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A diagnostic illusory? The case of distinguishing between “vegetative” and “minimally conscious” states

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ABSTRACT

Throughout affluent societies there are growing numbers of people who survive severe brain injuries only to be left with long-term chronic disorders of consciousness. This patient group who exist betwixt and between life and death are variously diagnosed as in ‘comatose’, ‘vegetative’, and, more recently, ‘minimally conscious’ states. Drawing on a nascent body of sociological work in this field and developments in the sociology of diagnosis in concert with Bauman's thesis of ‘ambivalence’ and Turner's work on ‘liminality’, this article proposes a concept we label as *diagnostic illusory* in order to capture the ambiguities, nuanced complexities and tensions that the biomedical imperative to name and classify these patients give rise to. Our concept emerged through a reading of debates within medical journals alongside an analysis of qualitative data generated by way of a study of accounts of those close to patients: primarily relatives ($N = 51$); neurologists ($N = 4$); lawyers ($N = 2$); and others ($N = 5$) involved in their health care in the UK.

1. Introduction

This article seeks to propose a novel concept – *diagnostic illusory* – in order to capture the ambiguities and nuanced complexities associated with the biomedical imperative to name and classify. We suggest that diagnosis is something of a modernist notion, rooted in the idea that we can have bounded, stable and more precise diagnostic categories identified by increasingly sophisticated technologies. In more and more areas of medicine – for example, breast cancer (Curtis et al., 2012) and dementia (Richards and Brayne, 2010) – we are witnessing the sub-categorization of diagnoses, and although sociologists have demonstrated the unstable nature of diagnostic categories (Mol, 2002; Buscher et al., 2010), the lure of technological innovations in, for instance, genetics and neuroscience, that offer the promise of greater diagnostic precision remains strong (Borup et al., 2006). However, such diagnostic fine-tuning may, rather ironically, harbour unintended consequences; the imperative for diagnostic conviction could generate as many anomalies as it seeks to resolve. Moreover, diagnostic certainty could, in some instances, exacerbate existential doubt.

To ground this theorization we draw on empirical research into chronic disorders of consciousness (CDoCs) and in particular the circumstances of patients who have survived severe brain injury yet remain in long-term vegetative or minimally conscious states. The study provides a window through which we might understand this contemporary trend within medicine. It was through the analysis of our data, informed by insights from the sociology of diagnosis, that our concept took shape. We begin by introducing the extant literature on the sociology of (what are loosely and controversially called) ‘vegetative’ states and the sociology of diagnosis. We then introduce diagnostic categories applied in the context of CDoCs focusing on the distinction between vegetative states (VS) and minimally conscious states (MCS), outline their prognostic, legal, and social consequences and explore debates within the associated biomedical literatures. Turning to our empirical material we reveal conundrums associated with the determination of consciousness found amongst the views of relatives, carers and clinical practitioners. Drawing on concepts of ambivalence (Bauman, 1991) and liminality (Turner, 1967) we conclude with a discussion on the ways in which a biomedical ontology of ‘consciousness’ reifies its existence as a ‘thing’ (Taussig, 1980) that can be detected and ‘seen’ within the brain, and how this

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in turn generates ambiguities for those who care for and care about these patients.

1.1. Sociology of chronic disorders of consciousness

The survival of patients who have sustained severe brain injuries and who are (at least initially) unable to breathe or swallow is a recent phenomenon. Forty years ago they would have died relatively quickly. In many affluent societies, as the result of technologies such as, mechanical ventilators and improvements in the clinical delivery of nutrition and hydration, in concert with a medico-legal imperative to preserve life, a growing number of patients with CDoC survive for years and sometimes decades. Articles report on the reactions of care givers and the socio-legal and ethical implications of their views (Kuehlmeyer et al., 2012; Samuel and Kitzinger, 2013; Kitzinger and Kitzinger, 2013; Halliday et al., 2014), however as yet, there is only a small literature on their conceptual significance (Ben-David and Israeli, 2010; Kaufman, 2003, 2005) and it is with these theoretical contributions that we seek to engage. From these, and related studies on ‘brain death’ (Giacomini, 1997; Lock, 2002; Kaufman and Morgan, 2005), it is evident that professionals, families and wider publics struggle to make sense of patients who are neither fully ‘alive’ nor unambiguously ‘dead’. Kaufman's (2005) ethnography of North American hospital units where health workers and relatives care for patients in ‘vegetative states’ is instructive. She demonstrates how this growing patient population trouble ontologies of life and death, and challenge Western notions of personhood. New categories of patients in the uncharted territory betwixt and between life and death exist in what Kaufman calls the ‘gray zone’, that is ‘… states of being that are neither “comatose” nor “awake” or “alert,” taken together, have created zones of indistinction’ (Kaufman, 2005: 62).

