his 11-month admission. This suggests that the IGSS rehab hospital's culture already included knowledge of rehabilitation-relevant clinical standards. No similar guidelines could be located for this study at either the public or IGSS general hospitals.

Hospital-acquired ulcers are a recognised danger and the focus of intense prevention efforts even in well-resourced settings like Australia[32] and the US.[33] By contrast, the experience of these Guatemalan participants suggests that in the country's two major public hospitals, the emphasis is on saving life and stabilising patients immediately, with less concern for likely complications or their wellbeing thereafter. Also, despite pressure ulcers being common, the general hospitals apparently lack the skills or capacity for surgery to repair them, or even to give evidence-informed advice to patients.

Another concerning aspect of the participants' experience was the universal use of permanent urinary catheters, either indwelling (IDC), inserted through the urethra; or suprapubic (SPC), inserted through the abdomen. These catheters remain in the body, draining urine continuously into a collection bag strapped to the user's leg. They are changed (or washed and re-used) every 2-3 weeks. Wearing a plastic tube and a bag of urine all day is detrimental not only to personal dignity but also to health, because of the high risk of infection and blockages. For this reason, the international standard is to use IDCs and SPC only for short-term hospitalised patients, and to replace them with intermittent self-catheterisation (ISC) for long-term use (Hooton et al 2010). An ISC user retains urine in their bladder, like a person without a spinal cord injury. Several times per day, the user inserts the catheter in the urethra, voids their bladder and then removes the catheter.

In Guatemala, the IGSS guidelines for managing SCI stipulate that intermittent catheterisation should be the norm, because it is proven to cause fewer infections than indwelling units (IGSS 2014). This shows knowledge of international standards, at least in the IGSS rehab hospital in recent years. However it appears that this knowledge may not be reaching the general hospitals, since none of the study participants used ISC; and all of them have suffered serious and sometimes chronic UTIs. Contrast this with the Transitions members who have SCI, who use intermittent catheters and are rarely ill. Like the study participants, the Transitions staff came out of hospital wearing indwelling catheters. Then they learned about intermittent catheterisation when a colleague received medical treatment in the US. With support from a urologist, the Transitions staff changed to intermittent catheterisation, which has saved them embarrassment and most importantly prevented infections.

[32] A 2017 study in NSW hospitals found that 4% of inpatients developed pressure ulcers (down from 5.3% in 2016 and 6.1% in 2015) (Clinical Excellence Commission 2018).

[33] Prevention is a major preoccupation for US hospitals, which since 2008 have been penalised financially for each elderly patient who develops ulcers (Centers for Medicare & Medicaid Services 200733.

UTIs, like pressure ulcers, can be largely prevented if the patient knows what to do. In other countries, people being discharged from hospital with SCI are given guidelines emphasising two instructions for preventive care: (a) change position often and check skin regularly to avoid ulcers, and (b) drink plenty of water and use catheters correctly to avoid UTIs (eg St Joseph's Hospital and Medical Center n.d.). Best practice also requires demonstrating what to do, and providing opportunities for the patients to learn under supervision. Given the gravity of the consequences, it is difficult to understand the failure to provide these instructions, except by seeing this omission as part of the poor level of care overall.

A further information gap was evident, relating to what spinal cord injury would mean in the participants' daily life. As Alvarez and Sugiyama (2010) found in Mexico, the news was framed exclusively as an impossibility: "You'll never walk again." No one in the public hospitals talked to the participants about possibilities for leading productive lives with spinal cord injury, or about what support might help them and their families adjust to the new reality. Guidance was rare as to who might help them to obtain a wheelchair. No referrals were made to organisations that might assist. This lack of information and hope may well have contributed to the participants' depression, which in some cases, according to their self-report, lasted for years. Participants were unaware that rehabilitation was available and appropriate for them. The process of referral for rehabilitation is unclear. Flory and Manuel had good experiences at the Von Ahn national rehabilitation hospital; but their admissions resulted from both Flory and Manuel's mother phoning to ask whether there was space available, rather than referral by the general hospitals. According to the 2016 National Disability Study in Guatemala, only 43% of people with disabilities who need rehabilitation actually have received it (ICED 2017).

The most positive health sector experiences were at dedicated rehabilitation facilities, whether in the public system (Flory and Manuel), IGSS (Byron) or the US (Kimberly). The participants who had inpatient rehabilitation were impressed by the professionalism of the staff and by how much they learned. In contrast, those who sampled the outpatient rehabilitation sections in the two large public hospitals got the impression that they were not considered to be worth rehabilitating, because they were never going to be able to walk.

Post-hospital and/or post-rehabilitation, the participants have continued to battle secondary health problems without the benefit of a follow-up plan or a safety net for ongoing or newly developing conditions. Jairo keeps in touch with the surgeon Dr C, but otherwise no one has a regular health care practitioner who is familiar with them or their clinical history. Those reporting the fewest health problems are Manuel, Kimberly and Flory, who rarely leave home because accessibility is so poor in their neighbourhoods. Kevin, Jairo and Byron, who are more mobile, get sick more often. Kevin is battling pressure ulcers, Jairo gets UTIs, and Byron suffers from both conditions. Jairo, having lost eight years and almost his life to pressure ulcers, is scrupulous about prevention, through careful attention to hygiene and changing position every 5–10 minutes. The basic knowledge available at local health centres is too limited to help with the problems of people with SCI, so health care for the participants consists of emergency trips to hospital or a private pharmacy. Availability of medication and essential supplies is patchy, pricey and sometimes non-existent.

Four of the six participants had active infections when they came to be interviewed; nevertheless, all but Kevin (the most recently injured) described their health as good, and no worse than that of their family members. They have found ways to work around the constraints, not only of the inadequate health system and their scant resources, but also of their disabling living conditions: most participants cannot move easily around at home or enter the bathroom because the doorways are too narrow or a concrete step is in the way. They have learned a lot about how to maintain their health, including eating a healthy diet; and they are not afraid to ask for help occasionally from neighbours, church members or Transitions.

Despite the trauma they have survived, their mental health seems good by their own accounts, which most attribute to their family and religious faith. Most believed at some point that they would be better off dead, feeling useless, a burden on their family, and worried about money. None holds this view now, although Kevin, the most recently injured, seems potentially still vulnerable. He feels the need for mental health support, a service which Guatemala's woefully inadequate public health system is unable to provide.

11.2 Justice – "It's only if you're a powerful person that the investigation would go forward"

The study participants had remarkably little contact with the criminal justice system, considering the gravity of the crimes that had been committed against them. All six were victims of attempted homicide; in Byron's case several additional people had been shot, including his father; and in Manuel's and Kimberly's cases at least one person had been murdered. Most of the participants spoke only once, briefly, to uniformed police or detectives, in hospital shortly after being shot.

Based on the contact they had, the participants did not get the impression that law enforcement authorities felt an obligation to assist or protect them. For example, Kevin said the police who took him to hospital seemed mostly concerned about the potential inconvenience if he died en route. Police were portrayed in the study interviews as occasionally rude or dismissive, but mainly as going through the motions. This was in keeping with the bureaucratic, form-filling mentality decried by Mendaña (2007). The participants were not surprised by this half-hearted approach, most seeing the police as at best indifferent and at worst corrupt. This reflects the low expectations and lack of confidence in government services generally prevailing. According to the Latin American Democracy Barometer, only 25% of Guatemalans have confidence in the police, and only 15% in the government overall (Latinobarómetro 2018) as mentioned in Chapter 4 – Guatemalan context).

Even if the police did want to perform their job diligently, they were not assisted by the survivors' lack of interest in cooperating. Byron and Kimberly specifically told the police they did not want their attackers investigated. Kevin and Flory made no effort to bring about investigations, despite knowing who had shot them. Manuel spoke to police but was relieved that they did not arrest anyone. Only Jairo tried to secure justice. The main reason for failing to cooperate with police was fear of reprisal by the assailants, although as Kevin found, this strategy does not guarantee peace of mind. By keeping quiet, it seemed that victims hoped to buy their safety; but as this is a lopsided 'negotiation' conducted without any communication with the perpetrator, the victim can never know whether the deal has been accepted and therefore whether the danger of retaliation has subsided. The participants' fear of reprisals was shared by the gunshot survivors and families

of homicide victims in Venezuela (Rangel and Santos 2011), as well as the former gang members in Los Angeles and Boston studied by Hoffman (2004).

In addition to fear of reprisals, the study participants mentioned other reasons for not sharing information with police: fear of corrupt police collaborating with criminals, the belief that police only investigate crimes against the wealthy and powerful, and the perception that there would be no benefit to the victim if the perpetrator was caught. Their reasons generally coincide with the national victimisation survey analysis of why 77% of crimes go unreported (Viceministerio de Prevención de la Violencia y el Delito 2019b).

When a person is gunned down, especially in a public place, bystanders or the hospital generally notify the police; so the question of whether to report does not arise for the victim. However, when later interviewed by the police, a survivor must decide whether to share what they remember or know about the circumstances of the crime, or whether to simply say they do not recall anything. Fear of a further attack is entirely logical for a shooting survivor, since an assailant tried to kill them and the job remains unfinished.

Mistrust of the police seems understandable, since most of the male participants were initially viewed by police with suspicion, as though they were perpetrators rather than victims of crime. This reflects the demonisation of young men that is common across Latin America: since most perpetrators (and victims) of violence are young men, young men as a class, especially those from poor neighbourhoods, have become stereotyped as potential offenders, a presumption sometimes used to advantage by female criminals who are able to operate without raising suspicions. In Guatemala, where gun violence occupies so much space in the news and in the public consciousness, a young man with a gunshot injury is often assumed to be a criminal, shot in a gang fight. Police suspicion of male gunshot survivors seems to be a characteristic of very violent contexts; it has also been reported in Venezuela (Rangel and Santos 2011) and in high-crime neighbourhoods of major US Cities (Hoffman 2004; Patton et al 2019).

The stereotype of gunshot victims and survivors as criminals seems to have created a general stigma associated with being shot, leading Kevin and Byron to lie about the cause of their disability by attributing it to a road accident. Thus, on top of the physical, social and psychological consequences of being shot, these survivors have the burden of pretending that someone did not attempt to kill them, and of being unable to share their feelings about it outside their closest circle of intimates. Jairo and Manuel have also encountered this stigma, but they always take the trouble to explain that they were shot but are not criminals. Flory and Kimberly said they have never felt judged as gunshot survivors, presumably because as women they do not fit the male criminal stereotype in the public imagination.

The failure to cooperate with police, and subsequent lack of investigation, would have disqualified most of the study participants from receiving assistance from the government's Office for Victim Support (OAV), whose services are linked to an official case being opened (Instrucción General No 10-2008). This logic adds insult to (literally) injury for victims like the participants, by assuming that if no investigation is underway, then no victimisation occurred. It doubly penalises victims who are poor, since as Byron pointed out, crimes against them are less likely to be investigated, compared with crimes against the powerful; and the poor are less able

to pay from their own pocket for services such as counselling which OAV would have provided. None of the survivors were informed of the possibility of assistance from OAV, not even Manuel, who cooperated fully with police in his limited contact with them.

The exclusionary definition used by the Office for Victim Support breaches the UN Basic Principles of Justice for Victims of Crime and Abuse of Power (United Nations Office of the High Commissioner on Human Rights 1985). The UN Basic Principles are not legally binding but are considered the international standard on states' obligations to crime victims. Under Article 2, a person may be considered a victim "regardless of whether the perpetrator is identified, apprehended, prosecuted or convicted". Article 14 provides that victims should receive whatever material, medical, psychological and social assistance they need; while Article 17 specifically mentions "those who have special needs because of the nature of the harm inflicted" – for example, people who have acquired a spinal cord injury through gun violence.

As of early 2020, the situation for Guatemalan crime victims may be about to improve, as a previously failed attempt to create a support system has been resuscitated. In 2016 the Congress passed a law to create a statutory Institute for Assistance and Support to Crime Victims (Decreto No 21-2016). The proposed Institute would have guaranteed the rights contained in the UN Basic Principles, including the inclusive definition of crime victims "regardless of whether the perpetrator is identified, apprehended, prosecuted or convicted" (Art4). Although the legislation passed in Congress, the initiative lapsed because the timetable for implementation was not met (Castañeda 2018). However, in November 2019, the Congress passed another law amending the 2016 legislation to extend the time period for implementation (Decreto 9-2019). In December 2019, Q50 million (US$6.5 million) was promised for the new Institute in the national budget (Coronado 2019). This development provides the possibility of state assistance for the seven Guatemalans on average who, according to police figures (Viceministerio de Prevención de la Violencia y el Delito 2019a), survive gunshots every day. The domains of assistance to be provided by the proposed Institute include mental and physical health; legal and social work; clothing, food and housing; as well as education and training (Art32).

11.3 Economic Impact– "We have to pay the rent, and sometimes there's no money to pay it and I wonder what we're going to do"

The study participants say they are poorer since they were shot, because their spinal cord injury caused them or a family member to lose their livelihood. In other words, they see a relationship in their own lives between disability and poverty.

All the male participants lost their jobs, and Kimberly's and Manuel's mothers had to give up theirs as well. Flory feels that having a spinal cord injury cost her the chance to ever have a job. None of the participants has employment now, except Jairo who considers himself to be self-employed. This experience supports the finding in the Guatemalan National Disability Study that adults with disabilities have less stable livelihood opportunities than people without disabilities (ICED 2017). Only one participant, Byron, has a household income of more than one monthly minimum wage, a wage that is (as described in Chapter 4 – Guatemalan

Context) officially recognised as insufficient to support a family. His family has that income thanks to his wife's formal factory job. For all the other participants, any household members working are in the informal sector, like 70% of the population, and therefore earning less than the minimum wage.

Loss of employment was a major finding in Kroll et al's (2003) interviews with 25 gunshot survivors in Washington DC: most had jobs before being shot, but almost none had one after acquiring a spinal cord injury. Large reductions in household incomes were also reported by Rangel and Santos (2011), the Amnesty International researchers who interviewed families of people killed or injured by gunshot in Caracas, Venezuela. The Venezuelan families had lost income because the person who was shot was no longer bringing in a wage, because another family member had to give up paid work in order to care for a gunshot survivor, and in one case because a family member was fired for missing too many days of work immediately after her cousin was murdered.

Another economic impact on the Guatemalan study participants was additional costs resulting from having a spinal cord injury. The costs began in hospital, where their families had to pay for tests, supplies and medications – all items which should be provided for free, according to the Office of the Human Rights Advocate (PDH 2019). After leaving hospital, the cost of incontinence supplies and medications mount up. Prices of supplies vary widely, and availability is intermittent. The participants would be well served by a reliable and reasonably priced supplier of the products they need, but none of them is aware of such a supplier. Transport costs (including to medical appointments) are a significant burden for everyone, because the lack of wheelchair-accessible transportation forces them to use private taxis.

Transport and medication costs are similarly a preoccupation for people with spinal cord injuries in high income countries, including the 10 gunshot survivors interviewed in Chicago by Patton et al (2019). Those survivors also faced a US-specific financial challenge, feeling overwhelmed by medical bills, insurance paperwork, and even the application process for crime victims' compensation which requires detailed documentation.

The direct costs of disability were the focus of a "systematized" [sic] review by Mitra et al (2017), encompassing 20 qualitative and quantitative studies from 1995 to 2014, from 10 countries including three low- or middle-income (Vietnam, China and Bosnia). The results showed that disability is accompanied by sizeable extra costs that vary with severity of disability, the individual's life cycle and household composition. These include disability-specific items like wheelchairs, medication, rehabilitation and house modification, as well as general expenses that cost more for people with disabilities such transportation. Costs tend to be higher for people with more severe disabilities and for people living alone or in small households. This finding was borne out by the experience of Kevin in the Guatemalan study. Since he lives alone, he pays someone to assist him with the personal care tasks that are carried out by Jairo's nephews, Flory's sister, Byron's wife or Kimberly's and Manuel's mothers in their respective households.

Mitra et al (2017) noted that information on costs can be misleading when it comes to unmet needs, since a low level of disability expenditure does not necessarily mean that the person has a low level of need. This was

illustrated by Manuel in the present study: although his impairment is the most severe among the participants, he spends just Q100 (US$14) a month on incontinence supplies, which is less than the others. This is probably because his mother cannot afford more than Q100, rather than because his need is less.

The relationship between disability and poverty is often described as a mutually reinforcing cycle (Mitra 2018), or a bidirectional link: "disability may increase the risk of poverty, and poverty may increase the risk of disability" (Sen 2009, quoted in WHO 2011, p. 10). However, Grech (2015) points out the need for a more complex description of the disability-poverty dynamic, recognising that historical, social, locational, economic and other factors come into play. His qualitative research in rural Guatemala highlights the inadequacy of the simplistic cyclical which he says assumes a distinction between the poverty experienced by people who acquire disabilities and the general poverty prevailing in the family, community and society. For example, Manuel and his family were already very poor before he was shot. His SCI caused further impoverishment, but it was their pre-existing level of poverty that made them so vulnerable. Also, the pre-existing poverty of his family and community is an environmental factor influencing how disabled he is by his spinal cord injury: if his family were not so poor, Manuel could be working or studying, despite having only partial use of one hand. In addition, both disability and poverty vary over time, depending on personal factors and external events. For example, Flory's move to live with her sister's family 12 years ago could be said to have increased her degree of disability, because access to the street is now extremely difficult. On the other hand, her economic poverty has decreased, because she began earning income for the first time in her life with her textile piecework. And her wellbeing dramatically improved by swapping her abusive parents for her supportive sister and brother-in-law.

11.4 Family – "What makes me happy is to arrive every day, 'You're home, Dad!'"

Flory's shooting was an example of domestic or family violence, which according to the World Health Organization affects 30% of all women who have had a relationship with a partner (WHO 2017). Her experience mirrors that of the participants in a US qualitative study based on in-depth interviews with 30 women aged 17 to 54 who had been shot by their abusive partners (Nicolaidis et al 2003). Like Flory, most of the women had previously experienced physical violence and/or controlling behaviour from their partner. However, half of them did not realise their lives were in danger. One of the participants in that study had asked her partner to move out, "and he said, 'I am not going to ever leave you. I'll kill you before I leave you.' And the next thing you know, I was shot." Although women are the minority among shooting victims generally, they are far more likely than men to be shot by their intimate partner (Wiebe 2003).

