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'YOU DON'T MAKE GENETIC TEST DECISIONS FROM ONE DAY TO THE NEXT' – USING TIME TO PRESERVE MORAL SPACE

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ABSTRACT
The part played by time in ethics is often taken for granted, yet time is essential to moral decision making. This paper looks at time in ethical decisions about having a genetic test.

We use a patient-centred approach, combining empirical research methods with normative ethical analysis to investigate the patients' experience of time in (i) prenatal testing of a foetus for a genetic condition, (ii) predictive or diagnostic testing for breast and colon cancer, or (iii) testing for Huntington's disease (HD). We found that participants often manipulated their experience of time, either using a stepwise process of microdecisions to extend it or, under the time pressure of pregnancy, changing their temporal 'depth of field'. We discuss the implications of these strategies for normative concepts of moral agency, and for clinical ethics.

TIME AND MORAL DECISION-MAKING

> *Choices need time, the fullness of time, time being the horizontal axis of morality – you make a decision and then you wait and see, wait and see.*[1]

Time is essential to moral decision making. To grasp the combination of intention, agency, behaviour, consequences and relationships that we characterise as moral responsibility means taking its constitutive temporality into account. However, while a number of authors have drawn attention to the relation between time and ethics, systematic philosophical studies have been rarer.[2] Based on empirical research with patients making decisions about genetic testing, we have been investigating the role of time in the process of making normative ethical judgements. In this paper we describe an unexpected manipulation of time by people making test decisions, and consider the implications for a broader concept of moral agency.

THE TEMPORAL STRUCTURE OF GENETIC TESTING DECISIONS

The area of genetic testing is interesting in multiple ways for considering the relationship between

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[1] Z. Smith. 2001. *White Teeth*. Harmondsworth: Penguin.

[2] E. Levinas. 1979. *Time and the Other*. Montpellier: fata morgana; P. Ricoeur. 1990. *Oneself as Another*. Paris: Seuil; J. Butler. 2003. *Kritik der ethischen Gewalt. Adorno Lectures 2002*. Frankfurt a.M. Suhrkamp; H. Haker. The Fragility of the Moral Self. *Harv Theol Rev* 2004; 97/4: 359–381. A recent contribution is H. Dyke (ed.). 2003. *Time and Ethics: Essays at the Intersection*. Dordrecht: Kluwer Academic.

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ethical choice and time. For one thing, genetic tests share common temporal elements. All genetic testing has predictive fuzziness – even when the test confirms a clinical diagnosis, it generally does not remove uncertainty about the course or severity of the disease. A genetic test gives *probabilistic* statements about the individual's future. Beyond the test lie multiple possible futures, some of which will be closed off by the test result, while others remain open because of the uncertainty. Because of this orientation, genetic tests force people to imagine their future(s). In the present in which a decision is made, it is also obvious that at some point in the future, this event will be history. When the patient asks, *How will I live with this decision?* she is struggling to make an assessment of a past which has not yet happened.

Genetic information can also change the patient's past, present and future in more unexpected ways. The predictive information provided by the test may not only describe but also influence the actual future course of events.[3] Discovering that he carries a genetic lesion could alter a patient's own account of his *past*. The facts of past events may be unalterable, but interpretation is not, and genetic information can provide new interpretations of an individual life, a family history and a person's place within it. Evidence from cognitive science indicates that stimuli in the present modify how a person reassembles the components of stored memories,[4] and so new interpretations of past events may literally re-construct the memory of these events.

Although they have points in common, not all genetic testing situations have the same temporal structure. In testing for a late onset disease, or for a recessive condition, the consequences of the result may be remote; other situations, for example in diagnostic or prenatal testing, may demand an immediate decision about further intervention. Prenatal test decisions are made under time pressure, while others, such as testing for Huntington's disease, are generally not. Real-life genetic testing decisions are grounded in nonidentical moments of history and of personal biography. The test takes place in a period of days or weeks, but is overlaid on the lifespan of the individual being tested. For familial conditions this in turn is overlaid on the family history, sometimes extending generations into the past, and projected onto the generations to come. From the point of view of the patient, then, genetic testing starts before and extends beyond the limited timeframe of the clinical encounter. This longer perspective is absent from most of the literature on the ethics of genetic testing.[5]

PATIENT-CENTRED RESEARCH INTO GENETIC TESTING DECISIONS

Although the ethics of genetic testing have been exhaustively rehearsed in the bioethical and policy literature, the discussion has concentrated on what medical professionals, healthcare providers or policy makers should or should not do when providing genetic tests, or how genetic counsellors can help patients reach satisfactory decisions. Much less has been said about the moral worlds of patients and about the ethical dilemmas they might perceive.

