Cohort monitoring of persons with hypertension: an illustrated example from a primary healthcare clinic for Palestine refugees in Jordan

Ali Khader[1], Loai Farajallah[1], Yousef Shahin[1], Majed Hababeh[1], Ishtaiwi Abu-Zayed[2], Arata Kochi[3], Anthony D. Harries[4,5], Rony Zachariah[6], Anil Kapur[7], Wendy Venter[1] and Akihiro Seita[1]

1 United Nations Relief and Works Agency for Palestine Refugees in the Near East, UNRWA HQ (A), Amman, Jordan
2 Field Health Programme, UNRWA, Amman, Jordan
3 Tokyo University Medical School, Tokyo, Japan
4 International Union Against Tuberculosis and Lung Disease, Paris, France
5 London School of Hygiene and Tropical Medicine, London, UK
6 Medecins sans Frontieres, Medical Department, Operational Research Unit, Brussels Operational Center, Luxembourg, Luxembourg
7 World Diabetes Foundation, Gentofte, Denmark

Abstract

OBJECTIVE Recording and reporting systems borrowed from the DOTS framework for tuberculosis control can be used to record, monitor and report on chronic disease. In a primary healthcare clinic run by UNRWA in Amman, Jordan, serving Palestine refugees with hypertension, we set out to illustrate the method of cohort reporting for persons with hypertension by presenting on quarterly and cumulative case finding, cumulative and 12-month analysis of cohort outcomes and to assess how these data may inform and improve the quality of hypertension care services.

METHOD This was a descriptive study using routine programme data collected through E-Health.

RESULTS There were 97 newly registered patients with hypertension in quarter 1, 2012, and a total of 4130 patients with hypertension ever registered since E-Health started in October 2009. By 31 March 2012, 3119 (76%) of 4130 patients were retained in care, 878 (21%) had failed to present to a healthcare worker in the last 3 months and the remainder had died, transferred out or were lost to follow-up. Cumulative and 12-month cohort outcome analysis indicated deficiencies in several components of clinical performance related to blood pressure measurements and fasting blood glucose tests to screen simultaneously for diabetes. Between 8% and 15% of patients with HT had serious complications such as cardiovascular disease and stroke.

CONCLUSION Cohort analysis is a valuable tool for the monitoring and management of non-communicable chronic diseases such as HT.

keywords hypertension, diabetes mellitus, Palestine refugees, Jordan, cohort reports

Introduction

The diagnosis and treatment of hypertension (HT) has been one of medicine's great successes over these past 50 years, but despite this achievement the global burden of HT is immense and increasing. In 2000, the estimated number of adults with HT globally was 972 million, with the numbers expected to rise to 1.56 billion by 2025 (Editorial 2007). Lifestyle factors such as lack of physical exercise, excess salt, alcohol and tobacco are inexorably linked to this disease burden. The Global Burden of Disease study estimated that for the year 2001, about 7.6 million (13.5%) of all deaths and 92 million (6%) of all DALYs (disability-adjusted life years) were caused by hypertension, with high blood pressure causing 54% of strokes and 25% of cardiovascular disease worldwide, much of this in young age groups (Lawes *et al.* 2008).

In many parts of the world, a major obstacle to the control of blood pressure–related diseases is the absence of appropriate primary healthcare services (MacMahon *et al.* 2008). Most such services provide only episodic, unstructured and unmonitored care with little or no record about previous visits and no information about HT incidence and prevalence, treatment outcomes, associated morbidity or mortality. These services need to change and adapt to provide continuing chronic care. We have suggested

previously that the 'cohort' recording and reporting systems borrowed from the 'DOTS' (directly observed therapy, short course) framework for tuberculosis control can be used to record, monitor and report on chronic disease (Harries *et al.* 2008), and indeed, this has been performed in Malawi for the management of HIV/AIDS (Harries *et al.* 2009a) and diabetes mellitus (Allain *et al.* 2011).

