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ORIGINAL ARTICLE

Experience of Asian males communicating cardiac genetic risk within the family

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Abstract

The genetic nature of an inherited cardiac condition (ICC) places first- and second-degree relatives at risk of cardiac complications and sudden death, even in the absence of symptoms. Communication of cardiac genetic risk information allows at-risk relatives to clarify, manage, and potentially prevent ICC-associated risks through cardiac screening. Literature regarding family communication of genetic risk information are predominantly based on Western populations, with limited insight into the Asian experience. This qualitative exploratory study provides a male perspective into the communication of ICC risks within families in Singapore. Eight male participants with clinically diagnosed cardiomyopathy, who had all received genetic counseling, were recruited. A phenomenological perspective was used to identify emergent themes from semi-structured interviews. In this study, most participants recalled their healthcare professional's emphasis on family communication. Notably, participants revealed that at-risk relatives were not accessing screening, and many described family members as currently asymptomatic and "healthy." These findings coincide with documented Asian beliefs regarding perceptions of health, which have important implications for the provision of genetic counseling support within Asian communities, especially in facilitating family communication such that at-risk relatives are informed about their ICC risks and available management options.

Keywords Genetic counseling · Inherited cardiac conditions · Family communication · Genetic risk information · Singapore · Asia

Introduction

The implications of being diagnosed with a genetic condition extend beyond the health of the individual, because family members are also at increased risk of developing the same condition. This research focuses on individuals diagnosed

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with an inherited cardiac condition (ICC), in particular, hypertrophic cardiomyopathy (HCM) and dilated cardiomyopathy (DCM). The former presents with common symptoms such as shortness of breath, palpitations, chest pain, dizziness, and syncope (Cirino and Ho 2014) while the latter may present with heart failure coupled with symptoms of congestion with possible reduced cardiac output; arrhythmias with, or without, conduction system disease; thromboembolic disease, as well as stroke (Hershberger and Morales 2015). A common feature of ICCs is sudden cardiac death.

The first affected individual identified by the healthcare professional, referred to as the proband, is often responsible for communicating ICC risk information to their family members. Genetic counseling helps to support probands in their understanding of the ICC as well as the ICC-related implications for family members (Cowan et al. 2008). The process of genetic counseling also allows at-risk individuals within the family to be identified and genetic testing options to be explored (Cowan et al. 2008). Sharing ICC risk information is particularly important because family members without any of experience of symptoms are often unaware of their risk. Disclosing this risk information can potentially prevent cardiac complications and even sudden death (Batte et al. 2014; Charron et al. 2010). It also gives at-risk relatives the opportunity to access risk management options before any symptoms manifest.

In countries where genetic counseling is well established, much research has been done to explore facilitators and barriers to family communication about genetic risk. However, the majority of these studies focus on the communication of inherited cancer risks and are mostly based on Western populations. Studies involving ICC risk communication within families in Western societies are emerging (Batte et al. 2014; Vavolizza et al. 2014; Whyte et al. 2016; Wiley et al. 2016), but data on the Asian experience of family communication regarding ICCs is lacking. Culture is integral to the way an individual understands, perceives, and acts. As McCarthy Veach et al. (2003) aptly described, "[t]o ignore cultural influences is to ignore the framework of an individual's way of thinking and behaving." Since cultural differences between Western and Asian populations have been postulated to influence the effectiveness of genetic counseling strategies (Allford et al. 2014; Morris 2014), it is important to identify areas of differences in order to adapt and ensure that the efficacy of genetic counseling is not compromised. In addition, qualitative scientific studies, in the absence of recruitment restrictions or bias, tend to have a higher female participation rate (Galea and Tracy 2007; Markanday et al. 2013), resulting in limited male perspectives.

Singapore is an English-speaking cosmopolitan city in Southeast Asia with a population size of 5.61 million (Singapore Department of Statistics 2016). The population is made up of three main ethnic groups, the largest of which are the Chinese (74.3%), followed by Malays (13.4%), and Indians (9.1%), while other ethnicities, such as Eurasians and other Asian races, account for the remaining (3.2%). This multi-ethnic Asian nation is a melting pot of cultures within a rather Westernized society. In particular, the practice of Western medicine is predominant in Singapore (Lim 2012).

