

PUBLIC PERCEPTIONS OF CANCER CLUSTERS, ASSOCIATED EVENTS, AND APPROPRIATE INSTITUTIONAL RESPONSE

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Abstract

Cancer clusters are high-profile public health issues prompting public anxiety, but little is known regarding public perceptions of cancer clusters and the influences on them. In this article, we analyse public perceptions of cancer clusters and associated events within the Australian public, providing evidence-based recommendations for policy. We conducted and thematically analysed six focus-groups (four varying by age and education levels; two from occupations publicly associated with cancer clusters) during 2010 (total = 53 participants). Participants consistently discussed cancer clusters in reference to well-known events perceived as involving organisational concealment of information to ensure profit. Cancer clusters were associated with particular work practices or environments, but concern typically centred on perceived personal relevance. Participants deemed prompt, independent and transparent organisational investigation of cancer clusters as mandatory, nonetheless noting a tension between a responsibility to ensure workplace or public safety and to set appropriate fiscal limits to investigations. Perceived difficulties however, in 'disproving' cancer clusters and researching potentially contributory practices or products ultimately sustained enduring doubts about public safety.

A cancer cluster, defined as a "greater-than-expected number of cancer cases that occurs within a group of people in a geographic area over a defined period of time,"[1] usually attracts considerable public and scientific attention.[2] Typically, an informed and vocal community concerned about environmental factors influencing health identify and then report the event to health agencies.[3-5] The media's role in shaping public perceptions of cancer clusters has been noted, typically accompanied by observations of misrepresentation, or uneven coverage of events preceding and following scientific investigation of cancer clusters.[1,4,6,7]

The normative response of institutions and public health bodies to public concerns regarding cancer clusters is to gather scientific data regarding environmental exposure to possible carcinogens, and epidemiological data evaluating the target population against predicted incidences of cancer in a comparable population.[1] Such investigations, however, regularly fail to alleviate public concern regarding their own risk,[1,3] either because of differences in scientific and lay definitions of cancer clusters,[4] or in their judgements regarding a risk situation derived from different prioritisation and evaluation of diverse factors.[3,8] These discrepancies often widen rifts between parties and exacerbate public concern.[7,8] Furthermore, public responses to scientific findings regarding environmental risk may vary across demographic groups, with trust in authority appearing to play some role.[9,10]

Growing public awareness about the effect of the environment on individual health, and the increased capacity to detect, track and analyse patterns of disease via population datasets, may lead to increased reporting of suspected clusters,[11] with associated increased public anxiety and costs of investigation. Despite claims, however, that the most important challenge for public health agencies dealing with cancer clusters is to communicate effectively with the public,[12] little is known of the perceptions and beliefs regarding cancer clusters within the general public, within which concerns about cancer clusters arise. Such knowledge is vital to public health organisations, informing the development of appropriate evidence-based policy regarding managerial response to public concerns about cancer clusters. This study analyses and describes the perceptions of the general public as they discuss the definition of, cause, effect, significance and appropriate responses to, a cancer cluster.

Method

The University of Adelaide Human Research Ethics Committee (South Australia) approved this research.

Data collection

Six focus groups (total 53 participants) were conducted, providing qualitative data enabling exploration of people's knowledge and experience.[13] Sampling was purposive – four groups following a 2-by-2 design were drawn from the general population, and stratified by: (1) age (25-35; 55-65), because the presence of older persons can hinder young persons from offering opinions, and vice versa;[13] and (2) educational level (primary/secondary, tertiary), as this reportedly influences recall of cancer-related materials.[14] Two additional groups were drawn from populations previously associated within local media with cancer clusters (namely, nurses and fire-officers), as personal relevance influences perceptions of health-related environmental events (table 1).[10] All individuals were fluent English-speakers. Individuals who had previously received a cancer diagnosis, or worked or had previously worked at a location that was or had been the site of a cancer cluster investigation, were excluded because of probable heightened personal relevance.

