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Review Article

The Experiences of Presentation, Diagnosis, Treatment and Care for School-Based Education Workers with Mesothelioma: A Scoping Review

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Abstract

Aim: To identify and synthesize studies regarding the experiences of presentation, diagnosis, treatment and care for school-based education workers (SEWs) with mesothelioma. **Design**: Scoping Review. **Method:** Eligibility: English language publications from the UK/Ireland, Canada, New Zealand, Australia and USA; b) research studies investigating SEWs' experiences of mesothelioma; plus, c) UK online, newspaper and other reports of SEWs experiences of mesothelioma. Sources of evidence: 1) Medical and education databases; 2) Nexis (UK newspaper reports); 3) Open Grey, YouTube and Google. **Results:** No primary research studies were found. Grey material covering 84 individual cases in the UK were found: 19 were ancillary staff, the remainder, and teachers. Alongside the physical, social and emotional impacts shared with other mesothelioma patients, SEWs had specific experiences related to causation such as concern about poor management of the problem and the risk to others, particularly pupils.

Patient and Public Contribution

Patients and professionals with relevant expertise were consulted.

Keywords: Asbestos; Mesothelioma; Schools; Pupils; Teachers; Scoping review

Introduction

Malignant Mesothelioma (MM) is a rare, life limiting and aggressive cancer with a high symptom burden [1]. Incidence rates have been increasing since cases first started to be systematically recorded in the 1960s. Incidence is higher in certain occupational groups including asbestos mining and disposal and construction industries [2]. These industries are male-dominated and as a result, the disease itself disproportionately affects men (83%) [3]. Over time, it is expected that incidence of MM in these industries will reduce as asbestos use itself disappears.

However, some commentators have expressed concern that those who work in buildings in which asbestos is present will also be at risk of exposure [4,5]. Old public buildings, such as schools and hospitals, are thought to be particularly problematic. Those who work in such buildings will not share the demographic profile of those in the traditional high-risk industries. A recent study looked at the experiences of health care workers who had developed mesothelioma [6]. The scoping review reported here is part of a similar study that will look at school-based education workers (SEWs) such as teachers, caretakers and cleaners.

Background

The UK has the highest rates of mesothelioma in the world [7,8]. A 2019 report predicted that cases in the UK would peak at approximately 2500 per annum but then begin to decline [9]. However, the report is cautious because of two uncertainties about the longer term.

One is that the report assumes there are no other important higher-risk industries beyond those already identified. By contrast, some commentators have spoken of a third wave of mesothelioma amongst those who work in buildings where asbestos is in situ, particularly where it is poorly maintained, such as schools and hospitals [10]. The second uncertainty concerns the rate of decline, which might be slower than expected if the population at large is, or has been, exposed to greater levels of asbestos than predicted or assumed in the mathematical modelling.

Schools are a particular concern. In 2013, the Committee on Carcinogenicity said that around 75% of schools have "some buildings that contain asbestos-containing products" [para. II] (Committee on Carcinogenicity of Chemicals in Food Consumer Products and the Environment, 2013) [11]. (Subsequent Freedom of Information Requests put the figure a little higher [12].) In addition, the report says that, "Because of differences in life expectancy, for a given dose of asbestos the lifetime risk of developing mesothelioma is predicted to be about 3.5 times greater for a child first exposed at age 5 compared to an adult first exposed at age 25 and about 5 times greater when compared to an adult first exposed at age 30." [Para. V].

In other words, children are more likely to live long enough after exposure to develop mesothelioma. Whether the concerns will eventuate is not yet known. In relation to the so-called third wave, between 2001-16 the UK Office for National Statistics recorded 305 deaths in England of teaching and educational professionals [13]. Commenting on earlier but similar data, Peto et al state [7], "There was little or no evidence of increased risk in non-industrial workplaces such as schools or hospitals after excluding those who also worked in higher risk jobs" [7].

