
Kinscapes, timescapes and genescapes: families living with genetic risk

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Abstract This article synthesises recent research examining how families live with genetic risk and the processes of genetic decision-making and disclosure among family members who have been 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 of genetic risk in families. The article is structured around three interrelated 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 and 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.

Keywords: kinship, genetic, time, risk

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 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.

Kinscapes: Family and generation

The family and the lineage are conduits of economic, social and cultural capital (Bertaux and Thompson 2005). The notion of kinscapes 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 in 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 interactional work and the management of transmissions and interruptions. In the context of genetic risk, 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 Europe and the USA (for example, 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 (Bonaccorso 2007, Edwards 2000, Edwards and Salazar 2008).

The development of assistive reproductive technologies has led to an examination of the commercialisation of parenthood (Goodwin 1992), the position of gay men and lesbian women in relation to donated gametes (Haimes and Weiner 2000, Levine 2008) and the identity of those conceived using these practices (Haimes 1998). Some argue that the increasing availability of these technologies gives 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 (see Franklin 1993). However, the conflation of assistive reproductive technologies with the genetic technologies of diagnosis and risk assessment in this context is unhelpful. While the literature suggests that reproductive technologies have weakened these categories; in contrast, genetic technologies involved in diagnosis and risk assessment of inherited conditions '*strengthen* the conventional categories of reproduction and biological relatedness' (Featherstone *et al.* 2006: 6, emphasis in original).

The principal focus of the field has been the examination of Euro-American kinship; however, diverse cultural practices exist around kinship (see Holy 1997). For example, evidence suggests that consanguineous marriage among 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 in these groups (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 groups, 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 groups (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 as 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, understandings about genetics, inheritance and causality among British Pakistani patients attending clinical genetics services reflect the broad range of more 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 about their management of risk, with only a few studies (Featherstone *et al.* 2006, Gregory *et al.* 2007, Geelen *et al.* 2011, Sobel and Cowan, 2000) 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 in 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 of 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, 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: 477). 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 in 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 focused on the ways in which people manage the burden of responsibility (Arribas-Ayllon *et al.* 2008a, 2008b, Hallowell 1999, Hallowell *et al.* 2003). 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 and 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. Everyday life is unthinkable without multiple temporal dimensions. Clock-time regulates much of our contemporary, modern social world. Equally, there is a naturally driven temporality that underlies natural and biological ageing and decay, entropy and evolutionary change. 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 (see 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 (1999) and of van Gennep (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 life-course, 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 the generations progress, such as when children are born and grow up, new marital alliances are entered into, members die and marriages are dissolved. These temporal cycles are part of the rhythms of domestic timescapes:

family members locate themselves in relation to past and future generations and 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 and religious festivals) and celebrations of personal transformation (rites of passage, such as birth, marriage and 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, their organisation and allocation is also 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 life-course 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 in 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 or 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 and so on all create junctures and transitions in the collective career of the domestic group.

Contemporary research on families and genetic conditions demonstrates the relevance of everyday notions of a generation and how they are embedded in constructions of past and present. For instance, family members invoke past generations to account for a 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 that is 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 in those cycles. In other words, members create accounts of normal family life that include characterisations of generations and the communication between them. Into those normal family patterns they identify typical turning-points and junctures, at which either a new disclosure or an 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, longstanding 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 individuals temporarily from normal everyday life, subject them 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 the 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 in terms such as grandparents, aunts and uncles and cousins). 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 *et al.* (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 or 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 the past and present into futures that are contingent on possible behaviour 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, among 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 mobilised to make sense of and to assess clinical risk information (Chiliback *et al.* 2011: 1771).

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 the past and the 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 *et al.* 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 genscape. 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 (see 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 genscape. As we have described elsewhere, genes are not distributed in terms of simple packets of information that are transmitted in clinics and counselling 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, families 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 (for example, 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 conditions 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 previous and succeeding generations as well. 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 focused on children but did not extend to wider kin or raise concerns about reproductive decision-making (Weiner 2011).

