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# Diagnosis by documentary: professional responsibilities in informal encounters

**Running title:** Diagnosis by documentary

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## Abstract

Most work addressing clinical workers' professional responsibilities concerns the norms of conduct within established professional-patient relationships, but such responsibilities may extend beyond the clinical context. We explore health workers' professional responsibilities in such 'informal' encounters through the example of a doctor witnessing the misdiagnosis and mistreatment of a serious long-term condition in a television documentary, arguing that neither internalist approaches to professional responsibility (such as virtue ethics or care ethics) nor externalist ones (such as the 'social contract' model) provide sufficiently clear guidance in such situations. We propose that a ~~doctor's behaviour is best directed with~~ mix of both approaches, emphasising the non-complacency and practical wisdom of virtue ethics, but grounding the normative authority of virtue in an external source, is able to engage with the health worker's responsibilities in such situations to the individual, the health care system, and the population at large.

## Introduction

~~The vast majority of work in medical ethics concerns~~ Medical ethics scholarship focuses chiefly on what is sometimes called ‘clinical’ ethics, examination of the responsibilities of health workers within the context of an established professional-patient relationship. But medical problems ~~do not~~ may arise ~~only within~~ outside the confines of such relationships, and professional responsibilities ~~may~~ extend beyond the clinical context. ‘Good Samaritan’ cases offer the most striking example, but “informal medicine” ~~extends beyond such situations~~ covers a range of other situations (Leavitt, Peleg, and Peleg 2005). We ~~explore~~ describe one such situation, ~~faced by one of us~~, of ~~deciding what to do~~ a clinician’s response to having witnessed witnessing the likely misdiagnosis and mistreatment of a disabling long-term condition while watching a medical television documentary.

This case ~~brings up~~ raises a range of several questions regarding clinicians’ professional ~~responsibility~~ responsibilities, concerning: their *scope* – ~~to what extent is the viewer responsible to act at all~~ whether they extend to cover such situations; their *object* – to whom are they, or on whose behalf, is the responsibility owed; and their *content* – what action(s) do ~~such responsibilities~~ they require? To answer these we explore the normative foundations of professional responsibility – the grounds upon which the claims of professional obligation are seen to be morally binding for health workers. Two different approaches ~~to grounding professional responsibilities~~ – *internalism* and *externalism* – offer potential guidance in answering these questions. Internalism views professional responsibilities as arising from the nature of medical practice itself, a viewpoint ~~perhaps~~ most thoroughly explored in the virtue ethics (VE) of Edmund Pellegrino (Pellegrino 2001; Pellegrino 2006), also found ~~in much work~~ frequently in the care ethics (CE) tradition (Held 2005). Externalism ~~instead, by contrast,~~ grounds professional responsibility in some more general moral theory, applied to the profession’s position in society. We focus here on ‘social contract’ (SC) models of professional responsibility as an exemplar of ~~an externalist~~ position, given the ~~widespread~~ popularity of this approach among medical professionals ~~as an account of the normative underpinnings of~~

~~professionalism~~ (Medical Professionalism Project 2002; Working Party of the Royal College of Physicians 2005; Wynia 2008). This position ~~maintains that grounds~~ professional responsibilities ~~are grounded~~ in a contract between the medical profession and ~~the society in which it is situated, with the responsibilities of the~~ ~~that commits the~~ profession ~~directed toward to~~ promotion and protection of the health, not only of individual patients, but also the public at large.

We use insights from both internalist and externalist accounts to engage with professional responsibilities in situations like ours. Externalist accounts ~~offer a more secure grounding for settling more securely settle~~ the scope and object of responsibilities in such settings, while the ‘practical wisdom’ and responsiveness to moral nuances of particular situations emphasised in internalist accounts also prove valuable. We ~~suggest that these complementary strengths may be applied~~ ~~apply these complementary strengths~~ through an ‘instrumental’ VE – where the *telos* of ~~medical practice~~ ~~ine~~ is determined by external deliberation, not viewed as being internal to ~~certain aspects of~~ the practice. This approach emphasises the clinician’s responsibilities to the patient at the centre of the case, the healthcare team featured in the documentary, and the viewing public. It stresses the normative significance of supporting the capacities of individual patients against their specific vulnerabilities, and enabling all others working within a health care setting – including journalists – to promote resilience against these vulnerabilities.

## Informal diagnosis by television

Documentaries showing real people in real crises ~~– in particular, health crises –~~ consistently attract ~~great~~ public interest. ~~Health crises – resolved or otherwise – are a popular topic of such documentaries.~~ One of these, set in emergency departments (EDs) of large acute hospitals in the United Kingdom, follows individual cases as they present and receive treatment. One episode followed a man<sup>a</sup> in his twenties who was brought to an identified ~~emergency department (ED)~~ ED by

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<sup>a</sup> Referred to henceforth as ‘the patient’ – this is for clarity of reference, though NB he does not stand in a formal doctor-patient relationship to some of the clinicians involved in this scenario.

ambulance in a seizure which ~~by his arrival~~ had already been going on for nearly 30 minutes ~~at the time of his arrival~~. The ambulance staff and ~~emergency room~~ ED doctors made a diagnosis of status epilepticus (SE - prolonged or recurrent epileptic seizures without recovery), a condition with significant morbidity and mortality requiring urgent assessment and treatment to address any acute underlying cause or prevent brain injury through persistent epileptic activity (Brophy et al. 2012). ~~A personally identifiable~~ The ED doctor in charge of his treatment administered several boluses of intravenous benzodiazepines (~~a~~ potent and sedative anticonvulsant medication) well in excess of maximum recommended daily doses. When this treatment proved unsuccessful, intravenous phenytoin was given (a second-line anticonvulsant medication with a wide range of possible serious side effects). When ~~both approaches these had~~ failed to stop the seizure ~~activity~~, the doctor called an anaesthetist to intubate the patient and induce general anaesthesia (~~as~~ the ultimate emergency treatment for ~~status epilepticus~~ SE). The seizure stopped as the anaesthetist was on the verge of intubating the patient ~~on~~. ~~Follow-up~~ Interviews with the patient recorded after his discharge from hospital made clear that he had presented in this fashion several times before, and that he had been discharged with a diagnosis of epilepsy ~~/- SE status epilepticus, which had apparently never been challenged or changed during his admission~~. He remained on anti-epileptic drugs (AEDs) as a treatment for his seizures.

