RESEARCH

People with Disability in Libya are a Medicalised Minority: Findings of a Scoping Review

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This study used a scoping review methodology to identify, collate and summarise published literature relating to people with disability in Libya. Most sources came from peak international agencies, some from humanitarian agency media releases, a few were Libyan government reports and very little from scholarly journals. Four themes summarize findings and provide a means to examine assumptions regarding people with disability in Libya: (1) scant data and information gaps are the norm; (2) disability is a medical problem to be managed; (3) acquisition context matters: conflict versus non-conflict disability; and (4) disability human rights – social model on paper but not yet in practice. Findings reveal gaps in knowledge, promising signs of change and areas for action. People with disability in Libya need: a stable and secure community; visibility in reporting, planning and evaluation of services that are inclusive in design and delivery; and measures, technical definitions and socio-cultural understandings of disability that value function, activity and participation in everyday life as much as medical conditions, impairments and expert treatment. These actions will help provide people with disability in Libya an opportunity to actively contribute in rebuilding their communities in a post-conflict future.

Introduction

Since 2011, Libya has been wracked with internal conflict and effects of regional instability. Thousands of people have been adversely affected – including people with disability. Yet there is a dearth of information regarding people with disability in Libya. A cursory search of the internet reveals on the one hand, pre-revolutionary government reports of Libya's signing of the United Nations Convention on the Rights of People with Disability (CRPD) in 2006 and the Libyan "Law on Disabled Persons" (People's General Congress 1981). On the other hand, recent media releases from humanitarian agencies have survivor stories of people with disabilities, agency help and calls for donor support. 'Hannah's story', for example, is about a young woman with cerebral palsy living with disability in Libya and how a non-government organisation (NGO) helped (International Medical Corps 2012). Little is readily available on the topic of people with disability in Libya in between these extremes of national regulation and individual stories.

To understand the attributes, needs and goals of post-conflict communities, decision makers need accurate, reliable and relevant information about the people in them. This needs to include information from and about people with disability. No research about people with disability in Libya has been published in indexed scholarly journals since 1983 (Singh & Abudejaja 1983). Medical research regularly appears in the *Libyan Journal of Medicine* and elsewhere, but apart from a 2013 paper by El-Oakley, Ghrew, Aboutwerat et al. (2013), which recommended patient-centred services in Libyan health system reconstruction efforts (not disability services), scholarship on disability is rare.

When information is hard to find, people with disability are at risk of being 'invisible' (United Nations High Commissioner for Refugees [UNHCR] 2013). As people with disability are known to be vulnerable in conflict and post-conflict environments (Smith-Khan, Crock, Saul & McCallum 2014; Katsui & Kumpuvuori 2008), there is an urgent need to consolidate what has been published to help make the invisible visible. To date no study has attempted to identify, describe and summarize information published about people with disability in Libya. The present study aims to fill this gap through a scoping review.

Scoping reviews are a literature search methodology that enables descriptions of the extent, type and content of information regarding a previously unexamined topic (Pham, Rajić, Greig et al. 2014). The aim of this study was thus to make previously hard-to-find information about people with disability in Libya visible and accessible, and to consider finding implications. It does not evaluate services or provisions for people with disability in Libya. This article

first introduces Libya and its recent history, so the context of findings is clear. It then describes the methodology used to locate and summarise information. Findings are presented and discussed, and the article concludes with recommendations.

Libya – the country

Libya lies within the Eastern Mediterranean Region (EMR) and the Middle East and North African Region (MENA). This vast country borders Egypt in the east, five North African countries to the south and west (Sudan, Chad, Niger, Algeria and Tunisia) and the Mediterranean Sea to the north (World Health Organization Regional Office for the Eastern Mediterranean [WHO EMR] 2010). Before the 2011 revolution, Libya was an upper-middle income country (World Health Organization [WHO] 2014). National wealth was primarily the function of oil experts and oil reserves.

Libya – population

The most accurate Libyan population estimates come from before the 2011 revolution; in 2008; 85% of the estimated N = 5,527,000 population lived in 10% of the land area, mostly urban (WHO EMR 2010). In addition to Libyan citizens, many thousands of voluntary and forced migrants, asylum seekers and refugees, mostly from sub-Saharan Africa, lived in Libya. No population data was collected on these people because of limited United Nations (UN) reception and processing services.

Since 2011, the number of internally displaced persons (IDPs) has dramatically escalated. From a 2012 estimate of N = 80,000 IDPs (UN Special Mission in Libya [UNSMIL] 2012), 2016 Libya (excluding the Benghazi region) has N = 331,622 IDPs; N = 150,362 returnees and N = 142,370 migrants (UNSMIL 2016). The total IDP estimate for Libya in 2016 is between N = 400,000 (United Nations Children's Fund [UNICEF] 2016) and N = 435,000 (Mottaghi 2016). The Benghazi region in the west has fragile security conditions so a separate general estimate of IDPs and migrants is used here – it is at least N = 180,000 (UNICEF 2016). North-west areas are under militia control, so estimates cannot be made. Outside Libya, 'many Libyans [are] fleeing to Tunisia, although the exact number is uncertain given that Libyans have been crossing the border for commerce and other purposes for some time' (Mottaghi 2016, p. 2). There are also many reports of Libyans trying to cross the Mediterranean Sea to Europe (Amnesty International, 2015).

