

What happens to Palestine refugees with diabetes mellitus in a primary healthcare centre in Jordan who fail to attend a quarterly clinic appointment?

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Abstract

OBJECTIVE In a primary healthcare clinic in Jordan to determine: (i) treatment outcomes stratified by baseline characteristics of all patients with diabetes mellitus (DM) ever registered as of June 2012 and (ii) in those who failed to attend the clinic in the quarter (April–June 2012), the number who repeatedly did not attend in subsequent quarters up to 1 year later, again stratified by baseline characteristics.

METHOD A retrospective cohort study with treatment outcome data collected and analysed using e-health and the cohort analysis approach in UNRWA Nuzha Primary Health Care Clinic for Palestine refugees, Amman, Jordan.

RESULTS As of June 2012, there were 2974 patients with DM ever registered, of whom 2246 (76%) attended the clinic, 279 (9%) did not attend, 81 (3%) died, 67 (2%) were transferred out and 301 (10%) were lost to follow-up. A higher proportion of males and patients with undetermined or poor disease control failed to attend the clinic compared with those who attended the clinic. Of the 279 patients who did not attend the clinic in quarter 2, 2012, 144 (52%) were never seen for four consecutive quarters and were therefore defined as lost to follow-up. There were a few differences between patients who were lost to follow-up and those who re-attended at another visit that included some variation in age and fewer disease-related complications amongst those who were lost to follow-up.

CONCLUSION This study endorses the value of e-health and cohort analysis for monitoring and managing patients with DM. Just over half of patients who fail to attend a scheduled quarterly appointment are declared lost to follow-up 1 year later, and systems need to be set up to identify and contact such patients so that those who are late for their appointments can be brought back to care and those who might have died or silently transferred out can be correctly recorded.

keywords diabetes mellitus, Palestine refugees, Jordan, cohort reports, failure to attend the clinic, lost to follow-up

Introduction

Non-communicable diseases (NCDs) are now a high priority international health issue, and monitoring progress and accountability in disease control is one of the five priority actions agreed by countries and international agencies (Beaglehole *et al.* 2012; WHO 2012).

In 2012, we reported on the use of cohort analysis and e-health for monitoring and managing Palestine refugees with diabetes mellitus (DM) in Nuzha primary healthcare (PHC) clinic in Jordan, a clinic run by the United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA) (Khader *et al.* 2012). At that time, we reported on cumulative cohort treatment outcomes of

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patients ever registered at the clinic, and of these nearly 20% had failed to attend their quarterly scheduled visit at the clinic.

We are currently working on further development of the cohort analysis approach and failure to attend the clinic at quarterly time intervals appears as an ongoing problem, not only in Nuzha PHC but also in other similar PHC clinics that have adopted this approach. We do not know whether patients with DM who have failed to attend during one-quarter come back in the following quarters for a clinic review or whether they eventually end up as lost to follow-up, defined in UNRWA NCD guidelines as no clinic attendance for 1 year or four consecutive quarters (UNRWA 2009). The objectives of this study were to determine in Nuzha PHC clinic: (i) the treatment outcomes of all DM patients ever registered as of June 2012, stratified by baseline characteristics and (ii) in those who failed to attend the clinic in the quarter (April–June 2012) the number who repeatedly did not attend in subsequent quarters up to 1 year of follow-up, again stratified by baseline characteristics.

Methods

This was a retrospective cohort study of routinely collected data using e-health, conducted in Nuzha PHC clinic in Amman, Jordan. The clinic is staffed by doctors, nurses and support staff, and it serves a catchment population of approximately 55 000 refugees, and all services are provided free of charge (Khader *et al.* 2012). There is a regular and ongoing screening programme for both DM and hypertension with the diagnosis of DM based on at least two fasting blood glucose (FBG) measurements, both of which must be ≥ 126 mg/dl or 7.0 mmol/l within a week (WHO 2006; UNRWA 2009).

Patients are managed according to the standard guidelines with lifestyle advice, oral hypoglycaemic drugs and insulin, and every quarter, they are expected to attend the clinic for a clinical assessment and quarterly measurements of body mass index, blood pressure, 2-h postprandial blood glucose (PPBG) and urine for albumin and glucose.

