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Dusted But Connected: A Case Study of Australian Online Community for People Affected by Asbestos-Related Disease

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Abstract

The impact of an asbestos-related diagnosis in Australia is multi-faceted and complex. Sufferers and carers face a range of life-limiting physical symptoms as well as the additional anxiety frequently associated with pursuing a claim for legal compensation. The result is that those affected by asbestos-related disease, their carers and families, often experience social isolation and a lack of social support. While traditional, face-to-face support groups can provide geographically proximate members with a valuable opportunity for interaction and support, they are not readily accessible outside major population centres and for people with acute symptoms of mesothelioma where all forms of social interaction, including travelling to and attending a support group meeting is problematic. Digital technologies and in particular online communities have the capacity to provide social support and thereby reduce the social isolation experienced by people affected, both directly and indirectly, by an asbestos-related diagnosis. Online communities have the potential to connect members of this community to experientially similar others. They have a particularly important role to play in Australia, a geographically large but relatively sparsely populated country characterised by a mix of urban, regional, rural and remote communities. This paper presents details and findings from a members' evaluation of a pilot project that involved the creation of the *Dusted Community*, a peer-to-peer online community for men and women affected by an asbestos-related diagnosis. It was hoped that the *Dusted Community*, by addressing social support directly, would provide substantial benefits both for individuals with an asbestos diagnosis and for their carers. The members of the *Dusted Community* expressed strong support for an online community and emphasised the unique nature and challenges associated with an asbestos-related disease and the importance of being able to share their own stories.

Introduction

Australia faces considerable challenges in meeting both the current and future health needs of its citizens notwithstanding that Australia's health care system continues to perform well when judged by the international standards of average life expectancy and rate of infant mortality (Armstrong, Gillespie, Leeder, Rubin and Russell, 2007). Research suggests that Australia's challenges include both an ageing population and "the growing burden of chronic illness" (Armstrong et al., 2007, p. 485). To this scenario must also be added the significant costs associated with advances in medical technology together with problems of health workforce supply and distribution (Armstrong et al., 2007). In addition there is considerable evidence of widespread and persistent inequality in health outcomes and access to health services (Turrell, Stanley, de Looper and Oldenburg, 2007). Many outer metropolitan, rural and remote communities face significant health workforce shortages, including general practitioners, nurses and some allied health professionals (Joyce, McNeil and Stoelwinder, 2006). According to Dixon and Welch, "The reality of living in rural and remote areas of Australia is that there are fewer health-care services" (2000, p. 257).

Despite the inequitable access to health care and other related challenges, digital technologies have the potential to provide a viable solution (Halvorson, 2012) to some of the issues outlined above. Telehealth (TH), for example, which "involves the use of information and communications technology to deliver health services, expertise and information over distance, geographic, time, social and cultural barriers" (Elliot et al., 2012) has been successfully employed in many countries since the 1990s. Online or "virtual" communities provide a further example of the potential of digital technologies to provide support to communities experiencing significant health-related challenges. According to Eysenbach, Powell, Englesakis, Rizo and Stern (2004, p. 1126) "[O]ne of the most promising aspects of the rise of e-health is the widespread availability of electronic peer-to-peer community venues, where people with common interests gather "virtually" to share experiences, ask questions, or provide emotional support and self-help. Virtual communities can be seen as mental health and social support interventions." Virtual communities that enable peer-to-peer support amongst members are commonly referred to as electronic or online support groups (Eysenbach et al., 2004).

A diagnosis of an asbestos-related disease is a devastating and life-changing experience, for the person diagnosed, for their carers, and for their families. Asbestos causes diseases such as asbestosis, pleural thickening, pleural plaques, lung cancer, and mesothelioma (Johnston and McIvor, 2000), with mesothelioma

being a particularly debilitating disease whose symptoms are frequently exacerbated due to late diagnosis (Tomasetti, Amati, Santarelli, Alleva, and Neuzil, 2009). The disease is also often confused with lung cancer with many mesothelioma patients reported to be receiving treatment for lung cancer (Arber and Spencer, 2013) despite the two diseases being inherently different (Moore et al., 2010). Those diagnosed generally face a rapid decline in health followed by death (Weder, 2010). In addition to a range of life-limiting physical symptoms including coughing, pain and breathlessness leading to gradual and severe disablement (Clayson, 2007; Hughes, 2006), it is not uncommon for sufferers to experience additional anxiety-associated issues related to pursuing a claim for legal compensation.

