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Mesothelioma: are nurses being put at risk in the workplace?

Malignant mesothelioma is an aggressive, rare cancer. It is caused by exposure to and inhalation of asbestos. Because of this it is associated with male-dominated industries that use asbestos, including asbestos mining and disposal, and the construction industry. Although the UK has the highest rates of mesothelioma in the world, the Office for National Statistics recorded only 177 mesothelioma deaths of health and social welfare professionals between 2002-15. Its analysis concluded that non-industrial workplaces such as hospitals had little or no evidence of increased risk over the general population.

This analysis, however, does not tally with the experience of many mesothelioma nurse specialists, or with that of others who work in the area, such as the charity *Mesothelioma UK* and some legal professionals. They report seeing far greater numbers than the official statistics suggest.

In addition, several healthcare professionals, particularly doctors, have reported online or in newspapers their experience of developing the illness. In some cases there is difficulty in getting a diagnosis because it is believed to be so rare in this group.

For this reason, *Mesothelioma UK* commissioned us to do a study that aimed to find out what the experience of presentation, diagnosis, treatment and care was like for healthcare professionals and other NHS workers. The full study report was published at the end of September 2020 and is available on the charity's website (www.mesothelioma.uk.mags).

Are nurses at risk?

In 2018 the BBC made a Freedom of Information request to all 243 NHS trusts in the UK. 211 responded and 198 said they ran hospitals containing asbestos. They concluded that around 90% of hospitals contain the material.

<https://www.bbc.co.uk/news/uk-england-45561384>

Any blue or brown asbestos will be removed as high risk. White asbestos is considered lower risk and is generally left in situ and monitored unless it is visibly damaged (see boxes 1 and 2). One problem with this is that it is not the visible material that is the problem but rather the invisible fibres that are released from it. Improved air monitoring might be more effective, particularly as damage is not always easy to detect where the asbestos is hidden behind walls or floors (see our recommendations, below).

BOX 1 TYPES OF ASBESTOS

There are three main types of asbestos used in industry and construction.

White asbestos (chrysotile) is the most common and was used widely in construction.

Brown asbestos (amosite) was used in insulation and ceiling tiles.

Blue asbestos (crocidolite) was used in some coatings and insulation.

BOX 2 ASBESTOS IN HOSPITALS AND THE LAW

The law requires those who manage the hospital to have an asbestos plan in which they identify all the asbestos in the building and say how it will be managed. In practice, this usually involves removal of high-risk material, particularly brown asbestos, and of material that is easily accessible. Other than that, asbestos assessed as of lower risk is sealed and left in situ, where it is re-inspected, usually annually.

How many nurses get mesothelioma?

Because mesothelioma is such an aggressive disease, the time from diagnosis to death is usually fairly short; most people who get it die of it. According to the ONS data, 114 of the 177 deaths of healthcare professionals between 2002-15 were of nurses. Because of the doubts expressed about these figures, we tried to get a more accurate picture through a different route. Using a Freedom of Information Request, we asked the body called *NHS Resolution* how many NHS workers had sued the NHS claiming they had developed mesothelioma claiming they had been negligently exposed to asbestos at work. The results are presented in Table 1/Graph 1.

