

Does undertaking genome sequencing prompt actual and planned lifestyle-related behavior change in cancer patients and survivors? A qualitative study

Sabina Vatter, PhD^{a,*}, Nicci Bartley, MA^a, Megan Best, PhD^{a,b}, Ilona Juraskova, PhD^c, Chris Jacobs, PhD^d, Mandy L. Ballinger, PhD^{e,f}, David M. Thomas, PhD^{e,f}, Phyllis Butow, PhD^a

Abstract

Background: In order for genomic testing to fulfil its promise of helping cancer patients and survivors to prevent future disease, it is important to consider its behavioral impact and outcomes. This study explored the factors that participants perceived would impact lifestyle-related behavioral intentions following genome sequencing (GS). **Methods:** Individual semistructured interviews were conducted to explore behavioral intentions with a purposive subsample of 24 adults with a past or current cancer of likely heritable aetiology who undertook germline GS as part of a larger genetic study (RisC). Participants were interviewed 12 months following their consent to a longitudinal psychosocial sub-study of RisC (PiGeOn study), before receipt of results. Data were analyzed using thematic analysis. **Results:** Analysis revealed 3 main themes: past prompts, barriers, and motivators to behavior change. The primary goal for behavioral change was to be healthy for oneself and one's family. Past experience of cancer facilitated positive modifications to lifestyle, such as increased exercise and healthy diet, higher prioritization of mental health and well-being, and regular health check-ups and tests. Maintaining these changes, however, was difficult for some due to daily commitments and lack of self-control. Limited knowledge and perceived inevitability of developing cancer due to genetic predisposition were recognized as barriers to making lifestyle changes. Concurrently, future receipt of actionable results was perceived as a powerful driver of behavior change. **Conclusion:** Understanding barriers and facilitators to behavior intention and patients' attitudes to recommended lifestyle change in the context of genomic testing can be useful for health care professionals, to guide their discussions of behavioral change.

Keywords: cancer, genetic testing, genome sequencing, health behavior, psychosocial, qualitative research

1. Introduction

Since the entire human genome was first mapped in 2003,^[1] genomic technologies have rapidly advanced, leading to improvements in clinical utility for a range of diseases. Genome sequencing (GS) is increasingly applied in complex illness to expand understanding of disease aetiology, prognosis, prevention, and treatment options. GS can offer information that is relevant to one's specific cancer (primary), relevant to other cancers or diseases

(secondary), or of unknown significance.^[2] Receiving such information could encourage more frequent health screening, altered lifestyle behaviors and other preventative strategies in healthy adults,^[3] particularly if the results are linked to known effective preventive strategies (ie, are actionable).^[4,5]

In the general population, following receipt of genomic information from either direct-to-consumer (DTC) genetic testing^[6,7] or whole genome sequencing (WGS) in the research

Sponsorships or competing interests that may be relevant to content are disclosed at the end of this article.

Members of the Psychosocial Issues in Genomic Oncology (PiGeOn) Study are named authors, plus Christine Napier, David Goldstein, Ainsley Newson, Jacqueline Savard, Bettina Meiser, Barbara Biesecker, Katherine Tucker, Timothy Schlub, Mary-Anne Young, Judy Kirk, Richard Vines, and Kate Vines.

Author contributions: PB, NB, SV, MB, IJ, CJ, MLB, and DMT all made substantial contributions to the conception and design of the work and the acquisition, analysis, and interpretation of the data; made detailed and critical revision of the work for important intellectual content; approved of the final publication version; and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved; SV drafted the manuscript and circulated drafts of the work to the other authors.

^a School of Psychology, Faculty of Science, Psycho-Oncology Co-operative Research Group (PoCoG), University of Sydney, Sydney, NSW, Australia, ^b Institute for Ethics and Society, University of Notre Dame Australia, Sydney, NSW, Australia, ^c School of Psychology, Faculty of Science, Centre for Medical Psychology and Evidence-Based Decision-Making (CeMPED), University of Sydney, Sydney, NSW, Australia, ^d Graduate School of Health, University of Technology Sydney, Sydney, NSW, Australia, ^e Cancer Theme, Garvan Institute of Medical Research, Sydney, NSW, Australia, ^f St Vincent's Clinical School, University of New South Wales, Sydney, NSW, Australia.

* Corresponding author. Address: School of Psychology, Faculty of Science, Psycho-Oncology Co-operative Research Group (PoCoG), University of Sydney, Sydney, NSW 2006, Australia. E-mail address: sabina.vatter@sydney.edu.au (S.Vatter).

Copyright © 2021 The Authors. Published by Wolters Kluwer Health Inc., on behalf of the International Psycho-Oncology Society.