The severe impacts from asbestos-related disease are a major concern since Australia has the second-highest rate of mesothelioma deaths in the world, behind only the United Kingdom. There have been more than 10,000 deaths from the disease since the early 1980s (Asbestos.com, n.d.). It is estimated that there will be more 3,000 asbestos-related disease fatalities annually. For example, in 2011, there were an estimated 606 deaths caused by mesothelioma and further 125 deaths caused by asbestosis. The number of deaths caused by lung cancer and other diseases possibly related to asbestos exposure is unknown (Safe Work Australia, 2014). The per person costs including treatment, statutory compensation and judgements and settlements associated with mesothelioma were estimated to be $667,000, while for asbestosis the estimated total per person cost was $182,200 (National Occupation and Health Safety Commission, 2001).

Those affected by asbestos-related disease, their carers and families, often experience social isolation (Hughes and Arber, 2008). Beyond being merely an unfortunate emotional consequence of facing the many challenges that come with an asbestos-related diagnosis, social isolation has robustly been associated with a wide range of suboptimal experiences and outcomes and, ultimately, with higher mortality (Wagner, 2007; Reblin and Uchino, 2008). At the same time a number of studies have shown that social support can be protective for health (Reblin and Uchino, 2008). This paper presents details and findings from a pilot project that involved the creation of the *Dusted Community*, a peer- to- peer online community for men and women affected by an asbestos-related diagnosis. This first iteration of the *Dusted Community* took the form of an online support group for members. It was hoped that the *Dusted Community*, by addressing social support directly, would provide substantial benefits both for individuals with an asbestos diagnosis and their carers (Kozlowski, Provost, Tucker and van der Zwan, 2014).

This paper begins with an exploration of the literature around the relationship between social support and health as well as the use of online support groups. This is followed by an explanation of the methods and the results of an evaluation of the *Dusted Community* by its most important stakeholders - its members. To our knowledge, such an evaluation of an Australian online support group for people affected by an asbestos-related disease has not previously been published.

Social support for health in cyber space

The relationship between social support and health has been the subject of significant research, particularly during the last 30 years. Social support is a multidimensional concept. Reblin and Uchino (2008) make the distinction between the structural components of social support, like for example, belonging to a network or being socially integrated within a community and the actual social support transactions taking place between individuals. They also note that support can be further classified as instrumental or emotional (Reblin and Uchino, 2008, p. 201). The link between social support characterised by either a high quantity or a high quality of relationships and improved health outcomes is well documented (Reblin and Uchino, 2008). At the other end of the spectrum social isolation, defined as a limited number of interactions between a person and a social network, "has been identified as an independent major risk for all-cause mortality" (Reblin and Uchino, 2008, p. 201 citing House, Landis and Umberson, 1988). Other studies (Krause, 2006; Piferi and Lawler, 2006) have also identified the protective health effects of being a support provider within a community or social network.

The effectiveness of social support groups as well as the growing access to technology and rising health care costs have contributed to the increasing popularity of online support groups (OSGs) both as a replacement for, or supplement to, traditional healthcare (Eysenbach et al., 2004; Lederman, Fan, Smith and Chang, 2014). Online support groups are now commonly used by people with a range of health conditions to connect with peers who have similar health concerns and to exchange emotional support, experiences, and advice (Turner, Grube and Meyers, 2001). Growing research in this field indicates there are numerous benefits for participants in OSGs including the promotion of emotional and psychosocial wellbeing (Gustafson et al., 2001; Lieberman, 2004; Lieberman and Goldstein, 2005; Rodgers and Chen, 2005; Winzelberg et al., 2003), increased personal empowerment (Bartlett and Coulson, 2011), and improved competence for managing health conditions (van Uden-Kraan et al., 2008).

