



Association for
Palliative Medicine
Of Great Britain and Ireland

APM JUNIORS NEWSLETTER

Brand new APMJ Newsletter

Welcome to our second APMJ newsletter! Would love to hear your thoughts about the newsletter. If you love it, let us know, share it with your friends and get them to join the APM too! Why not check out our July newsletter here as well. Do get in touch via email if you would like to submit an article for the newsletter too.

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A word from our Committee Chair Dr Angus Grant

Welcome to this month's APM Juniors newsletter! Within this edition, you'll be able to read the winning entry for the APM undergraduate essay prize 2022, focusing on ethics and the role of truth telling within palliative care. Thank you Lily for sharing your excellent piece of work with us. If you fancy seeing your own piece of writing featured in one of our future blogs, please do get in touch. We would love to hear about your experiences of palliative care and about any interesting cases with learning points that you would like to share. Finally, for anyone looking to get involved in palliative care research make sure to check out our new research directory highlighted within this newsletter for information about local research institutions.





UPCOMING EVENTS

September 2023

An APM Ethics & Research Committee Virtual Course

<https://apmeducationhub.org/events/virtual-ethics-september-2023/#mec-events-meta-group-booking-6750>

7th & 21st September 2023

Hospice Doctors Medical Updates Study Series

<https://apmeducationhub.org/events/ptlhdmu/>

28th September & 12th October 2023

Understanding and applying research methods in practice

<https://pcrs.org.uk/events/apm-pcrs-research-course-2023/>

18th October 2023

APM Undergraduate Medical Education Special Interest Forum

<https://payments.liv.ac.uk/conferences-and-events/events-at-liverpool/faculty-of-health-and-life-sciences/institute-of-life-course-medical-sciences/apm-undergraduate-medical-education-special-interest-forum-2023>

21st & 22nd March 2024

Palliative Care Congress

<https://pccongress.org.uk/>



OTHER OPPORTUNITIES

Medical Student Rep

The APM juniors committee to recruit medical school representatives from each of the UKs medical schools. This is a role that would involve spreading awareness amongst medical students of the APM juniors and its opportunities. The role would include:

- Promotion of the APM including membership, events, and educational opportunities
- Stimulating interest and awareness of palliative medicine as a specialty
- The opportunity to take part in a national network of medical students interested in palliative medicine
- Gathering feedback from medical students regarding educational needs
- Helping recruit a new member for the role following your graduation

If you are a medical student and this is something you would be interested in, please contact Dr Angus Grant, APM Juniors Chair, at angus.grant1@nhs.net

APM Juniors Survey

We want to better understand what you want from an APM Juniors membership and would appreciate your feedback via this survey. It should take no longer than 10 minutes.

<https://docs.google.com/forms/d/e/1FAIpQLSdne2yTuwoZsrMljp3u1C39qkRgEzLz5orrbiWi2UH1HfWmw/viewform?pli=1>

PCC 2024 Image Competition

Would you like your design to be the branding image of PCC 2024 and win a free entry to the congress? Find out how here

<https://pccongress.org.uk/competition/>

USEFUL RESOURCES

APM/ PCRS Research directory

<https://apmeducationhub.org/wp-content/uploads/2023/06/Palliative-Care-Network-April-2023.pdf>

e-ELCA

https://portal.e-lfh.org.uk/myElearning/Index?HierarchyId=0_29&programmeld=29

Palliative Medicine Curriculum

<https://www.jrcptb.org.uk/sites/default/files/Palliative%20Medicine%202022%20curriculum%20FINAL.pdf>



APM UNDERGRADUATE ESSAY PRIZE WINNER 2022- LILY JOHNSON

This month, we feature Lily Johnson, who is the winner of the 2022 APM Undergraduate Essay Prize.

Lily Johnson is a third year medical student at the University of Manchester. Having come to medicine from a humanities background she maintains an interest in the philosophy and ethics. In her spare time she likes running (from 5km parkruns to ultra marathons) and looking after her three very silly guinea pigs.

We are lucky to have Lily sharing her winning essay and her motivation in writing it. It is definitely an eye-opening piece.