Moreover, the unfolding of the genetic status of an individual and of family members 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 families do discuss their genetic risk, 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 an 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 a 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. The future implies that the gene is socially and temporally more extended 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 one's 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 memories. The social organisation 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 while 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 in a social network. As has been repeatedly demonstrated, kindred may be partitioned or have biased networks in which lines of cleavage reflect distinctions of gender, generation, degrees of consanguinity, together with 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 stories, suspicions, and disclosures circulate. Some authors emphasise 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 (see 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 coexist 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. These are 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 and 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 (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. In the clinic disclosure is often treated as a discrete event and this is reflected in 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 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. Timescapes, the temporal cycles of kindred and the processes of generation and maturation ensure that the contours of kinscapes are always in flux. The genescapes of 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 turn, 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.

The dominant focus of the field has been the examination of the retrospective experiences and deliberations of individuals attending specialist clinical services, often for a restricted range of single gene familial conditions where the genetic risk is known and genetic testing is available. Sociologists of health and illness, and of the family, must move beyond these case studies of specific genetic conditions to provide 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 field of genetics and genomics is developing rapidly into examining the multifactorial and polygenic interaction of genetic and non-genetic environmental factors for a wide spectrum of common diseases. Understanding these complex disorders poses greater challenges to biomedical science but, with the emergence of personal genomics, direct-to-consumer testing and the marketing of susceptibility testing for an increasing array of conditions, also to society. It is therefore timely and important for social scientists to be in a position to examine personal and professional responses to these new challenges, the role of stigma and the personal consequences of the practices of medical classification and the assessment, not only of genetic risk, but complex genetic susceptibility.

The interplays between scientific research, medical practice, mass media reportage and everyday understandings are always complex: scientific knowledge is always received and interpreted against a backcloth of rich and varied and adaptable repertoires of everyday culture. However, reductionism of various sorts still haunts contemporary discourse about genetics and post-genomic science, with many authors too readily exaggerating its impacts. While there is clearly potential for genetic science to transform, this cannot be read from a body of work that has focused on extreme cases. We need the corrective of empirical research to balance claims that these technologies are transforming the social categories of family, kinship and personhood. Our work and that of others show how genetic knowledge becomes integrated in the context and style of pre-existing family relationships (Featherstone *et al.* 2006; Geelen *et al.* 2011), and are embedded within the everyday frameworks of family life (Chiliback, Lock, and Sehdev 2011). Everyday decision-making takes priority, suggesting that family life continues as one living with disease rather than one that has been transformed by risk.

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 genetic phenomena as social processes rather than decision-making moments. The world of genetic medicine, and the everyday life-worlds of the families they work with, are equally complex. They are traversed by the new knowledge of genetic medicine and the cultural knowledge of family, kinship and inheritance. We have tried to remain faithful to that complexity.

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Acknowledgements

Our research was made possible by a research grant from the Wellcome Trust, whose financial support we gratefully acknowledge. We would also like to thank the families and our clinical colleagues who have taken part in our research. We are also grateful to the referees for their comments, which have strengthened this paper. In addition, the support of the Economic and Social Research Council (ESRC) is gratefully acknowledged. The work was part of the programme of the ESRC Research Centre for Economic and Social Aspects of Genomics.

Note

- 1 Works consulted in the current review are Armstrong, *et al.* (1998), Boddington and Gregory (2008), Claes *et al.* (2002), Clarke *et al.* (2005), Cox and McKellin (1999), D'Agincourt-Canning (2001), Featherstone *et al.* (2006), Finkler (2000), Forrest *et al.* (2003), Gaff *et al.* (2005, 2007), Green *et al.* (1997), Gregory *et al.* (2007), Hallowell (1999), Ormond *et al.* (2002), Peterson *et al.* (2003) and Richards (1996).

