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Lymphoedema: an underestimated health problem

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Summary

Background: Lymphoedema/chronic oedema is an important cause of morbidity in the population, but little is known of its epidemiology and impact on patients or health services.

Aim: To determine the magnitude of the problem of chronic oedema in the community, and the likely impact of oedema on use of health resources, employment and patient's quality of life.

Design: Questionnaire-based survey.

Methods: Health professionals from dedicated lymphoedema services, specific out-patient clinics, hospital wards and community services (GP clinics and district nurses) were contacted to provide information on patients from within South West London Community Trust. A subset of the identified patients was interviewed.

Results: Within the catchment area, 823 patients had chronic oedema (crude prevalence 1.33/1000). Prevalence increased with age (5.4/1000 in those aged > 65 years), and was higher in women (2.15 vs.

0.47/1000). Only 529 (64%) were receiving treatment, despite two specialist lymphoedema clinics within the catchment area. Of 228 patients interviewed, 78% had oedema lasting >1 year. Over the previous year, 64/218 (29%) had had an acute infection in the affected area, 17/64 (27%) being admitted for intravenous antibiotics. Mean length of stay for this condition was 12 days, estimated mean cost £2300. Oedema caused time off work in >80%, and affected employment status in 9%. Quality of life was below normal, with 50% experiencing pain or discomfort from their oedema.

Discussion: Chronic oedema is a common problem in the community with at least 100 000 patients suffering in the UK alone, a problem poorly recognized by health professionals. Lymphoedema arising for reasons other than cancer treatment is much more prevalent than generally perceived, yet resources for treatment are mainly cancer-based, leading to inequalities of care.

Introduction

Lymphoedema is a chronic condition characterized by oedema, usually of one or more limbs and in some cases involving the trunk, head or genital area.

While it is acknowledged as a serious complication following treatments for cancer, there has been little appreciation that lymphoedema may affect many

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other types of patient where the cause is not oncology-related, and provision of care has focused on patients following treatment for cancer. There is no proven drug treatment for lymphoedema. Management aims to reduce or delay the progression of swelling and prevent associated infection. This is usually achieved using a combination of skin care, external pressure (bandaging or hosiery), isotonic exercise and massage.^{1,2} The proof of concept for using physical means to stimulate a failing lymph drainage has a sound physiological basis, but the quality of evidence on the relative effectiveness of therapies is poor. Few randomized controlled trials have been published, and none has evaluated patients' treatment preferences or effects on quality of life.³

At present, service delivery is based on the relationship of lymphoedema with cancer, and patients with other forms of lymphoedema are often denied access to care. As part of the National Service Framework for cancer services, lymphoedema treatment is highlighted for provision.⁴ This two-tiered system has developed due to a lack of appreciation of the true prevalence of lymphoedema within the general population, leading to lymphoedema being a low priority in an already over-stretched health service.

It is difficult to make recommendations about service delivery when little is known about either the magnitude of the problem or the deficits of care. Current epidemiology estimates are based frequently on small selected populations with specific clinical problems such as breast cancer.⁵ Little is known of the numbers of patients being managed in general practice or by community services. Many of the existing lymphoedema services are based in hospices or oncology departments of acute hospitals, by their nature restricting access to other patient groups. The patients' representative body, the Lymphoedema Support Network (LSN), has identified major deficits in care delivery across the country.⁶ Anecdotal reports suggest that patients travel many miles for diagnosis and treatment of their problem.

The present study is the first stage of a strategy to develop effective lymphoedema services within the UK, using best available evidence on cost-effective care. The objective of this epidemiology study was to identify all patients with chronic oedema, likely to be lymphoedema, of >3 months duration who were known to, or being treated by, health professionals within a specified geographical area at the time of survey. Ideally, the diagnosis of lymphoedema is made on clinical grounds and confirmed by lymphoscintigraphy.⁷ For the purposes of this epidemiological study,

lymphoscintigraphy on all suspected cases was impractical and therefore the diagnosis was made according to set clinical criteria, namely: (i) persistent oedema of >3 months duration; (ii) minimal response to overnight elevation or diuretics; and (iii) the presence of skin changes indicating early elephantiasis (thickened skin, hyperkeratosis and papillomatosis). Criticism that chronic oedema due to other aetiologies was included can be defended on the basis that (a) patients with systemic disorders likely to cause oedema, e.g. acute heart failure, were excluded from the study and (b) all other forms of oedema, whatever the underlying cause, are due to an imbalance between capillary filtration and lymph drainage.⁸ Increases in filtration should be compensated for by an increase in lymph drainage. Any oedema therefore implicates the lymphatic system to some extent, even though it may not be primarily at fault.⁹