Models of genetic decision making that draw on normative decision theory[6] tend to assume that

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[3] C. Rehmann-Sutter. 2002. Prädiktive Vernunft. Das Orakel und die prädiktive Medizin als Erfahrungsbereiche für Rationalität. In *Zugänge zur Rationalität der Zukunft*. N.C. Karafyllis & J.C. Schmidt, eds. Stuttgart: Metzler: 203–232.

[4] J.L. McClelland. 1995. Constructive Memory and Memory Distortions: a parallel distributed processing approach. In D. Schachter (ed.), *Memory distortion. How minds, brains, and societies reconstruct the past*. Cambridge, MA: Harvard University Press: 69–90; J. Sutton. 1998. *Philosophy and Memory Traces: Descartes to Connectionism*. Cambridge: Cambridge University Press.

[5] Nuffield Council on Bioethics. 1993. *Genetic Screening: Ethical Issues*. London: Nuffield Council on Bioethics; D.H. Smith et al. (eds). 1998. *Early Warning: Cases and Ethical Guidance for Presymptomatic Testing in Genetic Diseases*. Bloomington and Indianapolis: Indiana University Press; R. Chadwick et al. (eds). 1999. *The Ethics of Genetic Screening*. Dordrecht: Kluwer Academic; Human Genetics Commission. 2002. *Inside Information: Balancing Interests in the Use of Personal Genetic Data*. London: Human Genetics Commission. For a discussion of this point see T. Chambers. 1999. *The Fiction of Bioethics*. New York: Routledge.

[6] J. von Neumann & O. Morgenstern. 1947. *Theory of Games and Economic Behaviour*. 2nd edition. Princeton, New Jersey: Princeton University Press; M.C. Weinstein & H.V. Fineberg. 1980. *Clinical Decision Analysis*. Philadelphia: W.B. Saunders and Company; S.G. Pauker & S.P. Pauker. 1987. Prescriptive Models to Support Decision Making in Genetics. In *Genetic risks, risk perception, and decision making*. G. Evers-Kiebooms et al. eds. New York: Alan R. Liss: 279–296; G.F. Pitz. 1987. Evaluating Decision Aiding Technologies for Genetic Counseling. Ibid: 251–278.

when faced with an epistemological problem about (genetic) information and its handling, 'decision makers have pre-existing preferences that obey the axioms of rational choice and . . . the only difficulty is discovering what they are' in a genetic context.[7] But models based on the rational maximisation of benefit tend to neglect other features of real-life genetic decisions, which from the point of view of the patient may be as influential as uncovering preferences, such as the difficulty of understanding probabilistic information,[8] the trade-off between probability and severity, the effect on other family members or friends, and the powerful influence of moral emotions such as regret, guilt or shame. In sociology and psychology, research into patients' behaviour in genetic testing decisions has generally been concerned with correlating social or psychological variables and specific outcomes.[9] Little of this work so far has dealt with how patients themselves regard the ethical aspects of the decisions they make.[10]

In a 3-year project we combined qualitative empirical research methods with normative ethical analysis to explore the part played by time and its perception in the moral world of patients making genetic testing decisions. The study was reviewed and approved by the *Ethikkommission beider Basel*. Using semi-structured interviews we asked people about their decisions for or against genetic testing, and how their reasons were affected by time – for example, the time in life when it happened, how long they took to consider it, whether the passage of time had affected their evaluation of the decision, and so on. Our participants had undergone or were undergoing (i) prenatal testing of a foetus for a genetic condition, (ii) predictive or diagnostic testing for breast and colon cancer, or (iii) testing for Huntington's disease (HD). Interviews, which lasted 60 to 90 minutes, were conducted in German except in one case where the interviewee was a native English speaker. The extracts in this paper have been translated by one of the authors. Participants could choose to be interviewed in their homes in Basel or Zurich, or at our Institute. The interviews were audio recorded, transcribed, and analysed using interpretative phenomenological analysis (IPA),[11] a methodology suitable to our goal of understanding the implicit as well as explicit ethical content of a phenomenological account. The analytical strategy identified themes related to time and explicit or implicit moral claims within each interview, and used the content and context of the claim, and comparison within and between interview transcripts, to follow interviewees' processes of moral evaluation.

