Scabies outbreaks in residential care homes: factors associated with late recognition, burden and impact. A mixed methods study in England

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SUMMARY

Scabies is an important public health problem in residential care homes. Delayed diagnosis contributes to outbreaks, which may be prolonged and difficult to control. We investigated factors influencing outbreak recognition, diagnosis and treatment, and staff experiences of outbreak control, identifying areas for intervention. We carried out a semi-structured survey of managers, affected residents and staff of seven care homes reporting suspected scabies outbreaks in southern England over a 6-month period. Attack rates ranged from 2% to 50%, and most cases had dementia (37/39, 95%). Cases were diagnosed clinically by GPs (59%) or home staff (41%), none by dermatologists. Most outbreaks were attributable to avoidably late diagnosis of the index case. Participants reported considerable challenges in managing scabies outbreaks, including late diagnosis and recognition of outbreaks; logistically difficult mass treatment; distressing treatment processes and high costs. This study demonstrates the need for improved support for care homes in detecting and managing these outbreaks.

Key words: Ectoparasites, occupation-related infections, outbreaks, public health, scabies.

INTRODUCTION

Scabies is an important source of morbidity in residential care homes for the elderly, where outbreaks are common, and control is challenging [1–3]. It is caused by a mite, Sarcoptes scabiei, which is transmitted via direct skin-to-skin contact, or occasionally by fomites [3]. Scabies is common in tropical and subtropical countries where it is associated with poverty and overcrowded living conditions. Large epidemics are associated with war, poverty, overcrowding and poor hygiene [4]. In developed countries those most vulnerable to scabies infestation are the young, elderly and immunosuppressed, and outbreaks are seen in institutions such as schools and residential care homes. People who are incapacitated, particularly due to dementia, are at particularly high risk of acquiring scabies [5, 6]. Within care homes, unrecognized cases of scabies are a frequent source of transmission to other residents and staff due to their atypical presentation, particularly of the highly infectious crusted ‘Norwegian’ form [7]. Outbreaks in these settings tend to go on for several months, with a median duration of 120 days in one review, and can have very high attack rates, ranging from 15% to 93% [6]. Controlling outbreaks of scabies is particularly challenging in institutions caring for people with dementia, due to
communication difficulties and patient behaviours such as ‘wandering’ contributing to transmission [8].

Outbreak control in institutional settings requires a carefully coordinated response including mass treatment of all cases and contacts. Public Health England (PHE) is the national agency responsible for communicable disease control in England. PHE provides outbreak management advice via local Health Protection Teams (HPTs), which cover a set geographical area and work alongside the National Health Service (NHS) and local authorities to provide specialist support for communicable disease control. General Practitioners (GPs) are generally responsible for the treatment of scabies in the community; however, specialist dermatology services are provided at many hospitals and may be involved in the care of severe cases of crusted scabies.

Community health service provision varies geographically, but all services in England registered under the Health and Social Care Act 2008 are expected to have an outbreak control policy, which is usually developed with the local Infection Control and Prevention Team. Outbreak management is the joint responsibility of the care home provider, Community Infection Control teams, GPs, PHE, and others as required. The Care Quality Commission regulates homes but does not provide specifications for how homes should manage problems relating to scabies.

Department of Health infection control guidance for care homes states that managers should inform their local HPT if they suspect an outbreak of an infection [9]. However, this guidance is primarily designed for bacterial or viral outbreaks, and there is no legal requirement for GPs or care home managers to notify scabies outbreaks, although this is recommended. The guidance briefly refers to scabies, but does not include specific details of responsibility, other than to say that the Community Infection Prevention and Control Practitioner (CIPCP) can advise on how to coordinate mass treatment; however, these practitioners are not available in every area. HPTs provide practical advice but are not responsible for routine infection prevention and control in care homes.

