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Constructing denial as a disease object: accounts by medical students meeting dying patients

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Abstract As part of the general shift in contemporary healthcare from a focus on specific diseases to treating the whole person, doctors are now expected to be reflective and engage empathetically with patients. Yet, the context of end of life potentially confounds this commitment. Here we draw on the written submissions of UK medical students confronting dying patients to offer insight into a range of entangled issues. Although the exercise is designed to highlight the value of listening to patients and to encourage reflective practice, the experience of ultimately not being able to treat or cure frequently challenges the students' understanding of the central purpose of clinical care and their future role as doctors. Because they invariably draw on the notion of 'good death', whenever they have to make sense of patient behaviour deemed as irrational or obstructive the students employ the concept of 'denial' as a strategic category. In this context denial is referred to as a disease-like object that the students feel they can, and should, diagnose and treat. Such conceptual operations consequently illustrate a tension arising from trying to acknowledge the value of a whole-patient approach while simultaneously reproducing the emphasis placed on identifying those discrete elements that determine legitimate medical intervention.

Keywords: end of life, denial, medical education, good death, palliative care

Introduction

In an attempt to align medical teaching with the changing medical practice of the 21st century, students are increasingly being exposed to so-called holistic models and a broader range of compulsory experiential exercises that accord with the more tacit dimensions of medical education (Braddock *et al.* 2004). They are encouraged to engage with patients on an empathetic as well as a strictly clinical level and think about how their own experiences might usefully relate to the care they provide for others. Such reflective practices were introduced into general education nearly 30 years ago (Schon 1983), although the underlying concepts are much older. Driven by the idea that learning is achieved not merely from passive reception but also from active engagement, the notion of reflection has consequently increasingly been adopted in mainstream nursing education and, more recently, that of doctors (Mann *et al.* 2009). It is specifically aimed at encouraging medical students to address

the ways in which their own subjectivity influences the translation of knowledge into practice when they interact with patients.

The promotion of reflection as a means to promote patient-centred care has paralleled the way in which patients, too, are expected not merely to present their physical symptoms for assessment but also talk about what subjectively they feel is wrong. In line with this, Armstrong (2011) has argued that one of the key developments in medicine during the 20th century has been the growing inclusion of elements considered to be valid symptoms that nevertheless are not expressed through overt bodily signs but instead are constituted from the words spoken by the patient. Acknowledging that patients are reflective beings and not just passive bodies, he identifies primary care, in particular, as having increasingly provided regulated spaces in which patients can talk about their experiences and which are thereby subject to the medical gaze.

A more specific response to broader re-evaluations of what now constitutes an appropriate medical remit has been the inclusion of end of life and palliative care issues in medical school curricula (Field and Wee 2002). Although in the past some raised concerns that students dealing with terminally ill patients, death and grief would cause them considerable stress (Firth 1986) and that their 'youth and immaturity' might make them emotionally unprepared (Doyal 2001: 685), such encounters with people at the end of life are now seen as an essential part of their training. Given the broad value now placed on reflection, medical students are encouraged to contemplate their own feelings of mortality, imagine what they themselves might experience if they were in the same situation and how such insights might influence the care they provide to others (Feest and Forbes 2007).

The convergence of promoting experiential knowledge, the encouragement of personal reflection and the current significance of end of life contexts for medical education is not coincidental: a great deal of international literature now describes end of life contact as providing a unique, highly valuable and significant learning experience for students (Billings and Block 1997). End of life and palliative care contexts are framed as potentially problematic dimensions for traditional medical intervention and hence are deemed to require a different approach in medical education (Macleod 1993). As a result, there is a widespread assumption that such instances offer a very productive opportunity to illustrate alternative values relevant for contemporary medical practice in general. Strongly informing this is what has been termed a revivalist approach to end of life, which rejects any overly medicalised death experience (Walter 1994). According to this, patients should be made appropriately aware that they are dying while clinicians are encouraged to enable a good death through holistic care. Although the concept resists a universal definition, suggesting that it inescapably includes a range of subjective values alongside more practical and objective measures (Frank 2004), it is nevertheless viewed as an achievable goal (Ellershaw *et al.* 2010).

