

'Relatively speaking': relativisation of genetic risk in counselling for predictive testing

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Abstract *The activity of risk communication in the healthcare setting is contingent upon the associated notions of uncertainty, normality and decision making. Focusing on the context of counselling for predictive genetic testing, we point out that because there is 'medical' uncertainty surrounding such testing, the discourse of risk assessment concerning an unwanted event is articulated in terms of the likelihood (in objective, probabilistic language) and the relative aversiveness (in subjective, evaluative language) of the different possible test results. Our data, taken from counselling clinics for Huntington's Disease and Familial Cancers (of the breast and colon), allow us to make a distinction between the risk that the genetic disorder will manifest (the 'risk of occurrence of disease') and the risk that might arise from undergoing genetic tests to clarify that risk (the 'risk of knowing'). In a given counselling session, both types of risk—the strictly genetic risk of occurrence of disease, and the more contextual risk of 'knowing'—become conflated, and in fact the risk of occurrence of disease is understood in the light of the other, external risk factors. We suggest the analytic notion of relativisation to capture this dynamics and go on to identify six discourse strategies that are used by participants, i.e., abstraction, reformulation, externalisation, localisation, temporalisation and agentivisation. Although it is not possible to determine the exact valency of these discourse strategies and plot them into a continuum, we argue that these strategy-types are selectively and cumulatively drawn upon by both counsellors and clients so as to escalate or de-escalate the risks under discussion. These manoeuvres serve as a way of managing the pragmatically informed decision-making process, while simultaneously attending to the relevant epistemological levels of uncertainty.*

Key words: genetic counselling, predictive testing, discourse analysis, risk communication, escalation and de-escalation of risk, risk of knowing, risk of occurrence of disease

Introduction

The notion of risk in the healthcare setting is intimately tied up with notions of uncertainty, normality and decision-making. In suggesting such a complex inter-relation, we move away

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from the traditional view, which holds that experts have definitive knowledge about future risk that they can pass on, neutrally and unproblematically, to clients who lack such knowledge. Studies devoted to the sociological construction of expert knowledge systems claim that professionals' engagement with risk constitutes a new form of expertise. Indeed it amounts to an acknowledgement of the end of the lay/expert divide on the one hand, and the difficulty involved in solving problems with expert knowledge, on the other. In contemporary societies, experts no longer solve problems through a straightforward application of theoretical/scientific knowledge, but increasingly engage in assessment of problems, and hence by extension, generation of risks associated with events that might or might not occur. The traditional role of experts has undergone a reconfiguration in the wake of epistemological and ontological uncertainties in many professional spheres. Funtowicz and Ravetz (1992) refer to this phenomenon as 'post-normal science' in order to underscore how scientific facts are increasingly becoming 'soft' in comparison to 'hard' moral and ethical value systems. In healthcare generally, and genetics in particular, we see that experts do not always possess the exact knowledge to explain in a strictly causal manner what one's risk status is or will become and what means there are, if any, for avoiding such risks. It is because of such uncertainty that the experts tend to make use of probabilistic reasoning that underpins the quantification of risk in abstract and absolute terms (Reichenbach 1951).

A related development is that human problems defy a single-handed expert intervention, which has led to the pluralisation of expert knowledge (Williams and Calnan, 1996). The assessment and management of risk requires multi-professional intervention and it also means that clients need to play a significant part in the decision making process. The general public now has unlimited access to scientific knowledge via internet sites and support groups, although debates continue regarding people's ability to synthesise such knowledge in a meaningful way. An extreme scenario would be for clients not, or scarcely, to engage with the risk and so to continue life as it is. The other extreme would be for clients to engage in radical action because of panic about their future risk. In between lies a position where clients attend to a specific fragment of the risk they face, based on their present understanding, as a way of coping with the situation. In other words, the risk assessment and management is very much a dynamic process and it will vary across clients, professionals and health/illness conditions. At the interactional level, then, risks become relativised as a means of understanding and acting in response to specific elements of the risks clients may face. Talking about different types of risk in the genetics clinic, both clients and counsellors employ a range of discourse strategies to construct these risks so as to suit their communicative goals at hand, effectively escalating or de-escalating their threat. A closer examination of these relativising discourse strategies in their interactional context will form the data-analytic part of this paper.

Many researchers in a range of healthcare sites have studied the relationship between risk and decision-making. In discussing risks with patients, Bogardus *et al.* (1999) propose the following five dimensions of risk as relevant for decision-making:

- identity (the nature of the risk, including its wider implications)
- permanency (duration of the unwanted outcome)
- timing (when will the unwanted outcome occur?)
- probability (how likely is the unwanted outcome?)
- subjective badness (how much does the unwanted outcome matter to the patient?)

They single out 'subjective badness' as possibly the most important dimension for decision-making. Although Bogardus *et al.* (1999) do not analyse real-life encounters, such a differentiation between different dimensions of risk is helpful to understand how clients' risk perceptions may be modified by intervening factors such as the remoteness of the threat from

the client's current position, or the development of coping strategies that may modify the client's attitude towards the disease.