There is no national guidance for the public health management of scabies outbreaks in residential care homes in England and individual HPTs generally develop their own guidance. In Surrey and Sussex, in south east England, mass treatment of all residents, staff and household contacts of staff cases is recommended regardless of symptoms, with two applications of scabicide lotion (permethrin or malathion) 7 days apart, which is the standard treatment for uncomplicated scabies. Some other HPTs recommend only one treatment for asymptomatic contacts. The lotion is applied to the whole body (including genitals) and is washed off after several hours, and all those included should be treated on the same day. This is a substantial undertaking in an institutional setting with a large number of residents, and is potentially embarrassing and distressing for all concerned, particularly those with dementia. The logistical aspects of coordinating a mass treatment exercise of this nature, and the economic implications, can be substantial [10].

A Cochrane review in 2010 recommended topical permethrin for scabies treatment, but concluded that oral ivermectin also appears to be effective, although it is not licensed in many countries, including the UK [11]. In this setting ivermectin would have the advantage of ease of use, requiring a single oral dose, as opposed to one or more applications of topical treatment.

Scabies is not a notifiable disease in the UK and routine epidemiological data are limited. Most studies rely on GP consultation rates, which likely underestimate the incidence of scabies due to underreporting and self-treatment. Studies report substantial geographical variation in the incidence of scabies, with the highest rates seen in urbanized areas, and some seasonality, peaking in the winter months [12]. Incidence is generally highest in groups with high levels of personal contact [13]. GP consultation data for 1997–2005 show that incidence in England is highest in children and young adults and generally declines with age, but rises again in those aged >80 years [14]. The same data show a higher risk of scabies in women than men (relative risk 1·24, \( P < 0·001 \)). An earlier national study estimated the annual incidence of scabies at between 233–470/100 000 person-years from 1994 to 2003, with similar age- and sex-specific patterns [13].

Scabies is usually diagnosed in these settings on the basis of clinical signs and symptoms, or less commonly by microscopic examination of skin scrapings, or dermatoscopy to examine skin lesions. Early diagnosis of scabies can be difficult, and misdiagnosis is a problem in outbreak situations, even when dermatologists are involved [15]. Scabies in immunocompromised and elderly patients can be particularly difficult to diagnose as it may present atypically [5].
and this can lead to late recognition of outbreaks in care homes [16]. Scabies can be complicated by secondary bacterial infection with Staphylococcus aureus and group A streptococci, a particular concern for vulnerable care home residents.

We describe a series of scabies outbreaks in residential care homes in Surrey and Sussex, England. We investigated the factors influencing the recognition of outbreaks in this setting, delays in diagnosis and treatment of cases and the experience of staff dealing with outbreak control.

METHODS

Design

This is a prospective mixed methods study investigating a series of suspected scabies outbreaks in residential care homes, exploring barriers to early recognition and optimal management.

Ethical considerations

This work was carried out as part of a service evaluation to optimize advice and inform practice locally, so ethical review was not required.

Setting

All residential care homes in Surrey and Sussex with outbreaks of scabies occurring between November 2012 and April 2013 were eligible for inclusion. Those which reported outbreaks to Surrey and Sussex HPTs during this time were invited to participate. There are 1194 registered care homes in Surrey and Sussex (458 in Surrey, 386 in West Sussex, 350 in East Sussex), of which 411 (34%) offer specialist care for people with dementia.

Participants

During the study period eight outbreaks of scabies in care homes were reported to the HPT. All eight care homes were invited, and seven agreed to participate in the study.

Recruitment

Homes were recruited on the basis of having reported an outbreak of scabies to the HPT. The outbreaks were all managed by the HPT according to usual practice, which involves provision of advice over the telephone regarding mass treatment and infection control measures, and regular follow-up until the outbreak is declared over. The investigator was undertaking training at the HPT at the time of the study but was not involved in the management of these outbreaks.

Once the HPT had provided their initial advice, details were passed to the investigator, who contacted the home to arrange a data collection visit. Visits were made as soon as possible after the outbreak was reported, at a convenient time agreed with the home management.

Case definitions

Outbreak. A report of two or more clinically suspected cases of scabies in a residential care home in Surrey or Sussex, reported to the Surrey and Sussex HPTs by a GP or care home manager between 1 November 2012 and 30 April 2013.

Resident case. A clinically suspected case of scabies in a resident of the above care homes, in whom scabies was recognized between 1 November 2012 and 30 April 2013.

Staff case. A clinically suspected case of scabies in a staff member of the above care homes, in whom scabies was recognized between 1 November 2012 and 30 April 2013.

