

“Ignorance is bliss?”:
With attention to ethical theories,
discuss the role of truth-telling within
good palliative care?

APM UNDERGRADUATE PALLIATIVE MEDICINE ESSAY PRIZE

Introduction

“Honesty is the best policy” is, arguably, a saying applicable to most walks of life. However, the concept of truth-telling in palliative care is multi-faceted; with a whole host of ethical dilemmas arising^{1,2}. Barriers to honest communication will be explored following appraisal of the moral tools available to palliative care doctors. Specifically, this essay will discuss the shift from traditional medical ethics³ to an ‘ethics of care’⁴ model and the impact that this ethical model has on clinical practice will also be assessed. Finally, the idea that ‘ignorance is bliss’ will be explored in the context of patient outcomes and healthcare professionals’ perspectives.

Ethics of Care

There exists academic discourse with regards to the application of traditional medical ethics in palliative care⁴. Indeed, Hermsen and Ten⁵ argue that the classical biomedical model proposed by Beauchamp and Childress³; autonomy, beneficence, non-maleficence, and justice, does not fit palliative care very simply. This is argued by Lloyd *et al.*⁶ in their 2004 narrative review to be due to traditional bioethicists distancing themselves from the practicalities of clinical care; thus, affording impartiality in its theorising. This in itself was rejected by feminist ethicists⁷ who instead believe that philosophy must be considerate of its implications in reality. Indeed, Liedtka’s⁸ narrative review discusses the move away from a formulaic approach to moral decision making, as seen in Beauchamp and Childress, to one of holistic care incorporating the whole being. The rigid Kantian view of autonomy by Beauchamp and Childress ascribes to a certain rationality rooted in believing all people view morality the same way⁸. Feminist ethicists argue that this, when adopted into practice, can lead to care providers assuming all patients have the same expectations and needs⁹. Instead, in seminal work by Joan Tronto¹⁰, this impracticality is identified, and in opposition to Kant’s Principlism, the moral values of Aristotle and Hume inform Tronto’s view of ethics of care. This means that ethics of care views the patient as a product of their environment and considers contextual factors¹¹. Necessitating this, as postulated by Aristotle, is one’s

innate social and political being⁸ that must be accommodated in the application of ethics. In an explicitly clinical interpretation, de Vries and Leget¹² argue that non-malevolence and beneficence in the biomedical model can precipitate an incentive within physicians to pursue their own goals of trying to do good. This can translate into losing sight of what is best for the patient. This could also explain the move towards ethics of care, in an effort to achieve better alignment of patient and healthcare professionals' interests. Therefore, ethics of care is increasingly opted for to facilitate patient-centredness earnestly sought¹³.

With an understanding of the reasoning for the adoption of ethics of care in palliative medicine, it is necessary to review its implications. For example, it can manifest in clinicians broadening their definition of autonomy to accommodate their patients' needs. Indeed, van Nistelrooij¹⁴ state that autonomy in the context of ethics of care can manifest in shared decision making, where the patient and doctor can share the burden of knowledge. This phenomenon leads to 'relational autonomy', as opposed to individual autonomy advocated for in the biomedical model¹⁴. This is concordant with feminist philosophy⁶ focussing on the importance of community in palliative care, exemplified by Grogono in his exploration of the idea of '*amicus mortis*', a friend at death¹⁵. It is important to note that relational autonomy in this context can involve not only the patient and healthcare staff, but also family¹⁶. This has been justified in medical ethics literature to accommodate the innate need for patients in their end of life to shift from isolated individualism to a culture of communalism^{17,18}. Feminist ethicists in palliative care literature apply a more subjective approach to the extent of communalism that will be explored throughout this essay¹³.

Truth-telling and Ethics of Care

Given ethics of care's core interest in practicality, it is necessary to evaluate current research into how it is delivered. Johnson *et al.*¹⁹ conducted a qualitative study in 2018 which showed that despite recognising their patients' wishes, doctors admitted to ignoring patient wishes when difficult decisions were required. When viewed under the traditional ethical

model, this could be construed as misguided beneficence. However, Sjostrand²⁰ argue that it is autonomy in the context of feminist interpretation being a fluid ideal rather than a right that can be used to justify acts of paternalism. Therefore, Johnson *et al.*'s study¹⁹ could be viewed to warn of the susceptibility of the ethics of care model to this dangerous practice due to the degree of flexibility afforded.

