

Palliative Health Care in Jordan for Syrian Refugees



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Acronyms

CIA – Central Intelligence Agency

ECC – Exceptional Care Committee

JOD – Jordanian Dinar

JPCI – Jordan Palliative Care Initiative

JUH – Jordan University Hospital

KAUH – King Abdullah University Hospital

KHCC – King Hussein Cancer Centre

MoH – Ministry of Health of Jordan

MOI – Ministry of Interior

NCD – Non-communicable Diseases

RMS – Royal Medical Services

UN – United Nations

UNHCR – United Nations High Commissioner for Refugees

UNOCHA – United Nations Office for the Coordination of Humanitarian Affairs

UNRWA – United Nations Relief and Works Agency

USD – United States Dollar

Executive Summary

The Hashemite Kingdom of Jordan shares its northern border with the Syrian Arab Republic, and has been one of the main receiving countries of fleeing refugees since the beginning of the Syrian conflict in 2011. Currently over 650,000 Syrian refugees live in Jordan; less than 20% live in one of three refugee camps in the north, while over 80% live in urban and rural areas (Ministry of Planning and International Cooperation, 2015).

Refugees face many significant health concerns, both acute and chronic. While some are related to the conflict such as injuries and infections, non-communicable diseases claim the most Syrian lives (UNHCR, 2016b). Refugees receive care within the extensive Jordanian health system, which includes public, private and NGO facilities and services. The influx of refugees has put increased strain on both medical and human resources within the Ministry of Health in Jordan.

The focus of this paper was to examine factors affecting provision and accessibility of palliative care in particular for Syrian refugees. Palliative care focuses on providing relief from symptoms, pain and stress of a serious illness for patients and families (Razzak & Smith, 2014). Formal palliative care services are only available in the capital city of Amman. One in-patient palliative care unit is housed within a major oncology centre, and another NGO offers home-based care for patients and families (Al Qadire et al., 2014). Jordan has no national policies on palliative care, nor palliative care education for health care providers.

Factors influencing provision and accessibility of palliative care services for refugees fell into three distinct categories: financial; systemic & organizational; and cultural & ideological;

- Financial factors include costs to the patients and families for registration documents, medications and transportation to health care facilities. A 2014 policy change introduced subsidized user fees for refugees where care had previously been free. The health care system also incurred sizeable costs from providing health care for the incoming refugees in addition to citizens. Once established, appropriate palliative care can be a cost-effective approach to providing better care for patients with serious illnesses.
- Systemic and organizational factors complicate access to care through rigorous identification and registration requirements for refugees. Health care services are not evenly dispersed, nor are they equally accessible to all. Strict regulations surrounding the distribution and use of opioids restrict use for pain management.
- Important cultural and ideological factors include a tradition of non-disclosure about poor prognosis, and the role of the family unit in decision-making and caring for patients. Many Muslims have strong religious beliefs about illness and death, which are reinforced by cultural norms. Finally,

negative perceptions, misconceptions, and lack of awareness about palliative care, pain management and the use of opioids play an important role.

In conclusion, some future directions for research and policy are proposed for the national and international levels. These will support improvement and expansion of palliative care services in Jordan as a resource- and cost-effective way to provide better care for refugees and citizens alike.

Jordan

The Hashemite Kingdom of Jordan is a small country in the Middle East, home to a population of 9,531,712 (Jordan Ministry of Health, 2015). It is bordered by Syria to the North, Iraq and Saudi Arabia to the east, Saudi Arabia to the south, and Israel and the Palestinian West Bank to the west (CIA, n.d.). Jordan is considered among the most stable countries in the Middle East, and has been governed by the constitutional monarchy of King Abdullah II since 1999 (Première Urgence, 2014). The majority of the population are ethnically Arab (98%), with small minority groups of Circassian and Armenian peoples (together 2%) (CIA, n.d.). Jordanian culture is characterized as Arabic Islamic, as 97% identify as Muslim (predominantly Sunni Muslim), 2% identify as Christian, and Buddhist, Hindu, Jewish and the unaffiliated comprise less than 1% (Al Qadire et al., 2014; CIA, n.d.). The age structure of the population is young, as 35% are 0-14 years old, and 55% are younger than 24 years old (CIA, n.d.). Average life expectancy is 75 years, and the total fertility rate is 3.5 children per woman (Jordan Ministry of Health, 2015).

Brief History of Refugees in Jordan

Due to its geographical location, and relative political stability, Jordan has long been a destination for refugees and migrants fleeing conflict in surrounding countries (Nimri, 2016). Since 1948, Jordan has received refugees from Palestine, from the civil wars in Lebanon between (1975 and 1991), from the Gulf War in Iraq since (past-1991, 2003 to 2011) and most recently from the Syrian Crisis since 2011 (Arnaout, 2016).

Syria is now in its sixth consecutive year of armed conflict and war, and the human toll has been disastrous. The UN Special Envoy for Syria estimated in April 2016 that approximately 400,000 lives have been lost, and over 12 million people have been displaced as a result of the conflict thus far (UN, 2016; 2015). In addition, the conflict has caused one of the largest flows of refugees since World War II; over 4.8 million Syrians have fled to other countries within the region, as well as across the world (Amnesty International, 2016). The host countries with the largest Syrian refugee populations include Turkey, Lebanon and Jordan (Amnesty International, 2016). All three initially supported 'open-border' policies towards Syrian refugees, however recent changes in government policy and border security in these three countries have made escaping Syria increasingly difficult (Amnesty International, 2016).

Syrian Refugees in Jordan

As of February 2017, Jordan hosts 655,732 Syrian refugees registered with the United Nations High Commissioner for Refugees (UNHCR), and up to hundreds of thousands more who are unregistered (UNHCR, 2017). Iraqi, Yemeni, Sudanese and

other peoples constitute another 73,000 refugees living in Jordan (UNHCR, 2017). Thus Jordan has the second highest number of refugees relative to its population (87 refugees per 10,000 inhabitants) and the sixth highest number of refugees in total of any nation (UNHCR, 2017).

There are three refugee camps in Jordan, all located in the north and close to the Jordan-Syrian border; Al Za'atari, Azraq and Emirati-Jordanian. However these house less than 20% of the Syrian refugee population, as the rest live in urban areas concentrated in northern governorates (Ministry of Planning and International Cooperation, 2015). In 2015, UNHCR's Vulnerability Assessment Framework Baseline Survey reported that 86% of Syrians outside camps are living below the Jordanian poverty line (Washington et al., 2015). A more recent report from February 2017 re-estimated the number at 93% (UNHCR, 2017).

Refugees have described multiple reasons for choosing not to live in refugee camps. Azraq is located in a remote desert area in the north, and refugees have said that they feel isolated from services and from urban centres (Amnesty International, 2016). In Al Za'atari, the Syrian population is primarily people from rural areas such as the Dera'a district in Syria, close to the Jordanian border. Other refugees from urban areas including Aleppo have had trouble integrating and being accepted into the community (Amnesty International, 2016). Some described being threatened and harassed by other groups in the camp, and thus felt safer outside the camp (Amnesty International, 2016). Still others stated that they chose to leave and try to find somewhere to live in a more normal community setting and more economic independence (Amnesty International, 2016). For those choosing to leave, there is a complex and burdensome "bailout" process (discussed below).