We interviewed a total of 18 participants: eight prenatal testing, three familial cancer, and seven HD. We understood this to be a preliminary study in which our aim was to sample a range of testing experiences, analyse these in detail, and uncover issues to be followed up in further work, rather than generate statistically representative data from a larger number of patients at this stage. The small number of interviews is appropriate for this, and for the detailed analysis required by IPA. We had hoped for approximately equal numbers in each group; the smaller group of cancer patients reflects the health status of these patients (two who consented to interview had to withdraw for health reasons), as well as the fact that familial cancer testing is relatively new to Swiss clinical practice.

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[7] J.M. Kaplan. A Philosophical Critique of Decision Analysis as a Tool in Genetic Testing. *Genet Test* 1999; 3: 85–91.

[8] R.B. Black. 1979. The Effects of Diagnostic Uncertainty and Available Options on Perceptions of Risk. In *Risk, communication, and decision making in genetic counselling*. C.J. Epstein et al. eds. New York: Alan R. Liss: 341–354; B.K. Koenig & H.L. Silverberg. Understanding Probabilistic Risk in Predisposition Genetic Testing for Alzheimer Disease. *Genet Test* 1999; 3: 55–63.

[9] S. Shiloh. 1996. Decision-making in the Context of Genetic Risk. In *The troubled helix: social and psychological implications of the new human genetics*. T. Marteau & M. Richards, eds. Cambridge: Cambridge University Press: 82–103; D.W. Coon et al. The Psychological Impact of Genetic Testing for Alzheimer Disease. *Genet Test* 1999; 3: 121–131; T.E. Power & P.C. Adams. Psychosocial Impact of C282Y Mutation Testing for Hemochromatosis. *Genet Test* 2001; 5: 107–110; E. Claes et al. Diagnostic Genetic Testing for Hereditary Breast and Ovarian Cancer in Cancer Patients: Women's Looking Back on the Pre-Test Period and a Psychological Evaluation. *Genet Test* 2004; 8: 13–21; B.L. Hicken et al. Attitudes About and Psychosocial Outcomes of HFE Genotyping for Hemochromatosis. *Genet Test* 2004; 8: 90–97.

[10] For gene therapy see J.L. Scully, C. Rippberger & C. Rehmann-Sutter. Non-professionals' Evaluations of Gene Therapy Ethics. *Soc Sci Med* 2004; 58: 1415–1425.

[11] J. Smith & M. Osborn. 2003. Interpretative Phenomenological Analysis. In *Qualitative psychology: A practical guide to methods*. J.A. Smith (ed.) London: Sage: 51–80.

Using subjective accounts raises methodological issues of accuracy, articulation, memory and the reconstruction of past events. However, our primary aim was not to judge the veracity of people's accounts, but to see how, from the point in time when they were asked, participants constructed a moral account of their decision. For this purpose, subjective accounts are the appropriate information sources as long as their limitations are kept in mind.

In this paper we outline some results from three different participant groups, and then focus on one theme: the patient's manipulation of their passage through time in the decision-making process. We relate this cognitive mechanism to the patient's sense of moral agency.

PRENATAL TESTING: 'I'LL CROSS THAT BRIDGE WHEN I COME TO IT'

Our eight prenatal test interviewees had considered whether to have amniocentesis or a chorionic villus biopsy plus karyotyping or DNA testing to confirm a possible abnormality. In Switzerland this testing is offered from the 10th week of pregnancy. The biological timetable of pregnancy, the scheduling of testing, and the greater clinical and emotional difficulty of late abortion, all create a sense of time pressure. Four interviewees spoke about the pressure and their ambivalence about it:

> *On the one hand I was looking forward to the moment when I would at least have something to base my decision on, when I could have some peace of mind . . . and on the other hand this pressure, 'it's coming, it's coming, it's coming, I have to choose then, I have to choose.' [KT, 36 years old, talking about testing in her second pregnancy]*

Beyond the test and result lie multiple possible futures: life with a normal child, with a disabled child, with no child, as a woman who has had an abortion, and so on. We had anticipated that the decision process would include choosing between these possible futures. Our interviewees would be comparing the possible long-term outcomes, imaginatively projecting themselves into the future to assess life in the scenarios. Our interviewees certainly did do this, but in a more complex way than expected. When imagining the long-term future, for example, DT and others described feeling initially torn 'this way and that' between all the possible outcomes, to an extent that she found intolerable:

