Institution: University of Essex

Unit of Assessment: 30 – Philosophy

Title of case study: Influencing Public Policy and Improving both Public and Professional Understanding: A Tripartite Response to Experiences of Powerlessness and Moral Distress in Healthcare Contexts

Period when the underpinning research was undertaken: 2008 - 2019

Details of staff conducting the underpinning research from the submitting unit:

Name(s):	**Role(s) (e.g. job title):**	**Period(s) employed by submitting HEI:**
Béatrice Han-Pile	Philosophy Professor	01/10/1997 to present
Dan Watts	Senior Lecturer in Philosophy and Co-Investigator	01/10/2014 to present
David Batho	Senior Research Officer	01/07/2015-30/06/2018

Period when the claimed impact occurred: 2015 - present

Is this case study continued from a case study submitted in 2014? No

1. Summary of the impact

Healthcare contexts frequently give rise to situations which leave individuals feeling powerless: chronic illness, end of life, as well as caring for people affected by these issues. In such situations, are there ways for individuals to flourish, or at least cope better? This was the core question of our 3-year, interdisciplinary, AHRC-funded project: ‘The Ethics of Powerlessness: The Theological Virtues today’ (EoP). Our research has (i) influenced NICE (National Institute for Clinical Excellence) guidelines for palliative care; (ii) promoted public understanding of powerlessness and the distinctive importance of ‘virtues of powerlessness’ such as hope, with public engagements such as involvement with Radio 4’s *In Our Time* broadcast and podcast reaching in excess of 3,000,000 people (iii) improved professional understanding of powerlessness in end-of-life care and moral distress and influenced the delivery of ethical practice in palliative care through CPD training.

2. Underpinning research

In the course of our lives we are likely to be faced with situations which can lead to acute feelings of powerlessness: being given a life-changing or terminal diagnosis; or caring for a loved one with a chronic or terminal condition; or practicing as a healthcare professional in a hospice or discharge unit with tight financial constraints**.** Patients report feeling powerless as they lose familiarity with their own bodily movements or environment, for example, or as they face increased social insecurity or loneliness. Carers and family members report feeling powerless because of their inability to remedy the situation or simply in the face of its relentless demands.

Such feelings of powerlessness often have an ethical dimension, as in the case of moral distress, where the powerlessness is typically experienced in relation to institutional constraints. Moral distress is a widespread experience in which carers (typically nurses) believe that they know the best way to care for a patient but feel prevented (often by senior staff or institutional circumstances) from doing what they believe is right. Moral distress is an acute experience which involves a complex interplay of feelings of guilt and victimhood: carers blame themselves for failing to meet their standards of care and yet also feel disempowered by their context. US studies suggest that moral distress is a significant contributor to burnout and drop-out rates in the medical profession.

While widespread, such experiences of powerlessness are often poorly understood. For example, to this day there is no primary NHS literature on moral distress. Consequently, our impact work focuses on two main questions: 1) How are we best to understand experiences of powerlessness such as moral distress? 2) How might we best respond to them, whether in our own case or in those for whom we care?

In a UK context of an aging population and urgent policy review around palliative care as well as rising dropout rates in the NHS, EoP has adopted a tripartite approach:

- **First**, we offered an account of a core feature of all experiences of powerlessness: namely a felt loss of *the power to be oneself*. This account is articulated in **[R1, R2]** and has its foundations in primary research on the theme of powerlessness and selfhood in the tradition of existential phenomenology, especially on Nietzsche, Heidegger and Kierkegaard **[R3, R4, R5]**. This account has been central to the delivery of our aim, in CPD training and in the wider public sphere, to advance understanding of powerlessness as a lived experience: for example, by helping to correct one-dimensional views of powerlessness merely as loss of control.

