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Chronic Oedema: a Prevalent Health Care Problem for UK Health Services

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Summary

Chronic oedema is a major clinical problem worldwide, which has many important secondary consequences for health, activity and participation. Effective treatment planning and organisation of services is dependent on an understanding of the condition and its epidemiology. This cross sectional study was designed to estimate the point prevalence of chronic oedema within the health services of one UK urban population and to determine the proportions that have concurrent leg ulceration.

Patients with chronic oedema were ascertained by health care professionals in one acute and one community hospital, all relevant out-patient and community nursing services, general practices and all nursing/residential homes in one urban catchment area (Derby City). The presence and distribution of oedema was confirmed through a brief clinical examination. A battery of demographic and clinical details was recorded for each case.

Within the study population of Derby City residents, 971 patients were identified with chronic oedema (estimated crude prevalence 3.93 per 1,000, 95% CI 3.69-4.19). The prevalence was highest amongst those aged 85 or above (28.75 per 1,000) and was higher amongst women (5.37 per 1,000) than men (2.48 per 1,000). The prevalence amongst hospital in-patients was 28.5%. Only 5 (3%) patients in the community population had oedema related to cancer or cancer treatment. Of the 304 patients identified with oedema from the Derby hospitals or community health services 121 (40%) had a concurrent leg ulcer.

Prevalence statistics and current demographic trends indicate that chronic oedema is a major and growing health care problem.

Introduction

Chronic oedema (CO) is a major clinical problem worldwide which has many important secondary consequences [1]. The term 'chronic oedema' is now commonly used in place of 'lymphoedema' as this encompasses all forms of oedema which persist for three months, irrespective of the aetiology [2]. CO is associated with many long term conditions such as cancer and diabetes. It is also related to reduced mobility and obesity, both of which are expected to escalate exponentially over the next 10-15 years due to population ageing [3,4]. Although CO has potentially life threatening consequences, the prevalence and impact of the problem remains poorly understood.

To date, the focus of previous research has been to estimate prevalence in specific patient groups [5, 6] however, since CO is the final common pathway for many conditions, it is important that prevalence is examined amongst heterogeneous populations. One earlier study of a mixed London based population, estimated the prevalence of CO to be 1.33 per 1,000 [2].

In order to understand the current scale of this health care problem, this study was designed to estimate the point prevalence and impact of CO amongst a heterogeneous population within the health services of one urban geographical area of the UK and to determine the proportions that have concurrent leg ulceration.

Methods

Setting and Sampling Frame

This cross sectional study was carried out in Derby City (UK) which has a population of approximately 247,100. Data were obtained from ten sources, namely: the in-patients of one acute and one community hospital, one specialist and three non-specialist out-patient clinics (dermatology, plastic surgery and diabetic foot clinic), all community nursing services, general practices (n=41) and nursing/residential homes (n=26) in the Derby City catchment area.

Case Ascertainment and Inclusion Criteria

People with CO were identified initially by an observational 'Pitting Oedema Test' [7]. The procedure has been shown to be valid and reliable [8] and is widely used in clinical practice. The test is carried out by pressing the thumb into the site of the swelling for 10 seconds. A positive result is indicated if a 'pit' remains following removal of pressure.

Oedema was judged to be chronic if it had been present for three months or more. Participants were also selected on the basis of the following criteria:

- children and adults of both genders and of any age or ethnicity
- patients who were residents of Derby City (as determined by home postcode)
- all patients accessible to staff for CO screening (this excluded patients in theatre, intensive care or maternity suites)

Core Data Set

The following core data set was collected for all patients identified with CO during March 2012:

- demographic details
- presence, site and history of CO, cellulitis (reported during the last six months) and leg ulceration (recorded for all body parts using a body map)
- presence and site of cancer related CO (or cancer treatment related CO)
- treatment currently received for CO

These data were collected using a standard questionnaire, the development of which has been described in full previously [2] and which is available on request. The feasibility of adopting the questionnaire in this setting was piloted initially to ensure the content was clear and the data could be completed in the time available. In all settings, clinicians were trained in the use of the questionnaire and the Pitting Test.

Data Collection Procedures

Staff in each case ascertainment setting screened all patients who consented to participate irrespective of the underlying disease or treatment regimen. A unique patient identification code was issued per person to avoid 'double counting' and all questionnaires were pre-printed with participant ID numbers. Master identifier lists were retained by each service manager to ensure anonymity was maintained and for data protection purposes.