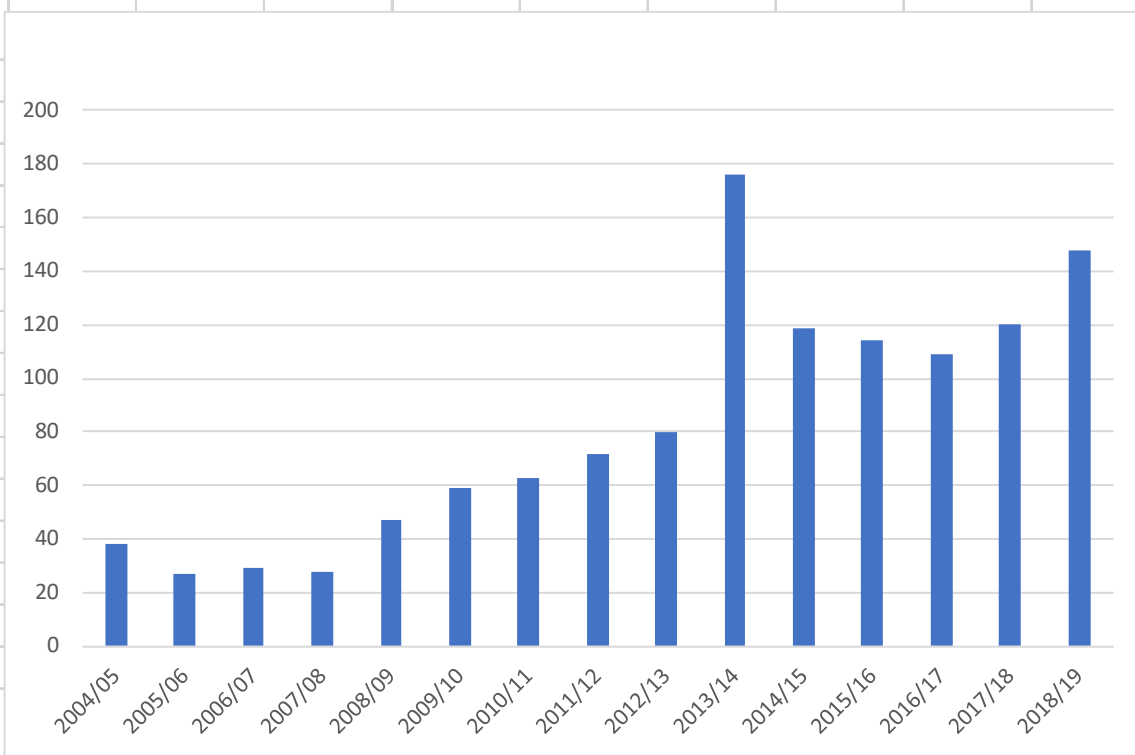
We found that between 2004-19, 1229 claims had been made. All of these were NHS workers who had developed mesothelioma, although only about half had won their claim against the NHS by showing it was due to negligent exposure at work. In addition, even this higher figure underestimates the true extent of mesothelioma amongst current and former NHS workers. This is because it only includes those who made a claim against the NHS. Many who develop mesothelioma will not do so because, for example, their legal team is unable to identify a specific incidence of negligent exposure to asbestos. Many nurses have careers ranging over many sites – this makes tracing very difficult.

To return to the question of how many nurses get mesothelioma, it is, unfortunately, impossible to say from these figures. *NHS Resolution* would not provide a breakdown of the figures by job or profession. We can say with some certainty that the ONS figures are too low. The 1229 claims we found will include other healthcare workers, such as laundry staff. But it is likely that nurses are a large proportion of the figures. And it is worth repeating that these figures underestimate the actual figure of NHS staff who develop mesothelioma; by how much, we don't currently know.

Table/Graph 1

Table 1: Number of Claims received between financial years 2004/05 to 2018/19 injury coding: Injuries to Internal Organs\Lung Disease\Mesothelioma

Notification Year	No. of Claims
2004/05	38
2005/06	27
2006/07	29
2007/08	28
2008/09	47
2009/10	59
2010/11	63
2011/12	72
2012/13	80
2013/14	176
2014/15	119
2015/16	114
2016/17	109
2017/18	120
2018/19	148
Grand Total	1,229



Source: NHS Resolution: Freedom of Information Request# 3992 Data correct as at: 2019-08-31

What is it like for healthcare workers who get mesothelioma?

To answer this question, we did a literature review looking at published papers and also at information on the internet in, for example, blogs and YouTube broadcasts. We also interviewed seven former healthcare workers who had developed mesothelioma, or their partners. All the literature related to healthcare professionals, mainly doctors or nurses. Our interviews were all with nurses, care assistants or doctors (or their partners where the person had died).

Symptoms and diagnosis

They reported many physical symptoms that were similar to those of other mesothelioma patients, such as pain, nausea and breathlessness (see Box 3, physical symptoms of mesothelioma).