Even though a holistic model of medicine may underlie some of their curriculum, students are nevertheless trained in a system that still privileges reductionism and the identification of specific diseases (Brown 1995). Recent sociological work has emphasised how diagnosis is both a process and a category (see, for example, Jutel and Nettleton 2011). It is a classification project which attempts to make sense of, and give order to, an apparently random selection of symptoms and signs through a set of descriptive practices. The task of identifying a disorder, however, is also shaped by the extent to which a diagnosis can lead to some practical action (Davenport 2011). In other words, the purpose of diagnostics is to identify in order to treat. This inevitably leads students to conceptualise patients as a collection of symptoms and signs that need to be deciphered in order to know firstly what they, as students, need to learn to pass their exams, and secondly what they, as doctors, might be able to successfully treat in the future.

Although it is normally assumed that clinical diagnosis ultimately concerns the identification of a patho-physiology of the body, the process frequently must include careful interpretation of what patients describe. While this tends to be equated with eliciting subjective patient reports that a good clinician has then to filter and sift through in order to identify what is actually of relevance, in practice everything that is said is contingent on doctor–patient intersubjectivity (Atkinson and Heath 1985). In other words, doctors are likely to be as active as patients in the process that brings certain accounts to the fore.

Overall, then, from a more critical perspective, the developments of reflection and palliative care teaching in the medical curriculum might suggest a further extension of the traditional gaze, which now potentially tries to make sense of, and hence makes medical, not only physical and mental states deemed to be abnormal and debilitating, but also emotional experiences emerging from doctor–patient encounters themselves. In this article we explore these issues by looking at the way in which medical students from one particular UK institution report their firsthand experiences of patients identified to be approaching the end of life as part of a compulsory reflective exercise. We describe how the students adopt variations of the concept of denial whenever patients, and sometimes others, do not behave in a way deemed appropriate to achieve a good death. In doing so, the attribution is also indicative of the nature of relationship that they establish with the patients they meet. More generally, we argue that the underlying logic of disease identification and management, with its corresponding doctor role coupled to specific expectations of patient engagement, ultimately shapes how the students make sense of their experiences when writing about end of life care.

Background and methods

In this article we analyse the written submissions of a cohort of medical students as a means to explore the ways in which the underlying pedagogical values that are associated with end of life encounters are revealed in work they submit as part of their palliative care course. The material is from Cambridge University clinical school and forms part of their final year curriculum. Prior to their final year, students have had some teaching in end of life care issues, but many report having not spent much time with dying patients. They attend a palliative care course that describes skills to manage symptoms and communicate in an appropriate and sensitive manner, are introduced to different models of grief and loss, and have a session on ethical issues at the end of life encouraging students to consider euthanasia, assisted suicide and the reasons people might want to end their lives. In an attempt to make their teaching more holistic, they are also given a brief summary of two non-clinical texts; Glaser and Strauss' *Awareness of Dying* (1965) and Kubler-Ross' model describing stages of grief (1969). While these texts are now dated, and the students are encouraged to review more contemporary literature, they still appear to be standard resources in medical schools and palliative care literature (Downe-Wamboldt and Tamlyn 1997; see, for example, Horne *et al.* 2011).

Students are required to pass the course in order to become registered doctors, although the marks received in this particular course do not affect their overall academic grades. The compulsory assignment consists of writing about their observations and interactions with two patients approaching the end of their life; one in the hospital (H) and the other during a general practice placement in the community (GP).¹ The research was approved by a university ethics committee and written consent to examine their written work for research after it had been processed in their course was given by 123 (86%) final year students in the 2007–2008 cohort, providing 234 essays in total. Each student was given an anonymous identification code, including abbreviations for clinical setting, by a data manager. The

students had already anonymised the patients' identifiable data as part of the exercise. Electronic versions were imported into NVivo for thematic analysis. The students' and patients' basic characteristics were also included in the database, most notably gender, although no trends or associations were later established with the themes that were eventually identified and so are not referred to in the data presented here.