However, the appearance of the seizure ~~, which was (clearly displayed in the documentary),~~ cast serious doubt on the diagnosis of SE; one of us (an expert in seizure disorders and in the analysis of video-electroencephalographic (VEEG) recordings) saw the documentary and thought it highly likely that the patient was in fact experiencing a non-epileptic seizure (NES). NES resemble epileptic seizures superficially but (as the name suggests) they are not caused by the abnormal electrical activity in the brain which is the neurophysiological basis of epileptic seizures. Instead, most NES are interpreted as episodes of reduced self-control representing an experiential and behavioural response to aversive internal or external stimuli which the patient is unable to cope with in other ways (Reuber 2009). Although the diagnostic gold standard for the distinction of epileptic and

nonepileptic seizures involves ~~the simultaneous VEEG~~ recording of a typical seizure ~~with VEEG~~ (LaFrance et al. 2013), ~~it has been shown that the~~ observable differences in seizure semiology ~~which have been described in previous video EEG studies~~ allow experts to make correct clinical diagnoses in over 90% of cases (Avbersek and Sisodiya 2010; Chen et al. 2008). Given the very prolonged nature of the seizure captured in the TV documentary, characterised by unremitting tremulous, asynchronous movements of the patient's limbs, closed eyes, an undulating intensity of the motor activity and semipurposeful movements (e.g. lack of movement in one arm during removal of clothing from this limb), the expert watching the ~~TV~~ documentary was quite certain of the diagnosis of NES ~~rather than SE~~. The use of AEDs, especially during prolonged seizures, can aggravate NES and has no therapeutic role (Niedermeyer et al. 1970; Reuber, Enright, and Goulding 2000); in fact managing NES as epilepsy, especially treating non-epileptic status as SE, carries a significant risk of iatrogenic morbidity and mortality (Reuber, Baker, et al. 2004; LaFrance and Benbadis 2006).

### Ethical issues arising from the case

It will be a major contention of the argument below that the first ethical challenge confronting the clinician in such a scenario is that of discerning all the morally salient features. We propose these concern at least: how or whether one should approach a patient one believes to have been misdiagnosed toward whom one has no formal clinical responsibilities; how or whether to respond to evidence of 'poor' practice (insofar as the patient was given an incorrect diagnosis and given dangerous and ineffective treatment as a result); and what to do when a common, severe, and disabling medical condition is misrepresented in national media.

Addressing first the patient, the question is whether the doctor should communicate (e.g. to health workers responsible for their care) a 'passer-by diagnosis' of NES (Mitchell 2008; Mitchell 2011). Not clarifying the diagnosis impairs access to effective treatment (AEDs are of no benefit for NES, but interventions including careful explanation of the condition, psychoeducation and psychotherapy may help (LaFrance, Reuber, and Goldstein 2013)) and carries the risk of severe iatrogenic harm

(Reuber, Baker, et al. 2004; LaFrance and Benbadis 2006). But there is also the potential of harm arising from intervening, for example through misdiagnosis. Whilst the appearance of the seizure shown in the documentary made a diagnosis of NES highly likely, error remains possible; furthermore, there is no way to establish from viewing one seizure whether a person may experience both NES *and* epileptic seizures, which would necessitate different and careful intervention. 'Undiagnosing' epilepsy presents a further potential threat – chronic health conditions become closely associated with individuals' social identities and self-representations, so that changing diagnostic labels can cause psychological distress, affect social networks or alter available social or financial support (Karterud, Knizek, and Nakken 2010; Solomon, Klein, and Bourdette 2012).

The question is not simply one of *whether* to diagnose, but *how*; conveyed well, ~~the introduction of simply making~~ the NES diagnosis ~~alone~~ can be ~~an~~ important ~~intervention~~ in management of the condition (LaFrance, Reuber, and Goldstein 2013), but (as with other functional disorders) the implied psychogenic component of the diagnosis can be a source of significant resistance and distress for patients (Thompson et al. 2009; Monzoni et al. 2011). Even the decision of what to call NES is complicated by the stigmatising nature of some labels such as 'hysteria' or 'pseudoseizures' (Stone et al. 2002).

Focussing instead on the health workers involved in treatment, ~~the normative questions arising concern~~ we must consider the risk to future patients whom the health workers involved may encounter. Responding to this risk will depend on the extent to which the event witnessed is thought to be an individual aberration or a systematic failure; in the first case intervention would ~~be directed at rectifying the aim to rectify~~ deficiencies in knowledge or ability of a few specific individuals, while the second would require more widespread alteration of medical training to ~~rectify correct~~ an injustice faced by individuals with NES, — ('injustice' being the appropriate term here since medical institutions — ~~perhaps compounded by stigmatising beliefs regarding functional disorders held by many health workers, especially those dealing with medical emergencies~~ (Worsely et al.