- **Second**, we identified a distinct response to powerlessness according to which, rather than trying to wrench back control, individuals seek to accept their powerlessness, and find themselves empowered by such acceptance. Paradigmatic examples can be found in twelve-step programmes, which begin with the acknowledgement that ‘we were powerless over […]’. Acceptance is both something that happens to us (the result of a complex process) and something we do. EoP research has shown that the distinctive character of this type of response is occluded by standard accounts of the dichotomy between patients and agents **[R1]**. Han-Pile has worked out an original account of the mode of human agency at work in such cases as acceptance **[R3, R4, R6]**. These results are reflected in our influence on NICE guidelines and also in the recommendations we advanced, for example, in our EoP leaflet on moral distress.

- **Third,** we drew on the Christian tradition of the so-called theological virtues – faith, hope and love – to show how these and related virtues can help with experiences of powerlessness across both religious and secular contexts, through instances of ‘strong hope’, for example, or ‘practices of acknowledged dependence’ **[R1, R6]**. This dimension of our research has come to the fore in our advocacy for the distinctive importance of ‘virtues of powerlessness’, for example through the In Our Time broadcast on hope.

3. References to the research (available from HEI on request)

R1 Batho, D. (2015-18). Series of 6 major Green Papers on EoP themes published on the project website: https://powerlessness.essex.ac.uk/experiences-of-powerlessness-in-end-of-life-care-green-paper.

R2. Batho, D. ‘Experiences of Powerlessness and the Limits of Control’. Conference paper presented in January 2019 at the 80th anniversary of the *International Journal of Philosophy and Theology*.
https://www.academia.edu/38777566/Experiences_of_Powerlessness_and_the_Limits_Control
(PDF of paper and schedule of conference available from HEI on request)

R3 Han-Pile, B. (2009) ‘Nietzsche and Amor Fati’, *European Journal of Philosophy*, online publishing 2009, p. 1-38. https://doi.org/10.1111/j.1468-0378.2009.00380.x

R4 Han-Pile, B. (2013) ‘Freedom and the choice to choose oneself in Being and Time’. In *The Cambridge Companion to Heidegger’s ‘Being and Time’.* Editor: Wrathall, M.A. Cambridge University Press, Cambridge. ISBN: 9780521720564

R5 Watts, D. (2017) 'Kierkegaard, Repetition and Ethical Constancy.' *Philosophical Investigations*, 40 (4): 414 – 439. https://doi.org/10.1111/phin.12169

R6 Han-Pile, B. (2017) ‘Hope, Powerlessness and Agency’ in *Midwest Studies in Philosophy* 41

(1): 175 – 201. http://dx.doi.org/10.1111/misp.12069

G1 Han-Pile, Watts, 'The Ethics of Powerlessness: The Theological Virtues Today', AHRC. July 2015-June 2018, £662 019.

4. Details of the impact

(i) Shaping public policy: changing NICE guidelines on End of Life Care

According to a recent NICE report, '*around half a million people die in England each year … effective end of life care improves the quality of the dying person and those important to them*' **[S1]**. Yet the typical emphasis on autonomy and choice in NHS guidelines and policies can be counterproductive. This is because some patients in situations of powerlessness are not able to make rational choices: they may be too worn out or lack motivation. Such patients only feel all the more disempowered by the demand that they should take control, so another approach is needed **[R1]**. The Ethics of Powerlessness (EoP) thus decided to register as a stakeholder in NICE guidelines so as to be able to influence future changes in policy. EoP first participated in an NHS consultation exercise on a draft of the NICE guidelines: Care for Dying Adults in the Last Days of Life. NICE accepted an EoP recommendation on this draft and Han-Pile was then invited to a scoping workshop for a further set of NICE guidelines on Care at the End of Life, in November 2016. Through her contributions at this workshop, EoP recommended that a key phrase running through this draft should be changed: from '*live as actively as possible*' to '*live as well as possible*' **[S2]**.