In a similar vein, Linell *et al.* (2002) have suggested that the degree of explicitness with which risk gets discussed in various healthcare settings is likely to be affected by a number of variables, such as whether clients are aware that they belong to a high risk group, how imminent or how far in the future the adverse event is likely to affect the client's life, whether talk about risk is an acknowledged part of the agenda, what source the risk is attributed to (e.g., genes vs. lifestyle) and how much autonomy the client might possess in actively reducing his or her risk. The two predictive testing contexts from which we draw our data—Huntington's Disease (henceforth HD) and Familial Breast Cancer (FBC) or Colon Cancer (HNPCC)—share some of these variables but differ significantly in others.

Before examining in more detail how risk is presented in the genetic counselling context, it is important to note that a lot of talk may not be about risk as such, and when risk is mentioned or alluded to, it may not specifically be the *genetic* risk of disease, but the various risks associated with clarifying one's genetic status, i.e. the risk of 'knowing'. In what follows, we offer a brief overview of how we conceptualise the relationship between these two types of risk for the purposes of this paper.

Probabilistic genetic risk vs. contextual process-related risks

The assertion that an individual is at increased risk of a genetic disorder will usually be based initially upon a knowledge of the pattern of disease in their family, and if a genetic test confirms that the individual is indeed at increased risk of disease, then it will often have implications for the health of other family members. As Novas and Rose (2000: p. 487) suggest: 'When an illness or a pathology is thought of as genetic, it is no longer an individual matter. It has become familial, a matter both of family histories and potential family futures'. This reminds one of the age-old dictum, 'don't treat the disease, treat the patient', which will require the professional, in the genetic counselling context, to accommodate the social and family circumstances—past, present and future—in relation to decisions about disclosure of information to other family members, reproductive choices etc. This is, for us, an exercise in relativisation, which makes it analytically difficult to categorise genetic risk as distinct from non-genetic risk. In other words, the—strictly speaking, non-genetic—risk of 'knowing' one's genetic status creates awareness of potential genetic risks for a future pregnancy or for other family members and can thus be regarded as falling within the remit of genetic risk discourse. Relevant elements in the construction of genetic risk, therefore, encompass not only the technical and clinical assessment of probabilities but also the anxieties and the interpersonal problems potentially generated by the testing process itself and the test results, the risks associated with risk management strategies (e.g. colonoscopy, mammography), and the risk of discrimination in insurance and employment.

With regard to the probability of occurrence of the genetic disorders, HD, FBC and HNPCC, all are autosomal dominant conditions so that there is a 50% chance that the child of an affected parent will have inherited the disease-associated mutation. Carriers of the HD gene mutation are certain to develop the condition at some point in their lives (i.e., 100% penetrance), although uncertainties remain with regard to the age of onset and the way in which the disease will manifest (Bates *et al.* 2002). Carriers of FBC and HNPCC, on the other hand, have a very substantially increased risk of developing cancer at some point in their lives but some will 'escape'—they will die of other causes (i.e., mutations in these genes seem to have a penetrance of 60–80%; Lucassen 1999). There is currently no effective treatment available for HD and clients typically die from the condition some 15 to 20 years after onset (Kremer 2002), while surveillance to detect tumours early and treatments that are believed to

improve clinical outcomes are available for those at risk of FBC and HNPCC (Lucassen 1999; McAllister *et al.* 2002).

The absence of direct medical benefits to be gained from an HD predictive testing result, in contrast to the situation in the familial cancers, is reflected in the amount of interactional space devoted to discussing the risks of testing and the benefits of knowing in a counselling session. In the HD clinic, discussions may encompass issues such as future care arrangements or reproductive decisions in the place of talk about disease prevention or surveillance, and are more likely to focus on the problems that may arise from taking the test and being given a result. In counselling for predictive testing for familial cancers, the genetic risk arising from carrying a cancer susceptibility gene is often explained with reference to the general population risk for cancer. The associated risks that are frequently discussed include the 'pros and cons' of the preventive measures (e.g., mastectomy) or of screening to detect tumours early.

In conceptual terms, we would like to suggest that the unwanted development of a given genetic condition—event E—can be regarded as located in the future. Both HD and FBC/HNPCC clients often know of their high-risk status before they come to a clinic, as they invariably seek predictive testing because of their knowledge of the history of affected family members. It is commonplace for clients to have had access to such risk information via contact with support groups and other healthcare professionals, including specialist nurses who offer home visits prior to a clinic appointment. With the unwanted event (E) in mind, the genetic counselling activity can be characterised as focusing on two types of risk: a close-at-hand risk associated with knowing one's genetic constitution (Risk 1, henceforth R^1) and a (hopefully) more remote risk of occurrence of the genetic disorder in question (Risk 2, henceforth R^2). We approached the data with this distinction in mind, with the presupposition that the ethos of genetic counselling is to minimise harm from the testing process (R^1) and, where practical, to do whatever can be done to minimise the risk of disease, R^2 , as well—although that is much more feasible for HNPCC (and to some extent for FBC) than for HD.