2011)—would be ~~established in such a way that they~~ systematically treat~~ing~~ NES patients in ways ~~that threaten their deleterious to~~ health and wellbeing ~~— perhaps compounded by stigmatising~~ ~~beliefs regarding functional disorders held by many health workers (Worsely et al. 2011)).~~

The third set of questions concerns the appropriate response to the nationwide broadcasting of NES misdiagnosed as SE and the consequent potential for misunderstanding, both of epilepsy and NES.

Filming of acutely unwell people in ~~emergency departments~~EDs ~~raises suspicions of the potential for~~ ~~exploitation of~~potentially exploits people in vulnerable situations (Geiderman 2001; Godfrey and Henning 2007). Dramatic representations of epilepsy as a dangerous and unmanageable condition can feed into a public anxiety at odds with medical reality (Baxendale 2003); and public misunderstanding of conditions like epilepsy or NES may facilitate stigma surrounding those conditions, and make inappropriate emergency admissions more likely if similar NES are mistaken for SE. Furthermore, for individuals struggling with a diagnosis of NES made on the basis of a presentation similar to that depicted, seeing another person with the same presentation instead being diagnosed with epilepsy may compound that confusion and amplify the sense of being ‘left in limbo’ that some NES patients ~~with NES~~ report after ~~they have received~~receiving this diagnosis (Thompson et al. 2009), ~~if not or even result in~~create resistance to and rejection of ~~what can~~ ~~already~~ ~~a~~ ~~sometimes~~ ~~often~~ ~~be~~ ~~a~~ ~~fraught~~ ~~and~~ ~~contested~~ diagnosis (Monzoni et al. 2011). To ~~determine~~ ~~examine~~ the scope, object, and content of professional responsibility on these issues, we examine putative normative foundations for such responsibilities.

## Normative foundations for professional responsibilities

While being a member of a profession is widely held to entail the assumption of moral responsibilities beyond those attendant upon lay members of a ~~given~~ community, there is no clear agreement on why this should be the case. ~~Approaches to providing such responsibilities with a~~ ~~normative grounding can broadly be divided into two categories~~There are two broad categories of ~~potential normative foundations for such responsibilities~~. *Internalist* accounts look to the nature and

practice (in Alasdair MacIntyre's (2007) sense) of the profession itself, viewing professional responsibilities as integral to ~~being able to perform properly~~proper performance of itsthe characteristic activities ~~of the profession~~; *externalist* accounts ground professional responsibility in some external source – e.g. a fully general moral theory such as utilitarianism.

The medical profession's own interpretation of its responsibilities commonly endorse an externalist account – the 'social contract' (SC) model (Wynia 2008; Medical Professionalism Project 2002; Royal College of Physicians et al. 2010). This views professional responsibilities as emerging from a bargain between society and the profession. The profession agrees to provide a vital social good – promotion and protection of the health of patients and the public – in return for the right to self-regulation, and a degree of monopoly over the political, economic and labour activity needed to achieve such provision. Other externalist accounts include those grounded in Rawlsian contractualism, and consequentialist theories –these often also converge on assigning the profession responsibility for patient and public health promotion and protection.<sup>b</sup>

The SC model makes healthcare professions responsible for protection and promotion of health of patients and public, but that does not straightforwardly mean each professional bears that responsibility. Distribution of group responsibilities to members depends upon the thing for which they are held responsible, and how the collective devolves responsibility to its members (Lawford-Smith 2012). The difficulty for our case, though, is that, in the United Kingdom at least, the professional standards invoked to devolve responsibility offer little guidance. ~~Legal advice sought by~~

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<sup>b</sup> According to Normal Daniels' Rawlsian account, health professions serve as the public institution discharging a collective social obligation to protect fair equality of opportunity through promotion of public health (Daniels 1985); and it is plausible that a consequentialist account of professional responsibility would maintain that (a) *professional* responsibilities are determined by the role the profession (as a collective) is able to play in promoting best outcomes; and (b) the manner in which the profession is able to promote best outcomes is by protecting and promoting health of the community.

~~the doctor in the above scenario stated that there was no legal responsibility to act in any particular fashion (Medical Defence Union, personal communication).~~

The only informal encounter explicitly discussed in professional standards is the 'Good Samaritan' act – when a health worker encounters a person in immediate need of medical attention and there is no other more suitable person around to offer it. In such cases ~~both~~ professional guidance and ~~professional~~ opinion alike are (in the UK) fairly clear ~~and conclude~~ that there is a responsibility to act (Williams 2003; General Medical Council 2013). However, Good Samaritan ~~scenarios-responsibilities~~ offer little guidance for our case; ~~and even if the Good Samaritan framework was extended, it would still be inadequate for dealing fully with our case. Good Samaritan responsibilities~~ They address only a physician's responsibility to individuals they encounter, ~~but but several of the ethical questions raised by our scenario also raised questions regarding concerned the team responsible for treating the patient originally~~ other health workers, and the state of care for NES patients as a whole, ~~and~~ and their representation in the media.