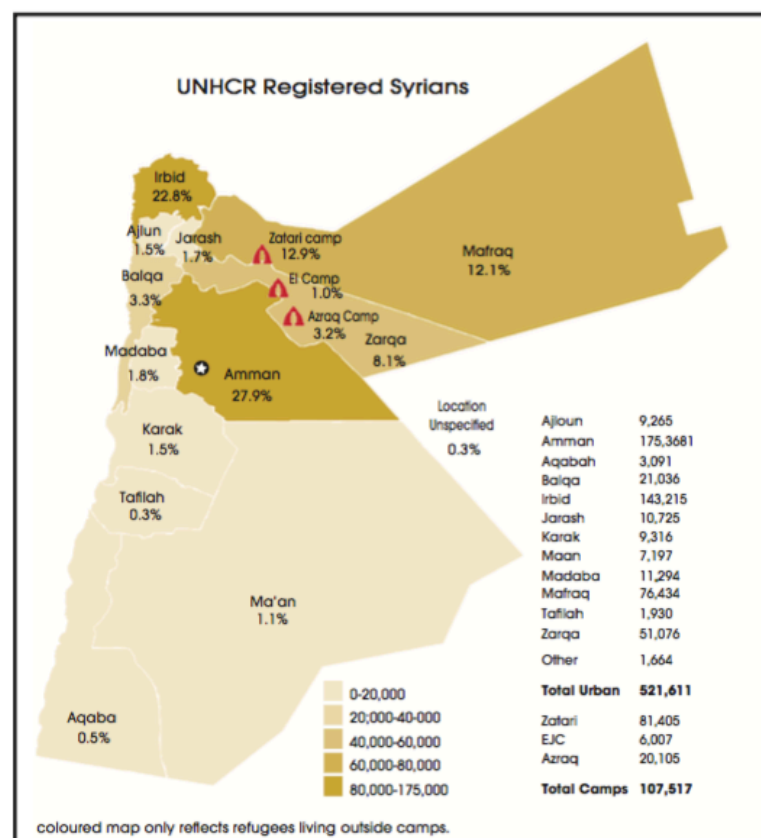


Figure A: Map of UNHCR Registered Syrians in Jordan (Ministry of Planning and International Cooperation, Hashemite Kingdom of Jordan, 2015).

Health Status of Syrian Refugees in Jordan

Due to specific challenges faced by Syrian refugees, many are facing significant health concerns. Factors such as exposure to armed conflict, lifestyle modification, displacement and interruption of regular screening practices have put refugees at a higher risk for health concerns. In addition, conflict conditions may have exacerbated existing health issues through the interruption of health care services, avoidance of treatment and the existence of underlying multiple co-morbidities (Nimri, 2016).

Acute Health Concerns

The most common type of acute health concerns are infectious diseases and injuries. Detailed health records from Al Za'atri Refugee Camp, the largest of the Jordanian camps holding Syrian refugees, indicate that there were 27,530 cases of injuries in 2016, including injuries due to war, assault, burns and bites (UNHCR, 2016b). Infectious and acute diseases were twelve times more common, as they accounted for 333,175 new cases in 2016. The most common were upper and lower respiratory tract infections (35%), influenza-like illnesses (11%), dental conditions (10%), skin infections (6%) and ear infections (5%) (UNHCR, 2016b). However, acute conditions and injuries combined accounted for only 5% of deaths (8 cases) during the year 2016 in Al Za'atri (UNHCR, 2016b).

Chronic Health Concerns

Chronic health conditions and non-communicable diseases (NCDs) accounted for 81,466 new and re-visit cases at Al Za'atri in 2016, less than one quarter as frequent as acute and infectious cases (UNHCR, 2016b). However, NCDs represented 55% of the mortalities (89 cases), by far the most common cause of death (UNHCR, 2016b). Ischemic heart disease, other cardiovascular diseases and cerebrovascular disease alone accounted for 44% of mortality in 2016 (UNHCR, 2016c). Cancer accounted for another 10% of deaths (UNHCR, 2016b). Among Syrians at Al Za'atri, the most common chronic health conditions were hypertension (22%), diabetes (18%), chronic respiratory diseases (17%), cardiovascular diseases (12%), and thyroid conditions (9%) (UNHCR, 2016b). A cross-sectional study of Syrian refugees living outside refugee camps in Jordan in 2014 recorded that hypertension, arthritis, diabetes, chronic respiratory diseases and cardiovascular diseases were the most common conditions, in order of prevalence (Doocy et al., 2015).

Health care system in Jordan

Jordan boasts one of the most advanced and well-resourced health care systems in the Middle East (Première Urgence, 2014). Health care services are provided by both public and private services (Amnesty International, 2016). The proportion of citizens with some form of health insurance coverage has been steadily increasing (from 70% in 1999 to 88% as of 2014) (Al Qadire et al., 2014; Première Urgence, 2014). Those without insurance can access care by paying an uninsured rate, which is subsidized in public hospitals. Certain health services such as perinatal care for pregnant women, family planning services and some vaccinations are provided to all Jordanians free of charge, regardless of insurance status (Première Urgence, 2014).

Total expenditures on health in the past few years has hovered around 8% of Gross Domestic Product, which is higher than most other low-middle income countries (Arnaout, 2016; WHO, 2014). In total, there were 106 hospitals providing 12,117 hospital beds in 2011, approximately 1.8 beds/1000 people (Arnaout, 2016). In 2014, Jordan had 2.8 nursing and midwifery personnel per 1000 population, 1.3 pharmaceutical personnel per 1000 population (second highest rate in the world) and 2.6 physicians per 1000 population (second highest rate of the WHO's Eastern Mediterranean region) (Global Health Observatory, 2017).

Public Health Care Sector

The public health care sector in Jordan is comprised of the following institutions:

- The Ministry of Health (MoH) operates 31 hospitals and provides 38% of hospital beds nation-wide. The MoH is the single largest provider of health services in Jordan (Première Urgence, 2014). MoH facilities are fully funded by the government, and are located all over the country in both cities and villages (Al Qadire et al., 2014).
- The Royal Medical Services (RMS) operate 12 hospitals, including the King Hussein Medical Centre, a compound of five hospitals and laboratories in the capital of Amman. RMS facilities account for 20% of hospital beds across the country (Première Urgence, 2014). The RMS facilities are operated by the leadership of the Jordanian Armed Forces, and serve both military and civilian patients (Al Qadire et al., 2014).
- University Hospitals comprise an additional 9% of hospital beds. There are two university hospitals: the Jordan University Hospital (JUH) in Amman and the King Abdullah University Hospital (KAUH) in Irbid. They operate as tertiary hospitals for complicated case referrals (Première Urgence, 2014).
- Primary Health Care centres are clinics offering outpatient services by a nurse or a general or family physician, and are located across the country. This is the entry point into the public system and referrals are typically required before visiting a hospital or consulting a specialist. Primary Health Care centres also provide preventative health care such as family planning

services and immunizations (Première Urgence, 2014). These centres are typically available free of charge to all Jordanians (Al Qadire et al., 2014)

Private Health Care Sector

The private health care sector is constituted of for-profit companies, UNRWA (United Nations Relief and Works Agency) clinics, and NGOs clinics and services (Jordan Health Aid Society, International Medical Corps, Médecins Sans Frontières, and many more). The private health care sector is reputed to be well resourced and highly skilled, such that many foreign patients from across the Gulf region come to Jordan to seek medical care. (Al Qadire et al., 2014). In total, the private sector provides 61 hospitals and 33% of hospital beds nation-wide (Première Urgence, 2014).

Refugee Health Care

As in all refugee crises, meeting health care needs of Syrian refugees is a major concern (Doocy et al., 2015). The UNHCR and other NGOs have been prioritizing primary health care and emergency services for those in need.

Within Refugee Camps

All Syrian refugees living in one of the three refugee camps are registered and have a “Proof of Registration” document that is valid while they remain in the camp (Amnesty International, 2016). Within the camps, UNHCR reports to provide “a comprehensive health care package for refugees in Azraq and [Al] Za’atari camps includ[ing] primary health care, reproductive health, dental, mental health and nutritional care, and secondary and tertiary out of camp referrals” (UNHCR, 2017).

Outside Refugee Camps

Hospitals and health centers in Jordan’s northern governorates are MoH facilities, and are charged with servicing the local population as well as Syrian refugees living outside the camps (Arnaout, 2016). They have reported straining under the growing demands, reporting upwards of 35,200 visits by Syrian refugees per month, and have faced instances of supply and medicine shortage related to these visits (Arnaout, 2016).

