UK TTP Psychological Practitioners Network

A Good Practice Guideline

for Psychological Practitioners supporting adults diagnosed with Thrombotic Thrombocytopenic Purpura (TTP)

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(in alphabetical order)

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Endorsements

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Contents

1. Scope of the guidelines

These guidelines have been developed by a working group within the UK Thrombotic Thrombocytopenic Purpura (TTP) Psychological Practitioners Network. The guidelines are aimed at highly trained, accredited and registered psychological professionals providing specialist psychological support within Thrombotic Thrombocytopenic Purpura (TTP) centres.

Clinical guidelines serve as an essential tool for supporting healthcare professionals in delivering effective, evidence-based care. However, due to the rarity of TTP and relatively recent specialist commissioning of services, research in the area of best practice has been limited. In such cases, practice-based evidence, derived from expert consensus, clinical experience and real-world patient outcomes plays a critical role in guiding decision making. This guidance has been developed with a recognition of these limitations, and has drawn upon best available evidence, including from comparable conditions. It has also incorporated the experiences and opinions of experts by training and experts by experience to suggest base level standards for psychosocial care within TTP care pathways.

As new evidence emerges, these guidelines will be reviewed and updated accordingly to maintain relevance and accuracy. We encourage ongoing clinical judgement, shared decision making and adaptability in applying these recommendations to individual patient needs.

2. Executive summary

Summary of Practice Points

- All members of a care team should be clear about how to access the TTP psychological practitioner, where to access relevant information documents related to the mental health impact of TTP and wider psychological and social support available to patients.
- Patients should be aware of the option to access psychological support throughout their TTP journey
- When indicated, TTP patients should be offered referral for psychological support.
- Where possible, psychological practitioners working in TTP teams should aim to introduce themselves to the patient during their initial inpatient stay.
- Patients should be made aware of the extent of confidentiality, with agreement about when information might be relevant for the MDT to be aware of. It should be clear where and how psychological notes will be recorded, stored and accessed.
- Patients should be assessed within six to eight weeks of referral to a psychological practitioner. Assessment from a psychological practitioner should include reviewing the impact of recent admission alongside other psychosocial factors.
- Following an assessment, patients should be offered follow-up psychological support as indicated unless otherwise specified.
- Following completion of psychological intervention, patients will be discharged but can seek support in the future via re-referral.
- Patients who are experiencing a relapse of their TTP should also be offered the support of a psychological practitioner. This can be during their inpatient admission, outpatient day treatment or following the completion of their treatment.
- Neuropsychological concerns should be identified early, assessed and observed where possible and monitored over time.
- The needs, concerns, and distress of family members should be considered by the health care team. Family members should be made aware of what is often the impact of TTP on a patient, and how it may also impact others in the family. Good psychological practice would be to offer a single signposting appointment with family members, and in some settings, there may be scope to offer more provision.
- Psychological practitioners should aim to attend MDT meetings, be aware of new or relapsed patients who the team are working with and contribute meaningfully to discussions to enhance collaborative care where relevant.
- Psychological practitioners should aim to offer consultation and training with other members of the MDT to ensure the team is effective in the delivery of psychologically safe support to patients and family members.
- Psychological practitioners should stay informed of, and be engaged in, research activities related to mental health and TTP, to continue to drive development in the field and keep updated on current knowledge.

3. Background Information and the Psychological Impact of TTP

3.1. Brief Introduction to TTP

Thrombotic thrombocytopenic purpura (TTP) is a rare, acute life-threatening illness that is characterised by a severe deficiency of the metalloproteinase ADAMTS-13. Deficiency of ADAMTS-13 results in platelet-rich thrombi in microvasculature, red cell fragmentation, and organ damage often including the brain, heart and kidneys. TTP requires prompt diagnosis and treatment. Delays are associated with increased morbidity and mortality. In England, identification of cases results in transfer to nine regional centres to initiate specialist treatment. Without treatment, the mortality of TTP is over 90%. With treatment survival is over 90%.

TTP can be either congenital (hereditary) or acquired. Congenital TTP is caused by a genetic mutation leading to a deficiency of the ADAMTS-13 enzyme, while 'acquired' (or 'immune-mediated') TTP (iTTP) is typically caused by autoantibodies that target ADAMTS-13. ITTP accounts for approximately 95% of all cases of TTP.