However, there are several reasons to doubt the accuracy of the official figures. The first is that mesothelioma death rates increase with age, with most dying in the over-75 categories. The Office for National Statistics (ONS) does not record the occupation of the deceased in the over-75 category. Given the slow rate of growth of the disease, particularly where exposure is relatively low-level, this is likely to mean that those with mesothelioma due to exposure in environments such as schools and hospitals will not be recorded as such. A recent report estimated that the number of teachers aged 75 and over dying of mesothelioma in a year would be in a ratio approximately equal to deaths due to mesothelioma in women aged over 75/ women aged under 75 [14]. This method reduces the distorting effects of the (overwhelmingly male) deaths from known high-risk industries. It also appears reasonable because around three quarters of teachers are female. When this is done, the death of teachers in all ages between 1980-2017 is estimated at 692 rather than the 380 recorded in ONS data. If deaths over the age of 75 were labelled with the last occupation, it is possible that occupations such as teachers would emerge as disproportionately at risk from asbestos exposure.

A further problem is that the ONS record only the final occupation of the deceased; those who went on to other careers or who became full-time mothers or fathers and informal carers will not be recorded as former teachers and so on. In addition, it is not always clear in the data that someone has worked in a healthcare or education environment; this is particularly the case if they are recorded as engaged in ancillary work, such as caretaking, cleaning or kitchen work. Some education support worker deaths are recorded in the ONS data, 71 deaths between 2003-17. This figure would rise to 142 if the ratio adjustment suggested above were performed. In addition, a recent report suggests that support staff often work in areas where they are most likely to be exposed, such as boiler rooms and kitchens. The report estimates deaths of such staff in the 2003-17 period at over 300 [14].

Perhaps of greatest concern is that pupils constitute the other group that can be exposed to asbestos in schools. The question of how many die in later life as a result is moot; no official records are kept and there is no estimate endorsed by official bodies such as the UK NHS. In 2013, Professor Peto informed the House of Commons Education Select Committee that he believed around 100-150 female deaths per year were due to asbestos exposure in school buildings in the 1960s and 70s [15]. (Peto also presumed a similar number of male pupils would be exposed, such that we should expect 200-300 deaths of former pupils each year due to this exposure).

At the same Select Committee Peto also said that the numbers were likely to decline. However, both the number and the predicted trend are contested, particularly as the known trend for teachers has shown an increase rather than decline. In addition, a US report from its Environmental Protection Agency used data from industry and schools to develop an extrapolation model for deaths due to asbestos exposure in school [16]. It concludes, "About 90% of the premature deaths are expected to occur among persons exposed as school children. The remaining 10% includes teachers, custodians and other adult occupants of the buildings." If this is correct, for every school education worker who dies of mesothelioma, nine former pupils will die. As the level of teacher deaths from 1980-2017 was between 380 (under 75) and 692 (corrected to cover all ages), this gives a figure of up to 6228. The true figure of SEWs dying with mesothelioma is probably much higher given the problems with official data on education workers noted above [14].

It follows that the phenomenon of mesothelioma developed from asbestos exposure in schools is important. In addition, it is likely that the experiences of victims will differ from those exposed through the more standard industrial routes. The objective of this scoping review was to identify and synthesize studies regarding the experiences of presentation, diagnosis, treatment and care for school-based education workers (SEWs) with mesothelioma.

The Research Question

What is known regarding the experiences of presentation, diagnosis, treatment and care for school-based education workers with mesothelioma in the so-called big five nations (UK and Ireland; Canada; New Zealand, Australia and USA)? As the purpose of the review was to identify available evidence in a given field, this indicated the need for a scoping rather than systematic review [17].

The Study

Design

The scoping review protocol was developed between the University of Sheffield and the UK-based charity, Mesothelioma UK. The latter provided patient and public involvement in the process. The protocol was registered at Open Science Framework on 10/12/2020 [https://osf.io/qts4c/].