In genetic counselling, the consequences for the individual if they were to develop the genetic condition under discussion need to be described and understood in terms of how the individual would be likely to experience the condition and the full range of implications this would have for the client and those close to them. Factors involved in the subjective weighting of the possible test result, 'You have the gene for condition X' (one of the outcomes included within the risk of knowing, R^1), thus include: How will it affect me (symptoms)? How far away is it (age of onset)? Can something be done about it (prevention, treatment)? How will I cope? How will it affect my relationships and my quality of life (e.g., discrimination)? With whom would I discuss the test results and what would it mean for them?

Data and methodology

Our data consists of 50 hours of audio-recordings of consecutive counselling sessions involving predictive testing for HD, HNPCC and FBC. These have been transcribed following standard procedure for anonymisation (using pseudonyms and modifying incidental personal details). Each transcript is then mapped along interactional and thematic lines, and the findings reported here are based on these mappings.

To date, research on risk communication in genetic counselling literature has largely been limited to quantitative psychological studies exploring the connections between risk framing effects, clients' attitudes and decision-making. Most of these studies operate with a narrow conception of risk not taking into account its qualitative aspects (see e.g. Welkenhuysen *et al.* 2001). Furthermore, the task of risk communication is typically seen as a one-way transfer of information from professional to client. In contrast to such studies, our approach conceptualises risk as multi-faceted and interactionally co-constructed.

Our approach to the data can broadly be labelled discourse analysis. We adopt a wider notion of discourse, which is conventionally defined as the making of meaning above the utterance level. The multi-functional, context-specific nature of language use (here, the language of risk in both senses as outlined above) includes what lies behind the utterance, e.g., participants' role-relationships and their motives/accountability as well as wider institutional, ideological and socio-political underpinnings (Cameron 2001; Drew and Heritage 1992; Sarangi and Roberts 1999; Sarangi and Coulthard 2000). Discourse analysis thus focuses on the jointly constructed process of interaction while uncovering potential links between micro-level accomplishment of topics/roles and the conversational outcomes (for discourse analytic approaches to genetic counselling, see Sarangi 2000, 2001, 2002, 2003; Sarangi and Clarke 2002a, b).

Types of relativisation strategies in genetic risk assessment

From our discussion so far it follows that risk is both a probabilistic and an evaluative concept, that it can be articulated in very objective terms (i.e. numerically) as well as being made subjectively relevant to a specific context (see also Lupton 1999). We suggest that a number of discourse strategies may be employed to relativise risk – to weight it as more or less serious or relevant. Our understanding of 'discourse strategy' does not assume conscious manipulation or even intent on the part of the speaker. Instead, we see participants' utterances as having 'strategic' effects in the sense that they construct and frame risk in certain ways, thereby foregrounding a particular perspective. Depending on what perspective is adopted, risk might be escalated or de-escalated through counsellors' and clients' discursive moves. The resulting shifts in the weight of the perceived threat we refer to as risk relativisation.

We identify the following strategies that are utilised selectively by both clients and counsellors as a way of escalating or de-escalating the present and future risk status of clients:

- Abstraction
- Reformulation
- Externalisation
- Localisation
- Temporalisation
- Agentivisation

In what follows, we illustrate each strategy type with brief examples taken from Cancer and HD clinics.¹ Although we suggest that each strategy can be used by both clients and counsellors, for lack of space we will indiscriminately draw examples from either context under each category, followed by an extended extract. As will become apparent, the strategy-types are not mutually exclusive and can be overlapping or allow for multiple categorisation. In our view, however, it is important to treat the strategy types as analytically separate.

Abstraction

By this strategy we refer to the use of statistical, scientific facts and figures about the patterns of occurrence of a genetic condition. For instance, that 1 in every 12 women develops breast

1. *Transcription conventions:*

GC: genetic counsellor; GN: genetic nurse; AF/M: adult female/male client; F/MP; female/male partner; MO: mother of client; question mark [?]: rising intonation; underlined text: special emphasis; [text in square brackets]: overlapping speech; (text in round brackets): transcriber's guess; ((text in double round brackets)): description or anonymised information.

cancer is an abstraction (in the sense of R^2 as suggested above). If the individual client's personal risk of developing cancer is being discussed, a statement of the risk of other individuals in the same situation (e.g., with the same genetic mutation) may be presented. In one sense, it may seem odd to consider such 'abstraction' as a strategy of relativisation at all, but such abstract statements can be seen as relativising a particular risk category in relation to other phenomena, e.g., the population risks associated with different kinds of cancer—breast cancer, lung cancer, colon cancer etc.—or non-cancer disorders. Such statements of abstraction are usually derived from epidemiological studies and can be seen as 'academic' unless of course they are applicable to the situation in hand.

Example 1

GC: Some people can have the gene for the whole of their lives and and and stay healthy and on the other hand actually about one in three people get a cancer somewhere in their body in their life and about one in four people die of it anyway.

