Workforce Planning: Psychologists in Services for People with Haemoglobin Disorders

This document should be read in conjunction with UK Standards for the Clinical Care of Adults with Sickle Cell Disease (2017) (see Appendix A), Sickle Cell Disease in Childhood: Standards and Guidelines for Clinical Care in the UK (2010), and Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK (2016) (Appendix B).

- There is wide variability in psychology staffing levels in services for people with haemoglobin disorders in the UK.
- Peer Review Programme for Health Services for People with Haemoglobin Disorders 2014-16 Overview Report highlighted concerns about poor access to psychology services in 65% of those services reviewed; many services lacked dedicated support from psychologists with specialist expertise in haemoglobin disorders; and many services had poor access to neuropsychology. Recommendations to NHS Trusts included a review of specialist psychology and neuropsychology provision available to services (www.wmqrs.nhs.uk/publications).
- It is useful to consider what are adequate psychology staffing levels for services for haemoglobin disorders. Standards for psychology provision in other chronic health conditions (Stroke, HIV, Diabetes, Cancer, Cystic Fibrosis) were reviewed to help determine number of psychologists to patient ratio. Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK (2nd Ed, 2011) and London Cancer Alliance: Developing a Pathway for Mental Health and Psychological Support Services to Adults (2012) recommends a minimum of 1 psychologist to 150 patients. The other standards reviewed did not specify a number but recommended the need for access to psychologists with specialist expertise in the chronic condition.

Role of psychologist in the Haemoglobinopathy Team

- Provide psychological assessment, psycho-education, and evidence-based therapy to patients and families
- Provide psychological support within the Transition Service for young people and their families
- Contribute to annual reviews of patients attending clinics by screening for concerns re mood, quality of life and coping.
- Attend multidisciplinary team ward rounds
- Provide neuropsychological assessment and recommendations or facilitate such assessments as necessary
- Facilitate support groups
- Offer consultation and support to staff
- Liaise with health, social and education professionals
- Contribute to multidisciplinary team guidelines, protocols, research and education.

Recommendations

- We suggest at least a 1:300 ratio of psychologists to patients. This is a conservative recommendation compared to other similar services (eg cystic fibrosis and cancer) but is realistic when current service provision and financial constraints are considered. There are no services which currently reach even this conservative recommendation.
- Psychologists in some haemoglobinopathy services are asked to accept external referrals when haemoglobinopathy psychology provision does not exist locally. This

should be taken into consideration when calculating the psychologist to patients ratio.

- If the service for people with haemoglobin disorders has a sole psychologist, they should be at least a band 8a or above.
- Neuropsychological assessment is a specialist skill that some psychologists have. Where possible, a minimum of one psychologist in the haemoglobinopathy psychology team should be competent in undertaking and interpreting comprehensive neuropsychological assessments. This is feasible when ratio of psychologist:patient population approaches 1:300. Until that ratio is reached, it is important that the psychologist has an understanding of the rationale for a neuropsychology service for people with haemoglobinopathies, determines referral pathways to external neuropsychology services and is competent in discussing implications of results of neuropsychological assessments with the MDT and incorporating recommendations into psychological work.
- Permanent contracts are necessary to ensure consistency and stability in psychology provision. This is especially important when working with people with haemoglobin disorders where building trust over time is vital in order to engage patients with psychological support.
- Effectiveness of the psychologist will depend on factors such as: stability of the haemoglobinopathy team in terms of staff turnover; willingness of haemoglobinopathy team to take on board psychological approach to patient care; provision of clinical nurse specialists (who can provide level 2 psychological skills under supervision); administration support.
- Haemoglobinopathy services providing highly specialist care eg multispecialist neurology clinics or receiving high numbers of tertiary referrals, are more likely to see patients with more complex needs who may require increased levels of psychological support.