Doctors and nurses use the e-health system (Khader *et al.* 2012), to record all clinical information. Quarterly cohort analysis is carried out routinely through the use of e-health, with standard patient outcomes recorded every quarter (attended clinic, did not attend clinic, died, transferred out to another health centre and lost to follow-up). A patient is defined as lost to follow-up if he/she fails to attend the clinic during four consecutive quarters of a treatment year.

The study population was the cohort of patients with DM who were ever registered at Nuzha PHC clinic up to 30 June 2012 and included those who failed to attend the clinic to see a doctor or nurse in the second quarter from 1 April to 30 June 2012.

Patient data were obtained from the clinic e-health system. Data variables included baseline characteristics and primary treatment outcomes. For patients who failed to attend the clinic in quarter 2, 2012, it was determined whether they attended the clinic in quarter 3, 2012. For those who failed to attend the clinic in quarter 3, 2012, it was determined whether they attended the clinic in quarter 4, 2012. Those who failed to attend in quarter 4, 2012, were followed up in quarter 1, 2013, and the process repeated for quarter 2, 2013. In this way, there were four subsequent quarterly assessments for patients who failed to attend the clinic, with the denominator for each quarter being the non-attending patients of the previous quarter. Those who did not attend quarter 2, 2103 (1 year later), were defined according to UNRWA technical guidelines as being lost to follow-up (UNRWA 2009). Comparisons of outcomes by baseline characteristics were carried out by chi-square tests, using odds ratios (OR) and 95% confidence intervals. Levels of significance were set at 5%.

Approval for the study was obtained from UNRWA Headquarters, Jordan, and as this was a programme audit, no local ethics approval was required. Ethics approval for publication of the study was obtained from the Union Ethics Advisory Group, Paris, France.

Results

Treatment outcomes of patients ever registered up to 30 June 2012 are shown in Table 1. There were 2246 (76%) patients who attended the clinic and 279 (9%) who did not attend, the remainder having died, been transferred out or lost to follow-up. Baseline characteristics between those who failed to attend the clinic and those who attended the clinic are shown in Table 2. There were statistically significant differences in several characteristics, but the main findings of interest were that more males, more patients whose diabetes control status was undetermined and more patients with poor diabetes control failed to attend the clinic.

Two hundred and seventy-nine registered patients who failed to attend the clinic in quarter 2 (April–June 2012), were followed up over the next four quarters, with the denominator for each quarter being the number failing to attend the previous quarter (Table 3). At the end of 1 year of follow-up, 144 (52%) of 279 patients had never been seen for four consecutive quarters and were

A. Khader *et al.* **Diabetes and follow up clinic visits****Table 1** Treatment outcomes of patients with diabetes mellitus ever registered at the Nuzha Primary Health Care Centre, Jordan, up to 30 June 2012

Patients and treatment outcomes	Number (%)
All patients with DM patients ever registered up to 30 June, 2012	2974
Principal outcome as determined up to 30 June, 2012	
Attended the clinic in quarter 2 (April to June), 2012	2246 (75.5)
Not attended the clinic in quarter 2 (April to June), 2012	279 (9.4)
Dead	81 (2.7)
Transferred out	67 (2.3)
Lost to follow-up	301 (10.1)

DM, diabetes mellitus.

therefore defined as lost to follow-up. Baseline characteristics of those who repeatedly failed to attend the clinic (and were defined as lost to follow-up), and those who returned to the clinic at another visit are shown in Table 4. There were a few differences between the two groups of patients, with those who repeatedly failed to attend showing some variation in age and having fewer disease complications.

Discussion

This report on patients with DM used routine cohort analysis and e-health to track what happens to patients who fail to attend the clinic in one-quarter. A sizeable proportion of these patients repeatedly failed to attend in subsequent quarters with just over half being declared lost to follow-up at 1 year. In the first cross-sectional assessment of patients ever registered at the clinic, more males and more patients whose disease control was undetermined or whose disease control was poor failed to attend the clinic. However, when these patients were subsequently followed up, there was little difference in baseline characteristics between those who were eventually defined as lost to follow-up and those who re-attended the clinic again at another time, except for some variation in age and fewer complications amongst those lost to follow-up.