References

- Adam, B. (1990) *Time and Social Theory*. Cambridge: Polity.
- Alexias, G. (2008) Medical discourse and time: authoritative reconstruction of present, future and past, *Social Theory and Health*, 6, 1, 167–83.
- Armstrong, D., Michie, S. and Marteau, T. (1998) Revealed identity: a study of the process of genetic counselling, *Social Science & Medicine*, 47, 11, 1653–8.
- Arribas-Ayllon, M., Sarangi, S. and Clarke, A. (2008a) Managing self-responsibility through other-oriented blame: family accounts of genetic testing, *Social Science & Medicine*, 66, 7, 1521–32.
- Arribas-Ayllon, M., Sarangi, S. and Clarke, A. (2008b) The micropolitics of responsibility vis-à-vis autonomy: parental accounts of childhood genetic testing and (non)disclosure, *Sociology of Health & Illness*, 30, 2, 255–71.
- Atkin, K., Ahmed, S., Hewison, J. and Green, J. (2008) Decision making and ante-natal screening for sickle cell and thalassaemia disorders: to what extent do faith and religious identity mediate choice? *Current Sociology*, 56, 1, 77–98.
- Bar-On, D. (1989) *Legacy of Silence: Encounters with Children of the Third Reich*. Cambridge: Harvard University Press.
- Bertaux, D. and Thompson, P. (eds) (2005) *Between Generations: Family Models, Myths and Memories*. New Brunswick: Transaction.
- Boddington, P. and Gregory, M. (2008) Communicating genetic information in the family: enriching the debate through the notion of integrity, *Medicine, Health Care and Philosophy*, 11, 4, 445–54.
- Bonaccorso, M. (2007) *Conceiving Kinship: Procreation, Family and Assisted Conception in South Europe*. Oxford: Berghahn.
- Bouquet, M. (1996) Family trees and their affinities: the visual imperative of the genealogical diagram, *Journal of the Royal Anthropological Institute*, 2, 1, 43–66.
- Carsten, J. (2004) *After Kinship*. Cambridge: Cambridge University Press.

