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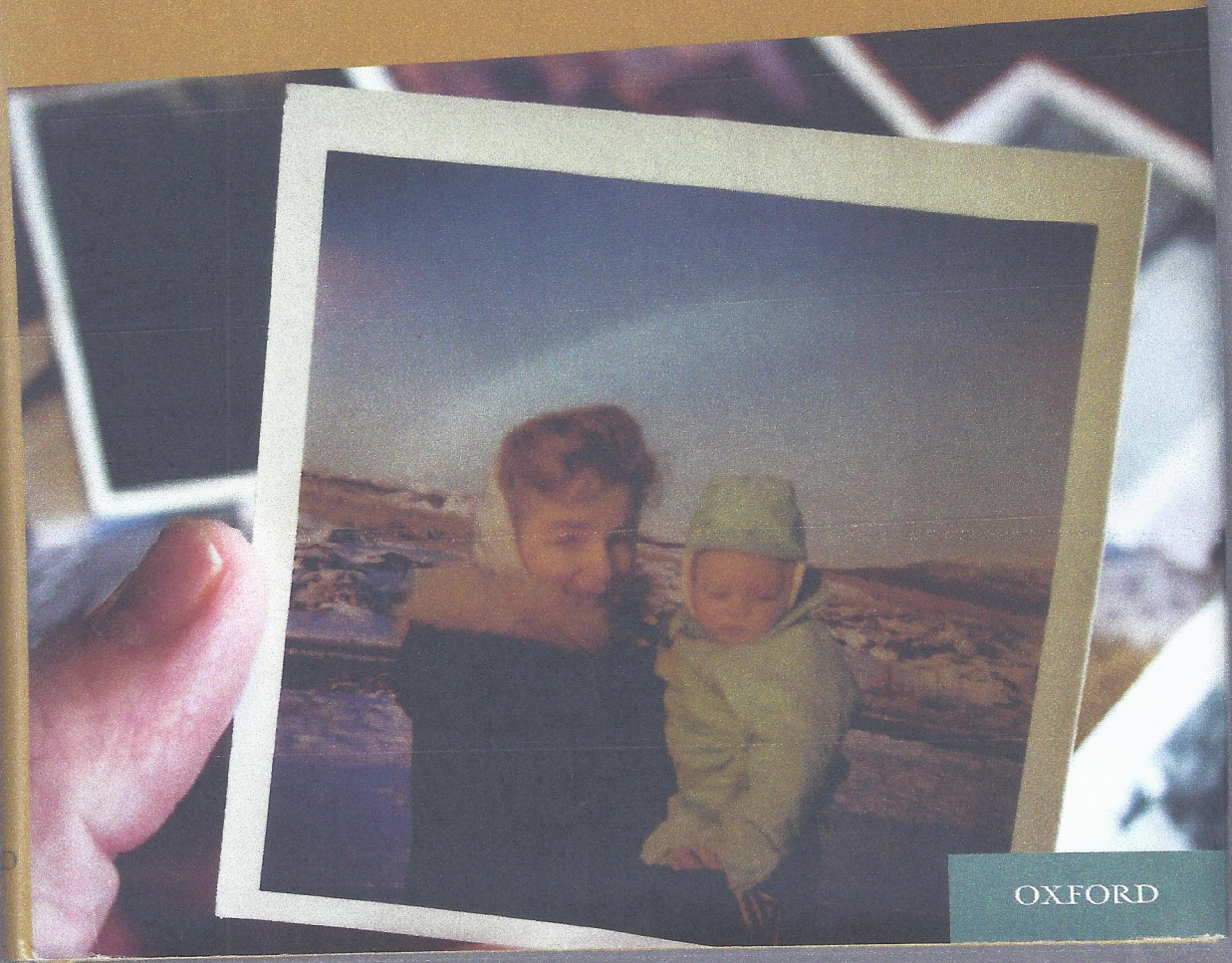
Family Communication About Genetics

Theory and Practice



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TIMESCAPES

Maggie Gregory, Anna Middleton, & Paul Atkinson

The implications of genetic information reverberate throughout a person's life cycle and over generations. A theoretical perspective on time offers a novel dimension for health-care practitioners to consider as they work with individuals or families adjusting to and communicating about a genetic condition.