Putting the client's specific genetic risk in the context of risk(s) for the general population or for a condition-specific sub-population can be used for both escalating or de-escalating their at-risk status. Genetic counsellors might adopt this strategy to facilitate clients' engagement with hypothetical scenarios, whereas the adoption of a purely probabilistic perspective on their risk might be used by clients to cut short such reflective talk and steer interaction back to a more information-focused format, as illustrated in example 2, taken from an HD clinic.

Example 2

GC: I mean, did it—((client's brother being diagnosed with Huntington's)) make your fifty-fifty risk feel any different for you or ((pause))

AF: [well]

GC: [or] more determined to know [or more in other]

AF: [just the luck of the] draw, isn't it, you know? I mean you can't make it less and you can't make it more, you can't do anything, you know, it just *is*.

Here we see an interface between R^2 and R^1 with regard to the event that cannot change—'it just is'. This strategy type is usually applied in the context of R^2 —the risk of occurrence of disease—but can be applied to R^1 contexts when counsellors discuss how other individuals and families have responded to genetic testing (see example 9 below).

Reformulation

By reformulation we mean the opposite of abstraction—how the statistical facts are presented in a more context-specific way. The notion of recontextualisation (Linell and Sarangi 1998) is similar but broader than this, including temporality as well as the wider socio-cultural context, but here we restrict it to the articulation of alternative formulations, either through the use of different words or metaphors or through the use of visual aids. Edwards *et al.* (2002) argue that visual representation of risk information assists patients' decision making. Whether employing words or images, we are dealing with the reformulation of quantitative risk information such as explicit/implicit levels of risk elaboration. Such approaches still assume the division of labour between expert and lay perceptions/abilities and deal with normality in one way or another. They do not generally link the discussion of risk explanation/assessment to decision-making and uncertainty.

Example 3

GC: so the odds are in your favour but we here know very well from our past experience that that's not a reason for shortcutting this process because, you know, if you've got eh odds of one in seven and we see seven people who've got odds of one in seven, well one of those is likely to – it's going to turn out – it's like betting a horse, and so it's important for you not to say oh well it's only one in seven, couldn't happen to me. It's important to think through the issues.

As with abstraction, this strategy type is often applied to explain and put emphasis on the personal, numerical (probabilistic) risk information (most relevant to R^2). This process of placing risk information in the very personal context of the individual's life entails addressing very much wider issues beyond the required numeracy skills. The analogy – it's like betting on a horse – is meant to help understanding of the risk (in the sense of R^1 , see also the formulation 'luck of the draw' in example 2 above).

Adelswärd and Sachs (1998) have shown how clients do not always understand abstract/absolute notions of risk as intended. They suggest that numerical expressions such as percentages need to be recontextualised and made relevant to clients' lived experiences. Rapp (2000: p. 63) uses the term 'code-switching' to foreground 'the ability and perceived necessity of counsellors (or anyone else) to move from one language framework – statistical, biomedical, familial, colloquial – to another, adjusting the message to the speaker's perceptions of who the listener might be'. She goes on to show how the benefits and risks associated with amniocentesis need to be coded in context specific ways in relation to who the clients are: someone from a working class or a middle class background, someone with a first pregnancy, someone with a different linguistic, ethnic background etc. This attention to the form and content of message is relativisation and it includes figurative speech such as the use of metaphors. When issues pertaining to personal and social context are examined, however, this moves beyond reformulation to the strategy of localisation.

Localisation

Localisation strategies contextualise the scope of reference from the comprehension of risk in the probabilistic sense – as addressed by the strategies of abstraction and reformulation – to a fuller appreciation of the significance of the risk for the whole life of the individual and their family. It is no surprise therefore that this strategy is applied especially in the context of risks of knowing (R^1), and only occasionally in relation to risks of occurrence (R^2). While in some ways similar to reformulation, localisation tries to focus on applicability and relevance to the individual situation. It is one thing to say that we can understand our risk better if we are presented with visual aids, but it is another to say whether our at-risk status has changed because of the various factors that are brought into the equation. This strategy therefore encompasses the subtle, non-numerical and imprecise modification of risk figures (probabilities) that attempt to incorporate individual-specific factors that cannot be precisely weighted but may be expected to have some influence on the probability of the unwelcome event under discussion.

Example 4

GC: so you tell me [what-] what you understand about Huntington's now? ((quietly))
(and I) ((unclear))

AM: uhm right ((laughs)) well I know it's fifty-fifty. Ehm, so it's fifty percent I – I've got it and it's fifty percent that I haven't got it, ehm I know that it can occur any time? but you know, I guess I'm looking at my mother and her sister and think well if it's

mid sixties for them, I suppose there probably may be a chance that it'd be in mid sixties, if I do have it, that it'd kick in for for me and my brothers (or whatever).

Here AM displays her knowing of the risk as 50% – not just in either/or terms of having or not having the condition. She then goes on to contextualise the onset along the temporal dimension and draws upon the local knowledge about her mother's and aunt's situation as a way of localising the timing of occurrence (R^2). This inference is arrived at on the basis of AF's knowledge of family surroundings, not generic, population risk figures. In the next example, the client, AF, has lived through most of her risk of developing HD without doing so and she correctly interprets her residual risk as small.