Coulson, Buchanan and Aubeeluck (2007) suggest that there are five categories of OSGs. The first category provides information support including advice, referrals to experts and/or directions to further information or resources. The next category - esteem support - offers encouragement or compliments, and anchorage within the community referring to the sense of belonging within that online community. The third category, network support, offers users a social support network. The emotional category refers to messages expressing empathy, sympathy, compassion and encouragement, while the tangible category refers to the provision of specific actions such as emailing information or physically meeting. Coulson et al., (2007) found that the majority of OSGs fell into the information or network social support categories.

OSGs enable users to seek and share information and knowledge relating to the management of their illness, empower members through the sharing of experiences and feelings, and enable members to educate themselves about their conditions (Chung, 2013; Buchanan and Coulson, 2007). They can also assist in building social networks (Barak, Boniel-Nissim and Suler, 2008) and can contribute to a feeling of normalcy by connecting with people who are experiencing the same health issues (Lowe, Powell, Griffiths, Thorogood and Locock, 2009). Other benefits of online support groups include the convenience to connect at a time and place that suits the user, overcoming geographical and temporal issues (Coulson et al., 2007) and assisting people with mobility challenges (Eichhorn, 1999). In addition, there is less pressure on people to reciprocate the giving of advice and support using OSGs (Takahashi, 2000; von dem Knesebeck and Siegrist, 2003) and people are able to 'lurk' until such a time as they are ready to participate (Preece, Nonnecke and Andrews, 2004). Another benefit that OSGs can offer in counterpart to traditional medicine is the emotional care, understanding and empathy that fellow patients can provide, and that medical doctors are often unable to satisfy due to a lack of personal experience, information, or time restrictions (Lederman et al., 2014). In this respect OSGs operate in a unique space not occupied by traditional medicine.

Despite the benefits, OSGs have been seen to exclude certain groups such as those without access to the internet or those who are illiterate or disabled (Finfgeld, 2000). There can also be long delays between responses which may cause anxiety amongst some members (Lamerichs, 2003). Alternatively, some forums are so active with posts it can become overwhelming for users (Han and Belcher, 2001). Another issue relates to the risk of misinterpretation as meaning can be difficult to discern without having access to non-verbal clues (Finfgeld, 2000). However, research by van Uden Kraan et al. (2008) found the use of emoticons

compensated for the lack of non-verbal cues and was considered satisfactory by users.

Another perceived issue with OSGs is that some physicians believe the availability of health information on the internet is problematic. There are concerns about a lack of quality control and validity, and of patient self-diagnosis through internet research based on possible misinformation (Coulson, 2005). It is feared that this could cause confusion, distress, or even detrimental self-treatment (Ahmad, Hudak, Bercovitz, Hollenberg and Levinson, 2006). However, research conducted by van Uden-Kraan et al. (2008) analysing 1,500 posts on OSGs for patients with breast cancer, arthritis and fibromyalgia did not find evidence of misinformation or incorrect information and concluded that this feared disadvantage of OSGs is unfounded. This was further supported by research by Lederman et al. (2014) who found that OSGs can complement institutional sites[1]. In addition, it appears that if unreliable or inaccurate information does appear it is often speedily removed and corrected by other members shortly after it is posted (Esquivel, Meric-Bernstam and Bernstam, 2006).

Another perceived problem of OSGs is that excessive use and over dependence may result in negative thoughts and an aggravation of pre-existing depressive tendencies (Takahashi, Uchida, Miyaki, Sakai, Shimbo and Nakayama, 2009; Demiris, 2009). Furthermore there are concerns about de-socialising or what Demiris has termed "progressive de-humanisation" caused by lack of human social interaction (2006, p. 183). Long term or excessive use of online social media can result in a preference for online relationships over human face-to-face relationships (Demiris, 2006). This is a particular problem when people are suffering health problems and the types of support that are needed cannot easily be found online (Chang, 2009).

There is concern too that health care professionals might be identified online and criticised by members of OSGs causing other users to delay seeking critical health attention as a result. Users might also delay seeking professional health due to an overreliance on OSGs (Finn, 1995; Mursch and Benke-Mursch, 2003). However these fears have been disconfirmed by research finding that criticism of healthcare professionals rarely occurs, that only 4 posts out of 1,500 contained clues of participants delaying visits to health professionals, and that there were no indications of users convincing others to switch healthcare professionals (van Uden Kraan et al., 2008).