Despite being shot by her partner, family has been the main source of practical and psychological support for Flory, and indeed for all the participants. This is consistent with the findings from research in Venezuela (Rangel and Santos 2011) and Brazil (Bega 2017) on the daily lived experience of gunshot survivors.

The scientific literature on spinal cord injury more generally points to the importance of family as a source of support. A systematic review of quantitative research on social support and social skills of people with SCI identified the family as the major source of social support (Muller et al 2012). The systematic review covered

68 studies from 1990 to 2010 from high-income countries, plus one from China. Despite the overwhelmingly positive role of family in supporting people with spinal cord injury, the review also noted that family can be a source of stress; and the provision of support can create an uncomfortable and unequal relationship of dependency. This has some resonance with Flory's feeling of dependency and guilt when she lived with her parents who assisted but also resented her.

In Grech's (2015), rural Guatemalan study, the overriding importance of family led the author to suggest that researchers and practitioners should focus on the "disabled family" rather than the disabled individual, because the impoverishment that can accompany a serious disability has a devastating impact on the whole family among the very poor. He also rejects the commonly used phrase "coping strategy", which implies a degree of agency and capacity for planning that is absent among the families he studied; a better term, he observes, is "survival struggle".

The urban participants in the present study are far less poor than those interviewed by Grech, but their accounts contain some similar patterns – the need to choose which necessity to go without, the increase in workload for Manuel's and Kimberley's mothers, and the shame that overcame Byron when he could not support his family and therefore turned to begging. In high income countries, a systematic review of qualitative and quantitative research on caregiving for people with spinal cord injury from 1980 to 2015 (16 studies) (Smith et al 2016) found most caregivers to be women. The authors said this was not surprising given that the primary caregiver is usually a spouse, and most people with SCI are male.

The Guatemalan participants all expressed love and appreciation for their family members, but most did not comment on the burden of care they might be carrying. Kevin is aware of the financial stress he has caused for his mother: "There have been sooo many expenses, my poor mother, my mother has gotten sick a lot because of that." Manuel has seen his mother cry due to worry about his health. Kimberly did not express concern for her mother, but her mother began to cry when I spoke to her separately about the economics of their household.

In terms of couple relationships, Flory's and Kevin's relationships ended as a result of their shootings, and Byron was the only other study participant with a partner when he was shot. His decision to get married while in hospital may have helped his relationship to survive, based on the small number of studies that have explored family relationships of people with spinal cord injuries. A frequently cited study from high income countries by Devivo and Fine (1985) found that people with SCI are less likely to marry and more likely to be divorced (especially if they are women) than the general population. However, Kreuter's (2000) review of the literature examined the research comparing pre-injury and post-injury relationships, suggesting that post-injury relationships have greater stability and better adjustment to SCI, compared with pre-existing relationships where a spinal cord injury comes as a surprise. Thus, the fact that Byron and his wife got married after he was injured augurs well for their future.

11.5 Religious Faith – "God has a purpose in the situation, and He knows what is best"

All the study participants are strong Christian believers who believe that being shot was part of God's plan for their lives. This seems to enable them to come to terms with the failure of the criminal justice system to pursue their attackers or to recognise their own loss and suffering.

The participants have embraced versions of theodicy, reconciling belief in a just God with the calamity that He allowed to befall them. The leading writer on faith and spinal cord injury is Shane Clifton, a theologian who acquired quadriplegia in his late 30s. As a person with a disability, he questions some assumptions commonly associated with theodicy. These include the notion that spinal cord injury is a punishment for past sin; or that it is inflicted in order to achieve a higher purpose such as for the affected person to serve as an inspiration to others (Clifton 2014).

The participants all believe God had a reason for permitting them to be shot, even if the reason is not clear. This fits with the observation by Grech (2015) that disability in Guatemala is often seen as part of God's plan. Most study participants see God as rewarding good behaviour and punishing people who do bad things. For Byron, this explains his success in begging (because he is helpful to others), and why his shooters have been punished with death. All the participants except Kimberly can point to past failings that they consider could justify God's decision for them to be shot. However, they do not see it as punishment, rather as a correction or reminder. God also underpins Jairo's ability to forgo retaliation, despite his original determination to seek revenge.

Like 97% of Guatemalans (Pew Research Center 2014), the study participants believe in principle that God could do a miracle to make them walk again, and some, especially Jairo, pinned their hopes on that solution at the beginning. All six, including those most recently injured, now accept that a miracle is unlikely. Acceptance of the reality that they will never walk again may be primarily a function of the passage of time. It also appears to be made easier by the skills they have acquired in negotiating daily life as a wheelchair user (and by having an appropriate wheelchair); but also by their conviction that their lives are still worthwhile and purposeful (see the discussion of subjective wellbeing below).

In addition to describing the pain, frustration and other negative consequences of having a spinal cord injury, everyone could identify positive effects in their lives, mainly related to their relationships with family members. In fact, Kimberly and Manuel cited those relationship improvements as possible reasons for God's decision to allow them to be shot. These two young people took comfort in becoming closer to their brothers and mothers after SCI forced them to spend more time at home. Most participants said they are less self-centred, better people now. Similarly many of the ex-gang members interviewed by Hoffman (2004) and Kroll et al (2003) said that being shot had awakened a desire to be more responsible and contribute to their communities.

All the Guatemalan participants said their religious faith has helped them to adjust to life with a spinal cord injury. This is consistent with research reviews from Western countries on religion or spirituality as coping

strategies for disability in general (eg Johnstone et al (2007), as well for SCI specifically (eg Jones et al 2016). Religious faith or practice has also emerged as essential for adjusting to life with SCI in Buddhist Sri Lanka (Arya et al 2016; Xue et al 2016)[34] and Moslem Iran (Babamohamadi et al 2011; Khanjani et al (2017).

God plays an especially large role in the lives of Flory, Byron and Jairo, the three Guatemalan participants who are aged over 30. These three could be said to have had the hardest experience of living with spinal cord injuries since they have adult responsibilities, not only for themselves but for others. By contrast, Kimberly, Manuel and Kevin have only had to think about themselves, as the road has been made smoother by their mothers. The older three also expressed the clearest understanding of why God may have allowed them to be shot. For Flory and Jairo, the purpose was to refocus their attention on God, and to serve as an example for other people. For Byron it was to steer him away from his wayward friends and back toward his family responsibilities.

11.6 Disability Identity and Wellbeing – "I know I was a victim of violence and now I'm a person with a disability, but I don't think of myself in that way"

The findings from the present study demonstrate that a spinal cord injury produces a very severe disability in a society like Guatemala, where the physical, economic and social environment can make everyday life difficult for anyone from the poorer sector of society, and even more so for a wheelchair user. Yet all the study participants manifest satisfaction with their lives, and four of the six say they are happy. (Manuel and Jairo did not seem sad, but they replied to the question "Are you happy?" with expressions of concern over money). This is an example of the disability paradox identified by Albrecht and Devlieger (1999), whereby people with serious disabilities say their quality of life is good, contrary to the perception of outside observers without disabilities. Albrecht and Devlieger's qualitative study relied on semi-structured interviews with 153 people with serious physical disabilities living on limited incomes in Chicago.[35] Asked about their quality of life, 54.3% said it was good or excellent, offering reasons such as a positive attitude, helping others, religious faith and realising other people are worse off. The authors concluded that many people with disabilities have a high quality of life because they achieve a balanced relationship between body, mind and spirit. In other words, they had some control over their bodies, they were able to think rationally and take satisfaction in achievements, and they feel they have a higher purpose. Having a harmonious relationship with the (social) environment was also a factor. Low quality of life was particularly associated with chronic pain or fatigue, with losing control over the body or the mind, or with having no spiritual life.

Twenty years after the articulation of the disability paradox, research is increasingly showing that the relationship between disability and quality of life is more complex than Albrecht and Devlieger suggested.

[34] Karma, the Buddhist belief in a causal relationship between an individual's past intent and future outcomes, was cited in the Sri Lankan studies as both an explanation for having been injured ("I think I'm suffering now because of the sins of past lives") and also as the reason for having survived ("I believe that I am still alive because of my contributions of good deed"). This parallels some of the beliefs expressed by the Guatemalan study participants who are Christians.

[35] A small proportion but unknown number of the participants had spinal cord injuries or paralysis.

Subjective well-being or life satisfaction is shaped by a range of additional individual and contextual factors such as age, gender, health, time spent living with a disability, inclusion, stigma, personal resilience, support and economic conditions (Graham and Ross 2016, Bickenbach 2011).

Considering spinal cord injury specifically, Post and Van Leeuwen (2012) undertook a narrative review of the literature since 2000 on subjective well-being and psychological and social support factors. The studies reviewed were mostly from the US, Canada and Northern/ Western Europe, and none were from lower-income countries. The authors also considered their earlier systematic review on psychological variables and quality of life in Van Leeuwen et al (2012), as well as the systematic review on social support and social skills by Muller et al (2012), mentioned earlier. Post and Van Leeuwen concluded that average life satisfaction among people with SCI was substantially less than in the general population, with large variations among individuals. Psychosocial factors that impacted quality of life included perceived control, resilience, sense of coherence, self-worth, hope and purpose in life.

For a qualitative study of seven people with quadriplegia in Australia, Clifton et al (2018), framed subjective wellbeing as flourishing or living "the good life". The qualities emerging as key to the good life included hope, optimism, determination, patience, friendship and love, living a meaningful life, overcoming obstacles, achievement – positive attitudes that align with the Aristotelian virtues. Three participants also considered spirituality important, and an individual's personality before being injured was also determined to be a factor in flourishing. (In the Guatemalan study Flory is the exception to this rule: before being shot she recounts having no sense of self at all, but now she is exuberant and engaged.)

The participants in the present study some or all the coping mechanisms or virtues identified in the literature, especially optimism, religious faith, patience and love for their families. A purpose in life and sense of making progress is most obvious in Kimberly with her studies, but is also evident in Byron and Jairo who are supporting their families, in Flory who helps in her family, and in Kevin who is focussed on recovering his health and then plans to travel to visit his father in the US. Manuel is the only one who did not identify a clear purpose for his life, and he is also the participant who could be said to be flourishing the least. He wishes he could get a job but does not know how to go about it; he worries a great deal about money; and he rarely leaves the house.

Neither Clifton's participants nor the Guatemalan survivors in this study appear to have suffered the dramatic loss of identity reported by Ostrander (2008) in his study of gang members with SCI. The gang members' identity depended on their capacity to dominate other people by force, since before becoming victims of violence they had been perpetrators, and in some cases had themselves shot people. The ability to defend against other perpetrators was also part of their identity: "Several participants commented that being in a wheelchair might require them to use a gun more readily than before their injury when they could fight someone standing up …. Their weaknesses are more readily apparent now, requiring them to take more drastic measures if necessary." (Ostrander 2008, p. 80)

The Guatemalan participants are a very different group. Two of them are women, and none of the men manifested any preoccupation with masculinity, apart from Byron and Jairo's concern to be a responsible provider for their families. Importantly, the Guatemalan participants did not experience a loss of power over others, since they never had it in the first place. Nor did any of them have any kind of identity as part of a group (not even the identity as a member of a Christian church that is so important to Jairo now).

One commonality between the Guatemalans and Chicagoans is that acquiring a spinal cord injury cost them a great deal of agency or control in their lives. Participants in both studies described this loss by comparing themselves to children. As one of the gang members put it, "I just be looking at myself like a boy, because if you're a man you say you make your own rules, but a boy don't make his own rules." Similarly, Flory, recalling the early days of her injury: "At that time I thought, how am I going to live, how am I going to do all this in the long term? Even soiling myself in a nappy, I'm not a child!" The Guatemalan participants have recovered their sense of agency over time, with support and the development of skills, though Manuel still seems somewhat lost.

Disability is a stigmatised identity in Guatemala, as pointed out in the government's national policy statement (CONADI 2015) and as confirmed by the study participants' hesitation to adopt it. This does not seem to be a question of self-esteem; they do not think less of themselves for having a disability. (Disability identity is forced on them in any case by the government's official labelling practice with DISABILITY stamped on their identity cards.) In some countries there is an incentive to identify as disabled, because specific services or benefits are provided for people with disabilities. According to Shakespeare (2014) this can create a quandary for people with disabilities. They may reject the disability label, insisting (like the participants in the current study) that their family and friends see them as "normal". On the other hand. they must emphasise their impairment to prove they have a disability in order to qualify for the support services that can enable greater social inclusion. In Guatemala there is no practical advantage in identifying as disabled, except, in theory, for IGSS members who can receive a disability pension – although Byron discovered to his chagrin that he was not considered sufficiently disabled to qualify. Perhaps if disability support services were available, the study participants would be less inclined to distance themselves from the disability identity. In addition, if such services existed, the participants would meet other people who are similarly situated, since at present most of them know very few other wheelchair users.

Further, none of the participants want disability to be their most salient characteristic. They have worked hard to recover from their losses and to reduce the extent to which their physical impairments govern their daily activities. They are wary of "identity spread", the phenomenon whereby the characteristic of a class of people (in this case spinal cord impairment) comes to dominate their interactions with society (Shakespeare 2014). Reluctance to claim the disability identity is not limited to a particular country. Shakespeare (2014) cites for example a study by Watson (2002) based on in-depth interviews with 14 men and 14 women with physical disabilities in Scotland. Although all the participants experienced regular discrimination, only three saw disability as part of their identity. Most saw themselves – and wanted to be seen – as part of the mainstream culture, rather than draw attention to what made them different.

Another reason to embrace disability identity would be to identify with a group, a community or the disability rights movement which is prominent in many countries (Shakespeare 2014). However, the landscape is different in Guatemala. CONADI, the principal disability organisation, is a government agency; and Guatemalan disability organisations are mainly small grassroots groups advocating for services for specific populations, often made up of parents or carers, and lacking capacity for research or policy discussion. Likewise, many individuals with disabilities (like Byron and Jairo) are fully occupied ensuring daily subsistence for their families; or (like Flory and Manuel) are trapped by architectural, geographic and economic barriers. Perhaps Kimberly or Kevin will eventually decide to be part of a social movement for disability rights, and decide to identify proudly as people with a disability. Currently however, as Shakespeare says, “they want to be seen as ordinary members of society, free of limitation or classification” (Shakespeare 2014, p. 97).

Chapter 12 Conclusion and Recommendations

12.1 Introduction

Every day in Guatemala at least seven people are shot and survive with injuries of varying types and severity, and an unknown number of these survivors will acquire a spinal cord injury (SCI). Even in high-income countries with functioning health, legal and welfare systems, this is a catastrophic event with life-altering consequences, not only for the injured individual but also for their family. In Guatemala, the facilities needed simply to survive a spinal cord injury are extremely under-resourced. The supports and services required to achieve an independent life and participate in society are non-existent.

The poor quality of health care experienced by the study participants can presumably be blamed in part on funding shortfalls. However, as the World Bank's Disease Control Priorities project observes, deficiencies in quality do not necessarily reflect a lack of resources in the health care systems of developing countries; rather they are more likely to result from gaps in knowledge (Peabody et al 2006). The apparent lack of knowledge and common sense among public hospital staff reported by the participants in this research study indicate gaps in education and training. In addition, the participants' experience suggests an attitudinal failure to look beyond the hospital doors; in other words, a lack of feeling of responsibility on behalf of hospital personnel for the wellbeing (or even just the physical health) of people with spinal cord injuries after discharge.

These three shortcomings – underfunding, inadequate education/training and a short-sighted disregard for larger or longer-term outcomes – also characterise the criminal justice system, the other arm of the state which should be most relevant to people who survive an attempted murder.

There are two conclusions drawn from the findings of this study about the experiences of survivors of gunshot violence with SCI in Guatemala. After first presenting the limitations of the study, I draw on these two conclusions to present five categories of practical recommendations that could with collaborative efforts be achieved over the short to medium term. The thesis closes with a few personal reflections on undertaking this graduate research degree in a location affected by logistical and communications difficulties.

12.2 Conclusions

Conclusion 1: The health and justice systems of Guatemala are falling far short of fulfilling the needs and rights of gunshot survivors with spinal cord injuries.

The primary purpose of a state is to maintain order and protect its citizens from harm (Gilbert 2002). By failing to prevent, investigate, prosecute or secure convictions for criminal offenses, the Guatemalan state failed in its duty to protect the study participants from harm. Having failed to protect them in the first place, the state has subsequently failed to mitigate the physical, psychological, economic and social damage resulting from being shot, through inadequate provision of health and social services and lack of enforcement of existing policies.

The Guatemalan state's duty toward the participants as survivors of gun violence with a life-long disability arise from a range of obligations under international instruments which it has ratified or adopted. Some of these are legally binding, most importantly the 2006 United Nations Convention on the Rights of Persons with Disabilities (CRPD), which provides rights related to health, rehabilitation, work, social protection and an adequate standard of living (Arts 25-28). Further, the state had an obligation to protect Flory from domestic violence under the 1979 Convention on the Elimination of All Forms of Discrimination against Women; obligations to Kimberly and Manuel both before and after their shootings under the 1989 UN Convention on the Rights of the Child; and potentially an obligation to investigate the attacks on Manuel, Kimberly and Byron under the 2000 United Nations Convention against Transnational Organized Crime, which requires that crimes involving organized groups be investigated. (That same convention, through its 2001 Firearms Protocol, creates obligations in relation to preventing and investigating gun trafficking). All the participants have rights to health, social protection and non-discrimination under the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR).

Obligations also arise under politically binding instruments including provision of information, financial compensation and "material, medical, psychological and social assistance" under the 1985 Declaration of Basic Principles of Justice for Victims of Crime and Abuse of Power; victim assistance under the 1995 UN Guidelines for Cooperation and Technical Assistance in the Field of Urban Crime Prevention; collection of data and provision of support to family caregivers under the 2013 World Health Assembly Resolution 66.9: Disability; and a range of measures to improve health care under the 2000 ECOSOC General Comment No 14: The right to the highest attainable standard of health (GC14).