Methods

The research partnership included clinicians, researchers, organisational consultants and the LSN, who shared responsibility for the development and delivery of the project. The study was carried out in the former South West London Community Trust (SWLCT) in 2000. At the time of study, the Trust was responsible for delivering care to a population of approximately 619 000, of whom 14% were over the age of 65, and 15% were from ethnic minority groups. In addition to the community services, the area was served by two specialist lymphoedema services (St George's Hospital and the Royal Marsden Hospital, Fulham Road and Sutton). Acute general services were also provided by St Helier and Epsom Hospitals and Care of the Elderly at Bolingbroke and Epsom Hospitals. All local ethics committees were contacted and gave consent for the study to be undertaken in their clinical areas.

Case ascertainment

Aim

The aim of the case ascertainment was to identify all patients with chronic oedema/lymphoedema receiving care or known to health professionals within the geographical area bounded by South West London Community Trust. An expert panel of lymphoedema specialists defined chronic oedema/lymphoedema using the following definition: '*Chronic oedema is a broad term used to describe oedema which has been present for more than 3 months and involves one or more of the following areas: limb/s, hands/feet, upper body (breast/chest,*

shoulder, back), lower body (buttocks, abdomen), genital (scrotum, penis, vulva), head, neck or face. Oedema which develops as a result of a failure in the lymphatic system is referred to as lymphoedema but chronic oedema may have a more complex underlying aetiology. At this stage we do not expect to make a differential diagnosis but need to record the actual numbers of people with oedema suggestive of chronic oedema/lymphoedema, even if a medical diagnosis has not been confirmed.'

The clinicians were asked to identify patients based on these criteria. Many of the patients had been previously diagnosed with lymphoedema by virtue of past cancer treatment or investigation by a lymphoedema clinic.

A process of consultation was undertaken with relevant managers and staff prior to the formal identification process. As part of the process, community clinical staff were involved in designing and piloting the questions used. A proforma was designed to identify all patients suffering from chronic oedema/lymphoedema. The information requested included simple demographic details and GP contact details. The site of oedema was identified using a diagram of anterior and posterior views of the body and tick boxes. Questions relating to the definitions of lymphoedema were asked, including duration of oedema, complete resolution overnight or on elevation, and proven diagnosis or treatment for lymphoedema. Professionals were asked to describe whether treatment was provided, and if so, what treatments were used for these patients. A subjective assessment of whether the clinician felt the patient's oedema was well controlled or not was also included.

Study design

The questionnaire was sent to all health professionals within the area. Apart from community and acute trust staff this included all private and social service residential nursing homes and day care centres, hospice units and private lymphoedema practitioners. Named staff were contacted to ensure completeness of data. In addition, the acute services were visited, and all patients on wards assessed for inclusion into the study, with each hospital assessed over a two-week period using a trained research team. Designated out-patient clinics were identified, and patients attending these were screened for inclusion. The specialist lymphoedema services at St George's and Royal Marsden Hospitals provided additional data from their patients' notes and database systems. To avoid double counting, an individual patient coding system was developed. Each patient's postcode was found to ensure that

all patients identified were living within the boundaries of the study area. The recording of postcodes allowed for evaluation of patients attending the two national centres who fell outside the immediate catchment area. Three weeks after the initial contact, the returned forms were checked to identify health professionals who had failed to respond. A further contact was made either by telephone or by a clinical visit to ensure completeness of data. Patients were entered on to a dedicated database. A further check was made to ensure completeness of data, and professionals were re-contacted to provide missing data.

Clinical interviews

Within this study, there was an opportunity to interview patients who attended for care over a four-week period. While this group of patients may not truly reflect the population suffering from lymphoedema, the interviews allowed for a detailed examination of some of the key issues in lymphoedema management. This process also allowed us to profile patients in terms of their clinical and psychosocial status.