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[1] Institutional sites refer to those sites established by government, non-government and business.

While posts about negative experiences may not necessarily be detrimental (Pennebaker and Francis, 1996), the reinforcement of this negativity by other participants may be (Johnsen, Rosenvinge and Gammon, 2002). There are also fears that OSGs may contain aggressive or socially inappropriate remarks, or that advice offered by people who are untrained could be damaging, especially for those who are emotionally vulnerable (Finfgeld, 2000).

Finally, the ultimate benefit of OSGs for users with cancer has been called into question because, despite the known advantages of OSGs, the overall quality of life of cancer patients has not been shown to be improved by participation in these groups (Gustafson et al., 2001; Winzelberg et al., 2003; Owen et al., 2005).

Influences on the use of OSGs

It is important to understand the ways in which people use online support and the factors leading people to preference online over face- to- face support in order to design, implement and monitor online groups. This understanding will then allow for the greatest benefit and smallest risk to participants.

A major factor determining the effectiveness of OSGs is emotional communication competence. Communication competence refers to a person's ability to extract and elicit social support (Heller, 1979; Sarason, Sarason, Hacker and Basham, 1985; Wentowski, 1981). Yoo et al. (2014), in a study of women with breast cancer, found that those with higher emotional communication abilities benefited from the giving and receiving of emotional support from online groups. The same exchanges however, were found to have detrimental effects on users with lower communication competence. This result led the researchers to recommend that health professionals consider different care guidelines depending on their patient's level of communication competence. Strategies should be developed to help promote the use of OSGs for those with high levels; for those with low levels, certain types of OSG interactions should be avoided and strategies implemented to support the development of communication competence.

It was also found that people who actively contribute, post comments and make connections with other users online are likely to receive greater benefit in terms of interactional empowerment, than 'lurkers' or people who only read messages (Petrovčič and Petric, 2014). Evidence suggests active posters are more satisfied with their online experience, and more empowered and self-reliant in terms of finding and exchanging information (Barak and Dolev-Cohen, 2006; van Uden-Kraan et al., 2008; Petrovčič and Petric, 2014). Yet, despite the documented

benefits of actively contributing to online communities, it is estimated that lurker-to-poster ratios run as high as 99:1 in some online forums, and in a study on health communities specifically, lurkers made up 45.5 per cent of participants (Preece, Nonnecke and Andrews, 2004). There are still benefits to be gained from lurking. Lurkers can assess whether their concerns are relevant and valid and can also obtain support and information from reading posts without actually revealing themselves or actively posting (Walther and Boyd, 2002).

In acknowledging there are numerous reasons for people to lurk, Preece et al. (2004) recommend improving online communities to make them safer, more interesting and more accessible environments for both posters and lurkers. Some suggestions included improved software and tools and upskilling moderators to ensure better interaction and the overall success of online communities.

The style of moderation can also be an important influence on the participation in OSGs. There are some styles of moderation that are acceptable in some types of OSGs but that are not suitable in others. Therefore, in order to increase membership and use of OSGs for health, it is important to choose a style of moderation that reflects the values of the online community (Mazat and Rooks, 2014). Through a study which examined moderation styles in online health communities, researchers found that direct forms of control, whereby members are provided with incentives, tend to be regarded as ineffective whereas indirect forms of control, that rely on relational interests and normative obligations, are thought of as more effective and acceptable (Mazat and Rooks, 2014). Positive or rewarding styles of moderation were thought to be more effective than negative or punishing styles. However negative styles were considered more effective when dealing with unacceptable behaviour on online forum sites (Mazat and Rooks, 2014).

Methods

The *Dusted Community* pilot project formed part of a larger research project examining the psychological, economic, and social impacts of an asbestos-related diagnosis on a sample of individuals and their families during 2013-2014. The research team worked in collaboration with a number of project partners and used oral testimony and data generated by participants to examine, document and understand the disadvantage experienced. Project partners comprised organisations with significant and practical experience of the impacts of asbestos-related disease in Australia and included asbestos support groups and a national firm of solicitors with a well-established (plaintiff) asbestos compensation

practice. Project participants were drawn from urban Sydney and rural areas between Sydney and the Queensland border.