Psychologist Qualifications

- Psychology services can be provided by a clinical, health, or counselling psychologist provided they have the relevant competencies and experience required for this specialist area of work.
- Psychologists must have completed the British Psychology Society accredited doctoral training in clinical/health/counselling psychology (or statement of equivalence)
- Psychologists must be eligible for Health and Care Professions Council registration as Practitioner Psychologist (Modalities: Clinical or Health or Counselling Psychologist)

References

London Cancer Alliance: Developing Pathway for Mental Health and Psychological Support Services for Adults (2012)

UK Standards for the Care of Adults with Sickle Cell Disease (2017) In press.

Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK, 3rd Edition (2016) UK Thalassaemia Society

Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK (2011) Cystic Fibrosis Trust

Dick, M (2010) Sickle Cell Disease in Childhood: Standards and Guidelines for Clinical Care. NHS Sickle Cell and Thalassaemia Screening Programme in partnership with the Sickle Cell Society.

This document has been created by the British Psychology Society Special Interest Group for Psychologists working in Sickle cell and Thalassaemia
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Appendix A
From: UK Standards for the Care of Adults with Sickle Cell Disease (2017)
P81-82

Psychological interventions

"It is not death or pain that is to be dreaded, but the fear of pain or death." – Epictetus

Introduction

Sickle cell disease is inherited, chronic, and life-limiting and therefore can pose multiple and severe psychological challenges to patients, families, health care professionals, and the health care system. Being present from birth, it can interfere with normal adjustment to developmental challenges and achievement of personal goals. This all occurs in the context of SCD being a stigmatising medical disorder which is experienced in an already stigmatised group of people who also face considerable socio-economic challenges. On a more individual level, psychosocial issues for people with SCD and their families can result from the impact and disruption due to pain and symptoms on their daily lives affecting their quality of life. For example, stress, depression, fear or anxiety may affect pain experience leading to frequent hospital admissions. People with SCD have different levels of health, and variations in their ability to cope with day-to-day. Studies suggest a person's way of coping appears to be a significant predictor of adjustment, independent of the severity of their disease. Psychological interventions should be offered as standard care in the management of SCD adjunctive to medical treatment and nursing care. The overall goal is to help people build resilience, enhance coping strategies, develop ways to manage symptoms such as anxiety, depression and anger, be able to engage in valued activity and roles, and improve their quality of life. These interventions should be available in both hospital and community based settings. Furthermore, cognitive impairment is well recognised as a complication of SCD, both in patients who have had an overt or silent stroke, or in those without MRI evidence of disease. Neuropsychological evaluation can establish the extent of cognitive damage, map this over time and offer treatment strategies.

Standards

- All patients with SCD should have access to specialist psychology support.
- Core staffing of Specialist Centres for SCD should include a clinical/health/counselling psychologist with a special interest and experience in SCD.
- Psychological assessments should be carried out when indicated or annually, and include the following:
    - Emotional well-being and pain – subjective estimates and objective measures
    - Physical and social function i.e. participation / non-participation or reduction in activities e.g. work, social – subjective estimates and objective measures
    - Coping strategies and sources of support – objective measures
    - Neuropsychological assessments should be carried out as appropriate when neurological complications are indicated

- Psychological therapies including Cognitive Behavioural Therapy (CBT) should be offered as required, and could be offered in individual or group sessions.

- Where serious mental health difficulties or psychiatric problems are identified, referral to a secondary mental health service should be considered and, if possible, discussed with the team psychologist in a timely fashion.

- Psychological support should be offered to patient and carer support groups.

- All specialist staff should be aware of the importance of psychosocial issues in providing care for people with SCD and should have access to training, support consultation or supervision from a psychologist with a special interest in SCD.

Background Evidence

Reviews of psychological studies have shown that people with SCD have a severely compromised health-related quality of life in comparison to the general population and other medical conditions (Anie, 2005; McClish et al., 2005). Moreover, depression, anxiety, and psychological difficulties are prevalent among people with SCD, and predictive of pain experience (Levenson et al., 2008; Sogutlu, Levenson, McClish, Rosef, & Smith, 2011). There is good evidence to suggest that cognitive behavioural therapy in adults with SCD is beneficial to moderate chronic pain, disability, depression and anxiety associated with SCD (Anie & Green, 2015; Chen, Cole, & Kato, 2004; H. Williams & Tanabe, 2016). This is supported by studies of chronic pain management (in non-SCD samples) with psychological therapies delivered via the internet that were shown to be effective in reducing pain, disability, depression and anxiety in adults, comparable to effectiveness in face-to-face therapies (Eccleston, Fisher, et al., 2014).