Presentation can be with a variety of symptoms, from bleeding (haematuria, heavier menstruation), bruising or petechiae. In addition, 70% of patients have neurological features (severe headaches, TIA or stroke, epileptic fit or coma), over 50% have cardiac involvement (primarily raised troponin levels) and 25% have renal impairment.

3.2. Impact of TTP on Psychological Wellbeing

Research into the health-related quality of life (HRQoL) of people living with iTTP primarily stems from cohort studies in the United States (Deford et al, 2013; Hovinga et al, 2010; Lewis et al, 2008; Han et al, 2015). The Oklahoma Registry was the first to demonstrate that following recovery from an acute episode, patients have long-term risks for cognitive impairment and major depression (Kennedy et al, 2009; Han et al, 2015). Multiple

subsequent studies have confirmed the frequency and severity of cognitive impairment and depression in patients with TTP (Alwan et al, 2020; Riva et al, 2020; Falter et al, 2017; Chaturvedi et al, 2017). And yet, depression and cognitive impairment in patients with TTP often remain unrecognized and untreated (Falter et al, 2017), with some patients believing that their depression is not severe enough to warrant treatment (Terrell et al, 2013).

Following an acute episode, survivors report various ongoing negative impacts on HRQoL, including activities of daily living, family and social life, and physical functioning (Lewis et al, 2008), in addition to the challenges to psychological wellbeing and cognitive ability already mentioned (Deford et al, 2013; Vesely, 2015; Han et al, 2015; Kennedy et al, 2009).

Chaturvedi and colleagues (2017) were the first to report a high prevalence of posttraumatic stress disorder (PTSD) in their large online study of TTP survivors. They found that a third of participants (81/231) met the criteria for a provisional diagnosis of post-traumatic stress disorder, which was much higher than the 3.5% prevalence in the general primary care population at that time (Kessler et al, 2005). A large proportion of individuals with TTP were also found to have at least mild depressive symptoms (80.8%), again higher than the prevalence reported in the general population (10.5%).

Holmes and colleagues conducted one of the few UK studies into the mental health of patients with TTP. In their online study of 50 patients (Holmes et al, 2021), 43% reported a decrease in work productivity following recovery from TTP and moderate levels of anxiety and depression. Patients were recruited through the TTPNetwork closed Facebook group, and most of the patients reported that fatigue affected their family life, social activities, and work, with 84% of patients worried about having a relapse (Holmes et al, 2021).

More recently, Azoulay and colleagues (2023) conducted 52 follow-up telephone interviews with adults who had experienced TTP requiring ICU admission in France. The interviews were held to assess and compare mental health symptoms and HRQoL in adult survivors of TTP or atypical haemolytic-uremic syndrome (aHUS). The prevalence of anxiety, depression and PTSD in TTP patients was found to be 50%, 17% and 29% respectively.

Kelley and colleagues (2023) recently conducted a qualitative study of 44 Oklahoma and Ohio patients with TTP. They explored the most important symptoms during remission, the impact of these symptoms on patient's daily activities, and the effectiveness of communication with haematologists. They found patients described cognitive issues, fatigue, depression, and anxiety, consistent with previous research (Han et al, 2015; Deford et al, 2013; Alwan et al, 2020; Riva et al, 2020; Falter et al, 2017; Chaturvedi et al, 2017). However, the impact of residual symptoms on remission and social health are aspects of TTP not previously described. Patients with TTP described that they were less likely to want to socialize following recovery and had an increased tendency to isolate themselves from others. Patients also described themselves as more short-tempered, impatient, and argumentative following recovery. In addition, fatigue limited patients from spending time with their loved ones and affected their self-esteem (Kelley et al, 2023).

The most recent study in this area by Mulas et al (2024) conducted in Italy similarly suggested that most patients suffered from anxiety (72%) and depression (82%), even a long time after diagnosis. The median of their time since follow-up was 97 months. ITTP patients also had lower physical and mental health scores than the general population. Resilience was found to be negatively correlated with depression.

These studies suggest that there is a real need among patients with TTP for psychological support, and the potential value of psychology in TTP care is reflected by the formal integration within recently commissioned TTP specialist services in the England.