Time pervades human life, but it is usually taken for granted. If you look around any of the main rooms in your home or workplace, it is almost certain that you will see some reminder of the importance of time in the organization of your life. Clocks, calendars, wall planners, and the small icon on your computer screen all map the hours of the day, week, or month. Time is central to the way that humans organize and plan the way that they live and work. It is also central to the concept of inheritance and families' experiences of and communication about genetics. In the course of this chapter, we use time as an organizing theme, drawing on theory that conceptualizes time within a social context. Consideration of relevant time theory offers a new dimension to understanding how genetic risk information is incorporated into the lives of individuals. It can also shed light on the process of disclosure of genetic risk information in a family.

Timescapes in our title derives from the work of the sociologist Barbara Adam [1–3]. She uses the term to encompass the multiple and complex forms of time that are involved in any given social organization. The term could be considered equivalent to a "landscape," although this obviously

has the addition of spatial arrangements. In this chapter, we expand on the complexities of time and introduce some key ideas from Adam. We show how aspects of time pervade the genetic counseling process itself, drawing on examples of illustrative cases. We parallel our discussion of timescapes with a commentary on *genescapes*. By that we mean not just the biological distribution of genes among a family but also the social distribution of knowledge, beliefs, and actions relating to inheritance and genetics. Timescapes and genescapes together incorporate time, biology, and social perspectives simultaneously.

TIME AND SOCIOLOGICAL THEORY

Sociological theory distinguishes between four different aspects of time. *Time* itself measures the passage of time in seconds, hours, days, years, lifetimes, and eras; *temporality* is concerned with the process of change, of the irreversibility of what has taken place and the knowledge that life as we know it is impermanent; *timing* relates to the synchronization of events and actions (an important part of social interactions); and *tempo* relates to the speed and pace of activity. Further development of these elements includes time sequences (e.g., cause and effect); time extensions (duration of activity, continuity, time horizons, and the past, present, and future); and time patterns (rhythms, cycles, and periodicity) [1]. Thus, multiple facets of time intersect in daily life. An individual is able to hold several notions of time simultaneously in his or her mind—the present embracing the past and the future, the status quo being changed by new information, and so on. For instance, in consultations involving genetics, both the health-care practitioner and client are simultaneously required to consider past family health, present choices, and future outcomes, modifying these as additional information is provided.

One of the key messages of sociological theory is the way that the human conception of time has changed over the centuries. Capitalism and the industrial way of life wrought major changes on the human relationship with time. Our modern world places substantial emphasis on the measurement of time. Time is controlled, and the natural time patterns of life (e.g., the change of seasons, the rising and setting of the sun) have been evened out. Much of everyday life puts a value on the use of time, especially in the world of industry and institutions, where the "time is money" approach is evident. When time is understood and related to primarily as having a monetary value, the consequence is that the faster something happens, whether in an industrial or institutional setting, the better it is perceived to be [1, 3]. Both profitability (a primary concern of industry) and efficiency (a concern for institutions and industries alike) are tied to the pace (tempo) of the activity undertaken. Any underutilized time is regarded as wasted money.

Social time differs fundamentally from the "time is money" concept. Here, we may speak of "good times" and "bad times" and "the right time," of "quality time" with family, and of being "time poor" in our everyday

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life. People also perceive time passing more slowly or more quickly at different stages of their life. This has nothing to do with the linear, standardized time of the clock. Time might appear to accelerate as individuals consider what courses of action would be appropriate should a particular genetic test result be given; conversely, time might appear to slow down as a client waits "in limbo" to know his or her genetic status. In both cases the time of the calendar and the clock are fixed; it is the human perception of the passage of time that has changed as a result of the individual's specific circumstances.

Time is a fundamental part of human existence. However it is measured, whether by the natural order of the seasons or by the tick of the clock, it has a part to play in ordering daily life and social interactions. By using the sociological theory of time as an ordering tool, it is possible to see how what appears to be a straightforward human transaction—in this case, imparting knowledge to other family members—may be more difficult and thus protracted than might be assumed.

TIME AND THE GENETIC COUNSELING PROCESS

Time issues are fundamental to people's actions and thus have a bearing upon their relationship with the genetic counseling clinic. We consider some examples of clinical cases in order to examine how various aspects of time have an impact upon encounters with the health-care practitioner. We then explain the need to recognize, understand, and manage these aspects as part of the counseling process.

