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ORIGINAL RESEARCH

A Relational Approach to Genetic Counseling for Hereditary Breast and Ovarian Cancer

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Abstract Ethical issues arise for genetic counselors when a client fails to disclose a genetic diagnosis of hereditary disease to family: they must consider the rights of the individual client to privacy and confidentiality as well as the rights of the family to know their genetic risk. Although considerable work has addressed issues of non-disclosure from the client's perspective, there is a lack of qualitative research into how genetic counselors address this issue in practice. In this study, a qualitative approach was taken to investigate whether genetic counselors in Australia use a relational approach to encourage the disclosure of genetic information from hereditary breast and ovarian cancer (HBOC) clients among family members; and if so, how they use it. Semi-structured qualitative interviews were conducted with 16 genetic counselors from selected states across Australia. Data collection and analysis were guided by a basic iterative approach incorporating a hybrid methodology to thematic analysis. The findings provide indicative evidence of genetic counselors employing a relational approach in three escalating stages—covert, overt and authoritative—to encourage the disclosure of genetic information. The findings lend credence to the notion that genetic counselors envision a form of relational autonomy for their clients in the context of sharing genetic information, and they depart from individualistic conceptions of care/solely client-centered counseling when addressing the needs of other family members to know their genetic status.

Keywords Relational approach · Genetic information · Disclosure · Ethical duty · Familial responsibility · Genetic counseling practice and theory

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Introduction

Genetic testing for the management of certain hereditary cancers has become commonplace in clinical genetics. It has the potential to provide helpful genetic information for the client, allowing him or her to make informed healthcare decisions based on their risk of developing specific cancer(s). However, because of the familial nature of hereditary disease, genetic testing can reveal the genetic risk of disease for not only the proband but also their family members. Despite genetic testing being a powerful predictive and diagnostic clinical tool, it does not provide clients with the necessary skills or knowledge to navigate the complex issues concerning the communication of genetic information to other family members.

Due to the shared nature of genetic information there exists a tension between the needs of the individual in terms of privacy and the needs of the family in terms of access to genetic risk information (Parker and Lucassen 2003). To address this tension, the process of disclosing genetic information to other family members requires sensitive management by the consulting genetic counselor. Genetic counselors occupy an important mediator role in the communication of genetic risk within the

family, as they are acutely aware of the familial implications of genetic diagnoses (Forrest et al. 2010). In this sense they take on a professional duty to identify at-risk family members and discuss the familial implications of hereditary genetics with the client (Forrest et al. 2007). This professional duty can create an ethical tension for the counselor when a client does not disclose genetic information to their at-risk relatives.[1]

In cases of non-disclosure generally, counselors are faced with an ethical dilemma: on one hand they have a duty to their client in terms of confidentiality and privacy of medical information, while on the other hand they also feel a sense of responsibility to the relatives of the client who are also at risk of genetic disease. Studies have shown that genetic counselors are cognizant of their ethical responsibility to encourage the dissemination of information to at-risk relatives, and feel obligated to facilitate that responsibility (Andorno 2004; Dugan et al. 2003; Lucassen and Parker 2004). In Australia, legal restrictions prevent genetic counselors from disclosing the personal medical information of their clients without their consent (Forrest et al. 2010)—unless in certain defined circumstances where the condition is a serious threat to the health of the at-risk relative and disclosure will lessen or prevent that threat (National Health and Medical Research Council 2014). However, cancers that meet these conditions are rare (e.g., Familial Adenomatous Polyposis), and invariably the responsibility of disseminating genetic information falls on the client (Forrest et al. 2007; Gaff et al. 2005; Hallowell 1999). This restricts the genetic counselors to operating within a family mediated communication model—i.e., relying on the client to pass on information to at-risk family members (Newson and Humphries 2005).[2]

Some studies have shed light on factors affecting how and whether family members communicate information regarding the risk of HBOC to each other (Koehly et al. 2009; Peters et al. 2011). However, to date it remains unclear how counselors facilitate the disclosure of genetic information for their clients via family mediated communication and there are limited data available that describe the communication strategies of genetic health professionals use in practice (Gaff et al. 2010). Currently in Australia, a principal tenet of general genetic counseling practice is to take a "client-centered approach to facilitate client support and decision-making" (Human Genetics Society of Australasia 2014, p. 12). Modern interpretations of the client-centered approach aim to promote client autonomy and active, self-confident decision making (Kessler 1997; Koerner et al. 2010; White 1997). Respect for client autonomy in genetic counseling is now considered to be an active, deliberative and dialogical engagement with the client (White 1997), and is compatible with the concepts of obligation and commitment to others (Hodgson and Spriggs 2005). It remains explicitly not client-centered, however, to focus on the needs of other family members rather than those of the client (Gaff et al. 2010), which would seem an understandable focus for counselors in the context of encouraging the disclosure of genetic information. How genetic counselors practice in family mediated communication is unclear, but some studies provide an indication of current practices generally.

Two Australian studies (Forrest et al. 2008; Hodgson et al. 2016), working within family mediated communication models, had mixed results when assessing the effectiveness of genetic counseling interventions in enhancing the family communication of genetic information. Forrest et al. (2008) found that increasing genetic counseling support for probands with hereditary genetic conditions—with a strategy specifically focused on un-informed at-risk relatives—significantly increased the proportion of at-risk relatives to contact a genetics service compared with the control cohort (61 % versus 36 %, $p = 0.01$).

Conversely, Hodgson et al. (2014) developed a client-centered and non-directive intervention to improve family communication about a new genetic diagnosis or carrier status in a proband. In a randomized clinical trial assessing the effectiveness of the intervention, the authors found that there was no significant overall difference in the proportion of at-risk relatives contacting genetics services between the intervention and control groups (25.6 % versus 20.9 %, $p = 0.40$) (Hodgson et al. 2016). Combined, these studies suggest that applying genetic counseling interventions—either client-centered and/or family focused—is a difficult prospect when communication is family mediated.

It has been previously suggested that family mediated communication of genetic information needs improvement and that genetic counseling practice should be more direct when considering the necessity of informing at-risk relatives (Sermijn et al. 2004). Reflecting the acceptance of more direct approaches in practice, the authors of an international review found there was a clear focus on uninformed relatives and an endorsement of proactive approaches to encourage dissemination among family members in practice guidelines and position papers (Forrest et al. 2007). Despite two studies establishing that writing directly to at-risk family members nearly doubles the amount of relatives presenting to the genetics service to clarify their risk (Sermijn et al. 2016; Suthers et al. 2006), outside of research settings, the direct contact of at-risk relatives is not currently feasible in genetic counseling practice.

Nonetheless, survey data suggest that when facilitating the disclosure of genetic information in practice, genetic counselors at least widen their scope of care to focus on the risk

[1] Non-disclosure can be either active: when a client explicitly refuses to inform their relatives. This is considered rare in practice (Clarke et al. 2005; Gaff et al. 2010). Or passive: a client states they plan to tell "all" of their relatives but fails to do so for a variety of reasons (Gaff et al. 2005, 2010).

[2] It is worth noting that client-centered counselling is a very Western concept. Other cultures are more family-centered, so the discussion throughout this paper may not be applicable to other cultures.

of other family members. One international survey on genetic health professionals' practice established that 93 % of respondents reported they always encourage the client to disclose genetic information to family, irrespective of the diagnosed genetic condition (Forrest et al. 2010). The same study reported that genetic health professionals provided counseling and education to their clients during consultations about dissemination to encourage the sharing of genetic information (Forrest et al. 2010). Similar findings were made in the United States, where two national surveys found that 97 % of the clinical geneticists/genetic counselors surveyed always or often encourage their clients to communicate information to their family members (Dugan et al. 2003; Falk et al. 2003).