Palliative Care

Definition and Scope of Palliative Care

A definition by Dr. Diane Meier, Director of the Center to Advance Palliative Care in New York, USA defined palliative care as:

a specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain and stress of a serious illness - whatever the diagnosis. The goal is to improve quality of life for both the patient and family. Palliative care is provided by a team of doctors, nurses and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment (Razzak & Smith, 2014).

Three pillars of palliative care are the management of symptoms, reduction of pain, and improvement of quality of life (Al Qadire et al., 2014). It equally includes helping patients identify what is most important to their quality of life and creating a plan to achieve these (Silbermann, 2014). Palliative care is not in principle reserved for patients with cancer or other terminal illnesses, neither for end-of-life. It can be provided in a number of different care arrangements ranging from home visits by a trained family physician or nurse, to in-patient wards in hospitals, to coordinated community services (Silbermann, 2014). Palliative care programs focus on "interdisciplinary collaboration" to provide comfort for patients and their families (Baider & Goldzweig, 2014). Critically, a nuanced understanding of social and cultural contexts is integral to the introduction of palliative care to patients and their families (Silbermann, 2012).

Confusion exists around the definition of palliative care. In all cultures, people attach different meanings and understandings of words associated with palliative care such as pain, illness and death (International Observatory on End of Life Care, 2005). Further difficulties arise in trying to translate the words and concept into a different language, as seen in other countries (International Observatory on End of Life Care, 2005). Some health care providers, such as oncologists, may already be providing pain control and symptom management. However in many cases, the full range of health care services under the modern palliative care concept are yet to be established as part of comprehensive patient care (Mutafoğlu, 2014).

Recent Developments

While palliative care is a relatively new specialty, it has yet to earn as much attention and investment as compared to other medical specialities. In a report on the Global State of Pain Treatment: Access to Palliative Care as a Human Right, the Human Rights watch called palliative care "the neglected child of the health care family", and lamented its low priority on health policy agendas and both research and funding line-ups (Human Rights Watch, 2011). Experts estimate that 60% of those who die each year in the developing world would benefit from palliative care, which translates to 33 million people yearly (Human Rights Watch, 2011; Silbermann, 2014). However, the vast majority of the world's palliative care services exist in high-income countries, and are thus available to fewer than 20% of the world's population (Baider & Goldzweig, 2014).

There have been recent developments to encourage accessibility and provision of palliative care around the world. In 2014, the World Health Assembly passed a resolution insisting that member states to improve access to palliative care as part of universal and comprehensive health coverage, stating that “palliative care is an ethical responsibility of health systems” (Silbermann, 2014). The WHO also maintains a Model List of Essential Medicines, which represents a list of minimum medicines needed for a basic health care system. The list is revised every few years based on evidence of the most efficacious, safe and cost-effective medicines (WHO, 2015). The 19th version, published in April 2015 has a section of medicines specifically for pain and palliative care, including twenty medications, which should be available in various formulations (WHO, 2015).

Evidence of Impact of Palliative Care

Data from multiple randomised trials from the USA involving patients with advanced cancers observed the impact of adding interdisciplinary palliative care to regular oncology care. They concluded that the addition of palliative care significantly improves quality of care, quality of life and gives equal or better survival (Parikh, 2013). Patients receiving palliative care consultations early in their treatment reported better symptom control, and had lower rates of depression as compared to controls, and more frequently died in their place of choice (Parikh, 2013; Razzak & Smith, 2014). One trial with lung cancer patients even found that those who had access to palliative care lived on average 2.7 months longer than those without (Temel et al., 2010).

Another benefit of palliative care lies in the honest discussions with health care providers about prognosis and death, as well as proactive planning around care and quality of life both currently and at the end of life care. In the United States, end-of-life discussions were associated with no increases in depression or anxiety, and a better quality of life and less aggressive end-of-life care (Wright et al., 2008). Further, palliative care discussions were associated with less depression among caregivers, and patient quality of life was associated with better coping mechanisms, and better quality of life for caregivers (Wright et al., 2008).

As Razzak & Smith discussed, the same American studies found that palliative care was effective in reducing readmissions and lowering health care system costs (2014). Funds and resources were saved with reduced length of stay and readmissions through an increase in referrals to hospice and home-based care settings (Razzak & Smith, 2014). Patients were also moved from a high-cost venue such as an intensive care unit to a lower-cost setting such as a palliative care unit earlier, reducing costs to the patient and system (Razzak & Smith, 2014). They insist that palliative care is relatively low-tech and low cost compared to other aggressive care options.

Palliative Care in Jordan

While there are a number of different organizations, initiatives and projects working on palliative care in Jordan, provision of these services is still sparse and underdeveloped (Al Qadire et al., 2014). In 2011, the Jordan Palliative Care Initiative (JPCI) was founded as a WHO Demonstration Project, undertaken with joint collaboration between the Jordanian MoH, WHO, and local as well as international medical institutions (Stjernswärd et al., 2007). This initiative helped expand services at certain specific centres, advocate for policy change to expand accessibility of analgesics, and start the conversations about palliative care (Stjernswärd et al., 2007). The JPCI was also successful in establishing a National Palliative Care Committee in 2003, with three work groups in policy, drug availability and education (Stjernswärd et al., 2007). All across the Middle East, the Middle East Cancer Consortium (MECC), the Oncology Nursing Society (ONS), and the American Society of Clinical Oncology (ASCO) have built partnerships with palliative care institutions in the USA to train local care providers through regional workshops as well as exchange programs to the USA (Silbermann, 2014).

In Jordan, palliative care services are provided by two main organizations: the King Hussein Cancer Centre (KHCC) and the Al Malath Foundation for Humanistic Care (Al Qadire et al., 2014).

King Hussein Cancer Center (KHCC)

KHCC is a MoH hospital in the Amman, Jordan's capital city. Its Department of Palliative Care was established in 2004, to provide palliative care for hospitalized cancer patients, as well as training in palliative care for staff nurses and physicians (Al Qadire et al., 2014). KHCC provided the first in-patient palliative care unit as well as the first home care service in Jordan (Stjernswärd et al., 2007). The multidisciplinary care team includes of a physician, a nurse, a social worker, a physiotherapist, a nutritionist and a spiritual healer (Al Qadire et al., 2014). As KHCC is a cancer center, in-patient services are available to adult and pediatric oncology patients and their families from diagnosis until end of life (Al Qadire et al., 2014). Out-patient services include twice weekly home visits to patients, and a 24-hour phone service (Al Qadire et al., 2014). The unit has a capacity of 30 beds, and cares for 60-80 patients per month, half of which are home care patients (Stjernswärd et al., 2007). Depending on the source, the service admits between 200 and 400 new patients annually (Al Qadire et al., 2014; Stjernswärd et al., 2007).

Al Malath Foundation for Humanistic Care

Established in 1993, the NGO Al Malath Foundation was the only service to provide palliative care in Jordan for over a decade. Their service provides symptom management medical care, psychosocial and spiritual care for patients with end-stage diseases and their families (Al Qadire et al., 2014). Al Malath also provides support for patients and families with end of life, and grieving processes after death

(Al Qadire et al., 2014). Care is provided by a team of a nurse, a physician, a pain management specialist, a social worker, a dietician, and a religious cleric who visit the patient in their home (Al Qadire et al., 2014). Due to limited funds and staff, Al Malath only services patients within the Amman governate (Al Qadire et al., 2014). A small percentage of their patients are children and approximately half are oncology patients (Al Qadire et al., 2014).

Al Bashir Hospital, another MoH hospital located in Amman also has a palliative care team within the oncology unit, that provides palliative care as part of their cancer care services, without specific support (Stjernswärd et al., 2007). One source also briefly mentioned a training seminar in palliative care in “other major oncology units in Amman and Irbid” possibly referring to the King Abdullah University Hospital, though no further references were found (Bingley & Clark, 2009).