To improve the transparency around shared decision making and relational autonomy, Advanced Care Plans (ACPs) have been introduced to palliative care practice²¹. This is a statement made in advance of end-of-life care while one still has capacity to make decisions and can make clear directives for one's care²². The emphasis in ACP is on communication to ensure a patients' wishes are met. This in itself adheres to the ethics of care model, demonstrating a flexible approach to aligning with the patients' priorities¹³. The execution of ACPs in practice have been explored in a qualitative evidence-based study, with doctors viewing them as a useful tool to explore the patients' expectations¹⁹. A key finding was that they were used in practice to shift the focus from one of treatment to supportive care. This is where the doctor with clinical experience takes on some of the decision making for the direction of care to manage the patients' expectations. ACPs used as a tool for better communication to navigate this complex encounter enables good palliative care. Therefore, it can be seen that ACPs are a useful communicative tool in exploring a patient's end-of-life decisions, keeping them at the centre of decision-making, a priority in ethics of care.

Communication and the Patient Perspective

It is also necessary to explore the impact that a lack of truth-telling can have on patient outcomes. Indeed, through a doctor's well-intentioned means of preserving hope, patients can be overly optimistic on their prognosis²³. This is evidenced in Gramling *et al.*'s²⁴ cross-sectional study of 236 advanced cancer patients, of whom 68% were differing in their understanding of their survival prognosis compared to their oncologist. It was also found that 89% of these patients did not know their views conflicted their oncologists, and 96% were

more optimistic than their doctor's survival prognosis estimate. This can complicate clinical practice, leading to patients wishing for interventions such as CPR which doctors find inappropriate²⁵. As such, patients can grow frustrated, believing their care providers are not acting in their best interests. Therefore, evidence suggests that dishonesty fosters a potential source of conflict that could be mediated with open communication. This evidence advocating for open communication inherently contrasts the perspective of 'ignorance is bliss' and shows the importance of truth-telling in providing good palliative care.

This is furthered by evidence from Ten *et al.*'s²⁶ randomised controlled trial from 1998, which found that patients were statistically significantly less likely to request CPR when informed of their poor prognosis. Discordance in patient understanding can lead to unsafe, ill-informed decision making from patients. This lack of understanding can be contributed to doctors being shown to "tone down" their language^{27 p.138}, misleading patients into believing their prognosis is falsely auspicious. This impacts the delivery of care, as Collins *et al.*²⁷ found that ill-informed patients may be less open to receiving palliative treatments shown to improve quality of life, including talking therapy and complementary medicine. Poor communication in palliative care has been recognised in United Kingdom-based palliative care guidelines²⁸. This guidance found two key factors contributing to this phenomenon: lack of communication training availability and insufficient quality of said training. This finding is supported by de Panfilis *et al.*¹³, whose deductive thematic analysis also concluded that palliative care staff should receive both communication and moral training. This indicates an evidence-based direction for future research.

The Impact of Collusion and Omission on the MDT

In order to best understand how to provide holistic palliative care, it is critical to recognise how dishonesty affects the multidisciplinary team. Testoni *et al.*²⁹ performed a discourse analysis on the impact that collusion has on nurses. A key theme was the "conspiracy of silence"^{29 p.5} between relatives and the healthcare team. Interestingly, in a more patient-

facing role, nurses said that they found it difficult to tread the balance between doctors, family members, and patients without saying anything compromising. Nurses reported feeling uncomfortable around their patients due to guilt and fear of saying something they should not. This is an important barrier to good palliative care. Dishonesty and collusion have also been shown to cause high levels of stress and increased work turnover among both nurses and other healthcare professionals. The study also highlighted the resentment that can build from nurses towards doctors, as they view the doctors as the individuals deciding to lie to their patients, but it is nurses who have to participate most. This has the potential to greatly hinder patient care.

