Institution: Swansea University		
Unit of Assessment: 4		
Title of case study: Raised awareness and development of interventions for improved psychological support of patients with thrombosis and other health-related stress		
Period when the underpinning research was undertaken: 2007 – present		
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:**
Paul Bennett Rachael Hunter	Professor Senior Lecturer	2003-2006 & 2009 – present 2013 - present
Period when the claimed impact occurred: 2014 – Dec 2020		
Is this case study continued from a case study submitted in 2014? No		

1. Summary of the impact

Venous thromboembolism (VTE) comprises potentially fatal blood clots throughout the body. Swansea University research has identified both the emotional burden of VTE and means to alleviate it. This has benefitted patient well-being by: (1) influencing UK (NICE) and USA treatment guidelines (2) influencing NHS service provision, (3) developing and disseminating an intervention designed to help patients cope with adverse emotional sequelae. This self-help intervention has provided support through the Thrombosis UK website, associated webinars and YouTube presentations addressing >1,000 participants worldwide, and health care providers across Wales. Variants of the intervention have been successfully used by patients undergoing cancer risk assessment and health professionals caring for COVID-19 patients.

2. Underpinning research

Venous Thromboembolism is a major cause of morbidity and mortality affecting 1:1000 patients annually. Its long-term impacts include post-thrombotic syndrome and pulmonary hypertension. The experience of a VTE has the hallmarks of an event likely to cause significant psychological distress. It is typically sudden, unexpected and can be life threatening. In addition, patients have to live with the likelihood of subsequent (and likely more problematic) VTEs. While local clinicians with whom we worked were aware of these issues, at the inception of our research they had received minimal empirical investigation.

This research has two strands: a) identifying the scope of the problem and the characteristics of the short- and long-term consequences of VTE, and b) the development and assessment of an intervention designed to reduce this impact.

a) Adverse psychological consequences of VTE

The first research strand was among the first to identify the adverse psychological consequences of VTE. The first study [**R1**], a qualitative study of a random sample of patients with VTE, was followed by a yearlong longitudinal study in a representative sample of patients [**R2, R3**]. These data have been augmented by additional quantitative data [**R3, R4**] and together, highlight the personal consequences and high rates of anxiety, health anxiety, and post-traumatic stress among VTE survivors - a 20-40% prevalence for up to one year following the thrombosis.

b) Development and testing of an intervention

The second research strand involved developing an effective intervention to provide psychological support for this sample. For this, Bennett revisited a brief self-help intervention previously developed through his 2013 research on reducing distress among individuals undergoing genetic risk assessment for breast cancer [**R5**] and in patients with cardiac

problems. Based on cognitive behavioural principles, this self-help intervention provided strategies considered relevant to VTE survivors, such as the need to control worry and feelings of panic. A new intervention was developed that incorporated mindfulness, relaxation, distraction, and cognitive restructuring as a suite of techniques described in a series of simple one-/two-page leaflets: a highly cost-effective intervention likely to benefit all but the most distressed individuals. These techniques are widely used. However, the research presented here was the first application of these techniques in the context of VTE.

Evidence of the effectiveness of the intervention was obtained from two sources (i) a quantitative survey of user's views on the useability of the leaflets and (ii) an uncontrolled study of the effectiveness of the leaflets in reducing worry and panic. The intervention for VTE patients proved highly successful, achieving significant reductions in anxiety and worry, with data to be reported in future publications. As an example, there was evidence of a reduction in the percentage of participants experiencing clinically significant levels of trauma symptoms, including intrusive worries, from 40 to 23 percent, and a significant (p 0.015) reduction in health anxiety. As evidence of the adaptability of the intervention approach, variants of the intervention have also proven effective in reducing distress associated with cardiac conditions and the distress associated with caring for patients with COVID-19 [**R6**].

3. References to the research

All papers have been peer reviewed; the research has made important contributions to the discipline internationally and contributes important knowledge to the field likely to have a lasting influence.

