Disclosure in Health and Illness

Edited by
Mark Davis and Lenore Manderson

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Disclosure is a frequently used but rarely interrogated concept in health and social welfare. Abuse, disability, sexuality and health status can be 'disclosed' to peers and professionals and, on some occasions, disclosure is a requirement and not a choice. This innovative collection examines the new social and political implications of disclosure practices in health and illness.

We make our identities and our connections with others by sharing life stories, experiences and innermost desires, and are often asked to disclose facts about our lives, bodies and minds, at times with unintended consequences. Yet how and what, why and when people 'disclose' – and perceive, question and expose – and in what ways, has rarely received critical analytic attention. The contributors take up these problems by foregrounding the many shades of disclosure: from the secret, through the telling of diagnosis, to the more prosaic sharing of narratives from everyday life. The processes and implications of disclosing are addressed in areas such as: illness trajectories and end-of-life decisions; ethical research practices; medical procedures; and interpersonal relationships.

Exploring the idea of disclosure as a moral imperative and a social act, this book offers a diverse range of empirical case studies, social theories and methodological insights to show how dominant and normative understandings of social relationships and their obligations shape our understanding of acts of disclosure, enquiry and exposure. It will be of interest to students and academics with an interest in narrative studies, medical anthropology, bioethics, health psychology, health studies and the sociology of health and illness.

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Routledge Studies in the Sociology of Health and Illness

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1 Telling points

Lenore Manderson

Disclosure is about telling, in all meanings of the word. Telling is an act of narration, it is a revelation, and it is a reflection of the importance of the information so imparted; the telling in disclosure is therefore a noun, a verb and an adjective. The stories that are told in disclosure typically hold deep significance for the storyteller; they are neither mundane facts nor simple biographic details. For this reason, the telling is staged. How such telling occurs tells us much about the teller, the witness, and the social times in which such acts of disclosure take place, as well as of the secrets that are disclosed. Yet typically we speak of disclosure lightly, as Corinne Squire suggests (this volume), without questioning its content, form, or cultural salience. We rarely interrogate the nature of disclosure, or the ways in which telling is structured and institutionalised, mandated and manipulated. In this introductory chapter, I worry at the complexities of disclosure and telling, anticipating the rich empirical examples and analytic details provided in the chapters that follow.

The social imperatives of disclosure

Disclosure, and the cultural protocols that shape telling, are central to how we establish and maintain intimate relationships, learn of and address medical diagnoses, disease and dying, conduct research with other humans, and manage public life. In various official contractual settings, disclosure is mandatory: a person wishing to borrow money or access credit is obliged to reveal all financial encumbrances; applicants for life insurance must disclose preexisting health problems. Everyday acts of disclosure are underpinned by social conventions that draw upon ideas about truth and the importance of truth telling. Official documents, including birth and marriage certificates, passports and drivers' licences, are presumed to tell certain personal truths as much as demographic facts about the bearer, and given this, the production and possession of forged documents are indictable offences. But such documents are also technologies of disclosure and exposure. Consider sex, in this context, and the power of documentation for people who are transsexual (see Vernon, this volume). The letter of the

law, its rule, and its processes centre on ideas of truth and truth telling, reinforced in court hearings through oath or pledge. Similarly, cultural ideas about the importance of truth telling and the right to know influence how private, secret or suppressed information is provided to and reported by journalists.

Disclosure shapes much of economic life too. Selling and purchasing anything from food or medication to a house or a car are underpinned by explicit disclosures, including statements that prove that an item can be sold or that the product is safe. Ideas about disclosure inform the law, and establish what people are required to do by law, and these ideas are echoed in ethical statements and practices, economic transactions, everyday interactions and interpersonal relationships.