It is necessary to appraise the methods used for this research. Testoni *et al.*² were largely interested in eliciting narratives, using a validated interpretative phenomenological analysis³⁰ approach to perform their ethnographic³¹ healthcare research. This analysis is defined by Smith *et al.*³⁰ as a method designed to best examine an individual's life experiences. The use of this method was justified by allowing the researcher to get closer to the point of view of the person who experiences the certain phenomenon. Similarly, Collins *et al.*²⁷, opted for interpretative phenomenology when eliciting narratives of patients and their views on what they value most in palliative care. The reasoning behind this can better inform us of directions for future ethical research in palliative care. The focus in both studies on phenomenological interpretive inquiry research is a testament the importance of the individual and their own personal story³². However, since the main focus in such a methodology is on the individual, some academics, namely Renaut³³, argue that this interpretation lacks layers of social dimensions. These include the individual's societal and cultural inputs. Awareness of the philosophical bases of the methodologies employed is essential to ensure critical awareness and justification for the research exploring palliative care practice.

Conclusion

It has been evidenced that healthcare professionals approach palliative patients from an 'ethics of care' perspective, viewed as more nuanced than traditional biomedical ethics rooted in Principlism⁹. This in itself adds flexibility to the well-established concepts of autonomy and what it really means to benefit one's patients³⁴. However, evidence shows that in applying a more flexible idea of morality, physicians can complicate truth-telling in difficult conversations. Therefore, while ethics of care occupies an increasing space, evidence suggests it is important to recognise personal biases making such a model susceptible to stereotyping and paternalism. This is not to say that ethics of care itself has no place in the delivery of good palliative care, but the assumption of 'ignorance is bliss' that can exist in such a model must be addressed due to its potential harm to patients and palliative care providers. The use of communicative tools, such as ACPs, and more evidence-based moral and communication education are potential means of improving ethics of care practice in the United Kingdom.

Word Count: 1869

Reference List

1. Vivian R. Truth telling in palliative care nursing: the dilemmas of collusion. *Int J Palliat Nurs* [Internet]. 2006 [cited 2022 Oct 25]; 12(7):341-348. Available from: <https://pubmed.ncbi.nlm.nih.gov/16926733/> 10.12968/ijpn.2006.12.7.21612
2. Pontin D, Jordan N. Issues in prognostication for hospital specialist palliative care doctors and nurses: a qualitative inquiry. *Palliat Med* [Internet]. 2013 [cited 2022 Oct 25]; 27(2):165-171. Available from: <https://pubmed.ncbi.nlm.nih.gov/22190605/> 10.1177/0269216311432898
3. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. Oxford: Oxford University Press; 2012.
4. De Panfilis L, Di Leo S, Peruselli C, Ghirotto L, Tanzi S. "I go into crisis when ...": ethics of care and moral dilemmas in palliative care. *BMC Palliat Care* [Internet]. 2019 [cited 2022 Nov 8]; 18(1):70. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6689155/pdf/12904_2019_Article_453.pdf 10.1186/s12904-019-0453-2
5. Hermsen MA, ten Have HA. Practical ethics of palliative care. *Am J Hosp Palliat* [Internet]. 2003 [cited 2022 Oct 24]; 20(2):97-98. Available from: <https://pubmed.ncbi.nlm.nih.gov/12693640/> 10.1177/104990910302000206

