Reconstructing lives

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Reconstructing lives

Victims of war in the Middle East and Médecins Sans Frontières

Vanja Kovačič

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Cover image: Male relatives gathered around their injured family member. Illustration by Sarah Imani.

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To Sir Iain Chalmers

This work is dedicated to a person who has greatly influenced me with his values and integrity. Sir Iain Chalmers, I will be eternally grateful for your outstanding inspiration, example, and support in standing for the right things.

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Abbreviations

CRASH	Centre de Réflexion sur l'Action et les Savoirs Humanitaires
ICRC	International Committee of the Red Cross
IMA	Iraqi Medical Association
ISIS	Islamic State of Iraq and the Levant
MBA	maximum benefit achieved
MLO	medical liaison officer
MSF	Médecins Sans Frontières
NGO	non-governmental organization
OPD	outpatient department
OT	operating theatre
PTSD	post-traumatic stress disorder
RSP	Reconstructive Surgery Programme
UNHCR	United Nations High Commissioner for Refugees
WHO	World Health Organization

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Introduction

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The intention

This book is a result of my three-year collaboration with Médecins Sans Frontières (MSF), or Doctors Without Borders, a medical humanitarian organization. MSF, winner of the Nobel Peace Prize in 1999, places its primary focus on the delivery of emergency aid and works under the maxim "alleviate human suffering."

I was not new to MSF. In 2010 I joined the organization to conduct anthropological research focused on access to care for HIV patients in Kenya (Kovačič and Amondi, 2011a; 2011b). When I was contacted again in 2017 by MSF's CRASH unit (Centre de Réflexion sur l'Action et les Savoirs Humanitaires) – the internal body engaged in critical reflection on field practices – I realized the significant nature of the project being proposed. As a medical anthropologist I would be given the unique opportunity to carry out independent research centred on MSF's Reconstructive Surgery Programme (RSP) for the victims of war in the Middle East.

Working as an anthropologist in the humanitarian field, I would be joining a group of authors who have critically examined humanitarian practice, including those researching MSF. The importance of such study had already been discussed in publications such as "Medical anthropologies. Ethnographies of practice" (Panter Brick and Abramowitz, 2015). But the proposed research into the RSP, rather than being principally occupied with its political or institutional structure, required me to design an exploration of the microcosm of relations among humans who, like me, shared a time and space influenced directly or indirectly by the experience of war. To look at this microcosm meant uncovering the layers of what it means to be human in the context of war. And I was offered the exceptional chance to look at the worlds of both war victims and humanitarian workers. I readily accepted the challenge. The resulting study, presented here, is unique among critical anthropological studies of humanitarian aid.

My work differs from the extant critical ethnography of aid in a number of ways. Principally, it focuses on the relationships, tensions, and negotiations between patients and their social environment, including their medical environment, rather than critiquing institutions, structures, and power relations. In addition, unlike the authors who have examined political economy, structural violence, or critical humanitarianism (Mosse, 2004; Mosse and Kruckenberg, 2017; Farmer, 2001; 2006; Fox, 2014; Redfield, 2013), I do not use a critical lens per se. I maintain an observational stance, open to interpretation. The book is written in a narrative style, rich with the voices of the participants, who highlight, in their own words, the authentic world they are describing.

With regard to those who write on the anthropology of war from a theoretical perspective, this book speaks to the "experimentalists" (McCutcheon, 2006; Schröder and Schmidt, 2001). These theorists view war violence as something that has a basic impact on life, which they say can only be grasped through the individual's experience. With *Reconstructing Lives* I have not taken a theoretical standpoint. But my unique anthropological lens acknowledges the physical, economic, psychological, social, and symbolic types of violence that are in line with the experimentalists' view. This was my framework when I developed my research model, and this was my guide as I wrote the book you hold in your hands.

My work documents the daily reality of patients in hospital and after their return home. I also researched and recorded the experiences of the people who treat them. The overarching goal of the research was to contribute to knowledge that might establish a more holistic approach to rehabilitation – one that could make adjustments for a patient's long-term needs. I wanted to develop a new way to look at patients by describing their daily lives during and after rehabilitation, to respect them within their own reality, and to involve them in their own care and reconstruction of their lives.

Bearing this in mind, I did not focus only on the delivery of medical care. The book describes Syrian and Iraqi war victims. Their journey starts with an injury, continues through the improvised medical treatment in their home countries, leads them to the MSF-run hospital in Amman, Jordan, and ends with their return home. Along the way, individuals attempt to pick up the pieces of their previous lives, add new elements from their treatment and travel experiences, and finally establish a new, reconstructed reality. I explore how the MSF staff and their patients interact and how this interaction contributes to the immense task of healing that awaits the victims of war. The reader visits the intimate spaces that usually remain closed to the outside observer: the interior of the MSF hospital and the interiors of the patients' homes. Both spaces are rich with human contact, perceptions, emotions, conflicts, and reconciliations. The struggle of the individual to overcome

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visceral reactions that result from seeing injured bodies, the need to follow social and institutional norms, and that to keep ethical dilemmas in check have a tangible impact on both patient and medical worker.

Reconstructing Lives marks yet another departure. As a reminder of the severe personal and social consequences of war, its main "actors" are the permanently injured – too often the silent survivors of war. One of them is Ismael, whose story we get to know. *Reconstructing Lives* gives Ismael a voice and unlocks the link between resilience, self-interest, and survival. It presents the perspective of a patient's own reckoning with the rehabilitation process and its aftermath. The book's findings move our understanding beyond medical rehabilitation alone, to grasping what is involved in the rehabilitation of an individual's emotional, symbolic, spiritual, and social existence.

The MSF-run RSP has been providing care for neglected war victims for over a decade, and the book captures a part of their cumulative experience. We will explore the political and organizational context that led MSF to open the RSP in Amman. The book's first chapter explains in detail the anthropological research that resulted from my being embedded in the RSP from April 2017 to December 2018. Chapter 2 then explores the relationships between patients and hospital staff and the staff's perceptions of patients. Chapter 3 looks at the patients and their personal and medical histories before they entered the RSP, and Chapter 4 uncovers the patients' own perceptions of the programme. In Chapter 5, patients' descriptions of their daily lives after they have returned home are presented along with reflections on how the RSP has influenced them. I conclude in Chapter 6 with a description of research reflexivity and a discussion of the broader areas of support needed for victims of war and other patients who struggle to become a viable part of society.

Ismael, one of the many war-injured

It was 6 April 2012. About 20,000 soldiers invaded the neighbourhood near Ismael's home. Mortars started shelling. Ismael was in the house with some men who had attempted to rescue injured people from under the collapsed houses. An explosion hit the house in the early afternoon, and he was among those who were injured by shrapnel. His leg was wounded. In a panic, another injured person unintentionally trampled over his thigh and completely fractured his femur. His leg was now dislocated, and it moved like the leg of a puppet.

His friends evacuated him by placing him on a door used as a stretcher. The street was under sniper fire and mortar bombardment. In the surrounding

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area, holes were opened in the walls to allow passage from one house to another more safely. Ismael and his rescuers managed to get into a car and a tank shell barely missed them. They arrived at the first-aid post sheltered in a school. Desks had been replaced by beds. Basic medical supplies were missing; pieces of fabric replaced compresses.

Soon after, he was attended in another makeshift hospital, where he was cared for by a car mechanic, who, in the dire context of war, was acting as a nurse. His wound was sutured even though it was still filled with dirt, and this contributed to the development of infection. Everyone was quite aware that this was the likely outcome, but nobody was able to prevent dangerous infections under those conditions.

The next day, Ismael's relatives brought him to a governmental hospital in Homs, quite far from his neighbourhood. The road was extremely dangerous. The vehicle zigzagged to avoid being hit. Dead bodies were lying all over the streets. It was said about that journey that "the one who comes out alive had his mother praying for him." The driver and all the passengers had to duck their heads to avoid bullets along the way. Ismael was hidden in the back of a Škoda mini truck, under a tarpaulin.

The vehicle's passage over a bump caused Ismael's fractured limb to shift. It took them an hour to correctly realign it. On the way, Ismael was transformed into a Red Crescent ambulance and he fainted before arriving at the hospital. He woke up when he was taken out of the ambulance. A nurse told them that a security official was tracking them. Fortunately, the regime's soldiers had not stopped the ambulance in which they were travelling. Because of their wounds, they were wanted men. Due to the fear of arrest, they had less than an hour inside the hospital. After the X-ray, Ismael was taken to the operating room. Under local-regional anaesthesia, the surgeon inserted an external fixator, a set of metal pieces, into the bone, to maintain the alignment of the two bone segments of the fractured femur.

Ismael left his hometown, Homs, to seek treatment in a hospital in the suburbs of Damascus, thinking he would be safer there. Upon arrival, he was again housed in a school that had been transformed into a care centre. The doctor there was injured himself, so he was replaced by an electrician who acted as a nurse. Regardless, Ismael felt that he did a better job than the trained hospital staff. Ismael's wounds were severely infected by then. The stitches had opened, and pus was flowing out. In the hospital, the cleaning and excision of dead tissue began. He finally received an intravenous injection against infection. He remained in that hospital in the suburbs of Damascus for six months.

The area was subsequently bombed. Tanks fired more intensely than Ismael had ever seen before. The hospital was hit. Civil defence evacuated him, and Ismael found himself in the street leaning on his walker to run

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away. While on the run, he had to crawl for over two kilometres to escape. His wounds reopened. All roads were blocked by the regime's forces and he could not go back to the hospital.

Ismael decided to settle in a location controlled by the regime's forces, but he could only stay in the area by hiding in holes or under stairs, living in constant fear of missile fire. By luck, he met persons with the necessary security clearances able to take him to a doctor. He was unable to lean on his injured limb. The doctor was an elderly man who had worked in Gaza (Palestine) and who advised him to abandon his walker and to start using a wooden stick instead. This helped him regain some ability to walk.

At this point Ismael decided to leave Syria. It took him a month and a half to reach Jordan. On the way, the regime's soldiers shot and killed two members of the group travelling with him. But this was not the end of the tragedies. Upon arriving at the border, Jordanian border guards were welcoming. But they would not let a man enter the country alone, without his relatives. Entire Syrian families at the border at the same time as Ismael who tried to enter the country without the required documents suffered the same fate and were denied asylum. When they were turned away, the Syrian border guards opened fire. Five families were killed, and Ismael joined others in burying them on the spot. The survivors found refuge in a mosque where Ismael – by his own description – spent one of the worst nights of his life.

Finally, Ismael managed to enter the Zaatari refugee camp in Jordan. He spent two weeks there but was unable to get treatment because of long wait times to access care. He left the camp to take a job as a baker in Jordan, work that required him to stand twelve hours a day. The pain was so severe that one day he collapsed. His wounds opened again, and the infection resumed. Friends informed him about a hospital in Amman where a team of Médecins Sans Frontières was working. Ismael talked of a suspension of misery upon entering the MSF hospital. It was where his definitive treatment began.

Surgical care for the neglected war victims

Ismael's story is comparable to that of hundreds of thousands of civilians in the contemporary Middle Eastern conflict. Though these individuals may never have participated in combat,[1] they are nevertheless bombarded, hunted down, tortured, and executed. These survivors of war violence emerge physically and emotionally affected. In the societies where they live, they are not recognized as war invalids. Indeed, this definition is reserved for wounded war veterans. Those who are recognized as wounded war veterans have access to specialized medical care and, to a certain extent,

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social and economic support. In this way, the society communicates their recognition of the ultimate sacrifice they have made in the name of their countries/political groups (Blanck and Song, 2002). The civilians injured in war, however, experience hardships similar to disabled veterans but are forgotten when it comes to any benefits. They remain an unnoticed and ignored part of society.

War takes an undeniable toll on civilian lives. Civilian deaths in the current conflicts in the Middle East number in the hundreds of thousands. For instance, the Iraqi Body Count,[2] thought to be the world's largest public database of violent civilian deaths, estimates that since 2003 over 205,000 deaths have occurred. Between January and February 2019 alone, over 500 civilian deaths were reported in Iraq (Iraq Body Count, n.d.).

The number of fatalities since the beginning of the war in Syria is equally high. In December 2018 the Syrian Observatory for Human Rights (SOHR, 2018) reported 111,330 civilian casualties, including 20,819 children under the age of eighteen and 13,084 women over the age of eighteen. In Yemen the reports are sporadic, and the figure most often cited by politicians and the media is more than 10,000 deaths,[3] a serious underestimation. All these figures are approximate, since the records of war casualties often do not count the dead and wounded unless they are military personnel (SOHR, 2018; Iraq Body Count, n.d.; ACLED, 2019).

We can only assume that the count of bodies that have been deformed by war-related injuries should be far greater. The lack of accurate records is a real problem. Even for wounded military personnel, the count of injuries is not straightforward. Categories such as "died of wound," "survived and evacuated," or "slightly injured" (and returned to duty), do not count those injured in an accident, nor those with less severe injuries not treated in a medical facility (Bellamy, 1995). In sum, war victims are frequently counted only as those who have lost lives. The numbers who survive but are permanently damaged – physically, emotionally, or socially – remain undercounted.

In the humanitarian field, wars are considered the ultimate source of human suffering, and war surgery has always been an integral part of humanitarian practice (Giannou et al., 2013). The war situation is sometimes called an epidemic of injuries due to the sharp increase in trauma cases compared to peacetime (Bellamy, 1995). War wounds, with related extensive tissue destruction and contamination, are wholly different from routine emergency trauma care (Giannou et al., 2013). This is not surprising considering that there is a constant race between new sophisticated armaments, whose sole purpose is to effectively destroy human bodies, and the surgical advancements necessary to manage increasingly severe wounds.

In fact, military surgery has contributed to the development of surgical practices and knowledge since the beginning of human warfare (Pruitt,

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2006). Military personnel are predominantly treated in military hospitals placed close to the battlefield (Gawande, 2004; Pruitt, 2006; Potter and Scoville, 2006). Civilians and non-combatants, combatants who no longer participate in hostilities, may receive surgical care in improvised local medical structures, at the medical facilities of organizations such as the International Committee of the Red Cross (ICRC) or its partners, the International Red Cross and Red Crescent Movement (Giannou et al., 2013), or with organizations such as MSF (Trelles et al. 2015).

For trauma victims in war, medical studies have established that lifesaving first aid must be delivered within the first hour after the injury or the chance of survival for the critically wounded becomes increasingly reduced (Bellamy, 1995). In addition to the time it takes to reach emergency care, the site of the wound is also of great importance for the chance of survival. The sites where the most fatal injuries occur are the head and chest. For non-fatal injuries, seen mainly on patients who survive the transport to a medical facility, the most common location of injuries is on the extremities, particularly the legs. Superficial wounds on skin and skeletal muscles are often in the non-fatal group as well (Champion et al., 2003).[4] The characteristics of modern arms are responsible for this typical distribution of injuries, with most injuries being of a penetrating type caused by fragments from explosive devices, such as shells and grenades. Burn, blast, or bullet injuries are much less common today than they are in the historical data compiled in past wars. The causes of injuries to civilians are similar. The ICRC hospital in Kabul recorded that the highest proportion of admitted civilians was injured by fragments and mines (Coupland and Samnegaard, 1999).

Despite similar causes of injuries, the severity of combatants' and civilians' wounds and their follow-up surgical care differ. An analysis of the Emergency Management Centre in Erbil, which received the injured from the battle for Mosul in Iraq between 2016 and 2017, focused on the epidemiology of war-related injuries among patients (Nerlander et al., 2019). Of 1,725 total patients included in the study, 46% were civilians. Civilian patients were more than twice as likely to have injuries to their abdomens and six times more likely to undergo amputations of their limbs than combatants. Authors noted that civilian injuries were due to the lack of ballistic protection, and that their need for surgical care was more intense than combatants'.

War surgery is predominantly emergency care. Surgeries are often performed with limited resources under improvised conditions. Proximity to the battlefield, staff fatigue, overwhelmed hospital facilities, disruptions in electricity, water, and medical supplies, and the unpredictability of events make the delivery of surgical care extremely challenging. The mass casualties in war are also far greater than and radically different from those in civilian practice. ICRC, for instance, reports on the war triage category of

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"leave to die in dignity," a category non-existent in ordinary emergency practice (Giannou et al., 2013). The triage protocols are often applied to "save life and limb for the greatest number with the least possible expenditure on time and resources" (Giannou et al., 2013: 10). Severe injuries and suboptimal medical care leave many survivors of war permanently disabled. Sophisticated techniques that could diminish or possibly eliminate the effects of disability cannot be performed under field conditions. And such techniques as those required in reconstructive surgery can usually only be delivered later in referral hospitals.

During the years-long armed conflicts in Iraq, Syria, and Yemen, such specialized referral hospitals have been scarce or non-existent, and they may lack surgical equipment and personnel. Patients who have undergone surgical procedures under improvised conditions not only often suffer side effects from the field surgeries: they are often left without support for their physical, emotional, and social recovery. For veterans of combat, rehabilitation is provided in their own country, which, however, despite technological advances, is not always satisfactory (Messinger, 2009). For war-injured civilians from the countries participating in war, such care is simply non-existent. MSF is one of the few organizations that offers specialized surgical care and rehabilitation for survivors of war in the Middle East. The programme – the RSP – is located in a specialized hospital, the Al Mowasah hospital, in Amman. It has been in operation for over ten years. But before we go deeper into the programme details, let us explore what motivated MSF to focus on the provision of war-related surgery.

A brief history of MSF's surgical practices

Surgery has been a medical specialty practised by MSF since its creation in 1971. In its early days, due to a lack of resources and expertise, MSF's contribution to the provision of surgical care took the form of assigning surgeons to other aid or public health agencies such as ministries of health, faith-based institutions, non-governmental organizations (NGOs), such as Terre des Hommes, and the United Nations High Commissioner for Refugees (UNHCR) (Rigal and Dixmeras, 2011).

In the 1970s, however, MSF pursued its ambition to carry out surgical activities autonomously in Lebanon (1976) and Chad (1979) (Bradol, 2011). The value of humanitarian surgeons sent from abroad into an emergency context was soon questioned by the field teams themselves. In organizing a response to natural disasters – for example, earthquakes, floods, and hurricanes – the field staff were often faced with restricted access to the affected sites, particularly during the initial emergency phase. Their delayed arrival

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on the scene greatly reduced the possibility of preventing death through surgical intervention (Brauman and Vidal, 2011).

There were exceptions – for example, during the earthquakes in Pakistan (2005) and Haiti (2010), where, due to the nature of local construction, many victims were injured by concrete blocks or large stones. Even after the acute emergency phase was over, a large number of victims who survived needed orthopaedic surgeries over the long term – a call to which MSF responded.

MSF soon recognized that surgical assistance to refugee populations was a more efficient use of its resources compared with responding to so-called natural disasters. In the mid-1980s MSF offered surgical care to refugees in Sudan, Zaire, and Uganda.

The increase in surgical activity also caused MSF to become the subject of internal and external criticism due to the lack of quality in the care they were able to provide. The brisk rotation of the expatriate surgeons, lack of standardization of surgical protocols, and inefficient recruitment of patients came under a critical lens. MSF responded with an attempt to professionalize its surgical activities, which led to surgical training for a number of the foreign general practitioners working for MSF. These trainings were first conducted in 1984 during field missions in Uganda and Sudan and were later repeated in Zambia. The concept of the doctor-surgeon was not foreign to the countries where MSF worked, such as Sudan and Colombia, as in those places basic surgical procedures were performed by non-specialists, such as general practitioners.

As the surgical needs at MSF field missions increased, MSF responded by increasing the number of its field staff who were trained but were not formal specialists in surgery. Foreign doctors from the "rich countries" were often associated with colonialism, and the fact that they were often underqualified created embarrassment for MSF. A discussion was sparked within the organization to begin providing surgical training for general practitioners in the countries where MSF had missions. In this spirit, MSF devoted six years to the school of anaesthetist nurses in Phnom Penh, Cambodia (opened in 1991 as a joint collaboration between MSF, the Ministry of Health, and the French universities Paris-Nord and Bordeaux), and opened a surgical training project for Ethiopian doctors in Weldiya (1993).

Parallel to the attempts to improve the surgical skills of its staff, MSF continued to deliver surgical care for the war-wounded. Following an example from the ICRC, MSF settled along the borders of countries at war to attract the wounded from the areas of conflict. For instance, from 1983 on, the wounded in the Tigray People's Liberation Front were transported from Ethiopia to Sudan, where MSF treated them. Staff mostly received cases suffering open fractures on limbs, and the discussions on how best to treat

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them were lively. This was an opportunity for MSF to make choices and to take a step towards standardization of care. For example, the use of external fixators for such injuries was introduced as a standard around this time.

The opportunity to further develop field surgical practices arose with the civil war in Sri Lanka. By 1986 four surgical programs had been opened by MSF to replace the shortage of local surgeons, who had, particularly if they were Tamil, fled the country. Each year dozens of foreign surgeons were sent to Sri Lanka to care for the war-wounded amid a population of about 1 million people. Until the year 2000, when the peace agreement was signed, MSF collected vast experience managing surgical activities. Both the scale and the duration of the surgical programmes in Sri Lanka created a favourable framework for major developments in anaesthesiology and operating-room management. Thereafter, surgeons sent to the field were systematically accompanied by an anaesthetist (nurse or doctor) and an operating-room nurse.

MSF also started to move closer to the frontlines of war, particularly in urban areas. Examples of such missions are Somalia (1991), Bosnia (1992), and Rwanda (1994). Exposure to recently injured patients caused an evolution in MSF field surgical practice. MSF introduced complex procedures, such as abdominal, orthopaedic, or vascular surgery, which are usually reserved for specialist surgeons.

There were also improvements in logistical supply links that allowed for a better response in surgical situations. During the genocide of Rwandan Tutsis in 1994, for instance, MSF deployed Kit 300, which consisted of the medical materials for 300 surgical interventions. The kits, which were designed by Jacques Pinel in 1990, were compact, so that their transport was simplified, and they could be carried to the field in two pickup trucks. This was essential for providing a rapid response in the context of genocide in Rwanda. This logistical innovation further contributed to the standardization of surgical practices as well as to the efficacy of MSF's relief activities (Vidal and Pinel, 2009).

From the 2000s on the focus of MSF was to improve the quality of surgical care, so that it would become comparable with the care provided in countries that do not lack resources. Recruitment of surgical referents – specialist advisors providing technical support to their counterparts in the field missions – at headquarters, systematic use of staff specialized in anaesthesia, generalization of recovery rooms, focus on pain management, and design of clean hospital structures were just some of the actions undertaken. Since the mid-2000s the organization has revolutionized the effectiveness of rapid response by developing an entire hospital structure under inflatable tents. The inflatable hospitals were successfully used in Pakistan in 2005 and in Haiti in 2010.

To improve the quality of care, MSF looked at US trauma centres. Those centres had experience with bullet-related injuries from urban violence, and

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they had the advantage of providing care in a stable context, quite unlike MSF. The idea was to go beyond objectives, which by then were almost exclusively aimed at the survival of the injured person while taking into account their long-term functional potential.

Missions such as those at Port-Harcourt, Nigeria, and Port-au-Prince, Haiti, were examples of the intention to adapt trauma-centre protocols to the humanitarian context, and to focus more on improvements in the functional impacts of trauma. The traditional traction suspension (a set of mechanisms for strengthening broken bones) to manage lower-limb fracture was replaced by internal fixators (metal implants surgically inserted into the bones to repairing the fracture). This practice reduced hospitalization times and gave better functional outcomes to patients. The use of internal fixators was unusual in humanitarian settings due to the need to provide high levels of infection control. MSF was concerned whether they could ensure sufficiently sterile facilities under unstable field conditions. Their solution was to introduce field microbiology labs to monitor the spread of infection, particularly those resistant to antibiotics.

Ultimately, all this knowledge in surgical care that MSF accumulated was reflected in the MSF RSP in Amman, the longest-standing MSF surgical programme to date.

The origins of MSF's RSP

The origins of the RSP have a unique and complex background that is, to a certain extent, still reflected in today's programme. In 2003, after the attack and invasion of Iraq by a US-led military coalition, working in that country became increasingly dangerous for international humanitarian organizations. Difficulties accessing populations in distress dated back more than twenty years to the time of the Iran–Iraq war (1980–1988). The establishment of an embargo (1990) and the international military offensive in response to the invasion of Kuwait (1991) only served to exacerbate the lack of access. The embargo continued until 2003, and the new US-led invasion in March 2003 took the situation to new, nearly impossible levels. Previously, Saddam Hussein's regime had invited a large number of aid agencies into the country to help alleviate the health consequences of the embargo. In March 2003 the invasion of the country by foreign forces only strengthened the resolve of humanitarian workers to carry out activities in Iraq. But their enthusiasm was short-lived. On 19 August 2003 a truck full of explosives detonated at the UN headquarters in Baghdad killing 22 people. While the UN primarily had a political role, several of its agencies were essential to humanitarian work (UNHCR, World Food Programme (WFP), United Nations International

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Children's Fund (UNICEF), World Health Organization (WHO)). Two months later, also in the capital, the ICRC suffered a bomb attack in which two people died. As humanitarian workers considered their activities in the country, these crimes were on everyone's mind. In the small world of international aid to Iraq, Margaret Hassan was an important figure. She was Irish and had lived in Iraq for decades. She was an Arabic speaker and a head of the local branch of Cooperative for Assistance and Relief Everywhere (CARE). Her pleasant personality was the subject of the broadest consensus. No one imagined that she would be kidnapped and executed. But in November 2004 that is exactly what happened. Even radicals, including the leader of Al Qaeda in Iraq, called for her release. Circulation of the shocking video showing Margaret Hassan's execution struck aid workers with profound alarm.

It became clear that no one was safe from kidnapping and attack except, perhaps, in certain areas of Iraqi Kurdistan. MSF decided in 2005 to withdraw its teams from all other areas of Iraq. But the interest in providing humanitarian aid to Iraqis remained.

The resumption of contacts with Iraq and the start of the RSP occurred in a roundabout way. The MSF team and the surgical team of the Iraqi Medical Association (IMA, the equivalent of the National Order of Physicians in France) met in Pakistan, where they were responding to surgical needs after an earthquake in 2005. What was eye-opening to MSF representatives was how Iraqi doctors collaborated, regardless of their political or religious affiliation. This collaborative spirit was unique at the time, in a context in which sectarian and violent political groups of all persuasions were rapidly emerging. The friendliness and group cohesion of the Iraqi doctors remained unchanged by the situation in their own country, where military and militiamen were systematically entering hospital rooms to finish off the wounded and attack health workers.

Iraqi representatives initiated a discussion on how surgical support could be provided in Iraq by MSF, and two possible avenues were discussed. The first was the improvement of emergency-room competence in general in Iraq by establishing a steady flow of supplies and ongoing training of staff. These adjustments were essential because of the huge increase in injured people that Iraqi hospitals were receiving at the time due to mass-casualty events. But the ambition was greater than that. Since the patient profile was made up of those with severe functional deficits, those involved in the discussions thought that long-term care was key. Extended treatment beyond emergency care was needed, and the idea of specialized reconstructive surgery hospital was born. The two teams left Pakistan committed to keeping in touch in the hope of achieving collaboration on this objective in Iraq.

The actual implementation of the plan was not far behind. It began in June 2006, in Amman, with a round of discussions and negotiations initiated

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Figure 1 The RSP cornerstone meeting. An illustration showing the meeting between representatives of the IMA and MSF, which was a cornerstone of the MSF RSP in Amman.

by MSF. The Jordanian Ministry of Foreign Affairs, the Jordanian Red Crescent, the IMA, and the Iraqi Ministry of Health all participated along with MSF. For MSF, the aim was to obtain the agreement of the Jordanian and Iraqi authorities to open the RSP. Once an agreement was signed allowing MSF to start its activities in Amman, including expediting visas for injured Iraqis to come to Jordan for treatment, MSF's specialized RSP hospital opened in 2006 utilizing operating rooms and hospital beds rented from the Jordanian Red Crescent. Initially, the RSP only received the injured from Iraq, but later, after violence erupted during Arab Spring (2011) and in other ongoing or new armed conflicts, patients from Syria, Yemen, Libya, and Palestine also started to arrive.

The RSP today

The RSP is currently run in Al Mowasah hospital in Amman. Some of the surgeons who participated in the initial brainstorming in Pakistan are still there. The programme performs specialized orthopaedic, plastic, and maxillofacial surgeries, often on patients who suffered severe injuries years before their entry to the hospital. They have lived with different levels of disability or post-surgical complications and upon arrival at the MSF hospital some

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cannot walk or stand up. Some cannot speak or chew food, or their skin is so contracted due to burn scars that they are unable to move their hands or neck.

Besides numerous complicated anatomical deformities, many patients also suffer from infections that occurred when dirt and other infectious material penetrated the wounds together with the shrapnel or bullet. Such infections – common among patients at the RSP – are extremely persistent, causing severe pain and potentially threatening life (Fily et al., 2019). For instance, in the study of 727 patients examined for infections at the RSP, over 70% were positive and over 80% of those were infected with bacteria resistant to many ordinarily available antibiotics. Bacterial resistance is a global problem and, for the type of infections seen at the RSP specifically, extremely costly antibiotics are needed. It is not surprising that a large part of the RSP budget is allocated to cover the cost of antibiotics. In the patients' countries of origin it would simply be impossible for the health systems, already weakened by war and conflict, to afford such specialized, expensive treatment.

Often, numerous surgeries are needed to clear tissue that is no longer vital due to infection, to fix bones in their correct positions and extend them where necessary, to transplant skin and muscles, or to reconstruct missing noses, fingers, or jaws. Surgeries are typically followed by intensive physiotherapy, during which patients who suffer amputations also must learn how to use artificial hands or legs. Patients in the hospital are also treated by psychologists and psychiatrists, who offer individual or group sessions to reduce the impact of psychological disorders and to help them deal emotionally with the challenges associated with life in a hospital setting.

Undergoing several surgeries and participating in post-surgery rehabilitation means that patients' treatment in Amman is lengthy, ranging from a couple of months to over three years. And it is not only the processes in the hospital that are long: the preparations for a patient's arrival in Amman can take months. Doctors known as medical liaison officers (MLOs) work in Jordan, Iraq, and Yemen, where they register patients in need of surgical care. Through their contacts in local hospitals, refugee camps, and through their personal social networks, they identify patients with specific surgical needs. The patient then provides medical reports and X-rays, which are sent to Amman to be reviewed by the surgical committee. This committee, during weekly meetings, discusses potential cases and gives the green light to those whose injuries that could be improved by one of the surgical interventions offered at the RSP. The planning for a patient's departure from their home then starts, and the MLOs assist them with administrative work to obtain visas and arrangements for their flights to Amman. Once the patient arrives in Amman, they reside either in hotel rooms rented for them by MSF or in the hospital. Each patient also receives a daily per diem for

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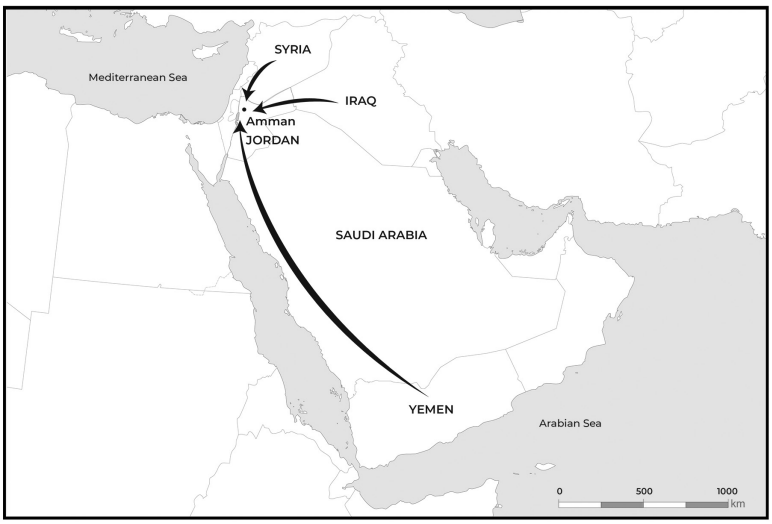

Figure 2 The RSP operational area map. A map showing the countries from which patients travel to Amman (indicated by arrows) to receive treatment in the RSP hospital.

expenses. Those patients who have severe mobility limitations or who are children are accompanied by a carer, usually a family member who also receives accommodation and a per diem.

There are exceptional aspects to the MSF RSP. First, the types of surgery are focused entirely on functional improvements for patients who have extremely complicated medical profiles. They are not considered lifesaving. Management of such complex surgical cases is considered extraordinarily taxing even in hospitals around the world with the best technical and human-resource capacity (Fakri et al., 2011). The daily work of surgeons in Amman is often characterized by innovation, since there are no established surgical protocols to guide the interventions in such complicated medical cases.

Second, the long-term rehabilitation of patients, delivered away from their home countries, creates a special kind of healthcare setting. Also unique is MSF's comprehensive social support for the patients and their carers. Furthermore, surgical care is delivered by surgeons originating from the patients' home countries, creating a bond between patient and surgeon. Surgeons' long-standing presence in the RSP is also vital for building up and maintaining their surgical skills – skills that are geared to such specialized circumstances. Their knowledge can potentially be transmitted back to the medical systems in the countries affected by war.

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Third, the scale of the programme and the treatment provided to injured non-combats makes the RSP unique not only in the MSF framework but also in the global landscape of war surgery (Hornez et al., 2015; Edwards et al., 2016). The treatment is delivered free of charge and targets patients who would otherwise be medically neglected. Finally, the durability of the programme provides an opportunity for extensive research that can make a contribution to scientific literature.

All of these aspects provided the time and space necessary for the comprehensive anthropological fieldwork I carried out in Amman and that I present in the following pages.

Notes

1 In fact, even if they were previously on the battlefield, an injury or their capture places them in the category of "non-combatant" in the eyes of international humanitarian law (ICRC, 2019). Hence, they have the same rights to the medical assistance as anyone else but rarely have access to it.
2 Their records are drawn from cross-checked media reports, hospitals, morgues, NGOs, and other official reports.
3 The underestimation of the number of deaths due to war violence is, according to the Armed Conflict Location and Event Data Project (ACLED, 2019), fuelled by all parties involved in pro-regime and anti-regime coalitions to avoid public pressure.
4 Such injuries are also the most common among patients in MSF hospital in Amman.

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Anthropological research at Médecins Sans Frontières' Reconstructive Surgery Programme

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Initiation of the research at RSP

The idea of an anthropological assessment had been discussed at MSF for some years before my arrival in Amman. As the RSP entered its tenth year, in 2017, the organization's determination to make an assessment that went beyond an evaluation of its medical aspects intensified. The mutual interest of the field and desk managers and CRASH, MSF's centre for research and reflection, drove the launch of a deep, multifaceted research project. The programme managers wanted a more operational focus in the research, while CRASH personnel, some of whom were involved in the RSP from its beginning, had a long-standing interest in its development.

Multiple concerns about patients' wellbeing in the hospital and after they returned home required answers. How did hospital staff and patients relate to one another and how much of their interaction was conducive to the patients' recovery process? Were there any gaps in providing a truly healing environment for the victims of war? The RSP had been predominantly focused on improved mobility and functionality of patients' limbs. To what extent did these programme objectives improve patients' lives after hospitalization? How was their physical, emotional, social, and economic wellbeing after they returned home?

The research came at a time when the concept of a patient-centred approach was flourishing at MSF, and the RSP had declared it one of its main strategies. However, "patient-centred care" is a widely used but poorly understood concept in medicine, including within MSF operations. Despite attempts to develop a universal definition of this term (Stewart, 2001), there is currently no general consensus on what patient-centredness might mean or how it should be practised. Some of the literature focuses on patients' needs and values (Kvåle and Bondevik, 2008), while others emphasize the involvement of a patient's family members (Epstein and Street, 2011). Still more explore interactions between patients and healthcare providers (Berwick,

2009; Bauman et al., 2003; Epstein and Street, 2011). In the absence of a clear definition, I decided to take a unique approach and to focus my research on the patients' perspectives and to ascertain what was important to them. The underlying goal was for these assessments to become the core element driving operational change in the future.

Additional institutional enquiries in the research had a more strategic lens. Could the considerably high budget that MSF allocated to the RSP (10 million EUR per year[1]) potentially be used more effectively in other humanitarian aid projects? The very sustainability of the RSP was in question. An interesting and challenging task awaited me!

Methodology

I conducted the research between September 2017 and December 2018. An exploration of views of both the healthcare providers and the patients was needed, and I designed a research plan as a twofold process: in the first part of the investigation I focused on relations and perceptions between hospital staff and patients; in the second part I assessed the outcomes of the RSP from the patients' perspective. This process resulted in comprehensive original data from 173 formal interviews with patients and MSF staff, as well as extended field observations. The information was further enriched with the review of internal MSF documents.[2]

Interviews with MSF personnel and observations in the hospital

My research started in Al Mowasah hospital, where over a six-month period I observed interactions between hospital staff and patients, and explored staff perceptions of patients. Upon arriving in Amman in April 2017, I was soon integrated into the hospital microcosm and was invited to participate in department meetings, celebrations, and events. Daily observations of hospital life also took place during medical rounds, surgical interventions, in the hospital cafeteria, and in the outdoor recreation space.

Furthermore, my office became a place where staff members would stop to visit, bring me homemade desserts, show me photos of their families, chat about their weekend activities, and so on. At times, they also asked for confidential advice on issues such as how to resolve a conflict with a colleague. These visits to my office included descriptions of professional aspirations, gossip about colleagues and patients, chats about difficulties in their countries, and worries about possible complications arising from events in the

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operation theatre. This insider's position allowed for interaction with staff both formally and informally.

My interactions with patients in the hospital were mostly based on observations of their daily life and limited chats in Arabic (greetings, enquiries about their names and country of origin). Those who spoke some English would occasionally talk about their injuries, how they acquired them, and their progress after surgery. They also expressed curiosity about where I was from, what my country was like, and my family.

In the first period of study I conducted daily observations of hospital life, following doctors and surgeons on their medical rounds, spending hours in the operation theatre and physiotherapy sessions, in medical consultation rooms, and in social spaces such as the hospital cafeteria and the outdoor recreational space for patients. The purposes of these observations were to establish a base of knowledge of medical procedures and to observe how patients and their caregivers interacted with each other.

In a hospital like Al Mowasah, the diverse backgrounds of patients and the hospital staff (Iraq, Syria, Yemen, Jordan, European countries, Peru, the US, and Canada) created an interesting ground for exploration. Would nationality matter when it came to perception? Would the hospital staff's perceptions of patients be in line with views that patients have about their own health?

Such questions led me to interview MSF staff and examine their opinions. The in-depth interviews I conducted with ninety-nine members of staff[3] represented almost half of all the employees (209) at the RSP. Staff who participated in the interviews had medical and non-medical profiles, and I included expatriates and non-expatriates. I interviewed representatives from all hospital departments, including administration and management[4] (19), hospital support[5] (20), paramedical[6] (20), medical[7] (27), and surgical[8] (13).