The state has also failed in its obligations to the study participants under its own national laws. The Constitution proclaims that the purpose of the State is "to protect the person and the family" (Art 1), and its duty is "to guarantee to the inhabitants of the Republic life, liberty, justice, security, peace, and the integral development of the person" (Art 2). As noted earlier, the Constitution also guarantees the right to health (Arts. 93, 94); the right to social security (Art 100), the rights of people with disabilities in terms of rehabilitation (Art 53) and employment (Art 102). Apart from the Constitution, Guatemala's Assistance to People with Disabilities Law provides a range of disability rights; the Criminal Procedure Code requires that serious crimes be investigated (Art 24), and the Health Code guarantees that health care shall be free (Art 4).

The codification of rights under national law is often intended as a means of implementing international obligations; thus the failure to deliver under the former also implies non-compliance with the latter. It appears that Guatemala finds formal adoption of international agreements easier than implementing them; and the same applies to national law. As one official remarked at an international conference against gun violence, "We have a tendency to pass laws without putting in place the supporting regulations or a budget, and without identifying the institutions to implement them." (Zavala 2011, p32)

Conclusion 2: Looking across the policy and service landscape, there are some positive elements that can be built on, adapted, expanded or promoted to benefit gunshot survivors with spinal cord injury.

It is always easier to build on or adapt an existing idea rather than creating an initiative from zero, because less of a conceptual leap is demanded of implementers and donors. There are many examples of relevant policies, programs and resources, within Guatemala, in the region and beyond, that could make a significant difference to survivors and their families. These are described in the Recommendations in section 12.4 below.

12.3 Limitations of the study

The study limitations arose mainly from the challenges associated with doing research of this nature in Guatemala. Obtaining Human Ethics Approval took longer than expected because of concerns by the Committee about my safety in a country where DFAT's advice was to 'Exercise a high degree of caution'.

Conditions in Guatemala also affected recruitment of my participants. I had originally anticipated a larger number of participants, and in principle the Transitions database was an accessible and highly relevant avenue of recruitment. However, the initial list of candidates fitting my selection criteria (over 18, survivor of gun violence, paraplegia, received their wheelchair free, less than two hours away, diversity of circumstances and of time elapsed since acquisition of injury) was shorter than I had expected. In addition, the contact details in the Transitions database for many potential participants proved to be outdated, because mobile phone numbers in Guatemala change frequently. This meant that the Transitions receptionist was unable to contact many of the survivors on the initial list. Two who had originally agreed to participate did not end up taking part, because of logistical challenges arising from illness, landslides and road closures (also frequent occurrences in Guatemala). However, I ultimately did achieve diversity, even with a smaller than expected sample.

I did not make use of all the data collected for the study, for example I administered the Washington Group Extended Question Set on Functioning to all participants but do not make use of the resulting information. I had anticipated there may be a relationship between level of functioning and participant experiences after they sustained their SCI. This turned out not to be the case. This was because there was little diversity in the responses on the instrument: five of the six participants self-reported the same level of functioning. Manuel was the only exception, and the greater severity of his impairment did not appear to contribute to his responses across the narrative sections of the interview schedule.

12.4 Recommendations

The governance, fiscal and security problems that plague Guatemala are far beyond the scope of this study. In the meantime, gun violence and spinal cord injury will continue to impose a heavy burden on shooting survivors and their families in health, economic, emotional, and social terms. The following sections contain recommendations for practical measures that would give survivors like the study participants a better chance

of rebuilding a dignified life, and that could realistically be implemented in the short to medium term, regardless of how long it takes the national government to address the larger systemic problems.

The recommendations are divided into 5 categories:

1. Knowledge, training and information, for:
    a) Public health system leadership, management and staff
    b) Justice system personnel
    c) Gunshot survivors with spinal cord injury and their families
    d) Community awareness
2. Policy reform
3. Services and programs
4. Further research on:
    a) Lived experience of gunshot survivors
    b) Data on gun violence and on spinal cord injury
    c) Services available for people with spinal cord injury
5. Advocacy

Most of the recommendations will have benefits for other sectors of the population, not just gunshot survivors with SCI, for example for crime victims generally or people with disabilities generally.

12.4.1. Recommendations related to Knowledge, training and information

a) Public health system leadership, management and staff

Based on the participants' accounts, the poor quality of care in the public general hospitals seems to relate not only to the under-resourced health infrastructure, but also to attitudes and knowledge.

Health system leaders and managers should insist on and be held accountable for implementing existing guidelines and international standards in relation to pressure ulcers, UTIs, referrals for rehabilitation and discharge planning. Resources and information are available online from WHO and the International Spinal Cord Society, including lessons learned from other developing countries. There is a precedent for expecting international standards to be utilised. Some international standards are already known in Guatemala but not being generally applied. For example, the IGSS Rehabilitation Hospital and the public hospitals are both under the authority of the Ministry of Health, but at present it appears that only IGSS has appropriate guidelines for management of SCI.

Knowledge and attitudes among health system staff could be improved through pre-service and in-service training. The study participants only recalled hearing bad news about spinal cord injury from general hospital staff, summed up as "you'll never walk again". It would have been helpful for them if staff had addressed not only the limitations created by SCI but also the possibilities for living a satisfying and productive life as a

wheelchair user. In the general hospitals, Jairo and Kimberly encountered staff who said rehabilitation was pointless for people who would never regain the ability to walk.

In dedicated rehabilitation facilities (Von Ahn and the IGSS rehabilitation hospital), the participants' experiences were far more positive; although even those facilities appear not to have adopted international best practice on use of appropriate urinary catheters.

Training could also help to challenge the belief among some hospital staff that a person who has been shot is likely to be a criminal – though even if a patient did have a criminal history, that would not justify treating the person more harshly in a health care setting.

Since Guatemala's health system is heavily focussed on hospitals, staff have a crucial role to play in educating and informing people with SCI and their families. This means that, in addition to knowledge relating to their own jobs, staff should be trained on how to answer common questions and be equipped with information on support services and products, on how to maintain health at home, and ideally on non-health topics such as the rights of people with disabilities.

b) Justice system staff

Training to counter equating gunshot survivors with criminals would also be helpful among police officers and detectives from the Attorney General's Department. Eliminating that assumption would not only reduce the trauma for survivors, but also help to bridge the mistrust of police among crime victims.

Trust might also be built, and police effectiveness improved, if police had more training on dealing with crime victims generally – for example on the importance of always interviewing the victim, and of providing information to the victim about progress on their investigation. There may be lessons to learn from the recent improvements in prosecution of domestic violence, another stigmatised crime which now ranks second in number of reports made to police (Unidad Criminológica 2019). In a country renowned for impunity, 75% of prosecutions for violence against women from 2015 to 2019 resulted in conviction (Sanchez 2019). Among the factors believed to have contributed to this improvement has been the appointment of dedicated officers specifically trained in assisting victims of gender-based violence (Millard 2018). A similar approach might help to build trust with shooting victims.

c) People with spinal cord injuries and their families

The study participants described grave consequences which they had suffered as a result of ignorance, and the difficulty of obtaining information even if it occurred to them to ask. Gunshot survivors and other people who acquire SCI would benefit significantly from training or information on procedures for starting rehabilitation once they leave the general hospital, how to maintain health and prevent secondary conditions, how to treat those conditions if they eventuate, and when and where to seek assistance. They also need referrals to help find a wheelchair, incontinence supplies and other items and services to support independent living, including assistance with vocational training, employment and social opportunities. The most likely point of intervention to receive such information is at the general hospital before discharge; this would require some

hospital staff to receive information or training (see earlier recommendations on training for health system staff).

Family members would also benefit from knowledge about protecting their own health; and about finding the balance between providing support to the person with SCI and avoiding dependency. Crucially, people with SCI and their families would benefit from understanding that Guatemalans with disabilities have the legal right to non-discrimination. The right is not easy to enforce, but the Office of the Human Rights Advocate (PDH) can intervene through advocacy, mediation and in some cases litigation. For example, if Byron had sought to involve the PDH when he was turned away by his employer, he might have been able to get his job back.

d) Community awareness

Community knowledge and attitudes about disability could be improved with advocacy and campaigns to raise awareness that discrimination against people with disabilities is against national law as well as the CRPD. Employers should be targeted specifically: a clothing factory should not dismiss a worker who returns from sick leave in a wheelchair. An awareness campaign could also counter the violence stigma: a gunshot survivor should receive the same degree of sympathy and support as another wheelchair user who survived a car crash.

Ideally such awareness campaigns would be launched by the national government, including the Office of the Human Rights Advocate, which has the mandate to enforce the law against discrimination. (As a bonus, this would give the government a positive achievement to report in its next report to the UNCRPD Monitoring Committee.) However, campaigns could also be run by NGOs or the local office of UN agencies including UNICEF and the Office of the High Commissioner for Human Rights. The study participants have indicated their willingness to lend their stories to awareness or advocacy campaigns.

12.4.2. Recommendations related to Policy Reform

Two proposals currently on the public agenda represent major steps toward implementing Guatemala's international human rights obligations on crime victims and on disability rights. Decree No 21-2016 for an Institute for Assistance and Support to Crime Victims, resurrected in late 2019, appears to have a chance of becoming reality (see Chapter 11 – Discussion). The proposed Institute would enable access to mental and physical health support; legal and social work; clothing, food and housing; as well as education and training. Meanwhile Initiative 5125 for a new law on disability rights (including accessible transport and employment quotas) has broad popular support but has been rejected once by the Congress (see Chapter 4 – Guatemalan Context). Adopting and implementing these two pieces of legislation would significantly advance the rights of gunshot survivors like the study participants, as well as other crime victims and people with disabilities generally.

Guatemala should also look to other countries in the region for ideas that could usefully be replicated or adapted. For example, the neighbouring country of El Salvador has similar problems of gun violence, gang

activity and mistrust of police. The Salvadoran Health Ministry has pioneered a model of crime victim support based in six public hospitals. Each hospital has a Comprehensive Care Unit for Victims of Violence very close to the Emergency Department, staffed by medical and mental health personnel, plus a lawyer and social worker. The Units identify and address the broader health and other needs of survivors of violence, prevent later health problems, help survivors to feel supported and encourage reporting of crime. El Salvador has also explored innovative funding models related to injury and non-communicable diseases. For example, an agency called FOSALUD (Fondo Solidario para la Salud or Health Solidarity Fund), specifically dedicated to prevention, is funded from taxes on guns and ammunition, alcoholic beverages and tobacco products. FONAT (Fondo para la Atención a las Víctimas de Accidentes de Tránsito or Traffic Accident Victims Support Fund) is funded from traffic fines.

12.4.3. Recommendations related to Services and Programs

The services or programs that would address some gaps revealed in the study include a systematic approach to the provision of wheelchairs, an accessible van service affiliated with the hospitals to enable wheelchair users to attend medical appointment or outpatient rehabilitation, and a program providing incontinence supplies at moderate prices. Such programs are often run by disability NGOs; for example in Australia, the Paraplegia and Quadriplegia Association of NSW (ParaQuad), buys incontinence and wound care supplies in bulk, passing on the savings to people with spinal cord injuries who are spared the high prices in pharmacies (ParaQuad nd).

The municipality of Villa Nueva has physiotherapy clinics for local residents – for example, to do stretching exercises to prevent contractures (Municipalidad de Villanueva 2019). Villa Nueva is one of the most dangerous sectors of Guatemala City, and the clinic sees many gunshot survivors. This model could be adopted by other municipalities, or international donors could support its expansion to serve people coming from other areas.

A service to advise on or modify dwellings to make them wheelchair accessible would not only facilitate movement in and out of the house, but also enable privacy for wheelchair users who would be able to use the toilet and bathe or shower like other family members. An NGO like the Dutch-based ConstruCASA, which builds houses for poor Guatemalans, could partner with disability organisations to provide such a service (ConstruCASA n.d.)

Employment or income-generation could enable people with disabilities to become contributors rather than a cost to their families. Microcredit or grants for home businesses could help in this regard. Such programs could include training but also outreach to potential employers unsure about hiring a wheelchair user (especially a gunshot survivor). They could be run by municipalities, NGOs or INGOs. An NGO called DIGNA was recently created in Guatemala to promote employment for people with intellectual disabilities. DIGNA provides training, coaching, job support and information, and builds alliances with companies interested in becoming inclusive employers. This approach could be replicated or expanded with other NGOs such as Transitions to promote opportunities for people with other types of disabilities such as SCI.

Mental health or general support groups for survivors of violence, people with disabilities and/ or their family members could be provided by NGOs. For example, the Guatemalan Red Cross runs a support group for amputees who have received Red Cross prosthetics, while Transitions holds occasional workshops on disability topics. Recognising the mobility challenges confronting survivors like Flory, such programs should also involve online options.

12.4.4. Recommendations related to Research

a) Lived experience

This study is the first ever on the experience of people who have survived being shot in Guatemala, and one of very few studies of non-fatal gun violence anywhere in the world (see Buchanan 2014 for the first international collection by the Surviving Gun Violence Project). Inevitably it points to questions to address in further studies, whether in Guatemala or other countries. Future expansion should include a wider range of participants, since mine were all from one city and all recruited through one NGO. This study focussed on people with spinal cord injuries, but gun violence also causes blindness, amputations and brain injuries, as well as cognitive and psychiatric disabilities as pointed out by Rustrian in her 2018 thesis on applicants for IGSS disability pensions. The broader impact of gun violence could be illuminated by research involving participants with different types of injuries, from other geographic areas, from a broader socio-economic base, as well as people who have been shot by police.

Some of my participants suggested that I would understand their accessibility problems better if I visited them at home – in other words that observation be added as a qualitative study technique. I support this approach which was regrettably not possible within the resources available for this Masters level research. Recognising Grech's observations about the 'disabled family' in his study of people with disabilities in rural Guatemala, it would be useful to conduct a study that includes the experience and insights of family members as well as the survivors themselves. In my study, family members sometimes tended to handle transactions involving the external environment, and did not always share their knowledge and experiences with their relative with SCI, out of concern for their feelings. This reflected the experience of Clifton and Clifton (2015) in Australia. The Venezuelan study by Rangel and Santos (2011) found that the whole family suffered from the stigmatisation of gun violence survivors as criminals. I caught a glimpse of the suffering affecting family members when I asked Kimberly's mother an informal question and she burst into tears. The impact on household roles after a shooting, it could be anticipated, would be perceived variously by different family members.

The economic impact of gun violence deserves a great deal more exploration, not only at the household level (as I attempted) but also at a village or neighbourhood level. Attempts to estimate the cost of violence in general, or of gun violence specifically, are always phrased in terms that not surprisingly have little or no meaning for most people: for example, the Inter-American Development Bank estimates that crime and violence cost Latin American countries 3.5% of GDP (Jaitman 2017). Not everyone in the community understands what GDP is and how significant a 3.5% impost might be. Such a revelation does not provoke much reaction in Guatemala where mismanagement of government funds is the norm, and where a large part

of the ‘cost’ of violence translates into income for the powerful private security industry. Legislators, public officials, media organisations and citizens might be more spurred to outrage or action if they had a sense of what violence is costing real individuals, families and communities.

b) Data about gun violence and on SCI

During the study it became evident that there is a dearth of relevant data on all aspects of gun violence, including fatalities, non-fatal injuries, the circumstance of shooting and types of weapons used. The police data on criminal injuries contain no information on the nature, severity or circumstances of those injuries or on the legal dimension: how many of the over 4000 criminal gunshot injuries recorded by police each year are investigated, and what are the outcomes? Is anyone ever convicted?

Nor is the health system able to provide data on important questions like the number of people seen in hospital with gunshot wounds; the incidence, prevalence or causes of spinal cord injuries; or any information on the path followed by these individuals. How do the outcomes for people with SCI by gunshot compare with those injured by other causes? How often are people with SCI readmitted to hospital due to secondary infections? What is the life expectancy of people with SCI? How many gunshot survivors die from secondary infections, which in reality could be seen as delayed homicides? (During my time at Transitions I have known two gunshot survivors to die from infections, at least two years after they were shot. If deaths like these were linked back to the firearm injuries, the fatality rate from gun violence could be even higher than generally believed.)

An important area of research relates to the burden imposed on the health system by gun violence. A 2005 study based on hospital records in El Salvador calculated that gunshot injuries treated in public hospitals absorbed 7% of the entire health budget (Paniagua et al 2005). El Salvador is a regional leader in terms of health system data: its public hospitals collect detailed data related to diagnosis, treatment and resources dedicated to each patient, enabling analysis not only for research purposes but also to support policy and service evaluation and planning. This is another area where Guatemala could learn from its neighbour.

c) Research on services available for people with SCI

Notwithstanding the gaps in services for people with disabilities in Guatemala, there are some services available from NGOs like Transitions or INGOs like the Red Cross. However, there is no directory or information platform to help people with newly acquired disabilities or their families in identifying these services. A project to map the services available in the national government, municipal, non-government, church and private sectors would be enormously helpful, especially if it could be regularly updated. Facebook, which is widely used in Guatemala, could be used to create an entry point for services and information; as a bonus, it would lead to the development of networks of people interested in locating the same services. It would be important for hospital staff to be aware of this information.

12.4.5. Recommendations related to Advocacy

The study participants' response to catastrophic injury is characterised by courage and determination, but not by activism or demand for change. This is understandable given the existing demands on their energy and the daily challenges they face. However, there is clearly a need for concerted advocacy for prevention of gun violence, victim assistance and disability rights; and for a much higher standard of performance by government institutions in Guatemala. All these recommendations for training, policy reform, service provision and research will require advocacy, because resources are scarce and apathy is entrenched. With one in every six Guatemalans falling victim to crime each year, and one third of all households containing a person with a disability, the number of lives affected is very large. An effort should be made to develop a broad coalition for advocacy on these and related issues.

The disability group CONADI, despite its constraints as a government body, has a key role to play. So do the domestic violence advocacy groups, which have been very successful in raising awareness of violence against women and improving prosecutions. The churches, which command so much respect and wield great influence, should be enlisted as part of this advocacy coalition. The new president of Guatemala (from January 2020) is a polio survivor who is sometimes seen using crutches and has expressed interest in improving services for vulnerable groups in the population. This creates a potential advocacy opportunity.

Successful advocacy requires information, and even a small amount of information has value in a context where little is available. This was one of my main reasons for undertaking this study: the hope that knowledge about the lived experience of even a small group of survivors can inform advocacy and awareness campaigns to benefit gunshot survivors and people with disabilities in general.

