THE COMPLEXITY OF CAREGIVING FOR A CRITICALLY ILL PARTNER FOR ERITREAN ASYLUM SEEKERS IN ISRAEL

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Many Eritrean asylum–seekers in Israel suffer from physical and psychological trauma. Denied basic medical care because of their status, ill–health has a ripple effect in the community, impacting family, caregivers, and the wider community. Physicians for Human Rights Israel (PHRI), which operates an Open Clinic in south Tel Aviv, seeks to expand its support of marginalized communities by creating support groups for the families and caregivers of people in the Eritrean community with critical illnesses a space for reflection and support in coping with a community–wide challenge.

There are currently about 22,000 asylum seekers from Eritrea living in Israel.¹ Many fled Eritrea as a result of the Eritrean dictatorship's violations of its citizens' basic human rights.² En route to Israel, many of these asylum seekers faced torture and exploitation in the Sinai desert of Egypt, where they were held captive in exchange for ransom payments.³ While Israel has refused, for the most part, to grant them refugee status, it does recognize the dangers that asylum seekers face back in their home country, and has granted them collective temporary protection. Still, the Israeli authorities have been slow to review asylum seekers' requests for recognition as refugees – denying them of health and social rights, among others.⁴

On arrival in Israel, the lives of Eritrean asylum seekers are affected by many social determinants of health, such as their living conditions. Most live in south Tel Aviv,⁵ in cheap and dilapidated apartments that they can ill afford. As a result, it is not unusual for two or more families to live together, or for a few non-related people to share a bedroom. In addition, in the absence of formal work permits, their employment opportunities are limited and therefore also



PHRI Clinic Activity

influence their health and wellbeing. Many work in "chik chak" jobs - daily unskilled labor, usually physically demanding work that puts them at risk of injury while leaving them without employment rights or occupational security. Furthermore, there is no proper arrangement regarding health insurance for asylum seekers in Israel. As the Ministry of Health, for the most part, refuses to acknowledge its responsibility for their health needs, they are left to their own devices. They can either receive coverage through their employers, or insure themselves with limited and short-term tourist or foreign worker insurance policies.⁶ Due to their limited access to fair and consistent employment – and therefore inadequate to nonexistent income - they are forced to prioritize their expenses, and many

do not possess sufficient health insurance. This leads asylum seekers to avoid health services, even in critical circumstances. due to the fear or knowledge that they will not be able to pay for these services. Even if they do have health insurance, these policies do not cover mental health issues and pre-existing conditions. Hence, they do not provide an adequate solution to people suffering from trauma and physical impairments as a result of their journey to Israel or the torture they experienced in Sinai.7 Physicians for Human Rights (PHRI), an organization founded in 1988, strives to provide asylum seekers, migrants, and status-less people, among others, with access to health care. PHRI implements their objectives through an open clinic, staffed by volunteers and operated free of "At the PHRI Open Clinic, we see that people in support roles, taking care of family members or friends suffering from a critical disease, often have many responsibilities.... These caregivers are, in fact, carrying a very heavy load and dealing with many responsibilities. But their role in supporting people coping with an illness is often overlooked."

charge; and through advocacy for their clients' rights, and lobbying for structural changes that will facilitate their access to appropriate health care.

While we at PHRI try to provide access to health services, we cannot ignore the emotional aspect of being diagnosed with an illness, living with it, or supporting someone suffering from a critical illness. At the PHRI Open Clinic, we see that people in support roles, taking care of family members or friends suffering from a critical disease, often have many responsibilities. These start with "managing" the care – setting and accompanying them to medical appointments, getting second opinions, taking notes and buying medication; supporting the ill person financially or collecting donations; taking care of the children or other dependents of the ill person; running errands and doing house work; and, most importantly, providing the ill person with emotional support. These caregivers are, in fact, carrying a very heavy load and dealing with many responsibilities, but their role in supporting people coping with an illness is often overlooked. At the clinic, we often see that the families of caregivers are also affected by the caregiver's dedication; in addition to dealing with the illness of their family member or friend, they sometimes