In order to provide the context and supplement the essay data, all formal course material, including lecture handouts and reading lists, were scrutinised and several course tutors were informally interviewed by EB and SC, neither of whom teach on the course themselves. This helped determine how the course and assignment were presented and what types of resources were provided. EB also attended many of the teaching elements in 2009 to observe the more informal pedagogical messages delivered, while SB designed and taught the course, and therefore provided access to all the documentation that recorded how this particular teaching element was introduced initially. The guidelines for the essays were also examined; the students were asked to consider the case history, psycho-social and existential issues, professional issues including ethical and legal concerns and care planning, and personal reflections. This additional information shed light on some of the structural and content elements present, such as the students' emphasis on autonomy and use of literary references, allowing us to make analytical links across the different levels of the curriculum (Hafferty 1991).

Acknowledging that the primary dataset for this study is perhaps unusual, consisting as it does of compulsory written submissions from final year medical students, the written material was treated as a resource for secondary analysis, much like an archival resource (Brettell 1998). Our approach, therefore, was to read across the essays; that is, given the primary purpose of the texts, and the extent to which the students were guided by course expectations, our interpretation of the material was framed by the recognition that these essays are objects pertaining to the medical education process, rather than straightforward accounts of experiences with patients. Such a stance provides the context in which the essays constitute a very rich set of data not simply in addition to their educational purpose, but by virtue of it. In this way, not only does this study relate how medical students discuss end of life care issues, but it also adds to the sociology of medical education by highlighting how these issues are embedded in the teaching they receive and go on to be reproduced in their attempts to demonstrate their knowledge and skills (Brosnan and Turner 2009).

The essays were, therefore, initially coded to establish key descriptive themes derived from the directive sources – that is, the things that were an explicit part of their teaching and that constituted elements that would have been noted by course examiners as demonstrating successful learning. For example, there was a strong expectation that students mention the value of patient discussions and shared decision-making in relation to care planning. To these we added underlying analytical themes, such as the notion of a good death, which did not constitute overt pedagogical elements but rather the informal knowledge and hidden values imparted in the course. Thus, although this study only looks at a single cohort of students from one medical school, by drawing on these particular kinds of data we nevertheless illustrate the extent to which underlying ideas and values in contemporary palliative care provision – such as a good death and denial – are implicitly taught, encountered by students and re-envisioned as part of their education.²

Good death and denial

Most of the submitted essays demonstrated reflection almost entirely in terms of consideration of issues experienced by patients; that is, through interpreting not only how

patients behaved, but the ways students thought a patient felt about very difficult situations. What is striking is that these preoccupations ensured the students' own subjective experiences and emotional reactions remained largely obscured.

Although a range of topics were included, for example, what constituted professionalism in the modern context (Borgstrom *et al.* 2010), virtually all students organised their accounts using the concept of a good death and what values determine a certain approved way of dying – a dying script of sorts (Seale 1998). Although they were never instructed that it should comprise an essential element for their coursework, students seized on the concept of a good death to provide a framework for writing about the ambiguities they observed and felt in relation to the patients who were facing death. In relation to this, the essays included comments about time, communication, location, care, pain management, social relations, preparation and patient autonomy, as well as issues of awareness and acceptance, many of which correspond to the palliative care literature and course material. For example:

After visiting Mrs N ... I realised ... it is important that measures are taken to adequately prepare for the future, involving careful discussion with the patient ... so ... they can be cared for in a way that is in accordance with their wishes. (146-GP)

More frequently, however, students referred to a good death in terms of it not actually being achieved and hence noting components they felt to be missing. For instance, one student declared, 'when things go wrong and they die in pain or are distressed it would be very hard as there is no opportunity to correct mistakes' (075-GP). The model of a good death served both to shape expectations and to make sense of the potentially problematic aspects of the patients they confronted. In particular, it was commonly drawn upon as a way to circumvent the idea that death might inevitably be regarded as a medical failure. The students' invariable adoption of the notion of a good death in their essays demonstrates the extent to which it rapidly became a model for, rather than model of, their understanding of patient experience; despite its inherent ambiguity, the concept swiftly provides normative expectations by which patients' behaviour could be understood.