Singapore's first ICC clinic, housed at the National University Heart Centre, Singapore (NUHCS), offers genetic counseling, genetic testing, and cardiac management services. All Singaporean males are enlisted for compulsory military training, also known as National Service, and are required to undergo cardiac screening as part of the pre-enlistment medical screening. NUHCS, being one of the two national heart centers in the country, therefore sees a higher proportion of males in comparison to females, as males with cardiac issues are likely to be detected during the pre-enlistment medical screening.

As there is currently no known data on the experience of communicating cardiac genetic risk within families in Asia, the aim of this qualitative exploratory research study was to examine and contribute evidence to the experience of family communication regarding ICC risk within an Asian context. These findings will support the practice and development of local cardiac genetic counseling services and could provide a model for additional existing genetics services in Singapore. The following research questions guided the study to elicit experiences of communicating cardiac genetic risk with family members:

1. Do probands discuss cardiac genetic risk information with family members?
2. How do probands communicate cardiac genetic risk information to family members?
3. What factors, motivators, and/or barriers influence the probands' communication?

Methods

Sampling and recruitment

Ethics approvals for this study were granted by the National Healthcare Group Domain Specific Review Board, Singapore (DSRB Study Reference: 2014/01233, 12 February 2015) and the University of Melbourne's Paediatrics Human Ethics Advisory Group (HREC Number: 1544009.1, 21 May 2015). A purposive sample was derived from a pre-existing ethics-approved study which offered genetic testing to cardiac patients and their family members on a research basis at NUHCS. Only individuals who had attended at least one consultation session with the ICC clinic's genetic counselor were recruited, to ensure that all participants had the opportunity to discuss inherited risks. Individuals fluent in written and spoken English, aged between 21 to 75 years, with an ICC diagnosis, and residing in Singapore were eligible. Those with prior diagnoses of psychiatric disorders, or had formerly declined to be contacted for future research,

were excluded. Potential participants were stratified according to their ICC diagnosis and verified against the inclusion criteria. According to the purposive sampling strategy and to promote homogeneity within the sample population, individuals with HCM were initially approached, and once this potential population was exhausted, the invite was extended to those with DCM.

Eleven invitations were mailed to individuals with a clinical diagnosis of HCM and had previously attended a consultation with the genetic counselor, while six were distributed during the consultation with the genetic counselor, one of whom was clinically diagnosed with DCM. Individuals who indicated their interest to participate were contacted by SK, then a student researcher, to confirm an interview time and location. The Participant Information Sheet (PIS) was sent via email to all participants once the interview had been confirmed. The PIS was also reiterated by the interviewer, SK, at the beginning of the interview, before obtaining an audio-recorded verbal consent.

Data collection and analysis

One-on-one semi-structured interviews were conducted between June and July 2015. An interview schedule (Appendix 1) was developed to guide the flexible inquiry process that aimed to understand the participants' experience of communicating cardiac genetic risk information with their family members. Audio-recorded interviews were transcribed verbatim, with the help of briefly jotted field notes to promote interviewer recall. Transcripts were de-identified and the participants' names replaced with pseudonyms prior to analysis.

Analysis of the data involved an iterative process of repeatedly reading through the transcripts for meanings and recurrent notions, as well as to gain a holistic view of the data (Liamputtong 2013). Each transcript was independently read prior to the initial coding of data and involved the categorizing of data into groups. The identification of themes followed the initial phase of coding, to classify the codes into broader, overarching themes (Braun and Clarke 2006). An inductive analytical approach helped to stimulate the emergence of themes and the recursive process of analyzing the data and categorizing overarching notions and themes collectively refined the themes to make sense of the participants' stories and the data as a whole (Braun and Clarke 2006; Holloway and Todres 2003). Analytic rigor was achieved through independent co-coding of data by authors, YB, LF, SK, and IM, while SK subsequently continued the recursive process of refining the themes. Consensus on the final, refined themes was established through discussions between all authors.

Results

Six of the 17 invitees declined to participate, while the personal circumstances of three invitees prevented them from participating during the interview period despite their initial expression of interest.

