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Full Length Research

"You Can't Do Anything Like You Used To": An Australian Study of the Implications of Asbestos-Related Disease for both Caregivers and Society

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Asbestos-related diseases have considerable physical, economic and social impacts on the person diagnosed along with their caregivers and family. However the social impacts have been a relatively under-researched area, especially in Australia. This paper reports on the thematic findings from a qualitative study of 26 men and women with an asbestos-related diagnosis and their caregivers in New South Wales, Australia as well as representatives from support group organizations. The participants confirmed that there is considerable functional disability and loss of mobility associated with the diseases, especially mesothelioma. The loss of mobility results in a very high level of dependency on caregivers, as well as substantial social isolation for both the person diagnosed and their caregiver. These major impacts on caregivers are one of the major concerns for the person diagnosed. Another serious and complex issue is associated with younger asbestos victims, particularly when young children are involved. The results indicate that government and policy makers need to provide better information and support systems for all sufferers and their caregivers. There is also a need for advance planning in order to cater for the wider effects of 'third wave' cases. A failure to address these needs and a reliance on a reactive approach could prove to be very costly.

Keywords: Socio-economic costs, policy implications, third wave asbestos issues.

INTRODUCTION

Exposure to asbestos has been conclusively linked to a range of life-threatening diseases including asbestosis, asbestos-related lung cancer, malignant mesothelioma and as pleural plaques, a chronic long term condition characterized by compromised lung capacity and function. The physical impacts of asbestos-related disease are well understood since the epidemiology and biology of asbestos-related diseases have been the subject of much research, internationally and in Australia (Leigh et al., 2002;

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Musk et al., 2007; Kanarek, 2011). The treatment of asbestos-related diseases, particularly chemotherapy and surgery has also been well researched. In contrast, there has been relatively little research into the social impacts of asbestos-related disease on the diagnosed person, their caregivers and other family members, resulting in a relatively poor understanding of these impacts (Hawley et al., 2004). Research to date has mostly been undertaken in the United States (Ochinko, 1999) and Scotland (Johnston and McIvor, 2000) and has focused on the experiences of people, predominantly older men, exposed to asbestos in an occupational setting - the so-called 'first' and 'second' waves of exposure to asbestos (Ochinko, 1999; Johnston and McIvor, 2000). Research into the social impacts of the emerging third wave exposures has been limited internationally and in Australia. Third wave exposures occur typically, although not exclusively, during or as a result of home renovations and repairs of asbestos embedded built environments such as school buildings and hospitals, which usually deteriorate over time (Olsen et al., 2011). Third wave victims are usually comparatively young, frequently working, and often with responsibility for young families. In addition, unlike earlier exposures, the third wave include a substantial number of women (Olsen et al., 2011). For example, Olsen et al. (2011) reported that 35.7% of female mesothelioma cases and 8.4% of male mesothelioma cases in Western Australia between 2005 and 2008 could be ascribed to home renovation.

In support of Olsen et al., (2011) findings of KPMG Consulting (2014, 2018) identified women asbestos-related sufferers as a public issue that warrants further exploration.

The prevalence of home renovation sufferers highlights the fact, in contrast to heavily regulated workplaces in relation to classifying and managing asbestos, that there is little or no regulation in relation to domestic buildings in Australia (Segelov, 2012).

The lack of investigation into the social impacts, especially amongst third wave sufferers, in an Australian setting is unfortunate. The aim of this study is to address this shortcoming by providing an examination of the social impacts on a group of men and women sufferers, their caregivers and their families in New South Wales, Australia. Importantly the experiences of those exposed in the first, second and third wave are included in this study.

The paper begins with an examination of asbestos-related diseases, a brief coverage of the epidemiological aspects of the diseases and their social and economic impacts. The next section outlines the methods used for the study followed by an examination of the findings. This is followed by a discussion of the implications of the study as well as some thoughts on how the social impacts of asbestos-related diseases can be better addressed.

