Institution: Ulster University

Unit of Assessment: Psychology, Psychiatry and Neuroscience (4)

Title of case study: ICD-11 Complex Posttraumatic Stress Disorder: Introduction of a new psychological disorder and a tailored diagnostic assessment tool

Period when the underpinning research was undertaken: September 2013 to December 2020

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:
Mark Shevlin	Professor	1998 - present
Jamie Murphy	Professor	2010 - present

Period when the claimed impact occurred: January 2014 - December 2020

Is this case study continued from a case study submitted in 2014? N

1. Summary of the impact

Ulster University (UU) research **led to the introduction of a new psychological disorder** in the **International Classification of Diseases** (ICD-11): **Complex Post-Traumatic Stress Disorder** (CPTSD) (I1), **ratified by the World Health Assembly** in May 2019. UU researchers also **developed, published and ensured global access** to the **International Trauma Questionnaire** (ITQ), a novel and tailored **assessment instrument for CPTSD** that is aligned with ICD-11 diagnostic criteria (I2). The ITQ has been used in **international clinical practice** to **enhance diagnostic capability**. This valid and reliable assessment tool for CPTSD has meant that clients **experience streamlined and optimised treatment pathways** (I3).

2. Underpinning research

The International Classification of Diseases (ICD) forms the basis for diagnoses for all physical and mental diseases globally. In 2013, under the auspices of the World Health Organisation (WHO), a working group on the ‘Classification of Disorders Specifically Associated with Stress’ was appointed, reporting to the International Advisory Group for the ‘Revision of the ICD: Mental and Behavioural Disorders’. Subsequently, a further working group was established to report to the International Advisory Group on the development of a new psychological disorder, CPTSD, for inclusion in the 11th edition of the ICD. The addition of an entirely new disorder to the ICD occurs infrequently. This significant change provided a new diagnostic approach to disorders related to stress which (a) narrowed the symptom range for the diagnosis of PTSD from 20 to 6 core symptoms and (b) introduced a ‘sibling’ disorder, CPTSD, which was specified to be PTSD plus symptoms associated with ‘Disturbances in Self-Organisation' (DSO). The inclusion of CPTSD in the ICD-11was based on UU research [**R1-R3**].

A series of initial nosological studies was conducted by UU researchers with a team of international collaborators at 12 partner universities to assess the construct validity of PTSD and CPTSD. As there was no established measure of ICD-11 PTSD/CPTSD symptoms, these studies relied on archived data with extant trauma and psychopathological variables to act as symptom analogues [**R1-R3**]. These studies showed that the variables representing PTSD and DSO symptoms clustered as specified by the narrative description in the new ICD-11, and furthermore, that there was evidence of distinct groups that reflected symptom endorsement profiles consistent with PTSD (high PTSD, low DSO) and CPTSD (high PTSD, high DSO). Professor Shevlin was instrumental in developing and delivering the analytic strategy for these studies.

The next phase of research involved testing an initial trial version of a tailored measure of PTSD/CPTSD known as the ICD Trauma Questionnaire (ICD-TQ) which assessed a broad range of PTSD and DSO symptoms. Factor analytic methods and mixture models supported the construct validity of the measure based on a large sample of patients recruited from the Rivers Centre, a National Health Service (NHS) trauma centre in Scotland [**R4**]. Similar findings were reported based on a sample of mental health service users recruited to the National Centre for Mental Health via primary and secondary mental health services [**R5**]. These studies employed contemporary multivariate methods and were conducted and reported by Professor Shevlin.

Research developing and testing the ICD-TQ was used to inform the development of the International Trauma Questionnaire (ITQ), an assessment instrument that can be used to assess both PTSD and CPTSD symptoms in accordance with ICD-11 diagnostic criteria in both research and clinical settings [**R6**]. The primary validation study was based on data from a large nationally representative trauma-exposed community sample and a trauma-exposed clinical sample. Professor Shevlin co-ordinated and led the psychometric analyses, which included innovative use of multi-dimensional item response theory models that produced the optimal symptom selection from the PTSD and DSO clusters. The ITQ is a validated, open access tool that has been used globally for both research and clinical practice.

3. References to the research

All research references have been subject to blind peer review by international editorial boards.

[**R1**] Elklit, A., Hyland, P., & Shevlin, M. (2014). Evidence of symptom profiles consistent with post-traumatic stress disorder and complex post-traumatic stress disorder in different trauma samples. *European Journal of Psychotraumatology, 5*, 24221. doi: 10.3402/ejpt.v5.24221.

[**R2**] Hyland, P., Shevlin, M., Elklit, A., Murphy, J., Vallières, F., Garvert D., W., & Cloitre, M. (2017). An assessment of the construct validity of the ICD-11 proposals for complex post-traumatic stress disorder. *Psychological Trauma: Theory, Research, Practice, and Policy*, 9, 1-9. doi: 10.1037/tra0000114.

[**R3**] Shevlin, M., Hyland, P., Karatzias, T., Fyvie, C., Roberts, N., Bisson, J. I., Brewin, C. R., & Cloitre, M. (2017). Alternative models of post-traumatic stress disorder (PTSD) and complex post-traumatic stress disorder (CPTSD) based on the new ICD-11 proposals. *Acta Psychiatrica Scandinavica, 135*, 419-428. DOI: 10.1111/acps.12695.