Various methods have been proposed for extending medical ethical principles and codes of conduct in situations where no clear guidance is offered. These include *specification*, whereby more explicit guidance is derived from more basic principles and codified into existing practice guidance (Richardson 2000); *casuistry*, which looks to settled decisions from relevantly similar cases for guidance (Strong 2000); and *balancing*, which proposes to weigh competing considerations to determine which take priority in a given situation (DeMarco and Ford 2006). While space prevents us from engaging extensively with these ~~positions~~, we find none satisfactory for our and similar cases. If rules of specification were sufficiently detailed to engage with all the morally salient particulars of different cases, codes of practice would become impractically extensive ~~and unwieldy~~ (DeMarco and Ford 2006, 486), and would always be struggling to keep up with new developments in the social landscape. ~~(suppose rules are extended to cover television diagnosis; what of cases encountered on internet video platforms, or publicised via social media?).~~ Casuistry, ~~with its reliance on moral~~

~~resemblance of different situations~~, obscures moral work by assuming ~~such comparators that morally similar situations~~ are readily identifiable, ~~e.g.~~ ignoring the details that separate problem cases from ~~the~~ 'easier' exemplars (DeMarco and Ford 2006, 490). And balancing assumes that all ethical dilemmas are "crisis issues", conflicts between competing well-defined claims; this ~~can neglects~~ the "housekeeping issues" of clinical ethics, ~~the subtleties of~~ how we construct and conduct relationships, engage with others, and go about working and living (Warren 1992, 37).

Furthermore, all these approaches suffer from what has been called the 'positivist bias' ~~of some approaches to bioethical deliberation~~— the "taken-for-granted attitude according to which the narrative construction of human reality is transparent, readily accessible and rarely controversial" (Barilan and Brusa 2013). Each assumes that ~~the~~ morally salient features of and relevant norms for a given case are readily apparent; but in our case ~~(and similar situations)~~, much ~~of the~~ normative work involves ~~simply~~ establishing what these features and norms may be, before we even begin to ~~question what might constitute deliberate over~~ an appropriate response to them; ~~"awareness of the morally relevant features of a situation is no easy or automatic matter"~~ (Little 1995, 121).

An alternative ~~means of resolving this dual requirement for subtlety and flexibility in the response to informal encounters approach such as our case~~ is to focus, not on ~~the~~ appropriate rules of conduct, but rather ~~on the kinds of~~ dispositions and habits ~~that enable~~ professionals ~~need to display~~ to fulfil their ~~professional~~ responsibilities in such situations; in other words, to conceive of professional responsibilities as *virtues*. ~~Such an approach is more~~ These are commonly ~~found emphasised~~ in internalist accounts of professional responsibility.

The most famous such account is Edmund Pellegrino's VE, which derives norms from a description of the characteristic activity of medicine as the clinical encounter, its end a "right and good healing action for a particular human being" (Pellegrino 2006). Pellegrino conceives of virtues as dispositions ~~to think and act~~ that permit a person to work toward achieving the ends of medicine ~~— Attributes such as fidelity, honesty, compassion, prudence (or practical wisdom) and suppression of self-~~

~~interest may help the doctor perceive and balance~~ balancing the different dimensions of the patient's good and ~~to employ~~ ing medical knowledge and skill to further ~~this richly-conceived good~~ this good through 'healing action' (Pellegrino 2001; Pellegrino and Thomasma 1993). A similar approach is found in some formulations of CE that focus on "the compelling moral salience of attending to and meeting the needs of the particular others for whom we take responsibility" (Held 2005).

The main difficulty with applying such internalist moralities to ~~our case, and to~~ informal medicine ~~in general,~~ is that both Pellegrino's VE and medical CE provide ethics for *existing relationships*, but the first ethical problem in informal medicine is *establishing the relationship in the first place*. A professional morality grounded in the clinical relationship assumes matters of scope are already settled and so struggles to provide guidance where the scope of responsibilities is precisely what is at issue. While one might argue that the virtues necessary for excellence in clinical practice would automatically dispose clinicians to view themselves as bearing responsibilities to others in formal scenarios, there ~~is no~~ ~~does not seem to be a~~ non-circular reason to hold that this should be the case. Indeed, authors such as Pellegrino (VE) and Nel Noddings (CE) stress the *partiality* of the appropriate dispositions that require the virtuous agent to be engrossed in the needs of those with whom they are in established relationships, to the exclusion of more distant others (Veatch 1990; Noddings 1986).<sup>c</sup>

While internalist accounts struggle to settle ~~questions about~~ the scope of professional responsibility in cases like ours, they are more illuminating regarding ~~object and the~~ content of those responsibilities. By contrast, externalist accounts clearly demonstrate that there is at least a collective responsibility on the part of the profession to act in cases like ours, but methods of

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<sup>c</sup> A reviewer for an earlier version of this paper stated that it would be ~~a very odd~~ to conclude ~~to conclude to draw~~ that Pellegrino's VE was silent on questions outside the doctor-patient relationship. We agree this is so, but nonetheless it appears to follow from the strict internalist account. Pellegrino does in fact look at virtue beyond the clinical encounter, but when he does so it is by shifting the foundations of professional virtue – to a broader definition of the 'characteristic practice' that involves caring for all in society, or even by introducing explicitly externalist elements through a 'covenant' between profession and society.

inferring individual responsibilities in our case proved difficult to apply. This suggests one possible means of progress; to infer professional responsibilities in our scenario drawing on a virtue-based framework, but one grounded in an externalist account of professional morality.

Though it might ~~initially~~ seem contradictory to invoke ~~apparently~~ internalist and externalist accounts simultaneously, this need not be the case. Some VE and CE authors define the characteristic practices of healthcare more broadly, ~~so as to encompass~~ ing the health of all in society (Pellegrino and Thomasma 1993, 86; Tronto 1995, 142).<sup>d</sup> Alternatively, one can explicitly invoke a virtue framework as an 'instrumental' tool to realising an externalist ~~account~~ morality (Driver 2007) – this ~~holds professional responsibilities to be grounded~~ approach grounds responsibilities in the SC model (or some other framework entailing a collective professional responsibility to protect and promote the health of all in society), but ~~that to devolve these responsibilities to individuals it is more useful to ask not what to do, but how to respond – devolves this to individuals not by rather than~~ stating what ~~it is one must do~~ to behave professionally, ~~but by~~ exploring what it is to *be* a professional (Nussbaum 1999; Verkerk 2005). We consider this ~~to be~~ a promising approach to ~~answering the dilemmas of~~ our case, and ~~in~~ other informal encounters.