As the only established palliative care services are available in the city of Amman, it is clear that palliative care services are not accessible to the vast majority of those living in Jordan. Only a few physicians practice pain and symptom management outside these centers, mainly in the private sector (Al Qadire et al., 2014). There is also no information available about to what extent palliative care services are offered within refugee camps. It is fair to assume that some pain management services may be provided but details are unknown.

Palliative Care Policy

While the JPCI and other groups have put considerable effort in advocating and mobilizing efforts among policy makers, palliative care has yet to be incorporated into the Jordanian National Cancer Control Plan, the MoH's National Health Plan, the RMS health care or any other policies (Stjernswärd et al., 2007). In the 164-page Jordan Response Plan for the Syrian Crisis 2016-2018 released by the Hashemite Kingdom of Jordan Ministry of Planning and International Cooperation, 1 of the 36 proposed interventions within the health sector is to “support the delivery of essential secondary and tertiary care for Syrians not covered by MoH including [...] palliative care including psychosocial support, symptomatic relief and pain management” (Ministry of Planning and International Cooperation, Hashemite Kingdom of Jordan, 2015). While actions towards this goal are not yet seen, it is reassuring while low on the list of priorities; palliative care is on the government's radar.

Lack of Palliative Care Education

Palliative care education is not yet integrated into undergraduate medical, nursing, social work nor pharmacy curricula (Al Qadire et al., 2014; Stjernswärd et al., 2007). There is one single Masters Level graduate palliative care program offered at the University of Jordan School of Nursing, and one academic diploma program in palliative care offered at a private university (Al Qadire et al., 2014). Furthermore, education about pain management is absent from undergraduate medical education,

post-graduate medical education and the clinical subspecialty of pain medicine for physicians does not exist in Jordan (Al Qadire et al., 2014). However, a handful of physicians have received in-depth training in palliative care through international fellowships and are putting their knowledge to use in major oncology units in Amman (likely referring to KHCC) (Human Rights Watch, 2011).

Financial Factors

Cost to Patients and Families

Between the onset of the Syrian Crisis in 2011 and November 2014, Syrian refugees with a valid MOI service card could access any MoH facility the receive care for free (Amnesty International, 2016). They received the same services and quality of care as insured Jordanians. The government changed its policy in November 2014, now requiring Syrians with valid MOI service cards to pay the same rates as uninsured Jordanians, where fees are still partly subsidized by the state. Those without valid MOI service cards are required to pay the same fees as other foreigners, at a steep 35-60% more than uninsured rates (Amnesty International, 2016). Between 2014 and 2015, the average cost for health care paid by a refugee in the first facility increased from 23 JOD (\$32 USD) to 33 JOD (\$46 USD), and the rate of those needing care who did not seek it tripled from 4% to 13% (UNHCR, 2015a). Transportation costs and medication costs are then added on top, and are not subsidized for refugees by the state.

When the 'urban verification exercise' began in early 2015, Jordanian authorities were charging 30 JOD (\$42 USD) per person, and later reduced the fee to 5 JOD (\$7 USD) (Amnesty International, 2016). This piece of ID is essential to accessing all public services including education and MoH health care at the uninsured rates (Amnesty International, 2016).

In Doocy et al.'s investigation of care-seeking habits among those with NCDs, inability to afford care was the most common reason for not seeking care in each of the included conditions (2015). This finding is aligned with other studies that report that cost is the main reason why refugees do not seek care (UNHCR, 2015a).

While even the uninsured Jordanian rates do not appear high, they are often unaffordable for Syrian refugees who are already struggling to meet the needs of their families (Amnesty International, 2016). As Syrians are not legally allowed to be employed in Jordan, options for earning a livelihood are very limited (MSF, 2015a). Nearly all those Syrian refugees living outside camps (93%) fell below the Jordanian poverty line of 68 JOD (\$96 USD) per capita per month or 816 JOD (\$1,152 USD) per year (UNHCR, 2017).

Persons with disabilities which have arisen due to conflict-related injuries face an additional burden of meeting costs for specialized care (Amnesty International, 2016). Families have reported making difficult choices between meeting the basic needs of the entire family and those of the person with disabilities (HelpAge International & Handicap International, 2014). The 2015 UNHCR utilization survey found that only 63% of Syrian refugees with disabilities interviewed including those with war wounds received some type of surgical, rehabilitation or psychological treatment or assistive device (UNHCR, 2015a).

NGOs have been stepping in to try to fill the gaps to reach those in greatest need. At Al Ramtha MoH hospital in Irbid, Médecins Sans Frontières provides emergency surgery, general inpatient care, physiotherapy and psychosocial support for war-wounded Syrians (MSF, 2015a). MSF runs a 40-bed post-operative facility in Al Za'atari refugee camp for rehabilitative care, a reconstructive surgery project in Amman, a microbiology laboratory, and a maternity and neonatal project (MSF, 2015a). They also expanded a project caring for Syrian refugees and Jordanians specifically with NCDs, responding to a huge need for treatment through two clinics and home visits to patients (MSF, 2015a). This is just one example of many national and international NGOs who are contributing to health care for refugees in Jordan, a comprehensive stakeholder mapping by Première Urgence – Aide Médicale Internationale from 2014 can be found in Appendix A (Première Urgence, 2014).

Other initiatives have been established, such as UNHCR's conditional cash transfer intervention targeting pregnancy women with income vulnerability (UNHCR, 2015b). On the condition that she attends a minimum of one medical check-up, UNHCR will transfer her cash to pay for antenatal visits, a normal or C-section delivery and any birth-related complications at a public MoH facility (UNHCR, 2015b). UNHCR also has an Exceptional Care Committee (ECC), which receives applications from refugees with serious medical needs for a funding grant (Arnaout, 2016). Decision criteria include necessity and adequacy of recommended treatment, prognosis, feasibility of treatment and cost of care. While average amounts approved for a Syrian refugee with cancer was \$3501 per person in 2012, it is almost certain that none would be allocated for palliative care due to the criteria of a favourable disease prognosis (Arnaout, 2016). Some individuals and families have also been able to rely on private donors to finance their health care costs, through organized donations or even the generosity of Jordanian strangers (Amnesty International, 2016).

It is difficult to comment on any financial costs to patients related to palliative care in particular. Because of the locally produced formulation for morphine, cost is unlikely to represent a significant barrier even for uninsured individuals (Global Health Watch, 2011).

Costs to the Health Care System

The influx of refugees from Syria and the need to care for them is placing enormous pressure on the MoH financial and health systems (Nimri, 2016). Studies have shown that the public health system is dangerously overstretched (Nimri, 2016). In 2013, the Government of Jordan took out an emergency loan of \$150 million USD from the World Bank to help cope with the increased needs (Amnesty International, 2016). Jordan has also received some international support, but the support has not kept up with the increasing needs (Ministry of Planning and International Cooperation, 2015). A Financial Update from May 15, 2017 reports that only \$191.2 million (7.2%) of the \$2.65 billion needed for the 2017 Jordan Response Plan has been funded (Ministry of Planning and International Cooperation, 2017). This funding has been granted by 22 nations, with top donor Germany, Japan and France (Ministry of Planning and International Cooperation, 2017). In contrast, the UN Office for the Coordination of Humanitarian Affairs' Financial Tracking Service report that as of May 8, 2017, \$245.2 million USD have been funded for the year, with top donors as the European Commission's Humanitarian Aid and Civil Protection Department, the USA, Japan and Canada (UNOCHA, 2017). In either case, the international funding is falling far short of the funds required to adequately support the MoH.