> *. . . This being pulled to and fro, shall I have it, I mean the test, shall I not, what shall I do afterwards if there's another decision to make, can I trust that decision, erm, shall I keep it, shall I abort it; I'd already been through this three times . . . and I just had the feeling, I didn't have the strength left to deal with this backwards-and-forwards stuff. [DT, 54 years old, talking about 4th pregnancy 11 years previously]*

Five of our eight interviewees claimed that to avoid this tension, they deliberately *limited* their mental projection into the future during the decision-making process. They were well aware that a test at this point in the pregnancy could entail a further decision about continuing the pregnancy if an abnormality were detected:

> *I knew that I would be faced with a difficult decision if it turned out [one of the twins] were ill. [KT, 36 years old, talking about her second pregnancy]*

But although they were fully aware of it, they also said they mentally *excluded* this knowledge when thinking about the test, restricting their focus of attention to the immediate weeks or even days ahead:

> *In the end I decided to go ahead [with the test]. Everyone said to me, that means you will abort it if there's a problem, and I said, I can think about that later. [DT, 54 years old, talking about her first pregnancy]*

> *Well, I felt that I would be able to make that decision [to terminate or not], deal with that, if something showed up on the test, and I just didn't want to start worrying about something unless I had to. {Interviewer: So were you holding off thinking about that consciously?} Oh yeah, yeah, very consciously, yes. [OH, 49 years old, talking about her first pregnancy]*

These participants were not describing a passive state, but rather an *active* manipulation of their subjective experience of time passing, by fractioning the anticipated future into an immediate step and further steps that could be thought about later. We describe this active contraction of their concern onto the immediate future as a shift in the *temporal depth of the field* of their attention.

FAMILIAL CANCER: ON THE MEDICAL CONVEYOR BELT

Three interviewees who were being tested for familial cancer each separately exemplified important model situations: tests offered (1) presymptomatically because of known family history, (2) to a patient during treatment of existing disease, or (3) after successful treatment of disease, when the test result will primarily be of interest to their children or other family members. In these cases it appeared that the ongoing clinical context played a subtle but decisive role in perceptions of the timecourse of testing. The two patients who were offered a test during medical treatment had a sense of being part of an unstoppable chain of medical processes. Metaphorically on a conveyor belt, they experienced the test decision as submerged in a context of numerous other interventions. By the time of interview both of these interviewees felt that they had never actively *decided* to have a test. The same point was made by a woman in our prenatal testing group who, because she became pregnant through IVF, was similarly embedded in a clinical context during her two pregnancies: '*[The test] wasn't really any kind of decision*.' OH)

One interpretation would be that whether or not the decision was made in a clinical context could radically alter the patient's perception of her involvement. For one cancer patient the test, taken without much thought while on the conveyor belt of treatment, later gave rise to a crisis of identity and ambivalence about knowing her genetic status. If a clinical setting (temporarily) alters the patient's judgement in ways they may later regret, ethical questions are raised about whether it is appropriate to offer genetic testing at the same time as other treatment, if the test result is not of immediate therapeutic use.

HUNTINGTON'S DISEASE

Family stories

Huntington's disease is a dominantly inherited, severe late-onset neurological disorder. Since the gene responsible for the production of the aberrant huntingtin protein was cloned it has been possible for family members at risk of developing the disease to be tested to see if they have inherited the gene.[12] Thus many members of HD families are now, for the first time, faced with deciding whether or not have this predictive knowledge. For older people, the decision is largely about having knowledge of their own future health, but for the younger generation the availability of the test will inform their reproductive plans as well.[13]

We interviewed seven members of HD families, three of whom had opted for testing and four against. In two families we were able to interview both the affected parent and their presymptomatic children. For all of them, the decision-making process was embedded in a sense of extended family history and in the participants' individual experiences of the condition in their families. All the interviewees spontaneously began their account of the test decision by introducing their first affected relative, usually a grandparent, and went on to consider their own (real or potential) children. The familial cancer patients used a similar narrative structure. By contrast, women talking about prenatal testing generally began their accounts from a point within their own lifetimes, with their first plans to have a child. It seems that prenatal testing 'belongs to' the individual woman's biography rather than to the family chronicle, in contrast to the narratives of the individual HD and cancer patients that needed integrating into an over-arching family narrative to acquire meaning.

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[12] The Huntington's Disease Collaborative Research Group. A Novel Gene Containing a Trinucleotide Repeat that is Expanded and Unstable on Huntington's Disease Chromosomes. *Cell* 1993; 72: 971–983.