Case Study 1: An Uncertain Future

Amanda is 32 years old and has a family history of Huntington disease (HD), a neurological disorder involving loss of coordination, progressive physical disability, and a gradual loss of some mental functioning. Amanda's mother and maternal grandmother both had the disease, which started in their thirties, and Amanda has grown up knowing she is at risk of inheriting the HD disease gene. She has felt a "weight" on her mind about this since she was a little girl, and her future has always felt vague. In fact, she has not planned a future at all, having left school with few qualifications because she always felt uncertain about the careers that might be suitable for her if she developed the condition. Time is standing still. Amanda finds it hard to open her mind to a possible future because she is frightened that it may be taken away from her. It is easiest to live in the moment. Amanda comes for a routine genetic counseling session offered periodically to all clients at risk of having the HD gene fault; the genetics practitioner discusses the option of having a predictive genetic test. Amanda realizes that living with uncertainty is becoming intolerable, and she starts to wonder what the reality of a future might be like. The genetics practitioner spends a long time engaging with Amanda about her current coping mechanisms, and Amanda takes the lead on discussing the potential timing of a test and the plans that she could make on the basis of the results. A structure begins to emerge: Amanda begins to think about what she would do if she is found to have the family gene fault and what she would do if she does not. A future gradually materializes; the time ahead soon appears to have meaning.

Case Study 2: The Tempo of Action

Harry is in his fifties and has just learned that his sister, Mary, has terminal ovarian cancer. The diagnosis is quick, the prognosis is dreadful, and time is running out. Mary happened to take part in a research project at the time of her diagnosis and as part of this learns she carries a *BRCA1* mutation. This means that her ovarian cancer is likely to have a genetic cause, and her relatives are at risk of developing early-onset breast and ovarian cancer. Mary makes frenetic phone calls to her family with the news; she calls relatives she has not spoken to in years, urging them to seek genetic counseling and receive genetic testing quickly. Harry contacts his local genetic counseling department and demands an urgent appointment; he is frantic with worry, fuelled by Mary's anxiety. Harry has a 20-year-old daughter, and all he can think of is her risk of breast and ovarian cancer, imagining the worst, fearing he may lose her too. Time has sped up. Harry feels panicked and rushed. The genetics practitioner enables Harry to tell his story and gradually as she listens and he talks, the pace of the conversation begins to slow. At first he speaks in a manner that is fervent and without control, but then as he talks the pace of his language slows and in doing so the urgency dissipates. As the conversation develops, the genetics practitioner helps Harry to realize for himself that there is no urgency for genetic testing immediately. Harry begins to feel control again, and he visibly begins to relax in the consultation. Understanding his own grief reaction to Mary's news helps him to separate out Mary's need to do something for her family, to salvage useful information for her relatives, when she is helpless to do anything further for herself. Harry sees the genetics practitioner for several sessions and soon decides that genetic testing for himself and his own family can wait until another day, and he decides to focus on caring for Mary in the time he has left with her.

Case Study 3: Cycles of Events

Julie and David are referred to the genetics service because Julie has had seven successive, first-trimester miscarriages. After the first miscarriage, each subsequent pregnancy is embarked on with trepidation. Julie is frightened of the next miscarriage—the loss of a potential future, the loss of a dream, the loss of feeling normal. She is also frightened of the possibility that every future pregnancy will end in miscarriage—always the same conclusion with no prospect of anything different. Julie becomes obsessive about pregnancy; each time she sees a pregnant stranger on the street, she becomes jealous and wonders if she will ever have a normal pregnancy. Time appears to be repeating itself. Julie feels trapped in a nightmare that is always the same. Julie and David have their chromosomes tested in the genetics clinic and Julie is found to have a rearrangement of two chromosomes (translocation carrier), which means she has an increased risk of miscarriage as well a small risk of having a child with a serious disability. It also means that she has a good chance of having a successful pregnancy and a healthy child. The genetic counseling process helps Julie and David to reflect on their "living nightmare" and to wake up to their reality. Julie gradually begins to accept that a good outcome is possible if she can maintain a sense of patience. She continues to try for a new pregnancy, knowing that, in time, there is a chance that she will have a healthy baby.

