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# Incorporating information about pre-implantation genetic diagnosis into discussions about testing and risk-management for BRCA1/2 mutations: A qualitative study of patient preferences

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## Abstract

**Background—**Studies show that BRCA1/2 mutation carriers are interested in learning about reproductive options such as pre-implantation genetic diagnosis (PGD) to prevent passing their risk onto their children. However, attitudes vary widely, and the procedure raises complex ethical and psychosocial issues. This complexity, plus the highly technical nature of PGD, makes it difficult to integrate PGD information into genetic counseling sessions that already cover probabilistic, emotionally-charged risk information.

**Method—**Thirty-three reproductive age BRCA1/2 mutation carriers who had previously undergone genetic counseling viewed a tutorial about PGD and were interviewed about attitudes towards PGD, and preferences about how to include PGD information in genetic counseling.

**Results—**Most participants preferred to be briefly informed of availability of PGD information, and to receive written materials about PGD, but with the option of deferring detailed discussion if they already feel overloaded or perceive that PGD is not immediately relevant to their risk management and/or childbearing plans. For some, the stress of testing temporarily interfered with information processing, producing states of cognitive avoidance ("in a fog," "tuning out"). Some preferred to discuss PGD with a physician with whom they had an ongoing relationship (e.g., OB/GYN, primary care provider, oncologist).

**Conclusions—**Providers offering cancer genetic testing can consider indicating availability of PGD information, while attending to patients' level of interest and ability to absorb information. Research is needed to link patient responses to information overload to psychosocial outcomes (e.g., distress, decision quality). Continuing medical education is needed to support providers in facilitating informed decisions about PGD.

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BRCA1/2mutation carriers face a 50% chance that their cancer predisposition will be transmitted to their children, and individuals undergoing cancer genetic testing frequently express concern about passing on a BRCA1/2 mutation. [1–3] Many patients seeking testing are of reproductive age, either actively engaged in family planning, or will be in the near future. Pre-implantation genetic diagnosis (PGD) involves genetic analysis of embryos obtained through IVF, and transfer of mutation-free embryos to the mother for implantation and gestation. Recent surveys demonstrate interest by BRCA1/2 carriers in learning about PGD as a means to avoid transmitting BRCA1/2 mutations while still being able to have genetically related children. [4,5] The process, however, can be arduous and expensive, at times requiring multiple cycles of fertility medication and implantation attempts to achieve a successful pregnancy. Furthermore, consideration of PGD for BRCA1/2 mutations introduces the possibility of medically invasive procedures to those who otherwise might be able to conceive normally, in a population that is already being asked to weigh multiple risk management options (e.g., surgery, intensive surveillance).[6]

Currently, professional guidelines regarding discussion of PGD for BRCA during cancer genetic counseling call for providing "..as much information as possible while acting in an ethical context that minimizes harm to clients and their families."[7] The challenge for health care providers is how to incorporate information about PGD, which is highly technical, into sessions that are already pressed for time due to the complex, probabilistic, and emotionally charged nature of genetic risk information and risk management. [8,9] Furthermore, several studies have shown that PGD can trigger a host of psychosocial and ethical issues, and opinions about the acceptability of PGD for adult-onset cancer syndromes with incomplete penetrance vary widely among both patients and providers.[4,5,10,11] With such variability, guidance is needed to avoid inadvertently harming patients in the process of informing them of their options.

We elicited patient preferences about when and how they would want to learn about PGD as part of a larger qualitative study of attitudes about PGD and prenatal diagnosis (PND) with BRCA mutation carriers of reproductive age who had previously undergone genetic counseling and testing for breast/ovarian cancer risk. For this report, we asked patients to reflect on their counseling experience and how they would have wanted to integrate PGD information into the counseling process.

## Participants

For this IRB-approved study, 98 BRCA1/2 mutation carriers of reproductive age (< 43 for women; < 50 for men) and capacity (no history of hysterectomy or bilateral oophorectomy in females) who completed genetic counseling and testing at MSKCC were invited by letter for a 2-hour in-person interview regarding attitudes about PGD and PND for breast/ovarian cancer risk. Thirty-four percent accepted, 45% did not respond, and 21% declined. Most

decliners cited being too busy and/or scheduling conflicts; a few (*N*=5) expressed that cancer risk and/or PGD were too emotionally difficult to discuss. One woman consented and began study participation, but her interview was not transcribed or included in this analysis after signs of psychiatric impairment emerged during her interview.