3.3. Neurological and Cognitive Changes

Many patients with TTP exhibit abnormal neurological manifestations, with the brain being the most common site of ischaemic injury (Zhu & Liu, 2022). Patients can present with widespread neurological deficits, including headache, seizures, ataxia and aphasia, as well as changes in cognitive function, including confusion, memory loss, disorientation, and changes in emotional regulation and unusual behaviour. These symptoms can be mistaken for acute ischaemic stroke without the presence of detectable ischaemic lesions (Zhang & He, 2023), and there is an increased risk of actual stroke during an initial TTP crisis and after recovery (Boattini & Procaccianti, 2013; Upreti et al, 2019). After remission, it is not

uncommon for patients to report persistent neurological impairment, including problems with memory and attention and the presence of neurological symptoms at the time of TTP crisis is a predictor of prolonged symptoms (Riva et al, 2020).

However, it is currently unclear whether these persistent neurological symptoms are only the result of abnormal neurological manifestations, or may also be a consequence of concurrent depression, which has been postulated, for example, by Falter et al (2017) in their German study of TTP patients.

An evaluation of a UK TTP centre psychology referrals (Shaw et al, 2023) found that within this specific site, 50% of patients referred to psychology underwent neuropsychological assessment by a Clinical Psychologist, and of those, 25% were identified as having a neurocognitive deficit as measured by the RBANS (Repeatable Battery for Assessment of Neuropsychological Status; Randolph, 1998). Little is known about the extent of cognitive impairment following acute TTP episode in the UK TTP population because no national studies have looked at cognitive changes across the whole TTP population and testing isn't mandated. Greater awareness and assessment of TTP patients for cognitive impacts (with or without formal neuropsychological testing as required) following acute admission may help to develop further understanding. By contrast, NHS Improvement recommendations for psychological care after stroke recommend that all patients should be screened for cognitive impairment within six weeks using a validated tool (NHS Improvement, 2011), and this recommendation allows further understanding of possible cognitive changes following TTP episodes in this population.

3.4. Impact On, and Role Of, Family in Patient Recovery and Psychological Wellbeing

The impact of supporting a relative with a long-term condition should not be underestimated. Depending on the severity and progression of the condition, family members often experience increased stress and anxiety, alongside additional practical responsibilities such as taking time off work for medical appointments or assisting with activities of daily living during the patient's recovery (Holmes & Deb, 2003; Wittenberg et al, 2013; Anderson & Bury, 2024).

In the context of TTP, existing literature provides only limited anecdotal insights into the impact of the condition on family members (Bradbury & Bell, 2024; Holmes et al, 2021). However, research from other chronic conditions suggests that family members are likely to experience a bi-directional psychological impact, both influencing and being affected by the patient's health journey. Some family members may also experience vicarious trauma, if they have accompanied the patient closely on their treatment journey.

In the case of congenital TTP, families have to come to terms with the potential of multiple family members suffering with the condition. Often, patients also describe worry and guilt about passing the condition on to their children.

As TTP can occur in the context of pregnancy, for some patients this brings the added challenges of complications and treatment during pregnancy, and sometimes a necessitated early delivery of the baby. This can feel very traumatic for the whole family. TTP can therefore also have a subsequent bearing on decision-making around family planning. In terms of family support, it is widely recognised that family members play a central role in both the management and recovery of a patient's health, as well as in reducing the likelihood of relapse and further hospital admissions (Lee et al, 2021). Additionally, the psychological resilience of a patient's support network can significantly influence patient outcomes (Ascoba, 2024). However, this support can take a toll on family members, who in turn might need their own strategies to help them manage this impact.

4. Good Practice Recommendations for the Support of TTP Patients and Their Families

4.1. Introduction: Acute Admissions, Relapse and Lifelong Outpatient Support

As discussed above, TTP is a life-threatening emergency, and as such, admission to hospital for the first episode of TTP is often very traumatic and overwhelming for patients. Some patients are very acutely unwell and their condition necessitates intense treatments and prolonged hospital stays, often with a period of admission to intensive care units (ICU). For others, TTP is diagnosed in the context of another medical emergency, such as a stroke, or even suspected pre-eclampsia during pregnancy, which necessitates similar immediate and often traumatic admissions and treatments. Yet other patients may have very broad and generalised or not have very noticeable symptoms, so their diagnosis with TTP can come seemingly 'out of the blue'. This can add to the unreality and shock that is common as an initial reaction to the diagnosis. The early phase of a new diagnosis of TTP is often very confusing, frightening and overwhelming. In addition to the shock of the diagnosis and difficult treatments, the hospital environment itself can also pose many challenges and can be a cause of psychological distress (Dziadzko et al, 2017). A highly medicalised focus, lack of structured routine, disrupted sleep (Lane and East, 2008), a reduction in personal value and a lack of control over an environment which has the propensity to be loud and busy can all contribute to this (Williams, Dawson and Kristjanson (2007). In the early days following diagnosis, psychological support can help patients to process some of these initially very difficult and potentially traumatic experiences.