A total of eight semi-structured interviews, which lasted between 20 and 36 min, were conducted. Two were face-to-face interviews, while six interviews were conducted over the telephone. All participants were males, aged between 33 and 67 years, one of whom had a clinical diagnosis of DCM, while the remaining seven were diagnosed with HCM. The participants' demographics, along with information about any family history that was disclosed during the interview, are listed in Table 1. Majority of the participants were the first to be diagnosed in their families, with other family members being diagnosed afterwards. Some mentioned during the interview that family members had cardiac issues, but it was unclear if the issues were associated with the ICC.

The conversations involved the use of colloquial Singapore English, better known as Singlish, which includes discourse particles such as "*la*" and "*ah*" at the end of the speech. The same particle often has different functions, such as to soften or to assert, or to alter the tone or connotation, without affecting the actual grammatical meaning (Gupta 1992; Kwan-Terry 1978). Key themes which emerged from the interview data are supported by representative participant quotes.[1]

The experience of communicating ICC risk

Participants of this study had shared their ICC diagnosis, and its potential implications, with more than one family member, as indicated in Table 2. The three main themes which emerged from the interview data were (1) facilitators of family communication, including a pre-existing open nature of communication and the healthcare professionals' emphasis; (2) communication barriers, such as the absence of contact and not wanting to cause anxiety; and (3) the perception that relatives were not undergoing cardiac screening despite having been informed about their risk, which also seemed to be associated with the notion of being healthy.

Facilitators of communication

Openness within the family

Participants who claimed to have more frequent contact with their family members described the process of communicating ICC risk rather matter of factly, suggesting that pre-established family dynamics and communication patterns facilitated the process of communicating ICC risk.

[1] Quotes are reflected verbatim. Two-dot ellipses (..) represent short pauses; three-dot ellipses (...) represent longer pauses; four-dot ellipses flanked by spaces (....) represent speech that has been truncated but without altering the meaning. Square brackets [] are included to add clarification, while round brackets () indicate non-verbal communication such as laughter or gestures.

Table 1 Participant demographics

	Pseudonym	Ethnicity	Age (at interview)	Age (at diagnosis)	Diagnosis	Family history of ICC and/or cardiac problems
1	Alex	Malay	55	40	HCM	Daughter diagnosed with HCM; son, brother, niece, and father passed away due to HCM
2	Ben	Indian	62	42	HCM	No known family history
3	Jack	Malay	52	45	HCM	Mother diagnosed with HCM
4	Kyle	Chinese	35	19	DCM	Late father had cardiac problems; unclear if DCM related
5	Max	Malay	33	31	HCM	Maternal uncles have cardiac problems; unclear if HCM related
6	Paul	Indian	61	59	HCM	Sister and brother have cardiac problems; unclear if HCM related
7	Sam	Indian	55	49	HCM	No known family history
8	Tom	Chinese	67	64	HCM	No known family history

"We always share our experiences... including medical stuff .... Like for instance one of my family members got Glaucoma so everyone goes and check for Glaucoma .... we share about everything.. there's nothing to hide"
Ben, HCM

"I will still share my uh.. uh... what's happening to me la.. because my family is quite close-knit.. I usually share things la.. there's nothing to hide"
Jack, HCM

"The doctor advised that it could be hereditary so he emphasized that I should inform my family members.. 'if you care for your family members, you should inform them to just go for a check-up'.. see whether they have the same condition like me which they may not be aware of... so all the family members went for the check-up"
Ben, HCM

"[The genetic counselor]also told me that um the kids.. my kids have a 50% chance of having this condition also"
Max, HCM

The healthcare professionals' emphasis

Healthcare professionals may also be considered as facilitators of family communication because participants recalled being informed about the inherited familial risks and being encouraged to convey the ICC risk to their family members.

The way in which participants described how they relayed the information to their family members reflected what they had understood from the healthcare professionals' explanation.