- Carsten, J. (2000) Introduction: cultures of relatedness. In Carsten, J. (ed.) *Cultures of Relatedness: New Approaches to the Study of Kinship*. Cambridge: Cambridge University Press.
- Chiliback, G., Lock, M. and Sehdev, M. (2011) Postgenomics, uncertain futures, and the familiarization of susceptibility genes, *Social Science & Medicine*, 72, 11, 1768–75.
- Claes, E., Evers-Kiebooms, G., Boogaerts, A., Decruyenaere, M. *et al.* (2002) Communication with close and distant relatives in the context of genetic testing for hereditary breast and ovarian cancer in cancer patients, *American Journal of Medical Genetics Part A*, 116, 1, 11–19.
- Clarke, A., Richards, M., Kerzin-Storarr, L., Halliday, J. *et al.* (2005) Genetic professionals' reports of nondisclosure of genetic risk information within families, *European Journal of Human Genetics*, 13, 5, 556–62.
- Corbin, J. and Strauss, A.L. (1987) Accompaniments of chronic illness: changes in body, self, biography, and biographical time. In Roth, J. and Conrad, P. (eds) *Research in the Sociology of Health Care*, Vol. 6, Greenwich: JAI Press.
- Cox, S. and McKellin, W. (1999) 'There's this thing in our family': predictive testing and the social construction of risk for Huntington disease, *Sociology of Health & Illness*, 21, 5, 622–46.
- D'Agincourt-Canning, L. (2001) Experiences of genetic risk: disclosure and the gendering of responsibility, *Bioethics*, 15, 3, 231–47.
- Edwards, J. (2000) *Born and bred: idioms of kinship and new reproductive technologies in England*. Oxford: Oxford University Press.
- Edwards, J. and Salazar, C. (eds) (2008) *European kinship in the age of biotechnology*. Oxford: Berg-hahn Books.
- Featherstone, K., Atkinson, P. and Bharadwaj, A. (2003) Inheritance in society. In Cooper, D. (ed.) *Nature Encyclopaedia of the Human Genome*, Vol. 3. London: Nature Publishing Group.
- Featherstone, K., Atkinson, P., Bharadwaj, A. and Clarke, A. (2006) *Risky Relations: Family, Kinship and the New Genetics*. Oxford: Berg.
- Finkler, K. (2000) *Experiencing the New Genetics: Family and Kinship on the Medical Frontier*. Philadelphia: University of Pennsylvania Press.
- Forrest, K., Simpson, S.A., Wilson, B.J., van Teijlingen, E.R. *et al.* (2003) To tell or not to tell: barriers and facilitators in family communication about genetic risk, *Clinical Genetics*, 64, 4, 317–26.
- Franklin, S. (1993) Essentialism, which essentialism? Some implications of reproductive and genetic techno-science. In De Cecco, J.P. and Elia, J.P. (eds) *If You Seduce a Straight Person, Can You Make Them Gay?: Issues in Biological Essentialism Versus Social Constructionism in Gay and Lesbian Identities*. London: Routledge.
- Franklin, S. (1997) *Embodied Progress: A Cultural Account of Assisted Conception*. London: Routledge.
- Franklin, S. (2003) Rethinking nature/culture: anthropology and the new genetics, *Anthropological Theory*, 3, 1, 65–86.
- Gaff, C.L. and Bylund, C.L. (2010) *Family Communication about Genetics: Theory and Practice*. Oxford: Oxford University Press.
- Gaff, C.L., Collins, V., Symes, T. and Halliday, J. (2005) *Facilitating family communication about predictive genetic testing: probands' perceptions*, *Journal of Genetic Counseling*, 14, 2, 133–40.
- Gaff, C.L., Clarke, A.J., Atkinson, P., Sivell, S. *et al.* (2007) Process and outcome in communication of genetic information within families: a systematic review, *European Journal of Human Genetics*, 15, 10, 999–1011.
- Geelen, E., Van Hoyweghen, I. and Horstman, K. (2011) Making genetics not so important: family work in dealing with familial hypertrophic cardiomyopathy, *Social Science & Medicine*, 72, 11, 1752–9.
- Glaser, B. and Strauss, A.L. (1965) *Awareness of Dying*. Chicago: Aldine.
- Goffman, E. (1969) *Strategic Interaction*. Philadelphia: University of Pennsylvania Press.
- Goodwin, A. (1992) Determination of legal parentage in egg donation, embryo transplantation, and gestational surrogacy arrangements. *Family Law Quarterly*, 26, 3, 275–9.
- Green, J., Richards, M., Murton, F., Statham, H. *et al.* (1997) Family communication and genetic counseling: the case of hereditary breast and ovarian cancer, *Journal of Genetic Counseling*, 6, 1, 45–60.
- Gregory, M., Boddington, P., Dimond, R., Atkinson, P. *et al.* (2007) Communicating about haemophilia: the importance of context and of experience, *Haemophilia*, 13, 2, 189–98.