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Case Study 4: Wanting to Know the Future

Helen develops bowel cancer at the age of 20 and has most of her bowel removed. She copes well and feels reassured by the frequent screening she receives. She knows there is a 50/50 chance that her children may have inherited this condition, familial adenomatous polyposis (FAP), but feels optimistic that if they have inherited it that screening will pick up any cancers before they became life threatening. Helen's children are currently under the age of 5 and she knows that they are too young to be tested for the FAP gene fault at the moment. However, as they become older, Helen becomes more anxious to know. She begins to waiver from her calm state of mind, knowing the risks to her children and understanding the consequences. Helen begins to feel she cannot wait anymore for them to reach an age when they can be tested. Time is going too slowly; she needs it to speed up. She oscillates between wanting to relish the innocence they all have at the moment—not knowing either way—to needing certainty and clarity. On the one hand, Helen wants to plan, to construct their future, and wants time to speed up so she can know. Yet, on the other hand, she wants it to stand still, so that she never needs to know.

Case Study 5: Having to Face the Future

Valerie lives in an area where all newborn babies are tested for Duchenne muscular dystrophy, a progressive muscle wasting condition. Valerie does not remember that her new baby was tested for this, and so when the results show he is affected, she is shocked and cannot believe this new information. Ben is only 10 weeks old, is perfect in every way, and yet Valerie now knows that when he is around 4 years old he may begin to show signs of the condition that will gradually engulf him; the degenerative disease will take his life in his twenties and begin to take effect before he even starts school. Valerie feels cheated. The joy she felt initially when her new baby boy was born is soon tainted. She wrestles with this information; she feels her innocence has been stolen from her. She longs for an open future, she longs for a time when she does not know; she cannot look at Ben, even though he is now perfectly normal, without thinking how he will become in the future. The time that Ben is well seems so short; she can now count it in years on one hand. There is not enough time for him to be normal; there is not enough time for Valerie to have him before he becomes disabled. Time is slipping away, and she feels helpless to do anything about it.

Each of these cases illustrates a particular facet of time that is likely to be experienced in the clinical encounter. Pasts and futures are a dominant part of each account, interwoven with other aspects of social time. A sensitive health-care practitioner working regularly with clients grappling with issues relating to genetics, inheritance, and their family will be working with an awareness of *timescapes*, even if the practitioner is not consciously familiar with time theory. This is because the genetic counseling consultation naturally encompasses discussion about the past, present, and future, and the client will frequently change the tempo within a consultation as he or she incorporates new information. For example, it is quite common for a client to arrive at a consultation with a real sense of urgency about

rushing through a quick predictive test; this is usually because the client has only just discovered that he or she is at risk of developing or passing on a dreadful genetic condition. This is demonstrated in the case study with Harry. The practitioner can use communication skills to help diffuse the urgency and panic. By focusing on the client, listening carefully, and using both verbal and nonverbal communication to show empathy, it is usually possible to slow the pace down and create an opportunity for a time extension. The genetic practitioner will often regulate the pace of his or her own speech and take care not to inadvertently match the pitch and panic of the client's voice. The genetic practitioner may also remain quite quiet and listen as the client tells his or her story naturally and eventually comes to a stop. This is a tactic that can help to restore a sense of balance. It is very important that the practitioner does not join the client in a state of alarm and stress (and thus ultimately helplessness); the practitioner can be of enormous benefit if he or she remains calm and on top of the situation because this helps the client to find this calmness too. In this way, the practitioner does not collude with the client's sense of panic and feel forced into ordering a fast-track predictive genetic test, which is usually unnecessary unless there are immediate diagnostic decisions to be made on the basis of the person's genetic status. Indeed, genetics services have predictive testing protocols that encourage clients to have at least two genetic counseling sessions first before blood is taken for testing [4]. This can allow time for reflection, further discussion with family, and careful and considered thought about what will be done with the results.

We turn now to a more detailed discussion of time in several relevant contexts: the family, health and illness, and, specifically, in genetic conditions. In concert, we explore some of the factors that impact upon family communication of genetic information.

THE FAMILY, BIOGRAPHIES, HEALTH, AND GENESCAPES

As the earlier sections of this chapter illustrate, time is a central part of human life and is integral to our way of being. This section seeks to show how time is implicated in family life, in general considerations of the experience of health and illness and in illnesses with a genetic underpinning. The temporal dimensions of these situations work together to produce interwoven cycles.