[13] J. Binedell, J.R. Soldan & P.S. Harper. Predictive testing for Huntington's Disease: II. Qualitative Findings from a Study of Uptake in South Wales. *Clin Genet* 1998; 54: 489–496; S. Creighton et al. Predictive, Pre-natal and Diagnostic Genetic Testing for Huntington's Disease: the Experience in Canada from 1987 to 2000. *Clin Genet* 2003; 63: 462–475.

> {*Interviewer: Could you tell us the story of your genetic test, from your own point of view?*} *Yes, the story really began with my grandfather, just before his retirement . . . [TK, 29, at-risk HD]*

Microdecisions

For our HD individuals, progress towards a point where they could say ‘yes’, ‘no’, or ‘not yet’ to a test, was incremental. As we paraphrase in the title of this paper, one of our participants said, ‘Of course, you don’t make a decision like this from one day to the next’. Instead, something more like a series of microdecisions is involved. A good example is given by Sabine J (name changed), aged 29 at the time of interview, whose mother already had symptoms of HD. As the timeline in Figure 1 shows, Sabine noticed her grandfather’s illness during her childhood but at that time it had no real meaning for her. During her paramedical training she learned of HD’s heritability, but in the first of her microdecisions chose not to find out more. On a shopping trip Sabine realised that her mother was showing symptoms; she chose to push the knowledge aside. Then at a party her brother revealed that he too had noticed their mother’s symptoms. Over Christmas 2000 her mother’s deterioration was apparent to her. This was the point at which she decided to engage with the problem, and in January 2001 began to read and search the internet for information about HD. Coincidentally, her mother announced that she herself was going to have a genetic test, and two weeks later reported her result – which was, as expected, positive. After that, Sabine went through a series of microdecisions. She decided to get psychological counselling, then to get information about what having the test entailed, and then asked herself the question: ‘Shall I do it sometime, or not?’ Having decided that she would do it, sometime, she found out which institutes in Switzerland offered testing, sorted out her insurance, and made an appointment with a HD specialist to discuss things further. When we interviewed her, she had decided against having the test – for the moment.

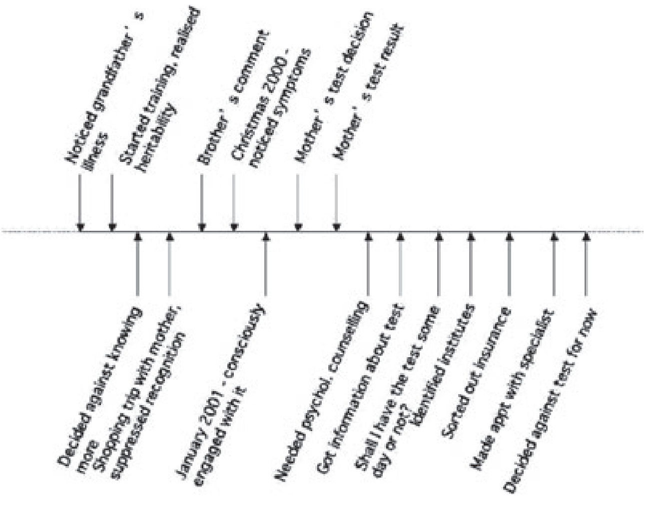

Figure 1. Timecourse of Sabine’s microdecisions
The horizontal axis indicates time. Events in her life that she recounted in her interview are indicated by arrows above the line, her microdecisions by arrows below the line.

We could differentiate between types of microdecisions. In terms of the actual *outcome* of the decision process (i.e. does it lead to yes, no, or don’t know), then a crucial moment was when Sabine asked herself whether she would *ever* have the test or not. She has decided that she will be tested if not knowing becomes intolerable, or if she wants to have children. So her decision against testing in the present entails a commitment in the future: ‘Yes, but not yet’ rather than ‘No’.

For other patients, the decisive step in the series of microdecisions had actually been taken long before making contact with a medical professional. In some accounts the trigger (to take the test *now*) was an ostensibly trivial event:

> *Since 1993 you could have the blood test, I’ve known about it since then. I just said to myself, I’ll put it off as long as I can . . . erm, I’ll have the test, when there’s nothing else to be done. And the stimulus for the blood test was actually a visit to my new doctor. The practice had been taken over, a doctor from K___ . . . he knew about HD and it was a problem for him at first, because he was afraid of talking to me about it, about what I might have. So I reassured him a bit, by saying there’s no point in doing any more investigations, I’ll take the test. [WH, 59, HD]*

The subjective turning point in the process might not be the decision that leads most obviously to the final outcome. So although for Sabine the key decision was whether to have the test at all, she said that the turning point for her, and the most taxing microdecision, had been earlier, when she chose to confront the disease and its implications for her life.