The eligibility criteria were:

- Publications from the so-called big five predominantly Anglophone nations (UK and Ireland; Canada; New Zealand, Australia and USA.)
- Primary original research studies investigating SEWs' experiences of mesothelioma.
- Online, newspaper and other reports of SEWs' experiences of mesothelioma [in the UK only] [time line from 2000].
- English language: this was required as translation resources were not available for the project – however, given eligibility criterion a, above, we expected most resources to be in English.

The information sources used were:

For primary research studies Medline, Cinahl, Scopus, PsychINFO, Education database and British Education Index; plus Google Scholar; in addition, ProQuest for doctoral theses.

For newspaper reports of the experiences of SEWs with mesothelioma in the UK only, a database of UK news sources, Nexis.

For other grey literature: A European open access repository of information unpublished in academic journals, OpenGrey, plus YouTube and Google for video diaries, blogs and similar.

Method

The search was performed as follows. For primary research studies, Medline, Cinahl, and Scopus using the search terms "patient experienc* OR patient narrativ* OR patient stories OR patient story OR patient perspectiv* OR patient perception* OR "psych*" AND mesothelioma. PsycINFO, Education database and British Education Index were searched using the term "mesothelioma". ProQuest was searched using the term "mesothelioma". In addition, the search terms for Medline were used in Google Scholar and the first 1000 items were checked for additional articles. The records were reviewed for reports from SEWs. Articles and theses of potential relevance were downloaded as full text and formally searched for relevant terms, such as teachers and janitors, and for the term 'school' in ten-word proximity with 'asbestos'.

For the NEXIS and OpenGrey search of online, newspaper and other reports of SEWs' experiences of mesothelioma, used the terms Mesothelioma AND Schools. The search was narrowed by i) date (from 2000), ii) Publication location Europe/United Kingdom, iii) Subject (Medicine and Health, Law & Legal system, Labour & Employment, Reports, Reviews & Sections, and Population & Demographics), iv) Industry (Educational Services and Health care). Audio or video material was transcribed. All data were entered into a qualitative analysis software package, QUIRKOS. The data were analysed thematically initially using a framework of themes developed from the literature on the experience of mesothelioma patients in general, rather than specific occupational groups, that had been reviewed by Moore et al (2010) [18] and Bonafede et al (2018) [19].

Results

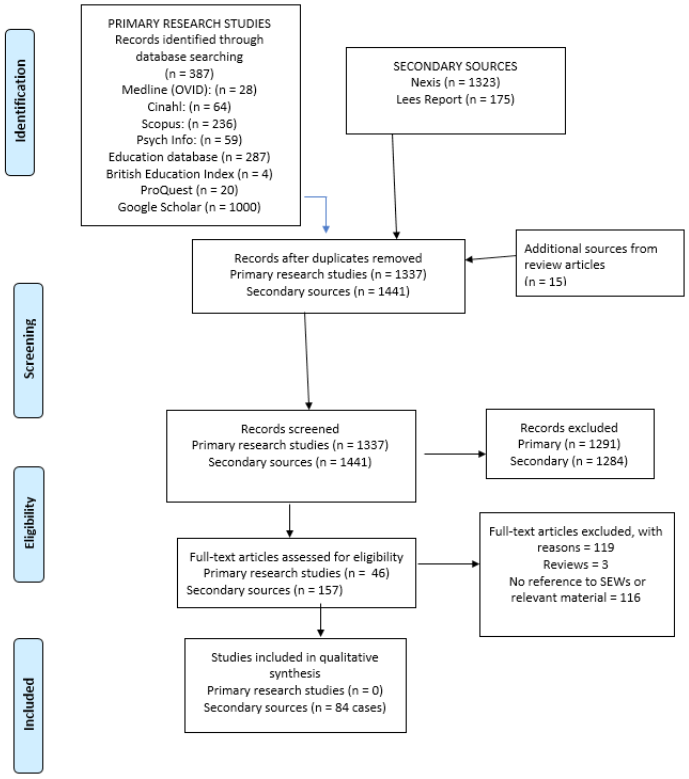

Figure: The search results are summarised in the PRISMA chart.