There is also evidence that palliative care may be effective in reducing health care system costs, as it has done in the USA (Razzak & Smith, 2014). In the USA, savings come from moving patients from high-cost venues such as intensive care to lower-cost ones such as regular or palliative care units, in addition to less time spent in hospital and higher use of hospice care at home (Razzak & Smith, 2014). Clearly, there will be significant upfront costs to the Jordanian system to build more palliative care units, develop appropriate hospice care services and train specialists. However once established, a robust palliative care system could be a cost-saving vehicle while simultaneously providing better care for patients and families.

Systemic and Organizational Factors

Registration and Identification

Syrian refugees living in urban areas who are registered with UNHCR receive an Asylum Seeker's Certificate, which identifies "persons of concern" to the UNHCR as those listed on the certificate (typically a family). The Jordanian government also requires refugees to obtain a Ministry of Interior (MOI) service card, which remains valid as long as a refugee continues to live in the district where the card was first registered. Both documents are required to access UN funded and public services provided by the Jordanian government including health care, education, etc (Amnesty International, 2016). If a refugee moves from their initial place of registration, they are required to re-register with the police in the new location, and

update their MOI service card. It requires obtaining new proof of residency documents and the process for the updating of MOI cards can take months (Amnesty International, 2016). In addition to being a barrier to accessing public services during this time without valid identification, Syrians are at risk of being involuntarily moved to refugee camps or deported back to Syria (Amnesty International, 2016).

In 2015, Jordanian authorities began an 'urban verification exercise' to register previously unregistered Syrian refugees living in urban areas. This involved issuing new biometric MOI service cards to refugees, which require additional documentation. New MOI service cards, Syrian refugees must make a request at the local police station for documents, which may have been previously taken by Jordanian authorities at the border (until 2015, the policy was to retain identity documents of Syrians that entered through unofficial border crossings). Further requirements include a stamped lease agreement or residence certificate provided by UNHCR and a copy of the landlord's identity document. Finally, all those above 12 years of age are required to obtain a health certificate from the Ministry of Health identifying the person's state of health. For many refugees, these documents are difficult to obtain, especially copies of lease agreements or landlord's ID (Amnesty International, 2016).

As of February 2016, Jordanian authorities have issued approximately 299,000 MOI service cards to Syrians registered with UNHCR. According to UNHCR, public government services are accepting both old and new MOI service cards while the 'urban verification process' is ongoing, however Amnesty International has reported some cases of refugees with old cards being turned away (Amnesty International, 2016).

For those seeking to leave refugee camps, there is a similarly involved process to complete the official "bailout" process. It requires refugees to have a direct male Jordanian relative over 35 years old and married complete paperwork, and pay 300-600 JOD (\$400-900 USD) (Amnesty International, 2016). As these criteria are so difficult to satisfy, many Syrians have found other ways to leave refugee camps but since July 2014, Jordanian authorities have prevented UNHCR from providing Asylum Seeker Certificates for those who have not completed the official bailout process (Amnesty International, 2016). In January 2015, the official bailout process was suspended, stopping all Syrians from formally leaving camps, however UNHCR noted as of August 2015, 160,000 Syrians had left unofficially (Amnesty International, 2016). Without the appropriate UNHCR documentation, all those will be prevented from accessing UN services outside the camps, and from getting a MOI service card and thus accessing any public services as well (Amnesty International, 2016).

A Health Needs Assessment was done by the NGO Première Urgence - Aide Médicale Internationale in 2014 and found that from the Syrian refugee's perspective, the most significant barrier to accessing health care included valid MOI and UNHCR

registration documents (Première Urgence, 2014). Those surveyed reported having to provide “at least 4 copies of the UNHCR registration document for every consultation” (Première Urgence, 2014).

Accessibility of Health Care Services

Based on a survey in 2015 by UNHCR among Syrian refugees living outside of camps in Jordan, only 64% of households knew that at the time, refugees had subsidized access to government primary health care (UNHCR, 2015a). The researchers attributed this in part to the November 2014 change in Jordanian policy from offering free health care services for Syrian refugees to offering care at a subsidized rate (UNHCR, 2015a). Since this policy change, a number of international organizations and NGOs have sought to step in to provide free health care services. However they state that they were not given prior warning from Jordanian authorities and thus had little time to scale up their responses (Amnesty International, 2016). NGOs have not been able to meet the increased demands for free health care, and have been forced to turn patients away (Amnesty International, 2016). An additional implication of the new policy is the introduction of a referral fee for NGO health care providers when referring patients to MoH facilities, where they are charged a ‘foreigner’s rate’ for care, which is more expensive (Amnesty International, 2016). If a Syrian with valid documents were to go to a MoH facility directly, bypassing an NGO referral, they would be charged the less expensive ‘subsidized rate’ (Amnesty International, 2016).

Sources have also described long wait times, poor treatment by staff and transportation as factors in health care accessibility (Doocy et al., 2015; Amnesty International, 2016). These are partly due to the increasing strain on Jordan’s capacity and infrastructure in health with the influx of refugees (Doocy et al., 2015).

Accessibility of Palliative Care Services

There is no available data about the demographics of patients seen accessing palliative care services through the KHCC, the Al Malath Foundation or other sources, so it is impossible to comment on the utilization by Syrian refugees in particular. However, the MoH treated 134 Syrians with cancer in 2011; and 188 cases in 2012 with projected trends upwards of 600 as of present (Arnaout, 2016). Thus, it is likely that many of these patients were treated in Amman, and quite possible that some were able to access the palliative care services.

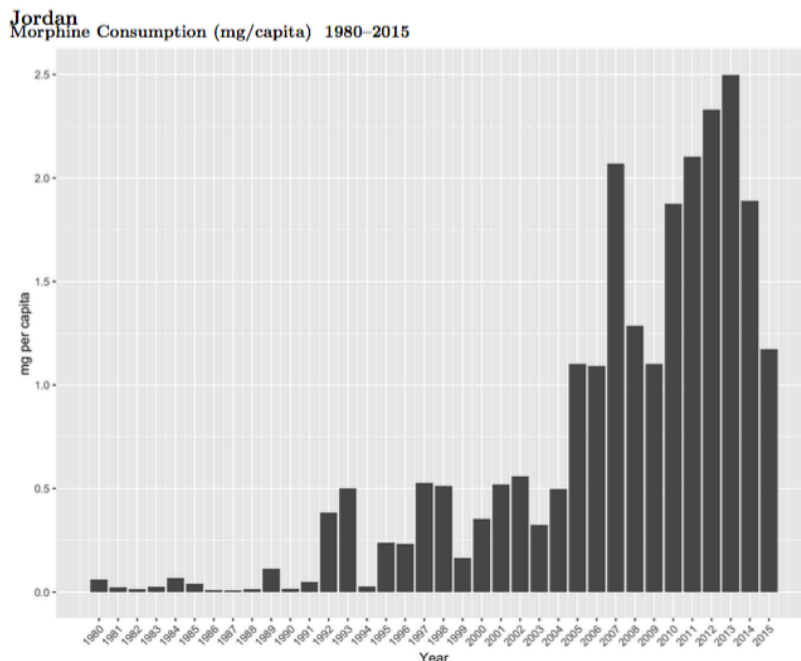
It is justified to assume that similar challenges arise in accessing palliative care as in accessing other health services, as mentioned above. Additional factors to consider are that the overall palliative care service capacity is very small, and unevenly distributed as they are primarily located in Amman.

Accessibility to Analgesics

Pain management is a key pillar within palliative care, and under the right to health, governments are obliged to ensure that all those medications included in the WHO's Model List of Essential Medicines are available to patients (Human Rights Watch, 2011). The consumption of the opioid morphine, while controversial, is used as indicator of how well health systems in countries around the world are able to treat and manage pain (Human Rights Watch, 2011).