Family Timescapes: Generations and Life Courses

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, and so on. These temporal cycles are part of the rhythms of domestic timescapes and are not based exclusively

on the lapse of chronological time. They reflect the social and cultural marking of time. These include personal and calendar rituals (e.g., 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.

Generations are among the ways in which the passage of time is recognized within kinship and domestic groups. They are simultaneously natural and social phenomena. 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, the responsibilities of adulthood, and the limitations of older age. 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, and productive activities and leisure. Notions of temporal progression therefore underlie patterns and expectations concerning communication within kindred, including the management of genetic information. A new genetic diagnosis within a family can modify these transitions. For example, consider the case of an 18-year-old boy diagnosed with neurofibromatosis type 2 (NF2), a progressive, chronic condition involving tumors on the auditory nerve in the brain which cause hearing loss. Any 18 year old would usually be on the verge of a transition into adulthood, with plans to leave home and detach himself from his parents. However, an 18 year old with a new diagnosis of NF2 may need to put his plans for university on hold. The usual transition may become stalled because he now needs to stay at home with his parents as he and the family adapt to his sudden hearing loss; the 18 year old becomes a child again, relying on his parents to help him communicate and learn how to speak and understand without hearing.

Generational differences imply differential access to information. Age and generation affect what is kept private, what is divulged, and what is kept from family members [5]. The distribution of 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 [6, 7]. The life course and generation shape patterns of disclosure, and of the distribution of information within a social network. For example, in the second case study, Harry may decide that his daughter does not yet have the maturity to participate in his conversations with Mary about hereditary breast ovarian cancer.

Generations and the succession of generations are ways of accounting for time, change, and succession. The importance of generations is evident in accounts of families with genetic conditions [8]. Families seek to make sense of change and continuity by looking to the past to account for the origin of a mutation or the route of its transmission. Past generations are inspected; everyday family pedigrees are invoked; and medical histories are

located within that sense of the past [9]. All of this is part of the process of deciding which members of the family are at risk of the genetic condition and as a result need to be informed of the results of genetic testing and counseling.

Health and Genescapes

Health and illness always imply temporal dimensions. Acute illness can be a major turning point in people's unfolding lives, and chronic illness transforms the way a person's current and future life will be lived. Even when discovered genetic conditions have no immediate effect (e.g., discovering the presence of a *BRCA1* gene fault), this knowledge also changes the way a person thinks about his or her health and the choices the person makes. Thus, discovery of a genetic anomaly can lead to two different types of trajectories: the *trajectory of the illness* that the genetic anomaly gives rise to and the *trajectory of the gene* (over generations, across the boundaries of family and kin, and over the entire lifetime of the individual).

An *illness trajectory* is the path by which an individual progresses from the point of initial symptoms, through diagnosis into subsequent outcomes. Along similar lines, people affected by a condition have "patient careers." That is the stages through which they identify and evaluate symptoms, seek lay or professional advice, go through stages of treatment, and experience recovery, deterioration, or even death. Health and ill health always imply perspectives on the past as well as the present and the future [10–13]. The past is inspected for causes and origins of ill health, and future treatment or recovery is envisaged. Just as the past is inspected for causes and origins of ill health, similar narrative work is undertaken by those affected (directly or indirectly) by genetic illness. The search for origins includes not merely the work to understand and interpret the cause of the condition (the nature of genetic inheritance) but also the search for its origins in social relationships, the intersection of genetic constitution and lifestyle, and the routes of inheritance and risk transmission [9, 14].

There is a difference between a *genetic trajectory or career* and an *illness trajectory*. In contrast to illness, the disclosure of a predictive genetic test result to a healthy person provides a career or trajectory that is neither "acute" nor "chronic" in conventional terms. The master status [10] of being a carrier or being at risk is an emergent, but permanent one; it dominates a person's self-perception and interaction with others. It thus becomes different in form from a biographical "disruption" of illness diagnosis, being more akin to a biographical "translation" into a genetically defined past, present, and future.