6. Lloyd LIZ. Mortality and morality: ageing and the ethics of care. *Ageing Soc* [Internet]. 2004 [cited 2022 Oct 28]; 24(2):235-256. Available from: <https://www.cambridge.org/core/article/mortality-and-morality-ageing-and-the-ethics-of-care/6C9CD03B3F2A209C879DF5792FE4F639> 10.1017/S0144686X03001648
7. Benhabib S. *Situating the Self: Gender, Community, and Postmodernism in Contemporary Ethics*. New York: Routledge; 1992.
8. Liedtka JM. Feminist Morality and Competitive Reality: A Role for an Ethic of Care? *Bus Ethics Q* [Internet]. 1996 [cited 2022 Oct 28]; 6(2):179-200. Available from: <https://www.cambridge.org/core/article/feminist-morality-and-competitive-reality-a-role-for-an-ethic-of-care/5FB94169554251B34FAB95BBE56FFF84> 10.2307/3857622
9. Schuchter P, Heller A. The Care Dialog: the “ethics of care” approach and its importance for clinical ethics consultation. *Med Health Care Philos* [Internet]. 2018 21(1):51-62. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5814518/> 10.1007/s11019-017-9784-z
10. Tronto J. *Moral boundaries: a political argument for an ethic of care*. New York: Routledge; 1993.
11. Curzer HJ. Aristotle: Founder of the Ethics of Care. *J Value Inq* [Internet]. 2007 [cited 2022 Oct 28]; 41(2):221-243. Available from: <https://doi.org/10.1007/s10790-007-9088-2> 10.1007/s10790-007-9088-2

12. De Vries M, Leget CJ. Ethical dilemmas in elderly cancer patients: a perspective from the ethics of care. *Clin Geriatr Med* [Internet]. 2012 [cited 2022 Oct 22]; 28(1):93-104. Available from: <https://pubmed.ncbi.nlm.nih.gov/22326037/> 10.1016/j.cger.2011.10.004
13. De Panfilis L, Di Leo S, Peruselli C, Ghirotto L, Tanzi S. "I go into crisis when ...": ethics of care and moral dilemmas in palliative care. *BMC Palliat Care* [Internet]. 2019 [cited 2022 Oct 20]; 18(1):70. Available from: <https://doi.org/10.1186/s12904-019-0453-2> 10.1186/s12904-019-0453-2
14. Van Nistelrooij I, Visse M, Spekkink A, de Lange J. How shared is shared decision-making? A care-ethical view on the role of partner and family. *J Med Ethics* [Internet]. 2017 [cited 2022 Oct 25]; 43(9):637-644. Available from: <https://pubmed.ncbi.nlm.nih.gov/28356489/> 10.1136/medethics-2016-103791
15. Grogono J. A good death. Sharing control in death: the role of an "amicus mortis". *BMJ* [Internet]. 2000 [cited 2022 Oct 22]; 320(7243):1205. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1127591/>
16. Mathew B, Mohanti BK, Tewari S, Kabra V, Gulia P, Bajpai P, et al. Collusion: The Facade and its Implications on Total Pain Management in Palliative Care. *Indian J Palliat Care* [Internet]. 2021 [cited 2022 Oct 28]; 27(1):176-179. Available from: <https://pubmed.ncbi.nlm.nih.gov/34035636/> 10.4103/ijpc.ijpc_81_20
17. Gómez-Vírseda C, de Maeseneer Y, Gastmans C. Relational autonomy: what does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics

literature. BMC Med [Internet]. 2019 [cited 2022 Oct 22]; 20(1):1-15. Available from:
<https://doi.org/10.1186/s12910-019-0417-3> 10.1186/s12910-019-0417-3

18. Walter JK, Ross LF. Relational Autonomy: Moving Beyond the Limits of Isolated Individualism. Pediatrics [Internet]. 2014 [cited 2022 Nov 8]; 133(1):16-23. Available from:
https://publications.aap.org/pediatrics/article-abstract/133/Supplement_1/S16/32797/Relational-Autonomy-Moving-Beyond-the-Limits-of?redirectedFrom=fulltext 10.1542/peds.2013-3608D

19. Johnson SB, Butow PN, Kerridge I, Tattersall MHN. Patient autonomy and advance care planning: a qualitative study of oncologist and palliative care physicians' perspectives. Support Care Cancer [Internet]. 2018 [cited 2022 Oct 28]; 26(2):565-574. Available from:
<https://link.springer.com/content/pdf/10.1007/s00520-017-3867-5.pdf> 10.1007/s00520-017-3867-5

20. Sjöstrand M, Eriksson S, Juth N, Helgesson G. Paternalism in the Name of Autonomy. J Med Philos [Internet]. 2013 [cited 2022 Nov 8]; 38(6):710-724. Available from:
<https://pubmed.ncbi.nlm.nih.gov/24158963/> 10.1093/jmp/jht049