The microdecision strategy was also reported by one of the cancer patients, whose decision was being made at the time of interview, against a background of a strong family history of the disease but who unlike our other cancer patients was presymptomatic. She too described the process of decision as a stepwise one:

> *And then my sister had treatment . . . I had never felt directly threatened, really not thought about it, and then last winter, about a year ago, I started to think about it, slowly, what exactly does it mean for me, what, what, what should I do? (Pause) And then I sort of made an appointment with my doctor . . . and she offered to give me more information about my risk and maybe the risk to my daughters . . . and now I think I'm really in the middle of this phase of thinking it over, about what I should do. [TC, 42 years old, familial breast cancer]*

MANIPULATION OF TIME AS A MORAL STRATEGY

Enduring agency

We identified two time manipulation processes: (i) the stepwise process involving multiple microdecisions, seen in predictive testing or testing for late onset diseases; and (ii) 'crossing that bridge when I come to it', or changing the depth of temporal field of the evaluation, by women making prenatal testing decisions. Both of these involve manipulating the relationship between decision time and chronological time, and both may be explained as strategies to retain a sense of internal control over major life events. Patients manage the affective and cognitive burden of the decision by slicing it up into manageable time intervals. In (i), the stepwise process, this is done by patients inching forward through microdecisions. Sabine's slow passage through the process enables her to make decisions that are small enough not to be irreversible commitments (for example, to find out about the location of testing centres). In (ii) they narrow the temporal depth of field of their attention, to achieve the same effect under conditions where time pressure does not allow them to inch forward in chronological time. Since HD patients are not under acute time pressure for testing, they can take this process at a pace they find comfortable. Pregnancy offers less time to spare, and it may be this encourages the prenatal approach of 'I'll cross that bridge when I come to it', which separates difficult moral decisions that in practice are interlinked. These decisions might be overwhelming if considered together, but the change in depth of field allows women to treat them cognitively as separate microdecisions.

Some authors in traditional moral philosophy, most famously Kant, have taken mental processes like these as irrelevant to the validity of an ethical judgement or a line of reasoning. In this view, the correctness of an act is evaluated by its fit to moral laws, principles, or rights; and evaluation of this sort has no interest in what goes on inside someone's psyche as the decision is made. For other philosophers, however, moral psychology is a necessary part of ethics. Moral psychologists model moral behaviour as requiring both cognitive and affective functions, usually in a sequence involving perception, judgement, motivation and implementation.[14] Although the models proposed by moral psychologists differ in detail most take the approach that accounts of moral agency are inadequate if they draw solely on the vocabulary of rationality, conscious deliberation, or autonomy. Some of these involve aspects of mental life that are traditionally neglected by or considered irrelevant to moral philosophy. However, we consider that although it may be acceptable for some discussion of ethical *theory* not to be empirically grounded, a theory of moral *agency* has to be, because it attempts to account for the behaviour of real moral agents and is therefore

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[14] D. Narvaez & J. Rest. 1995. The Four Components of Acting Morally. In *Moral development: An introduction*. W. Kurtines & J. Gewirtz, eds. Needham Heights, MA: Allyn & Bacon: 385–400; A. Blasi. 1984. Moral Identity: Its Role in Moral Functioning. In *Morality, moral behaviour and moral development*. W. Kurtines & J. Gewirtz, eds. New York: Wiley: 123–129; A. Blasi. 1995. Moral Understanding and Moral Personality: the Process of Moral Integration. In *Moral development: an introduction*. W. Kurtines & J. Gewirtz, eds. Needham Heights, MA: Allyn & Bacon: 229–253; L. Blum. 1994. *Moral Perception and Particularity*. Cambridge: Cambridge University Press.

ontological as well as ethical. A compelling philosophical account of moral agency must take seriously what other disciplines tell us about how people really do think and behave if it is not to be epistemically unsound and lacking in moral authority.

Moral agency in a genetic test is the ability to make and carry out a decision for or against having the test. If the decision is imagined as a singular event in a clinical setting, the ethical analysis of agency will focus on the capacity and competence of the patient, adequacy of the information provided by the medical professional, or the power differentials or other constraints of the patient/doctor relationship that might compromise the ability of the patient to exercise agency. But although this analysis identifies many salient problems in the clinical encounter, it is inadequate from the moral perspective of the patient. Decision making has to be seen as a *process over time* in order to perceive the patient's full exercise of moral agency.

