Journal of Public Health | pp. 1–5 | doi:10.1093/pubmed/fdz133

The politics of exclusion: fighting for patients with Kidney failure in Yemen's War

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ABSTRACT

Background To contribute toward the dialogue on addressing non-communicable and chronic disease in humanitarian emergencies, this article will explore the experiences of Médecins Sans Frontières in attempting to find support for the haemodialysis network in Yemen. With the changing profile of the global disease burden and a broadening concept of emergency health needs to include chronic illness and disability, the aid sector has committed through the World Humanitarian Summit and the Sustainable Development Goals to leave no one behind and thus to meet the health needs of these previously excluded and highly vulnerable people. The civil war in Yemen compromised the medical supply chain supporting the health facilities providing dialysis for patients with end-stage renal disease. The article will critique the aid sector's slow response to this issue and expose the gap between principles, commitments, and practice related to noncommunicable disease in emergencies.

Method Following direct experiences from the authors as leaders in the aid response in Yemen, reviews of grey literature from aid and health actors in Yemen were conducted along with a review of literature and policy documents related to noncommunicable disease in emergency. Key informant interviews and press statements supported analysis and events that took place in the time span of roughly 4 years that frames this period of analysis.

Results Examination of the impacted patient population, interviews, literature and documented events indicates that there is discord between policy, commitments stated by aid donors and practice.

Conclusion The aid sector must use a more contextualised approach when designing programmes to manage the burden of non-communicable diseases in health contexts where crises occur, particularly for lifesaving forms of therapy. Aid agencies and the global health community must increase pressure on donors and implementing agencies to live up to their commitments to include these patient populations.

Introduction

This article will explore a policy question related to health provision in humanitarian crises. Why was it so difficult to find support for Yemen's collapsing dialysis network as a result of the war that began in 2015? The patient population experiencing end-stage renal disease (ESRD) is highly vulnerable as they require regular dialysis or a kidney transplant to survive; and the aid sector has made a commitment to meet the needs of the highly vulnerable. This topic is also relevant for the growing discourse on addressing non-communicable disease (NCD) in emergencies. By tracing the collapse of Yemen's dialysis network, the measures taken by emergency responders Médecins Sans Frontières (MSF) and the International Committee of the Red Cross (ICRC), the slow response by the international donor community to offer support and the extent of advocacy efforts required to raise the profile of these otherwise invisible victims of Yemen's conflict, it becomes clear that the global health community must work harder to ensure that the needs of highly vulnerable populations are met. While this topic explores patients suffering from a specific health condition in a particular context, the findings can be applied more broadly to inform a more ethically consistent prioritisation of humanitarian healthcare provision in similar future contexts.

NCD in emergencies

Proactive strategies addressing NCDs in humanitarian crises have been increasingly mainstreamed in recent years. Research

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shows that many common conditions, such as vascular disease and diabetes, if left untreated, can lead to more acute, life-threatening, costly, and difficult to manage health consequences.[1] The Global Strategy for Prevention and Control of NCDs was endorsed by the World Health Assembly in May 2008. In December of the same year, the World Health Organization (WHO) began work on its Package of Essential Noncommunicable Disease Interventions (PEN) for primary health care in low-resource settings in order to enable a rollout of essential drugs and materials to support programming in such contexts.[2] A Global Action Plan supporting PEN was validated and implemented in 2011 at regional level, and the leadership of the WHO bolstered the efforts to strengthen NCD treatment in humanitarian contexts by developing an NCD emergency health kit, first trialled in northern Syria in October 2018.[3]