Participants were mostly female (88%), White (91%), married/partnered (73%), highly educated (42% > 16 years in school) and high SES (42% > $200K/year). Female participants were younger (X= 33.24, range 21–41) than the males (X= 37.5, range 26–48). Approximately half (51.5%) had children, and one-quarter (24.2%) reported their childbearing was complete.

## Procedure

Interviews were completed by doctoral level licensed mental health professionals experienced with hereditary cancer risk patients. Upon providing informed consent, patients completed a demographic questionnaire and assessment of prior knowledge about PGD and PND. Patients varied in time since initial genetic counseling and whether PGD had been discussed during genetic counseling. Therefore, interviewers presented a standardized tutorial reviewing risk and inheritance patterns associated with BRCA1/2 mutations, defining PGD and PND, and describing the procedures and associated considerations (e.g., cost, availability) of each so that all participants were exposed to basic concepts relevant to PGD and PND before the interview. To minimize possible order effects, participants randomly viewed either PGD information first or PND. The tutorial was developed in collaboration with a doctoral level genetic counselor, reproductive endocrinologist and reviewed by MSKCC genetic counselors and physicians. Following the tutorial, interviewers confirmed that participants comprehended the information via brief assessment. Interview questions covered personal and family history of cancer, risk management decisions, perceived benefits and drawbacks of PGD and PND, ethical and emotional considerations related to PGD and PND, and opinions about incorporating information about PGD and PND into cancer genetic counseling. Thus, opinions elicited from participants about incorporating PGD into cancer genetic counseling occurred as part of a wide-ranging discussing of attitudes, and in the context of the participant's experience of the impact of her or his mutation carrier status.

## Data Analysis

We used thematic analysis to code and analyze data about patient preferences, as this question represented an *a priori* goal of the study.[12] Thematic analysis is "a method for identifying, analyzing, and reporting patterns (themes) within data".[12] The research team reviewed an initial subset of transcripts to generate a preliminary code book of themes articulated by participants. Two independent raters then coded each transcript, with coding discrepancies resolved through discussion by the coding team. Atlas.*ti* qualitative data analysis software was used to organize and sort data. This report focuses on a subset of the themes identified, specifically those that are relevant to participant's views on how information about PGD should be incorporated into genetic counseling. In addition, we

present counseling-related themes only for PGD, not PND, because acceptability and practice of PND for adult-onset cancer syndromes is less well established.[8]

## Results

### Main Theme: The value and burden of PGD information

Participants nearly universally agreed that PGD should be addressed during cancer genetic counseling, regardless of whether or not they would avail themselves of it.

> "I think I'd want to know that I had that option, even if I wouldn't want to use it." (052)

The core dilemma revealed in the interviews was that participants wanted as much information as possible about BRCA-related options, including PGD, but at the same time many felt that they got too much. For example, one participant stated:

> I'm somebody who likes to have information. I'm not scared by information. I find information useful and comforting, no matter what the information is. (026)

Later on, however, the same woman declared:

> "I got way too much information at the first session!" (026; participant's emphasis)

Participants also recognized that not everyone would be equally receptive to information about PGD:

> "….I think for some people it [PGD] is going to be a big relief. For others, it would actually pile more on… (034)

Thus, although participants were near unanimity in favor of equal access to information for all, it was clear that a one-sized approach would not fit all. To navigate this dilemma, we identified four themes reflecting patient preferences regarding presentation of PGD information.

### Theme 1: Preferred level of detail

Most participants did not favor of a detailed presentation on PGD during genetic counseling. Rather, they suggested that providers touch upon PGD as an option that could be discussed if the person was interested and/or at a future visit.

> "..put it out there and just say, "I don't know if this is right for you, but know that it's an option." (002)

> "Maybe just mention it quickly but not to really go into depth unless a person wants to know more.." (092)

Patients expressed concern about "overload" if too much detailed information about PGD were added to their genetic counseling sessions. For some, the feeling of being overloaded reflected the volume of information covered during the sessions:

> "That appointment is a couple hours long, and it is information overload, even just with what they give you." (006)

For others, “overload” implied a psychological state in which they were negatively affected by receiving too much information. Negative impacts included distress, conflicting priorities, and inability to absorb new information. Several participants used metaphors referring to the head or mind to signify a process of figuring what risk information meant for them personally, and expressed that feeling emotionally overwhelmed interfered with that process:

> “I think it would have been too much information, because it’s hard enough to wrap your head around how that [risk information] impacts you, let alone thinking how’s that going to impact my possibly unconceived child?” (072; emphasis added)

> “Initially…all I cared about was what it [mutation] was and the percent chance I could pass it on and then the percent chance it increased my breast cancer coming back…once I figured that out and was able to process everything and do everything else I was doing at that time…then your mind can be open for more information.” (006; emphasis added)