The collection of studies above provide some indication as to how challenging it must be for genetic counselors to be simultaneously client-centered, family focused and appropriately direct when encouraging disclosure of genetic information. How exactly counselors help their clients to disseminate information—especially when communication is family mediated and without specific intervention—still remains unclear. Until now, there has been no qualitative study in Australia that specifically explores how genetic counselors currently encourage the disclosure of genetic information for their clients in a family mediated communication context.

A relational approach, as defined for this study, considers that individuals are not isolated social units—akin to atoms floating in a social vacuum, detached from their surrounding social environment. A relational approach takes into account the full range of influential human relations that affect one's decision-making processes. It conceptualizes individuals as fundamentally social beings, shaped and molded by the web of relations they share with others throughout life because, as Sherwin explains, "much of who we are and what we value is rooted in our relationships and affinities with others" (Sherwin 1998, p. 35). In the context of healthcare, a relational approach emphasizes that the client is socially situated or contextualized, taking into account client relationships. It also takes into account the needs and rights of other family members with respect to client decision-making, fostering the client's relational autonomy. To deliver an appropriate level of care this must be considered by the consulting healthcare professional.

Previous studies have suggested that HBOC clients disclose genetic information from a sense of familial responsibility, enacting a kind of relational autonomy (D'Agincourt-Canning 2006; Hallowell et al. 2003)—the active consideration of one's obligations and responsibilities to others when making personal autonomous decisions (Bell and Bennett 2001). Davey et al. (2006) note that relational elements may already inform genetic counselor practice, in so far as genetic counselors routinely encourage their clients to disclose genetic information to their families (as supported by studies above), thereby promoting the client's relational autonomy. Genetic counselors operating from a relational stance is further supported by current research in Australia focusing on the development of practical tools to facilitate information dissemination for *BRCA1/2* families (Healey et al. 2015). This suggests that genetic counselors already implicitly operate from a relational model that collectively takes into account family interests.

Our study sought to determine whether genetic counselors in Australia employed a relational approach to mediate genetic information disclosure within *BRCA1/2* families; and if so, how they employed it. Using hereditary breast and ovarian cancer (HBOC) as a model hereditary condition, a qualitative approach was used to interview a purposive sample of Australian genetic counselors about their approach to mediating the family communication of mutation positive *BRAC1/2* test results. HBOC was chosen as a model condition based on the majority (80–90 %) of cases being attributed to germline *BRCA1/2* mutations (Ford et al. 1998; Frank et al. 1998; Narod et al. 1995). Due to the availability and high volume of germline mutation *BRCA1/2* testing in Australia through family cancer clinics (FCCs), genetic counselors are regularly exposed to helping their clients share genetic information after undergoing germline genetic testing for HBOC. We suggest that genetic counselors promote the relational autonomy of their clients in the context of communicating genetic information within a family.

Methods

Participants and Recruitment

The genetic counselors who participated in this qualitative study were from a range of institutions and health districts located across Australia: New South Wales (NSW), Victoria (Vic), Western Australia (WA) and the Australian Capital Territory (ACT). Those who volunteered were either Associate (junior/board eligible to undertake certification) or Human Genetics Society of Australasia (HGSA) Certified Genetic Counselors; both referred to as "genetic counselors" or "counselors" hereafter. All participants for this study were randomly assigned a pseudonym to protect their identity.

The third author—a senior genetic counselor at The Canberra Hospital Genetic Service, who was able to act as institutional gatekeeper both locally and interstate—principally facilitated recruitment of genetic counselors. Advertisement for the study was also posted on the HGSA website, where members (all genetic counselors Australia-wide) had access to invitation and information for this study. Invited counselors were made aware of the advertisement online for participation, or information was given directly to service managers of invitees by the principal investigator after contact was made. Ethics approval was gained from the Australian National University Human Research Ethics Committee (Protocol No 2014/082)

and the ACT Health Human Research Ethics Committee (ETHLR.14.021) to conduct this research.

Sampling

A purposive sampling approach was used to acquire Australian genetic counselors that possessed criteria relevant to the research question. The selection criteria were: a genetic counselor currently practising, or having previously practised, in a clinical setting with client interactions, and who have regular contact with HBOC clients. The sample was purposively representative of the Australian genetic counselor population (as per the Australasian Society of Genetic Counselors (ASGC) 2012 Census—see Table 1). Chi-squared testing was carried out to compare the study sample characteristics with the ASGC population. On all applicable characteristics (gender distribution, age range, time employed and certification level), there were no significant differences between the study sample and the ASGC population. Note that due to excessive variables and limited numbers in the study sample, Chi-squared testing was not carried out for state-wide distribution of genetic counselors.

The sample size was selected based on Guest's (2006) study on qualitative interview data saturation, which found thematic saturation from interview data could be reached with a minimum of 12 interviews with high quality informants. The sample size was increased to include genetic counselors from a range of states and territories, but was capped at 16 due to constraints on time and feasibility. As a result, genetic counselors from the other states and territories of Australia—the Northern Territory, Tasmania, Queensland and South Australia—were not included.

Data Collection

Data were collected via semi-structured qualitative interviews between March and June, 2014. Interviews were carried out in person, individually with participants. Interviews were principally based on several themes from the literature relevant to the research question: relational and individualistic autonomy; moral agency; genetic responsibility; choice; individual privacy; and genetic counseling models. The flexibility of semi-structured interviews allowed for any emergent topics raised by the interviewees to be fully explored and discussed. Each interview was guided by an interview protocol incorporating the themes above, designed to ask open-ended questions on current genetic counseling practice when encouraging genetic information disclosure. Participant responses made up the body of data for analysis. The protocol was modified as necessary as part of concurrent data collection and analysis to address emergent themes. All interviews were recorded with participant permission, de-identified and outsourced to an independent transcription service for verbatim transcription. Interview transcripts were checked for translational accuracy and modified if necessary according to the original interview audio recording.

Table 1 Sample characteristics compared to ASGC 2012 census

Population characteristics	Study sample ($N = 15$)				ASGC survey ($N = 238$)[a]							Chi-squared values[b]
Gender distribution	93.33 % female				95 % female							$p = 0.72$
Age range	<35 years	35–54 years	≥55years[c]		<35 years	35–54 years	≥55 years					
	50 %	50 %	0 %		47 %	44 %	9 %					$p = 0.48$
Time employed in field of genetic counseling	<5 years	5–9 years	>9 years		<5 years	5–9 years	>9 years					
	40 %	33.3 %	26.6 %		39 %	28 %	25 %					$p = 0.94$
Proportion of associate genetic counselors	60 %				50.4 %							
Proportion of board-certified genetic counselors	40 %				30.7 %							$p = 0.87$ (combined)
State wide distribution of genetic counselors[d]	NSW	Vic	ACT	WA	NSW	Vic	QLD	WA	SA	ACT	TAS&NT	N/A
	40 %	33.3 %	20 %	6.6 %	33.8 %	34.3 %	13.5 %	8.2 %	5.3 %	2.4 %	2 %	

The ASGC survey was conducted across the ASGC membership, which includes other non-genetic counseling professions; as such only 75 % of respondents were employed as genetic counselors. For this reason, ASGC proportion values may not add up to 100 % when referring to genetic counseling-specific variables. ASGC survey results are representative at the 95 % confidence level ± 3 % confidence interval (Australian Survey Research Group Pty Ltd., 2012)

