

***“ You Have to Deal
With the Public
Perception as Well as
the Reality” : Public
Perceptions of
Cancer Clusters***

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Cancer clusters

‘The observation of a number of similar illnesses, and the perception that the number is excessive’

Cancer clusters exhibiting spatial and/or temporal clusters receive the most public and scientific attention ¹

The media is instrumental in shaping public perceptions, but often represent events inaccurately or unevenly ²⁻⁴

Typical institutional and public health body responses to cancer cluster concerns

Gather scientific data on

- environmental exposure to possible carcinogens
- epidemiological data evaluating target population against predicted cancer incidence in comparable population⁵

AIMS OF STUDY

To report perceptions of cancer clusters in a general public population regarding the

- cause, effect, and significance of...
- appropriate responses to...

cancer clusters

METHOD

Participants

- General Public aged 25-35, with Tertiary Education
- General Public aged 25-35, without Tertiary Education
- General Public aged 55-65, with Tertiary Education
- General Public aged 55-65, without Tertiary Education

- Fire-officers (no age or educational restrictions)
- Nurses (no age or educational restrictions)

Participant detail

GROUP	No. Female	No. Male	Total No.
Young with Tertiary Ed	6	3	9
Older with Tertiary Ed	3	6	9
Young without Tertiary Ed	3	6	9
Older without Tertiary Ed	5	4	9
Nurses	6	1	7
Fire officers	-	11/10	11/10
TOTAL	23	30/31	53/54

4 SHORT VIDEO CLIPS

1. Cancer cluster fears (fire station),
December 18, 2007 (42 secs)
2. Cancer cluster fears (government office),
May 8, 2008 (1 min 24 secs)
3. High School cleared (school),
January 15, 2008 (28 secs)
4. Breast cancer 'cluster' random, says report
(hospital), November 25, 2008 (1 min 25 secs)

Process and Analysis

- study prompt questions reflected the aims of the study
- all sessions were video-recorded, then transcribed
- all names and identifying information changed
- data were thematically analysed
- different colour quote = different group quote

Difficulties defining Cancer clusters

A group of people who are in the same workplace where they all get the same cancer

A group of people exposed to the same thing, toxin, whatever, ... by different workplaces

Statistically it's a significant deviation from the norm that's related to a location or a context.

Difficulties defining Cancer clusters

What criteria, what incidence of cancer has to be a cluster?

... How much higher than the average?

Archetypal CCs: Erin Brockovich

Erin Brockovich in America, she found a cancer cluster, that's what sticks in my mind.

What about Erin Brockovich?...

No-one did anything about it until she did ...

They did that write-up about what happened, how many millions of dollars the company had to pay

Archetypal CCs: the ABC

The ABC one [yeah that's the famous one], the ABC situation where it was really unexplained

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.

Look at James Hardie, the way they tried to cover up for so long, ...It took a long time to get it out of Hardies, they were kicking and screaming, ... there's so much against really admitting liability.

A lot of it comes down to money over people.

And maybe the govt is partly liable, maybe it's not good for all the insurance organisations, ... it's in their interests just generally to keep all that under wraps.

No organisation would want to know or be involved in saying you have a cancer cluster with that organisation, because there's a lot of fear around litigation associated with that.

I think the organisation will do everything in their power to prove that it isn't connected or they have no responsibility

Increased awareness

It's identified now ... now we've got a label for it, ... It is easy for us to then draw conclusions

Probably just the media as such, taking more notice of it.

Cancer awareness/aging population

I feel like cancer is everywhere because I just hear about it all the time.

It's probably more noticeable now because more people are dying of cancer because they're just living longer in the first place

Screening

Particularly people like the fire dept, 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.

Media

Just because it's in the media, it comes up in conversation

Initially if I saw one of those programs, I would say that's a load of hoo ha, but having watched 3 or 4 now, ... it does make you aware and think further.