In this volume we set aside considerations of politics, law and economics, and focus on health, illness and personal life. But it is important to note, at the outset, that ideas about telling and truth inform how people interact in all kinds of social contexts. Jurisdictions vary, even within one nation, with regard to the mandatory or volitional disclosure of being HIV positive prior to having sex, for instance, regardless of the decision around safe sex. Yet at the same time, in everyday life, truth telling is implicit and normative, and the word of the individual is often enough. While legally people who are HIV-positive cannot donate blood, semen, ova or any other body tissues, the means of disclosure, a statement on an application form, is usually sufficient. We assume that people introduce themselves in a truthful way, and we accept as truthful the disclosures that unfold in autobiographic accounts. Hence the distress for the person who has received and accepted such stories when the accounts unravel, and the disclosure is discovered or exposed to be confabulation, fraud, delusion or wilful misrepresentation.

The timing of telling

Because disclosure is a particular kind of telling (Flaherty, Pleloran and Browner, this volume), the construction of truth and how its telling unfolds is never a trivial matter. In intimate contexts, both small specific and larger more profound disclosures take place as private acts. The timing and intent of telling are also disclosures, often of expectation, trust and risk, and understandings of intimacy and care. They illustrate how disclosure can occur in anticipation of changes in relationships, or reflect the perceived maturity of and evolving trust within a relationship.

Disclosure involves telling the truth of an aspect of the self – being HIV positive, for instance, or experiencing depression. This is so even if the teller resists the facts that are disclosed as revealing essential or fundamental truths, as suggested in this volume in relation to mental health status (Kokanovic and Philip) and natal sex (Vernon). Consequently, disclosure positions the discloser in relation to others (or one other, the disclosee); in this volume, these disclosures are often statements of biosociality, as illustrated in relation

to HIV (see Davis and Flowers, Root, and Squire) and Huntington's disease (Flaherty, Pleloran and Browner). And by virtue of the need for another, the telling, although often treated as private, is also always a public fact.

The risks to telling the truth include rejection, discriminatory actions and physical violence, and hence people employ various strategies to disclose or conceal. Each decision about disclosure asks an individual to weigh up the costs of truth or its suppression, including the relevance of a truth to other interpersonal and social ties, acts and engagement. For instance, HIV may not be considered by a person to be an essential truth of the self, but telling (or not telling) is an aspect of the representation of self, and the context of telling can shape the receipt and interpretation of knowledge. Disclosure of a medical condition may be received as a warning of risk of infection, for instance, but it also or instead may be presented and interpreted as a statement of community identity and membership, or as a gesture of trust.

In deliberating on the nature of truth and the importance of disclosure, as revisited and elaborated in the following chapters, I wish to consider how a single statement to one other person about the bioself (disclosing HIV status, transsexuality, or living with depression, for instance) is only the beginning of a sequence of social acts and exchanges of information. Our understanding of this, as social researchers, reveals how disclosure features in social and political, private and public lives. With HIV, for example, disclosure has become a central act in negotiating intimate relationships, in light of understandings of the moral and public health responsibility (as opposed to the legal imperative) to tell (potential) partners of possible health risks or exposure to infection. These ideas extend variably to STIs such as chlamydia, HPV and HSV, and to other blood-borne viruses (e.g. HBV, HCV). Each of these disclosures – the presence of an infection – is also a disclosure by proxy of other personal culturally nuanced facts, such as a history of unprotected sex, possible multiple partners, possible injecting drug use.

Disclosure unfolds in many different ways, even in this contained example of HIV. This includes the decision that must be made to tell or not to tell of HIV status in the context of an imminent or anticipated sexually intimate encounter. The disclosure may occur through a speech act, itself a simple statement of infection status or an extended revelatory explanation of sexual history and testing, or it may occur by proxy, by openly taking medication or reaching for a condom, for instance. These decisions of timing, form and content are framed by legal requirements, moral values, fear and expediency. Other HIV disclosures and concealments occur in the course of various mundane and strategic activities. They involve decision-making about whether and how to tell family members, friends, doctors and dentists, work colleagues, insurance companies, superannuation fund managers, and national governments (on applying for a visa, for instance) (see for instance Hardon and Posel 2012). The strategic concealments, in these contexts, are as important as the disclosures, and as self-conscious, as one example on the

website of the Australian Federation of AIDS Organizations (AFAO) (2013) illustrates: 'I keep my HIV-pills in vitamin bottles. It avoids unplanned disclosure.' And, insofar as social life is always fluid and changing, as relationships evolve, this decision making about disclosure is also routinely revisited.

