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COMMENTARY

Communication about DTC Testing: Commentary on a 'Family Experience of Personal Genomics'

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Abstract This paper provides a commentary on 'Family Experience of Personal Genomics' (Corpas 2012). An overview is offered on the communication literature available to help support individuals and families to communicate about genetic information. Despite there being a wealth of evidence, built on years of genetic counseling practice, this does not appear to have been translated clearly to the Direct to Consumer (DTC) testing market. In many countries it is possible to order a DTC genetic test without the involvement of any health professional; there has been heated debate about whether this is appropriate or not. Much of the focus surrounding this has been on whether it is necessary to have a health professional available to offer their clinical knowledge and help with interpreting the DTC genetic test data. What has been missed from this debate is the importance of enabling customers of DTC testing services access to the abundance of information about *how to* communicate their genetic risks to others, including immediate family. Family communication about health and indeed genetics can be fraught with difficulty. Genetic health professionals, specifically genetic counselors, have particular expertise in *family communication* about genetics. Such information could be incredibly useful to kinships as they grapple with knowing how to communicate their genomic information with relatives.

Keywords Family communication · Genomics · DTC testing · Genetic counseling · Genetic counselor

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Introduction

For many years now healthcare has been moving away from a paternalistic model where 'doctor knows best' to a person-centred model where clients share decision making about their health. Thus enabling personal control of one's health is at the centre of medical care within both the National Health Service (NHS) in the United Kingdom (Department of Health 2010), in the United States of America (House of Representatives 2011) and elsewhere around the world (Australian Government 2011). Engaging with Direct to Consumer (DTC) genomic testing and learning more about our health risks therefore chimes with the current ethos within healthcare.

In the paper, 'Family Experience of Personal Genomics' also appearing in this issue, Dr Manuel Corpas seeks to uncover health information held within his own genome. Influenced by his work as a bioinformatician, he is excited to reveal the secrets held within his genes and learn more about himself. He discovers, via genome-wide SNP analysis that he has a raised risk of developing prostate cancer; this new information is a surprise since he has no family history of this and thus no psychological warning shots to guide him. He develops a curiosity about where his prostate cancer risk alleles have come from and with this in mind approaches his family (parents, sister and aunt) to see if they would be interested in being genotyped. He sends off their saliva samples to the DTC testing company. On receipt of the results, Dr Corpas becomes the custodian of the family genotypes. He soon becomes aware that not only does he need to communicate the new genomic information accurately, but the manner in which this is communicated is of utter importance. When suddenly faced with a direct

conversation with his parents about their potential future health he struggles to know what words to use.

Participant-Centred Services in the Absence of a Health Professional

We should all have a right to be able to access our genomic information if we so choose (MacArthur and Wright 2010). Without the direct involvement of any health professional, the participant is totally in control of what they engage with (Foster and Sharp 2008) and the process couldn't be any more 'person-centred'. However, there is huge debate at the moment about whether DTC testing should only be available via a health professional (Frueh et al. 2011) and how it could be regulated (Patch et al. 2009; MacArthur and Wright 2010; Wagner 2010; Wright et al. 2011) and some evidence to suggest that genetic counselors (in the US at least) feel they *should* be involved in the DTC testing process (Hock et al. 2011).

Whilst participants have full autonomy over their decision making when they embark solo on a genomic testing journey, one observation is that the absence of a linked health professional does make it seem rather a lonely experience. Whilst it would be imprudent to suggest that a paternalistic and directive health professional is necessary (one might suggest, such a health professional should be avoided at all costs), however, simply having the opportunity to share the experience might have helped Dr Corpas feel slightly less overwhelmed with the task of communicating the genomic information to his family. What is most striking is that he had not anticipated how important it was to get the communication with his family right, nor how he would actually do this. He was left to his own devices to work this out for himself. As a genetic counselor myself I felt a real sadness about this. There is a wealth of evidence-based literature on the communication processes about genetics (McAllister et al. 2008; Harvey 2010; McAllister et al. 2011) and practical guidance (McCarthy Veach et al. 2003; Skirton et al. 2005; Gaff and Bylund 2010) that come from years of working with individual's grappling with the uncertainties of how to communicate about genetics to their families. Why wasn't a précis of this information available to Dr Corpas? Even if a direct consultation with a genetic counselor was not possible through the DTC testing service he had, at least some information could have been available on the strategies that genetic counselors, 'experts' in communication about genetics (McCarthy Veach et al. 2003), routinely use when helping people to talk about genetic risk to their relatives. In the context of this paper the term 'genetic counselor' applies to a health professional who has done a specific training in genetic counseling (e.g. at Masters level) that covers counseling and health communication theory. There are also many clinical and medical geneticists as well as other health professionals who have formal training and experience of genetics in the context of counseling theory and practice.