12.5 Personal Reflections

This study fills a small part of the void about which I have often complained to my friends in the research community: why is there no research on people who have been shot? I am happy to have put in my little grain of sand, as we say in Guatemala, and hope it will lead to more research and advocacy. As I discovered in my literature search (Chapter 2), several other Latin American countries also suffer from high rates of gun violence but lack information on the experience of survivors. The results of this study might also prove useful beyond the borders of Guatemala, perhaps by inspiring research in other contexts.

I learned a great deal on the way, about disability and catheters and the research process; about power outages and volcanic eruptions; about how individuals living in very challenging circumstances can maintain patience, grace and good humour.

It is no small thing to ask survivors of violence who are wheelchair users to take half a day to travel to another city and share the most distressing and painful experiences of their lives for a foreign audience. I had wondered if they might find the process tiring or traumatic, and some appeared nervous at the start. However, after the interviews all the participants seemed energised and proud to have taken part in a study that might

eventually help to improve conditions for survivors. I have been in contact with most of the participants during the subsequent year since they were interviewed, and they have expressed interest in my progress. I have undertaken to brief them on the study once the examination process is complete.

Flory, perhaps the most eloquent of the six, articulated her feelings about the study and Transitions during our conversation at the end of her interview She mentioned Sonia, another survivor who had originally been on the list of participants for my study but who was unable to take part because of health problems. Sonia was the first Guatemalan survivor I ever knew outside of Transitions. Shortly after being shot in a robbery, she saw me interviewed on an overseas tv program and emailed me, suggesting that women who have been shot should be supported to learn handicraft skills to maintain their families (she is a knitter and bead jewellery maker). The next time I came to Guatemala I contacted her, and she was included in the first Transitions wheelchair project for gunshot survivors. Sonia knew Flory from church, and she organised for Flory to receive a Transitions wheelchair as well. This was how Flory came to be involved in my study.

Sonia

Here is Flory's comment:

> And I thank God for knowing the members of Transitions because in fact, here in Transitions is where I have spoken and told my story as it really is, without putting on [a gloss], or taking away [any] elements, and without adding anything. Because I must be truthful and simply tell you what really happened, there's no benefit in my telling a story that isn't true, because a lie is always discovered, So I want to thank God and you for giving me the opportunity to realise how much my wounds have healed and what the hurdles are that I still need to overcome, because talking to you I've discovered that there are still things that hurt – and there are also many that have healed. And there are many people I can thank for the fact that I am here today, because if it hadn't been for God, for Sonia and you, I wouldn't be here. Since it's through Sonia that I'm here. So I want to thank you and tell you, thank you for giving me the opportunity to tell my story and hopefully help someone else.

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Appendix A: Jairo's story

Jairo has been profoundly affected by gun violence, as both a primary and secondary survivor. Not only does he have paraplegia from gunfire, but three family members have also been murdered. He was shot 14 years ago when he was 25, a taxi driver and single father of two girls. The assailants forced him off the road to steal his taxi, shot him seven times and left him for dead. Jairo had been robbed before, and assumed this time would be similar:

> [I thought], They're going to assault me and they're going to take my car, no big deal. That's why I handed over [the key], there you go.

Just one week before this attack, his younger brother had been shot dead for refusing to join a local gang. A year later his sister was also shot dead, apparently because her mother refused to pay extortionists, so Jairo took over raising her three young children as well as his own daughters. Jairo's father had died many years before, and his mother was the sole income earner for the tri-generational family.

Nine years after the attack on Jairo, his mother was also shot dead. She worked for the local mayor, a controversial political figure, but Jairo does not know what lay behind her killing. After their mother's murder, Jairo's other sister abandoned the family home, leaving her teenage son in his care.

When Jairo was shot, he felt bullets hitting him but no pain:

> You don't feel anything, but when you realise it, if you manage to stay alive, you react – but by then you're dying, and it is a really horrible feeling.

In the first moments, he thought about disability:

> I figured I was going to end up in a wheelchair…. I immediately thought about that. Because I couldn't move my legs, I didn't feel them. I was conscious, but I did not feel my legs.

The thieves took Jairo's car, leaving him lying by the side of the road in the dark until another motorist spotted him and called the paramedics. He was taken to the closest emergency department, at a hospital in the Social Security (IGSS) system, of which he is not a member. When he regained consciousness:

> The doctor came and said, "Look, I have several pieces of bad news. The first is that I'm going to remove you from this hospital and send you to the Roosevelt [public hospital] because you don't pay IGSS." "Well, that's ok, I told him." "The other bad news is that your arm is badly damaged but since

> you don’t pay IGSS, they’ll operate on you over there [at Roosevelt]. And the other is that you're never going to walk again.” My response was not to be frightened or anything but to say, “Ok doctor, that’s ok, don’t worry.” “You’re taking it well,” he said. “What can I do,” I said, “at least I'm alive.”

In principle, the public hospitals are free. In practice, patients or their families are often required to provide supplies (PDH 2019). Having been shot in the arm, neck, chest and abdomen, Jairo needed X-rays and CT scans. His family was told the equipment at Roosevelt was broken, so they would have to pay for these exams at a private laboratory. His family also had to bring him food, water, catheters, colostomy bags, and adult nappies.

The Roosevelt staff seemed too busy to attend to his needs. For example:

> One day I needed a drink of water. My family had brought me water … and it was maybe about a metre away and I said to the nurse, “Excuse me please, would you be able to pass me some water?” “I’ll be back soon,” she said. “Ok fine,” [I said]. It was about five in the morning, and my mother came to see me at eight and they had not given me the water. Or “Nurse, excuse me, it hurts, would you be able to give me something for the pain?” “I’m busy now, I can’t do it.”

His sister and mother took turns staying with him, changing his nappies and catheter, dealing with his colostomy bag and other needs.

Although public hospitals are notorious for inattentive care, Jairo felt that he was being singled out for poor treatment.

> One day I asked one of the doctors, “Doctor, excuse the question, why is that when you come to treat me, you look at me kind of with contempt or something?” He said, “That’s how we treat thieves around here.” “Oh sure,” I said, “but I’m not a thief. You must not have read my file. My car was stolen from me, I didn’t steal a car.” “Really?” “Yes, you can read it, or ask my family or whoever.” So then he looked like [surprised] and he probably went to read it because the next day they treated me a little better. But by then I was already due to leave the hospital.

This was Jairo’s first encounter with the stigma associated with being shot.

The worst consequence of staff indifference was that he was not regularly turned or checked for pressure sores. He lay “looking at the ceiling” for a month, and as a result developed a pressure ulcer on his sacrum. Shortly before he was discharged, his mother was giving him a sponge bath when she discovered the open wound. It quickly grew to what he called a “mega-ulcer” that stayed with him for eight years.

Jairo was discharged from hospital with a worsening sacral pressure ulcer and incorrect advice on how to treat it: “They told my mum to pour soapy water on it and that would cure it.” He received no information on how to prevent future ulcers, no wheelchair, and no referral for rehabilitation, “Nothing. I left there, it’s like

sending a soldier to war without a rifle." Most of the other interviewees were similarly poorly advised on how to deal with life after hospital, and thus took no steps to avoid pressure sores and urinary infections.

Once home, his mother and nephews used as a makeshift stretcher to carry him inside. He felt "partly happy to be home, but sad at the same time. Because I couldn't go out, I had no wheelchair, nothing."

Eight years of deteriorating health followed. He developed two more pressure sores in the groin area, and the sacral ulcer grew to around 15cm across:

> You could fit your whole hand into it ... My mum put her hand inside it to clean it. Inside, it almost touched my stomach, the bone of my spine was almost exposed. And because of that ulcer, my coccyx and the bone above disappeared, so I'm missing those 2 bones... dissolved, you could say, by the ulcers.

His mental health also suffered. After discharge from hospital he became so depressed that he did not leave the house for over a year. Though unable to work, he was raising five children: his two daughters plus the three children of his murdered sister. Everyone depended economically on Jairo's mother. Even with intermittent access to a borrowed wheelchair, he was too depressed to go out:

> There came a time when I thought it was better to die, because it was affecting my family, just seeing me so sick [with ulcers] made them worry… I thought I was a hindrance to my family, that's what I thought, even though my family always showed me the opposite, my family always supported me…
>
> Q: Did you feel like you were a burden?
>
> Exactly, because sometimes my mum would have to stop doing things to take me to the hospital or something. And also when I needed something, I thought they're busy, I don't want to take up their time.

A friend began to visit, inviting him to go to church. At first Jairo felt it would be hypocritical to start attending church simply because he had fallen on hard times:

> [I thought] no, no, if I didn't go when I was healthy, what will people think? That's what goes through your head: I can't.

His friend's persistence eventually paid off and Jairo went to church. His mobility and mental health improved when a faith-based NGO gave him his own wheelchair, and he became active in the church and his community.

His mother pursued avenues of information on treatment for pressure sores and how to teach Jairo daily living skills such as bathing and dressing. She found a place for him in the Roosevelt rehabilitation program (where he should have been referred after hospital). In rehab he learned "that I had to fend for myself … They told me, if your hands still work… you can do everything." After a month the program rejected him "because they said I definitely had no chance of walking."

As time passed and he grew sicker, his mother took him to see a plastic surgeon at San Juan de Dios, the other major public hospital:

> I was yellow, thin, I was at the end, I was going to die. The plastic surgeon called my mum in and said "Look, ma'am… take your son home because I can't do anything for him – what he has is too severe and I won't be able to cure it here. If you have money, pay for plastic surgery elsewhere, but that will cost you money. I can't do it." So he turned me away from the hospital … he said not to come back because I was going to die, within the year I was going to die.

The turning point came through a connection with a social worker from SOSEP, a government program which Jairo's mother had approached for help. Through clerical error or divine intervention, photos of his ulcers became mixed in with the SOSEP files sent to Dr C for a cleft palate surgical mission:

> And the doctor saw [photos of] my ulcers and he called [the social worker] … "Hey, whose wounds are these?" "They're from a guy named Jairo. You know, the San Juan de Dios hospital turned him away…" He said, "Contact him! Call him on the phone and get him to come to your office in an hour…"

More than eight years after Jairo's discharge from hospital, Dr C treated him with negative pressure wound therapy, which uses a vacuum to promote healing: "and from that day the ulcer began filling up with flesh." The treatment was successful, but recovery required a year in bed:

> I spent all of 2014 lying face down. And at the end of 2014, on December 1st, my mum who works in the municipality of Mixco, my mum was murdered.

Jairo wept during the interview remembering his mother: "Everything changed, because then I was practically all alone, everything fell apart because my mum was no longer there." She had held the family together until his ulcer healed, and now the responsibility fell to him. "But to this day God has been good to me and has helped me – I'm still here, right?"

His health has steadily improved, thanks to Dr C, and the two of them have teamed up to help other people with spinal cord injuries and ulcers:

> They contact me and I take them to him. He operates on them for free in his clinic. It's a cosmetic surgery clinic, but he takes us on.

Jairo describes his physical and mental health now as good. He knows how to avoid further pressure sores and his nephew checks his skin every day. He gets occasional urinary tract infections if he waits too long to change his catheter and urine bag. He cannot afford colostomy bags, so he improvises with an ordinary plastic bag and tape. He has chronic back pain, including pain associated with the bullet still in his body. He takes no medication for pain, but lying down helps to relieve it.

In the early days he used to go over the shooting in his mind, wondering if he could have done anything differently; but not anymore. Back then the faces of his assailants were imprinted on his mind, but he now says he would no longer recognise them. However, a lasting effect has been fear:

> In fact, I am afraid to go outside, with my family, because sometimes you're not looking for trouble, but other people go around looking to make trouble.
>
> Q: Are you more afraid because of your experience?
>
> I am more afraid, not only because something could happen to me, but because of my family.

His main cause of stress is financial worry. After his mother's murder he revived sewing skills from his youth and began to earn a living making clothes and doing alterations. His two daughters have grown up and one is working, but he is still supporting his niece and nephews, whose schooling is his biggest expense. Dr C is sponsoring education for one of the nephews, and fortunately there is no rent to pay as the family lives in a house built by Jairo's grandfather. Still, his income does not go far.

Besides the doctor, Jairo's principal source of outside support is his church, which has helped him spiritually and in practical ways. Church members have given him sewing work and referrals, as well as financial gifts. Attending church has made a big difference: "It has changed my way of being … I'm not the same person, being inside the church has helped me to raise my family better, to behave better with people, to be more aware." This is described further in Chapter 9 – Religion.

The key to maintaining his physical and mental health, he said, is his sense of responsibility for his family:

> My niece and nephews, my two children and my grandson… if I'm not fine, they're not going to be fine. That's my motivation every day.

Appendix B: Kevin's story

Kevin comes from Puerto Barrios, a city of 100,000 people on the Caribbean coast of Guatemala, which he describes as a safe place with no gang activity.[36] He was shot there three years ago, at age 19, by a sexual rival.

Kevin's family lives on remittances sent home by his mother, an undocumented immigrant in the United States. His father abandoned the family, also for the US, when Kevin was small.

Like many Guatemalan children, Kevin and his two siblings were brought up by their grandmother, and thanks to the remittances he did not feel that they were poor. After leaving school in Year 6, he spent his days helping his grandmother with her used clothing business. Later he filled his time riding his motorcycle, partying with friends and flirting with girls. He was never in trouble with the police, and at age 18 started a steady job repairing tyres at a petrol station. A few months later he became romantically involved with a customer who said her ex-boyfriend kept bothering her. Kevin spoke to the ex-boyfriend:

> I said, "Look, I'm going to ask you please not to bother her, because now she's with me and wants to get serious."
>
> "Oh sure, we'll soon fix that," [he said], and he left.
>
> Well, I thought, he's going to get some guys and come back here to beat me up. [Then] I was talking to her, asking what was going on, and while I was talking to her, he came by on a motorbike, BRUMMM, BRUMMMM, and he went past the office [mock] shooting in the air, like threatening me. And that's when I should have taken precautions, but I was too trusting, since I'd never had that kind of problem.

Four days later, Kevin left his girlfriend's house at around 1am, and another motorbike rode up beside him on a dark stretch of road. The passenger on the second bike was the ex-boyfriend, who pointed a pistol at Kevin:

> He came up and BOOM the first shot in the back. Then I was falling back like this, then the bike pulled ahead and came up next to me and he was shooting at me, he kept shooting me, bang, bang, bang.

The initial shot severed Kevin's spinal cord, causing him to fall backwards off his bike. After three more shots the pistol jammed, the attackers' bike stopped, and Kevin saw the shooter's angry face as he struggled to get the gun working again. At that moment two motorcycle police came down the road; and the assailants sped

[36] Kevin's assessment reflects his personal feeling of security in his hometown rather than official crime statistics. In 2018 Puerto Barrios had a homicide rate of 54/100,000, close behind the Guatemala City rate of 61/100,000 and more than twice the national rate of 22/100,000 (Viceministerio de Prevención de la Violencia y el Delito 2019a).

away with the police in pursuit. Thus the fortuitous appearance of the police saved Kevin's life by chasing away his attacker. They did not return to assist him.

He lay by the side of the road, unable to move:

> And when cars passed, I shouted, "Help me!" but nobody stopped … I shouted and shouted, and nobody stopped until a drunk guy on a motorbike stopped. By then I didn't have the strength to keep shouting, I was shouting but no sound came out. So I would just raise my hands like this when the headlights of a motorbike or car went by, and then I saw this young guy stop. He parked his bike in the middle of the road and came to help... I still remember, he was walking kind of drunk and he began to stop all the cars.

A group began to gather as drivers stopped to see what was happening, and a utility truck driven by police pulled up. The bystanders urged the officers to take Kevin to hospital, but they hesitated, fearful that he might die while in their care. Then the group opened the tailgate and lifted Kevin onto the bed of the utility, so the police reluctantly drove him to the hospital. (On his way to hospital Kevin was robbed of his phone, wallet and chain by the man who accompanied him in the back of the truck – the same motorcyclist who had first noticed him lying by the road and stopped to help.)

Kevin was treated for three gunshot wounds at the local Puerto Barrios hospital, but an operation on his lungs required transfer to San Juan de Dios public hospital in the capital, five hours away. He said the staff treated him well at the coastal hospital, "because in the hospitals there, there are no gangs." However, in the city hospital he was viewed with suspicion because he was a gunshot patient and had a tattoo. He was accused of being a gang member by police guarding prisoners who had been brought in from the jail for medical treatment:

> [My tattoo] is nothing to do with gangs, but here in the hospital there was an officer who hassled me a lot. I was [on a stretcher] on my way to get an X-ray… and there were several police guarding a prisoner and I passed through the middle of them. And one officer approached me… and he lifted up my shirt and saw my tattoo, he lifted my shirt and asked what gang I was from… And my brother was alongside me, "What's the matter with you?" and we all got upset and started arguing.
>
> I said, "Do you see a number or something that identifies me as a gang member?[37] Don't be like that, we are not all criminals here."

His subsequent interaction with the criminal justice system was less negative, but still not conducive to justice. In Guatemala, criminal investigation is the responsibility of detectives who work for the Prosecutor's Office in the Attorney General's department. Detectives came to take a statement from Kevin just as he was

[37] The two major crime gangs in Central America are known by numbers, MS-13 and Calle 18, and gang tattoos often incorporate 13 or 18 in their designs (International Crisis Group 2017).

emerging from surgery, but he was unable to speak "since my lungs had collapsed and I had too much phlegm, too much pain". He asked the detectives to return in two weeks to talk to him, but they never did:

> If they had been a bit more professional, let's say, they would have come back 15 days later, because I even signed [a document] that I wanted them to return in 15 days so that they could take my statement. But they didn't return, they didn't care.

Kevin did not see this failure as another manifestation of stigma against gunshot survivors, but simply as a lack of professionalism by the detectives. Although he blames the detectives for not following through, he admits that he himself made no attempt to report the crime either. After his health stabilised, he could have contacted the authorities but did not, because of the risk of retaliation by the shooter:

> I don't know if it was out of fear or just laziness.
>
> Q: Fear of what?
>
> Fear of getting into legal trouble [ie another crime] with him. Let's say I reported him [and he was arrested], then he couldn't do anything to me, but he could send someone to do something to my family, to my brother or something like that… Because a criminal looks for your weak point to fuck you.