By relating the circumstances of the patients they met to the ideas and values associated with a good death, most students also introduced the idea of denial and presented it as the main obstacle that needed to be overcome. In other words, the idea of denial was, we shall argue, mobilised to make sense of patients who, for a range of reasons, appeared not to be heading towards a good death, thereby serving to articulate a general theme of their education – that is, establishing a clear focus for medical intervention. Denial is consequently used in a variety of ways to capture a range of apparent impediments that students regarded as issues that either they or the medical profession more generally should somehow put right.

Previously, Zimmermann (2004, 2007) found that despite the interweaving of new ideals such as patients' choice in end of life care, patients' denial is viewed by medics as obstructive. While our results will broadly concur with this, the employment of three very different forms of denial, tied to the normative expectation of what constitutes a good death, suggests that the two terms are co-constituted in the medical context. Furthermore, since in the context of end of life care curative treatment is no longer a possibility, denial itself is variously constructed as a medical problem which, even if a patient will not get better, nevertheless demands to be a focus for medical intervention. The rest of the article, therefore, explores this by outlining the three main types of denial as described by students in their essays: patients being stuck 'in denial'; patients deliberately choosing to 'deny their reality'; and the effects of denial by other people. In each case, denial is constructed in ways that serve not merely to

protect the notion of a good death as being that which a doctor (and patient) should strive for but that, by being such an impediment, denial resembles any other disease object.

In denial

Most students wrote about patients being in denial to mean an inevitable internal reaction to being told they were dying. As several students mentioned, it is the cornerstone of Kubler-Ross's now disputed five stages of grief (1969) and also a key period in various 12-step programmes to treat addiction. The psychoanalytic term, first used by Freud (1923), refers to an unconscious psychological defence mechanism in which a person involuntarily rejects an unpleasant reality. Because it is an automatic reaction, overt avoidance tactics, deliberate lying or blaming other people, which might be considered common reactions to bad situations, cannot be said to stem from true denial since they all involve at least a partial acknowledgement of the situation. Yet the students frequently drew on such behaviour as evidence that patients were in denial alongside appearing generally unaware or non-accepting. Their interpretations indirectly tended to blame the patient by presenting accounts that made them ultimately responsible. In one account, for example, a student wrote 'the fact that Dr T [the patient] is medical highlights the remarkable nature of denial – that it can trump rationality' (100-HP). The student went on to say that the patient was 'clearly well informed about his condition' but refused 'to acknowledge the reality of his prognosis'.

The general point is that students readily drew on ideas of denial when faced with patients who presented problems for them. Although blocking out the news that one is nearing death as a transitory stage was viewed by many students as a natural and even a healthy response, they readily described patients as being 'stuck in the denial phase' (022-HP), and hence were not able to progress towards a state of acceptance. For example:

Dan totally avoided discussion about the future ... When open questions failed I tried more direct ones, but was met with replies such as; 'I'll wait and see'; 'Let nature take its course'; 'Nothing in particular' ... avoiding the discussion allows him to be in denial, thus protecting himself from the idea of his mortality. (148-HP)

Students also suggested that if patients are in denial they may avoid seeing or 'bothering' a doctor (095-GP). Even more problematic than this, if patients reject any palliative treatment or pain management, students saw this as evidence that denial caused people to 'struggle unnecessarily' (022-HP). For example, morphine was interpreted as symbolic of 'an acceptance of death' (146-GP) but meant things were likely to escalate in a way that was akin to self-harm as patients refused medication.