Although 1137 primary research studies were screened, none met the inclusion criteria. The results from secondary sources, such as NEXIS, came to 84 individual cases in the UK. Nineteen were non-teaching staff such as caretakers, cleaners, dinner ladies and one secretary; the remainder were teachers and head-teachers. Six had relevant online video resources.

Physical and emotional impacts were apparent in SEWs and their carers. The physical aspect of the mesothelioma was reported in three stages; the lead up to diagnosis, the ongoing symptoms and the end of life. Unsurprisingly, the physical impacts of mesothelioma in education workers are the same as those reported by the wider group of mesothelioma patients in the reviews noted above. More marked than in the wider group of patients, however, was disbelief on learning the likely origin in asbestos at their place of work. Some patients were surprised to find themselves being quizzed about their exposure to asbestos.

They started asking me whether I've been exposed to asbestos and I was thinking no I don't think so[...]and the chest surgeon […} couldn't believe a teacher would have it because I wasn't in any of the industries known for this disease.' Source: RP Video.

Alongside this, there is also at least one report of what has been termed the nihilism of clinicians in relation to this diagnosis [20-22].

A consultant turned up and she told me quite blankly that I had less than a year to live so I was in considerable shock. It seemed rather sudden and they diagnosed mesothelioma. Source: JS video.

Often there was simply surprise and anger that asbestos was present in schools at all. In addition, SEWs often had no awareness or training in relation to asbestos.

In the case of my husband, the solicitors tried to track down the source of asbestos in the London school where he worked but there was only a very scanty record, and by that, I mean scrappy notes on a sheet of A4 paper. Source: AA .

A Former school cleaner and caretaker died because of exposure to asbestos throughout her career, a court heard yesterday… she was never told the dangers the potentially deadly substance posed, nor was she given any protective equipment such as a facemask when working with it. Source: BB.

In some cases, the patients reported having been told that their building was safe because, for example, it was being properly managed.

In fact, I had been told it was asbestos but it was white asbestos and it was safe. Source: EB video.

Causation was by far the main theme in the material we reviewed. Some material contained patients or carers reporting their memory of working in the school and their beliefs concerning where they were exposed to asbestos. These are summarised in Table 1.

Cause	Teaching staff	Other staff
Pinning items to walls and boards	6	
Ceiling or floor tiles	2	2
Work on lagging of pipes and cables		2
Art and science room specialized equipment	3	
Building work in the school	3	
Storage areas	1	
Wear and tear, vandalism	4	
Boiler room	3	3

Table 1: Possible sources of asbestos exposure.

Noteworthy here is the cause related to wear and tear, and vandalism. Frighteningly, the disturbance was what could be described as natural 'wear and tear' – pupils disturbing it with bags, rulers etc. Source: JH.

The second element in the theme of causation was concern for others, particularly pupils.

What was also incredibly upsetting to Pearl was the idea that children may have been put at risk on those premises. It does not bear thinking about. Source: PD

Also regarding causation, it was striking that some reports from coroners' courts suggested inconsistency in approach. In 7/28 cases of education workers, an open verdict or verdict of natural causes was recorded.

The coroner ruled the death was industrial disease, but said it was not clear where PD had been exposed to asbestos." Source: PD.

But Coroner RW recorded an open verdict because he said he could not be sure asbestos at the school was the culprit. Source: JK.

Another report states that, [The] coroner recorded an open verdict that SM had died from malignant pleural mesothelioma but that he could not determine if it was a natural disease. Source: SM.

And another, "Although there was some contact with asbestos, this was unlikely to be the cause of death." Source: EG.

This reluctance was not shared by all coroners. In the remaining 21 cases, a verdict of industrial disease was given. In 11 of those cases, the coroner attributes the asbestos exposure to work in schools; in the others, it is left open as a possibility.