The United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA) has been working in the region for 62 years and provides education, health and social services for about five million Palestine refugees in Jordan, Lebanon, Syria, the West Bank and Gaza Strip (UNRWA 2011). UNRWA currently provides services from 138 primary healthcare (PHC) centres and one hospital in the West Bank, with an important component being the diagnosis and care of non-communicable diseases, particularly DM and HT (United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA) 2011). Prevalence of DM and HT among UNRWA served populations aged 40 years and older is 11.4% and 17.5%, respectively, and in 2011, almost 211 000 people with DM and/or HT were being cared for at UNRWA clinics in the region (United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA) 2011).

In 2009, UNRWA started an electronic health record system (E-Health), which currently operates in six PHC clinics in Jordan. In Nuzha PHC clinic, Amman, where the E-Health system has been operational for about 30 months, we developed a cohort reporting system for Palestine refugees with HT. The aim of this study is to illustrate the methodology by reporting on quarterly and cumulative case finding, cumulative and 12-month cohort outcome analysis and assess how these data may usefully inform and improve the quality of HT management services.

Methods

This is a retrospective descriptive study of the use of the E-Health and cohort reporting framework to monitor persons with HT at Nuzha PHC Clinic.

The Arab-Israeli war of 1948 created the largest refugee population in the world, with 2.8 million people residing outside the occupied Palestinian territory in Syria, Lebanon and Jordan (Sabatinelli *et al.* 2009). Health care for these people is provided mainly by UNRWA. Two million refugees reside in Jordan where they are entitled to full citizenship except for those who arrived from the Gaza strip. These refugees are generally a young population. Over the last 60 years, the incidence of communicable

disease has gradually fallen, and as the lifestyle has changed and life expectancy has risen, non-communicable diseases, especially DM and HT, have emerged as major health problems. Rates of DM and HT reported by UNRWA are in fact similar to those reported for Palestine refugees living within the occupied Palestinian territory of the West Bank and Gaza (Giacaman *et al.* 2009; Husseini *et al.* 2009), with similar risk factors of obesity, lack of physical activity and increasingly unhealthy diets.

The study was conducted in Nuzha PHC Clinic in Amman, Jordan's capital city. Jordan is a country of six million people, including two million registered Palestine refugees, of whom 17% live inside 10 camps. There are 24 PHC clinics that are run by UNRWA staff, accessed by more than 50% of registered Palestine refugees in Jordan. Nuzha PHC clinic is located outside of the camps and serves a catchment population of 55 000 refugees. The clinic is staffed by four doctors and a variable number of nurses and support staff. All screening, diagnosis and treatment services at the clinic are provided free of charge.

All Palestine refugees who attend the clinic are screened for HT if they are 40 years or older, if they are judged to be at risk of non-communicable diseases and if they are pre-conception or pregnant women. HT screening is performed by the trained nurse and the diagnosis is confirmed by a medical officer if the blood pressure is ≥140/90 mmHg on several separate occasions. Those who do not have HT are followed up and screened every 6 months (UNRWA 2009). Persons diagnosed with HT are clinically assessed for complications and comorbidities such as diabetes mellitus (defined as two fasting blood glucose measurements, both of which must be ≥126 mg/dl (UNRWA Health Department 2009; WHO 2006), and these data along with demographic and clinical information are recorded in E-Health system. Patients are classified as having new or previously diagnosed hypertension, the diagnosis made either within or outside of the UNRWA system, and a record is also made about whether the patient has been transferred in from another UNRWA clinic.

Patients are managed according to a standard algorithm with diet and lifestyle advice and different classes of antihypertensive drugs that include beta-blockers, diuretics, calcium channel blockers, angiotensin-converting enzyme (ACE) inhibitors and methyldopa (Box 1). Methyldopa is mainly used for pregnancy-induced hypertension, and there are plans to replace it with labetolol. Patients with uncontrolled HT are seen weekly or monthly until their blood pressure is <140/90 mmHg, and they are then followed every 3 months. During the quarterly visit, the patients are supposed to be assessed as follows: body mass index, blood pressure measurement and the

Box 1 Guidance for the management of hypertension in Nuzha Primary Health Clinic, Jordan

Step 0	Lifestyle modification
	If BP still uncontrolled, then low dose of diuretic such as hydrochlorothiazide or beta-blocker
Step 1	>55 years – calcium channel blocker or diuretic
	≤55 years – ACE inhibitor or beta-blocker
Step 2	ACE inhibitor or beta-blocker PLUS calcium channel blockers or diuretics
Step 3	ACE inhibitor or beta-blocker PLUS calcium channel blockers and diuretics
Step 4	Refer to hospital for investigation and new/ management plan