The social impacts of asbestos-related disease

The paucity of studies examining the social consequences of asbestos-related diseases (Johnston and McIvor, 2000; Gorman et al., 2004; Walker and LaMontagne, 2004; Lee et al., 2009) is unfortunate given the extent of impacts arising from asbestos-related disease, particularly mesothelioma. Watson (2012) estimated the average societal costs of asbestos related diseases in Australia to be $1,076,920 (AUD) for cases involving fatalities and $2,064,070 for full incapacity cases. Social costs for both sufferers and caregivers did not form part of Watson's analysis.

Social costs are substantial since these diseases usually curtail the mainstream life of patients and their caregivers to a very significant extent (Johnston and McIvor, 2000) and worsen rapidly in a relatively short time after diagnosis. Even with treatment, a return to work or even to previous daily routines is difficult and usually impossible (Otis-Green and Juarez 2012). Daily domestic activities such as cleaning, washing clothes and shopping, as well as recreational activities such as gardening, sport and/ dancing become problematic (Gorman et al., 2004). There is also an increased dependence upon others for the meeting of needs (Johnston and McIvor, 2000). The inability to undertake activities of daily living can result in those diagnosed as well as their main caregivers withdrawing from other social activities. This withdrawal can arise for a number of reasons. For example, chronic and severe breathlessness restricts access to public places such as hotels, clubs, cinemas, particularly where people are permitted to smoke (Ochinko, 1999; Johnston and McIvor, 2000; Hawley et al., 2004; Clayson et al., 2005 ; Moore et al., 2010). This restricted access is further exacerbated when the patient is required to carry bottled oxygen. In addition, the physical and physiological impacts associated with asbestos-related disease can result in weaker family relationships and possibly the permanent loss of intimacy between partners (Otis-Green and Juarez, 2012). Those with a diagnosis and their caregivers may also experience a loss of attachment to and loss of companionship with their peer group (Gorman et al., 2004).

The isolation of sufferers and their caregivers may be further exacerbated by financial constraints arising from the loss of income often together with high medical and/or legal costs (Johnston and McIvor, 2000; Gorman et al., 2004; Hughes and Arber, 2008). A sudden drop in earnings and the inability to continue working is a common challenge experienced by asbestos patients and their caregivers (Gordon et al., 2000) and contribute to social impacts. For example, Johnston and McIvor (2000) reported, a 60-year old 'lagger' (or insulation applier) had their income reduced by almost 80%. The impact of reduced income is even more pronounced for the middle and younger aged patients emerging from the third wave. The loss of income as well as increased medical and legal costs suggests monetary support is crucial for sufferers and their families to maintain a minimum standard of living. Johnston and McIvor (2000) concluded that patients who received compensation experience a lesser impact than others. Concerns over finances also result in increased anxiety and stress amongst the people diagnosed with the illness, their caregiver and family (Lee et al., 2009).

The impacts from financial constraints are likely to be worse for third wave sufferers and their families. For example, in New South Wales, sufferers and families are not likely to receive support from the Asbestos Injuries Compensation Fund Trust (KPMG, 2014, 2018) or from the New South Wales Dust Diseases Board (DDB) since these only cover those who are diagnosed with illness as a result of workplace exposure.

Economic disadvantage may also be aggravated due to geographical location. Specialist care and associated medical services are often not available in rural or remote locations, and people living in these areas need to travel to some distant medical facilities in an urban area to access treatment. This travel entails additional costs and hardships for sufferers and care givers (Cappelletto and Merler, 2003; Lee et al., 2009).

This issue is particularly pertinent in Australia given the 'tyranny of distance' and the relatively small rural and remote populations. This is further aggravated by the fact that there are more asbestos-related disease sufferers per capita basis in rural and remote areas in Australia than in other countries.

Finally despite the expected third wave increase, there is very little understanding about when, and at what level, non-occupational mesothelioma might reach its peak.

Asbestos-related illnesses in Australia

As outlined earlier there are a range of asbestos-related diseases (Johnston and McIvor, 2000) that are characterized by a variety of symptoms including coughing, pain, breathlessness, gradual disablement, eventually leading to death in most cases (Hughes, 2006; Clayson, 2007). Mesothelioma, the most common disease, is particularly pernicious with a diagnosis usually resulting in the death of the sufferer within two years (Yates et al., 1997).

