

KINSCAPES, TIMESCAPES & GENESCAPES: FAMILIES LIVING WITH GENETIC RISK

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Abstract

This paper synthesises recent research examining how families live with genetic risk and the processes of genetic decision-making and disclosure among family members who have or are at risk of transmitting a familial genetic condition. Its aim is to generate substantive theory that can inform our understanding of the interactional processes at work in the distribution of mutual knowledge and awareness within families. The paper is structured round three inter-related concepts: *kinscape* refers to the constellation of relations and relatedness that are recognised practically; *timescape* to the multiple temporal frames of social relations and their transformation; *genescape* to the constellation of knowledge, belief and practice surrounding

genetic inheritance. All three concepts are simultaneously ‘natural’ and ‘cultural’. Their intersections create the conditions of kinship and genetics.

Word count:

Introduction

We offer a meta-analysis of previous research on patterns of disclosure and awareness among families with an inherited genetic medical condition. Our discussion is based partly on our own research, partly on that of others. While there has been a succession of studies examining communication and similar issues surrounding genetics and family life, there has been too little effort to generate substantive theory or to explore a repertoire of generic concepts in order to inform a general understanding of the interactional processes. Ours is a synthesis or meta-analysis of a wide range of research. It is certainly not a systematic review. Systematic reviews have, however, been generated, and we draw on those analyses examined in recent reviews of research: see Gaff and Bylund (2010).¹ Our intention is to use a series of generic concepts to summarise and to model some of the key social *processes* that have been documented.

Kinshaps: Family and generation

The family and the lineage are conduits of economic, social and cultural capital (Bertaux and Thompson 2005). The notion of kinshaps adds to that perspective the need to understand the distribution of mutual knowledge and awareness within families and kindred. By examining the flow and blockages of genetic risk information through family networks we trace how the cultural categories and practices of inheritance, practical kinship, and everyday ethics are linked

in the accounts within a kindred (Featherstone et al, 2006). As Inowlocki (2005: 154) reminds us, 'generation' is something that is achieved through the work of practical kinship.. While the biological facts of generations are, to a certain extent, given or *ascribed*, the realisation of generations in everyday family life is *achieved* through the management of *transmissions and interruptions*. Together these regulate what is and is not, what may and may not, be talked about, reflected upon, reproduced or rejected, across generational boundaries. The particular configurations of transmission and interruption define the forms and functions of generational work (Thompson, 2005).

The field of anthropology has provided a body of studies examining reproduction and kinship in EuroAmerica (e.g. Carsten, 2000, 2004; Franklin, 1997, 2003; Strathern, 1992a, 1992b).

Biomedical innovations have given this topic a renewed significance, with a particular focus examining the impact of assistive reproductive technologies, which are seen as embodying the influence of biotechnologies in shaping identity and family (Inhorn and Birenbaum-Carmeli 2008). This field increasingly sees kinship as something more fluid and subject to transformation (Carsten 2004; Strathern 2005) and there is a growing body of work examining how these technologies may redefine and expand our ideas of family and relatedness (Edwards 2000, Bonaccorso 2007, Edwards and Salazar 2008).

The development of assistive reproductive technologies has led to an examination of the commercialization of parenthood (Goodwin, 1992), the position of gay men and lesbian women in relation to donated gametes (Levine 2008; Haines and Weiner 2000) and the identity of those conceived using these practices (Haines, 1998). Some argue that the increasing availability of

these technologies give rise to increasing social change and challenge what it means to be a 'parent' by providing opportunities for the formation of non-traditional familial units (New, 2006) produced through different patterns of social relationships, for example the processes of 'kinning' whereby the transnationally adopted child is made to be kin (Howell 2007). In contrast, others suggest it has led to new forms of essentialism (c.f. Franklin 1993). However, the conflation of reproductive with genetic technologies in this context is unhelpful, while reproductive technologies have weakened these categories; genetic technologies of diagnosis and risk assessment '*strengthen* the conventional categories of reproduction and biological relatedness' (Featherstone et al, 2006:6).