Despite his extensive experience as a bioinformatician, Dr Corpas is still, in effect, a lay member of the public. We should not assume that just because he has extensive scientific knowledge about genetics, that he should also have expertise in how to communicate this information. It is understandable that he felt he oscillated "between the roles of 'expert or professional' and son", (in this issue, Corpas 2012); however, a genetic counselor would be able to help him explore this and create a more comfortable balance. His reaction—"how will I do this [sic]", "what words will I use [sic]" are to be expected (O'Daniel et al. 2010). Gaff and Bylund (2010), in their book 'Family Communication about Genetics', give numerous examples of how individuals can be helped to communicate with their family about genetic information (Gaff and Bylund 2010). When reorientating his parents with the genotyping process, before he gave them their results, Dr Corpas presents a story to them: "Imagine that you perform an extremely detailed blood analysis, where doctors measure thousands, millions of things. The doctors will find some things that are reassuring to know about your health and other things that you might not like" (in this issue, Corpas 2012). Trees et al (2010) reminds us that 'humans are storytellers, giving meaning to experience through narrative' (p68 Trees et al. 2010). Thus, it is natural that Dr Corpas found this approach helpful for re-engaging his parents. Genetic counselors will often consciously work with their client's 'story' (Egan 2010), even if this mechanism is not overt to the client. By listening closely to how an individual tells their story (be it how genetic testing was initiated in a family or how a genetic condition was revealed) insight can be gained into family dynamics, family cohesion and coping mechanisms—all of these are useful in creating appropriate communication strategies (Trees et al. 2010).

It is well known that initiating the family conversation about genetics can be difficult and this is why genetic counselors might use the 'goal-plan-action' mechanism to help clients follow a structure to facilitate family communication (Samp et al. 2010). Planning together how genetic information might be shared within families is incredibly helpful for enabling clients feel less of a burden associated with this; indeed Dr Corpas identified that he felt such a burden.

The 'lay beliefs' that people have about genetics and inheritance may also impact on communication (Richards 1998; Henderson and Maguire 2000; Parrott et al. 2010). A genetic counselor brings a knowledge and awareness of these and thus can help a client to identify their own beliefs (e.g. 'some genes are stronger than others', 'genes in my family always skip a generation') and navigate their way through these as they communicate with their family. As the

Corpas family explored their genomic information together they created their own 'lay beliefs' about who had the 'best' or 'fittest' genotype. Whilst this is presented in a lightheartened manner in the paper, when this theme is extrapolated, there is a worrying undertone that demonstrates how easy it is to make eugenic comparisons. I wonder whether, if by having a genetic counselor present to share these conversations there could have been the opportunity to rationalise the sense of vulnerability that members of the family with the least 'fit' genome might have had. Part of the genetic counseling process often involves a sense of rationalising a genetic result and putting it in context of other risk factors.

It may be considered unnecessary, and even paternalistic (Foster and Sharp 2008; Platt 2009) to expect that a health professional *must* be involved in every DTC test. However, some feel that a health professional should be involved in predictive genetic testing for highly penetrant single genes (e.g. for Duchenne Muscular Dystrophy carrier status, Huntington Disease) (Human Genetics Commission 2003) and others feel health professionals should be involved in every type of genetic test (American Medical Association 2009; European Society of Human Genetics 2010). Indeed the practical implications are enormous of involving a health professional in the clinical interpretation of a full genome; some genetic counselors, clinicians and researchers suggest an 'average' genome would take 5 h of clinic time to discuss 100 genetic risks (Ormond et al. 2010).

The information provided by many DTC testing companies is incredibly detailed and many times thoughtful consideration is given to how to present risk information. There is often a real sense that careful consideration has been given about how to provide this information to *an individual*. However, what is sometimes missing is the availability of information about how to internalise, work with and communicate genetic information *between* individuals. Perhaps some written literature or even a podcast would offer a useful addition, even if face-to-face involvement of a genetic counselor were not possible. It seems unnecessarily cruel to expect participants of DTC testing to work out the communication methods for themselves, when tried and tested methods are already in use and there are a whole host of professionals able to offer expertise on this.