Timmermans' (2005) concept of ‘death brokering’ is also useful here, since it captures the ways in which medical experts work to make these, and other ever more diversified modes of allowing or delaying death, meaningful. Health professionals:

> ‘offer increasingly flexible cultural scripts to render the end-of-life socially meaningful while accentuating death's existential ambiguity. Medical professionals help to create the ambiguity they promise to resolve, reinforcing the cultural need for more expert death brokering’ (p. 993).

Attempts to further demarcate and categorize ‘anomalous’ patients within the ‘grey zone’ provide one such example of medical efforts to ‘resolve’ ambiguities. Indeed, since Kaufman carried out her fieldwork in the 1990s, a new label has been applied to those who are neither ‘vegetative’ nor fully ‘conscious’ but ‘minimally conscious’ (Giacino et al., 2002). In this liminal landscape diagnostic categories are currently in the making (see RCP, 2013). Thus turning the sociological lens on to these processes is timely.

1.2. Sociology of diagnosis

The subfield ‘sociology of diagnosis’ (Jutel, 2011; McGann and Hutson, 2011) urges us to ‘see diagnosis as a kind of focal point where numerous interests, anxieties, values, knowledge, practices and other factors merge and converge’ (Jutel and Nettleton, 2011: 798). Diagnosis is at once a *category* and a *process* (Blaxter, 1978) that carries social, moral, economic, political as well as prognostic *consequences*. Diagnosis is a noun, a label that can serve as an apparently stable descriptor of a discrete condition. But diagnosis is also a verb that implies the act of diagnosing and is deeply embedded in our notions of medical work. As Rosenberg (2002) argues, diagnosis throughout the 20th century came to be understood as objective descriptor of a disease that, in turn, had a correspondent pathological lesion. Diseases and diagnoses he writes became ‘entities existing outside the unique manifestations of illness in particular men and women’ (p. 237). Once encoded in classificatory systems such as the International Classification of Diseases (ICD), a diagnosis feeds back into the diagnostic process (Hacking, 1999). The process is dialectical; clinically accepted diagnostic categories found in medical texts and diagnostic manuals inform day to day diagnostic work within the clinic and vice versa. The diagnostic categories of, and diagnostic ‘work’ associated with, VS and MCS should therefore be understood as an amalgam of practices that circulate throughout medical texts, scientists, clinical practitioners, relatives, bureaucrats, and patients (cf Foucault, 1980; Buscher et al. 2010; Mesman, 2008). As such it is a worthwhile line of inquiry and one we follow in our analysis of the contemporary concretization of VS and MCS. We explore what Bowker and Star (2000: 44) refer to as the ‘practical politics of classifying.’

> ‘Someone, somewhere, must decide and argue over the minutiae of classifying and standardizing. The negotiations themselves form the basis for a fascinating practical ontology – our favorite example is when is someone really alive? Is it breathing, attempts at breathing, or movement? How long must each of those last? Whose voice will determine the outcome is sometimes an exercise of pure power’.

The implication here is that determining evidence of ‘life’ and ‘death’ is (at the risk of understatement) difficult. Our attention is on the relatively new landscape of ‘death in life’ (Kaufman, 2005: 7) where the determination of consciousness within these borderlands has come to carry significant prognostic, legal, ethical and social consequences.

1.3. MCS and VS: categories and consequences

In the UK, a VS is formally defined in guidelines (RCP, 2013) as ‘permanent’ [PVS] a year after traumatic and six months after non-traumatic brain injury (in the USA the equivalent time after non-traumatic injury is three months). The diagnostic label ‘minimally conscious state’ (MCS) was ‘invented’ in 2002 by neurologists in the USA who sought to label a subgroup patients, who did not ‘fit’ the criteria of the VS, precisely because they appeared to manifest awareness, albeit at a low level and intermittently (Giacino et al., 2002). Formally described as ‘minimally responsive states’, the semantic shift from ‘responsiveness’ to ‘consciousness’ is significant because of the socio-cultural resonances and because it serves to contribute to the reification of ‘consciousness’ as a ‘thing’ (Taussig, 1980).

Attempting to assess whether the patient is in a VS or MCS is relatively routine in practice across ‘the West.’ There are calls to subdivide the MCS diagnostic category still further. Bruno et al. (2011) propose sub-categorization into minimally conscious PLUS (MCS+) and minimally conscious MINUS (MCS−) to reflect degrees of complexity of observed behavioral responses. MCS− is defined as closer to the ‘vegetative’ state – a state also referred to as ‘unresponsive wakefulness syndrome’ (UWS) (Laureys et al., 2010) to avoid the negative connotations of ‘vegetative’, and allow for the possibility that unresponsive patients *may* have some level of awareness albeit inaccessible during clinical observations.

Current clinical assessment in the UK predominantly relies on two tools: the Wessex Head Injury Matrix (WHIM) and the Sensory Modality Assessment and Rehabilitation Technique (SMART). Diagnosis based on the latter is now required in English court cases for treatment withdrawal. SMART is a formal assessment conducted in ten sessions over a three week period and is designed to