

Reflections on overdetection: longitudinal qualitative follow-up after mammography decision aid

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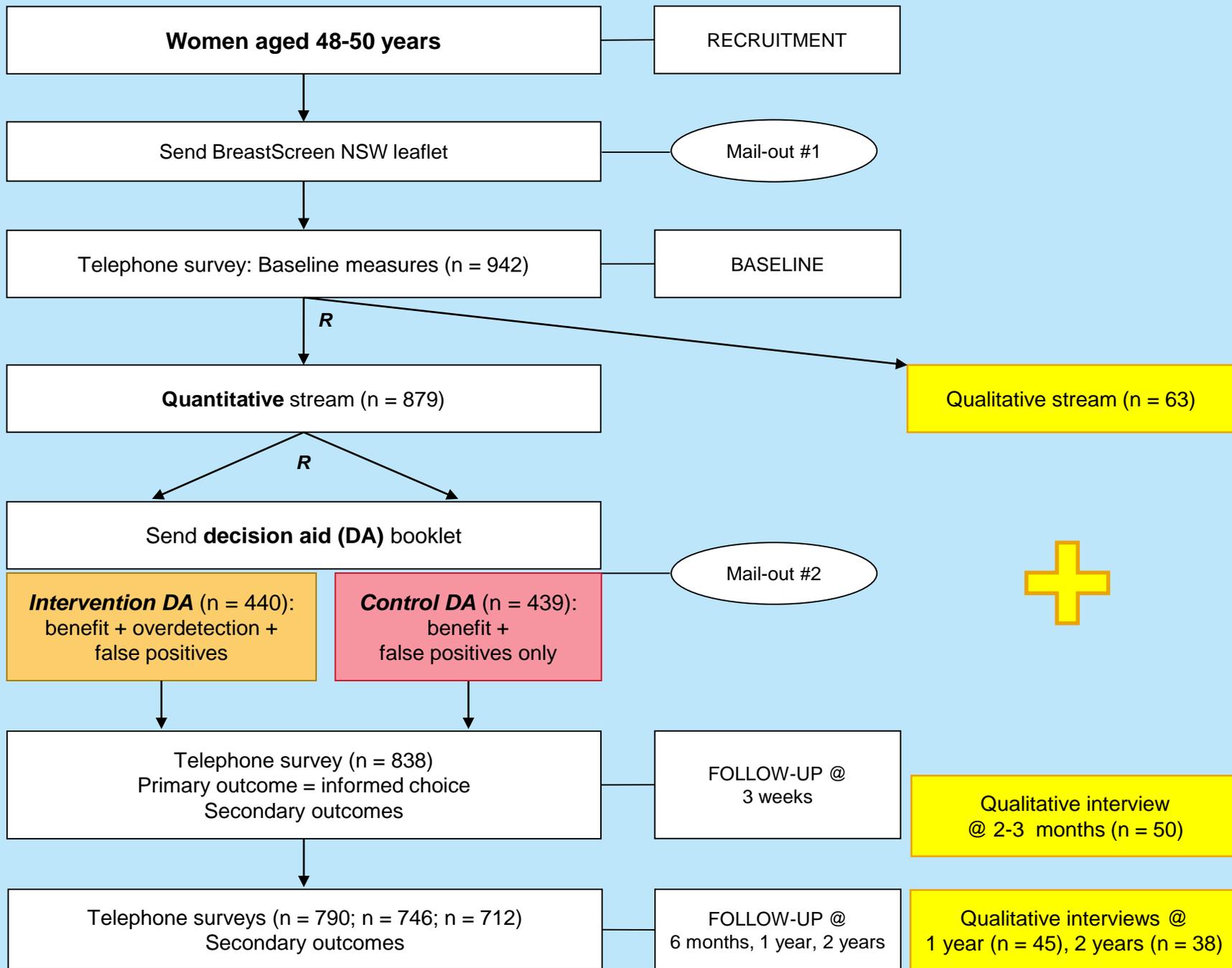
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INTERVIEW TOPICS

- › Reaction to DA (general impressions, unclear/surprising bits)
- › Perceptions of breast screening (pros & cons, overall attitude)
- › Response to overdetected (salience, clarity of info, influence)
- › Attitude to informed decision making for breast screening
- › Influence of DA on views & decisions about breast screening
- › Other factors of influence (family, friends, doctors, media)

- › Decision re screening (action in response to being invited etc.)
- › Experience of screening (having mammogram, getting results)
- › Reflections on DA, other info received, & study participation

KEY POINTS FOR TODAY

- › Intervention group gained new knowledge about overdetection
 - *Though not every woman fully understood / engaged with it*
- › For some, this info significantly affected attitudes & intentions
 - *Whereas others were unconcerned (& remained positive)*
- › Over time, knowledge remained but other effects ‘washed out’
- › Most women favoured presenting balanced info on screening (including harms) to encourage informed decision making

RESULTS

- › Info about overdetection was new, surprising, eye-opening

“I didn’t know... the overdetection... the whole thing about them being treated for something that might not have ever become a problem. You know, like the whole idea of you just dying of old age, and there being a problem there but it’s not what’s going to cause your death...