The principal focus of the field has been the examination of Euro-American kinship, however, diverse cultural practices exist around kinship (c.f. Holy, 1997). For example, evidence suggests that consanguineous marriage amongst British Pakistanis persists and is an increasingly preferred practice for a range of cultural reasons (Shaw, 2001). This in turn has implications for genetic risk and is associated with an increased incidence of a range of recessive conditions with these populations (Modell and Darr, 2002). However, a focus on consanguineous marriage as a problematic practice means that genetic risk and the associated personal and ethical issues are not seen in their wider social and cultural context (Shaw, 2009). Similarly, an important focus has been the examination of public health initiatives screening for genetic conditions associated with specific racial and ethnic populations, particularly haemoglobinopathies such as Thalassaemia and Sickle Cell Disease (Atkin et al, 2008). This includes studies of screening initiatives aimed at Tay-Sachs affecting Jewish populations (Raz, 2008), sickle cell disease affecting African Americans and cystic fibrosis affecting white Euro-American populations

(Wailoo and Pemberton, 2006). Nevertheless, understanding the practical consequences and the ethical implications of these screening practices for individuals and families have yet to be sufficiently explored (Raz, 2010).

In addition, religious beliefs have a complex bearing on the management of genetic risk and the discourse around decision-making in the context of genetic knowledge, for example predictive testing (Shaw 2000), beliefs about causation (Rozario and Gilliat Ray, 2007) and acceptance of a genetic condition in the context of being a ‘good Muslim’, with Allah the ultimate decision-maker (Rozario, 2008). In the context of the practice of arranged marriage, British Pakistani families face the additional concern of protecting the reputation of the family as healthy or ‘pure’, particularly where children’s prospects may be damaged by such disclosures of genetic risk (Rozario and Gilliat Ray, 2007; Shaw and Hurst, 2009), thus disclosure practices within Bangladeshi communities must be understood in the context of marriage as an essential rite of passage (Rozario 1992). However, beliefs about genetics, inheritance and causality amongst British Pakistani patients attending clinical genetics services reflect a range of everyday beliefs and theories about genetic risk (Shaw and Hurst, 2008; Rozario and Gilliat Ray, 2007) and approaches to the disclosure of genetic risk information (Rozario and Gilliat Ray, 2007; Shaw and Hurst, 2009) that closely reflect those found amongst White British patients and their families (Featherstone et al 2006).

Studies exploring genetic information have predominantly examined individual responses to and deliberations concerning their management of risk, with only a few studies (Sobel and Cowan, 2000; Featherstone et al, 2006; Gregory et al, 2007; Geelen et al, 2011) examining genetic risk

and disclosure in the broader context of kin networks. The trajectories of the gene are embedded in the social construction of generations. While generations have the appearance of naturally, biologically defined phenomena, they are equally social in character. They are defined and constructed through interactional work within the family, through acts of collective memory, and familial acts of demarcation. Generations become visible at key turning-points in the collective trajectories and processes of status-passage within networks of kin. The major *rites de passage* define them: new births, marriages and deaths help to shape the interpersonal accomplishment of generations. Less dramatic turning-points may also be occasions when generational distinctions and boundaries become salient.

Practical kinship: Contours of relevance, zones of responsibility. The social relations, and therefore the channels that are the conduits of genetic knowledge, are defined by *contours of relevance* and *zones of responsibility*. The contours of relevance are shaped by family members' *active* mobilisation of relations among their kindred, we do not merely document our family tree, rather we actively construct narratives that create our family and ancestry, drawing on individual and collective strategies that include or exclude particular individuals or groups of kin (Zerubavel, 2011), what has been referred to as the 'genealogical imagination' (Tyler, 2005). Contours of relevance thus reflect social proximity (importantly this does not necessarily reflect biological or genetic proximity). Geographical proximity may be a factor in shaping contours, which in turn reflect the frequency and density of everyday encounters. The social density of kinship linkages – frequency and intimacy – shapes the contours of relevance within the kindred.