The focus of the interviews was on participants' views on their professional role in relation to patients, their personal experiences with the patients and their perceptions of different patient groups (adults vs. children, differences between Iraqi, Syrian, and Yemeni, male vs. female, etc.). Depending on the preference of participants, the interviews were in English or Arabic, with translation provided by my assistant.

Selection of participants from among the patients

After the period of assessment in the hospital, my focus shifted to the patients, who I also aimed to interview during home visits. The process started with purposeful selection of potential candidates from the patients' hospital register. The criteria I followed when selecting appropriate candidates were as

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follows: first, I focused on adult patients from Syria who now live in Jordan, and Iraqi patients who had returned to Iraq; second, preference was given to those who had had multiple procedures and a longer stay in the hospital; third, the candidates had to have completed the programme and been discharged after 2012. I did not select candidates from earlier in the programme in order to reduce recall biases – errors occurring in selective, incomplete, or inaccurate reporting of past events (Richie and Lewis, 2003).

I also left out those patients who were discharged less than six months prior to the study, as they were more likely still to be undergoing re-adjustment at home; and I excluded persons younger than eighteen (on the day of the interview) as the impact of treatment is different for adults, and it was beyond the scope of my project to explore in detail the situation for young people. Yemeni patients too were excluded from the study even though they represented a large group of patients in the hospital register. The security situation in Yemen at the time of the fieldwork prevented me from travelling to that country and thus there was no way I could gather comparable data from them.

After the selection was completed, I contacted patients by phone with the assistance of interpreters. We found that about two thirds of the registered phone numbers no longer functioned. In a few cases, relatives reported that the patient had moved abroad. However, none of the patients we reached refused the interview. In all, we reached seventy-four patients from Syria and Iraq (fifty-four men, twenty women) who were able and willing to participate in the interview and who had undergone a range of surgical procedures: orthopaedic, plastic, and maxillofacial (see Appendix). We set the dates and venues for our meetings with them.

Fieldwork

I travelled with my interpreter around Jordan to meet the thirty-nine Syrian participants, who had originally come from Daraa, Homs, Damascus (including Eastern Ghouta), and Aleppo. All of them now lived in Jordan as refugees, but many had resettled from the refugee camps to private accommodation. The majority received us in rented apartments, mostly in suburbs of Amman, or in rented houses in rural areas in the north of Jordan. Their homes differed in the size and amount of furnishing, from very simple (lacking any source of heating in winter, for instance) to more sophisticated (equipped with flat-screen TVs, sofas, and carpets). One of the families we visited in southern Jordan resided in a tent that they moved north in summer and south in winter to avoid the high cost of heating.

Initially, I expected to spend much of my fieldwork in the refugee camps in Jordan, but only three participants still resided in Za'tari refugee camp,

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living in metal containers. The Za'tari camp is organized in lines of these containers, which are separated by mostly unpaved streets. Small shops with basic items and NGO offices are located between residential containers. The entire area of the Za'tari camp is fenced and only accessible at entry checkpoints. Each family unit that we visited had one or two containers arranged next to each other. There was a tiny kitchen, a small bathroom, and family living space. Each family unit had a water tank. Electricity was provided for limited hours a day, but one family had a small generator to cover the electricity gaps.

The second part of my fieldwork took me to Iraq. When I first arrived in Iraq I was struck by the reminders of war that could be seen on every corner, now mingled with ordinary life. I was impressed by the nicely manicured bushes along the highway, a smell of cardamom spiced coffee spreading through the hustle and bustle of the streets, and shopping malls filled with upper-class Baghdadi residents who were shopping, chatting in the cafés, eating delicious meals, or smoking sweet-smelling shishas. But military checkpoints, high walls, observation towers, and body searches at the entrances of buildings were routine, standing in stark contrast to ordinary day-to-day Middle Eastern life – a clear reminder that existence in Iraq is far from peaceful.

Compared to Jordan, fieldwork in Iraq was more challenging. We conducted interviews during Ramadan (May, June 2018), when fasting made patients reluctant to travel a great distance. In addition, security rules were stricter in this period, which was right after national elections, and hence our movements were limited. For each participant who agreed to be interviewed, we needed to carry out additional security assessments to confirm that their residence was relatively safe. Sometimes participants did not feel comfortable sharing the location of their residence, and they requested that the interview take place at MSF premises. Eventually, we were only able to visit eleven in their homes and we met the other twenty-four either in a MSF-run hospital in Baghdad or at the Fallujah hospital in Anbar.[9]

We conducted fieldwork in Baghdad and Al-Anbar provinces. Some participants from other provinces (two from Babylon and two from Diyala) travelled to meet us in Baghdad.[10] The home visits we carried out in Baghdad were in the districts/neighbourhoods of Dara, Adhamiyah, Sleikh, and Saydia. These neighbourhoods are predominantly occupied by Sunni families, and the residents are middle to upper-middle class. The neighbourhoods we visited varied from those that looked obviously more upscale, characterized by large houses and wide, clean streets, to those with houses under construction, rubbish on the streets, and plots of agricultural land stretching along the railways. Regardless of the area, all of the houses were well maintained and equipped. These areas of Baghdad were controlled either by the Iraqi

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army, the federal police, or Kurdish security forces. According to the MSF security in charge, the level of incidents (explosions, kidnaping) was relatively low in these districts (two to three per month) during the period of fieldwork.

The areas of Baghdad where we were denied access due to security restrictions (New Baghdad, Shuala, Sadar City, Abu Ghreb, Shaab, Mahmudia, Rifak, and Alan) are mostly occupied by Shia or mixed communities. Mostly lower-economic-status to middle-class families reside in these areas. Despite security forces operating there (federal police or the Iraqi army), the MSF security advisor commented that the areas were still controlled by the sectarian militia and may have Islamic State of Iraq and the Levant (ISIS) sleeper cells. Security incidents were still frequent (daily explosions, shooting, kidnapping), and, thus, we stayed away from these neighbourhoods.

The area we visited in Anbar had a rural, green feel to it, with date-palm plantations and some patches of agricultural land stretching between them. Anbar was drastically affected during the US invasion and ISIS control. There were still security incidents reported daily, particularly from the Western Anbar (Iraqi News, 2018). Evidence of the recent mass destruction was obvious and was an ever present part of our drives through the area. Half-demolished buildings were everywhere, and bullet holes were visible on many of the intact buildings. Roads were in relatively good condition but were characterized by frequent military checkpoints, where we needed to exit the car and show our IDs before we were allowed to pass. On the main highway every day, I observed passing military convoys armed to the teeth.

In Anbar we conducted home visits in Ramadi town, its rural suburbs, and Falujah town. Here the houses varied widely from very comfortable upper middle-class houses to improvised shelters covered with iron sheets, with cupboards instead of windowpanes, and a lack of furnishings. One participant resided illegally in an abandoned government apartment. We conducted one of the interviews in the MSF car, due to the participant's embarrassment at the condition of his significantly damaged house. He resided with his relatives. We were restricted from visiting participants in Garnea, which was still considered unstable, so we arranged to interview them in the Fallujah hospital. My impression from fieldwork is that Anbar maintains a better sense of social cohesion than Baghdad, but the long-term destruction of the physical environment is more evident there.

Home visits and the interviews with MSF patients

My aim was, as far as possible, to interview our participants at home in the hopes of making them feel at ease and to observe their living situation and

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their interactions with family members and friends, important elements that bear on their daily reality and reveal the truth of their life with disability. The central focus of the interviews was participants' descriptions of the events that led to the injuries, their experiences of treatment at MSF and with other health providers, and their perception of their quality of life and wellbeing after the treatment at the RSP. The interpreters who accompanied me in the fieldwork assisted me with direct interpretation from English to Arabic and vice versa.

I recorded all interviews on a digital voice recorder, which in total exceeded eighty-six hours of interviews, averaging an hour and ten minutes per participant. My field team and I spent at least an additional hour and a half per participant in introductions, informal chatting, reassurance, responding to questions, and social interactions with family members. I also carried out supplementary observations (participant observations[11]) – for example, of patients' physical and social environments – and noted them during home visits. To determine socio-economic profile of participants (details in Appendix) I completed a short socio-economic questionnaire for each participant at the end of the interview.

We were received with generous expressions of hospitality during our home visits. After initial greetings from family members, we were invited into the salon, typically an entry room of the house/apartment, furnished with ground mats and pillows, where visitors are usually seated. In Jordan we were frequently served tea or Syrian-style coffee. On occasion, a traditional breakfast (bread, olive oil, olives, cheese, stuffed aubergine, and sweet pastries) was brought to us after the interview. Iraqi participants often invited us to stay for *iftar*, an evening meal that breaks the fast during Ramadan. In Anbar, as a part of the expected dress code, I wore a hijab (a head scarf), and this was greatly appreciated, particularly after I clarified that I am not a Muslim.

Often, family members (spouses, parents, and children) were present throughout the interview; occasionally, they would enter the room during the home visits. In order to respect confidentiality, we confirmed with participants that this arrangement was acceptable to them, and they usually responded along the lines of "After what we went through together there are no secrets between us." The family members present often acted as the patient's caregiver, and they added important information to the patient's narrative. Such information might otherwise have been missing, because participants were often unconscious right after the injury. Caregivers provided insight into changes in the participants' behaviour over time. Family members also accompanied those participants who came to meet us at MSF premises.

I was concerned that the interviews focused on memories related to war would cause emotional pain to the participants. Before we started the

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interviews, I reassured them that they were under no obligation to respond to my questions and should share only the details they felt comfortable sharing. I put forward my best effort to be as sensitive as possible, observing participants' reactions to my questions. If I observed any sign of distress, I asked if they wished to continue. When talking about the war context and the circumstances under which the injury occurred, my questions were never specific to the events but, rather, open-ended, such as "And then? And what happened after?" With this strategy I aimed to place participants in control of the narrative and the details they wanted to remember and share.

Some participants communicated very clearly that "they did not mind my questions, but they did not want to remember related traumatic events." I respected this, and on such occasions shifted to another line of questioning. In contrast, some insisted on describing, quite graphically, the events of violence. Additionally, some showed me videos taken during the event that caused the injury. I still wonder if these video examples were used to communicate that this was the participant's destiny. Or whether they were an attempt to make me a witness to their suffering, which extended beyond their bodies to those who were killed in front of them.

Surprisingly, despite many of participants still experiencing a high level of emotional distress during the interview, many of them communicated gratitude that "somebody took time and was willing to listen to them," and their mood seem to lift by the end of the process. Their eagerness was obvious in some of their comments. For instance, "I am happy that you came here to my home and asked me questions. Even if you want to interview me every day, I am ready" (RSP9, Syrian, male (M)). Or another participant, who was a political prisoner commented: "I'm sorry I bothered you with my story while you have nothing to do with this information. I just wanted to tell you my story; I honestly don't know why [smiles]" (RSP46, Iraqi, M).

Analysis of the interviews

After we completed the interviewing process the audio recorded material was prepared for analysis. I used a thematic-analysis approach (Richie and Lewis, 2003), applying the following steps. My field assistants transcribed hours of audio records into Word documents. After the transcription process was finished, I read the transcripts to develop a coding system. The transcripts were coded using MAXQDA software. After coding was complete, segments of the data were organized into tables (matrices) and further examined to identify patterns (themes in the thematic-analysis approach).

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Figure 3 Patient at home. Male relatives gathered around their injured family member.

Figure 4 Researcher conducting interviews. The researcher was usually placed opposite the participant and recorded the interview on a digital voice recorder.

When analysing data from the interviews with the hospital staff I noted any similarities or differences in the views of the participants from different hospital departments or different geographical regions. In analysis of the patients' interviews I made a comparison between participants living with

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similar disabilities in different contexts. For example, I compared Syrian refugees in Jordan with residents in Iraq and/or the outcomes for male and female participants. Each theme was described in detail and illuminated by using participants' direct quotes. I analysed information collected by questionnaire in Excel to determine the average socio-economic status of participants (Appendix).

Processes to ensure good quality of data

Having only a one-off opportunity to record each interview, it was essential to ensure good quality of data. This required accurate translation and transcription, and as both processes were performed by research assistants, I paid special attention to their selection. I carefully evaluated each applicant's research background, their fluency in both Arabic and English, and previous experience in humanitarian settings. During the selection process potential candidates underwent written tests of their translation and transcription skills. The tests were designed to assess the candidate's written and oral translations and computer-based transcriptions. Texts in English and in Arabic (one page in each language) were translated. Subsequently, their work was compared to originals translated by a professional interpreter to assess the accuracy of translation and efficiency of time management.

Oral interpretations were tested by providing candidates with short sections of written text (in English and Arabic) for them to translate into either Arabic or English. When translation was given in Arabic, a third person translated it back to me in English. This was, again, compared with the original written text. Transcriptions were tested by giving candidates instructions and audio recordings of two short dialogues in English to be transcribed. The accuracy of the transcripts (how many words/phrases were missing, any changes in meanings) and time management were assessed and scored.

The interpreters who were ultimately selected were further trained during a two-day workshop that I organized and ran. We covered specific behavioural guidelines for fieldwork, research ethics, and the main principles of qualitative research. Explanations, illustrative videos, and written materials were provided.

Before starting the fieldwork and interviewing patients we pre-tested an interviewing guide and socio-economic questionnaire on volunteers (patients) in the hospital. Through this process, the research assistants practised translations while interviewing and had the opportunity to check if any words used by Syrian volunteers appeared difficult to understand. In such

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cases, those words were double-checked with a Syrian member of staff (we took this approach to all interviews). Volunteers gave us feedback on the clarity of the questions and their sequence. The topic guide, which was ultimately used for interviews, was then revised to include the suggested improvements.

When a research assistant started transcribing the interviews, I often randomly compared parts of the transcriptions with the audio recordings. If there was a difference, we discussed why this had occurred and how to correct for it in the future. I repeated this process of cross-checking until we achieved good-quality transcriptions. To achieve a consistent level of translation and to double-check the on-site translations, some interviews were transcribed by an interpreter who had not been involved in the interview process.

The entire research project received ethics clearance from ethics committees at Comité de protection des personnes Sud-Ouest et outre-mer III, Bordeaux, France, and from Al Mowasah hospital, in Amman.

By implementing these rigorous steps, I was able to collect, document, and analyse a trove of rich information portraying the life of war victims and the staff providing their care. We will now continue and look into the daily life that unfolds inside the MSF hospital and that carries with it unique emotional bonds between the people behind the hospital walls.

Notes

1 This is one of the highest budgets for a single programme within MSF operations. It is comparable to budgets required for specialized surgical hospitals in Europe or the US.
2 Triangulation was achieved using the mix of methods described above and debriefing the research assistants/interpreters after each interview.
3 The sample size in qualitative research is not pre-determined. The interviewing process is considered complete when a so-called data saturation point has been reached. Data saturation is achieved when no new information emerges from additional data collection (Richie and Lewis, 2003).
4 Programme managers, researchers, HR and finance departments, communications department.
5 Logistics department, laboratory staff, pharmacy staff.
6 Physiotherapy and psychosocial departments.
7 Doctors, nurses, and medical-department supervisors.
8 Surgeons, surgical assistants, operating-theatre nurses, anesthesiologists.
9 Transport reimbursement was provided to participants who travelled to meet the research team.

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10 Babylon was relatively stable at that time, but Diyala still had many security incidents. In the month of June 2018, it was the worst affected governorate, with fifty-two civilian casualties (sixteen killed, thirty-six injured) (UNAMI, 2018a; 2018b).

11 Participant observation is a core method in anthropology that offers researchers the opportunity to gain additional insights through experiencing and observing phenomena under study (Richie and Lewis, 2003).

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2

In the Médecins Sans Frontières hospital

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In this chapter we will follow patients and staff through their daily routines at the MSF hospital so that we can discover the unique texture of life in the RSP in Amman. We will examine the relationships that develop between patients and their healthcare providers and conclude by recounting the widespread perceptions staff have of their patients. In the end we will see that in many ways these perceptions conflict with the patient-centred approach which drove this research and which MSF seeks to achieve.

Daily life in the hospital

Al Mowasah hospital is an impressive-looking five-storey building located in the popular market area of Amman, called Marka. Entering through the automatic sliding glass doors reveals the first surprise: there is an absence of an emergency atmosphere[1] and the hospital feels unexpectedly quiet. Especially in the morning hours, the feeling of calm is palpable; a few patients might be moving through the hospital lobby on crutches and wheelchairs, a couple of members of staff might be getting coffee at the mostly empty cafeteria, or a group of nurses might be chatting in the hospital corridor.

As the day progresses the atmosphere becomes slightly livelier. Groups of patients might be sitting in the outdoor area, chatting and playing table games. Or there may be children chasing cats and playing in the outdoor playground, with women sitting on the nearby benches and observing them. Never was the sense of tranquillity interrupted. On quiet afternoons staff pass the time in their hospital offices, and patients relax in the outdoor hospital space.

The life of the patients and staff seemed to be comfortably routinized: morning ward rounds, physiotherapy sessions, patients being rolled in and out of the OT (operating theatre), outpatient consultations, activities in the psychosocial department, and time spent in the cafeteria during lunch hours. Occasionally this routinized daily life in the hospital is disrupted by the

Figure 5 The entry to the RSP hospital.

arrival of new patients, visits from external journalists, volunteers, or MSF representatives. Or there are small conflicts among patients, celebrations of religious days, or gatherings organized for the departure of patients, which bring some liveliness to the usual quiet of the hospital day.

Another surprise was that the world of the hospital employees and patients merges in mutual informal interactions. This was particularly obvious in the hospital cafeteria, which offered a rich environment for observations. The cafeteria is a large open space on the ground floor that is furnished with colourful tables and chairs and provides a relaxing environment for both patients and staff, who frequently share the space. To make it even homelier, the cafeteria manager knows everyone's coffee preferences and serves them without needing to hear their order. Patients and their caregivers often join the table where staff members sit, and informal chatting takes place.

Patients sometimes wandered on to the first floor where my office and the OTs were located. They would come to talk with a member of staff such as the pain nurse or nursing supervisor, who were next to my office. Sometimes the patients would just come to greet anyone whose office door was left ajar. Paediatric patients soon started treating the hospital as their home, and, despite rules against it, everyone's mood lifted when the children made their rounds in the offices, taking pens, drawing pictures, and chatting or playing football in the hospital corridors. I was sometimes invited into this informal

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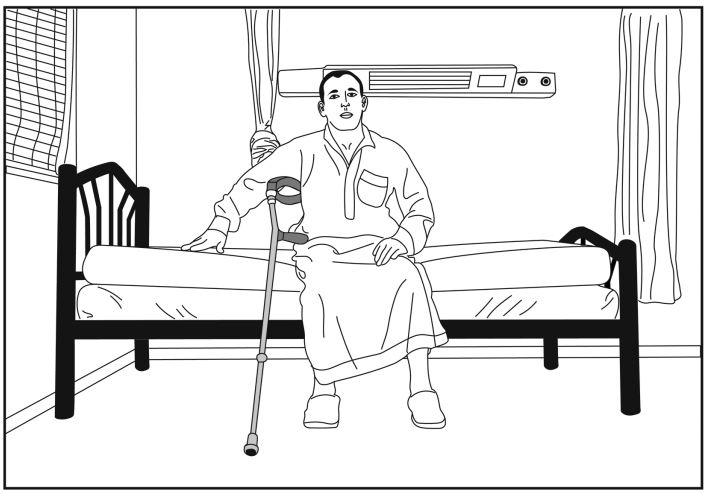

Figure 6 Patient in the hospital room, seated on the hospital bed.

merging of the two worlds by patients approaching me for a chat or offering me a sweet, female patients greeting me by kisses on my cheeks, or paediatric patients inviting me to play with them. Patients do not wear the usual institutional hospital clothes but are dressed in clothes that they bring from home or receive as donations in the hospital. Sometimes they looked so familiar and confident within the hospital environment that I would have to ask if they were members of staff or patients.

An extension of hospital life takes place in the Karamana hotel, where patients who stay in the RSP for extended periods are accommodated. One floor of the hotel is permanently rented for MSF patients, and an MSF van travels between the hotel and the hospital to bring the patients back and forth for treatment. Life in the hotel appears even less institutionalized than in the hospital. On a usual day, patients rest in shared rooms watching TV; some go shopping at the local markets, some perform their prayers in the spacious area between hotel corridors, and some cook in the shared kitchen. Like in the hospital, the general sense of slow motion and ease is palpable among the residents, for whom the hotel is their second home.

Unique relationships between patients and their carers

The atmosphere inside the hospital is also characterized by the unique relationships that develop between hospital staff and patients. These dynamics were not obvious at the first glance, but over time, in observations and

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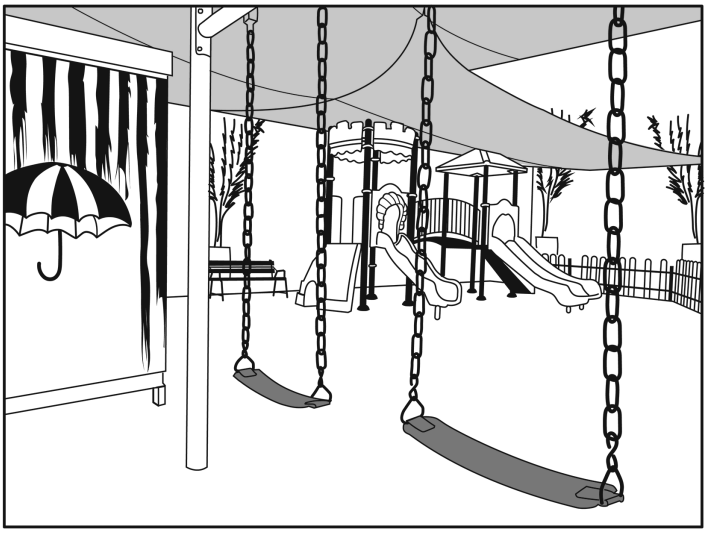

Figure 7 The hospital's outdoor area has a playground for paediatric patients.

interviews, the hospital staff revealed what drove these distinctive interactions. Let us examine the details.

As mentioned, the hospital staff and patients feel a strong sense of informality and general friendliness. It was not uncommon, for instance, to see patients interacting with surgeons outside of the consultation room, at the cafeteria or in the hospital corridors. The way patients refer to surgeons is "doctor" followed by their first names. Depending on the surgeon's personality, this relationship has more or less closeness and informality. The surgeons who were more extroverted often joked with patients, shook their hands, tapped their shoulders, or kissed paediatric patients on the forehead. Patients generally seemed at ease and relaxed during medical rounds with these surgeons, and I did not observe any reluctance to speak directly to them. Those surgeons who were more reserved had less interaction time and fewer verbal or physical gestures of communication with patients, but patients who were more confident and extroverted themselves managed to gain the attention of surgeons in spite of a surgeon's communication style. Hence, the relationships were generally characterized as an interplay between personalities of all types on both sides.

The relationship between nurses and patients seemed to be even more relaxed, light, and filled with humour. Nurses called patients by their first names, and as soon as they entered a patient's room they heard complaints about hospital food, wishes to be discharged soon, worries about a patient's

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Figure 8 The interior of the hotel. The part of the hotel where patients are located as they wait for their surgeries.

family, and so on. Sometimes the patient–nurse boundaries were blurred, and it seemed that both parties were willing to participate in this. For instance, I observed a nurse throwing a role of gauze at a young male Iraqi patient and laughing out loud during the surgical round. On another occasion, a female patient asked to try on the nurse's lab coat, which was allowed without any reluctance.

When talking about their relationships with patients, hospital staff generally described them as "unique," and many participants, including those from non-medical departments, such as administrators and members of the logistics department, referred to the patients as "family" or "friends." Nurses in particular warmly described how they relate to the patients. "Yes, we [nurses] develop quite personal relationship [with patients] – I think because they need it," commented one of the nurses (P10, nurse, female (F)). Another nurse was similarly open about her personal approach, "Other than the professional relationship, it is a sibling relationship" (P11, nurse, F). Administrative staff were also informal: "The relationship between us is not like hospital employee and patient: it's like friends and family" (P58, administration and management, M).

Some individual patients receive an even greater share of attention, and nurses in particular develop a strong sense of attachment to them. This aspect became obvious when one of the paediatric patients, a boy with a

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lively personality, left the hospital. One of the expatriates described the boy's character: "He had like really personal way about him and something that a lot of people found kind of magnetic. And as a result, you know, people became quite fond of him, myself included. He was just, really, like a special kid" (P41, administration and management, M). A sense of sadness prevailed along the hospital corridor on the day of his departure. One of the supervisors, who also reported being emotionally touched, tried to motivate his staff to move on. He reported to me about it:

> When he [gives patient's name] left, everybody was crying, even though he wasn't finally discharged [he is coming back to the hospital]. I was just in a meeting on the third floor [to calm down the staff] because they said he was the one who made the third floor busy, because he was noisy, he was moving around [interacting with everybody]. At that time, I saw some nurses crying, and I said, "OK, go to OPD [outpatient department]. There are two new patients who arrived today…" Two Iraqi children… Two girls, sisters. They were in a wheelchair… And I said: "We need to move on. He [gives patient's name] left…" I told them: "In one week you will forget him because you will have other things to do" [other patients to mind]. (P76, nurse, M)

This example of the "special boy" and the pain that accompanied his departure was just one of the many daily emotional rollercoasters that played out in the hospital. Many staff members described how hard it was on them when patients finally left the RSP, saying, "We cry, feel sad and worry about them." They reported that they used social media to keep in contact with patients, and sometimes they are able to keep in touch for several years after the patient's discharge. One of the surgeons felt flattered that years after the surgeries patients still referred to him on Facebook: "It's nice [to keep in touch]. One of them [a patient] just wrote on Facebook and he said that 'It's the tenth anniversary of my injury. Thanks for all the doctors who saved my limb.' And he mentioned me, by my name" (P55, surgeon, M).

Such closeness, however, while unusual for a hospital environment, was not what physiotherapists and most surgeons reported. Despite some exceptions, they generally emphasized the need to maintain professional boundaries, and unlike other participants they did not refer to patients as "family" or "friends." Most of the physiotherapists also did not consider psychological support of the patient as any part of their professional or personal responsibility, although this was quite common among doctors and nurses. Referring patients to the psychosocial team was mentioned very frequently: "We try our best to explain to the patient that this is [it]… If he wants more, we usually refer them to the psychosocial support counsellors to help us communicate: 'don't expect more from us.'" (P37, physiotherapist, F). The tendency to hand patients over to the psychosocial team seemed to help physiotherapists maintain their boundaries, which is not surprising considering that their daily

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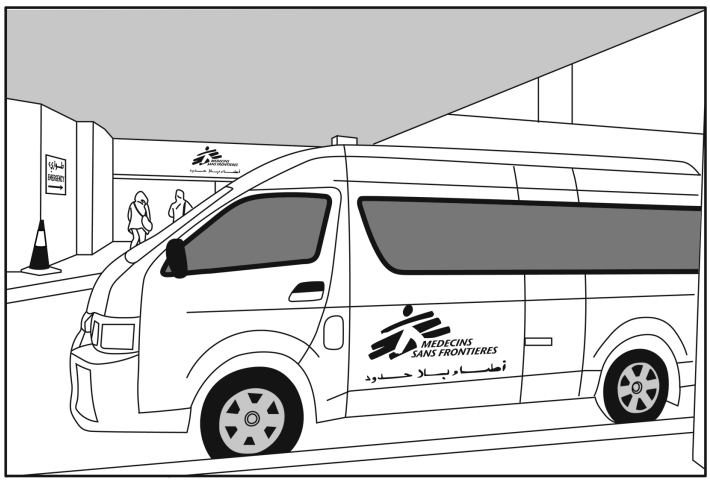

Figure 9 An MSF van transports patients between the hospital and the hotel.

interactions with patients were lengthier and more interactive than those of other members of staff.

When I spoke with surgeons, there was a wide spectrum of opinion regarding how much information, particularly of a personal nature, they sought from their patients. Some preferred to know only the essentials – the injury and past treatment – while some sought information on the origin of injury, and one participant reported seeking detailed information on a patient's general social situation. All participants justified this by saying that the level of information they seek helps them to manage cases clinically. Those who were reluctant to seek detailed information explained that being without such information prevents them from becoming emotional, and "emotions would cloud [their] clinical decision-making." On the contrary, the few who did seek more details of a patient's situation commented that this helped them to manage and support patients clinically and personally, and they considered it a part of their professional duty.

Non-Middle Eastern expatriate staff reported having limited interaction with patients due to a lack of Arabic language skills: "Here, I just have a lot of difficulties to communicate with the patients. First, I don't have lots of contacts because of my work as a manager, I don't directly work with the patients. And, even if I want to communicate with them, it's very difficult because of the language [barrier]" (P32, expatriate, M). With a few exceptions, no personal relationships with the patients were reported by this group. Many, however, expressed their appreciation for the little daily gestures that took place between them and the patients: greetings, smoking together in front

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of the hospital, and randomly playing with kids. Most of the interviewed expatriate staff expressed a wish for more interactions, and they also stated that, despite limited opportunities, their sense of responsibility and purpose was driven by their daily observations of patients.

Empathy

What was also obvious in the daily life of the hospital was a display of a great sense of empathy by the hospital staff dealing with patients. For example, nurses gently reassured the father of a child who suffered from pain, or drivers played football with children in front of the hospital, or a surgeon expressed worries about a patient's family situation. There were moments in the hospital when everyone was shaken by patients' obvious suffering. I recall a day when a child was brought out of the operation theatre and a number of staff members, including the nurses, surgical assistants, and the surgeon in charge, talked about the event to me with tears in their eyes. The surgeon described it as it follows:

> He [the patient] is four years old. I did surgery for him around two months ago. This patient lost all his family in a blast in Syria, and he is [now] only left with his uncle [to look after him]. He came here [to the MSF hospital] with an injury in his upper limb and has fracture in his radius in his forearm. And he has bone loss [shortened bone]. So, I did surgery for him, but when… [hesitates] When we went… When we prepared him for the surgery, he was shouting in front of the OT because he, he didn't want to go inside… [Participant looks emotionally shaken and starts tearing up.] He didn't want to go to the OT because he wanted his father and mother to be with him! So, we told the uncle to come with him, inside the OT. The uncle came with him and when we finished the surgery, we told him [the uncle]: "OK also come to the recovery room because when the patient wakes up from the anaesthesia, he also started shouting: 'I want my mum! I want my dad!'" So, I was a bit like… [hesitates] I wanted to cry because it was really devastating [to witness this]. It's really sad. And as I told you, he's a child who doesn't know what happened to him. This is the beginning of his journey, his life [has just begun] and he has this devastating effect [of emotional pain to suffer]. (P66, surgeon, M)

It was not an isolated event to witness hospital staff deeply shaken. During interviews, many staff members shed tears when talking about patients' personal tragedies, the "unfairness of their situation," and the "difficulties these individuals will encounter in their future lives." Particularly when they reflected on paediatric patients, the participants were not disinclined to describe the sense of misfortune of these children. For instance, another surgeon commented: "A child with his father is passing in the wrong place

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at the wrong time, when an explosion happens. So, if they were a few minutes later or a few minutes earlier, they wouldn't have had this accident… And this accident will change their life forever. So unfortunate!" (P63, surgeon, M). One of the housekeepers also expressed the particular sense of injustice that arises when children are affected by war: "Many of them [patients] are children who make you feel heartache because they are not guilty at all and don't have any political or any kind of affiliation for what happened with them" (P72, housekeeper, F).

The price of providing a healing environment

Members of the hospital staff agreed that "This is not an ordinary hospital: this is a place for healing physical and emotional wounds." Many expressed a willingness to help reduce not only a patient's physical suffering but also their emotional distress. But these attempts to "absorb patients' pain" left an indelible mark on MSF staff.

The heaviness of patients' stories, even if they remained untold, was tangible in the hospital. On a daily basis members of staff complained about a lack of energy and about "stress" related to their working environment. They talked about how working with these particular patients has consequences in their personal lives. Having to "face a case that will affect you again" is felt to be a daily risk. One of the medical doctors commented: "Recent challenge that I am having [is that] I thought by now I would be desensitized and have got used to bad news or bad cases… But like I recently learnt from a case that came last week [and shook me], like sometimes this [emotional distress] will happen even if you have seen a million cases. It will come again, and it will affect you" (P91, medical doctor, M).

In daily contact with patients, the visual impact of deformed limbs and faces evokes additional emotion. I remember my first days in the hospital when I felt almost nauseous due to the emotional charge associated with the sight of deformed human bodies. As I observed injured patients during hospital rounds it became easier for me to feel and act "neutral." But on one occasion a female patient, who had large burn scars covering her face, causing her lips and one of her eyes to pull to one side, entered my office and caught me by surprise, as I had not heard her come in and my back was turned towards the door. She gently tapped my shoulder to get my attention to ask a question. When I turned my head, I could feel an overwhelming emotional wave and was sure that in a matter of seconds my face was transparent with my feelings. It made me feel embarrassed to think I may have hurt her. I helped her with the information she sought, but an overwhelming feeling of guilt and sadness followed me through the day. As I said, over time

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in the hospital my emotions and reactions were slowly brought to a more neutral state, but I never felt untouched by the look of somebody with severe and visible impairments or the sight of an injured child. Members of staff, even those who had spent years with MSF, communicated struggling with the same sensation. One of the nurses noted her difficulties: "For example, five-year-old has an abnormal face, burned face, and there's no nose, no eyes. I think this is the most difficult thing [for me to cope with in the hospital]" (P16, nurse, F).

The most frequently reported emotions in regard to interaction with patients were feelings of sadness, hurt, pain, worry, guilt, and depression, and these feelings had a high correlation to the severity of the patient's injury and the level of knowledge of the patient's background story. In particular, staff new to MSF, and those who could clearly recall their initiation period, disclosed how acutely emotionally challenging their adjustment had been to the working environment in the RSP. Facing cases of physical deformity and severe injury for the first time, combined with hearing patients' stories, was described as "something you see in a horror movie":

> To be honest, the first time working here, the first month was miserable for me. Because I've never seen directly [such cases]. Maybe we can see [something like this] in a horror movie on TV, but this is a real story [that the patient is telling you]. It's different, really. And in the first month, I was really shocked. [After] You hear from the patients [what they went through], you have to find a good self-care for yourself. (P57, psychosocial counsellor, M)

A male participant from the administrative department reported how his first impressions in the hospital made him cry: "The first month, the first two weeks, I was going home crying" (P58, administrative personnel, M). Loss of appetite was also commonly reported: "Very much [I felt affected]! I hadn't eaten [properly] for two months. And I really lost eight kilos as this is the first time I work in such job in such place that's related to wars and injuries. I always kept on crying, especially over children. I really lost eight kilos!" (P72, housekeeper, F). Both male and female participants in medical and non-medical departments described feeling shocked, crying, losing their appetite, losing weight, suffering from nightmares, feeling sad, and replaying patients' stories in their minds after work. Some participants mentioned that they initially "could not imagine continuing doing this work" due to the shock they felt while new on the job. The vast majority then explained that after the first few weeks or months they were able to "adjust," or "get used to it," "manage their emotions better," and develop a capacity to "switch off" after work hours.

The administrators, managers, and hospital support (drivers, logistic team members) expressed being emotionally affected by the situation at least as

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frequently as the staff providing medical care. One of the administrators clearly expressed this:

> Some examples [cases], yes [have an impact on me]. I remember that, myself, I was very happy in my life and with very smiley face… Sometimes [lately], my mother and family say to me that "You look sad, why?" It's accumulated sad moments for me. [Initially,] I didn't feel that this has accumulated in me. But, through the years, I feel these affect every employee of MSF. (P6, administrative personnel, F)

Physiotherapists gave many such examples when describing the emotional impact of their work. One of the physiotherapists, for instance, reported: "So always psychological things [related to my work] like cut me [the feeling of harm]; they really cut me. For example, this is very simple [to explain]. Sometimes we go into depression" (P35, physiotherapist, F). Another physiotherapist also sounded desperate: "Sometimes, really, I think of changing my job. Sometimes, especially when you face not one case, a lot of cases [like this], and there is no serious effect [of your work on them] or [they are] blocked [in the therapeutic process]. Sometimes, I think it's the time to change my work, really" (P29, physiotherapist, M).

It was alarming to hear how excruciating the emotional impact was on the surgical team at the RSP. Surgeons mostly used the term "stress" to describe their emotions. One of the surgeons explained the origin of the stress: "The stress. The stress is always present, especially in these cases. The most disappointing thing is just to go to a surgery [and come out] without any results. Without any good results" (P88, surgeon, M). Another surgeon had a similar view: "Because even after finishing the surgery, you're stressed out because you need to know: 'Did I do the best for the patient? Is that OK? Did that section that I did [operated] on the nerve, did it affect the nerve? Did I injure the muscular repair that they did [in a surgery] before?' So, it's really stressful for us as surgeons" (P66, surgeon, M).

What they were describing when they used the term "stress" involved overwhelming feelings of anxiety, depression, repressed emotions, frustration, anger, and sleepless nights worrying about the outcome of a surgery, or an ethical dilemma resulting from surgery ("Did I do the right thing?" "Did I do enough?"). The impact of these emotions was described as devastating: "The impact, first of all, is depression, [I'm talking about] myself. Because of the severity of cases. Sometimes, I see the females, middle aged, and young kids with amputation or something. How can I tolerate such things?" (P87, surgeon, M). Another surgeon made it clear that his family life was affected: "It's a misery. Really misery. Of course, it is reflected on me, even on my family. My wife is always asking me 'Why are you angry? All the time!' I don't know [what to answer]" (P87, surgeon, M). With one exception, all surgeons

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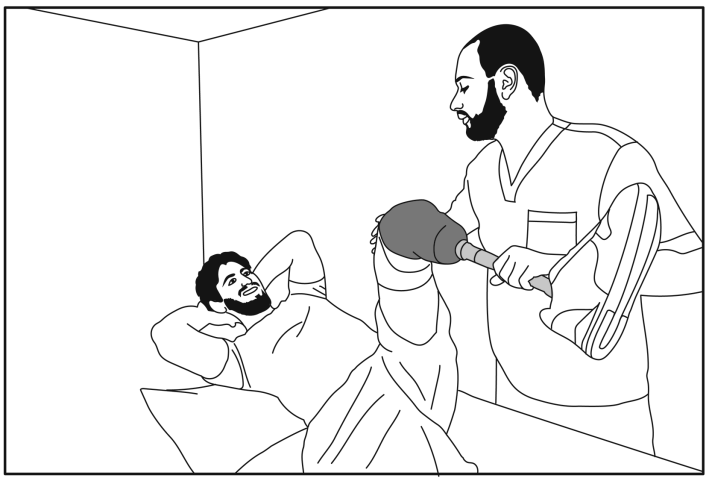

Figure 10 A physiotherapy session. Patients often undergo daily physiotherapy sessions.

interviewed reported that the nature of their work in the RSP impacted their personal and family lives.