Example 5

GC: I was going to ask you actually how your view of yourself and the risk? to yourself has been over time. How do you see it?

AF: well you see I think the older you get, you think well I'm fine ((pause)) I'm fine at the moment that's the way that I'm looking at it. But each year that I'm going through well I'm going to be fine. I mean I'm sixty-six now so the risks are going lower and lower, aren't they? of me having it.

It is not just clients who localise risk; counsellors may resort to this strategy as a way of putting clients' concerns into perspective. In example 6, GC is talking to a client who fears that her risk of inheritance for the HNPCC mutation is increased because of her history of bowel problems.

Example 6

GC: I do believe that it's fifty-fifty chance, I don't have any feeling that it's any more than that. Lots of people have bad stomachs and, you know, you've had an irritable bowel for a long time so I'm starting as believing, you know, it's fifty-fifty.

The formulation of risk as fifty-fifty can be regarded as 'normal risk' for someone who has a parent affected by HNPCC – the woman's symptoms are unlikely to be relevant and do not increase her individual risk; *her* reasons for modifying her personal risk are not accepted.

Externalisation

This strategy is the mirror opposite of localisation and is usually employed by counsellors to move away from the individual client's case, as they tend to explain general patterns of inheritance or the course/outcome of a disease as well as their preferences for decisions and actions where appropriate. By making reference to 'another person' or 'some people', counsellors are drawing upon their breadth of clinical experience ('we here know very well from our past experience' in example 3, and 'lots of people have bad stomachs' in example 6). This strategy is thus different from both abstraction and reformulation, although at times the mention of 'someone' can have a general or hypothetical referent.

Example 7

GC: the other options they mention are things like there are some people who want to reduce their risk as much as it's humanly possible to do and some people opt to have their bowel removed.

The referent 'they' stands for other specialists, which invokes a sense of collegial authority. GC then outlines two options, comprising two kinds of reactions: some people do x and some

people to *y*. Such reference to how other clients might react to or (mis)interpret the testing process, the result or the risk information also provides counsellors with ways of accounting for institutional procedures and their own professional practice without threatening the individual client's face. In example 8 below, the counsellor uses externalisation to minimise the possibility of an individual client drawing wrong inferences from a test result (part of the risk of knowing, R^1).

Example 8

GC: that doesn't mean that you never might never get cancer and I just have to be really clear about that because we have had situations where people have gone out thinking ((GC)) and ((nurse)) have said I'll be fine for the rest of my life almost you know that it's a guarantee. It's not.

Here the reference to 'other people' helps the counsellor to communicate the risk of a false sense of security after a negative test result, foregrounding his professional responsibilities rather than the client's potential lack of expertise.

Clients also deploy the strategy of externalisation in a selective manner. In example 9, which occurs at the very end of a pre-result protocol, the client's partner invites the counsellor to comment on patterns of decision-making when the client has affirmed her decision to take the test:

Example 9

MP: can I ask later are there many people- find actually asking them ((unclear))

GC: what going through the testing bit?

MP: yeah taking the test

((pause))

GC: across- in a sense- if you're looking across the country at all those people who like yourself are at risk it's about one in five

AF: mm

MP: only one in five.

It is interesting to note how an externalisation strategy can lead to a statement of abstraction ('it's about one in five'). It is however not about the risk of occurrence of the disease (R^2) but about the pattern of decision-making (R^1). A regular example of externalisation that addresses R^2 is the suggestion that R^2 is not so great—attention to it should be de-escalated—because, after all, as one client put it, one could always step outside the clinic and 'get knocked over by a bus'.

Temporalisation

This strategy relativises risk by invoking a time axis along which risk becomes gradually more or less significant for the individual's current concerns. For example, the temporal differentiation between clients' genetic status and their actually being affected by the condition relativises the risk of actually taking the test because 'having the gene in itself doesn't make you ill'. Particularly in the case of Familial Cancers where penetrance is not 100%, but also with regard to Huntington's Disease where age of onset can show marked variation, adopting a life course perspective might increase uncertainty. It does, however, allow counsellors to offer clients more favourable risk assessments at least for the more immediate future.

Example 10

GC: how do you think it ((having a positive result)) would affect you?

AF: well I don't know, it's – I don't think it's changes. because like it wouldn't – hopefully wouldn't come into effect for another ten- ten odd years you know and –

GC: mm

AF: I just wait and see what's round the corner.

AF's optimistic remark about the condition being 10 years away is a reinforcement of the unwantedness associated with this event. 'Round the corner' works both as a spatial and temporal metaphor to underline the waiting game. This marks a way of de-escalation, although achieved differently from the localisation dimension noticed in examples 4 and 5.

In example 11 below, the client upgrades the risk when she individualises the counsellor's externalised account by identifying herself as temporally within the group he has been talking about.

