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A QUALITATIVE STUDY EXPLORING THE INFLUENCE OF CANCER LABELS ON GENERAL PUBLIC'S PREFERENCES

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Decision-making in cancer

- Cancer therapies come at a high cost
 - Increased burden on healthcare system
- Economic evaluation of therapies
 - CUA ($\Delta\text{cost}/\Delta\text{QALY}$) recommended

Whose preferences?

- General public preferences
 - Value hypothetical health states
 - Maximize societal preferences
 - Operate behind a veil of ignorance
 - Not informed and consider it to be ‘dread’ disease
- Patient preferences
 - Direct experience with the disease
 - Minimal changes to their health can be captured using PROMs

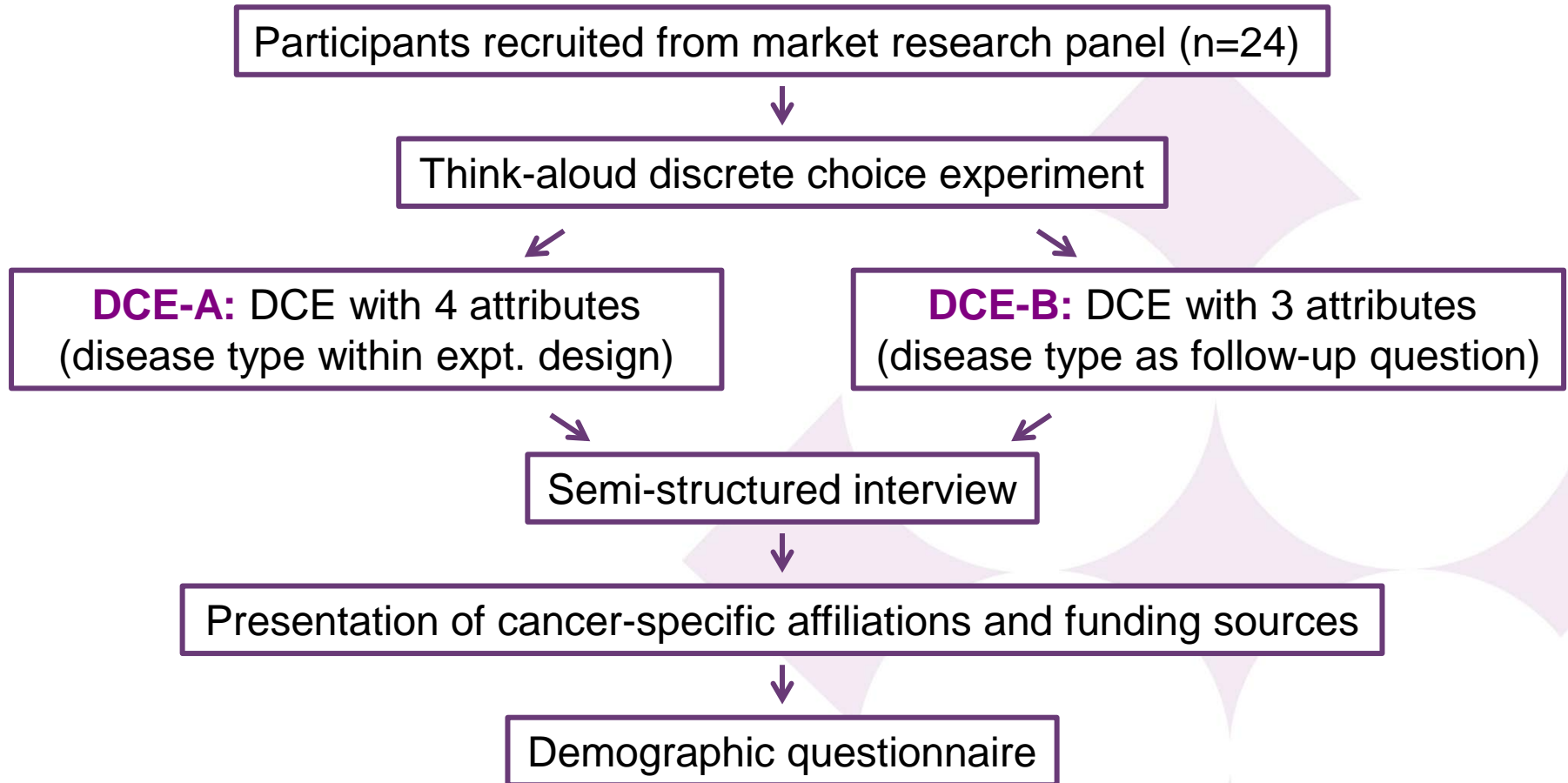
The impact of cancer labels on preferences

- Mixed results reported
 - No differences (Gerard et al., 1993)
 - Lower values for non-labelled states but not for breast cancer states (Robinson & Bryan, 2001)
 - Lower values for stomach cancer states (Rowen et al., 2012)
 - After adjustment for the label and severity, significant reduction in more severe states

Study objective

- Explore the effect of cancer and other disease labels on general public's preferences
- Determine if disease labels:
 - Introduce unwanted emotions and stereotypes
 - Clarify assumptions

Methods



DCE versions

DCE-A

	Scenario A	Scenario B
HS before treatment	Usual activities: unable to perform Pain: moderate	Usual activities: unable to perform Pain: extreme
HS after treatment	Usual activities: some problems Pain: moderate	Usual activities: some problems Pain: moderate
Duration of life	5	10
Disease type	Colorectal cancer	Type 2 diabetes

Which scenario do you prefer?