My interactions with surgeons confirmed what they described during interviews. At times I was able to talk to them before or after a difficult surgery. On one occasion, for instance, a surgeon displayed visible signs of being affected – sunken eyes, a worried expression on his face. He told me that after hours of research he had found no literature to support his medical decisions on the complicated operation he was going to perform the next day. He mentioned that he was worried about the outcome of the surgery, especially since the patient was a victim of torture, with a tragic family story. What he communicated between the lines was the immense pressure he was under and how isolated and unsupported he felt in that difficult moment. Occasionally, surgeons talked about regretting their choice of profession and (jokingly) suggested that they would choose "nothing related to medicine" if they were to choose again.

Surgical work in the hospital is characterized by unique emotional and intellectual demands. With such complicated surgical cases there are often no well-established surgical protocols to follow. Some of the plastic and maxillofacial surgeons work as the single expert on the team, meaning they have no one with whom to consult when making decisions or attempting to resolve surgical problems. It is not surprising therefore that participants describe an immense sense of responsibility and consider it overwhelming. Dealing with victims of war, particularly if those victims

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come from a surgeon's (or any staff member's) home country, adds to the emotional distress.

Shared war experience of patients and MSF staff

Iraqi, Yemeni, and Syrian staff often spontaneously, without being specifically asked, shared personal experiences of the war – yet another reminder of the emotionally complex work at the RSP. Such stories were almost always accompanied by nervous twitching, facial expressions exhibiting stress, periods of silence afterwards, or participants' apologies for talking about "such distressing details." It appeared that their work in the hospital provided a daily reminder of the difficulties experienced in their home countries.

One member of surgical staff mentioned working under immense pressure in the context of the war in Iraq. They described events as "life changing," "unforgettable," and "difficult to deal with," reporting that the events still "caused flashbacks." One surgeon described the overwhelming situation: "I was responsible for everything, even the blanket for the patient, even the dressing, even the analgesia, everything. That's why it was so stressful! And [responsible for] all of them [the patients]! I was the only [specialized] surgeon there for 2 million people. It was so stressful… I was working every day and on-call every day. Even Friday, Saturday – every day" (P61, M).

According to participants, a number of factors exist that make working while at war particularly traumatic. The first is the level of responsibility doctors and surgeons shoulder for medical decisions and for any questions arising from those decisions – questions that can continue for years after the surgery. The second is the intense pressure of working with a large number of severely injured people, hampered by insufficient resources and working round the clock. Finally, surgeons describe working in circumstances of extreme personal risk with hospitals under attack, guns pointed at them, and health personnel systematically targeted. These traumatic events still resonate clearly in participants' minds, and the emotions associated with them are still very much present and unresolved.

In addition, daily worry about the people who remain under attack in their home countries, the unpredictability of events, and the frustration that "my country has been destroyed" also cause suffering. Members of staff who were not able to connect with family and friends after receiving word of new attacks and casualties appeared completely shaken. The staff originating in war-torn countries have a more intense dependence on MSF than others. Returning to unbearable working conditions at home is not an option, and, due to administrative and legal requirements, MSF remains one of the few, if not the only, employment option in Jordan. While some are

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accompanied by their families in Amman, many have families who remain under war conditions and depend on them for financial support. Their vulnerable position, combined with the work-related stresses, creates a sense of personal and family instability making for an extremely difficult existence.

In sum, members of staff in the MSF hospital were clearly motivated to provide a healing environment for the patients, even at their own emotional cost. The willingness to absorb patients' pain and provide them with support was obvious. But the capacity of staff members to deal with their emotions, especially in the absence of internal professional support, was precarious. The staff that were most affected included nurses, surgeons, those originating from war countries, and new recruits. By describing their emotional crises, the staff were calling out for more emotional support, something they saw as crucial for their personal and professional wellbeing.

Are patients' expectations unrealistic?

The sense of stress that surgeons in particular expressed was also associated with feelings of responsibility towards patients. Curiously, and in addition to the ongoing pressures related to medical decisions, some of the surgeons expressed feeling responsible for patients' lives beyond the scope of medical care. For example, they talked about attempts to "give patients new lives," to "reconstruct their old lives," or to "bring them back to their normal lives." This goal seemed overly ambitious, given that the war and their injuries had drastically changed the patients' social and physical environments. Hence, "old lives" were gone for good, and the surgeons' own expectations of what was achievable were unrealistic.

A fascinating aspect of our conversations was that my participants seemed unaware of the dynamics affecting them and projected the "unrealistic expectations" on to patients. Participants, particularly surgeons and physiotherapists, appeared stressed when talking about "patients' high expectations." This encouraged me to explore the topic further. Surgeons and physiotherapists described patients' expectations as going beyond their capacity to solve them, and that even any talk of "managing them was not being straightforward." Patients expected to get "back to normal," back to "100%," or to "run a marathon after treatment." Some physiotherapists even reported that this mismatch in expectations caused conflicts between them and some of their patients. They further explained how challenging it was to "make the patient unconditionally accept themselves" and how much they tried to "bring patients to realistic thinking" and to "accept my vision even if it doesn't match theirs." One of the physiotherapists commented, for instance: "I had huge conflicts with them [patients] in the beginning because of the

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expectation thing. But, in the end, when they have the result and they really understand what their limits are I say [to myself]: 'I'm really satisfied with what I'm giving to my patient'" (P36, physiotherapist, M). When asked how they proceed if they experienced resistance from the patient, physiotherapists explained that they most often refer such patients to the psychosocial team, who can work to "lower their expectations."

Members of the surgical team were, in contrast, more concerned with the daily dilemmas they faced themselves. Uncertainties surrounding surgical procedures, doubts about a patient's capacity to accept these uncertainties, and the unpredictability of the final treatment outcome tended to create communication difficulties with patients and uncertainty about whether the doctors could respond to patients' expectations. Some surgeons commented that previous experience helped them to reach an agreement with patients in these difficult circumstances.

A few surgeons, however, were convinced that patients had the "right to hope," and they explained that "without promising them the impossible" they were willing to foster these hopes. A surgeon clarified: "All the time they [patients] have hope and this is their right. If I was in their place, for sure [I would feel the same]" (P63, surgeon, M). Another surgeon gently explained his struggle to maintain patients' hopes while at the same time balancing transparency about what was going to happen in the surgical procedure:

> I personally don't lie to the patients, even the child [paediatric patients]. I usually explain everything for the patients. I think, [in] my opinion, this is right. He should know everything about his condition… So I explain things many times. Every person [patient] cries in my office when I face such things [confront them]. But I promise them that I will do my best to help them as much as I can… At the same time, I give them hope. And, you know, depending on the case, depending on the transfer [surgical procedure], or to re-explore the nerve again [to see if something more can be done]. If we can manage something [like this], it is giving them hope. But, at the same time, I can't promise them [the impossible]. Once the time has passed to repair such a [damaged] nerve, it can be too late. I can't promise them [the impossible]! So, I have to be clear with the patients. I tell the patient: "We have a complication. Now, we are going to manage the complication. Not to treat the condition itself." So, this is the conflict that I face, and the patient faces with me, personally. (P87, surgeon, M)

In spite of all these accounts, it is not the surgical options and treatment expectations that form the core of these participants' concerns. What appears to cause the greatest stress among physiotherapists and surgeons is patients' expressions of grief for what has been lost and their hope that things can be recovered or restored "back to normal, back to doing a

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favourite sport, back to running." The fear of disappointing the patients seems to be the source that creates the greatest unease among participants since patients' hopes simply cannot be met. Essentially, they are talking at cross purposes.

Staff members are placed in an ambivalent state between the desire to restore what has been destroyed in war and feelings of guilt and inadequacy arising from the realization that the war irreparably robbed their patients of their dignity and future. Processing the emotions that accompany such an awareness is psychically costly and in addition, many physiotherapists and surgeons are convinced that "being emotional" would "not be professional." They think it would negatively affect their work with patients if this internal struggle were revealed.

This tendency to stay guarded and protective of ones' emotions is common in medical settings. The literature describes the fear of exposing strong emotions arising from patient/doctor communications and labels this phenomenon as the "Pandora's box phobia" (Hardee and Platt, 2009; Cushman, 2014). This phenomenon is defined as a "desire to avoid strong emotions, especially fear, anger or sadness," sadness being the expected emotion in the context of the RSP. Accordingly, the "Pandora's box phobia" results in creating barriers to empathic communication with patients and this seems to be a potential threat in the RSP.

Furthermore, the RSP at the time of this writing offered only a limited range of surgical interventions and related treatments. It is important to acknowledge that the RSP cannot fully respond to patients' hopes, not only because they are too "high and unrealistic," but also because there is a lack of sufficient surgical/medical expertise in the programme. For instance, no procedures considered cosmetic can be used in the treatment of burns at the RSP, and no joint can be surgically replaced, apart from hips. Providing patients with more information on procedures that may benefit them but that are not currently available in RSP, might help reduce the tensions which accompany the "mismatch in expectations." In communication with patients, uncertainty around medical and therapeutic procedures undoubtedly needs to be explained. Trusting the patients' capacity to deal with these uncertainties – remembering that uncertainty is part and parcel of any war context – is essential to this process. Also, acknowledging patients' hopes could bring some relief for both patients and staff.

Moreover, it is important to acknowledge that a patient's time in Amman does not always end with surgical interventions, let alone success. Sometimes "the injury is beyond repair or does not require surgical intervention," or the patient is "out of the programme criteria," or does not fit "criteria for anaesthesia." There are administrative reasons, such as issues with visas and

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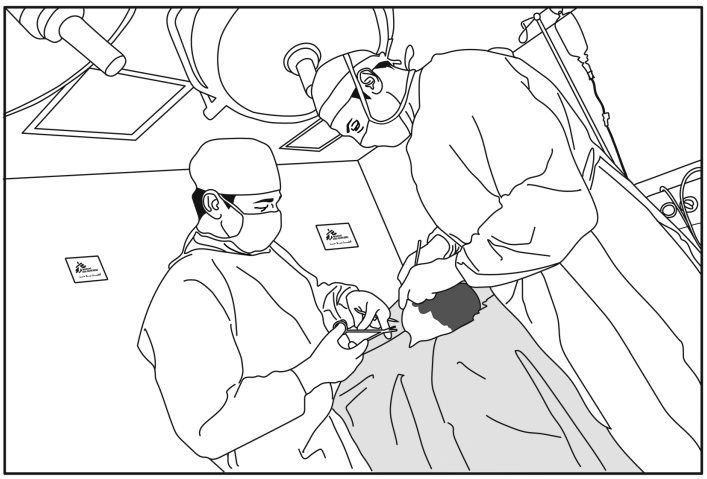

Figure 11 In the operating theatre. A surgeon and surgical assistant performing surgery.

passports that may hinder the process of obtaining care. Or the patients themselves might refuse treatment. Between 2013 and 2016, out of 2,902 validated cases at RSP, 454 (15.6%) decided to stop treatment before the treatment plan was completed or to not receive treatment at all (analysis of the patients' database, personal communication, Gilles Brabant, June 2018).

A twenty-year-old patient, for example, left the hospital and returned to Yemen. He refused to sign the treatment plan, explaining to staff that he "came to aesthetically improve his hand," but had been told that "they will remove the bone on his wrist." His hand looked relatively normal, but his wrist was slightly twisted and out of the hand line. He added that he was told that "the bone needs to be removed to improve the mobility of his hand." In considering his own hand, he commented that "my hand is mobile already." When pressed to clarify what information he had received about the surgical procedure before his trip to Amman, he confirmed that "they told me about the removal of the bone," but he "was not focusing enough during the information group session." He stated that during the session in Yemen he "was worried about his travelling and his family." He ended by stating, "I am very sorry for all the trouble, and I thank MSF for everything they have done for me. But there may be somebody out there who needs this surgery more than me." This case was an interesting one, and I wondered if he was disappointed in the lack of acknowledgement of his wishes despite the fact that he had expressed them.

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Perceptions of patients by the hospital staff

Patients perceived as passive victims

I observed a tendency to perceive patients predominantly as victims without agency and lacking the emotional tools needed to deal with the situation. This tendency was first indicated in interviews when I enquired "What is the first word association that comes to your mind when I mention patients in RSP?" "Victims" was the most frequently mentioned word, followed by "people in need," "humanitarian cases," and "misery." "Resilience," "strength," "courage," or "ambition" were only mentioned by a few when describing their patients. This was surprising considering that hospital staff observe patients starting a demanding physiotherapy regimen a day after surgery, or walking after having been brought to the hospital in a wheelchair, or receiving devastating news from home but remaining in the hospital dedicated to the programme. Such activities do not bring to mind victimhood.

A common phrase used when talking about patients in interviews was "We are emotionally supporting them because they need it." The predominant opinion saw patients as passive recipients of help, dependent on MSF and the hospital staff and without their own emotional means to cope. In reality, patients developed their own coping strategies regardless of their difficult situation.

Sometimes, projecting empathy was used to cover a patronizing attitude, and to impose institutional discipline. Several of the nursing staff, for instance, mentioned getting to know a patient's personality and then making adjustments in their relationship with them. This was partly communicated in the context of responding to the patient's needs and sometimes in the context of responding to the institutional need to make patients respect the rules, such as the restriction on smoking. Those patients who did not follow the rules were often labelled as "troublemakers," and the assumption that they should be compliant without questioning was prevalent. "This one is so naggy; he never stops asking questions" was an often repeated comment made by staff members in reference to a particular patient or a caregiver. One of the physiotherapists even reported "avoiding" particular "non-co-operative patients," at the same time justifying his attitude by saying that they "carry a negative energy, because they are victims of war." "Sometimes I try to avoid this [particular] patient," he commented,

> because, you know, we work with war victims. And the negative energy is around us, you know. You need to find the positive things, the positive energy [around you]. This non-co-operative patient is very negative patient. If we deal a lot with this [kind of] patients, after a while… At the end of the day, you will feel depressed and feel not [motivated]… Because I need to continue for

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> another five years [in this position], I try to stay away from this patient. (P29, physiotherapist, M)

This "non-co-operation," as the physiotherapist called it, may simply be linked to patients' disagreements with the therapeutic plan, a conflict that many of the physiotherapists reported.

The notion that patients pose a threat to the social order in the hospital if they abandon their "passive position" and become more "active" also became obvious when the hospital director, members of the hospital management team, and I tried to launch a patients' committee. The idea of the committee was that it would consist of patient representatives who would act as a communications body between the patients and hospital management. This patient-feedback mechanism would open a channel for patients to express their concerns and report potential abuses. I ran a number of focus groups to discuss the topic with the patients and collect their ideas on the organization of such a committee. The patients clearly communicated that they were in the best position to choose their representatives. When I reported this to the management team, one of them reacted very strongly and questioned if we were "attempting to start a new Arab spring in the hospital." Other members of staff were also reluctant to adopt this idea and tried to push an agenda where they would be the ones to select representatives from among the patients, "because they know them, so they would be able to select those that best fit the role."

So, on the one hand, the predominant association – patient as victim – triggered empathy among members of staff. On the other hand, this association caused patronizing and controlling attitudes towards the patients. A strong motivation in my research was to support the RSP's efforts to improve patient-centred care. But staff perceptions of patients worked against the likelihood that patients would be involved in decisions about their own healthcare.

Children: perfect patients, perfect victims

In many ways, children appear to be the perfect patients: innocent, resilient, motivated, and progressing well in their physical recovery. Their presence in the hospital certainly brought a vibrant energy. Children often approached staff with a spontaneous hug, a chat, a need to be comforted, or with an invitation to play. Despite the rules against it, it was not unusual to see paediatric patients in the office areas of the hospital, borrowing pens or asking for printouts of pictures so they could colour. Many children adopt the hospital environment as their own and confidently move between the rooms, hospital corridors, cafeteria, and outdoor playground. One of the expatriate

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staff mentioned the ease with which she developed relationships with children in the hospital:

> [Of all patients] I interact mostly with children. Of course, it's always easier [to develop relationships] with children. Some just look at you because you are Western person, or because you are a woman. So, they just stare at you like you are a kind of a lion, a star, or something [unusual] like that. So, of course, it's easier [to break the ice], because they go easily to you, they smile. It's very easy. (P98, manager, F)

When talking about paediatric patients, staff members from all hospital departments reported a soft spot for them. Even those who meant to keep their professional boundaries in check admitted getting personal when interacting with children. Not surprisingly, staff members frequently compared paediatric patients with their own children of the same age or gender and emphasized that "We are parents as well as medical staff" (administration and management, hospital support, and surgical departments, both male and female participants). "I have a story of two-year-old kid in the hospital. When I returned from my maternity [leave], she was one year and half old. My son was at the same age as her, so every time I saw her I started crying. She had an amputation," recalled one of the physiotherapists (P38, physiotherapist, F).

This association is combined with "children being innocent victims affected by politics," "just starting their lives," and "not being aware of the difficult future they will experience." In particular, children with burns and amputations cause strong emotional reactions. Hence, paediatric patients receive a lot of social interaction with staff and at first glance it appears that children and their emotional needs are the centre of everyone's attention.

But it was during my observations of medical procedures in the RSP that I realized that this was not the whole story. On one occasion I was present in the OT when a child was carried in by a male staff member. The child was crying in panic. In the absence of a family member to provide care, members of staff were trying their best to calm him down. They were unsuccessful, and it was only after he received anaesthesia that the crying stopped. On another occasion I observed a young girl who was already lying on the surgical table, obviously sacred and moving away from the nurses, who were trying to reassure her by saying, "It will be OK. You will get an injection and then you will just sleep." There was no recognition that this might not be a reassuring thing to say to a child who is about to undergo surgery.

The third time I witnessed a similar lack of capacity to prepare the child for what was coming was during a consultation in the OPD. A boy of about ten years old was there with his grandfather. The boy looked completely frozen with stiff body posture, no eye contact, and no response to questions. The staff

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members who were there tried to explain the procedure to him, but he pushed away anyone who touched him. After persuasion failed, the staff had less patience, and three of them grabbed him forcefully, held him on the examination table, and performed the minor procedure. He was crying loudly and trying to fight back. His grandfather, who was present, was completely unable to intervene or reassure the boy, either before or after the event. The boy was eventually labelled as "unco-operative." Later, the psychosocial team explained to me that the boy had shown signs of trauma upon his arrival at the hospital, but the staff who performed the procedure confirmed to me that they had not been told and were unaware of such a history.

Furthermore, children most frequently arrive at the hospital with their fathers as their single caregivers, and the men are often inadequately informed about what the programme expects from them. Very few children are accompanied by their mothers. The capacity of fathers to look after their children's physical and emotional needs varies. Despite nurses covering for those fathers who were less engaged, it was obvious that some children received very little support. Those who are abandoned by their caregivers and are not properly handled by medical staff during medical procedures receive no support of their basic psychosocial needs. Arriving at the RSP with underlying psychological trauma and then undergoing a highly stressful medical procedure puts them at severe risk of developing additional psychological symptoms (for examples of post-surgical trauma in paediatric patients, see McGarry et al., 2014; Papakostas at al., 2003; Lerwick 2013; Solter, 2007).

Paediatric patients appear to be the perfect "victims." Staff members, on the one hand, use them as examples to describe the most unjust aspects of war. And, on the other hand, they demonstrate that the insensitive and unjust treatment of children affected by war can continue inside a medical institution. It was not the lack of motivation that prevented the hospital staff from paying attention to paediatric patients, but there seemed to be a lack of the necessary skills for the emotional preparation and support of children throughout their medical and surgical ordeal.[2]

Negative perceptions of Yemeni patients

My next exploration was to uncover how staff and patients' origins played a part in perceptions and interactions. Many on the staff acknowledged similarities among all patients (Arabs, Muslims, war-affected); however, ideas about different nationalities in the hospital were quite distinct. The most neutral perceptions came from expatriate staff who were non-Middle Eastern – "We don't interact with patients enough to notice much difference" – and from the

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surgical team – "You don't notice any difference in the OT." But representatives from other hospital departments showed no reluctance in describing the "obvious" differences between Iraqi, Yemeni, and Syrian patients.

Furthermore, the hospital culture of stereotyping patients based on nationality is passed on to new staff members. One of the newly recruited physiotherapists told me that during her orientation to the hospital, colleagues on her team described Iraqi, Yemeni, and Syrian patients in stereotypic terms. This formed a persistent storyline in the MSF-run hospital in Amman. Let us now examine what these perceptions and stereotypes are.

The vast majority of participants described Iraqi patients positively and with a sense of admiration. Representatives from all the hospital departments described them as "more educated compared to others," "intellectually broad," "smart," and, as a rule, "well connected to the world." One of the nurses, for instance, commented, "The differences [with other patients] lie in the fact that the Iraqi patient understands what's said to him easily; his intellectual level is broader and more inclusive than the Yemeni's" (P6, nurse, M). This also extended to the idea of a patient having clinical knowledge, and in particular the medical, paramedical, and surgical departments commented that Iraqi patients knew and understood their clinical situation "in detail" and generally "have better health education." One of the nurses was strongly convinced of this: "Even when it comes to medical and surgical work, the Iraqi keep checking on their case on a regular basis and they disagree and discuss with the doctors. They always ask about the tests results, they ask about X-rays, they are more aware. Much more aware. They are educated, well-educated people" (P9, nurse, F).

The differences in patients' expectations were attributed to differences in medical knowledge. Iraqi patients were often described as "demanding" in terms of wanting information, explanations, and discussions with medical staff. One of the surgeons said, "Iraqis, I can say, are more able to understand the clinical situation. They are more suspicious because usually they read a lot about everything" (P55, surgeon, M). A few participants portrayed them as controlling, saying, "they make you feel you work for them." Despite this, the medical department in general described them as "easy to deal with," and by and large as willing to comply with the hospital rules.

Other common descriptions used of Iraqis by staff from all departments apart from surgical were "charismatic" and "proud" (of their culture, country, food, way of life). "In general, Iraqi people, they have their own prestige… Pride. They like to be treated respectfully and with elegance" (P30, physiotherapist, M). Sometimes this same attitude was described as a tendency to "show off." "Iraqis are proud of themselves and like to show off, but they still like to open their hearts to other people" (P27, hospital support department, M). Some Jordanian participants even described them as "more advanced" and having a "higher culture" than Jordanians, "They tell us they

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have more delicious food, better clothes and more beautiful nature. They always make us feel they come from a much better country" (P9, nurse, F). A tendency to treat Iraqis with more "respect, more formally/politely, with more elegance, and with more caution" was also frequently mentioned. One participant even commented that buying clothes with Iraqi children was different than with Yemeni children, as they were "pickier" and "needed more time to choose their clothes."

Iraqi patients were complimented by the medical department for their "good hygiene practices," their tendency to "take daily baths, frequently change clothes, and wear perfume [unlike others]." Less commonly mentioned, but still noted by the medical, paramedical, and surgical departments, was that Iraqis were "stronger than others," and this was expressed in terms of their physical strength ("strongly built, tall") as well as their emotional strength ("don't express their feelings, don't cry, able to deal with difficulties, courageous"). Their open-mindedness, "modern attitudes," hospitable nature, and friendliness were also praised: "Iraqis are always being famous for being extremely hospitable and generous and friendly… I would certainly say that an Iraqi is quite charismatic, generous, and friendly" (P41, expatriate, M).

When it came to describing Yemeni patients, the views expressed were much less favourable. In the hospital environment many Yemeni patients appear visually distinct due to their clothing (some wear traditional wraps around their waists) and/or due to their physical appearance (darker skinned, shorter and thinner body construction). I often observed Yemenis spending time together in groups, chatting or smoking outside of the hospital. Sometimes I met them in a nearby Yemeni restaurant, where I often shared lunch with my colleagues. I had an opportunity to interact with Yemeni patients more formally when I was collecting patients' views on the organization of an outdoor recreation space in the form of a focus group. Patient representatives from different nationalities participated in the group, and on those occasions it struck me that Yemeni patients appeared shy and agreed without opposition to what the rest of the group was suggesting.

Even before the formal interviews started, I regularly heard negative and disapproving remarks about Yemeni patients. The interviews only confirmed the scope and the nature of these negative comments. Yemenis were generally described as a unique group with little (or nothing) in common with Iraqi or Syrian patients: "Yemenis are careless about the hygiene, the appointment. When they have an appointment or a date at the OPD they forget it and they are also lazier. So that's the difference compared to others (Iraqi and Syrian)" (P4, nurse, M). The most frequently mentioned perceptions were that they have "weak hygiene practices," "uncivilized backgrounds," and "low levels of education." Staff also normally mentioned having "Difficulty understanding their language and way of speaking."

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"Poor hygiene practices" were associated with Yemeni patients by members of almost all hospital departments – paramedical, medical, hospital support, and surgical. "No habit of daily bathing, changing of clothes, regularly combing their hair." One of the nurses emphasized that Yemeni patients were not able to use a comb: "As for the hygiene practices, they don't bath on a daily basis. Some Yemeni patients don't know the comb [what it is], or how to comb their hair" (P6, nurse, M). They were considered "smelly and sweaty," and the fact that they were "not used to the Western toilets" was mentioned in this respect. The need to "force them" to take daily baths was also repeatedly cited by the medical department.

Yemeni patients were described as "uncivilized" due to their having "no schools, no streets, no technology, no electricity, no healthcare systems in Yemen." None of the participants made a link with the war situation in Yemen and the lack of public facilities. Yemenis were also described as "primitive," "simple," and "conservative." In addition, their culture and way of life were portrayed as very different from Iraqi, Syrian, or Jordanian societies. In this regard, comments were made about "making children wear hijab," "marrying at an early age and during the first date," and having stricter gender rules. Their way of eating ("mixing the food together and eating with hands") and their way of speaking ("they speak fast and loud") were also expressed as culturally inferior. The less common negative comments faulted Yemeni patients for being "lazy," "not ambitious enough" with regard to physiotherapy, "not compliant," "not honest," "suspicious," "careless about themselves and their children," addicted ("which is in their nature") to khat,[3] and "nervous/aggressive." These perceptions were expressed particularly by medical (nurses, doctors) and paramedical departments (physiotherapists, health educators, professional carers, psychosocial team members).

The general assumption was that Yemeni patients were "poorly educated," which includes perceptions of "poor health education," as reported by all hospital departments. Participants sometimes attributed the low level of education to Yemenis being "hard minded," "quick to forget," "child-like," "suffering from weak logic," and "having low IQs." One of the physiotherapists, for instance, stated: "The one who's not compliant is the patient who's usually really having low IQ, coming from very tough environment. Like we have patients from Yemen living in mountains, they have no contact with civilization, they still don't care about what's [happening] the next day" (P36, physiotherapist, M). One of the nurses had no hesitation in commenting how difficult it was to deal with Yemeni patients due to them being "hard-minded": "Yemenis are hard people, yes, hard-minded. Yes, they are really hard-minded. It's not easy for you to deal with them" (P18, nurse, M). These negative connotations were mentioned by both male and female

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members of medical and paramedical departments, and all of this was further linked to Yemenis being perceived as "challenging" compared to other patients. For instance, staff mentioned the need to "repeat things to them several times," that "dealing with them takes longer compared to others," and that there was a "need to reinforce rules with them."

When I looked into the actual education level of Yemeni patients, the perception of low education proved to be incorrect. In the database of patients' electronic medical records, where the level of education is reported (based on 242 entries, between April 2017 and March 2018), Yemeni patients were on average more educated, with more than 50% attending secondary school, than Syrian or Iraqi patients, of whom more than 50% have only a primary-school education. The level of university education was comparable for the three groups (Iraqi: 9%, Syrian: 8%, Yemeni: 8%). These surprising numbers show how little information the hospital staff actually had about the patients, even when dealing with them on a daily basis, and how their negative perceptions of Yemeni patients remained unquestioned.

The most positive descriptions of Yemeni patients had to do with their demeanour. The point was made that they were "extremely thankful," "kind-hearted," "pure," "sweet," "gentle," "sociable," "respectful," "honest," and that they "have a good sense of humour." This type of comment came most frequently from administration and management and surgical departments, and it was striking that none of the surgeons commented on poor hygiene or low IQ among the Yemenis. Participants from all departments other than administration and management perceived them as "inclined to accept everything, without complaining" and being "the most appreciative and forgiving" of all the patient groups.

Often the challenge in communicating with Yemeni patients, as explained by the logistics, medical, and paramedical departments, was attributable to linguistic barriers. Yemeni Arabic is considered a conservative dialect cluster with many classical features not found across the Arabic-speaking world. It is considered significantly different from the Arabic spoken in Syria, Jordan, or Iraq. The participants were unsure if they correctly understood Yemeni patients and vice versa. They reported having to seek help from caregivers or other Yemeni patients in an attempt to translate what the patient was communicating.

One of the Yemeni members of staff pointed out that some Yemeni patients "feel ashamed to say, 'I don't know' or 'I don't understand.'" He further explained that a Yemeni patient "will feel like he should say 'yes' regardless of his understanding, so he won't say 'No, I didn't understand.'" I witnessed this when following one of the nurses on her daily routines. She visited with a Yemeni patient and started explaining the pain medication he

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was taking. At the end of her clarification, the patient asked a couple of questions and thanked her for an explanation. He confessed that he "didn't understand what they were telling him during the surgical round." When I enquired how the medical staff ensured that Yemeni patients understand them, one of the participants mentioned that "he reads this in their eyes." These accounts indicate that communication between hospital staff and Yemeni patients is compromised, which raises the question of how much medical information remains uncommunicated or misunderstood. Furthermore, Yemeni patients seem reluctant to ask questions and do not debate the decisions of their healthcare providers.

In my observations, a Yemeni staff member was always called upon to mediate between Yemeni patients and other staff when a misunderstanding occurred. This staff member was asked daily to "speak for" the Yemeni patients. He would "explain treatment plans and make patients agree on them," sort out disputes, deliver information, and comfort patients whose family member had died, or try to convince other members of staff to "believe what the patients were saying" if they felt suspicious. Without this particular staff member, Yemeni patients would have remained voiceless.

When participants talked about Syrian patients, it was in a more dispassionate tone than that used to describe Yemenis and Iraqis. To a certain extent, staff saw many similarities between Iraqi and Syrian patients, but the Iraqis still held the most positive place in their hierarchy. Syrians were talked about with less of a sense of fascination, and it was a narrower sample of departments that had positive views. Still, Syrian patients were described as "open minded" and "well educated," especially in relation to Yemeni patients, and they were seen as generally easy to deal with due to their cultural proximity to Jordan in the use of the Arabic language, food, dress, habits, and technology. Jordanian staff members in particular brought out the similarities they felt with Syrians. One of the members of the psychosocial team, for instance, stated: "The cultural things in Syria are the same as here in Jordan. Because they are very close to Jordan, it's not far from here to Syria. To Syria you can go by car; you can go by bus or anything. So this is the effect of [geographical] proximity on the [proximity of] culture. And they can adjust with all cultures, the Syrians can [unlike others]" (P57, psychosocial department, M). One of the nurses made a comparison to Yemeni patients, adding: "I understand everything he says. As for the culture, their clothes, the way they treat others are all very close to us. They're closer to us as Jordanians, more than the Yemeni, much closer" (P9, nurse, F). Less frequently, Syrians were described as "easy to adjust, having good acceptance of their injury, having good compliance with medical recommendations, the most united as a community of patients, easier to express pain, hardworking, technologically advanced and generally sociable."

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The medical, paramedical, and surgical departments held some negative perceptions of Syrian patients, commenting that they were "demanding" – for example, "asking for additional explanations," especially if they faced surgical complications. A few participants also mentioned that they "complain a lot" and are "the least satisfied with treatment." Other participants from the paramedical and surgical departments commented that Syrian patients "are not honest when they report their medical complaints" – they are seen as using their complaint to extend their hospital stay.

Patients transforming the "self"

Al Mowasah hospital is a cultural melting pot. Regardless of nationality, similar age groups frequently mix together smoking, chatting, playing table games, or relaxing in the hospital outdoor area. Yemeni patients seem to spend more time in the company of their own countrymen, but the effect of the cultural blending was most obvious in relation to them. Younger male patients wearing traditional Yemeni clothes on their arrival at the hospital soon replaced them with jeans and a T-shirt. Their haircuts also became more daring over time. This may have been an effort to avoid the widespread negativity about what are perceived as traditional Yemeni characteristics, but the neutralization over time was unmistakeable.

What was seen as a cultural transformation was praised by some of the staff members interviewed. Yemeni patients were described as "open to new things," "willing to change," and "all of them eventually adapt to the new culture." In particular, participants highlighted a desirable tendency among Yeminis to accept "Iraqi culture" (for instance, "all children enjoy dancing Iraqi dances, even the Yemeni," and "Yemeni patients start speaking with an Iraqi accent"), and members of staff were pleased to report that Yemeni patients over time "become more modern" and "improve on their style." One of the participants described that "They became really nice people using laptops, using social media, everything and improving their dressing style, compared to the first time in the hospital, when they were really not well dressed." This participant further added: "We are supporting them culturally and from the style point of view" (P54, M). One of the nurses described how she intervened when she saw a Yemeni girl wearing a hijab and long dark dresses "at a young age." The nurse proudly described how she managed to convince the girl's father to replace his daughter's clothes with "something more colourful, adjusted to her age" (P3, nurse, F). This indicates that some staff members eagerly participated in the cultural transformations.

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The transformations that occurred in the hospital were not only cultural. I observed a fascinating process through which patients gradually transformed how they portrayed themselves to the world. The behaviour of female burn victims from all nationalities rapidly changed during their time in the hospital. Some of them had large deformities on their faces, necks, and hands such as contracted skin, depigmentation, and a rough appearance. Upon arrival at the hospital they were shy and guarded and made obvious efforts to cover their scars. They also tended to spend more time in their rooms. Over time they left their rooms more frequently, exposed their faces, wore makeup over their scars and generally acted with greater self-confidence. Two weekly events organized by the psychosocial team exclusively for female patients contributed to these changes. I observed the so-called DJ parties. These women-only parties happen behind closed doors on the fourth floor of the hospital. Lively music plays from the recording machine, and the female patients who gather are dressed up. Some of them take off their head scarves and dance energetically. They certainly seem to be freer with their bodies. Another event that perhaps also supports female burn victims in their transformation is the weekly shopping they do together at the local market. The objective, as explained to me, was to expose the women to the public so they could work on social acceptance. Female patients who go shopping together walk out of the hospital looking confident and empowered.

Thus, the hospital provides a closed and protected environment where a patient can develop and adjust to his/her new self. Group pressure, from both fellow patients and staff members, to "appear less Yemeni" has an impact on the Yemeni patients, and group support for female burn victims helps to foster new identities for these women. With so much time spent restoring their bodies and emotional health, it is consistent that the hospital and the patients would make an effort to develop new social identities. What is the result of such a transformation after the patient returns home? This question remains, and we will explore it next.

Notes

1 As the part of legal requirement in Jordan, the hospital has an equipped emergency room. Emergency cases managed at Al Mowasah hospital, however, are rare.
2 The lack of skill in paediatric patients' management was, decades ago, common in hospitals worldwide.
3 The leaves of a shrub which are chewed as a stimulant.

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3

Patients and their history

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Thus far we have seen that war-injured patients do not use the hospital environment only to fix their bodies; they also attempt to reconstruct their emotional wellbeing and their sense of social identity. To fully understand the scope of the recovery they are seeking, we must have a closer look at their pasts, and at the events related to their injuries and the treatment they received before entering the MSF hospital. Different staff members shared that they could only acknowledge a patient's personal history in a way that made sense for themselves. Some who were not involved directly in patients' medical care were willing to offer a compassionate ear; others thought that learning about a patient's medical and personal history was necessary to be able to provide medical care; and others, in an attempt to protect their own emotional wellbeing, avoided hearing more than what they perceived was absolutely necessary for medical decision-making. Inevitably, the heaviness of what my participants reported on touched the world of human emotions.

Hearing patient stories, particularly the way they framed them, provided insight. Their stories were statements on the brutality of war, described not only as direct violence, but also as an undeniable change in the social environment making it impossible to access proper medical treatment. Let us start with the narrative of a Syrian patient, who I call Ali. He described how he was injured, how his situation after the injury gradually deteriorated, how risky it was to access medical care in Syria, and how he eventually entered the MSF hospital. Not only was his narrative informative: it was enriched with comments from his family members, who indicated the larger impact the injury had had on all aspects of their family unit. The grandfather emphasized how "they [the injured] were still teenagers when they shot at them"; the father expressed his pain when he found "the pieces of bone on the clothes they brought him as a proof of his son's injury"; the mother worried when her son called her but "the line was closed" (it went dead). Through this narrative, it is important to keep in mind that patients carry a double burden: their own injury and the disruption of the family environment caused by their injured body.

Ali's narrative

[Participant (P)[1] speaks in a calm tone; grandfather and participants' parents occasionally add details to the narrative.]

P: The situation in our village was complicated. One day before my injury happened, there were demonstrations, and they killed a number of people. The next day was normal. We went to school. We were there for a half day, then the teachers told us: "You should go home. There is demonstration near the school. You should go back home (it is dangerous)." Because the teachers were concerned about us. They knew that people [army] would come to mess with the demonstrators and there will be shooting. [They told us] "It's for your own sake." We really left the school and wanted to go home. We were a group of pupils and the teachers were with us. Once we went out of the gate and walked for 50 metres, there was shooting. The army came and they didn't distinguish between the young and old or pupils and teachers: they were just shooting. They started shooting everyone! They didn't want to have people gathering in the street.

Grandfather: There was random gun strike.

P: The shooting was [carried out] randomly.

Grandfather: Wherever they shot at, they shot. [They shot] the old [person], young, boy, child, or woman. His [my grandson's] friend got injured in his leg. When he collapsed, they shot him again and killed him.

Mother: The shot was in his head.

Father: That was the regime army [shooting at them].

Grandfather: In his head [they fired the final shot]! He [grandson's friend] got injured in his leg first and fell down. Why couldn't they just leave him alone?! But, no they killed him!!

Mother: They followed him [to kill him].

Grandfather: He was a school student at his [my grandson's] age. He was [only] fourteen years old.

[Father searches for a video on his phone; shaky video shows teenagers running and sounds of screaming in panic. One of the teenagers was recorded when falling down on the ground, with an obvious bleeding wound in his chest.]

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Father: There is a video on YouTube that was taken when my son was shot. [comments while showing us the video] These are the school students. They are wearing the school uniforms. This is when my son was injured. This is his voice [a voice screaming on the video]. All the people who were there had mobile phones and they were taking videos. They sent it to Orient TV channel.

P [continues]: I was shot in the right leg. Then there was a large number of people who were running away. Some of those people carried me and took me away from the street. Because their [the army's] goal was to kill. When the army saw people carrying us, in addition to the shooting they asked around for the assistance of people to collect our names, the names of all injured people. They knew our names in five minutes. They knew our names! There were me, Omar, and other injured people who got blacklisted. It was only the matter of a moment when I got injured and then carried away [and they managed to collect our names]. One couldn't wait for one minute! People who helped us took us to their houses and moved us from one house to another to be away from [the army] because we couldn't go out to the street [we were under severe risk]. There was no time at all! They [the army] could come anytime, and it would be risky not only for us, but also for the owner of the house.

Immediately after the injury they let us take off our outfits and they tied them around the injury – [this was the only first aid] there was no doctor to assist us. They took out a fridge door and let me lie down on it. And they took out a window that was serving as an opening for the passage with the next house. They moved us in this way [from house to house] until we were on the other side of the village. They brought a car and took us to a farm. And here, a new episode [of struggle] has started.