[a] $N = 238$ for the entire survey, including non-genetic counseling professions, see below note. For genetic counselor-specific variables, $N < 238$

[b] Statistical significance is set to $p = 0.05$

[c] Based on $N = 14$ due to one counselor not providing a response for this question

[d] ASGC survey, $N = 207$ – Australian based jobs only

Data Analysis

This study used a basic hermeneutic (iterative) approach (Crabtree and Miller 1992; Grbich 2007). Data collection and analysis were carried out concurrently in an iterative manner: i.e., the interpretation of each data collection cycle directed the next cycle so that later cycles were more specific and tailored to answer the research question. A hybrid (inductive and deductive) approach to thematic analysis guided the overarching analytic strategy (Fereday and Muir-Cochrane 2006). Specifically, a coding method was employed for reducing interview data into words, phrases or passages that represented evidence of answers to the research question (DeCuir-Gunby et al. 2010; Grbich 2007). The coding method necessarily produced codes, and collectively they made up the codebook used to analyze the interview data for this study. Codebook development and application was also an iterative process. The codebook evolved via a cyclical and repetitive process of adding new codes to account for new datum, re-assessing initial codes, dropping some and modifying or combining others.

Following a hybrid approach to thematic analysis, the codebook consisted of data-driven and theory-driven codes to capture the range of relevant themes across interview data. An inductive approach was used to develop data-driven codes that emerged directly from raw data, closely matching the language used by participants. Data-driven coding was employed to give the participants' voices primacy and ensure that any findings remained grounded in the area of investigation. The exploratory nature of this study meant the main body of codes generated was intentionally data-driven.

In addition, theory-driven codes were developed prior to data collection and included in the codebook. They were used primarily to incorporate pre-existing genetic counseling models from the literature into analysis (Crabtree and Miller 1992), and as meta-codes (Saldana 2013) to organize data-driven codes relevant to a relational approach. Theory-driven coding made up the core of the deductive analysis required for hypothesis testing. Hypothesis testing was specifically used in this study to answer the first research question: "Do genetic counselors use a relational approach to encourage genetic information disclosure for their HBOC clients?" By allotting data-driven codes into pre-defined theory-driven meta-codes—based on inclusion criteria—hypothesis testing with these specific data then indicated whether genetic counselors used a relational approach to encourage genetic information disclosure. The underlying inductive analysis provided the rich qualitative data necessary to answer the second research question, "If counselors do use a relational approach, how do they use it to encourage genetic information disclosure?"

Reliability of the coding process was established by using a modified form of inter-coder agreement (MacQueen et al. 1998). Each author independently coded a selected interview excerpt using the codebook. Discrepancies were discussed until a consensus was reached. *QSR NVivo* qualitative research software was used for data management and the coding process. Interview data were coded until saturation and no new themes emerged. A post-coding management method—code mapping (Saldana 2013)—was applied to extract analytical conclusions. In tandem with continuous analytical "memoing", this allowed for the systematic identification of major themes and concepts embedded in the data, producing qualitative evidence for this study.

Results

In total, nineteen participants were invited to take part in the study between March and June 2014, however the sample size was capped at sixteen due to practical constraints. Data gained from one participant was discarded due to difficulties with the interview audio recording, making the final sample size fifteen participants.

Interview duration across the sample ranged between 30 and 90 min and analysis revealed that genetic counselors use a relational approach to encourage the communication of genetic information among the family members of their HBOC clients. Counselors implement a relational approach in three escalating stages: covert, overt and authoritative. Each stage represents the increasingly direct attempts of counselors to steer their clients towards disclosure. Counselors use a relational approach exclusively in pre-test consultations when clients are faced with the decision to undergo *BRCA1/2* mutation testing. The relational elements of their approach are presented below, illustrated by participants' accounts.

It is important to note that counselors were client-centered in their general approach to genetic counseling. The relational approach described below was exclusively applied in the context of disclosing genetic information to other family members and was used as a means of encouraging clients to consider the familial implications of hereditary genetic testing.

When a Client Declined Testing

Genetic counselor-client interactions during pre-test consultations are critical in terms of influencing a client's decision to undergo genetic testing for HBOC. They are also critical to the client's understanding of the familial implications of genetic testing (Trepanier and Allain 2014). Counselors in this study were aware of the importance of pre-test consultations in influencing a client's future healthcare decisions and took a client-centered approach to discussing the benefits of genetic testing, such as having the option for individualized screening to enable informed decision-making about prevention strategies and risk-reducing surgeries (Christinat and Pagani 2013). Importantly, as a part of being client-centered, counselors were content for a client to decline the option of genetic

testing, but only if they felt the client was making an informed decision:

> I'm comfortable for the person in front of me not to have the test because they know all of the information. They know the risks. They know the chances. We can recommend that they have certain screening. (Trish)

Another counselor explained she was happy for a client to decline testing so as long as they took on board general medical advice based on their family history and individual risk assessment:

> You can still present you know, what genetic testing will be able to tell you, how the information could be applied to that person and their family and let them decide whether that's a good thing or a bad thing and the alternative you know, if someone doesn't want to know that testing—where that, you know what that leaves them with, what options it leaves them with. […] I find myself being quite comfortable leaving a session if someone decides that they're not going to have genetic testing provided that they will still […] stay open to the medical advice that's given to them. (Natalie)

The excerpts above illustrate the predominant view of counselors if a client declined genetic testing for germline *BRCA1/2* mutations.

When a Client Accepted Testing

All counselors felt that non-communication of genetic test results within a family was very rare among their clients, and their clients were generally comfortable with the familial nature of genetic information. One counselor explained:

> I think problems with family communication are quite rare overall and they're more related to problems in family communication that pre-exist rather than being specifically related to the genetic information. (Cathy)

Concurrently, most counselors noticeably felt that accepting to undergo testing had obvious familial implications.[3] They explained feeling uncomfortable with a client considering genetic testing but then declining to inform other family members about the availability of predictive genetic testing for the potentially identified germline mutation. One counselor described the difference in attitudes thus:

> I mean I'm very comfortable with the concept that people could choose not to have testing, but I'm not comfortable with the concept that someone would withhold information that that test is available [to family]. (Cathy)

This illustrates that typically, counselors saw disclosing the availability of genetic testing as an obligation for the client as it would benefit the family. From one counselor's point of view, however, a client presenting for genetic testing had an obligation to disclose their genetic test results for the benefit of society:

> The whole purpose [of] the genetic service being around is to reduce the cancer burden in our society. So identification of mutations and therefore offering appropriate screening for family members is one of the main goals. So if we can't do that, then that defeats the whole purpose of the entire thing. So that is explained to people at the start so it's kind of implicitly assumed that that's one of the things they've weighed up. (John)

Other counselors did not raise John's viewpoint, but it highlights an interesting perspective in pre-test consulting whereby the counselor links familial disclosure of genetic test results with societal benefit. More generally, counselors viewed agreeing to undergo testing as an implicit agreement and understanding by the client to then disclose their results to family (or to the familial cancer clinic) for the benefit of family. This stance was reflected in the implementation of a relational approach to encourage the disclosure of genetic information once a client had agreed or was considering testing. In this way, counselors embedded the task of disclosing test results within the process of consenting to testing. They did so in three escalating stages—covert, overt and authoritative—each successive stage being more direct than the last.