Genetic trajectories are always socially shared and distributed among kin, and therefore they imply a somewhat different order of complexity from the individualized trajectories of acute or even chronic illness. *Genescapes* encompass the multiple constructions of the gene—biological and cultural—and inheritance. Beyond the temporal unfolding of an

individual's genetic status and illness trajectory, for genetic conditions there are multiple family members' biographies to be constructed and reconstructed, and there may be multiple illness trajectories evident in the family [10, 12, 15]. As has been demonstrated from many disciplinary and theoretical perspectives, genescapes entail complex patterns of interpretation [16]. While we know that genetic understanding is not uniformly shared among kin, where there is sharing, narratives of past, present, and future may be jointly constructed and shared. As a consequence, the temporal dimensions of genetic knowledge are rendered potentially more complex than the narratives and interpretations of individual disease.

Biography and Health

There has been an emphasis on biographies and life histories in recent qualitative social research. Biographies are actively constructed by social actors, who make sense of their past and current lives, interpreting and evaluating experiences, events, and other people. They are, therefore, among the most significant ways in which the passage of time is understood in everyday social life. Biographies are not regulated solely by the passage of clock time or by the strict calendrical process of aging. Lives are constructed and understood in terms of *biographical time*. Key features include turning points, for example, the point of deciding to have a predictive test after years at risk (such as Amanda wanting to find out about Huntington disease, in the first case study); epiphanies (moments of revelation and identity transformation, such as Julie receiving a chromosome result identifying the cause of her miscarriages, in the third case study); and status passages such as transitions to adulthood, marriage, reaching the age when cancer screening must start, the birth of a child, or the death of a partner or parent. There are very general notions of time in the construction of a life: time to grow up, time to mature, time to "move on," time to start a family, time to settle down, and so on.

When thinking about genetic conditions, we need to recognize that there are different possible careers, biographies, and trajectories. First, there is the possible difference between a *genetic trajectory* (over generations, across the boundaries of family and kin, and over the entire lifetime of the individual) and a consequent *illness trajectory* mentioned above. So conditions like myotonic dystrophy or cystic fibrosis will follow a conventional illness trajectory (the symptoms and prognosis are recognized and fairly consistent), while the genetic trajectory may appear and disappear, seemingly at random, among relatives (i.e., some develop the condition and others do not). It also encompasses not merely the individual life but also that of previous and succeeding 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. 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 unborn.

Turning Points

Rites of passage are among the classic, long-standing interests of social and cultural anthropology [17]. They mark the passage from one culturally defined stage of life to another or from one social category to another. The key events, and their social ceremonials, include birth, initiations, marriage, death, and bereavement. They are marked by collective celebrations. For instance, the birth of a child not only triggers the arrival of a new social person and redefines the status of the parents; it also 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. Relatives who are linked by the same genetic condition, such as women in a family who have all inherited the same family *BRCA1* mutation, share a common bond, both genetic and social in construction. This may unite the family within shared rites of passage, for example, a "coming of age" as younger women in the family reach an age where they can start breast/ovarian screening or make a decision to have a preventative mastectomy. These key turning points in the biographies of individuals and families are, therefore, key markers in the passage of time; they are also key moments at which genetic decision making may achieve enhanced salience.

TIME AND THE HEALTH-CARE PRACTITIONER

The intervention of the health-care practitioner is 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 standardized procedures that make the past comprehensible, and that bring the past under the scrutiny of the professional gaze, for example, through the drawing of the pedigree [18, 19]. Alexias [20], 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 past history is not merely that of the individual attending the clinic. It is a shared past, defined

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by shared genetic inheritance between family members. The present always—potentially at least—implicates others beyond that person. The future extends well beyond the individual, as genetic risk and patterns of inheritance extend to offspring and to generations as yet unborn. The construction of the family tree or pedigree is one mechanism whereby the past is reconstructed and transformed into a clinical present and a potential future [21, 22].

The genetics clinic, therefore, is a point of surveillance of past, present, and future. Such surveillance is not, however, confined to the clinical setting. The same dimensions define the mutual gaze of "lay" family members. Featherstone et al. [9] show how mutual surveillance takes place across the generations within families. Previous generations may be inspected in order to construct etiological accounts of the origins and routes of inherited mutations. 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 present to make assessments of their own future.

In the same way, surveillance and prediction operate from older generations to younger ones. 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 a resource to predict the future by family members in the attempt to predict the outcomes of genetic predispositions.