Although the incidence of all asbestos-related diseases is not comprehensively documented, mesothelioma has been tracked closely for quite some time in some developed countries. For example, Australia, which has the highest rate of mesothelioma in the world (Henderson and Leigh, 2011), has maintained a national register of its occurrence since 1980. For example in August 2012, there were 612 reported diagnoses of mesothelioma (Australian Mesothelioma Registry, 2012).

The number of cases annually is expected to fall post-2020 (Leigh et al., 2002; Phillips and Lindgren, 2010) when the number of years since the introduction of the asbestos ban exceeds the lower range of the overall latency period which KPMG (2014: 22) estimated to be 35 years. However, Olsen et al. (2011) warn any projected decrease in occupational-related mesothelioma is likely to be offset by the rise in third wave mesothelioma as a consequence of the popularity of 'do it yourself' (DIY) home renovation. Various recent media reports (for example: Mirror, 2010; Schmidt, 2013) and research findings (UWA, 2012) also highlight the vulnerability of the general population, irrespective of their age and gender as a consequence of the third wave because, in part, of the popularity of do-it-yourself (DIY) home renovation, particularly in Australia where "over 70% of homes built before 1965 contained asbestos" (Olsen et al., 2011: 274), This vulnerability is supported by a survey undertaken by the Australian Asbestos Safety and Eradication

Agency (2014) which showed that “four in ten DIY home renovators rate their knowledge of asbestos and its related dangers at moderate or below.”

METHODS

Ethical clearance and considerations

This study was cleared in accordance with the ethical review process of the institutional Human Research Ethics Committee and was conducted within the guidelines of the Australian National Statement on Ethical Conduct in Human Research. Individuals asked to participate in research regarding asbestos-related diseases can sometimes feel obligated to partake in the research and/or feel pressured to discuss private or sensitive topics (Allmark et al., 2009). The researchers in this study were cognizant that they were not known by the participants prior to commencement of interviews. To ensure this, as a consequence participants were treated in a highly sensitive manner. They were informed that there was no compulsion to engage in the research and that they did not need to discuss any facets of their experiences that they were not comfortable with. They were also informed that they could stop the interviews at any time. In addition, participants were also advised that counselling was available to them after their interview should the interview have raised issues that caused them concerns.

Design

This study used two methods, document content analysis and semi-structured interview, to determine the social impacts of sufferers and their care givers. These two methods were used in order to triangulate the data and allow the researchers to examine convergence and provide credibility of the findings (Bowen, 2009).

Document analysis involves the systematic procedure for reviewing or evaluating documents (Bowen, 2009) which can then be organized into major themes or categories (Labuschagne, 2003). The researchers used a comprehensive review of published and unpublished documents regarding asbestos-related illness and its impacts. These data sources included government policy documents, parliamentary proceedings, and commentary from books, academic journals and a range of websites. The document analysis underpinned the development of the questions used in the interviews. The in-depth interviews were conducted with either respondents who were currently diagnosed with an asbestos-related disease and their caregivers or other respondents closely associated with asbestos-related disease sufferers.

A semi-structured interview guide was developed by the researchers in collaboration with the research partners. The interview guide was then reviewed by the relevant Ethics Committee as part of the ethics application process. The interview guide was piloted via two preliminary one-on-one interviews with two representatives of Asbestos Diseases Foundation of Australia (ADFA). ADFA is a not-for profit organization offering support to people living with asbestos-related diseases and their family members, care givers and friends. Minor alterations, namely, question phraseologies, were then made to ensure clarity of questions.

Open-ended questions were used to explore key areas relevant to patients’ and care givers’ experiences of treatment engagement, including experience of support and primary/secondary and tertiary care, identified helpful/unhelpful aspects of the treatment and support experience, group versus individual experiences, factors that facilitated support and treatment engagement, experiences of care providers, government agencies and any suggestions for change.

Sampling and Recruitment

A non-probability sampling method was used to select interview participants via a non-random, convenience and snowball sampling method (Kitchenham and Pfleeger, 2002). A non-probability sample was considered appropriate for this study given the sensitivity of the issues being investigated and the serious medical conditions of the likely participants.