There are N = 37,000 registered refugees in Libya and an estimated N = 100,000 unregistered refugees and asylum seekers (UNSMIL 2016). It is not known how many have a disability; this lack of knowledge is typical for refugees (Smith-Khan et al. 2014; UN High Commissioner for Refugees [UNHCR] 2013). UNSMIL reports regularly include population estimates, but none of these include people with disability. The situation of these people on the move is 'dire' (Amnesty International 2015; UNSMIL 2014b, 2015a, 2016). Libya's population is thus one in flux.

Libya – pre-revolutionary government

For nearly half the 20th century, the Libyan region was under Italian control. A post-World War Two (WWII) agreement meant Italians surrendered control and the independent Kingdom of Libya began in 1951. It ended in a 1969 coup d'état; replaced by a Revolutionary Command Council that ruled until 1977 (Encyclopædia Britannica Online 2016). The General People's Congress (GPC) followed. Muammar al-Qaddafi was the Secretary-General until his resignation in 1979, whereupon he became the de facto authoritarian ruler (Encyclopædia Britannica Online 2016). During the GCP regime, the country was renamed Libyan Arab Jamāhīriyyah. In July 1977 there was armed conflict between with Egypt (a short border war) and in the 1980s with Chad (Besharah 1995).

This history is directly relevant to people with disability because conflicts since WWII left many hundreds of thousands of explosive remnants of war (ERW), causing many amputation injuries (Besharah 1995; Burckhardt 2012; Handicap International 2014; Landmine Monitor and Cluster Munition Monitor [LCMM] 2004). During the 1990s and 2000s Libya established, or had humanitarian support, for extensive demining, community awareness and amputee rehabilitation programs and infrastructure (LCMM 2005; Handicap International 2014). As the next phase of Libya's history unfolded, ERW continued to be a cause of disability.

In 2008 Libya signed the CRPD. Pre-revolutionary social security legislative frameworks covered people with disability in relation to pensions and entitlements (including a 1987 law specifically for people with disability) (Social Security United States Government 2016). To be eligible people with disability needed to demonstrate an '80% loss of earning capacity' and in doing so they received a pension of at least 50% of the full old-age pension, together with dependent supplements for a 'wife and each child under age 18 (no limit for an unmarried daughter)' as well as a 'constant attendant allowance … [for] constant attendance of others to perform daily functions' which was 25% of the disability pension (Social Security United States Government 2016). The Social Affairs Ministry was responsible for rehabilitation and community services for people with disability in addition to other welfare recipients. The Ministry of Health was responsible for emergency, acute and primary care of people with disability in addition to general medical primary, district and hospital care. The ministries had separate budgets, infrastructure, services and employment conditions. Apart from pensions, people with disability were eligible for equipment and free treatment in hospitals and designated rehabilitation centres. As yet no CRPD implementation report has been submitted to the United Nations by Libya (United Nations Human Rights Office of the High Commissioner 2016) and no 'shadow' report is available from non-government organisations (Hamed El Sahly & Cusick 2016), but a law relating to the 2008 ratification of the CRPD was implemented in 2013 (Libyan Security Sector Legislation 2013a).

In 2011 a violent internal uprising led to the collapse of the Qaddafi regime (UNSMIL 2013a). In 2012 a hopeful but precarious few months of national stability followed. Provisional government emerged and elections were held. The country was again known as 'Libya' rather than the GPC's 'Libyan Arab Jamāhīriyyah'.

Revolutionary and post-revolutionary governance relevant to people with disability
High-level planning and local humanitarian interventions commenced in the post-conflict period, in collaboration with peak international agencies (UNICEF 2011; UNSMIL 2012, 2013b). Existing government ministries continued into the post-revolutionary period. Both Health and Social Affairs Ministries were identified to be inefficient and ineffective by stakeholders inside and outside Libya before and after the revolution (UNSMIL 2013a). In addition to these two ministries, two new ones were established to cater specifically for people injured in the revolution.

The new Ministry of Martyrs and Missing provided financial assistance to families of people killed or missing (Libyan Security Sector Legislation 2012a). For injured survivors, the new Ministry of Wounded Affairs (Libyan Security Sector Legislation 2012b; UNSMIL 2012) provided benefits. They received generous immediate and ongoing financial assistance, more than that provided to other people with disabilities acquired through other means (Libyan Security Sector Legislation 2013a,b). This included funding to travel and stay in other countries for treatment, rehabilitation and education. International treatment and rehabilitation was needed because services in post-revolutionary Libya were scant; by the end of the revolution only one rehabilitation centre was functioning (Benghazi Rehabilitation and Handicap Center) (Hamed El Sahly & Cusick 2016). Within a year, these new ministries were brought under the Ministry of Health following evidence of widespread rorting and corruption (Hamroush 2012). Superior privileges and benefits for war-related disability did, however, continue.

Since late 2012 and from 2013 onwards, governance and government in Libya has been fragile, with rival governments, criminal activity, internal tribal conflict, armed militia, insurgent violence, terrorist occupation of some areas and long-range explosive attacks (Medicine sans Frontier 2013; UNSMIL 2016). Movements of thousands of IDPs, refugees, asylum seekers and migrants across the country have been coupled with faltering, failing, restarting and efforts to continue government functions (Amnesty International 2015; Commissioner General for Refugees and Stateless Persons Office 2014; International Organization for Migration 2015; Mottaghi 2016; UN Security Council 2015; UNHCR 2015b; UNSMIL 2013a, 2015a, 2015b). Even the UNSMIL services were disrupted, only recently planning return to a base in Libya (UNSMIL 2016).