Others interpreted being in denial largely in terms of not preparing for the future and it as an 'avoidance of responsibilities' (081-GP). It was felt that for such patients 'making plans ... would be particularly problematic' since they are unwilling to consider the possibility of their condition deteriorating (037-HP). Moreover, 'a patient who denies that they have a terminal disease would be unlikely to choose a proxy for their medical decisions' (132-GP), making the clinician's job even more difficult by forcing the doctor to make decisions solely on impersonal standards of best interests. Planning and preparing for death are noticeably regarded as important aspects to a good death and students report being frustrated when patients are not actively taking part in this.

Despite being taught that UK doctors are advised not to share or allow their religious beliefs to affect patient care (General Medical Council [GMC] 2008), a minority of students

(less than 5%) took the coursework as an opportunity to find ways of relating their own personal beliefs with their role as a doctor. Given they are directed by the suggested essay structure to discuss what are termed 'existential issues' (although this term is never precisely defined and, somewhat ironically, is taken to include the religious and spiritual beliefs of patients), those who were religious themselves, especially self-described Christian students, found it relatively easy to transpose their own beliefs on to the apparently secular language of denial and good death. This is perhaps less surprising when one considers that the history of good death in palliative care is highly influenced by Christian ideals of dying (Bradshaw 1996). Moreover, as one student put it, Kubler-Ross herself 'glorified ... [a] very spiritual view of death' in her discussions of acceptance (132-GP). Some students were upset that their patients could not gain the confidence and comfort they themselves had. One stated that in Christianity both 'truth' and 'hope' combine 'even in the face of death' (070-HP). Others went as far as suggesting patients might be in denial because they lacked the support of spiritual belief. For example:

for Mr S, the future was bleak. For him, after death meant nothing ... [I am] grateful that my religion will help me to see death, not as an end, but a new beginning. (136-GP)

More problematic for students than all this, however, were those cases in which patients refused to talk about anything at all. As one student recalled:

It was certainly not easy to raise the issue of dying, as he flatly refused to consider a poor outcome, almost as if just thinking about it would somehow bring it about. (137-HP)

A common interpretation of such a situation was that patients in this state do not 'see any reason to start thinking about such things now' (038-HP) because they do 'not fully believe' they will die (140-GP). Since many of the students tend to focus on Kubler-Ross' model of grief, a patient who not only refuses to acknowledge their mortality in any way but refuses to even engage in the topic is particularly difficult to deal with and write about. Thus, while denial is ostensibly used as a description of the psychological status of the patient, what is clear is that the idea of blocking or getting stuck is, in parallel, a way of describing the thwarted role of medical staff, and the fact that a range of practical interventions are themselves being denied. As a consequence, a good death is unachievable – both for the patient and for the medical staff – not only because denial is regarded as counter to rational awareness but, just as significantly, because it prevents the medical profession from practising what it deems is the most appropriate care.

Fluctuating and deliberate denial

So far, we have described how students in their written submissions conceive of denial as an internal state, envisioned as normally a transitory initial stage along a linear pathway towards acceptance. Those patients who are stuck in denial are somehow trapped in a liminal state of personhood and require help to initiate a forward trajectory. However, students also used the term to describe how some patients, at various times, seem to choose to deny or overtly refute their situation to others, even if they personally might be fully aware of the prognosis. Such outwardly directed variations, in which denial is acted out with other people rather than being an internal state, result not only in a blurring of agency but also a blurring for medical students of any sense of where responsibility might lie.

As a result, some students revised their conception and adopted a more flexible model of denial. Several suggested that their patient ‘has not yet entered the pathway’ (025-GP) or that it was ‘not yet helpful’ to ‘place’ their patient in a category of denial or acceptance (096-GP). Others, however, were willing to construct an even more ambivalent notion of denial. For instance, one claimed that:

Those dealing with a terminal diagnosis can experience different stages of the grieving process simultaneously and that it’s not necessarily a linear process of well-defined stages. (096-HP)

This variant of denial can, in this way, be regarded as fluctuating and ‘transient’ (133-HP), with patients judged as having accepted ‘some aspects of the illness trajectory while remaining in denial over others’ (044-HP), perhaps even achieving a balance between accepting the finality of death and remaining in a state of refutation (022-HP). However, attributing denial to actions and interactions rather than an internal psychological state serves to complicate things even further by potentially confusing staff, interrupting systems of care and undermining the communication skills the students have acquired.