Questionnaire design

A questionnaire was developed by the research group following a literature search of methods of assessing lymphoedema outcomes and their validity in clinical populations. The first section aimed to clarify the presence of lymphoedema and consisted of: demographic and socio-economics; details of oedema and complications; and clinical examination (clarification of proven lymphoedema and volume measurement of affected limbs). After physical examination, patients without lymphoedema did not progress further in the study. The second section was completed for patients with proven lymphoedema, and consisted of: medical history; the McGill short form pain assessment tool;¹⁰ treatment history and use of health resources; and the SF-36.¹¹

Lymphoedema specialists trained the clinical research team in questionnaire administration and in the clinical measurements.

The research team were able to interview all patients who attended the acute services on the wards and patients attending community services over a four-week period with concurrent lymphoedema. Many patients identified in the specialist lymphoedema out-patient services were not attending for treatment during the four-week period, and were not interviewed.

Statistical analysis

Information from all questionnaire responses was entered into a database system, and when complete, downloaded to SPSS for analysis. Calculation of age-specific rates used information on the catchment population provided by the Trust. Comparative analysis of the SF-36 was undertaken using previously published normative data,^{12,13} the results being expressed as mean differences with 95% CIs.

Results

Case ascertainment

In all, 1609 patients were identified, of whom 1578 had oedema present for >3 months, and of whom 823 (52%) were resident in the study area. Mean (SD) age was 66.9 (16.5) years with 683 (83%) women. The total crude estimated prevalence was 1.33/1000 population (Table 1). There was a clear age gradient, with a prevalence of 5.4/1000 in those aged >65 years, and 10.3/1000 in those aged >85 years. Ninety percent of men presented with leg oedema, compared with only 51% of women. Conversely, 48% of women suffered from arm oedema compared with only 6% of men (Table 2). The clinical services that were contacted and the proportion of respondents are shown in Table 3.

Table 1 Ascertainment of patients with chronic oedema/lymphoedema by age within South West London Trust

Age (years)	<i>n</i>	Population	Prevalence (per 1000)
<i>Total group</i>			
<5	0	42 967	0
5–14	1	66 407	0.02
15–44	83	303 980	0.27
45–64	282	120 534	2.35
65–74	155	43 660	3.55
75–84	180	29 287	6.14
85+	122	11 822	10.31
Total	823	618 657	1.33
<i>Women</i>			
<5	0	21 110	0
5–14	1	32 290	0.03
15–44	69	150 645	0.46
45–64	249	61 522	4.05
65–74	117	24 609	4.75
75–84	141	18 701	7.53
85+	106	9037	11.73
Total	683	317 914	2.15
<i>Men</i>			
<5	0	21 857	0
5–14	0	34 117	0
15–44	14	153 335	0.09
45–64	33	59 012	0.56
65–74	38	19 051	1.99
75–84	39	10 586	3.68
85+	16	2785	5.75
Total	140	300 743	0.47

Table 2 Oedema of arms and legs, by age and gender

	Male	Female	Total
<i>Arm oedema</i>			
<5	0 (–)	0 (–)	–
5–14	0 (–)	0/1 (0)	0
15–44	0/14 (0)	27/69 (39.1%)	27/83 (32.5%)
45–64	2/33 (6.1%)	165/249 (66.2%)	167/282 (59.2%)
65–74	3/38 (7.9%)	73/117 (62.4%)	76/155 (49.0%)
75–84	4/39 (10.3%)	44/141 (31.2%)	48/180 (26.7%)
85+	0/16 (0)	16/106 (15.1%)	16/122 (13.1%)
Total	9/140 (6.4%)	325/683 (47.6%)	334/823 (40.6%)
<i>Leg oedema</i>			
<5	0 (–)	0 (–)	–
5–14	0 (–)	1/1 (100%)	1/1 (100%)
15–44	13/14 (92.8%)	44/69 (63.8%)	57/83 (68.7%)
45–64	29/33 (87.9%)	76/249 (30.5%)	105/282 (37.2%)
65–74	35/38 (92.1%)	41/117 (35.0%)	76/155 (49.0%)
75–84	35/39 (89.7%)	98/141 (69.5%)	133/180 (73.9%)
85+	14/16 (87.5%)	90/106 (84.9%)	104/122 (85.2%)
Total	126/140 (90.0%)	350/683 (51.2%)	476/823 (57.8%)