A

B

DCE-B

	Scenario A	Scenario B
HS before treatment	Usual activities: unable to perform Pain: moderate	Usual activities: unable to perform Pain: extreme
HS after treatment	Usual activities: some problems Pain: moderate	Usual activities: some problems Pain: moderate
Duration of life	5	10

Which scenario do you prefer?

A

B

Would your answer change if the scenario you selected pertained to colorectal cancer?

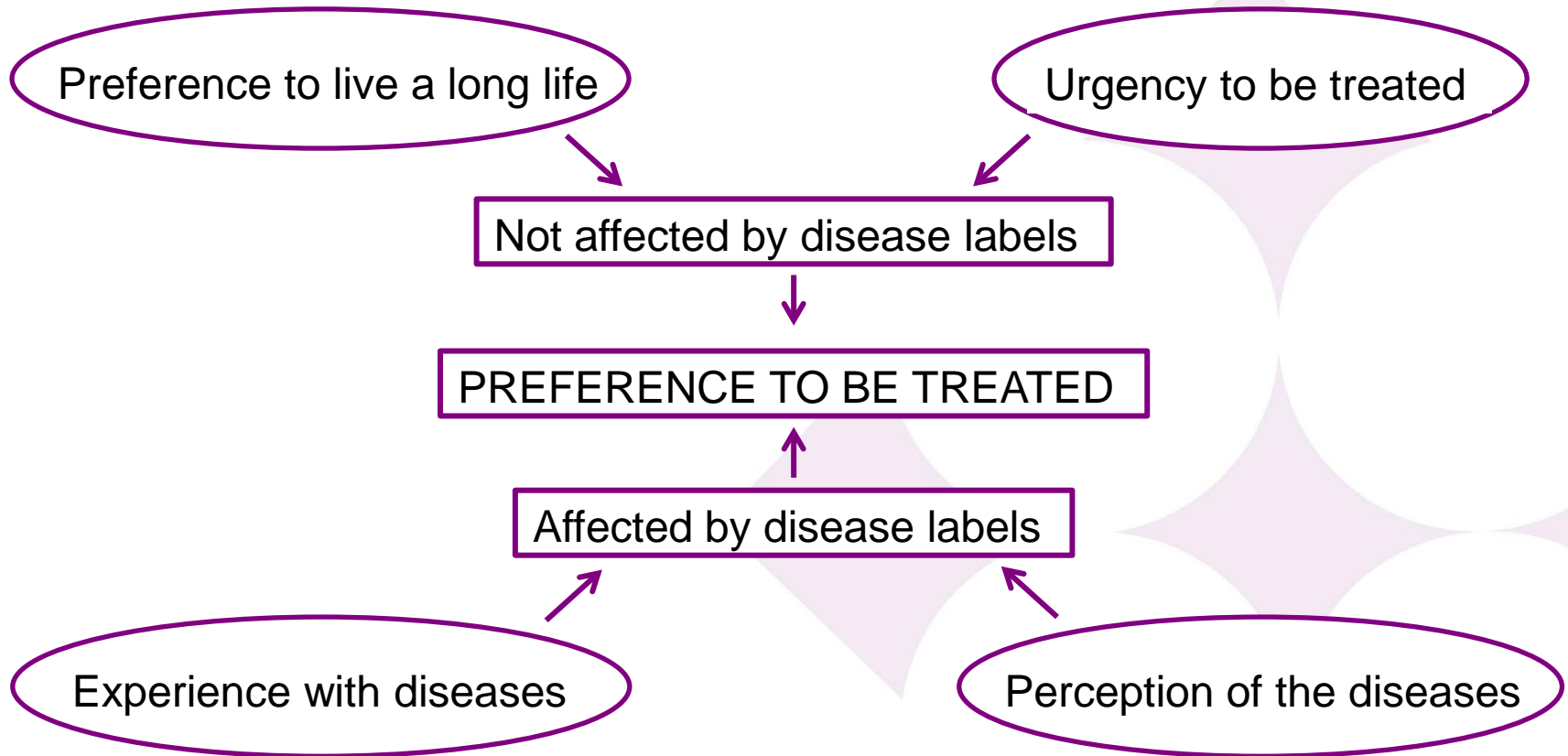
Yes

No

Don't know

Findings

- All interviews were transcribed and analyzed using the framework approach



Experience with disease

- Think-aloud DCEs permitted some participants to refer back to previous personal events