Example 11

GC: and there's also an increased risk to your womb, and what people would be talking about with you we would talk with you, if we knew you carried the faulty gene would be discussing if you'd finished your family some people might opt to have those taken away or screened ((pause)) again this is quite a lot of information but just to raise it so that we can pick this back up again later if we needed to. I think bowel cancer's the major issue but these other things are there as well and we need to tackle them, so how does that feel? does that feel quite a lot

AF: no no ((pause)) well I have finished my family ((pause))

GC: but it's sort of a step away for you.

Here the counsellor uses temporalisation to withhold information and discussion on a topic that the client then suggests she could deal with. The client is prepared to face the risks of going through testing as she would be ready to act on the genetic test result if it were unfavourable. Information about the condition and possible action plans are part of temporalisation, and the counselling protocol is organised to reflect this. Note that, as in example 7, we also have the externalisation strategy used to refer to other colleagues ('what people would be talking to you') and to other clients ('some people might opt').

Temporalisation can also include discussion of availability of more sophisticated diagnostic and predictive tools in the future ('I'm sure by that time the methods of screening would be more efficient'). Such anticipated progress in medicine offers a different risk assessment, and so will have implications for decision-making.

It is not surprising that in the predictive testing situation, risk is temporalised by both counsellors and clients. Clients normalise their risk perception in different ways, i.e. they talk about future risk as something yet to happen (or not happen), and so carry on as usual. From the client's perspective, the temporalisation of risk may be used as a strategy for postponing full engagement with certain aspects of risk – but it may also be used to focus on the need or opportunity to deal with the risk constructively.

Agentivisation

This strategy draws attention to both the counsellors' and the at-risk individuals' capacity for action and responsibility. It demands active risk engagement through the regular use of routinised medical surveillance (screening, or self-examination) or other concrete actions to be

taken by the client. By aiming to control and minimise the adverse effects of the risk (or in the case of HD, modify expectations rather than behaviour and prepare for the anticipated changes) such risk mitigation strategies feed back into clients' risk assessments in the sense that a threat that can be known and/or managed is experienced as a lesser threat. Example 12 is an illustration of a counsellor using the agentivisation strategy signalled through 'we'd want to put you into some screening programme'.

Example 12

GC: and I think it's quite a significantly increased risk. It's more likely you would get bowel cancer in your lifetime than not. And therefore we'd want to put you into some screening programme. The screening programmes we know work. They're very good it would mean regular bowel checks though, probably every two years.

In the next example, we have an HD Client formulating why she wants to know her at-risk status:

Example 13

AF: I mean if I have got it, well then I can prepare myself for (having a wheel chair or ((unclear)) but I mean my mother is fine, she still gets around about the place and- ((pause)) you know?((pause)) she's fine with it, at the moment, aren't you?

MO: yeah

G5: what sort of preparations—when you say preparing yourself for the future, what would you do?

AF: well I'd start saving some money for a start ((slight laugh)) so if I do get it, I can start (living it up a bit) but I can start, you know, putting money away.

It is worth comparing what AF says in the opening turn with the localisation strategy in example 4. Unlike screening, which is appropriate in cancer, AF here alludes to lifestyle choices, given that HD is incurable.

As we can see, the temporalisation strategy slices the risk of occurrence (R^2) by mapping out lifetime risk, or by highlighting the difference between having the mutation and becoming ill, or passing the gene on to the next generation. However, we also find temporalisation of the risk of knowing (R^1) when counsellors structure the counselling process to talk about one risk at a time, taking things step by step.

The strategy of agentivisation, on the other hand, manipulates primarily the risk of knowing (R^1). By rehearsing what one would do to manage or prevent the occurrence of the unwanted event in the case of an unfavourable test result, the risks of knowing become concretised, although not necessarily de-escalated, and therefore more manageable.

The cumulative use of relativisation strategies in genetic risk assessments

Each of these six strategies has a special affinity to its oppositional strategy: i.e., Abstraction/Reformulation, Localisation/Externalisation and Temporalisation/Agentivisation constitute three dynamic pairs in the sense that deployment of one strategy is frequently complemented by its counterpart. At the same time, the proposed categories are not meant to be mutually exclusive and as we will see are often overlapping in any extended episode. As we have already shown, none of these strategies can be regarded as fixed in their function to either escalate or de-escalate client's genetic risk. It is their contextual deployment as well as the combination of these strategies alongside each other that accomplishes the escalation or de-escalation of clients' risk perceptions.

Let us now examine how the different relativisation strategies are employed in conjunction with each other in a more extended data example and how, in this particular example, the counsellor's use of risk relativisation strategies coincides with moves of escalation and de-escalation. The client (AF) is a young woman who is very frightened about the prospect of having inherited the cancer predisposing gene from her father, particularly after she has been told by her GP that a preventive mastectomy would be advisable in case she carries the gene. GC has already mentioned the possibilities for screening and lifestyle changes that could be thought about if someone is found to have the gene, but stresses that it is premature to go into the details at this pre-test stage.