In our interviewees' accounts there was rarely a single point where *the* decision about options with their different consequences and implications was consciously taken. More often people made a series of microdecisions of greater or lesser magnitude. This could appear to the outside observer – and even to the patient – as the absence of any real choice. A series of microdecisions can seem to lack any point at which the patient exploited their agential capacity. And in one sense this is true: the microdecision sequence does lack a *single* moment that can be identified with 'the decision'. But in our view, this does not mean that no moral agency was involved. A microdecision model sees the genetic testing decision as constituted by multiple steps that do result, ultimately, in an outcome. At each of these microdecisions our interviewees were able to make a genuine choice (their actions could conceivably have been otherwise), which was as autonomous as possible within the constraints of their circumstances, and for which they could generally provide reasons (so they were not *unreasonable* choices, even if they were influenced by more than rationality or logic alone).

A series-of-microdecisions could even imply *more* agency than a single decision. At each of Sabine's *n* microdecisions, she had to consider her immediate and long-term goals, and how she wanted to reach them, in order to pursue her decision sequence over time consistently enough to feel that she was continuing to do the right thing. As Sabine's decision illustrates, the test can still be rejected, even after a series of earlier steps have led her closer to consent. Subsequently, a narrative recollection of all the earlier steps, together with the experience of their consequences as far as they are yet known, can lead to a new assessment. This enduring form of agency is different to the kind of agency visible in a single crucial moment of choice.

Preserving the integrity of the moral agent

But as well as *permitting* the exercise of enduring moral agency, time manipulation also *defends the ability* to act as a moral agent in difficult circumstances. It is clearly a mental coping mechanism, but its ethical character is uncovered by asking, why do people in these situations feel they need to cope at all? Why not just fail to cope (at least temporarily)? One reason, of course, is that most people will avoid failure because of the unpleasant feelings and social consequences associated with it. But we want to suggest that the manipulation of time is not simply about controlling the process of decision making, but also about preserving a 'space' in which moral agency can be exercised. Moral agency requires moral competence, and full moral competence demands the ability to perceive the ethical dimensions of a situation, to describe them accurately and scrupulously, to identify morally salient features, to judge whether action is required and what that action might be, and to relate this to one's guiding moral values. All these functions in turn demand a high degree of cognitive, affective, imaginative and motivational capacity. These capacities are vulnerable to the mental state of the agent. Conditions of external pressure and internal distress compromise a person's ability to perceive and evaluate, and reduce the ability to empathise at the expense of an increased urge towards self-protection: this is why 'grace under pressure' is recognised as an extraordinary virtue, while acting well under ordinary circumstances is not.

If a person's ability to perceive, reflect and empathise is compromised, so is her capacity for moral agency. Note that these prerequisites for moral agency are not the same as the well known Kantian ones, where agency is defined by the abilities to think rationally and act autonomously. Although an individual may not be completely rational under extreme conditions, they would be in just as much trouble if they lose the ability to make use of other morally salient mental skills: emotional intelligence, empathy, or a sense of proportion and perspective.

We suggest that our participants knew that their moral competence was likely to be put at risk if their emotional stability was severely reduced. Strategies that include restricting the focus of moral attention or slicing the process up into manageable microdecisions are used not solely to attenuate the psychic pain of difficult choices – although that comes into it – but also to preserve a cognitive and affective space within which he or she can continue to perceive the situation sensitively and accurately, and recognise his or her moral responsibilities within it.

Demonstration of moral commitment

Irrespective of whether it is done primarily with the aim of preserving psychological stability or to maintain coherence as a moral agent, time manipulation also demonstrates the *desire* to take up a morally responsible position. The individual is making an effort to avoid being *morally* overwhelmed, because being overwhelmed is not a good state in which to make reliable decisions that are congruent with one's enduring moral values. The importance of being able to do this has been demonstrated by philosophers who have discussed how orientating oneself to ethical norms provides one of the key 'sources of the self' of the modern world.[15] Defensive strategies, like the ones our participants used, prevent the fragmentation of the self as a moral as well as a psychological entity. The aim is to maintain the coherence of the interior sense of self, including the capacity to act as a moral self. From this point of view the defence of moral capacity is itself a demonstration of moral commitment.

IMPLICATIONS FOR CLINICAL PRACTICE AND ETHICS

Finally, we want to sketch out some questions these observations raise for clinical practice and bioethics.