On one hand, behaviour that refutes the linear denial-acceptance model threatens a good death since it does not allow for the usual progression expected by the students. It is clear that constant changes in mood or attitude made it difficult for students to clearly identify the patient’s ‘stage’, which they frequently drew on in order to know how to interact with patients. This aspect of matching appropriate care can be further complicated if a patient’s behaviour is interpreted differently by various health professionals, as was the case with one woman reported on extensively by a student. Although the nurse, GP and student believed she was denying her condition, another doctor believed she had an appreciation of her condition. The student wondered if it was possible that she ‘was confiding her fears to only one member of the healthcare team ... or that her “denial” waxed and waned’ (132-GP). What is worth noting is that the student did not at any point consider that the judgment of denial might be highly subjective, or that it perhaps meant different things to different members of staff. As a result, a definitive notion of denial is itself largely protected, even in such a case.

Some students extended this notion of denial even further to identify what they perceived to be an overt display of intentional denial; that is, a choice to actively contest their health status (110-HP). For many students this was unexpected and complicated, since it was experienced as completely unhelpful. As one student wrote, ‘I had believed that when approaching death someone is either okay with it or not, and that their attitude to it would be more-or-less consistent’ (070-GP). Patients who appeared to be consciously denying their prognosis were deemed to be ‘ignoring’ their illness (140-GP), which might even be ‘premeditated’ (095-GP). For some students ‘this deliberate blindness’ not only perplexed them (070-HP) but made them worried that it would obstruct the care received (148-GP). For others, the very act of denial was by definition a flight from rationality:

This was a very deliberate decision to overlook the facts as presented to her, and surprised me in someone so apparently rational. Her desire to remain optimistic superseded even her own intellectual assessment of the situation ... If the comfort is not based in reality, what comfort can it be? (070-HP)

The same student saw another patient who accepted her prognosis enough to make plans, but nevertheless failed to ask certain questions. The student wrote disapprovingly that ‘not

asking questions does not mean that the answers aren't of great consequence' (070-GP). Finally, because denial was for some simultaneously thought of as irrational and also framed as a choice, it raised a 'particularly difficult relationship with consent' (100-HP), considered a central issue in treatment during end of life care. The students viewed consent as an important aspect of a good death since it allows patients to demonstrate their autonomy despite the fact that in practice 'patients receiving palliative care have very few choices they are able to make' (028-GP).

Overall, the general descriptions of interpersonal, socially expressed denial are seen by the students to contradict a 'genuine' internal state. Identified by either oscillation in acceptance or as a deliberate chosen strategy, this apparently inauthentic form is reported as being far more unsettling for the students than the idea a patient might simply be stuck in a denial stage. It potentially not only undermined the logic of a simple linear model towards acceptance but called into question what a good death might really mean, inviting reflection as to whether some of the underlying abstract values used to define it, such as rationality, choice and autonomy, might themselves be far more problematic than usually assumed. The point is, from the students' perspective, there is an irreconcilable paradox if patients can 'choose to be in denial', not only in terms of what denial might actually refer to, but also what it might mean to facilitate a good death. By using the idea of denial in this particular way the students were then faced with the conundrum that if denial can be a conscious choice this implies that it might also be rational; yet if it might be rational, then it might not be contrary to a good death.