However, no statistical inferences should be drawn from this type of sample (Kitchenham and Pfleeger, 2002).

The names of potential participants were provided by the project partners. The first partner was ADFA. The other partner was a large, national firm of solicitors, Slater and Gordon Ltd, who have acted for more than 2,500 mesothelioma victims and their families over the 25 years to 2017. They have also acted for many others who have experienced asbestos-related lung cancer and asbestosis.

The sample

Interviews with individuals diagnosed with an asbestos-related disease and their families were undertaken during 2013-2014 with some follow up in early 2015. Interviews were also undertaken with representatives from support group organizations during the same time period. The participants were based in New South Wales (NSW), in both Sydney and the regions. In many situations, interviews were undertaken together with both the person diagnosed with an illness and their caregiver, who in all situations was also the partner. The researchers undertook twenty-six interviews, with eight taking place in Sydney suburbs, two in Newcastle, and the remaining 16 in regional NSW. Seven of the participants had been diagnosed with Mesothelioma, one with Asbestosis, and a further eight with pleural plaques. There were also six current caregivers, four past caregivers and two other people who had been exposed but not diagnosed.

Of the participants, six were men diagnosed with mesothelioma and five were men with pleural plaques. Three of the women participants had asbestos related diseases; one was diagnosed with mesothelioma, one with a asbestosis and the other with plural plaques.

The youngest person diagnosed with mesothelioma, a female exposed through third wave activity, was 37 at the time of the interview and the oldest; a male diagnosed with mesothelioma was 85. All of the males diagnosed with either mesothelioma or asbestosis or pleural plaques were exposed in the workplace between the mid-1950s and the mid-1980s. The remaining (women) were diagnosed with pleural plaques and was exposed to asbestos through the washing of their husbands' work clothes during the 1980s.

Of those males exposed in the workplace, eight worked in construction (often constructing power stations), one in a shipyard, one in the railways, one was an engineer on a ship and two worked in asbestos packing factories for James Hardie Limited, Australia's major asbestos producer.

DATA ANALYSIS

There was a considerable volume of data generated (in excess of 200 pages of interview transcript) that suggested a computer assisted analysis would be appropriate however a decision was taken to analyze the data manually.

For this study, thematic analysis was chosen over other forms of qualitative analysis such as narrative analysis, the biographic narrative interview process and interpretative phenomenological analysis because they are supported by explicit epistemological orientations. Thematic analysis applies to a wide variety of data sources and, in this case, the technique employed in the research interview, that is, semi-structured interviews, allowed the authors to use inductive and deductive approaches to themes, driven by the identified research questions

The face-to-face interview also allowed follow up questions that were the result of inductive reasoning which were the outcome from the observations, patterns and regularities that began to emerge during the interviews. Where these did emerge respondents from earlier interviews were then contacted again by phone and re-questioned in relation to any emergent themes that were not raised at the time of their initial face-to-face interview. This later process helped uncover important beliefs in regard to patients' and caregivers' perceptions about understandings in relations to health and legal services, for example. Together this sequential use of deductive and then inductive reasoning allowed the researchers to use what Dewey described as a "double movement of reflective thought" (1910, p. 79). Of particular relevance was the fact that respondents expressed similar ideas and concepts in completely different ways. For example, when talking about the social impact of a diagnosis, respondents expressed the loss of social mobility using a range of different concepts. One bereaved caregiver, Trudy, highlighted her husband's inability to engage in simple everyday forms of recreation:

Like Ben would have loved to have gone on his bike and gone for a ride, or just gone for a walk down to the beach. But he couldn't do it, like, so you have nothing. That is all your life is.

Another interviewee, Danny who was diagnosed with mesothelioma, spoke of the retirement he had planned but lost:

That was what I was going to do in my retirement, join the local bowling club. I was doing that for about one year. I didn't retire until I was 68. That was my plan cause [sic] I was pretty good at it. I was going to became a full time member and travel around and play against other clubs. But this thing *came up and I threw it all away.*

Doing the thematic analysis manually with fellow researchers helped identify similar responses described anecdotally by respondents because of the different vernacular ways in which the idea of loss had been expressed.