Even though he had not reported the crime, Kevin still worried about what might happen if he encountered his attacker again:

> [I thought,] What will I do the day we meet and look each other in the eyes? What will he do, or what will I feel? I wouldn't do anything – I mean I'm not going to shout, "Look, I've come to kill you!" No, because I know that whoever does something pays for it, and if I had done something to him, I would have to pay for that – or else a member of my family. Who knows what he might have done – in that moment he might have grabbed his gun and finished me off right there.

The fear persists even after the individual perpetrator is no longer a threat. In Kevin's case, the man who tried to murder him was himself murdered a year later. Nonetheless, Kevin is afraid:

> To this day I think about it, even though the guy who hurt me is no longer alive… But his friends are still there … They're not gang members, just young guys who like to go around robbing or mugging – it's the same thing. They treat each other as if they were brothers, sometimes they're in large groups, or sometimes just two of them, but when something happens to one of them, the other wants to take revenge for what happened.

Asked if he is still in danger if he returns to his hometown, Kevin began to cry:

> That still worries me, although he's not there anymore, that a friend [of his] might see me and I won't recognise him and he'll say, "There's the wretch" and want to hurt me.

In any case Kevin's health is keeping him in the capital: he rents a room and pays a young woman to help him with personal care and exercises to build up his strength, all funded by his mother's remittances. He talks to his grandmother every day by phone, and has unexpectedly reconnected with his father, who also lives in the US:

> Because for 20 years [we didn't have contact], but when this happened – I don't know, maybe out of fear that I could die, he came from the States to talk to me. He came to see me in hospital, and that's how I started to communicate with him.

Like the other study participants, Kevin perceives his personal situation as individual, rather than part of a larger phenomenon such as gun crime, gender-based violence or disability. For example, when he sees news about gun violence on TV:

> I think about the mothers of those people who die, of those young people who die from this, that their mothers are the ones who are left destroyed, and their children.
>
> Q: Do you think of people who didn't die, like you?
>
> No, how do you mean?
>
> Q: You said you think of the mothers of those who die. But do you also think about gunshot victims who don't die? Which is what you are, a gunshot victim who didn't die.
>
> Well, no.
>
> Q: Do you think there are many like you?
>
> Well, there are not many of us who survive, but I'd say that many people are affected by [gun violence].

The stigma against gunshot survivors that Kevin encountered from police at the hospital also exists in the wider society. Many people assume that someone who was shot must have been involved in criminal activity:

> When I'm out on the street and someone asks what happened to me… Let's say I tell them I was shot by a gun, they'll think, "he was involved in something [suspicious]."

To avoid the stigma, Kevin provides an alternative explanation for his spinal cord injury:

> [I say] I had an accident on the motorcycle, I was hit by a car – just so they don't look at me with different eyes.

He is not troubled by having to resort to this subterfuge:

> Well sometimes I feel – not bad for me, but bad for the people who are like that, and who think bad things in their mind even though I know that isn't the case. But I've never been upset by anything they say to me.

Like many young men, he likes guns, and in the past has shot at tin cans for fun with a pistol belonging to cattle farmer friends. Kevin does not consider it dangerous for the population to be armed:

> Over there [on the coast] a lot of people carry guns… the ranchers like to go around carrying their guns… People who carry guns in the open, I think they carry it out of fear of those who carry concealed guns, and who have the mentality of harming other people. I think [the open gun carriers] don't cause that fear, rather they want to protect against it.

Nonetheless, it has not occurred to him to carry a gun: "No, I don't think I need it."

Appendix C: Manuel's story

Manuel is a shy, soft-faced young man who speaks so quietly that many of his answers were difficult to hear. He was shot four years ago at age 14. His spinal cord injury is higher than for the other study participants, so he has only partial use of one arm and hand. (He was the only participant who responded "Some difficulty" or "Cannot do at all" to the questions about self-care and upper body mobility in the Washington Group Extended Set of Questions on Functioning.)

Manuel's family was already poor, but his shooting drove the household deeper into hardship. He lived with his mother and two brothers in a dangerous neighbourhood of Guatemala City, and all three boys had left school around 4th grade to work on the public buses. They worked as assistants to the drivers – collecting fares, herding passengers further back to make space, calling out the destinations, stepping down into the road to negotiate traffic jams when necessary.

So-called public buses in Guatemala are actually privately owned, but they fill the role of providing cheap (US$0.15) transportation for the majority of the population to move around this crowded city. The buses are a dangerous environment for workers as well as passengers, providing an easy target for armed robbery and extortion. Extortionists charge bus owners and/or drivers a regular "quota" to be allowed to operate, generally between Q400-1200 (US$50-$150) per week (PDH 2016). Since bus drivers earn very little – a small percentage of the modest fare paid by each passenger – they are sometimes unable or unwilling to pay. This can result in the drivers or their assistants being shot. Passengers often suffer collateral damage, or they may be shot while being robbed. The year 2014, when Manuel was shot, was the peak year for public transport shootings. Attacks mainly on buses, but also on taxis, motor-taxis and private minibuses, killed 418 people and left 434 wounded (PDH 2015).

When extortion activity is very high, drivers may decide to keep the bus off the road. This is a safety measure, but it means no income for driver or assistant during the period of inactivity. On the day before the shooting, Manuel's boss kept the bus in the depot. However, he needed money to pay for his baby daughter's baptism the following weekend; so on the second day they went back to work. In the early morning, before taking on passengers, they were parked in a petrol station when the assailant climbed onto the bus. The driver was at the steering wheel reading a newspaper and Manuel was seated several rows back. The attacker stepped up, shot the driver point blank several times, then turned and fired one shot at Manuel before getting off the bus and onto a waiting motorbike. The driver slumped forward dead on his newspaper, while Manuel survived with a spinal cord injury.

The bullet penetrated Manuel's jaw, travelled across his chest and came out through his shoulder. He heard the noise of the shot and then felt something hot:

> It was hot where I was bleeding, I just looked down at my shirt and there was like a little river of blood coming out… I was sitting just like you are right now, and when he shot me I stayed sitting there.
>
> Q: And your body?
>
> It went numb immediately, I couldn't move anything, my body was asleep. But I kind of thought to myself, maybe that's normal. I thought that must be the usual thing, and in a while I'll be able to move again, but that didn't happen.

Manuel had been earning Q50-100 (US$7-$14) per day as a bus assistant. His brothers earned a similar amount, and they all contributed about half their income to the household. His mother was also working, while his father (who did not live with them) occasionally contributed something. Manuel estimates that the amount available for household expenses was at least Q200 (US$28) per day. This was the equivalent of around two Guatemala minimum wage salaries among the family of four.

The most obvious financial impact of the shooting was that Manuel could no longer work and therefore lost his income. Occasionally the bus owners make ex gratia payments to injured drivers or assistants (or the widows of those murdered), but Manuel was not so fortunate. The only contribution from his bus's owner was Q1000 (US$140) to cover X-rays and exams in hospital.

A second financial impact was that his mother's income plummeted, because she dropped out of paid work to care for him. She had been earning about Q50 (US$7) per day cleaning houses. Although Manuel learned many skills in rehabilitation, he depends heavily on his mother in his daily life and she is reluctant to leave him home alone:

> I say to her, "Don't stay here just to look after me, go out if you want to. Just because I'm in a wheelchair doesn't mean you have to stay with me."
>
> Q: And what does she say?
>
> She feels bad because, for example when she saw that I was getting a pressure sore she started to cry, "I don't like to see you this way!" But I tell her, "Don't get upset, it'll heal."
>
> Q: If you weren't in a wheelchair would your mum be working?
>
> I think so. She always says, "I like to work." She says she likes to have money in her pocket.

Other events have also affected the household's income during the four years since the shooting. Manuel's older brother got married, moved out and is now supporting his own family, though he still helps occasionally: Manuel's father has died; and he now has a stepfather who lives with the family and has sporadic earnings from gardening. The only person bringing in a regular income is his younger brother, who is still a bus assistant.

Because of all these changes, the total daily income of the household now averages Q100 (US$14). This adds up to one minimum monthly wage for a household of four adults – a drop of around 50% from when Manuel was shot.

Along with a reduction in income, Manuel's shooting brought an eventual increase in living costs. At first this was not evident. His hospital stay was less than a week and his memory of that time is vague, so he does not recall what costs were incurred, apart from the expensive tests covered by the bus owner. By the time of discharge he had developed a pressure sore. His mother rang around for advice on pressure sores, and learned that a bed was available at the Von Ahn public rehabilitation hospital. Admitted to Von Ahn for eight months, Manuel learned daily living skills and was included in a group of gunshot survivors receiving wheelchairs from Transitions. He does not recall having to pay for anything. This contrasted with the experience of most study participants in the general public hospitals, where they were obliged to pay for tests, medication and supplies.

After leaving Von Ahn, the real economic impact of the shooting began to be felt. No longer able to afford their rent, the family moved to cheaper accommodation. Manuel says the new place does have its advantages: the floor is concrete rather than dirt, and it is closer to a health centre. However, it is much smaller; all four of them live, sleep and cook in one room of a house occupied by several families. The neighbourhood is fairly flat but the house itself is inaccessible due to steps at the front. Manuel can only get into or out of the house if two people carry him, so he rarely goes out. Inside, there is no room for him to wheel around, so he does not get much practice mobilising himself. He cannot get into the communal bathroom, so his mother bathes him outside three times a week, pouring cold water over him with a plastic bowl.

His principal additional expense is for incontinence supplies (catheters, urine bags, gel, gloves, distilled water) and medication for recurring urinary tract infections. Those costs come to about Q100 (US$14) per month. If he goes anywhere, he must take a taxi, since he cannot get on buses; and this cost is another reason he rarely leaves home. A trip to the medical clinic costs Q50 (US$7) each way.

Manuel mentions money when asked about his mental health:

> Q: And how is your mental health? Are you happy?
>
> Happy, but sometimes I do worry.
>
> Q: What do you worry about?
>
> We have to pay the rent, and sometimes there's no money to pay it and I wonder what we're going to do.

He would like to help improve the family's economic situation but has not looked for a job because he doesn't know what he could do:

> At least if I had good use of one hand, I could do something like make bread… My brothers have teased me, [saying] "We'll buy a box of chewing gum and you can sell gum on the street". [Selling chewing gum is a common pretext in Guatemala for someone who is actually begging.]
>
> Q: And what do you think of that?
>
> Oh no, I told them I'd be ashamed to be selling chewing gum.

Shame is another factor preventing Manuel from leaving his house to participate in his community:

> People stare at me, that's why I don't like to go out because I'm embarrassed… Sometimes I'll be going down the street and someone I know from the busses will come by, and they stop the bus and say, "Here, have some money". No way, that's so embarrassing!
>
> Q: But do you accept the money?
>
> Sure, but I'm embarrassed… People giving me money on the street, I don't like that.

Asked how he would spend it if he had more money, Manuel answers like any young person of his age:

> The first thing I'd do is buy a new phone… and a pair of shoes, and some clothes.

Appendix D: Flory's story

Flory is a lively woman with a broad smile and a candid manner. She is 40 years old and has paraplegia as a result of being shot by her boyfriend when she was 17. The course of her life has been profoundly affected by that violent relationship and by her family and social context.

When she was growing up in the 1980s, three generations (about 15 people) lived in Flory's grandparents' house in a poor neighbourhood in Guatemala City. She recalls a deprived childhood dominated by a cruel father and a strict grandmother. Flory and her four sisters left school after Year 3:

> because we had to go to work and there was no time and my father wouldn't pay for school…. maybe because my dad was sexist, that a woman should learn to work and be at home, not to study. And since most of us were girls, no one in our family has any level of schooling.

Instead she worked in the market with her grandmother, selling fruit and food. She was not paid for her work, but her grandmother bought her clothes and shoes. Looking back, Flory observes that she never had a sense of individual agency or any plans for her life.

> I never imagined a future. I had no vision of getting to be someone in life, to say I'm going to study or I want to become a secretary or something like that – no, that did not even cross my mind… They taught us to work in the moment, so tomorrow you go to the market, you buy, tomorrow you have to do this, but I was told to do everything by someone. It's not like I ever had dreams, I did not have dreams.
>
> Q: Did you feel you had the capacity to act or decide for yourself?
>
> No, we could never decide, they always told us what to do, what not to do, what was right and what was not right… My grandmother was very strict, even in the sense of not letting us go out even to talk or to stop at the shop, or at the door of the house because it was bad. My dad would come to the door and say, "Lazy girls, what are you doing there? Find something to do, go wash dishes." So it was not a life where I even thought, "I'd like to do this or that," at least not for me.

At age 16 she decided to leave home:

> My dad drank a lot, my mum with so many children became jaded, she paid attention to some and not to others, so I went on my way. I went off even though my grandmother went to look for me to come back, but I didn't want to go back. So it was my decision to take and I took it … Maybe I was looking to leave the mistreatment that was in the house, the lack of affection, even the lack of food since sometimes there wasn't any.

She went to live with her boyfriend:

> Maybe I was looking for a better life, but unfortunately I didn't know how to choose, because it went worse for me than at home…. Same as my dad, [the boyfriend] would touch things, check that I had everything clean, everything neat – the cleanliness had to be impeccable… He would leave every day and I stayed home doing the housework, trying so that when he came home, everything was in place, everything was clean. He had to find everything exactly as he had left it, because if I moved something, he said I had moved it for someone else.

In hindsight she sees that she had replaced her controlling father with a controlling partner:

> It's like you get used to a pattern of life where you're told by other people how to live. So in a sense I was stuck in the past and to this day I can see how badly off I was.

Just as in childhood, her movements were restricted, her life defined mainly by the need to avoid offending her boyfriend. She stayed inside the flat most of the time, "because if I went somewhere, he would say that I was going with someone." He physically abused her regularly:

> He hit me with whatever [object] he had, he would grab me or kick me, take off his belt and beat me with the belt or hit me with the pistol butt, throw me on the bed and grab me around the neck with both hands, climb on top of me and hit me like he would hit a man…
>
> It was a rare day that he didn't hit me because he would be in a good mood, since supposedly I had not done anything to anger him, so then he didn't hit me.
>
> Of course I was scared, I was afraid of him, maybe even worse than the fear I had of my dad, because the first time he hit me, he threw me to the ground and stood on top of me, he put his foot on my neck, hit me and told me I was going to do what he said, and not what I wanted. So in fact I was very afraid of him.

He worked as a security guard and kept an unlicensed pistol at home. Long before he shot her, he had used the gun in threats against her:

> He would aim at me or hit me in the chest, in the head or wherever, hit me with the butt, like "I'm going to shoot you in a minute." Or there were times that I sat on the bed and he shot, but he shot to the sides, he didn't shoot right at me.
>
> Q: He shot the wall?
>
> Yes, the walls next to me, I was in the middle and the bullets...
>
> Q: Do you mean there were bullet holes in the walls?
>
> Yes, there were holes where the bullet went in.

Fear of violence made her submit to sex, although she did not see it as rape. Perhaps distancing herself from the experience, she occasionally refers to herself in the third person:

> No, thank God I cannot say I was taken by force. It was difficult because after he hit me, having sex with him was something that Flory did not want to do, it was disgusting and nauseating. But if I let him see or feel that, it would go worse for me. So I said to myself, stay calm and pretend you want to be with him in that moment, even if it wasn't true. But it's not like he would grab me by force and force me, no. Basically I gave in to prevent him hitting me, that was the main reason, to avoid saying "I don't want to," because who knows what would have happened?

Sometimes he would apologise for his behaviour, but he was less concerned with Flory's welfare than with what his sister (who lived in the same building) might think:

> He would say sorry the next day, "I'm sorry, I didn't mean to do it" or if I had a black eye, he would come and clean up where I was bleeding, and say to me, "It was unintentional, when my sister sees you she'll scold me, she'll yell at me". But later in the week he would do it again. His sister told me not to let him do it, she'd say "Flory, hit him with whatever you have, if you have a frying pan, hit him with the pan, but don't let him do this to you." She said it so often that I followed her advice, but he kept hitting me, and then we would grapple with each other, it was like the cat and the mouse had come upon each other. And sometimes what I did was run away and go to his sister, so she basically hid me at her place. He respected her a lot and when the sister said, "You're not coming in here and that's that", then he would go.

Flory did not consider leaving, since the only option would be returning to the family she had fled:

> Basically out of fear, for one thing that at [my family's] home they would not take me back, they would mistreat me, throw it in my face. Unfortunately my family was – or some of them still blame me for mistakes and never pass up the opportunity to make me feel guilty, or say "it's your fault, for being stupid". So I had nowhere to go.

In addition, Flory says she loved him:

> I loved him so much that I didn't care what he did to me, or what he said to me. I was happy just to see him, to listen to him, I liked to take care of him… I mean, for me he came first, I didn't even exist… That's why I say that I paid a very high price for someone who wasn't… well, I loved him incredibly, I loved him a lot, to the point of giving my life for him if he had asked. It's very difficult.

She nearly did give her life for him. One day he came home in and accused Flory of sending love notes to a neighbour. Flory served him his dinner and stood back while he ate.

> Then he started to complain… He was going to show me that no one would make a fool of him, he preferred to see me dead than to see me with someone else – and took out the gun. But it was something so common and normal for me, that he would take out the gun and load it and threaten me, because it was something he almost always did when he got upset, so I didn't react, I just … said to

> myself oh well, he'll hit me as usual. So I turned off the stove and sat on the edge of the bed. Then, complaining and accusing me of cheating on him with the guy upstairs, he sat on the edge of the bed.
>
> I don't know at what moment he shot me because I didn't hear it, I didn't feel it, in that moment I blanked, maybe from sheer nerves.

Although she suddenly fell back on the bed, Flory did not realise she had been shot until he told her:

> It was he who told me, "I didn't mean to do it, I didn't mean to shoot you." I reacted and looked at him like, You shot me? with a look of surprise, and he said, "I didn't mean to do it – I was just going to hit you, but I took the safety off and when I held the gun hard, it fired."

She recalls the boyfriend crying:

> I don't know if they were real tears or fake ones, only he and God would know if he really regretted it or if it hurt him to shoot me – I don't know, because he never [again] said anything to me about it… Then he said to me, "What will I tell my sister, my sister will kill me, she will yell at me, my sister will hit me, what shall I do?" "Tell her what happened, what's done is done, what can we do?" "I'll go to call the paramedics, but first I'll go tell my sister to come and take care of you, to stay with you while I call them," and then he left.