Zones of responsibility are defined by understandings of who may be responsible or accountable within a social network – within ‘the family’ – for particular classes of action and knowledge. Genetic knowledge generates new forms of obligations (Novas and Rose 2000; Rose 2006) and a large body of literature has focussed on the ways in which people manage the burden of responsibility (Hallowell 1999; Hallowell et al, 2003; Arribas-Ayllon, Sarangi, & Clarke, 2008a and 2008b). Responsibility is predicated on judgments of *trust* and other moral evaluations, such as *competence* and *capacity*. Kinscapes change over time. There are individual and collective trajectories of shifts in moral status. Relationships themselves change over time, reflecting changes within the kindred (the passage of generations, status passages such as births and marriages). As kindreds change, so the contours of kinscapes are subject to reconfiguration.

Timescapes

These trajectories and generational configurations are embedded in collective *timescapes* (Adam 1990): the multiple and complex forms of time that are involved in any given social organisation or cultural domain. It is equivalent to a ‘landscape’, insofar as the latter encompasses all of the spatial arrangements of any given milieu. There are multiple frames of reference through which we apprehend and define time. Everyday life is unthinkable without a temporal dimension – or rather a multiple set of dimensions. Clock-time regulates much of our contemporary, modern social world. Based on a mixture of natural phenomena and arbitrary, culturally-defined divisions, such time has become well-nigh universal, in that the entire globe is subject to the same temporal ordering. Equally, we may recognise a naturally-driven temporality that underlies natural and biological ageing and decay, entropy in physical systems, evolutionary change and the like. It is, however, abundantly clear that the social world produces and is in turn regulated

by many other temporal frames, cycles and rhythms. Social scientists in various traditions have attempted to make sense of those temporal phenomena, and to incorporate temporal understanding into the analysis of social organisation. We outline some of the key contributions to those analytic traditions (cf Zerubavel 1981).

Time was central to one of the founding traditions of modern anthropology (James and Mills (2005). It can be traced back to the Durkheimian school, and in particular to the work of Hubert (1905/1999) and of van Gennep (1909/1960). Hubert's analysis of calendrical rituals, festivals and similar collective observances demonstrated how they endow social life with *rhythm*. They do not merely punctuate time, but endow it with cultural significance. This perspective is closely aligned to van Gennep's pioneering work on *rites de passage*, which provides a grammar for the temporal and ceremonial order. Leach (1961) stresses the cyclical, oscillating nature of time, as it moves between 'profane' and 'sacred' periods. Hubert, van Gennep and Leach together constitute a major tradition in the anthropological treatment of time. They encapsulate a distinctive approach to the temporal management of everyday life. As we shall see when we come to focus on genescapes, these ideas are highly illuminating in the context of families and communication.

The emphasis on biographies, life-histories and moral careers in much recent qualitative social research also brings a temporal focus to bear on everyday life. Biographies are not regulated solely by the passage of clock-time or by the strict calendrical process of biological ageing. Lives are constructed and understood in terms of biographical time. Key features include turning points and *epiphanies* (moments of revelation and identity transformation), status passages such as

transitions to adulthood, marriage, the birth of a child, or the death of a partner or parent, career contingencies, divorce or retirement from work. Biographies and biographically-based social research are therefore suffused with temporal phenomena, and everyday notions of a life-span and personal development are also predicated on general notions of time. Taken together, therefore, the various traditions of anthropological and sociological theory provide us with a rich sense of social time and the various timescapes that pervade everyday life. In combination they furnish ways of thinking about rhythms and cycles of ordinary life, the ceremonial marking of time's passing, the celebration of key stages in the lifecourse, and the significance of key ideas such as 'generation', 'childhood', 'adulthood', or 'maturity'.

Domestic cycles and generations. Timescapes and temporal cycles are central to domestic relationships and family relations. Domestic groups have 'developmental cycles' as generations progress, children are born and grow up, new marital alliances are entered into, members die, marriages are dissolved etc. etc. These temporal cycles are part of the rhythms of domestic timescapes: family members locate themselves in relation to past and future generations, in relation to the emergence of new domestic groups (new families formed by marriage). These are not based exclusively on the elapse of chronological time – although this is a background feature- but reflect the social and cultural marking of time. These include personal and calendar rituals (anniversaries, birthdays, religious festivals) and celebrations of personal transformation (rites of passage, such as birth, marriage, death). In these observances, social time and chronological time intersect.