While analyzing the data, emerging themes were identified and then organized into an analysis template and the interviews coded accordingly. In order to ensure consistency of interpretation within the team, the first 10 interviews were coded independently by two researchers and the results compared. After confirming a consistent approach, the remaining interviews were also independently coded and triangulated by two members of the research team.

RESULTS

Five major themes emerged – the impact of the diagnosis; the importance of the family as a source of support; support and advice from external organizations and support groups; difficulty accessing information about the disease and about support groups. The themes are discussed below.

The impact of a diagnosis

The research confirmed that an asbestos-related diagnosis, particularly mesothelioma, is a catastrophic event and that the person diagnosed, their caregivers and families face these difficulties with considerable courage. The research identified a number of generic impacts experienced by all interviewees as well as a range of impacts specific to several distinct but related cohorts within the broader community. These cohorts comprise men with a diagnosis, men and women exposed previously to asbestos but not diagnosed, women with a diagnosis, caregivers (current and past), people living in regional and remote areas and younger people, including women, affected by the third wave of exposure to asbestos.

The research identified substantial variations in the medical, social and economic consequences associated with the different asbestos-related diseases. For example, people diagnosed with mesothelioma face a relatively short time between diagnosis and death. This period is also associated with a rapid physical deterioration in the health of the person diagnosed. Not all participants the diagnosed. Not all participants understood the implications of this diagnosis. One recently diagnosed participant appeared unaware of his likely rapid physical decline. Instead he and his caregiver (and partner) were planning activities which they were unlikely to be able to undertake.

Other participants were only too aware of the implications of a diagnosis of mesothelioma. Mal, diagnosed with mesothelioma, stated:

And given the type of disease, there is no cure – it is a terminal disease. It is not like others. There is no cure. When you are diagnosed – you are diagnosed. There is no escaping it – no curing it. In contrast interviewees diagnosed with other asbestos-related diseases spoke both of a sense of relief that the diagnosis was not mesothelioma and of their underlying sense of concern for the future.

Both men and women diagnosed, regardless of their specific disease, spoke about the loss of their enjoyment of life.

It slows you down yeah. You are weak, I try and go for a walk everyday but I started getting pain this year. You can't do much when you're weak. You can't do anything like you used to.

(David, diagnosed with mesothelioma).

Many participants were concerned about the impact of their disease on their partner. For example, David spoke of wanting to end his relationship with his partner, and caregiver, when first diagnosed in order to prevent her from suffering.

My lady, we don't live together but I see her regularly on weekends, I was thinking to myself why should she have to put up with what I've got? You aren't thinking very logically.

Unsurprisingly asbestos-related disease puts an incredible strain on caregivers, who are usually the partner. Many of the interviews were undertaken in the presence of both the person diagnosed and their caregiver and it appeared to the researchers, that while feeling completely devastated, caregivers were also extremely stoic and attempted to maintain a positive outlook.

Despite their stoicism it was obvious the caregivers were under enormous stress and often felt they could not leave their sick partner alone. This had a considerable impact on the caregiver's lifestyle and identity. Caregivers spoke of a life put on hold in order to care for a partner and loss of a shared future:

You know, your day revolves around taking the medication in the morning, your Doctor's *appointments, your tests, your this, your that there was nothing else other than hospital appointments and stuff like that. There is no other life. It just stopped!*

(Tracey, bereaved caregiver).

That is right – we were planning for retirement the whole time we were together. Because we used to sit over there and we used to say we were going to go backpacking around Australia and his friends used to say we would get from one Hilton to the other.

(Jean, bereaved caregiver).

This has an effect on these care givers character in that the diagnosis to their partners meant that their aspirations and future opportunities had also been removed for the foreseeable future both as caregivers and as survivors.

The constant care and support provided by the women caregivers was usually also at the expense of their own health:

It was a very big responsibility. It was. It nearly broke me as well.

(Tracey, bereaved caregiver).

I was half the size I am; I was as white as a ghost. I had big black rings under my eyes and I didn't realize it at the time how terrible I looked. I wasn't eating or sleeping. It was 24/7 care and even when he was asleep I would be laying there watching him to make sure his chest was still going up and down.