This is an open access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

J of Psychosocial Oncology Research and Practice (2021) 3:3

Received: 19 January 2021 / Received in final form: 21 June 2021 / Accepted: 24 June 2021

<http://dx.doi.org/10.1097/OR9.000000000000059>

setting,^[3,8] up to about one-third of healthy individuals appeared to make positive lifestyle changes, which further increased to 41% when receiving a family history report alongside GS results.^[9] Conversely, single-nucleotide polymorphism (SNP) testing outside of the DTC setting had no or only a minimal effect on participants' intention to change their lifestyle, either due to already leading a healthy lifestyle or perceiving the risk to be non-significant.^[10–14] This is not unexpected given that SNP testing is usually conducted to inform prognosis and potentially treatment (with a focus on the present), whereas DTC and WGS results inform future risks where patients may feel more empowered and motivated to act to reduce those risks. Furthermore, the level of risk identified is potentially greater with WGS where monogenic drivers of disease can be detected compared to SNP-based testing where risks vary slightly from population averages. The difference in behavior in the DTC and WGS groups in the research setting compared to SNP based testing may be due to patient motivation (DTC) or the potential for higher risks being described (WGS).^[15–18] Behavioral change is however relevant to both groups but may be more significant for the WGS group.

The influence of GS on behavioral change has been studied in cancer survivors. In a study with 1667 breast and prostate cancer survivors, participants had made changes or were motivated to make changes to their lifestyle, such as quitting smoking, exercising more, and increasing consumption of fruits and vegetables.^[19] Compared to the general population who received risk estimates based on genetic testing,^[11] cancer survivors appeared to be more motivated to change their behavior, indicating that a predisposition to cancer is an important driver in encouraging behavioral changes. However, in 1 survey, although 75% of breast cancer survivors thought that having a healthy body mass index, eating fruits and vegetables daily, and working out regularly could reduce their cancer risk in the future, the majority did not participate in these behaviors. Moreover, a higher recurrence risk, based on their GS results, did not influence uptake of healthy behavior recommendations in breast cancer survivors. However, adherence to these recommendations was higher if women were white, college-educated and had high incomes.^[20]

Protection Motivation Theory^[21] can be applied to understand behavioral intentions in this context. According to Protection Motivation Theory, people modify their behavior according to perceptions of the threat to their health ("threat appraisal") and their ability to employ health-protective behaviors ("coping appraisal"). It is likely that individuals with a history of cancer, as a result of their lived experience, will be more likely than the general population to view cancer as a serious threat and to have resilience in dealing with that threat. Therefore, they may be more motivated to act on genomic results to minimize or prevent recurrence. Earlier research findings regarding behavioral intentions following cancer and receipt of genetic information have, however, been mixed,^[22–29] so it remains unclear what impact pursuing GS information might have on behavioral intentions in individuals who have had a diagnosis of cancer.

Therefore, we aimed to explore behavioral intentions of people with a history of cancer 12 months following consent to undergo GS (but before receiving results) as part of the Psychosocial issues in Genomic Oncology study (PiGeOn).^[30] PiGeOn is a longitudinal, mixed methods study, investigating the psychosocial, behavioral, and ethical impact of GS for cancer patients/survivors with a likely heritable origin. Results from an earlier analysis of quantitative baseline data from 379 participants of the PiGeOn study^[31] indicated that participants (particularly women) anticipated being highly motivated to change their

behavior related to lifestyle if GS data indicated a high risk of developing another cancer. In the current analysis of PiGeOn study qualitative data, at 1 year following their decision to have GS we sought to explore whether participants made changes to their lifestyle in the past 12 months while awaiting GS results, and how and why their behavioral intentions changed over time.

2. Materials and methods

The methods and results presented below follow the consolidated criteria for reporting qualitative research (COREQ).^[32]

Ethical approval for this study was granted by the St Vincent's Hospital Human Research Ethics Committee (HREC/16/SVH/24).

2.1. Participants

PiGeOn study participants are participants in the Genetic Cancer Risk in the Young (RisC) project. Participants were invited to take part in the RisC study by their oncologist, cancer geneticist, or a RisC researcher. The RisC study is recruiting 1000 participants with the following inclusion criteria: histologically confirmed malignancy and age 16 to 40 years at diagnosis, or having >1 primary cancer diagnosed <50 years of age, or having >2 primary cancers at any age. All RisC participants were eligible to participate in the PiGeON substudy, with the additional inclusion criteria of adequate English to complete study assessments.

2.2. Design and procedures

Participants provided written consent to take part in RisC and PiGeOn at the same time. RisC participants provide a blood sample for germline GS and future research. The timeframe of GS is approximately 18 to 24 months and the results are returned only to those participants whose GS identifies important information about their health, where participants have indicated that they would like to receive such results. Those RisC participants who would like to be informed about results can opt to receive information regarding having a pathogenic variant that increases the likelihood of cancer, and/or having a secondary finding (based on the recommendations of the American College of Medical Genetics and Genomic and the Association for Molecular Pathology for reporting secondary findings in clinical exome testing and GS that could be of paramount importance to their health).^[33] If RisC participants receive an actionable result after GS, they are offered an appointment with a genetic counselor, and those who receive a result of a pathogenic variant with an increased risk of developing cancer are offered tailored risk management in a future study.