My path to studying medicine was not a typical one as it was via a BA and an MPhil in Philosophy and Theology. Becoming a medical student was by no means the obvious choice but throughout my previous studies I became more interested in philosophical questions in relation to medicine, as well as a practical impulse to do something about this. The kind of Philosophy I am particularly interested in is largely inspired by Wittgenstein which, while being very much engaged in the kind of theoretical discussions Philosophy has always embraced, also recognises the need to practically engage with the world. My MPhil research focussed on the nature of faith and reason and how we understand the relationship between the two as perhaps being closer than otherwise characterised. This allowed me to develop my interest in other people's beliefs and perspectives.

During my time applying for medical school, I volunteered in a care home and was a carer for a woman with Alzheimer's. These were my first experiences of people with life limiting conditions and I really enjoyed the focus of both these roles on making the most of the life they had left. I also really enjoyed building relationships with the patients and their families. It was probably around this time that I first heard a bit more about Palliative Medicine and began to see how, as a specialism, it brings together my philosophical and personal interests.



When I saw the Undergraduate Essay Competition from the APM on the ethics of truth-telling in palliative medicine, it was a question that immediately caught my interest. My initial thoughts were around the nature of truth-telling and what its purpose was. Intuitively, it seems right to tell the truth, although in practice this is not always the case. Re-centering on the purpose of telling the truth seem like a good start for explaining this ethical impulse. I was reminded of Miranda Fricker's "Epistemic Injustice", which I read several years ago as an undergraduate. I wanted to explore the ways in which telling the truth to patients would allow them to comprehend what is happening to them, something with which Fricker's theory of hermeneutical injustice fits really well. When looking at the literature out there already I couldn't see this aspect of Fricker's work being applied to patients in this way so knew I had an interesting angle to take on the question which I wanted to try out.

I enjoyed the process of writing the essay in itself and relished the opportunity to bring together thoughts from my different areas of study. When I then found out I had won the prize I was thrilled. It was really validating to know that thoughts I had been working through by myself were of interest to people with vastly more experience than me. I was also really excited to have the opportunity to go to Edinburgh and present my research at the Palliative Care Congress. It was the first time I had spoken at a conference and seeing other people talk about their own experiences and being questioned about my ideas was a fantastic experience.



“IGNORANCE IS BLISS?”: WITH ATTENTION TO ETHICAL THEORIES, DISCUSS THE ROLE OF TRUTH-TELLING WITHIN GOOD PALLIATIVE CARE

It is widely acknowledged that in palliative medicine telling the truth is beneficial to patients⁹ and to clinicians^{8,11} however it is also recognised that there are challenges for both groups that serve as a barrier and disincentive.¹¹ I will not focus on whether it is right to tell the truth to patients undergoing end of life care but rather assess the role that truth-telling can have for patients and, by extension, their clinical teams and care-givers, within the ethical arena. I will frame the importance of truth-telling as a matter of hermeneutical justice. This is not to say that I will be ignoring the ethical complexities of whether to tell the truth, but rather capturing these difficulties through a lens of justice and providing a framework supporting the ethical compulsion to tell the truth to terminally ill patients, while also recognising uncertainties.

Truth-telling

There are two possible ways of understanding “truth-telling”. The first is one in which “truth” is used as a noun: telling-a-truth. This is the dominant interpretation with truth-telling in the context of palliative care being typically defined as ‘total openness about the diagnosis and prognosis’.^{9,p.443} This often includes “breaking bad news”,¹¹ meaning imparting information of a life-changing and negative nature. It assumes the clinicians know the truth of the patient’s diagnosis and prognosis, that such things are factual and epistemically attainable. The ethical discussion comes from whether to impart these truths to the patient. In the second interpretation, “truth” is used as an adverb, so it is telling-in-truth. Under this definition, the ethically pertinent act is how the clinician imparts their situational evaluation to the patient. In focussing on telling things truthfully, attention is shifted away from the veracity of the information and toward the spirit in which it is told.