Approval for the project was granted by the Research and Innovation Department of the Royal Derby Hospital, the Trust data protection and senior management teams.

The types and sources of data collected in each setting, the services contacted and the respective response rates are summarised in Tables 1 and 2.

Hospital in-Patients

All in-patients present at Royal Derby Hospital and London Road Community Hospital during a 48 hour period were reviewed for eligibility.

Patients were examined clinically to determine the presence of CO and this was repeated by a second independent assessor, to check the reliability of information obtained. Other core data were recorded using the questionnaire described above.

Specialist and Non-Specialist Out-Patient Services

The lymphoedema service database was searched to identify current patients who met the inclusion criteria. Additional information about BMI and aetiology were also recorded.

Patients attending non-specialist but related clinics were examined during a five day period to determine if they met the inclusion criteria. Clinic staff completed a questionnaire for each patient and undertook the clinical screening test.

Community Nursing Services and GP Practices

Clinicians in all community nursing teams and GP practices were asked to complete one questionnaire for each patient who met the inclusion criteria. Clinicians who did not respond initially were contacted one month later.

Nursing and Residential Homes

The managers of all social service and privately funded nursing and residential homes were asked to complete a questionnaire for each resident who met the inclusion criteria. Completed questionnaires were collected by the lead for tissue viability in community nursing services. Non responders were contacted one month later.

Data Analysis

Data quality checks were made by designated managers in each participating service. A study monitor carried out additional quality checks.

All data were imported into Stata 11 where descriptive statistics were undertaken. Age and gender specific rates were calculated based on the resident population. Direct standardisation was undertaken using a standard population of primary care organisations in England in 2010 to compare the rates from Derby and a previous study using similar methodology [2].

Results

Prevalence of Chronic Oedema in Derby City

In all, 992 patients living in Derby City were identified from the services studied. Of these, 21 patients did not have CO but were thought to be at risk of its development and were removed from the analysis. The remaining 971 patients had CO of greater than 3 months duration (Table 3). The mean age (SD) was 68.5 (16.5) years. The total crude prevalence was 3.93/1,000 population (95% CI 3.69-4.19) with a prevalence of 2.48 for men and 5.37 for women. There was an age gradient with a prevalence of 10.31 /1,000 in those aged over 65 to 74 rising further to 28.75 in those aged over 85 years of age.

Prevalence of Chronic Oedema and Leg Ulceration

Amongst the in-patient population, 453 people were assessed and this revealed that 129 (28.5%) people had CO. Twenty nine people in this group also had leg ulceration (22.5%). Amongst the community population, 175 patients were identified with swelling of whom 92 (52.6%) also had leg ulceration.

Proportion and Characteristics of Out-Patients Managed by the Specialist Lymphoedema Service

From the total population (n=971) of patients identified, 667 (69%) were being managed by the Specialist Out-Patient Lymphoedema Service. Four hundred and eighty nine people in this group were women (73%).

Based on the standard classification system used in this service, the largest patient group was found to have secondary oedema (n=246, 38%), followed by obesity and/or reduced mobility (n=169, 26%) (Table 4). Primary lymphoedema was diagnosed amongst 80 patients (12%).

A large proportion of patients for whom a BMI was available were obese or morbidly obese (n=251/361, 69.5%) (Table 5). The mean (SD) BMI was 35.5 (9.9) kg/m^2. The indices fell within the obese range (Class I and II) for 44% of the group, with a further 25% in Class III.

Cancer and Cellulitis

Only a minority of patients in the hospital in-patient (n=5, 4%) and community (n=5, 3%) setting had CO associated with cancer. Cellulitis was a common co-morbidity amongst community based patients with 105/175 (60%) having experienced at least one episode during the previous six months. Of these 23 (22%) people had been admitted to hospital for treatment of the infection. A total of 232 infections had been recorded for this patient group.

Discussion

Attempts to define the prevalence of CO in the general population are sparse [9] and most previous studies have relied on information which has been obtained from specific patient groups [5, 6, 10]. This study shows that the point prevalence of CO in a heterogeneous health service population is high and comparable to or greater than the prevalence of other serious long term conditions such as stroke. Patients were identified in all age categories and throughout the primary and secondary care sector.