Furthermore, reviews of psychological therapies with children and young people have been effective in reducing pain and perceived disability amongst those with non-headache pain (including sickle cell disease), but only soon after treatment (Eccleston, Palermo, et al., 2014); and group psychoeducation in families of children and adolescents with SCD has shown improvements in knowledge (Anie & Green, 2015).
Cognitive impairments have been highlighted in adults with SCD who have normal MRIs, suggesting the importance of neuropsychological assessments (Rawle, Holmes, Thomas, Cartwright, & Howard, 2015)(E. P. Vichinsky, Neumayr, Gold, & et al., 2010). Further psychological therapies are outlined in Appendix.

Recommendations

- Psychologists should be an integral part of multidisciplinary teams for the management of SCD in order for comprehensive care to be achieved.
- Health professionals should routinely assess a patient's desire/need for psychological intervention/support by asking questions such as 'How are you feeling/coping?' and should identify patients who would benefit from psychological intervention in order to maximise health related behavioural changes e.g. improving

adherence. Patients should be able to access evidence-based psychological therapies as relevant to their needs

- Patients and their families should be made aware of what psychological support is available within hospital and community settings.

P227

1. Psychological Therapies

I. Psychological Therapies
a. Cognitive Behavioural Therapy
Cognitive Behavioural Therapy (CBT) is a gold standard psychological intervention and comprises two approaches i.e. cognitive and behavioural techniques.
b. Psychoeducation
Psychoeducational interventions primarily focus on improving knowledge and understanding of patients about their illness while at the same time providing psychological support.
II. Other Psychological Therapies
There are other established and emerging psychological therapies, which should also be considered for people with SCD based on evidence in other conditions.
a. Mindfulness-Based Cognitive Therapy (MBCT) specifically helps people with recurring depression, and also chronic pain, by combining mindfulness techniques including meditation, breathing exercises and stretching, with elements from cognitive therapy to help break negative thought patterns.
b. Acceptance and Commitment Therapy (ACT) uses acceptance and mindfulness strategies, together with commitment and behavioural change schemes to help people accept difficulties that come with their lives to build resilience.
c. Motivational Interviewing is an evidence-based treatment that addresses ambivalence to behavioural change. This helps to motivate people to stop habits such as smoking, and engage in valued activities, for instance, adhere to medication.

Appendix B

From: Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK (2016) (p39-42).

Psychosocial Issues in Thalassaemia

"People don't and can't understand thalassaemia as they can't see from the outside how unwell you are and what you're going through every day of your life – especially when your haemoglobin is dropping before transfusion. It's like looking at a house, it might look OK on the outside but you can't tell what's happening on the inside."

"I wish they would offer counselling services to people who have thalassemia."

"Some people think you are diseased and don't have a right to the same emotions and relationships as everyone else. You are broken."

"I find it difficult to form relationships. The fear of negative attitudes from people plus my own lack of self-esteem and body image issues mean I am shy when meeting new people."

Aims

To promote the patient's capacity to adapt optimally to having thalassaemia.

To improve quality of life and emotional wellbeing among patients.

To support patients to manage their health alongside their normal lives.

To minimise the negative impact of thalassaemia on emotional wellbeing.

To reduce levels of emotional distress and the effect such distress can have on physical wellbeing and engagement with treatment.

Standards

Consideration of the psychosocial demands and support needs of living with thalassaemia is a key role and responsibility for all professionals involved in the provision of care for people with this condition.

Consideration of the family context and developmental/life stage of the person with thalassaemia is key to ensuring that care and treatment recommendations are individually tailored and appropriate for each patient.