The case definitions included suspected cases because definite diagnosis of scabies by dermatoscopy or microscopy is rare in this setting, and not all symptomatic cases had been seen by a doctor.

Onset of symptoms was defined as the first reported day of itching or rash. Frequently an exact date was not provided and participants stated that symptoms began, e.g. ‘over a year ago’. In these cases the onset date was estimated using the information given.

Data collection

Three questionnaires were developed: one to gather information about the outbreak from the home manager; and two for case level information from staff and resident cases. These included details about dates of onset, diagnosis and treatment; clinical features; underlying illnesses; pre-existing skin conditions; mobility and continence. Variables included were based on the findings of a previous needs assessment which indicated a potential association between these factors and the risk of scabies [17]. The manager and
staff questionnaires included open-ended exploratory questions about the outbreak, including challenges and experiences of managing the outbreak, and detailed field notes were taken during the interviews. These interviews were not recorded, and responses were recorded by hand. Questionnaires were piloted with HPT staff and further questions were included based on this. Questionnaires were administered by one investigator, in a private location at each home, and those for cases with dementia were completed with a member of care home staff.

A follow-up call was made at least 1 week after the visit to find out whether a second mass treatment had been carried out. A further follow-up call was made 8 weeks after the visit, to determine whether any further cases had arisen. If no further cases had been reported in this time (the maximum incubation period for scabies) the outbreak was considered to be over.

**Data processing and confidentiality**

Data were entered using Epi Info database software (CDC, USA) and checked for errors. Hard copies of field notes and questionnaires were stored in a locked cabinet and electronic information was stored in a password-protected database.

**Data analysis**

Data analysis was conducted using Epi Info and MS Excel (Microsoft Corp., USA). The non-parametric Mann–Whitney test was used to investigate factors associated with time to diagnosis and derive $P$ values. The $t$ test was used for continuous variables.

A thematic analysis was performed on the qualitative data gathered. Field notes and qualitative questionnaire responses were typed up by the investigator, and open coding was used to identify key themes in the data. Field notes were examined line by line and the frequency of codes was examined to identify the overarching themes. Subthemes were identified based on these, and relevant quotes were extracted.

**RESULTS**

These outbreaks involved a total of 39 cases among residents, of which three had crusted scabies, in two homes. There were at least 28 cases reported among staff, and none reported among care home visitors. Interviews were carried out with representatives of all 39 resident cases, and 28 staff. The maximum period from notification to the first visit was 10 days, and visits were generally after the first mass treatment had been carried out.

The majority of resident cases had dementia (37/39, 94·9%), and were female (29/39, 74·4%). Incontinence was a frequent feature of cases (31/39, 79·5%), and many had mobility problems (28/39, 61·5%) (Table 1). Attack rates varied widely, from 2% to 50% among residents in these outbreaks (Table 2).

Based upon clinical signs and symptoms, 59% of cases had been diagnosed by a GP and 41% by care home nursing staff. No cases were diagnosed by a dermatologist.

All staff and residents were treated as part of the mass treatment process, and therefore it is likely that managers were not aware of all symptomatic staff. Two staff cases reported that their household contacts had also developed symptoms.

The most frequently reported symptoms were itching and rash, in over 80% of all cases (Table 1). Dry skin was reported more frequently among resident cases than staff, and is a common symptom among the elderly. Burrows had been noted in only 18% of residents and 14% of affected staff, indicating that diagnosis based on the presence of burrows may miss a significant proportion of cases.

Most cases were diagnosed within a week of onset of symptoms (Table 3); however, there was substantial variation and a small number of cases had very delayed diagnoses. This was a particular problem for the index cases, with a median of almost 5 months from onset of symptoms to diagnosis. In all but one outbreak the index case had been symptomatic and potentially infectious for over 8 weeks, at least one full scabies incubation period. Frequently scabies was not detected in the index case until a number of cases had developed symptoms and the outbreak was recognized, and time from onset to diagnosis of non-index cases was generally shorter.

While delayed diagnosis was a feature of almost all of these outbreaks, most cases received their first treatment within a few days of diagnosis (Table 2). There was little variation in time from first to second treatment, indicating that most of these care homes followed the local HPT advice to undertake a second mass treatment 7 days after the first.