THE RELEVANCE OF TIME TO FAMILY COMMUNICATION ABOUT RISK INFORMATION

We turn now to two specific examples relating to the temporal aspects of risk communication. At present there is no body of literature that deals specifically with time in this context, although previous studies of the communication of risk information have referred to some temporal issues. These include the belief that a family member is too young to be informed [23–29], that it is the responsibility of parents to inform their children [24, 30], and the timing of disclosure and finding the right time to tell [24, 26, 29, 30]. Further discussion on communicating genetic information with children can be found in Chapter 14.

The first of the examples relates to time processes following the genetic counseling appointment. It might be assumed that when a person leaves her appointment, armed with knowledge of her own risk of inheriting and passing on the condition and aware of the need to bring the risk to the attention of other family members, she has every intention of acting as a conduit for the passage of this knowledge to other members

of her family. It is assumed that the person will feel a sense of obligation to other family members to protect them from harm. In the first instance, however, she may need to *take time* in order to come to an acceptance of the information that she has been given because it represents a shift in her understanding of her own future biography.

Thereafter, imparting this knowledge to other family members needs to take place in a way that is respectful of the *rhythms* of that family's communication patterns. Conversations with first-degree relatives are likely to be more regular than with those who are less close; attendance at genetic counseling will probably already have been raised as part and parcel of the usual interchange with close family members about how one's daily life proceeds. It is thus potentially easier for the person to communicate the results of the appointment as it affects him or her and, by extension, others who share a similar risk of inheriting the genetic defect.

However, even in these circumstances of close personal contact, there is a judgment to be made about whether it is the *right time* to impart information that may have serious implications for the *future* of another member of the family. It will take account of whether the age of the relative means that disclosure is appropriate. If that factor is not a stumbling block, a decision needs to be made about whether all should be revealed in one conversation or whether it is better to plant the seed by divulging results, following that up at a *later date* with a discussion of what the information obtained might mean for the relative.

In this process of disclosure, the right time has nothing to do with the time of the clock and the calendar. It is based on a judgment of whether at that particular time in the life of the relative it is appropriate to convey information that might provoke concern and anxiety. It takes account of other issues that the individual may be experiencing at that time that may make the disclosure inappropriate or unwelcome.

The second example deals with genetic information disclosure to more distant relatives. Many published studies of family communication have found that first-degree relatives are more likely to be informed about genetic risk than second- or third-degree relatives [28, 29, 31–33]. In the case of more distant relatives, it cannot be assumed that practical kinship involves close and intimate relations. The biomedical conceptualization of relationships does not map onto the emotional and social ties that are the reality of family life. For many families it is only at the times of rites of passage that more distant relatives are likely to meet face to face. Such occasions are likely to be celebratory (christenings, weddings, marking important birthdays or other anniversaries) or at more sombre occasions such as funeral or memorial services. Such occasions are not necessarily appropriate times for raising issues of genetic inheritance. So it is perhaps not surprising that clients tend not to communicate directly with their more distant relatives and that communication within the family is inclined to follow a more circuitous route.

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CONCLUSION

From everything we have discussed so far, it is apparent that there are multiple trajectories and timeframes in play at any given time in relation to individuals and family members. Patterns of family communication are clearly shaped by such temporal (and spatial) constraints. We need, therefore, to recognize the extent to which *clinical* and *biographical* timeframes do not coincide.

The cycles of clinical intervention and consultation cannot be assumed to map onto the temporal cycles of families and domestic groups. Processes of information sharing and disclosure of genetic information are more complex than the organizational and professional imperatives of genetics clinics and professional personnel.

As Zerubavel [34] points out, organizations like hospitals and clinics are regulated by their own temporal imperatives. These rely heavily on the time of clocks and calendars, as described earlier. Appointments are scheduled within particular timeframes with regard to the efficiency of the organization. While they intersect with the biographical trajectories of clients and patients, such patients and clients are not constrained by organizational routines. While genetic counseling is not a one-off affair, and while families may be followed over long periods of time, the healthcare practitioner cannot and should not assume that the timing of family processes matches the cycles of clinic encounters and counseling sessions. Genetic counseling, as with other medical encounters, is based on the efficient use of time. The disclosure and sharing of genetic information is—as numerous studies have shown—an event, or even a series of events, subject to uncertain timing, and grounded in the practical circumstances of everyday life.

Practitioners' counseling and expectations need to be sensitive, therefore, to the *timescapes* of family life described here as well as their *genescapes*.

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