

The effect of home-based care on housebound patients and their caregivers in two Palestinian refugee camps in Lebanon: a qualitative study

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Abstract

Background The incidence of non-communicable diseases (NCDs) increases annually by approximately 5% among older (age 50 years and older) Palestinian refugees in Lebanon, of whom around 10% are housebound. Care for housebound patients does not exist in the over-medicalised and highly privatised Lebanese health system or within the health system for Palestinian refugees in Lebanon. This has led to a neglected population. In 2016, Médecins Sans Frontières (MSF) started to provide home-based care (HBC) for housebound patients in two Palestinian camps: Bourj-el-Barajneh and Ain-al-Hilweh. HBC is carried out by a team comprising a doctor, nurse, and social worker, and includes basic medical monitoring, health literacy educational sessions, support for treatment adherence, as well as networking with relevant social service providers.

Methods A qualitative study was carried out between January and October, 2018, nine patients, ten caregivers, and personnel from two main international non-governmental organisations providing health care for refugees were interviewed, and one focus group discussion was conducted with MSF HBC staff. Thematic content analysis was carried out manually, with investigators' observations for triangulation. The study was approved by the MSF ethical review board.

Findings The housebound patients described various ways in which they felt socially isolated, useless, and unproductive. These are underserved needs. Caregivers reported feeling burdened socially, mentally, and financially. They also reported that they assumed full responsibility for the housebound relative, as there was no alternative. HBC was appreciated by patients and caregivers for providing psychosocial and medical support; patients viewed MSF staff as a "friend in care", a temporary escape from isolation, and caregivers expressed appreciation for sharing the burden of caring for the housebound person. There was a decrease in anxiety expressed by caregivers and patients, as well as a declining sense of burden described by caregivers, during the provision of HBC by the MSF staff. To a lesser extent, patients and caregivers sensed improved self management as their disease literacy and treatment adherence increased, and as caregivers became more efficient in handling toilet care, bathing, and wound dressing. Missing components of HBC were perceived to be "outdoor" activities and mental health services.

Interpretation HBC had an effect in reducing patients' social isolation, decreasing caregivers' burden and anxiety, and enhancing self management of disease for both. HBC should be considered for replication by all refugee health care providers as well as by the Lebanese Ministry of Public Health. This model of care needs to adopt a more holistic approach by including provision of mental health care and by increasing the focus on social isolation.

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Contributors

MS designed the study, conducted the in-depth interviews, and participated in data analysis and in writing of the manuscript. WvdB contributed to the study design, and participated in data analysis and in writing of the manuscript. CL conducted the focus group discussion and participated in data analysis. LR and LS provided input to the study design and the protocols, and contributed to the final draft of the manuscript. All authors have seen and approved the final version of the Abstract for publication.

Declaration of interests

We declare no competing interests.

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