Furthermore, a clinical relapse, where the level of ADAMTS-13 drops below what is considered a safe level, occur fairly commonly at some point in their lives for TTP patients. Doyle et al. (2023) put the cumulative relapse rate at 40% within five years, meaning it is expected that 40% of patients would have experienced at least one relapse five years into their TTP journey. A relapse of TTP can be psychologically distressing. Patients with TTP need to adjust to living with a high degree of uncertainty, with the potential for a relapse being a possibility for the rest of their lives. Whilst improvements in monitoring and

treatment have meant that relapses are often much less traumatic in terms of actual treatment experiences than the initial acute episode, and inpatient admissions for TTP relapses are increasingly less common, they are nevertheless a part of some patients' journeys. Admissions for treatment can be difficult for multiple reasons, including worries about the treatment itself, impact on their life, or a re-triggering of previous traumatic experiences. Psychology has a role both in terms of supporting the adaptation to relapse, if and when it occurs, and the management of uncertainty in the context of understandable anxiety over what the future holds.

Outside of a patient's initial TTP diagnosis, patients require long-term follow up to help manage the physical and psychological challenges of their diagnosis (Scully et al, 2023). Examples of the different challenges that may impact patients include adjusting to their new diagnosis, a 'new norm' of multiple hospital appointments, TTP-terminology (ADAMTS-13, elective treatments, treatment names), and the prospect of relapse. Even following this initial period, the prospect of relapse, treatment and attending hospital appointments, as well as ongoing clinical review can also be anxiety provoking or challenging for patients. It is common, for example, for patient anxiety to follow a pattern where it is heightened before a blood test and clinical review, subsides for a while after a 'good' (normal range ADAMTS-13) result, only to build up again in time for the next test. As TTP symptoms are often fairly diffuse, and benign or common on their own (e.g. headaches, fatigue), many patients find it very challenging to monitor their own symptoms and rely on their own judgment to decide whether this is a normal symptom or potential TTP relapse. This can lead to heightened anxiety, uncertainty, and sometimes avoidance to engage with health care overall, or to hypervigilance and fear of bodily aches, bruises or other symptoms.

Psychological research into this area is currently in its infancy; however, studies as outlined earlier in this guideline have suggested TTP patients may have symptoms of depression, anxiety or PTSD following their diagnosis. One qualitative study into patient experience of TTP highlighted themes of feeling like a changed person, as well as their TTP impacting their quality of life (including work and relationships). A subset of people with TTP also report ongoing cognitive fatigue.

4.2. Psychological Support for TTP Patients

Patients should be offered the chance to meet with a registered psychological practitioner, whether it is a put a ‘face to a name’ - providing familiarity - to follow up on questions patients have about their emotional or cognitive functioning following a TTP episode, or to have a full assessment of their needs and subsequent support options. Ideally, patients should be offered a space to speak with a psychological practitioner whilst they are an inpatient and receiving treatment for their first episode of TTP. This should be offered wherever practical, but will in reality depend on the timing and length of the inpatient stay and the psychological practitioner's availability. Following their discharge, patients should be offered a referral to a TTP psychology service if they would like support for any changes within their mood arising from their relapse.

4.2.1. Referral Process

All patients should be aware of the ability to access psychological support in relation to their TTP as soon as possible after their diagnosis. If indicated by the medical team or asked for by the patient, patients should be offered a referral to the psychological practitioner through their medical team.

4.2.2. Timing of Referral

Once referred to a TTP psychological practitioner, patients should be offered a psychological assessment within a 6–8-week window after the referral has been accepted.

4.2.3. Psychological Assessment

Patients should be invited to attend a psychological assessment either in person or remotely if unable to attend in person. An assessment will generally consist of information gathering in relation to a patient’s emotional wellbeing. Depending on need, it may be a more informal or formal assessment, and it may include the following components:

- Current emotional well-being
- Impact of TTP on quality of life
- History of mental and physical health conditions
- Cognitive functioning and coping strategies
- Family and social support systems
- Personal goals for psychological therapy
- Inclusion of standardised outcome measures, with the ambition to have uniform measures across the TTP specialist centres

4.2.4. Psychological Follow-up and Interventions

If indicated, patients will be offered follow-up psychological support with a psychological practitioner. Sessions typically last around 50 minutes and the number of sessions that will be offered will be subject to several factors including: the goals of the patient, clinician judgement and psychological formulation, local service guidelines, and evidence-based practice on common psychological difficulties.