Table 1: *Details and participant numbers for focus groups*

Group	No. Female	No. Male	Total
Young (25-35) with tertiary education	6	3	9
Older (55-65) with tertiary education	3	6	9
Young (25-35) without tertiary education	3	6	9
Older (55-65) without tertiary education	5	4	9
Nurses	6	1	7
Fire officers	-	10*	10
TOTAL	**23**	**30**	**53**

* 11 attended, but one never spoke, despite encouragement from workmates.

A social marketing agency recruited and hosted all groups except fire-officers, and provided a trained moderator. Fire-officers were recruited through the fire-services state office, participating during work-hours at the local headquarters. Informed consent was obtained, and participants provided with a small honorarium, which fire-officers donated to a workplace-organised charity for fire victims.

Sessions were audio and video recorded. Discussion covered knowledge, perceptions and beliefs about cancer clusters. Following focus group methodology,[15] participants determined the content of discussions, although prompt questions initiated or extended conversations, particularly regarding perceptions of named instances (eg. "What do you recall/think about what happened in that instance?"). At approximately the session mid-point, four brief videos of local (Australian) news coverage of cancer clusters, covering various locations (a fire-station, a public high school, a government office and a public hospital), were shown to prompt additional discussion.

Analysis

Sessions were transcribed verbatim and individuals de-identified. Transcriptions were entered into the NVIVO software,[16] and thematically analysed. Thematic analysis is a qualitative analytic method used in applied healthcare research for identifying, describing, analysing and reporting themes (representing patterns or sets of meanings) in data.[17] Our theoretical framework was explicitly essentialist or realist, as we aimed to understand and report the experiences, meanings and the reality of participants with regard to cancer clusters.[17] Texts were repeatedly scanned to identify similarities and differences in how cancer clusters, and media coverage of these, were presented or discussed. Themes identified on initial readings were reviewed and refined or collapsed through comparison across the dataset, and relationships between themes clarified. Quotes selected to illustrate a theme were compared, and the most concise and/or representative quotes presented,[18] with differences in speakers identified and the group of origin cited in brackets.

Results

Several inter-related and overlapping themes, capturing how participants (struggled to) understand and make sense of cancer clusters, were identified in the data. These were difficulties of definition, explaining the (increased) public interest, the sensationalist media, evil industries, ambivalence about scientific investigation and investigators, and enduring perceptions of (personal) risk. We indicate when themes were evident across all groups, surmising that this may indicate a dominant belief regarding cancer clusters within the general population. We caution however, that qualitative techniques do not justify conclusions drawn based on the comparative presence or absence of themes within particular demographic or vocational populations.

There was remarkable consistency in how groups talked about cancer clusters, particularly in the attempt to arrive at definitive positions. All groups struggled in defining cancer clusters, noting that distinguishing them from 'normal' rates of cancer was difficult.

> *Speaker* (SP) *1: What criteria, what incidence of cancer has to be a cluster?*
>
> *SP2: A higher proportion than cancer in the general public, be it a specific area or a workplace?*
>
> *SP1: How much higher than the average though?* (younger, no tertiary education) *An unusual number of cancer incidents in a particular context. Statistically it's a significant deviation from the norm that's related to a location or a context.* (older, tertiary education)

All groups stated that, over time, there was a greater awareness of cancer clusters, suggesting various explanations. These included increased coverage of cancer clusters by the media, the naming of cancer clusters as a phenomenon, as well as increased media coverage of cancer and acceptability of disclosing a cancer diagnosis.

> *SP1: Cancer clusters are more well known now than 10 years ago.*
>
> *SP2:* [It's] *probably just the media as such, taking more notice of it.*
>
> *SP3: It's identified now. … Now we've got a label for it, like we have become more aware about it … it is easy for us to then draw conclusions* (younger, no tertiary education).
>
> *Years ago when people got* [cancer] *they didn't want to tell anybody they had it, … but as years went on people started discussing it more because of the media, and people got an idea that 'oh hang on, it's not just me that's got it, it's other people.'* (older, no tertiary education)

All groups raised the possibility that cancer clusters reported within specific populations might be because of regular screening or health checks. Most suggested that awareness of more cases of cancer, because of an aging population or workforce, might be significant.