[R1]. Noble S, Thomas R, Whithers J, Lewis S & **Bennett P.** (2014) The long-term psychological consequences of symptomatic pulmonary embolism: a qualitative study. *BMJ Open,* e004561 DOI:10.1136/bmjopen-2013-004561. Citations: 47; >12,000 downloads.

[R2]. Hunter RA, Lewis S, Rance J, Noble S & **Bennett P**. (2017) Post-thrombotic panic syndrome: A thematic analysis of the experience of venous-thromboembolism. *British Journal of Health Psychology, 22: 8-25.* DOI: 10.1111/bjhp.12213 Citations: 28.

[R3]. Hunter R, Noble S, Lewis S & **Bennett P.** (2019) Long-term psychosocial impact of venous thromboembolism: A qualitative study in the community. *BMJ Open,* e024805 DOI: 10.1136/bmjopen-2018-024805. Citations: 10. >5,000 downloads and Altmetric score of 58 (Nov 2020).

[R4]. Bennett P, Patterson K & Noble S. (2014). Predicting post-traumatic stress and health anxiety following a venous thrombotic embolism. *Journal of Health Psychology, 21: 863-871.* DOI: 10.1177/1359105314540965 Citations: 20.

[R5]. Phelps P, **Bennett P,** Hood K, Brain K & Murray A. (2013). A self-help coping intervention can reduce anxiety and avoidant health behaviours whilst waiting for cancer genetic risk information: results of a phase III randomised trial. *Psycho-Oncology*, 22: 837-44. DOI: 10.1002/pon.3072 Citations: 10.

[R6]. **Bennett P, Hunter R,** Johnston S, Jones D & Noble S. (2020) COVID-19 confessions: a qualitative exploration of healthcare workers experiences of working with COVID-19. *British Medical Journal*, 369: m2536 DOI: 10.1136/bmj.m2536 Views in BMJ Open (Nov 2020): 1418.

4. Details of the impact

Influencing health care and health care policy

As a consequence of our research, Bennett was the only psychologist invited on a working party organised by Anticoagulation UK and the Bristol Myers Squibbs-Pfizer Alliance, tasked with developing optimal standards of care for VTE patients. These guidelines (**C4**) highlight the need for good psychological care: '*Healthcare professionals should consider the psychological implications … and provide appropriate support. This should take place at every stage of the patient pathway…*'. In addition, our work [**R1**] was the only relevant research cited in a state-of-the-art review by the International Society on Thrombosis and Haematology Steering Committee for World Thrombosis Day (**C1**). The same paper was cited in the 2019 NICE Guidelines for Treatment of Venous Thromboembolism (**C2**) and review of papers contributing to the US American Society of Hematology 2020 guidelines (**C3**).

Additionally, we have worked closely with the charity Thrombosis UK (TUK), giving talks at over 20 clinician (CPD-accredited) and 10 patient meetings throughout the UK over the past five years, with a reach of over 3000 attenders. Its CEO provides a testimonial on the high demand for psychological support within the VTE patient population and how we have increased awareness of this (**C5**). Finally, two Health Trusts (Liverpool and Leeds) have established psychological provision for VTE patients, through employing clinical psychologists, as a result of our research (**C6**).

Influencing patient outcomes

The intervention, described in section 2b above (Development and testing of an intervention), is available through a range of outlets:

Thrombosis UK website

Downloadable information 'fact sheets' have been available on the TUK website since January 2020. Between January and October 2020, these were 'visited' 1,328 times and were the 7th most visited page on the website (from a potential 1,902). During the same period, recordings of four videos based around the intervention, on YouTube and the TUK website, had approximately 1,700 views. A further video aimed at health professionals had 102 views. Feedback on both was positive from patients and health professionals*: "The new booklets are brilliant, I have read and re-read them and am going to share them with my clinician, every patient needs to be given these."* (patient), *"I wanted to let you know we are downloading the leaflets on psychological impact and VTE and sharing them with our whole team as well as with patients in our care. It is so good to at last have resources that share this really important impact of VTE in an easy-to-read format and offer information and tips for patients. Brilliant."* (professional) (**C7**). Early evidence of the clinical effectiveness of the intervention is reported in section 2b, above.