In the PiGeOn substudy, participants completed quantitative questionnaires (and a subset, interviews) at three time-points: at baseline (within 1 month of consent), at 3 months and 1 year after consent. Participants for interviews were purposively selected to ensure diversity in cancer types, gender and age. All participants who completed baseline and 3-month follow-up interviews were approached to participate in 12-month follow-up interviews. Recruitment continued until data saturation was reached as ascertained from the ongoing analysis. Participants' sociodemographic and disease data were extracted from the RisC questionnaires.

This analysis reports results from the 12-month telephone interview, conducted by 1 researcher (NB) with expertise in

genomic psycho-oncology. Interviewees had participated in at least 1 previous interview with the same researcher. A semi-structured interview schedule was devised by a team of multidisciplinary experts and consumers and guided by relevant literature. In view of our aims, the questions relevant to the current analysis explored whether participants had made changes to their lifestyle to reduce their cancer risk in the last 12 months, and intended to make any lifestyle changes if they were found to have an increased risk for cancer following GS. Rationales for and experience of these changes were explored. Other questions addressed attitudes towards GS, planned communication of results to health care professionals and relatives, and experience of uncertainty related to GS.^[34]

2.3. Data analysis

All interviews were audio-recorded, transcribed verbatim, and analyzed in MSOffice Word (Microsoft Corp.) with inductive thematic analysis.^[35] Individual line-by-line coding on the initial 6 transcripts was completed by 3 researchers (SV, NB, PB). Following discussions to resolve any discrepancies, a preliminary set of codes was applied to additional transcripts by SV and further refined through an iterative process of review and discussion between SV, NB, and PB. Higher-order themes and subthemes were identified by SV. This process continued until consensus was reached within all themes and sub-themes. Researchers' diverse background in psycho-oncology, genetics, and genomics ensured reflexivity in the analysis process.^[36]

3. Results

Twenty-four interviews were conducted between August 2018 and October 2019, 1 year after undertaking GS but before receiving results. The interviews lasted between 9 and 27 minutes ($m=15.2$ minutes, $SD=4.33$). Participants' ages at the time of consent ranged between 31 and 78 years, and 16 were female. Ten participants were diagnosed with a second or third cancer and the time since most recent cancer diagnosis varied between 4 months and 21.7 years. Two participants were undergoing cancer treatment at the time of consent. A summary of the sociodemographic and disease data is provided in Table 1.

Three main themes emerged from the thematic analysis: past prompts; barriers; and motivators for behavior change.

3.1. Past prompts for behavior change

3.1.1. Cancer. The majority of participants had incorporated changes to their lifestyle as a result of their cancer diagnosis, which had made them more aware of their health and what they could be doing to improve their health outcomes. Most participants were attempting to sustain these changes, including healthy eating, consuming less alcohol and sugar, exercising, getting enough sleep, and increasing sun protection.

I would probably say I don't drink like I used to [laughs]. So, I've probably culled that out a little bit. Am very conscious of trying to eat healthier and exercise more because that's benefitting me . . . in the healing process as well. But just trying to get back on track with having a healthier lifestyle . . . I don't think I was too bad before, but I think it just makes you more conscious of it. P16, F 50 years, patient

Respondents also highlighted changes they had made to maintain their mental health, including minimizing stress,

Table 1

Participant characteristics (n=24).

Variable	M (SD), range
Age at interview	48.8 (14.14), range 31–78 y
Age at first diagnosis	36.3 (13.24), range 5–67 y
Years since most recent diagnosis	6.8 (6.27), range 4 mo to 21.7 y
	N (%)
Female	16 (66.7)
Have biological children	18 (75.0)
Education*	
Secondary school (some or all)	6 (25.0)
Vocational training	8 (33.3)
University graduated	8 (33.3)
Cancer diagnosis	
Breast	10 (24.4)
Gastrointestinal	7 (17.1)
Genitourinary	5 (12.2)
Blood	4 (9.8)
Brain	3 (7.3)
Sarcoma	2 (4.9)
Neuroendocrine	2 (4.9)
Other	8 (19.5)
No. of tumors	
1	14 (58.3)
2	5 (20.8)
≥3	5 (20.8)
Incidence	
Common (>12 cases/100,000)	18 (43.9)
Less common (6–12 cases/100,000)	3 (7.3)
Rare (<6 cases/100,000)	20 (48.8)
Medical or science occupation	3 (12.5)
Non-English speaking at home	3 (12.5)
Previous genetic testing	14 (58.3)

*Missing data.

changing job to de-stress, surrounding themselves with positive people, better self-care and maintaining normality.

I decided to surround myself with people who are positive people and just try and take care of myself a bit better, don't stress. P05, F 42 years, survivor

I don't live a stressful life anymore . . . I just live a little bit different, I suppose, my attitude's a little bit different. P19, F 42 years, survivor

Some participants mentioned they had not made many changes to or had maintained their already healthy lifestyle. One participant noted that adopting health behaviors did not guarantee good health, with some factors being out of one's control.

I, kind of did that when I was diagnosed and have continued on that path . . . I feel like I am very aware of what I'm doing and the choices that I'm making to try and be as healthy or whatever as possible given that some things are seriously beyond your control so, you can only do what you can do. There are some other factors that you just don't have any control over. P10, F 39 years, survivor

3.1.2. Expert advice. Some participants had made changes to their lifestyle in accordance with recommendations from their health professionals. Several participants were keeping up their

regular check-ups, (blood) tests, scans, PET scans, and doctor's appointments. Others had been given lifestyle recommendations which were not necessarily cancer-related but were targeting other medical conditions.