Even these examples limit our understanding of how and when disclosure occurs. Disclosure can be the unintended consequences of other actions or associations, as occurs for people with HIV who present to a health service established to meet their needs. Matthew Wilhelm-Solomon (2013) illustrates how in a displacement camp in northern Uganda, the provision and distribution of food aid and water containers, as well as antiretroviral therapy and other services, by association exposed some people to others in the camp as HIV-positive, in consequence producing HIV-specific health identities with ambiguous results. In this example, the different kinds of foods provided to people registered as HIV-positive (yellow soy beans rather than white maize), the days on which food parcels were delivered, and the colour of water containers (white not yellow) all indexed HIV positivity, 'transcending the paradigms of voluntary or involuntary disclosure' (Wilhelm-Solomon 2013: 232). Isak Niehaus similarly illustrates the cost of disclosure in relation to a person's HIV status. In his research setting, knowledge of HIV infection implied sexual promiscuity, so opening up speculation about others who might be infected, and precipitating social interactions based on ideas of the liminality of people with HIV, as living between life and death (Niehaus 2014).

Ashforth and Nattrass (2005: 293) draw attention to the power of these presumptions in shaping the decisions of people to disclose publicly, even for those who are in other ways outspoken activists, because of the possibility of discrimination including in health services, or because knowledge of another's HIV status might precipitate violent assault. Such public acts of abjection reinforce concerns about the risks of disclosing either volitionally or unintentionally (Tenkorang et al. 2011, Parle and Scorgie 2012, Scorgie et al. 2013). Since institutions, settings, bodies and technologies are not innocent, people who directly address whether or not to reveal a particular truth of the self must manage the flow of information to prevent the seepage of knowledge that might cause harm. Wilhelm-Solomon's examples of the discriminatory distribution of food aid and the colour-coding of water containers illustrate how easy it is to expose someone else, pre-empting their choice to disclose or not. Where knowledge has public currency of some kind, disclosures can occur through context, association and action, as well as explicit speech acts.

By way of a different example, Sargent and Kitobi (2012) write of the challenges faced by north African women living in Paris to control their fertility, and the strategies that they employ to disguise from their husbands and others their use of contraception. Accordingly, women hide contraceptive pills, or choose a method such as an injectable or an implant to avoid

detection and possible consequent physical and verbal violence, abandonment, or polygamy, were they found to be using contraception without spousal permission. Yet even the most 'secret' methods may be discovered by a suspicious husband feeling for and discovering an implantable rod under the skin of his wife's upper arm, for instance, or by others, observing the woman's regular visits to a clinic and speculating on the causes of her doing so. Woman therefore regularly make difficult decisions as they negotiate fragile relationships which might implode in the face of disclosures of various histories of the body: sexual history, experience and preference, abortion, contraceptive use, sterilisation, sexually transmissible infections, HIV, or a history of sexual assault (see, for instance, de Zorda 2012).

Containing the truth

Because much is at stake when private information becomes public knowledge, people use complicated manoeuvres to contain disclosure and keep private facts secret. Any exposure or disclosure, whether orchestrated, unintended or circumstantial, impacts personally and interpersonally. Abortion is routinely concealed when it is procured, to avoid interference by the sexual partner responsible (or other partner), by family members, and, where its procurement is illegal, by the state and its representatives. But it is also concealed over the long term so that the woman can avoid disapproval and unsolicited questions of honour (Shellenberg et al. 2011, van der Sijpt 2012, Astbury-Ward, Parry and Carnwell 2012). Further, negative attitudes to abortion impact health providers as well as clients (Harris et al. 2011, Youatt et al. 2012), for the stigma that is associated with certain actions, bodily histories and diseases routinely flows from the primary actor to others in their social world.