Covert

According to counselors' accounts across the cohort, the most commonly implemented stage of the relational approach was covert. Counselors indicated that they subtly and indirectly applied a relational approach to encourage their clients to disseminate their genetic test results after testing, regardless of their disclosure preferences. Most counselors recognized that HBOC client-family relationships were highly influential on patterns of disclosure. In order to make use of these relationships to facilitate disclosure the counselors first attempted to understand them. This took the form of subtly piecing together the client's family dynamic, usually by being receptive to their client's personal story and engaging them in conversation about their family when taking a family tree or pedigree.

[3] 3/15 counselors did not raise familial implications for genetic testing within the interview. This, however, should not be viewed as an indication of how they feel regarding the familial implications of genetic testing.

One counselor explained the role of client relationships in the context of family communication:

> You're looking at the wider family, so where they sit in that, who else this information is going to be useful for, how those relationships do work, whether there are open communication styles within the family or whether they are very closed. (Chloe)

Another counselor contextualized client relationships within the family dynamic, placing an emphasis on understanding the client's role amongst those familial relationships:

> I think a lot of [non-disclosure] is about the family dynamic because you know; everyone in their family plays a certain role so I'd want to understand what their role was in the family. (Trish)

These excerpts reveal that counselors were keenly aware of the familial context of their HBOC clients, and to better facilitate genetic information disclosure they attempted to understand the relationships that made up the familial network of their client. By appreciating the extent and mechanisms of these relationships, counselors could later make use of them to actively aid in the disclosure of genetic information in a more overt approach if necessary.

Nearly all of the genetic counselors demonstrated they were acutely aware of their clients' social situation. By adhering to a strong family focus—talking about the family in general—during pre-test consultations counselors emphasized the familial implications of genetic testing for the individual client. This served to subtly contextualize the client's decision to undergo testing within their family context:

> When I do testing I constantly talk about the family […] I just talk about the familial [genetic] fault and lots of people in the family could have [the mutation]. If we test you it might give us a clue as to what's going on in the family you know, rather than in you. So instead of focusing on this caused your cancer, it's like: "the cancer's in the family". (Tess)

In addition, counselors felt that maintaining a family focus early in the pre-test consultation process served to prime the client to disclose, making them aware of their responsibility to disseminate the information post-test. They explained that this ensured the concept of disclosure was not something new at the time of the results consultation where a client might be experiencing the emotional impact of a mutation positive result. This gave the client time to consider their approach to dissemination before possibly receiving a positive result. In this way, the very concept of disclosure was embedded in the pre-test consultation process, representing a covert relational approach to facilitate the disclosure of genetic information. One of the counselors described the idea of priming the client in this way:

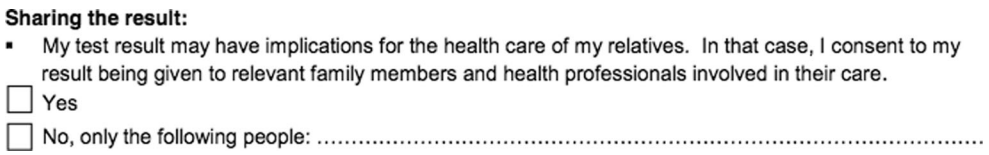
> The implications for family members is something I think is a pretty important aspect of the testing and that you want people to know that the information is useful for family members and that other family members might be at risk. I don't think it's something you want to surprise them with when you're giving them a result as well so just to get that kind of all out of the way beforehand and it also can give them an opportunity to have a chat about the fact that they're having testing before they get the result so they can tell family members look, I'm having this test, if it comes back positive it's going to mean something for you and that way kind of everyone can get prepared for what might come as well. (Alison)

A discussion of the familial implications of testing naturally occurred when the counselor collected family history information from the client for a risk assessment in the initial consultation. At this stage the counselor was concerned with how the client was positioned in the family network, representing a distinctly relational element in their practice.

> By the time you come to taking a family history, essentially you are talking about them in the family context and how they fit in and, I guess from that point on, the focus probably shifts from just an individual to an individual within a family network and what the family structure and the family history of cancer means for them. (Alison)

One of the counselors used the family pedigree (mapped out earlier in the consultation) as a visual aid to ensure the familial implications were relatable to the individual client. By physically pointing out potentially at-risk family members and discussing the implications of a positive test result, the counselor, while being overt in terms of using a visual aid and emphasizing the client's position within their family network, was covertly relational in that the issue of disclosure or non-disclosure was not directly addressed. This was a subtle way for the counselor to prime the client to disclose results by ensuring the client developed an appreciation for the familial context of genetic testing.

> I kind of say […] assuming [the mutation] is from your mum's side well, this is important for your sisters, for your aunts, for that cousin of yours over there and so I guess really trying to point out to them and make it relatable for them, you know, using people's names on that pedigree so your sister so and so, that's going to be important for her and her children. (Sarah)


Sharing the result:

- My test result may have implications for the health care of my relatives. In that case, I consent to my result being given to relevant family members and health professionals involved in their care.

☐ Yes

☐ No, only the following people: .....

Fig. 1 Excerpt from "Consent Form for Analysis of Genes Associated with Cancer"

Notably, in their practice, two senior counselors explicitly omitted the option of non-disclosure in their explanation of the final section of the consent form for genetic testing (Fig. 1)—which specifically addresses the issue of disclosing results.[4]

Excerpt from the "Consent Form for Analysis of Genes Associated with Cancer" (2010)—Ministry of Health, NSW. This section is on all consent forms used for HBOC genetic testing across the States and Territories in the study sample.

From their accounts, the omission of the option for non-disclosure itself was explicit, but how they achieved this in practice was subtle. One counselor explained disclosure in terms of passively providing information for the state database for access by other family members, feeling strongly that an individual should not have the power to deny others in their family information that could benefit their healthcare. The counselor viewed the presenting client as a representative of their family, and any information gained from genetic testing was to be shared. She explained:

> When we do the consent form, I don't really offer them […], I don't really set to say, now you can choose not to tell any of your family. I don't actually tell them that. I say, now we ask permission to put this result on our database so that other family members can also benefit from it. Are you happy with that? And they all say yes […] No one should be in the position of being allowed to say no one is allowed [to know] my family history. (Tess)

A stance such as this seems to place the concern for other family members on at least the same level as concern for the client.

Overt

The second stage represented an escalation of the relational approach to an overt level: that is, counselors were more actively and obviously relational when discussing the disclosure of genetic test results. Counselors carried out this approach when clients showed signs of being reluctant to share their genetic test results or being uncomfortable with taking on the responsibility of dissemination, but not in cases of active non-disclosure in which a client would explicitly refuse disclosure. In some cases, they carried out the approach pre-emptively, before a client showed any reluctance to disclosure.