have to assume some of the practical roles previously performed by the caregiver. Israeli caregivers dealing with this significant responsibility are presented with numerous opportunities to relieve some of the burden that they experience. They are eligible for many social benefits such as financial aid; they also have greater access to support groups and to emotional care through dedicated organizations and their own health insurance, supporting them in coping better with the emotional aspect of caregiving. Many asylum seekers, on the other hand, are ineligible for the most basic of social benefits – while experiencing the linguistic and cultural barriers that prevent them from expressing their needs, asking questions, and demanding their rights. Also, many of them feel that the hospitals are working against them, due to their status, staff impatience or lack of training in overcoming cultural barriers, or the struggle to cover the cost of the treatment. They feel as if the hospital is "doing them a favor": that the team wants to get them out of the hospital as fast as possible, and that any interaction with the medical team could harm the treatment they are receiving. Therefore, many minimize their interactions with the medical and psychosocial

teams in hospitals, abstaining from using the support offered by the hospital.

H., the mother of four young children, was diagnosed with Devic's disease (neuromyelitis optica spectrum disorder, NMO) and is dealing with neurological degradation. Constantly in and out of the hospital, her judgment is impaired and she needs help with Activities of Daily Living (ADL). Therefore, she cannot be left alone. S., her husband, struggles to be by his wife's side at the hospital while simultaneously working hard to support their family and take care of the children and all their needs. The children, for their part, must cope with their beloved mother losing her light in front of their eyes; the eldest is sometimes asked to stay at home with her, instead of going to school.

B., husband of R., who is battling breast cancer, was forced to quit his job in order to take care of their three children and support his wife during her treatment. He was able to raise over 40,000 NIS for her treatment but is still struggling to feed his family, and to finance medication and further treatment. He also shared that he himself deals with anxiety and depression, deriving from the fear of losing his beloved wife, and of not being able to provide their children with all their needs.

Both S. and B. have dealt with incidents where they suffered from the language barriers, impatient medical practitioners, and their lack



Sister Aziza and a client at the PHRI clinic

of familiarity with Israeli hospitals and health systems. For both, as well as for many others in similar situations, life would have been a little less stressful if they and their spouses were granted basic health and social rights. Treatment would have been cheaper, the patients would have had access to rehabilitation and support from a professional caregiver, and they would have access to pensions and stipends, as well as access to emotional support. Though PHRI cannot always provide financial support or access to the health and social rights received by Israeli citizens, we are currently working on opening the first support group for the partners and caregivers of people with critical illnesses in the Eritrean community. Through this, we hope to provide participants with the tools necessary to deal with difficult feelings, anxiety, and stress by creating a safe space for reflection, discussion, and learning to cope with their emotions. Though we believe that support groups could be beneficial to the caregivers, we expect to face many challenges. Support groups are not culturally popular within the Eritrean community, and might be perceived as irrelevant or even a burden. We further expect that potential participants may find it difficult to attend the group, given their many obligations such as caregiving, work obligations, and taking care of their family, which does not leave them with much time for anything else. Participants may also feel embarrassed about sharing their thoughts and feelings within a group. Even so, we are working to overcome these challenges, adjusting the common model of such groups in order to support the needs of our potential participants, as we hope to provide caregivers with as much support as we can.

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¹ Population & Immigration Authority. 2020. "Foreigners in Israel data." p.1. Retrieved from:

https://www.gov.il/BlobFolder/generalpage/foreign_workers_stats/he/foreign_workers_report_q2_2020.pdf ² Israeli asylum seekers and refugees aid organizations forum. 2021. "What are we talking about when we talk about asylum seekers." p. 3.

⁸ Ibid, p. 5.

⁴ Ibid, p. 3.

⁵ Ibid, p.2.

⁶ Israeli asylum seekers and refugees aid organizations forum. 2021. "Medical insurance arrangement for asylum seekers." P.1.

⁷ Ibid.