Within families the cycles of temporal change are marked by the existence of generations. 'Generations', like family and kinship, are simultaneously natural and social phenomena. They are, moreover, among the ways in which the passage of time is recognised within kinship and domestic groups. Generations are not naturally-given categories, however. Even in societies that have clearly-defined systems based on generation, such as East African age-grade societies, they are based on social conventions, and are not dependent simply on temporality and the 'natural' facts of procreation. East African societies have long had a distinctive system of male age-grades, whereby men are grouped into major generational divisions. In one of the most recent studies addressing this phenomenon, Peatrik (2005) stresses that while the system of age-grades provides an important structural feature of Meru society, the practical organisation of age-grades, and allocation to them, is equally a practical matter. These formally recognised generations are, therefore, simultaneously structural and practical arrangements. They are, however, significant markers of temporal, cyclical social time.

Generation is linked directly to everyday, practical notions of growth and development. The lifecourse and the cycle of generations shape, and are in turn shaped by, cultural assumptions and expectations. They include formal and informal ideas about 'childhood' (always a cultural construct, not a naturally given category), the responsibilities of 'adulthood' (equally dependent on cultural assumptions), older age and the like. Transitions between such stages are dependent on status-passages of various sorts; each stage of life carries with it responsibilities and presumptions of competence or incompetence, innocence and experience, productive activities and leisure. Notions of temporal progression therefore underlie patterns and expectations concerning communication within kindred, including the management of genetic information.

Petronio (2002) points out that ownership of private information, and the boundaries of information control are restricted for children, expand during adolescence, but diminish once more for the elderly. Her focus is what individuals can *keep private* themselves, rather than a consideration of what is *kept from* children, adolescents, parents, elders and so on. However, information and perceived competence are linked to social (and not merely chronological) age, and hence to membership of generation. Competence and coping are also linked to notions of maturity, 'readiness' and other practical concepts of biographical development. Petronio's general observations are a useful point of reference: reminding us that life-course and generation are significant in the shaping of contours of disclosure, and of the distribution of information within a social network.

In addition to individual life-cycles, there are equivalent cycles of change for family groups (or at least for households). For instance, as children grow up and marry/start partnerships they may leave the parental home and start a new household. If and when they have children of their own, then a new domestic grouping is created, with new affines and new networks to be managed. Likewise, key events such as the death of one or both parents, separation and divorce, step-parenthood etc all create junctures and transitions in the collective career of the domestic group.

Contemporary research on families and genetic conditions demonstrate the relevance of everyday notions of 'generation' and how they are embedded in constructions of past and present. For instance, family members invoke past generations to account for change in patterns of family relationships and modes of communication. These temporal constructions depend upon

contrastive rhetoric (Hargreaves 1984): the past is contrasted with the present – and sometimes a projected future – in order not simply to portray changing mores, but also to legitimise the present. In the course of such contrasts, a picture of changing *generations* is achieved.

Generations – parent, grandparent, children and one's self – are not simply reported on, but are themselves *constructed* as part of an explanatory or interpretative framework. Practices of disclosure are used to capture the very nature of kinship and the succession of generations themselves. The latter is, of course, profoundly true when families reconstruct the past in order to account for the origin of a genetic condition, or the route of its transmission. Past generations are inspected; everyday family pedigrees are invoked; medical histories are located within that sense of the past (Featherstone et al, 2006)

Within these temporal frameworks specific junctures and turning-points are located. They reflect the cultural marking of time and generation, not necessarily coterminous with biological time or chronological age. A critical juncture may be when children become sexually active, when they have partners, get married; for others, it may be an imagined projected moment or alignment of particular personal and practical factors that will provide the most appropriate time to tell.

Everyday social actors locate acts of communication and the sharing of information within a framework of ideas about time, generations, personal development and key junctures within those cycles. In other words, lay members create accounts of normal family life, which include characterisations of generations and the communication between them. Into those normal family patterns they identify typical turning-points and junctures, at which either new disclosure or enhanced disclosure is treated or will be treated as an issue. This latter projection is not

necessarily treated as a major ‘problem’, but rather as a further aspect of ‘normal’ family development and the progression of successive generations.