"I told them about .... it being passed over.. something to do with genes.. from my family members ah.. and then I

Table 2 The participants' communication with family members

	Pseudonym	Communication between family members
1	Alex	Alex's relationship with his siblings deteriorated after his father's death and his experience of family communication was limited.
		The cardiac-related death of several family members prompted health professionals to recruit the family into the initial NUHCS study which offered genetic testing. It is likely that they were made aware of their risk during the recruitment process of that study.
2	Ben	Family members made aware: wife, 2 children, 5 siblings
		Family arranged for a cardiac check-up together
3	Jack	Family members made aware: wife, 4 children, 5 siblings, mother
		ICC risk not communicated to his mother's siblings or his cousins
4	Kyle	Family members made aware: 2 siblings, late father
5	Max	Family members made aware: 2 siblings, mother
		ICC risk not communicated his 3 children or maternal uncles who reportedly had cardiac issues; 1 sibling was away and not contactable
6	Paul	Family members made aware: wife, 2 children, 2 siblings
7	Sam	Family members made aware: wife, 3 children
		ICC risk not communicated to 7 siblings
8	Tom	Family members made aware: 2 children, mother
		ICC risk not communicated to 3 siblings

caught it la.. so I told them that they.. uh some of our siblings may have like what I have la ..... just tell them that uh 'my disease ah, is something that got to do with hereditary one' .... just tell them that you know 'maybe.. maybe one of us may have a similar condition like me la'"
Jack, HCM

"When we have a gathering.. meeting.. then once we talk about medical stuff and all that you know.. somebody had a heart attack or somebody you know.. relatives and all that.. then I'll also say 'yea I got a big heart' (laughs)"
Ben, HCM

Barriers to communication

Lack of communication

While every participant had informed at least one member within their families, some described factors which prevented them from communicating ICC risk information to other family members. These barriers often were often caused by emotional or geographical circumstances rather than deliberate withholding of information. Reasons for non-communication included minimized, or complete absence, of contact.

"Because we don't connect each other.... any function then we meet up.. so other than that.. we don't talk so much .... because from young.. my siblings all.. we all never grow up together in one house.. all separate, separate after my family.. my parents passed away. So that's why after they come to age, they marry, they go.. so we don't have that kind of connection."
Sam, HCM

"Because we have no communication .... since 1990.. I uh .... have no contact with him [his brother] .... We lost contact"
Paul, HCM

Not wanting to cause harm

There appeared to be a resistance to communicating risk information beyond first-degree relatives. One participant revealed the possibility that a few of his uncles had medical histories of cardiac issues, but was uncertain if it was related to the ICC. When asked if he had informed them about the possibility of an ICC, he described a reluctance to stir up anxiety.

"They're [his uncles] averaging about sixty odd over years old la.. so I think I better not bother them with this type of information ah .... because they've lived through their life quite well"
Max, HCM

Another participant disclosed that his elderly mother had recently been diagnosed with the ICC. His mother and her siblings were fairly elderly, and he believed that she did not comprehend the ICC and its familial implication. Communication with his cousins to inform them about the ICC risk for their parents, as well as themselves, was thus explored. He felt that it was important information but perceived that communicating this ICC risk would "blow up" the situation.

"I think it's important la .... but the level of uh communication ah.. we seldom talk …. I don't want to make this conversation blown up la .... They [his cousins] deserve to know but that is another layer of family uh communication you know .... No need to blow up this.. you know.. kind of story la"
Jack, HCM

Perceived reluctance of relatives to initiate cardiac screening

Relatives were not accessing cardiac screening

When asked if family members were undergoing screening, or had the intention to arrange for screening, participants related accounts which reflected that family members were not acting on the information despite having been informed about their risk.

"I told them.. but they not taking seriously .... 'Let it come then we go and check'.. this is the answer"
Sam, HCM

In addition, participants with younger children had been advised that their children should undergo screening as well, but it was not something that they were acting on with immediacy.

"My daughter.. I haven't brought her for any check up yet... mmm.. maybe.. maybe.. I will fix an appointment"
Paul, HCM

In exploring their communication of ICC risk information, participants were asked what they thought their relatives understood about the inherited risk. Several participants perceived that relatives did not fully comprehend the nature of the risk.

> "Uh I don't think so they [his siblings] understand their risk that much because they were not told directly by a doctor you see"
> Paul, HCM

One participant offered a vivid portrayal, described rather colloquially, which encapsulates a possible reason for the common reluctance to screen—a fear of finding out. He likened a health check to having a faulty part of a car repaired and subsequently finding out that there were many other faulty parts, alluding to the belief that screening was bound to detect problems and uncover problems beyond the primary indication for screening.