In a similar way, tuberculosis is 'risky' for the person infected, not only because of its infectious nature and severe morbidity, and the effects that this has on diagnosis and treatment (Murray et al. 2013), but also because of its symbolic and symptomatic links to HIV and the stigma and social marginalisation associated with both infections (Daftary 2012). Again, family members, health workers and others share this stigma. Further, because stigma extends to people working in occupations and industries most despised for cultural reasons (waste management, for instance), even a person's occupation may be withheld because of the social risks of disclosure. Ben Okri's award-winning novel *The Famished Road* (1991), and the account therein of the efforts that Azaro's father takes to avoid exposure to his family and community as a night soil collector, is a case in point. The idea of disclosure as impacting only or primarily on the speaker – the keeper of the secret – is therefore a very partial truth. The recipient of the truth disclosed is also affected, if only because telling cannot be revoked; the acts and facts of disclosure are indelible. This is true for both private and public disclosures which, as already indicated, reveal far more than a person's

biostatus. Health-related disclosures, for example, routinely index other aspects of sexuality, sexual practices, drug-related behaviour, and so on. Further, while there is an illusion of relative equality when disclosures are made between the one who discloses and the one who receives the disclosure in intimate relationships of private actors, gender, age and other social structures destabilise presumed equality and sharpen concerns of what might be at stake in any disclosure. Differences in social and structural status trouble statements of the self.

The adoption of children provides a vivid example in this respect, partly because all people are affected by the decision (forced or voluntary) to surrender an infant to another person. In different jurisdictions, this act of surrender has changed significantly over a very short time, with changes to social attitudes and the state's accommodation of ex-nuptial births, as well as changes in laws that govern the right to adoption and access to personal information (e.g. the date and place of birth, the name of the mother, genetics and birthright). The formal apologies to women who were forced to give up children for adoption, which took place in 2013 in Australia, illustrate dramatic shifts in ideas about genetic origin and social parenting, and the scientific, social and economic policies that help shape these in the past fifty years. But they also rehearse the ethical and moral dilemmas and emotional weight of other reproductive decisions and possible disclosures – around surrogacy, gamete donation, and IVF (in vitro fertilisation), for example (van Berkell et al. 2007, Readings et al. 2011).

The stigma that makes disclosure a risk is explored in this volume particularly in relation to mental health problems (see chapters from Kokanovic and Philip, this volume; Seeman 2013) and sleep disorders (Wolf-Meyer, this volume). Because of the social and economic impact of a history of mental illness, or of sleepiness, consciousness and its productive importance, knowledge is managed at multiple levels. As both Kokanovic and Philip, and Wolf-Meyer illustrate, people very carefully weigh up the costs and benefits before speaking or acting. The high risk for parents with mental illness of losing their children (Hollingsworth, Swick and Choi 2013), temporarily or permanently through state intervention, suggests one reason behind the reluctance of people to seek mental health care and practical assistance, although the surveillance of parents by child protection agencies is compounded by other considerations. In the case of intimate partner violence, for instance, Rose and colleagues (2011) argue that people with mental health problems also fear that disclosure (of violence) would not be believed, compounding reasons that prevent reporting and ameliorative action in such circumstances (Westad and McConnell 2012).

Although disclosure is understood to be a statement of an important truth, how and when that truth is shared is subject to debate and circumstance, context and culture. The decision to disclose or withhold is always framed by interpersonal relationships and their value, since disclosure definitionally is a statement of the self to another (or others). It implies personal agency

and, if this is true, then Wilhelm-Solomon's example of food aid and water containers is an instance of exposure rather than disclosure. One discloses one's self; others expose. But in addition, the private or quasi-private interpersonal nature of disclosure, as sketched out above in relation to HIV, is one small example of how we might understand telling. Since disclosure is about the self, the decision to disclose is richly imbued with questions of identity and relationality. As we illustrate, chronic non-communicable conditions, HIV, sexual health, inheritable diseases and mental illness provide us with case studies to consider methodological questions and substantive concerns, including the particularities and commonalities of different health states and communities. Further, our focus on health and illness allows us to develop theoretical understandings that translate readily to other domains. Sexual abuse, addiction, criminality, wealth, inheritance and family history all come to mind as personal fields that may be no less volatile than sexual history, infection or health status, or genetic risk. These matters of disclosure all evoke considerations around confidentiality, trust, risk, intimacy, and fear or its disposition.