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### An instrumental virtue-ethical approach to diagnosis by documentary

~~As stressed above, e~~ Ethical medical practice is not simply a matter of weighing competing moral claims or principles in crisis scenarios and determining the best course of action. The first moral challenge is simply to notice what is morally salient in the world around us, and how our interactions with it spread out to affect those around us (Little 1995). In our case, important issues will hinge upon features like the nature of the programme (where the patient had retroactively consented to their care being filmed, rather than actively seeking to publicise his condition), the specific nature of the NES diagnosis, its relation and similarity to epilepsy, the importance of conversational/-relational considerations in the diagnosis and management of NES, cultural and professional interpretations of

<sup>d</sup> Though some question whether expanding definitions in this fashion means they lose their distinctive internalist element, since 'practices' are both learned and defined by their exercise (Annas 2011) and caring essentially concerns sensitivity to and engrossment in needs of close others (Held 2005, 31–2).

functional disorders, and so forth. And while the moral salience of these particulars may be underlined in dealing with ~~contested diagnoses such as~~ NES, they will arise in different forms in engaging with any condition or patient group, ~~and will demand~~ing appropriately different responses from the professional. VE, through its emphasis on 'practical wisdom', and its understanding of virtue as a skill to be learned rather than a code to adhere to, is well equipped to face these challenges.

Most formulations of VE since Aristotle ~~make central to their accounts of virtue~~emphasise some ~~form~~the import of 'practical wisdom' (*phronesis*, in Aristotelian terminology). This is a capacity to discern the morally salient features of a given situation, the possible courses of action available, and to navigate through them appropriately; ~~as John McDowell (McDowell 1979) puts it, "an ability to recognize requirements which situations impose on one's behaviour."~~ Recognising the requirements of a collective professional responsibility to promote health is not the same as directly assigning the profession's responsibility to individuals. The ~~prudent~~ professional *phronimos* acknowledges that promoting a healthy society cannot be pursued independently ~~and requires coordination across healthcare and public health services~~, and will for the most part guide her actions accordingly, ~~in coordination with other health workers~~. But she goes beyond the usual standards of clinical practice ~~and organisation of clinical services~~ in adopting an attitude of *non-complacency* toward the ~~profession's~~ responsibilities ~~of the profession~~. She will be aware that the usual mechanisms for distributing responsibilities amongst professionals may sometimes fail, and be disposed to go beyond usual norms of professional conduct to rectify these failures, and ensure that systems will be more resilient against such failures in future.

A VE approach emphasises both the practical wisdom required to identify different morally salient dimensions of the situation, ~~(relating to the individual patient, to other NES patients, to the treating team/hospital, and to the health service at large)~~; and the non-complacency to acknowledge a potential need to act. ~~Fully displaying such sensitivity~~It would furthermore require acknowledging

~~the various different~~ facets of the patient's good ~~in this context~~: the risks of medical harm, but also their understanding of old and new diagnoses, the impact the new diagnosis might have on their self-view and relationships with others, and the potential for resistance to psychologising interpretations of their condition. In lieu of the sensitivity of these features to the manner in which an NES diagnosis is introduced and explained, it is important to consider not just whether or not to make known the diagnosis to a patient, but how to go about doing so – to determine who would be the best person to undertake a more complete diagnostic ~~assessment (not only taking account of the seizures shown on TV but also the patient's previous history and potential other symptoms)~~ and be responsible for ongoing management, and how to avoid undermining confidence in other healthcare professionals following misdiagnosis and mistreatment. To engage with these factors sufficiently would require more knowledge than is available to the viewing doctor, and may be best attempted through those already in a formal professional-patient relationship with the patient. Thus a non-complacent but sensitive course of action in this case might first be to raise the issue with colleagues already responsible for some aspect of the patient's care.

Discussing the situation first with others already involved in the care of the patient has a further advantage. Virtue-based understandings of professional responsibility view it as a skill to be learned, not a set of rules to be followed. According to Aristotle, virtue is learned through its practice, and we learn how to perform virtuous actions first by emulating those we think virtuous. But skill – or virtue – is not emulation alone; as Julia Annas (2011) argues, learning such practices instead requires seeing how they are performed in a variety of contexts, reflecting on salient points and coming to *understand* what makes given actions skilful or virtuous. Reflective deliberation on a community's standards of virtue is ~~on her account, crucial in~~ learning virtue to be virtuous. By consulting with colleagues, the doctor in this scenario is able to test their own interpretation of the situation against the assessment of others, and work toward consensus on clinical assessment of the patient – providing a kind of moral and medical 'peer review'. Moral peer review would further permit coordination of different professionals' practice – through collective deliberation, rather than

through each independently following a given decision procedure or abstract specification of principles.<sup>e</sup>