The ambulance took a long time to arrive because the boyfriend hid the gun before making the call. Hiding the gun was Flory's idea. Again she refers to herself in the third person:

> He said, "What should I do, the paramedics will come, they'll search and they'll find the gun." But since that Flory didn't value herself, at all, at all, at all! I said, "…Get rid of it, hide it, put it where they won't search." … [So] he dug a hole in the garden and buried it there so that if they searched, they wouldn't find it.

He rode with her in the ambulance to the San Juan de Dios public hospital, where he gave a false account of the shooting, saying Flory had been shot during a robbery at a bakery. She learned of the lie four days later when she awoke after surgery:

> [The boyfriend] approached me as though to hug me, and I stared at him and he said, "If they ask you, tell them it was a robbery at a bakery, a stray bullet." And I stared at him and asked, "Why?" "Because that's what I told them." "But that isn't what happened." "It's what I told them because I didn't know what to say." "Oh well, ok," I said.

Her family also came to visit, displaying their usual lack of warmth:

> Nobody said anything to me, no one criticised me, everyone just looked at me: "How are you?" "Fine." "Ok." It was like a vigil for a dead person because there was no chatting, nobody said anything, nobody asked me anything, nobody made any comments.
>
> Q: Why do you think they were like that?

> I think they always blamed me and held me responsible for what happened.

They had been told the bakery robbery story but did not ask her for details. The boyfriend's sister, who knew the truth, did not come to visit; in fact, Flory never saw her again after the shooting. Her family believed the bakery story, except for one aunt. While Flory was still unconscious:

> Right there in the hospital, according to my sister who was there, my aunt told my grandmother that it was a lie, she swore and was absolutely sure that he was the one who had shot me. But the family scolded her. People who grow up in the market are foul-mouthed and my grandmother started to insult [my aunt] because she insisted that he was the one who had shot me. But since his version was that it had been a robbery, then of course – everyone even now thinks it was like that because I don't tell my real story.

After five days in hospital she was discharged, and moved with the boyfriend into her family's house, in a space partitioned off by sheets of black plastic. Like the other study participants, she found the homecoming depressing:

> [At] the hospital, when everyone around you is sick, you don't really assimilate that you are sick, because you all share the same situation. By contrast at home it was another reality: everyone can walk, everyone comes and goes, everyone does things, and I'm stuck there unable to move… The house is full of steps, there had never been a disabled person there so no one thought, "That will be difficult for her..." They all had their lives and could continue as usual, but not me… They were like, Oh, Flory's back, lay her in that room, fine. Whoever remembered that I was there might come in and say "Hi, how are you?" "Fine." "Ok, bye!"

She stayed home all day in bed, while family members and the boyfriend went out to work. Her principal relationship was with her mother, who was her carer as well as going out to work. For the first few months Flory was never dressed:

> My mum just put on my nappy and wrapped me in a blanket like when we wrap newborn babies – although nowadays they put pants on them. No, just my nappy and they wrapped me in a towel or a blanket and left me. Or [just] my blouse, that was what it meant to dress me.

She was "dressed" in a blanket for her first follow-up outpatient appointment at the hospital:

> Oh dear Jesus [laughing], I had forgotten that! My mum took me wrapped in a blanket and since we didn't know how to use the urine bag, I wore it over my legs, covered with a towel. That was how my mum took me to the hospital. Afterwards they bought me pants and I put on my own pants, but the catheter was always on top, because we didn't know that I could tie it on my leg, trying to fit it, nobody taught us.

The blame that Flory felt from family members permeated the care she received at home. For example, when her mother bathed her with a bowl of water:

> My mum doesn't have any tact in dealing with people, she was brusque. So she didn't take care when she poured water on me, I had to grab the basin because I felt I might drown. But really if it had not been for my mum in those early times, I would have died, not only from sadness but from filth, from not bathing. At least she would sometimes ask me, "Do you want anything?" If not for her attending me in the first difficult months, I think even if the bullet didn't kill me, something else would have.

At the first outpatient appointment, Flory was informed that she had paraplegia. She remembers the focus of the conversation being mainly on toileting:

> It means you don't feel from the waist down, that you'll have to use catheters until the day you die, because you can't [go to the bathroom], when you soil yourself you have to learn to change yourself because you don't feel … you have to be aware if you knock yourself… At that time I thought, how am I going to live, how am I going to do all this in the long term? Even soiling myself in a nappy, I'm not a child!

She was referred for rehabilitation as an outpatient at the same hospital where she had been treated. This was when she understood that she had lost her mobility permanently.

> The doctor told me, "I'm going to send you to rehabilitation but you're not going to walk again, no matter what exercise you do… And I'm staring at him saying, "Doctor, isn't there an operation?" "No, it doesn't matter what we do, [you won't walk]."
>
> …[Then] I understood that essentially my life had collapsed, life for me was no longer life if I couldn't walk anymore. I already felt that I was useless, but now I really wasn't worth anything, I couldn't do anything.

Her despair was accompanied by regret:

> I thought, if I had not done this or that, this would not have happened. But by then there was nothing I could do. Everything was already done.

Because of logistical difficulties in taking Flory to rehab, her boyfriend instead paid a physiotherapist, Dr H, to come to the house. She still considers Dr H one of her sources of moral support. She ran into him 15 years later at the hospital:

> He had never believed the bakery robbery story. He asked me directly, "I read that story in your file, is it true?" I told him the truth, I said no, it wasn't true. And he asked me, "And you still lived with him?" In other words, the stupidest thing I could've done. Yes, I said. "Oh Flory," he said (he is a Christian) ... "This was what you got, trust in God, you have to try hard, it's true there are lots of things you can't do, but there's also a lot that that you can."
>
> He helped me with my morale back in those years, even though I didn't understand, I didn't comprehend, I didn't accept the advice he gave me. But I remember very well, that he was always there.

Although Flory felt powerless spending all day in the black plastic room, the presence of her relatives in the evenings made her less vulnerable than when she had lived alone with the boyfriend. He no longer hit her, although he still complained. Her mother and sister cooked, washed and ironed for the boyfriend, and this troubled Flory because "it wasn't their obligation, it was mine." Eventually, after eight months, she used this as a reason to end the relationship:

> I found the courage that I'd never had…. The first good thing I did for myself, to tell him to leave, that I detested him, that I hated him. Of course it wasn't true, but I needed an argument that he would believe, and one thing I knew he would believe, was that I did not love him, that I did not like him – and he believed me.
>
> Q: You say it wasn't true, so why really did you want him to leave?
>
> Because I couldn't attend to him anymore, I couldn't be the Flory he was used to, who washed for him, ironed for him, cooked for him, was there for him. I didn't want my mother to have to take care of something that wasn't her responsibility. I didn't want him to keep being a burden for my mum.
>
> Q: You kicked him out because you were worried about your mum, not because you were worried about you?
>
> Exactly, I did not think about myself. At no time did I worry about what would be best for me, I just saw how difficult the situation was for my mother and I didn't want to be reproached anymore that it was my fault that my mum had more work. That was what my grandmother always repeated, that because of me, my mum had more work, because of me my mum had to wash nappies, because of me my mum had to bathe me. It's your fault, it's your fault. So for him to be complaining that the room wasn't clean or there was nothing to eat – I said it's better if he leaves.

Before leaving, the boyfriend sought to salve his conscious by telling her family the truth about the shooting. They were surprised and somewhat incredulous, but not angry. He asked if they wanted to report him to the police, but Flory recalls her father saying, "No, you should be grateful that I am a churchgoer, because otherwise I would have come after you. But it's up to God to judge you."

The boyfriend's departure put an end to Flory's sessions with the physiotherapist, but she contacted the Von Ahn National Rehabilitation Hospital and was accepted there as an inpatient. She learned to change her catheter and to avoid pressure sores. She built up her confidence, and since she had received a wheelchair as a gift, ventured out and became involved with the local church. In the years that followed she went back to school, eventually completing Year 6, as well as clerical and typing courses. She applied for jobs occasionally, but to no avail.

Although she could now mobilise, bathe and dress herself, the family still made her feel like a burden:

> You're so annoying, you're an idiot, you're a burden to your mum or we're tired of your being here. They made me feel… I already felt that I was useless, but they ended up making me feel like why

> didn’t you die, you’re in the way, why are you still here? And it's something I used to ask, Lord, why didn’t I die, I’m just in the way now.

(As noted in Chapter 9 - Religion, other participants also wished they had died because they felt guilty about burdening their families. However, Flory was the only one whose relatives verbalised their resentment.)

Nine years after Flory was shot, her grandmother died. The house was sold, and the new owner blocked off the only wheelchair-accessible exit to the street. This meant Flory could no longer leave the house. Trapped inside, she became depressed again and stopped eating. The dysfunction in her family had continued through the years; her father would come home drunk and beat his wife, with consequences for Flory:

> I had to deal with him, protecting my mum. He didn’t intend to hit me but defending my mother, I was obviously at risk of getting hit. But it would be a lie if I said that he intended to hit me because, no. But covering my mum, of course – he would say, “Get out of the way, get out of the way”, but of course I was not going to just let him beat my mum.

The solution for Flory’s living situation was provided by another part of her family: her sister and brother-in-law invited her to stay with them, “because in the house I was going to die of the combination of loneliness and sadness, from being confined.” She has now lived with them and their daughters for over 10 years. The location is precarious, on a shelf of illegally squatted land dug out of a sheer canyon wall. Access to the street above is via steep, rickety steps, difficult and dangerous even for a person not in a wheelchair. For Flory to leave the house, her brother-in-law carries her up the steps, pausing twice to rest. Thus she is still trapped, unable to go out on the street; but at least now she lives with supportive family. The small income she earns shredding rags covers her catheters, nappies and toiletries.

Flory says her life now is happy, because she has finally developed confidence and agency:

> Believing in myself that I can, if I propose it to myself, I can get ahead if I want to, that I am worthwhile in myself, I can do what I want, get up, sit down, lie down. If I want to sew, I can sew; if I want to wash, I can wash if I decide to. That makes the difference, knowing that I can.

She feels valued in the relationship with her sister and her family:

> I can count on my nieces and my sister, especially when [my niece] asks me, "Auntie, help me with my maths." It's true that I'm not a professional but I know something, and I can teach her. That makes me feel satisfied, that they value the little that I know and that I'm there, and that I'm not in their way – on the contrary, for them I am important. If I get sick, it's "Auntie what's the matter, take this, I'll put a cloth on you for your fever." So that makes me fight every day to be better. Yes, I feel happy because God gave me a new life, in this wheelchair but he gave me a new one and I find meaning in life.

Flory has lived with her spinal cord injury much longer than the other interviewees, and over that time has reflected on her shooting and its aftermath. Despite recognising that the shooter was responsible, she still says the family members who blamed her were "partly right that it was my fault."

> I feel or I think that I'm also to blame for allowing it… if I hadn't allowed [the abuse] and learned to stop it, to say I deserve a better life, if I made decisions – because you can love someone a lot, but not so much that you'd give up your life for someone who doesn't deserve it… We only learn it when we grow up, because as a child we're idiots, maybe that sounds ugly, but we're stupid, foolish, they buy us with some little gift, with a trinket. You think you're in heaven but actually it's hell itself, and you brought it on yourself.

She has mixed feelings about the family members who treated her harshly over the years:

> But my mother was there in the worst moments, my dad too. My mum's name is Teresa, and he would call out "Teresa, did you check on the girl?" – because he always called me the girl – "Yes, I did."… Going to church helped my dad to treat me better, because he never criticised me for it, he died without ever saying to me, "This happened because you were a fool or because you were stupid." He just said, "You brought it on yourself but now the thing is to try your hardest." Those were my dad's words.

Appendix E: Byron's story

Byron was shot eight years ago at age 26. On the evening of his father's birthday, the pair went to the local shop to buy soft drinks to accompany the birthday cake. At the shop a pair of young teenagers approached, pulled pistols out of their waistbands and began shooting. Byron saw the flash of the guns and just managed to duck his head and chest behind a wall before being hit 12 times in the legs, buttocks, ankle, foot, back and side. His father, who dove in front of his son to protect him, was shot four times in the stomach. Several other people were also wounded in the gunfire. His father had major surgery and recovered from his injuries, but Byron was left with paraplegia.

Byron remembers the sensation of being shot:

> It just feels HOT, HOT! And like something is going on inside your body, because you can't breathe the same anymore. My lungs were filling up with blood, I could hardly speak.
>
> Q: Did you try to move?
>
> Sure, I tried to stand up… I grabbed the railing in the shop, but I couldn't, I couldn't! My body was dead, I could only move my arms, but nothing else, I didn't know why. Then they took me to the hospital, along with my dad, the lady who owned the shop, and others hit by the bullets.

In the ambulance on the way to hospital, Byron received a call on his mobile phone informing him that he had been attacked in error – the young shooters had mistaken him for a gang rival they had been ordered to kill. The intended target was a bearded man, and Byron also had a beard. The next day, in the hospital, a woman approached him carrying an envelope, saying it contained Q2000 (US$260) as an apology from the gang. "But I knew that taking that money was like making a pact with the devil. So I said no, not to worry because I wasn't one to tell tales."

Byron's neighbourhood in the capital is classified as a "red zone" for crime, and as a child he had been friends with a boy who grew up to be a gang leader:

> I grew up with that friend, but he got into drugs, extortion, murder and trafficking, you know – so he became a dangerous, powerful person. He had several spots for selling drugs, so then it was just "hi" and "goodbye", because it's not good to have communication with them. Anyway, he sent them to kill the guy [with the beard]. He knew me, because we grew up together. So it was the kids who made the mistake.
>
> Q: And they were like 14 years old?

> Yes, 12 to 14… So they just thought, "There's the guy, the one with the beard," and shot me.

At the time Byron lived with his partner and young son. (That son is now 11 and has a baby brother aged three.) The couple met in church when they were 12 years old: "I was her first boyfriend and here we still are." Both had secure, long-term jobs at a clothing factory, earning slightly more than the minimum wage. Because they were in formal employment, as mentioned above, they were members of the social security scheme or IGSS. Members have access to IGSS hospitals and clinics which are better than the public facilities, and IGSS provides pensions for disability and old age. Byron spent three months in an IGSS general hospital, followed by 11 months in the IGSS in-patient rehabilitation program. Byron's hospital experience was more positive than that of other study participants in the public system. He was the only participant to be given a wheelchair on discharge from hospital, although the procedure was tedious and the chair was heavy and awkward. Byron and his partner were so relieved that he survived being shot, they got married while he was in hospital.

Byron assumed he would go back to work after rehab, because there were many functions at the clothing factory that could be performed in a wheelchair. However, when he went to speak to the personnel officer, she leaned over and pinched his leg "to see whether I could feel it or not." (He could not.) Then she declared that there was no job for him anymore.

> I begged her, I said, "Take me back, put me on anything, even if it's just sweeping, cleaning the toilets, I'll do it," I told her – because I've always been that way, active, I don't sit still.
>
> Q: And did they say why they wouldn't give you a job again?
>
> No, they just said, "We can't." And I said, "Please, look, my wife has been here a long time, we're people who have never given any trouble…" "Oh Byron, it's just that we can't do it."

He received a modest one-off payment from IGSS, and then began a period of unemployment and depression. He stayed home with nothing to do, suffering chronic pain from two bullets remaining in his back, and depressed about being poor and powerless.

> We just didn't have enough money and what could I do, it just wasn't enough… At that time my mother-in-law was taking care of my son, she would take him at 6am and I didn't leave the house, I stayed home alone, all alone, all day. And I didn't have anything to occupy my mind, and a mind that isn't occupied, it's dangerous and depression set in. Depression, what am I going to do, what am I doing here, and everything. And I sank down to the point of wanting to take my life.

It was at that time that he made his two suicide attempts – once by overdose and once by hanging – but on both occasions was rescued by a neighbour and taken to hospital. Following the second attempt, he was persuaded by a friend to take up begging for a living.

> But I said, "I'm too ashamed." "Do you have a family?" "Yes." "Then there's no reason to be ashamed, stop being ashamed." So I went, and now it's been about two or three years, and that's what has helped me to survive, because my wife's salary alone isn't enough.

Now his daily routine involves begging at a major intersection, usually sitting on the pavement. Three times he has been run over – once by a bus and twice by cars whose drivers were looking at their phones: "when he hit me, I saw the white light of the phone – he was texting as he drove." The first time he was hit, he was sewn up at the local Emergency and sent home. The second and third times landed him in hospital for six and two months respectively.

The place where he begs is a long way from his house, and his morning commute involves pushing himself up steep hills. He leaves home at 3 or 4am and returns around 7pm. Just near the house is a shortcut which saves him an hour if he can ascend a flight of 33 steps; so his wife and 11-year-old son sometimes come out in the dawn to assist him with that section.

Byron mentions God frequently in conversation, which is common in Guatemalan discourse (e.g., "I've always believed that God helps the early riser"). He was an irregular churchgoer before being shot, and describes himself as having been "a bit loose" or somewhat irresponsible, considering he had a young child at home: "I would go to a party on Saturday and come home on Sunday, things like that." Was he happy?

> Well, apparently – you believe things are fine, you're happy and everything, because at that moment you're enjoying yourself. But afterwards come the consequences, problems like you spent your money on one thing but you needed to buy something else...

He believes prayer helped him survive in the moments after the shooting, as he and his father lay bleeding on the ground and a crowd of onlookers gathered:

> One of my uncles who is a churchgoer, later when he came to see me he said, "Look [Byron], what use was it for me to come running to see you lying there shot? That wouldn't have been any use. What I did was call my family, the family unit, we knelt to pray and asked God for you two, so that God would not cut off your lives, would give you another chance. Because there's no point in joining a crowd, that doesn't help at all, better to bend our knees and ask God for your lives." So I think it helped that people interceded for us, that God had a little mercy and it wasn't our turn that day.

On the ground, Byron himself was praying, or negotiating with God:

> I clung on, saying I'm not going to die, we cannot die, because I had a wish to someday see my mum who had left us. So that was my heart's desire, and to see my son grow up and teach him and do things that maybe my dad didn't do with me, to do those things with my son – so I clung to that and asked God not to cut off our lives, to give us another chance.