Autobiographic and other personal information may be deemed worthy to tell as 'essential truths' of the teller, but also, as suggested in the case of HIV, because of the direct impact of the disclosed facts on the health and wellbeing of the other. In such cases, acts of disclosure and the ethical considerations that influence telling are reasonably clear. But we need to look more closely at other allied concepts and contexts to better understand disclosure as both a public and private act, and to link disclosure to related and distinctive concepts and actions, including those of truth, privacy, secrecy, exposure and closure. These are concepts all at the heart of much social (inter)action. In the process of such unpacking, disclosure takes us back to Foucault's world of biopolitics, power and knowledge (e.g. Foucault 1978). Differences in social and structural status, always apparent in clinical encounters but also in work settings, overdetermine who discloses what information, and at what cost.

Medical disclosures

Disclosure is a fundamental and underlying principle of clinical relationships, human bioethics and professional and institutional life. Disclosure is translated into a set of responsibilities in research practices, working environments and in clinical relationships, although what is disclosed, and by whom, is routinely subject to review. Disclosure by doctors to patients is incorporated into medical training, a central element in effective medical care despite shifts in guidelines and their practice. Disclosure is central to any discussion of the practice of medical diagnosis, treatment choices and regimes, and prognosis, and to the component parts of these sequences of events. Ideas of the cultural significance of disclosure of a diagnosis of cancer, for example, fold into disclosures of its prognosis, the risks and the outcomes

of surgery, future monitoring and adjuvant therapy, of who else needs to be told, and at what level of detail. Medical ethics frame discourse around the risks of treatment, stipulate informed consent, and provide ways of preventing, informing and managing adverse events. In medical discourse, disclosure centres on the communication of knowledge of a person's health (or illness) status, or the potential to develop an illness in time, as suggested by the example of cancer (above) or of Huntington's disease (Flaherty, Preloran and Browner, this volume). Thus disclosure includes questions of the etiology, diagnosis and prognosis of a given condition, the propensity for illness, and its transmission and risk to others. The dilemmas of truth telling in such circumstances have increased in recent years with the growing confidence of geneticists and clinicians to understand the development of disease, the improved sensitivity of diagnostic and screening technologies, increased access to such technologies, and a growing expectation that people will wish to take advantage of these. The dilemmas of truth telling have intensified, therefore, with expectations that people already identified as at risk will undergo specific tests and act in ways concordant with the results. From this point, screening becomes routine, creating an increasing need (if unmet, in global terms) for counselling to ensure informed consent and to help people decide on action, including how to disclose their diagnosis to loved ones and others. Here, the imperative of disclosure produces specific social relations, as the discloser seeks out relations of support and service, and reflects on and acts in accordance with understandings of personal morality and ethical responsibility.

While ethical considerations shape theoretical understandings and the practical use of genetic diagnostic technology, the information produced through this technology must necessarily be disclosed to the owners of the genetic material in terms of advice on reproductive futures and the possibilities of disease in future generations (Hanssen 2004, Hertogh et al. 2004, Padilla et al. 2008, Root 2010). Flaherty, Pleloran and Browner (this volume) illustrate this in relation to Huntington's disease, when they highlight distinct local understandings of medical, biological and personal knowledge, and so draw attention to the challenges in clinical medicine and public health in relation to truth, revelation and risk.

