Discourse communities and the discourse of experience

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ABSTRACT Discourse communities are groups of people who share common ideologies, and common ways of speaking about things. They can be sharply or loosely defined. We are each members of multiple discourse communities. Discourse can colonize the members of discourse communities, taking over domains of thought by means of ideology.

The development of new discourse communities can serve positive ends, but discourse communities create risks as well. In our own work on the narratives of people with interests in health care, for example, we find that patients speak of their illness experiences as victims of circumstance; policy makers construct adverse experiences and challenges as opportunities to be taken; health care workers speak from a mixed perspective, seeing themselves as both victims and opportunists depending on context. To be trapped within the discourse of a particular community is to put at risk the ability to communicate across discourses. Membership of a discourse community can impair the habit of critique, and deny opportunities for heteroglossic discourse. Privileging critique as a mode of discourse perhaps might define the *ethical community*, suggesting that ethical community may be an antidote to the constraining effects of conventional discourse community.

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Introduction

We are surrounded by discourse communities, which make up the society in which we live (Bakhtin, 1981). A 'discourse community' can be defined as a group of people with sufficiently common interests to use a vocabulary of words and concepts, whose meanings are accepted and whose definitions are assumed, that are brought to bear on the subjects of the discourse. It is a 'community of assent', to use Paul Morris's term, a grouping determined by agreement about ideology (Morris, 1996: 238–45). Each member of the group subscribes, in whole or part, to the 'ensemble of statements which . . . constitute [the subject of the discourse].' Thus, members of the medical profession share common concepts of disease-causation and disease treatment, and common understanding of words like 'cancer' and 'shock' which need no explanation in discussions among doctors. Discourse communities may not be so clearly defined as is the medical profession. There are discourse communities whose common 'ensemble of statements' define its members as 'racists' or 'postmodernists', for example, without necessarily implying membership of a registered association. Membership is defined by a particular use of language.

Each of us belongs to a number of discourse communities. We may belong to particular religions or churches, to trades or professions, to political organizations, to belief systems, family groups, sporting affiliations and so on. Each affiliation carries its own language rules. A doctor, for example, may use a familiar word like 'shock' in different ways in different discourse communities. When among colleagues at work, 'shock' means a state of inadequacy of the circulation, in which the vital organs and the patient's life may be imperiled. Among family and friends, however, the word 'shock' may be used in another sense to mean an emotional disturbance. In other audiences, the doctor may hear seismologists, futurologists or electricians use the word in entirely different contexts. He or she will hear these usages without any sense of confusion, recognizing a move from one discourse community to another, with a simultaneous shift in values, meanings, understandings and interpretations.

A discourse community is not, of course, a sharply defined group. Its margins will almost always be blurred in pluralist societies. Nevertheless, discourse communities exert considerable influence in most people's lives. Humans are both social and societal, and group membership is important to most (Dunbar, 1996; Warren, 1997). We like to belong, and belonging to a community of discourse is important. To be known to have particular political, social, aesthetic or sporting affiliations is to declare membership of groups that 'speak the same language'. There is comfort in belonging. There are also risks. Commitment to a discourse community provides support, but demands a certain degree of conformity if acceptance by the community is to be assured. Membership of a discourse community therefore potentially constrains what we should think, or at least say what we

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think. What begins as a voluntary process may become one of 'colonization', in the sense in which Habermas uses the word to describe the way in which the political/administrative System invades the personal, cultural Lifeworld (Habermas, 1987: 336–67). 'Master narratives', as Nelson points out, may determine the ways in which we construct our identities (Nelson, 2001). In Bakhtin's terms, discourse communities try to create a 'monoglossic' way of speaking, in which words are fixed in their meanings and limited in their uses (Bakhtin, 1981: 259–300).

Bakhtin has distinguished heteroglossia as the presence in a discourse or text of 'a multiplicity of social voices and a wide variety of their links and interrelationships (always more or less dialogized)' (Bakhtin, 1981: 263). Heteroglossia implies the importance of context over text, a capacity to move meaning from context to context, and a recognition of many nuances. It denies the monoglossic hegemony of meaning, as defined by powerful groups. It is the demotic, centrifugal force in language. It is a mode of speech which enables the construction of Nelson's 'counterstories' (Nelson, 2001: 150–88), the healing narratives which may restore autonomy to the disempowered.