For people in need of health and disability services, the situation is difficult. Just after the revolution, the Ministry of Health was described as 'overstretched' (Integrated Regional Information Networks [IRIN] 2012); this has continued. Little is known about how primary care services are functioning (UNSMIL 2013b). In relation to disability specific services, even before the revolution, the Ministry of Social Affairs rarely published information in either English or Arabic about their activities, and little has been published from this Ministry since (Ministry of Social Affairs 2012).

Libya's security situation destabilized in late 2012. In 2016 the UNSMIL situation report said 'the security situation on the ground remains largely unstable, with significant incidents linked to armed conflict and terrorism… [and] … criminal activity' (p. 13). UNSMIL identified a breakdown in law and order, violations of human rights and humanitarian law (UNSMIL 2016, p. 6). Although people with disability are not specifically mentioned in UNSMIL reports, it is evident that these adverse conditions affect them. Parts of Libya are currently under control of militia, while other regions are working hard to stabilize, and there are national efforts to secure government through political initiatives; for example, the Libyan Political Agreement of December 2015 (UNSMIL 2016). Despite this, for much of the country, there is a 'deteriorating human rights and humanitarian situation' (UNSMIL 2016, p. 14) and attacks on infrastructure 'including hospitals' (p. 16) occur regularly. The current state in Libya and the MENA region is thus 'cautiously pessimistic' (Mottaghi 2016).

It is against this history and recent background that the study aims to aims to locate and summarise published information about people with disability in Libya. In this review, 'disability' was not defined *a priori*. Instead the term was used on a standalone basis in searches so that assumptions underlying the way the term was used could be explored. Specifically, models of disability inferred through use of the term were considered – whether a medical/charity model or a social/cultural model (Guernsey, Nicolo & Ninio 2006). From the authors' perspective, our understanding of disability was the Australian Institute of Health and Welfare technical definition (AIHW 2016). This was selected because it is used for data collection purposes. It is based on the WHO International Classification of Functioning Disability and Health (2001). It identifies problems or difficulties in impairments, activity limitations and/or participation restrictions influenced by environment as components contributing to disability.

Methods
The scoping review adapted a framework recommended by Arksey and O'Malley (2005): the research question was developed; relevant literature was identified; sources addressing the question were selected; the findings were collated and summarized. Usually scoping reviews focus on research information (Levac, Colquhoun & O'Brien 2010; Pham et al. 2014); however, as information about disability in Libya is scant, the decision was made to seek out any information on the topic so long as it was published by reputable sources. 'Published' meant publicly available on the internet; 'reputable' meant any government or non-government humanitarian organisation or media-company or university (or their employees or representatives in an official capacity). Individual blogs or communications were excluded. There

was no minimum threshold of methodological quality; this was deemed acceptable because scoping reviews typically do not attempt critical appraisal of findings (Levac et al. 2010; Pham et al. 2014).

Stage 1: Review question
What do published reputable sources reveal about people with disability living in pre and post- revolutionary Libya?

Stage 2: Identifying relevant studies
The search was conducted in English and Arabic. First the terms 'disability' and 'Libya' and/or 'population' were entered into proprietary academic search engines (e.g., PubMed, ProQuest). These terms were chosen on face value as most likely to reveal anything related to people with disability in Libya. Few Libyan sources were identified (e.g., Singh & Abudejaja 1983). Research relating to health policy and planning in the MENA region was, however, revealed and this reinforced what we had found – that 'almost nothing is known' (El-Jardali, Jamal, Abdallah & Kassak 2007). We thus adopted a second, more intuitive approach, using a wide range of search terms selected on face value (**Table 1**)

Table 1: Search Terms.

Dimension sought	Terms (truncated forms not used in either English or Arabic)
Location	Libya Libyan Arab Jamāhīriyyah Middle East North Africa Middle-East-North-African Region (MENA) Africa Eastern Mediterranean Region (EMR)
Disability	Disability Handicap Injury Casualty Amputee
Potential causes	War Conflict Explosive Remnants of War Congenital Motor Vehicle Accidents/Traffic Accidents Communicable Disease Endemic disease/endemic conditions Cardiovascular
Organisations	United Nations UNHCR UNICEF WHO Ministry of Social Affairs – Libya Ministry of Health – Libya Ministry of Wounded Affairs – Libya Ministry of Martyrs and Missing – Libya
Service types	Rehabilitation Community Based Rehabilitation (or) CBR Primary Care Community Care Humanitarian Aid Emergency Hospital Center/ Centre Disability
Status of People with Disability	Convention Human Rights Law Decree Advocacy

and putting them into publicly accessible search engines used by our universities (Google, Bing and Google Scholar), together with the careful inspection, detection and location of sources in the reference lists, bibliographies and resource links of items retrieved.

Hundreds of individual searches were performed; any attempt to describe the procedure as one that could be replicated or mapped on a neat flow-chart of studies located, selected, excluded and included would be disingenuous. In reality one source lead to another, potential sources were tracked down, inspected and used if relevant. The search was just like trying to 'find a needle in a haystack' or in Arabic 'العثور على إبرة في كومة قش'. Even though we were intentionally searching for material on the topic and had previous experience with literature search and research strategies, we had to be 'more observant than Zarquaa' Al Yamma' (زرقاء اليمامة) as the saying goes (a famous woman of Arabic legend with incredible eyesight). The search commenced in December 2012 and concluded in August 2016.