Jordan has made significant strides in the past ten years in facilitating accessibility to analgesics and opioid medications (Human Rights Watch, 2011). Initially, opioid prescription was only possibly for an oncologist, and limited to a three-day supply, but in 2004 reformed drug regulations allowed all physicians to prescribe up to ten days of medication (Stjernswärd et al., 2007). The limit of a three-day supply still remains for non-cancer patients, and regulations do not allow nurses to prescribe opioids (Human Rights Watch, 2011). Also in 2004, a local pharmaceutical company began producing a 10mg immediate-release morphine tablet for \$0.14 USD per tablet, seven times cheaper than the branded option, leading to a significant decrease in cost and increase in availability (Stjernswärd et al., 2007). Figure B illustrated the trend of annual morphine consumption per capita, which has been fluctuating but on a generally upward trend (Pain & Policy Studies Group, 2016a) As seen in Figure C, Jordan ranked third among the WHO Eastern Mediterranean Region for annual morphine consumption, but still far below the global average use (Pain & Policy Studies Group, 2016b).

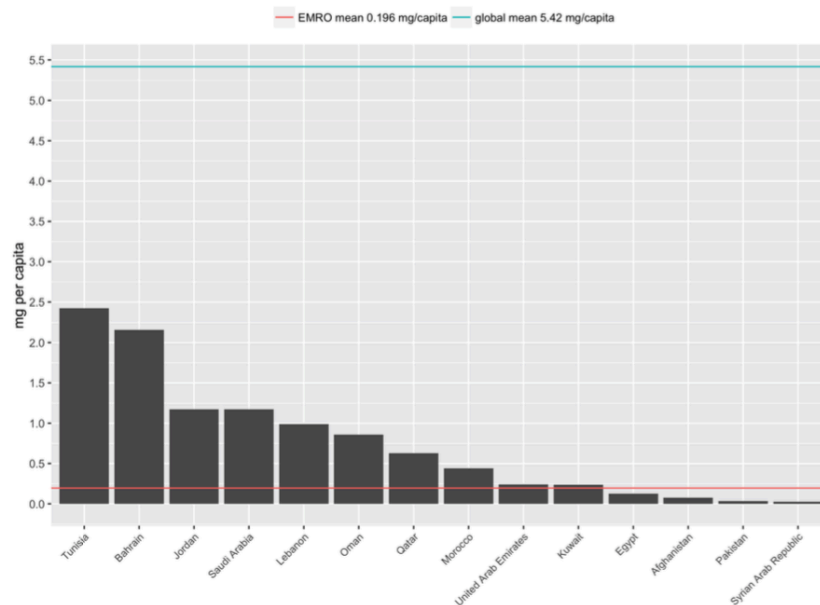
Figure A: Jordanian Morphine Consumption 1980-2015 (Pain & Policy Studies Group, 2016a)



Sources: International Narcotics Control Board; World Health Organization population data
By: Pain & Policy Studies Group, University of Wisconsin/WHO Collaborating Center, 2015

Figure B: WHO Eastern Mediterranean Region annual morphine consumption (Pain & Policy Studies Group, 2016b)

2015 EMRO Consumption of Morphine (mg/capita)



Sources: International Narcotics Control Board; World Health Organization population data
By: Pain & Policy Studies Group, University of Wisconsin/WHO Collaborating Center, 2015

Nonetheless, current opioids administration policy in Jordan requires a long process for prescription and dispensing, including a special prescription for morphine (Al Qadire et al., 2014; Human Rights Watch, 2011). Regulations are followed strictly for fear of legal sanction including both criminal and professional sanctions such as license revocation for mishandling (Human Rights Watch, 2011). Several sources had mentioned that these regulations cause physicians to be over-cautious and hesitant to prescribe and administer opioids, even encouraging patients to tolerate more pain to avoid the necessity of opioids (Al Qadire et al., 2014; Human Rights Watch, 2011).

Country	Injectable Morphine In Hospitals	Oral Morphine Accessibility					
		Tertiary Hospitals	Other Hospitals	Pharmacies	Health Centers	Hospices	AIDS Clinics
Pakistan	Some	Some	Few	Few	Few	None	None
Egypt	Most	Most	Some	Some	Some	All	N/A
Iran	All	None	None	None	None	None	None
Morocco	Most	Some	Few	Some	None	N/A	None
Jordan	Some	Some	Few	Few	None	All	N/A

Figure D: Accessibility of Morphine in Different Health Care Settings in the Middle East and North Africa (Human Rights Watch, 2011).

Figure D illustrated that while both injectable and oral morphine are available in some health care centers, it is not widely nor evenly accessible across the country. Further, access is poor in Jordan compared to other countries within the WHO Eastern Mediterranean region (Human Rights Watch, 2011)

Cultural and Ideological Factors

Cultural and ideological factors that influence both provision and utilization to palliative care include a tradition of non-disclosure about poor prognosis, important religious belief about illness and death, family dynamics, negative perceptions as well as misconceptions and lack of awareness.

Disclosure of Bad News

In the Middle East region, many sources report that disclosure of a 'bad news' is a complicated process, especially such as cancer or a terminal disease (Silbermann, 2016; Qaddoumi et al., 2009). A literature review evaluating attitudes, beliefs and practices of patients, family members and health professionals about cancer diagnoses in the Middle East elucidates ongoing social stigma and misconceptions about incurability (Khalil, 2013). Physicians balanced the historical and social norm of silence regarding a cancer diagnosis with the aim of maintaining a patient's hope, with the patient's right to know the truth (Khalil, 2013). While truth telling and informed consent are important ethical principles in other parts of the world, major cross-cultural differences in attitudes exist between "western and non-western" countries (Khalil, 2013; Silbermann, 2016).

Family members and caregivers' attitudes seem to prefer the "non-disclosure policy to avoid loss of hope" (Qaddoumi et al., 2009; Khalil, 2013). It has been noted that faith belief play a role in end of life decisions, however these issues are rarely openly addressed with Muslim patients (Qaddoumi et al., 2009). A single Jordan-specific study assessed the efficacy of up-front discussions with child patients and their families about prognosis and do-not-resuscitate status of children with terminal brain cancer. They found that discussing prognosis openly did cause anxiety among some families, but most parents eventually agreed with a palliative treatment plan (Qaddoumi et al., 2009). The study concluded, "Islamic attitudes and beliefs about end-of-life issues should not deter physicians from discussion such matters with patient's family" (Qaddoumi et al., 2009).

Patients' and families' disclosure preferences may also evolve over the course of an illness. This may be especially true once a trusting relationship is formed with the health care providers, who can communicate in a culturally specific way and explain situations and options without taking away hope (Kagawa-Singer et al., 2010).

Role of Culture and Islam in Illness and Death

Culture is foundational for wellbeing, human interactions, quality of life and proved context for all priorities in health care (Schim & Doorenbos, 2010). Culture is informed by shared beliefs and values, interactions between people and with their environments, and is passed down through generations (Baider & Goldzweig, 2014). Age, gender, socioeconomic status, education and life experiences are important factors within concepts of culture and health (Baider & Goldzweig, 2014). Often it is difficult to distinguish culture, religion and other aspects of life; in some cases religion exerts more influence than culture, in others culture is more prominent than religion (Kemp, 2005). Especially within the context of illness and death, traditions, rituals, family values and the meaning of life add nuanced complexity to each patient's care (Baider & Goldzweig, 2014).

In many parts of the world, Islam is considered not simply a religion, but as a cultural identity and heritage (Baider & Goldzweig, 2014). There are some interpretations within Islam, which align very closely to the values and goals of palliative care. For example, as noted by one researcher, "[i]n Islam, life is viewed as a time of preparation for the hereafter, while death is viewed as the beginning of a different form of life referred to as *Al-Barzakh* (the interval between death and resurrection)" (Baider & Goldzweig 2014). The Qur'an offers a reminder that there are times when people should recognize their limits; death does not happen except by Allah's will. "The Muslim world view of health and illness incorporates the notion of accepting illness and death with patience, meditation and prayers and accepting that illness, suffering and dying are part of life and a test from Allah" (Baider & Goldzweig 2014). Rassool argues that in Islam illness is not necessarily considered as enemy; rather, it is an opportunity to cleanse, purify and re-balance on the physical, emotional, mental and spiritual self (2000). "Health and illness become part of the continuum of being, and prayer remains the salvation in both health and in sickness" (Rassool, 2000).