Media

They contradict, and provide misinformation

So you wonder then, what is the true story?

How do you know then?... They don't give you any information [just sensationalise]. They just go 'this is a cancer cluster and it's a good story' because how much information did they give you [29 seconds] [laughter] Yeah not much.

Personal relevance

I find (media stories) 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.

With those buildings... if I knew about it ... 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

Miners: radiation, silicon–lung; **Vietnam:** agent orange–cancer; **Port Pirie/Augusta:** lead smelters–bowel; **Construction:** silico, asbestos, chemicals, sunlight–lung, skin; **Marine industry:** pipes, electricians–cancer; **Maralinga:** radiation–cancer; **Offices:** phones, electricians, computers–breast, brain; **Fire-fighters:** fire extinguishers, heat, nano particles–cancer, testicular cancer; **Machine oils–stomach, cancer;** **Medical staff:** toxins, chemo, electricians, radiation–cancer; **Wood-workers:** dust particles–nasal cancer

POWERLINES ELECTRICAL EQUIPMENT

Appropriate organisational response

If enough people have the same thing, they've got to do an investigation

Go through (individual) cases, through 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.

Dealing with the public

To a certain extent it'd be, you've got to do something, you've got to be seen to be doing something You've got to deal with public perceptions, ... you have to deal with the public perspective as well as the reality.

Investigate/communicate

To investigate us and test, to check if we are OK... And put us at ease. ... And communication. 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?

..., if they had a helpline or something like that set up, that you could just find out a bit more information on the specific incident, it would be helpful.

Trusted investigators: Independent

*they shouldn't have individual biases and interests
the CSIRO or somebody like that ... it would come
down to whether I trust him. ...*

*the Cancer Council ... I would believe them, I would
trust them. They're in the business of checking
cancer things and testing things.*

*the Cancer Council or, a government body as well,
yeah something that's actually probably be around in
40 years time so that you can hold them accountable*

Believe the report: lingering doubts

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.

I'd 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

Limits of science

I'm sceptical of the tests, because they can't even tell you definitely whether the mobile phones, the radiation will give you cancer. ... they can read the radiation,... but is that what's caused the cancer cluster cancer or is it something else?

If you're going to try to investigate causes and all that sort of stuff in an experimental way, you need things like control groups and ... you can't really, well it would be very difficult to go back and try to work out.

Limits of science

When you say the buildings 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.

Unsafe previously 'safe' practices

Panel beaters painting booths; Pest extermination; Nurses handling substances/x-ray procedures; Fire-fighters without airsets; Sheep dip; Handling chemicals in science labs; Cutting corrugated asbestos fences; Discarding factory wastes; Smoking; Renovations without checking or protecting for asbestos; Removing lagging from pipes; Using hydraulic oil

Unknown effects of the 'new'

There's also probably some greater risks with the new technologies that no one understands

We're also introducing lots of new stuff that we won't know about until another 20 years from here

Balance panic with information

I think yeah, there will be panic, I don't think you could say there wouldn't be, 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 ... if you're told 2 years later, you've had no voice in saying what you would have liked or how it would have helped you. It has just taken that completely away.

The costs of unlimited investigation

How wide do you cast your net? To test adequately, it's just undo-able.

Testing is expensive, very expensive. ...

I doubt that any big companies would go to the extent of paying for check up every year

It would cripple the business if they played every small chance [yeah totally]

What would happen to the health system as well?

Conclusions

Public awareness of poor organisational responses to media-reported health scares appears to undermine public trust in investigations into cancer clusters

Ensuring and reporting independence of investigations may counter this, but such measures are unlikely to reassure all

Conclusions

Workplace organisations are deemed responsible for prompt, transparent, and independent investigation of cancer clusters

Rapid and ongoing communication with employees is recommended

Appropriate media coverage of the processes and outcomes of investigations may facilitate improved public trust in organisational responses to suspected cancer clusters

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