Grandfather: He was bleeding!

P: We were prohibited from going to a hospital. Because it was very risky. 90% of the people were killed there. What would people do to us [in the hospital, we wondered]? It was dangerous even for those who were hiding the injured to stay at their homes. So, they [people who helped us] were transferring us from one house to another [to reduce the risk]. There was no other way

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than moving us between the houses but through narrow passages between the buildings. They [people who helped us] were thinking of how to let us run away. I didn't know them [but they were willing to help us].

Father: We didn't know where he was for fifteen days. We knew that he was injured. They brought us the clothes he had on when he got injured. But, we didn't know where he was. There was a piece of bone remaining on the clothes because the shot was an explosive one. There were blood stains on them too.

Grandfather: There was no bone left in his leg. Everything was destroyed in the explosion.

Mother: There was no first aid in the houses [where he was hiding]. Only later he received the treatment. All the movements were without him receiving even first aid. The houses [where he was kept] were just a mean of getting him out of the village that was under siege.

P [clarifying]: For the first fifteen days there wasn't [any first aid] in the houses. We didn't think about receiving anything, not even painkillers. We only thought about how not to die [how to survive].

Father: The main concern was: "We must put him far away from the army." The people of the village are like one big family. They all know each other. They know whose son was killed and whose son was injured. They immediately inform each other [so we knew he was injured]. It was in the midday when he got injured…

P: They [people who helped me] wanted to provide the treatment for us. They took us to a nearby village that was quiet [not under siege]. There was no first aid available there. I had bleeding and the foot was swollen. They [people helping us] called for a doctor from another village to check on us because they were friends with him. He looked at us and said: "I can't do anything. He needs to go to the hospital. He certainly needs [to go to] hospital! What can I offer him [I have no means to treat him]?" He [the doctor] couldn't do anything. They took us to another village and then again to another village; that was happening for eleven days. No doctor could do anything for me. Doctors just told people assisting us that we needed a hospital and nothing could be done otherwise.

Mother: Medicines and painkillers were provided at that stage.

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P: Yes, they gave me medicines and painkillers that they had available. But they didn't know what to do for eleven days [the wounds were too severe]. They cleaned the blood from the wound and gave me painkillers for eleven days. We were moved to eleven villages, eleven areas – and that was risky! They moved us in a closed car through the groves. There were checkpoints on the main streets so we couldn't use them. We were travelling through the groves. And, our screams were [expression of severe pain; participant pauses and looks into the distance].

[continues] There was no family member was with me yet. We travelled through the side streets. They put us to the car and there was a person driving us. He would take us to a village where he knew people, so that we could find a doctor or a hospital. But we couldn't be at the big governmental hospitals.

Father: That was impossible.

Mother: They [the people helping him] asked my son for our phone number. They called me… His father was away… They told me, "Your son is good. He wants to talk to you." He just said: "Hello, how are you? I'm good." And he closed it. And when I called back the same phone number, nobody answered me.

Father: All the phone lines are monitored.

Mother: Because all the phone lines are monitored.

P: Then they took us to a village called Harra, in Deraa. A doctor came and cleaned our injuries from the dirt. The legs got swollen a lot.

Father: The injury was rotten [infected]. The injury was rotten!

Mother: He had infection in the blood.

P: He [the doctor] told people looking after me: "We should take them to the hospital in any way. No matter what we do [it won't help]! We should take them to the hospital! They [the injured participant and others injured] shouldn't be left like that." They coordinated with my father because he was still working. He could find a route for us. He could let us pass the checkpoint without them inspecting the car. The doctor coordinated with him to get us to the hospital.

Father: It was a private hospital in Damascus. We paid money so that the staff there wouldn't say anything about him [report him to the army]. The first hospital where we

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treated him was called Jaffa Hospital, in the area of Mazzeh. Of course, it was a private hospital and therefore there was a possibility for preventing the regime knowing about him.

P: There was the connection my father used for the route [access to the hospital]. We paid money for the doctor and the medical staff to let us in the hospital without having anyone know. They did the surgery. I woke up from anaesthesia at home. It was prohibited to stay in the hospital [for long].

Father: We paid a big amount of money just to let him go into the hospital for one hour to have the surgery. He had a surgery of cleansing [the wound] and inserting a metal plate, and he was discharged in one hour. We took him home when he was still under anaesthesia.

P: The money which was paid was to prevent reporting me. They [the hospital staff] had instructions to report to the security, police, or army about any injured person admitted there. There was another amount of money [paid] for the medical care. The two amounts were equal to each other.

Father: The amount of money was 4,000 USD for one hour [in the hospital] so that they don't report him to the security. That was in addition to the 4,000 USD for the surgery of fixing the internal device [fixator], which they call nails. People who could not afford such amount of money just ended up with amputated legs! The hospital would not even receive you if you didn't pay.

Grandfather: In such cases they would just amputate [somewhere not even in the hospital]!

P: My memory from the hospital is that I went into the OT. I woke up at home.

Father: Yes [we were together].

P: Then we went to my uncle's place. We couldn't go back to where we were living.

Grandfather: We hid him [at the uncle's].

Mother: We hid him.

Father [explaining]: In the period after the surgery, we couldn't go back to the village. We found a safe house in Damascus. This was under my supervision… It was my brother's house. We let him stay there until we could coordinate our trip to Jordan. We started thinking about this only in that period. It was because we saw others. The injured person was either

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dying slowly [from the lack of medical care] or killed. There were inspections in all the houses, checkpoints on roads, and they took any injured person they found [and killed them]. I used all my power and potential connections just to let him out because he was injured [and under severe risk]. But the normal people [those not injured] could cross the regime checkpoints with me [without any problem]. But that was impossible for the injured one. We had to take roads that were…

Grandfather: Side roads!

Father: Not regular streets, but through the groves and bystreets to let him escape. It took us six months until we could coordinate his way out of Damascus to the Jordanian border. Six months! In the period, [uses son's name] had a disease in addition to the injury. He suffered platelet infection; he had infection in the blood. He had another surgery in Damascus that was done at home [in the uncle's house]. He had a surgery of transferring blood at home! The doctor removed the external device [fixator] for him. He fixed the internal plate during that time. And he treated the blood infection during that time.

P: There was a doctor that we didn't know – [we knew] his name only. We called him Mohammad, Dr Mohammad only. He used to come to my home. He certainly didn't come unless it was very urgent. He did the surgery for me by himself; there was nobody with him.

Father: I was assisting him because he asked me to. As I'm a father, he was afraid I would collapse [faint] and couldn't bear it. But I was strong enough and assisted him.

P: When I recall the event, the doctor came and told me: "I have this injection that would let you sleep for half an hour. Tell me once you feel dizzy. Other than that, you will feel the pain. And I would remove all the device [fixator] for you."

Father: There wasn't any other anaesthesia. My son needed blood during the surgery, and by coincidence the doctor's blood type was like his. He donated blood for him. After the surgery, we certainly were not brave enough to throw away the waste from the surgery or the blood waste in the garbage container that was close to home. We threw them away in a far place. Everything was difficult [extremely risky].

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[continues] After that period we were able to leave Damascus for the Jordanian border. I had another brother who was an officer; we coordinated with each other. Because if I left the army, he would have been killed. So we informed all my siblings about the plan of leaving Damascus and going to Deraa [southern Syria, border area with Jordan]. Our [target] village was away from the regime control. We coordinated with my relatives and came altogether to the Jordanian border. That was of course through side streets in the groves. We came to a deep valley that is an area between Syria and Jordan. My brother and I carried him [the patient] on our backs when we entered Jordan. It was 100 kilometres from Damascus to the border; those 100 kilometres took us two days (that is how slowly we were able to move). When we reached the Jordanian border everything was done for us to enter. We just waited at the spot controlled by the Jordanian army at the Jordanian border. We waited for twelve hours until they could receive us.

P: I couldn't walk at all at the time. This was happening a couple of days after my surgery in Damascus. I had painkillers [to control the pain]. My mother, siblings, and I went to Al Za'tari [refugee camp]. We stayed there for one week then we left it.

P: When we arrived in Al Za'tari…

Father: We said, "We wish we had stayed in Syria."

P: But, when we left Al Za'tari, the situations changed [improved there gradually]. Al Za'tari wasn't Al Za'tari as it is today. There were only a few tents at the time we got there.

P: I received no medical care before entering the MSF hospital. There were only a few stitches in my leg that I had removed [before].

Father: A few stitches? They were forty-one [stitches]! I was taking them out.

Mother: We were also assisting, his uncle and me. All the family [was participating in the removal of the stiches]!

Father: By then, I was medically trained for everything.

[continues] By chance we heard of MSF. When the Syrians arrive here to Jordan, they try to look for another Syrian to ask him "How is the situation? Where shall we reside? Where shall we rent a house? How shall we live?

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> How shall we get things? What could get us income?" One tries to ask a Syrian because he's from his home country and has come here before. There was a person who told us, "There is a French organization that's called Doctors without Borders which was in the Red Crescent [hospital] in Al Mesdar area in Amman. Go there." There was a nurse whose name I remember: it was [gives a name of the nurse]. She was extremely humanitarian. She was a very good human. I always send my greetings to her. Her name was [gives a name]. We went there. We took [uses the name of his son] and the papers and applied. They immediately admitted him. And I send greetings to Dr [mentions the name], as well.

Ali's story reports on multiple losses: of his health, social identity, loved ones, material objects, sense of security, and trust. His narrative was in many ways similar to narratives of other Syrian participants, but unique in comparison to the Iraqi participants I interviewed. Let us have a closer look at the difficulties and risks patients encounter before they can reach medical care at MSF.

An injury that changed life forever

The participants were injured in numerous ways. The majority of those from Syria were injured during air or ground bombing (twenty-one participants), while thirteen received a bullet wound. Two were victims of domestic accidents (burns), one was injured in a suicide attempt (self-immolation), one in a car explosion, and one fell accidently and suffered a bone fracture when she was a caregiver in Amman.

Iraqis were mostly victims of explosions (seventeen participants), in cars, buses, in front of a police station, a school, or a military checkpoint. One participant was the victim of a sticky bomb,[2] which was placed below his truck. Another was injured when an explosive device was thrown into the coffee shop where he was playing table games with his friends. And another was injured when a suicide bomber blew himself up during a funeral. Nine were injured during bombing raids, both from the air and on the ground; three received gunshot wounds; two were victims of traffic accidents; one stepped on a ground mine; and one suffered burns in a domestic accident.

When participants talked about the circumstances of their injuries it was obvious how vivid their memories were and how much emotional turmoil the memories still caused. The sense of horror, panic, and numbness was

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tangible during interviews. There was a big difference in the tone of the narrative between Syrian and Iraqi participants. A deep sense of sorrow and grief was communicated by Syrian participants, while Iraqis mostly expressed feelings of anger and frustration.

The narratives of Syrian participants were long and detailed; frequently they started by describing the change of political climate in Syria, before moving to the changes in their neighbourhoods, and finally to details of the day they got injured. Dates[3] and hours were frequently mentioned. For instance, "It was 6am or 5:30am and we were still sleeping. I woke up to prepare myself for work" (RSP2, Syrian, F). This indicates that their memory was made indelible by the intensity of events and then narrated as if the incident were happening in the moment. An exception to this was a participant (RSP4, Syrian, F) who had no injury-related memory. She described completely blacking out. She said that her only memory is that "they were running away, there were many people on the street and blood everywhere," but she recalled no details of how she got injured or how her husband died there.

Iraqi participants talked about their injuries as "the event that changed their life forever," because "I lost everything in my life": health, house, a family member, limb, economic stability, opportunity to continue education, sense of security, future, hope, self-confidence, trust in humanity, beauty, marriage. But in contrast to the Syrians, their narratives were briefer and were articulated as a single event rather than as a series of events. For instance, "We were in a wedding party and an explosion happened." Participant's husband: "It was a car bomb" (RSP41, Iraqi, F).

Narrative style gives some indication of how a participant frames, understands, and feels about the event of an injury. Hence, the differences between Syrian and Iraqi participants suggest more detailed and intensive traumatic memories among Syrians. These observations are in line with the studies of recall of traumatic memories, which can either be detailed, accurate and persistent, or totally absent due to "traumatic amnesia," a condition that can last for years after traumatic events (Van der Kolk and Fisler, 1995). According to the literature in psychology, the framing of traumatic events acts as a determining factor in the levels of war-related psychopathology and can still persist fifty years after the experience in war (Kraaij and Garnefski, 2006).

Experience of pain was largely absent from the patients' narratives. Most participants did not mention pain at all when talking about receiving their injury, nor did it come up in describing their treatment – unless I probed them with a question about access to pain-relief medication. When they did mention pain it was often placed in a mix of descriptions of physical and emotional pain – for example, grief over loss of dear ones, property, and country. Many of the participants (both Syrian and Iraqi) reported losing children, spouses, parents, grandparents, brothers, sisters, cousins, nephews,

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and friends during the same incident that injured them. The way they reported it, the experience of emotional pain clearly exceeded the level of suffering caused by their physical pain.

During the injury event, many participants reported feeling completely numb, especially if they had witnessed an injury to somebody else around them. The narrative of a father illustrates this:

> I didn't feel anything, but something hit my leg and hand. My son was sleeping beside me. He was just beside me lying like this [indicates a short distance from him with a hand gesture]. He was bleeding from his mouth. He was about to die. And I couldn't do anything. I lifted him and wanted to get him out; he got injured in his back. A shot passed through his shoulder and it hit his hand. I went out and my leg was bleeding. (RSP6, Syrian, M)

Some participants kept material evidence of their injury event and they would show it to me. Two of the participants – Ali was one of them – showed me videos recorded on their phones of events where their friends had been killed in front of them. Another video showed the dead body of a young man who was my participant's friend. His face was covered with blood, he was lying on the ground, and a piece of metal was coming out of his skull. I was told that he was hit by a piece of shrapnel from a mortar shell. In both videos, the people recording them mentioned the exact date and the name of the person killed. As Ali's father reported, they had passed these videos to the media as evidence of war crimes. Other material evidence that participants occasionally showed me included metal bone-fixators that had eventually been taken out of their limbs during surgery. One family had them packed in a transparent plastic cover and stored in the cupboard of their living room.

Views on perpetrators

Without being directly questioned by me, the vast majority of participants shared who had caused the injury. In this way they politically positioned themselves, but also disclosed how they perceive their perpetrators. Syrian participants, for instance, made statements referring to Bashar Al Assad, such as "He wants to finish us all," or "the government army has done this to us," or "we were scared of government military." The context in which the army was mentioned was typically as follows: "We were staying in an area called Al Mahatta, which is the new Daraa [southern Syria], and there was another area called Daraa Al Balad [Daraa downtown]. There was fighting between the two areas. We went there to check on the injured people and give them the first aid. Then the army of Bashar Al Assad shot at me" (RSP8, Syrian, M). None of the participants from Syria referred to

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ISIS as a source of injury, but some mentioned Iran as a source of political conflict.

Iraqi participants were mostly injured in random explosions. Hence any reference to the perpetrators was absent or presented more loosely. Those who were injured during sectarian violence, however, either by the US Army or by ISIS, specifically mentioned that. Those in Iraq who were injured during sectarian violence indicated personal knowledge of their perpetrators, making those accounts some of the most painful that I heard: "These people were from our community; they knew us." These participants were the ones who generally expressed the highest degree of fear and suspicion against us, the interviewing team, which indicates that their general trust in human beings has been severely damaged by events.

US troops were mentioned in patients' narratives as ruthless. "During the US invasion, a bomb exploded near my secondary school, in the area near Muhammed al-Qassim Street between Sileikh and Adhamiyah [the highway to the west of Baghdad]. At that time US troops were still in Iraq, and after the explosion, the forces opened fire randomly at people who were there so even those who hadn't been injured in the explosion were injured by the US attack" (RSP56, Iraqi, M).

Or another example:

> So once I was driving, and the US Army was deployed in the area. All I knew is I got shot by a bullet while driving. I knew afterwards that I was shot from a distance of 300 metres. The US Army had written in their report that I crossed their checkpoint, while there wasn't actually a checkpoint and I was shot from a far distance and I wasn't near them nor did I see them. They did not give a warning [such as] a bullet in the air, nor a bullet in the car or its engine as a warning sign. The bullet was intended for me as a target, aimed to KILL me. (RSP71, Iraqi, M)

Some other participants clearly identified ISIS as a causative agent in their injury: "I got shot by ISIS" (RSP59, Iraqi, M), and "We were sitting like this [like us in a living room] at home, and across the river – the river you've seen when you came here – at the other bank there were the terrorists of ISIS. At 3am they crossed the river to this bank [where the patient's house is], and they attacked this area. There was fighting here and my son got injured. It was a mortar shell that fell on our living room" (RSP60, Iraqi, M). Those who indicated they were injured by ISIS (participants from Anbar) appeared cautious and talked about the incident in whispers. In comparison to those injured in sectarian violence, they did not express a high degree of mistrust towards myself nor my team.

What was surprising, however, was a lack of anger, blame, or any kind of resentful emotion towards the individual that specifically caused the injury. For example, the participant who received a gunshot from an American

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soldier and later met him in the hospital expressed no harsh feelings towards the perpetrator at the time nor at any later time:

> I saw the one who shot me [while I was] in the hospital. He was a kid; he was trembling and shaking [when he saw me]. Maybe he was about nineteen years old. The damage was already done. I was only thinking about myself [and how to get better] at that moment. Even if he would come to me now, there's nothing I would do to him, I would not tell him anything [harsh]. It's up to God to make him pay back. (RSP71, M, Iraqi)

The narrative of another participant, who got shot by while working in his field in Syria, illustrates how he too remained "neutral" when talking about the soldier who fired the gun against him. The only reference that this participant made to account for the soldier's violent act was simply "not knowing what was on soldier's mind." This participant appeared almost apologetic when he explained the necessity of using his motorbike to work in his fields, which in his opinion triggered the shooting. A larger segment of his narrative illustrates his interpretation of the event:

> The injury happened on 22.6.2012. I had a farming project that was across the highway. It was (relatively) far from the highway. It is a double lane highway; the cars never stop there. The highway was the main travel route for everybody [in that area].
>
> On 22 June it rarely rains. I am a man [a farmer] that planted ten acres of potatoes, and thirty acres of cucumbers. I planted twenty acres of watermelon. I planted fifty-five acres of tomatoes. In addition to that, we wanted to use an opportunity and double the planting project. We planted eggplants with cucumbers. We planted tomatoes with watermelon. We planted bell peppers with tomatoes. To benefit [from this], I planted one hundred and ten acres in that way. We planted the same amount as would otherwise be planted in two hundred and twenty acres. We had better products this way. This is what was happening to us.
>
> On 22 June I collected cucumbers with the workers. I had thirty workers. We collected the cucumbers and it started raining. And it rarely rains at that time. It rarely rains on 22 June. It rained. When we send the cucumbers to Damascus, it should be shiny and clean. It shouldn't be muddy. Nobody would buy it if it was muddy. It should be clean. You should pick it up in the morning and there should be no water on it. I remember it rained on that day. But I collected cucumbers [we were in a hurry to harvest them]. I went [there to the field] towards the end of the project [harvesting]. I saw a village that was three kilometres away from us which is called Mahajjeh. It was two and half or three kilometres away from me. There was fighting in it but I didn't know between whom. I heard shootings and bombings. The workers were afraid. I told them, "Be patient! Let me prepare the delivery. Be calm. Be patient. The situation is fine. It will be solved now." Then, I suddenly saw a group of tanks and soldiers' cars and BMB [vehicle type used by military] crossed nearby us on the highway. They crossed nearby us. My brother who is in the US [now], my three

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> sons, my two nephews, and the third brother and me were there. I told them to pretend they were collecting the potatoes so that we avoid them [the military]. The potatoes were the closest to the road. It was right next to the highway. They [my family members] turned and went away fifty metres away from me. Fifty metres away from me! My three sons, two nephews, and my brother were obliged to be next to the road [harvesting potatoes]. I went fifty metres away from them. Why was I away from them? Because I had a motorcycle. They [the military] didn't like that motorcycle. They were bothered. The one who had a motorcycle was a terrorist [in their eyes]. The [planting] project needed a motorcycle and it wouldn't work well without it. A car wouldn't work well. There were narrow paths [between fields] that couldn't be driven on by a car, but only by a motorcycle. The project was big. When it is of one hundred and ten acres, you are forced to have a motorcycle. I went away from them and started collecting potatoes. That military man thought I would bomb them [do something harmful to them]. I don't know what happened to him [what was in his mind]. He got further from me and shot me twice! I was shot. He shot me twice and I got injured by one shot. (RSP13, Syrian, M)

The multiple losses my participants reported carried no personal blame for the perpetrators; the blame was collective. This was important for me to keep in mind when reviewing my participants' reflections on their rehabilitation process. Before moving to the rehabilitation phase at the RSP, there is another important aspect of patients' histories that requires our attention: their struggle to access healthcare after suffering their injuries.

Multiple risks

In the interim between suffering an injury and arriving in Amman, Syrian participants in particular endured a number of events that influenced how they perceived the treatment at the MSF hospital. For instance, in Syria, being injured increased one's personal risk increases dramatically, especially for men. Suddenly they were living under the suspicion that they collaborated with anti-government forces. This meant they could be killed at home or at any checkpoint along the road. One participant described this dire situation:

> When I got injured in Syria I stayed at home, and there was always fear, because they were attacking and checking the houses, and they shot any injured person. They killed him [the injured] and his family. I was always afraid of that, of them attacking our house, arresting my father, arresting my brother, arresting me or anybody. It was like a horror movie and the ghost would come up at any time. (RSP8, Syrian, M)

Another participant, a farmer who reported being shot when the army passed by as he worked in the fields with his children, explained:

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> And here [once I got shot] the misery happened. If you went to the checkpoint while you had a shot wound, then you were under suspicion of either participating in a demonstration and you were shot there, or you were [collaborating] with the armed terrorist gangs who fight and call themselves rebels. There was no solution. Only God knows about you [and your truth]. I had to be treated in a hidden hospital away from the government. (RSP13, Syrian, M)

This risky situation compromised access to medical services. Initial first aid was given mainly in improvised field hospitals where often nobody was medically trained and medical supplies were scarce. One of the participants (RSP1, Syrian F) reported that the only treatment available for her deeply infected hand was honey. "The goal of this treatment," she reported, "was to heal the wound regardless of how it looked or if it was good [functional any longer]." The available "hospitals" were reported as operating in abandoned schools and private houses. First aid was occasionally given by friends or relatives who had some limited medical training. One participant, who was injured in a bomb explosion in his house, described his friend treating him after he suffered severe burns and injuries to his face: "I remember that when my friend was stitching my face, he was trying to joke with me to make me laugh. We were always joking and laughing. I remember he was the one who was always joking with me [to try to lift my spirit]. But every time he felt tired while working on me, he went away and cried" (RSP25, Syrian, M). Participants often reported feeling shaken by observing others dying while they were receiving the improvised treatment: "In the field hospital there was a boy who was fourteen years old. He stayed there until the morning and died. He had a simple wound in his tummy, but it turned out that it was internal bleeding. But there was no X-ray or anything. He was bleeding until he died" (RSP25, Syrian, M).

Sometimes surgeries were performed in patients' homes under high secrecy, as Ali's story indicates. Some participants reported that travelling to a larger hospital for surgery was simply not an option and their only treatment for a long period of time was what was available under improvised conditions. A female patient, who was injured when her house was bombed, described the situation as follows:

> They took me to the hospital of the village where I received care. I had an X-ray for my head and arm. They told me that the joint was fractured. There was a doctor from the village who put a temporary cast [on my hand] and told me to keep it. Then he died in Syria before I finished the treatment. The treatment that I received was painkillers and the temporary cast. This is the only treatment that I received! We could not go from that village to the capital city, Damascus, for treatment. It was dangerous [to go there]. We were under siege for more than one month. We had no food and could not receive anything from outside. (RSP2, Syrian, F)

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Even those who managed to access hospitals in Damascus faced severe risk. A patient spoke of the risk he and his brother took every time they made the trip to the capital:

> From the capital city, Damascus, to our countryside, where we lived, there were around fifty checkpoints. When they saw somebody injured, they took him [arrested him]. I left the hospital and went back home. While going back home, a regime-controlled checkpoint stopped us. They saw me in the car with the cast on my leg from here [points at the ankle] to here [points at the end of the thigh]. I was lying in the car. One of the solders told me: "Your ID!" We gave him the ID. My beard was like this [indicating very long]. They used to arrest injured people. He thought I was one of the armed people. I told him: "No, sir. I have nothing to do with them." He told them [other solders]: "Bring him [out]!" I told him: "I swear, I have nothing to do with them, sir!" They wanted to arrest both my brother and me. Then we finally called the hospital. Hospital staff told them: "This is the true story. He was here. You could leave him alone." After fifteen days, I went back to the hospital. My brother and I woke up early. He told me: "Let's go to the hospital to see the X-ray. And check if the infection is gone." We went to the hospital. They did the X-ray. They told me: "You still have infections. Go back home. Come back after fifteen days." The checkpoints were the same. They were not removed. There were the same things [problems at the checkpoints]. They wanted to arrest me at the checkpoint. I arrived at the house and told my brother: "I won't go out there again even if I was dying." (RSP6, Syrian, M)

Not only was travel to the hospital dangerous, staying there was too. According to participants, hospitals were frequently targeted by the army, and patients were killed on the spot. The hospital staff in government hospitals were told to report any patient "under suspicion" and to account for any patients suffering from gunshots, regardless of the circumstances under which the shots had occurred. One of the patients described the situation: "Then I had one surgery for my leg there [in Syria]. But it was not successful. The hospital was attacked. There was bombing. The soldiers attacked [invaded] the hospital and wanted to take [to kill] the war-injured [people]. They [the hospital staff] made us run away. And I didn't continue with the treatment" (RSP3, Syrian, F). Another participant reported being hidden in the female ward until the morning when he had surgery, because "the army of Bashar was in the hospital" (RSP8, Syrian, M). Another one reported that his friend smuggled him in by using a fake name (RSP9, Syrian, M). Surgeries were described as being done in a rush: "The surgery was extremely fast so that they could let me run away from the hospital. Because if the people of Bashar Al Assad came in, they would shoot at me and kill me" (RSP8, Syrian, M). Patients still under anaesthesia were sent out of the hospitals to reduce the risk to them and the medical staff who let them enter in the first place.

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Paying large sums of money to bribe hospital personnel and paying again for the surgeries was reported. This placed an additional constraint on access to medical care. One of the patients commented that he could not afford the amount they were asking: "I had an infection and they cleaned it for me. Then, the doctor who did the surgeries came and told me: 'We will put a device [external fixator] and nails. It cost 300,500 Syrian pounds [600 USD]. I told him: 'I don't have [money]. I don't have [money]! Where could I get [money]? I don't have [any].' My brother was next to me … Then, in the end, my brother told me: 'They are not going to do the surgery'" (RSP6, Syrian, M). Another participant reported paying equivalent of 8,000 USD in a private hospital in Damascus for a one-hour surgery. Half of this amount was to bribe the hospital staff and prevent them from reporting the patient to the army, and the other half was paid for the actual medical care (RSP12, Syrian, M).

Some patients reported that surgeries were done under such severe time pressure that anaesthesia was not given at all. One of the patients described this in detail:

> There were two plates here in my fingers. They were inserted from here [points at the top of the finger] to here [points at the end of the finger]. They were taken out when I was in Syria. They [surgeons] took them out without giving me anaesthesia. It was so painful that I can't even describe it. I asked the doctor to give me anaesthesia, but he told me: "There's no time to give you anaesthesia. Because it will take long until you are ready [for a surgery if I do it]. And there are many things [procedures to do]." So, he took the plates out without giving me anaesthesia. It was very painful. (RSP1, Syrian, F)

Another participant had a similar experience involving the lack of pain management:

> My leg was injured. They took me to the doctor. He removed the bullet. He removed the bullet without [giving me] anaesthesia. He said: "There are still shrapnel in her leg. I can't remove them now. Because she would scream, and the army would come." Most of the surgical operations were done without anaesthesia. Because the army could come any time and they would take the doctor and patients! He didn't give me anaesthesia so that the army didn't come in while I was still under anaesthesia. He did the surgery while I was awake. (RSP37, Syrian, F)

Another participant confirmed: "No, there was not pain control in the hospital. Patients shouted so loudly. There was no treatment and painkillers for the pain" (RSP3, Syrian, F).

Some participants, however, reported having access to Tramadol or Ibuprofen. And some drugs seemed to be available as painkillers as well. One of the participants mentioned:

> Thank God he did not take Pentagone [most likely the drug called Captagon]. There were people who were taking these drugs to be able to live and walk

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> [after the injury]. It was a problem for those who took it. Those taking these drugs don't have any religion or life [they make one to lose a sense of everything]. When a person takes it, he loses his mind and could do anything, like go out on the street while there were shootings and bombings [completely losing sense of control]. (RSP9, Syrian, M)

Captagon® is an amphetamine-based drug which has euphoric and analgesic properties and induces aggression, alertness, and detachment. It is reported to be frequently used by militia groups in the Middle East, including in Syria and Iraq. It is presumably manufactured in Syria (Arslan et al., 2015; Al-imam et al., 2017; Lutfi, 2016). But according to my participant, it was also used to cope with pain induced by injuries.

For many participants, the injury event triggered their decision to leave Syria and travel to Jordan as refugees. This decision was frequently accompanied by other deeply distressing events and the threat of dying. Some Syrian participants who were injured near the Jordanian border, however, were transported to Jordan within a couple of hours, still unconscious. They faced no difficulty in crossing the border. Indeed, there is a large variation in the number, severity, and types of distressing event MSF patients face before they enter the RSP.

Since the beginning of the war in Syria, several organizations have independently reported on the Syrian authorities targeting medical facilities, killing medical staff and arresting, torturing, and killing patients admitted for treatment (Cousins, 2015; MSF International, n.d.; Sankari et al., 2013; SOHR, 2015). The establishment of field hospitals – operating in basements, deserted buildings, mosques, factories, all under improvised conditions as described by my participants – is well documented (Sankari et al., 2013). Participants' testimonies and medical records at the RSP provide additional evidence of related war crimes.

Entering Jordan could mean obtaining further treatment for many, but it was not always successful or satisfactory. There are reported incidents of up to thirty surgeries being performed before MSF took over an individual's care (RSP6, Syrian, M). Some participants reported that the amputation of a limb was suggested in Jordanian hospitals, but that their limbs were eventually saved after treatment in the RSP. One of the participants described how desperate he felt: "I asked to be discharged [from that hospital in Jordan], because they brought me a counsellor to convince me in amputating both legs from above the knee. But I told them I wanted to be discharged and go back to Syria as the treatment there was better" (RSP7, Syrian, M). Patients were sometimes discharged from hospitals in Jordan that provided free services, because the hospitals had run out of funding in the middle of the treatment. Some participants who illegally left the refugee camps in Jordan reported being stripped of any access to medical treatment in that country until the RSP stepped in and admitted them.

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In contrast, Iraqi participants, regardless of the period in which they were injured, did not report having to struggle to access hospital care. The quality of care, however, varied greatly depending on the political context at the time of injury. Participants from Anbar, for instance, gave examples of how, during ISIS control, their movements were compromised. They could not easily pass government military checkpoints and, additionally, they were required to obtain a special permit from ISIS to leave Anbar. Hence, they could not reach hospitals in Baghdad and had only limited treatment available nearby.

During the US occupation of Iraq, participants described how hospitals were completely overwhelmed and access to medical equipment was scarce. One of the patients, who was brought to the hospital in a coma, reported being placed together with dead bodies:

> I didn't get that much of a treatment. You know our country was busy with all kinds of explosions. At that time [when I was brought to the hospital] I was unconscious. As I was told, I had been thrown together with corpses [in the hospital], and when my family was trying to talk with the doctors, they were saying to my family that I was a lost cause [I will die anyway] and they should give up on me. It was a horrible thing! I mean the corpses, you cannot imagine. (RSP69, Iraqi, M)

This participant ended up with amputation of both legs but had no hard feelings towards the Iraqi medical staff: "Honestly, I don't blame them. With the horrible events in 2008 or 2009, I don't blame the medical staff back then. They had a heavy workload on them because of what was happening in Iraq. They couldn't cover all the casualties. It was like 300 casualties a day." Another participant similarly reported that, after being in coma, his treatment was neglected. He, however, was more bitter about it: "There were also wounds in my leg; these wounds got worse because of the neglect of the hospital, because they expected me to die when I was in a coma and assumed the percentage of my death would be 98 or 99% and that's why they didn't take care of my injuries and they got worse over time. If they would have taken care of them [my wounds], then the amputation maybe would never have happened" (RSP54, Iraqi, M).

Things were particularly severe when the injured were under suspicion of collaborating with the "terrorists." One of the participants described how he was arrested in the hospital, along with dozens of others, just two days after he suffered injuries caused by an explosion in the street:

> I was on a visit to Baghdad like today, I was shopping for my mechanic workshop, and then the explosion happened, and they took me to the hospital. After that the US Army and Iraqi commandos [collaborating with them] arrested us in the hospital [arrested people who were injured in the explosion]. The second day they [the US Army] arrested us and imprisoned us with these severe injuries. Yes,

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> you can imagine that two tubes were connected to my chest because of the bleeding, and my arm was sagging, with so much shrapnel in my back they even reached the heart. Despite all that they imprisoned me! Only God rescued me and saved me! I received no medical care in the prison! It was a miracle from Allah [to stay alive despite the severe injuries]. My arm was bandaged with a plastic sac and because of the lack of care it was stinking so that everyone was staying away from me because of this horrible smell. Also, the tubes were left in my chest for three days after the arrest, and then prisoners pulled them out and threw them [away]. It was a miracle from God that I survived. (RSP46, Iraqi, M)

He reported that only occasionally, when "the committee from the US Army visited the prison," did they deliver painkillers to "the most severe cases." This treatment and the absence of adequate meals caused him to develop a chronic stomach ulcer. Of the eighty-seven people who were arrested with the participant, he reported that only four survived the "two years' imprisonment": "God has written a new life for us. Only after two years we were able to prove that we were innocent, so they released us." Participants' narratives correspond with published reports on human rights violations and the lack of medical care for detainees held in US prisons in Iraq (Allen et al., 2006; Jassam et al., 2015).

The participant who reported being shot by an American soldier while driving said that later the army took responsibility for the shooting and transported him to a US Army base for treatment. His narrative was rather unique:

> Actually, right after the injury I was taken to Heet hospital. It was a very humble hospital with no capacities. My injury [after the gunshot to the face] was a very difficult, unusual injury that required special treatment. The hospital's manager referred me to Ramadi Hospital. The [US] forces that shot me came to the hospital. Yes, they came in to see me, but I'm not sure why! Did they want to check on [me]? Or just wanted to check if I was a terrorist? There was an American officer standing by me and I was lying on a stretcher. He was carrying a pen in his suit. I was not able to talk, so I tapped on his hand and pointed at his pen. I wrote on my hand in English: "If you keep me here, I will die." The officer tapped me on my shoulder and told me: "Don't worry." After that they put me in an ambulance, escorted by two American hummer vehicles, and took me to the US Army base which was near to Heet. Then they took me by helicopter to Ain Al Asad base [US base] … I was conscious until I reached Ain Al Asad US base, then I passed out. I remained unconscious for three days. I opened my eyes, and it was the Eid al Fitr [Muslim feast at the end of Ramadan]. They had made me an initial surgery [by then]. They connected an external piece of plate to my chin, as my jaw was totally destroyed, and there was another surgery where they connected a tube to my stomach. So they were inserting food through this tube to reach my stomach. Then I was transferred to another [military] base with a limited capacity in terms of providing medical

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> services and surgeries. And then I was relocated [again] to Balad base. It was an enormous base with great medical potential that was not available in any Iraqi hospital. They started making surgeries by working on internal soft-tissue implantation. And they were very successful surgeries. Whoever saw their work was impressed by their achievement. (RSP71, Iraqi, M)

This participant had exclusive access to specialized healthcare that was not available to any other participant I interviewed.

Some patients who had been treated in Iraq during times that were relatively more peaceful complained that the hygiene conditions and the specialized surgeries there were far from the MSF standard. The father of a young male burn victim described this:

> After my experiences with many hospitals I realized that we don't have access to sterilized hospital [at all], and we also lack a hospital specialized in burns [in Iraq]. I haven't studied medicine, but I know that this [procedure they have done on my son in Iraq] is wrong because while I was accompanying my son during his surgeries – he had about eighty surgeries – I have not seen such surgeries. There was something like slight peeling of the skin to do skin transplantation. Please [mentions the name of his son] stand up and show your back [son lifts his shirt; superficial scar marks run across a large part of his back]. This is peeling [pointing at the scars on son's back]. They peeled the skin and transplanted it on to the legs. They didn't use an expanding device like in Amman to expand the skin and take the extra skin to cover the injured areas. The difficulties we have faced here in Iraq were the things I mentioned; their treatment was not good. They don't take care of the patients. (RSP43, Iraqi, M)

Many participants also described acquiring infections in the Iraqi hospitals, which had severe consequences for their health. The husband of a burn victim reported:

> I remember in February when we were going to the hospital [in Iraq]. At that time there was a germ that affected the patients' wounds and was widespread in Iraqi hospitals. This germ was especially [dangerous] for burns cases. These germs are transmitted from the hospital [to the patients], not from the patient to patient. My wife was infected by this germ and suffered a lot after that. One of her ears was swollen, so they had to do some surgical intervention and amputate it. Even her whole body was swollen because of blood poisoning: the germ reached the blood, and these were the late stages of infection. (RSP44, Iraqi, F)

Furthermore, many Iraqi participants mentioned how treatment for bone infections in Iraq did not improve their condition, "I wasn't able to walk, there was an inflammation in my leg, and I didn't get any better here [in Iraq]. I was going to doctors for an entire year, but I didn't get any better" (RSP45, Iraqi, F).

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Unsatisfactory experiences during hospitalization were reported by other burn victims. One of the fathers, whose son was injured in an explosion, talked about it while crying: "On one of the moments when we were in Kindi Hospital [in Iraq] they were cleaning the [burn] wounds of my son with Aleppo soap [a soap traditionally made with olive and laurel oils] and vinegar. I remember he [my son] said to me: 'Baba [father, affectionately], I'm so tired, I hope God takes my soul' [I wish I was dead]. He was only ten years old, and you can see how difficult life was for him" (RSP43, M, Iraqi). Another burn victim reported: "I stayed in the hospital for a month; they did nothing for me. We were not able to afford treatment [elsewhere]. Where I was treated it was a hospital where treatment was free. They were just applying oils on the burns of my body, and because of that I was suffering from fibrosis [thickening and scarring of connective tissue as a result of burns] and this increased over time" (RSP50, Iraqi, F).