BP, blood pressure; ACE inhibitor, angiotensin-converting enzyme inhibitor.

presence/absence of late complications (defined as blindness, end-stage renal failure, myocardial infarction, congestive cardiac failure, stroke and above ankle amputation). Urine is assessed for glucose and protein every 6 months. Once in every 12 months, all patients with HT are expected to have fasting blood tests for total cholesterol and serum creatinine and those without DM are also expected to be screened for the disease with fasting blood glucose.

The electronic health system (E-Health) was set up in 2009 for non-communicable diseases, maternal health, child health and general outpatients and is currently operational in six UNRWA clinics in Jordan, including Nuzha PHC clinic. All clinical information, including prescriptions and laboratory requests, are managed electronically, with patient baseline and follow-up data

stored in E-Health. There are electronic keyboard operated work stations in every clinic room, including the pharmacy and laboratory, and these are connected to a central server that stores the data. Clinicians and nurses use the computers (password protected) at the point-of-care to enter patient information during clinical encounters. New patients are registered by a clerk and thereafter clinicians and nurses can access that patient's electronic data file using the patient health card and identification number. In addition to being an electronic tool to facilitate good clinical care, E-Health also allows cohort data to be collected.

All patients who were registered and entered into the E-Health system with HT from 1 October 2009 to 31 March 2012 in Nuzha PHC Clinic were included in the analysis. Patient data were obtained from the Clinic E-Health system. Data variables for the cohorts included: age, sex, diagnosis of HT, associated DM, new or previous diagnosis of HT, diagnosis made inside or outside UNRWA health centres, whether the patient has been transferred in from another UNRWA clinic, current treatment outcome status as of 31 March 2012, current management, quarterly blood pressure measurements, whether quarterly or annual screening tests (and results) had been conducted and the presence or absence of late complications. Definitions of variables for the management of patients and for the cohort reports are shown in Table 1.

For this study, data were collected and aggregated into four cohort reports: (i) Quarterly Registration (patients with HT newly registered in quarter 1, 2012 – from 1 January to 31 March 2012; (ii) Cumulative Registration (total number of patients with HT ever registered up to 31

Table 1 Definitions for the management and recording of patients with hypertension (HT) for the cohort reports

Quarterly and Cumulative Registrations	
New diagnosis	Date of registration occurs within four weeks of date of diagnosis
Previous diagnosis	Date of registration occurs four weeks or later from date of diagnosis
Transferred in	Previously registered in another UNRWA clinic and now transferred to the current clinic
Diabetes mellitus	Two fasting blood glucose measurements, both of which must be ≥126 mg/dl
Cumulative treatment outcomes and 12-month survival analysis	
Remaining in care	Alive and in care and seen by a doctor or nurse during quarter 1, 2012
Dead	Died at any time from any cause
Transferred out	Permanently transferred out from the clinic to another clinic
No quarterly attendance	Not seen in the clinic in quarter 1, 2012, by a doctor or a nurse
Lost to follow-up	No quarterly attendances on four consecutive occasions at the clinic

March 2012, including the new quarterly registrations); (iii) Cumulative Outcomes (outcomes of all patients with HT ever registered up to 31 March 2012, with the outcomes censored on 31 March); and (iv) 12-month Cohort Outcome Analysis (the outcomes of patients with HT who were newly registered in quarter 1, 2011 – from 1 January to 31 March 2011 – with data censored on 31 March 2012). The data for these four types of cohort reports are presented and analysed in terms of assessment and impact on programme performance.

The data for the study included retrospectively collected routine patient information on HT. Data were aggregated for the cohort reporting and no individual patient identifiers were used. Approval for the study was obtained from UNRWA Headquarters and it was decided that no local ethical approval was required. Ethical approval for reporting on the study was obtained from the Union Ethics Advisory Group.