## Application to the case

### Responsibilities to the patient

Given the patient's history of recurrent SE-like presentations, if he were ~~instead to be~~ suffering from NES, then he would have a strong interest in correction of this misdiagnosis, due to the substantial morbidity and mortality associated with management of prolonged NES as SE, and the inappropriate treatment of his NES disorder with AEDs (Reuber, Enright, and Goulding 2000; Reuber, Baker, et al. 2004; LaFrance and Benbadis 2006). ~~The A~~ ~~correction of the~~ diagnosis would also allow him to gain access to ~~NES~~ ~~the potential benefits of~~ appropriate ~~therapeutic approaches for NES~~ ~~interventions~~ (such as e.g. psychotherapy). However, the potential threat of misdiagnosis (or comorbid epilepsy) must also be entertained here, even though previous studies demonstrate the high level of diagnostic accuracy which can be achieved when experts see video-recordings of seizures (without additional EEG or clinical data) (Chen et al. 2008).<sup>f</sup> Furthermore, any effort to correct such a putative misdiagnosis must be sensitive both to the potential therapeutic benefits and harms of the manner in which the diagnosis is given (LaFrance, Reuber, and Goldstein 2013; Thompson et al. 2009) and the psychological and social sequelae of 'undiagnosing' epilepsy (Karterud, Knizek, and Nakken 2010; Solomon, Klein, and Bourdette 2012).

A cautious approach to action in light of these sensitivities was, in fact, pursued by one of the authors, ~~a~~ first approaching neurologists and psychiatrists at the hospital in question who would know more about ~~local~~ ~~the~~ procedures ~~at the hospital~~ and may have ~~more of a relationship~~ ~~had prior~~

<sup>e</sup> Drawing attention to this conception of learning virtue may also have important ramifications ~~for how for~~ ~~medical~~ ethics and professionalism ~~is taught~~ ~~teaching~~ in healthcare education. Rather than insist ~~ingence~~ of application of certain principles of conduct, it would look instead to the exemplars of professionalism provided to students and trainees by clinical role models, thus emphasising the 'hidden curriculum' (Hafferty 1998) of medical education.

<sup>f</sup> It is difficult to operationalise the level of certainty in the diagnosis here; while diagnostic levels of certainty for NES have been proposed (LaFrance et al. 2013), they are of limited applicability here given the very prolonged nature of the seizure and the lack of a semiologically-similar epileptic seizure against which to compare its clinical and EEG characteristics. We thank a reviewer of a previous version of this paper for raising the question of defining level of certainty in the diagnosis.

~~contact~~ with the patient in question. This offered multiple advantages. ~~Given the stress on professional virtue as a practical skill~~As discussed above, 'peer review' of individual clinicians' interpretation of the morally salient features of events becomes an important means of developing virtuous practice and ensuring that the profession collectively discharges its responsibilities to society; ~~such discussions afford an opportunity for such review~~. Furthermore, it permits an enhanced understanding of the situation and the actions required by drawing upon the experience of others who may be more knowledgeable regarding relevant details concerning the patient or the hospital. Additionally, it minimised the risk of misdiagnosis, by making the ~~assertion of a clinical~~ diagnosis the collective action of a group of experts, ~~with rather than a lone individual~~. There is evidence suggesting that such group diagnoses are more likely to be accurate than any individual's independent efforts (Stroink et al. 2004).

~~Having discussed the case with~~In our case, the neurological and psychiatric teams – who corroborated suspicions regarding the likely misdiagnosis – ~~they were well-placed to and identify identified~~ a doctor in an appropriate doctor-patient relationship with the patient to arrange ~~appropriate follow-up ongoing management~~, thus the viewing clinician was able to initiate action ~~furthering the patient's good~~.

### Responsibilities to the healthcare team

The evidence of misdiagnosis and subsequent mismanagement, with potential for severe iatrogenic morbidity and mortality, raises further questions of responsibility toward the treating healthcare team and their future patients. ~~Patient safety and quality improvement research consistently highlights the~~A range of systemic, institutional, social and personal factors ~~are~~ implicated in clinical error (Reason 2000); it would be unfair and ineffective to treat this case as arising solely from error on the part of treating clinicians. It may even be the case that – given the need for prompt intervention in cases of true SE – that best practice might involve intervening even where NES cannot be ruled out, if it were thought that the risks of not intervening in SE outweigh those of intervening in NES. However, the non-complacency stressed by us above as being central to virtuous

practice suggests that the clinician should not *assume* that this is the case, and be prepared actively to pursue better ways of training healthcare workers and constructing management guidelines that might minimise both types of risk. Given that ‘suspected seizure’ is amongst the top ten reasons for accessing emergency healthcare (Dickson et al. Forthcoming), such actions are all the more important since this is not an isolated incident, but an instance of a more widespread problem (Reuber, Enright, and Goulding 2000; Reuber et al. 2002; Leach et al. 2005).

The ~~clinician who observed the likely misdiagnosis and –management on TV~~ viewing clinician contacted the Clinical Director of the ~~Emergency Department~~ ED in question so that the issue could be discussed with the treating doctor(s) ~~and –confirmed that extra training would be arranged for ED staff.~~ Whether this ~~is an effective means of effectively protecting~~ protects future patients against similar error is an empirical question to which we as yet do not know the answer, but ~~studies show that~~ short teaching interventions raising awareness of NES and familiarising trainees with the visible semiology of NES and epilepsy using video recordings can markedly improve doctors’ diagnostic skills (O’Sullivan et al. 2013; Seneviratne et al. 2014). This could be an instance of a more general problem across the health service, so witnessing such episodes reaffirms the importance of educating not only neurologists but also generalists about NES and related conditions, especially when considering ~~–Bringing the case to the attention of other colleagues (in all specialties) when opportunities arise may be of value in prompting further reflection on~~ guidelines for emergency management in cases of suspected SE, highlighting that alternative diagnoses should be considered. ~~Guidelines already incorporate consideration of o~~ Other differentials such as eclampsia are already included (Brophy et al. 2012) ~~and suggestions for~~ alternative management outlined; while features raising suspicion of eclampsia (~~i.e.~~ pregnancy!) may be more obvious, this shows the potential for incorporating flexibility into such guidance.

