

Impact case study (REF3)

Institution: University of Aberdeen		
Unit of Assessment: UoA30 (Philosophy)		
Title of case study: 'Enabling people to live (and die) well': enhancing patient care and policy with philosophical research on 'person-centred' approaches to healthcare		
Period when the underpinning research was undertaken: 2013-2018		
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:
Vikki Entwistle	Professor	1998-2005; 2013-2018; April 2020 - current
Period when the claimed impact occurred: 2013-2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact (indicative maximum 100 words)		
<p>Entwistle's philosophical analysis of 'collaborative approaches' to healthcare and 'support for self-management' for people with long-term conditions has significantly shifted the thinking and practice of clinicians who have engaged with it. Their practical adoption of the central idea of 'enabling people to live (and die) well' has been positively received by patients, and their professional reflections have benefited from the insights the research provided into the inevitable ethical tensions of person-centred approaches. The further spread of these benefits is now supported by the adoption of the central idea and associated insights within professional training programmes, NHS and third sector service development work, Scottish health policy and international guidance.</p>		
2. Underpinning research (indicative maximum 500 words)		
<p>Health services often fall short in terms of respecting and responding appropriately to patients' humanity. Efforts to make healthcare more 'person-centred' via the promotion of approaches such as shared decision-making and collaborative support for self-management have had limited success. Professor Vikki Entwistle recognised that the problems are in large part philosophical, arising from weak characterisations of key concepts. Her research illuminated the conceptual-theoretical roots of the practical and ethical challenges experienced by clinicians and patients, and developed a new conceptual account of support for self-management.</p> <p>The research was conducted in collaboration with Professor Alan Cribb (Kings College London) between 2012 and 2018. It involved two projects, both funded by The Health Foundation, an independent charity committed to bringing about better health and health care for people in the UK.</p> <p>An initial proof of concept project served to demonstrate how philosophy can inform healthcare improvement. It focused on 'collaborative approaches' to care for people with long-term conditions. It included two knowledge exchange events with health professionals and patient advocates to ensure the philosophical problems were elucidated in practically relevant ways. These events generated nuanced insight into what patients and clinicians consider meaningfully collaborative.</p> <p>This project identified several conceptual-theoretical problems with prevailing characterisations of collaborative working. Not only do they obscure social-structural influences on people's priorities, scope to adopt recommended behaviours and health, they also reflect and foster an impoverished view of relationships between patients and health professionals, and of why these relationships matter. As a result, they lack the conceptual means to differentiate between healthcare that</p>		

patients and health professionals experience as more and less collaborative, effective and person-centred (respectful, responsive and enabling).

The initial project identified several philosophical approaches that could be useful for the development of more adequate accounts of person-centred and collaborative working. A capabilities approach to thinking about quality of life, which emphasises the salience of what people have genuine opportunities to be and to do, could help accommodate the range of what matters to both patients and health professionals. Relational theorising could reflect and facilitate recognition that patients' priorities and capabilities are socially and situationally influenced. The resulting 'Enabling people to live well' report [1] was peer reviewed and published by the Health Foundation.

A second, larger, project built constructively from the pilot to develop a new account of support for self-management (SSM) to facilitate the pursuit of more person-centred approaches in practice. This project included a critical interpretive synthesis of published studies of health professionals' experiences of SSM [2], interviews with 26 health professionals about their work with people with diabetes or Parkinson's [3,4] and five group discussions with health professionals [3,4]. Key insights were synthesised in a briefing document that informed six group discussions with policy and service development leads from government, the NHS and third sector, was refined for a larger dissemination event, and developed into an academic article [5].

The new account was founded on the drawing of a critical distinction between two (usually implicit) views of the **purpose** of SSM: to help people **manage their health conditions** in biomedical terms (for example to keep blood glucose and blood pressure levels within recommended limits), and to help people **live (and die) well with their health conditions** [2,5]. The research demonstrated how and why the first, narrower view of purpose could constrain health professionals' respect for, responsiveness to, and enablement of, patients, for example by keeping a focus on targets that were impossible for many (health conditions deteriorate and people will die even with the best healthcare and selfcare) and by leaving little room for what matters to people (holding down a job, participating in a family celebration etc.) [2,5]. The new account thus centred on the adoption of the broader view of purpose as essential for person-centred working.

A focus on enabling people to live (and die) well has several significant benefits. It still allows recognition of the importance of biomedical aspects of condition-management but keeps these in better perspective. Especially when living (and dying) well is understood in terms of capabilities, it also encourages recognition of the broader range of ways in which health professionals can support patients. And it further illuminates how health professionals can disenfranchise and harm patients, for example by conveying blame and shame in response to poor biomedical indicators and (presumed) non-compliance with recommended diet and exercise regimens [5].