Turning-points, rites of passage and genetic communication. As we have seen, anthropological analyses of time are predicated on the *cycles* of personal and collective change that are a feature of virtually all social arrangements. These include the ritual observances of *rites of passage* or status passages, as they have also been called by sociologists. Rites of passage, marking the transition from one culturally defined stage of life to another, or from one social category to another, are among the classic, long-standing interests of social and cultural anthropology. They define the main turning-points in an individual biography or career; they may also define the collective, shared transitions of cohorts of social actors. The key events, and their social ceremonials, include birth, initiations, marriage, death and bereavement. They are marked by collective celebrations. Importantly, they do not merely remove the individual temporarily from ‘normal’ everyday life, subject him or her to special treatment, and then reintegrate the celebrants into a new normality; they may also rearrange others into new sets of relationships and statuses as a consequence of the status passage. So, for instance, a marriage not only defines new statuses for bride and groom, it also creates new relationships between affines (‘in-laws’) by contracting a new configuration of family alliance. Likewise, the birth of a child not only triggers the arrival of a new social person, it also redefines the status of the parents and reconfigures other members of the kindred (defining individuals as grandparents, aunts and uncles, cousins etc.). These markers of social time and of biographical development thus have major implications for the patterns of social relations. For families with genetic conditions, these junctures may precipitate major considerations of genetic information, the projection of genetic futures, and interpretations of genetic pasts.

The intervention of the genetics counsellor or medical practitioner is always a temporal one. The professional encounter and its associated activities are always predicated on reconstructions of the past, and projected futures, grounded in a present that is itself open to negotiation. As a number of authors have pointed out, the past is captured through a number of standardised procedures that make the past comprehensible, and bring it under the scrutiny of the professional gaze. Alexias (2008), for instance, argues that medical genetics reconstructs the past through its investigation and documentation of inheritance. It brings together the *social* past of the family and the *biological* past of inherited genetic material. The intersection of the medical history (past), diagnosis (present) and prognosis (future) is fundamental to any mode of medical discourse. It is, however, given greater salience in the context of medical genetics. The past history is not merely that of the individual patient. It is a shared past, defined by shared genetic inheritance between family members. The present always – potentially at least – implicates others beyond the patient or proband. The future extends well beyond the individual patient, as genetic risk and patterns of inheritance extend to offspring and to generations yet unborn.

Nukaga and Cambrosio (1997) have discussed the construction of medical pedigrees as the translation of families into standardised formats. So too have Parsons, Atkinson and Featherstone (2001), who have documented the clinical and laboratory work of reconstructing the generations and relationships of families into pedigrees from which genetic relations and transmissions may be inferred. There is a constant interplay between the information gained from laboratory studies on the one hand and family studies on the other. These are matters of representation: the forms of representation reflect historical practices of reconstructing the past (Bouquet 1996).

Surveillance, risk and genetic futures. The intervention of genetic services and risk assessment constructs a future in terms of carrier status, risk or susceptibility. Genetic futures go well beyond classical medical categories of prognosis. The very notion of 'risk' itself is predicated on future outcomes, both for the patient/proband, and for others, who at the moment of clinical intervention, may be invisible to the professional counsellor or clinician. It is this sense, therefore, that *time* reconstructs 'patienthood' itself. Risk always contains a temporal dimension. It projects past and present into futures that are contingent on possible behaviours and outcomes, such as reproductive decision-making. This is predicated on a clinical genetics service that sees the delivery of risk information providing individuals with the opportunity to make informed and responsible choices about managing their (and other family member's) risk, disclosure and future health (Armstrong et al., 1998; Richards, 1999; Sarangi and Clarke, 2002a, 2002b; Sarangi, et al., 2003).