4.2.5. Discharge

Following the agreed number of sessions, patients will usually be discharged from the TTP Psychology service, but will be able to access the service in the future via re-referral from the team.

4.2.6. Summary of Recommendations for Psychological Support:

I. Patients should be aware of the option to attend psychological support throughout their TTP journey.
II. When indicated, TTP patients should be offered referral for psychological support.

III. Patients should be assessed within six to eight weeks of referral to a psychological practitioner.

IV. Following an assessment, patients should be offered follow-up psychological support, unless otherwise specified.

V. Following completion of psychological support, patients will be discharged but can seek support in the future via re-referral.

VI. Patients who are experiencing a relapse in their TTP should also be offered the support of a psychological practitioner. This can be during their inpatient admission, outpatient day treatment or following the completion of their treatment.

4.3. Neuropsychological Support for TTP patients

As discussed above, in addition to general psychological challenges, TTP patients may also experience cognitive impairment which may warrant further investigation. One key challenge for the psychological professional is to identify whether the cognitive difficulties the patient describes are related to neuropsychological impairment, or to the mood disorders common in the context of TTP (e.g. depression, anxiety or PTSD), and to surmise how presenting difficulties may differ from their pre-morbid cognitive functioning. A thorough assessment is therefore paramount.

4.3.1. Referral Process and Timing of Referral

If a referral is specifically due to neuropsychological concerns, and not in the context of wider psychological support, the same process as above for psychological support should be followed, e.g. a patient should be referred as soon as viable by the medical team, and an assessment should be scheduled within 6-8 weeks post referral. Only on rare occasions, and with justifiable cause, should any detailed neuropsychological assessments be completed before 6 weeks post discharge, allowing time for the patient to recover from the acute phase of the illness.

Ideally, all TTP patients should have a review of cognitive difficulties at 6-months with a psychology professional.

If a patient is still an inpatient during an initial TTP diagnosis episode, depending on timing and fitness, it may be feasible to offer_a brief screen for cognitive impairment. Early screening for cognitive difficulties would allow for tracking of changes over time and a baseline comparison data.

4.3.2. Neuropsychological Assessment

A neuropsychological assessment requires a thorough assessment of the circumstances of the individual patient, and in the first instance, can be completed by clinical interview and observation. It includes a patient's complex presentation of their difficulties, as well as consideration of fatigue, the impact of medications / treatments, any co-morbid mental health difficulties, patient's social circumstances including work, and other cognitively demanding activities and responsibilities.

Screening measures such as the MoCA (Nasreddine et al, 2005) or ACE-III (Hsieh et al, 2013), can be used in the first instance to gain further information[1].If indicated, more formal neuropsychological assessment should be considered using a test(s) that assess the broad range of cognitive domains, with appropriate norms, such as the RBANS (Randolph, 1998). Practice effects need to be considered and accounted for where the test has been used previously.

Neuropsychological assessment measures should only be used by staff trained to administer and interpret these tests, with an option for consultation with or onward referral to other clinical or neuropsychologists as needed. In that regard, service provision will depend on the experience of the individual psychological practitioners working in TTP services and local provision for more specialist neuropsychological input.

Further tests that may be useful include but are not limited to:

- Attention: Test of Everyday Attention (TEA; Robertson et al, 1994)

[1] TTP centre psychological practitioners should be aware of the online training available for MoCA and ACE-III screening tests (*or other suitably validated tests?*) and be available to support other colleagues accessing training if appropriate. See: https://www.mvls.gla.ac.uk/aceiiitrainer/ and https://mocacognition.com/

- Memory: Wechsler Memory Scale – Fifth Edition (WMS-V; Wechsler, 2020)
- Perceptual skills: Rivermead Perceptual Assessment Battery (RPAB; Whiting et al, 1985)
- Executive Functions: Behavioural Assessment of the Dysexecutive Syndrome (BADS; Wilson et al, 1996); the Hayling and Brixton Tests (Burgess & Shallice, 1997); Trail making Test (Reitan, 1958)
- Word Finding: Boston Naming Test (Kaplan et al, 2001)
- Processing Speed: Wechsler Memory Scale – Fifth Edition (WMS-V; Wechsler, 2020)
- Premorbid IQ: Test of Premorbid Functioning (TOPF; Wechsler, 2011)

4.3.3. Neuropsychological Intervention

Neuropsychological interventions aim to improve cognitive, emotional, and behavioural functioning. They may include interventions used in wider health psychology, which can help individuals adjust to the ongoing impact of physical health problems such as Cognitive Behavioural Therapy (CBT) and Acceptance and Commitment Therapy (ACT).