For the majority of counselors, stage two of the relational approach consisted of overtly reframing the concept of disclosure in a familial context. From counselors' accounts it was clear that reframing was used pre-emptively in most cases as an extension of covert relational approaches, but it also helped to convince clients who were hesitant to disclose their results that their family members would benefit from knowing their genetic risk. Generally, counselors would explore the decisions of their clients regarding the disclosure of genetic information, engaging them in an open dialogue if they revealed they were concerned about disclosure. They would ask about the client's reasoning for not sharing and provide reasons for why disclosure is helpful for others. Reframing disclosure in terms of the benefits it could provide for other family members showed that genetic counselors contextualized their clients within their family network, socially situating the decision of disclosure. Below, one counselor explains the idea of reframing disclosure to clients that have decided to withhold information from their family:

> You just try to explain or explore with them the implications of the decision that they're making, that they're denying family members access to genetic testing altogether. Because you'd hate for them to make the decision and then not realize what the implications were, so you gently and without trying to sound judgmental, just kind of explore the implications of that decision for family members. (Alison)

One of the approaches counselors took to reframing disclosure was to identify disclosure as empowering for the client and other family members. Empowerment in this relational context refers to counselors highlighting the benefits of genetic testing for the individual—that is, the acquisition of information to make informed healthcare decisions—and then explaining that those very same benefits are extended to other family members by informing them of their genetic risk of disease. In this way, disclosure of test results by the client facilitates choice for their family members: the choice to undergo genetic testing and therefore have the same opportunity to make their own decisions regarding their screening and management for HBOC. By facilitating choice for other

[4] When referring to implications for the health care of relatives, genetic counselors generally explore test results in the context of the proband and their pedigree, leading to the discussion on who the result is relevant to. This includes first, second and third degree relatives as appropriate.

family members the client is empowering them. As one counselor explained:

> They feel like [genetic information] is helpful because it means that other family members can have testing and be screened and know what their risks are. (Laura)

From another perspective, one counselor described non-disclosure to clients as limiting the choice of at-risk family members with regards to their healthcare:

> You're taking away their choice to decide for themselves. (Mary)

Another aspect to reframing disclosure used by the counselors was a type of relational empathy. Relational empathy here refers to genetic counselors trying to convince their clients to empathize with their family members and to understand how an act of non-disclosure on their part would impact on their family. One way the counselors did this was to specifically focus on another family member and how they would react to not being told of their genetic risk. This was an overt attempt to convince the client to understand other perspectives when considering genetic information disclosure. One counselor focused on a client's sister and her reactions to non-disclosure:

> What if she got a breast cancer and you hadn't told her about this? How do you think that would make her feel? (Sarah)

In most cases, after highlighting how others would feel with acts of non-disclosure the counselor would then 'flip it back' onto the client, asking them how *they* would feel if their family member was not informed as a result of their decision and then later developed cancer.

> If in two years your sister got breast cancer and you hadn't told her about this, how would that make you feel? And I guess playing that devil's advocate and trying to get them to think about it from different points of view. (Sarah)

In this way, the counselors attempted to provide other perspectives to the decision of disclosure, ensuring the client was aware of the social context and ramifications of their decision.

An additional aspect to the overt relational approach was the use of relational circumvention by the counselors. Beyond understanding the client's relationships, as seen in the covert approach, nearly all counselors overtly attempted to make use of client relationships to aid in the dissemination of genetic information. By recruiting another family member to aid in the process of informing other relatives counselors circumvented barriers to disclosure communicated by the individual client. Most commonly, this approach was implemented when a client expressed concern about having to take on the role of primary disseminator amidst coming to terms with a newly identified increased cancer risk. Genetic counselors would overtly probe for other supportive family members who could help.

> I talk through a number of alternatives [to disclosure]. If they're unwell or tired or say, I just can't face it. I say, fair enough: you've been through a lot. Is there anyone else who can help you with this? Is there someone who would take this off your shoulders? You know, who does your son talk to? And we actually look at the family tree and I say, now you've got this branch here. Is anyone in contact with them at all? And almost always they say, oh my sister talks to her a bit. (Tess)

There were cases described by counselors in which disclosure for their clients was difficult for justified reasons: for example, if a client was going through cancer treatment and family communication about genetics a secondary consideration at that time. On a case-by-case basis, counselors made it clear that disclosure of genetic information to family may not be an immediate cause for concern in *BRCA1/2* genetic testing. Rather, they encouraged handling disclosure one step at a time, first becoming comfortable with the diagnosis themselves and then considering how to effectively disseminate that information at a later date.

> I would never push somebody in that result disclosure appointment that this [communicating genetic information] is what you have to do right now [...] They need that time to assimilate and absorb that information into their life and what's going on for them before we kind of move on to, you know, making sure everybody else is informed. (Jane)

This approach was considered a client-centered technique to facilitating genetic information disclosure.

The final aspect to the overt relational approach was the distinct relational use of the consent form for genetic testing (see Fig. 1)—termed here as relational consent. The final section of the consent form for HBOC genetic testing specifically addresses the disclosure of genetic information. Counselors used this section to revisit conversations about the familial implications of testing. In this way, counselors socially situated their clients' decision-making processes, making clear the impact they would have on other family members. This conversation was mediated in a particular way by many of the counselors: instead of using the wording on the consent form the counselor would guide the client

through the form and at this section would explain the concept of disclosure in their own words. One counselor felt that phrasing the concept of disclosure was important in achieving a positive perception of disclosure for the client. For predictive testing, she explained:

> I think sometimes the way in which you phrase and you read that consent form you could get very different answers […] Anyone having predictive testing, I usually say to them […] are you willing to disclose this information to any other family members? […] Whereas, you could phrase it and say, so who can know about your result? […] If I phrase it like that they start thinking, oh gosh there's these options. Maybe there's a reason why people shouldn't know […] my result. […] Two ways of phrasing it, you get two different answers. (Laura)

Most counselors explained the consent form by specifically emphasizing the benefits of sharing for other family members. Jane's comments are representative of the cohort's attitudes in this context:

> I say this part of the form is really because this information is important for you, but it's also important for other people in the family and if there's a result that's relevant for them, are you happy for that information to be shared with them? (Jane)

Some counselors explained that consenting to sharing their results would not be an active process of dissemination: that is, the clinic would not contact relatives and inform them of the mutation. Rather, they explained that the information would be available for other family members if they presented to a FCC across Australia. Family members then would have the option to undergo predictive testing for the identified germline mutation. This explanation tied in with a common distinction many counselors made between family cancer risk and individual cancer risk. Information about family cancer risk was to be shared; this consisted of simply informing other family members of the presence of a heritable mutation in the family, whereas individual cancer risk—the specific mutation and whom it was first identified in—could remain private. This kind of distinction helped HBOC clients to understand that sharing did not have to implicate them and represented a distinctly relational approach taken by the counselor to position individual cancer risk within the broader context of family information. One counselor explained it in this way:

> I try and clarify it. It's not like this consent form is a sort of a license for me to go and call your family members and tell them straight away, it's just if another genetic service calls me and asks me if I can release the mutation report. Like I try and explain what it is […] it's not: I go around and say: "Oh Jenny, your brother, sister and uncle have the mutation positive gene [...] but your other sister doesn't." You know? All I say is – all that consent is really doing in practice is when another genetic counseling service calls me and says we want to arrange predictive testing, I can facilitate that for somebody. (Laura)

Overtly using a relational approach to explain the consent form represents the final step in embedding the process of disclosure into the process of consenting to testing.