Psychosocial support alongside specialist psychological care should be provided as a standard part of thalassaemia clinical care, in both paediatric and adult services.

Core staffing of Specialist Haemoglobinopathy Centres should include a clinical psychologist with a special interest and experience in thalassaemia.

Background

Living with physical illness can be difficult and upsetting (Christie and Khatum 2012). The physical and emotional disruption caused by illness, along with the potential demands and the toll ill health places on the individual can be substantial. Illness challenges our sense of health, control, stability and self, and impacts our day to day life and relationships with others. Chronic illness can have particularly life-changing effects: rather than involving a full return to health and normal life, it demands that the individual must adjust to and accept some level of ill health and manage periods of remission and exacerbation over time (Rolland 1984; Rolland 1987). Serious chronic illness requires permanent changes to normal life and an ability on the part of the individual to continually readjust and redefine goals and personal identity, making changes to his/her way of living and being (Fennell 2003).

As a chronic, lifelong and life-limiting condition, thalassaemia poses multiple and severe challenges (Anionwu and Atkin 2001; Politis 1998). Alongside the physical symptoms of thalassaemia, and its impact on family, relationships, emotional wellbeing and quality of life, the child or adult with thalassaemia must also cope with invasive, complex and demanding treatments, frequent hospital visits, and a lifelong reliance on health services. Thalassaemia has an impact on both physical and emotional functioning as the individual must adjust to the impact illness has on his/her physical wellbeing and on his/her hopes and ambitions for life. Feelings of difference, uncertainty, anxiety, helplessness and loss are common and the individual must make physical and emotional adaptations to build a life that incorporates illness, managing physical symptoms and treatments while struggling to maintain a sense of self-worth and normalcy (Atkin and Ahmad 2001; Georganda 1998).

Not only does growing up with a chronic medical condition present significant challenges to children in accomplishing developmental tasks (Eiser 1993; Immelt 2006) but high rates of depression and anxiety are consistently found among seriously physically ill adult populations (Royal College of Psychiatrists, 2012). Given that a number of psychosocial factors are known to influence patient adjustment and adherence (Goldbeck *et al.* 2000; Joshi 1998), failing to provide psychosocial care, as part of standard care, in thalassaemia runs the risk that higher levels of untreated emotional distress will lead to lower treatment adherence, poorer self-management and reduced clinical outcomes. Many patients acknowledge that the ways in which their doctors and nurses approach them, and the messages and expectations they convey in clinical interactions, are centrally important to the way in which they think about themselves and their illness, so the psychosocial wellbeing of the individual needs to be a significant concern for the whole team.

Requirements

The psychosocial needs and challenges faced by thalassaemia patients at different stages of life should be prioritised, to provide comprehensive and effective care. Psychological support should be available to address a variety of challenges associated with thalassaemia including, but not limited to, adjustment difficulties, poor self-esteem, low mood, health anxieties, needle phobia, treatment compliance, school and work difficulties, relationship problems and cultural issues.

Comprehensive care requires a multidisciplinary biopsychosocial team approach and regular multidisciplinary meetings.

A clinical psychologist should be an embedded member of the multidisciplinary team.

All specialist staff should be aware of the importance of psychosocial issues in providing care for people with thalassaemia and should have access to training, support, consultation or supervision from a psychologist with a special interest in thalassaemia.

Patients should have access to specialist psychology services; they should have the opportunity to self-refer and, where there are people from within the same family using the service, patients should be able to seek support from another clinician if requested. The opportunity for individual, couple and family sessions should be available.

40 2016 Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK, 3rd Edition

Where psychological difficulties are suspected, a referral to a clinical psychologist should first be discussed and agreed with the patient.

Psychology assessments and reviews should include an overview of psychological and social aspects of the individual including details of their development, life stage, mental health history, family, relationships, schooling, employment, understanding of thalassaemia, coping skills, health beliefs and issues of self-esteem and identity.

Diagnosis of a child with thalassaemia is a challenging time for families and appropriate support should be available to enable the family to discuss the diagnosis, management and overall psychosocial impact on the child and family.