[**R4**] Karatzias, T., Shevlin, M., Fyvie, C., Hyland, P., Efthimiadou, E., Wilson, D., Roberts, N., Bisson, J., Brewin, C. R., & Cloitre, M. (2016). An initial psychometric assessment of an ICD-11 based measure of PTSD and Complex PTSD (ICD-TQ): Evidence of construct validity. *Journal of Anxiety Disorders, 44*, 73-79. doi: 10.1016/j.janxdis.2016.10.009.

[**R5**] Hyland, P., Shevlin, M., Brewin, C. R., Cloitre, M., Downes, A. J., Jumbe, S., Karatzias, T., Bisson, J.I., & Roberts, N. P. (2017). Validation of post-traumatic stress disorder (PTSD) and complex PTSD using the International Trauma Questionnaire. *Acta Psychiatrica Scandinavica, 136*, 231-338. doi: 10.1111/acps.12771.

[**R6**] Cloitre, M., Shevlin, M., Brewin, C. R., Bisson, J. I., Roberts, N. P., Maercker, A., Karatzias, T., & Hyland, P. (2018). The International Trauma Questionnaire (ITQ): Development of a self-report measure of ICD-11 PTSD and Complex PTSD. *Acta Psychiatrica Scandinavica, 138*, 536-546. doi: 10.1111/acps.12956.

4. Details of the impact

Professor Shevlin's research directly influenced the introduction by WHO in 2018 of a **new psychological disorder** to the ICD-11, CPTSD [**I1; R1, R3**], and subsequently led to the **development, validation and international clinical roll-out of a new diagnostic tool for the disorder, the ITQ** [**I2; R2, R4 - R6**]. The Chair of the WHO Working Group on classification of the disorder stated that Professor Shevlin's research *"...contributed to this work by **providing expertise in the areas of psychometrics and his understanding of trauma assessment**, and [he] was among the **key developers of the International Trauma Questionnaire (ITQ)**, a*

self-report measure of the ICD-11 CPTSD diagnosis with ***demonstrated reliability and validity in over 30 countries****… Overall, the* ***ITQ played an important role in strengthening the research basis for this new disorder****"* [**C1**]. Another member of the Working Group noted the ability of the ITQ to "…*fulfil the WHO's goal to provide a measure that can be used globally to unify nationalities and ethnicities in recognition of psychological consequences… from complex trauma*" [**C2**]. In addition, directly linked to UU outputs [**R2, R4 - R6**], the ITQ has been validated and made open access [**C3**].

While researchers and clinicians have historically recognised that symptoms that can make PTSD 'complex' originate from early and sustained trauma - generally of an interpersonal nature - they have **lacked a formally recognized diagnosis and valid diagnostic tool to assess this prior to CPTSD being included in the ICD-11** [**I1**] and the **development and validation of the ITQ** [**I2**] respectively. Previously, inadequate clinical assessment was **associated with poor treatment pathways** being used, as the national Psychological Therapies Lead at Traumatic Stress Service Wales affirms: "…*variability in clinicians' ability to screen and assess for trauma, leading to a higher level of people being misdiagnosed and not receiving appropriate care"* [**C4**]. Therefore, these two significant achievements [I1, I2] have subsequently **led to improvements in assessing, recognizing, and treating CPTSD** (**I3**; see below); this is important as **the majority of people worldwide will experience a stressful event that would satisfy the 'stressor' criterion for PTSD/CPTSD.**

The ITQ [**I2; R2, R4 - R6**] is freely available online for clinical assessment and research purposes [**C3**]. As of October 2020, the ITQ has been translated into **14 different languages** and is being used extensively in **mental health services for clinical diagnoses, determining treatment pathways, and assessing clinical impact** [**C3**]. As of 31 December 2020, the ITQ webpage has been visited **24,641 times** and used in **over 30 countries** across the world [**C3**]. The utility and reach of the ITQ is exemplified by its adoption by the **International Medical Corps** in response to the **largest ever refugee population in Syria**. The ITQ was **translated and validated in Arabic as an easy to understand and clinically reliable method of determining severity of PTSD/CPTSD symptoms to determine appropriate care plans** [**C5**].

A global survey assessing impact was completed by clinicians and academics who have used the ITQ across the world (including Spain, China, United States of America) [**C3**]. Respondents indicated that they have used the **ITQ in treatment studies, prevalence studies, and comorbidity studies as a method of identifying and distinguishing CPTSD from PTSD**. The ITQ was administered to approximately **59,917 participants** for research purposes to inform clinical practice and included a range of populations such as military and victims of intimate partner violence [**C3**]. The ITQ is also used for **training purposes** in diverse disciplines such as psychology, psychiatry and nursing; approximately **520 students have received training in the use of the ITQ within these departments** [**C3**]. This indicates the **widespread uptake of the ITQ across clinical practice**. The ITQ was also used in the **Child and Adolescent Mental Health (CAMH) Survey** in Northern Ireland (**Health and Social Care Trust, HSC, GBP1,000,000), Northern Ireland's first mental health prevalence study of children and young people,** facilitated by Shevlin and Murphy. The initial report was published in October 2020 [**C6**]. As stated by the **Minister for Health** the associated report informs *"…****the longer-term strategic priorities and investment profile for mental health services****, as development of the new 10-year Mental Health Strategy gets underway***." The Mental Health Strategy for Northern Ireland (December 2020), currently under consultation, **bases pathways for care and support on CAMH study data** [**C6**]. The census has also led to the **commissioning** (HSC, GBP73,000) of a **data analyst** based at UU tasked with **responding to community-based queries (i.e. from headteachers, commissioners, etc.) to inform policy and practice.**