Some Muslims who interpret suffering as atonement for one's sins believe that they should not use opiates to relieve pain (Baider & Goldzweig, 2014; Forgeron et al., 2006; Al Qadire et al., 2014). However many Muslims do not agree, and while they may still see it as Allah's will, they will accept pain management care (Forgeron et al., 2006). Islamic teachings encourage Muslims to seek treatment and care when they fall ill, because needless pain and suffering are frowned upon (Al-Atiyyat & Mohammed, 2009). Muslim patients may opt for a combination of prayer from the Qur'an, spiritual healing and traditional healing practices, in conjunction with modern medicine (Baider & Goldzweig, 2014).

In seeming opposition to the notion of accepting the inevitability of death, some families view palliative care as a sign of "giving up" on their loved one (Al Qadire et al., 2014; Silbermann, 2014). In Islam it is also a sin to forego treatment if is available and accessible (Al Qadire et al., 2014). The propensity to deny that a family member is dying may be strengthened in an Islamic Arab culture such as in

Jordan where the family unit is central (Al Qadire et al., 2014). Muslims believe that Allah determines death and thus some may be skeptical about definitive statements by health care providers around life expectancy (Baider & Goldzweig, 2014). These beliefs may also influence care providers extraordinary measures to keep treating patients to satisfy families, when instead palliative measures may be in the best interest of the patient (Al Qadire et al., 2014).

Family Responsibility

Within Muslim families, health related decisions are more often joint decisions by family members, and less often made by autonomous individuals. Traditionally, parents, spouses, and elder children, in descending order, tend to be the decision makers, and men more often than women (Baider & Goldzweig, 2014). The family is the basic unit responsible for decisions about treatment and disclosure, and may even come to decisions with health care providers without involving the patient themselves. In some instances, questions are even referred to the religious leader for input in the decision. These practices value loyalty and solidarity as well as protecting patients from any emotional harm caused by addressing illness or end-of-life (Baider & Goldzweig, 2014).

Care for the ill or dying has been seen as a family responsibility, and to be managed at home. Some Muslim families believe that sending a relative to a hospice or hospital without curative intent is shirking the responsibility of family member to care at the end of life (Baider & Goldzweig, 2014). Evidence about the benefits of home care suggest that overall wellbeing is better at home, and this tends to be patients' and families' first choice for end of life care (Silbermann, 2014). As the family unit in Middle Eastern cultures is an integral part of a palliative care team, there is some advocacy for "increased recognition of the need to further empower the family by instruction in treatment approaches, care goals, and the decision-making process" (Silbermann, 2014).

Negative Perceptions

By the Jordanian Public

There is no question that although the presence of Syrian refugees in Jordan may stimulate local retail economy, the larger impact is causing strain on public resources including health care services (Nimri, 2016). A report from the Ministry of Planning and Internal Cooperation in Jordan says that "resentment and alienation of growing in northern governorates, where most of the refugees are concentrated" (Ministry of Planning and Internal Cooperation, 2015). Resource strain and tensions between host communities and refugees have contributed to growing negative public perception and the Syrian refugee population being used as a scapegoat for other infrastructure and resource problems (Amnesty International, 2016). Overcrowding in the health services and uneven access between Jordanians and Syrians both contribute to perceived inequality in access to health care by both

groups, and reduced social cohesion (Doocy et al., 2015).

On an individual level, Syrian refugees have perceived strong resentment from host communities and being targeted by Jordanians (Première Urgence, 2014). Reports have included verbal harassment, being charged higher prices for goods or services, discrimination from teachers towards Syrian students etc (Première Urgence, 2014).

Of Health Care Standards for Refugees

A 2014 Health Need Assessment by the NGO Première Urgence – Aide Médicale Internationale described many complaints and concerns that Syrian refugees have about the quality of health care services in the MoH facilities. These included that medications were often out of stock in MoH facilities, and limited trust in the effectiveness of the medications, comparing them to previous medications they used in Syria (may be due to different brand names rather than different standards (Première Urgence, 2014). There were complaints about limited scope of services, the need for referral other centers, overcrowded facilities and overworked staff. Refugees felt that a lack of attention and physical examination was an indication of low quality care (Première Urgence, 2014). Health care providers were also sometimes described as being rude or uncaring, and the perception of a lack of respect contributed to feelings of humiliation and discrimination (Première Urgence, 2014). Overall, poor perception and mistrust discouraged some to seek treatment, with one person commenting: “you enter the health center sick, you get even sicker of the process” (Première Urgence, 2014). The perception of health services provided by NGOs and UNHCR was more positive, however these centers were equally likely to be overloaded and under-resourced (Première Urgence, 2014). Whether these perceptions were based in fact or in bias, they had real negative impacts on case-seeking behaviours and institutional trust.

Lack of Awareness & Misconceptions

About Palliative Care

Lack of Awareness and misconceptions surrounding palliative care are prevalent both among health care providers and among patients and the general public. Physicians in Jordan may perceive making a referral for palliative care as a failure of their medical capability to cure the patient, and a sign of loss of prestige when disclosing this to the patient, family or colleagues (Al Qadire et al., 2014). This may arise due to the way medicine is taught, where the dominant paradigm is that death equates failure and that physician-patient communication about end-of-life is an auxiliary skill rather than a core competency (Al Qadire et al., 2014). In the same respect, the beliefs of some Muslim health care providers or family members that Allah will ultimately determine death may pressure patients to undergo futile and aggressive treatments (Al Qadire et al., 2014).

An absence of public awareness about palliative care equally prevents patients and families from exploring or requesting this service (Al Qadire et al., 2014). While many of the few existing services are offered to and accessed primarily by oncology patients, palliative care would be helpful to many other kinds of patients including those with NCDs, war-related injuries, chronic pain etc., as well as their caregivers and family members.

Lastly, increased use of other care providers such as social workers, mental health specialists, religious or spiritual counselors could help spread awareness and acceptance of palliative care services (Al Qadire et al., 2014). In addition, this could help lighten the load on physicians and nurses, while providing a better experience for patients and their families.

About Pain Management & Opiate Addiction

Some of the practices within health care settings represent a lack of awareness about the importance of pain assessment and management (Al Qadire et al., 2014). One source reported that it is a common practice to provide pain management treatment to patients only once pain becomes severe and intolerable (Al Qadire et al., 2014). Because of strict procedures surrounding the prescription, time between a patient reporting pain and administration of medication can be up to one hour (Al Qadire et al., 2014). Patients are also typically given a single dose at a time, and pain re-assessment is not always completed (Al Qadire et al., 2014).

Health care providers have also been found to have low levels of knowledge regarding pain management including the preferred pharmacological interventions and method of administration (Al Qadire & Al Khalaileh, 2014). The most common misconception regarding pain medications among health care providers, patients and among the wider public is the exaggerated fear of addiction (Al Qadire & Al Khalaileh, 2014; Al Qadire et al., 2014). This has contributed to a state of “opioid phobia” where health providers are hesitant to prescribe and administer morphine and other opioids, and patients avoid taking them, even for those at end of life (Al Qadire et al., 2014). The Human Rights Watch report on the Global State of Pain Treatment included the following quotation from a Jordanian oncologist: “Doctors are fearful of everything to do with opioids” (Human Rights Watch, 2011).

Further Directions for Research and Policy

Several directions for future research and policy are identified in existing literature.

Research

- Investigation into unique Jordanian and Syrian preferences, beliefs and values surrounding illness, end-of-life and palliative care. This is needed to

- develop appropriate and culturally proficient palliative care services and clinical practices (Silbermann, 2014).
- Knowledge, attitudes and behaviours of health care providers, patients and families regarding the use of opioids and other analgesics should be explored to better address barriers (Baider & Goldzweig, 2014).
- Research should also be encouraged and funded to enable continuous progress to reduce the suffering and stress for patients and families (Al Qadire et al., 2014).