Paediatric services should utilise a developmental framework and have regular multidisciplinary reviews of all children within the service. Reviews should take place at key developmental milestones and after important medical, life or family events.

If cognitive or developmental problems are suspected, a referral should be made to clinical psychology for an initial assessment and a further referral made, if necessary, on to a specialist neuropsychologist.

Transition from paediatric to the adult care is stressful for young adults and their families, and it is important to provide psychosocial support to ensure that optimal care continues throughout adult life. Paediatric and adult centres should collaborate to ease transition using a standardised process to ensure that the proper steps are taken to equip and prepare the young person. Transition should not take place during a time of acute illness or another period of stress.

Where serious mental health difficulties or psychiatric problems are identified, referral to a secondary child or adult mental health service should be considered and, if possible, discussed with the team psychologist in a timely fashion.

If issues of safeguarding or child protection arise in regard to the safety of a child or an adult during the course of clinical care (whether the person at risk is the patient of the service or not), staff should promptly seek guidance by referring to their local safeguarding and child protection policies and guidelines, and by discussing directly with their organisation's Safeguarding Lead.

All specialist staff should be aware of the importance of cultural influences on health and have access to training in cross-cultural work. Access to professional interpreters should be available and staff should be experienced in working with interpreters.

Information should be made available in a variety of formats, including verbal and written. Information given verbally should be adequately documented and written information should be provided in the patient's preferred language. Information should be age appropriate and given at repeated points during the course of the condition and at times when changes in treatment or in the course of the condition occur.

Recommendations

•Best practice should include a multidisciplinary assessment of all new patients and regular psychosocial review and discussion of all patients.

•Specialist psychological support should be made available at critical milestones in patients' lives including initial diagnosis, first transfusion, start of chelation, puberty, transition to adult care, and other major life events such as university, first employment, marriage, pregnancy, and parenthood.

•The opportunity for patients to meet one another at specialist facilitated support groups within the service should be provided as a standard part of care and on an ongoing basis.

•To promote adherence, recommended treatments should take into account the patient's developmental level, family structure, cultural ideas around illness and treatment, social context and life demands. The constraints imposed by treatment should also be considered and wherever possible some flexibility incorporated to accommodate any minor difficulties and issues. Patients should, whenever possible, be involved fully in decisions and details about treatment regimes. Changes in treatment should always be discussed fully, and the rationale

and reasons for any changes made clear. Information about treatment options, including the relative benefits or disadvantages and the potential consequences of non-adherence to should be made available to patients. Patients should also be involved in monitoring their progress, for example ferritin levels, and the results of imaging tests quantifying tissue iron, so that their understanding of the impact of adherence and non-adherence is enhanced. More regular reviews can prove helpful in initially establishing a routine for a new treatment regime.

•Planning for transition from paediatric to adult care settings should start several years in advance, educating the adolescent about the biological, medical, and psychosocial aspects of thalassaemia, and equipping him/her with the skills to become responsible and independent in caring for his/her health. To ease transition and reduce anxiety, the process works best if individualised to take into account the developmental stage and readiness of the patient and family to take on new responsibilities. Following transition, adult patients should be followed up routinely to ensure that they are receiving optimal care and appropriate psychosocial support.

Standard annual reviews of patients should include a measure of emotional wellbeing to monitor psychosocial well-being among patients in order to identify any difficulties pro-actively, providing prompt psychological assessment and early support and treatment, if necessary.

•Wherever possible when breaking bad news the patient's support networks should be included. Staff should remain aware of the significant impact bad news can have on patients, and should be prepared for a range of emotional responses from the patient including anger, denial, shock or distress. Staff should be trained and supported in breaking bad news. They should be prepared to offer support in accepting losses associated with the bad news and in fostering realistic hope. Giving false promises should be avoided. Staff should remain alert to the possibility of depression in response to bad news, and the impact low mood can have on motivation to adhere to medical regimes. Where appropriate, support from or referral to the psychologist should be considered.

42