These considerations – much like the involvement of other clinicians in ‘peer review’ ~~discussed above~~ – also highlight that virtuous practice is a *collaborative* process. The success of interventions

on the part of the witnessing clinician here depend on the receptiveness of others to his concerns and advice. Thus moral sensitivity and noncomplacency ~~in the face of moral need~~ must not just concern what health workers see around them, but also reflection on their own practice, and their skill and knowledge limitations.

### Responsibilities to the media and public

This last set of questions concerns the relationship between health professionals and media workers producing health-related content, and the responsibilities of health workers for public engagement around conditions they ~~see, treat,~~ and research. Without cooperation between media and health workers, there is potential for exploitation of people in situations rendering them particularly vulnerable, and for misrepresentation of stigmatised conditions in public arenas.

The making of documentary series involves film crews being granted privileged access to sensitive clinical areas which would normally be out of the public eye. For emergency presentations such as apparent SE, it would ~~obviously~~ be highly unlikely that prior informed consent could be gained from subjects for such filming; thus retrospective consent is usually sought by documentary makers. ~~Most~~ ~~d~~Discussions of the ethics of such documentaries have focussed on the quality of this consent (Geiderman 2001; Godfrey and Henning 2007; Marco et al. 2002). Properly informed consent is difficult to obtain in such conditions, and may still leave individuals open to harm or exploitation; even competent adults will be in a position of some vulnerability from being acutely unwell ~~and~~ under time pressures, and may feel compelled to agree (Godfrey and Henning 2007), ~~perhaps~~ ~~exacerbated by concerns~~ concerned that refusal may affect their treatment (Geiderman 2001). While the observer of our scenario is not best positioned to engage in this controversy, they may still be able to ~~make some contribution~~ contribute to better consent processes.

The UK broadcasting code<sup>8</sup> requires only that consent be obtained for filming and broadcasting such footage, without specifying conditions of adequacy for such consent. It makes a broad exception for “vulnerable people”, (a term ~~it considers to include~~ covering “those with learning difficulties, those

<sup>8</sup> Set by Ofcom, the independent regulator and competition authority for the UK communications industries.

with mental health problems, the bereaved, people with brain damage or forms of dementia, people who have been traumatised or who are sick or mentally ill” (Ofcom 2015, 44)), who are deemed to lack capacity to consent altogether without simultaneous consent of a guardian. It is unclear whether people with epilepsy or NES would be deemed vulnerable on this ‘labelling’ approach to vulnerability, which is in any case overly simplistic.

The labelling approach is at once too narrow (~~by~~ looking at only the individual’s status as a source of vulnerability, it neglects contextual and situational factors that may render them so), and too broad (~~since~~ it labels whole groups as ‘vulnerable’ in a whole-broad range of situations, without considering their individuals’ specific circumstances and capacities) (Rogers 2013). A more adequate conception ~~of vulnerability~~ for these purposes considers vulnerability as: *relational* (people are not vulnerable *simpliciter*, but vulnerable *to* certain threats *in* certain situations); *dynamic* (changing through time and situationally modifiable); and *a continuum* (~~not a binary condition, but continuously graded~~)—thus interventions should be tailored less toward denying the decision-making capacity of ‘vulnerable’ people, more toward supporting their movement away from the vulnerable end of the spectrum) (Bell et al. 2014).

~~A relational and dynamic understanding~~This conception of vulnerability highlights that questionable consent can be improved by modifying aspects of the decision environment to promote authentic decision-making. ~~Adopting t~~Temporal strategies that treat consent as a continuing process rather than a discrete event ~~has been suggested as being of particular value~~may be of us here (Bell et al. 2014). Medical professional associations recommend their members adopt temporally-extended ‘dual consent’ processes when filming their patients for secondary purposes such as teaching (Marco et al. 2002; BMA Medical Ethics Department 2011) – this could be suggested ~~as a first approach for~~to media workers ~~also~~too.

More generally, clinicians ~~will~~ develop a range of communication skills ~~they find useful for~~supporting that support the decision-making capacities of different patients, and these can be shared

with others ~~who are~~ seeking dialogue with them. ~~This is of particular significance in our case since~~

~~p~~Patients with NES may be particularly susceptible to certain forms of exploitation through inadequately-designed consent procedures, ~~quite apart from the situational features that make retrospective consent in the case of questionable merit. Though It is plausible (though a matter of ongoing controversy) that, it could be argued that~~ certain personality traits ~~which characterisedisplayed by~~ many ~~patients with~~ NES patients (Reuber, Pukrop, et al. 2004; Cragar et al. 2005) render them particularly vulnerable to inauthentic decision-making even when competent.:

One important subgroups ~~of patients with NES~~ is characterised by high emotional lability, high levels of impulsivity, and a tendency to emotion-linked cognitive distortions. This can ~~make it difficult to establishimpede~~ consistent communication of authentic values, ~~or even adequate interpersonal relationships to facilitate such communication~~ (Winburn and Mullen 2008). Another major subgroup of NES patients ~~with NES~~ has a tendency to strictly-conforming, highly-controlled behaviour (Reuber, Pukrop, et al. 2004). This may exacerbate the unequal status relationship between those seeking and giving consent in the clinical setting and call the validity of consent into question for different reasons (Geiderman 2001). Highlighting these potential vulnerabilities to documentary makers, and describing ~~some~~ strategies useful for ameliorating them in clinical contexts (Szmukler 2009), may ~~help~~ prevent inadvertent exploitation of such patients in future encounters.