“Every time I see rheumatoid arthritis [on the page], *some ping goes off in my head* cuz it’s like, ‘oh yeah’”. (Participant 6, DCE-A)

“You know, it’s amazing how the *body and mind can adapt to daily chronic pain* if you’re willing to give a bit of time and energy towards the dealing with it.” (Participant 6, DCE-A)

“Diabetes and cancer affected my dad. So I’m very familiar with both of them. And I’ve watched him really suffered. And he’s a real fighter. You know most people would have written him off many times over. *Doesn’t matter how bad it gets, he still manages to get back.*” (Participant 22, DCE-A)

Perception of the diseases (1)

- Consideration of disease prevalence

“[T]ype 2 diabetes is a much more common occurring condition in Canada. It’s much better known [...]. [T]here’s a lot *more information about how to live* with [diabetes] available and how [...] you can live a normal life.” (Participant 19, DCE-B)

- Perception of control

“[P]eople are handling [type 2 diabetes] compar[ed] to [rheumatoid arthritis and colorectal cancer] cuz these are, in my mind, were things that when it hits you, it hits you. [...] So I looked at type 2 diabetes like a motorbike that hits you. I knew that if I was fast enough to move out of the way, I could get out of the bike. But if one of these guys hit me, well, *I just got hit by the bus.*” (Participant 14, DCE-B)

Perception of the diseases (2)

- Ranking of severity

“Colorectal cancer[... is] almost *like a roulette wheel*, I guess. How lucky do you feel you’ll be in avoiding it spreading? It recurring? And how strong you feel you can overcome it?” (Participant 19, DCE-B)

“The word cancer has some sort of implication, right? I mean it’s like the worst disease you can have. [...] [W]hen you have cancer, *it’s like you’re doomed*, right? (Participant 18, DCE-A)

“[T]he cancer could *spread to other parts of your body* and [become] even more complicated; [...] it’s basically a collection of diseases rather than one disease.” (Participant 16, DCE-A)

Preference to live a long life

- Overwhelming desire to have a long life
 - Not dependent on which DCE version was completed

“I rather have the *longer time with my loved ones* even if I had to, you know, deal with some pretty bad days.” (Participant 4, DCE-B)

“[Y]ou never know what happens in ten years, *science is [...] advancing.*” (Participant 12, DCE-B)

“So given a choice if I could have, I guess, two years but no pain and a full good quality of life, I would rather choose that; at least, I could *cross [items] off my bucket list.*” (Participant 16, DCE-A)

Urgency to be treated

- Fundamental desire to be treated

“I don’t think one disease is worse than another.” (Participant 5, DCE-B)

“It doesn’t really matter what kind of disease you have, right? I mean, as long as you feel OK and you can live a longer life. It doesn’t matter. In the end, *you’re going to die anyways.*” (Participant 18, DCE-A)

“[I]f I could be completely back to normal and no pain, I would be living a *more productive* five years than suffering 10 years. And then extending the burden to other people, like the nurses or my family or whoever’s taking care of me [...]”. (Participant 16, DCE-A)

Reaction after learning affiliations and funding sources

- Majority appeared not to be affected about researchers' cancer-specific affiliations and funding sources
 - Pleased that their responses will be received by a nationally recognized funding agency
- One participant stated he should not have been as forthcoming in his responses

Conclusions (1)

- Think-aloud approach encouraged the participants to thoughtfully consider the DCE attributes
- Whether the participants completed DCE-A or DCE-B did not affect whether disease labels had an impact on preferences
- Presence of a disease ‘premium’

Conclusions (2)

- Next stage will be to administer both versions of the DCEs in a large-scale online study across Canada
 - Quantify the presence of a cancer premium

Acknowledgements

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Canadian
Cancer
Society

Société
canadienne
du cancer



Cancer Care Ontario
Action Cancer Ontario

Study participants

	DCE A (n=12)	DCE B (n=12)
Males		
18-34 years	2 (50.0%)	2 (50.0%)
35-50 years	2 (50.0%)	2 (50.0%)
51-65 years	2 (50.0%)	2 (50.0%)
Females		
18-34 years	2 (33.3%)	2 (33.3%)
35-50 years	2 (33.3%)	2 (33.3%)
51-65 years	2 (33.3%)	2 (33.3%)
Marital status		
Single	7 (58.3%)	10 (83.3%)
Married	4 (33.3%)	2 (16.7%)
Divorced	1 (8.3%)	0
Education level		
Secondary School	1 (8.3%)	3 (25.0%)
College	2 (16.7%)	4 (33.3%)
University	8 (66.7%)	4 (33.3%)
Other	1 (8.3%)	0
Prefer not to answer	0	1 (8.3%)
Employment level		
Self-employed	3 (25.0%)	2 (16.7%)
Paid-employment	5 (50.0%)	5 (41.7%)
Unemployed	1 (8.3%)	4 (33.3%)
Retired	1 (8.3%)	0
Student	0	1 (8.3%)
Personal experience with chronic illnesses	7 (58.3%)	3 (25.0%)