- Haimes, E. (1998) The making of 'the DI Child': changing representations of people conceived through donor insemination. In Daniels, K. and Haimes, E. (eds) *Donor Insemination: International Social Science Perspectives*. Cambridge: Cambridge University Press.
- Haimes, E. and Weiner, K. (2000) 'Everybody's got a dad' issues for lesbian families in the management of donor insemination. *Sociology of Health & Illness*, 22, 4, 477–99.
- Hallowell, N. (1999) Doing the right thing: genetic risk and responsibility, *Sociology of Health & Illness*, 21, 5, 597–621.
- Hallowell, N., Foster, C., Eeles, R., Ardern-Jones, A. *et al.* (2003) Balancing autonomy and responsibility: the ethics of generating and disclosing genetic information, *Journal of Medical Ethics*, 29, 2, 74–83.
- Hargreaves, A. (1984) Contrastive rhetoric and extremist talk. In Hargreaves, A. and Woods, P. (eds) *Classrooms and Staffrooms*. Milton Keynes: Open University Press.
- Holy, L. (1997) *Anthropological Perspectives on Kinship*. Michigan: University of Michigan Press.
- Howell, S. (2007) *The Kinning of Foreigners: Transnational Adoption in a Global Perspective*. Oxford: Berghahn Books.
- Hubert, H. (1999 [1905]) *Essay on time: A Brief Study of the Representation of Time in Religion and Magic*, trans. R. Parkin and J. Redding. Oxford: Berghahn.
- Inhorn, M.C. and Birenbaum-Carmeli, D. (2008) Assisted reproductive technologies and culture change, *Annual Review of Anthropology*, 37, 177–96.
- Inowlocki, L. (2005) Grandmothers, mothers, and daughters. In Bertaux, D. and Thompson, P. (eds) *Between Generations: Family Models, Myths and Memories*. New Brunswick: Transaction.
- James, W. and Mills, D. (2005) Introduction: from representation to action in the flow of time. In James, W. and Mills, D. (eds) *The Qualities of Time: Anthropological Approaches*. Oxford: Berg.
- Leach, E.R. (1961) *Rethinking Anthropology*, London: Athlone.
- Levine, N.E. (2008) Alternative marriage, and reproduction kinship, *Annual Review of Anthropology*, 37, 375–89.
- Modell, B. and Darr, A. (2002) Genetic counselling and customary consanguineous marriage, *Nature Reviews, Genetics*, 3, 3, 225–9.
- New, J.G. (2006) 'Aren't you lucky you have two mamas?': redefining parenthood in light of evolving reproductive technologies and social change. *Chicago-Kent Law Review*, 81, 2, 773.
- Novas, C. and Rose, N. (2000) Genetic risk and the birth of the somatic individual, *Economy and Society*, 29, 4, 485–513.
- Nukaga, Y. and Cambrosio, A. (1997) Medical pedigrees and the visual production of family disease in Canadian and Japanese genetic counselling practice. In Elston, M.A. (ed.) *The Sociology of Medical Science and Technology*. Oxford: Blackwell.
- Ormond, K.E., Mills, P.L., Lester, L.A. and Ross, L.F. (2002) Effect of family history on disclosure patterns of cystic fibrosis carrier status, *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, 119, 1, 70–77.
- Parsons, E., Atkinson, P. and Featherstone, K. (2001) Professional constructions of family and kinship in medical genetics, *New Genetics and Society*, 20, 1, 5–24.
- Peatrik, A.M. (2005) Old system, new conflicts: age, generation and discord among the Meru, Kenya. In James, W. and Mills, D. (eds) *The Qualities of Time: Anthropological Approaches*. Oxford: Berg.
- Peterson, S.K., Watts, B.G., Koehly, L.M., Vernon, S.W. *et al.* (2003) How families communicate about HNPCC genetic testing: findings from a qualitative study, *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, 119, 1, 78–86.
- Petronio, S. (2002) *Boundaries of Privacy: Dialectics of Disclosure*. Albany: State University of New York Press.
- Raz, A.E. (2008) Carrier matching and collective socialization in community genetics: Dor Yeshorim and the reinforcement of stigma, *Social Science & Medicine*, 67, 9, 1361–9.
- Raz, A.E. (2010) Commentary: a sociologist's view on community genetics, *Journal of Community Genetics*, 1, 1, 3–10.
- Richards, M. (1996) Families, kinship and genetics. In Marteau, T. and Richards, M (eds) *The Troubled Helix: Social and Psychological Implications of the New Human Genetics*. Cambridge: Cambridge University Press.