The genetics clinic, is therefore, a point of surveillance of past, present and future. Such surveillance is not, however, confined to the clinical setting. The same temporal dimensions define the mutual gaze of 'lay' family members. Families can thus become sites in which members of different generations inspect one another (Featherstone et al 2006). Previous generations may be inspected in order to construct aetiological accounts of the origins and routes of inherited mutations or deletions. Equally, family members who have inherited a condition or a risk of developing a disease may inspect members of older generations in order to form an assessment of what might happen to them, the likely severity of their symptoms and the trajectory of the condition. This is one practical way in which individuals may use the past and

the present to make assessments of their own future. Importantly, amongst individuals and families of British Pakistani heritage attending a clinical genetics service, a remarkably similar range of everyday theories about inheritance were reported, with the additional identification of an emphasis given to inheritance via men or the male line (Shaw and Hurst, 2008). Families are ‘living laboratories’ through which genetic knowledge can be ‘evaluated and tested’ in the context of kin whose phenotypic resemblance and health status becomes actively mobilized to make sense of and to assess clinical risk information (Chiliback et al, 2011).

Equally, surveillance and prediction operate from older generations to younger. Children and young people are inspected in order to predict whether they are developing a condition, whether the genetic cause is ‘coming out’ in them. Resemblances to family members are used to try to make such assessments of future outcomes. Past and present appearances and health problems are used as key resources to predict the outcomes of genetic predispositions and to foresee the future of family members. These patterns of mutual surveillance follow lines of practical kinship and relatedness, and do not necessarily follow the biomedical definitions of inheritance patterns: for instance, all members of a younger generation may be inspected, irrespective of whether they are equally at risk of inheritance. Mutual inspection pieces together past and present in order to visualise the future. The family and the clinic are thus equally sites of temporal work.

Genescapes

Genescapes encompass the multiple constructions of the gene – biological and cultural – and inheritance. As has been demonstrated from many disciplinary and theoretical perspectives, genescapes entail complex patterns of interpretation (Featherstone, Atkinson and Bharadwaj

2003). Genescapes are simultaneously cultural and biological. Genescapes do not conform simply to the ‘facts’ of biological inheritance, rather the social distribution of knowledge about inheritance and genetic medical conditions is the defining characteristic of a genescape. However, this is not meant to imply that we seek to contrast biological facts with social or cultural epiphenomena; we do not privilege the biological phenomena of genetic science or genetic medicine. On the other hand, some such distinction is a necessary preliminary to our discussion of how the biological and the social are mutually implicated. We are fully conscious of the extent to which those biological phenomena are themselves socially constructed (cf. Featherstone et al, 2006).

Circuits and trajectories of the Gene. As kindred are shaped over time and through the active maintenance of practical social ties, so ‘the gene’, as a social object, travels differentially through the many possible pathways of communication. Genescapes therefore imply the *circuits of the gene*. What is conventionally described as ‘genetic risk information’, is dispersed and distributed across the genescape. As we have described elsewhere, genes are not distributed in terms of simple packets of ‘information’ that are transmitted in clinics and counseling sessions, and which individuals unproblematically receive to become ‘informed’ of their risk. On the contrary, as we have already indicated, there are processes of translation and interpretation that are brought to bear on genetic information. Background cultural assumptions about inheritance and local assumptions about one’s family and kin all interact with professional advice and information.

In addition, there can be no assumptions that in the everyday world family members ‘share’ information in an explicit fashion, if at all. It is more helpful to think in terms of fragmentary disclosure, partial disclosure, or even ‘family secrets’ (Zerubavel, 2006). In everyday cultural terms, they inhabit secrets, evasions, family conferences, tacit acknowledgment, and so on. The entirely ‘open’ family may be an ideal, but it is rarely reflected in our own research experience.