> “the genetic counselors need to consider what’s the right amount of information to give at that visit so that the real issues of being positive and what that means for your life are – because it’s already so confusing and it’s so emotional, it’s hard to get your head around it. Then to get a barrage of other details about PGD could be overwhelming.” (065; emphasis added)

They acknowledged tuning out information when they felt overwhelmed. At times patients described seemingly voluntary strategies:

> “It wasn’t the most effective time to hear it [information about PGD] …I let it go in one ear and out the other.” (041)

Other times, tuning out appeared to be an involuntary response:

> “…when they [patients] go [to genetic counseling] and they’re in the initial stages, they go into a fog after five minutes...” (051)

Some participants were concerned that having information about PGD created pressure to make a decision and act on it, perhaps before they were ready. That pressure, coupled with any emotional distress they were already experiencing about learning their risk status, led some to express fears that patients still in the early phases of coping with their risk status would make impulsive decisions about PGD:

> “…you also have to worry about people’s mental states at that point, too, because a lot of the time, they are just diagnosed, or the sister of someone just diagnosed, or something, so I feel like people are a lot more emotional and maybe not as logical in their decision-making.” (006)

> “If you want to make sales on IVF, tell them then [in counseling session before testing] because they’re scared and they’re going to go do it, and they’re going to make impulsive decisions.” (010)

Ultimately, most were in favor of providing at least a minimal amount of information on PGD in patient sessions, because even with drawbacks, not to be aware of PGD as an option would be worse:

> "I would have been so upset if I'd found about it after I'd already made my planning decisions." (034)

### Theme 2. Preferred mode of transmission

Many participants suggested that they be given a pamphlet about PGD that they could review on their own time.

> "Since this [PGD information] may all float over their heads that might be a good thing to give them in a hand out to take home with them and peruse later." (052)

> "If you want to pick it up you can, if you don't you don't. It's more like if the headline interests you, you're going to pick it up…" (080)

Having the information written down would make it easier for patients who wanted to do their own research on the internet but were unfamiliar with the terminology:

> "There was no information handed to me…Because I still think I don't even know who I'd Google, I don't even know any of the terms…" (082)

However, a pamphlet would need to stand out from other written materials handed out at genetic counseling sessions, such as risk management summaries and referral information:

> "I [was overwhelmed]… by this packet of information I got in the beginning with these dozens of doctors-most of whom have nothing to do with what I needed." (026)

> "…printouts of basic information and some pamphlet[s].. but if you gave me too much I probably wouldn't have read it anyway." (080)

Others suggested that a follow-up session focused on PGD be available for those who were interested. Perceived benefits of this approach were to allow assessment of how the patient was handling his or her results, and to allow time to digest the information.

> "Definitely the better thing to do [than to discuss PGD at results session] would have been to have a follow up appointment in two weeks to make sure that I was functioning, and then to find out if I…was ready to discuss at that point." (034)

However, other participants doubted that patients would attend additional sessions:

> "You have to give it [information] all at once…nobody's coming back for more." (051)

### Theme 3. Preferred provider of information

Participants expressed a variety of opinions about from whom they would prefer to hear about PGD. They expected that genetic counselors would be able to provide information if they wanted to discuss it:

> "..the genetic counselors definitely should be well-versed with this information.." (074)

However, the fact that considering PGD opens up sensitive questions in a number of realms, from ethics to personal and family goals, led some to emphasize that they would want to talk with a physician whom they already knew:

> "A lot of this does touch on a lot of personal and very ethical issues, maybe it would be easier coming from someone that you feel like you have a relationship with." (041)

> "At least my oncologist has a longer-standing relationship with me. The genetic counselor I had only met for about half an hour the day they took the blood." (013)

Some preferred their obstetrician, with whom they had already discussed other important medical decisions, and who were perceived as experts in childbearing issues:

> "I mean, they are the ones, you know, the trusted doctors that are delivering your babies, and they could be a great support of it." (025; participant's emphasis)

> "I think [information about PGD] coming from a genetic counselor of course, but I see my OB/GYN annually, so I feel like if I were to talk about having a child that I would probably go to her first." (021)

However, others preferred their primary care provider in order to start the discussion earlier in the family planning process:

> "I think it should start with your [primary] medical doctor, because once you're pregnant it's too late." (074)

One recurrent suggestion was that the genetic counselor provide introductory information, but that a more extended discussion take place with the physician.