> "You know Chinese we got this saying you know 'you better don't check.. you check everything... (gestures falling apart)'.. really you know! just like your car right.. one part is really.. wear off.. you just repair this.. the other parts (gestures falling apart).. unless overhaul.. everything change.."
> Tom, HCM

The notion of being healthy

Despite participants being aware about the genetic risks for family members, much of the rhetoric revolved around asymptomatic relatives being healthy and active in sport, conveying a perception that healthy relatives were not currently at-risk.

> "Now my son still very healthy.. every Monday.. badminton.."
> Tom, HCM

> "Uh ya.. I told him [his brother].. I told him... but he's also active in sports and all these things"
> Paul, HCM

> "They [his uncles in their 60s] live long lives and then they're healthy people playing badminton.. cycling.."
> Max, HCM

Moreover, participants and their family members also expressed notions that being healthy meant that medical help and care were not required.

> "I tell him [his son] many times.. even today also.. morning I tell him 'I need to go NUH, you want to follow me?' 'You want, you go. Why should I go? I'm healthy'"
> Sam, HCM

> "Younger.. very fit.. what for (laughs) get checked? .... Singaporeans are like that.. isn't it? If I have no disease.. what for I come here.. better don't come to this place [the hospital] ah.."
> Tom, HCM

Discussion

Experience of communicating ICC risk

Participants of this study communicated that they understood that their diagnosis of an ICC had implications for their family members. In addition, they were aware of the importance of communicating information about ICC risk to their family members. Facilitators and barriers to family communication which have been described in Western literature were observed in this study. Facilitators of communication, such as pre-existing close family relationships and open patterns of communication (Seymour et al. 2010), were evident in the participants' responses. In contrast, the perception that communicating this risk information would cause harm to relatives has previously been cited as a barrier to the communication of genetic risk information between family members (Hodgson and Gaff 2013; Keenan et al. 2005; Wiseman et al. 2010) and was also observed in this study. This type of barrier has been described as passive non-disclosure, defined as a process where the information is not deliberately withheld but rather, hindered by prevailing factors that impact the ability or desire to communicate to family members (Hodgson and Gaff 2013; Keenan et al. 2005). For instance, some participants in this study had lost contact with family members over the years, or only met each other at events such as weddings or funerals, which seemed like inappropriate settings to disclose and discuss ICC risk.

Also consistent with the literature is the fact that communication was limited to first-degree relatives, with diminished tendency to communicate with second-degree relatives. This is often due to perceived closeness through blood relations, as well as a higher likelihood of emotional closeness to first-degree relatives (Gaff et al. 2007; Wilson et al. 2004). While the ICC risk to second-degree relatives may not be relevant if there is no intervening affected individual, the risk of cardiac complications and sudden cardiac death is still imminent without the knowledge of their gene status. In this study, the average age of the participants was 52.5 years old. Even if their parents had been diagnosed with the ICC, or were suspected to be the intervening family member, participants did not feel that they were in the position to discuss ICC-risk information with second-degree relatives as these relatives have "lived through their lives quite well." While it is a possibility that these participants felt the distance, either in terms of

relationships or emotionally, another explanation could be because they felt that they did not want to instigate anxiety or cause harm to older relatives by disclosing ICC risk information. Some key discussion points for genetic counselors during consultation sessions would be to clarify the inherited risk to all relevant family members, as well as to explore family relationships and communication processes to facilitate contact with at-risk relatives.

Role of healthcare professionals

Most participants recalled healthcare professionals, mainly their clinicians, emphasizing the importance of communicating information about the ICC to their family members, when they were diagnosed. It has been documented that the doctors' opinions and advice are highly respected by individuals in Asia (Chieng et al. 2011). A Singaporean study conducted in an oncology setting found that "the doctor asked me to" was a distinctive key factor for patients to attend genetic counseling, regardless of whether they were cancer patients or cancer-free individuals (Chin et al. 2005). Chin et al. (2005) thus recommended that healthcare professionals be educated about familial risks, and the availability of genetic services, in order for them to be adequately equipped to offer advice to patients. Provision of information, about the inherited condition and available services for management and support, empowers individuals to communicate genetic risk information to their family members. At the same time, it provides at-risk relatives with the chance to clarify and manage their inherited risk at relevant genetic services. In another study exploring barriers to cervical cancer screening in Malaysia, Wong et al. (2009) found that "the doctor did not advise me" was a reason for not receiving cervical cancer screening. Since it was not advised, the women did not see the need to screen. Despite the practice of Western medicine, it is plausible that the inherent Asian culture of holding high regard for doctors continues to prevail since in Singapore the paternalistic doctor-patient style of communication generally remains prevalent in South East Asia (Claramita et al. 2013).