Being treated for something that’s not going to kill you basically. I suppose the whole idea is that you don’t know that it’s not going to kill you... (laughs)... I just remember thinking, that’s quite a few ladies who have had treatment that didn’t really need to have treatment...

It might be something that never gets beyond a certain size and... it’s never going to harm you.”

RESULTS

- › Info about overdetection was new, surprising, eye-opening

“Just the idea that the screening picks up cancer that aren’t ever going to cause any problems. That was eye-opening...

You could be diagnosed with a cancer and then probably have invasive surgery to remove something that was probably never going to bother you in the first place. Yeah, that’s very surprising... It made me think, I wish they could find a way to decide whether the cancer was a problem before they took it out. And I was surprised that that’s not always possible...

To be diagnosed with something that... may never have caused any trouble. But yet you’ve had surgery... So I guess that’s a definite con.”

RESULTS

› Overdetection info led some women to question screening

“I had no idea that they were actually operating on a lot of cancers which weren’t going to affect you and could have remained where they were. I was actually quite shocked by it. And it’s really made me think twice... because I live alone, it’s the time off work, it’s the money... Is it better not to know than to know and go through it all...

I was thinking, I’ve just turned 50, I should go have a mammogram... I still would say, yes you should have the screening done because if something does show up it can be investigated further, but emotionally, I’m thinking well I really don’t know if I am prepared to take those steps, or whether ignorance is bliss. I can see pros and cons... I’m just kind of sitting on the fence at the moment...”

› Overdetection info led some women to question screening

“Would you say that it changed your feelings about breast screening? Definitely. I felt before, you went and got a mammogram and you had a fairly clear path forward: yes, you did have it - no, you didn’t have it. I thought it was more clear-cut. Whereas now I can see that that isn’t the case, and in fact it may put you in a place where you’re having interventions or high levels of stress and anxiety for no reason...”

Has the information booklet made you feel more sure or less sure about what you want to do?

Overall I think I’d say it’s made me feel less sure... before I was quite reasonably confident that getting a mammogram was the way to go. I mean the TV ads would have suggested that. Now I’m less sure...”

RESULTS

- › Women decided they would still screen, despite the risk of overdetetection, because other factors were more important...

*“Does the idea of overdetetection change your feelings about screening?
Not really. I’d still rather it was removed. I guess it’s like having a skin cancer taken off, that’s not really going to cause – well, they don’t know whether it’s going to cause problems or not. They remove it just in case”*

“My girlfriends that are a similar age are saying, oh you should – we’re going to go. They booked an appointment at the same time so they could go together. So I guess that would influence me because my peers are doing it and, you know, perhaps then I should, I really should”

“I wouldn’t ignore the advice of a doctor to go and have screening done.”

RESULTS

- › Women decided they would still screen, despite the risk of overdetection, because other factors were more important...

“In the end after weighing up both sides of it I thought, well, what do you want to do? Do you want to have a lump there and not have it detected and die? No, you don't. So you've got the information. Yes, there can be overdetection, but you're much better having it than not having it.”

“Being treated for a cancer that might not kill you... radiotherapy and chemotherapy and surgery are not fun... it was very interesting... but... I myself would rather still know and you take that risk. 'Cause my grandmother had breast cancer and I guess it's sort of there in the back of your mind that it's in the family, so you'd rather know than not.”

RESULTS

- › Most women favoured presenting balanced info on screening (including harms) to encourage informed decision making

“How do you feel about being told you can choose whether or not you’d prefer to be screened, as opposed to simply being told you should? Well, I feel a little bit more like they’re treating you with, you know, that you’re an intelligent person. You can actually make your own mind up if you have the information available.”

“You tell me I should do something and chances are I won’t do it. You give me the choice and provide me with the information, and I can make an informed decision myself. So I think that’s better than being told, you need to do this”

RESULTS

- › Most women favoured presenting balanced info on screening (including harms) to encourage informed decision making

“On the one hand knowledge is power, but on the other hand, making that choice is obviously not as easy as it was before... In saying that, if I’d found out after having the breast screen, having the lump... and for them to turn around and say, in some instances this happens... I would have been absolutely furious that I hadn’t had the information prior.”

“Screening is still important... making the point that there are these cons... that you really do need to bear in mind... I didn’t feel like it was trying to convince me not to be screened. I suppose I went into it with a mindset of, I’m going to be screened... And I didn’t feel swayed. I felt – I know empowered is such a clichéd word, but I felt more educated.”

SUMMARY

- › Longitudinal qualitative study, embedded within RCT, provides unique opportunity to examine women's thoughts & feelings about breast screening over the course of 2 years after a DA
- › Intervention group gained new knowledge about overdetected
- › For some, this info significantly affected attitudes & intentions
- › After 2 years, most women had screened or still intended to
- › Most women favoured presenting balanced info on screening (including harms) to encourage informed decision making

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Decision Aid and papers: <https://ses.library.usyd.edu.au/handle/2123/16636>