The TTP psychological practitioner can offer strategies and techniques designed to help individuals manage specific cognitive skills that have been impaired due to brain injury or illness. These may include:

- Strategies to support with issues like word-finding difficulties
- Memory training: exercises to enhance memory recall and retention.
- Attention and concentration exercises: activities to improve focus and sustained attention.
- Problem-solving tasks: activities that challenge executive functions like planning and decision-making.

Evidence of the effectiveness of cognitive rehabilitation interventions is limited, although interventions to improve attentional deficits may be effective (Xu et al, 2013).

Carer support in the form of a neuropsychological needs assessment should be provided where severity of cognitive impairment warrants this intervention (BPS, 2023), and where appropriate this should also be shared with other agencies involved in the patients care.

Recommendations and strategies based on each individual's specific cognitive profile should be provided.

4.3.4. Summary of Neuropsychological Recommendations:

I. If cognitive challenges have been identified, patients should receive a timely referral to the TTP psychological practitioner in the first instance.
II. TTP psychological practitioners should complete a thorough assessment of the patient and their circumstances, including all mood- and life-related issues of potential relevance.
III. If indicated, a cognitive screening measure should be completed.
IV. If needed, further neuropsychological assessment should be completed, either by the TTP psychological practitioner, or, if not suitably qualified, the patient should be referred to the relevant neuropsychological team.
V. Neuropsychological interventions or recommendations tailored to the individual's cognitive profile should be offered where appropriate

4.4. Indirect Patient Support: The Role of Psychology in Multidisciplinary Team (MDT) Working

The BPS guidance for employing practitioner psychologists in physical health settings (2024) highlights an ambition for all patients living with long-term conditions to have timely access to appropriate psychological support, including input to their MDT medical care and rehabilitation. A psychological practitioner's perspective can enrich the MDT discussion by highlighting the psychological factors influencing a patient's physical health.

MDT meetings that include a psychosocial professional have been shown to enhance decision-making, align treatments with guidelines and improve care coordination with the collaborative approach leading to a greater sense of security for patients (Polomeni, Bordessoule & Malak, 2023).

In the context of TTP, this positive role has been recognised, and commissioning for nine TTP specialist centres over eleven sites has ensured that each centre has the support of a designated mental health professional. These guidelines recommend that psychological practitioners working into TTP specialist teams should be available for regular discussions with the wider TTP MDT. There should be an aim for attendance at MDT meetings, but as a baseline standard, psychological practitioners should be aware of new or relapsed patients who the team are working with and provide meaningful contributions to discussions to enhance collaborative care for these patients.

There is an importance of building effective relationships with the wider TTP MDT members to allow for regular and ad hoc, formal and informal conversations so that the team can grow in its understanding of the psychological impacts of TTP and individual's needs. Teams should be made aware of the availability of the psychological practitioner, with dedicated space for consultation and support offered to ensure the team is effective in its delivery of care.

This guideline also recommends that all psychological practitioners working within TTP services are involved in the development and implementation of psychologically informed approaches and training packages with their wider TTP MDT colleagues. Members of the MDT should be encouraged to attend any training offered to ensure the psychological impact and needs of patients are fully understood and integrated into care plans. In turn, psychological practitioners are required to gain medical understanding of TTP, its treatments and impact via shadowing, discussions and training with TTP MDT colleagues.

4.4.1. Summary of MDT Recommendations

I. Psychological specialists should be involved in the development of training programs for TTP MDTs.
II. Psychological practitioners should aim to attend MDT meetings, be aware of new or relapsed patients who the team is working with, and contribute meaningfully to discussions to enhance collaborative and holistic care where relevant.

III. Psychological practitioners should aim to offer consultation and training with other members of the MDT to ensure the team is effective in delivery of psychologically safe support to patients and family members.