Authoritative

The third and final stage of the relational approach used by counselors was highly direct—termed here as authoritative. This was rarely applied across the cohort, with only three senior (average of 13 years experience) counselors implementing this kind of relational approach to encourage the disclosure of genetic information. From their accounts it was clear that this escalation was an extension of the overt approach and was used specifically in cases of active non-disclosure. It was characterized by the counselors engaging and challenging the client's decision of non-disclosure with similar techniques as the overt approach (i.e., reframing, relational empathy, relational consent etc.) but in a markedly more authoritative capacity. This was to ensure the importance and scope of genetic information disclosure was persuasively considered before consenting to testing, making this stage distinctive in terms of scale rather than in terms of specific qualities. Two senior counselors explained they would host authoritative conversations about the idea of disclosing test results, demonstrating their convictions for relational aspects and familial disclosure:

> If somebody said to me at that point [when consenting for genetic testing] I don't want any family member to know, I would then question why they are having the test in the first place […] alarm bells would be ringing and I would be saying, well we need to look at this […] I wouldn't deny a person a test based on that, but I would explore the reasons behind that statement then and there before we moved on. (Cathy)

Similarly, another counselor explained:

> It's a warning bell for me if somebody says that they can't tell anybody on that [consent form]. […] There's some reason why this individual's decided that this information is just for them and for them only. Genetic information doesn't work like that. That means that I'm going to have to counsel her and say, but aren't you aware that there are other people that might have the

> right to this knowledge? Don't you think that maybe other people might need to know what their risk of developing cancer is? And it's a huge red flag that there's going to be a lot of other issues pop up. (Laura)

There were cases of active non-disclosure described by these counselors in which disclosure for the client was difficult for justified reasons: for example, in cases of complicated family dynamics. One counselor described:

> One lady who had diagnostic *BRCA* testing who came in to see us and was not in touch with her sister because her sister had gone out and told everyone she had a *BRCA* mutation. She [the first sister] didn't. […] Basically this sister's breast cancer diagnosis had ruined her relationship with her sister so this woman who came in to us to have the diagnostic testing said, I don't want to share this information. […] She saw it as personal health information. (Louisa)

Counselors in these cases described still challenging the patient on their views to understand their perspective and counsel for disclosure at some level. When asked how the counselor would approach the situation above if the result was positive, she responded:

> I'd be focusing on the fact that there could be major benefits in knowing […] I'd probably be speaking to this first sister and saying, look this is completely up to you, but we see this person [your sister] would value from having this useful information. (Louisa)

It is imperative to note that although using an authoritative approach to encourage informing other family members, these counselors did not deny a client the option of genetic testing based on their preferences for disclosure.

Discussion

The aim of this study was to discern whether Australian genetic counselors use a relational approach to encourage genetic information disclosure for their HBOC clients; and if so, how they use it. The findings demonstrate genetic counselors in this sample use a relational approach exclusively in pre-test consultations to encourage disclosure. Implemented in three increasingly direct stages (covert, overt and authoritative), the relational approach evident in participants' accounts is characterized by counselors using techniques to socially situate their client. Counselors are aware that clients take their family into account when making healthcare decisions. They also seek to understand and make use of client relationships to facilitate the dissemination of information and they contextualize their client's potential actions and decisions within the network of relations they share with others. Finally, they focus on the needs of other family members when necessary to encourage disclosure.

Proactive Encouragement

When encouraging clients to disclose results, qualitative data from this study suggests genetic counselors explicitly focus on the rights and needs of other family members to know their genetic risk, not just on the needs of their client, indicating that when facilitating genetic information disclosure they do not only practice a client-centered approach. Encouraging clients to disclose family information does not in itself go against individual autonomy or a client-centered approach. It is only when the family's needs *rather than* the client's become the focus of counseling that it ceases to be *client-centered*. This result supports previous survey studies portraying similar findings (Dugan et al. 2003; Falk et al. 2003; Forrest et al. 2010). The relational approach employed by counselors in this study is characterized by increasingly direct attempts to socially situate a client's decision to undergo genetic testing. When facilitating genetic information disclosure, the use of a relational approach in different forms seems to be common practice for the counselors in this study. This is consistent with several international guidelines (including the National Health and Medical Research Council (NHMRC) in Australia) recommending counselors take on a proactive stance to encourage their clients to disclose genetic information to family members (Forrest et al. 2007).

Taking on proactive approaches to encourage dissemination also reflects the professional responsibility felt by counselors to expand their scope of care beyond the individual to incorporate other at-risk family members (Forrest et al. 2010; Patterson et al. 2005). Realistically however, in a family mediated communication context where counselors cannot legally pass on genetic information to at-risk relatives without client consent (National Health and Medical Research Council 2014), the only method remaining to counselors is to take on a proactive stance and persuade their client that disclosure is indeed beneficial. This suggests that the practical and legal context of genetic counseling for the disclosure of genetic information at times requires an approach that departs from client-centered perspectives that guide genetic counseling as a profession if they are to fulfil what they also feel is their professional duty to at-risk family members. This study provides indicative evidence that in practice counselors enact this duty by using a relational approach with increasingly direct attempts to encourage the disclosure of genetic information.

A limitation to more proactive approaches addressing passive non-disclosure is that they can infringe on a relative's "right not to know" their genetic status (Andorno 2004). The argument here is that if autonomy gives us the right to

know our genetic status, then autonomy equally gives us the right to remain uninformed of our genetic status. A common stance of genetic counselors is that "being informed is better than being uninformed" (McCarthy Veach et al. 2007, p. 719), which is more evident when there is the option for well established beneficial medical intervention (Hodgson and Gaff 2013)—for example, in cases of HBOC.

Covert

Family Systems Theory and The Reciprocal Engagement Model

The findings demonstrate that counselors initially implement a covert relational approach to encourage genetic information disclosure, irrespective of their clients' disclosure preferences. One aspect of the covert relational approach has elements consistent with Family Systems Theory (FST) (Galvin and Young 2010). Specifically, it resonates strongly with the concept of interdependence: because family members are interconnected within their family unit—i.e., they share biological and social bonds—a health change in one family member will affect the whole family (Galvin and Young 2010). Counselors demonstrate an appreciation for this concept when they attempt to understand the client's family dynamic and communication patterns because they realize that decision-making regarding the disclosure of genetic test results will affect the entire family unit.

Attempts at understanding the client's family dynamic and communication patterns are also consistent with elements of the Reciprocal Engagement Model (REM) (McCarthy Veach et al. 2007). The REM was developed from a workshop of North American genetic counseling program directors and considers five main tenets: (1) the genetic counselor-patient relationship is integral to genetic counseling; (2) genetic information is key; (3) patient autonomy must be supported; (4) patients are resilient; and (5) patient emotions make a difference (McCarthy Veach et al. 2007). The REM is generally centered on the counselor understanding the individual patient: focusing on their resilience, their emotions, their autonomy and their need to know genetic information.

Two tenets of the REM have process goals consistent with the covert relational approach proposed in this study:

- Tenet: patient emotions make a difference
    - Process goal: the genetic counselor and patient both understand the patient's family dynamics and psychosocial context
- Tenet: patient autonomy must be supported
    - Process goal: the genetic counselor understands the patient's familial and cultural context and works within this context to engage in decision-making with the patient (McCarthy Veach et al. 2007, p. 722).

Both process goals are consistent with the covert relational approach. Each goal concerns the genetic counselor being acutely aware of, and taking steps to understand, the familial context of disclosing genetic information and the dynamics of communicating that information. Similarly, the counselors in this study described having a strong family focus early in consultations and socially situating client decision-making for genetic testing. The extent to which the REM as a normative model of practice reflects actual genetic counseling practice remains to be seen (Hodgson and Gaff 2013), but at least some specific elements seem to be in practice in this study in the form of a relational approach.

The consistency of the relational approach described here with FST and the REM may be a reflection of genetic counselor training. Currently in Australia there are two postgraduate Masters courses that offer genetic counseling training. In accordance with the accreditation requirements for Masters courses set by the HGSA, both courses have curricula covering the domain of "psychosocial content": within which there are subjects relating to the development of counseling skills (Human Genetics Society of Australasia 2011). These subjects incorporate a mix of counseling theories such as FST, psychoanalytic theory, cognitive behavior theory and models of practice such as the REM in an attempt to develop genetic counseling skills.[5] Notably, their training spans both client-centered and more family-based theories. However, our study suggests that in the context of family cancer counseling, counselors are intrinsically relational and apply their FST knowledge and relational components of the REM to encourage the disclosure of genetic information. While a counselor could choose to use more client-centered approaches and focus solely on proband mediated issues (whether they are familial or not), this study indicates that counselors also promote familial values independent of articulated proband concerns.