In this article, we examine the ways in which different discourse communities with interests in health care construct discourses about their life experiences. The differences are radical, and probably contribute significantly to the communicative problems which have been documented by many authors over many years (see, for example, Carnocham, 1992; Illich, 1975; Little, 1995; Little et al., 2002; Moynihan, 1998). In making comparisons, we have drawn from biographical narratives given by cancer patients and their lay and professional carers; by those who make and implement health policy (politicians, health bureaucrats, health administrators, health economists); and business people working in health products.

Methodology

Details of methodology have been reported elsewhere (Jordens et al., 2001; Little et al., 1998; Little et al., 1999a; Little et al., 2000; Little et al., 2002). Briefly, narrative interviews were initiated with the generic question 'How did you get to be where you are today?' Narratives were allowed to proceed as freely as possible. Interviewers adopted the stance of 'empathic witness', engaging in conversation rather than trying to direct the interview. Interviews were transcribed and edited, and read by the research team. Each interview lasted from 40 to 75 minutes, and produced between 20 and 40 pages of transcript. Members of the research team used immersion/crystallization, ethnographic techniques, thematic analysis and novel linguistic methods (Jordens et al., 2001) in their examination of the transcripts. Weekly meetings of the research group used grounded theory to generate explanations of the data, and discussion continued until there was consensus. The material used in this article draws on 11 interviews with cancer

patients (most with colorectal cancer), 9 interviews with clinical carers, and 8 with policy makers and implementers. Names have been changed. Ethical clearances were obtained from participating institutions, and interviewees gave written informed consent to interviews and the use of material in subsequent publications.

Discourse communities and the nature of experience

It is reasonable to suspect that our membership of discourse communities will – to a significant extent – determine the ways in which we construct narratives of our experience. We experience events which involve us and which engage us. Events are always happening around us, but they constitute no experience for us unless we are aware that they are happening. We can experience events at first hand as participants in them, or at one or more removes when, for example, we observe or care for those who suffer, or by involvement in such things as literature, art, dance, cinema, television or sporting events. Experiences happen to us in our personal space, and within personal time. They involve change to ourselves and to things we care about at least enough to notice them. *Extreme* experience is experience which challenges our sense of identity in all its elements (Little et al., 2001: 94–105). Imprisonment, torture, natural disasters like earthquakes and cancer illness are examples of extreme experience. Extreme experience is extreme because it leaves no aspect of identity untouched. The physical, embodied component of identity is challenged, and its vulnerability made clear. There may also be physical changes in the body as a result of the extreme experience – changes made by treatment of dangerous disease or trauma, for example. The content of cognition, the perceptions and remembered experiences that make up the background to our thinking, changes. There is now available to it the knowledge that comes from the extreme experience, a knowledge that is hard to share with those who have not had similar experience. Similarly, emotions such as abjection, fear, depression or elation at the realization of survival, are experienced with an immediacy and intensity that cannot be freely communicated to others who have not had similar experiences.

We have no desire to revisit arguments about the epistemological status of experience (Scott, 1991), nor to re-examine the correspondence relationship between narrative and the events that make up experience (Mattingly, 1998: 43–7). We accept that experience does not have foundational status, that the claim to have experienced something does not certify the possession of 'truth'. Williams distinguishes between two senses of experience – (i) knowledge gathered from past events, whether by conscious observation or by consideration and reflection; and (ii) a particular kind of consciousness, which can in some contexts be distinguished from 'reason' or 'knowledge' (Williams, 1998: 126). We can distinguish, in the first of these definitions, 'experience' as the product of many events experienced and

reflected upon, in the second 'experiencing' as the subjective state or states produced by an event in which a person is involved. We agree with Scott when she writes that narratives of experience are 'discursive productions of knowledge of the self, not reflections of external or internal truth' (Scott, 1991: 795), and again with her claim that 'Experience is at once always already an interpretation *and* something that needs to be interpreted' (Scott, 1991: 797). In our context, experience in both senses is the material of narration, the matrix upon which meaning and values are mounted and presented to an interlocutor. For interlocutors, their own experience is also a matrix on which to lay out the meaning of the narrative heard. As Hastrup writes: 'Events make sense, not in terms of propositions, but in their coherence with our own experience' (Hastrup, 1995: 83).