Lost to follow-up is a term used to describe patients who are no longer in care, but what exactly has happened to them requires further understanding. This has been an important and fruitful area of operational research within HIV/AIDS care and treatment programmes (Yu *et al.* 2007; Brinkhof *et al.* 2008; Caluwaerts *et al.* 2009; Fox & Rosen 2010), with various cost-effective interventions proposed and assessed

Table 2 Demographic and clinical characteristics of patients with DM who did not attend and who attended Nuzha Primary Health Care Centre, Jordan, in quarter 2 (April–June) 2012

Characteristics	Did not attend clinic <i>n</i> (%)	Attended clinic <i>n</i> (%)	OR (95% CI) <i>P</i> -value
Total	279	2246	
Female	123 (44)	1271 (57)	Reference
Male	156 (56)	975 (43)	1.7 (1.3–2.9) <i>P</i> < 0.001
Age <20 years	6 (2)	17 (1)	2.9 (1.1–7.4) <i>P</i> = 0.02
Age 21–39 years	15 (5)	93 (4)	1.3 (0.7–2.3)
Age 40–59 years	140 (50)	1002 (45)	1.3 (0.9–1.6)
Age 60 years and above	118 (42)	1134 (50)	0.7 (0.6–0.9) <i>P</i> < 0.01
DM type 1	12 (4)	47 (2)	2.1 (1.1–4.0) <i>P</i> = 0.02
DM type 2	73 (26)	378 (17)	1.8 (1.3–2.3) <i>P</i> < 0.001
DM type 2 and HT	194 (70)	1821 (81)	0.5 (0.4–0.7) <i>P</i> < 0.001
DM <5 years	72 (26)	473 (21)	1.3 (0.9–1.7)
DM 5–10 years	100 (36)	808 (36)	1.0 (0.8–1.3)
DM >10 years	107 (38)	965 (43)	0.8 (0.6–1.1)
DM control determined	128 (46)	2159 (96)	Reference
DM control undetermined†	151 (54)	87 (4)	29.3 (21–40) <i>P</i> < 0.001
DM controlled‡	63 (49)*	1256 (58)*	Reference
DM uncontrolled§	65 (51)*	903 (42)*	1.4 (1.0–2.1) <i>P</i> = 0.04
Complications of disease	41 (15)	384 (17)	0.8 (0.6–1.2)

DM, diabetes mellitus; HT, hypertension.

*Percentage of patients with DM whose disease control was determined.

†DM control not determined = 2 or more postprandial blood glucose measurements not carried out in last three visits and <3 measurements in 1 year.

‡DM controlled = 2 of the last three postprandial blood glucose measurements ≤180 mg/dl.

§DM uncontrolled = 2 of the last three postprandial blood glucose measurements >180 mg/dl.

to improve long-term retention in care (Losina *et al.* 2009). Furthermore, e-health systems have been used successfully in Africa to identify and then to track patients who have missed their scheduled clinic visits, and this has resulted in marked improvement in known treatment outcomes and better retention in care (Tweya *et al.* 2010). There is a need for similar research and interventions in the management and care of patients with non-communicable diseases, including diabetes mellitus. Suitable interventions that might be implemented and assessed

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Quarter 2-2012	Quarter 3-2012	Quarter 4-2012	Quarter 1-2013	Quarter 2-2013
Did not attend <i>n</i> = 279	Attended <i>n</i> = 5 Did not attend <i>n</i> = 274	Attended <i>n</i> = 24 Did not attend <i>n</i> = 250	Attended <i>n</i> = 64 Did not attend <i>n</i> = 186	Attended <i>n</i> = 42 Did not attend* <i>n</i> = 144

The denominator for each quarter from quarter 3-2012 onwards is the number who did not attend the clinic in the previous quarter.
*Defined as loss to follow-up.