There were also strong emotional reactions; for some this was exacerbated by knowledge of the condition and its poor prognosis. In addition, knowledge of the link to asbestos and to industry left some puzzled. A care assistant told us,

I kept thinking, well where could I have had it from, you know?

The same thought meant that diagnosis was delayed for some. A GP's partner said,

And the consultant ... said it couldn't be some things because she hadn't worked in industry.

Alongside this there was for some health-carers a sense of anger or disappointment that they had been exposed to the risk in their workplace, in an environment that is supposed to be about health care. One nurse said,

I think personally now, it's ironic, that I've dedicated 44 years of my life, and you know, that dedication is what's killing me now. It's ironic really.

Treatment and care

The problem of how healthcare professionals treat their colleagues when they are patients has been noted in wider health care literature. One article captures this with the quote in its title 'Just so you know, the patient is staff.'

As nurses, we could all learn something useful from the evidence we reviewed and the interviews. If you have time, have a look at the blog by Mags Portman or the YouTube broadcast by Kieron Sweeney. Details are available in our full report.

One problem was that healthcare professionals with mesothelioma were sometimes treated more like colleagues than patients, despite them having such a devastating diagnosis. The GP's partner told us,

It can be very, very brutal when you're not expecting it... The scan showed a massive lump and things. The consultant just turned to her and showed her the scan and said, this is bad, you understand this. And XX she could see that it wasn't correct. But that was it.

This harsh tone extended to some of the care given. When the same GP went to A&E with an exacerbation of mesothelioma symptoms, she was told she should not be there, that

You've got mesothelioma, you need to be at home, basically to die.

The GP's partner said that she needed reassurance as much as treatment; she did not need to be told that she should know that A&E was not the place for her.

There was another occasion when a former healthcare administrator with mesothelioma wanted to call an ambulance when his symptoms worsened only to be told by the District Nurse that it would not come because there was a non-resuscitation order in place.

As well as harshness of tone, there could also be undue lightness because they were treated as a colleague rather than patient. Dr Sweeney, in his YouTube broadcast reports an incident,

when a senior radiographer walked briskly into the patients' area and said, Kieran Sweeney, follow I... But this crass attempt at humour, follow I, just humiliated me. I felt just utterly degraded. I felt seriously upset by it. That he should so trivialise what was for me a shocking passage into my health care problem; I'm so angry about that.

There were, of course, many reports of positive treatment. There are 26 clinical nurse specialists working across the UK under the Mesothelioma UK charity and they were spoken of highly by interviewees. At a wider level, the data we reviewed suggested that, in general, technical care was good but it was the emotional care that fell short.

Recommendations

At the end of our report we make a number of recommendations. Some concern the care that we give to other health care professionals. For example, we suggest:

- 1) As nurses, we should remember that the person is a patient first, a professional second. Unless they actively say so, they should not be spoken to as though they are a member of the team, with the bluntness that goes with it.
- 2) On the other hand, some health carers may feel the loss of professional role; some found alleviation of this loss in using their skills to help fellow patients, for example, through support groups.
- 3) We must beware of what was termed in one article 'nihilism' with regard to the diagnosis of mesothelioma. The diagnosis does not imply that there is 'nothing that can be done'; as the reports of care from the clinical nurse specialists show, there is much that can be done.
- 4) In addition, we should remember that a DNAR order implies nothing with regard to any treatment aside from attempted resuscitation. It does not, for example, mean it is wrong to call an ambulance or go to A&E if the patient feels it is necessary.

We also make recommendations regarding the management of asbestos. These include improving the monitoring of levels of asbestos using techniques that are now available, and used widely in other countries. The UK currently relies on specifications set in 1969, when Asbestos Regulations came into force. In addition,

Mesothelioma RCN 27092020v1

we suggest that the health care workforce is taught about asbestos and its management, perhaps at induction and update days. We also propose that, when leaving the NHS, staff should be reminded that asbestos exists in most NHS premises and that asbestos-related illness is a possibility that should be borne in mind if the symptoms are present.

You can read the full report and appendices on the Mesothelioma UK website:

<https://www.mesothelioma.uk.com/mags/>.

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