Ethics

This was a scoping review of material already published; almost all is in the public domain. As such, ethical approval was not required. Informed consent was not applicable for this study.

Discussion

In the results section, we have highlighted the issues that appear to separate the experience of education workers from those who developed mesothelioma in the well-known high-risk industries. These centred on causation. They included shock and surprise that asbestos was present in schools in ways that could cause mesothelioma, and a concern for others similarly exposed, particularly children.

We might speculate that these are also the issues that were of interest to the newspapers reporting the cases. We were surprised by the number of cases we found in newspapers; 84 is a high proportion of those education workers known to have developed mesothelioma. Newspapers would be less likely, perhaps, to report cases of former carpenters and builders who developed mesothelioma. It may be the presence of danger from asbestos in schools that provokes interest and concern. It may also explain the lack of information on the social effects of the diagnosis, as this is also likely to be of less interest to newspapers.

Newspaper interest is also driven by concern for pupils. It is striking that there is no official data or modelling of how exposure to asbestos as a pupil is affecting rates of mesothelioma in later life. Given that i) we found 84 cases of education workers developing mesothelioma in reports and ii) the US modelling noted earlier suggests that up to 9 pupils will develop mesothelioma for every such case, then this is a concern for future patterns of mesothelioma.

In addition, our findings reflect worries about management. The current law in the UK says that while the new use of all forms of asbestos is banned, existing asbestos is allowed to remain in situ provided it is in good condition and undisturbed [5]. It is for this reason that many schools, the majority in the UK, continue to have asbestos. However, such in-situ management needs to be set against the presence of vandalism and excessive wear and tear in schools noted in the findings of this review. An algorithm published by the UK Health and Safety Executive draws attention to.

High levels of disturbance, in area children running in and out of classroom, knocking wall panels, wall displays. [23].

Unfortunately, it is far from clear that this concern has been fully acknowledged in practice in, for example, asbestos management plans in schools that might be, as noted above, merely "scrappy notes on a sheet of A4 paper".

Finally, we noted in the introduction that official figures regarding deaths of SEWs due to asbestos exposure in schools are likely to be underestimates. Many of the articles we reviewed were reports from coroners' courts. It was striking that some of this suggested inconsistency in approach. The key example of this is in the apparent reluctance of some coroners to give a verdict of industrial disease and exposure to asbestos. However, here the caveat about data quality must be emphasised; there is insufficient data to parse the verdicts and, as the data is from local newspapers in the main, it is not wholly reliable. Nonetheless, it may be that here is another factor that leads to an under-recording of deaths due to asbestos exposure in schools.

Limitations

The research question was: What is known regarding the experiences of presentation, diagnosis, treatment and care for school-based education workers with mesothelioma in the so-called big five nations (UK and Ireland; Canada; New Zealand, Australia and USA)? The search of academic sources suggests that there have been no studies examining this topic. We found a number of secondary sources in UK newspaper reports and some online video materials. None of this was collected following a research protocol or even with the aim of answering anything like the research question leading our scoping review. As such, this is a major limitation on any conclusions that can be drawn.

Conclusion

One conclusion of this scoping review is that almost nothing is known regarding the experiences of school-based education workers who develop mesothelioma. Secondary sources suggest that these experiences may be different to those of workers in standard high-risk industries. Education workers may also be a useful source of information when considering how to tackle the risk of asbestos in schools. A case could be made, therefore, for undertaking prospective research in this area.

For nurses working with mesothelioma patients, it is worth noting that an increasing number will come from industries not traditionally associated with the disease. They may have different experiences, as even the limited data reviewed here suggest. In addition, they may be involved in complicated legal cases regarding causation, which may add to their stress. Finally, nurses should be wary of the so-called nihilism associated with the diagnosis of the disease. It is not the case that there is nothing that can be done, even if curative treatment is not yet possible for most.