I have changed a little bit my diet, . . . it's not cancer-reduction, it's something that my doctors, my oncologist, suggested. I tend to have problems with my liver, stress, so I need to increase my vegetables, and decrease alcohol, cheese and meat. P14, M 44years, survivor

The other thing I do, I have a colonoscopy and a gastroscopy . . . , it'll be two years. I've got to see the gastro man, next month, and he'll do a colonoscopy in February so, I suppose these tests are reducing the risk. P20, M 78years, survivor

3.2. Barriers to behavior change

3.2.1. The busyness of life. Some participants found it challenging to fit lifestyle changes around their daily life due to work, raising children and other commitments. One participant highlighted the challenge of keeping up with the comprehensive lifestyle regime that was recommended during cancer treatment, due to returning to full-time work. Others acknowledged that they had a sedentary job but were mindful about increasing their exercise. For some participants, raising children was a barrier to increasing exercise or having regular check-ups (eg, MRI) and they emphasized that oftentimes life takes priority over lifestyle change.

The regime I had throughout cancer was really hard to keep up. It was kind of whole lifestyle change, involving physio, . . . it was very comprehensive. I haven't been able to keep that up because I'm back to full-time work. P01, F 43years, survivor

No [sighs]. I'm meant to have an MRI every year but haven't done that. Supposed to go, had it booked for August and I ended up in Children's Hospital. I'm meant to go on Monday and I could be back there tomorrow, so [laughs] I'm not meant to have this MRI [laughs]. P11, F 34years, survivor

3.2.2. Self-control. Some participants found it challenging to make and maintain certain lifestyle changes, such as cutting out sugar or alcohol, due to finding it difficult to resist cravings, or give up the enjoyment of an occasional alcoholic drink.

I probably don't really know where to start [laugh]. And I'm terrible with eating, . . . even when I had gestational diabetes, I'd find it really hard to restrict what I eat . . . I'm like the worst [laugh], I'm in no place to be [laugh] saying, oh, yeah, I'll do this, especially with food. I don't drink or smoke or anything like that . . . but [laugh] with food I can't help myself [laugh]. P23, F 31years, survivor

That depends what is that that I have to stop doing or do more of . . . I like a bit of drinking every now and again and suddenly I have to quit completely. I'm not sure if I'm ready for that. P24, F 39years, survivor

3.2.3. Perceived nonutility. Some participants saw no utility in changing their lifestyle. They highlighted their genetic predisposition to developing cancer, perceiving that their past cancer, and risk of developing cancer in the future, were not related to their lifestyle. A few participants perceived no additional utility in further changing their lifestyle, which was already healthy. One participant did not perceive certain recommendations as useful or important for their health or lifestyle, for example going on a special diet, whereas another noted that unless recommendations were tailored for the individual, their utility would likely be low.

I think my lifestyle is pretty good. I'm a very healthy person, I don't really think it has to do with your lifestyle, I think it comes down to the way your body is made up, and for what reason we get these cancers, I don't really know, but you can't change what it is. So . . . my view is I will just carry on with my exact same lifestyle, . . . and if that came about again, I would do exactly the same thing that I did last time. P05, F 42 years, survivor

So if someone said, "You are this blood type, you have these issues, if you do this, this and this, it will have a significant effect" I think people would do it more . . . I'm a lawyer, so I can't really do it, but I've always thought there'd be a business in, . . . , particularly for executives, people that can afford it, taking a bunch of tests and then doing a very, very, very tailored health and wellness plan. P01, F 43 years, survivor

3.2.4. Need to do it my way. A few participants noted that they had their own way of coping with cancer and that they felt some resistance to coping or behaving in other ways. They felt that their resilience, and ability to stay calm and not dwell on past occurrences, meant that they could cope with anything that came their way; however, this reliance on their own inner strength meant that they might be less motivated to change their lifestyle.

So even physio, after having a mastectomy and stuff like that, I kept away from all that. I wasn't that sort of person. (...) And I know having three lots of cancers you think, oh, maybe I'd wake up to myself and do something [laughs]. But I'm the sort of person, you work it out yourself. P22, F 57years, survivor

With the challenge of the drought we've just been through . . . I get the feeling a lot of people are in awe of my calmness. (. . .) I like the challenge of the rough and tumble. (. . .) If it was all too easy . . . Life would be a bit boring really. P06, M 47years, survivor

3.2.5. Lack of knowledge. Some participants recognized that lack of information and knowledge made it more difficult to decide whether they should change their lifestyle. One participant highlighted that lifestyle advice is inconsistent, confusing, excessive and overwhelming, making it more difficult to follow, and suggested the creation of a personalised health plan which could act as a motivation to behavior change.