Table 4 Demographic and clinical characteristics of non-attending patients in quarter 2, 2012, who were lost to follow-up 1 year later or who re-attended at one of the quarterly visits during the following year

Characteristics of the non-attending patients in quarter 2, 2012	Who were lost to follow-up 1 year later <i>n</i> (%)	Who re-attended the clinic during the following year <i>n</i> (%)	OR (95% CI) <i>P</i> -value
Total	144	135	
Female	57 (40)	67 (50)	Reference
Male	87 (60)	68 (50)	1.5 (0.9–2.4)
Age <20 years	3 (2)	3 (2)	0.9 (0.2–4.7)
Age 21–39 years	5 (4)	8 (6)	0.6 (0.2–1.8)
Age 40–59 years	84 (58)	53 (39)	2.2 (1.3–3.5) <i>P</i> < 0.01
Age 60 years and above	52 (36)	71 (53)	0.5 (0.3–0.8) <i>P</i> < 0.01
DM type 1	4 (3)	7 (5)	0.5 (0.1–1.8)
DM type 2	44 (31)	27 (20)	1.8 (1.0–3.0) <i>P</i> = 0.04
DM type 2 and HT	96 (67)	101 (75)	0.7 (0.4–1.1)
DM <5 years	26 (18)	28 (21)	0.8 (0.5–1.5)
DM 5–10 years	57 (40)	47 (35)	1.2 (0.8–2.0)
DM >10 years	61 (42)	60 (44)	0.9 (0.6–1.5)
DM control determined	63 (44)	45 (33)	Reference
DM control undetermined†	81 (56)	90 (67)	0.6 (0.4–1.0)
DM controlled‡	31 (49)*	23 (51)*	Reference
DM uncontrolled§	32 (51)*	22 (49)*	1.1 (0.5–2.3)
Complications of disease	17 (12)	29 (21)	0.5 (0.3–0.9) <i>P</i> = 0.03

DM, diabetes mellitus; HT, hypertension.

*Percentage of patients with DM whose disease control was determined.

†DM control not determined = 2 or more postprandial blood glucose measurements not carried out in last three visits and <3 measurements in 1 year.

‡DM controlled = 2 of the last three postprandial blood glucose measurements ≤180 mg/dl.

§DM uncontrolled = 2 of the last three postprandial blood glucose measurements >180 mg/dl.

include timely SMS messages or telephone calls to patients, a telephone hotline service for patients to call in and reschedule their appointments, home visits to patients who are disabled and finally a safety net of drugs if delayed appointments are anticipated.

It is also crucial that patients themselves, their families and social support groups are involved in their disease management as this has been shown to improve adherence to treatment (Miller & Dimatteo 2013). Education and patient empowerment in fact hold the key to successful DM management. Self-care education is now recognised as an important component of management of all

types of DM and is part of the standard clinical practice recommendations of all major professional diabetes organizations. Programmes to educate people with DM about self-care management have become the focus of evaluations (Minet *et al.* 2010), and these are widely advocated as a means to acquire the skills necessary for active responsibility in the day-to-day management of their condition (Rutten 2005). A trend towards the use of peers has also emerged as an important factor for social and community support (Funnell 2010), and this can be augmented through the use of new technology such as smartphone applications (Kirwan *et al.* 2013). All of

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these interventions could be used to help patients to understand the importance of attending clinic regularly as well as adhering to lifestyle changes that improve overall general health.

The strengths of this study are the large number of patients followed up and the standardised system of reporting treatment outcomes, which means that the results are probably representative of what happens in other clinics in the country. Limitations relate to the operational nature of the study and the current lack of information about the true causes of loss to follow-up.

This study again endorses the value of e-health and cohort analysis for monitoring and managing patients with DM and highlights the importance of setting up systems at the primary healthcare level by which non-attending patients can be quickly identified and contacted so that those who are late for their appointments can be brought back to care and those who might have died or silently transferred out be properly recorded.

In conclusion, cohort analysis and e-health have enabled Nuzha PCH clinic to follow a cohort of nearly 300 patients who failed to attend their scheduled appointment and to determine their outcomes at 1 year. The eventual high losses to follow-up might be improved through suitable health service and patient-led interventions.

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