The research also demonstrated that the plurality and complexity of what makes for living well means that health professionals will inevitably face ethical tensions in pursuit of person-centred working. Prioritisation among a patient's and their own multiple, interconnected short and long-term concerns will often be contested and tricky balances must be struck, for example, when trying to deal respectfully with uncertainties about the accuracy or truth of what patients are saying. The research made the case that these tensions, which had not been acknowledged in policy advocacy or professional training materials, need to be recognised and addressed [4,5].

3. References to the research (indicative maximum of six references)

- [1] Entwistle VA, Cribb A. "Enabling people to live well". The Health Foundation., 2013. <https://www.health.org.uk/sites/default/files/EnablingPeopleToLiveWell.pdf> (report)
- [2] Morgan HM, Entwistle VA, Cribb A, Christmas S, Owens J, Skea Z, Watt I. "We need to talk about purpose": a critical interpretive synthesis of health and social care professionals' approaches to self-management support for people with long-term conditions. *Health Expectations*, 2017; 20(2): 243-259. DOI: 10.1111/hex.12453

- [3] Owens J, Entwistle VA, Cribb A, Skea ZC, Christmas S, Morgan H, Watt IS. 'Was that a success or not a success?' A qualitative study of health professionals' perspectives on support for people with long-term conditions. *BMC Family Practice*, 2017; 18:39. DOI: 10.1186/s12875-017-0611-7
- [4] Entwistle VA, Cribb A, Watt IS, Skea ZC, Owens J, Morgan H, Christmas S. "The more you know, the more you realise it is really challenging to do": tensions and uncertainties in 'person-centred' support for people with long-term conditions. *Patient Education and Counselling*, 2018; 101 (8): 1460-7. DOI: 10.1016/j.pec.2018.03.028.
- [5] Entwistle VA, Cribb A, Owens J. Why health and social care support for people with long-term conditions should be oriented towards enabling them to live well. *Health Care Analysis*, 2018, 26(1): 48-65. DOI: 10.1007/s10728-016-0335-1.

These were all written and published while VE was employed at University of Aberdeen

Research Grants

Outputs [2-5] were the result of the following grant, subject to competitive peer review providing further assurance of 2* quality:

[P1] Re-conceptualising support for self-management of long-term conditions. The Health Foundation, 1/09/13-30/06/17 (GBP180,219)

4. Details of the impact (indicative maximum 750 words)

The idea of 'enabling people to live (and die) well' has led to significant improvements across the interacting levels of clinical practice; professional training; service development (NHS and voluntary sector), national health policy and international health policy guidance.

Clinical practice

Clinicians who engage with the research recognise its significance and incorporate key insights into their interactions with patients and broader practice.

A consultant physician in North East England who participated in knowledge exchange and dissemination events describes here the positive impact of opening up his consultations to attend more flexibly to what matters to each individual patient and what, from their perspective, would enable them to live well with diabetes:

"this has undoubtedly affected the way that I have approached individual consultations... It has resulted in exploration of wider areas that the person attaches value to, a reshaping of my use of language and a more permissive approach to the goals a person may identify. This ... has been noticed and commented on by patients and colleagues" [a]

In work for the Royal College of Physicians, this physician used key ideas from the research "to influence the content of postgraduate clinical examinations, with the incorporation of assessment of the types of conversation that candidates have with patients", contributing to the shaping of professional standards more generally [a].

A consultant clinical psychologist in South West England, who found the first *Enabling people to live well* report [1] on the Health Foundation's website, illustrates how the philosophical research has helped clinicians understand why person-centred working can be more difficult in practice than it first sounds. He highlights the value of recognising that some tensions are inevitable. This can help health professionals avoid being inappropriately negatively judgemental or demoralised about their clinical performance.

"There's no shortage of promotion of personalisation in healthcare literature, but ... the missing piece is usually the complexities of 'how'... as if policy-makers don't quite 'get' the reality on the ground. I remember reading Enabling people to live well the first time: it was

literally jaw dropping. I felt like I'd been waiting my whole career to read something so clearly articulating some of the things I've struggled with" [b].

He found this and the subsequent research “*provide a language and conceptual framework that connects clinically, feels realistic; and is therefore helpful and hopeful*”. He gives copies of three outputs ([1,4, and 5]) to trainees and qualified psychologists who join his team to “*acknowledge and give clear description of why these policy areas feel more complex than they seem at first sight*” and “*add value to our existing thinking*” [b]. This clinician also finds the research has enabled him to bring “*nuance and subtlety*” to discussions between service managers and clinical leaders about “*the ‘competing’ needs of systems and people*”. He has used it to provide a language to “*helpfully voice*” and so open up a discussion of practical tensions that were previously difficult to articulate and communicate about [b].