All web links were checked on 12 August 2016 to determine if they were still live. We found a number of media releases from humanitarian aid agencies were no longer active (e.g., individual victim stories reported in donor calls to action) and alternative web links could not be located in agency archives. This was particularly the case for Handicap International, which appeared to have had a website refresh in the past 12 months. To ensure the utility of this article, all sources without live links were removed from the review if a suitable alternative exemplar was still accessible (e.g., individual victim stories from other humanitarian agencies in Libya that were released about the same time). There is one exception: the Libyan Ministry of Health (2010); this source was no longer available and the link led to a web-hacker post; the 2012 download record we held was thus used.

Stage 3: Study selection

A source was included if people with disability in Libya were specifically mentioned. The search involved reading hundreds of potential sources relating to Libyan population/health/humanitarian/community or emergency situations or services to find the 'needle in the haystack'. One example illustrates this process: *United Nations Office for the Coordination of Humanitarian Affairs Country Team Relief Libya Appeal September 2014 – September 2015* (United Nations Office for the Coordination of Humanitarian Affairs 2014) report was obtained and read. It detailed assessment of displaced persons, security, protection, food security, logistics and emergency telecommunications, health and coordination arrangements. Only one mention of people with disability was found (inter-sectorial objective point 2, p. 14). Four international partners with missions to assist people with disabilities were in the report, but no explanation of their role in the Coordinated Libya response was made (Handicap International, Mine Action Group, Federation Swiss Demining, Danish Demining Group). No partner organisations were representative of people with disability (e.g., the Arab Disability Alliance was not mentioned). Thus to find one piece of information, a full report had to be interrogated line by line. This occurred for hundreds of sources.

When a source was in Arabic, an existing English translation was sought; where this was not available one author (RHES) made written notes in English in the margins, then both authors met to go point by point through each note to determine the key points of relevance to the review. It is these key points that are reported. It is possible some information was missed in the search, but this is the most comprehensive attempt to date to locate what is known. This scoping review focussed specifically on *people* with disability, not services. Where a service described characteristics or attributes of people with disability in Libya it was this information that was extracted.

Arksey and O'Malley (2005) recommend consultation to ensure findings are contextualised and summarised in a way that is meaningful. In this study, the information was contextualised as follows. One of the investigators was a Libyan citizen, fluent in Arabic with previous experience working in Benghazi in health administration (RHES). One of the investigators was a registered allied health professional, clinical and social science researcher with a three-decade background in rehabilitation and disability (AC). Before the scoping study one author (RHES) spent two months in Libya (September–October 2012) on site at a rehabilitation centre collecting data for a different study exploring disability worker characteristics (Hamed & Cusick 2014; Hamed El Sahly & Cusick 2016). Review findings could thus be understood in terms of the real-life context of post-revolutionary Libya. A limitation is that the perspectives of people with disability living in Libya were almost absent in the literature search, and their perspectives were not sought out by investigators during the in-country visit.

Stage 4: Collating, summarising and reporting the results

A narrative review mapped findings into themes (Arksey & O'Malley 2005). Themes were developed by collating together common topics that answered the review question. Given the iterative, intuitive and multi-method approach used to find sources, we did not use flow-charting to map the search strategy and results. Relevant theoretical and planning issues are raised in each theme and in the conclusion.

Results and Discussion

Information about people with disability in Libya is summarised in four themes: (1) scant data and information gaps are the norm; (2) disability is a medical problem to be managed; (3) acquisition context matters: conflict versus non-conflict disability; and (4) disability human rights – social model on paper but not yet in practice. Each theme is now presented.

Scant data and information gaps are the norm

There are no government or international agency nation-wide estimates of people with disability in Libya in English. A 2005 World Bank report (World Bank 2005) uses global estimates of disability to infer there are 30 million people with disability in MENA, but a country estimate for Libya was not made. We could not locate a population census with disability data. A nation-wide estimate was prepared by the Libyan General Authority for Social Solidarity Fund (2012) using data from people who are recorded as receiving disability social security through the Public Authority for Social Security Fund (reported in Aljanzouri, Anwar & Zaika 2014). This report estimated that 1.46% of the total population had a disability or N = 87,746 people (57.8% male). A report by the Ministry of Social Affairs (2006) identified that almost half were under 35 years of age (<15 years 10.3%; 15–25 years 14.9%; 26–35 years 20.6%) (cited in Aljanzouri et al. 2014). A report in Arabic from the Libyan government provided national and regional estimates of people with disability (Health Information Center Department 2012; Libyan Ministry of Health 2010) (**Table 2**). Disability was categorized by type of impairment (as translated by Alhanzouri et al. 2014): 43.57% mobility impairment; 22.84% 'mental disability'; 13.74% hearing impairment; 12.64% visual impairment; and 7.21% psychiatric disability.

One in-country disability advocacy organisation was identified in the search: the Libyan National Organization for the Development of People with Disabilities (2014). This did not have information about numbers of people with disability in Libya, nor did regional advocacy organisations such as Arab Organisation of Disabled People (2015), Inclusion International MENA Region (2016) or global bodies such as the International Disability Alliance (2015).