In its guidelines on management of NCDs in humanitarian crises, the WHO suggests that health providers must account for, 'the subgroup of NCD patients with special needs for which interruption of treatment could be fatal or critical. . .'.[4] In a recent 'Call to Action', on NCD treatment in emergencies, Alessandro Demaio and others explain that preventing excess morbidity and mortality due to NCDs in emergencies should be a priority at both policy and operational level. They observe that people living with NCDs experience heightened potential of an acute medical emergency due to the interruption of regular services and access to medicines that help them manage their illness.[5] The Inclusion Charter endorsed broadly by the aid sector also focuses on meeting the needs of the most vulnerable and is broadly accepted as a guiding principle for humanitarian response.[6] Patients suffering from ESRD require a kidney transplant or dialysis in order to survive and an interruption of dialysis results in a painful and certain death-sentence.[7]

Yemen's health system pre-2015 and subsequent collapse

Before April 2015, Yemen's health system was well behind other Middle Eastern countries.[8] However, with support from international development agencies and charitable endeavours from regional donors, Yemen's Ministry of Health maintained a broad public health infrastructure that was improving in the decades leading up to 2015 and the number of high-quality private healthcare facilities was also steadily increasing.

Data on health outcomes indicated significant improvements from 2000 until the start of the war in 2015. According to the Institute for Health Metrics and Evaluation, life expectancy at birth went from roughly 59 years in 1990 to 67 years in 2014. Infant mortality (per 1000 live births) decreased from 54.5 to 35.1 in the same timeframe[9] and maternal mortality (per 100 000 births) went from 346.93 to 299.23.[10]

Despite this, access to healthcare remained inconsistent and was particularly compromised in impoverished rural areas and parts of the country experiencing political instability. Global health indicators remained weak with life expectancy lower than the regional average, and the country struggled to manage ongoing problems such as malnutrition and inconsistent vaccination coverage.[11] NCDs represented a significant burden of disease, accounting for 57% of all age mortality in 2015.[12] While it was still considered to be a 'developing' health system, the Yemeni Ministry of Health supported a relatively robust public/private network providing haemodialysis, comprised of 28 dialysis treatment centres supporting a cohort of approximately 4400 registered patients with ESRD.

In March 2015, Yemen's civil war intensified dramatically as an international coalition entered the conflict in response to the coup d'état launched by an alliance of the northern rebel movement, commonly referred to as the 'Houthis', and state forces that were loyal to the ex-president Ali Abdallah Saleh (now deceased). United Nations Security Council resolution 2216 marked the start of the Saudi-led Coalition's armed intervention and the establishment of import restrictions that intended to stem the flow of arms to the rebel groups.[13] Various forms of hostilities intensified throughout the country, including airstrikes and ground combat, in both urban and rural areas.

As a result of hostilities and import restrictions, Yemen's health system suffered a massive shock and reduction in capacity while the health needs of the Yemeni population increased greatly. The WHO, as early as July 2015, characterised the crisis as a 'health system failure':

> Serious shortages of medicines and medical supplies, as well as acute fuel shortages, have resulted in a gradual collapse of the health system. Medicines for diabetes, hypertension, cancer and other forms of chronic diseases are no longer available and there are acute shortages in critical medical supplies—trauma kits, medicines, blood bags and other necessities.[14]

As the conflict intensified, health facilities closed and were damaged in the fallout of the intense armed conflict. WHO statistics from November 2016 stated that, at that time, there were only 6.2 hospital beds available per 10 000 people, and out of 3507 health facilities, only 1579 were fully functional, with 1343 partially functional and 504 entirely non-functional.[15] That same year, UNICEF reported that there had been 63 attacks on hospitals in Yemen and approximately 14.8 million people cut off from healthcare.[16]

Impact of conflict on Yemen's dialysis network

Yemen's state-supported dialysis centres experienced critical shortfalls in supplies, including fuel to run hospital generators, payment for staff and, most importantly, the materials required for the procedure. Patients were left unsure where to go for treatment and in order to access the open facilities, they had no choice but to navigate landscapes fraught with intense gun battles, shelling, shifting frontlines of fighting and frequent airstrikes through the country. Many of the smaller facilities were closed and others maintained unreliable hours. This increased the burden on the centres that were able to remain consistently open. As Yahya Abbas, a patient requiring dialysis treatment explains, 'I used to get my dialysis sessions in Dhamar, but sometimes they don't have materials, sometimes the electricity was off. We were suffering a lot. This is why I had to move with my family to Sana'a.[17]' The WHO confirmed the impact on the open centres:

> The demand for services from Dialysis Centre in Al-Thawra Hospital in Ibb governorate is now far beyond the centre's capacity and it is overwhelmed with more than 200 new kidney failure patients who have been displaced from Taiz[18].