(Jean, bereaved caregiver)

Significantly a bereaved caregiver whose husband had been briefly exposed to asbestos as an apprentice also spoke of her feelings of anger at the injustice of his death:

I was very angry at the beginning, I can tell you that, I was very, very angry.

He never smoked a cigarette in his life. He wasn't a heavy drinker - he would have maybe a Jack Daniels on a Friday night when he finished work, he always ate healthy and look what happened to him. And you know what I used to do? I would go and eat McDonalds.

(Tania, bereaved caregiver)

The importance of family support

For many participants family members including children and grandchildren provided considerable support.

We have a magnificent family … When they knew I was crook (sick) I'd just got out of hospital - they turned up at home

(Mal, diagnosed with mesothelioma)

It was one of the blokes (guys) because he told me he was 64 and the other bloke (guy) was 68 (they had both been diagnosed with mesothelioma) … I said the first thing to do was get your family around you. You are going to have to get your family around you and sort that problem out".

(Liam, diagnosed with mesothelioma).

We have four daughters and heaps of grandkids and our great thing is having the family here or going to them.

(Mal, diagnosed with mesothelioma)

This type of support was seen as being essential, particularly given that some of those diagnosed lived in regional and remote areas where no formal administrative support mechanisms existed in proximity.

In addition to providing emotional support, families, the younger computer-literate family members to be specific, were seen as providing a valuable source of support and expertise when it came to the use of computers in general and the internet in particular. A number of the older participants expressed a general lack of confidence in their ability to navigate information using new technology although some, if they could get help, were compensated for loss of mobility and social isolation by access to some forms of information and communication technology:

This is only one big problem a lot of people our age [we] have no idea what to do with a computer.

(Susan, caregiver).

Given many of those diagnosed with mesothelioma and their care givers found it hard to use new technology to keep social contact with friends and family, it often meant that their families moved to be with them, if only for short holiday periods. This, in turn, meant that the social impacts and costs, both social and economic, were magnified across and throughout family networks.

The importance of external support and advice

Unsurprisingly, given the very significant impacts of an asbestos-related diagnosis, particularly mesothelioma, the majority of interviewees sought advice and support from external networks, organizations and legal and/or medical professionals. The nature of the support sought varied, however, several common areas of need emerged namely: financial support and advice, particularly with respect to workers compensation, medical expenses and claims for compensation, support with the day to day challenges associated with a diagnosis including reduced mobility, medical advice regarding treatment options and specialist support and finally psychological support around the implications of a diagnosis. Neither access to advice and support, nor the quality of advice received was consistent across the cohort of interviewees. Access to asbestos support groups, for example, was largely dependent upon the availability of a proximate group managed by a dedicated coordinator. The quality of legal advice regarding access to legal compensation was poor, particularly for claimants in regional areas. Likewise access to specialist medical services, and specialist asbestos related information, was more problematic outside major urban centers like Sydney and Newcastle. The interviewees identified a number of external sources of support and advice. A number of participants highlighted the importance of support and advice from the ADFA, a national asbestos support organization with a strong presence in NSW, especially western Sydney and the Central Coast of NSW. Several interviewees identified the DDB, a statutory authority established by the NSW Government pursuant to the Workers Compensation (Dust Diseases) Act 1942 as an important source of support and information. The support provided by solicitors specializing in plaintiff personal injury law and doctors, particularly in regional areas, was also mentioned.

The primary role of the DDB is the administration of fortnightly compensation payments and the reimbursement of medical expenses to eligible disabled workers, namely workers who contract a specified dust disease, including mesothelioma. In addition, the DDB also provides funding for a range of other services including cleaning and gardening and the provision of bottled oxygen that are designed to help maintain the quality of life of eligible disabled workers. Unfortunately the DDB is unique to New South Wales with no statutory equivalent in any of the other States and Territories. The majority of interviewees who were eligible for support from the DDB spoke positively of the experience and acknowledged the significant impact of this support on their lives.

