

DENY, DISMISS, DEHUMANIZE

What happened when I went to Hospital

By Adrienne Cullen

BOOK REVIEW (by dr. Volkert Wreesmann)

An Irish national, expatriate Adrienne Cullen works in Amsterdam when disaster strikes: a medical test report which indicates early cervix cancer gets lost in a Dutch University Hospital. Two years later the report accidentally resurfaces and she is diagnosed with late stage disease, which soon proves to be incurable. Shocked and devastated, Adrienne embarks upon a journey to determine what happened. Although she expects to be met with empathy and support, she instead encounters bureaucracy and indifference. She soon discovers that her doctor has been disqualified from counselling her, while still in charge of her treatment; a treatment that she is not allowed to choose herself. Instead, her case is referred to the legal department where it is quarantined, while legally-mandated notification of the Healthcare Inspectorate is not performed. When Adrienne submits a report from an independent medical expert which confirms medical negligence, the hospital can no longer deny responsibility. However, prospects of adequate compensation remain limited by Dutch Law, which discourages immaterial reparations and favours out-of-court settlements over objective evaluation by a judge. What follows is a 2-year ordeal in which her privacy is meticulously dissected by a hospital-appointed loss-adjuster, in order to determine her material damage. Her dignity is further jeopardized by lack of personal attention or apology from the hospital leadership, their refusal to perform a root-cause analysis, and their demand for her signing a gagging clause before any financial compensation is considered. Pushed to her ultimate limits, she is driven to go public and involve a newspaper in her case. One day after a TV program airs an unrelated story about patient and employee safety issues at the hospital, a limited compensation is finally agreed upon. Adrienne passes away 3 years later, in the presence of her caring husband, free of resentment towards her doctors, whose evolving support has led her to forgive them. Root-cause analysis results remain pending however.

Adrienne's' desolate struggle for justice is illuminated by an array of adversaries she meets and beats along the way; each Pharisees in their own right: a hospital CEO who is happy to accept his elevation into Royal Knighthood, while disembarking the hospital in a storm after an incident-ridden tenure, his successor who publicly markets herself as a supporter of transparency, while allowing pressure for a gagging clause behind the scenes, a Dutch senator and professor who lectures ethics to medical students at Adrienne's' hospital, but is uninterested to help resolve Adrienne's ethical issues with the hospital leadership, and Health Inspectorate officials who are happy to accept that their surveillance of hospital bosses is based upon trust, but are suspicious when quality of care is questioned by patients or doctors. It is not so much the choices that these individuals make, but the stark contrast offered by the kind and caring support of many others which really sets the stage for Adrienne's relentless conquest. The "coming of age" of her gynaecologist and his departmental chief, who manage to break free from their superiors and choose Adrienne's

side, is an exemplary story of forgiveness and redemption in this regard, and it demonstrates the importance for doctors and patients to stick together after medical incidents.

The reliability of Adrienne's experience is independently confirmed by multiple whistle-blowers and journalists who revealed an array of seemingly avoidable medical incidents at the hospital. These incidents are attributed to a suboptimal hospital culture marked by fear, distrust, repression, and disengagement among employees. A recent Health Inspectorate investigation suggests that this atmosphere reflects a compensatory reaction to a lack of direction and control perceived by employees. Primary hallmarks of inadequate organisation include a vertically-oriented top-down command structure and resultant quenching of vital informational exchange within the bureaucracy of its multiple middle-management layers, marginalization of employee assistance and participation programs, and insufficient surveillance by internal and external regulatory bodies. It is these issues that fuel insufficient communication within the hospital and caused Adrienne's demise, rather than the short-sighted belief held by some hospital officials that the incident merely related to a transition from paper to electronic medical files.

For these reasons, I would argue that this book is not just another story of good people versus bad people. Rather, it documents how well-intentioned people can make the wrong choices when part of a defective organisation. It is this realization that may provide us with an opportunity to improve the system and prevent future cases like Adrienne's. It seems that the common denominator of the problems in Adrienne's hospital is an organisational focus upon centralization of power rather than a more democratically arranged, decentralized governance structure. Although the former may seem more efficient, the question is whether it is an optimal choice in the healthcare setting as it not only tends to increase the power difference between hospital employees and their superiors, but also between patients and their health care providers. These consequences may fuel suboptimal healthcare outcomes due to employee disengagement and reduced patient autonomy respectively. This is well illustrated by Adrienne's experience, and the lack of regard she suffered in the hospital. Not only was she not informed that biopsy tissue had been removed from her body without her consent, but the remainder of her journey was marked by a general disregard for her autonomy. A pertinent example includes the pressure she received to sign a gagging clause, a clear human rights violation of her constitutionally granted Freedom of Speech rights. Patient-centred policies such as "Duty of Candour" and "Open Disclosure", which are widely accepted in the USA and UK, were surprisingly non-existent in The Netherlands before Adrienne addressed these. Such guidelines are meant to provide an ethical and legal requirement for healthcare providers to be open and honest when something goes wrong, with the aims to maintain patient autonomy. Being well informed avoids occurrence of "second harm", which includes the secondary psychological harm that affects patients affected by medical incidents when their grief is dismissed. The absence of such policies in the Netherlands, suggests that patient autonomy problems are likely not limited to Adrienne's hospital alone. In fact, not only Adrienne's experience in other hospitals, but a range of media publications over the last few years suggest that these problems are widespread, and may be resolved through decentralization of authority. For this reason, I think this book may serve as an important warning to patients, physicians, hospitals leaders, regulatory authorities and politicians. In a

time in which western societies are increasingly affected by political choices that favour centralization of power at the expense of rights and liberties of its individual citizens, Adrienne's Orwellian struggle is a clear example of the grave consequences such policies may inflict.

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