Translation of Communication about Single Genes to Many Genes

Whilst the last 30 years has provided a wealth of communication literature about genetics, since genomic testing is so new, most of this established literature relates to single genes rather than whole genomes. It is possible that some comparisons can be made, but we don't yet know if this work translates in its entirety. Genetic testing for single genes tends to occur when the related condition is rare, monogenically inherited and causes a serious or life-impacting phenotype. This sort of testing is also utilized in the main by people with a strong family history of the condition of interest. Families may then have a firm emotional connection to the condition being tested for. However, single gene testing in a family with a specific health concern is somewhat different from genome-wide genotyping in a completely unaffected ('healthy') individual with no specific concerns. In genome-wide genotyping a broad spectrum of information is revealed. For example, this might relate to ancestry or the ability to metabolise certain medications as well as risk information relating to more common conditions (e.g. Type 2 diabetes or heart disease) and carrier status for serious life threatening conditions. The breadth of conditions covered in a whole genotype test is vast and so too is the range of risk information; the participant has to explore multiple small, increased/decreased risks of hundreds of conditions, some serious (Alzheimers disease, Parkinson's disease), others less so (restless leg syndrome, propensity to make wet ear wax).

For the majority of conditions the participant is unlikely to have ever heard of them, nor have personal experience (Richards 2010) and so one observation is that there may be less of an emotional connection to the testing journey. That is not to say participants may not be emotionally affected by the results, this is entirely possible. Indeed, with no family experience to offer guidance on the impact of a condition (DiLorenzo et al. 2006), it may be even more of a shock when new genetic predispositions are revealed, particularly if the risk of occurrence is significant.

Too Many Genes to Be Emotionally Connected to the Process?

What strikes me about the genotyping exercise that Dr Corpas embarked on was how technically easy it was to do. All that is needed is a saliva sample, a credit card payment and an online account. He provided his sample without any particular worries about what the testing might reveal. Dr Corpas reflects that he was not overtly concerned about the fact that the testing may identify an increased lifetime risk of developing a serious, life-threatening condition, despite the warnings from the DTC company (and also despite his own knowledge on the subject). One might wonder if it is so easy to be relaxed about this because multiple conditions are being tested for, perhaps it is impossible to be emotionally connected to any of them? Maybe, due to the vast range of conditions and possible results it may be too much of a task to be emotionally connected at all? Indeed Dr Corpas reflects that he felt 'disconnected' to his results, possibly because of the volume of different

findings. He said he 'felt a lack of connection between myself as a person and what I was seeing in the results. I saw a series of illnesses I had never heard of for which I had either a minimal disease risk or a low relative risk' (in this issue, Corpas 2012). He later wonders if 'having somebody to talk it through would have made me more aware of the value of this information'. It is very fortunate in this instance that there were no 'high risks' nor significant predictions of serious, life-threatening conditions. It is distinctly possible that had there been, Dr Corpas would have been forced, very quickly and with little preparation, to become connected to the findings. Handling one or even two very significant results amongst a background of 'noise' (multiple low risk results) may add a new level of confusion and potential anxiety. We do not yet know if this might be a reality as no long term psychological studies have been done on this. Having a health professional (genetic counselor or other) to hand to help the recipient deal with any of these potential issues seems obvious.

There is such a sense that engaging with a genomic test has the potential to force the participant to deal with psychological reactions after the horse has bolted. When there is no family history to guide us there are limited cues from anyone (O'Daniel et al. 2010) that having 'emotions' about any of the information is appropriate. There is extensive literature to indicate that emotional reactions to genetic information are possible (Gaff and Metcalfe 2010), yet Dr Corpas was not given a *clear* steer from the DTC testing company that this could be relevant to his reality.

Dr Corpas had not given any thought or rehearsal to how he might feel if he was given a 'bad' news result ("prior to testing I found it difficult to consider potential scenarios when I did not know what would be relevant to me", in this issue, Corpas 2012); there was no help with psychological preparation. We know that psychological preparation (via pre-test counseling) does make a difference in helping people to adapt to adverse genetic results (Arver et al. 2004; Raymond and Everett 2009; Ashida et al. 2010; Dufrasne et al. 2011). Thus one might assume that a similar psychological preparation when testing for a whole genome may also have beneficial effects. Again, we have limited evidence for this. Indeed the few studies that have been done looking at psychosocial measures such as anxiety before and after genome-wide genotyping show no particular change, i.e. genotyping does not appear to cause anxiety (O'Daniel et al. 2010; Bloss et al. 2011). However, these studies have involved testing for a set of SNPs that are only able to predict relatively small increased risks of developing various conditions and did not take into consideration the influence of family history. Therefore, if participants had a strong family history of breast and ovarian cancer and their genomic profile included a test for the various mutations in BRCA1 then it is distinctly possible some anxiety would be caused as a direct consequence of having the test and revealing a bad news result. There is a caveat to this: although we know that finding out one has a significantly increased risk of developing a serious, life-threatening condition can cause anxiety, this response is often short lived and such carriers often quickly adapt to this information (Heshka et al. 2008). Therefore, it seems that testing for high-risk, single genes can cause an increase in anxiety and testing for multiple low risk SNPs may not. What we do not yet know is what the psychological impact is for a whole genome analysis that includes a series of highly penetrant single genes for dominant conditions, e.g. BRCA1, BRCA2, Huntington Disease. One might argue that the reason adaptation has been reported to be swift is because of the input of the genetic counseling process. Alternatively, there is one other hypothesis; perhaps it is simply impossible, on a practical level, to emotionally engage with 1 million variants as we might do for one?