Table 3 Services contacted and respondents to case ascertainment

	Contacted (% response)	Patients identified
<i>St George's Hospital</i>		
Lymphoedema Service	2 (100%)	325 (39%)
Dermatology	1 (100%)	45 (6%)
Specialist Nurse		
Leg ulcer service	3 (100%)	43 (5%)
Physiotherapy	1 (100%)	3
Occupational therapists	1 (100%)	1
<i>Other hospital services</i>		
Royal Marsden Hospital	2 (100%)	125 (15%)
St Helier	1 (100%)	48 (6%)
Epsom	1 (100%)	5
Hospices	2 (100%)	0
<i>Community services</i>		
District Nursing teams	50 (100%)	184 (22%)
GPs and practice nurses	50 (78%)	24 (3%)
Nelson Hospital	1 (100%)	4
Community podiatry	1 (100%)	3
Community physiotherapy	1 (100%)	0
Macmillan nurses	3 (100%)	6
Nursing home	–	2
Elderly surveillance	1 (100%)	1
Other/missing	–	5

Patient sources

Only 529/823 (64%) were receiving treatment for their lymphoedema. Of the total 445/823 (54%) patients were seen by specialist lymphoedema practitioners. Sixty-one (12%) were receiving care from community services alone. Patients were also treated by a number of acute hospital departments, including dermatology and vascular surgery departments (128, 24%).

Treatment provision

Skin care (88%) and elastic hosiery (82%) were the most commonly used treatments. However, patients treated by community services would only have access to hosiery available through the Drug Tariff and not the specialist garments required for lymphoedema care. Despite the value of exercise in the control of lymphoedema, only 53% patients were using exercises in their management. Although 13% patients were receiving bandaging, this picture is likely to be obscured by the numbers of patients receiving below-knee bandaging designed for leg ulcer treatment rather than lymphoedema bandaging regimens. Manual lymph drainage was rarely used (4%), but self-massage was more frequent

Table 4 Control of oedema, by gender, age, site and treatment

	Controlled	Not controlled	Don't know
<i>Gender</i>			
Female	427 (62.5%)	179 (26.2%)	77 (11.3%)
Male	62 (44.3%)	56 (40.0%)	22 (15.7%)
<i>Age (years)</i>			
0–44	70 (83.3%)	10 (11.9%)	4 (4.8%)
45–64	199 (70.6%)	40 (14.2%)	43 (15.2%)
65–74	98 (63.2%)	37 (23.9%)	20 (12.9%)
75–84	81 (45.0%)	76 (42.2%)	23 (12.8%)
85 +	41 (33.6%)	72 (59.0%)	9 (7.4%)
<i>Site</i>			
Arm	284 (85.0%)	14 (4.2%)	36 (10.8%)
Leg	200 (42.0%)	221 (46.4%)	55 (11.6%)
<i>Treatment</i>			
Treated	412 (77.9%)	59 (11.2%)	58 (11.0%)
Not treated	74 (29.4%)	169 (67.1%)	9 (3.6%)

(17%). Three percent of patients were receiving psychological support. Diuretics were used in 8% patients despite their lack of effect in the treatment of lymphoedema.

Health professionals considered control of swelling to be better in women compared with men (62.5% vs. 44.3%) (Table 4). In the youngest age group (<45 years), only 11.9% were reported to have uncontrolled oedema. This increased with age to 59.0% in those aged >85 years. Professionals reported that patients with arm oedema experienced better control than patients with leg oedema (85.0% vs. 42.0%). Nearly 80% of patients who were being actively treated for their lymphoedema had control, compared with just 29.4% in those not being offered treatment.

Clinical interviews

A total of 239 patients were interviewed, of whom 11 were found not to be suffering from lymphoedema on clinical examination, and were excluded from the analysis. This would suggest that prevalence may be overestimated during the case ascertainment by the same proportion. The total number of patient interviews was therefore 228.

Demographics and details of oedema

As with the case ascertainment, patients were elderly with mean (SD) age of 71.4 (16.6) years; 170 (75%) were women. A high proportion (97, 44%) were widowed, with 114 (51%) living alone. Over half were owner-occupiers (51%), with 73%

retired. In all, 85% had an income <£15 000 per year.