The **ITQ** is a significant development for **clinical services** and is regularly used for **initial assessments, routine assessments, referrals to treatment, and to monitor clinical intervention progress** [**I3; C8-C11**]. The ITQ has been described by **clinicians** as "…***valuable to [their] organisation"*** (National Psychological Therapies Lead at Traumatic Stress Service Wales) [**C4**]; and has been used in **service redesigns** in institutes such as Combat Stress as a

"new and better way of exploring CPTSD for triage and clinical services" (President of the UK Psychological Trauma Society) [**C7**]. **Clinicians** describe the **ITQ** in terms such **as *"user-friendly", "easy to administer"***, and ***"an economical method of assessing CPTSD"*** (National Psychological Therapies Lead at Traumatic Stress Wales; Consultant Clinical Psychologist at Clinic St. Irmingard) [**C4, C8**]. Clinicians have also observed that clients find completing the ITQ to be a ***"validating experience"*** that provides "***a full description of their difficulties in black-and-white"*** *and helps them to* ***"feel they are in the right place for treatment"*** (Professional Lead at the Rivers Centre, NHS Lothian; staff member within the National Center for PTSD Division of Dissemination and Training) [**C9; C2**]. For example, yhe **Welsh Government commissioned the Traumatic Stress Wales Quality Improvement Initiative in May 2019**, a *"national network which provides* ***gold-standard pathways for therapy"*** (National Psychological Therapies Lead at Traumatic Stress Wales) [**C4**]. This initiative creates a **standardised approach to managing trauma symptoms in Wales which includes diagnoses and treatment options for CPTSD.** As emphasised by the National Psychological Therapies Lead at Traumatic Stress Wales, without **UU research this diagnosis would not be available and care pathways would be sub-optimal** [**C4**]. The **ITQ is the only measure used at all time points for managing both PTSD and CPTSD at Traumatic Stress Service Wales**, ranging from assessment to post-intervention follow-up. This tool is **essential to assess efficacy of the interventions provided by the service** [**C4**].

The ability to diagnose CPTSD *"has introduced new treatment paths"* in clinical services which *"offer clients better options for treatment"* (President of the UK Psychological Trauma Society) [**R1; C7**]. Evidence provided by the Medical Director at the Helen Bamber Foundation and by the Royal College of Psychiatrists' lead on Refugee and Asylum Mental Health indicates that these **new treatment paths are effective, with symptoms reducing almost twofold post-intervention** [**C10, C8**]. An example of an intervention beneficial to those with CPTSD is **Skills Training in Affective and Interpersonal Regulation (STAIR) Therapy**, an intervention focused on relationship difficulties and emotional dysregulation alongside treating PTSD symptoms. At least **seven published studies have supported the benefits of STAIR Therapy** [**C2**], and the **ITQ is used to both refer clients to the therapy and to communicate with funders at a policy level the need to deliver more CPTSD-focused interventions due to the prevalence of CPTSD** [**R2, R4 - R6; C10, C11**].

5. Sources to corroborate the impact

[**C1**] Statement from the Chair of the WHO Working Group on the Classification of Trauma and Stress Related Disorders for the development of the 11th revision of the ICD-11.

[**C2**] Testimonial from organisational representative and member of the WHO Working Group: staff member at the National Centre for PTSD Division of Dissemination and Training within the United States Department of Veterans Affairs.

[**C3**] International Trauma Questionnaire Website Report data provided by the webmaster based at Maynooth University, Ireland and International Trauma Questionnaire impact analysis.

[**C4**] Testimonial from national Psychological Therapies Lead at Traumatic Stress Service Wales.

[**C5**] Testimonial from Support Manager for MHPSS case management at the International Medical Corps.

[**C6**] Health and Social Care Board report on the CAMH study and Draft Mental Health Strategy for Northern Ireland consultation document.

[**C7**] Testimonial from organisation representative: President of the UK Psychological Trauma Society and Head of Research at Combat Stress.

[**C8**] Testimonial from clinician: Consultant Clinical Psychologist at Clinic St. Irmingard, Germany.

[**C9**] Testimonial from clinician: Professional Lead at the Rivers Centre, NHS Lothian.

[**C10**] Testimonial from clinician: Medical Director at the Helen Bamber Foundation and the Royal College of Psychiatrists' lead on refugee and asylum mental health.

[**C11**] Testimonial from clinician: Clinical Psychologist at Uppsala University Hospital, Sweden.