21. NHS England. Universal Principles for Advance Care Planning. [Internet]. 2022 [cited 2022 Oct 28]. Available from: <https://www.england.nhs.uk/publication/universal-principles-for-advance-care-planning/>

22. NHS. End of Life Care. [Internet]. 2021 [cited 2022 Oct 28]. Available from:
<https://www.nhs.uk/conditions/end-of-life-care/>

23. Werner A, Steihaug S. Conveying hope in consultations with patients with life-threatening diseases: the balance between supporting and challenging the patient. *Scand J Prim Health Care* [Internet]. 2017 [cited 2022 Oct 28]; 35(2):143-152. Available from: <https://pubmed.ncbi.nlm.nih.gov/28585884/> 10.1080/02813432.2017.1333322
24. Gramling R, Fiscella K, Xing G, Hoerger M, Duberstein P, Plumb S, et al. Determinants of Patient-Oncologist Prognostic Discordance in Advanced Cancer. *JAMA Oncol* [Internet]. 2016 [cited 2022 Nov 10]; 2(11):1421-1426. Available from: <https://pubmed.ncbi.nlm.nih.gov/27415765/> 10.1001/jamaoncol.2016.1861
25. Edmonds P, Rogers A. 'If only someone had told me . . .' A review of the care of patients dying in hospital. *Clin Med (Lond)* [Internet]. 2003 [cited 2022 Nov 10]; 3(2):149-152. Available from: <https://pubmed.ncbi.nlm.nih.gov/12737372/> 10.7861/clinmedicine.3-2-149
26. Teno JM, Stevens M, Spernak S, Lynn J. Role of written advance directives in decision making: insights from qualitative and quantitative data. *J Gen Intern Med* [Internet]. 1998 [cited 2022 Nov 12]; 13(7):439-446. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1496979/> 10.1046/j.1525-1497.1998.00132.x
27. Collins A, McLachlan SA, Philip J. Communication about palliative care: A phenomenological study exploring patient views and responses to its discussion. *Palliat Med* [Internet]. 2018 [cited 2022 Nov 8]; 32(1):133-142. Available from: <https://pubmed.ncbi.nlm.nih.gov/29130425/> 10.1177/0269216317735247

28. Institute for Public Policy Research. The State of End of Life Care- Building back better after Covid-19. [Internet]. 2021 [cited 2022 Oct 25]. Available from: <https://www.ippr.org/files/2021-04/end-of-life-care-april21.pdf>
29. Testoni I, Wieser MA, Kapelis D, Pompele S, Bonaventura M, Crupi R. Lack of Truth-Telling in Palliative Care and Its Effects among Nurses and Nursing Students. *Behav Sci (Basel)* [Internet]. 2020 [cited 2022 Oct 22]; 10(5):Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7287675/> 10.3390/bs10050088
30. Smith JA, Flowers P, Larkin M. *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: SAGE; 2009.
31. Atkinson P, Pugsley L. Making sense of ethnography and medical education. *Med Educ* [Internet]. 2005 [cited 2022 Nov 8]; 39(2):228-234. Available from: <https://pubmed.ncbi.nlm.nih.gov/15679691/> 10.1111/j.1365-2929.2004.02070.x
32. Frechette J, Bitzas V, Aubry M, Kilpatrick K, Lavoie-Tremblay M. Capturing Lived Experience: Methodological Considerations for Interpretive Phenomenological Inquiry. *Int J Qual Methods* [Internet]. 2020 [cited 2022 Oct 22]; 19(1):1-12. Available from: <https://doi.org/10.1177/1609406920907254> 10.1177/1609406920907254
33. Renaut A. *The era of the individual*. The Era of the Individual. New Jersey: Princeton University Press; 1999.

34. Mohanti BK. Ethics in palliative care. *Indian J Palliat Care* [Internet]. 2009 [cited 2022 Oct 20]; 15(2):89-92. Available from:
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2902121/> 10.4103/0973-1075.58450