

## BRIEF REPORT

# How do women talk about self-funded breast cancer genetic testing?: Small stories and stance-taking strategies

Alan Bechaz<sup>1</sup>  | Adrienne Sexton<sup>2,3,4</sup>  | Gulvir Gill<sup>5</sup>  | Maria Karidakis<sup>1</sup> 

<sup>1</sup>School of Languages and Linguistics,  
The University of Melbourne, Parkville,  
Victoria, Australia

<sup>2</sup>Genomic Medicine & Familial Cancer  
Centre, Royal Melbourne Hospital & Peter  
MacCallum Cancer Centre, Melbourne,  
Victoria, Australia

<sup>3</sup>Discipline of Genetic Counselling,  
Graduate School of Health, The University  
of Technology Sydney, Sydney, New South  
Wales, Australia

<sup>4</sup>Department of Medicine – Royal  
Melbourne Hospital, The University of  
Melbourne, Parkville, Victoria, Australia

<sup>5</sup>Genetics in the North East, The Mercy  
Hospital for Women, Victoria, Heidelberg,  
Australia

**Correspondence**

Alan Bechaz, School of Languages and  
Linguistics, The University of Melbourne,  
Parkville, Vic., Australia.

Email: [abechaz@student.unimelb.edu.au](mailto:abechaz@student.unimelb.edu.au)

**Abstract**

Genetic testing for breast cancer genes is an experience which is inextricably linked with health communication practices and the broader social context in which it occurs. Linguistic approaches can provide perspective on how women seeking self-funded *BRCA1/2* gene testing represent their experiences, knowledge, roles, choices and emotions through the way they talk. A discursive constructionist epistemology and narrative theoretical framework informed the applied linguistics methodology. Analysis of 'small stories' and stance-taking was performed on eight transcripts of audio-recorded telephone interviews with women at low to moderate risk of carrying *BRCA1/2* pathogenic variants who self-funded genetic testing. We found a high prevalence of 'small stories' including accounts of events, hypotheticals, habitual narratives, and stories which combined multiple genres. Stance-taking was a means by which participants constructed personal identities in the conversational context, such as that of a responsible person. Via stance-taking strategies, participants also actively negotiated the conversational agenda, for example expressing different degrees of alignment with the interviewer's orientation towards emotions. This study provides a basis for recognizing linguistic markers in genetic counseling interactions about genetic testing for breast cancer genes. Enhanced awareness of client language choice, and the ways in which small stories and stance can signify the client's evaluation of experience and choices, alignment with the genetic counselor's questions/statements, and investment in the conversation, has potential to improve the therapeutic interaction.

**KEYWORDS**

breast cancer, communication, counseling techniques, genetic counseling, small stories, stancetaking

Discourse-oriented research is valuable for understanding how clients engage with genetics services and represent their experiences (Ellington et al., 2011; Hui et al., 2022; Sarangi et al., 2005). These interactions occur within multiple layers of social, institutional and

individual contexts which frame experience (cf. Goffman, 1974). As with health practices generally (see Jones, 2013), genetic testing and counseling are mediated by discourse practices and the ways in which clients and professionals communicate are consequential

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for genetic counseling processes such as giving/seeking information and facilitating decision-making (Sarangi, 2013). This report aims to show how a linguistic approach can provide perspective on how women seeking self-funded BRCA1/2 gene testing represent their experiences, knowledge, choices, emotions, motivations, interactions, and roles through the way they talk.

We addressed this aim through the following research questions: *What kinds of stories do women assessed as low-risk for hereditary breast cancer tell when talking about self-funded genetic testing experiences? What stance-taking strategies do women assessed as low-risk employ when talking about self-funded genetic testing experiences?*