At the time of writing (April 2022), a Parliamentary Work and Pensions Committee is considering the present approach to asbestos management in the UK. That approach is one of in-situ management, where asbestos is logged and examined annually by a building duty holder (or several in larger premises); this person is an employee such as a head teacher. Elsewhere in Europe, approaches differ but include more active air monitoring and phased removal

of asbestos. At least two points from the present study are relevant to this discussion. The first is that in-situ management is difficult in schools, where levels of wear and tear are high. The second is that the asbestos plans on which in-situ management relies can be poor and ineffective.

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References

1. Odgerel CO, Takahashi K, Sorahan T, Driscoll T, Fitzmaurice C, et al. (2017) Estimation of the global burden of mesothelioma deaths from incomplete national mortality data. Occup Environ Med 74: 851-858.
2. Rake C, Gilham C, Hatch J, Darnton A, Hodgson J, et al. (2009) Occupational, domestic and environmental mesothelioma risks in the British population: A case-control study. Br J Cancer 100: 1175-1183.
3. Cancer Research UK (2021) Mesothelioma statistics.
4. Howie R (2017) Mesothelioma Deaths in Teachers and Nurses in Great Britain. Environmental Health Scotland. 29: 35-37.
5. Pickles C (2018) Why the UK needs tighter asbestos controls.
6. Allmark P, Tod AM, Darlison L (2020) MAGS: The Healthcare Staff Mesothelioma Asbestos Guidance Study. 1-73.
7. Peto J, Rake C, Gilham C, Hatch J (2009) Occupational, domestic and environmental mesothelioma risks in Britain: a case-control study.
8. Bianchi C, Bianchi T (2014) Global mesothelioma epidemic: Trend and features. Indian J Occup Environ Med 18:82-88.
9. Health and Safety Executive (2019) Mesothelioma in Great Britain in 1968-2017.
10. van Zandwijk N, Reid G, Frank AL (2020) Asbestos-related cancers: the 'Hidden Killer' remains a global threat. Expert Rev Anticancer Ther 20: 271-278.
11. Committee on Carcinogenicity of Chemicals in Food Consumer Products and the Environment (2013) Relative vulnerability of children to asbestos compared to adults.
12. BBC (2015) The teachers who say their classrooms gave them cancer.
13. Office for National Statistics (2019) The number of deaths where the underlying cause was mesothelioma, for teaching and educational professionals in England, deaths occurring between 2001 and 2016.
14. Joint Union Asbestos Committee (2021) Continuing Government Failure Leads to Rise in School Mesothelioma Deaths.
15. Education Committee (2013) Education Committee - Minutes of Evidence HC1056.
16. Environmental Protection Agency (USA) (1980) Support document for proposed rule on friable asbestos-containing materials in schools: reoirt no. 560/12-80-003. Washington.
17. Munn Z, Peters MDJ, Stern C, Tufanaru C, McArthur A, et al. (2018) Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. BMC Med Res Methodol 18: 1-7.
18. Moore S, Darlison L, Tod AM (2010) Living with mesothelioma. A literature review. Eur J Cancer Care 19: 458-468.
19. Bonafede M, Ghelli M, Corfiati M, Rosa V, Guglielmucci F, et al. (2018) The psychological distress and care needs of mesothelioma patients and asbestos-exposed subjects: A systematic review of published studies. Am J Ind Med 61: 400-412.
20. Edwards JG, Abrams KR, Leverment JN, Spyt TJ, Waller DA, et al. (2000) Prognostic factors for malignant mesothelioma in 142 patients: validation of CALGB and EORTC prognostic scoring systems. Thorax. 55: 731-735.
21. Clayson H (2007) The Experience of Mesothelioma in Northern England.
22. Warby A, Dhillon HM, Kao S, Vardy JL (2019) Managing malignant pleural mesothelioma: experience and perceptions of health care professionals caring for people with mesothelioma. Support Care Cancer. 27: 3509-3519.
23. Health and Safety Executive (2002) A comprehensive guide to Managing Asbestos in premises.