Discourses of experience and health care

We have found that, at the extremes, narrators talking about their associations with health care tell of their experiences in two different modes. Patients and their lay-carers are victims of circumstance, people to whom things happen (passive mode). The events that overtake them are beyond their control. They may rise to the occasion, or they may be overwhelmed by it, but basically they are victims who do not choose what happens. Bill, a successful businessman, records his loss of autonomy when his rectal cancer is diagnosed:

> So that night I saw Dr. K—. He examined me. Confirmed that. Did a week of tests – biopsies, colonscopies. In those days it was done without any anaesthetic at C— here. And he said 'Right I have to get you into hospital straight away.' I said 'look can't I clean my desk? Can't I do this? Can't I do that?' He said 'No.' So furious racing around, and the following morning, 26th of July 1989, I went into hospital and was operated on the 28th.

Administrators, bureaucrats, business people, lawyers and insurance representatives generally tell us of the ways in which they made events into opportunities (active mode). Rani, a senior medical administrator, for example, tells us how she managed angry opposition from medical staff to an administrative decision, and emerged stronger and more settled in her position. Ken explains his move from medical research to medical industry by telling the story of his determination to understand business principles, about which he was completely ignorant. Seizing an opportunity, he re-creates himself in a new role, and succeeds with a major pharmaceutical firm:

> . . . with my *peculiar,* odd way of looking at things, I was valued. Probably valued more there than I have ever been in my life.

Ken stresses his role as agent in this transition in his life, and emphasizes the positive outcome of his choice and action.

Roy, manager of a medium-sized firm, which markets appliances for

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colostomies and ileostomies, explains how his satisfactions come from capitalizing on opportunities to create successful companies:

> I think firstly the challenge. I suppose a lot of people say that. But I mean, I have set up a number of companies and I like to see them successful. From a commercial point of view it has to be successful, because there would be nothing worse than having to put people off and so forth, so I like a company that is growing and expanding.

Events for this group of people are recounted as challenges to be dealt with by personal exertion, determination, intelligence and leadership. Their stories fall within the Heroic Quest genre (Campbell, 1973 [1949]; Frank, 1995), just as some illness narratives do (Frank, 1995), but the pattern of development is different from that of the cancer patient (Little et al., 1999b). Although the policy makers and business people tell us about challenges, they stress their own potency as agents of change to the systems in which they work. Patients are changed by those systems, over which they have little control.

Health care workers tell stories which sit somewhere betwixt and between. They are clearly agents of change for their patients, but they are victims of circumstance in two ways. First, they are involved morally with the extreme experiences of their patients. Jon is a medical oncologist, dealing with advanced cancer:

> But ah, I'm certainly aware that my approach to that interaction has changed a lot over the last few years. Because it is hard work carrying that burden. It might sound strange to you, but you *do* carry people's burdens to some extent if you sort of care about it to some extent. When you see thirty people a day, that is a lot of burdens to carry. And you go home and in the end you've got nothing left for your family or anything else, and so, you know, I am aware of that.

Max is an experienced colorectal surgeon:

> You know when you are simpatico with the patient. Now that takes a long time to learn how to do that. In the early days when you start off as a surgeon, your anxiety is: will I be able to convince this person that what I am saying is kosher, and that what I am proposing is all right? . . . You involve your insecurities in that story. As you become more secure and older, and you know that what you say sounds right because your experience proves it to be so, you start to communicate at a different level with patients. You start to communicate with their –, you greet their guardian angel, rather than greeting the patient. In other words, instead of greeting the patient you greet his suffering.

Second, they are profoundly affected by the vagaries and demands of the administrative and economic systems within which they must work. Jon, the oncologist, reflects on his reactions to administrative and bureaucratic interventions that might compromise his care of patients:

> Yeah, I think if it got to a point where someone couldn't get a treatment because of purely financial reasons, I couldn't then listen to somebody saying that there's

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universal health care available for all and you can get anything you want. Because if it really finally comes down to the proof that I have got someone who *can't* get something that they ought to have, I'd have to stand up and say, 'Nup. This isn't right.'