> *A lot more people out there have cancer, the awareness is there, and they're diagnosed earlier. … Particularly people like the fire department, they would have health checks … so they would pick it up a lot earlier. … Why were they all picked up at the same time? It could have been because they screened them all.* (nurses)
>
> *Now we're living longer, the cancers are in the foreground now and people are taking notice of it. … You used to retire at 65 and within two years after that, the majority of people who retired had passed away, so you didn't ever come into the area where cancers are more prevalent for your age.* (older, no tertiary education)

Media coverage of cancer clusters was also typically cited as prompting public awareness and discussion, and invariably concern about personal risk. This emerged most when media stories were seen to have personal relevance, either for those in occupations associated with reported cancer clusters, or when practices or places associated with cancer clusters were not occupation-specific.

> *I think the media plays an important part in the way that's sort of brought about … just talking about it at work, if someone's got cancer, you … start to think, well, 'so and so had that and so and so had this, … maybe we are more prone in our occupation to cancer.'* (fire officers)
>
> *SP1: I find it a bit frightening because I work in a building, everyone goes into a building at some time, that seems to be the common ground, so I really want*
>
> *to know what was causing the cancer in each instance so I can stay away from it.*
>
> *SP2: Those buildings … I wouldn't go in, I'd be reticent to go in, so I'd bypass it, … it may be a hoax or anything else, but I don't tempt fate* [laughs] *if I possibly can avoid it.* (older, no tertiary education)
>
> *Referring to the ABC* [Australian Broadcasting Corporation: see below] *situation, we might surmise rightly or wrongly that it was caused by electro-magnetic radiation, so those of us who are working in environments where we've been sitting in front of a computer for a great part of the day, to what degrees has that exposed us to potential cancer?* (older, tertiary education)

However, all groups criticised media accuracy and motives in reporting on cancer clusters, some observing that notification of suspected cancer clusters was not followed by information on subsequent events.

> *SP1: They* [media] *contradict, and provide misinformation.… Just sensationalise.*
>
> *SP2: They just go 'this is a cancer cluster and it's a good story' because how much information did they give you?*
>
> *Interviewer: Twenty-nine seconds.* [laughter]
>
> *SP3: Yeah, not much.* (nurses)
>
> *We haven't actually received any outcomes from any of those stories. … Nothing seems to have been released since.* (fire officers)

All discussed specific workplaces as relevant to cancer clusters, referring to three well-publicised adverse events, arguing that named companies (often motivated by profit) had denied or concealed information; moreover, that the ultimate revelation of potential public risk was because of concerted efforts of concerned individuals or groups. All but one named Erin Brockovich, some mentioning reported significant financial consequences to the relevant company.

> *SP1: Erin Brockovich, no-one did anything about it until she did. …*
>
> *SP 2: They did that write-up about what happened, how many millions of dollars the company had to pay and how many people were affected.* (younger, tertiary education)

Four discussed a reported cancer cluster at the Australian Broadcasting Corporation (ABC) studios in Queensland, Australia, usually voicing concerns that no explanation was forthcoming. Some implied that there was an explanation, but it was not currently available because of limitations in current scientific knowledge.

> *The ABC situation where it was really unexplained, … it's the unexplained bit that I get a bit concerned about too.* (older, tertiary education)
>
> *There's some cases, we don't even have the knowledge or the expertise to find out why they happen, like that ABC one, they haven't actually worked out why.* (younger, tertiary education)

In discussing probable industry responses to public concerns about cancer risk and/or cancer clusters, events associated with James Hardie (asbestos manufacturers who denied, then moved to limit liability for compensation to mesothelioma victims), were cited as exemplifying perceived reprehensible corporate behaviour, cover-up and denial of liability. Although this particular instance does not meet scientific criteria for a cancer cluster, participants raised them in this context. Moreover, their knowledge regarding the James Hardie saga and similar corporate behaviour often justified distrust of institutional responses to cancer cluster concerns.