Data obtained from this East Midlands study differ greatly from those obtained previously even though the same methods were adopted. In 2001 the London study indicated that the crude prevalence was approximately one third of that reported here [2] (Table 6). When standardised to the population of England this difference was reduced slightly to three times that observed in London, with adjusted rates for Derby City and South West London 4.15/1000 and 1.55/1000 respectively. It is unlikely that this difference can be attributed to methodological discrepancies or variations in the populations studied, as both samples were derived from an urban community. It is possible that differences in characteristics of the population other than age and gender such as obesity may be partially responsible for the higher prevalence, particularly as the elderly and obese have reduced mobility and often have long term conditions. Other findings were comparable to the earlier London study [2], for

example, the prevalence of CO was much higher amongst women than man. It was also more prevalent amongst the obese and was highest amongst people over 85 years.

Analysis of the subsets for which site of swelling was identified (889 patients identified) indicates that the proportion of patients with lower limb oedema was much higher in Derby City compared with South West London (Table 7). This may have occurred as a result of the higher awareness of CO locally or an increase in referrals of patients with lower limb oedema to the Derby service compared with South West London. If this is the case, some of the difference in overall estimated prevalence could be attributed to greater identification of lower limb oedema rather than a real increase in overall prevalence.

Nearly a third of the hospital in-patient population had CO which highlights that a number of conditions are associated with its occurrence and it can develop through a number of underlying pathophysiological mechanisms. This finding also dispels the commonly held belief that CO is confined to community based populations and services. Whilst it is well recognised that many community patients have venous leg ulceration, this study highlights that many of these cases have concurrent CO, an association which has received scant attention previously.

The East Midlands data support the hypothesis that obesity is a common problem amongst patients with CO in specialist services. Whilst it is not certain why CO and obesity co-exist, a number of mechanisms have been postulated. These include impaired lymphatic flow [11], chronic inflammation, elevated production of interstitial fluid and reduced mobility. Obesity is also implicated in the development of CO amongst people with cancer [10] and those with other long term conditions, particularly those who are wheelchair users. In a case record review of patients with spina bifida, for example, CO was common compared to the general population [12].

One limitation of this study is that comprehensive data could not be obtained from General Practices as diagnostic codes have not been created for CO in the UK health service. Poor recognition and limited knowledge of CO may have limited the number of patients identified, particularly in nursing/residential home settings where opportunities for continuing education are limited and the proportion of qualified staff is low. Of greater importance is the lack of awareness of CO amongst the general population, as this limits the number of people who present to health services. It is very difficult to estimate the true percentage of the population that have CO, particularly as symptoms can develop at a relatively late stage. A major strength of this study is that patients were surveyed in all public health service settings available to Derby City residents and all nursing/residential homes.

Although it is probable that the true prevalence of CO is even higher than estimated here, the findings of this study clearly illustrate that CO presents a major public health concern which has implications for the delivery of many health and social services.

Conclusions

Chronic oedema was found to affect approximately 4 per thousand in an East Midlands population. There was a clear rise in prevalence with increasing age and surprisingly nearly a third of in-patients had CO. Primary lymphoedema affected only a minority of patients known to a specialist service. In contrast, secondary causes of CO such as venous disease and immobility were common.

As this study was undertaken in an urban population with well-established lymphoedema services and adopted very similar methods to an earlier study conducted in London, it appears that the prevalence of CO has risen during the last decade and this could be attributable to population ageing and a concomitant increase in the prevalence of long term conditions. Applying the prevalence figures from this study would indicate that there are at least 240,000

patients affected by CO in the UK. Clearly, there is a need to undertake further studies using a variety of methodologies to determine how robust these estimates are in relation to different populations and in rural settings. Finally, since CO was prevalent in all health care settings surveyed, this highlights the importance of inter-agency collaboration, and the need for clinical pathways which span primary and secondary care sectors.

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Table 1: Type and Sources of Data Collected in each Setting

Data Sources	**Hospital Wards**	**Specialist Lymphoedema Out-Patient Service**	**Other Out-Patient Services**	**Community Services**
Case Ascertainment (clinical examination – 'Pitting test' for chronic oedema)	✓	✓	✓	✓
Demographic Details Clinical History (questionnaire)	✓	✓	✓	✓
Site of swelling (reported by health professionals)	✓	✓	✓	✓
Presence of Leg Ulceration (reported by health professionals)	✓	✓	✓	✓
Control of Swelling (reported by health professionals)	✓	✓	✓	✓
BMI (measured objectively when feasible)		✓		
Specialist classification of oedema (clinical examination)		✓		

Table 2: Prevalence of Chronic Oedema and Response Rate for Questionnaires Administered in each Service