Refugee Health Policy

For the Jordanian Government

- The Jordanian Government should remove additional user fees charged to Syrian refugees and ensure that health care is affordable, accessible and appropriate for all (Amnesty International, 2016).
- Expedite the urban verification process and revise the requirements to reduce burden and cost for Syrian refugees. Meanwhile, ensure that health services are not denied to anyone for lack of identification or registration (Amnesty International, 2016).

For the International Community

- International donors must increase levels of sustainable long-term funding to support Jordan in responding to the Syrian conflict and care for refugees (Ministry of Planning and International Cooperation, 2015; Amnesty International, 2016).

Palliative Care Policy

For the Jordanian Government

- The government should adopt a National Palliative Care Program to support and manage efforts in health care settings across the country (Al Qadire et al., 2014).
- Palliative care courses and education should be introduced into undergraduate level curricula for nurses, physicians, social workers, pharmacists and other health care professionals. Postgraduate and subspecialty training in palliative care is also needed (Al Qadire et al., 2014).

For the International Community

- The World Health Assembly should be vocal in instructing member states to take effective steps to improve palliative care (Human Rights Watch, 2011).

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Appendix A: Stakeholder Map

Stakeholder Mapping as part of a March 2014 Health Need Assessment Report for the Jordanian Ministry of Health, prepared by Première Urgence – Aide Médicale Internationale.

Stakeholder	Activity	Target population	Facilities	Location
National NGOs				
JHAS	Comprehensive PHC PHC with MMU and Outreach team (10ppl) Referral Secondary and tertiary HC 24/7 hospital and maternity in camp Medevac team for cross-border medical evacuation	Syrian and Iraqi refugees All services are provided for free in Zarqa (and rest of the country except for the clinic in Amman)	6 CHC clinics Private trauma hospital (D'lail) 2 to 3 MMU 10 outreach workers Zaatari clinic Cyber city PHC	Irbid, Mafraq, Ramtha, Zarqa Zaatari and Cyber city camps
Bright Future for Mental Health	Psychosocial and mental health services: Psychiatric clinic and psychotherapy Teaching recovery techniques Recreational and development program Parental counselling Children and youth counselling Etc.	All Syrians	Psychiatric clinics in Amman and Irbid Psychosocial in Zaatari	Amman, Irbid Zaatari camp
ARDD - LEGAL AID	Legal advice (eviction, rent issues) and protection, registration issues	All Syrian refugees	2 centres	Amman, Zarqa
JWU	PHC	All Syrian refugees	2 facilities (+more in the country?)	Amman, Zarqa
Syrian private practice	PHC and specialist consultations	All (Syrians for 1JoD)	1 clinic in Zarqa town	Zarqa
Noor al Hussein	Primary and secondary health care (Gynaecology, dental care, nutrition, lab. tests, paediatric, physiotherapy, etc...) in IFH clinic Psychosocial services	All	2 clinics (Amman) + new in Zarqa	Amman, Zarqa, Ramtha and Salt
Jordanian Red Crescent	Hospital care	All Syrian refugees, for free		
National Woman's Health care centre (supported by Standard Chartered bank)	Mobile dental and eye clinics, preventive care, scan for breast cancer. pilot in most needy areas, target of 100 women	100 women	Mobile (at CBOs)	Zarqa

International NGOs				
IMC	Mental health Comprehensive PHC through JHAS PHC with MMU Referral Secondary and tertiary HC	All Syrian refugees For free except for clinics in Amman (Vulnerable Iraqis and host community population, including Syrians)		Amman, Zarqa remote areas Mafraq, Salt, Halabat, Ramtha and Zarqa
MDM	Support provision of PHC in MoH facility Community based health (2CHW) Mental health and psychosocial services with Bright Future	All Syrians as well as Jordanians	Ramtha King Abdallah Park + 2 clinics in Zaatari camp	Ramtha Zaatari
MSF France	Reconstructive surgery, orthopaedics, maxillo-facial and plastic Emergency surgical programme in Al Ramtha Hospital OPD treatment - acute needs and chronic conditions such as diabetes and hypertension Paediatrics hospital in Zaatari Mother and child hospital in Irbid	Victims of war related violence (Iraq, Syria, Libya, Yemen, Gaza)	Ramtha MoH hospital Jordanian Red Crescent hospital Hospitals in Zaatari, Irbid and Amman	Amman Northern governorates

Caritas	Comprehensive PHC	UNHCR registered Iraqi and non-Iraqis, and vulnerable Jordanians User fees apply Syrian refugees	2 clinics	Zarqa Amman
IFRC	Secondary care		Jordan Crescent facilities	Amman and others
Medair	Nutrition screening and treatment of acute malnutrition	Syrians	6 JHAS clinics Outreach	Irbid, Ramtha, Mafraq, Zarqa, Amman
Save the Children	Children protection and psychosocial services (level? type?)	Syrian refugees	?	Zarqa Other
Handicap International	Physical rehabilitation services (rehabilitation care, prosthetics and orthotics, assistive devices and mobility aids) Psychosocial support Support to hospitals through training and donation of materials Support to Syrian flats/referrals	Persons affected by the Syrian crisis	Irbid, Ramtha, Mafraq, Zarqa, D'lail hospital and camps Government hospitals and D'lail hospital	Amman, Irbid, Ramtha, Mafraq, Zarqa Governorates
Centre for Victims of Torture	Mental Health Counselling (group, individual, and family) Physical Therapy, Social Referrals of Complex Cases & Case Management	Survivors of Torture (Iraqis, Syrians, and others) and Victims of War Trauma (Iraqis and Syrians). All ages	2 centres + Mobile unites	Amman, Zarqa
Danish Red Cross	Psychosocial services	All Syrian refugees	Amman	Amman
French Red Cross with Jordanian Red crescent	Community-based health volunteers, primary health and chronic conditions	All	Psychosocial centre	East Amman
IRD	Equipment Capacity building Rehabilitation Health education/outreach	All Iraqis and Syrians	MoH facilities	Nationwide

International agencies /cooperation agencies				
UNICEF	Support immunization, capacity building (neonatal and maternal care, IMCI)	All	MoH + camps	Nationwide
UNRWA	Comprehensive PHC Secondary HC on referral	Displaced Palestinian communities	24 clinics Cyber city camp	Nationwide
WHO	Various support to MoH: Mental Health department Surveillance system Immunization Medication support (e.g. life-threatening and chronic diseases) Strengthening of coordination services and crisis management	All	MoH	Nationwide Focus on Northern Governorates for Syrian crisis
UNFPA	Support to NGOs/MoH for provision of reproductive health services	All Syrian refugees and vulnerable Jordanians	Static clinics MMU Urban and rural areas in Northern and southern governorates Network of Village health centres	Amman (Hashemi Chamali + Nazzal) Zarqa, Irbid, Ramtha and Mafraq Southern Governorate, will soon start in the North
JICA	Support to peripheral level services: training and equipment	Jordanian and registered refugees		
CBOs				
Community development Committee	PSS one on one sessions, Group sessions, children	All	Zarqa	Zarqa
Community development Committee Al Sabirin	Community activities	All	Sohkneh	Zarqa
	PSS sessions, outreach programme Formerly, primary health clinic	All	Ruseifah	Zarqa
Working women society	Community activities	All	Ruseifah	Zarqa
Houswife CBO		All	Zarqaa	Zarqa
Islamic Center CBO	Community activities	All	Zarqaa	Zarqa

Community center/women Al Sokhneh	Community activities	All	Sokhneh	Zarqa
Khawla Bint Al Azwar	Community activities (soon will start a clinic with NHF)	All	Zarqaa	Zarqa
Ramla CBO	Community activities	All	Zarqaa	Zarqa