This second interpretation is better related to situations of “truth-telling” within palliative care. Often the truth is about a likely outcome, or a likely timeline, but there is uncertainty present. It is an expression of this uncertainty which is the most honest thing to do, but also the most challenging.^{8,p.511} This is both a matter of patient-expectation and clinician-discomfort. There is a view from patients that doctors and nurses are working on solid epistemological ground, that there is certainty within the research and that there is a clear path forward. Likewise, in medical training, assessments by necessity focus on how much the student is able to get “right”, thus setting up the expectation that clinicians ought to know the definitive answer.¹² Bodies, though, do not work exactly according to humanlyconstructed schemas. Knowledge of prognostics is derived from prior experience and statistical analysis based on a population⁴ and need not fit with the exact circumstances of individual patient.

In this context, the ethical feature in question is the honesty of clinicians (their telling-in-truth and not necessarily their capacity to just tell the truth. This is not to say that “the truth” is without importance; the clinician ought to formulate to their fullest capacity their evaluation of the patient’s diagnosis and prognosis. However, some of the most complex ethical questions arise from how to communicate uncertainty, requiring a truth-telling not limited to the truth but more broadly related to honesty. This is truthfulness beyond just provision of facts. Such facts may be unavailable, or the knowledge that is imparted to the patient might turn out to be untrue, but this does not mean there cannot be a telling-in-truth.

Truth-telling can also be seen in the context of narrative development. The importance of narrative in medicine has been framed as a move away from a biomedical preoccupation towards re-humanising medicine.¹³ The incorporation of narrative in medicine gives an understanding of the patient’s condition, giving an insight into the phenomenological aspects of illness, centred on patientperspective.⁶ It also helps navigate the ethical intricacies of cases, bringing patients and clinicians together in agreement of the issues at stake and the next steps involved.³



Hermeneutical Injustice

Narrative, as the linguistic expression of a temporally-located individual viewpoint,⁶ naturally arises from experiencing illness. However, patient narratives can be more or less informed, and more or less comprehensible. It is here, in providing an interpretive framework, equipping a patient in their ability to understand and express themselves, that truth-telling can have a particular impact.

Miranda Fricker's Epistemic Injustice provides a framework for the ethical pertinence of enabling patient narratives through truth-telling. This is a form of injustice of a distinctively epistemic kind whereby there is an inequality in the value we give to certain people in relation to their roles as knowers.⁵ Fricker defines two kinds of epistemic injustice. Firstly, there is testimonial injustice in which certain people or classes of people are less likely to be believed owing to a 'deflated level of credibility'^{5,p.1} given to them. Secondly, and most pertinently for this discussion, there is hermeneutical injustice which she defines as when 'a gap in the interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences'.^{5,p.1} In other words, hermeneutical injustice occurs when certain people are epistemically disadvantaged when it comes to the interpretive resources at their disposal, as a result of an imbalance in social power relations.^{5,p.148} Fricker talks of "hermeneutical blindspots"^{5,p.152} wherein those of more powerful groups have no interest in validating meanings more pertinent to the hermeneutically marginalised, so marginalised meanings fail to enter mainstream discourse.

Hermeneutical injustice underlines the ethical importance of truth-telling in palliative care through seeing it as providing patients with the necessary interpretative resources. In not giving open and truthfully-oriented information to patients, clinicians are depriving them of the hermeneutical resources they require to be able to fully express their situation. In other words, the role of truth within good palliative care should be viewed as a matter of epistemic justice. The ethical impulse in having those difficult conversations should be with the intent of equipping patients to comprehend their own situation. Knowledge of a diagnosis gives validation and helps the patient have something to point towards while a prognosis allows families to prepare for the future.



For example, T is 85 and has been in remission from bowel cancer for over two decades. Owing to discomfort, T elected to stop having annual screening colonoscopies. She began to experience symptoms again, leading to significant concern her cancer had returned. A scan confirmed this, and her doctor referred her to have a colonoscopy as part of preparation for surgery. She did not realise this, though, mistakenly thinking the colonoscopy had a diagnostic purpose. T's epistemic needs give rise to truth-telling duties on the part of her clinical team. In the absence of clear understanding of her diagnosis T had an epistemic lacuna, preventing her from making informed decisions about treatments and procedures. More broadly she was prevented from understanding what was happening to her. In experiencing certain symptoms, she knows there is something wrong with her, but without clarity to direct her interpretation she is left with an incomplete narrative.