Denial by others

A distinct third general area in which denial was used by students in the submitted written work in relation to trying to facilitate a good death referred not to the psychology of the patients but those around them. The students described how, if ever, those caring for a patient were themselves in denial, this could also lead to a prolonged and undignified death. They described in some instances how some family members demanded 'an onslaught of investigations' (142-HP) while in other cases relatives would 'try and dodge around the issue' (021-GP) and not be honest with the patient. Many students argued that such actions conflict with a good death model and so should be resisted. Some proclaimed that doctors 'have neither a duty nor the right to prescribe a lingering death' (027-GP), and that 'if life cannot be prolonged there is no need to prolong death' (048-GP). These are explicitly not intended to be statements in favour of euthanasia or assisted suicide; rather, the students opposed what some termed as a 'technological' approach to medicine that blindly tries to refute death. This is contrasted with what they understand to be good palliative care. It is for this reason that many also felt that dying in hospital is inevitably 'bad' because of the 'intensive monitoring' (055-HP) and it being a 'public' environment (094-HP), which precludes any dignity.

Crucially, the students also suggested that in addition to friends and relatives, doctors themselves might be in denial about the outcome of one of their patients. The students made sense of this form of denial, expressed as a delayed acknowledgement that a patient is approaching the end of life, by claiming that doctors are trained only to 'help' patients and that they sometimes find it hard 'to know when to stop' (028-GP). Interestingly, one student, who felt that she herself had denied the inevitable outcome of a patient with tuberculosis and HIV and had continued with unnecessary treatment, wrote:

I think I was too busy trying to work out what to do and trying to keep her alive, and I neglected to consider palliative aspects. We probably extended her life by a day but I'm not

sure that I wasn't denying that her death was inevitable at this point and therefore continuing unnecessary treatment when I should have been starting down a different pathway. I found it difficult to stop treatment and have a patient of mine die. (048-GP)

Other students suggested that some doctors might well be 'frightened to confront ... the reality' (146-GP) of having to tell a patient or their relatives. Some were openly critical of established doctors treating patients 'like a number in their book' (046-GP) and telling patients 'what they should know instead of what they want[ed] to know' (047-GP). One student described how a doctor continually focused on measurements and trying to make the patient better, rather than 'letting him die the way he wanted' (046-GP).

Almost all the students mentioned the current professional commitment to shared decision-making and argued it was especially important in relation to end of life issues. This corresponded with their uncritically stressing the importance of what they called 'holistic palliative care', since 'good clinical decisions do not always result in "happy [medical] endings"' (053-GP). This adoption of the contemporary language of collaborative care, however, competed with the reality that many observed, and hence opened up the space for invoking this third logic of denial.

The sentiment that patients 'deserve our respect for their dignity' (055-HP) and that this should be an essential component of care was challenged by the observations that some doctors lose interest in, ignore, or pass off patients once they become 'palliative' or if the patient has given up (036-HP). The students suggested that by distancing themselves from patients or focusing 'solely on the patient's physical needs' (094-HP) some doctors deny the practicalities of the dying process and the relational needs of the patient, causing patients to feel like a 'medical curiosity' with over-medicalisation in an attempt to cure them (027-GP). Thus, this final area of denial, not merely of relatives but of individual doctors and by implication the healthcare service itself, was presented as particularly worrying to the students. These people and systems are expected to facilitate a good death and in the instances described by the students, this type of denial blocked it, even if patients were not denying their own death.

Discussion: diagnosing denial and treating the patient

Students constructed their own categories of different forms of denial from a largely superficial understanding of its more technical psychological meaning. Although they considered that if denial is only temporary it is natural and even potentially beneficial, almost all raised the caveat that this is only as long as it does not interfere with medical decisions. If prolonged, it is seen as 'inherently destructive' (131-HP). Consequently, patients judged to exhibit denial are effectively considered to be in a state that is obstructive to the care that can be offered to them. The result is that denial itself is rapidly regarded as a condition that needs to be swiftly identified and thus a legitimate focus for clinical scrutiny.