Some Iraqi participants reported paying for their surgeries, but they were mostly disappointed by the final outcome: "Let's be realistic and honest, because I'm an old guy. The [successful] surgeries and medications are not guaranteed in Iraq. I have tried for my son to have a paid-for surgery. Despite that, they didn't guarantee the results, including a specialized dermatologist! He asked for 3 million Iraqi dinars [2,500 USD] and mentioned that the success is not guaranteed" (RSP43, Iraqi, M). One of the participants reported spending a total equivalent of 21,000 USD, an amount he borrowed from neighbours, to treat his leg. After this investment and eleven surgeries he still reported that "They wanted to amputate my leg [in the Iraqi hospital] but, thank God, I travelled to Amman and they treated me until I got better" (RSP53, Iraqi, M). For some, all of their livelihood was sacrificed for treatment in Iraq. One interviewee described how paying these large sums impoverished him and brought him to the brink of disaster. He now illegally occupies one of the abandoned government buildings in Anbar, where he lives with his wife, children, and orphaned nephews.

Some Iraqis managed to travel to other countries (Syria, the US, India, Iran) to receive treatment. They reported spending large sums of money on their surgeries ("I spent everything I had"), but none of them reported being satisfied with the treatment or its final outcome. One of the fathers whose son was severely burned as a child went, based on recommendations, for treatment in Syria (before the crisis). He reported:

> In Syria we rented a room for him and the person responsible for treatment was yelling and treating him in a cruel way while my son wasn't even able to speak or do anything because of the injury, as his burns were of third degree [very severe]. They bandaged his entire body with gauze while his burns were still raw, and this is something really wrong. The gauze then stuck to his skin,

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> as when they removed them, the skin was coming out with the gauze until the bones were shown. The cost of the treatment in this hospital was around 6,700 USD with this poor treatment. (RSP57, Iraqi, M)

Previous medical treatment and its impact on patients at the RSP

After such difficult events, many Syrian patients reported reaching MSF feeling emotionally exhausted – so much so that undergoing medical procedures was seen as an additional stress that was difficult to deal with: "The situation was horrific. The surgery was big. There were many stitches. And I was already emotionally tired" (RSP15, Syrian, F). Traumatic moments during previous treatment left emotional traces and clearly influenced participants' responses when they faced treatment in the MSF hospital.

Some reported that their troubled memories re-emerged in the critical moment right before entering the OT. Female participants most often reported experiencing anxiety and panic when facing those moments. For instance, participants remembered severe conditions during surgeries in Syria: "The injured people were operated on in front of each other! So, of course, I remembered those surgeries when I was having my surgery in Amman. And those memories are painful and difficult" (RSP1, Syrian F). Another woman reported that she remembered how the hospital was bombed when she was waiting for her surgery in Syria and how the hospital staff made patients run away. She recalled that when she entered the OT in the MSF hospital, "I was crying. My feelings were so bad. I was so afraid" (RSP3, Syrian, F). In contrast, male participants mainly worried at the time of their surgery in Amman, that the surgery would not be successful or that they would die because of the anaesthesia.

Those who had undergone surgical procedures without anaesthesia in Syria had an acute fear of pain. One female participant reported being severely afraid of physiotherapy, but on listening to her narrative it became clear that her fear was actually associated with the memory of the terrible pain she had previously experienced. Even the colour of iodine was enough to trigger a memory of pain for a burn victim:

> After we got out of the operation [at the RSP] we had to take a bath in order to get rid of the red iodine. I felt afraid when I saw the red iodine on the wounds! They [nurses] were trying to convince me to wash it off and not to be scared. I was scared because when I was burned, this iodine was painful for me, when they were cleaning the wounds [with it in Iraq]. So I was scared of it! I was worried that what happened in the past [the pain] will happen again. (RSP44, Iraqi, F)

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The same participant also recalled memories of post-surgical pain: "They are difficult [the surgeries], the anaesthesia, and the post-operation time. Like when they cut my ear here [in Iraq] I was suffering for a long time after the surgery because of the pain" (RSP44, Iraqi, F).

Not only experience with pain but also experience with persistent infections caused a state of anxiety. One of the Iraqi patients who acquired an infection before arriving in Amman was paranoid about being near patients with infections. He attended the MSF psychosocial support sessions to try to rid himself of this fear, but unsuccessfully: "They [psychosocial team] are good, and they reassure people, but they never convinced me to get closer to those infected people. I only felt comfortable if I kept a distance from them" (RSP45, Iraqi, M).

The fear and threats related to their exposure to war also left strong emotional traces, which could be triggered by the hospital environment. I recall one patient whom I approached when I was organizing the focus group. He thanked me for "gently" knocking on his door and reported another staff member abruptly entering his room, which caused a sense of panic related to his fear of potentially being arrested in his house at any time. Patients silently dealt with such emotional reactions, and the hospital staff were surprised when I communicated this example to them.

Experience with traumatic previous treatment contributes to feelings of anxiety among RSP patients that far exceed the usual anxiety associated with medical procedures. This is in line with some pain-experience models that propose that the fear of pain exaggerates the pain experience and pain perception (Lethem et al., 1983). Furthermore, medical guidelines for the care of burn victims highlight that during treatment burn patients may re-experience the trauma and even post-traumatic stress disorder (PTSD), not linked to the initial burn but rather to the subsequent painful care of their wounds (Greenhalgh, 2016).

Notes

1 RSP12, twenty-one years old, Syrian, M, transcript (questions and repetitions omitted).
2 A sticky bomb is an improvised, adhesive explosive device placed under a vehicle and detonated remotely.
3 Syrian participants frequently mentioned the dates when they entered Jordan as refugees.

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4

Patients' reflections on care at the Reconstructive Surgery Programme

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We have already explored how hospital staff perceive their working environment and their relationship with patients. Following up on patients' perilous experiences with treatment before entering the MSF hospital, we will now examine how our participants reflected on the care they received at the RSP. Patients opened up to talk about the many aspects that contributed to their healing. They were also candid about the gaps in care that they thought the programme needed to improve to align the care more closely with patient need.

Hospital environment fosters healing

After looking back at the horrendous risks they faced while accessing medical care in their home countries, my participants described the MSF hospital as a place where their physical and emotional wounds could finally begin to heal. The sense of safety, the warm attitude of staff towards the patients, organized appointments, and satisfactory pain management were some of the elements that were most frequently emphasized when describing the healing process.

When I asked patients how they felt in Al Mowasah hospital, the question repeatedly lightened their faces, and a smile played on their lips as they started to enthusiastically express their fondness for the hospital. They described their time as "happy," and they communicated a sense of relief and joy: "I felt I was on a trip, not in a hospital" and "I never faced any difficulty. Total relief. Total comfort. Perfect staff, perfect care, perfect treatment, perfect meals, transportation was perfect and in an organized manner" (RSP63, Iraqi, M). The hospital environment was described as pleasant and not comparable to any other hospital the participants had ever experienced, "Honestly, it is the only hospital that I didn't feel it was a hospital. Whenever I go into another hospital, I would smell the anaesthesia [perhaps the participant meant disinfectant] and such things; I would remember the

OT [operation theatre] and vomit; except MSF hospital, which was very comfortable" (RSP21, Syrian, F.). The father of a female patient complimented the hospital similarly: "Their way of dealing was very great, in terms of morals and appointments. We weren't treated like that even in the private hospitals" (father of RSP32, Syrian, F).

Patients also reported feeling safe – a crucial element for their emotional recovery. One of the patients said; "I was coming from a place with no safety and security [Syria], and I came to a place [MSF hospital] where I [felt] I had a family [I was treated like a family member]. I came from a difficult place to a place of relief" (RSP18, Syrian, M). A female patient who was not accompanied by her family during treatment also felt relieved by the sense of security: "When one sends his daughter there [to the MSF hospital], the situation is safe. I told you I used to go to have surgeries [at the RSP] and be there by myself. If I slept there for one week or ten days, it didn't matter for me if nobody from the family came [to visit]. There were thousands of people like me in a safe situation" (RSP15, Syrian, F).

Another crucial aspect for participants was that of equal treatment and lack of discrimination by the staff.[1] Among Iraqi patients, for instance, there is a mix of Shia and Sunni Muslims. But representatives of both groups confirmed that they never felt discrimination nor were they treated differently from others, despite the fact that most of the Iraqi staff at the RSP were Sunni. Some participants indicated that it was important to them to have some sort of affiliation with the staff, and that they felt comfortable among their same religious/political group. These patients fondly mentioned the names of surgeons and emphasized which part of Iraq they originated from: Mosul or Anbar, which are predominantly Sunni areas.

There were many examples of patients reporting on the lack of discrimination:

> This is an organization that treats everybody equally. They don't assume this is a good person and this is not, so they treat people regardless of their behaviours. I should be honest: they [MSF medical staff] didn't only treat me in a good way; they treated all of us [patients] the same. They follow the rules, and they have standards that have never been exceeded [in other hospitals I tried]. They treated us all equally, politely, and with high ethics. (RSP46, Iraqi, M)

Also: "They [MSF staff] treated all the patients the same way, and they treated all the patients in a good way, equally. We all were treated the same way – whether Iraqis, Syrians, Yemenis, all were the same. No patient was favoured over the other; they all got the same care, the same service, and the same treatment" (RSP49, Iraqi, M). On a few occasions participants were convinced that they themselves were "a doctors' favourite," and this arose from the fact that a different treatment was described as available for them compared to others.

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When I enquired about patients' satisfaction with pain management, the vast majority reported being fully satisfied with the pain medication and access to it at the MSF hospital. They compared this positive experience to the lack of pain management they had had in Syria and Iraq. For instance: "In terms of pain, whenever I have a surgery here in Iraq, I suffer a lot from pain, but there [in Amman] I didn't even feel the anaesthesia. After the surgery I was as if I was asleep or have just woke up from sleeping" (RSP44, Iraqi, F). The amount of attention given to pain management at the RSP was described by another patient: "Even before the surgery they did not install the cannula while I was awake. They waited for me to go under anaesthesia, then they would proceed. So I wouldn't panic or fear or feel any pain. Throughout the whole programme I didn't feel a single needle" (RSP73, Iraqi, F). Only a very few patients complained about the length of time before pain-control medication was delivered to them.

The notion that a patient should simply abide the pain was sometimes expressed as a good thing by participants, "to make the body strong and resilient." For instance: "If the patient always takes painkillers, he wouldn't resist anything, and the body wouldn't be so strong. So, it's better not to have painkillers so that the body becomes stronger" (RSP7, M, Syrian). The tendency to "laugh at those" who expressed anguish at the feeling of pain was also mentioned a couple of times by male participants: "When I heard someone [a patient] screaming at the physiotherapy, I laughed at him. Even if he was in pain, I laughed. [I asked him] 'Why do you scream? Are you screaming to make the physiotherapist feel in pain [uncomfortable]?'" (RSP16, Syrian, M). Hence, the stigma attached to expressions of agony from pain still exists among some patients. The unregulated use of pain medication and potentially of "recreational drugs," often accessible in the chaotic environment of war, may explain the high threshold some patients have for anaesthetics and pain-control drugs.

Above all my participants communicated a sense of gratitude. From their homes, many conveyed their greetings to the MSF staff and listed names of surgeons and other members of staff whom they "pray for every day and ask God to bless them with good luck and wellbeing." They also frequently expressed gratitude to MSF as an organization:

> A simple thing. We would like to send thanks message to the organization [MSF]. Many, many thanks. Because we couldn't have treated our son if it wasn't the organization [MSF] [that treated him]. We saw many cases [back in Syria]. We personally know those who got injured and had severe injuries; they had the injured limbs amputated [because they could not reach medical care, such as provided by MSF]. There were people who died and there were people whose injuries got rotten [infected] and died [in that situation]. But, as we got to know the organization [MSF] and they treated him, we just thank them. It's indescribable thanks, a huge thanks. (RSP12, Syrian, M)

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The importance of MSF humanitarian work was also communicated along the same lines: "I really thank MSF. They helped me a lot. I hope they will continue with their work. Because it's great when one saves humans. This is very important for humanity" (RSP24, Syrian, M), "It was a non-financial relationship: it was a humanitarian-based relationship [we had with MSF]. It was the first time that one, outside his home country, feels that people are treating him because he is a human, not for financial reasons" (RSP12, Syrian, M).

Patients' views on their relationship with the hospital staff

A sense of closeness to staff became clear when participants talked about their relationship with those who had cared for them. "Excellent" was the word used most frequently to describe this relationship. "The relationship between us was excellent. You would never feel that this is a doctor or nurse, or you are a patient" (RSP1, Syrian, F). Participants mentioned particular physiotherapists, doctors, nurses, and surgeons, and, even years after their discharge, they recalled the names of staff members who had been the most supportive of them. Every word of reassurance, any smile, any gesture of kindness, and attempt to lift their spirits with humour was greatly appreciated. For instance: "In Amman Dr [gives a name of the surgeon] informed about the news [amputation] in a smooth way; he was joking and smiling at the same time, so I was fine with this procedure" (RSP54, Iraqi, M); and "When the [war] memories started coming back, it was difficult. I coped with it by thinking of the medical staff [that were there with me]. When we went to the OT, we laughed and made jokes with each other. I took a picture with them. They let me forget a bit [my worries]. They made me feel more secure" (RSP8, Syrian, M). Another participant described how much he enjoyed the physiotherapy sessions: "The joking and laughing with the physiotherapy guys [physiotherapists] – the treatment was done with jokes, it wasn't something serious or boring. It made one feel like he is not going to have the treatment [only] – [it made one feel] like you are going to enjoy it, honestly" (RSP20, Syrian, M).

Participants spoke with the highest regard about the hospital staff. "They did their best," "they were very polite, kind and respectful," "they dealt with us in a humanitarian way," "they had love and dedication," "MSF staff were more like angels to us." These were characteristic compliments. I had to promise I would communicate these tributes back to MSF. In accordance with staff perceptions of staff patients, the patients frequently referred to staff as family and friends: "I swear to God they are better than a family" (RSP4, Syrian, F); and "I left Syria and my family [there]; I felt I was among

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my family [again] when I went to the hospital" (RSP18, Syrian, M). It was mentioned that the staff were expert in "not making them feel that they are the nurses and doctors separated in any fundamental way from the patients." Hence, warm, informal, and close relationships existed between patients and their healthcare providers in the RSP.

This close relationship was expressed as invaluable. A sense of optimism, new hope, and emotional recovery was directly linked to these interactions. For instance, one of the participants explained: "If they dealt with me badly, I would hate my life" (RSP9, Syrian, M). Another reported how the surgeon made him not only feel comfortable with the surgery, but also with other aspects of life: "It meant a lot. I never imagined I would go [to a hospital] and have the surgery done. When you go in, you see the doctor [surgeon] feeling comfortable and he makes you feel comfortable, too, with his words. Everything else in life starts feeling comfortable" (RSP10, Syrian, M). Some patients attributed their medical recovery, in part, to the pleasant relations they had experienced: "Being in a good mood is a part of the treatment. When the doctor comes and smiles at you and says 'How are you?', this is a part of the treatment" (RSP49, Iraqi, M). Participants reported that interactions with staff enhanced emotional recovery: "We made jokes and laughed with the doctors and nurses just to get rid of the atmosphere of sickness and [emotional] tiredness that we were in" (RSP9, Syrian, M).

The close relationships that patients developed with staff were so important, in fact, that participants expressed a sense of pain and abandonment when the links were cut after their return home. The husband of a female patient suggested that this pattern should change and proposed creating an open communication link:

> Even if the patient won't undergo the second treatment stage [they will not return to the hospital anymore], they [MSF] should stay in contact with the patient through a communication channel like the internet. Because when the patient is treated in this organization, they build a kind of bond with the organization [MSF], and they shouldn't cut these bonds and would better stay connected through medical consultancy. You know what I mean: they [patients] would love to stay in touch with MSF. (RSP40, Iraqi, F)

Relationships among patients

The network created among patients offered them immense support and benefits. Participants communicated a sense of closeness and emotional comfort arising from their relationship with other patients; they exchanged information about surgeons and treatment and gave practical help to carers or each other. All of these things were communicated to me with a great deal

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of fondness. The sense that they were able to provide practical support to those who were "worse off than them" was in many ways therapeutic, giving a feeling of purpose and solidarity. Shopping for others, washing dishes, doing the laundry, and helping those with mobility difficulties to move around the hospital were just some examples of the practical support patients provided to each other.

The bonds with follow patients developed over time. A young Iraqi participant described how he gradually became close with a Syrian patient:

> You asked me about the other patients. I remember there was a guy with me in the same room; he was Syrian. He was young: I think he was born in 1995 or maybe 1998. He looked nice with long hair; his name was [mentions his name]. He was injured in his back and spine during the Syrian events, so he was paralysed. From the way he talked, I sensed that he didn't like Iraqis because of all the bad things that he had heard about us. I was good to him. He had never seen the garden of the hospital, so I carried him and took him out there. He was impressed and said that nobody did that for him, and since then he started liking Iraqis. He wanted to visit Iraq with me; I was helping and supporting him a lot. Whenever he needed something, I was there for him. He said that he had a different image in his mind about Iraqi people: he never thought that they were this kind and gentle. When I checked out of the hospital he was crying about my departure. (RSP74, Iraqi, M)

Many burn victims also expressed a sense of connectedness and noted with relief that they were finally accepted and "among similar" [patients with similar deformities]. As one of them expressed: "It was important for me to meet other patients with burns. I wouldn't feel different from them because they all have the same conditions as mine" (RSP48, Iraqi, M). Sharing a similar destiny was generally perceived as an important factor in bonding and "complimenting each other." "Maybe our stories are similar. Maybe each of us has found what she needs and lacks in the other [her friend]. Probably. The three of us complemented each other; me, [mentions the name of her friend], and [mentions the name of her other friend]. We spent our time mostly together. And we're still close" (RSP4, Syrian, F). Another participant used the shared experience of pain to explain the factors creating closeness with fellow patients: "I share with them [other patients] their pain and try to ease their pain though sharing that I have my own [pain]" (RSP61, Iraqi, M).

Meeting different nationalities in the hospital was also described as enriching: "I met a lot of nationalities that I knew I would (otherwise) never be able to meet within probably twenty or thirty years. They were patients from Yemen, Libya, different governorates of Iraq, Palestine, also from Syria with the beginning of the Syrian events. So, you can say that MSF was like a small Arab homeland that brought together various Arab nationalities" (RSP65, Iraqi, M).

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Syrian patients talked about making friends with others from Syria and with Iraqis and Yemenis, while Iraqi patients mostly reported socializing with fellow Iraqis or Syrians. Some male Iraqi patients had negative comments about Yemeni patients, which reinforced the negative perceptions of Yemeni patients reported by hospital staff. Here is an example of how an Iraqi participant described a Yemeni patient:

> But in the hospital, you know, there were some people from Yemen, and you know they are ignorant, and they have no civilization, so it was difficult in the hospital [to co-exist with them]. What I meant is that they were unorganized, and not cultured! … There were people from Iraq and Syria in the hospital and they all were respectful and co-operative! We would bring shopping and food to share together, and we helped each other in cleaning. Our relationship was very good with each other. But Yemenis were noisy and uncultured. (RSP54, Iraqi, M)

Many participants are still in touch with fellow patients from the RSP through social media. One participant, for instance, came for the interview in Baghdad accompanied by the friend whom she met at the hospital. They talked about the closeness they had developed: "We supported each other; we eased the pain for each other. We were helping each other all the time. When she had a surgery, I used to go with her; when I had a surgery, she used to come with me. We never felt we were in a hospital: it was like we were together at our home" (RSP66, Iraqi, F). Her friend reportedly encouraged the participant to continue her education once she returned home, so the impact of their friendship is long-term and beneficial.

Patients' views on hopes and expectations

The topic of patients' expectations and hopes was delicate for the hospital staff. Surgical and physiotherapy teams complained that patients had "unrealistic expectations" and that this created huge pressure on the therapists. But is this really the case?

According to the patients I interviewed, "hope" played a big role in their perception of their own emotional recovery, and it influenced their view of the care they received at MSF. Many reported having lost hope and given up on treatment before arriving in Amman, but then MSF became a new source of hope for them: "It's like God opened the window of hope for me through this organization, and I feel all respect and appreciation towards them" (RSP49, Iraqi, M). Another patient was similarly inspired: "As I mentioned earlier, when I was in Amman for treatment, at the beginning I used to think that my case was hopeless with my face situation [deformity] and all [other issues]. But when I saw many cases who were worse than mine being treated

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by MSF [and improving], GOD BLESS THEIR EFFORTS! They gave me hope and I realized that there is nothing impossible in this life" (RSP65, Iraqi, M). The importance of preserving "hope" was crystallized by the participant whose only recommendation to the RSP was "just to give the patients hope" (RSP48, Iraqi, M).

It came as a surprise to the hospital staff that more than half of the participants reported that their expectations of the programme were met or even exceeded. Syrian patients in particular were generally satisfied with the treatment at the RSP: "It was a dream to have the surgeries and walk again. I didn't expect to find some party to treat me because I was hopeless regarding the treatment. We can't afford it" (RSP12, Syrian, M). Twice as many Syrian participants as Iraqis reported a sense of satisfaction with the programme.

The participants expected a range of outcomes when they started their treatment. People mentioned wanting a number of things depending on their specific situation: "to be able to walk again," "to keep the limb which was at risk of amputation," "to wipe out the physical pain," "to heal the infection," "to finally be able to have access to surgery," "to get artificial teeth inserted," "to be treated better than in Iraq," "to be treated respectfully," "to be able to go to the bathroom by myself," "to finish the treatment of infection," "to be treated for all my conditions," "to feel better emotionally," "to improve my health and return to my children," "all bodily deformities to be treated, including neck, ear, and breast," "not to be neglected in the hospital as I was there alone," "to have my hand 90% functional," and "to receive the leg prosthesis." Considering this list, most patients appear to be realistic in their expectations. Only a few expressed more ambitious hopes, such as "to be able to return to work," "to look like I looked before [plastic surgery]," "to be able to practise my normal life again," and "to have my life back to normal as it was before." Nevertheless, the hospital staff felt that patients had quite unrealizable dreams for their futures.

Patients who expected to have a limb amputated but avoided that outcome reported that their treatment exceeded expectations. For instance, "I thought I had no future. As my leg got worse, I thought it would be amputated. I thought about my situation or what would happen to me later. Until I came here and had the surgeries, thank God. I improved" (RSP3, Syrian, F). But even those who anticipated an amputation and did indeed have a limb removed at RSP still reported the treatment to be "as expected" and commented that "everything there was excellent in terms of healthcare": "I already had some idea about what is going to happen in Amman [an amputation of leg]. I had a full understanding of my case; I expected that. I expected them to treat me [with the best option available] and I found what I expected; everything there was excellent – the healthcare, the physiotherapy, and they [the staff] were as I expected" (RSP54, Iraqi, M).

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Those who had hoped to walk again reported feeling thrilled when they achieved that through the efforts of MSF: "I didn't expect that they were that good [in treatment] and that I would benefit and be good again. I was hoping to walk even with limping; the important thing was to walk. Thank God, I'm completely treated; I became normal [with my walking]" (RSP13, M, Syrian). Complete satisfaction with treatment was also reported by those who hoped "to start eating again": "My first and last objective was to have teeth transplanted whether the face was [normal] as before or not. That was what I thought about. The main reason for that is to finally be able to eat and drink. I had only liquids for four or five months [beforehand]. Now I can eat normally" (RSP22, Syrian, M).

Some participants, particularly those who travelled unaccompanied and were worried that they would be "neglected" in the hospital, were also clear that the treatment "exceeded" their expectations: "I don't know – I thought that I might be neglected. Frankly, they exceeded my expectations by the support and service they provided. They even took me for tourism and even gave me money [patient per diems]" (RSP62, Iraqi, M). One participant was also surprised by the "credibility" he experienced at MSF: "All I hoped for was treatment for my condition and to get rid of this constant pain. Certainly, it took time to reduce the pain, but I never imagined [I'd see] this much honesty and credibility from the organization. I was surprised by the credibility of staff. Most organizations and people I dealt with were fake; this is our society [in Iraq]. This is the truth and I'm not flattering. I felt truth, integrity, trust, and credibility from MSF" (RSP64, Iraqi, M).

For about one quarter of those interviewed, expectations were only partly met. This group frequently identified the percentage of improvement they expected and how much lower the percentage was that they finally achieved (ranging from the highest, 100% expected, to the lowest, 45% achieved). Most of these participants concluded that "their treatment was not completed," something they reported in a frustrated and sometimes angry tone. The father of one plastic-surgery patient said, "I expected to return home with 90% of improvement. We didn't complete the treatment! We reached about 75% and returned [back to Iraq; we were discharged]." Another plastic-surgery case complained: "I hoped they would fix my neck, my ear, and my breast, but they didn't do them all [they did them only partly]. They didn't do my ear, and only a small part of my neck has been done. And this is important to me because currently I cannot take off my hijab" (RSP44, Iraqi, F).

Among the staff at the RSP there was a common assumption that patients' expectations were high because they were being treated abroad and by MSF, a well-known international organization. Some participants indeed commented that their expectations rose once they were told the treatment would

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be provided by MSF. Others, however, were "sceptical" and "had an unusual hesitation" because MSF offered services free of charge. These participants questioned whether "their [MSF's] performance might not be up to the level that they aspired to, considering that paid treatment before did not bring them desired outcomes" (RSP71, Iraqi, M).

In sum, for two thirds of the patients, treatment expectations were fully or partly met. This confirms the hypothesis discussed in Chapter 2: patients express realistic expectations for treatment, but when they communicate these expectations, they add to them expressions of "hope." This is more closely related to their outlook on life than it is to the treatment itself. At the same time, the expressions of hope are partly a manifestation of grief for what they have lost. For the RSP staff feeling "under pressure" when patients express their hopes, this discomfort could be reduced simply by providing patients with a safe space in which to express such sentiments.

The other third of my participants (equal proportion Syrian and Iraqi) reported not gaining what they expected from the programme. Some suffered side effects of the surgery, or had unexpected amputations, or their condition had not improved after treatment in Amman. "I expected my arm to be completely fixed and to be treated the way I want. I didn't expect them [MSF] to make it look worse and feel worse. That was never expected by me at all as the surgery took seven hours and there was a bones transplantation from my leg to my arm. I even don't like the way it looks now" (RSP46, Iraqi, M). Still others explained that, from their perspective, there were shortcomings in the RSP unrelated to their treatment outcomes but that still needed to be addressed. Let us have a look at the details.

Mismatch between patient and programme priorities

I observed a sixteen-year-old female Iraqi patient during her last session in physiotherapy at the RSP. Her image is clear in my mind due to her striking appearance: long curly honey-blonde hair, beautiful facial features covered with freckles, green eyes, and elegant posture in her long dress. It was obvious that she paid special attention to the way she looked and presented herself. The physiotherapist was asking her to do different exercises: sit down and get up from the chair, walk a short distance using one crutch. The patient had a good sense of balance and was walking confidently. The physiotherapist explained to me that she was "some sort of medical miracle." Initially one of her legs was fifteen centimetres shorter than the other. This was repaired during surgery and physiotherapy. I asked the patient if she was satisfied with her treatment and if she had received what she hoped for. She looked straight into my eyes and said, "No." Surprised, I asked for an

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explanation. She lifted her skirt, exposing her foot on the non-shortened leg, which looked enlarged and slightly twisted. She commented: "I was coping just fine with my shorter leg, but what I was hoping for was a surgery to improve the appearance of this leg" (Field notes, 21 May 2017).

Many other patients with aesthetic deformities were dissatisfied and expressed that they felt MSF was not doing them justice by prioritizing "functional improvements." One of the patients shared her insights:

> They [MSF personnel] take a picture of my face, then they display it in front of the [validation] committee. They [the committee] says, "This person can move" [they don't have functional difficulties]. Then they take [admit] other, more severe cases instead. There are people who have more right to have the treatment [than me, because their cases are severe]. But, if you sit with me [and listen to me], there are things that have destroyed me too. I feel that the appearance of the burns is what has destroyed me. I have the right to be treated, and so does he [the other person with functional difficulties]. (RSP15, Syrian, F)

Some of the participants were well informed about the existence of alternative medical procedures and felt it was disturbing and unjust when those procedures were not offered to them at the RSP. One of the female burn victims, for instance, said:

> I always check on websites how developed the treatment is. As for the condition of my legs [skin deformities], they can become normal with laser. I saw that on a website. I contacted an Egyptian doctor. The laser is developed. I saw a case of woman that is exactly like mine. When I saw her, she was without her clothes. She was like me and had the same [injury] in the legs [burns over the thigh and over the foot]. The skin has become normal with the laser treatment. The problem is that there is treatment available for me, but there's no [financial] capability. I need laser! My face would be normal [with laser too]. They all consider it cosmetic [in MSF]. As I saw the children who have burns [in the hospital], the children lack laser [treatment] too. The MSF hospital does big surgeries; it should have laser as a help for aesthetics. The hospital needs [improved] capacities for the plastic patients. (RSP21, Syrian, F)

There is no clear-cut definition of what is "reconstructive" and what is "cosmetic" surgery. Both fall under the "plastic surgery" domain and both use similar surgical techniques with aesthetic improvement being a desired outcome. The difference, according to the American Society of Plastic Surgeons, is in the ultimate aim of the surgical process: reconstructive surgery aims to rebuild a normal appearance, while cosmetic surgery manipulates "normal" anatomy to appear "more beautiful" (American Society of Plastic Surgeons, 2018). But according to some patients, the team at the RSP refused them further treatment saying that it was "cosmetic," even when, for instance, it included reconstruction of a damaged ear (RSP57, Iraqi, M).

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There were some patients who dedicated their income to obtaining laser treatment after they were discharged from the RSP. This demonstrates just how crucial it was for them to try to improve their appearance. As we have already explored, compromised appearance greatly influences patients' perception of "self" and can have severe social consequences ranging from complete social isolation to a lack of opportunity to marry, obtain work, or complete studies. Hence, plastic-surgery and some maxillofacial patients who suffer these consequences understandably question why their treatment preferences, as they perceive them, were not taken into consideration. While research into the effectiveness of laser treatment for the management of scars is not conclusive (Greenhalgh, 2016), patients hold out hope for an improvement in their condition using this technique.

It was not only those patients who hoped to achieve visual improvements that complained. Some with more functional disabilities also communicated disappointment and felt that their priorities had not been acknowledged by MSF.

> My eyes were my priority. As my fingers were not cut and they were still there [not amputated], I had no problem if they were not healed well. I wasn't concerned about them as much as about my eyesight. They [doctors at MSF] said, "We don't have ophthalmologists, only orthopaedics and such things." I didn't have my ambition realized as a patient who was being treated. As for my hand, they worked a lot on it until it could help me, even if it was only a bit [better]. But, my needs are not met in regards to other problems [my eyes, my teeth]. It [the treatment] was excellent for my hand. As for the teeth, they refused to fix them in the beginning. They said, "We don't fix teeth unless the face is fractured." (RSP25, Syrian, M)

A set of comments was focused on the single type of prosthesis available for amputated limbs, described as "suboptimal" by some patients:

> The prosthesis available from MSF presses the air [an adaptable prosthetic socket]. I have a quarter of the bone. From any movement and when the air is pressed, the prosthesis moves from its place and I couldn't walk with it. After around one week, the centre of Ibn Sina [in Jordan] called me [and told me that] I got a prosthesis from the Islamic hospital; a donation paid for it. I had hope I will be able to walk with it. It was silicon. When I tried it, it was good. I had told [the people in] MSF to make a silicon one for me [before]. Then they told me I can't get silicon and that patients [at MSF] aren't provided with the silicon ones. To those patients who need a silicon prosthesis, they [MSF] should give them a silicon one. They shouldn't refuse it. They refused [giving me one] because it was expensive. I still look after it as something that is very precious, so that I don't damage it. (RSP16, Syrian, M)

Some other participants questioned whether all available procedures at the RSP were used to the optimal level for them. An example was an Iraqi patient, who said,

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> I wished for the alternative solutions, like an artificial lens for my missing eye, but they did not place it [the lance] properly. The lens was too small for my eyes. I complained to the doctor and asked him to fix it and asked him to change it with a bigger one. But what he did is he enlarged the same lens, and he made it a bit too big and installed it in my eye. But this made my eye look a bit bigger than the other normal one. I like everything to be perfect to some extent. So, I wanted it [the eye] to be right so I would look normal. Same goes for my hand: I wanted an artificial hand [prosthesis] that could be moved. On the one I received I had to fold fingers on it [manually] to move it into my pocket. It only added weight so I did not like it. It did not help, and I threw it away, because it was useless. I feel angry right now [remembering all this]. (RSP61, Iraqi, M)

The push to use a particular prosthesis may be purely "practical," having a quantitative, measurable outcome in terms of the progress of the programme. This, however, is the very thing that translates, in the patient's opinion, to a limitation on the care offered and ultimately provided. There is very little negotiation space for patients to communicate that their treatment preferences include physical, emotional, or social outcomes. Yet, all of these things will be important aspects in their future lives.

Dissatisfaction with the process of hospital discharge and continuity of treatment

The process of discharge and follow-up also caused some concern and dissatisfaction among the participants in the study. The usual procedure is as follows: patients are discharged from the hospital in Amman on the notion of maximum benefit achieved.[2] This decision is grounded in individual validation and the conclusion that a patient has benefited as much as possible from the programme as it is currently constituted. After the final discharge, patients return to their residences and are considered to be in a follow-up period, the duration of which is decided case by case by the surgeon in charge. During this period, which typically lasts for a couple of months, they are followed by medical liaison officers (MLOs), who perform patients' medical check-ups and document their progress. After the period of follow-up, if MLOs do not raise any concerns, the patients are considered as "finalized," a term used by MSF to indicate that no further treatments or medical assessments are planned for them. Interviewed patients reported on different challenges that arose from this course of action and the difficulties they encountered when institutional rules were tightly applied.

The decision to discharge a patient could cause disappointment for some if they felt that they were discharged from the hospital "prematurely" or that more could have been done with RSP expertise:

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> Honestly, I didn't expect they would discharge me from the hospital until everything was completely done, such as treating my legs. My legs are important! I showed them to the doctor and he said, "No. I don't know how to do anything but with your hands [plastic surgery]." I just want to be able to practise my life. I can't stand up while they [my legs] are straight [fixed]. I was surprised when they discharged me. Even my face – look at my lips. The skin is all tightened. It all bothers me. But, honestly, they didn't do anything for me [for the face]. (RSP21, Syrian, F)

Another patient thought that fixing his missing teeth was an obvious need before discharge: "I swear I didn't feel well when I was discharged from the hospital. Because I didn't finish [the treatment] for the face [maxillofacial patient]. It wasn't good. My teeth needed to be fixed, if there was a dentist there [to fix them, but there wasn't]" (RSP14, Syrian, M).

The term "maximum benefit achieved," or "MBA," itself impacted some patients' ability to cope. One of them described this as follows:

> They [MSF] should treat us without telling us [patients], "This is the maximum. You cannot get better than this." This caused frustration for us patients and made us feel down. And there were many doctors who just nodded their heads and walked away when somebody asked them for something [more to be done]. They didn't do anything [in response]. I felt bad because I hadn't completed the treatment when I was discharged from the hospital. There is a donor here, may God give him good things, who helped to complete the treatment. (RSP31, Syrian, M)

Hence, MBA is perceived by patients as something on their way to recovery and has a negative emotional impact on them. The use of a more neutral term, such as "RSP treatment completed," "discharged from the programme," or "the programme target achieved," might be more suitable and reduce some of the current tension that comes up between patients and hospital staff.

When we discussed the continuity of treatment, the participants' major complaint was related to what they considered misleading information they received. No fewer than twenty-two patients whom I interviewed (four Syrian and eighteen Iraqi) reported being promised (by the surgeons in charge of their cases) that their treatment would continue after a period of rest at home. They reported feeling misled, shocked, and emotionally affected after their attempts to contact MSF failed and they were unable to talk with programme officials about the continuation of treatment. They reported not being able to get a response or that the response they did get from the MLOs was along the lines of "your medical files is closed" and there are "no more treatment options for you." They reported that no explanation was provided to them, and they continued to wonder about their cases. They felt disappointed also because they believed that they "had developed a personal relationship with the surgeon" and they "trusted the credibility of MSF."

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One of the patients received me in his home and expressed anger and frustration. He is currently suffering from kidney failure, for which he blamed MSF and their "neglect" of him as a patient:

> You know that Iraq has gone through very hard circumstances: at that time the Iraqi hospitals didn't have the capacity to receive the very large numbers of patients. But MSF – and we appreciated their efforts at that time – made great efforts. But then when they did my surgery on my leg, they left me in the middle of the way [in the middle of treatment] and didn't complete the job [treatment]. The last time, nine years ago, they [in MSF] told me to go home and that they will contact me later. But when I travelled back home, I tried to contact them many times [over years] and tried to even contact the surgeon in charge of me and I didn't get any response. During this period, I was in severe pain, so I had to take a lot of painkillers, which caused complications. These painkillers affected my kidneys negatively and now I'm suffering from kidney failure. I contacted MSF many times, but they completely ignored me. If MSF had contacted me or treated me one or two years after my discharge that would have eased my pain and I might have had these plates [internal fixators] removed from my leg [and avoided further consequences]. (RSP49, Iraqi, M)

Another patient felt misled by communications from MSF:

> They [the hospital staff] honestly were good, but I was supposed to complete my treatment when I was there. The specialist who was responsible for my case said, "You return to Iraq so you feel emotionally better, and then we will request for you to come back to Amman again." When I returned to Iraq, I was contacting the doctor [MLO] who was here [in Baghdad], believing that they will reconsider my situation and complete the treatments related to my neck movement [restricted movement due to scar tissue], in addition to the deformed ear. But then they informed me that I'm not entitled to any more treatment. After some time [of trying] I was suffering [emotionally] because the surgery wasn't completed and I was in the middle of the way [in the middle of treatment]. (RSP44, Iraqi, F)

A young woman who needed breast reconstruction had a similar experience:

> When I travelled [to Amman] there was some maintenance work in the operating room, so I didn't get treated immediately. They only fixed my armpit [the skin release] and added a nipple to my left breast. He [the surgeon] said if it [the nipple] disappears I will do it again for you. They [MSF doctors] also opened my right arm [which does not extend fully] to treat it, but they didn't complete the treatment. They told me in MSF, "We will call you back to travel to Jordan and get treated," but they didn't. I sent them my X-rays three times before; they didn't answer me and then I was surprised when they said that my file has been closed and I won't be admitted to any surgery [within MSF programme], and there was no explanation why. (RSP50, Iraqi, F)

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Back in Amman I tried to follow up on her case. It was clearly stated in her follow-up summary (dated 22 January 2018) that she had raised the same concerns about the continuation of her breast reconstruction and that, indeed, she was supposed to travel back to Amman for further procedures on her hand. One of the surgeons and another person from the medical department who remembered her case confirmed that she was telling the truth. Despite that, it was explained to me, that she could not be readmitted if her orthopaedic surgeon would not confirm that she needed more procedures on one of her hands. Her admission to "only" fix the breast was considered out of the question as it was not judged to be a "functional improvement."