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In this the importance of the different definition of truth-telling proposed is also apparent. T's clinicians did tell her the truth (they did not lie or deliberately mislead her however, the way they acted might not have been deemed as speaking truthfully; they neglected to tell-in-truth given her misunderstanding. In doing so, they failed to provide the narrative-forming tools she needed. While the patient will be able to form a narrative based on how they feel, with a paucity in knowledge of what this means, they will struggle to make sense of it. This should also help to mitigate some of the concerns expressed by clinicians⁸ around whether telling the truth to patients is helpful to them or if it can, in fact, be detrimental to them.

In the face of these potential issues for truth-telling, the ethical approach I have thus far outlined can come to the fore. In focussing on a narrative form of truth-telling, we acknowledge the importance of communicating nuance, contextualising uncertainty within the needs of the patient, and accepting that "the truth" goes beyond just telling patients their diagnosis and prognosis. This is important for the facilitation of patient sense-making. In not telling them the best clinical understanding of the nature of their condition, the patient is not spared from knowing anything as they have symptoms and will still feel declines in their condition. Blissful ignorance misrepresents the patient's position: they know a lot as their illness comprises their experience. They are lacking a framework within which to interpret this which is where the input of a clinician is beneficial.

A Non-Didactic View

Thus far the truth-telling in question functions from doctor to patient. However, this can be broadened to include the importance of listening to the truth of the patient. Havi Carel has published numerous works^{2,10} applying Fricker's epistemic injustice to healthcare from this perspective. For Carel, the hermeneutic blindspot lies in doctors regarding patient narratives as too subjective to be considered epistemically valuable. In this, hermeneutic injustice functions as an exacerbator of testimonial injustice, whereas my characterisation focuses more on the injustice done to the patient by not providing them the resources to interpret what is happening.



As Carel says, 'certain experiences of illness can afford epistemic privileges to the ill person that are not otherwise available'^{2,p.197} and so clinicians should listen to patient narratives, viewing them as the "patient-expert".^{2,p.194} The hermeneutical lacuna for Carel is in clinicians' dominant narrated and as such patients are victims of exclusion, 'forced to adopt an epistemically marginal role in consultative exercises'.^{10,p.185} Contrary to this, the previously characterised hermeneutical lacuna was within the patient's understanding of their own condition. However, these interpretations are not mutually exclusive. Ethical action towards patients encompasses the responsiveness of clinicians to patients. To take a definition of truth-telling to be purely doctor-to-patient is to maintain a didactic and paternalistic view of medical care.¹ Good communication, oriented toward truthfulness, requires both patient and doctor to be able to talk to each other. The clinician can add to the patient's understanding only if through listening to them to understand their epistemic needs.

This dialectical approach helps with the evaluation of what the patient wants, which is often seen as a barrier to telling the truth. A patient's expression of their condition in their narrative may not match with the clinician's understanding. This does not mean they are not truthfully representing their experience. There is an ethical imperative for the clinician firstly to listen to this and secondly to help develop the patient's comprehension. Neither side of truth-telling is complete without the other: the patient's truth-telling informs the clinician of their state, helping to direct the clinician's truth-telling which provides a hermeneutical framework for understanding this state. A just approach involves acknowledging both sides.

Conclusion

Truth-telling in palliative care is best understood as having a role in helping patients understand their illness, aiding them with interpretation of their affective and biological states, as well as facilitating conversations over future-planning. The ethical imperative to equip them with truthfully-formulated information necessary for this should be seen as an act of hermeneutical justice. In order to make sure this is as far-reaching as possible, I have argued that the truth in truth-telling should be understood as telling-in-truth, or acting truthfully



Furthermore, another important role of truth-telling within palliative medicine involves clinicians listening to patient experiences and truths. In the absence of medical knowledge, patients will often express themselves in a way not recognised as being “factual” or fitting the hermeneutically dominant model of medical understanding. This provides a further need for hermeneutic justice, involving a move away from a didactic model of truth-telling towards treatment of the patient as a co-expert. As a model of good practice, this should aim to promote greater collaboration and trust between patients and clinicians.

Rather than being in ignorant bliss, the patient who is not informed of the extent of their illness or of its likely prognosis is left with insufficient cognitive scaffolding for forming their epistemic judgement and future plans.



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