- Richards, M.P.M. (1999) Genetic counselling for those with a family history of breast or ovarian cancer: current practice and ethical issues, *Acta Oncologica*, 38, 5, 559–65.
- Rose, N. (2006) *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century*. Princeton: Princeton University Press.
- Rozario, S. (1992) *Purity and Communal Boundaries: Women and Social Change in a Bangladeshi Village*. London: Zed.
- Rozario, S. (2008) Allah is the scientist of the scientists: modern medicine and religious healing among British Bangladeshis. Working paper Series no. 101. Asia Research Institute. Available at doi <http://dx.doi.org/10.2139/ssrn.1316756> (accessed 18 December 2012).
- Rozario, S. and Gilliat-Ray, S. (2007) Genetics, religion and identity: a study of British Bangladeshis (2004–7). Working paper series no. 93. Cardiff: School of Social Sciences, Cardiff University.
- Saranghi, S. and Clarke, A. (2002a) Zones of expertise and the management of uncertainty in genetics risk communication, *Research on Language and Social Interaction*, 35, 2, 139–71.
- Saranghi, S. and Clarke, A. (2002b) Constructing an account by contrast in counselling for childhood genetic testing, *Social Science & Medicine*, 54, 2, 295–308.
- Saranghi, S., Clarke, A., Bennert, K. and Howell, L. (2003) Categorisation practices across professional boundaries: some analytic insights from genetic counselling. In Saranghi, S. and van Leeuwen, T. (eds) *Applied Linguistics and Communities of Practice*. London: Continuum.
- Shaw, A. (2000) *Kinship And Continuity: Pakistani Families in Britain*. London: Routledge/Harwood.
- Shaw, A. (2001) Kinship, cultural preference and immigration: consanguineous marriage among British Pakistanis, *Journal of the Royal Anthropological Institute*, 7, 2, 315–34.
- Shaw, A. (2009) *Negotiating Risk: British Pakistani Experiences of Genetics*. Oxford: Berghahn.
- Shaw, A. and Hurst, J.A. (2008) ‘What is this genetics, anyway?’ Understandings of genetics, illness causality and inheritance among British Pakistani users of genetic services, *Journal of Genetic Counseling*, 17, 4, 373–83.
- Shaw, A. and Hurst, J.A. (2009) ‘I don’t see any point in telling them’: attitudes to sharing genetic information in the family and carrier testing of relatives among British Pakistani adults referred to a genetics clinic, *Ethnicity & Health*, 14, 2, 205–24.
- Sobel, S. and Cowan, D.B. (2000) Impact of genetic testing for Huntington disease on the family system, *American Journal of Medical Genetics*, 90, 1, 49–59.
- Strathern, M. (1992a) *Reproducing the Future: Essays on Anthropology, Kinship and the New Reproductive Technologies*. Manchester: Manchester University Press.
- Strathern, M. (1992b) *After Nature: English Kinship in the Late Twentieth Century*. Cambridge: Cambridge University Press.
- Strathern, M. (2005) *Kinship, Law and the Unexpected: Relatives Are Always A Surprise*. Cambridge: Cambridge University Press.
- Thompson, P. (2005) Family myth, models, and denials in the shaping of individual life paths. In Bertaux, D. and Thompson, P. (eds) *Between Generations: Family Models, Myths and Memories*. New Brunswick: Transaction.
- Tyler, K. (2005) The genealogical imagination: the inheritance of interracial identities, *Sociological Review*, 53, 3, 476–94.
- Van Gennep, A. (1960 [1909]) *The Rites of Passage*. London: Routledge and Kegan Paul.
- Wailoo, K. and Pemberton, S (2006) *The Troubled Dream of Genetic Medicine*. Baltimore: Johns Hopkins University Press.
- Weiner, K. (2011) Exploring genetic responsibility for the self, family and kin in the case of hereditary raised cholesterol, *Social Science and Medicine*, 72, 11, 1760–7.
- Zerubavel, E. (1981) *Hidden Rhythms: Schedules and Calendars in Social Life*. Chicago: University of Chicago Press.
- Zerubavel, E. (2006) *The Elephant in the Room: Silence and Denial in Everyday Life*. Oxford: Oxford University Press.
- Zerubavel, E. (2011) *Ancestors and Relatives: Genealogy, Identity, and Community*. Oxford: Oxford University Press.