Yemen's Ministry of Health implemented desperate measures in an attempt to accommodate a maximum number of patients in the country's functioning centres. With no other available option, they chose to decrease the number of dialysis sessions allocated to each patient from three to two per week and decreased the duration of each session, meaning they were forced to implement an insufficient treatment protocol. While this measure was the only possible solution to the dilemma they faced, patients suffered as a result.

When patients with renal failure cannot have regular dialysis sessions of the correct duration, toxins will build up in their blood. This leads to debilitating symptoms of lethargy, disorientation, irregular breathing, loss of appetite, agitation, hallucinations, pain, anxiety and airways congested with fluids. Their quality of life is significantly reduced, and death will quickly ensue for those not receiving any treatment at all.[19]

The presentation of these facts and circumstances establishes ESRD as an urgent humanitarian need as these patients experienced increased suffering due to infrequent treatment, forced displacement in search of reliable treatment, increased financial burden and high exposure to extreme violence in having to make multiple visits to hospitals amidst intense fighting, often crossing front lines of conflict to seek care.

Humanitarian response

Responding to the lack of international support for this serious humanitarian issue, MSF provided supplies to the dialysis centres within hospitals in Sana'a, al-Mawhit, Saada and Hajjah from May 2015 to July 2017 and donated supplies on an *ad hoc* basis to the Ministry of Health to support other centres around the country. The ICRC also stepped in to offer support and took responsibility for five dialysis centres in Sana'a, Shabwa, Mahwitt and Hajja.[20]

The support programme was essentially a procurement system, which was costly but relatively simple to implement and maintain. Between April and December 2016, MSF supported the provision of dialysis to 617 patients with a total budget of €1.63 million. For a duration of six months, the average cost per patient for three weekly sessions of dialysis was €2429. Following a standard treatment protocol, the supplies consisted of essential agents needed for a dialysis: bicarbonate (one per session), a dialyzer filter, a set of blood lines, two lumen catheters (one per new patient unless they have an arteriovenous fistula), 4–5 L of acid concentrate, salt tablets (~10 kg per machine, which is equivalent to ~700 g per machine per session), one fistula needle per session, cleaning products (citric acid or alternate cleancart), injectable heparin sodium (quantity is patient specific), calcium gluconate (quantity is patient specific), 1000 mL of sodium chloride per patient per session and 40 00lU or 2000 IU of Epoetin Alfa for patients weighing over or under 50 kg, respectively.

The Ministry of Health, the ICRC and MSF lobbied for greater support of this patient cohort from the onset of the crisis, but years into the conflict, and with no end in sight, no health partners were able to receive funds to assume this responsibility. While the programme had a relatively high cost per patient, it was simple, clearly defined, and met a lifesaving humanitarian need. We are left with the question, why was it so difficult to find support among traditional humanitarian donors?

Discussion

The need for a contextualised approach for NCD in emergencies

MSF Director of Emergency Response, Karline Kleijer, states that the aid sector prioritises some forms of lifesaving care while neglecting others. She describes actions taken by MSF as a form of critique of an unjust system:

> Humanitarian medicine is not just surgery and basic healthcare provision in major crises, but also the act of caring for the neglected and vulnerable, many of whom are completely off the radar of the international system. Our decision to engage in dialysis wasn't just a lifesaving medical programme, it was a rejection of the injustice of this conflict, and by helping them, we refuse to stand idly by while these people are left to suffer and die. Despite very clear identification of this problem, the