As with most of the other participants, his religious faith and his character have been strengthened by his experience of being shot and living with a serious disability. He can cite further examples of God answering his prayers:

> With respect to God, I don't go to any church but when I ask Him... Like I told my wife, "You see, when I ask, I first ask His forgiveness for my sins and then I don't promise much, in case I can't deliver. Better to promise little, to be able to deliver, and He delivers for me." So I pray to Him, I say "Lord, look I can't pay the gas bill," and suddenly BOOM a car stops, "Here's Q100 (US$14)." And I had just prayed to God not half an hour before. And sometimes, "Lord, send me one of your servants to give me a lift, because I'm really tired today," and suddenly [someone stops], "Where are you going?" "To the Aguilar Batres [neighbourhood]," "I'll drop you at the cloverleaf interchange," "Ok, that's fine."

Byron believes God's purpose in allowing him to be shot was to force him to change his attitude toward life:

> I think so, He gave me a [message] – "settle down, that's enough, slow down in what you're doing, do something better." Now I think better, I see things more clearly than before. Nowadays if I have Q50 (US$7) and someone says, "Hey, let's have a beer," I'll say "No, we can use that money at home." Not like before…. [The shooting] helped to put the brakes on me a bit."

He has kept his promise from the day of the shooting, to be a better father than his own father had been:

> I am a better father. Sometimes I get angry – I don't hit him, I hardly ever hit my son, sometimes I raise my voice – but I say, "Sorry for shouting at you, but you know how I am, try to do as I tell you." I recognise when I overstep and raise my voice with him and I say sorry. Apologising is good for you, it's good for a person.

Most participants have received no mental health support, but because Byron has IGSS coverage he was offered counselling after his suicide attempts. He saw an IGSS psychologist a couple of times but gave it up because the taxi ride was too costly. Counselling did help him a little, although his main mental health strategy is faith:

> [Counselling] helped me to understand a little, and as I have always said, we all make mistakes. And I've always believed in things to do with God, I've always believed that He has control over everything. I recognise that I'm a sinner, but I ask Him for forgiveness, day after day – because we are not perfect, He's the only one who is.

He believes God has assisted him because, despite his flaws, he was fundamentally a good person before he was shot:

> What has helped me since the accident is that I was never one of those people who denied help to anybody. And I'm amazed and I say that everything you do comes back to you. And thank God I did a lot of good, so I thank God, it's come back to me. I say Thank you Lord, that you didn't leave me.

As mentioned in Chapter 7 – Justice, Byron's view that "that everything you do comes back to you" was confirmed by the fate of the two teenagers who shot him. Although they were never prosecuted for the attack on him, they were executed by other criminals. Meanwhile their boss who ordered the hit is in prison for

another crime. As Byron noted, “There’s no justice here on earth, from the authorities. But you can’t escape the justice of God.”

He thanks God for the failure of his suicide attempts, and now categorically rejects the idea that he would be better off dead. Although he doesn’t attend regularly, he says church is important in his family:

> My mother-in-law has always gone to church and my son always goes with her to church, now they’re even taking my younger son to church on Sundays. The baby wakes up at 7am and asks [immediately] for his coffee with bread so he can go to church with his grandmother.

Asked about the key to overcoming his challenges, Byron cites God as the first factor:

> It is thinking that God is with me, and it’s my family and that there’s work, because sometimes there’s none and what can you do? But that’s always the motivation – well there was none today, but maybe tomorrow.

Appendix F: Kimberly's story

Kimberly lives with her mother and two younger half-brothers in a dangerous neighbourhood of Guatemala City. It is the same area where she was shot 13 years ago by a gun pointed out the window of a passing car.

She was 12 years old at the time, and her family lived comfortably thanks to her mother's job as a manager in a clothing factory. That job, though well-paid, required long hours of work, so Kimberly was looked after during the day by an aunt while the boys had a babysitter paid by their father. She recalls a happy childhood with everything she needed, attending a small private school, playing with her friends and occasionally going to the movies. The family did not own a car, but their lifestyle was closer to middle-class than that of the other study participants.

On the day of the shooting, Kimberly was walking home from the shop when suddenly she found herself flat on the footpath. She had not seen the car nor heard the shot, and wondered if she had been electrocuted:

> By the time I realised, I was lying face down. I looked up and there were some power lines, and I saw those and thought, "Ok, what just happened, why am I lying here on the ground?" I tried to get up, I was face down and bleeding, bleeding from my sides toward my belly, and when I tried to get up I couldn't. I just felt my legs tingle and I said, "That's weird." I didn't realise what was happening, I didn't feel sick, absolutely nothing...
>
> Q: At that moment did it hurt?
>
> No, it didn't hurt.
>
> Q: And did you know you had been shot?
>
> No, I didn't even realise I was short of breath, nothing. I felt fine, I felt totally fine… Then a lot of people came over and my mother arrived, relatives arrived and my mum was talking to me, and I said, "I'm fine."

She arrived by ambulance at the San Juan de Dios public hospital, still not understanding what had occurred:

> A lot of nurses and doctors were waiting and they said, "There comes the girl with the gunshot wound." Even then, I turned to my mother and asked, "Who is it?" and it was me.

The family was later informed by police that there had been two shots, probably fired as part of a gang initiation ritual. One shot had just missed Kimberly's head; the other had entered under one shoulder, travelling across her torso, damaging the spinal cord, and exiting under the other shoulder. Around the same time, two other people had also been shot in the neighbourhood, one fatally.

At the hospital Kimberly's main concern was for her modesty. She resisted attempts by male staff to undress her for examination, and was able to negotiate a sheet to cover herself:

> Now it kind of makes me laugh, because I think how I was so worried about clothes, about being naked, when I was losing my life.

She spent three weeks in intensive care and then a month recovering in a children's ward occupied mostly by leukaemia patients. Her mother was constantly at her side to wash, change and feed her.

Like Flory, Kimberly does not recall anyone telling her that she had lost the use of her legs. She believes the staff must have informed her mother, but the news may have been considered too upsetting for a child to receive.

As described in Chapter 5 – Health, Kimberly's homecoming jolted her into realising for the first time that everything in her life had changed. She found it difficult to come to terms with her mobility impairment, and felt upset by visitors asking her about it:

> People came to visit me, neighbours, from church, and everyone asked questions, so it was uncomfortable... [They asked] "What did they say, are you going to walk again?" … "What did they tell you in hospital?" Incoherent things like that, which, no, I don't think they should ask someone who's going through that situation… so because of those questions I felt like oh no, just go away!

Her resistance extended to refusing to follow advice about moving regularly to prevent further pressure ulcers: "I got a bit rebellious and didn't want to do it." As her mood plummeted, so did her weight, from 54kg to 32kg (she was 1.6m tall).

She lost a year to depression but then experienced her own miracle by coming to the attention of a Hollywood film star, through a US-based friend of a friend of Kimberly's mother. The film star visited her in Guatemala and then paid for her to travel to Atlanta, US, accompanied by her mother. Kimberly had surgery for her ulcers followed by three months of rehabilitation at a children's hospital. There she learned to bathe and dress herself, to cook, to transfer to and from a wheelchair:

> They taught me… to be independent – whatever I know now, they taught me.
>
> Q: Was it difficult to learn the things you had to learn?
>
> Yes, very difficult, because my mum was kind of obsessive, you could say, I don't know the word but she wanted everything under control, was I sitting correctly, were my feet ok, so they had to separate her from me so

‘’I could make progress, and that’s how I learned …

Q: Did you speak any English?

No… Well, there was one therapist from Puerto Rico and she spoke some Spanish, but she was the only one.

The contrast in hospital attitudes toward children as participants in health decisions was striking to her:

When I was in the United States, I was 13 years old and before any procedure, everything was up to me. They would ask me, they said it's your body, it's your life, it's your choice. If your mum does not want to sign that’s another matter, but it's your life. Here in Guatemala I wasn’t asked anything. [It’s just] “We’re going to do this, ma'am, do you agree?” It was [all] with my mum.

Her time in the US was cut short by family problems which necessitated her mother’s return to Guatemala. By that time she had learned “a lot… Well, I still need to learn some things now. Like I can’t go down steps, that type of thing I can’t do.”

The bullet that damaged her body also destroyed the family’s financial security, because her mother was obliged to quit work to care for her (See Chapter 7 – Economic Impact). The rhythm of the household changed, too. Since their mother no longer went out to work, the little boys stopped going to childcare. Whereas previously Kimberly rarely spent time with her brothers, “Now we are all together. We are much closer now.”

The shooting severely disrupted her education. She fell two years behind, mainly due to hospital readmissions for infections and time spent in rehabilitation; but also because she felt embarrassed and depressed about returning to school with an acquired disability:

Because of the situation, because you're 12 years old and you’ve learnt to do everything on your own and then you have to begin again. That was what made me feel oh no! … [It] was not so much being in a wheelchair, but having to start over, that's what I didn’t like.

Eventually she did go back, enrolling at the local public school since tuition fees at her private school were now out of reach. Her mother pushed her to school in a large, heavy wheelchair which she had bought at a medical supply store. Having the wrong type of wheelchair was another obstacle to Kimberly’s independence:

I <u>could</u> mobilise myself, but most of the time someone pushed me because it was too high and I felt really uncomfortable in the chair, I couldn’t grab it properly.

Accessibility at the school was poor, with large steps at the entrance and in every doorway. However, her mother helped her to get into the building each morning, and her schoolfriends pushed her chair during the day. At first it felt strange, “because I saw all the kids playing and everything and I had to stay in one place, but later I adapted.” She never felt rejected or excluded by students or teachers, and successfully completed high school there.

Infection and illness overshadowed the first eight years of Kimberly's life after being shot, with frequent readmission to hospital. In the US she had been told the importance of changing positions frequently to avoid pressure ulcers, but she only mastered the skills of prevention after joining the online disability community where she has learned about "all kinds of sensitive topics". She has now been ulcer-free for several years, but still occasionally gets a UTI.

Today Kimberly is a full-time university student, halfway through a degree in computing at an online Mexican university. She says university was always in her sights: as a child she thought she would grow up to be a doctor. Her mother had only a high school education but was determined that her children would go further.

Kimberly first enrolled in a regular university in Guatemala, but transport difficulties forced her to quit. She is very happy with her course and the international online community of students where she has made friends, including two who have identified themselves as fellow wheelchair users. Her marks are good, and she is confident that she will find work after graduation, perhaps as a web developer or games designer. She now has a lightweight active wheelchair from Transitions, which enables her to move around at home more easily. She does not go out much because of the lack of accessible transport.

Looking back, she can trace the change in her outlook over time. The initial depression and feeling of uselessness lifted as she learned skills. Travelling to the US and then going back to school brought a major improvement in morale. Since then she has tried to take things calmly:

> Yes, it is difficult, but I try not to think so much about it, but instead to see the possibilities. Because if I keep thinking "I can't walk, I can't walk anymore" – no, no, I'll spend my life tormenting myself and life will pass me by, and then I'll feel I wasted my time thinking about that.

Despite never receiving mental health support, she says she is happy and has overcome the trauma of being shot:

> It doesn't hurt so much to talk about it… sometimes when I'm not busy I kind of remember, "Wow, everything I've had to live through", but it's not to get nostalgic or anything… I look at how I was before and how my life could have been, and how I am now, and it's worth it, it's not as bad as I thought.

As noted in Chapter 7 – Justice, she bears no rancour toward the shooter.

Apart from belonging to a wheelchair users' Facebook group, Kimberly says she does not identify either as a person with a disability or as a crime victim:

> The truth is I've never labelled myself like that, I wouldn't know how to identify myself. I know I was a victim of violence and now I'm a person with a disability, but I don't think of myself in that way, honestly.

Q: And how do other people see you?

Well, my family, they see me the same way, it doesn't matter to them…. When I go out, people do still stare, they stare, but it's not something that bothers me.

She says she has not encountered discrimination, though she recognises that she leads a sheltered existence as a student who rarely leaves home:

Maybe it has happened but I didn't notice, I am very distracted – I haven't noticed it and I don't take it to heart.

She has heard from friends that Guatemalan employers are prejudiced:

I think … most people do not want to hire people with disabilities… It's "Ah, but he uses a wheelchair, so what problems is that going to cause in the office?"

Q: What kind of problems?

Well, I couldn't say what problems might arise, but that's what other people think. Maybe because they have to adapt the workplace or something like that, I think.

She occasionally applies for a job to "test the waters" but has never received a response. This could be due to discrimination, since job applications must include a copy of the applicant's national ID card, which for wheelchair users carries the label DISABILITY. However, Kimberly said she prefers to believe it is simply her lack of professional experience holding her back. In any case, she says she could not afford the taxi to attend a job interview if one were offered. Accessible transport, she says, is the change that would make the biggest difference to her life. If transport were available, she would be interested in playing sport.

Outside of her family, Kimberly's entire social life is conducted on the internet, largely compensating for the disabling impact of the physical environment where she lives. Once she finishes university, she expects to work online in a digital career, competing and participating on the same terms as other graduates. Thanks to good luck, good parenting, education and technology, she represents the potential for people with mobility impairments to overcome societal restrictions, even in a low-resource setting like Guatemala:

I think sometimes you have money and sometimes not. Money is something so common that anyone can have it. So if I try hard I will achieve it. I'm not afraid, I believe I am going to achieve it, if I really give it my best.

Appendix G: Asociación Transiciones Letter of support

Asociación Transiciones
Una Asociación de Personas con Discapacidad de La Antigua Guatemala
Callejón de Los Horcones No. 48, Aldea San Felipe de Jesús
La Antigua Guatemala, Sacatepéquez, Guatemala

26 July 2017

Rebecca Peters
University of Sydney, Australia

Dear Rebecca

Research on gun violence survivors

Thank you for talking with us about your research project entitled "Health and Disability Outcomes for People Injured by Firearms in Guatemala". I understand that this research is for your post-graduate study at the University of Sydney's Faculty of Health Sciences.

As you know, Asociación Transiciones is a Guatemalan non-profit organization providing mobility devices, training, expert advice, and other services to promote inclusion and independence of disabled people from poor communities. Many of our clients and several of our staff – including myself – are living with spinal cord injuries as a result of being shot. We have personal experience of our country's epidemic of gun violence, and also of the many obstacles to health, economic and social inclusion for people seriously injured by those bullets. However, as far as I know, no research has ever been conducted on this topic.

We believe your research will be of great importance not only to Guatemala, but also to other developing countries which have similar problems to ours. Therefore, Asociación Transiciones is interested in collaborating with your research in any way we can. We invite you to use our facilities as your research base, and we would be happy to distribute information about the project to potential participants, provide space for interviews, and provide whatever other assistance may be helpful.

Please do not hesitate to let us know how we may assist with your research, or with any aspect of your stay in Guatemala.

Yours sincerely,

Alexander Galvez, Executive Director
Phone: (+502) 7831 0779
E-mail: alex@transitionsfoundation.org
Website: www.transitionsfoundation.org

Appendix H: Ethics Approval

THE UNIVERSITY OF SYDNEY

Research Integrity & Ethics Administration
Human Research Ethics Committee

Monday, 27 November 2017

Prof Gwynnyth Llewellyn
Disability and Community; Faculty of Health Sciences
Email: gwynnyth.llewellyn@sydney.edu.au

Dear Gwynnyth

The University of Sydney Human Research Ethics Committee (HREC) has considered your application.

After consideration of your response to the comments raised your project has been approved.

Approval is granted for a period of four years from **27 November 2017** to **27 November 2021**

Project title: **Surviving gun violence in Guatemala: health and disability impacts.**

Project no.: **2017/803**

First Annual Report due: **27 November 2018**

Authorised Personnel: **Llewellyn Gwynnyth; Peters Rebecca; Smith-Merry Jennifer;**

Documents Approved:

Date Uploaded	Version number	Document Name
13/11/2017	Version 1	Interview Guide
30/10/2017	Version 2	Invitation to participate (email)
30/10/2017	Version 2	Recruitment talking points for Vinicio Cabrera
30/10/2017	Version 2	Participant Information Sheet
30/10/2017	Version 2	Participant Consent Form
30/10/2017	Version 2	Student Safety protocol

Special Condition/s of Approval

1. It will be a condition of approval that certified translations of your public documents (Participant Information Statement, Participant Consent Form etc.) are uploaded to IRMA once they have been approved in English. For further information, please visit the Ethics website.
2. It will be a condition of approval to also have a description in the PIS matching the intent of the PCF, and this should not only describe the opt-out process, but also the rationale for the request for use of participants' stories, details, and photos (i.e. advocacy).
3. It would be helpful if the researchers would upload any correspondence from their HoS acknowledging his/her duty of care and departmental acceptance of risk under the University's current policy for travel to DFaT regions with "Exercise a high degree of caution" warnings. This is a condition of approval

Condition/s of Approval

4. Research must be conducted according to the approved proposal.

Research Integrity & Ethics Administration
Level 2, Margaret Telfer Building (K07)
The University of Sydney
NSW 2006 Australia

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E human.ethics@sydney.edu.au
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ABN 15 211 513 464
CRICOS 00026A

5. An annual progress report must be submitted to the Ethics Office on or before the anniversary of approval and on completion of the project.

6. You must report as soon as practicable anything that might warrant review of ethical approval of the project including:
   - Serious or unexpected adverse events (which should be reported within 72 hours).
   - Unforeseen events that might affect continued ethical acceptability of the project.

7. Any changes to the proposal must be approved prior to their implementation (except where an amendment is undertaken to eliminate *immediate* risk to participants).

- Personnel working on this project must be sufficiently qualified by education, training and experience for their role, or adequately supervised. Changes to personnel must be reported and approved.

8. Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, as relevant to this project.

9. Data and primary materials must be retained and stored in accordance with the relevant legislation and University guidelines.

10. Ethics approval is dependent upon ongoing compliance of the research with the *National Statement on Ethical Conduct in Human Research*, the *Australian Code for the Responsible Conduct of Research*, applicable legal requirements, and with University policies, procedures and governance requirements.

11. The Ethics Office may conduct audits on approved projects.

12. The Chief Investigator has ultimate responsibility for the conduct of the research and is responsible for ensuring all others involved will conduct the research in accordance with the above.

l approval only.

ffice should you require further information or clarification.

Sincerely

Chair
Human Research Ethics Committee (HREC 2)

The University of Sydney HRECs are constituted and operate in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007) and the NHMRC's Australian Code for the Responsible Conduct of Research (2007).