Well I have been lucky as I get help from the DDB. Luckily, financially that is one thing at least I can't say I have had a problem. Financially I have been covered as the DDB has reimbursed me for everything. So I am not out of pocket. (Tracey, bereaved caregiver)

Despite the overall positive perception of the DDB, one interviewee commented that support from the DDB depended on the case manager:

Actually it depends on who you have as your case worker. We had a fantastic case worker first off and lucky we have a good one now but in between the one we had you would swear the money was coming out of his own pocket.

(Russell, diagnosed with mesothelioma)

A number of interview participants noted that they did not know how people coped without the support of the DDB.

I don't know how they do it. Like if it wasn't for the DDB reimbursing us for medications and travel, things like that – we would have gone under financially – and we were pretty well set up and we would have gone under. Not a doubt in this world!

(Danny, diagnosed with mesothelioma)

ADFA was another organization that received positive comments:

Yeah they [ADFA] have been terrific … Any problem you have, any questions or problem they sort it all out and the Dust board (DDB) has been really good with us.

On being asked how the respondent found out about ADFA:

First of all your friend Peter found it in the local newspaper about the meeting with Jane [a coordinator]. They gave us information about the Dust Board [DDB].

(Malcom, diagnosed with mesothelioma)

Support groups such as ADFA and Government organizations such as the DDB were vital for the respondents who made use of them. They were crucial in helping overcome social and economic isolation, both for those diagnosed and for their caregivers too.

Difficulty accessing information about the disease

Another emerging theme from the interviews was the difficulty in accessing information about the diseases, the assistance available and the continuing dangers associated with asbestos. Many sufferers found their disease had been misdiagnosed, and when finally diagnosed correctly, they had no idea about what they were dealing with. People found it hard to access adequate and relevant information when they were first diagnosed. It was also apparent that they often received inconsistent and confusing information, for example, some sufferers received contradictory feedback from doctors about the effectiveness of chemotherapy.

There is so little information out there and we were (when Rob was diagnosed) – I don't know but you can't put the word to it as being 'lucky' but like it is never lucky – but Karen B happened to be at Coffs Hospital at the time and she worked with Professor Morris who does all the liver and stuff and things like that. But if she hadn't by chance been there, we wouldn't have gotten onto Professor Morris or ADFA or anything like that (Tracey, bereaved caregiver).

Many of the respondents alluded to just how difficult getting accurate and timely information about asbestos related diseases was and also how they thought members of the medical profession were under-resourced when it came to asbestos-related diseases and diagnostics.

Difficulty accessing information about support groups

On being asked about how the respondent found out about ADFA:

A friend told a friend who is also a friend of ours that Robert (another sufferer who was a friend) was diagnosed. She rang me and said I spoke to Deb about Robert because her husband has pleural plaques and she is going to get in touch with you. We went down to the club one day she brought Deb over to me but I knew Deb because our daughters used to be friends and they went to school together - she got us onto Mary [the support coordinator]. (Sue, caregiver)

Many interviewees also noted that there was considerable ignorance about asbestos and related illnesses.

I'm in a sewing group and I told them that my husband had mesothelioma and they said from what, what is that? I said that it's from asbestos and they went oh how do you get that? (Sue, caregiver).

I think the further you get out west the less they know about it. People in the city know about it but in the country they don't know anything about it. (Michael, diagnosed with mesothelioma)

This highlighted the urban-regional divide between respondents that became apparent as the study went on.

Some of the participants also voiced the opinion that there is a need for providing sufferers with better information about compensation and the caregiver's allowance provided by Centrelink, an Australian Federal Government Department that disperses welfare payments and advice.

It also became apparent that the lack of awareness about the disease and the potential for illness amongst the community meant that problematic asbestos practices were still continuing.

People know next to nothing about it. If they do they think it's a man's disease – a 60 year old man's disease. That's what I remember about it when I was first diagnosed when I read up about it. Even today, I think a lot of people still consider it to be an older man's disease.