That's one interesting thing and problem, with all the lifestyle information in the world, it's not all consistent. It isn't possible to follow it all, and I think that's why people get frustrated

with it . . . There's so much information and competing information, it's overwhelming. P01, F 43 years, survivor

I'm sure there's hundreds of things that I do, that I don't know about. But you can only be so paranoid. P12, M 43 years, patient

3.3. Motivators for future behavior change

3.3.1. Genomic risk information: a potent motivator. Most participants thought they would be motivated to change their lifestyle if their genomic sequencing results showed they were at risk for another cancer or disease. Positive genomic results were seen as implying significantly greater cancer risk which would be “a wake-up call,” triggering action.

Like, straight away. Like, I would cut out sugar, I would do all the things [laughs] you're supposed to do, and live that life because you know that you got to do everything you can to give yourself the best chance to get over it. P19, F 42 years, survivor

I would change my lifestyle . . . It would give me that, motivation or that focus, like, wake up and you have to get this sorted. [. . .] I assume food wise, I don't know really, more exercise, less stress. P02, F 40 years, survivor

For some participants, the exact changes they would make would depend on what specific cancer risks they faced. They would research which behaviors would have most impact on those specific risks.

It depends on the cancer. And the associations with the behavioral or lifestyle associations. [. . .] I could increase fruit and vegetable intake if that's shown in one of the cancers. I could spend less time in the sun . . . It depends on the type of cancer risk factor I have, I guess. P08, M 35 years, survivor

3.3.2. Responsibility for own health. Some participants felt a responsibility to take control of their own health. For example, one woman decided to have breast implant removal surgery to minimize her risk of breast cancer. A few participants emphasized that ultimately, they were responsible for their own health to be well for themselves and for their loved ones.

I think I probably could {change my lifestyle} . . . I've got a lot of people relying on me [laugh] . . . So I've got to be well. P23, F 31 years, survivor

I suppose you'd make other choices. You wouldn't live carelessly anyway, you know. P06, M 47 years, survivor

This sense of responsibility was experienced in a variety of ways. One participant recalled feelings of guilt when she had occasionally indulged in sweets and alcohol in the past and was concerned whether this could lead to negative consequences in the future. This also acted as a motivation to make certain changes to her lifestyle now.

I think . . . there probably would be more things that I could do. I probably would be a bit less carefree, but then I think

with that goes, that sort of guilt, like if you go and have a night out with friends and eat birthday cake and have a bottle of wine and all of that then you have this guilt going, oh jeez, those nights that I did that did that make the cancer come back, . . . and just that responsibility of being healthy, but I wonder if it would exacerbate that if I had those results. P03, F 41 years, survivor

3.3.3. Longevity. Some participants discussed wanting to live longer and age healthily as a motivator to do everything possible to extend life. One participant in his late seventies was motivated to consider making changes to his lifestyle to avoid going into a nursing home. He spoke of living longer to take advantage of new treatments as they emerged, should he later develop cancer.

And while ever there's the opportunity of future treatments and what have you, being a benefit to you I suppose you'd be a fool not to try and extend it, your longevity I suppose . . . New drugs, new treatments, new strategies are always coming into play. P06, M 47 years, survivor

Everyone wants to live longer, especially when they are forty plus. They think about the fact that you might not live forever. P01, F 43 years, survivor

4. Discussion

In this study, we explored what changes participants made to their lifestyle in the past 12 months and how behavioral intentions changed over time in people previously diagnosed with cancer who undertook germline GS, but before receipt of results. We found that the strongest motivators for lifestyle-related behavioral change were lived experiences of cancer and results emerging from GS, although some barriers exist to implementing change.

Many participants had altered their lifestyle during their cancer journey and were sustaining these changes, indicating that cancer *per se* is a strong catalyst to improving lifestyle. Cancer increased awareness of the need to improve physical and mental health, prompting changes in daily life and lifestyle, and encouraging regular health check-ups. This both supports^[22–25] and contradicts^[21,22,26–28] earlier findings. It is possible that several factors, such as type of cancer, age, and extent of risk, can influence intention to change lifestyle, which warrants further research with cancer patients/survivors.

Motivation to change behavior regarding lifestyle following GS testing (but prior to receipt of results), to minimize risk of developing another cancer or illness in the future, was more pronounced in our study compared to that reported in noncancer populations following receipt of genetic test results.^[3] Understanding the behavioral intentions of patients/survivors upon the return of GS results is important as the clinical utility of GS for cancer prevention is largely dependent on identifying patients/survivors who will benefit from and subsequently engage in various risk management strategies. Similar to other studies, and in accordance with Protection Motivation Theory,^[20] behavioral intention was greater if perceived risk of developing cancer was higher.^[15–18,36] Proximity to the cancer experience would explain this increased motivation. A strong desire to live longer and age well encouraged participants to take health-protective actions.

Despite generally high motivation for behavior change in our study, it was challenging for some participants to make lifestyle changes due to competing commitments and priorities, such as work and family, lack of emotional control, and the demanding nature of exercising and diet regimens. Our findings are consistent with earlier research. Lack of time has been identified by breast and prostate cancer survivors as one of the main barriers to lifestyle change.^[37,38] In cancer-free populations, emotional control has been recognized as a barrier to changing eating behavior,^[39] similarly to our study with a cancer population. Altering one's lifestyle was perceived as unnecessary by a few participants as they believed genetic predisposition is immutable and unrelated to lifestyle. Our results are comparable to research findings outside of cancer whereby receiving genetic information^[40–43] did not lead to risk-reducing lifestyle behaviors as genetic data was perceived as deterministic.