These examples show the deep significance of the research findings for clinical practice.

Incorporation into Professional Training and Voluntary Sector Development

The transformative potential of the research is now being realised more generally through incorporation into professional training and service development.

The research findings are now reaching a much broader professional audience as a result of their adoption by the Year of Care Partnership (YOCP). YOCP provides training and support to NHS teams of varying sizes across the UK (including at Trust and Scottish Health Board levels) [c]. A former YOCP Director who participated in knowledge exchange and dissemination events reports having been “*greatly influenced in many aspects of [the] work*”, *appreciating the “great ideas and exposition” and using the briefing document and slides from the final dissemination event “multiple times in discussion and small groups” [d].* YOCP credit the research with leading to their recognition of the importance in training of “*Being explicit about purpose*” and “*Reframing the practitioner role*” [e]. They have adopted the distinction between supporting people to manage their health conditions well and living well with their health conditions as key, and draw heavily on the research in order to achieve a “*better articulation of purpose of CSP*” and to “*debate tensions around roles and goal setting with practitioners*” [e, a]. Positive experiences of their training, including among clinicians visiting from abroad, has led to some international spread [f, a].

Third sector patient organisations have also used the concepts and analysis from this research in their campaigning and service development activities. For example, the Director of Policy and Care Improvement at Diabetes UK, who participated in a knowledge exchange event and has read subsequent research outputs, reports that Diabetes UK has used ideas from the research, and particularly the view of purpose as enabling people to live (and die) well:

“to inform our language, how we approach communications and deliver support to both people with diabetes and health professionals to facilitate better conversations” [g].

Influencing Scottish Government policy and international advice

Key insights from this research have been incorporated into national policy and the recommendations of a respected international advisory group for health systems.

Several policy leads from Scottish Government engaged in group discussions and dissemination events, and the research influenced their work on health literacy, support for self-management and palliative care [h,i,a]. The Chief Medical Officer’s acclaimed *Realistic Medicine* report, which continues to guide service development in NHS Scotland and attract interest internationally, notably adopts the recommended view of purpose, stressing a need for “*Decisions that help [people] live well, and indeed die well, on their own terms*” [j]. The author of the relevant section of the report reflects that the research’s articulation of a shift towards medicine as

“an enabler of peoples’ capabilities and autonomy has been hugely powerful. “Enabling people to live, and die, well on their own terms” has been an elegant and helpful phrase that

has subsequently guided both policy and practice with respect to long term conditions and palliative care” [i]

Wider uptake and influence of this research will also be encouraged because it has been extensively cited in a major review of strategies for achieving person-centred health systems by the World Health Organization’s European Observatory on Health Systems and Policies [k]. The chapter on support for self-management concluded that “the emphasis should be on supporting people to manage well (or live well) with their condition(s) (broad approaches)” and highlighted a need for the wider policy framework “to be alert to the potential tensions” [k].

5. Sources to corroborate the impact (indicative maximum of 10 references)

- a] Email from NLB, Consultant in Psychological Medicine at North Bristol Trust (26 October 2020)
- b] Email from CJ, Consultant Physician at Northumbria Healthcare NHS Foundation Trust and Year of Care Partnerships (26 October 2020)
- c] Year of Care Partnership. <https://www.yearofcare.co.uk/>
- d] Email from SR, (former) Director, Year of Care Partnerships (31 January 2016)
- e] Robert S, Eaton S, Finch T et al. The Year of Care approach. *BMC Family Practice*, 2019; 20: 153 (See p.6)
- f] Tan WH, Loh VWK, Venkataraman K et al. The Patient Activation through Community Empowerment/Engagement for Diabetes Management (PACE_D) protocol *BMC Family Practice*, 2020; 21:114. <https://doi.org/10.1186/s12875-020-01173-2>
- g] Email from BT, Director of Policy & Care Improvement, Diabetes UK (14 October 2020)
- h] Email from BR, formerly policy lead on self-management and health literacy, Healthcare Quality and Improvement Team, Scottish Government (12 October 2020)
- i] Email from GK, GP and formerly clinical lead on self-management and health literacy, Healthcare Quality and Improvement Team, Scottish Government (26 October 2020)
- j] NHS Scotland (2016). Realistic Medicine. Chief Medical Officer’s Annual Report 2014-15. Edinburgh: Scottish Government. <https://www2.gov.scot/resource/0049/00492520.pdf>
- k] Review by World Health Organization’s European Observatory on Health Systems and Policies. https://www.euro.who.int/data/assets/pdf_file/0010/455986/person-centred-health-systems.pdf (p60)