The historical legacy of landmines means there has been particular international interest in assessing numbers of people injured through ERW. The Landmine and Cluster Munition Monitor Libya Country Report (LCMM 2005) reported that it found it hard to ascertain ERW casualties in Libya. They found Libya had no disability data collection methodology or archive. Instead, the report used information from Libyan police to estimate N = 11,845 ERW casualties in 1940–1995 (n = 6,749 killed; n = 5,096 injured), and a report cited from the Libyan Jihad Center for Historical Studies identified N = 12,258 casualties (n = 3,874 killed; n = 8,384 injured) between 1952–1975. More recently, the United Nations Mine Action Service (2013) estimated that between February 2011 and early 2013, N = 222 people were injured by land mines (including n = 55 deaths). Other, less specific estimates not limited to landmines suggest thousands of people were killed or injured by landmines and ERW during and after the revolution (IRIN 2012).

Another source used to try to find estimates of people with disability in Libya, was the Ministry of Wounded Affairs. The investigation into this Ministry's expenditure and operations received by the Minister for Health, Fatima Hamroush (2012), found thousands of people travelled for health care to: Turkey (n = 17,000), Egypt (n = 12,000), Greece (n = 9000), Jordan (n = 50,000), Tunisia (n = 5000) and Germany (n = 1800). The Wounded Affairs scheme was designed to assist people who had been injured in the revolution, so numbers suggest catastrophic population impacts. However, a Ministry of Health investigation revealed only a fraction of these people met eligibility criteria (Hamroush, 2012). In total, the audited Ministry of Health figures found N = 3116 people had conflict-related injury eligible for Wounded Affairs care. This suggests that the number of people living with disability from revolution-related combat injuries is relatively small when compared to other causes.

A range of other sources was explored to try to find non-conflict estimates of people with disability living in Libya. International peak and humanitarian agency web sites and reports were searched but no further information specific to Libya was found. Agencies included: Amnesty International, Women's Refugee Commission, Handicap International,

Table 2: Cause of Disability.

N	Cause of disability	Number (2007)*	Number (2012)**
1	Congenital	36179	54293
2	Birth trauma	987	2417
3	Non-vaccination	730	
4	Disease (not specified)	19427	
5	Accident	8116	9808
6	Conflict or war related	1150	
7	Work-related injuries	730	2245
8	Burns	362	
9	Other (not specified)	3040	2519
	TOTAL	70721	

*Libyan Ministry of Health (2010) Health and environment statistical report [Arabic];
**Libyan Health Information Center (2012) [Arabic].

Internal Displacement Monitoring Center, International Medical Corps, International Red Cross and Red Crescent, LCMM, Medicine sans Frontier, Commissioner General for Refugees and Stateless Persons, Office of the UN High Commissioner for Human Rights, North Atlantic Treaty Organization, UNICEF, UN Office for the Coordination of Humanitarian Affairs, UNHCR, UN Security Council, the Washington Group for Disability Statistics and WHO. All UNSMIL reports were inspected, but no specific mention of people with disability was made.

The World Bank provided a number of useful documents and a 2005 'Note on Disability Issues in the Middle East and North Africa' (2005) was the most detailed regional attempt to map numbers of people with disability, but this did not include Libyan country-specific data. The dearth of information has been confirmed in previous reviews for immigration assessment purposes (Immigration and Refugee Board of Canada 2004). The lack also reflects conclusions drawn by other scholars in relation to regional gaps in publicly available health information and health system information policies in the MENA Region (El-Jardahli et al. 2007; El-Jardahli, Alameddine, Dumit et al. 2011; Saleh, Alameddine & El-Jardahli 2009).

In summary, this part of the review found that estimates of people with disability in Libya vary and there is a marked gap in knowledge. The population census did not appear to include questions for disability because no information is reported. Many sources from peak agencies do not mention people with disability, and authoritative information and statistics are not available for Libya or much of the MENA region. This means the needs of people with disability cannot be adequately factored into specific emergency, humanitarian or development plans (Rockhold & McDonald 2009). If little is known about people with disability they are at risk of being 'invisible' (UN High Commissioner for Refugees 2013). Although not from Libya, Arab disability campaigner Nawwaf Kabbara, President of the Arab Organization of Persons with Disabilities (2016), says this one of the greatest challenges: 'Invisible, that's what we are. People here forget that we exist and that we have special needs. Whatever their disability, whether it be a physical impairment, blindness, a mental disability, or anything else, people with disabilities are often invisible to the rest of society' (Kabbara 2014).

There is a need for research that collects data about people with disability in Libya. A technical definition of disability and inclusion of disability measures in population and other planning data will therefore need to be developed and agreed for the purposes of research and agency planning in Libya. This will require agreement on assumptions underlying the term 'disability'. The next section of the review explores what existing sources reveal about assumptions.

Disability is a medical and minority problem to be managed

Libya has widespread disability as a result of: consanguineous marriage and consequent genetic and hereditary conditions; blindness relating to endemic trachoma; high motor vehicle accident rates; disability related consequences of communicable disease such as HIV/AIDS; and disabilities arising from ageing and lifestyle related diseases such as cardiovascular conditions (WHO 2014). These causes of disability are consistent with those in the MENA region (World Bank 2005). In addition, ERW and armed-conflict also cause disability in Libya.

