# A nurse-led home-care programme for people with restricted mobility and their caregivers living in refugee camps: a descriptive study

F. Tarantini[1,2], D. Soukarieh[3], M. Sunallah[2], K. Moussally[4], N. El-Hawari[2], M. Hajj[2], Z. Hammoud[2], H. Daher[2], N. Chamoun[2], C. Sawan[5]

[1]University of Florence, Department of Clinical and Experimental Medicine, Florence, Italy; [2]Médecins Sans Frontières (MSF), South Beirut, Lebanon; [3]MSF, Beirut, Lebanon; [4]Middle-East Medical Unit, MSF, Beirut, Lebanon; [5]Faculty of Medicine and Medical Sciences, University of Balamand, Beirut, Lebanon

## INTRODUCTION

In refugees' settings, disability-friendly services are rare and family support activities are needed. In South Beirut refugee camps (Lebanon), Médecins Sans Frontières has been running a nurse-led home-based care (HBC) programme for disabled people and their caregivers, since 2021. The programme comprises disease-specific education, medication adherence counseling, tailored coaching, psychosocial support and specialised nursing care. It is implemented by a multidisciplinary team over a period of 16 weeks, after which the patient is discharged.

We assessed the effect of the HBC programme on selected health outcomes and the perception of patients/caregivers on the service provided.

## METHODS

This mixed-methods study assessed the impact of the HBC programme on patients and caregivers enrolled between June 2021 and May 2023. Changes in selected outcomes were measured using validated scores and analysed with appropriate statistical tests (Wilcoxon, paired t-test, McNemar's) based on data distribution. Qualitative interviews were analysed using the Thematic Content Analysis model, where sub-codes from the transcripts were created and together formed codes. Similar codes were stringed together to generate categories, that begin to display the main findings. R-studio was used for statistical analyses.

## RESULTS

Preliminary results included **105 patients** (mean age 69±16.78 years; 63% (n=66) females; 78% (n=82) Palestinians) and **96 caregivers** (91% (n=87) family members). Major causes of disability were skeletal diseases/deformities (23%, n=24) and cerebrovascular disease (19%, n=20). Median score of Katz Basic Activities of Daily Living (BADL) was 2 indicating a high level of dependency. Other patients' baseline characteristics:

| | N | % |
|---|---|---|
| Patients bed-ridden | 36 | 34 |
| Patients with dysphagia | 24 | 23 |
| Patients with incontinence | 69 | 66 |
| Patients needing help for personal hygiene | 64 | 61 |
| Patients with wounds requiring specialized care | 12 | 11 |

### Outcomes

Retention in the programme was 82% (9 patients dropped out and 10 died). Patient's wellbeing was explored by the analysis of 5 domains among the NANDA's nursing diagnosis [*Nursing Diagnosis Handbook, 12th Edition Revised Reprint with 2021-2023 NANDA-I® Updates, 12th Edition*]: 1) Communication & Mental Status; 2) Moving & Positioning; 3) Nutrition; 4) Elimination; 5) Patient comfort. Domains were explored by the nurse during the first assessment and at discharge to identify areas in need of support. The proportion of patients with improvement of at least 1 domain at discharge was 96% (77/80).

| Domains | Proportion | p-value |
|---|---|---|
| Communication & Mental Health | 40% | 0.000* |
| Moving & Positioning | 34% | 0.001* |
| Nutrition | 25% | 0,123 |
| Elimination | 22% | 0.000* |
| Comfort & Hygiene | 33% | 0.007* |

BADL and VAS (analogical scale for self-reported level of pain) scores were recorded at entry into the programme and at discharge.

BADL and VAS scores significantly improved after the intervention (Wilcoxon signed rank test).

| | Admission | | Discharge | | | | % | p-value |
|---|---|---|---|---|---|---|---|---|
| | Median | IQR | Median | IQR | | | | |
| BADL | 2 | [1-4] | 2 | [1-5.75] | | BADL | 30% | 0.0032* |
| VAS | 4 | [1.5-8] | 4 | [0-6] | | VAS | 30% | 0.001* |

This nurse-led HBC programme produced a significant improvement in several patients' health outcomes and overall wellbeing. It also reduced anxiety and depressive symptoms of patients and caregivers.
Qualitative interviews revealed how this service enhanced patient's understanding of disease, delivered essential care, and offered emotional support amidst critical structural and personal obstacles. Participants highlighted the significance of addressing both physical and psychological wellbeing while also providing valuable insights into areas of improvement in service delivery.
Further studies will be necessary to determine the long-term effects of this programme.

Medication literacy questionnaire (MLQ) and medication adherence questionnaire (MAQ) (MMAS-8) were scored at entry into the programme and at discharge.

MLQ score significantly improved after the educational intervention (Wilcoxon signed rank test).

| | Admission | | Discharge | | | | % | p-value |
|---|---|---|---|---|---|---|---|---|
| | Median | IQR | Median | IQR | | | | |
| MLQ | 90 | [71.4-100] | 100 | [84.8-100] | | MLQ | 23% | 0.0032* |
| MAQ | 8 | [6-8] | 8 | [7-8] | | MAQ | 12% | 0,3287 |

Mental health for patient and caregiver was assessed at entry into the programme and at discharge using two validated scales targeting depression (PHQ-9) and anxiety (GAD-7).

PHQ-9 and GAD-7 scores significantly improved after the intervention for patients and caregivers (Paired t-test).

| | Admission | | Discharge | | | | % | p-value |
|---|---|---|---|---|---|---|---|---|
| | Mean | SD | Mean | SD | | | | |
| PHQ-9 patient | 12.22 | 5.42 | 6.69 | 4.25 | | PHQ-9 patient | 66% | 0.000* |
| PHQ-9 caregiver | 11.63 | 5.07 | 6.53 | 3.00 | | PHQ-9 caregiver | 45% | 0.000* |
| GAD-7 patient | 9.46 | 4.87 | 4.84 | 3.49 | | GAD-7 patient | 41% | 0.000* |
| GAD-7 caregiver | 11.31 | 4.86 | 6.65 | 3.36 | | GAD-7 caregiver | 50% | 0.000* |

Twelve in-depth interviews with patients with restricted mobility or bed-ridden and their caregivers.
✓ Vulnerable refugee communities face immense challenges, including limited healthcare, poor living conditions and widespread mental health struggles.
✓ MSF HBC services proved critical for patients with chronic conditions and their caregivers. **Quoted from one patient:**
*"It was MSF that made me understand my health better"*
✓ Patients and caregivers received essential care and felt valued by MSF staff. **One patient noted:**
*"There was a big difference in the service, at the hospital they didn't treat me well at all!"*
✓ The emotional support provided by MSF made a significant difference in both patient and caregiver wellbeing.
**However, there's still room to improve communication, address further needs and expand support for mental health.**

MEDECINS SANS FRONTIERES

English Charity Reg. No. 1026588