~~Issues around consent and vulnerability are not the only ethical concern that must be confronted with the documentary makers. In addition to the topic of consent and vulnerability, the~~

misdiagnosis itself and consequent misrepresentation of both epilepsy and NES by the documentary ~~may needs~~ addressing. Mass media and fictional representations of epilepsy present the condition as far more dangerous than it is in the majority of cases, which may exacerbate anxiety around receiving and living with such a diagnosis (Baxendale 2003). NES, meanwhile, is a diagnosis with which many initially struggle and which they may find hard to reconcile with their own self-understanding (Thompson et al. 2009; Whitehead, Kandler, and Reuber 2013). Misrepresentation of ~~pseudo~~status-prolonged NES as SE thus carries a double threat, obscuring understanding of both

epilepsy and [NESSE](#). Broadcasting codes and health care journalists' codes of ethics present a commitment to accuracy and fair contextualisation (Schwitzer 2004; Ofcom 2015),<sup>h</sup> and health journalists themselves emphasise the primacy of objectivity and avoiding sensationalism in quality journalism (Leask, Hooker, and King 2010). This suggests that media workers covering health issues should be responsive to attempts to improve their understanding of conditions the people they ~~seek~~ ~~to~~ portray are living with, and how these are shown to the ~~viewing~~ public.

It would be beyond the capacities of the viewing clinician in our case to act on all the potential moral threats to both documentary subjects and ~~viewing~~ public, however it is nonetheless within their scope to initiate action on these issues. A first step – as one of us pursued in this case – is simply to contact the documentary makers responsible to raise concerns; in doing so it is of particular importance to provide support and resources to address the knowledge gaps and procedural shortcomings that may make some patients vulnerable in the filming and consent processes, or lead to misrepresentation and misunderstanding of health conditions. Regarding inaccurate representation of conditions and possible consequent harms, this contact needs to address questions both of how to rectify past broadcasts of misleading content, and what procedural measures could be adopted to prevent such occurrences in future.

In other publishing arenas – such as academic literature – publishers' organisations such as the Committee on Publication Ethics offer clear guidance on how to identify and respond to errors in published material – with appropriate responses ranging from errata to retractions (Committee on Publication Ethics 2015). However, ~~there are~~ important disanalogies between academic publication and broadcast media ~~that~~ make such guidance of little utility ~~in this context~~[here](#). Academic publications stand as part of the research record and are more permanent – remaining accessible in journal archives ~~and the like~~ – than the relatively evanescent lifespan of broadcast television (even with the expansion of catch-up services). Erroneous data in scientific publications are also more

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<sup>h</sup> [An extensive range of ethical codes for newsrooms can be found at the website of the American Society of News Editors, www.asne.org. Most include principles similar to those referenced above.](#)

likely to have a direct impact on future work (e.g. treatment decisions, further research) than entertainment programmes; the latter's influences are more diffuse, ~~contributing to~~ shaping a general public perception of the services and conditions displayed rather than ~~being directly used~~ ~~as~~ ~~directly~~ ~~providing~~ grounds for action. For both these reasons, retraction and other post-hoc interventions are a less useful tool, but the reporting clinician can at least advise on errors that should be addressed if the broadcast were to be repeated or viewable online.

Perhaps more important is the attempt to create procedural measures that might reduce the future occurrence of such inaccuracies. Simply highlighting public educational and self-management tools relevant to portrayed conditions is a fairly easy first step to assist broadcasters in understanding better the experiences of the people whose lives they cover. In order to help contextualise the material broadcast on television, documentary makers could additionally publicise such support material as a part of future programmes (as many UK TV programmes already do for some issues *e.g.* mental health and suicide). Another (not exclusive) course of action might be to attempt to create dialogue between health workers and health journalists more generally regarding the intersection of their professions' responsibilities, contributing a new perspective on otherwise-neglected topics in the developing field of health journalism ethics (Schwitzer et al. 2005).<sup>1</sup>

## Conclusion

More and more people are happy being ~~to be~~ recorded in all sorts of situations, and illness narratives are shared through ever more media channels. Individuals post videos about – or of – their conditions on social media platforms. Their institutional interactions are routinely recorded on audio or video (e.g. “for training and quality assurance purposes”). And it is becoming increasingly routine to see people's real life health problems played out in TV programmes. Health workers can

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<sup>1</sup>[This case raises at least as many questions concerning journalistic professional responsibilities, and – as one reviewer of a previous draft highlighted – the intersection of different professions' responsibilities is significant in addressing cases like this. In this paper, however, we are concerned primarily with the practice of informal medicine and so focus on health workers' responsibilities.](#)

encounter people in apparent need of support in all these contexts. Virtue-based accounts of professional responsibility recognise the importance of moral perception in distinguishing the nuances of what is morally salient in such situations; externalist accounts, meanwhile, help to ensure that the professional's responsibilities are always viewed as being to the society in which they work, and to keep them directed toward a collectively-determined end of promoting health and wellbeing. While our case may be a somewhat unusual one, it is increasingly likely – given the explosion of interest in illness narrative<sup>s</sup> and healthcare documentaries – that health workers will encounter a range of mass-media portrayals of unwell people in situations requiring action by someone within the profession to discharge its collective responsibilities. Drawing on both internalist and externalist accounts of professional responsibility is a valuable exercise in determining how best to act in these encounters.

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