This recommendation was based on our research on the first-person experience of powerlessness as an experience of the loss of power to be oneself in **[R1]**, which had shown that prioritising activity and autonomy at the end of life may get in the way of living as well as possible, and that the latter is the most important goal. Our recommendation was accepted and is reflected throughout the published guidelines: *End of Life Care: Delivery of Adult Services for people in the last year of life (NICE; Jan 2016)* **[S2a]**. This benefited both health care practitioners, who follow the guidelines, and patients. A 2020 NICE document also reflects our engagement with the drafts by stating that palliative care '*ensures that people live well until they die'* **[S1]**. The breadth and depth of this impact is indicated by the wide reach of NICE guidelines: according to NICE, these '*have touched the lives of everyone in England in ways few realize*' **[S2a]**.

(ii) Improving public understanding: raising awareness of the ethics of powerlessness and moral distress

Having already taken part in three '*In Our Time*' programmes with Melvyn Bragg, Han-Pile contacted the producer of the series, in 2017 to suggest a further programme on 'Hope' (as a virtue of powerlessness) **[R6]**. He responded enthusiastically and the programme was aired on Thursday 21 November 2018.The programme reached a word-wide audience of circa 2,450,000 listeners for the first two broadcasts, with the podcast being downloaded circa 800,000 in the first month after broadcasting **[S3, p.1]**, and Han-Pile received many unsolicited emails from members of the public, commenting on how they had been inspired to rethink the ethical significance of hope: *'you gave me concepts and ways of thinking I hadn't dreamt of'; 'I greatly appreciate your skill in making profound ideas accessible to non-(professional)-philosophers.'* **[S3, p.2]**; *'it inspired a blog-post'* **[S3, p.3-4]**. The producer summarised the listener feedback he also received as: '*Brilliant—enlightening—really enjoyable—inspiring—and many stimulated to think about hope*' **[S3, p.5]**. The BBC hosted links to the project's research as part of its recommended further reading **[S3, p.6]**.

EoP also informed a leaflet on Moral Distress available to download on the project's website. This was designed to help informal carers and hospice staff to recognise the signs of moral distress and suggesting ways to help with these signs. The leaflet was co-produced with, and endorsed by, St Francis Hospice and disseminated in at least four hospices **[S4]**.

(iii) Improving professional understanding and influencing the delivery of ethical practice in palliative care

From the outset of the project, EoP established a close cooperation with the Chief Executive of St Helena Hospice in Colchester, who noted that *'[B]ringing academic and practitioner perspectives together to consider and reflect on real-world ethical challenges relating to experiences of powerlessness in the context of palliative and end of life care has helped generate new insight and understanding*.' **[S5]**. This involved visits to the hospice and interviews with staff. In July 2017, EoP delivered a one-day training module on 'Experiences of Powerlessness at the End-of-Life'. This was based on the research developed during our first year of the project and published in our first two Green Papers **[R1]**. The module, which was attended by staff across a wide range of roles within the Hospice, was very well received (100% of participants judged it *'very useful'*) and discursive feedback included the following: *'feel better equipped to talk with people re - how they perceive themselves and ['their] way forward'; 'Made me reflect on 'existential loneliness' and how this fits with practice; 'more understanding of how to help patients and family members'; 'helped me process emotional experience'* **[S6]**.

In the summer of 2017, EoP delivered a shortened version of the module at the Essex Autonomy Project (EAP) Summer School. This time, the audience comprised not only health care professionals, but also lawyers and social workers. Feedback questionnaires indicate again that the session was deemed very useful by the attendees, one of whom noted that *'the concept of powerlessness was extremely pertinent for the groups of people I work with'* **[S6]**.

Since 2017, the reach and significance of EoP impact on professionals and delivery of ethical practice in healthcare contexts has been building. A new research strand emerged from our work on powerlessness, namely an investigation of the concept of moral distress. This concept has been the object of numerous studies in the US, but not in the UK. We got in touch with Pat Benner, an emeritus professor at the University of California, a seminal figure in the anglophone palliative care nursing world. She was very enthusiastic about our work and organised a Knowledge Exchange Event on EoP research in Berkeley in the spring of 2018, attendees at this event included hospice palliative care physicians and nurses. She recognised that *'it is easy to imagine that nurses need help rather than empowerment … your work has built-in protection against this 'victimization' with your view of ways of overcoming loss of agency in states of powerlessness'* **[S7]**. Following up on this, we designed a CPD module on 'Moral Distress' which we delivered at the 2018 EAP Summer School. One practitioner commented on how it shifted her thinking from being focused on practical problem solving to attending to lived experience. Feedback also included the following: '*a fascinating concept. I felt I knew it intuitively – the session named it – I would like to know more'* **[S8]**. We are currently working with a group of 20,000+ physicians to develop UK-wide questionnaires about moral distress and pandemic-related moral distress.