(Sara, 37, diagnosed with mesothelioma from 'third wave' activities)

DISCUSSION

The findings indicated that there are some actions governments and other organizations could undertake in order to assist those diagnosed with asbestos-related diseases and their caregivers. For example, support for families could be introduced in the form of a travel allowance to help a family to visit a sufferer who has been moved to a metropolitan area for treatment. This would be of help when a person resides in regional/rural Australia. This is currently a cost that is particularly relevant in Australia yet underpins the findings of Otis-Green and Juarez, (2012), Cappelletto and Merler, (2003) and Lee *et al.* (2009) that distance and remoteness have socio-economic costs for those who suffer from asbestos related diseases. But in this instance, it is not only an issue for sufferers and caregivers but also for wider family and other support networks.

Another initiative, of specific relevance to medical practitioners, could be the introduction of an awareness program for doctors.

The data clearly identified the need for an improvement in the diagnosis of asbestos-related disease as well as the consistency in what is communicated to the sufferers and their families about the prognosis of the treatment. For example, the interviews indicated there were uncertainties around the usefulness and impacts of chemotherapy as well as whether the removing of a lung was either preferable or feasible.

This additionally ties in with the argument made by Menzell (Australian Broadcasting Commission, 2015; 2) that *"medical experts often …have not delved into the background of a lung cancer to* *determine whether asbestos might have been a contributing factor or might have been the cause of it"* thereby potentially underestimating the extent of asbestos-related cancers.

Some interviewees also suggested they would have liked some information on diet and exercise. A publicly funded, centralized repository providing knowledge and information for asbestos-related disease could be one very useful, cost-efficient and effective initiative for policy makers to consider so as helping to reduce the stress on patients and their caregivers.

The results from the study also indicated that there was a very strong need for governments, policy-makers, insurance companies and medical and allied professionals to plan proactively for the needs of the third wave sufferers and their families and to publicize the dangers asbestos materials pose to home renovators so as to overcome general ignorance in this area (UWA, 2012).

A lack of planning will result in substantial socio-economic costs and different challenges for governments, and caregivers because these claimants appear, for a number of reasons, to be younger on average than the first two waves of asbestos-related diseases (Olsen et al., 2011).

CONCLUSION

Exposure to asbestos can result in a range of diseases that can cause considerable physical and social impacts on the person diagnosed, their caregivers and their wider family. The physical impacts are relatively well-understood.

However, the social impacts are under-researched and under-appreciated, especially in Australia. The findings from this qualitative study confirmed a high level of functional disability resulting in the loss of mobility for sufferers and a very high level of dependency on caregivers. The loss of mobility also resulted in substantial social isolation for both the person diagnosed and their caregiver. These impacts are especially severe for people diagnosed with mesothelioma, their caregivers and associated family and other networks too.

In regards to the generally younger third wave cohort, the social impacts are complicated by a range of additional factors, particularly the involvement of young children. Furthermore, many third wave sufferers and caregivers do not qualify for compensation unless they can prove that asbestos manufacturers owed them a duty of care in common law. The potential socio-economic costs for this particular cohort and their families are resultantly more problematic.

The study's results indicate that governments and policy-makers need to provide better diagnostic, socio-economic support information and support systems to sufferers and their caregivers, the medical profession and also more specific information about the dangers of asbestos to the general public too. This is a finding that may well apply to countries other than just Australia.

There is also a need for advance planning in order to cater for third wave cases and what they will mean for sufferers, their caregivers and for society as a whole. A failure to address these needs and a reliance on a reactive approach could prove to be very costly for all stakeholders.

Ultimately a binding international ban on asbestos would be ideal. However, given that there are still some countries such as India, Thailand, Russia, China and Indonesia (Gordon and Leigh, 2011) who are still manufacturing building and other products with asbestos in them and that some of these products could still find their way into homes and workplaces in other countries and because many existing buildings and products built prior to the late 1990's have materials with asbestos traces in them, Governments need to be proactive in their planning for third wave outcomes rather than relying on reactive legislative or only common law approaches (Segelov, 2012).

In addition, it is argued that a more generic approach to helping the caregivers and family of those diagnosed from the first two waves as well as the third wave will have more immediate yet similar outcomes too.

Such an approach will be socially and economically desirable in the long run (Australian Asbestos Safety and Eradication Agency, 2014).

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