Timing of testing and counselling. Guidelines on genetic testing increasingly stress the need for adequate pre-test counselling. Although driven by proper concern for patient autonomy and welfare, the accounts of our participants suggest that in some cases pre-test counselling may miss the real decision point. Many of the interviewees had already done their thinking through, sometimes years earlier. In these cases, patients are likely to feel patronised by a doctor suggesting that they now need to reflect a bit more. We also need to raise the question of how public health services can optimally support people undertaking this longer decision process, even before they come into the surgery.

We saw that the overt rationale people give to explain their decision to test, and its timing, can appear contingent or unreflected (e.g. in one case the arrival of a new doctor at the practice). Yet detailed accounts of our interviewees emphasised that what appeared irrational could make sense in the context of a life story, and they also described how an overt, seemingly trivial reason could be the trigger activating a decision that had long been made. Bioethics' evaluations of patients' decision making needs to take into account the longterm narrative frameworks within which their choices make better ethical sense.

Time for reflection. Before the locus of the HD gene was cloned, a linkage test was available, which required samples from affected and unaffected members of the family to identify shared genetic markers, and could last for months. For many patients the wait was excruciating. This is in marked contrast to the speed with which test results using a cloned gene can be made available today. Faster testing is generally seen as benefiting both patient and the healthcare provider. But we might need to bear in mind that just because the test results come faster does not mean that the information they provide has also become trivial or more easily absorbed by patients. If our interpretations of the time manipulation strategies is correct, it may also be that a longer testing process

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[15] I. Murdoch. 1970. *The Sovereignty of Good*. London. Routledge; C. Taylor. 1989. *Sources of the Self: the Making of the Modern Identity*. Cambridge: Cambridge University Press.

offers unexpected benefits in giving extra time, not solely for rational consideration of the issues, but to safeguard their agential capacity in the way discussed earlier. As the mechanics of testing speed up, time for reflection may need to be built into the test process artificially.

Informed consent. Models of informed consent work from the premise that the information given to patients is understood by them and remains accessible to them throughout the whole decision making process. Our results call this assumption into question. Particularly where tests are closely coupled to another intervention (termination of pregnancy, surgery) requiring its own decision, some patients temporarily excluded longer term perspectives. To preserve moral competence, they chose not to draw on some of the information they had. The strategy of reducing the temporal depth of field may explain the discrepancies, shown by empirical studies, between the decision to test prenatally and the non-acceptability of termination.[16] Our interpretation suggests that a situation where a woman has agreed to testing, seemingly without thinking about the possible consequences of termination, is not necessarily a case of irrationality, nor due to errors of comprehension or communication, but might in fact be necessary for her moral agency.

Taking the patient's perspective. It comes naturally to doctors and ethicists to treat genetic tests as clinical events, and to focus on ethical issues close in time to the clinical encounter. But from the patient's perspective the test decision may not feel like a single event or act, and the important step towards their final decision may happen well outside the timeframe of the clinical story. Indeed, for some people the process itself may take on such importance that the test result becomes something of a side-issue. Sabine, who at the start of the process had not faced the reality of HD at all, finally said:

> *HD will always be in my life. My mother has the illness and there are four of us [in the family] who are potential gene carriers, and one of us will have the disease [sic]. So whether I have it or not, it will be in my life.*

From the point of view of the patient, her primary ethical responsibility is not to make the ethically correct or ideal decision, but to find a solution that she believes, from past experience, can be part of her moral biography of the future. Patient perspectives like these are harder to incorporate into bioethical thinking than the more familiar medical point of view, but they are essential if bioethics aims to contribute to moral understandings of the world beyond the clinic. Empirically-based studies, used as we have done, can enlarge our normative ethical theorising, in this case deepening our understanding of patient agency in the complexities of real-life decisions enacted over time.

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[16] E.M. Kraus & D.B. Brettler. Assessment of Reproductive Risks and Intentions by Mothers of Children with Hemophilia. *Am J Med Genet* 1987; 26: 259–279; S.Whitelaw, J.M. Northover & S.V. Hodgson. Attitudes to Predictive DNA Testing in Familial Adenomatous Polyposis. *J Med Genet* 1996; 33: 540–543; M. Levy & S. Richard. Attitudes of Von Hippel-Lindau Disease Patients Towards Presymptomatic Genetic Diagnosis in Children and Prenatal Diagnosis. *J Med Genet* 2000: 37: 476–479.