The extent to which this miscommunication affected patients in practical and emotional terms was explained by one of the Iraqi burn victims:

> In Amman they told me that they would send again for me after a few months to complete my treatment according to the programme schedule. So, I lived hoping to go back again. There were small saving projects that we used to subscribe for; I froze everything [all activities], I did not participate in anything and did not develop myself [financially], expecting that they would give me a call at any moment and tell me to pack up and go. And I kept waiting. After a couple of years they called me and told me that my treatment was over. But I did not understand why they didn't want to treat me. And [after having reached an emotional recovery] I became upset again" [participant crying]. (RSP73, Iraq, F)

Some other patients reported that they were informed that their treatment at MSF was complete; however, they struggled with long-term health-related difficulties and wondered if MSF could play a role in helping resolve them. Some patients' condition worsened years after the surgery. I met one who was living in a very harsh economic situation. He asked me: "I'd like to ask about my hand; when I contacted them in Baghdad, they told me that they had closed my file. What should I do now? Can I live with this hand? It's back to how it was before the treatment at MSF. My kids are even working with me and studying at the same time [to compensate for my lack of functionality]" (RSP59, Iraqi, M).

The most commonly reported conditions that lacked long-term treatment plans were differing degrees of pain (reported by twenty-seven participants), knee replacement, replacement of the leg prosthesis, and aesthetic improvements. A number of patients shared stories about how they, after receiving no response from MSF, tried to follow up with procedures in Iraq. But Iraqi doctors were reluctant to take on these cases because of patients' complicated medical histories and advised them to return to their original MSF doctor. For instance:

> Currently I suffer from pain that makes me even lose sleep. That was my complaint [to MSF]. You are a humanitarian organization, and that was a good

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> initiative you did, and treated me in a good way, and received me well in the beginning, but you should have completed your job and continued the good work you started. I tried to go to many doctors here [in Iraq] and whomever I visited asked me, "Who has done your surgery?" And when I tell them it was MSF, they only give me medications and painkillers and tell me to go back to MSF so they finish their work. I also feel worried by somebody else removing the plates, because the other doctors can't exactly know how it's been inserted by the original doctor, and they might damage the injury [the injured part] even more. (RSP49, Iraqi, M)

Patients in need of replacement prostheses reported difficulty accessing them in Iraq. A husband of a patient explained: "This prosthesis [pointing to his wife's prosthesis], this isn't good: it hurts her. They repaired it [in Iraq] in a poor way; every time we go, they fix it carelessly. Can't MSF bring a new good quality prosthesis for her?" (RSP41, Iraqi, F).

Another patient, who underwent above-the-knee amputation at MSF showed me her stump and the dark patches of skin where the prosthesis had rubbed against it. The upper part was covered by gauze to reduce the rubbing. The artificial leg was broken in half and taped. The woman commented that her prosthesis was six years old and does not suit her anymore because her stump has changed in form. She told me that she got a replacement in Iraq, but the new prosthesis was so uncomfortable that she stopped using it and continued with the broken one she received at MSF. The fact that it was MSF where the amputation was carried out made her feel strongly that the prosthesis should be replaced by the programme: "I expected them [MSF] to make another prosthesis for me and reduce the fat in the thigh so it becomes slimmer without that extra fat and fits into the prosthesis" (RSP40, Iraqi, F).

Another patient with a double amputation of legs talked of the impossible financial burden he would face if he had to organize replacement of his prosthesis himself:

> The two prostheses cost 4,000 dollars which is as expensive as a car; it's not easy for everyone to afford such expensive things. Our government here doesn't care about the patients; they have the materials, but they don't have the workforce [to manufacture good quality prostheses]. As for the private offices who can sell the prostheses, they sell them at a very expensive price and, also, they are distant from my home: I cannot easily reach them. They [MSF] told me, "Your case doesn't require further treatment and the prostheses are available in Iraq", while, as I told you, they are very expensive. 4,000 dollars is something very expensive: in addition to the surgery that I need in my leg, that all will cost about 5,000,000 Iraqi dinars [4,000 USD], which is very expensive and not really available here in Iraq, and I cannot afford it. (RSP54, Iraqi, M)

The trust those patients developed with the MSF surgeons was an important aspect of their explanations:

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> My problem isn't only the prostheses [which needs to be replaced]: it's also the extra skin in my stump. And I have concerns on doing it here in Iraq [surgery to remove it] because wherever I go they say, "No one can help you but the MSF surgeon, because he's a good doctor and professional in this field and he is the only one who can treat this for you." It [the procedure] is not something easy; it's about a palm size away from my knee, that's why it's very risky for me and I cannot do it here [in Iraq]. I have a concern about risking my leg! I even endure the pain rather than risking the rest of my leg. I cannot do it here in Iraq. All the good doctors have travelled out of Iraq and the professional ones [specialists] are not here anymore. (RSP54, Iraqi, M)

During the difficult conversations these patients had with doctors in Iraq, some heard suggestions that they submit a formal complaint against MSF due to their neglect: "One doctor even told me to file a complaint against the organization at the Doctors Union [in Iraq]. But I don't want to do this because I'm so grateful for what they did, may God reward them and bless them. They did for me a great favour. It's just that no one will receive my case and treat me, and they say that I can only be treated by my original doctor" (RSP72, Iraqi, F). Another had the idea that she might share her dissatisfaction on Facebook: "I wanted to share my story on Facebook and say that I have been treated by Doctors Without Borders and they left me in the middle of the way [in the middle of treatment]" (RSP40, Iraqi, F).

The father of a young male patient who is still in need of ear reconstruction recommended that more information should be shared with patients at discharge: "Even if they [MSF] cannot help us [with further surgeries], they can [at least] tell us where to go and refer us to other places because they know better than us, and that will be very helpful for us" (RSP57, Iraqi, M).

For some, the lack of treatment opportunities was not the issue. They simply felt hurt by nobody checking on them: "But as I told you no one called me since then [since the discharge] or asked 'How is your leg? Did you get better? Have your bones grown?' They [MSF] neglected me as if they mean it [meant to hurt me]. I know they didn't mean it. I know it's not on purpose, but I feel as if it was on purpose" (RSP49, Iraqi, M). Along the same lines, many participants were extremely pleased with our visit and that MSF had sent "somebody after all these years to check on them." I also received warm feedback on my visit: "Thank you very much for this nice visit, and I hope this will be repeated in future, so I won't say that the organization [MSF] have forgotten all about us [patients]" (RSP49, Iraq, M).

I was often encouraged to "take pictures and show them to the doctors in Amman" in the hope of obtaining "the missing parts" of their treatment. When I was in Iraq, I discussed with one of the MLOs the rules that pertained to patient follow-up. I mentioned "a chronic patient who needed long-term follow up." The MLO responded: "Just one medical thing: surgery is

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not a chronic treatment; when is done, it is over and the patient is discharged." This type of stance not only causes the RSP to be perceived as only a surgical programme: it highlights the limitations in MSF's thinking about holistic long-term care, and it shows a specific attitude that MLOs, who are the patients' entry point into the programme, have in relation to the patients. I will explore this further.

A few patients who attended the interviews in a Baghdad hospital requested a medical exam. Some of them insisted on showing me their injuries, despite my explaining that I was not medically trained and was therefore unable to give them medical advice. For such patients, I often enquired if a MLO could do a quick examination after the interview. There was great reluctance on the part of the MLOs, and instead of checking the patients they looked at the computerized patient database. Occasionally an MLO told me, "The patient is MBA-ed at Amman and we can't do anything. No matter what we say [if we examined them], Amman [meaning the surgical team that makes the decisions] will give us the same answer." In such cases, they refused to examine the patients and their advice to me was, "You will face many cases like this; try to get out of the conversation." I also observed the tendency to use excuses to avoid establishing contact. Notes that "patient's contacts are lost" were made. But I was able to contact these patients after repeated phone calls.

An MLO asked me, "Do you really want to call that particular patient for the interview? We know her, she is really naggy[3] and will give you a headache! We told her a number of times that there is nothing that can be done [for her]." The patient they were referring to was the case mentioned above who was promised a return to RSP but was later rejected without explanation. Her enquiries were interpreted as "nagginess," and she was "being difficult," hence it was better "not to talk to her at all." Another MLO used "high expectations" to explain that a patient "has a problem" because he requested some justification for why his trip to Amman was delayed for six months. All of these examples indicate that patients sometimes struggle to receive basic feedback information, and that if they insist, they are considered "naggy" and "problematic." MLOs also expressed suspicion about the information patients provided, and they frequently labelled patients as "untrustworthy."

MLOs in Iraq were clearly concerned with "what Amman will say," and it seems that in order to protect themselves from being "told off by Amman" they use different strategies to avoid hearing back from patients. They expressed the frustration that arises from being between two opposing forces: the patients and Amman. One of them told me that he had been threatened by a patient and his clan. It is understandable that feelings of unease and mistrust prevail in these interactions, which, in turn, seem to influence medical decisions.

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MLOs commented that the only feedback they receive from Amman is that "the file is closed." Hence, they feel they are not in a position to communicate anything more detailed to the patient. Their "duty as medical doctors" is also compromised since, with this current arrangement, they cannot influence medical decisions. The tendency to avoid re-evaluating a medical condition for a patient already fully discharged from the RSP, and hence to avoid any "pressure" from them, is understandable. But it is the patients who pay a high price in this context.

This indicates a need to formalize follow-up procedures for patients and to provide more support to MLOs. They are an important entry and exit point for RSP patients and, due to their contact outside the hospital setting, often have a more holistic outlook on the patients' personal, social, and medical situations.

Communication and related struggles

Most patients commented that any medical information delivered to them was "clear" and that they felt comfortable asking questions. For instance: "Of course, I was involved in decision-making. For my surgery, they gave me options. When they removed the nail, I was given choices. When I was going into the OT, I chose to have local anaesthesia in my hand and be awake when they remove the nail. They [first] wanted to give me general anaesthesia. There were things that they told me about and gave me choices, and I chose" (RSP28, Syrian, M). Some commented that they were involved in medical decision-making "to some extent, but not to a large extent." But some others were not at all satisfied with this element of the treatment.

This last group expressed their dissatisfaction with the difficulties they encountered when they tried to discuss their treatment priorities. They report feeling ignored:

> It was in Jordan one month or less after leaving Syria when I went to MSF – I don't exactly remember. But in MSF they focused on my hand the most. They focused on the fracture that was in my hand and finger. Every time I told them about my leg, the doctors said, "When we finish the treatment of your hand, we will start with your leg." I was like that in the hospital for three months or four months. (RSP28, Syrian, M)

Another patient felt similarly: "No, I could not contribute my ideas. I depended on them [the surgical team] and on their decisions" (RSP50, Iraqi, F); and another said, "The surgeon told me: 'We know our work.' I asked him: 'What are you going to do?' He said [again]: 'We know our work' [without further explanation]" (RSP27, Syrian, M).

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One of the patients was annoyed that a decision taken on a surgical procedure that he had agreed to was changed "at the door to the OT" without any discussion:

> As for the doctors, there was only one thing that annoyed me when I left MSF. There was Dr [mentions a name of a surgeon who has left MSF], who did tendon-transfer surgery in my hand. When I went into the surgery, I signed on to nerve-exploration surgery [not the tendon transfer]. Before [my surgery], I went to his clinic [at the hospital OPD] and he told me it would be [the surgery of] nerve exploration. I signed the [consent] paper. At the door of the OT, he looked at it [the arm] and said, "The nerve exploration needs a long time for treatment. Let's do the tendon transfer instead." That was at the door of the OT! I wish… The right arm is considered the fundamental thing of the body. So, I wished it was a nerve exploration [that had actually been done for me to improve my right arm]. (RSP20, Syrian, M)

Using English or employing specific medical terms was also seen as problematic for patients who did not fully understand planned medical procedures and who were given no chance to discuss what was going to take place: "When the surgeon came, he didn't explain to me what procedures I had. He just talked to the foreigner who was next to him. They didn't speak Arabic and I didn't understand" (RSP31, Syrian, M); "The way they delivered medical information to me, sometimes I understood it and sometimes I didn't. They tend to speak in English terms or specialized terms, and I don't understand the specifics within their specialty" (RSP53, Iraqi, M).

Lack of communication was identified in other non-medical areas of care as well:

> One would have an appointment and the doctor would postpone it for one month. When the patient knew the reason, he felt emotionally comfortable. But when one has a surgery planned for that week and it's postponed, [he asks the surgeon] "Why [is it postponed]?" and they would answer him, "We just postponed it." But we always told them, "When there's a reason for delaying the surgery, explain the reason to the patient. Does one have infection in the wound, and this is the reason for delay? Is it possible that the [physical] response from the physiotherapy [is lacking] and the lack of improvement would cancel the surgery?" When the doctors delay the surgery and there's no more discussion, this was annoying for the patients. One didn't feel emotionally comfortable with this. (RSP17, Syrian, M)

Hence, not every patient felt that they were listened to or that they received an appropriate response, particularly when it came to discussing their treatment priorities. According to these accounts, patients excluded from the dialogue involving their basic treatment are seen as passive recipients of care.

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The insufficient involvement of patients in their own healthcare starts at the admission process. I observed videos of deformed limbs presented to the validation committee. These videos do not feature the faces of the patients, and they do not feature the patients' own words describing their challenges in life and treatment preferences. The lack of a negotiating space between patients and their healthcare providers, the lack of systematic, transparent documentation of the circumstances surrounding patients' dismissal from the programme,[4] and the lack of a complaint mechanism or opportunity for patients to appeal are institutional deficiencies that remove patients from the decisions that will influence their future lives.

Unease around the definition of war-injured

A topic which appeared to be taboo with the participants was whether they were injured in war. The RSP accepts patients who fit surgical criteria and lack access to the same specialized healthcare in their war-torn countries, even if they were not injured directly in war.

Despite this, their concern that they might not be considered a victim was obvious in the way they narrated their past, particularly if they were not injured in war. An Iraqi male participant, for instance, described how he "stopped the car on the side of the highway to get some water from the trunk of his car because I was thirsty," but then he appeared nervous and added, "when bombing was going on." He continued: "Then another car [approached] at high speed and lost control and hit me." He paused again and added, "Perhaps he was shaken from the bombing sounds." This participant later admitted he was injured a car accident, but that he was "supposed to be registered as an explosion victim" at RSP (RSP69, Iraqi, M).

An Iraqi female participant similarly mentioned the war context despite having had an accident at home: "During the war we were running away from the bombing sounds and I fell into a pot with boiled water" (RSP50, Iraqi, F).

A victim of a suicide attempt – self-immolation – from Syria also mentioned that "not many people in the hospital knew about it." She expressed some concern about disclosing the real story to me. Throughout the interview it was obvious that this patient still suffered feelings of guilt: "If it was a car accident, it would be God's faith. But I was the one who did that to myself [crying]" (RSP15). She translated this into a perception that "others deserve treatment more than me," which was then reinforced by the idea that she wasn't a war victim. Her conclusion was that she should remain quiet about the history of her injuries. The emotional burden of keeping this secret was obvious in her emotional responses.

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I observed a related dilemma during discussions among doctors on the validation committee. During one of the validation meetings, we looked at a video of a patient who was limping. One of the surgeons was convinced that his deformities had existed since birth: "Look, there are no marks on his skin, no scars which would be obvious if the wall had fallen on him [in war] as he reported." The surgeons validated the case on the grounds that the patient was suffering from a deformity that could not be treated in his own country and "we have the capacity to do it here." The discussions, however, were carried out in a "hush-hush" way, and the sense of discomfort was obvious when the decision was taken.

One of the RSP doctors confirmed such cases. He said patients tend to adjust their stories when providing their medical histories, which, according to him, negatively affects medical decisions. He noted that these "exceptional cases" felt that "they could be sent home without treatment" if the truth were discovered. He further commented on how he needs to reassure them that "they, like all the others, are validated into the programme, so their treatment is not under threat."

It was unquestionable that the treatment at RSP greatly improved the lives of all three mentioned patients. But it was also clear that the patients and surgeons felt under pressure to "fit the story in" and make it appear war-related. The programme could much more accurately capture its scope if it were labelled as "RSP for the war-affected." This would reduce the pressure on surgical teams who are currently placed under an ethical dilemma of whether or not to validate certain patients. Changing the programme definition would also reduce the tendency for patients to tailor their stories to the definition rather than reporting them as they actually happened.

Gaps in psychosocial support

The likelihood that patients will suffer from injury-related psychological trauma is very high, and therefore psychosocial support was from the beginning of the programme one of its main treatment components. When I attempted to carry out observations in the psychosocial department, the idea was resisted on the basis of ensuring patients' confidentiality. As a result, observations of my participants are the dominant source of information in this field.

When I explored with them their experiences with the psychosocial support services at the RSP, some participants did not even know that it existed. I assumed, then, that they did not receive any treatment in this regard ("Nobody offered those sessions to me" (RSP5, Syrian, M)), or the sessions were not relevant enough for them to recall any impact. One patient, for instance, recalled a counsellor listing the hospital rules and nothing more:

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"He told me that 'The treatment in the hospital would be like this: Smoking inside the hospital is prohibited. Don't be close to the patients who have infections'" (RSP6, Syrian, M). Those who did know of psychological sessions at the RSP thought they were not adequately delivered. "The psychosocial sessions: it was as if I was a little kid and another person was telling me, 'Do that. Do this. This might be good and beneficial for you,' such things" (RSP31, Syrian, M). Another patient felt similarly: "There were four of them [psychosocial specialists] and every month a different one came and I had to repeat my life story over and over again" (RSP56, Iraqi, M). Some patients refused the counselling sessions altogether for fear of being stigmatized or labelled as "insane" because "people say so about someone who receives psychosocial counselling" (RSP3, Syrian, F).

Some other participants said they thought the sessions were too early in the process of their emotional recovery to be effective. The phrase "I was emotionally tired" was used frequently to express a level of emotional exhaustion: "No, it was difficult [to attend the psychosocial sessions], because I was feeling tired and in emotional pain. At that time, we were just arriving from Syria. It was difficult. In that year, we didn't feel comfortable at all. It [that year] was emotionally and physically tiring" (RSP2, Syrian, F). Another patient, who was a victim of torture, described how the counselling sessions were offered to him, but he just could not talk to anyone at the time: "No, I didn't accept the counselling in the hospital. When I was alone, I remembered the whole past as how I was living before [the torture] and how I am now, how my life was, and how it has become. I became an introvert [after the experience with torture]. I didn't like to speak with anybody" (RSP20, Syrian, M). Another participant recalled: "I didn't attend the counselling sessions. I might be asleep or sad at the time [they were being offered]" (RSP42, Iraqi, M).

One of the Iraqi participants mentioned that

> those sessions always made me cry. I don't have good memories there; I have sad ones. It was when the psycho support person came, every time he came to talk to me, I started to cry. We were like three or four in the session, Iraqis and Syrians; we would sit like this [indicating around the table], and whenever he [the counsellor] started talking or asked me a question I started to cry. I couldn't stand his questions! Because then I remember my family back in Iraq, especially that I have daughters. If they were boys I wouldn't care as much, but because they are girls, I worry a lot about them. (RSP51, Iraqi, M)

Some patients reported doing emotionally well and not needing the psychosocial sessions: "My emotional state was stable. There were no [emotional] pressures. I didn't have any [psychological] problems. So, it [the psychosocial sessions] didn't play a big role for me" (RSP11, Syrian, M); "I wasn't

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emotionally affected. I lost my hand, but there were two guys who were killed in front of me. The counsellors here evaluated my situation and decided that 'He doesn't need psychological sessions'" (RSP16, Syrian, M).

Other participants, however, benefited from the sessions, "feeling comfortable and comforted." Many reported that counselling sessions made their stay in the hospital much better: "My emotional state was very bad. I didn't accept being with others. I was always alone. I went downstairs by myself. I stayed in my room by myself. We had more intensive sessions with my counsellor. She told me, 'We should sit together for one hour to talk every day.' And we really talked for one hour every day. And in her own way, she made me have friends from the hospital and make social relations" (RSP12, Syrian, M). Some also commented how they managed to overcome the feeling of stigma related to the mental-health care: "We Iraqis hesitate to talk with shrinks but, honestly, it was very helpful for me to talk with a psychiatrist [in the MSF hospital]" (RSP65, Iraqi, M).

Many participants greatly appreciated the social activities organized by the psychosocial team. They especially liked the daily trips out of Amman into the countryside, parties for women, and parties to celebrate Eid, for example. They felt that keeping the planned activities in mind was something special that helped to break up the daily routine: "The nicest thing was the party. We couldn't wait until it was Monday to have the party" (RSP4, Syrian, F).

During the interviews, I observed many participants still suffering from mental-health issues. Some of them cried from the moment they saw me until the end of the interview, and many reported lingering feelings of depression. One of them described this:

> I saw the aircraft [before I got injured]. This is the most traumatic thing that I saw. Before my injury, when there was aircraft bombing, I wasn't afraid of it. I went out [of the house] to see what was bombed; I just stood there and looked at it. And I went out there to check on people [after]. But after the injury I feel so emotionally destroyed. I can't… at all. I can't stand anyone. I can't see anyone. It is like depression. I like loneliness. If aircrafts came now, I would pass out. (RSP29, Syrian, F)

Similar struggles were reported by other participants. For instance: "During the one month and half that I spent at home, I was very introverted. I couldn't go out of the house at all. I didn't speak with anyone. I was all alone. I reached a stage where depression was normal" (RSP20, Syrian, M).

From their perspectives of Syrian and Iraqi participants, their emotional stress was partly related to their past and partly to the difficult situation they face today: "Fear of the future, the fear of being lost, concern for our lost country, and concern for our children's future – sometimes the difficulty of

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getting a job as we are refugees. These are the emotional obstacles [we face daily]" (RSP20, Syrian, M).

Feelings of severe anxiety were often mentioned. Syrian participants talked of being overwhelmed by a sense of panic when they heard aircraft. Some reported suffering from short-term memory loss, and others said they still suffer from regular nightmares. Their memories of suffering still chase them. "Sometimes, I remember what happened with me, mostly in the night. I feel like there's heartache, but I can't let it out. When something difficult happens, it's difficult to forget it" (RSP9, Syrian, M). It was mostly Iraqi participants (both men and women) who talked about their outbursts of anger, leading them to be aggressive towards their family members: "It's rare that I feel calm. If you noticed when I came here I was mad, but then gradually [talking to you] I felt relaxed and fine. Even with my family I'm always frustrated and angry" (RSP46, Iraqi, M). Iraqi participants also reported feeling highly anxious as a result of their experience with explosions. For instance: "I cannot even cross the road, I feel scared" (RSP41, Iraqi, F). Some participants reported being under psychiatric care when they were at the RSP, but none of them was working with any kind of psychotherapy at the time of the interviews.

The family members of patients also appear to be strongly emotionally affected. During one of the family visits in Jordan (RSP10, Syrian, M), it was the participant's parents who mainly answered my questions. The father communicated how much he needed to sacrifice to keep their son "safe and hidden at home in order for the army not to mobilize him." He emphasized that he was "the one who was taking risks, trying to make money and as a result got imprisoned." The mother commented: "When they saw any guy, they would arrest him." The parents finally left the room and the participant, a young man in his mid-20s, was given space to talk freely. He communicated feelings of guilt "for all the sacrifice his parents made to save him." He reported feeling as if he was "a burden" to others and said it was difficult to live with this feeling.

Parents of other participants who were injured as teenagers were similarly extremely protective and attempted to dominate the interview. They referred to participants as "shy" and barely let them speak. After I managed these dynamics, it was obvious that the participants were open and well spoken. It was the overprotective parents who kept them silent during the interviews and, according to my observations, also contributed to their social isolation at home.

Hence, for many patients, psychosocial support is needed but is not adequately delivered. The psychosocial support offered to patients at the RSP is focused on short-term objectives related to their experience of trauma. Recent psychological models that explore the impact of armed conflict on mental

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health (Miller and Rasmussen, 2010) are, however, moving away from a narrow trauma-related focus to a broader exploration of daily stressors, such as social marginalization, inadequate housing, and changes in family structure and functioning, all of which add to the psychological distress of trauma victims such as RSP patients. Psychosocial support for parents is essential since, according to the literature, excessive parental control, overprotectiveness, and infantilization – all things I observed in my interaction with younger participants in their family environments – increase the symptoms of PTSD in adolescents and hamper their recovery (Bokszczanin, 2008).

In sum, participant feedback confirmed that the MSF RSP does indeed provide a healing environment for patients affected by war. The healing of their physical and emotional wounds is supported by the personalized relationships they develop with the hospital staff and among themselves. Patients assist each other and have an unmistakeable sense of solidarity. Patients' expectations of the MSF programme are often met, which include the satisfactory provision of pain management. However, patients too often do not feel that their priorities are sufficiently included in the treatment plan, shown mainly when they talked about the challenges they face after discharge from the hospital. Several communicated their concern with the lack of transparent communication, and they reported that they saw rigidity in the application of institutional procedures, which they felt sometimes compromised their medical care.

Notes

1 It is important to note that Yemeni participants were not included in the study due to security constraints. Considering the negative perceptions that hospital staff had of Yemeni patients, their views on discrimination may have been quite different from those of Syrian and Iraqi origin.
2 All interviewed patients stayed at the RSP until they were discharged on the notion of "maximum benefit achieved."
3 The expression "nagginess" is commonly used in the hospital to refer to patients who act outside of the expected norms of behaviour; asking too many questions, for instance, can be labelled as "nagginess."
4 Patients who cause "safety threats" to the hospital are dismissed from the programme. Currently there is no systematic documentation of such cases nor of the context in which the decision to dismiss them is taken.

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5

Patients' views on the quality of life

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One of the main questions posed at the start of my research was how do the patients treated at the MSF hospital live today? The hospital staff and desk managers communicated their intense interest in hearing back from patients on all matters related to their lives after leaving the hospital. It was felt that the most important aspects of the RSP could only unfold after patients returned to their homes and started their lives again outside the hospital walls that both protected and restricted them. The patients' reflections – mostly collected two to three years after their discharge – are presented in this chapter.

Victims of war and the notion of the quality of life

When exploring the participants' daily lives, the concept of the quality of life was of utmost importance. This concept is used by many disability-healthcare providers as a measurement of the success of their programmes – programmes that focus on the totality of the patient's physical, emotional, and social wellbeing (NDS, 2012). As MSF is aiming to adopt patient-centred care as its general operational strategy, and since patients' quality of life is the final programme outcome, there was an additional drive to explore the concept of quality of life specifically from the patients' perspective. Determining the patients' perspective was considered vital, yet it posed a certain degree of challenge. In the field of disability health and rights, over forty definitions and 800 tools exist to describe this complex phenomenon.

Furthermore, literature on disability reports on what is known as the "disability paradox." This paradox occurs when people living with severe or persistent disabilities still report an excellent quality of life in spite of what many external observers consider an "undesirable existence" (Albrecht and Devlieger, 1999). In the context of the lives of the participants, quality of life appears even more paradoxical considering that most of them are victims of violence, they live with disability, and they live in a war-related context

either as refugees (in Jordan) or in Iraq. Due to these underlying notions, it was not clear which elements would, in the eyes of the participants, be perceived as the most important for their wellbeing. I decided to focus on the patients' *own* definition of quality of life and from there to examine their perceptions of their lives today.

Many Syrian participants associated a good quality of life with the life they lived in Syria before the crisis. They characterized this as the strong family and social links they had had and as financial stability. They talked about it with obvious nostalgia: "Our life was so excellent in all aspects; we had no obstacles; life was nice – there was nothing bad in it; I was living happily; life was beautiful there; we were living in grace that nobody knows about it but God. By the way, we used to say [before becoming refugees in Jordan]: 'May God be with the Jordanian people' [because they are facing so much hardship]"; "my life was on a high level: I could afford anything." They often made comparisons with their current lives and mentioned having no social or financial security: "People look down at us here in Jordan; we have no financial stability; we don't know what tomorrow brings." This was in contrast to Iraqi participants, who spoke less nostalgically about their life before the injury and said things along the lines of "my life was normal."

There was a large variation in the definition of a good quality of life. Most commonly, participants referred to issues related to health, including emotional health. They emphasized that health is "everything in human life": for instance, "It's when the body is complete. It doesn't lack a limb or an organ. Richness is in health and body, not in money" (RSP7, Syrian, M). Iraqi participants, in contrast to Syrians, emphasized the importance of mental health over physical health. Absence of pain was also a commonly mentioned dimension of good health, as was having access to treatment. Another indicator of wellbeing was social acceptance, which was mentioned as frequently as personal independence. Restricted social acceptance caused a sense of personal suffering, and it was not surprising that the participants considered it an important element of their quality of life.

The concept of quality of life, however, was not only related to health, injury, and disability. Male participants from both countries also prioritized what they labelled as "stability." The concept of stability was partly related to work and financial security. Other aspects were described as the ability to obtain basic needs: food, a place to live, access to healthcare, clothing, education for their children, and having in place the necessary legal documents. The concept of stability was also related to a "stable family life" (being married, living with family members, family members healthy and alive), being able to perform family duties (provide for the family's fundamental needs and raise children). One of the participants, for instance, described his understanding of "stability" as follows: "The most important thing in life is

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stability: having a job, affording life necessities, and having stability in life, such as work, marriage, education" (RSP55, Iraqi, M). Female participants from both countries, more than males, emphasized the importance of personal independence, "living by one's own efforts," and "having nobody interfering with one's life": "Good quality of life for me means not needing anybody [being completely independent]" (RSP2, Syrian, F).

Other non-health-related definitions of quality of life, mentioned by both male and female participants, were more conceptual: "freedom, life in dignity, love, peace everywhere, life in itself (being alive), and life without fear." "The good quality of life for me is safety, security, love, and that peace is spread all over. And that there would be no racism, like Sunni, Shiite, Christian, Muslim, foreigner, or Arab. To have peace spread, love, safety, and security; these are the most important things" (RSP18, Syrian, M); and "Thank God I'm living. Good quality of life is when I'm alive" (RSP23, Syrian, M).

Participants also emphasized that "The most important aspect of human life is freedom" (RSP55, Iraqi, M), and this concept was sometimes expressed along the lines of the ability to live in one's home country (Syrians), but also to *leave* one's home country (Iraqis). The ability to practise their religion was important to some participants.

The impact of the MSF treatment on the quality of life

When I tried to reflect with the participants on the extent to which their quality of life improved after treatment in the MSF hospital, it became apparent that the impact was multidimensional. Very few patients reported receiving no benefit from the programme (some were disappointed with new scars or depigmentation after plastic or maxillofacial surgeries, and one regretted having a leg amputated). The vast majority of participants talked about the overlapping areas of improvement associated with physical, emotional, social, and symbolic changes triggered by the treatment. It is important to examine these changes in detail and to reflect on how aspects of the treatment outcomes mean a world of difference to the patients but are currently unacknowledged by MSF.

The participants enthusiastically talked about the immense difference the treatment made in their lives. One of them, for instance, said that "it [the changes in life after the treatment] was like a blind person who could see again" (RSP25, Syrian, M); and "The difference [in my life] was from the ground to the sky" (RSP55, Iraqi, M). What was interesting to note was that this sense of relief was also expressed in relation to their whole families, for whom worry and stress had been alleviated: "My family, they are more comfortable now;

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there is no worry; they don't feel worried about my health anymore. My mother [who worried a lot about me before] is seventy years old" (RSP45, Iraqi, M). This statement resonates with Ali's story, which we covered in Chapter 3, and clearly indicates the double burden that MSF patients carry, "worrying for their family members who worry about them." Essential to the impact of the treatment was the way it reached into the heart of the family and included the wellbeing of every member.

Some participants reflected on the fact that because MSF offered free treatment, "their stability in life was preserved." Even the patients who could afford treatment elsewhere (some Iraqi participants) indicated that their livelihood would have been highly compromised if they had had to pay for the treatment themselves:

> I have been to Iran and Italy, and I was able to travel and easily get visa [participant travelled a lot for work purposes], and I was financially capable of travelling to seek the right treatment. Other patients might not be able to travel like I did. Another point I want to make is that getting this kind of treatment based on my personal expenses requires an enormous amount of money. MSF covered this treatment and made a difference in my life. Things would have turned bad for me financially if I have done this elsewhere. For instance, if I had chosen to do the treatment on my own expenses, I would have lost everything here: the car, my house. Not that I did not spend my money before [to finance my treatment]. As I told you, I travelled a lot to seek treatment and it did not bring good results. But since I joined this [MSF] programme, I did not spend for the treatment [so I could keep my life stable]. This programme not only did not cause me any expenses: it also achieved marvellous successful treatment results. That's why this programme is VERY important. (RSP71, Iraqi, M)

Some participants specifically indicated that the treatment at MSF, in one way or another, "saved their life," and without treatment their "life would have no meaning and was not worth living." One of the fathers of a young male burn victim commented that without treatment, "He definitely would be gone [would have died by now]" (RSP57, Iraqi, M). Another patient considered that his leg certainly would have been amputated, and then said, "Something terrible could have happened to me [if I haven't been treated], because if my leg had been amputated, I would have died! I think it's better to die than to have your leg amputated" (RSP53, Iraqi, M). Another Iraqi patient similarly commented on how severe the consequences would have been: "If I wouldn't have had access to MSF treatment, I would have ended up with two options: I either get my leg amputated or I would die. This is the truth; the easiest way to deal with such cases in Iraq is, if they decide to let you live [give you at least basic treatment], to cut your leg and throw it away, simply like that" (RSP49, Iraqi, M).

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Those (both Syrian and Iraqi) who experienced a walking disability but recovered the ability to walk after treatment emphasized how life-changing this has been for them. Many participants reported being bed-ridden, fixed in wheelchairs, and unable to move in or out of the house before coming to the hospital. Many had been completely dependent on their carers for basic hygiene and other needs, such as using the toilet, taking baths, brushing their hair, and getting water and food. The new sense of control over one's life was associated with this newly gained independence. One of them described the relief he felt when he regained his basic independence: "I couldn't walk or step on the floor or bend my legs. But, thank God, now I'm able to walk and I can bend my legs and I'm still living my life and doing my daily activities like going to the bathroom and shaving my beard. I can handle a lot of things now, thank God" (RSP69, Iraqi, M). Another was similarly grateful for his regained independence: "Thank God, I can go in and out of the bathroom by myself now" (RSP6, Syrian, M). A female participant described her long state of dependence in a distressed tone:

> I didn't do anything for one year and a half. I was lying down on the bed. My hands were wrapped. They [family members] took me to the bathroom, fed me, and helped me drink. I couldn't even dress. You know the praying dress [comfortable outfit used during prayer]? I couldn't even wear trousers, scarf or anything for three years, just the praying dress. They put it on me and let me walk and move around like an elderly person [in that dress]. (RSP21, Syrian, F)

About one third of participants, particularly male participants whose capacity to walk had improved, reported having obtained work after they completed treatment at MSF. They were clear that this would not have been possible otherwise: "Because my leg was straight [in a fixed position], I wasn't able to get work. Whatever I wanted to do, I couldn't. For example, [I couldn't] bend down and carry something" (RSP5, Syrian, M). Practising their profession, they reflected, was also important and would not have been possible without physical improvements: "Workwise, my major is pharmacy and, as you know, it requires standing for a long time and moving around, so [lack of treatment] definitely would have affected my job" (RSP67, Iraqi, M). Furthermore, some Syrian participants who are now able to practise their profession as before in Syria stressed how important this was. They wanted to "have a life like before the war": "Before I went to the MSF hospital, I really suffered from pain. I couldn't carry things. I couldn't carry heavy things. I wasn't comfortable. But after I went there and had the surgery, my life became normal. Before, I couldn't work. I couldn't practise my profession [as a blacksmith]. But after I had the surgery, I can work now" (RSP9, Syrian, M). Another Syrian participant commented how he recovered his sense of "normality": "There are many things [I can do now]. I wasn't even in balance before.

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I can do everything. I can drive a car. I can carry doors and windows. I work. I am back to my normal life as if I was [still] in Syria. I can do anything" (RSP7, Syrian, M). Indeed, along with the reconstruction of their bodies, the reconstruction of what they referred to as a "normal life" was underway.

Removing the obvious signs of injury – for instance, having external fixators taken off – also made participants feel that their employment opportunities were further improved: "Nobody will notice that I am injured now" (RSP33, Syrian, M). The visual improvements reported by some plastic and maxillofacial patients similarly enhanced their opportunities for work. Some who were not employed connected their lack of a job to the severity of their injury or to their socio-political context: "Whether with crutches or without, there are no available job opportunities. Our economic situation is increasingly collapsing [in Iraq, particularly in Anbar]" (RSP64, Iraqi, M). Some female participants continued in their pre-treatment occupation; two, for instance, worked in a beauty salon. Some, who were engaged in household duties before, improved their ability to perform home chores and thus they could fulfil their family and social obligations, which they considered immensely important to their sense of purpose. Some younger participants also reported that after treatment they were able to continue their education. This was seen as quite a challenging step considering that after the injury they had spent many years outside the classroom.

For maxillofacial patients, the capacity to chew food again was described as simply revolutionary:

> This story I'm telling you [about my condition] is taking minutes to tell, but it took years of my life. One of the simplest examples [of my new life] was when I started gradually recovering and I started eating. At first, I started with baby-food items, eating soft food and liquids, no chewing, as I had no teeth. No food, no sandwiches. I used to sigh when I saw somebody bite a sandwich. I was hurt emotionally to see someone eating and chewing. I dreamed that I would be able to eat nuts again, which I love very much, and be able to bite and eat apples. (RSP71, Iraqi, M)

Besides physical improvement, a great sense of emotional relief was reported by both Syrian and Iraqi participants. Feeling "happier," "less fearful and upset about life," more "hopeful and optimistic," and "relieved" were common expressions used to describe this crucial impact. "It [the injury] was a worry, which vanished," one of them summarized (RSP38, Syrian, F). A "change of mood" was an expression frequently used to describe self-perceived emotional improvements. There were multiple reasons for this renewal. To begin with, emotional relief was immediately felt in the hospital in Amman due to the observed progress in treatment and physical improvement: for instance, "with every surgery, I could see my body improving."

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Some experienced this phenomenon after they had already given up on their limbs and despaired of their hopes. A sense of relief was particularly acute for those who knew that they were at risk for leg or hand amputation, but whose limbs were saved at the RSP. As they improved physically, participants' fear of becoming disabled in the future lifted: "Sometimes I see on the television disabled people with completely damaged arms or legs; if I hadn't gone to Amman I might have been like one of them – a disabled person" (RSP51, Iraqi, M).

The second cause of emotional relief was a reduction in the pain that had often caused daily suffering and disturbed sleep. One of the participants described his severe pain: "It was a very difficult time for me [before the treatment in Amman]. I had reached a point when I told them to give me a knife to cut off my arm because of the pain" (RSP59, Iraqi, M).