**Managers’ and staff experiences**

The thematic analysis identified four overarching themes from the interviews with staff and managers about their experiences of outbreak management (see Table 4).
DISCUSSION

Diagnosis and management of outbreaks

Most of these outbreaks resulted from avoidably late recognition of index cases that had been symptomatic for months. Several were not diagnosed with scabies until further cases had arisen, despite having been examined by GPs on several occasions and misdiagnosed with other skin conditions such as eczema. Misdiagnosis of the index case is a common feature of scabies outbreaks in institutional settings for the elderly [5], and illustrates the difficulty of diagnosing scabies for non-specialists. There are a wide range of differential diagnoses, and a lack of practical, sensitive diagnostic tools for use in primary care. In elderly populations these difficulties are compounded by atypical presentation, confounding skin conditions [5, 7, 16, 18], and a lack of specific diagnostic criteria.

Despite the recognition that accurate diagnosis of scabies requires specialist input, none of the homes in this study had accessed a dermatologist during the outbreak, and dermatology support in the community is not typically available for this purpose.

GPs are generally the first point of contact for homes with suspected scabies outbreaks; however, interviewees reported difficulties accessing GPs or other diagnostic expertise. This led to stress and frustration among managers and staff, who tended to...
attribute this to a reluctance to provide support, or insufficient knowledge of scabies. As a result, many cases were not confirmed by a doctor, and two outbreaks had been diagnosed by care staff without external clinical input. Many cases (41%) had not been diagnosed by a doctor. This situation is commonly encountered by public health teams receiving reports of suspected scabies outbreaks, and has important resource implications, as these reports typically lead to a recommendation for mass treatment. It is likely that GPs’ knowledge of scabies varies, and a Belgian study found that dermatologists had greater knowledge of scabies than GPs, and in both professions knowledge improved with years of experience and number of scabies patients seen. Scabies is a notifiable disease in Belgium; however, over half of GPs said they never reported cases of scabies to the public health department [19].

The implications of diagnosing a scabies outbreak in a care home are significant, increasing the workload for care home staff, and potentially their colleagues if residents are registered with other practitioners. GPs may be reluctant to do so if the diagnosis is uncertain. Mass treatment is cumbersome, stressful for residents and staff, and requires considerable health service resources. In some outbreaks GPs did not prescribe enough scabicidal lotion to enable two mass treatments to be carried out, as recommended by the local HPT. The reasons for these problems are unclear but it may be that GPs were unaware of the guidance, not confident in dealing with scabies outbreaks, or did not feel that their never reported cases of scabies to the public health department.

<table>
<thead>
<tr>
<th>Outbreak number</th>
<th>No. of resident cases of classical scabies (N = 39)</th>
<th>No. of crusted scabies cases (N = 2)</th>
<th>Total residents (N = 363)</th>
<th>Attack rate (residents)</th>
<th>Days from onset to diagnosis (residents)</th>
<th>Days from diagnosis to first treatment (residents)</th>
<th>Days from first to second treatment (residents)</th>
<th>No. of staff cases†</th>
<th>Median and IQR.</th>
<th>Interquartile range.</th>
<th>Accurate denominators were not available for staff and so attack rates could not be calculated.</th>
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<td>A</td>
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<tr>
<td>All outbreaks</td>
<td>39</td>
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<td>10.7%</td>
<td>142(61–172)†</td>
<td>7</td>
<td>2.5 (1–6)†</td>
<td>7(7–9)†</td>
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IQR, Interquartile range.

* A second mass treatment was not carried out.
† Median and IQR.
‡ Accurate denominators were not available for staff and so attack rates could not be calculated.