Many of our participants already had a healthy lifestyle and were not intending to change their behavior, feeling that their own way of doing things was working well for them. Similarly, in another study, a third of participants who received actionable genomic results had no intention to change lifestyle perceiving that results were either not sufficiently motivating to change behavior, the risk of developing a specific disorder was nonexistent or minimal, or they already had a healthy lifestyle.^[8] In addition, changing existing lifestyle habits tends to be more difficult than taking up new habits,^[42] which could explain why some participants were reluctant to implement changes in their existing lifestyles.

Insufficient or contradictory information made it harder for some participants to decide whether and how they should change their lifestyle. Advice was seen as unclear, confusing, superfluous and overwhelming. Participants suggested that very specific, tailored and evidence-based recommendations were required to convince them that changing their lifestyle would be of benefit. Health care professionals were seen as trusted experts whose recommendations held significant weight, and many participants were already following their advice. Indeed, specific lifestyle advice is known to facilitate behavior change in cancer patients/survivors.^[37] A comprehensive meta-analysis among healthy adults concluded that positive behavioral intentions are relatively small when genetic testing is provided in the absence of lifestyle advice or counseling.^[7] Therefore, it is crucial that health care professionals offer relevant, individualized, evidence-based lifestyle advice in a clear, comprehensive, tailored, and non-burdening manner, especially to those cancer patients/survivors who would benefit from such information and who express intention to act on the information they receive.

The barriers to behavior change identified in this study can be viewed from the perspective of Protection Motivation Theory, as participants had not yet received their GS results and either did not perceive any threats to encourage behavioral change or perceived their current actions as sufficient to reduce the potential threat on their health. The extent to which each person applies health-protective behaviors is highly variable and individual, which is rooted in their past cancer experiences and success in overcoming it as well as beliefs around genetic predisposition, current health status, and well-being, and personal motivation to be healthy, fight the disease, and extend life.

4.1. Study limitations

Limitations of the study should be considered. Our qualitative sample was comprised of participants in a larger GS study; thus,

some participants had altruistic motivations to participate in research and could be biased towards GS. Within this qualitative study, while we reached saturation of views, it is not known whether participants in other cohorts would hold these views. Participants are not representative of the general population as they were highly educated and English speaking and inclusion of participants with different stages of education and participants who are culturally and linguistically diverse would further increase our understanding of the intricacies of intention to change lifestyle-related behavior. The cohort was purposively selected to maximize diversity of age, sex, and cancer types; however, a wider range of cancer types and ages would allow a better understanding of whether specific types of cancers and age play a role in prompting behavior change. Future quantitative studies should be conducted with a larger sample size, including a broad range of cancers, ages and diverse backgrounds. Additionally, future research should be conducted with participants following receipt of GS results to enable comparisons between intentions and actual behavior change.

4.2. Practice implications

Our findings are important in understanding the barriers and facilitators of intention to change lifestyle-related behavior following GS in people previously diagnosed with cancer. As cancer survivors are at a higher risk of developing chronic conditions in the future compared to those without cancer^[44] and may have a poorer life expectancy,^[45] it is crucial to manage and minimize risk. Importantly, healthy lifestyle behaviors can be protective against developing cancer and cardiometabolic diseases in the future,^[46] increase health-related quality of life,^[47] and reduce the risk of premature death in cancer survivors.^[48] Furthermore, using GS to diagnose a cancer predisposition syndrome is valuable to mitigate cancer risk in such individuals via engagement in screening and preventative health.

The use of GS as a diagnostic tool in clinical settings is becoming more common^[2]; therefore, health care professionals will be increasingly required to advise on germline GS results and provide tailored lifestyle advice, as well as treatment recommendations. Understanding national public health guidelines (eg, Cancer Australia Lifestyle & Risk Reduction guidelines;^[49] the Clinical Oncology Society of Australia Position Statement on Exercise in Cancer Care;^[50] the Department of Health Australia's Physical Activity & Sedentary Behaviour Guidelines for Adults^[51]) on lifestyle advice will be required to enable clear communication of these evidence-based recommendations in a tailored and supportive manner to all cancer patients/survivors. These lifestyle choices include eating a balanced a nutritious diet, maintaining a healthy weight, limiting alcohol consumption, not smoking, being sun smart, and exercising.^[49] This could ultimately result in improved survival and quality of life, and potentially reduce the economic cost of cancer at a societal level.

Conflicts of interest

The authors declare to conflicts of interest.