The Decree of the Law on Disabled People in 1981 (People's General Congress 1981) set the scene for a medicalised approach to disability. This decree set out service and benefit arrangements for Libyans with condition-specific disability in housing, education, home care, education, rehabilitation and prosthetic limbs (Immigration and Refugee Board of Canada 2004; Social Security United States Government 2016). To receive support, a diagnosis and clear deficits in body structure or function were needed. Pre-revolutionary government reports from the ministry show impairment categories were used to profile the incidence of disability in the population and to characterize services (eg., **Table 2**). The Libyan Ministry of Health (2010), Health Information Center Department (2012), Libyan General Authority for Social Solidarity Fund (2012) and Ministry of Social Security Fund (cited in Aljanzouri, Anwar & Zaika 2014) present disability information as a checklist of impairments or conditions (the following terms were translated from Arabic): blind, deaf, mute, motor impairment or physical disability, psychiatric and mental health conditions. The use of impairment-based checklists is consistent with the approach used in many developing countries (Mgbogoni & Synneborn 2003).

Before the revolution, disability services were reportedly delivered through N = 46 condition-specific treatment centres and three 'rehabilitation and handicap' hospitals (Libyan Government Report to the UN on the Rights of the Child 1998). In 2008 when Libya signed the UNCRPD, impairment-related pensions, additional pension benefits for attendant care and free access to treatment remained the focus of support (Hamed El Sahly & Cusick 2016; WHO 2010). There does not appear to have been community-based rehabilitation (CBR) or employment, education and community inclusion programs.

The 2011 revolution brought some hope that a social model of disability might be embraced though health and humanitarian planning (International Medical Corps, 2012; El-Oakley et al. 2013; WHO 2012). In 2011, a Constitutional Declaration mandated state financial and social support for people with disability but it was reported not to have been carried out (LCMM 2014). To date no government report has been made to the UN on progress against the principles of the CRPD. Libya as yet does not appear to use WHO understandings of disability to characterise needs or services, although this may change with a 2013 Libyan Security Sector legislation relating to the ratification of the CRPD (2013a). However, for now, disability support is treatment orientated, condition specific and highly centralised. No systemic CBR services or home care services appear to be available. Disability welfare consists of pensions and benefits paid to the recipient. Disability from everyday causes is thus a 'medical problem' to be managed.

Further evidence of a lack of traction for social models of disability can be found in these examples: (a) the 2011 constitutional declaration did not prohibit discrimination on the basis of disability (LCMM 2014; United States Department of State 2015); (b) there were verified reports that public facilities did not provide physical access for people with disability (United States Department of State 2015); and (c) a diagnosis and impairment model underpinned the establishment of new ministries and funding in the post-revolutionary government for people wounded in the conflict (e.g., the Ministry of Wounded Affairs). The latter cemented the dominance of a medicalised approach, linking superior care and benefits to revolution-acquired impairment. This link is now explored.

Conflict-related disability in Libya comes from five causes. One is armed conflict from the 2011 revolution. A second is active combat that occurred after the revolution. A third cause is accidents causing limb amputation, neurological, sensory function and other damage from ERW left over from WWII and pre-revolutionary conflicts and from new post-2011 conflicts (LCMM 2010, 2011, 2014; Handicap International 2011, 2014; International Committee of the Red Cross 2013; International Medical Corps 2011, 2012; UN Mine Action Service 2013; UNSMIL 2013a, 2013b, 2014a, 2014b, 2015a). A fourth cause is the endemic proliferation of light arms in the community (Helios Global 2013). Finally, accidents arising from unsecured and/or unstable arms, ammunition and chemical stores have been identified (UNSMIL 2013a). Of all these conflict-related causes of disability, only one attracts superior government financial benefits and care – the combat injuries acquired during the 2011 revolution. The practical and socio-cultural implications of this differential approach are explored in the next theme.

In summary, this section of the review found that since at least 1981, a medicalised approach to disability has been taken in Libya. Reports show in-country action is focussed on provision of clinical treatment, equipment and benefits for recipients and carers related to degree of impairment. The lack of CBR services or policies relating to inclusion and participation in socioeconomic aspects of daily life suggests that a social model of disability has not yet been embraced.

Acquisition context matters: combat versus non-combat disability

As stated above, if a disability condition was acquired through revolutionary conflict, people had access to superior international treatment, rehabilitation and superior welfare benefits (Hamroush 2012; LSSL 2013b). If people were born with conditions or acquired them in the course of daily life through motor vehicle accidents, disease, heredity or even ERW after the revolution, they received standard, not superior, benefits.

The post-revolutionary environment thus introduced a tiered approach to disability assistance where context of disability acquisition directly influenced the extent and type of support available. Previously, all Libyan citizens had access to publicly funded domestic services, but wealthy Libyans could pay for medical or rehabilitation treatment in other countries where the standard of care was perceived superior. Before the revolution it was estimated that 20% of all Libyan health expenditure was paid for privately (WHO EMR 2010). After the revolution, any war-wounded casualty could have international care paid for by the government regardless of personal wealth. But people who acquired disability outside a revolutionary context and who did not have personal wealth to draw on were dependent on a post-revolutionary public rehabilitation system that was barely functioning.

Practically, the consequence of a tiered approach was and is that revolution-wounded people with disability receive better resourced international care when they want it, while others receive resource-constrained domestic care. For both groups, the lack of a social approach to disability in Libya means there are no system-wide CBR services available to support them when treatment is over and no policies to support inclusion and participation in daily life. Some people with complex conditions may thus never return to Libya, while others who live there have limited opportunities to contribute to their communities.