Although non-directiveness forms the central ethos of genetic counseling, a review of international publications revealed that taking a directive approach towards encouraging family communication was unanimous, although the extent of directiveness varied widely (Forrest et al. 2007). In a recent study, Forbes Shepherd et al. (2017) described three intensifying degrees of relational approaches—covert, overt, and authoritative—undertaken by Australian genetic counselors to encourage family communication of genetic risk information. The belief that genetic information belonged to the family and not just the individual shaped the practice of the covert approach and was most frequently used irrespective of the patient's intentions of disclosure. The overt approach was usually undertaken when the sharing of genetic information with family members was discussed, using it as a means to broach the topic of intentions to disclosure. The overt approach was also used to address passive non-disclosure through techniques such as reframing, empowerment, and circumvention. The authoritative approach was least commonly employed and only utilized by senior genetic counselors in the study, in order to address deliberate non-disclosure. This reflects the likely efficacy of the covert and overt approaches in promoting family communication, or even the likelihood that situations of deliberate non-disclosure are truly rare and only encountered after many years of practice (Forbes Shepherd et al. 2017).

Given that many participants of this study clearly recalled the emphasis on the need to inform family members about the ICC risk, healthcare professionals likely play a vital role as the initial driver of family communication within the Asian society. Even in the Western setting, emphasis is continually placed on the importance of sharing genetic risk information with family members (Forbes Shepherd et al. 2017; Forrest et al. 2007). Therefore, genetic counselors working in Asian settings can draw on a similar model of covert and overt approaches which have reportedly been effective in Western settings (Forbes Shepherd et al. 2017), as well as work in collaboration with clinicians to reiterate and promote the importance of communicating ICC risk to at-risk family members. The covert and overt approaches may likely suffice in practice, since healthcare professionals such as clinicians are well respected by their patients in Asia, and the authoritative approach may only be required in the occasional case of active non-disclosure. At the very least, guidelines assert that the onus remains on healthcare professionals to ensure that individuals under their care are aware that genetic information have potential familial implications (The American Society of Human Genetics Social Issues Subcommittee on Familial Disclosure 1998).

"Healthy" at-risk relatives were not accessing screening

During the interviews, participants were asked whether they were aware if family members were acting on the knowledge about their ICC risk, one of the indicators being scheduled cardiac screens. For most ICCs, screening includes a clinical examination by a cardiologist, an electrocardiogram to monitor the rhythm of the heart, and an echocardiogram to analyze the structural features and functions of the heart (Elliott et al. 2011). In response, participants conveyed a common perception that their relatives were not accessing cardiac screening, despite having been told that they were at risk of an ICC.

One participant compared it to the process of sending a car with one faulty part for repair and discovering many other faulty parts soon after. This notion of "you will find something if you go looking for it" has frequently emerged in literature about perspectives on screening, particularly in Asian communities (Juwita

et al. 2013; Stol et al. 2015; Wang 2014; Wu et al. 2006). A Singaporean study compared the views of women who actively participated in breast and cervical screening with those of women who did not screen (Wang 2014). Despite both groups recognizing the benefits of screening for early detection and treatment, breast and cervical cancer screening was described as "looking for trouble" and both groups of individuals also suggested that women, in general, avoided screening because they "rather not know they have cancer" (Wang 2014). The study found that while both groups of women, who engaged in screening and those who did not, shared the same fear of finding something if you go looking for it, women who screened were optimistic and determined to overcome cancer if it was detected, as compared to the non-screening group. In contrast, women who did not engage in screening were more fatalistic than the group using screening and perceived that they would succumb to cancer if it was detected during screening. A similar fearful mentality was also described in a study of Asian-American women, who were reluctant to have mammograms for fear that it would detect cancer (Wu et al. 2006). Likewise, the fear of detecting disease was also cited as a reason preventing Malay women in Malaysia from accessing cardiovascular screening (Juwita et al. 2013). These studies suggest that the fear of detecting an abnormality supersedes the reassurance of a healthy screen, which becomes a barrier to accessing screening programs for many Asians.