The third reason for an improvement in participants' emotional states was related to their new sense of security. Syrian participants, for instance, mentioned finally having stable accommodations at the MSF hospital, which had not been available to them from the moment they entered Jordan until their entry to the RSP. For Iraqis, a sense of security was gained simply by being removed from the tensions in Iraq. For some, a sense of insecurity, induced by injury-related trauma, hounded them for years. One of them, a former political prisoner, described this: "I changed my mood [recovered emotionally] by travelling outside Iraq; this was the first time for me to leave Iraq [after my imprisonment]" (RSP46, Iraqi, M). Another participant similarly commented: "I felt better in Amman. You know the situation in Iraq was at that time terrible: explosions everywhere and the security situation was deteriorating; so, when I was in Amman, I felt comfortable and everything there was better. I felt safe and my mood was better" (RSP53, Iraqi, M). These statements were frequently followed by an explanation that their emotional relief was only temporary and vanished once they returned to Iraq: "Believe me, when I was in Amman my mood changed and I felt better. And when I came back [to Iraq] I felt better for a while, and then later it [my emotional status] got worse and it's very bad now. It's rare that I feel calm. If you notice when I came here [to meet you] I was mad [angry]" (RSP46, Iraqi, M).

The MSF hospital staff often consider long hospitalizations a negative for the patient (absence from their families, from their work). The time the RSP patients spent away from the intense stress of daily life, however, seemed to be crucial for their emotional recovery. Kubiak (2005) suggests that chronic daily stress may gradually diminish people's capacity to cope effectively with traumatic life events, thereby increasing the likelihood that they will experience symptoms of PTSD. There is evidence that the participants' recovery was multifaceted and that the prolonged course of treatment at the

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RSP was instrumental in their recuperation, including long-term beneficial consequences for their mental health.

An improved emotional state was also reported to be directly related to enrichment in participants' social lives (reported by both Syrians and Iraqis). This was true particularly for those with increased mobility and aesthetic improvement. The emotional toll associated with being completely dependent on others socially isolated most of those participants. Much of this burden was lifted after treatment. A father of a female patient (RSP32, Syrian, F) described this: "Before she had the surgery, if she wanted to go to the toilet or just get up, she couldn't do that unless we helped her. When she had the surgery, she could walk by herself and bend her leg or walk alone in the street by herself; this was a big happiness for her." Some participants reported gaining new marriage opportunities after completing the treatment. One of them was clear that it was not only the improvement in his injured arm and leg but also his improved emotional state that enabled him to get married: "Honestly, I have disability in my arm, leg and poor eyesight. But I'm practising my life normally. I have a family. I got married. I have a girl [daughter]. They [MSF] treated my arm. They treated my leg. I've become capable of getting married. It wasn't possible before the treatment. Even my emotional state wouldn't have allowed me to get married before" (RSP20, Syrian, M).

New social opportunities were also reported by those with improvements in their appearance. One of the young male participants reported living in complete social isolation before plastic surgery on his face. He noted: "After I reached Amman my whole life changed in terms of treatment and my emotional state. My life has changed because before I was locking myself in my room twenty-four hours a day, but now I can go out" (RSP43, Iraqi, M). Even visual improvements on parts of the body other than the face seemed to have a positive impact on participants. One of them described how "shy" he felt when he was shaking hands with people, because his "pinkie finger was fixed in a bending position." Not being asked "about the injury all the time" was also mentioned as a life-changing benefit in social interactions.

Participants also described improved appearance as changing their sense of dignity. One of them described how the deformity of his mouth caused "the tea to pour out of it," which made him "feel embarrassed in front of people." He expressed his relief when this problem was solved after successful surgery. Another participant felt embarrassed "when saliva was coming out of my mouth when I was speaking." "The difference," he noted, "is that now I gain respect and what I speak about has an importance and people finally listen to me." "Speaking clearly" was also crucial for a participant who managed to maintain his professional life throughout the years-long treatment period. "Without teeth, I wasn't able to pronounce clearly, and it was hard for others to understand me. And physical appearance: I looked

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horrible before fixing my jaw and my teeth. This was so important, knowing that my work required meeting with other people, new people [and making positive impressions on them]" (RSP71, Iraqi, M).

Even the less obvious "gestures" from MSF increased patients' sense of dignity. Receiving MSF's per diem, for instance, not only helped Syrian patients to visit their families across Jordan in the intervals between treatment: it also had a great symbolic meaning attached to it. One of the participants, whose family was completely financially dependent on relatives, talked about the huge difference that arose when he was "finally able to manage his finances": "Everything has changed. Before, I was upset with this life. I didn't have money or anything. Her brothers [wife's brothers] used to pay our house rent. MSF gave me five JDs [Jordanian dinars]. I could manage [my finances] by myself, at least. I was so upset before. I had my soul back again because of the happiness I had for going to Al Mowasah hospital" (RSP19, Syrian, M).

There were other symbolic meanings attached to the treatment at MSF. A confirmation of Muslim values – stemming from the notion that participants lost trust because human life was uncared for in Iraq – is one example:

> For me as a Muslim, of course this [good treatment at the RSP] is important. Because the Quran says: 'Religion is all about good treatment.' The best thing in life is the nice treatment and that is what every Muslim loves and hopes for. In Western countries, who are Christians and Jews, they are not Muslims, but they treat each other with respect, and they rule with justice. But we all here [in Iraq] dream of justice! So why would you ask why this is important to me? Of course, this is important to me and to every Muslim. (RSP46, Iraqi, M)

Another participant expressed a new sense of loyalty: "[I learned] loyalty to the patients who were with me, and to the staff of the hospital" (RSP46, Iraqi, M).

Thus, the concept of quality of life appears to be a useful tool for assessing the impact of the programme, especially since understanding the quality of life for each patient is an essential part of establishing an individualized approach to care. According to participants' definitions of quality of life, the MSF programme currently addresses multiple aspects of the concept by directly improving the physical, emotional, and mental health of the patients and advancing their personal independence, by indirectly providing new opportunities for work, marriage, and social life, and by enhancing their general sense of stability. Other, less obvious aspects, such as the sense of safety, dignity, increased pleasure (for instance, the capacity to eat again), and a regained sense of "normality," are also tackled through a patient's exposure to the programme. Within MSF operations, the RSP is not considered a "lifesaving programme," but from the patients' perspective it is. The

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feeling that their "lives had been saved" was directly mentioned. A sense of freedom, "love and peace everywhere," and a "life without fear" are elements of the quality of life which were experienced by some patients in the RSP and are important for people affected by war.

Diverse mechanisms of adaptation

Thus far we have examined how aspects of participants' personal, professional, and social lives were influenced by treatment in the RSP. Improvements in the quality of life of the participants, however, were largely dependent on the participants' own ability to adapt to change. The participants reported a number of different mechanisms they employed in an effort to make sense of their current existence and gain a new perspective on life. Similar to the way they framed their war narratives, they strategically used observations and explanations and attached different meanings to their experiences. Let us look at some of these mechanisms.

Seeing the misery of others…

Surprisingly, the most commonly reported coping mechanism[1] was witnessing others who they perceived were in a worse situation: "When you see other people's misery, your misery is nothing compared to theirs" (RSP8, Syrian, M). Even participants whose injuries were rather severe maintained this approach. One of the Syrians who suffered from burns over large parts of her face and body commented: "I have my own skin. It's OK. There isn't anything very bad. I have a picture of a Palestinian woman [a burn victim]. When I look at it, I thank God [for my condition]. She's Palestinian. She was shown on the news. I compare myself to her. This gives me more motivation [in life]" (RSP15, Syrian, F).

Another participant who lost his eye and had one arm amputated after an explosion in Iraq reported:

> When I was observing other injured people [in the hospital] I realized I was not exceptional among all other people, and I'm not the only one who was injured. So, I was satisfied [with this realization] and I accepted my destiny. I also noticed that many patients had lost their legs, both legs, and one of the young children's faces was entirely burned. I know I have lost my eye, but I am better because I kept my facial features, and I have lost my hand. If I am ashamed somehow of my amputated hand, I can hide it in my pocket [if I don't want anyone else to see it] and I can cover my eyes [with sunglasses] [participant is wearing sunglasses during the entire interview]. But this poor child, how can she cover her face?! (RSP61, Iraqi, M)

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Religious inspirations

"Never will we be struck except by what Allah has decreed for us; He is our protector" (Surah At-Tawbah [9:51], Verse 51, Quran). This quote from the Quran was framed and hung on the living room wall in one of the participant's houses. Religious beliefs served as a source of strength and inspiration. One of the participants expressed it this way: "The strength is all from God" (RSP5, Syrian, M). The following quote from the Quran was mentioned by a number of participants when talking about religious inspirations: "The prophet says: 'The one who stays in his house, has good health and food for the day, is the one who owns all life.'"

A great level of acceptance and calm was also seen in those who had taken a fatalistic approach: "It was all God's will; it's our fate, and we should continue with our life." Some interpreted their past as "a lesson that God has sent to them to test them": "Thank God, it's a test from Him. It's His will" (RSP6, Syrian, M). Another participant also took a positive, religiously inspired outlook: "I believe that this is a message from God, and everything changed after that. He did not want me dead! Before the injury I was wild, way too wild. I had no faith, did not pray. But this is a lesson from God, and I have changed [for the better] since the incident" (RSP61, Iraqi, M).

Positive outlook on life

Many of the participants revealed a positive outlook on life and communicated a great deal of self-reliance and self-confidence when they talked about coping. One of them conceptualized his life lived with few available resources to be simply a part of the general human condition: "In the old days people lived similarly, with no water or electricity. So, one should be able to adapt" (RSP13, Syrian, M). Some appeared content and explained that they had drawn a line between their past and present lives: "Life has changed. When one is out of Syria, there's security. There's no bombs or anything else. We live here. We go to work. We have forgotten everything we went through. But it would be a memory of what happened with us in the past" (RSP9, Syrian, M).

The importance of hope was mentioned as a concept that kept them going: "Hope. One just keeps on hoping" (RSP14, Syrian, M); and "Let me tell you something: I have hope that we will go back to Syria and be like we were before. That is what gives me hope in life. I haven't given up on hope" (RSP28, Syrian, M).

An attachment to life was recognized as the ultimate source of strength: "Because we wanted to stay alive. Life has to continue" (RSP25, Syrian, M). Levels of acceptance and optimism were very high for those who had had near-death experiences. One of the participants, who was in coma for a long

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period of time, expressed this: "I thank God always for saving me because it was like a miracle [that I survived]! Even when people come to visit me, they say, 'This is like one of the Seven Wonders of the World,' by which they mean that it is not something normal that I survived such an accident, and I am still able to see my family and my kids. So, that was a miracle for me, and I accept it [with all the consequences]" (RSP54, Iraqi, M).

Focus on family roles

There was some gender-related difference in the way participants described their coping mechanisms, particularly when it came to discussing family roles. The idea of "men remaining strong" was communicated by both male and female participants. For instance, I asked one of the male participants, who suffered from an amputation of his right foot, about his ways of coping. His wife spoke up instead: "There is also responsibility: house, children, and their expenses. He should be emotionally and physically strong to be responsible for the family. He had the injury, then would he stay at home and cry for losing a limb? He has expenses and responsibility [to meet]! He should be strong." The same participant described how he was able to cope with a number of difficulties he encountered in Syria, but when he saw his family living in a refugee camp this made him "lose his mind": "When I arrived here [in Jordan] and saw that my wife and children were living in a tent, I lost my mind! They were living in a tent and it was cold [winter]. We were living in a normal house before. They were not used to being in a tent. Even during the crisis [in Syria], moving them from one house to another was better" (RSP7, Syrian, M).

I have often heard discourses on men in the Middle Eastern cultural context that claim men do not express their emotions for fear of being perceived as weak. This was in stark contrast to my observation that male participants were open and more than willing to express their emotions. At the same time, it is true that being unable to play the role of family provider certainly created pressure on men, both self-imposed and from the broader society. During interviews men reported constantly switching focus from their own injuries and personal suffering to their role as head of the family.

The family context for both male and female participants, particularly the protective role of parent caring for children and their wellbeing, put the awareness of injuries into a different perspective. A male participant stated: "The human himself is strong. And he's stronger when his children are around him" (RSP36, Syrian, M). Similarly, an elderly Syrian woman, who had sustained an injury after a bomb hit the well outside her house, commented: "I wasn't sad. I wasn't sad even when I got injured. I was conscious; I didn't pass out. Thank God. The grandchildren were all around me. I told them to go inside. Once they went in, the explosion hit me and I said, "Thank

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God, it hit me, not anybody else [not the grandchildren] from the family" (RSP34, Syrian, F).

Supportive family environment

It was not only the perception of family roles that influenced the participants. The practical and emotional support provided by family members was of immense importance during and after their rehabilitation. When I observed family dynamics, I saw many warm and affectionate relationships.

Having strong family links, particularly having a good relationship with a spouse, seems to be a strong psychologically protective mechanism. Most participants (both male and female, Syrian and Iraqi) reported that their spouses were extremely supportive of them. One of the husbands whose wife had suffered in an explosion talked about it as follows: "Our love for each other made us continue and be even stronger. We didn't allow the circumstances to break us, and will never let them do that" (RSP44, Iraqi, F). Another participant talked about her relationship: "No. My injury didn't affect our relationship [with her husband]." Her husband added: "My relationship with my wife… I love her; she's my beloved; she's very dear to me." She continued: "They even told him to get married with another woman when I travelled for treatment, but he…" Husband [interrupting his wife]: "I refused that" (RSP41, Iraqi, M).

The family safety net (parents, spouses, siblings) was also vital both in providing physical care for patients and in giving them emotional encouragement. Those who were in the hospital without caregivers – that is, without this coping mechanism – were much more frequently overwhelmed by the intense feeling of loneliness and depression: "The most difficult part of my time in the hospital for me was that nobody was around me. No one from my family [was with me]. I was alone. My family was still in Syria. I used to talk to them over the phone and that made me feel depressed. And my father and mother died" (RSP3, Syrian, F). Another patient became aware of these feelings when he observed others supported by their caregivers: "They took me out of the OT. There was another guy [in the OT] and his mother was waiting for him. She started praying for me: 'May God heal you, my son! May God be with you!' I started crying. I felt that I had nobody [I felt completely alone]. I can't forget that feeling and that scene at all" (RSP27, Syrian, M).

Shift in focus from injury to other aspects of life

Some participants completely shifted attention from their injuries to other aspects of their lives. An example was a female participant who throughout the interview attempted to change the topic of discussion to her recent

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weight gain. She wondered why it had happened. She explained that neither her diet nor lifestyle had changed, and she kept asking advice about losing weight. She reported that her body's reshaping and her husband's related negative comments were "her major problem in life." From the outside, this appeared extreme considering that her family, with four children, was living a nomadic life in a tent and her two sons (the youngest only eleven years old) were working to provide food for the entire group.

Three male Iraqi participants shifted their focus to romantic relationships. In all three cases their love did not result in marriage, but, despite that, they appeared optimistic about their lives and did not seem particularly emotionally affected when they discussed their injuries. When I asked one of them how he coped with missing his family while he was in Amman, he responded: "To be honest, I met a girl there [in Amman], and she was with me and comforting me [smiling]. I met her through a computer institute inside the hospital – so when I was there, I met her in this institute. She was studying there, and I fell in love with her" (RSP55, Iraqi, M). He reported that the girl eventually married somebody else, but they kept in touch. Another participant told of a hospital love story that also did not result in marriage because the families disapproved. But he reported feeling "better" once he had fallen in love, and his sister commented: "When he's in love, he starts to love life and starts to appreciate the value of life" (RSP74, Iraqi, M).

Another Iraqi participant – already mentioned as coping well with his amputated hand and missing eye – said his "only issue in life was a failing relationship with the girl that he loved": "I'm in great health. I don't suffer any disease thanks to God" (RSP61, Iraqi, M).

Struggling to cope

A few participants reported that despite their best efforts they are still not able to cope with their current situation or their memories. This is in line with their reporting on the insufficient psychosocial support they received during their time in the MSF hospital. Here are some of their accounts: "Do you know that I haven't coped with anything until now? It has been one or two years since I've been here [in Jordan]; I could not… Until now, I can't speak to people" (RSP2, Syrian, F).

Another example was an Iraqi participant who admitted that he was not dealing well with the situation: "I suffered a lot, especially since I keep my sorrow inside of me. I even smoke two packs of cigarettes per day because of the stress; you can see my teeth [all destroyed] because of smoking" (RSP51, Iraqi, M).

Our findings on multiple patients' adaptive mechanisms are in line with research on survivors of traumatic events and indicate that patients are generally far more resilient than clinical studies and case reports tend to suggest

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(Bonanno, 2004). Published evidence also proposes that with adequate support and the passing of time most trauma survivors are likely to regain their psychological equilibrium (Becker et al., 1999; Foa, 1997). Building on this understanding allowed us to ask what elements contributed to the resilience of patients in the RSP. The participants communicated multiple adaptive mechanisms that helped them live with their memories and their current situation. Their explanations demonstrated their sense of autonomy and resilience, elements that it is particularly important to acknowledge, since the hospital staff at the RSP too often perceived the patients as victims and passive receivers of help. Ultimately, it is important to study individual adaptive mechanisms to better understand what parts of the RSP MSF could enhance, as well as to contribute ideas to other organizations that support and care for victims of war.

Symbolic meanings and social integration

As we have seen, social interaction is one of the main elements of a good quality of life for patients. Throughout my interviews it was obvious that the participants do not view their bodies purely through the lens of function – the current priority outcome of the RSP. There are symbolic and social meanings attached to their injuries. These meanings are uniquely personal, but what is common is the tendency to associate them with the social relations they experience today, and it is important to fully understand this, a less obvious aspect of the lives of the victims of war.

An injury as a reminder

When discussing how they felt when exposing their injuries in public, Syrian participants in particular reported that other people's reactions disturbed them. This was predominantly related to questions people would pose; the questions provoked difficult memories. For instance:

> I was embarrassed and always used to hide my [deformed] fingers and never show them to anyone. Sometimes when I go out I like to wear gloves [to hide them]. Because if somebody sees the injury, s/he would ask me about it, "What happened and how did it happen?" So, I would remember all the traumatic events that happened to me. Of course, I would not forget what happened. But I would not like to think and talk about it all the time. It's difficult to talk about it. It's a feeling that I wouldn't like people to have. (RSP1, Syrian, F)

Another participant, who reported wearing gloves in public to hide her injured hand, felt similarly: "There are people who would have a look of sympathy [seeing my hands], and other people would ask, 'Why? From

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what? How?' And you would need to repeat the same [story over and over again]" (RSP21, Syrian, F).

Negative comments are a reminder of a life lost. A burn victim who otherwise led a successful professional life explained: "I am otherwise content, but it's the way that others look at you, or sometimes having to hear their painful comments. That's what really gets you down and reminds you of the life you lost: your home, your husband, your family, your health, your beauty, your youth. I mean I lost all of that years ago, at the peak of my youth" (RSP73, Iraqi, F).

And it was not only the comments they received. It was also the case that looking at their own injuries provoked memories. "No, in the beginning, whenever I looked at my legs, I felt emotionally tired. I couldn't look at the wound. I was afraid" (RSP7, Syrian, M). "When something strange [a foreign body, like shrapnel] gets into one's body, he suffers a lot. All the events that happened with that person are [stored in those wounds] like a disease. He remembers how his life was and how it has become. And how he suffers from that. This creates difficulty for him" (RSP9, Syrian, M).

But sometimes there was an active attempt to memorialize events. I have already mentioned a father who showed us the metal plate, nails, and bone screws that were taken out of his son's leg and stored in a plastic bag in their home. When he showed me these objects he commented, "These are to remember… These are like souvenirs" (RSP12, Syrian, M).

Family and social pressure

Many participants felt affected by the "looks of sympathy" they received in their social environment, and some reported how much these looks "hurt them": "It's from my personal experience: when you lack a certain aspect of your health and this is apparent to others, such as a disability in a certain part of your body, the way that others look at you REALLY HURTS, really gets to you and emotionally affects you" (RSP71, Iraqi, M). Participants were also clear that they did not want to be labelled "disabled." One explained:

> Some comments [people] don't mean to belittle you, like they try to show some compassion, but they don't actually know that this hurts! Like the word "disabled"! Like, for example, if I'm doing something and someone says "Don't let him do it: he cannot do it; he's disabled," this hurts my feeling even if they didn't mean it. It hurts, and I hate the word "disabled," especially knowing that I was a physically active person who couldn't stay still in one place before [I was always doing something]. (RSP58, Iraqi, M)

To avoid dealing with her husband's family, with whom she lives, one of the Iraqi participants adopted a strategy to completely hide her leg amputation.

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She arrived for the interview wearing a long skirt and crutches and moved relatively naturally, so that nobody would notice anything amiss. She commented: "Nobody knows about the amputation issue, except my family, and my husband. The wife of my brother-in-law, she's not a respectful woman. If she knew about my injury, she would hurt my feelings" (RSP41, Iraqi, F).

Social pressure exists in many forms. One of the female patients, a burn victim, reported that she constantly suffered pressure to "lower her expectations in life," and that this was said particularly in reference to choosing a life partner. She had been married and had divorced. She reflected:

> Everybody likes my ideas, morals, and everything. But everything stops when it comes to the burns. What most destroys me isn't the burns [on my body]: what destroys me is the people who are around me [my family] and the ones that I know [who comment on me]. [To the researcher] I'm a girl and you are a girl. Because I'm burnt, don't I have the right to have what you have? Your future is [supposed to be] different from mine? Your life, what you ask for [in life], I can't ask for it? I should be patient. I should live with anyone [even if I don't think they are good for me]. This is what kills me. Sometimes, I wonder if it's really me – that I'm wrong and the rest of the people are right. I'm a human being. I have the right to have my brother take care of me. I have the right to get married like any girl. I have the right to have a complete man who lets me live in a house and spends [money] on me. I have the right to eat, drink, and dress up. They [her family and other people] say, "No! Not you! Why don't you accept the minimum?" (RSP15, Syrian, F)

Family life was severely compromised for some participants. Four of them reported getting divorced because their spouses could not cope with their physical condition. One of the participants, who was limping due to a shortening of one leg, told me that he got divorced because his "ex-wife when she saw my injuries started negatively commenting on them and making me feel embarrassed" (RSP9, Syrian, M). This participant appeared cheerful and in control of his life. Hence, participants who are otherwise successful in dealing with their personal situation can suffer rejection at the hands of their social network.

Lost sense of manhood, womanhood

Perception of their bodies also influenced how participants felt about their masculinity or femininity. This topic caused obvious emotional distress for both male and female participants. One participant was severely embarrassed about using crutches. He commented that his appearance on crutches directly reflected on his masculinity and this had an emotional impact on him:

> I felt I was a disabled human. I was still disabled. You know better [than me], when you look at a man with crutches, [you know] things won't work out for

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> him. When I was walking with the crutches the human being [myself] was a quarter of a man. I was with crutches; how do you imagine I was like? My emotional state is different now [after I started walking normally]. It has changed now. I'm a 100% good [real] man. (RSP13, Syrian, M)

Another participant felt similarly, remarking that when he lost his fitness, he lost his sense of masculinity. He had a sense that he had become "only half human": "My situation was unstable; I felt like I was a half human [after the injury]. I was helpless. I wasn't able to move normally like I used to. I used to [before the injury] carry heavy objects on my back, like an air conditioner [a sign of physical strength and masculinity]. But then I was not able to lift anything [any more]" (RSP68, Iraqi, M).

The lack of facial hair also compromised the confidence of a young male participant, who was injured in an explosion as a child. His father commented on the difficulties related to his appearance: "Of course, he was emotionally hurt [after the injury]. He is still like this, and I don't like to say this in front of him. He feels bad when he sees other men grow beards, and you know how young men think. He also grew a moustache before, but as you can see there is no hair growing here now [points to the moustache area]" (RSP43, Iraqi, M).

For female participants, having scars was directly linked to notions of being "feminine and beautiful." This was ultimately related to their marriage opportunities and to the idea that "there is no future." One of them started crying when I enquired about the way in which she lives with her injury. Her father responded for her:

> As a young girl, she aspired to get married and establish a family. The injury has left scars, which make her feel insecure. Generally, she cannot live normally and be seen by other people. She lacks self-confidence and she feels she is lacking a good appearance. And this is something normal for girls at her age. Young ladies wish to get married and start a family. This element, a good appearance, is missing in her life. She cannot be [socialize] with other people. And you know currently people judge by appearance. I'm not getting into the details but, generally speaking, I know how she feels: she feels that there are missing things in her face and hand. So, she aspires to improve her looks and be normal once again – nothing more, nothing less. (RSP66, Iraqi, M)

Not being "feminine enough to have a future" was described by another young Iraqi woman, who, as a child, suffered from burns over her torso and neck. She commented: "It [the burns] affects everything in my life; it even affects my future. Sometimes I think I have no future." Her sister explained how the participant's marriage opportunities were close to non-existent:

> When someone comes to court her, and he hears about her injuries, he changes his mind. This is how things are in Iraq. Men think like this: women should

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> always be beautiful and perfect, otherwise they will shame her and make her feel insecure. Only her face looks normal, but everything else is deformed – who [which man] can accept that? Men, they don't accept the fact that she has burn scars on her body. And she always cries because of that! (RSP50, Iraqi, F)

Another female participant felt that divorce following her accident was inevitable after her "beauty was compromised": "I wasn't like this [before], you know [participant pulls out her personal ID and shows us a picture of herself before the injury]. When he [my husband] saw that I was deformed, he left me, right after the accident. We became separated. I accepted that. Because I was deformed, so I accepted the fact. And though we have four children, he just left us, without alimony [an allowance support]" (RSP73, Iraqi, F).

Contrary to this, a very supportive husband talked on his wife's behalf when she cried while reflecting on the impact of the injury on her sense of femininity. He confirmed how the challenges brought him closer to his wife. At the same time, he understood his wife's' emotional struggle:

> That was the period [after the injury] that made us close to each other the most. The problem she suffered was emotional also because she felt something is missing – and you know when someone undergoes such difficulties, she develops some self-esteem issues. All that caused problems [insecurities] for her as a woman, and she was asking me always, "What do I mean to you?" and "I'm not attractive anymore" – you know, all these problems, especially because for women the most important thing is their beauty and femininity. These things are like complimentary issues for them, and losing beauty and femininity causes problems for them. She suffered a lot. (RSP44, Iraqi, F)

Association of scars with deviant behaviour

Male participants with facial scars were similarly affected; they were extremely aware of their scars. They described the impact, even if, from the observers' perspective, their scars were not obvious. They strongly believed that their scars made them seem in some way deviant in the eyes of others. One of them, who suffered after an explosion, had a superficial scar, a dark patch under one of his eyes about five centimetres long. If he hadn't talked about it I would have barely noticed it, and my assistant confirmed my feeling. The participant said: "I feel that I lack something and that I'm not good. When people look at me, they don't say anything. But I feel that there's something [on their mind]. When they look at me, it's like [they notice] there's something on my face. They think that this person is a troublemaker or a criminal or someone [dangerous] like that" (RSP14, Syrian, M).

Another participant's face was severely damaged by gunshot. His lower jaw was damaged, but reconstructive surgery resulted in natural-looking

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features, including the growth of facial hair. There was a thin, about ten-centimetres-long scar running across the side of the jaw. He reported that his appearance caused him immense suffering: "I suffer from the injury. I am asked many questions. People think it's because I was cut with a knife in a fight. They think that any person who has a scar in the face has done bad things or is a troublemaker. You might be with a person whom you meet for the first time – he would think badly of you" (RSP22, Syrian, M).

Severe social anxiety

It was obvious that more severe facial deformities completely dominated a participant's life. Most participants with facial deformities reported living in complete social isolation and "never leaving the house." Younger participants, those injured as children, suffered particularly in this way. "Because of the external appearance, I cannot go out with my friends; I cannot go out of my house. Your face is your outlook; I even have injuries on the rest of my body, but these are kind of covered [with clothes], and the burns on the body don't have the same impact [on my social life] as the deformed face" (RSP48, Iraqi, M). His father reported that his son had left his education due to the negative comments he received: "In fact, when he got a little better, we let him go to school, but, you know, kids at school were calling him names and making comments, and he was so annoyed he left the school again."

Meeting one of the young male participants left a strong impression on me. He currently lives with his parents in Baghdad and suffers from severe social anxiety. His mother told me that he usually refuses to see visitors but made an exception for us. His statement that if he could, he would "erase his life [finish it]" was an indication that he had reached a deep level of depression and despair. From his intelligent and insightful answers, it was obvious that he reflects daily on his situation. His poor self-esteem and self-perception of weakness were related to his lack of constructive social interaction:

> There is no issue with my health except the visual appearance. Whenever I go out, I hear people say comments, and I ignore them and act like I didn't hear them. Weak people [like me] don't answer [to provocations]: they choose solitude. I haven't left the house since I came back from Amman in 2013. I don't go out except for going to the shop to buy things I need – and I go back home and stay alone. I never meet anybody [out of my house]. (RSP56, Iraqi, M)

This patient also said that he feels a lack of safety, a feeling that began the moment his injury occurred in childhood.

All these participants considered that the condition of their faces gave them no other option than to live in social isolation. Their only idea of a way to improve the situation was to improve the appearance of their faces.

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Social exclusion and feelings of not being understood by anyone caused immense emotional suffering among patients, particularly those with facial deformities. These patients have lost their most important personal asset: their physical and social integrity, and they feel "stuck" in an unbearable situation. They all reported different degrees of depression and anxiety.

The importance of lost limbs

For patients who lost a limb during their injury or who underwent amputation, the lost limb was associated with a complex mix of emotional and socio-religious meanings. It was extremely important for them to know if the remains of their limb were preserved after amputation and to know where they were located. They also wanted to know that burial of the limb would follow Islamic tradition.

One of them (RSP16) mentioned how essential it had been for him to locate his missing leg right after the explosion, but how he had worried that those efforts would cause more casualties: "I was encouraging others to take me away [right after explosion] even if there was no leg, so that a big number of people would not be hit again [while searching for it]." They took him to Jordan, and he was in a coma for days. Once he woke up, his question was "Did the leg really come with me here?" As proof, they showed him a video which was taken in the Mafraq hospital in Jordan – his "leg was still there" – but, as he explained, it was later fully amputated in the Islamic hospital in Amman. Another participant (RSP69, Iraqi, M), who was injured in a car accident, explained that both of his legs were amputated, but he added, "Actually, one of my legs couldn't be found [after the accident]."

One of the participants (RSP16) explained the proper procedure for burying an amputated leg. By Islamic tradition, it is supposed to be washed, wrapped in white cloth, and buried. At the RSP, this tradition and associated legal procedures are followed and documented, and burial of the amputated limbs takes place at an Islamic cemetery. Participants' comments indicate that there is a strong emotional and symbolic meaning attached to amputated limbs. Sufficient communication with patients about the procedures involved in disposing of them was an essential part of easing their grief.

Taking pride in their disabled body

"Disability is in the mind, not in the body and looks" was a statement made by one of the participants. In his eyes, being morally right (being on the repressed side in the war) and having taken action to save others while sustaining his own injury seemed to be immensely important. Today he lives optimistically but with a permanent limp. He is an example of somebody

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who does not describe their injury as a symbol of disability, but rather as a sign of heroism, and that makes him proud.[2] Some other participants took a similar outlook on their situation.

We met one participant in the countryside of northern Jordan. He met us near his car along the main road and then directed us to the simple house where he resides today with his wife and children. It was only after he exited the car that I noticed his amputated leg. He moved very confidently with the support of one crutch. He had an air of strength, pride, and charisma. He spoke with full self-confidence and appeared emotionally stable. This participant (RSP16, Syrian, M) reported being injured while "trying to help a man whom he knew from the village and whose car was hit by a missile." During the interview he emphasized that "he was not injured by any military operation, but while helping others." When I enquired about his disability he stated, "I have no physical disability; my disability is only financial."

We met a participant with a similar attitude in his rented apartment in Amman. He started his narrative by telling us how he was rescuing people when his injury occurred: "There were people whose houses were hit by bombs. We wanted to help them, to take the little children from under the ruins." He explained the way he looked at his body today: "It's a disability. I will have it till I die. I have a disability that I am not ashamed of, but proud of. It was an honour for me to take people from under the ruins" (RSP9, Syrian, M). Unlike many other participants, he did not report being embarrassed by limping in public. He looked cheerful, was articulate, and emotionally stable, and this despite reporting on (and showing us a video) of his friend who was hit by shrapnel and died on the spot during the same event.

Injury as a sense of empowerment

Some participants took a completely different approach to their injuries. They interpreted them as a source that enabled them to gain elements in life that would otherwise be missing. One, for example, was not bothered by the "merciful looks" he received in public when he walked with crutches. He was pleased to comment that, on occasion, walking with crutches would get him a free lift: "Sometimes when I walk, someone would let me get into his car [to give me a ride], and sometimes they don't let me pay" (RSP11, Syrian, M).

Another participant was convinced that with the "right type of injury" one could leave Jordan and emigrate more easily: "I said the truth [to UNCHR], 'I'm a man who was shot by a bullet.' My brother came here [to Jordan] after me and told them [UNCHR] he was injured by shrapnel, and he's in America now. I told them I was injured by a bullet and therefore I am still here" (RSP13, Syrian, M).

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A father who spent long periods of time at home in a wheelchair after his injury appreciated the opportunity to be with his children. He saw a clear advantage compared to other fathers. He warmly described this:

> Especially for us Iraqis, we can't be away from our children for a long time. In addition to that, I was so attached to them because since 2009 I had stayed at home with them. I was watching over them and studying and playing with them. So, I got attached and connected to them, probably more than the fathers who leave early in the morning for their jobs, like at 7am and come back home at 12am and then go straight to bed. But for me I wake up at seven in the morning and wait for them to come back from school at 12pm so I can play with them. So, we became attached and connected to each other. (RSP69, Iraqi, M)

A damaged face was interpreted as a means to make a political statement by a participant who was shot by an American soldier. He described this as follows:

> It's a big difference when you see someone who looks normal or semi normal and one who has a completely damaged face [like me], especially for people who don't know me. At the same time, this [pointing at his face] was a message to show to the rest of the world what the US Army did to our country and the people of our country. I don't want that people around the world look with admiration to the Americans or say they are good people. All they did was to cause us pain. (RSP71, Iraqi, M)

In sum, the participants reported differing degrees of quality in the lives they lead today. To a large extent their quality of life was associated with the improvements resulting from treatment at the RSP. Still, each of them employed an individual approach to managing adversity, and each one dealt with their injured bodies and their task of reintegrating into society in a decidedly unique way.

Notes

1 Psychological literature on stress and reaction to adversity distinguishes between "coping mechanisms" as a conscious (intentional) strategy and "defense mechanisms," which are considered to be applied outside of awareness (non-intentional). There is a controversial debate on the extent to which the categories overlap and whether they are considered "adjustment" or "maladjustment" (Cramer, 1998). I use the term "adaptation mechanisms" to refer to both conscious and sub-conscious processes. I use the term "coping mechanism" to describe conscious adaptation mechanisms, given that participants self-reported them.
2 This attitude is in conflict with the commonly expressed opinion of staff at the RSP, who perceive patients as victims.

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6

Reflection on the rehabilitation of civilian victims of war and beyond

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The experiences shared by MSF staff and their patients advances our understanding of the rehabilitation process. But before we delve into this, it is essential to review the limitations of this research and to reflect on how to interpret the results. During the research a number of limitations emerged, including our sampling of participants. In addition, my role as researcher working in an exceptional socio-political context deserves attention, as does my emotional response.

In this discussion we debate the need for multiple rehabilitation components. We start by reflecting on the relationship between healthcare providers and patients in two predominant theoretical models of disability, namely medical and social. With the change in attitude towards disability over time, we note how attitudes in the humanitarian field have also transformed. Of course, we focus on victims of war and their need for social recovery – an essential part of the rehabilitation process in past centuries but mostly forgotten in recent decades. And we pay special attention to the care of civilian victims of armed conflict. We discuss symbolic healing, too, the last and essential component of rehabilitation for victims of war. The chapter concludes with an assessment of the potential for implementing our findings in the broader context of disability care, and we close with proposed avenues for further research.

Research constraints and limitations

Limitations of sampling methods

To form a research cohort among RSP staff so we could study their perceptions of patients, we relied on self-selection and voluntary participation. Views of staff members who may have been more critical, or of those with a less outgoing personality, may therefore be missing. A large number of

participants (ninety-nine out of a total of 209 members of staff) was included in the study sample to minimize this bias.

Not being able to include Yemeni patients in the study when examining patient views was certainly a major constraint. As explored in Chapter 2, the perceptions of MSF staff towards Yemeni patients were strongly negative, and this could have potential consequences in delivery of care for this group. In addition, the potential for fieldwork in Yemen was thoroughly discussed. The war was raging in Yemen at the time research was conducted, and that situation strictly compromised access to humanitarian aid for the affected populations. Meanwhile, MSF activity in Yemen was based on a sensitive agreement between MSF and political actors. The idea that I do follow-up interviews in Yemen was vetoed as potentially having negative consequences. On balance, suspicion towards a researcher could have endangered MSF's negotiations. My mobility in Yemen would have been severely restricted, particularly in areas of active fighting, where the wounded originate. Furthermore, moving participants to an interview location could have put them in life-threatening situations. Considering all this, MSF concluded that it would not be ethical or even sensible to conduct interviews in Yemen. Phone interviews were considered but ruled out both because of the sensitivity of discussion topics and the need for translation over the phone, which could create the conditions for bias in data collection.

The selection of patient participants was based on those who had completed the programme. This was done to ensure that participants had taken part in all the treatment activities and that they had, from a programme perspective, received the maximum care currently available. The views of those who did not complete the programme due to their own initiative or because they returned home in the middle of treatment may well have been different and more critical than the ones I documented.

Interactions with participants

A critical evaluation of the researcher's role and the impact the researcher may have on the research and its outcomes is referred to as reflexivity (Patton, 2002; Berger, 2015). It allows one to identify personal characteristics that could potentially influence data collection, analysis, or interpretation. I used the lens of reflexivity to examine my interactions with the participants.

As a foreigner, I was given the label "expat," particularly by the staff from Arab countries, who often used a vocabulary of "us" and "them," meaning expats, when discussing issues in the hospital. Being from the former Yugoslavia appeared important, however, as I was perceived as a person with an understanding of the issues of war and related personal struggles. Iraqi members of staff in particular could make a connection with the former Yugoslavia

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due to past political and military collaboration. This put me in a slightly more favourable position and fostered my social relations.

Lack of knowledge of Arabic certainly created blind spots in my observations. I was unable to understand the side chats in the hospital corridors and meetings. Despite most members of staff speaking English, use of Arabic was quite common, even in the presence of non-Arabic speakers, particularly when an attempt was made to keep an issue away from the expats. I learned basic Arabic phrases of politeness and personal introduction, and when I used them as an icebreaker with patients and staff, it was greatly appreciated.

I developed informal relationships with my colleagues at the MSF hospital, which assisted in my understanding of their relationships with patients, their personal and professional struggles during their working day, and their attitudes towards their professional roles. At the same time, informal interactions presented the danger that my capacity as an observer would dissolve. Realizing this, my CRASH colleagues often reminded me of my role, and I made a consistent effort to keep my observational lens in focus.