Family Comity

Another important aspect of the covert relational approach evident in the counselors' accounts was the priming of the client to disclose results. Counselors did this by associating the client's consent to undergo testing with their agreement to disclose their results. That is, they ensure that consent to

[5] The Masters courses were initiated as of 2008 (Sahhar et al. 2013), therefore more experienced practising genetic counselors in Australia have not undergone the specific training mentioned here. This may not be reflected in this sample, as 60 % of the sample consisted of Associate Genetic Counselors, meaning they had undergone the Masters course recently.

testing is given under the premise of later disclosing the results to at-risk relatives. This suggests that counselors implicitly conceptualize genetic information as inescapably familial and therefore promote a co-ownership model of genetic information. The specific model of co-ownership of information in their accounts reflects the family comity (FC) model of co-ownership (Davey et al. 2006).

Family comity offers a way of conceiving genetic information in families that balances individualistic conceptions of autonomy—a person's right to hold views and make choices based on personal values and beliefs free from restricting influences (Beauchamp and Childress 2001)—and the rights of other family members to know their genetic risk of disease. Comity is considerate behavior towards others (Davey et al. 2006); in the FC model, when a client enacts their personal autonomy to undergo genetic testing a counselor encourages him or her to take into consideration their obligation to other family members with regard to sharing information. This is a markedly relational element in that this kind of encouragement by the counselor promotes the relational autonomy of the client.

A strikingly strong adherence to the FC model by two of the counselors in the cohort was the omission of non-disclosure as an explicit option when discussing the consent form for genetic testing. By generally presenting genetic information as necessarily familial and not individually owned, the counselors subtly shape the client's perceptions of disclosure in a way that leaves dissemination as the one and only ethically "right" option. This kind of adherence to the FC model could be considered directive based on the counselor deliberately attempting to shape the client's decision. This kind of action is closely linked with another theme, "relational consent", to be explained in the next section in that the counselor explains consenting to genetic testing in terms of familial implications and promotes the relational autonomy of the client.

By appealing to this form of relational autonomy, family comity as a concept demands "that the implications of genetic information for genetic relatives should also be routinely considered" by counselors when consulting their clients about disclosure of genetic test results (Davey et al. 2006, p. 164). This was clearly demonstrated by counselors in this study, suggesting they implicitly, and possibly unknowingly, operate from such a model. In addition, previous studies indicate that HBOC clients also act in a relational manner (D'Agincourt-Canning 2006; Hallowell et al. 2003). This suggests that an FC model reflecting relational perspectives accurately reflects what already happens in practice and could help address the issue of non-disclosure by ensuring all family members have a stake in consultations from the outset (Leonard and Newson 2010).

The use of the FC model by genetic counselors in this study adds a practical dimension to recent literature calling for a change in ethical frameworks in genetics generally. This call for change is aptly described by Widdows (2009): ethical models should recognize "the rights and interests not only of the individual but also of other genetically related individuals and groups who have an interest in such [genetic] information and who may potentially be harmed" (2009, p. 177). Widdows (2009) further proposes that an understanding of the individual that takes into account their relationships with others, specifically family, is more appropriate in genetics than focusing on the individual as the primary unit for ethical concern. Findings from this study provide suggestive evidence that counselors already encompass this kind of ethical framework in practice, lending support to potential changes in the future.

It should be recognized that there are some limitations to the FC model in practice. The principal drawback is that clients could avoid genetic testing if they feel they then have to disclose their results to family by default (Leonard and Newson 2010). Counselors in this study stopped short of denying a client genetic testing based on their preferences to disclosure. Nonetheless, by actively attempting to persuade clients to disclose results, the counselor could still be deterring their current and future clients from pursuing genetic testing.

Overt

Relational Consent

The overt approach was most strikingly demonstrated by the counselors' relational use of informed consent in the genetic testing process. The rewording and explaining of genetic testing in terms of what the implications are for family represents a departure from the customary process of gaining consent in medical decision-making.

By mapping the relations surrounding a client that could affect their medical decision-making, counselors ensured the process of consenting to genetic testing had a relational grounding. Ultimately the counselors respected a client's decision to decline testing and, as previously mentioned, they did not refuse the option of genetic testing based on clients' preferences regarding disclosure. However, the relational application of informed consent follows the argument that clients should be encouraged to include the interests of family members in thinking about medical choices, but that the choice intrinsically belongs to the client (Blustein 1993). This study shows that counselors already enact this kind of approach in practice.

Reframing Disclosure

Another overt relational technique described by counselors was the reframing of disclosure as a concept incorporating the implications for other family members. Reframing is a communication skill seen in many counseling professions whereby a practitioner restructures their client's thoughts to consider an issue from another perspective (Gaff et al. 2010).

This suggests that implementing a relational approach in practice makes use of current communication skills possessed by the counselors. What was unique in the reframing by counselors in this study was that it took on a relational nature in several different ways: including relational empathy, empowerment and a unique distinction between familial and individual cancer risk.

Relational empathy was one reframing technique that counselors employed to ensure their HBOC clients understood how non-disclosure would affect other family members. By encouraging them to empathize with their relatives, counselors emphasized the interdependence of the family unit, thereby facilitating disclosure with a distinctly relational outlook. Alternatively, in some cases, trying to offer a client an alternative perspective could be construed as a guilt-inducing strategy to consider disclosure; it should therefore be used judiciously. Overall, relational empathy as a concept is consistent with the FST element of interdependence mentioned previously. Another technique was the specific reframing of disclosure in terms of empowerment: that is, framing disclosure as empowering for other family members because they can then make their own healthcare decisions based on the information gained from testing. This is consistent with D'Agincourt-Canning's (2006) findings that HBOC clients can view genetic testing as an empowering procedure both for themselves and for other family members. Employing this kind of reframing reflects that counselors are aware of the relational aspects of genetic testing for the client. Furthermore, both approaches are distinctly not client-centered in that they explicitly focus on the needs and rights of other family members (Hodgson and Gaff 2013).

One aspect of reframing used by the counselors exhibited an element that, thus far, appears unique. This was the distinction counselors made between: a) disclosing familial cancer risk; and b) the disclosure of personal cancer risk. This distinction was made to reassure the client of his or her anonymity and was stated in the context of discussing the final section of the consent form for genetic testing, which relates to sharing familial cancer risk (the germline mutation report) with other FCCs for at-risk relatives to access.

If a client was concerned about being identified when taking on the responsibility of disclosure, counselors worked on this distinction by suggesting the first step of this responsibility only consisted of sharing the familial cancer risk. Individual cancer risk and any identifiable information could remain private and confidential if desired until a time when the client felt comfortable to actively disseminate information. This helped to facilitate disclosure because counselors ensured their clients at least consented to providing the results to other family cancer clinics for access by at-risk relatives. Once someone in the family informed them of their risk, relatives could then seek out testing using the identified germline mutation as the basis for predictive genetic testing. Reframing in this way also represented a distinctly relational approach in the sense that counselors situated individual cancer risk within the broader context of familial health.