Many studies have explored the relationship between fear and fatalism among different ethnicities, but these are primarily limited to the oncology setting (Martins and Hamilton 2016; Vrinten et al. 2016, 2017.). Majority of the studies with a sample population of non-Caucasians are based in Western settings. These non-Caucasians tend to belong to the ethnic minority and are often of education levels and/or lower socioeconomic status than their Western counterparts, which have been identified as factors contributing to higher levels of fear and fatalism and consequently lower levels of screening (Honein-AbouHaidar et al. 2016; Kressin et al. 2010; Vrinten et al. 2016). As education levels and socioeconomic status were not taken into consideration for this study, there is insufficient data to determine if these barriers stemmed from culture alone.

Another finding was that participants described asymptomatic at-risk family members as being healthy, and many mentioned that relatives were engaging in sports to keep healthy. These participants understood that ICCs were genetic in nature, rather than induced by lifestyle; however, the discourse about relatives being "healthy" and active in sport recurred in numerous interviews. A review of literature on reasons for and against cardiovascular screening revealed that it was common for individuals not to test for cardiovascular risk factors because they "feel healthy and fit" (Stol et al. 2015). The perspectives that "I am healthy; I don't need the exam" (Chen 2009) and screening is "not needed if I feel ok" (Wu et al. 2006) were also commonly cited barriers to breast screening in Asian women. Moreover, Asian Chinese in Australia perceived that being healthy prevented cancer (Kwok and Sullivan 2006) and Malaysian women who perceived themselves as healthy avoided cardiovascular screening, claiming that the clinic was for the "ill" (Juwita et al. 2013). This notion may have arisen from an Asian societal perception that only those who do not remain healthy will develop disease.

Practice implications

According to the knowledge of this study's participants, at the time of their interview, at-risk family members were not undergoing screening despite being informed about their ICC risk. At the same time, the rhetoric that participants collectively echoed about family members still "being healthy" reflects an erroneous perception that being healthy equates to a reduced risk of being affected by the ICC. This mentality has been observed in several other studies involving Asians of different origins and ethnicities, suggesting the importance of allocating time to focus on understanding the health beliefs of the individual during a genetic counseling session. Given that healthcare professionals have been found to play a vital role in encouraging screening, genetic counselors and treating clinicians should emphasize the importance of communicating ICC risks to family members to encourage greater compliance, particularly with Asian patients. At present, patients seen at the ICC clinic receive a letter summarizing the discussion at the appointment which includes implications for family members. An "at risk" family letter is also prepared for patients to pass on to family members if a pathogenic variant is identified. The development of family letters and facts sheets about the ICC could be useful to educate patients as well as their at-risk family members and to highlight that the absence of symptoms does not negate the risk of inheriting an ICC. Several studies have shown that letters are effective in informing family members about inherited conditions, as it provides relevant written information which relatives can follow up on (Gaff et al. 2005; Predham et al. 2017; van der Roest et al. 2009). However, not all patients are referred to the ICC clinic and little is known about the information these patients receive regarding cardiac genetic risk. As such, it would be useful for future recommendations to emphasize on the importance of family communication and encourage other cardiac specialists, outside the ICC clinic, to have a discussion about disclosure to family members with their patients.

Another option would be to extend the invitation to family members, to attend review appointments with the proband and/or affected individual. This provides an opportunity for at-risk family members to be advised of their risk and receive information about the ICC and risk management strategies. In addition, key motivators of screening for breast and cervical cancer as documented by Wang (2014) were social support from friends and family as well as the doctors' referrals. In general, educating families about genetic risk helps to address Asian beliefs that being healthy protects against inherited genetic conditions as well as the fear that screening will detect

disease. This would ultimately enable at-risk individuals to receive adequate information about the inherited condition and their risk, in order to make informed decisions to manage their health before the manifestation of symptoms.