Max, the colorectal surgeon, registers the frustrations of working within a health system driven by economic efficiency:

The frustration of the job has nothing to do with the patient, has nothing to do with the nursing staff; it has got everything to do with a de-humanizing system. A system that just does not appreciate the fact that you are dealing with human beings who've been mutilated. A system that deals with length of stays, with, you know, reams upon reams of administrative questions and requests and . . . I mean most of the frustrations that I have to deal with are basically identified with administrators, *their* structure, *their* insecurity, and the unhappiness which all of this brings to doctors, *their* practices, and their patients.

Tom, a senior general practitioner, expresses his dissatisfaction with the shape and pattern of contemporary practice:

. . . at the present time I am extremely disillusioned with medicine, because I think, I think politicians have finally driven general practitioners into being just medical clerks, and I think the specialists are not far behind us. The old philosophy, if you like, which drove me to general practice was one where I did get a lot of satisfaction from being of use to my patients . . .

The experiences of health care workers are thus conditioned by the shifting relationships they feel between themselves and the system in which they work. At the same time, they continue to feel personally responsible for meeting the needs of their patients. This tension places health care workers in a region of moral conflict that is like no other. On one hand, western societies demand of them that they deliver care to the ill. On the other, governments, bureaucracies and administrations demand economic restraint, which limits their capacity to deliver the services that are potentially available. The work of health care narratives is at least in part directed toward conveying this tension.

We can see that, in a broad sense, these three groups talk about their engagement with health care from the perspectives of different discourse communities. Administrators, businessmen and policy makers speak a discourse of management, in which actual or potential trouble is to be managed, and turned into a positive achievement. Patients and their carers speak a discourse of misfortune, one which reflects the overwhelming power of illness. Health care workers speak a discourse of coping, a mode of speech which reflects their constant struggle with the misfortunes of others, sometimes successful and sometimes not, with the system in which they work, and with the conflict between their professional and private lives. This basic division between discourse communities has to be recognized and understood before there can be any prospect of real dialogue between the representatives of different interests in health care.

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Ethical implications of discourse communities

Because we are both social and societal animals (Dunbar, 1996), most of us feel the need to be members of communities. The communities of family, friends, work colleagues, spirituality, recreation, self-realization and so on to which we belong construct their discourses in different ways (Bakhtin, 1981: 262–3). They draw on the same linguistic resources, the same lexicon and grammar, but construe meanings in different ways. This has serious ethical consequences. People align themselves with discourse communities for various reasons, as we have argued earlier. As members of each discourse community, they become 'representatives', speaking in terms that each community endorses and legitimates (Little et al., 2002). This means that common terms, such as 'outcomes', 'excellence', 'quality', 'evidence', 'care', 'power', and so on, become rhetorical devices that express ideological commitment, backed by a discourse community. Their meanings may differ profoundly from community to community. We have, for example, examined elsewhere how the word 'care' may mean adherence to protocols of care ('caring for') to one community, and a form of love ('caring about') to another (Little et al., 2001: 116–25). Care may thus mean something that expresses performative skill at one moment, and something ethical at another. Slippage from one domain to another can inhibit mutual understanding and the possibility of creative dialogue.

The need for community membership and solidarity runs deeply in social, societal humans (Dunbar, 1996). Once we commit ourselves to a discourse community, we feel senses of privilege, security and obligation to the community. We establish a part of our identities within the community. We may enter the community willingly, perhaps even with a sense of relief at finding support and response to our needs and beliefs. But the process of colonization is almost inevitable, and the meanings that the community endorses may subsume the individual capacity and desire for critique of the concepts and the language that expresses them. In other words, the community's values become to a varying extent the *expressed* values of the members of the community. Thus, what each member says in a given context will be influenced, or even determined, by the community's approved terms of discourse, or by Nelson's 'master narratives' (Nelson, 2001).