Secondary health care services

The intervention has been implemented across Wales. The VTE Pharmacy Lead of Swansea Bay UHB (**C8**) and the VTE Medical Lead of Aneurin Bevan UHB (**C9**) were early adopters of the intervention and provide testimony of benefits in their patient groups. In Swansea Bay UHB, an estimated 50-60 per cent of patients with VTE have been offered the intervention and found it of value (**C8**), while the leaflets are offered to all VTE patients in Aneurin Bevan UHB, with an estimated usage by at least 80% of those offered them from a total of 500 patients per annum (**C9**). Betsi Cadwalader and Cardiff and Vale UHBs have also agreed to its use. Together, these data suggest an approximate 1500-2000 patients per annum may benefit from this approach across the four UHBs in which it has been used.

Ad hoc developments

We have had multiple requests for early versions of the intervention from health care providers across the UK, including Birmingham, London, Liverpool and Leeds. As one example, in 12/2019, Kings College Hospital NHS Foundation Trust asked to use our intervention as a template for one they were developing. They have since decided to use the intervention without change: '*They're fantastic! Well done, it is great to have such lovely resources out there that we can use in clinic and signpost our patients to. We'll definitely use them and will signpost patients to the [TUK] site too'* (Coagulation Clinical Nurse Specialist, Kings College Hospital).

Variants of the intervention

Finally, the simplicity and easy adaptability of the intervention allow its use in a range of settings and health problems. Originally developed for patients undergoing assessment of genetic risk for breast cancer, one simple adaption has been the use of a strategy designed to help cope with worry, to help health care professionals cope with caring for patients with COVID-19. Simply 'telling their COVID story' to a remote and anonymous website as a means of emotional venting resulted in significant immediate emotional benefits for a range of health care workers (**C9**). Given the high levels of stress among multiple patient groups, including cancer and cardiac patients, this approach could easily and usefully be adapted for use with them.

5. Sources to corroborate the impact

C1: ISTH Steering Committee for World Thrombosis Day (2014) Thrombosis: a major contributor to the global disease burden. *Journal of Thrombosis and Haemostasis*, 12: 1580–1590.

C2: NICE (2019) *Venous thromboembolism in over 16s: reducing the risk of hospital-acquired deep vein thrombosis or pulmonary embolism.* NG89. https://www.nice.org.uk/guidance/ng89/evidence

C3: Etxeandia-Ikobaltzeta, I., Zhang, Y., Brundisini, F. et al. (2020). Patient values and preferences regarding VTE disease: a systematic review to inform American Society of Hematology guidelines. *Blood Advances*, 4(5), 953–968.

C4: http://www.nationalhealthexecutive.com/Health-Service-Focus/developing-optimal-standards-of-care-for-the-prevention-of-recurrent-venous-thromboembolism-vte-consensus-statement.

C5: Testimonial letter from the CEO of Thrombosis UK. Psychological impact of thrombosis: Summary of resources created for and hosted on Thrombosis UK website.

C6: Testimonial letter from a Consultant Haematologist at Royal Liverpool and Broadgreen University Hospital NHS Trust.

C7: Testimonial letter from the haematology lead at Aneurin Bevan UHB Thrombosis Service.

C8: Testimonial letter from the head of the Swansea Bay UHB Thrombosis Service.

C9: Bennett P, Hunter R, Johnston S, Jones D & Noble S. (2020) British Medical Journal, 369: m2536 DOI: 10.1136/bmj.m2536 Views in BMJ Open (Nov 2020): 1418.