Our CPD training has been extended to institutions across the East of England. In May 2019, we visited St Francis hospice to deliver a full study day on 'Moral Distress'. This study day complemented the Moral Distress leaflet: the Director of Education at St Francis noted that the leaflets supported learning from the 2019 Study Day and has '*generated further thought*' **[S9]** Again, 100% of attendees deemed the workshop '*very useful'*. On average, the audience's understanding of moral distress went from 2 to 5 (on a scale from 1 to 6), a gain of 50%. In September 2019, EoP delivered CPD training on Moral Distress to St Luke's Hospice (Basildon) and Arthur Rank Hospice (Cambridge) which was likewise well-received **[S8]**.

These events again drew participants from a wide range of roles within the Hospice setting including doctors, nurses, teachers, counsellors and managers. Many participants described their personal relief simply at being given resources properly to recognize moral distress as part of their experience. Comments included: '*gives me awareness of being more in tune to recognise situations that could potentially become moral distress situations'*; '*exploring moral distress has helped me to recognise when I had experienced this previously and different ways I have reacted throughout my career*' **[S8]**. Another form of impact, which was less anticipated, came more from a managerial perspective, in which participants advanced their understanding of how best to handle staff experiences of moral distress and of best practice in this area within healthcare institutions. Such feedback included: *'it will be good now as an organisation to take this further forward, helping others within our organisation to better understand the meaning of moral distress'*; '*will advance and enhance skills in recognising what clients bring to counselling sessions*'; '*Useful for clinical* *supervision of others*' **[S8]**. The Head of Quality and Education at St Luke's Hospice also acknowledged the significance of this training on moral distress in the increased capacity to offer targeted clinical support and training: '*There is a recognition of the importance of reflective discussion around some of the moral distress situations but following the training we have a name for the feelings expressed.* [...] *during the pandemic we have increased the availability of supervision sessions adding drop in supervision and support sessions for all staff three times a week.* [...]. *In addition to this St Luke's hospice is introducing a Human Rights training programme*' **[S10]**.

5. Sources to corroborate the impact

S1 End of Life Care: Delivery of Adult Services for people in the last year of life (2020)

S2 Information from NICE noting/ demonstrating changes made consistent with contributions (NICE: 2016) **2a.** Improving Supportive and Palliative Care for Adults (NICE: 2016), highlighting contribution from EoP p18.

(ii) Improving public understanding: raising awareness of the ethics of powerlessness and moral distress

S3 Listening figures and unsolicited emails about In Our Time on 'Hope' (BBC R4); email from programme producer estimating listening figures and podcast downloading figures and screenshot of BBC In Our Time links to EoP articles

S4 Moral Distress Leaflet, co-produced with St Francis.

(iii) Improving professional understanding and influencing the delivery of ethical practice in palliative care

S5 Testimonial from the Chief Executive of St Helena Hospice, Colchester

S6 Feedback questionnaires for Study Day on 'Experiences of Powerlessness at the End of Life' (St Helena Hospice 2017, EAP Summer School 2017).

S7 Email testimonial from Professor Patricia Benner

S8 Feedback questionnaires for Study Day on 'Moral Distress': St Francis Hospice 2019; St Luke's Hospice; Arthur Rank Hospice; St Helena Hospice

S9 Testimonial from the Director of Education at St Francis Hospice, Romford.

S10 Testimonial from the Head of Quality and Education at St Luke's Hospice, Basildon.