> aid system failed to provide a timely and coherent strategy to care for some of Yemen's most vulnerable people.[21]

In search of support, MSF engaged more vigorously in their advocacy effort with the goal of identifying donors who could fund this activity. In collaboration with the Yemeni Ministry of Health, a plan was drafted to raise the profile of this emergency inside Yemen[22] and externally to donors. MSF's Emergency Medical Director explained the lack of will among donors he contacted:

> We spent well over a year reaching out to donors including ECHO, the governments of Japan, Sweden and the UK, not to mention the World Bank. While our interlocutors were receptive to the discussion, these discussions still have yet to produce any material support. They said that due to cost and other priority, this programme could not be supported—and everyone know that this means a miserable death for a patient whose treatment is interrupted.[23]

It is important to note that the donor agencies listed above are all signatories to the Charter on Inclusion of Persons with Disabilities in Humanitarian Action. Patients with ESRD embody fully these criteria as their ability to travel to flee conflict and otherwise receive humanitarian aid is clearly limited by their condition.[24] This calls into question the political will behind these commitments.

Indeed, only in September 2018, over 3 years since the onset of the conflict, did the WHO publicise its success in securing funding for an order of supplies for a 1-year period of time. This order was thanks to a large donation from the Kingdom of Saudi Arabia's relief agency and support from manufacturers in dropping prices.[25] While it is encouraging that Saudi Arabia and the private sector stepped up, it remains deeply troubling that the world's largest and most common humanitarian donors never responded to this cry for help.

While the circumstances that produced the dialysis crisis in Yemen are unique, the principle demonstrated by this dilemma is general. Another clear example taking place at the time of this publication is the lack of support for patients suffering from Thalassemia in Syria. Much like the ESRD patients in Yemen, they will also die if treatment for their condition is interrupted and have yet to be included in a general aid response offered by the international community.[26]

A range of political and historical factors have positioned major humanitarian donors and implementing agencies to respond more coherently to dramatic deaths by infectious diseases such as Ebola and cholera or to respond to needs of war wounded civilians than to the slow and immiserating death as a result of NCD within the same contexts. Those promoting a more coherent approach towards addressing NCDs in emergencies must also face the fact that the ethical principle of helping the most vulnerable may well play a lesser role when compared with the political value of certain humanitarian programmes. Relief operations with high political value and more media-friendly deliveries will gain greater donor support than programmes for the treatment of NCD even though they may be among the largest killers in emergencies. A greater shift in perception is required to unlock more forthcoming funding for a more contextualised approach to treat NCDs in emergencies.

Conclusion

As a conclusion, the authors advise working towards a greater global perception shift. Aid agencies engaging in emergency medical work should further raise the profile of NCD in their public-facing communications in an effort to increase awareness and thus the political value of these patients in donor societies so that donor funding streams can be made available. The global health community should focus on further research and communication efforts to highlight the needs of patient communities with chronic conditions in conflict and other emergencies.

These special cases will become increasingly the norm as progress in the health sectors of lower- and middle-income countries continues. If the aid sector wishes to live up to the values it promotes and commitments it has made, it must interrogate more deeply how the politics of inclusion and exclusion impact the lives of the most vulnerable in times of crisis.

Acknowledgements

Special thanks to Karline Kleijer and Ronald Kremer for their support.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

AHP is first author. He was formerly the Head of Programmes at MSF UK, and is currently on the Board of Directors of MSF-USA. He held various positions with MSF as the Country Director/Head of Mission in emergencies around the world. He worked in Yemen in 2010 and 2011 and returned to Yemen in 2015 to launch MSF's emergency response.

CvL is second author. She is a member of MSF's emergency response team and has worked in various capacities in the as field medical director and as country-level emergency medical director. She worked in Yemen at various stages throughout the emergency response and managed MSF's dialysis programme and related advocacy in Yemen in 2016.

CF is third author and worked as an intern at MSF UK's London office, supporting the drafting of this article.

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