Service	Number of Questionnaires Distributed or Sites Contacted	Number Responded	Response Rate %	Number of Patients Identified
Community Nursing Services	214	214	100	171
GP Practices	41	2	5	2
Nursing and Residential Homes	26	26	100	2
Specialist Out-Patient Lymphoedema Service	688	688	100	688[#]
Non-Specialist Out-Patient Services	4	0	0	0
Hospital In-Patients	453	453	100	129

Includes 21 patients at risk with no oedema present

Table 3: Ascertainment of Patients with Chronic Oedema by Age in a Derby City Population in 2012

	Age Group (years)	n	Population*		Estimated Prevalence (per 1,000)
Whole group					
	<5	1	16,700		0.06
	5-14	1	27,700		0.04
	15-44	81	108,200		0.75
	45-64	283	55,900		5.06
	65-74	199	19,300		10.31
	75-84	244	13,700		17.81
	85+	161	5,600		28.75
Total:		971[$]	247,100		3.93
				95%CI	(3.69-4.19)
Women					
	<5	1	8100		0.12
	5-14	1	13300		0.08
	15-44	55	53400		1.03
	45-64	197	27800		7.09
	65-74	129	9800		13.16
	75-84	169	7800		21.67
	85+	113	3700		30.54
Sub-total:		666[$]	123900		5.37
				95%CI	(4.98-5.79)
Men					
	<5	0	8600		0
	5-14	0	14400		0
	15-44	26	54800		0.47
	45-64	86	28100		3.06
	65-74	70	9500		7.37
	75-84	75	5900		12.71
	85+	48	1900		25.26
Sub-total:		305	123200		2.48
				95%CI	(2.21-2.77)

* Mid-2010 Population Estimates: Quinary age groups for Primary Care Organisations in England; estimated resident population (experimental) obtained from ONS data [13].

Rates given are per 1,000 population. [$] age missing in one patient.

Table 4: Underlying Cause of Chronic Oedema for Patients Attending The Specialist Out-Patient Lymphoedema Service

Classification / Underlying Cause	Number	Percent
Secondary oedema	246	38
Obesity / reduced mobility	169	26
Primary lymphoedema	80	12
Venous disease	60	9
Other	43	7
Oedema of advanced cancer	13	2
Lipoedema	8	1
Heart Failure	7	1
Awaiting diagnosis/classification	24	4
Total	651	
Missing	16	

Table 5: Body Mass Index (Kg/m^2) and Risk of Co-Morbidities

BMI Range	Classification	Risk of ** Co-Morbidities	Frequency (n=361)	Percent
18.5-25.0	Normal Range	Average	48	13
25-29.9	Overweight	Mildly Increased	62	17
30-39.9	Class I / II	Moderate/ Severe	160	44
40+	Class III	Very Severe	91	25

** Mean Body Mass Index Situation and Trends [14]

Table 6: Estimated Prevalence of Chronic Oedema Assessed[1] in Two Urban Populations[2] and Decades[3]

	Derby (2012)			West London (2001)		
Age Group (years)	n	Population	Prevalence (per 1,000)	n	Population [4]	Prevalence (per 1,000)
Women						
<5	1	8100	0.12	0	21100	0
5-14	1	13300	0.08	1	32300	0.03
15-44	55	53400	1.03	69	150600	0.46
45-64	197	27800	7.09	249	61500	4.05
65-74	129	9800	13.16	117	24600	4.75
75-84	169	7800	21.67	141	18700	7.53
85+	113	3700	30.54	106	9000	11.73
	665	123900	5.37	683	317800	2.15
Men						
<5	0	8600	0	0	21900	0
5-14	0	14400	0	0	34100	0
15-44	26	54800	0.47	14	153300	0.09
45-64	86	28100	3.06	33	59000	0.56
65-74	70	9500	7.37	38	19100	1.99
75-84	75	5900	12.71	39	10600	3.68
85+	48	1900	25.26	16	2800	5.75
	305	123200	2.48	140	300800	0.47
Total: [5]	970	247100	3.93 (4.15)	823	618600	1.33 (1.55)

1 The same procedures were adopted in each instance
2 West London and Derby City, UK
3 2001 and 2012
4 Estimated population data have been rounded to the nearest 100 patients for consistency with Derby results. The total population is therefore slightly different from that reported in the original paper [7]
5 Standardised rates adjusted to the population of England in 2010 [13] are given in parentheses

Table 7: Site of swelling

Study	Upper Limb Oedema	Lower Limb oedema
Derby City	177/889 (19.9%)	745/889 (83.8%)
SW London	334/823 (40.5%)	476/823 (57.8%)