References

- [1] National Institutes of Health: All about the Human Genome Project. 2015. URL = <https://www.genome.gov/human-genome-project>. (Accessed January 14, 2021).
- [2] Ayuso C, Millán JM, Mancheño M, Dal-Ré R. Informed consent for whole-genome sequencing studies in the clinical setting. proposed

- recommendations on essential content and process. *Eur J Hum Genet* 2013;21:1054–1059.
- [3] Facio F, Eidem H, Fisher T, et al. Intentions to receive individual results from whole-genome sequencing among participants in the ClinSeq study. *Eur J Hum Genet* 2013;21:261–265.
 - [4] Bloss CS, Madlensky L, Schork NJ, Topol EJ. Genomic information as a behavioural health intervention: can it work? *Per Med* 2011;8:659–667.
 - [5] Horne J, Madill J, O'Connor C, et al. A systematic review of genetic testing and lifestyle behaviour change: are we using high-quality genetic interventions and considering behaviour change theory? *Lifestyle Genom* 2018;11:49–63.
 - [6] Egglestone C, Morris A, O'Brien A. Effect of direct-to-consumer genetic tests on health behaviour and anxiety: a survey of consumers and potential consumers. *J Genet Couns* 2013;22:565–575.
 - [7] Stewart KFJ, Wesseliuss A, Schreurs MAC, et al. Behavioural changes, sharing behaviour and psychological responses after receiving direct-to-consumer genetic test results: a systematic review and meta-analysis. *J Community Genet* 2018;9:1–18.
 - [8] Gordon ES, Griffin G, Wawak L, et al. It's not like judgment day": public understanding of and reactions to personalised genomic risk information. *J Genet Counsel* 2012;21:423–432.
 - [9] Vassy JL, Christensen KD, Schonman EF, et al. The impact of whole-genome sequencing on the primary care and outcomes of healthy adult patients: a pilot randomized trial. *Ann Intern Med* 2017;167:159–169.
 - [10] Graves KD, Leventhal K-G, Nusbaum R, et al. Behavioral and psychosocial responses to genomic testing for colorectal cancer risk. *Genomics* 2013;102:123–130.
 - [11] Hollands GJ, French DP, Griffin SJ, et al. The impact of communicating genetic risks of disease on risk-reducing health behaviour: systematic review with meta-analysis. *BMJ* 2016;352:i1102.
 - [12] Marteau TM, French DP, Griffin SJ, et al. Effects of communicating DNA-based disease risk estimates on risk-reducing behaviours. *Cochrane Database Syst Rev* 2010;6:CD007275.
 - [13] Leventhal K-G, Tuong W, Peshkin Beth N, et al. "Is it really worth it to get tested?": Primary care patients' impressions of predictive SNP testing for colon cancer. *J Genet Couns* 2013;22:138–151.
 - [14] Nusbaum R, Leventhal KG, Hooker GW, et al. Translational genomic research: Protocol development and initial outcomes following SNP testing for colon cancer risk. *Transl Behav Med* 2013;3:17–29.
 - [15] Fenton GL, Smit AK, Keogh L, Cust AE. Exploring the emotional and behavioural reactions to receiving personalised melanoma genomic risk information: a qualitative study. *Br J Dermatol* 2019;180 (6):1390–1396.
 - [16] Kaufman DJ, Bollinger JM, Dvoskin RL, Scott JA. Risky business: risk perception and the sue of medical services among customers of DTC personal genetic testing. *J Genet Couns* 2012;21:413–422.
 - [17] Ramsey S, Blough D, McDermott C, et al. Will knowledge of gene-based colorectal cancer disease risk influence quality of life and screening behavior? Findings from a population-based study. *Public Health Genomics* 2010;13:1–12.
 - [18] Smit AK, Keogh LA, Newson AJ, et al. Exploring the potential emotional and behavioural impact of providing personalised genomic risk information to the public: a focus group study. *Public Health Genom* 2015;18:309–317.
 - [19] O'Neill SC, DeFrank JT, Vegella P, et al. Engaging in health behaviors to lower risk for breast cancer recurrence. *PLoS One* 2013;8:e53607.
 - [20] Rogers RW. A protection motivation theory of fear appeals and attitude Change1. *J Psychol* 1975;91:93–114.
 - [21] Bellizzi KM, Rowland JH, Jeffery DD, McNeel T. Health behaviors of cancer survivors: examining opportunities for cancer control intervention. *J Clin Oncol* 2005;23:8884–8893.
 - [22] Caan B, Sternfeld B, Gunderson E, et al. Life after cancer epidemiology (LACE) study: a cohort of early stage breast cancer survivors (United States). *Cancer Causes Control* 2005;16:545–556.
 - [23] Corbett T, Cheetham T, Muller AM, et al. Exploring cancer survivors' views of health behaviour change: "Where do you start, where do you stop with everything?". *Psychooncology* 2018;27:1816–1824.
 - [24] Dennis DL, Waring JL, Payeur N, et al. Making lifestyle changes after colorectal cancer: insights from program development. *Curr Oncol* 2013;20:e493–e511.
 - [25] Satia JA, Campbell MK, Galanko JA, et al. Longitudinal changes in lifestyle behaviors and health status in colon cancer survivors. *Cancer Epidemiol Biomarkers Prev* 2004;13:1022–1031.