The methodology was based on a discursive constructionist epistemology (Potter & Hepburn, 2008). We adopted a small stories (Bamberg, 2006; Bamberg & Georgakopoulou, 2008; Georgakopoulou, 2015) approach which, less concerned with narratives as coherent life stories, is grounded in a 'narratives-as-practice' perspective on storytelling as a situated and highly variable social practice (see Bamberg, 2020; de Fina, 2013, 2021; de Fina & Georgakopoulou, 2008). Small stories research examines what people do with their brief and sometimes fragmentary storytelling in interaction and thus admits a range of discursive data as narrative (Bamberg & Georgakopoulou, 2008; Georgakopoulou, 2007, 2015). We performed a secondary analysis of source data consisting of eight de-identified verbatim semi-structured interview transcripts obtained in a previously published study by Gill et al. (2020) with ethical approval from the Peter MacCallum Cancer Institute HREC/46620/PMCC-2018. The 31–45 min audio-recorded interviews were with women who attended a Familial Cancer Centre, were not at high risk of a BRCA1/BRCA2 pathogenic variant, and self-funded genetic testing. Participants were aged between 31 and 70 years. Details pertaining to sociocultural background were not collected. Participants' discourse was coded for 'small stories' and further analyzed for stance-taking practices (Kiesling, 2022) in an iterative process.<sup>1</sup> This was based on an understanding of research interviews as a social practice distinct from spontaneous conversation but nonetheless an interactionally organized speech event (Talmy, 2010). Three main genres of small stories were identified: accounts of past events (de Fina, 2009),<sup>2</sup> habitual narratives of iterative events (Riessman, 1990), and hypothetical or counterfactual narratives of possible or alternative events (Carranza, 1998). In addition, due to their extensive

<sup>1</sup>The notion of 'small stories' has been criticized as unclear in its grouping of varied discourse as narrative data (see Norrick, 2009). To support analytic rigor, we adapted an approach from Karidakis (2021) to identify narrative data by use of story prefacing sequences (see Jefferson, 1978; Sacks et al., 1974; Schegloff & Sacks, 1973), discourse markers indicative of storytelling (e.g. Norrick, 2001), participants' own orientation towards talk as narrative (see Georgakopoulou, 2015), or features of narrative genres found in the literature (see de Fina & Georgakopoulou, 2012). Stance-taking was identified according to grammatical and lexical (see Biber et al., 1999) and discourse (e.g. Kiesling, 2020; Lampropoulou & Myers, 2012) stance markers.

<sup>2</sup>This use of 'accounts' differs somewhat from that in other genetic counseling research (e.g. Arribas-Ayllon et al., 2011, 2012). Following de Fina (2009), accounts are here understood as a genre of narrative discourse characterized as storied responses to evaluative inquiry, whereas Arribas-Ayllon and colleagues draw on Scott and Lyman's (1968) sense of the term to describe excuses and justifications without focus on narratives. Although there are interesting points of overlap and divergence between these approaches, a fuller theoretical discussion is beyond the scope of this paper.

### What is known about this topic?

The established body of discourse-oriented genetic counseling research to date has enhanced our understanding of communication strategies used by clients and counselors (e.g. Sarangi et al., 2004, 2005; Thomassen Hammerstad et al., 2020). However, little is known about the discourse practices of women when reporting their experiences and choices relating to self-funded BRCA1/2 gene testing.

### What this paper adds to the topic?

In this paper we show how small stories and stance-taking strategies are used in talk about experiences and choices relating to self-funded BRCA1/2 genetic testing. This linguistic analysis provides insights into women's strategies for representing their experiences, including how they explain decisions and manage talk about emotions in interactions.

blending of different functional and structural narrative features, some stories were found to mix otherwise common narrative types. Stance-taking analysis followed Kiesling's (2022) model and examined speakers' evaluation and positioning, alignment with co-participants, and investment in their talk.

The results identified 198 small stories in the eight interview transcripts. Recurrent types of small stories participants used are shown in Table 1. To illustrate, consider the participant Phyllis' (pseudonym) story in Extract 3. Here, the present tense constructions in Phyllis' discourse (e.g., *talk, is treated*) are indicative of a habitual story in which the narrative events are presented as recurring (see Table 1). In response to the interviewer previously asking if she communicates openly with her family about cancer, Phyllis begins her conversational turn with 'well', a discourse marker associated with initiating narratives (Norrick, 2001). The ensuing small story functions to support an implied claim that Phyllis' family does speak openly about cancer, evidencing this by presenting talk about breast cancer and treatment as recurrent. Phyllis then orients focus toward her own ease regarding genetics with a further habitual story about breeding and testing dogs (see Extract 3). This appeal to habitual exposure to genetic knowledge serves to present Phyllis as well-informed, supporting her claim that she 'was quite happy' to have testing herself. Thus, beyond simply answering the interviewer's questions, Phyllis' narrative discourse serves to argumentatively support her position, both with respect to the topic of family communication projected by the interviewer as well as self-initiated talk of her individual attitude towards genetic testing.