From a socio-cultural perspective, a tiered approach to disability which is based on medical deficit and acquisition context further erodes opportunities for inclusion and participation (Barnes & Mercer 2009). This is for two reasons. First, the concentration on impairment and deficit can create or reinforce a medicalised approach to disability. Second, the 'tiered' approach can lead to conflict-survivors having a higher social status than other people with disability. This 'moral dimension' can lead to people hanging onto and telling conflict-survivor stories of how they got their disability as both a means to receive benefit and a way of becoming visible in a society where they are otherwise not (Berghs 2011).

Post-conflict survivor storytelling by people with disabilities can have positive and negative effects. On the positive side, humanitarian aid agencies can present personal survivor stories in the 'tragedy' tradition to call donors to action. This has been done in Libya (e.g., Handicap International 2012; International Medical Corps 2012). Stories such as these can: motivate potential donors (Berghs 2011); maintain current donors (Hoffman 2004); justify preventative programs such as landmine clearance and awareness (UNSMIL 2013a, 2014a); and make visible people with disability who would otherwise have no voice in the public arena (Berghs 2011). On the negative side, tragedy stories are mostly about individuals, their unique circumstances, their deficits and problems needing charity or provider-led change. While aiming to help, they may actually undermine people with disability because the call to action is usually for funds so experts can provide charity to a marginalised minority (Berghs 2011). Tragedy stories can thus reinforce a medicalised model because these stories are not able to describe, explain or challenge system-wide planning, policy, service and infrastructure issues that might turn a condition into a disability.

Use of tragedy stories can also have adverse consequences for individuals and communities. They can elicit expectations of something in return in an environment where deficits are rewarded and capacity is not; commodification of impairment can result (Sharp 2000). Berghs (2011) suggests this can create a codified post-conflict culture of 'dependency, patronage and payment' (p. 256). There is a risk of this in Libya because pre-revolutionary approaches to disability were medicalised and now, post-revolution, benefits link to impairment severity, and humanitarian agencies use tragedy stories in their understandably desperate and commendable efforts to try to generate donor support.

Whether or not long-term adverse effects will happen in Libya is not clear. Since the revolution, Libya has not had much opportunity for anything but tragedy stories because of ongoing conflict, but there is always hope. Positive signs for a post-conflict future can be seen in the establishment of over-arching bodies such as the Libyan National Council on Civil Liberties and Human Rights (UN Human Rights Council 2016). It is hoped that a post-conflict economy of disability acquisition stories, injury showing and picture-taking will not appear as it has elsewhere (Olajumoke 2008 cited in Berghs 2011). This would only deepen the Libyan tradition of disability being a 'medicalised problem to be managed' and it might widen the gap between revolutionaries and the people whose disability arose from everyday circumstance.

In summary, this section of the review found that disability acquisition directly affected the type and level of support received. People injured in the revolution receive different support to others. Both face problems because CBR is not available nor are there programs to support inclusion and participation in community life. From a socio-cultural point of view, possible consequences of the tiered approach have been explored using research from other post-conflict settings. This includes the risk of tragedy stories reinforcing medicalised minority traditions in Libya, and the commodification of disability in a culture of patronage and dependency.

Disability human rights – social model on paper but not yet in practice

The unstable environment in Libya 2012–2016 makes a move away from a medicalised, minority and charity approach to a social model of disability based on human rights difficult. Stability and security needs to be established following conflict to protect vulnerable people (Harvard Medical School & NATO 2013). Constant risk of return to violence makes their situation more precarious (Smith-Khan et al. 2014). In an unstable context it is very difficult to create the socio-cultural 'space' needed to shift understandings from medicalised charity models to social models incorporating human rights. In post-conflict and unstable contexts, Katsui and Kumpuvuori (2008), suggest that a charity-based approach is almost inevitable because it only requires provision for material needs: 'in some sense charity is easier because it does not challenge structural problems which reinforce the status quo of discrimination' (Katsui & Kumpuvuori 2008, p. 235).

A charity approach in Libya may, at present, be the only workable support possible because Libya is more than unstable – much of it is dangerous and human rights activists face significant risks (UN Human Rights Council 2016). The UN High Commissioner for Refugees recently reported that 'attacks against human rights defenders, including killings, abductions, death and other threats via social media and phone have been on the rise in the country since the escalation of fighting in May 2014. This has created a climate of fear for the human rights defenders' (UNHCR, 2015a). In such situations government and agency work using any model that supports the wellbeing of people with disability is difficult and courageous – regardless of whether it is medicalised, based on charity, or a social model of inclusion and participation.

A social model of disability and a human rights approach to health have yet to take hold in the MENA region (World Bank 2005). But there are opportunities for change. There is a recent Libyan example of planning research where the needs and feedback of people with disability were sought. For example Aljanzouri et al. (2014) investigated public transport needs and experiences of men and women with disability living in Benghazi, to inform civil engineering plans for transport infrastructure in post-conflict reconstruction activity by the Libyan Ministry of Transportation and Utilities. This sort of research is novel for Libya –importantly, it assumes that people with disability have a right and need to move freely about the community and that their perspectives can inform plans.