A genetic anomaly gives rise to at least two trajectories: the *trajectory of the gene* (over generations, across the boundaries of family and kin, and over the entire lifetime of the individual) and the *trajectory of the illness*. The characteristics of genetic conditions vary greatly in their mode of inheritance and their phenotypic presentation (e.g. time of onset, severity) and in the technologies of risk assessment that are available. So familial conditions that have high penetrance, for example autosomal dominant condition such as Myotonic Dystrophy or Huntington’s Disease will trigger something akin to a conventional illness narrative and biographical work, while that interpretative work is underpinned by the genetic narrative and biographical work that encompasses not merely the individual, but that of previous and succeeding generations. However, the experience of individuals and families who are at risk of developing an autosomal dominant condition may be very different to those affected by a relatively common and treatable genetic condition such as Familial Hypercholesterolemia which leads to an increased risk of coronary heart disease, where a ‘fuzzier’ concept of responsibility and disclosure has been identified. In this context, individual strategies or concerns focussed on children, but did not extend to wider kin or raise concerns about reproductive decision-making (Weiner 2011).

Furthermore, the unfolding of an individual's and family members' genetic status is a further, more extended and socially distributed trajectory, or collection of trajectories. While we know that genetic understanding is not uniformly shared among kin, where there is such sharing, narratives of past, present and future may be jointly constructed and distributed. As a consequence, the temporal dimensions of genetic knowledge are rendered potentially more complex than the narratives and interpretations of individual disease. Part of the process of working out the pattern of transmission is making sense of the past and identifying where the condition originated in the family. This is often achieved by naming an individual believed to be the first case and tracing the condition through to later generations.

The future assumes a particular salience in the biographical work of individuals and families with genetic conditions. There is nothing unique in this: prognosis is always a feature of medical work, lay and professional, and all serious medical conditions carry possible implications for the future. As Corbin and Strauss (1987) show, notions of present and future are interlinked in people's constructions of biographical possibility and bodily constraint. Genetic conditions invite particular emphasis on future possibilities, however, in that they always, in principle, contain within them futures – for the individual, for their offspring and for generations as yet not born. Futures implies 'the gene' is more extended socially and temporally than most other biographical futures of health, illness and the body.

Strategic interaction and awareness contexts. The dynamics of strategic interaction characterise the genescape. Strategic interaction implies the artful disclosure or withholding of information within an encounter or a relationship (Goffman 1969). Of course, there is an important sense in

which *all* social relations are strategic. The management of the self always implies an element of controlled disclosure, and equally implies the maintenance of secrecy about aspects of personal life. In certain cases, however, the management of awareness becomes especially salient in the configuration of relationships. In the context of genetic risk, disclosure involves a potential loss of control over personal risk information. It also carries implications for the strategic control and management of information about other family members. Genescapes are, therefore, marked by gaps and absences in the social distribution of shared knowledge. The deliberate avoidance of communication reflects the dynamics of family systems. So too does the less conscious, taken-for-granted avoidance of particular topics within the canon of family stories and shared, collective memory. The social organization of denial and of the inter-personal dynamics of blocking knowledge deserves great scrutiny (Zerubavel, 2006).

Importantly, denial and silence both involve an *active* avoidance of the ‘elephant in the room’, an everyday cultural metaphor that captures those issues everyone is aware of, but are unwilling to publicly acknowledge. Zerubavel suggests that there is ‘a strikingly similar manner in which couples, organizations, and even entire nations collectively deny the presence of ‘elephants’ in their midst’ (2006:14). His examination of the ‘phenomenon of undiscussability’ and the ways in which information is controlled suggests that whilst there are many formal overt power structures that block the access to and circulation of sensitive or taboo knowledge, the collaborative nature of conspiracies of silence is important. The social dynamics of co-denial are characterised by a collective endeavour of ‘don’t ask, don’t tell’, which involves more than one person, the ‘double wall’ of silence (Bar-On, 1989).

Relatedness among kin who actually or potentially share a harmful genetic constitution is one contingency that has major consequences for the strategic management of knowledge and information within a social network. As has been demonstrated repeatedly, kindred may be partitioned or have biased networks, in which lines of cleavage reflect distinctions of gender, generation, degrees of consanguinity, and more localised distinctions between individuals or branches of a given lineage. We need, therefore, to think in terms of a complex ecology of relatedness, within which circulate stories, suspicions, and disclosures. Some authors emphasize the ways in which genetic knowledge can strengthen ‘the ties of kinship’ (Finkler 2000), or the acute pressures faced by families affected by rare and untreatable neurological conditions (c.f. Sobel and Cowan 2000). However, kinship is a complex social landscape of frankness and reticence, sharing and secrecy, blame, recrimination and guilt. It is an ecology in which mutual support may co-exist with mutual surveillance, and disclosure may alternate with avoidance or secrecy.