Results

The four cohort analyses and the results from Nuzha PHC Clinic are shown in Tables 2–5. The number of new quarterly HT registrations at the clinic and their demographic and clinical characteristics for quarter 1, 2012 are shown in Table 2. The main points of interest are that 86% of new registrations were 40 years and older, 54% were

new diagnoses and just over half the patients had associated DM at the time of registration. There were 4130 patients with HT cumulatively ever registered at Nuzha PHC since E-Health was set up, including those patients newly registered between January and March 2012. Their characteristics are shown in Table 3. The cumulative cohort was fairly similar to the new quarter registrations except there were more women, more patients with a previous diagnosis of HT and more patients with a diagnosis made from within UNRWA sites.

The outcomes of the whole cumulative cohort with data censored on 31 March 2012 are shown in Table 4. For all 4130 patients with HT, the primary outcome data shown were as follows: those remaining in care by 31 March 2012, those who were dead, transferred out or lost to follow-up, and those who did not present to a doctor or a nurse at the clinic during the last quarter (January–March 2012). Of those remaining in care, information is provided on current drug management, the number and proportion who had their blood pressure measured and controlled in quarter 1, 2012, the number with one or more late complications of disease and the numbers with each complication. The commonest drugs used were atenolol and enalapril (in about 75% of cases), followed by hydrochlorothiazide and nifedipine (in about one-third of

Table 2 Quarterly cohort registration of patients with hypertension (HT) (January–March 2012)

Patient characteristics	Number	%
Patients with HT newly registered in the quarter	97	
Gender		
Male	46	47
Female	51	53
Age group in years: at time of registration		
<20	0	0
20–39	14	14
40–59	56	58
60 and above	27	28
Category of disease: at time of registration		
Hypertension only	47	48
Hypertension and diabetes	50	52
Diagnosis		
New diagnosis of HT	52	54
Previous diagnosis of HT	45	46
Place of diagnosis		
Inside UNRWA	60	62
Outside UNRWA	37	38
Transferred in	2	2

HT, hypertension; UNRWA, United Nations Relief and Works Agency for Palestine Refugees in the Near East.

Table 3 Cumulative cohort registration of patients with hypertension (HT) (patients ever registered up to 31 March 2012)

Patient characteristics	Number	%
All patients with HT ever registered, including the new registrations between January and March 2012.	4130	
Gender		
Male	1595	39
Female	2535	61
Age group in years: at time of registration		
<20	5	<1
20–39	458	11
40–59	2443	59
60 and above	1224	30
Category of disease: at time of registration		
Hypertension only	2148	52
Hypertension and diabetes	1982	48
Diagnosis		
New diagnosis of HT	1442	35
Previous diagnosis of HT	2688	65
Previously diagnosed		
Inside UNRWA	3333	81
Outside UNRWA	797	19
Transferred in	142	3

DM, diabetes mellitus; UNRWA, United Nations Relief and Works Agency for Palestine Refugees in the Near East.

Table 4 Cumulative cohort outcomes of patients with hypertension (HT) (patients ever registered up to 31 March 2012)

Patient characteristics and treatment outcomes	Number	%
All patients with HT ever registered, including the new registrations between January and March 2012.	4130	
Principal outcome as determined on 31 March 2012:		
Remaining in care	3119	76
Dead	0	0
Transferred out	62	1.5
No attendance in quarter 1 (January–March) 2012 at the clinic	878	21
Lost to follow-up	71	1.5
Of patients remaining in care: current drug management	3119	
Atenolol (beta-blocker)	2281	73
Propranolol (beta-blocker)	52	2
Amiloride (diuretic)	29	<1
Frusemide (diuretic)	391	1
Hydrochlorothiazide (diuretic)	1043	33
Frusemide injection (diuretic)	20	<1
Methyl Dopa	84	3
Nifedipine (calcium channel blocker)	889	29
Diltiazem (calcium channel blocker)	61	2
Enalapril (ACE inhibitor)	2366	76
Of patients remaining in care: blood pressure	3119	
Number with blood pressure measured	2297	74
Number with blood pressure < 140/90 mmHg	1704	74
Of patients remaining in care: late complications	3119	
Patients with one or more late complications	475	15
Patients who are blind	29	<1
Patients with end-stage renal disease	5	<1
Patients with myocardial infarction	237	8
Patients with congestive cardiac failure	118	4
Patients with stroke	144	5
Patients with above ankle amputation	1	<1

HT, hypertension: ACE inhibitor, angiotensin-converting enzyme inhibitor.

cases). Almost 75% of patients had their blood pressure measured in the most recent quarter, and of those 75% had their hypertension controlled. One or more late complications were present in 15% of patients, with cardiovascular disease and stroke accounting for most of the morbidity.