There are also examples of cautious optimism in Libyan leadership and policy commitments showing inclusion, and human rights are on the radar (UNHCR 2015a; UN Human Rights Commission 2016). Libya is supported in this task through regional, UN and international humanitarian agency connections. These relationships can bring collaboration, cooperation and leadership which can promote human rights–based approaches to disability (Barnes & Mercer 2004). Already the positive effects of this are apparent in speeches from Libyan leaders to the UN (e.g., Dayri 2015). Political and social action can help stakeholders understand the social and economic benefits of shifting from a medicalised/charity model to an inclusive social model – benefits such as poverty reduction and increased wellbeing (Guernsey et al. 2006). The transport example previously cited is indicative of change, as are moves to update Libyan Standards and Specifications to include accessibility (cited in Aljanzuori et al. 2014).

So while a charity approach may be more straightforward in post-conflict environments, more is needed in the future to help construct a vibrant, inclusive community. The problem with a medicalised, minority and deficit approach is that there will never be enough resources to 'manage' and 'treat' people with disability, especially in post-conflict environments where everyone, including people with disability, need to contribute to community and nation-building. Moving forward, there are established and new advocacy organizations working for a more inclusive society. These

include: Middle East disability advocacy groups (e.g., Arab Organization of Disabled People), humanitarian agencies that adopt empowerment models (e.g., Women's Refugee Commission 2016); peak international agencies embedding social inclusion in programs and project guidelines (e.g., Australian Disability and Development Consortium [AADC] 2009; Guernsey et al. 2005; World Bank 2006); emerging national structures like Libyan National Council on Civil Liberties and Human Rights; and leadership statements from post-revolutionary government leaders like Dayri (2015). There are also workable models and measures for population and service-based data collection that ensure people with disability are included (Madans et al. 2011; Washington Group on Disability Statistics 2016).

In summary, this section of the review identified that while Libya had committed to social models of disability on paper before and after the revolution, a great deal remains to be done, with promising signs of change evident. The assumption in this review is based on the UN premise that human wellbeing is enhanced by having opportunities for participation and choice (cited by Guernsey et al. 2006). As Libya works to build governance arrangements and community life, people with disability need to be a visible part of that future.

Recommendations and Conclusion

This study provided an examination of information available on people with disability in Libya. There are method limitations in this study that have been acknowledged, but the picture has at least now been painted and whatever gaps exist, others can fill. This scoping review found that scant attention had been paid to people with disability in data collection, government or agency reporting, service planning or policy with the exception of people sustaining injuries, predominantly limb amputation, through conflict or ERW. Further it found a medicalised/charity model dominated which reinforced a minority and marginal status for people with disability.

The UNHCR (2013) warned that unless people with disability are specifically mentioned they are forgotten. This study has sought out information from reputable sources and summarised it to help information about people with disability in Libya become visible. It should be noted the perspectives of people with disability are notable by their absence. Future research should try to find out what is happening at a local level and reveal the experience and expertise of people with disability living in Libya. This research should be collaborative in design, implementation, interpretation, and reporting. Until efforts are made to understand what they need and want to do, medical rather than social models of disability will prevail.

The will to change is there. The UNSMIL Head of Mission said in 2013: 'I wish to underline the importance of ensuring inclusion and attention to the legitimate aspirations of all segments of Libyan society, including women, minorities and young people.' (UNSMIL 2013b, clause 93). Although being in a minority is not desirable in social models of disability, this commitment to inclusion is a watershed for Libya. It needs to be followed with action. Suggestions emerging from this review are:

(a) having a stable and secure community to underpin human rights approaches to inclusion (Harvard Medical School and NATO 2013; UNHRC 2016);

(b) ensuring project work is inclusive in design and delivery (e.g., AADC's 2009 *Principles for Disability and Development work*; CBM's 2016 *Make Development Inclusive*; UNHCR's 2010 *Conclusion on Refugees with Disabilities and Other Persons;* UNHCR's 2011 *Working with Persons with Disabilities in Forced Displacement*; World Bank's 2006 *Making Inclusion Operational* by Guernsey et al.);

(c) adopting technical definitions of disability that recognise social models of disability and using them in regulation, policies, government and non-government programs (e.g., AIHW 2016 based on the WHO ICF 2001);

(d) adopting statistical measures of disability in population census and other data collection that go beyond checklists of impairment to better inform planning and development. Examples are the Washington Group 'Short Set of Six Questions' or the 'Child Functioning Question Set' (Madans, Loeb & Altman 2011; Washington Group on Disability Statistics 2016);

(e) including data about disability and the expertise and perspectives of people with disability in situation reports, consultations and planning (e.g., CBM 2016; Women's Refugee Commission 2016);

(f) developing open-access avenues to disseminate disability-related innovation and good practice happening 'on the ground' (e.g., a journal, a website) that encourage, enable and support contributors to share what they are doing. This will: make it easier to find and connect people, programs and policies already in place to each other and to potential supporters; enable local knowledge to be developed and disseminated for disability services development; provide a local evidence base that can assist in reporting problems, progress and priorities; and be a focal point for disability workers to receive contemporary, locally appropriate information and continuing education; and

(g) disseminating government reports (and/or non-government 'shadow' reports) on a regular basis regarding Libyan activities and outcomes for people with disability with regard to their alignment with the CRPD.

Accurate and meaningful information, thoughtfully applied, will ultimately help the creative, committed and courageous work needed to achieve the aspiration of inclusion and participation of all people in a future post-conflict Libya.

Competing Interests
The authors have no competing interests to declare.

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