Example 14

- 261: AF: yeah 'cause that's what Doctor ((name)) said wasn't it (.) He scared the living daylights out of me ((laughs))
- 262: GC: right? (.) In what way
- 263: MO: oh yeah he did ((laughs))
- 264: AF: he just stuff he said you know replace if it was breast cancer replacement tissue. You know um what was it?
- 265: MO: you could have a mastectomy
- 266: AF: yeah it [I was in there for five minutes]
- 267: MO: [and she was you know] she was really frightened [when] she came out
- 268: GC: [right]
- 269: GN: [oh no] I can imagine that's quite a lot to [take in]
- 270: MO: [very disturbed] you know
- 271: GC: [right]
- 272: GN: [yeah]
- 273: GC: I don't think I've got the actual graphs on me ((looking in file)) but the other thing then that I think is important to try to realise is that even though the risk is increased ((starts a drawing)) and even though there is a higher chance of developing something like breast cancer or even ovarian cancer at a younger age, relatively speaking the risk – or in absolute terms the risk is still low um and by that I mean if I draw a graph? Okay and up here is say the number of cases
- 274: ((pause while GC is drawing))
- 275: GC: and over here is age
- 276: ((continues drawing))
- 277: GC: so if we sort of had N twenty thirty, forty what you find is that in the normal population the chances of developing breast cancer ((pause)) do something like that ((drawing line on graph)) (. . .) okay, and the chances of somebody – so this is the normal population
- 278: ((pause))
- 279: GC: for somebody who has actually got a cancer predisposing gene what you find is that it's a little bit higher, and then from here it starts to get a bit more, and then it sort of shoots on up and I- the lines aren't quite going- that would be fair to do that one more like that in fact, put that one as normal and that one if you've got a breast cancer predisposing gene. So what you'll see – but the point of me doing this is that relatively speaking down here it is still very low
- 280: AF: yeah he said to me round about forties
- 281: GC: yeah ((pause)) so I'm not saying – it's not impossible to get cancer then but
- 282: AF: mm
- 283: GC: neither is it even if somebody doesn't carry a gene you can still get cancer at a very young age even if you don't carry a predisposing gene ((pause)) but

most of the risk that starts to increase is when you're above thirty and most of it in fact when you're above forty. So we don't usually recommend doing certainly things like operations and things like that until maybe people have started thinking about families and children and things like that

It is worth pointing out the explicit reinforcement of relativisation in GC's formulation 'relatively speaking . . . in absolute terms the risk is still low' in turn 273, which is also repeated in turn 279. GC uses both abstraction and reformulation as he visualises/textualises the client's risk of developing cancer during her life-time by drawing two curves representing the population risk and the mutation carrier risk over the life course. The comparison between members of the general population and mutation carriers at the same time abstracts from the client as an individual at risk to the risk for the sub-population of all mutation carriers. By invoking a life course perspective, the counsellor further temporalises the client's risk: mapping out the (increase of) her risk into the future the counsellor is able to display her current risk as 'relatively' low.

Relativisation through temporalisation is also present in turn 283, when the counsellor implicitly situates the client as at the very beginning of the risk curve both in terms of age ('most of the risk starts to increase when you're above thirty' – the client is just twenty) and life stage ('until maybe people have started thinking about families' – the client has indicated at an earlier point that she doesn't feel ready to think about marriage or children). Here, the reference to risk management is used as a further de-escalating move in that GC negates the necessity for taking any sort of preventive action at the client's present life course position ('we certainly wouldn't recommend doing operations and things like that' [implicitly: 'yet']). This is what we have referred to as agentivisation earlier, and it is especially crucial given that AF is already actively contemplating mastectomy. There are several instances where GC also uses the externalisation strategy (in turns 277, 283) both to draw a contrast between the normal population and the case in hand, and to persuade AF not to take any drastic action as yet.

Discussion and Conclusion

Relativisation is an umbrella strategy for the framing of risk information. Both counsellors and clients use such risk relativising strategies in conjunction with escalating or de-escalating moves in the framing (or construction) of the client's genetic risk. The different relativising strategies have no fixed link to escalation or de-escalation in themselves, but they precipitate/project risk assessment slots that allow (the same) risk information to be presented in either more reassuring or more alarming terms. The use of risk relativising strategies thus allows counsellors to frame risk information in multiple ways, thereby balancing the need for accurate transmission of factual information and the promotion of clinically appropriate behaviours (e.g., compliance with surveillance for the disease) with the psychosocial goal of avoiding the creation of inappropriate anxieties.

As we have seen in our data examples, escalating risk assessments are almost invariably followed by de-escalating specifications in terms of *temporalisation* or *agentivisation*. Similarly, de-escalating risk assessments are frequently followed by escalating assertions about the risk of disease more generally (*abstraction*) and by negative examples of 'some other people' (*externalisation*) illustrating how the information should not be (mis)interpreted. *Externalisation* also allows counsellors to maintain a non-directive stance with regard to clients' future use of preventive strategies. At the same time, counsellors' mentioning of a course of action that would be effective at reducing the risk of disease promotes risk reduction through *agentivisation*. Supplying clients with options for actively making changes, e.g. through take-up of screening or life-style considerations, amounts to the conversion of danger into risk.