Another aspect of the overt relational approach was relational circumvention: the recruitment of another family member to aid in sharing the responsibility of disclosure. This approach reflects a similar recommendation made by the NHMRC of Australia in their information paper on the ethical aspects of human genetic testing: "involvement of another family member as go between may be helpful" in cases of genetic information non-disclosure (National Health and Medical Research Council 2000). This strategy is also similar to the family network approach, where different family members inform various branches of the family (McConkie-Rosell et al. 1995). Using this kind of technique is prudent in the context of family mediated communication and could explain why many counselors in the cohort adopt relational circumvention to facilitate the disclosure of genetic information.

Authoritative

A small number of counselors in this study described an authoritative relational approach to encourage genetic information disclosure. This approach, we suggest, represents the assertive enactment of the family comity co-ownership model of genetic information (Davey et al. 2006). This approach was implemented in the rare cases of active non-disclosure and here these counselors took on an authoritative stance to ensure a client did not consent to genetic testing without fully appreciating the familial context of that decision. This could be seen as a final attempt by the counselor to enact the family comity model and ensure that consent to testing is given under the premise of later disclosing the results to at-risk relatives.

As previously mentioned, the escalation to an authoritative approach could be due to the counselors following practice guidelines that encourage disclosure but having to do so within a family mediated contact model. They may feel that assertively emphasizing the shared nature of genetic information and the need for the client to disseminate that information is the only approach they really have in the context of family mediated contact with relatives. This is because if a client does not take on the responsibility there are limited options available for the counselor to inform other at-risk relatives without the consent of the client. As a result, if a client shows a strong reluctance to take on the responsibility of dissemination the counselor responds by taking an authoritative stance and actively attempting to implement the family comity model.

The authoritative approach seems to suggest that at least in practice, counselors have already reached a level of consensus on appropriate levels of directiveness when considering the family communication of genetic information (Hodgson and Spriggs 2005). Respecting client autonomy in terms of non-interference and distancing themselves via non-directive

counseling is no longer reflective of genetic counseling practice in these cases. Promoting the relational autonomy of the client sees the counselor at times being directive to encourage the disclosure of genetic information.

It is important to note that use of the authoritative relational approach was rare across the cohort generally. The rarity of the authoritative approach could be due to the fact that in most cases, the covert and overt approaches successfully instilled the imperative to disclose to family. The seniority of the few who have ever used this approach may well be a testament to the fact that it may be a number of years before a genetic counselor encounters a situation in which the first two approaches were insufficient, rather than an approach which only a few counselors would ever use. Alternatively, the scarcity of active non-disclosure cases amongst HBOC clients generally could be a contributing factor. In their prospective study on genetic professionals' reports of non-disclosure for a variety of hereditary disorders, Clarke et al. (2005) reported the approximate frequency of active non-disclosure for HBOC clients as being less than 0.1 %. This low frequency indicates the likelihood of a counselor encountering such a case is uncommon and therefore the opportunity to implement an authoritative approach is limited.

Study Limitations

The principal limitation to drawing general conclusions for this study is the small sample size ($N = 15$). Although the demographics of the participants in the study closely match those in the ASGC Survey (ASGC 2012), it does not mean their views are representative of genetic counselor practice Australia-wide. In addition, for this study the cohort happened to be more junior, reflecting the profession as a whole (ASGC 2012). This may have affected the range of responses with respect to clinical experience. Counselors were interviewed predominantly from NSW and Vic, limiting the broader generalizability of the findings. Overall, the small sample size and qualitative nature of the data mean that findings from this study are indicative of genetic counselor practice when facilitating genetic information disclosure, but are not conclusive.

An added limitation is the use of semi-structured interviews over survey responses with a larger cohort. With larger numbers and measurable answers, a survey would have provided more than indicative evidence of a relational approach. The use of semi-structured interviews were justified, however, as they were more in-depth and therefore more appropriate considering the exploratory nature of the present study. It is also important to note that the findings for this study are based on counselors' descriptions of their own practice. There could be a discrepancy between their reported and actual practices, and these might also be different to the client's experience, i.e. what they hear during the consultation. A final limit of the study was that using HBOC as a model condition meant that the findings might not be applicable to other hereditary diseases for which genetic testing is available: for example, Huntington's disease.

Implications

This study represents the first qualitative study in Australia to investigate how genetic counselors practice when encouraging genetic information disclosure. Participant responses suggest that when it comes to encouraging clients to disclose genetic information to families, current practice does not always reflect client-centered theory. If genetic counselors are already using a relational approach with a distinct focus on the interests of the family, not just the client, in practice (at least in facilitating genetic information disclosure), this goes beyond simply understanding the familial implications of genetic disease (Resta et al. 2006). Considering how disclosing information to family fulfills the client's motivations and concerns, and helps the client gain support is part of what it means to be client-centered (Hodgson and Gaff 2013), but an explicit focus on the needs and rights of family members for its own sake goes beyond this.

The overall implications for genetic counseling practice and theory are unclear as they were beyond the scope of this study. However, if in practice genetic counselors employ a relational approach with mixed theoretical influences, and depart from client-centered theoretical models by focusing on the needs of other family members, this intersection between practice and theory needs to be further explored. This study has shown that intuitively genetic counselors follow a family focus and this is the normative model of practice in genetic information disclosure. Clarifying the ethical reasoning for this represents a worthwhile research prospect for the future.

Future Directions

Looking to the future, this study provides a good platform for future studies. To determine how genetic counselors work to facilitate disclosure in a broader context, a quantitative project using survey responses gathered from a wide range of genetic services across Australia could be conducted. This would help to further substantiate these findings and render them more conclusive. Following the provision of more conclusive data, a longitudinal validation study could be conducted to determine how effective a relational approach is in terms of achieving dissemination of genetic test results over a period of time following consultations with a genetics service.

What is clear from the results of this study is that counselors pre-empt or address active non-disclosure for clients by implementing a relational approach. Passive non-disclosure, however, is likely to occur more often (Gaff et al. 2005), which suggests it may be the crux of the genetic information non-disclosure issues in genetic counseling generally. Yet

what remains unclear from these results is how counselors address passive non-disclosure. Because passive non-disclosure is manifest in the period following contact with a genetics service, and is therefore not plain to see during consultations (Hodgson and Gaff 2013), the implementation of the relational approach to address passive non-disclosure during pre-test and post-test consultations was not observed across the cohort.

The degree to which FST, the REM and client-centered genetic counseling theories actually inform practice in the context of family communication of genetic disease also remains an unexplored area. As such, it would be worthwhile to investigate exactly which theory is being used, when it is used, and why.

Conclusions

This study indicates that Australian genetic counselors use a relational approach to encourage the disclosure of genetic information for their HBOC clients. The relational approach is characterized by three escalating stages: covert, overt and authoritative. Based on these findings it seems reasonable to suggest that in the context of genetic information disclosure, genetic counselors do not only use client-centered theory but embrace a relational perspective with multiple theoretical influences that considers the needs of the family to know genetic information. While a counselor could choose to use more client-centered approaches and focus solely on proband mediated issues (whether they are familial or not), this study indicates that counselors also promote familial values independent of articulated proband concerns. Additional research would help to determine why they do so, and whether it is in fact a better approach to adopt when encouraging the disclosure of genetic information to family.

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Compliance with Ethical Standards

Conflict of Interest Rowan Forbes Shepherd, Tamara Kayali Browne and Linda Warwick declare that they have no conflicts of interest.

Human Studies and Informed Consent All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

Animal Studies This article does not contain any studies with animals performed by any of the authors.

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