 - [26] Eakin EG, Youlden DR, Baade PD, et al. Health behaviors of cancer survivors: data from an Australian population-based study. *Cancer Causes Control* 2007;18:881–894.
 - [27] Williams K, Steptoe A, Wardle J. Is a cancer diagnosis a trigger for health behaviour change? Findings from a prospective, population-based study. *Br J Cancer* 2013;108:2407–2412.
 - [28] Mayer DK, Terrin NC, Menon U, et al. Health behaviors in cancer survivors. *Oncol Nurs Forum* 2007;34:643–651.
 - [29] Best M, Newson AJ, Meiser B, et al. The PiGeOn project: protocol of a longitudinal study examining psychosocial and ethical issues and outcomes in germline genomic sequencing for cancer. *BMC Cancer* 2018;18:454.
 - [30] Napier C, Davies G, Butow P, et al. Cancer patient knowledge and attitudes towards germline whole genome sequencing. Under review.
 - [31] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349–357.
 - [32] Kalia SS, Adelman K, Bale SJ, et al. Recommendations for reporting of secondary findings in clinical exome and genome sequencing, 2016 update (AC MG SF v2.0): a policy statement of the American College of medical genetics and genomics. *Genet Med* 2017;19:249–255.
 - [33] Bartley N, Napier CE, Butt Z, et al. Cancer patient experience of uncertainty while waiting for genome sequencing results. *Frontiers in Psychology-Psycho-Oncology*. Accepted.
 - [34] Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
 - [35] Berger R. Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qual Res* 2015;15:219–234.
 - [36] Oliveri S, Ferrari F, Manfrinati A, Pravettoni G. A systematic review of the psychological implications of genetic testing: a comparative analysis among cardiovascular, neurodegenerative and cancer disease. *Front Genet* 2018;9:624.
 - [37] Yannitsos D, Murphy RA, Pollock P, Di Sebastiano KM. Facilitators and barriers to participation in lifestyle modification for men with prostate cancer: a scoping review. *Eur J Cancer Care* 2020;20:e13193.
 - [38] Ottenbacher AJ, Day RS, Taylor WC, et al. Exercise among breast and prostate cancer survivors—what are their barriers? *J Cancer Surviv* 2011;5:413–419.
 - [39] Spörndly-Nees S, Igelström H, Lindberg E, et al. Facilitators and barriers for eating behaviour changes in obstructive sleep apnoea and obesity – a qualitative content analysis. *Disabil Rehabil* 2014;36:74–81.
 - [40] Marteau T, Lerman C. Genetic risk and behavioural change. *BMJ* 2001;322:1056–1059.
 - [41] Marteau TM, Weinman J. Self-regulation and the behavioural response to DNA risk information: a theoretical analysis and framework for future research. *Soc Sci Med* 2006;62:1360–1368.
 - [42] Hietaranta-Luoma HL, Luomala HT, Puolijoki H, Hopia A. Using *ApoE* genotyping to promote healthy lifestyles in Finland—psychological impacts: randomized controlled trial. *J Genet Counsel* 2015;24:908–921.
 - [43] Marteau T, Senior V, Humphries SE, et al. Psychological impact of genetic testing for familial hypercholesterolemia within a previously aware population: a randomized controlled trial. *Am J Med Genet* 2004;128A:285–293.
 - [44] Berry NM, Miller MD, Woodman RJ, et al. Differences in chronic conditions and lifestyle behaviour between people with a history of cancer and matched controls. *Med J Aust* 2014;201:96–100.
 - [45] Yeh JM, Ward ZJ, Chaudhry A, et al. Life expectancy of adult survivors of childhood cancer over 3 decades. *JAMA Oncol* 2020;6:350–357.
 - [46] Freisling H, Viallon V, Lennon H, et al. Lifestyle factors and risk of multimorbidity of cancer and cardiometabolic diseases: a multinational cohort study. *BMC Med* 2020;18:5.
 - [47] Blanchard CM, Courneya KS, Stein K, et al. Cancer survivors' adherence to lifestyle behaviour recommendations and associations with health-related quality of life: results from the American Cancer Society's SCS-II. *J Clin Oncol* 2008;26:2198–2204.
 - [48] Karavasiloglou N, Pestoni G, Wanne M, et al. Healthy lifestyle is inversely associated with mortality in cancer survivors: results from the Third National Health and Nutrition Examination Survey (NHANES III). *PLoS One* 2019;14:e0218048.
 - [49] Cancer Australia. Lifestyle & risk reduction. 2021. URL = www.cancer.gov.au/healthy-living/lifestyle-risk-reduction. (Accessed April 16, 2021).
 - [50] Clinical Oncology Society of Australia. COSA Position Statement on Exercise in cancer care. 2018. URL = www.cosa.org.au/media/332488/cosa-position-statement-v4-web-final.pdf. (Accessed April 16, 2021).
 - [51] The Department of Health. Australia's Physical Activity and Sedentary Behaviour Guidelines and the Australian 24-hour Movement Guidelines. URL = Available at: <https://www1.health.gov.au/internet/main/publishing.nsf/Content/health-pubhlth-strateg-phys-act-guidelines>. (Accessed April 16, 2021).