Increasingly, disclosure is shaped by technological change, as occurs when the possibility of developing an illness and its probable trajectory can be mapped out. Individuals who are directly affected must determine who should do the telling, and make decisions about the social actions that follow from the disclosure. New forms of biomedical care intensify requirements of patient disclosure to diagnose and treat diseases and to prevent their onward transmission to progeny or in sexual life. Discourse on disclosure in these fields of action attends especially to the reasoning, processes and implications of disclosing in biomedical (or biosocial and medical) fields.

But disclosure is complicated by inequalities of power and cultural ideas of truthtelling. Joe Kaufert (1999), drawing on ethnographic work with

native Canadian communities in Manitoba, and Elizabeth Bennett (1999), with the Isaan in northern Thailand, highlighted the elasticity of this simple understanding of the right to know, and the relative role of people within given social networks – families and health professionals – of managing, translating and relaying information. In the case of illness trajectories and end-of-life decisions, senior health professionals may initiate disclosure, but who receives the disclosed information varies, as does their capacity to make sense of the knowledge imparted (Bennett 1999, Kaufert 1999). Moreover, social and structural status determines the occasion, content and comprehension of specific truths. Even the apparently simple act of relaying a diagnosis can be fraught with cultural, moral and ethical challenges, including who to tell and how much information, with what spin, to provide.

A focus on clinical disclosure elides the fact that any disclosure has a social life. The disclosure is not simply given and received in a consulting room. In any intimate relationship, for instance, questions of the body and its genetic provenance become relevant. Individuals grapple with the timing of when it is appropriate to reveal that they have (for example) a colostomy, that they carry the genetic markers for breast cancer, or that they had a parent who had died of suicide or a cousin in jail for sex crimes; they rehearse their capacity to speak about and address questions of inheritance, influence and trust. People often get the moment of timing wrong, too, for there is no 'right time' to disclose some facts of the self. Hence, people often choose to withhold knowledge, where it is not culpable, to ensure privacy and to avoid intrusion, so as to manage various social interactions and perceptions. People may, for example, elect to withhold a diagnosis from others even in the case of non-communicable disease, not to disguise the risk of transmission, but to manage other people's emotional responses to diagnosis and so to contain others' inquiries into their health and how they live their lives (with respect to diabetes, see Kokanovic and Manderson 2006).

While Goffman's ideas of stigma help us understand these considerations, his work on impression management is equally relevant here (1959, 1963). The management of 'essential truths' of the person occurs in relation to various problematic health conditions, including infections, as indicated above with respect to HIV, and for leprosy and TB, but also in relation to degenerative and potentially fatal conditions (multiple sclerosis, haemophilia and Alzheimer's disease). The management of truth is perhaps especially relevant for mental health conditions, even for very common conditions such as depression (Kokanovic and Philip, this volume), and for sleep disorders (Wolf-Meyer, this volume). People in paid employment are often mindful of the potential economic costs of disclosure, but also may be mindful that public disclosure can work strategically to ward off further invasions of privacy, and dilute any fear of risk of exposure by others. I am thinking here of trans people who, by choosing the timing of their disclosure of their gender identity, pre-empt their exposure by others (Vernon, this volume).

Technologies of telling

Historical traditions of truth telling, such as the confessional in religious traditions routinely and at end of life, suggest that disclosing matters are revelatory of the individual (Hymer 1995), and that the failure to tell is morally and emotionally corrosive, so reinforcing the idea of the confession as normalising (Foucault 1978, Munro and Randall 2007). The contrived confessions and disclosures of false consciousness, that symbolically marked the end of one life (capitalism, bourgeois desire) and augured a new life (for instance, under communism), extend this notion of the power of telling. Recent examples highlight the power of the confessional to manipulate the public. For example, Tonda (2001) illustrates how prophets and anti-sorcery pastors emerged at the centre of ethnic and national conflicts in the Congo, challenging other established political, medical and religious relations. This is not unique to religious and quasi-religious practice. However, the apprehension of criminals partly depends on the willingness of people to come forward to confess a crime, as an act preferable to the lifelong surveillance of the self to avoid exposure, and interrogational techniques shaped to elicit the confession and establish remorse (Kidwell and Martinez 2010, Martel 2010).