Potential community members were identified and approached in collaboration with the project's partner organisations. Membership was not limited to people with a diagnosis but extended to include anybody affected by a diagnosis. In practice this meant that both current and past (bereaved) carers were invited to join the community. The research team consulted with partner organisations and potential members to come up with the name for the community, which became 'the *Dusted Community*' (http://dustedcommunity.net). 'Dusted' is a term used in Australia to refer to someone exhibiting physical symptoms resulting from exposure to asbestos fibres (e.g., "I knew I was dusted as soon as I saw the doctor's face").

Further consultation took place over a number of months in order to identify member needs and priorities. Through this process of interactive suggestion, reflection, and refining, the brief became to create a virtual community able to support those affected by asbestos-related diseases rather than a community about asbestos-related disease *per se.* As a consequence the *Dusted Community* evolved from an online source of information into a friendly, supportive online environment where members could interact, share their stories, offer and receive support from their peers. The idea of a separate area for Carers emerged during the consultation process. Members identified the need for a separate carers' space within the broader community.

The *Dusted Community* was established over several months on the v-team (vteam.com.au) web server and was opened to its first intake - of 'friendly testers' - in August, 2013. Discussion and interaction was encouraged by the community moderator (the second author). In keeping with the overarching principles of participatory action research that had been applied to the development process from the outset, evaluation of the *Dusted Community* by its members was a priority. In October 2013 members were asked to provide feedback and suggestions after their initial period of membership (Member Evaluation).

Member Evaluation

In October 2013, the *Dusted Community* comprised fourteen members. Four were members with an asbestos-related diagnosis, five were carers, and five were partner members (these were members of the research team and of partner organisations). Of the members with a diagnosis, three were male and one was female. Of the carers, all were female; three were current carers and two were

bereaved carers. As stated earlier the participants were drawn from urban Sydney and rural areas between Sydney and the Queensland border.

The moderator invited feedback from all (14) members of the *Dusted Community* via email. There were four questions or statements to which members were invited to reply; these were:

> 1. Please let me know if there are things you like, or that you don't like about it up to this point – and please be totally honest, that is what we are after from you 'early adopters'.
> 2. Are there things that don't work – or are difficult or confusing? Do you have any suggestions for things that are missing from the site, or things we should change?
> 3. We are hoping in the very near future (when we open the community to more members) to include some simple games and to show via a Google Maps 'pin board' where all our members live. Are there any other things you would like to see us include?
> 4. Another thing we would like to include is a section for people's stories (these could be a mix of video or sound recordings or plain text). Do you like that idea? Would you like to tell your story?

Formal responses were received from four members: one member with a diagnosis, two carers, and one partner member. Although this response rate may seem low, two of the fourteen members were involved with inviting and analysing the member evaluations and excluded themselves from contributing in this phase of the evaluation and thus the effective response rate was 33.3%. Also, as outlined earlier, it is not unusual for a considerable proportion of members in online health communities to be lurkers, and therefore not to actively contribute, at least for some time.

Responses were broken into discrete statements and assessed at that level. Statement content was categorised via three variables: topic (general, communal, or technical); valence (positive, negative, or equivocal); and, tense (past or future). Each statement was assigned to a single category on each of the three variables. With regard to topic, 'general' was the category to which statements about the site as a whole were assigned; statements referring to the working of the site in terms of the platform and its useability were categorised as 'technical'; and statements referring to interpersonal aspects were categorised as 'communal'.

Table 1: Evaluative statements by topic in the past tense (i.e., experience of the *Dusted Community*).

Topic	Positive	Negative	Equivocal	Total

General	5	0	2	7
Communal	5	0	0	5
Technical	1	2	0	3

As can be seen in the summary of categorised responses in Table 1 above, the majority of members' evaluative statements regarding their experience so far were positive. Indeed, from a total of 15 statements, 11 (73.3%) were positive and positive statements were received from all respondents. All statements regarding communal aspects of the *Dusted Community* were positive; one example of these is "I feel, despite the fact that it is only a small group, we are already starting to support/inspire each other" (Diagnosed Member 1).