Working in a unique socio-political context

Conducting interviews in a sensitive socio-political environment was challenging. In the field, some former MSF patients met us with trepidation, often nervous and sometimes suspicious. Despite a clear explanation of the research objectives and procedures, I was frequently asked if I was working as a journalist. Taking pictures of participants was completely out of the question. Many expressed a fear of being identified, particularly when sharing political views, which was frequently done without any enquiry on my part. Syrian participants related concerns about family members who were still in Syria and thought that any political affiliation they expressed could potentially affect their loved ones.

Iraqi participants communicated their political affiliations in a more settled way. One participant communicated his fondness for the "old regime" by naming one of the hospital surgeons Saddam Hussein and comparing him accordingly, stating, "When he left [the surgeon and Saddam Hussein], everything collapsed." Another patient said that his son could not access education or work opportunities due to "the political climate, which is not favourable to [Sunnis] at the moment." This was in contrast to his son, who claimed that he could not work due to difficulties with his leg, which was "still stiff in a knee area." Yet another participant reported working in the military in the "old regime" and then commented how he has "lost everything: dignity, job, pension, and housing" due to the change of political climate. Another talked about her husband, who was imprisoned under Saddam Hussein's regime, and commented that they still do not feel secure.

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There were other, carefully chosen ways participants declared their background. One of them expressed his surprise at the doctor who treated him "well" in Iraq. According to my interpreter, the doctor's name he provided was a typical Shia clan name: "He was from another tribe, but he was very good [to me]; he treated me well."

It was important to understand such notions, and particularly to understand a participant's fears at the beginning of an interview. The process sometimes called for a lot of reassurance from our side. One of the patients in Baghdad, for instance, refused to allow us to visit his home, stating that it would be unsafe for him. He expressed concerns while talking to us and at one point asked if the Iraqi government had given us permission to do these interviews. At the end of the interview, he asked if the information he gave could in any way compromise his security. And then he wondered if he had said anything "wrongly" – that is, in a way that could be interpreted as being against the current government. Another participant, after inviting us to her house, wanted to confirm that "we really worked for MSF." We had to show her our work IDs to prove we were who we said we were.

Another example of the sensitivity of our interview environment emerged when we were arranging reimbursement for the travel costs for one of the participants in Baghdad. The hospital secretary asked the location of the participant's residence in order to pay the appropriate amount. The participant's husband was offended, saying that they "came to participate out of the gratitude to MSF and don't need any money." He continued: "You don't know how much we suffered due to sectarian violence. Our house was burned." We managed to calm him, and he accepted the reimbursement, but it become clear that even a residency location, which would be an indication of a Shia or Sunni neighbourhood, was considered a sensitive topic.

My own emotional world

The interview process was emotionally charged not only for the participants. Members of my research team and I also experienced a range of emotions. I am certain that my emotional responses and my previous experience in a war setting influenced my outlook on the patients' narratives.

Interviews with these participants were certainly the most challenging I have conducted in my career as a field researcher. Among the participants were victims of torture, parents whose children had died as a result of war violence, those who had witnessed mass killings, and many whose life had been at risk on numerous occasions. Witnessing the financial, social, and/or legal hardships they faced in the present was also profoundly moving.

"It feels like walking over a mine field." This was a thought that ran through my mind daily. Even the most general question could cause a

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participant to burst into tears. The emotional manifestations that patients exhibited ranged from complete memory block, through a frozen state where no visual sign of emotion could be detected, to extensive crying throughout the visit. The unpredictability of these responses made every day feel like a new beginning. The sense that there was nothing I could do to prepare for any specific interview was at times overwhelming.

Occasionally I experienced feelings of guilt, questioning if I had said the right thing and if there was anything else I could have said or done to comfort the person in the interview. After the interviews, I usually experienced a feeling of deep sorrow which only slowly lifted later in the day. The feeling of helplessness when reflecting on the absurdity of war and on the extent of human suffering lasted for a long time. During the research I was not able to follow the news from the Middle East without experiencing emotional distress.

Sometimes there were moments when I questioned if participants' mental health was compromised to the point that they might react aggressively to my questions. This was particularly true in Iraq, where participants often expressed their anger. On one occasion, for instance, we met a participant in Baghdad who made my interpreter and myself feel uneasy, particularly at the beginning of the interview. As soon as he entered the room his behaviour seemed neurotic: trembling hands, fast, sudden movements, and a distracted expression on his face. In addition, his responses were not always logical. He decided to show us his ID, which, according to him, "authorized him to carry weapons." While interacting with him, I remember hoping that he had been properly body-searched at the entrance to the hospital. As the interview went on, however, the participant calmed down and it became obvious that he was deeply troubled by the life he was living. This particular interview reinforced the feeling of daily unpredictability in our work.

There were times when we got caught in complex interactions with our participants. During one of the home visits, which we conducted at the beginning of March 2018, we met a young man from Eastern Ghouta. When we entered his apartment in Amman, the TV was on in the comfortable-looking living room. The sound was switched off, but the images continued. They were showing in real time buildings collapsing in the already destroyed neighbourhood of Eastern Ghouta. There were images of men carrying injured bodies, covered in blood. The participant had a desperate expression on his face and told us that his family members were right there, right then. I checked if he was still willing and able to answer to my questions, to which he eagerly agreed. During our interview his eyes would fix on the TV screen and he would pause. After a while he changed the TV channel to a children's show and his mood seemed to lift. He became more energetic describing his current living situation, and he was "thanking God that things turned out

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this way for me, my wife, and my child, who are with me in Jordan." When we approached the end of the visit, he wanted us to stay longer. We made numerous attempts to indicate that we were ready to leave, but our host kept on distracting us and pleading with us to stay longer. It seemed that our presence created a barrier between the horrible reality he was facing that day and relief from it. We finally left, but I carried a heavy feeling with me for the rest of the day.

My brief personal experience with the Yugoslav war undoubtedly influenced some of the reflections in this research. I first noticed this when I had difficulty reading articles related to war if they described the former Yugoslav conflict. This sensation of fear associated with my teenage experiences was something I had been unaware of until it emerged during my first visit to Baghdad. I experienced a sudden sense of fear when hearing low-flying military helicopters above us and memories of bombing alarms suddenly reappeared along with the sense of insecurity and confusion attached to that specific period of my childhood. These personal reference points gave me insight when talking to participants, not only in the sense of a shared experience, but also because I could understand the social and political complexity that characterizes countries at war.

In short, my interpretations of the patients' narratives was influenced by my own subjective views, and I cannot claim that they are completely objective. In preparation for the interviews, I followed professional guidelines to reduce the impact of subjectivity. This meant primarily that I had to be very aware of my emotional state. My conversations with the interpreters proved extremely useful and enriched my own thoughts and observations. My ability to gain an emotional distance improved during the course of analysing the research and throughout the writing of this book.

A number of social scientists report similar experiences and feelings during participant observations in emotionally charged research environments (Fox, 2017; Paul, 1953). Prolonged engagement with participants, triangulation of research methods, and debriefing sessions with the research team helped me check my own influence on the research process. Still, working as a researcher in a war context holds undeniable complexities.

We are now ready to proceed with the broader reflection on the rehabilitation process, not only of victims of war but also of others who live with disability.

Reflection on the multiple rehabilitation components

This book explores new ways to support and rehabilitate civilian victims of war. One of the core concerns raised at the opening of the book was injured

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non-combatants' severely limited access to medical treatment. This reflects the overall neglect they experience as members of society. The lack of focus on war-injured civilians is also obvious in the literature. Most literature that examines the rehabilitation of the war-injured focuses on war veterans rather than on injured non-combatants. The vast majority of titles on this topic take a state perspective (Carter and Kidder, 2015; Auerbach et al., 2013; Pupavac and Pupavac, 2012) or a purely medical/surgical perspective (Taylor et al., 2012; Foote et al., 2015; Der-Martirosian et al., 2013). War veterans are also a focus of the literature that studies post-war social reintegration, stigmatization, and mental-health topics (MacLean and Kleykamp, 2014; Vermetten et al., 2007; Huskey, 2015; Gade and Wilkins, 2013; Hasanović and Pajević, 2013). In addition, there are some anthropological ethnographic explorations that focus on the medical and social rehabilitation of combatants (Cohen, 2010; Hardgrove, 2017; Dickson-Gómez, 2002; MacLeish, 2012). Focusing on the rehabilitation of civilian victims of war is therefore unique, and dealing with the social aspects of rehabilitation is even more extraordinary.

Throughout *Reconstructing Lives*, I have examined different sets of relationships: between the disabled body and the sense of self, between the patient and their healthcare providers, and between the war victim and society. All these relationships contribute to the fragile process of healing – the main aim of patients entering MSF's RSP. It was apparent that the patients' aim was not only to fix their injured bodies but to rebuild all aspects of their existence: their personal, social, and moral identities, their economic power, and their sense of dignity. Symbolic meanings attached to their past experiences and the way they see their bodies today also play an important part in the reconstruction of their lives. This resonates with Behrouzan's work (2015) on the psycho-politics of wellbeing and mental health in the Middle East. Behrouzan acknowledges that after experiencing violence individuals mobilize different means of healing – for example, cultural, historical, clinical, and social.

In contrast, the healthcare providers at the MSF hospital – one of the leading programmes in the world to provide reconstructive care for civilian victims of war – focus predominantly on patients' medical treatment. As we have seen, this often creates tension between the staff and the patients. In my view, this issue stretches beyond questions of power and victimization explored by other authors (Mosse, 2004; Mosse and Kruckenberg, 2017; Farmer, 2001; 2006). It speaks to the subtle set of relationships between all actors that needs to be considered if the process of rehabilitation is to become patient-centred. It is both theoretical and practical. Here, I explore these notions and briefly touch on what has influenced our predominant understanding of disability and rehabilitation, particularly the ideas associated

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with war. The limitations of clinical rehabilitation and the need to embrace other forms of healing are also discussed.

Theoretical models of disability: a tension between medical and social

To understand the relationship between patients and their healthcare providers it is useful to review the theoretical models that deal with disability. These models differ from one another mainly in the way they perceive disability, whether they see it as an individual or a social phenomenon. The medical model, for instance, views disability as an individual pathology, commonly perceiving it as a personal tragedy (Goodley, 2011) and using medical terminology to describe it. In contrast, the social model describes disability as a purely social phenomenon. Here, the emphasis is placed on how the disabled person is limited in their opportunity to take part in the normal life of the community due to the physical and conceptual barriers imposed by society. Hence, according to this model, society determines who is disabled and who is not.

There are other models worth mentioning, such as the moral model, the charity model, and the minority model. The moral model diverts responsibility from the disabled to other people (for instance, parents for congenital deformities) or supernatural forces (God, destiny, or karma). The charity model perceives people with disabilities as victims who deserve pity. And the minority model emphasizes the discrimination suffered by the disabled and deals with their struggle for rights alongside other minority groups (Retief and Letšosa, 2018).

In the MSF hospital we were able to understand the nuances of all these models. Two main models, however, namely the medical and social models, were particularly useful in recognizing the internal tensions experienced by the staff as well as the tensions between staff and patients. For instance, in keeping with the medical model, MSF staff predominantly focused on providing medical treatment for deformed bodies (for example, improving measurable range-of-motion in injured limbs). Patients, on the other hand, understood the rehabilitation process as inseparable from their social recovery, corresponding more closely with the social model and social responsibility – that is, social responsibility is seen as part of the responsibility of the medical provider (for example, "smooth my skin, improve the appearance of my face so that I appear more normal"). It is not surprising therefore that tension and misunderstanding emerge between the parties, both of which believe they are simply practising their rights and responsibilities. Underscoring such insights

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and promoting alternative ways to think about rehabilitation can move the relationship in a more satisfactory direction.

Young promotes an alternative approach and describes two techniques in rehabilitation: "hard" and "soft" (1996: 678). Similar to the care received at RSP, hard rehabilitation involves medical treatments including drugs, physiotherapy, occupational therapy, and access to prosthetic appliances. Soft rehabilitation, in contrast, delivers counselling, encouragement, listening, and education. Young (1996) argues that some patients require only soft rehabilitation but insists that balancing soft and hard delivers the best outcome. If we examine treatment at the RSP, hard rehabilitation is considered medically justified, while soft rehabilitation, though greatly valued by the patients, is relegated to a supporting role.

In sum, a major alteration in the way disability is perceived in the RSP would redefine the responsibilities in the rehabilitation process shared between medical providers and their patients. The concept of disability itself has been evolving only slowly over time, however, and this explains why achieving conceptual change is so challenging.

Disabled body in the eyes of society

History illuminates some of the deeply embedded concepts of disability that, to a certain extent, still drive attitudes towards disability today, including in the humanitarian field.

There is some association between disability, disfigurement, and stigmatization as early as the late seventeenth and early eighteenth centuries. It has been argued by Ville et al. (2016) that the Enlightenment, the philosophical and intellectual movement that shaped ideas in Europe at the time, drove the contemporary concept of disability. The Enlightenment brought about a drastic shift in the way the body was perceived. The focus was on material and empirical knowledge, which influenced perceptions of the body as a biological entity with measurable and modifiable components. The medical discourse moved towards seeking biological causes for physical and mental variations. Along with these notions, the idea of average, normal, and desirable body shape and function emerged.

Anything that deviated from the norm was labelled abnormal and undesirable. This belief manifested in so-called "freak shows," shows in which "freaks" – people who lived with smaller, larger, or deformed parts of the body due to congenital deformities or diseases – were exhibited publicly as entertainment. The disabled were frequently abandoned as children or sold to such shows by their parents. The shows lured their audiences with advertisements such as "the legless wonder, the lobster boy, big foot girl, elephant

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man, four-legged girl," indicating the types of deformity suffered and available for view (Fordham, 2007).

Freak shows were popular in England and the US from the seventeenth to the nineteenth centuries, when scientific explanations for the mutations emerged and the shows were banned. The social view changed from "freaks" entertaining the public's curiosity about "how nature went wrong" to the disabled becoming objects of pity (Durbach, 2009).

Some authors (Ville et al., 2016) have argued that the centuries-long reinforcement of norms and the grotesque abuse of those who did not fit them left deep negative attitudes towards disability. Others, like Oaten et al. (2011), use an evolutionary approach and argue that apparent signs of disease trigger disgust and avoidance in order to prevent the spread of infection. Nevertheless, both hypotheses promote the predominant tendency among humans to feel threatened by and thus to avoid individuals who appear different or sick, even if in reality they are not.

A major transformation in these notions occurred in the 1980s and 1990s through disability-related activism (Ville et al., 2016). The ideological concept known as disability studies led this activism, which rebelled against a social definition of "normal" and against any marginalization of those who did not fit it. The understanding of disability shifted from the "individual" to the "social," and from "natural" to "socially constructed" (Goodley, 2011). Disability studies distinguished between "impairment" – that is, functional limitations – of the individual caused by physical, mental, or sensory deficit and the social construct that leads to oppression through the restriction of activities. Disability studies emphasized the socially imposed pressure on people living with impairment, noting that they were infantilized and perceived as helpless and asexual.

This activism brought significant changes in social attitudes as well as in legislation related to the rights of people living with impairments. Today the WHO describes disability as a "complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives" (WHO, n.d.). As such, it is generally acknowledged that environmental and social barriers need to be reduced to facilitate quality of life for people who live with disabilities.

Coping with a disabled self in the context of war

In the context of war, environmental and social barriers become more pronounced at the same time as the number of disabled people overwhelms society. One might expect that the disabled body would become the new normal and the social glance towards it would neutralize. According to my observations, this is too often not the case. My participants reported three

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levels of stigma: the first related to the appearance of their bodies, the second to assumptions about their having done something "wrong" – hence, to their moral self – and the third to internal integration of negative prejudices – that is, self-stigmatization. MSF patients consistently advocated for support in managing all these stigmas.

Social norms have driven the acceptance or marginalization of different bodily forms and functions. This does not change in the context of war. Those participants whose appearance was affected in a way that all could see were judged according to predominant ideas of beauty and gender norms. In addition, they were consistently asked whether they were victims or perpetrators. Those who may have been in combat but who possess no visual manifestation of injury are better off socially than those civilians with obvious visual markings who did not engage in combat. The non-combatants live under social suspicion that they were involved in war violence. Hence the "moral self," rather than the body, is what is being critically evaluated. But let us not get into the victim/perpetrator dichotomy. Other authors, such as Basic (2018) in the context of former Yugoslavia, and Bradol and Le Pape (2017) in the context of Rwanda, have already provided a profound discussion on how this dichotomy is unjustified in the reality of war violence. What is significant in this debate is that the perceived social glance plays an important role in how the war-injured feel about their place in society. In other words, stigma in war and stigma after war may influence an individual's survival and wellbeing.

Some aspects of Goffman's theory of stigmatization (1986), an influential work in the field of disability, resonated with the experience of the war victims I encountered. Goffman discusses how stigmatization occurs in contact with others – for example, "normals" – and how it influences one's perception of one's own identity. He emphasizes the constant need for the stigmatized to manage social interactions, and he lists a number of strategies. One of them is the stigmatized person's attempt to fit in with expectations. He writes: "I also learned that the cripple must be careful not to act differently from what people expect him to do. Above all they expect the cripple to be crippled; to be disabled and helpless; to be inferior to themselves, and they will become suspicious and insecure if the cripple falls short of these expectations. It is rather strange, but the cripple has to play the part of the cripple" (Goffman, 1986: 110). This illuminates the predominant notion at the MSF hospital that patients are "victims," and it explains the tensions that occurred when individuals did not act "helpless" enough, as, for example, when they questioned medical decisions. Thus, for patients at the MSF hospital, the common strategy was to adopt the position of the perfect victim and for their relationship with the care providers to appear "positive." However, the commonly established patronizing–dependent relationship between

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medical staff and their patients prevents the latter from becoming empowered during rehabilitation and hampers the development of self-realization in the disabled individual.

Another relevant point in Goffman is how stigma relates to public rather than private life. My participants reported that any stigma was completely absent when they were in the intimate circle of family members who did not consider their deformed bodies off-putting. As Goffman notes, uncomfortable situations occur in public, and particularly when strangers already know about the social identity of the stigmatized, who, in return, do not know anything about them. "He [the stigmatized who decides not to remove himself from the social contacts] can voluntarily disclose himself, thereby radically transforming himself from an individual with information to manage to that of an individual with uneasy social situations to manage" (Goffman, 1986: 100). This type of situation led my participants either to hide their injuries or transform the meanings attached to them into something socially acceptable – for example, by ascribing the injury to an act of heroism.

Goffman notes that when "normals" and the stigmatized enter one another's immediate presence, the causes and effects of stigma are confronted by both sides. The disabled can never be sure what the attitude of the new acquaintance will be. Will it be dismissive or accepting? The "normal" is faced with feelings of unease triggered by contact with the disabled. Reports by my participants and examples from the literature describe how facial disfigurement especially produces an emotional response such as fear, disgust, or contempt in the observer. There is already a predisposition to such reactions embedded in the social norms surrounding the concepts of beauty and perfect function (Harris, 2019).

Uncertainty about the reaction of others causes a great deal of self-consciousness and anxiety. This uncertainty will lessen, however, as the individual lives in a community for years and develops what Goffman calls a "biography": "a well-rounded… personal identification… in others' minds" (Goffman, 1986: 78). When the war-injured leave their communities and spend prolonged periods in rehabilitation, removed from their usual social circles, discontinuity of the "biography" occurs. New opportunities emerge for them to manage their background information or how they are going to be known in their new social circles. The disabled person experiences a sense of normalization in the hospital environment which facilitates development of a new social and personal identity. MSF patients seem to take advantage of this opportunity to explore who they were prior to the injury and who they will be after treatment and rehabilitation.

Lastly, if stigmatization does not occur externally, it may still be imposed from within. It was apparent that for some of my participants, being perceived as deviant in the eyes of others due to facial scars was sufficient to

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block them from participating in social life. In contrast with the public stigma arising as a negative stereotype that society places on an individual, self-stigmatization is the process of internalization of negative judgments (Corrigan and Watson, 2002). In the literature, self-stigmatization is mainly explored as a mental-health question (Corrigan and Watson, 2002; Corrigan and Rao, 2012), in connection with HIV/AIDS (Miller et al., 2011; Ajala, 2012), or in connection with addiction research (Frischknecht et al., 2011). To my knowledge, it has hardly been explored in the context of war victims. Shih (2004) notes that traditional work on stigma has focused predominantly on stigma's negative impact on the individual. The participants in this study, by contrast, seemed to flourish despite adversity, often applying strategies to ward off the negative consequences of stigma. Some of the strategies they used were in line with the management of stigma reported in the literature. Shih (2004), for instance, reports on compensation, strategic interpretation of the social environment, and the creation of multiple identities to combat self-stigmatization.

In employing the compensation strategy, stigmatized individuals become more assertive and persistent to achieve their goals. They build up skills that help them fit in, and they refine social interactions (Shih, 2004). At the MSF hospital there were daily examples of persistence in often painful moments of rehabilitation.

In strategically interpreting their social environment, individuals manipulate their perception of that environment to protect their sense of self-worth. For instance, they increase their sense of self-efficacy by comparing themselves to a group with similar challenges rather than to a group that has no disfigurement/disability. When faced with failure, these individuals preserve their self-esteem by attributing disappointments to prejudice rather than to personal causes, although they can also resist seeing themselves as victims and deny or minimize prejudices. It was apparent from my participants' point of view that "being among similar" was healing in its own terms.

The last strategy – the use of multiple identities – shifts the focus away from a single way of looking at oneself. Such switching of identities has many psychosocial benefits and allows the individual to decide which identity to use in any given social context. My participants partook of multiple identities in diverse situations: heroes, victims, mothers, husbands, survivors, professionals, optimists, Muslims… the list goes on.

The disabled can also be coached to manage self-stigma. Lucksted et al. (2011) describe a pilot project in which they demonstrated techniques that effectively reduced self-internalized public stigma. They utilized educational sessions to explore mental-health issues, they imparted skills that the stigmatized could use to respond to stigma in public settings, and they guided their participants to solidify relationships with family and friends.

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In sum, despite steep increases in disability as a result of war violence, solving the problem of stigma related to social interactions between disabled and "normal" people has not advanced rapidly enough. People living with impairments in a war context are constantly threatened with being perceived negatively in public life. This happens because of their appearance, because they are suspected of involvement in war violence, and/or because they impose a stigma upon themselves. During the rehabilitation process a window of opportunity opens that can facilitate social rehabilitation, a prospect which has implications for the improvement of the wellbeing of the war-injured. Regrettably, this understanding has not been fully incorporated into the MSF RSP.

When was social rehabilitation forgotten?

Social rehabilitation of war-injured persons is far from a novel approach. Pioneering efforts in rehabilitation were launched in the post-First World War era across Europe and the US when rehabilitation centres opened to assist the large number of war invalids. No less than 120,000 disabled soldiers were treated in US rehabilitation centres at that time. The injured represented an alarming number of young, previously healthy men at the height of their physical and professional development (Stagni et al., 2015). The large number of disabled war veterans who were eligible for financial compensation posed a considerable financial challenge to society, and this led to a tendency to return them as swiftly as possible to the labour force. In turn, pressure was placed on the medical profession to make decisive contributions so that veterans could be integrated back into civilian life.

Among the chief commitments was the development of orthopaedic prosthetics (Perry, 2014). The Laboratory for Military Prosthesis and Occupational Labour in the north of France, for instance, headed by the French scientist Jules Amar, based its work on Amar's understanding of the body as a motor and body parts as mechanical appendages, both amendable and optimizable (Verstraete and Herman, 2016). This notion led to the development of prostheses that were individualized, and training that was designed so that each patient could optimize their performance. In Amar's opinion, the disabled body was the principal site of a person's productive value and functionally disabled solders were perceived as a beneficial part of society. As such, the boundary between able and disabled was blurred and the result was a shared sense of community.

Similarly, in Italy, at the Istituto Ortopedico Rizzoli, one of the most renowned hospitals for the treatment of orthopaedic deformities, the rehabilitation programme consisted of physiotherapy, curative workshops, and vocational therapy. These new perspectives on physical medicine and

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rehabilitation established a pioneering and multifaceted approach to rehabilitation that involved functional recovery as well as the recovery of social roles and participation in social life (Stagni et al., 2015). The same efforts were made in other rehabilitation centres across Europe, the US, and Canada, and social integration of war veterans through gainful employment was considered a standard part of medical rehabilitation. The aim was to fully restore to severely wounded soldiers the use of their bodies and their ability to be economically self-sufficient. The First World War also saw comprehensive efforts at the restoration of normalcy to the war-injured. A report from 1918 shows that it wasn't only war veterans who had access to such support: sometimes war-injured civilians benefited too (Provision for Disabled Soldiers and Civilians, 1918). Doctors and surgeons led public discourse on disability, norms, and social performance (Wolters, 2015). They often joined the war-affected – particularly leg and arm amputees who became synonymous with disability – to advocate for social rights.

After the Second World War, work in plastic surgery broke new ground (Geomelas at al., 2011). Sir Archibald McIndoe, a pioneer in the field of plastic surgery, treated veterans, developing novel techniques, particularly for the reconstruction of faces damaged by burns. During this period, medical personnel were aware of the need to work not only on patients' bodies; they knew they must prepare them for a painful reintegration into their communities. McIndoe adopted mental, social, and physical approaches in his treatment of patients. He formed what they jokingly called The Guinea Pig Club, for patients with burn injuries. Photographs from the clubs' meetings portray men with obviously deformed faces, wearing suits, smoking cigars, and smiling over dinner toasts in what perhaps would have been considered a higher social setting. McIndoe set up these clubs to rehabilitate and protect the dignity of his patients and help them find their place again in society. He was a strong advocate for his patients and influenced society to better reintegrate the war-wounded.

In the US, it was acknowledged that war veterans from lower economic backgrounds needed a higher social standing, but, due to systemic racial discrimination, the vast majority of African Americans were excluded. Getting a leg-up on the class ladder was achieved for whites through their newly granted access to higher education in the GI Bill. This contributed to the new well-educated white middle class that emerged from the war.

Recent examples confirm the benefits of reintegrating the war-injured into society. A study of Bosnian war veterans with amputations who engaged in a scuba-diving rehabilitation programme originally aimed to assess their physical ability to participate in the sport. Results showed that scuba diving was not only a feasible activity for amputees but that it increased participants' perception of social support, a fact linked perhaps to the sport's association with higher socio-economic status (Aganović, 2019).

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Thus, modern concepts of rehabilitation of the war-injured through social participation were in place to a limited extent after the First World War, and by the Second World War they were quite well developed. In both periods, medical doctors and surgeons were on the frontline as advocates. Medical treatment, occupational therapy, and social reintegration were seen as medical duties in the effort to rehabilitate those with war related disabilities.

After the First World War, the focus was on rehabilitating the injured to function in the industrial boom of the time. After the Second World War, along with emerging class stratification in Europe and the US, there was a push to improve the class status of the rehabilitated.

Both models prepared the disabled to re-enter society as valued members. By focusing primarily on the functional aspects of rehabilitation, the RSP has missed out on the social component – long considered a part of rehabilitation. A number of questions arise: why have aspects of social rehabilitation been forgotten? Does the humanitarian field fully understand the social needs of victims of war? Is there enough flexibility built into rehabilitation programmes to allow them to adjust to the rapidly changing social norms on disability in war-torn communities?

Symbolic healing

Another aspect of rehabilitation that my participants raised was that of symbolic healing. There is symbolic violence in war: the violation of cultural symbols, social taboos, and the social structures that establish rules and mechanisms for settling disputes and keeping peace in ordinary times. According to Shepler (2016), who examined symbolic violence in Sierra Leone, the ultimate goal of war is to destroy collective methods for coping with stress. In Sierra Leone this was done through limb amputation, the parading of severed heads on sticks, rape, body mutilation, and stories of cannibalistic acts. In the recent wars in the Middle East, ISIS has used numerous means of symbolic violence: looting and destroying cultural and religious artefacts, and videotaping and broadcasting violent propaganda, including beheadings (Pauwels, 2016; Patruss, 2016). It is not surprising therefore that war victims aspire to symbolic healing as a (re)confirmation of their individual and collective values.

Omar Dewachi is one of the few researchers who explores war injuries beyond medical discourse (Dewachi, 2015). Describing war injuries as social wounds that incorporate local histories of violence, he writes about displaced Iraqis in Lebanon in the wake of the US occupation of Iraq, pointing out how wounds in a new setting become embedded in the new social structure through various social interactions and meanings. According to Dewachi, wounds either "bring people together or keep them apart." In the RSP, my

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participants confirmed that the symbolic meaning they attached to their injuries served as reminders of suffering, which "kept them apart," or as currency in a social network that "brought them together" with others who shared a destiny. Symbolic meaning holds the potential for both: symbolic violence and symbolic healing.

In previous wars, social rituals, the use of symbolic language, and symbols that reconfirm community values and ethics have been utilized as different aspects of symbolic healing. Collective re-burials of those who were killed and buried far from home during war is one such example (Zaremba, 2015; Ferrándiz, 2006). Such burials are a way to respect the victims and express grief about what was collectively lost in war. Re-burials in some settings hold yet another set of meanings. Anthropological research in Angola and Mozambique describes how war trauma is linked to the power and rage of dead spirits who were not properly buried during the war and who therefore continue to contribute to the community's misfortune. Re-burying them symbolically puts the spirits and the community at peace (Green and Honwana, 1999).

Purification rituals for those who participated in or witnessed killings are another example. They can cleanse the affected person and reintegrate them into their community. Shepler (2016) writes of how the reintegration of child soldiers in Sierra Leone was drawn from two different models: the Western model, based on children's rights and child-protective practices, and the Sierra Leonean model, centred on traditions of child labour, fosterage, and training. In addition, local models for dealing with child soldiers were tied to beliefs in ancestral healing powers and the importance of family and community involvement. Western therapeutic techniques established to treat PTSD among child soldiers in Sierra Leone all missed the local or country-intrinsic aspects. A contrasting example is the successful reintegration of boys who had been child soldiers in Uganda (Bower, 2008). The boys, after a rehabilitation period, returned to their home villages and underwent cleansing rituals that allowed their communities to "forgive" them. After this collective ritual, the child soldiers who were not physically injured but who carried both social stigma and emotional wounds became part of their communities again.

Another example of symbolic healing, which has also been used in conflict zones, is the symbolic language of poetry (Olszewska, 2007) and theatre performance (Dinesh, 2016; Brecht, 1964; Boal, 1985). Such language allows for political and social messages to be aired without the threat of censorship. The emotions and interpretations evoked in the spectators and in the society at large carry the potential of symbolic healing.

In summary, aspects of symbolic healing through collective traditions, symbols, and rituals are too often neglected in the rehabilitation of war

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victims. In medical institutions that assist victims of war, subtle means of recovery are often missed too, particularly if the medical model of rehabilitation predominates. It is the subtle means, however, that pervade the daily life of war victims. While there is certainly a limit on the symbolic healing a rehabilitation centre can incorporate into its programmes, in collaboration with patients, healthcare providers could embrace at least some aspects of symbolic healing as part of their medical decisions.

MSF already has some experience with such negotiations. In previous MSF surgical programmes, it was noted that tapping into the local understanding of the body could influence the level of acceptance of certain medical procedures. In 1991 in Somalia, for instance, MSF staff faced numerous challenges due to the low acceptance of amputations. Patients would accept and perhaps succumb to a life-threatening infection rather than lose a limb. This was linked to their idea of body integrity, which was sacred. For the MSF staff who performed amputations in a Burmese refugee camp in 1992–1993, by contrast, it was much easier to achieve patient consent for amputations. Yet another observation from the surgical programme, in Haiti in 2010, showed that patients preferred amputation rather than reconstructive surgery performed in the hope of regaining function, especially if the surgery did not improve the appearance of their hands (Jean-Hervé Bradol, personal communication, June 2020). Hence, the conflict between medical and symbolic meanings of the body varies greatly depending on the context – all of which points to the need for the profound involvement of patients in decisions about their bodies and lives.

Concluding remarks

Military actions have always targeted the human body with the aim of destroying the social body. The sense of social identity is violated not only through killing, torture, mutilation, rape, and displacement, but also through the destruction of symbols valuable to the society under attack. Reconstruction of the lives of war victims is therefore a complex process in which all aspects of treatment and healing must be taken into consideration.

Due to the achievements of disability activists, disability today is understood as both physical and social phenomena. Despite this, humanitarian actors such as MSF still predominantly follow the medical model. Compared to the rehabilitation efforts for the war-injured in past centuries, we have many sophisticated technological advances. Nevertheless, it may be true that we have less understanding of the social and emotional needs of the patients. MSF has begun to acknowledge this: it has recognized that tension exists between the medical and the social, and now promotes a more inclusive

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delivery of care; and it has declared its intention to adopt a patient-centred approach as one of its main strategies. Operational change, however, will require some conceptual, as well as practical, shifts in the programme.

To provide full medical and psychological support for patients at the RSP or other facilities for the war-injured it is essential to base programmes on detailed patient histories, including reports of traumatic life events and the specifics of previous treatment or lack thereof. The emotional impact that devastating events have had on patients and their family members is unpredictable. Without obtaining information specific to the individual, medical staff may wrongly interpret a patient's emotional reaction to a medical procedure, or they may overestimate the emotional support family members are able to provide. An open discussion of a patient's personal history facilitates an approach in medical care that helps the individual achieve a complex emotional, social, and physical recovery from their injuries.

When my participants narrated their personal histories related to war violence, they experienced a turning point in their lives. The participants' reflections, coming after a period of physical recovery, taught me an important lesson: their personal losses were intertwined with the collective losses that occurred in their families, among neighbours, and in the broader society.

Hence, those who provide care for war victims, such as MSF, play an important role in creating improved internal and external circumstances for their patients. For patients, an inescapable part of recovery and forward motion in the changed reality after severe injury depends on the patient's own agency, coping skills, and creativity.

This book has opened up a number of topics for future research. Among them is the process of combining the medical model and the social model in the humanitarian field and among other disability-healthcare providers. One of the original aspects of this research was to frame the concept of "quality of life" following patients' own definitions. This novel approach could be used as an evaluation tool in other humanitarian programmes. More broadly, the symbolic meanings attached to disabled bodies in different settings, and a comparison between attitudes in conflict zones and in areas of peace, might support better understanding of symbolic healing. Finally, how the Middle East incorporates its invalids into its social fabric after the wars are over is a topic that will enrich knowledge of disability and rehabilitation, which is, I believe, a fitting point with which to close my reflections.

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Epilogue

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At the conclusion of this research, I gave a number of presentations to all operational levels of MSF, where we also debated the findings. Our discussions focused on the patient-centred approach to rehabilitation. Current and prior research at the RSP provided some direction. The question that remained, however, was this: how can research results be transformed into operational change? In November 2019, the desk and programme management staff invited me back to Amman to facilitate the implementation of changes and to develop a long-term strategy for patient-centred care. After an intense period of listening to RSP staff and patients, and reflecting on the findings, an exciting phase opened for me, and as I look forward, I see the programme evolving in the future.

In collaboration with all hospital departments, new practices were initiated. One of the objectives was to strengthen patients' involvement in their care. This was achieved through the establishment of a patients' committee, consisting of representatives of the patients from all countries, and members of staff. The committee was formed to debate topics related to hospital life and to involve patients in decision-making. Another communication channel opened with the creation of a patients' suggestions and complaints box, something which had not previously existed in the hospital, and all hospital departments allocated one member of staff to be the point-person for patients' questions and concerns. In addition, a new patients' support committee was launched with representatives from all hospital departments, who would meet monthly to discuss patients' concerns.

There was much debate on how to tackle the issue of negative stereotyping in the hospital. The staff and I were hopeful that by raising awareness of patients' rights we could create positive change. In the process of discussion between patients and staff we produced the RSP Patients' Charter, a document that is now on the hospital walls for all to view and that comprises the conclusions agreed on collectively.

Psychosocial and nursing departments also collaborated on numerous initiatives related to the improvement of child-centredness at the RSP.

Similar to the patients' committee for adults, a children's committee was established for paediatric patients. Furthermore, we inaugurated a peer group for those who take care of paediatric patients in order to better involve and support them. For the needs of teenage patients, we assigned male and female nurses to act as a listening post for concerns. More effort was expended to prepare paediatric patients and their carers before their arrival in Amman. We are in pre-production planning for a video project in which current paediatric patients record the hospital and explain the features of hospital life. The video will eventually be downloadable to a smartphone so it can be shown to potential paediatric patients and their carers in Iraq, Yemen, and Gaza.

Follow-up care for patients after their return home also needed strengthening. It was determined that the first priority should be given to those who required replacement prostheses and those who asked for further psychological and psychiatric support. There were vibrant discussions on establishing patient peer-support groups in the various home countries – a debate that also engaged current patients, who offered useful ideas for how this might work. The objective of such support groups, in which former patients would play a major role, was seen as facilitating new patients' departures from home for the hospital as well as smooth homecomings for recently discharged patients.

The changes that have been put in place recognize the emotional impact that the RSP's work has on the staff, who often require additional support. A new staff-wellbeing team was created, linking the hospital personnel and the MSF regional staff. The organization also introduced a volunteer staff-support group designed to respond to situations in which staff suffer emotional distress from their interaction with patients. In addition, social activities for staff were scheduled more regularly to improve the spirit of solidarity and support in the hospital.

At the higher levels of decision-making in MSF, a debate was initiated that sought to create more comprehensive care for plastic-surgery cases, care that would take into consideration the patients' aesthetic preferences. The debate ultimately contemplated changing the framework of the programme from "surgical" to "surgical and rehabilitation." It was felt that this language better encompassed the nature of patient need and more comprehensively described what the programme aims to achieve.

This last phase of my work in Amman peacefully closed a vital chapter of my engagement with the RSP and, in the same moment, the findings from the research were put into action for those future generations who will work at reconstructing lives.

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Appendix

Breakdown of participants by the main surgical procedures received

	Syrian		*Iraqi*		*Total*
	Men	*Women*	*Men*	*Women*	
Orthopaedic	10	10	18	3	41
Plastic	10	3	7	4	24
Maxillofacial	6	0*	3	0*	9
Total	39		35		74

* Unable to reach (no functional working phone contacts; only 2 potential participants in the database)

Participants' profiles

The average age of participants was thirty-eight years. The majority of them had a primary (25) or secondary (32) education. Ten had obtained university degrees and seven had no schooling. Two thirds of participants (48) were married (only 1 in a polygamous marriage), 14 were single, 6 widowed, 4 divorced, and 1 separated. Syrian participants mostly lived in rented apartments (29); none owned a house or apartment, and Iraqis lived mostly in houses they owned or that were owned by their family (20). Both groups resided mostly in urban or suburban areas. Participants' family structures consisted predominantly of four adults and two children below sixteen years old. Most families (57) had no or only one family member engaged in income-generating activities. Most Syrians receive refugee-status-related financial support, and some Iraqis receive a pension, remittance, house rent, inheritance, or social welfare as an additional source of income. Iraqi participants reported an average monthly income of 500 USD and Jordanians an average of 400 USD per family per month.

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