Study limitations and research recommendations

Given the small sample size, the findings of this study are not expected to be generalizable. In addition, the finding that at-risk relatives were not undergoing screening was based solely on the perception and knowledge of the proband. It is possible that some relatives were accessing screening, or had screening scheduled, but had yet to discuss their experiences with the proband.

Time constraints also limited the duration of the recruitment and interview period for this study. The emergent theme that reached data saturation was the perceived reluctance of relatives to initiate cardiac screening, including the notion of being healthy. The other two themes did not reach data saturation due to the limitation of time. Although data saturation was not met for the facilitators and barriers to family communication, the data that emerged was useful in providing an insight into how ICC risk was being communicated within the family and the barriers that may exist. These findings allow future research to explore these issues in greater detail in order to inform the management of individuals and families with ICCs.

Prior research has described women as "kin keepers" of family genetic information, who frequently take responsibility for communicating genetic information to at-risk family members (D'Agincourt-Canning 2001; Richards 1996). Therefore, it may be useful for future research to explore female perspectives on the experience of communicating ICC risks to family members to examine whether the partners of men diagnosed with ICCs play a role in family communication of cardiac genetic risk, or whether women diagnosed with ICCs communicate genetic risk information more broadly to distant relatives than men. Exploring the experiences of a larger group of both males and females would help to uncover differences in communication, if any, and highlight additional support needs, to better inform the development and improvement of cardiac genetic counseling services.

Another limitation of this study was the short interview time. Qualitative healthcare interviews typically range between 20 to 60 min (Gill et al. 2008), but interviews in this study lasted no more than 36 min. This may have been attributed to structure of the interview or the ability and willingness of the participants to share their experiences. Overall, this study has uncovered novel findings which have not been discussed in great depth in the literature and has opened opportunities for further research. Future directions include an expanded interview schedule with additional prompts to elicit greater detail about the process of communication of ICC risk information, since participants of this study all appeared open and willing to share their experiences. It would also be useful to interview at-risk relatives, to determine if what was conveyed was indeed understood, and have an opportunity to discuss possible barriers preventing them from accessing screening. This information would help to enhance the genetic counselors' support and management of at-risk relatives. Exploring cultural beliefs of looking for trouble and "being healthy prevents disease," with probands and their family members, may also provide a better understanding and insight into the underlying reasons for the reluctance to screen, to allow the development of effective strategies to overcome these barriers.

Conclusion

This qualitative study has examined the collective experience of how probands, specifically males, who have been diagnosed with an ICC communicate information regarding inherited risk to their family members. The findings of this study can inform and direct appropriate genetic counseling strategies for this Asian population. Probands in this study indicated that they were aware of the inherited nature of their cardiac condition and recalled their healthcare professional's emphasis on the importance of communicating the ICC risk to their family members. Despite the fact that probands did communicate information about the ICC, not all at-risk relatives were informed about their ICC risk. Reasons included physical and emotional barriers between family members or the reluctance to stir up anxiety among relatives who were senior in age. Several emerging themes which aligned with features of other Asian studies include the perception that being healthy prevents disease, the association between the reluctance to screen and the fear of detecting disease, as well as the high regard for the clinicians' advice. Although only affected probands were interviewed, they raised plausible rationales to suggest why at-risk relatives were not acting on the ICC risk information. The fact that early detection tends to be associated with improved outcomes should be conveyed to patients and their at-risk family members. With the help of further research, genetic counselors can promote community awareness and education to alleviate the fear of screening by highlighting the value of early detection. Informing at-risk relatives about the ICC risk to prevent ICC-associated complications as well as sudden cardiac death may appear logical; however, it is important to recognize that lived experiences shape risk perceptions and decision-making and influence the process of family communication. The first steps in tackling these Asian barriers may be for genetic counselors to work together with treating clinicians to overcome the mentality that being healthy is an indicator of no disease, as well as the cultural belief that you will find something if you go looking for it. It is also imperative that genetic counselors in Asian settings be mindful about cultural beliefs that influence

perceptions, values, and practices, in order to adequately support the informed decision-making process.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Research involving human participants and/or animals 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.

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