> *Look at James Hardie, the way they tried to cover up for so long. … It was only through the individuals bringing it to the forefront of public attention that actually nailed James Hardie … there's so much against really admitting liability.* (older, tertiary education)

A ubiquitous belief, evident across all groups, was that named industries had attempted to conceal information and deny responsibility for any reported problems to avoid litigation or other costs, only reluctantly conceding following concerned individuals' exhaustive efforts prompting public outcry and action. It was also consistently assumed that such behaviours were endemic to all industries (including government).

> *SP1: With the ABC … my memory of it, they had been brought kicking and screaming to acknowledge that there was a problem in this building. … Someone has to go out on a limb and somehow stir up public emotion to actually get public consciousness aroused to bring government and private enterprise to acknowledge there's a problem. …*
>
> *SP2: I get the impression that we're not hearing a lot of people's concerns and that information has been dampened down and not given out to the public and you only hear it where people have been trying and trying and trying to get a voice heard and it's only after a long time, if ever, that it gets out. … big companies would be liable, and if it was proven that there was a cancer cluster.*
>
> *SP3: And then you wonder, … is it worth for the government for James Hardie to be sheltered from any sort of litigation because if the business goes down the spout, then presumably the government misses out on revenue and maybe the government is partly liable, maybe it's not good for all the insurance organisations and so on.* (older, tertiary education)

There was consensus, nonetheless, that organisations perceived to have increased numbers of cancer diagnoses in the workforce had a duty of care to respond to public concerns and undertake exhaustive investigation into environmental and personal work histories even where determining cause was thought unlikely. However, companies were typically perceived as motivated by concern for company image, not employees.

> *SP1: If enough people have the same thing, they've got to do an investigation. …*
>
> *SP2: I expect them to be quite extensive in their investigation, …* [considering] *everything …*
>
> *SP3: The first thing to do is to look at each individual, … their histories, where they're working, what type of work they do, what type of machinery they work with, and the environment they were working in.* (older, no tertiary education)
>
> *SP1: The company obviously has the ultimate duty of care…*
>
> *SP2:* [Employees are] *not going to be able to backlash if they [employers] cover their own backside, which seems to be the most common theme with most employers.*
>
> *SP3: To a certain extent it'd be, you've got to do something, you've got to be seen to be doing something.* (fire officers)

Groups held that informing the public of perceived higher incidences of cancer, by announcing an investigation, would always elicit panic, particularly among workers at the relevant site. They nonetheless argued that delays in providing information would additionally provoke anger at being disempowered or denied opportunity to have input. Establishing and using accessible lines of communication to inform those concerned about the progress and outcome of the investigation was viewed as likely to mitigate public concern, panic and spread of misinformation.

> *SP1: I think yeah, there will be panic, …* [but] *if they didn't tell you straight away, then there would be anger and frustration and much more. It would be a lot worse, and still panic. I would rather have the panic and control it. …*
>
> *SP2: Investigate us and test, to check if we are ok. … And put us at ease. … Ongoing communication, update us, how are things happening, what is happening so we don't have to listen to other people and spread the gossips and innuendos, stop the innuendoes, that's false communication, yes?* (nurses)

All groups insisted that investigations be conducted by independent and trustworthy sources with perceived expertise and a track record. Only then would reports that cancer clusters were probably products of random events or chance be deemed acceptable.

> *The Cancer Council… I would believe them, I would trust them. They're in the business of checking cancer things and testing things.* (younger, tertiary education)

However, regardless of probable acceptance of claims from trusted authoritative figures that a cancer cluster was not evident in a particular instance, all groups stated they would have enduring concerns about an ongoing risk. Many noted that they would personally continue to monitor the incidence of cancer that might signal additional evidence of a cancer cluster, some also insisting that management should do likewise.

> *SP1: I would be prepared to give some weight to a report which cleared the building, but being a careful*

person, I'd probably think, 'well yes, there's that ok, but there's sort of this little niggling concern.'