Moreover, the students frequently attempted to identify it, much like making any other diagnosis by identifying a salient pattern of what they termed verbal and non-verbal cues. The use of the word 'cues' is derived from their communication skills classes, in which they are encouraged to be receptive to the various ways in which the disposition of a patient can be ascertained. Yet it is clear that this word is used as a proxy for symptoms, with students describing how a range of subtle verbal signs can be identified and clustered together in order to identify the underlying psychological state. By doing so, denial is itself successfully pathologised, incorporated into a classification project that creates it as a disease object that

they feel compelled to try and treat. Through this mechanism, therefore, denial serves to stabilise and redefine their role as incipient doctors. Such a position is clear in the following excerpt:

I can understand the desire to live out your last days without having to constantly confront the shroud of your possible mortality. However, in reality this is a form of active denial ... I believe that the patient should be helped to confront these ideas and worries, helped to deal with them and in fact encouraged to deal with them as any phobia or fear would be considered through cognitive behavioural therapy. (142-HP)

Reaffirming an interventionist role for the doctor even when faced with end of life cases, the main management, or 'treatment' suggested is 'open, honest communication', with the implication that those suffering from denial will eventually become more aware and thereby in due course more accepting of their approaching death. The students talked about 'starting small' and increasing the significance of conversations over time – the 'gradual communication of the truth within the context of continued support' (141-HP) – so that a patient becomes more accustomed to the news and slowly displays signs of acceptance – akin to the titration of drug dosage. Nevertheless, it is not clear to students adopting this paradigm how to distinguish denial from other mental states, such as depression. Even more puzzling for them is that once reified as a valid entity, they generally have no sense what its aetiology might be, or its relationship to other medical issues. For instance, one student wondered if her patient's denial might either have been 'the cause of, or caused by, psychosocial distress' (132-GP), while another thought that it might be organic in nature and the side effect of a physical disease affecting cognitive function (069-HP).

However, there is an important additional dimension to our interpretation of the ways this varied concept of denial is mobilised by the medical students. As mentioned in the introduction, they, like all contemporary doctors, are now expected to be reflective (Accreditation Council for Graduate Medical Education 2008, GMC 2009). They are encouraged by their tutors to think about their actions and reactions in everyday practice in order to ensure sensitivity and awareness in addition to the delivery of expert knowledge and technique. This captures aspects of a new professional ethos which is now more accepting of the emotional and interactive dimensions of being a good doctor, and is consequently meant to be demonstrated in the written work they submitted. This led one student to write:

Unsure whether [the patient] was in denial or genuinely optimistic, I found myself asking whether the situation might only be 'hopeless' from the perspective of those who have tried and failed to rehabilitate him. (148-GP)

The point is that by setting reflection up as a necessary skill, a modern doctor reciprocally demands, by implication, reflection of their patients as well. Consequently, the medical students expect patients to have a degree of awareness and introspection now that this has become a necessity for the intersubjective style of the doctor-patient communication they are encouraged to enact. Patients who do not behave in the way expected, such as those displaying what is labelled as denial, can ultimately block what student doctors consider to be good treatment, care and death. For some students such a dynamic can lead to feelings of personal failure, for example:

It was very tough. I am normally quite good at picking up on cues but there just seemed to be no way in: every door was shut to me. I came away feeling like a complete failure. (085-GP)

The implicit expectation that patients must also be reflective, arising from the initiative that doctors be more sensitive and empathetic, is of course hidden. Yet, it is made visible in the data drawn on here, where the students use a notion of denial to make sense of patients who, paradoxically, appear to choose not to engage. The more general implications of this are that the drive for patient participation and shared decision-making might be leading to an unintended consequence; that a certain notion of patient activity and collaboration with the medical view is now expected. Thus, while student discussions of denial focus on how it invariably complicates care and obstructs the path towards a good death, conceptualising it as a pathological entity is ultimately driven by trying to demonstrate a patient-centred and holistic approach within a medical culture that still assumes the ultimate role of a doctor is based on identifying and attending to underlying disease objects.

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Notes

- 1 For an introduction to some of the ethical issues involved in medical education: see British Medical Association Ethics Department (2004).
- 2 Unintentionally, this study led to some critical examination of SB's own teaching practice as course leaders have since debated the transference of implicit values as part of medical education delivered, and has prompted thinking about how the course may be further developed.

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