Table 3. Time from reported symptom onset to diagnosis of resident cases

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<tr>
<th>Time from reported symptom onset (days)</th>
<th>No. of cases</th>
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<tr>
<td>Total</td>
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<td>≤ 1 day</td>
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<td>1–2 days</td>
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<td>2–4 weeks</td>
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<td>4–6 weeks</td>
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<td>6–8 weeks</td>
<td>6 (15.4%)</td>
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<td>8–10 weeks</td>
<td>2 (5.1%)</td>
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<td>10–20 weeks</td>
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<td>&gt; 30 weeks</td>
<td>1 (2.6%)</td>
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Table 2. Scabies attack rates among residents during outbreaks at residential care homes, and time to diagnosis and treatment for index cases and all other cases

<table>
<thead>
<tr>
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### Table 4. Thematic analysis of interviews with staff and managers about their experiences of outbreak management

<table>
<thead>
<tr>
<th>Theme</th>
<th>Issues reported</th>
<th>Examples</th>
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<tr>
<td><strong>1. Delayed diagnosis and access to diagnostic and management expertise</strong></td>
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</table>
| (a) Misdiagnosis of index case | • Most of the outbreaks were attributed to late diagnosis of the index case  
• In at least four outbreaks the index case had been visited by General Practitioners (GPs) repeatedly but scabies had been misdiagnosed as eczema or other skin conditions.  
• None of the homes had any access to specialist dermatological support and all relied on GP diagnoses of scabies.  
• Diagnostic tools (e.g. skin scrapings, dermatoscopes) were not used for any cases. | ‘Over 6 months ago several residents and staff developed a rash. The GP said it wasn’t scabies, and we suspected fleas … They have been treated for eczema several times, all were ineffective. A new GP visited and diagnosed crusted scabies. If it had been diagnosed from January when we started contacting GPs we wouldn’t have this large outbreak … We can’t do anything about it unless the GP diagnoses scabies.’ |
| (b) Lack of support from GPs | • Managers felt that GPs were reluctant to visit and prescribe for scabies outbreaks. In two outbreaks none of the cases had been visited by a GP, and scabies had been diagnosed by nursing staff. | ‘We were unable to get a GP to come to the home and were advised to look on the internet at pictures of scabies.’  
‘They [GPs] leave it to the care home to manage it, they don’t visit, they just do the prescriptions.’  
‘GP refused to prescribe for staff without a rash. Even when they did prescribe they only gave one tube per person.’ |
| (c) Lack of familiarity with local guidance | • The response from GPs was inconsistent, some did not wish to treat asymptomatic contacts of cases.  
• Several GPs only prescribed one treatment for household contacts despite local Health Protection Team guidance recommending two. |  |
| **2. Logistical difficulties with the mass treatment process** |  |  |
| (a) Resident treatment | • Applying the lotion to, and showering, all residents on the same day was logistically difficult.  
• Problems obtaining the treatment lotion in bulk delayed the mass treatment in some homes, particularly where residents were registered with more than one GP practice. | ‘It has been a nightmare getting everyone to cooperate with the treatment and with the showering.’  
‘We need a system for bulk ordering of cream, we had to phone around lots of chemists to get the amount we needed.’ |
| (b) Staff treatment | • Staff having different GPs complicated the process.  
• GPs often only prescribed one treatment for staff instead of two, leading to increased costs for the homes in paying for repeat prescriptions, and workload as the process had to be repeated 1 week later. | ‘The manager had to go to six GP practices to get prescriptions, they would only give us one tube for each person.’ |
| **3. Resource implications of outbreak management process** |  |  |
| (a) Staffing levels | • Mass treatment was a significant extra workload, and most homes needed extra staff for this. Staff described this process as very stressful. | ‘We have had to double the number of care staff on duty at some points.’  
‘A challenge is the sheer amount of work to cover all residents with cream and shower it off the next morning with no increase in staffing.’ |
| (b) Cost implications of outbreak management | • Treatment for residents was generally NHS funded, but there was some confusion about who was responsible for paying for treatment of staff and household contacts.  
• Incorrect prescribing increased costs.  
• Other costs cited included laundry and cleaning, and loss of income due to closure to new admissions. | ‘If GPs only prescribe one treatment for staff this doubles the cost as we have to pay two prescription charges instead of one … [staff] have to pay it first and be reimbursed, this is challenging as they are low waged.’ |
outbreak management was their responsibility. In addition there is limited evidence regarding the effectiveness of mass prophylaxis in controlling scabies outbreaks, and this may contribute to the reluctance of GPs to prescribe mass treatment for residents and staff [17]. These problems are further compounded by the fact that residents of care homes are often registered with different GPs.