Finally, a quarterly cohort outcome analysis on patients with HT newly registered 1 year previously (January–March 2011) and assessed in quarter 1, 2012, is shown in Table 5. This provides information about 12–15-month outcomes, current management and late complications within 1 year of registration, the number and proportion of those who had blood pressure measured and controlled, and the number and proportion that had annual screening assessments performed (fasting blood glucose, total cholesterol and serum creatinine) as recommended in the UNRWA guidelines. While some assessments had been well performed, others such as fasting blood glucose had not. Similarly, there was no record of blood pressure measurement in one quarter of patients who attended the clinic between January and March 2012.

Discussion

This is the first report from a primary healthcare clinic setting to show how the 'DOTS' cohort monitoring system can be adapted and used to monitor and report on persons with HT in Jordan. This is potentially useful for the UNRWA Hypertensive care services and can provide information that is relevant and helpful for clinical disease management programme performance, patient outcomes and assessing long-term healthcare impact (Table 6). The cohort monitoring system, particularly quarterly data on new and cumulative cases, is also useful for public health services planning and management, such as rational forecasting for drugs and other consumables and all the logistics necessary for providing quality care such as blood pressure machines, treatment cards, etc.

The number of patients newly registered in the HT clinic during a quarter provides informative data on 'new incident cases', which can be further stratified by sex, age, comorbid conditions such as diabetes mellitus and

Table 5 Twelve to 15-month cohort outcome analysis of patients with hypertension*

Patient characteristics	Number	%
Patients with HT newly registered in quarter 1 (January–March) 2011	226	
Principal outcome as determined on 31 March 2012		
Remaining in care	140	62
Dead	0	0
Transferred out	2	<1
No quarterly attendance at the clinic in quarter 1, 2012	84	38
Lost to follow-up	0	0
Of those remaining in care: current management	140	
Atenolol (beta-blocker)	93	66
Propranolol (beta-blocker)	2	1
Amiloride (diuretic)	0	0
Frusemide (diuretic)	8	6
Hydrochlorothiazide (diuretic)	31	22
Frusemide injection (diuretic)	1	<1
Methyl Dopa	3	2
Nifedipine (calcium channel blocker)	24	17
Diltiazem (calcium channel blocker)	0	0
Enalapril (ACE inhibitor)	101	72
Of those remaining in care: blood pressure in current quarter	140	
Patients with blood pressure measured	104	74
Patients with blood pressure < 140/90 mmHg	79	76
Of those remaining in care: annual assessment	140	
Patients with HT only	79	56
In patients with HT only, FBG measured	2	3
Of those, FBG ≤ 180 mg/dl	1	50
In those with HT and HT-DM, total cholesterol measured	140	100
Of those, total cholesterol < 200 mg/dl	89	64
In those with HT and HT-DM, serum creatinine measured	139	99
Of those, serum creatinine < 1.2 mg/dl	130	94
Of those remaining in care: late complications	140	
Patients with one or more late complications	11	8
Patients who are blind	0	0
Patients with end-stage renal disease	0	0
Patients with myocardial infarction	8	6
Patients with congestive cardiac failure	1	<1
Patients with stroke	2	1
Patients with above ankle amputation	0	0

HT, hypertension; DM, diabetes mellitus: FBG, fasting blood glucose; ACE inhibitor, angiotensin-converting enzyme inhibitor. *Patients newly registered with HT between January and March 2011 and assessed 12 months later in quarter 1, 2012.

whether patients are newly or previously diagnosed. These data can be compared with those from the cumulative registered cohort, allowing healthcare providers to assess over time whether patient and disease characteristics and the population's access to care services are changing.