Appendix I: Interview Schedule

Date **First name**

Health and disability experiences of people with spinal cord injury caused by firearm injury in Guatemala

1. Demographics
Sex:
Age now:
Age when shot:
Date (approx.) when shot:
Ethnicity (indigenous/non indigenous):
Family of origin: mother, father, brother, sisters?
Family of creation: spouse, children?
Area / neighbourhood where living at the time of being shot:
Area / neighbourhood where living now:
Level of formal education:
Occupation at time of being shot:
Occupation now:
Occupations of family members at the time of being shot:
Occupations of family members now:
Level of SCI (if known):

2. Life story – Tell me about your life before you were shot
Where did you grow up?
Who was in your household?
What language did you speak?
How much formal education did you have?
Did you consider yourself to be poor? If you compared yourself with other families, did they have more than you? Or less?
What work did you do, Or did your parents do?
How much did you (or they) earn?
What kinds of activities did you do - with your family? friends? Other people?
How did you feel about your life?
What did you want to do in your future? How did you see yourself at this age?

3. Tell me about the day when you were shot…
What was happening?
Did you see a gun?
How did you feel? (scared? angry?)
Did you hear the shot?
Did you realise you had been shot?
What did you feel physically?
Did you try to move?
How did you feel in those first minutes?

4. Aftermath – What happened after you were shot?
What do you remember? Who came to help you?
How did you get to hospital? (which hospital?) Do you remember the trip? What were you feeling?
What happened when you arrived at the hospital?
How did people treat you?
Did someone ask you what had happened?
Did you see police there? Did they speak to you? (What did they ask you?)
How did you feel about them?

5. Hospital experience

What injuries did you have?
What treatment did you receive, as far as you know?
What was the ward like? What were the conditions?
How long were you there?
What did you do all day? How did you feel about it?
How do you think your family members felt?
What did the hospital staff tell you about your injuries and the consequences? How did you feel about that?
Did you see the police again? Who did you see meet in hospital? How did they treat you?
Did you develop additional health problems in hospital?
How much did it cost you or your family, what kinds of things did you have to pay for?
Do you know what kind of weapon or what calibre of bullet caused your injury?
Do you know if you still have a bullet in your body? How do you feel about that?

6. Coming home – Tell me about when you were discharged from hospital

What did the hospital give you when you left – medications? instructions or information for you or your family members? An appointment to come back? A referral to another agency?
What did the hospital staff tell you about your future mobility?
How did you get home? How did you get into the house?
How did you feel being home?
Have you returned to hospital since that first discharge? How many times? Why? Did the hospital ask you to come? Did you go or stay away? Why?
What was your life like back home? What did you do all day?
When and how did you get a wheelchair? (what kind?) how did you find using it? And now?
Tell me about the challenges you faced. How did you deal with them? Did anyone suggest where to find assistance? or information?
Did you consider yourself to be permanently disabled? Did you think you would recover your mobility? How did you feel about your new situation?

7. Daily life – Let's talk about everyday functions

a) Here's a questionnaire for you to fill in, or you can tell me your answers, and I can fill it in. It's from an organisation called the Washington Group and it's used in research about disability in different countries…

AFTER THE WASHINGTON GROUP EXTENDED OF QUESTIONS

b) Can you do your normal activities like cooking, eating, going to the toilet, getting in and out of bed, bathing, getting dressed? Could you do those things when you were first injured? How did you learn to do them?
c) Did you go to a program or centre that was named "rehabilitation"? Where was it, how did you get there, did you have to pay for it?
Tell me about your experience there – how did you feel when you began? Did you think it was going to help you? Was it hard work? How did you feel about it by the end?
How long were you in rehabilitation and why did it finish?
Did you have any role models or specific people who helped to motivate you?
If you didn't receive rehabilitation – did anyone suggest it?
Are you doing any kind of rehabilitation or therapy now?

8. Health

a) Tell me about your physical health, how was it before you were injured? How is it now?
b) How is your health compared with other members of your family? If everyone gets the flu, do you get it worse than the others?
c) Do you have health problems related to your condition as a person with a spinal cord injury?
Have you had pressure sores? How bad were they, and what did you do about them?

Have you had UTIs? Problems with internal organs? What do you do to avoid health problems?
How about pain – Refer to WG questions: what kind of pain do you experience? Spasticity? How often? On a scale of 1 to 10, how prominent is is pain your life? How does it affect you? What do you do about it?

d) How is your mental health? Are you happy? What makes you happy? Refer to WG questions… Have you had any specific support for mental health, like seeing a therapist?

e) What are the most important factors in maintaining your health?

9. Family

a) Draw some concentric circles, with you in the middle, showing who were the most important people in your life before you were shot – and now? (specific family members, bosses/colleagues, friends, health workers…)

b) Has your life changed since you were shot? How? Has anything remained unchanged?
Do you live in the same place as before? If you moved, why? Who do you live with? Do you play the same role in your household as before? Or how has your role changed?
Have your relationships changed? (with spouse? parents? children?) Have any relationships faded away? New ones? How do you feel about your family and friends now?
What kinds of activities do you pursue now with family and friends?

c) Has life changed for your family members since you were shot? How has it changed for each person?

d) How does your household get money to pay the bills? Is that different from before you were shot?

e) How much income does the household have? Do you know how that compares with before you were shot?

f) Do you or your household have additional costs as a result of your disability?

10. Education and work

a) How has your education been affected by being shot? and/or: How has your working life been affected?
Are you working /studying now? Tell me about what it's like at work / in your studies.
If not, Have you looked for a job? What's it been like looking? Why do you think you haven't found a job?
What would make it possible for you to get a job? Or continue your education? Training? Transport?

b) Where do you go outside your home – to church? to play sport? volunteer?

11. Services

a) What have been the most important sources of support for you?

b) How did you get your first wheelchair, and when?

c) What support have you received, or what services have you used, for example:
- in the health system
- the legal system
- from churches
- from local government
- from community groups
- from other sources?

d) What was your experience of those services? What kind of support would make it easier to live your life?

12. Legal system

a) Tell me about the experience of reporting your shooting to the police. Where did that happen? How did they treat you? What did you expect would happen after you reported? Did your expectations come true?

b) Tell me about your experience with the justice system after your shooting - police investigation, arrests, prosecution? How do you feel the justice system treated you?

13. Faith

a) Are you a religious believer?

b) When you think about what happened to you, does your faith help you to understand it?
Was your faith affected by what happened to you? How was it affected?
How do you feel about the person who shot you?

14. Identity

a) Has there been a change in how you feel about yourself?

b) How do other people see you? family, neighbours, potential employers, people on the street?

c) Are there other people with similar mobility impairments in your neighbourhood, your church, your workplace – or are you the only one?

d) Do you know other people who have been victims of gun violence?

e) Have you experienced discrimination as a person with a mobility impairment? For example?

f) Have you ever felt that it was better not to say that you had been shot – like to pretend your impairment was from some other cause? Why?

g) Can you draw a graph of your life so far, starting when you were shot, showing how your quality of life has gotten better or worse over time, as various things have happened?

h) What will your future be like? Goals? Marriage? Work? Geographic location? Worries?

15. Those are all my questions, thanks for your patience. **Is there anything else you'd like to mention that I haven't asked about?**

16. I hope I've captured everything, but when I look the transcript, there may be issues where I didn't quite understand what you were trying to tell me. **In that case can I come back and ask you a few more questions so I can understand your experience better?**

17. **Also, if there's anything you've told me that you want to change or remove from this interview, I'll change it or remove it.** I'll be giving you the transcript so you can see what you told me, and we can remove anything that you don't feel comfortable sharing.

18. Thank you so much for sharing your experience!

Appendix J: Participant Information Sheet (English original)

ABN 15 211 513 464
CHIEF INVESTIGATOR (SUPERVISOR)
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Centre for Disability Research and Policy
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Surviving gun violence with spinal cord injury in Guatemala
PARTICIPANT INFORMATION STATEMENT

(1) What is this study about?

You are invited to take part in a research study about the experience of Guatemalans who have a spinal cord injury as a result of being shot. Guatemala suffers from high levels of gun violence, and media reports often mention the large number of people who die by gunshot. However, there is little public awareness about the even larger number of people who are shot and survive. This study will examine the challenges faced by survivors, as well as key factors enabling survivors to overcome those obstacles. It will describe the reality of survivorship, including the dimensions of health, rehabilitation, family, employment or education, the use of services; attitudes and beliefs. This will be the first study on this topic ever conducted in Guatemala. The results will improve understanding and awareness of the consequences of gun violence, the situation of survivors, and gaps in the services needed by people with mobility impairment.

You have been invited to participate in this study because you are a person living with a spinal cord injury as a result of being shot, and the shooting was reported to the law enforcement authorities. In total, about 10 survivors of gunshot are being invited to participate.

This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the study. **Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about**.

Participation in this research study is voluntary. You have no obligation to participate.

By giving consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

(2) Who is running the study?

Rebecca Peters is conducting this study as the basis for the degree of Master of Applied Science at The University of Sydney, Australia. She will work on the study under the supervision of Professor Gwynnyth Llewellyn and Associate Professor Jennifer Smith-Merry, Faculty of Health Science, University of Sydney.

You have been contacted through Asociación Transiciones, but the study is NOT a project of Asociación Transiciones – it is a project of the University of Sydney. Transiciones is helping to find participants for the study, but Transiciones is not being paid for this. Rebecca Peters has been a volunteer for several years at Transiciones. She is not paid for her work at Transiciones, and will not be paid for this study. She is conducting the study as part of her education. She is not involved with any decisions about services provided by Transiciones to individuals. Participation on this study is completely voluntary: whether or not you decide to participate, there will be no impact on your relationship with Transiciones or with the University of Sydney.

(3) What will the study involve for me?

You are invited to participate in a one-to-one interview about your experience as a survivor of gun violence and a person with a spinal cord injury. Participating in the interview involves answering a series of questions.

The interview will be conducted at the office of Asociación Transiciones in San Felipe de Jesús, La Antigua Guatemala. You will be reimbursed for the cost of travel to and from the interview.

If you would like a family member or friend to accompany you in the interview, that is fine. But the researcher will only ask questions to you.

The interview will be conducted in Spanish. The researcher will take notes, and if you give permission, the interview will also be recorded on an audio recorder. This will help to make sure the notes are accurate.

Rebecca Peters will ask you questions on topics including:

- Your life before the shooting and what happened on the day you were shot
- Your experience of hospital and rehabilitation
- Your health
- The impact on your family, your finances, your education or your work
- Your main sources of support and your experiences of support services
- How other people treat you
- The impact on your identity, your plans for the future

If you prefer not to answer some of the questions, that is fine. During the interview, you can change your mind about participating, and we will stop the interview.

The audio recording will be used to generate a transcript of the interview, to ensure the accuracy of information gathered for analysis. The transcript will be a written version of everything that was said in the interview. The researcher will provide you with a copy of the transcript, so that you can correct any errors or request removal of anything that you do not want published.

If you decide, after the interview, that you do not want to participate, your interview will not be used for the study.

(4) How much of my time will the study take?

The interview will last about two hours, with breaks for refreshments. It will be conducted at Asociación Transiciones in San Felipe de Jesús, La Antigua Guatemala, so you will have to travel to Antigua. You will be reimbursed for the cost of travel to and from the interview.

(5) Do I have to be in the study? Can I withdraw from the study once I've started?

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researcher, with anyone else at the University of Sydney, or with Asociación Transiciones.

If you decide to take part in the study and then change your mind later, you are free to withdraw at any time. You can do this by telling the researcher that you no longer wish to take part.

You are free to stop the interview at any time. Unless you say that you want us to keep them, any recordings will be erased and the information you have provided will not be included in the study results. You may also refuse to answer any questions that you do not wish to answer during the interview.

If you decide to stop the interview, your travel costs back to your home will still be reimbursed.

(6) Are there any risks or costs associated with being in the study?

In the interview, you will be asked to talk about the day when you were shot and about the impact this has had on your life. Talking about these subjects may cause you to feel psychological distress, sadness or anger. If you become uncomfortable, the interview will be suspended and you will be offered support by a clinical psychologist who has agreed to provide support during this study. The psychologist is:

Dora Alicia Muñoz Aguilar
RELAF- Red Latinoamericana de Acogimiento Familiar
Phone: [redacted], Email: damaisadora@hotmail.com

Another possible risk is that illegal activity might be discussed during the interview. Any information revealed about illegal activity will be kept confidential. You will also have a chance to read the transcript of the interview and request removal of any information which you do not wish to have included.

(7) Are there any benefits associated with being in the study?

You will be reimbursed for the cost of travel to and from the interview. You will receive refreshments during the interview. Even if you decide to withdraw from the study, you will still get these benefits.

There are no other personal benefits for participating in the study. We will not be providing any support or advice regarding emotional, medical or technical difficulties that participants experience in daily life. Participation will not result in you receiving any services from the researcher, the university or Asociación Transiciones.

The main benefit of the study is the possibility that the results may help to secure better services for people with spinal cord injuries and greater understanding of the challenges facing people who have been shot.

(8) What will happen to information about me that is collected during the study?

The audio recordings of the interview will be transcribed and used for data analysis. The transcript will be produced by the researcher and a professional transcription service. The transcription service will be required to keep the information confidential. The recording will only be used for transcription purposes.

In general, the information you provide will not be confidential, since it will be used for the study. However, your identity can be kept a secret if you like. In the results of the study, you will have the option of being identified by your first name, or with an identifier such as “Participant No3”. Even if you initially decide to be identified, you can change your mind at any time.

If you disclose any criminal activity during the interview, the researchers may have an obligation to report it to the authorities. As the research relates to disability, we strongly urge that you do not disclose criminal activity to the researchers. If you want to disclose criminal activity, this should be disclosed to the proper authorities. The researchers may be required to produce research data pursuant to a court order. If this occurs, the researchers will seek legal advice.

You will be given a copy of the transcript of your interview, and you will be able to indicate any information that you would like to remove. That information will not be included in the study.

The researcher will analyse the information in the notes and transcripts. The results will be published in a university thesis, in conference presentations or in journal articles. It is possible that the results may also be included in media articles and in materials produced for public information and awareness.

The paper documents from the study will be stored at the researcher's home in Antigua Guatemala while the interviews are being conducted, and afterwards they will be stored in a locked cupboard at the University of Sydney. Electronic files will be stored on the researcher's computer, which is encrypted and password-protected, and also on the University of Sydney computer server. The records will only be accessible to the researchers associated with this study. Records will be archived for 8 years at the University of Sydney, to allow the possibility of being used in additional research in future.

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

Your information will be stored securely and your identity/information will only be disclosed with your permission, except as required by law. Study findings may be published, but you will not be identified in these publications unless you agree to this using the tick box on the consent form.

The information from this study will be kept for up to 8 years, and may be used by Rebecca Peters in future research on a similar topic.

(9) Can I tell other people about the study?

Yes, you are welcome to tell other people about the study.

(10) What if I would like further information about the study?

When you have read this information, Rebecca Peters will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact Rebecca Peters, student investigator, on email rpet8298@uni.sydney.edu.au or telephone [redacted] in Guatemala. You can also contact Professor Gwynnyth Llewellyn in Australia (in English), on email gwynnyth.llewellyn@sydney.edu.au or telephone: +61 2 9351 9985.

(11) Will I be told the results of the study?

You have a right to receive feedback about the results of this study. You can tell us that you wish to receive feedback by ticking the relevant box on the Participants Consent Form. This feedback will be in the form of a summary of the research results. In addition, the researcher will hold a briefing at Asociación Transiciones to discuss the results with participants. If you prefer, she can discuss the results with you individually. You will receive this feedback after the study is finished, probably in late 2018.

(12) What if I have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney [Ethics approval No 2017/803]. As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007).* This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university in Australia using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- Telephone: +61 2 8627 8176
- Email: ro.humanethics@sydney.edu.au
- Fax: +61 2 8627 8177 (Facsimile)

There is also a local contact in Guatemala if you have any complaints or concerns about the study:

Alexander Gálvez, Executive Director
Asociación Transiciones
Ph +502 7831 0779
Email alex@transitionsfoundation.org

This information sheet is for you to keep.

Appendix K: Participant Consent Form (English original)

ABN 15 211 513 464
CHIEF INVESTIGATOR (SUPERVISOR)
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The University of Sydney
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Surviving gun violence with spinal cord injury in Guatemala
PARTICIPANT CONSENT FORM

I, ... [PRINT NAME], agree to take part in this research study.

In giving my consent I state that:

- ✓ I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.
- ✓ I have read the Participant Information Statement and have been able to discuss my involvement in the study with the researchers if I wished to do so.
- ✓ The researchers have answered any questions that I had about the study and I am happy with the answers.
- ✓ I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers, with the University of Sydney, or with Asociación Transiciones, now or in the future.
- ✓ I understand that I can withdraw from the study at any time.
- ✓ I understand that I may stop the interview at any time if I do not wish to continue, and that unless I indicate otherwise any recordings will then be erased and the information provided will not be included in the study. I also understand that I may refuse to answer any questions I don't wish to answer.
- ✓ I understand that the information from this study may also be used for further research in future.
- ✓ I understand that personal information about me that is collected over the course of this project will be stored securely for 8 years and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.

- ✓ I understand that the results of this study may be published, but these publications will not contain my name or any identifiable information about me unless I consent to being identified using the "Yes" checkbox below.

  ☐ Yes, I am happy to be identified by my first name.

  ☐ No, I don't want to be identified. Please keep my identity anonymous.

- ✓ I consent to:
  - Audio-recording YES ☐ NO ☐
  - Video-recording YES ☐ NO ☐
  - Being contacted about future studies YES ☐ NO ☐
  - Permanent archiving of study materials YES ☐ NO ☐
  - Reviewing transcripts YES ☐ NO ☐

Would you like to receive feedback about the overall results of this study?

☐ **YES** ☐ **NO**

If you answered **YES**, please provide contact details so that we can send you feedback:

☐ Email: _____

☐ Telephone: _____

After the study, some participants' stories or photos may be included in documents used for public awareness. Your information will not be included in these documents unless you give consent.

☐ Yes, I am happy for my story and photos to be used for public awareness.

☐ No, I don't want my story or photos to be used for public awareness.

.....
Signature

.....
PRINT name

.....
Date