SP2: I agree. … I'd probably be prepared … to go back into that work situation, but I'd be on the lookout to ensure that the incidence of those cancers didn't seem to be statistically aberrant again. (older, tertiary education)

I would probably stay [working] *there, … if it wasn't obvious that something was causing it. As long as they kept ongoing testing.* (younger, no tertiary education)

Widespread scepticism about the scientific investigation of cancer clusters appeared to sustain concern of enduring public risk. Doubt partly reflected participant understanding of the processes constituting relevant scientific testing, with more extensive debate about what this involved occurring within groups with a tertiary education. Participants variously perceived that there were limitations of determining causality, some suggesting that it was, in practice, impossible to follow gold-standard testing procedures in a cancer cluster situation (i.e. to retrospectively and accurately identify the presence of all potentially suspected carcinogens, or the extent or significance of individuals' exposure to these). Some implied that difficulties in accurately determining the incidence of cancer in the target population (perhaps due to a transient workforce) would undermine assessment of relative risk. Scepticism was additionally supported with observations that workplaces once deemed safe could be labelled unsafe at any time, often in the context of discussions about new products or technologies.

SP1: If you're going to try to investigate causes … you need things like control groups and you're not actually going to get 30 people to work in this building for 15 years to see if they catch cancer or not, to see what the differences are. … It would be very difficult to go back and try to work out.

SP2: You're left with a very difficult way of knowing, showing cause and effect, and you can end up with a lot of litigation and a lot of costs and they've still got to prove it. …

SP1: How wide do you cast your net? … Where do you start? What are you looking for? Every year, there are 200,000 new substances discovered, … it's only after they've been out there and people start suffering … that we know that there's a problem. … To try to anticipate how each one may have negative effects on people and to test adequately, it's just undoable. …

SP3: When you say the building's cleared, they're saying that they haven't identified any cause of the cancer cluster, which could mean one of two things – that it's just a random event, or that it's a cause that they haven't identified … and I'm not going to bet my life on that. (older, tertiary education)

SP1: There are some workplaces, like call centres that the turnover of staff is immense. ... probably there's no-one there to say 'six years ago, well so and so had cancer, and then so and so had cancer.'

SP2: Most people in their lives are gonna change jobs a number of times and without having a way of actually tracking where people work, it's very difficult … Like there's one workplace where 20 people went through and they developed cancer, but they didn't develop it until 20 years after they were there. (younger, no tertiary education)

Various factors (including the number of potential products perceived to be possibly implicated, time-lag between exposure and diagnosis, difficulties of establishing cause and effect, public distrust of institutions, and financial costs of reviewing all persons and products potentially involved) were thought insurmountable obstacles to garnering definitive proof of workplace safety and ultimately dispelling concern. Although participants cited these factors as reasons to query reported conclusions, paradoxically, they also served as reasons to limit the scope of investigation.

SP1: Why aren't tests done every two years on all buildings for example?

SP2: Does that mean you test every single building? ... If you're going to test for that, what else? Where do you draw the line? (older, without tertiary education).

SP1: Testing is expensive, very expensive.

SP2: I doubt that any big companies would go to the extent of paying for check-ups every year.

SP3: It would cripple the business if they played every small chance.

SP2: Yeah totally.

SP4: What would happen to the health system as well? (younger, tertiary education)

Discussion

This qualitative study is the first to elicit and analyse the perceptions of the public (including individuals in professions publicly associated with cancer clusters) regarding cancer clusters and surrounding events. As a qualitative study, it did not aim to determine the prevalence of particular views, or to make claims regarding generalisability of findings. Data collection was limited to six focus groups (53 participants) conducted in one city within a dominant language group. Nonetheless, sampling across demographic and vocational criteria ensured that multiple perspectives were included,[11] allowing identification of factors influencing perceptions of cancer clusters in various settings. Further research regarding the perceptions of individuals with additional demographic (including ethnicity) and vocational criteria is warranted, including those directly affected by cancer clusters.