The cumulative number of patients alive and remaining in care at a set moment in time (in this study by 31 March 2012) is an important piece of public health information that indicates prevalent disease at the clinic (Harries *et al.* 2009b). This information helps the clinic staff to make rational logistic plans and forecasts for consumables and drugs. Adverse outcomes such as death and lost to follow-up reflect to some extent clinic acceptability and performance and also whether patients are accessing services early or late. Of more relevance to immediate management is the number of patients who failed to attend the clinic in the quarter. E-Health could be used to identify and flag these patients, and, with the use of mobile technology (Lester *et al.* 2010), attempts could be made to encourage patients to attend the next quarter so that continuity of care and uninterrupted drug intake are maintained. Of patients who did attend the clinic in the last quarter, about one quarter failed to have their blood pressure measured. At the moment, it is uncertain whether this reflects shortcomings in recording or non-adherence to UNRWA guidelines (UNRWA Health Department 2009), but on both counts the two pieces of data indicate a need for improved performance of either E-Health and/or patient management.

While the cumulative outcome report provides a useful cross-sectional analysis of the clinic programme at a set point in time, it is limited by the fact that the time periods of the E-health registered patients range from years (when patients were first entered into the E-Health system) to a few days (the latest patients being entered just before the censor date on 31 March 2012). This is the reason for the 12-month cohort outcome analysis that provides a much better assessment of treatment outcomes, clinical management performance and quality of control for a smaller group of patients registered over a three-month period, in this case 1 January to 31 March 2011, with outcomes assessed 12 months in the future. This is not strictly a 12-month outcome analysis as some patients are followed for up to 15 months, but in the context of routine monitoring, this is good enough to inform about programme performance. This cohort analysis is a useful way of assessing whether interventions as specified in UNRWA guidelines are being performed and whether blood pressure is being controlled. The number with late complications at 1 year after registration also provides a baseline assessment from which to compare serious morbidity during long-term follow-up in 2, 5 or 10 years time.

Table 6 Value of cohort report system for patients with HT in terms of service performance, quality of care and health status

	Measures of HT service performance	Outcome	Impact on health status
Quarterly cohort registration	Quarterly incidence of HT	Information on case detection (new and old) Rational planning for drugs	Better access to diagnosis and care Uninterrupted drug supplies
Cumulative cohort registration	Updated prevalence of HT	Information on disease burden Rational planning for drugs	Attention to risk factors to reduce future disease burden Uninterrupted drug supplies
Cumulative cohort outcomes	% attendance in last quarter % lost to follow-up and died % BP measured in last quarter	% complying with care % normal BP	Better hypertensive control Prevent late complications
12-month cohort outcome analysis	% BP measured % HT controlled % Assessed for diabetes % Assessed for high cholesterol % Assessed for raised creatinine	% Normal BP % Needing statins % Needing attention to renal care	Prevent late complications Prevent cardiovascular disease Prevent congestive cardiac failure Prevent strokes

HT, hypertension; BP, blood pressure.

UNRWA proposes to collect and report on these cohort data on a quarterly basis, and this will enable the programme to look at whether performance and disease control in later cohorts are improving. E-Health is essential for enabling this type of cohort analysis to work as using paper-based registers and cards to do manual calculation of cohorts and outcomes is too time-consuming and takes health staff away from patient care (Douglas *et al.* 2010). The experience also shows the advantage of embracing new E-Health technology in routine primary healthcare services. Time will tell whether the quarterly cohort reporting can be continued under the routine system and whether hitherto unrecognised difficulties become apparent over time. However, it is clear that where such electronic medical record systems are not in place, this type of cohort reporting may be too difficult and time-consuming to do using a paper-based record and this is a downside of the current approach.

In conclusion, the use of E-Health and cohort reporting is seen as a valuable monitoring tool for managing HT in Palestine refugees. UNRWA has decided to expand cohort analysis to the other PHC clinics in Jordan that already have E-Health as well as expand E-Health to all PHC clinics in the country and to other fields where UNRWA operates, namely West Bank, Gaza Strip, Lebanon and Syria. Doing so should ultimately lead to improved patient outcomes and better health status.

Acknowledgements

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Corresponding Author Anthony D. Harries, Old Inn Cottage, Vears Lane, Colden Common, Winchester SO21 1TQ, UK. Tel.: +44 1962 714 297; E-mail: adharries@theunion.org