Informed Consent and Confidentiality

Family Communication Patterns Theory 'is built on the notion that families create a shared social reality' (p187 Koerner et al. 2010). Thus, through engaging his whole family in genotyping, Dr Corpas has created a new shared social reality. According to Family Communication Theory, families fall into one of four different Family Types: Consensual, Pluralistic, Protective and Laissez-faire (see Koerner et al. 2010 for more details). The fact that all of his relatives appeared to engage with the genotyping process so readily (irrespective of whether, in reality, they fully understood what they were consenting to) is indicative that his family may be of the 'consensual' type (Koerner et al. 2010). Within this family type communication is 'open, warm, supportive and cohesive. The family is open to the outside and enjoys making new experiences. Decision making is collaborative and involves all family members' (p192 Koerner et al. 2010). Thus, even though as individuals, Dr Corpas' family may not have had a very clear recollection of what they had been tested for ("would my family remember the issues we discussed before testing?" in this issue, Corpas 2012), it is still likely that they would have remembered that they were participating in a shared, family experience and creating a new social reality.

Dr Corpas reflects that he gathered informed consent from his relatives for genotyping. It is difficult to assess what information he provided them. How did they react? What other sources of advice did they seek? Did they ask questions? We know that he tried to seek advice from scientific colleagues before he presented the test results to his relatives (one might argue that such colleagues may also not be trained in family communication). However, it is

difficult to know what more could have been done—he engaged with his family in ways that were normal and 'consensual' for them and everyone participated. Dr Corpas wasn't *required* by the DTC testing company to demonstrate that consent had been informed; all he needed to do was check a box to say that the sample was provided by someone who consented and understood what they were being tested for. In fact, it was not even necessary for the individual members of his family to check these boxes – Dr Corpas did this on their behalf. It is difficult to be critical of Dr Corpas, all he did was what the DTC testing company allowed customers to do. However, this case demonstrates the exact situation that the Human Genetics Commission were concerned about – that DTC testing companies would not be able to enforce or even thoroughly support what the Clinical Genetics community would usually consider best practice in terms of informed consent (Human Genetics Commission 2007). The European Society of Human Genetics in their Statement on DTC genetic testing reports: 'Any genetic testing service that requires a sample to be collected at home runs the risk of samples being submitted for testing without obtaining proper consent or without even the knowledge of the person to whom it pertains. DTC genetic testing companies do not have the necessary mechanism in place to ensure that the biological sample provided for testing is obtained from the person claimed to be the sample provider' (p1272 European Society of Human Genetics 2010).

It appears that Dr Corpas' family was excited by the prospect of testing. The sheer volume of potential results makes it impossible to apply the model of informed consent that is currently used within single gene testing – involving a pre and post-test counseling session where the impact of the single gene test is explored (Berg et al. 2011). Scaling this model up to consider 1 million variants is completely impractical. So how should customers of DTC tests be prepared for the unexpected finding, the result that appears directly out of the blue, with no warning shot and with no emotional bolstering? Leaving them alone to figure this out does not appear ethical. Whilst they are at liberty to seek out a genetics health professional once they have their genotype results, why not allow them to access one immediately, if they so choose, as part of the process? Some DTC testing companies already offer this.

Within the 'consensual' family structure it is unlikely that individual confidentiality was of great importance. Indeed the fact that Dr Corpas' family members were accepting of their genotype results going directly to him rather than to them, is indicative of this. It may well be that they assumed he would understand the results better or even that they wanted him to interpret them for the family. The Transcultural/cross-cultural counseling literature highlights that there are different concepts surrounding 'self', i.e. in some cultures the 'individualist' concepts predominates, in others, the 'collectivist' approach is paramount (McLeod 1998). 'A person in a collectivist community is likely to regard himself or herself as a member of a family, clan or other social group, and to make decisions in light of the needs, values and priorities of this social network. Concepts such as self-actualization or authenticity (being true to one's individual self) do not make a lot of sense in the context of a collectivist culture.' (p164 McLeod 1998). Therefore, in this close-knit family from Malaga, Spain, it is possible that the consenting procedures employed and the disconnect to individual confidentiality are entirely appropriate. 'As ethnographic research makes clear, many cultures construct different understandings of kinship, health, and illness and these differences are likely to affect the way that genetic risk is understood' (p53 Parrott et al. 2010).