> "So genetic counseling, number one, to give you the idea, so then you can go and talk to your doctor about it." (025)

Patients recognized that not all physicians were equally versed in the details of PGD, and that a pamphlet could supplement physician knowledge

> "If the doctors are not comfortable talking about it, or they don't have enough information about it that they can speak on it professionally, the pamphlets are there." (074)

### Theme 4: Preferred timing for receipt of information

Participants expressed a variety of opinions about when PGD should be discussed. Some participants felt that learning about PGD before knowing their test result would not be meaningful:

> "…Let's face it, it's not an issue if they're not positive." (056)

Furthermore, learning that the future might hold additional medical procedures (beyond those a person had already undergone for cancer treatment and/or were considering for risk management) was also seen as stressful for some:

> "I didn't want to know until after I had my results, because what would be the point of getting all nervous about all these procedures before I knew for sure that I needed it?" (007)

However, others saw benefit in mentioning PGD at the initial pre-test visit:

> "I think it's important to say it then [at the initial session] because then you feel like there's hope for the future, as opposed to just stagnating on your own genetics." (051)

Some participants, particularly younger ones, expressed that they wanted to put off learning about PGD because they wanted to focus on their immediate risk management needs, rather than on reproductive issues that might not arise for several years:

> "There was a lot to sort out all at once for us; who was I going to see for surveillance… and then having this other thing to deal with that was a little more future oriented..." (065)

> "I was just more concerned about me at that point developing cancer than my children, at 19." (087)

Lastly, some thought that the information should only be discussed with those who were actively trying to conceive, when it would be mostly timely:

> "I think it's a good idea to be offering that to people as certainly part and parcel if you're already having the IVF and you're already screening the embryos for one thing or another…" (028)

Others saw benefit in letting everyone know about the availability of information about PGD, regardless of their childbearing status:

> "But someone in their 60s getting a BRCA diagnosis you may spend a little less time or just give her the information for her daughter." (091)

## Discussion

A majority of BRCA1/2 mutation carriers reflecting on their genetic counseling experience in this qualitative study expressed that they want to be briefly informed of the availability of PGD information, but that they want the option of deferring a more detailed presentation if they are already feeling overwhelmed or perceive that PGD is not immediately relevant to their medical and/or childbearing plans. PGD information was generally seen as valuable, but also potentially taxing of patients' psychological resources because it requires mastery of medical technicalities and introduces a set of ethically and emotionally charged decisions to be made on top of the ones patients were already making about testing and risk management.[6,13] Participants offered a diversity of opinions regarding with whom they would prefer to discuss PGD, and the timing of such a discussion, whether it should occur it should occur before genetic testing for cancer risk, or after receipt of a positive test result. Although prior studies have addressed patient attitudes regarding PGD for hereditary cancer risk, to our knowledge this study is the first to specifically address patient preferences about receiving PGD information for BRCA1/2 mutations.

Some participants described feelings of “information overload” consistent with prior reports in BRCA1/2 carriers,[14,15] and in cancer patients more broadly.[16,17] Furthermore, some participants appeared to limit their exposure to new information through cognitive avoidance, either purposefully (“in one ear and out the other”) or in an involuntary “fog”-like state, as a way to cope with emotional stress during genetic counseling. Indeed, some patients declined study participation, citing their high levels of distress. Research on stress and coping in a wide variety of domains shows that avoidance increases under stress.[18] Studies of cancer genetic counseling patients also show that mean levels of distress tend to be highest immediately before testing and after receipt of genetic test results,[19] which may be when patients are most likely to feel overwhelmed. Paradoxically, these are also times when it is most convenient for clinicians to deliver information about PGD, and for at least some patients, when information about PGD might be relevant to their testing and risk management decisions. Some participants reported that they were better able to process BRCA-related information after having time for reflection, which dovetails with studies showing that for most people, distress levels after testing decrease over time.[19,20] Therefore, for at least some patients, preferences about the timing and volume of PGD information appear to implicitly reflect their current level of coping with the genetic testing process.

Cognitive avoidance may be effective in the short run in coping with feeling distressed and overwhelmed.[21] However, tuning out overwhelming information may help the patient in the moment, but is not an effective use of a provider’s time, and may undermine patient satisfaction with the encounter. Furthermore, according to social-cognitive processing theory, avoidance can inhibit individuals’ ability to integrate information with core beliefs about self, values, and goals,[22] a process that would appear important to a decision with the ethical and emotional complexity of PGD. The question then becomes how to efficiently facilitate cognitive processing when decisions will yield the most clinical benefit. A recent study in genetic counseling communication found that counselors who engaged in facilitation of emotional expression not only increased clients’ expression of distress, but also of words indicating cognitive processing.[23] Future qualitative research can query patients specifically about the experience of information overload, generating a phenomenology of voluntary and involuntary coping that can be linked to outcomes such as distress, decision quality, and decision satisfaction. Such findings could be synthesized with provider-patient communication research focusing on verbal and nonverbal cues signaling information overload, in order to generate solutions that resolve the patient-provider impasse that such overload can produce.[24] In the interim, the suggested approach by our study participants to touch on availability of PGD information might be viewed as an invitation for providers to openly address information overload and negotiate timing of PGD discussions via an information plan.