Regarding the *Dusted Community* in general, again a majority (71.4%) of statements were positive and none were negative. One member wrote "So far, I think the website is great" (Diagnosed Member 1). An example of the equivocal responses about the site in general is "Still not terribly sure of its purpose other than as a Facebook type of site" (Carer 1).

Evaluative statements regarding technical aspects of the site were the exception to this positive trend with 2 out of 3 (66.6%) being negatively valenced. However, this may, at least in part, be due to characteristics of the membership in terms of age or computer literacy as was indicated by one member's statement "I quite often have trouble making sense of what goes where. Might be my age or my lack of computer literacy" (Carer 1).

Table 2: Evaluative statements by topic made in the future tense (i.e., potential of the *Dusted Community* looking ahead).

Topic	Positive	Negative	Equivocal	Total
General	6	0	1	7
Communal	8	0	0	8
Technical	2	0	0	2

With regard to the future potential of the *Dusted Community*, members' evaluations were almost exclusively positive, as illustrated in Table 2. Although experiencing some concerns regarding technical aspects of the site in the past, members seemed to be optimistic about the potential for improvement. In response to question 4, where the idea of using a video to tell one's story was raised, one member wrote "A video is great, I think it makes it a lot more

personal, and people will be able to connect more through a short video as opposed to a photo" (Diagnosed Member 1).

The single equivocal statement here was regarding the potential benefit of the site overall; that member wrote "Maybe that will take time. Maybe a Facebook type page is necessary. I don't know" (Carer 1). However, as is apparent from Table 2, every other statement looking to the future potential of the *Dusted Community* was a positive one.

The idea of facilitating members to tell their own stories seemed to be particularly important to the respondents. One member wrote, "I think the idea about telling your personal story is great, this after all is what is originally bringing us all together" (Diagnosed Member 1), another "I also think that an area for peoples stories is an excellent idea" (Partner Member 1). Similarly, the unique nature and challenges of asbestos-related diseases was a theme in several statements; for example, "Sufferers came in contact with asbestos many, many years before a diagnosis." (Carer 2). In summary, a final quote from one of the member responses: "Little steps, big results. Dusted Community is such a positive step forward to help people suffering from exposure to asbestos. Get it out there please!!" (Carer 2).

Conclusion

An asbestos-related diagnosis, especially mesothelioma, can often result in social isolation for sufferers, carers, and sometimes the rest of the family. This can be especially true in the Australian context where there are many people who reside regional, rural and remote communities located well away from the population centres. However, digital technologies and in particular online communities have the capacity to reduce the social isolation experienced by people suffering from an asbestos-related illness, and their carers. This paper reported on the evaluation of the pilot phase of the *Dusted Community*; the first such study of an Australian OSG for individuals affected both directly and indirectly by an asbestos-related disease. Members responding to an invitation to provide feedback on the *Dusted Community* evaluated it positively in terms of its utility. They also expressed strong support for further development of the site and were optimistic about the future potential of this online community. Members emphasised the unique nature and challenges associated with asbestos-related diseases and the importance of communal aspects, especially the idea of being able to share one's own story. This is reflected in the comment by Carer 2 - "I've just replied to [member's name] and

told her part of our story. I think it is a great idea. Sufferers and their families need vindication. They need to tell their stories."

The generally positive response clearly indicates that further funding should be forthcoming for the continuation and further expansion of the Community. In addition there needs to be an on-going evaluation of the Community. Unfortunately the number of people with asbestos-related illnesses is increasing and it is likely that a proportion of those affected will be younger and with a higher number of dependent children as well. These people will need support from government and non-government bodies and, ideally, from other men and women with a diagnosis, their families and supporters.

Although these initial results are encouraging, it should not be overlooked that this pilot study represents one small group of participants. Thus, caution should be exercised when making generalisations beyond this sample. Further work is both required and planned in order to establish the existence, nature, extent, and duration of any benefit of membership of OSGs in terms of social connectedness. Such research could also clarify whether or not these benefits apply across groups based on geographical location and specific health care issue.

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