Even within this small group of participants, there was variation in how cancer clusters were defined, suggesting that there is no single 'lay definition' of cancer clusters, and highlighting the challenge in communicating effectively to a diverse public about suspected incidents. Findings confirmed observations that the media, though providing information, could contribute to public confusion and anxiety regarding cancer clusters.[1,19] Participants typically

interpreted information regarding risks and outcomes of cancer clusters in the light of previous knowledge regarding highly-publicised adverse events (e.g. those associated with Erin Brockovich, the ABC Toowong incident and James Hardie), which effectively functioned as archetypal events. Not all such events met scientific criteria for cancer clusters, indicating a discrepancy between public and scientific definition and assessment of risks, which may increase the probability of social conflict.[20] Commonly noted features of archetypal events were perceived inadequacies, even reprehensible corporate responses to public or employee concerns, and such knowledge shaped current responses.[2, 21] The role of public trust in public health authorities charged with investigating suspected cancer clusters has been noted previously.[9,10] This analysis suggests that public awareness of poor organisational responses to media-reported health scares might undermine public trust in investigations into cancer clusters, and this could be exacerbated by (real or perceived) inadequate media coverage of the processes and outcomes of investigations. Nonetheless, participants' beliefs about various deficiencies in the extent and accuracy of media coverage also worked to moderate their perceptions of the nature, magnitude, or significance of a reported event, suggesting that the contemporaneous media cannot be held ultimately responsible for shaping public responses to reports of cancer clusters.[22]

Public concerns appeared most pronounced when media stories provided limited or conflicting information, or were perceived to have personal relevance. In these circumstances, participants' concerns regarding personal risk because of fears of 'insidious exposure to carcinogens',[19] endured despite lack of evidence of environmental hazard. Such fears also appeared susceptible to extrapolation beyond the named event, particularly where practices or products thought present at the suspected cancer cluster site were deemed common in other, personally-experienced situations. If not appropriately acknowledged and addressed, this may increase public anxiety following reports of cancer clusters, and ultimately increase the frequency with which suspected cancer clusters are reported by a concerned community. Public health responses to reports of cancer clusters in environments with potential perceived relevance to wider sections of the community should therefore elicit, acknowledge and counter public concerns. In particular, while investigations are underway, it would be desirable that media coverage of cancer clusters avoid language that either explicitly or implicitly infers a heightened yet nebulous risk to the general public, rather confining commentary to known facts and noting relevant contextual information.

To some extent, cancer clusters could represent one example of public confusion about how to apply population data to the individual, or the differences between association and causation. Therefore, the dissemination of public educational messages about these factors combined with information about the difficulties in, or low probability of definitively identifying a cause, might defuse speculation involving more sinister or devious explanations for scientific reports that do not reveal cause.

Faced with notification of a suspected cancer cluster within a workplace, participants considered that employers must undertake prompt, transparent, and independent investigation. Further, that panic, though inevitable, might be ameliorated by rapid and ongoing consultation and communication with those concerned. As the perception of risk implicitly includes assessment of consulted experts,[23] ensuring and communicating the independence of investigators, and reporting the process and outcomes of investigations, could counter scepticism about the perceived trustworthiness of reported outcomes.[12] Such measures are unlikely to reassure all however, in part for the reasons discussed above, but also because of differences in individual assessment of acceptable levels of risk, or awareness of limitations of scientific investigation. Given that some concerns were predicated upon particular misapprehensions regarding the nature of scientific enquiry into cancer clusters, clear communication of the scope and rationale of any scientific investigation may help allay some fears.

These participants actively and collectively worked to make sense of available information, drawing upon their shared accumulated knowledge of events, processes, stakeholders and outcomes perceived to be relevant.[24] Although able to identify various possibly relevant contributory factors to notification of a suspected cancer cluster, participants acknowledged the impossibility of exhaustively testing everything and everyone following said notification, citing the prohibitive costs this would entail to businesses and the community, and considering that this constituted acceptable justification for limiting the scope of investigation. Accessing and disseminating varying opinions within the community about cancer clusters (specific instances and general phenomena) might serve to mitigate the impact of concerned citizens who reject specific scientific findings and lobby for costly and ultimately inconclusive further investigation.[4] Ultimately, identifying and specifically addressing public concerns may prove the most acceptable, effective and responsible strategy to guide and constrain the scope of subsequent investigation.[25]

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