Counsellors use *temporalisation* and *localisation* to offer clients risk assessments that can be couched in more positive terms at least for the immediate future (and clients make use of the same strategy to de-escalate the risk of knowing/testing, R^1). Counsellors use *abstraction* (reference to population risks) to play down the genetic factor in the more general risk of being affected by disease (cancer) while clients often use *externalisation* (reference to everyday risks) to account for how they might cope with a positive test result.

Articulation in the clinic of the associated, contextual factors can play a significant part in the construction and understanding of the *genetic probabilistic risk* itself, insofar as counsellors and clients alike will introduce selective aspects of these risks to de-escalate and normalise genetic risk. This free movement between genetic and non-genetic dimensions of risk can make it difficult for the participants to determine what does or does not count as genetic risk because the discussion of the risks of occurrence of disease (R^2) blurs with the discussion of the risks of knowing (R^1).

The unwanted event (E) is then reconfigured in relation to R^1 and R^2 , while both R^1 and R^2 are constantly modified in a given interactional setting. Each risk is itself constituted as the product of two elements—the objective probability and the subjective aversiveness, or desirability, of each of the possible outcomes under consideration. R^1 usually incorporates the three possible outcomes of testing—a favourable result, an unfavourable result or an indeterminate result—as well as the *status quo* of not being tested, while R^2 incorporates the two possible outcomes in the patient's biography—developing the disease or not doing so. Each outcome then has a probabilistic component and a subjective weighting. We can represent this graphically as follows (Figure 1).

Risk communication in genetic counselling involves clients' knowledge about their at-risk status, including the possible consequences associated with taking the predictive test (R^1) as well as the likelihood of developing the condition (R^2). By supplying information about the condition (E) (e.g. symptoms, course, likely age of onset, options for screening, preventive or preparative measures) counsellors can alter (escalate or de-escalate) clients' perceptions of R^1 . The risks of knowing one's genetic status are made experiential by making available what is to be known as possible consequences of such knowledge, prior to the giving of the result. Furthermore, the information on the likelihood of occurrence of a positive test result (R^2) feeds back into the perceived risk of knowing, or of going through the process of genetic testing (R^1).

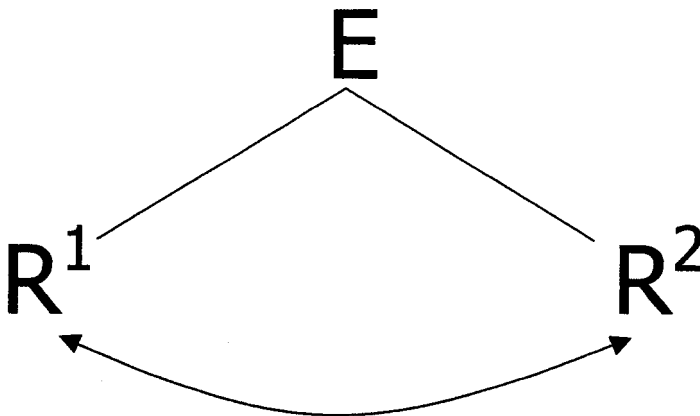


Figure 1. Unwanted event (E), Risk of Knowing (R^1) and Risk of Occurrence (R^2)

As Linell *et al.* (2002) have observed, communicative engagement with risk tends to generate its own risks. The risks that arise from simply being tested are entangled with the risks of developing the condition and therefore also with the process of making a decision. The distinction between risk and danger (Douglas 1990, 1992; Luhmann 1993) is helpful here. For Luhmann, risks are attributable to taking responsibilities and making decisions whereas danger almost always invokes external attribution. Danger here is the same as what we have called unwanted event (E) and external attribution might simply be reduced to formulations such as ‘it’s in the family’, or, ‘they couldn’t have done anything to prevent it’. Indeed, it is through talk that permits an active engagement with the future, that ‘danger’ can potentially be recast as ‘risk’.

In this paper we have illustrated how the two analytically distinct types of risk (the risk of knowing and the risk of occurrence) and their two components (the objective, probabilistic and the subjective, evaluative) are intermeshed in interaction. Genetic counselling for predictive testing can be regarded as an activity where both counsellors and clients want to minimise the overall risks – of going through the testing process and of developing the disease, although it is fair to suggest that the counsellor’s immediate focus is on minimising the risks associated with knowing (R^1), especially in the context of HD, rather than the risk of occurrence of the disease. Minimising the risk of disease (R^2) is certainly a relevant agenda to pursue in the case of cancers, where both parties may pursue agentivisation as an appropriate strategy, but not in all genetic contexts.

In the introductory section we raised the issue of new forms of expertise when it comes to genetic risk assessment, and why professionals and experts need to rely on probabilistic, predictive reasoning. It is this form of knowledge that professionals wish to impart to clients along with an understanding of the possible problems that may arise from the clarification of their genetic status. At times such probabilistic reasoning can exert persuasive influence on decision-making, but clients also need to be exposed to the wider consequences of probabilistic knowledge. What is important is that clients engage more actively with both forms of knowledge to come to a decision about genetic testing.

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