Of the patients interviewed, just 36 (16%) were suffering from arm oedema compared with 189 (83%) with leg oedema. This compares with 334 (41%) and 476 (58%) in the ascertainment study. The difference in patient groups was also seen for gender with 75% women in this part of the study, compared with 83% in the ascertainment. This difference is probably a reflection of the difference between those patients receiving care during the interview period and the overall population of patients suffering from lymphoedema within the community. Nine patients (4%) had oedema of another body part. In all, 169 (78%) had oedema present for longer than one year, of whom 71 (33%) had oedema for >10 years.

Fifty-seven (25%) suffered from oedema related to cancer therapy. Oedema following cancer treatment occurred rapidly in many patients, with 15/48 (31%) who could recall this experienced oedema within 3 months of treatment and a further seven (15%) experienced it within 1 year. Only three patients developed oedema >10 years after their cancer therapy. When directly questioned about their diagnosis, 124 (54%) had never been told the reason for their oedema.

Use of health-care resources

Few patients had undergone specialist investigations to confirm a diagnosis of lymphoedema, with just 16 patients having undergone a lymphangiogram and 15 having lymphoscintigraphy. In all, 137 of 201 respondents (68%) stated that they had used compression hosiery, although 24% had received it, but never worn it. Only 11/208 respondents (5%) had ever received manual lymphatic drainage, despite this being considered a cornerstone of effective lymphoedema treatment.^{1,2} Approximately one third (81/203) of all patients were currently receiving bandaging of the affected limb, although the majority of these were elastic regimens used in the treatment of venous leg ulceration, rather than the recommended short-stretch multi-layer lymphoedema bandaging. When bandaging was undertaken, it was for prolonged periods, with a median duration of 9 months.

Acute infections and medical admissions

In all, 64/218 (29%) of patients had experienced at least one acute infection in the affected area over the previous year, with 16 experiencing >3 episodes during this time. Of those experiencing acute infections, 17/64 (27%) were admitted for intravenous antibiotics. Over the duration of their

oedema, 33 (15%) had experienced at least one hospital admission for their oedema. The mean length of stay was 12 days, with an estimated cost of hospital stay of £2300.¹⁴

Employment

Over 80% of patients (188/217) had taken time off work due to their oedema, with an estimated mean time off work of 10.5 days for medical appointments. Overall, 9% stated that the oedema affected their employment status, with 4/209 (2%) respondents having to change jobs because of their oedema, and 17/209 (8%) having to give up work because of it.

Pain and quality of life

Despite the popular belief that lymphoedema is not painful, one half of patients (50%) stated that they experienced pain or discomfort from their oedema, with 56% of these taking regular prescribed analgesia. Most common pain symptoms were those of aching (36%), heaviness (33%) and tenderness (29%). For those who reported pain, the median score on the McGill visual analogue scale (0–10) was 4.2 (IQR 2.8–6.5). While 28% of these with pain reported it to occur most frequently at night, 38% felt that it was changeable in nature.

Comparison of scores of the SF-36 in these patients with published normative data showed clear deficits in all sub-scores of the SF-36, with the exception of mental health and general health scores. The largest mean differences (*d*) occurred in role physical (*d*=27.1, 95% CI 20.9–33.3), role emotional (*d*=25.5, 95% CI 18.9–32.1), social functioning (*d*=23.1, 95% CI 18.1–28.2) and physical functioning (*d*=21.5, 95% CI 17.0–26.0). All of these differences were significant at the *p*<0.001 level.

Discussion

This study shows that chronic oedema/lymphoedema is a common but under-reported condition, with a prevalence similar to other conditions such as leg ulceration. There are clear parallels to be drawn from the two conditions. The identification of the magnitude of the leg ulcer problem stimulated the development of national service provision for this patient group, through changes in policy and the development of the NSF for elderly care.¹⁵ With cancer-related lymphoedema, there are recommendations for service provision within the NSF for Cancer services, but little reference to it in the Cancer Plan or Manual for Cancer

Studies.^{4,16,17} However, this study shows that care is poorly provided for patients with non-cancer-related lymphoedema. There is a clear need for an integrated approach to care provision for this patient group.