Interestingly, in this highly educated and presumably computer-savvy group, there were numerous spontaneous mentions of wanting a pamphlet about PGD, but none of referring patients to the Internet for more information. Although no participant specifically commented on this, it may be that receiving a brief, tangible, written resource from the provider, rather than being sent to dive back into the flood of online information, would be perceived as more responsive to the patient’s implicit need to control their rate of exposure to PGD information. A pamphlet could also function as a neutral source of information for

discussion, so that patients would not be overly dependent on the attitude or knowledge level of any given provider regarding PGD.

Although the interview focused on integration of PGD information into genetic counseling, some participants expressed interest in discussing PGD with physicians with whom they have had an ongoing, trusting relationship, such as a primary care provider, oncologist, or OB/GYN. It appeared that participants looked to genetic counselors to inform them about the availability of PGD information, discuss in more detail if desired (e.g., would affect patient's testing decision) and provide a pamphlet. The fact that some patients would want to discuss PGD with physicians underscores the need for continuing medical education about the technical aspects and risks of PGD, as well as the breadth of psychological issues. Surveys have indicated that physicians are challenged to keep up with the rapid pace of genetic discovery and its clinical implications,[25,26] but can improve knowledge with educational interventions.[26]

Our results may not generalize to all cancer genetic patients because in this study, all participants had received cancer risk counseling from a genetic counselor, with an attending physician joining the session towards the end. Many participants remarked on the level of technical detail in their counseling sessions, and this may have influenced their reaction to the introduction of another large chunk of medical information. Patients who have not received the full measure of genetic counseling that is currently recommended by several professional organizations (e.g., ASCO, NSGC, ASHG, ACOG), [27–32] may have different preferences regarding the presentation of PGD information. Also, we presented standardized information about PGD as part of the research design so that we could focus discussion on the study questions. However, in practice, patients who have no prior knowledge of PGD and who do not receive a standardized presentation may have alternate preferences for PGD discussions. Similarly we included women who had already completed childbearing in order to explore their reflections on the genetic counseling process. One participant discussed the potential benefit of older women learning about PGD for their daughters; patients in this situation may have information preferences that we did not fully explore. Our group of respondents (34% of those to whom invitations were sent) may not fully represent the experience and preferences of all BRCA1/2 genetic counseling patients, particularly those who declined because the topic was distressing to them.

Males are underrepresented in our sample. Male BRCA1/2 mutation carriers do not face the number or degree of personal risks that female carriers face, and therefore may be less susceptible to information overload. However, they have other emotional challenges such as helplessness and guilt about possibly passing a mutation onto their children.[33] Furthermore, their attitudes towards PGD may be shaped by the fact that they would not undergo the IVF procedure).[34] Therefore they may have different needs regarding the timing and content of PGD-related discussions that merit further study. In addition, non-carrier partners were not interviewed for this study, but patients indirectly reported that partners' attitudes were influential. Future work should explore partners' information needs as well, particularly regarding management of disagreements about pursuing PGD.

Participants in this study preferred options that would help them control the flow of information about PGD to avoid feeling overwhelmed. This dynamic presents a challenge to providers to balance their mandate to provide information about BRCA-related options with sensitivity to individual differences in ability to process information. Based on suggestions by our participants, providers can briefly describe the potential benefits of learning about PGD, watching for cues indicating a patient is having difficulty absorbing information, such as inattention or requests to repeat information. They can then create an "information plan" with patients about when and how they will learn more about PGD if desired. Further research focusing on information overload in cancer risk consultations can inform efforts to enhance providers' ability to identify and respond to patients who are feeling overwhelmed.

Based on our results, it appears that the challenge of incorporating information regarding assisted reproductive options into cancer genetic counseling is not merely one of adding a large chunk of information to the details that already comprise the standard of preventive medical care. Rather, the health care provider is faced with challenge of actively assisting patients as they process information regarding reproductive choices on both a cognitive and emotional level. An emerging goal of preventive oncologic practice will be to help cancer-affected families balance individual goals and coping abilities, in order to facilitate optimal decision-making about PGD and other means of assisted reproduction as part of the management of their hereditary cancer risk.

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