A stable and unexamined relationship may exist indefinitely between the community and each member, but a Trouble (in the sense used by Bruner, 1990) may cause the relationship to be examined. A Trouble in this sense can be defined as a disruption or potential disruption to a valued order. Thus, one of the people we interviewed, David, becomes a secure and successful member of the community of consultant physicians, until the exigencies of work and the opportunity to change career combine to move him from one community to another:

Well one day, a [parliamentary] Minister phoned and said 'Would you like to

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enter politics'? and I said, 'Well . . .'. He said 'Well why don't we have lunch?' So we had lunch. We talked about it. And my medical practice, the one *real* drawback was that I was *so* successful that I was *very* busy and it was playing havoc with my comfort and my personal life, and just at that stage I was happy to go into politics.

David's change of career means that he changed his discourse community, and became conscious of the influence the new community had on his thinking and mode of speaking.

So then I had to try and walk in their shoes, and what I came to learn was that they [other politicians] were in fact the prisoners of their culture. And I thought 'Well maybe I am too.' But you get a different appreciation of people. Lawyers *think* like lawyers.

David expresses well the concept of 'colonization' that can occur when someone commits themselves to membership of a discourse community. Conventional, political colonization can occur by force, but discursive colonization usually works by stealth. The discourse may infiltrate a person's thought and language with its particular meanings, limiting freedom of thought without appearing to do so – indeed, at times apparently offering *increased* freedom. A cancer survivor who joins a support organization, for example, may feel a sense of liberation and relief at the recognition of like minds and like experiences. Thus, Eva says:

. . . so it gave me, quickly gave me opportunities to do more, like go and speak about my experience or to support other people if I chose to do so, which I did . . . because there was the sense in which I thought the organization was a good one and I thought that speaking engagements were really important to people, for people knowing about, maybe not whether they join or otherwise, but knew about the existence of the organization. That opportunity shouldn't be missed.

With time, however, a constrained discourse may limit opportunities for growth. What begins as an opportunity to be taken may become a subtle and unrecognized restraint, as David realized, and as Eva realizes when she says:

I don't feel that I want to, or that I am particularly able to be that person or be that patient any more that stands up and speaks for patients, and says 'This is what treatment is like, or diagnosis is like', and go through all that, that history. I don't really want to, I am not particularly interested in doing that any more and I am not, I am not there, I am detached from that. I can talk about it, but, I don't feel connected with that experience, or feel like I have to kind of recall it from the memory, and I am also in danger of just rehashing some old stories that I have told a million times before.

The creation of a new discourse community thus always includes the creation of risk. However benign its intent, the rhetoric which discourse communities construct may eventually constrain thought and limit development among their members. There are, therefore, significant ethical

dimensions to discourse communities. However much good they may do and mean to do, they run the risk of capitalizing on the need for sociation that all people have. Sociations demand loyalty and solidarity, without which they cease to be stable groups. Discourse communities are no different, and can easily slip from benign intent into exploitation, particularly when their members are intrinsically vulnerable people (the ill, the disempowered, ethnic minorities, and so on), as Nelson has argued (Nelson, 2001).

Evolution of discourse communities

We can perhaps trace the development of a discourse community through several stages. The discourse is mapped out by its seminalists, who define the issues (death and dying, postmodernism, scientific change and progress, for example). Their work is seen as helpful by others, and the discourse evolves. A new generation of epigones is drawn into the discourse, and the discourse community expands. As it does, new interests are brought into play. Arguments develop over interpretation and gospel, and schisms form. Ideology replaces intellectual originality, and critique becomes more inwardly directed against other 'schools' within the discourse community. The discourse may increasingly turn to rhetoric, intellectual leadership to authority. The community's power is expressed increasingly by colonization, by conversion.

The possibility of an ethical community

There seems no reason why this *must* always be so. Equally, it seems likely that it *will* usually be so, because sociation is so strongly embedded in human beings. We need to belong, and our ideologies are badges of belonging. It is possible, however, to conceive of an *ethical community* as the salvation of a discourse community.