The problems encountered in these outbreaks related primarily to the availability of diagnostic expertise, prescribing and the logistics of obtaining prescription treatment in bulk. Although this study was not designed to include a formal economic evaluation, it was clear that outbreak control required considerable economic and human resources, reinforcing the importance of accurate diagnosis.

A perceived lack of clinical support in the community for homes dealing with these outbreaks was evident, along with confusion about control measures, leading staff at one home to lock people with dementia in their rooms to prevent wandering and potential further transmission. Several interviewees felt unsupported by GPs; however, it is debatable to what extent it is the role of GPs to manage these situations, over and above the care of their individual patients. Many care homes have residents under the care of a number of GPs, further complicating the process.

Limitations

This study had several limitations. It was not possible to include outbreaks which were not reported to the HPT, and those described here may represent particularly large or challenging outbreaks (e.g. due to a high proportion of residents with dementia) which may be reported more readily. Data collection was carried out in association with the HPT, and this may have influenced respondents to report adherence to HPT guidance. Over-ascertainment is likely as not all of the cases were confirmed by a doctor, and none microscopically or using a dermatoscope. This was particularly so for staff, who frequently reported symptoms but did not go to a doctor because they were treated en masse. However there may also have been some under-ascertainment due to managers not being aware of all staff cases. A previous study found that S. scabiei was only present in a third of healthcare workers reporting symptoms [20]. Many cases could not recall an exact date of onset so this was generally estimated, and for cases with dementia this was done by a carer.

Scabies outbreak management posed a considerable challenge for the care homes in this study, which demonstrates confusion and a lack of clarity about responsibility for the various aspects of scabies outbreak control. There is an urgent need for extra support for homes managing these outbreaks, both to facilitate earlier recognition of outbreaks and to streamline the outbreak management process. Scabies presents particular logistical difficulties and requires dedicated resources, including access to diagnostic expertise, and practical support with outbreak management, including prescribing and bulk ordering of treatment.

Recommendations

Health service planners and commissioners should identify ways of providing support for the management of institutional scabies outbreaks in their residents, for example through commissioning integrated services, including community dermatology support where required.

Practical, evidence-based national public health guidelines for scabies outbreak management are needed, which clearly outline roles and responsibilities of stakeholders including care home management,
GPs, PHE and others. This would enable a consistent approach to outbreak management and potentially improve adherence to the recommendations of local HPTs. In the meantime, local HPTs should ensure that GPs are aware of local guidance for managing scabies outbreaks.

Scabies is a neglected problem and there are significant research needs relating to the control of institutional outbreaks. The authors of a 2010 Cochrane review noted that approaches to institutional outbreak control require evaluation [11]. Mass treatment with a topical lotion is a substantial undertaking, and the process was stressful for staff in this study, who had real concerns about the intimate nature of the treatment and the inability of many residents to consent to the process. Ivermectin is a potential alternative but requires evaluation as a mass treatment measure in this population.

The distress reported by staff who had applied permethrin lotion to residents suggests that any evaluation of outbreak control measures should include investigation of the acceptability of topical and oral treatment in residential care homes for the elderly, in particular those specializing in dementia care.

Scabies is an unpleasant, debilitating condition and as these outbreaks demonstrate, disproportionately affects those who are most vulnerable, often with multiple comorbidities. Delayed diagnosis, and therefore delayed treatment, prolongs suffering and increases the risk of outbreaks in this setting, where a majority of residents are at particularly high risk of scabies acquisition. Improving the diagnosis of scabies in the elderly is vital not only to identify single cases early and prevent outbreaks arising, but also to prevent unnecessary control efforts being undertaken. Two of the index cases had crusted scabies, which was unrecognized until other residents or staff had developed classical scabies symptoms. There is a need for the development of sensitive tools for diagnosing scabies in primary care, clear diagnostic criteria for scabies in the elderly, and education of GPs and others regarding the clinical presentation of scabies in this population. It is unacceptable for this vulnerable group, often approaching the end of life, to experience the unpleasant, debilitating symptoms of scabies for the extended periods of time demonstrated here.

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DECLARATION OF INTEREST

None.

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