While chronic oedema/lymphoedema can occur at any age, there was a clear increase in rate with age. Over the age of 65, the prevalence was 1 : 200. There was also a clear gender difference, with 83% of all patients identified being women. The difference between men and women is not explained purely by arm oedema related to breast cancer, as the prevalence of leg oedema was more than double in women compared to men.

Due to the difficulties in making a definite diagnosis of lymphoedema, we chose to provide health professionals with a clear working definition of chronic oedema, which included its presence for >3 months. Of the 823 patients, only 29 (4%) experienced resolution of their oedema during bed rest or elevation, supporting the presence of lymphoedema. In the clinical interviews, 78% of patients had oedema present for >1 year, and 34% for >10 years indicating that these patients have chronic oedema rather than a transient problem.

The ascertainment of patients through health professionals is limited, in that it may underestimate the true prevalence of a condition, as patients may not be receiving care for their condition. However, we can use the prevalence of arm lymphoedema as an indication of the under-reporting using this method. In the UK, it is estimated that 160 000–200 000 patients have had a diagnosis of breast cancer.¹⁸ While there are a range of prevalence figures for arm oedema in patients with breast cancer,^{5,19–21} we have assumed that approximately 29% will have arm oedema.¹⁹ The results from this study were chosen since it was carried out within the same area of south-west London. Using these figures, some 1696–2120 women in south-west London should have a history of breast cancer, of whom 490–615 would have breast-cancer-related lymphoedema (BCRL). In the present study (using arm oedema as a proxy for BCRL) we have identified 325 women with arm oedema. It is therefore likely that we have underestimated prevalence of arm oedema in this population by between 33% and 47%. While it is likely that a slight over-estimation will occur due to incorrect classification (4% in the present study), this effect is small in comparison with the predicted under-estimation of numbers. Also, patients with BCRL are likely to be better provided for than other non-cancer-related lymphoedema, so our estimates of prevalence are likely to considerably underestimate the problem.

A key finding of this project has been the impact that lymphoedema has on many aspects of patients' lives. One third had experienced an acute infection over the previous year, with 14 patients having more than three episodes, and 16 requiring admission for intravenous antibiotics. The combined effects of these episodes are likely to have a major impact on the patients' quality of life, as well as a clinical deterioration due to further lymphatic damage. While the acute complications associated with lymphoedema will cause major disruptions to daily life, there was clear evidence that even in the chronic phase, patients experienced significant deficits in quality of life, with particular emphasis on their ability to function physically and socially, and the emotional consequences of their condition. Despite professional perceptions that lymphoedema is not associated with pain, one half of all patients stated that they were experiencing pain or discomfort from their oedema. There was clear evidence that the condition affected their ability to work, forcing some to give up work completely, or take periods away from work for treatment.

The study showed major deficits in care provision for patients with lymphoedema, with only 64% reported to be receiving any treatment, this despite better provision of lymphoedema services within the catchment area. Nearly one half of all patients identified in this study seen in the specialist lymphoedema centres came from outside the local catchment area. This highlights the national problem that patients face of receiving care locally. Patients in this study came from as far as Ireland, Scotland and the Channel Islands. Set against the background that patients in the community were receiving sub-optimal care, these findings support the need for improved service provision. Evidence on reported treatment during the case ascertainment, showed that the cornerstones of treatment (bandaging and manual lymph drainage) were infrequently used. The type of hosiery prescribed was linked to the service provider, with community patients unable to access specialized garments. Inappropriate treatments such as diuretics were considered treatment options, indicating a lack of knowledge. Despite the obvious quality of life issues raised in this study, practitioners reported only 3% of patients received psychological support as a treatment strategy.

This study aimed to define the problem of chronic oedema/lymphoedema in the population. Rationalization of services will require a careful classification of the different types of lymphoedema in order to ensure that appropriate care is provided to all the patient groups, ranging from those at genetic risk

of developing the condition, through to those with severe complicated elephantiasis. The evidence base on the management of lymphoedema is currently weak and further work is required to assess the best practice and cost effectiveness of different management regimens.

Service development must seek to incorporate the specialist component of practice while introducing lymphoedema management into mainstream service provision to avoid the current two-tiered system for cancer and non-cancer patients. The high prevalence of chronic oedema and the cost implications, particularly from admissions for infection cannot be ignored by health planners in the future.

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