4.5. Supporting the Family to Support the Patient: Psychological Support for Family Members

To enhance the support provided to family members, this guideline draws on practice-based evidence and feedback from patient and multidisciplinary team questionnaires, leading to the following recommendations.

4.5.1. Early Education and Support for Family Members

It is essential to ensure that family members receive early and clear information about TTP, its common impacts on individuals, and the psychological adjustments required to support a relative with TTP.

Feedback suggests that this information is most effectively delivered by the wider TTP healthcare team, rather than psychology services alone. However, family members should be encouraged to consult with psychological practitioners if they have specific concerns about their relative's emotional or cognitive well-being, or their own ability to cope with the changes in their relative's health.

4.5.2. Normalising the Emotional Impact on Families

Healthcare teams should acknowledge and validate the emotional challenges that family members may face, including:

- Increased anxiety
- The distressing experience of seeing a loved one in intensive care
- Uncertainty about the condition's progression
- Concerns about the future, including financial and occupational adjustments
- Concerns and anxiety about the possibility of relapse
- Potential concerns about genetics and the impact on the wider family

Normalising these experiences can help families to feel understood and supported during a highly stressful time.

4.5.3. Encouraging Open Conversations

Family members should be given space to express their needs, concerns, and emotional distress. Prompting questions that healthcare teams might use include:

> **"How are you and your family coping following this admission?"**
> **"Would you like to talk about how this experience has been for you?"**

4.5.4. Providing Access to Support

Once family members have had the opportunity to share their concerns, they should be provided with clear information on available support within the hospital and community settings. Depending on the healthcare structure, psychological practitioners may take the lead in identifying and coordinating support for distressed family members, or work in collaboration with ward and specialist healthcare teams to ensure seamless access to resources.

4.5.5. Coordinating Support and Avoiding Duplication

To enhance efficiency and prevent fragmented care, it is recommended that psychological practitioners:

- Direct family members to accessible resources that explain TTP, its impact on patients and families, and strategies for adjustment.
- Establish relationships with internal and external support teams to facilitate the transfer of information and referrals. Maintaining a comprehensive list of local and national support options can improve access to appropriate services for family members.

- Develop tailored written resources for family members, including adapted versions for children and individuals with learning difficulties, to ensure accessibility and inclusivity.

By implementing these recommendations, healthcare teams can provide structured, compassionate, and proactive support to family members, ultimately enhancing both patient recovery and family well-being.

5. Research, Service Evaluation and Development

Service development, including service evaluation and research, are an important part of the role of a psychological practitioner which further improves the psychologically informed care offered to patients.

In view of the lack of current research in this area, these guidelines encourage the consideration of psychological research into the impact of TTP, and the potential for interdisciplinary collaboration in research to address complex issues from multiple perspectives.

Research involving psychological aspects must have a psychologist involved in the planning, at least with a psychologist being consulted, and at best being part of the research team.

If the research is likely to pull national data relating to mental health and psychological aspects, it is important to consult the 'UK Thrombotic Thrombocytopenic Purpura (TTP) Psychological Practitioners Network' and have their input on the analysis of the data.

Any research conducted should have its findings disseminated to both local and national TTP teams with presentations, publications and or reports.

When commissioning psychological services within TTP, it is important that time and funding is allocated for research and service development purposes, alongside the provision of therapy. This Good Practice Guideline is a byproduct of NHS England recognising the value of psychological practitioners embedded in specialist health services, and a commitment to encouraging and funding time for national collaboration and the establishment of research into best practice.

5.1. Summary of Research Recommendations

I. Regular service evaluation should be conducted to ensure best practice.

II. Research initiatives should be encouraged to further understanding of the psychological impact of TTP.

III. National collaboration across specialist centres and practice sites should be encouraged.

6. Summary Recommendations

- **Timely psychological assessments** within 6-8 weeks post-referral.
- **Integrated psychological support** for newly diagnosed and relapsed patients.
- **Neuropsychological support where needed.**
- **Regular MDT engagement** to enhance patient-centred care.
- **Psychological consultation to MDTs** to improve care quality.
- **Ongoing evaluation and research** into the psychological impact of TTP.
- **Family-inclusive approaches** in patient care.

Psychological well-being is a crucial aspect of TTP care. These guidelines establish a framework for integrating psychological support within MDTs and ensuring consistent, evidence-based care for TTP patients and their families.

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