Stance-taking analysis found that participants' talk enabled them to construct local identities through repetition of stance-taking across multiple conversational turns and to negotiate the trajectory of the conversation through strategic (mis)alignment with

TABLE 1 Examples of small stories in talk by women who had self-funded BRCA1/2 genetic testing.

| Example extracts  | Narrative type and features   |
|---|---|
| <p><b>Extract 1</b><br/>Celine: <i>Yeah, so my sister had breast cancer at 36. My mother had breast cancer at 65. My three maternal aunts once removed all had breast cancer and one maternal aunt had cervical cancer. So, I was of course diagnosed as high-risk.</i></p>   | Accounts as stories (see de Fina, 2009) involve a sequence of temporally related clauses representing past experiences. These have explanatory function and are factually oriented, designed in response to an evaluative inquiry.  |
| <p><b>Extract 2</b><br/>Abbie: <i>My sister is very, kind of put her head in the sand about it, she does not want to know. But I think that might just be that she's not ready to deal with it yet. And my brother, I do not know, I think he maybe when he starts having children and when he has a girl, he may change his feeling, knowing that it's a bit more common in females than males, I do not know. I have not really spoken to him about it very much in depth too much, but I know my sister is not really interested at all.</i></p> | Hypothetical and counterfactual stories (see Carranza, 1998) tell of possible or alternative events and are indicated by markers of tense, aspect, or modality. They support argumentative or persuasive functions of discourse.  |
| <p><b>Extract 3</b><br/>Phyllis: <i>Well, we talk about the breast cancer and the information and how everybody is treated differently, you know, has different treatment depending on what doctor they go to, which is interesting. I also breed dogs and that's why I was quite happy to be genetically tested as I test my show dogs.</i></p>  | Habitual stories (see Riessman, 1990) focus on generic versus specific sequence of events and use temporal markers (e.g., verb tense and adverbs) indicating iterative/ongoing events. They can support argumentative position through appeal to evidence of repeated experience. |
| <p><b>Extract 4</b><br/>Jorja: <i>Yeah, and I guess too like, getting into the loop of things, there's always a trial or something going on, if you are in the loop, you might have that opportunity to be in a trial. You hear about all these different wonderful things, but you cannot get into them for another 10 years until the government says that they are okay (laughs). And that's just to help alleviate their own fears and they can make their own decisions of what they want to do then.</i></p>                                  | Narratives which blend structural or functional features associated with different narrative types highlight the variability and embeddedness of narrative in discourse (cf. Bamberg, 2020; Georgakopoulou, 2007). Here, both habitual and hypothetical elements are used.        |

TABLE 2 Sample analysis of stance-taking in talk by women who had self-funded BRCA1/2 genetic testing.

| <b>Extract 5</b>  |   |
|---|---|
| Interviewer: <i>Yeah, so some people are glad to know this information while others regret having testing. How do you feel?</i>   |   |
| Katrina: <i>No, I have no regrets, none whatsoever. Even if I did carry a mutation, I would not have regretted doing it. If I did carry a mutation, I would have to have a lot of difficult phone calls with my brother and sisters and my aunts and cousins.</i> |   |
| Interviewer: <i>Were you planning that out while waiting for the results?</i>   |   |
| Katrina: <i>No. No. But I knew that if the results were positive, I would have to do the right thing for the family and let them know.</i>  |   |
| Stance-taking dimension   | Analysis  |
| Evaluation & Positioning  | <ul style="list-style-type: none"> <li>Affective evaluation towards genetics results through negation, 'no regrets'</li> <li>Stance-taking towards value of genetic knowledge through hypothetical construction, 'if I did carry a mutation' and repeated evaluation of not regretting a choice to test</li> <li>Negative orientation towards communicating genetic knowledge to family as 'difficult'</li> <li>Positive evaluation of communicating genetic information to family as moral, 'the right thing'</li> <li>Repeated positioning of self as bound by obligations in virtue of family role through modal construction expressing necessity 'I would have to...' and orientation of duty as 'for the family'</li> </ul> |
| Alignment   | <ul style="list-style-type: none"> <li>Initial alignment with the interviewer through shared orientation towards focus of talk; oriented towards genetics results, indicated by recycled lexeme 'regret'</li> <li>Negotiation of the conversational agenda; slight divergence from interviewer's focus through talk of hypothetical test results indicating a genetic variation, orienting attention away from feelings about actual results</li> </ul>   |
| Investment  | <ul style="list-style-type: none"> <li>High investment in evaluation and positioning indicated by repeated evaluation and positioning, 'No, I have no regrets, none whatsoever', sustained in the following turn with repetition of 'no'</li> </ul>   |

Note: For discussion of stance-taking dimensions, see Kiesling (2022).

their interlocutor. For example, in Extract 5 (see Table 2), the participant Katrina (pseudonym) uses lexical (e.g., the adjective 'difficult') and grammatical (e.g., the modal construction 'I would have to...') stance markers to express evaluation and subjective positioning.