Burden of Genomic Information

Dr Corpas mentions the word 'burden' many times – 'I felt the burden of explaining the results' (in this issue, Corpas 2012) and 'I felt burdened by the fact that my family might not share the same skepticism about the results as I did' (in this issue, Corpas 2012). It is clear that genomic information has a value, which may be different to different people, and it cannot be assumed it will always be useful or even positive (irrespective of whether there are any 'high risks' or not). Indeed Dr Corpas quite clearly understands that his results are likely to be interpreted differently over time as more research is done to understand their meaning. However, he is not so confident that his family will appreciate the uncertainty of the information they were being given. This is a very astute observation. It is difficult enough to describe something that may have health implications for a loved one (we inevitably have an emotional vested interest in their wellbeing) but to add a layer of confusion or uncertainty about whether this information might change adds a whole additional complexity.

To the lay person, seeing a result, delivered via a computer, in a very professional and articulate manner certainly has the air of credibility to it. Dr Corpas himself, even despite his knowledge and experience of the fallibility of genomic interpretations, admits that it was 'very easy to become drawn into believing the information provided' (in this issue, Corpas 2012). Thus not only did the genomic information feel 'burdensome' in terms of knowing how to share it, but it was also burdensome in terms of managing, and containing, its uncertainty. It felt 'convincing' and 'believable' despite a heightened level of awareness of the limitations in interpretation. Thus there were a range of values attached to it as well as a range of contradictory messages too.

The DTC testing company stresses (in the small print) that the information they provide should not be used for diagnostic purposes and is offered purely for information and in a research capacity. And yet in their marketing they also suggest that their information can be used for prolonging health, taking preventative steps and planning for a healthier future. The inference being from all these cues that it is appropriate to use the information clinically. Therefore, there are a myriad of messages and it is unreasonable to expect the average lay member of the public to appreciate the complexity of this. There is also evidence that customers are more likely to trust (and thus perceive as credible) websites that provide information that is attractively and professionally delivered (Fogg et al 2003). Most of the DTC testing companies have excellent websites that are delightfully inviting. To my mind, the input of a trained health professional (again, this could be a genetic counselor) would be of enormous value in helping and supporting the customer to work out what is actually meaningful to them.

Summary

In the not too distant future, whole genome sequencing will be available at an affordable price (Lander 2011) and to the masses (Mardis 2011). The utilization of these tests may become more widespread; members of the public engage with many providers of DTC testing with no input from the health profession. This may be seen as a positive step as consumers take more active control over their own health. An overview has been offered on the communication literature available to help support individuals and families to communicate about genetic information. Despite there being a wealth of evidence, built on years of genetic counseling practice, this does not appear to have been translated clearly to the DTC testing market. Family communication about health and indeed genetics can be fraught with difficulty. Genetic health professionals, specifically genetic counselors, have particular expertise in *family communication* about genetics. Thus, irrespective of whether consumers of DTC genetic testing choose the input of a health professional or not, there is still an abundance of knowledge and experience about family communication that is missing from the information that DTC testing companies provide. Such information could be incredibly useful to kinships as they grapple with knowing how to communicate their genomic information with relatives. When sharing DTC genomic testing within families, customers cannot be expected to follow, what would be considered 'best practice' in terms of a) informed consent, b) psychological preparation and c) accurate interpretation of results. These are all familiar territory in the clinical genetics world, however, when a DTC customer embarks on testing alone, none of these frameworks will be familiar. Whilst it may currently be 'acceptable' to offer DTC testing without the involvement of any health professional, I would like to suggest that the DTC testing service may be enhanced in many ways if a genetic counselor (or other health professional similarly trained in health communication) may be available as part of the process. The experiences described in 'A Family Experience of Personal Genomics' and also in this Commentary highlight that genomic information is neither simple nor without value. There is the potential for a myriad of unanticipated reactions, which even the most informed customer may not expect, nor be equipped, to deal with. Whilst it is distinctly possible that DTC testing recipients will simply 'cope' on their own, why not utilise the expertise and experience of health professionals, such as genetic counselors so that such customers can gain the maximum from their genomic information as well as help and support along the way in using and sharing this?

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