As a consequence, we can discern distinctive *types* of genescapes. They parallel the dynamics of what Glaser and Strauss (1965) refer to as *awareness contexts*. That is, the formal properties of small-scale, face-to-face social networks in which knowledge is differentially distributed, shared or withheld. Glaser and Strauss developed the idea originally in relation to dying patients in hospital. They generated a number of ideal types to capture characteristic patterns of communication, as between dying patients, medical/nursing staff and patients’ relatives. Under conditions of ‘open awareness’, all parties are equally aware of the patient’s terminal condition; under conditions of ‘closed awareness’, the patient is kept in ignorance; under conditions of ‘suspicion awareness’ patients and/or families may (as the label suggests) come to suspect that

the prognosis is bad; ‘pretence awareness’ exists when the parties each know that the illness is terminal, but keep up appearances to the contrary (Clearly this simple typology permits finer differences and graduations). Awareness, including genetic awareness, is determined as much by silence as by talk, by avoidance as much as by communication.

Genescapes change with the passage of time. Families are periodically transformed and reconfigured. Practical kinship- significant social junctures and events, such as status-passages and ceremonials, provide junctures at which the ecology of information may be subject to perturbation, and when actors may re-evaluate their strategy, and hence the distribution of awareness may be transformed. Within the clinic, disclosure is often treated as a discrete event and this is reflected within the literature in a focus on individual responses to risk information, often at one time point, yet within the context of family and generation, disclosure is always partial and is better understood as awareness or becoming aware (Geelen et al, 2011).

Genescapes therefore need to be mapped against timescapes and kinscapes. This means understanding how genescapes are transformed over time, and how family members’ sense of their own and others’ personal trajectories are reflected in their patterns of communication about their genetic heritage, genetic risks and genetic futures.

Discussion

We have outlined a general model of kinship and the management of genetic information. We have done so in order to do justice to the complexity of practical kinship, as reflected in the general notion of kinscapes. Kinscapes reflect the co-constitution of the biological and the social. The cultural categories of relatedness and the biological categories of genetics are dialectically

related through their everyday management and acts of recognition. Kinscapes are dynamic. Not only are they constituted through acts of relationships, they are subject to continuous reconfiguration. The temporal cycles of kindred, and the processes of generation and maturation, ensure that the contours of kinscapes are always in flux. Genetic knowledge and decision-making are mapped onto these processes and configurations. Key temporal junctures may trigger particular kinds of action and decisions to disclose and share genetically-relevant information. In the process, such actions themselves reconfigure the zones of responsibility within the kinscape. Kindred thus constitute continually evolving awareness contexts, with mutual awareness of genetic relatedness and its implications differentially distributed across them.

Genetic knowledge is embedded in pre-existing family relationships (Featherstone et al 2006; Gelen 2011) and in the everyday frameworks of family life (Chiliback et al 2011). Beyond case-studies based on specific genetic conditions, sociologists of health and illness, and sociologists of the family, need generic analyses of the intersection of genetic risk and family life. The significance of this will only increase as the range of physical, mental health and behavioural features that are identified as having a genetic component continues to expand. The world of genetic medicine, and the everyday lifeworlds of families are complex. They are traversed by the new knowledge of genetic medicine and the cultural knowledge of family, kinship and inheritance.

The dominant focus has been the examination of the retrospective experiences and deliberations of individuals who attend specialist clinical services and within the context of a clinical model of disclosure of risk information via discrete packages of information. Social scientists, clinical

geneticists and bioethicists need to extend their gaze by recognising and remaining faithful to the indigenous complexities of the natural and cultural domains and the importance of examining these phenomena as social processes rather than decision-making moments. The world of genetic medicine, and the everyday lifeworlds of the families they work with, is correspondingly complex. They are traversed by the new knowledge of genetic medicine and the cultural knowledge of family, kinship and inheritance.

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