With similar practices found throughout the data, Katrina here positions herself in relation to her family. She expresses a stance towards communicating genetic knowledge as a moral duty as a family member (e.g., through the noun phrase 'the right thing' and

prepositional phrase 'for the family'). From both small stories (e.g. Bamberg, 2020; Bamberg & Georgakopoulou, 2008) and stance-taking (Kiesling, 2022) perspectives, discourse practices in interaction allow people to build up situated self-presentations which may point toward recognizable social identities. In this example, the recurrence of alike stances across turns allows Katrina to perform 'responsible' talk, projecting a persona of a responsible person vis-à-vis genetic testing. Emotions were likewise a recurring focus of stance-taking. For example, despite the interviewer's explicit inquiry 'how do you feel' (Extract 5), Katrina's response orients only towards the absence of 'regret'. Her hypothetical narratives about not regretting testing in the event of a different result support this claim while also allowing her to re-negotiate the conversational trajectory away from emotions about her actual test results and towards a hypothesized scenario relating to family obligations.

This study adds to the existing discourse analytic literature in genetic counseling by interpreting the linguistic practices of an understudied population, women who self-fund *BRCA1/2* genetic testing. The findings highlight client language choice and the ways in which small stories and stance can signify the client's sense-making process, presentation of identity, and management of interaction. Consistent with prior studies (e.g. D'Agincourt-Canning, 2006; Shipman et al., 2017), participants related genetic testing motivations and experiences to familial and social factors, including a sense of responsibility. Attending to linguistic markers with which clients construct such meaning is consistent with genetic counseling approaches such as ensuring a client-led agenda and working with client narratives to facilitate decision-making and adaptation to genetic risk. This study was limited to stance and small story analysis and did not include other aspects of discourse analyses. Furthermore, analysis of intercultural or multilingual factors informing participants' talk was not possible with the available data, although linguistics is well-placed to investigate how these factors may influence interactional dynamics in genetic counseling communication (Zayts-Spence et al., 2021). Further research to enhance genetic counselors' awareness of communication patterns including linguistic markers is warranted.

#### AUTHOR CONTRIBUTIONS

Authors AB, GG, AS, and MK confirm that they had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All authors gave final approval of this version to be published 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.

#### ACKNOWLEDGMENTS

The authors wish to thank the participants in the original interview study (Gill et al., 2020) from which the data was derived. We also thank co-authors on the original interview study Catherine Beard, Kirsty Storey, and Shelby Taylor. The analysis upon which this report is based was conducted to fulfill the requirements of a minor thesis

in the Master of Applied Linguistics at the University of Melbourne, completed by author AB.

#### CONFLICT OF INTEREST STATEMENT

Authors AB, GG, AS, and MK declare that they have no conflict of interest.

#### DATA AVAILABILITY STATEMENT

Additional information and data from this manuscript are available upon reasonable request.

#### ETHICS STATEMENT

Human studies and informed consent: Approval to conduct the research was obtained from the Peter MacCallum Cancer Institute Human Research Ethics Committee (HREC/46620/PMCC-2018). All procedures followed were in accordance with the ethical standards of the responsible committee and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all participants for being included in the study.

Animal studies: No non-human animal studies were carried out by the authors of this article.

#### ORCID

Alan Bechaz  <https://orcid.org/0000-0002-9751-8556>

Adrienne Sexton  <https://orcid.org/0000-0001-8749-1639>

Gulvir Gill  <https://orcid.org/0000-0001-6898-9634>

Maria Karidakis  <https://orcid.org/0000-0002-1600-0027>

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**How to cite this article:** Bechaz, A., Sexton, A., Gill, G., & Karidakis, M. (2023). How do women talk about self-funded breast cancer genetic testing?: Small stories and stance-taking strategies. *Journal of Genetic Counseling*, 00, 1–5. <https://doi.org/10.1002/jgc4.1782>