At the same time, the increased bureaucratisation of everyday life and the rationalisation of education, work and law, to name a few, means that increasingly publics are asked to disclose facts about our lives, bodies, minds and pecuniary and material interests, at times with unintended consequences. Exposures that occur through Wikileaks, Facebook and other social media are flashpoints for strenuous debate about privacy, implying that a new politics of disclosure is taking shape in a densely networked world. Social research, too, depends on research participants' willingness to share their life stories, often on the claim that the telling will produce both personal and wider social good.

Disclosure therefore leads us to consider the dynamics of secrecy and truth telling, broadcast and exposure, in public and private domains. Ideas of the 'truth' of personhood and identity, distilled through specific 'facts' of the self, and notions of interpersonal responsibility, shape how secrecy and secrets, privacy and confidentiality are upheld, unsettled or resisted in particular settings (Bharadwaj 2003, Crook 1999, George 1993). Within families, for instance, the value of privacy, the maintenance of secrecy, the cost of confidentiality breaches, and the power that these values exercise over individuals, can have deep repercussions, as discussed in relation to abortion or fertility control, for instance, but also in relation to questions of infidelity and sexual abuse, or, in different cultural contexts, to questions of female genital cutting or male initiation, when disclosure across gender or ritual boundaries threatens social coherence (see Boddy, this volume).

Further, communication technology has reshaped how people disclose, to whom they disclose, and how they protect themselves from unintended

disclosure. For example, e-health is figured, in part, around the circulation of knowledge on health status, health and bodily aspirations, and other aspects of identity, and disclosure of a particular identity marker is a prerequisite to belonging to many online as well as in-life biocommunities, even when the information disclosed, and its associated identity, cannot be verified (Davis and Flowers, this volume). Increasingly, health care too is delivered by communication technologies, with disclosure the mechanism by which to gain access to care and support. Thus medical and communication technologies have contributed to our concern with disclosure: the effects of technologies of disclosure on social relationships, wellbeing and life circumstances; the slippages that routinely occur between secrecy, confidentiality, disclosure and exposure; and the implications of these for self-presentation, social relations and sociality.

As the above illustrates, disclosures occur at multiple levels. These include the proximate context of the telling; the choice of the person who is recipient of the disclosure; the presentation of self often politically and morally; the role of the discloser to others who are part of the account of disclosure; the nature of social relationships revealed in the context of disclosing; the emotional response of the discloser to the positions that others might have adopted; and the emotionality (or its absence) in the act of story-telling. These are not 'small stories' of everyday lives, as Janet Boddy (this volume) uses the term. Rather, small stories emerge in the sequencing of stories of disclosure, with each small story containing a new revelation and account of the self. Even the simplest most economic disclosure – 'I am HIV' (Davis and Flowers, this volume) – does more than inform the listener of the discloser's viral status. The metonym reveals much of how an infection, by virtue of its history, and its significance in shaping both the present and the future, comes to dominate an ordinary life. At the same time, the economy in telling leads the discloser and disclosee to reflect on the emotional impact of HIV, and its capacity to render almost mute those living with the virus. A disclosure is not (only) the words that are voiced, but the gestures, demeanour, silences and tears that accompany different matters of disclosure in different contexts and settings. The embodiment of nervousness, anxiety, fear or relief, or the display of any other emotion, frame the act of disclosure and invite or discourage inquiry from the disclosee. These facts in turn provide openings for, or close off, the potential for further disclosures.

In the public domain

Individual and government decisions to contain and prevent disclosure have much in common as strategies to maintain social order. The possible outcome of disclosure, even in the personal instance of telling someone about HIV status, is to destabilise and disrupt; the outcome of exposure is intentionally to destabilise the individual. But any disclosure can destabilise in unanticipated ways. Researchers of war and violence routinely