What would an ethical community look like, if we were to bring it into being? It would be a species of discourse community, which functions by repeated interrogation of ideologies, its own included. It would include people from many disciplines, with like and unlike, but always open, minds. It would not be committed to any one model of ethics, but to processes of ethical examination using many models. It would also be committed to the definition, examination and critique of underlying values that sustain and justify ethical endeavour of all kinds. Ethical community would be both deconstructive and creative. It would not seek only to destroy. It would seek to replace where it found fault and weakness. It would also seek to test its conclusions by political and social action, and to critique itself, as well as others, in the light of actual happenings and interactions. Because it would run the risk of settling into ideology and authority, it would need to re-create itself continually against changing times and social circumstances. It would have no special intellectual domain in which it operates. It would hold equal

engagement with science, aesthetics, the spiritual, the human sciences and philosophy. It would represent, in short, ethical heteroglossia.

An ethical community would continually examine the content, telos and effects of a discourse. It would not follow the Maoist ideal of 'keeping alive the revolution', an ideal patently devised to justify forced colonization of minds and behaviours. It would, instead, provide a continual, reflexive critique of the discourse and its effects, rather as some Reformed Churches have done within the Christian tradition.

It is, however, hard to find examples of successful ethical communities. We can perhaps point (rather tentatively) to the early Christian community, and to the Athenian Socratics, but the fate of their leaders may give us pause. Habermas has for many years examined the possible interface between discourse and ethics, and he knows well the difficulties of maintaining the force of critique in the interactions of politics. His examination of the evolution of the Green party in Germany makes clear the inevitable conflict between the desire to critique and the need to conform in order to succeed politically (Habermas, 1994: 90–3).

Some final comments and suggestions

Discourse communities are essential to our lives. They help us to create our identities, and they give us a sense of belonging and of having a mode of speaking in common with others. They may be quite clearly defined (professions, for example), or loose groupings (racists, postmodernists). Membership may be voluntary (political parties, sporting affiliations), or strongly determined (cultural membership, education), and anything between these extremes. Membership is determined by our engagement with the relevant discourse, and with the concepts that act as tokens of more complex groups of ideas.

To have a way of talking about something, such as death and dying, or cancer survival, or success in politics or business, can be liberating, and even therapeutic. The construction of a shared vocabulary that reaches the wider community is an essential part of the legitimation process for the experiences covered by the discourse. The way in which the discourse of Indigenous dispossession in Australia has been defined and legitimated by the concept of the stolen generation illustrates the power of a discourse in the hands of a discourse community (National Inquiry into the Separation of Aboriginal and Torres Strait Islanders from Their Families, 1997). It also illustrates the way in which a discourse community spreads its sphere of influence, and begins to colonize other discourses. At first confined to interested Aboriginal and Torres Strait Islander peoples and their immediate supporters, the stolen generation discourse quickly entered general discourse, and focused wider attention on issues of Indigenous rights, relationships to the land, cultural structures, and relationships between different concepts of law.

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The construction of a discourse and the formation of a discourse community may be entirely benign in intent, but always involves risks. Indeed, the discourse on risk in health provides an example of this process. The motives of the medical scientists who seek to define the levels of risk that dangerous diseases pose to susceptible populations are undoubtedly good. But the resulting discourse of risk has led to profound ambiguity, with susceptible people uncertain how much control they may purchase by disciplining the structures and processes of their lives (Lock, 2001; Robertson, 2001). Those whose life programmes 'fail' may then be colonized by a discourse of guilt (Annandale, 1998: 255–6). The process of colonization may be perverted or corrupted either consciously or unconsciously. Because people desire sociation, discourse communities can easily drift into being agencies for coercion or manipulation, denying opportunities for heteroglossic discourse. The desire to belong may easily become a need to conform, and the unscrupulous can use that need to direct the beliefs and actions of community members. This process is most graphically seen at the extreme of the cult (such as Jonestown), but can be seen in lesser form in apparently benign communities such as political parties, sporting clubs, lobby groups, committees of inquiry, and so on. Knowing the risk is the beginning of therapy for potential abuses. Much more work needs to be done to formalize ways to counter the insidious effects of discourse colonization. Some of the possible therapies are examined in books, such as that edited by Arrow and colleagues (Arrow et al., 1995). There are good grounds for believing, however, that no rationally determined therapy will ever completely prevent abuses (Hammond, 1996), simply because the human need for membership and the fundamental place of discourse in human relationships are so deeply entrenched as to be beyond the reach of instrumental rationality. We suggest that the cultivation of ethical communities within discourse communities may offer some protection against the potential abuses.

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