

Delivering psychological services for children and young people with physical health needs and their families

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Summary:

Good psychological services for children and young people with physical health needs and their families will:

- *Demonstrate the delivery of psychological interventions at different levels to improve patient resilience, prevent psychological difficulties, treat complex psychological issues and provide a cost effective service.*
- *Deliver hospital and community teaching, develop information resources and patient pathways, attend work/steering groups and multi-disciplinary team meetings, and provide consultation, supervision and targeted services to staff; plus highly specialist psychological assessments and interventions with CYPF.*
- *Demonstrate a non-stigmatising, collaborative approach, prioritising children, young people and families' goals for intervention, encouraging feedback and working in partnership with Child and Adolescent Mental Health and Community Paediatric Services.*
- *Demonstrate good governance of psychological treatments provided by psychology and non-psychology staff including CNSs, counsellors, hospital play specialists and community health teams.*
- *Implement goal-based outcomes for interventions with CYPF and staff and evaluate consultation, supervision and teaching.*
- *Be proactive in learning from referrals and the involvement of service users both in developing policies and implementing changes to the wider service.*
- *Anticipate vulnerabilities and deliver preventative interventions, for example, group work.*
- *Provide value for money, with a mix of grades, and a range of skills, stratifying referral complexity and making use (through supervision) of the skills of other professionals.*
- *Play a central collaborative role in research and audit.*
- *Work closely with commissioners of physical health services and psychology colleagues at national, regional and local levels to develop care standards and integrated care pathways.*

Introduction

Paediatric psychology is a field of research and practice that considers a wide variety of factors in the relationship between the psychological and physical wellbeing of children and young people (C&YP). This includes the behavioural and emotional impact of disease, illness and acute physical trauma on C&YP, their families, and the staff who care for them.

Between 10 and 30 per cent of children and young people in the UK have a chronic illness or physical health need (Kush & Campo, 1998) and 10 per cent of all young people under 19 are admitted to hospital every year (DoH, 2000). 'Families facing serious paediatric illness are essentially ordinary families facing extraordinary stressors' (Kazak, 1997). However, Children, Young People and their Families (CYPF) with health conditions experience four times more psychological distress than their healthy peers (Hysing et al., 2007). This increases the risk of developing psychological and behavioural difficulties which impact on their emotional, social and educational development; and future occupational opportunities (Glazebrook et

al., 2003; Meltzer et al., 2000). This vulnerability increases if the child's brain or central nervous system is involved.

The long-term process of adjusting to and coping with a medical condition, managing its demands and treatment, coping with setbacks and changes in health status, and navigating complex medical systems is a challenge. Each child and young person and their family reacts differently depending on their experience of health and health care systems, personality, relationships, social and family support, cultural factors, religious and spiritual beliefs and coping styles. Other issues such as financial worries, including poverty and debt, and the demands of treatment such as medicines, procedures and special dietary needs, frequent hospital visits or admissions, involving family disruption, days off work and school, and additional child care arrangements for siblings, can be an added burden. For this reason parental adjustment and coping, from acute distress to parental mental health difficulties, need to be identified and addressed as they can have a significant impact on children's ability to cope.

This group of children are a diverse and often disadvantaged and stigmatised population. Their condition can interfere with their access to education and in maintaining friendships. Having a different diet, doing self-care such as blood monitoring or catheterising, looking 'different', and having mobility problems can lead to further social exclusion, lower self-esteem and, often, bullying. Many children with long-term health conditions have developmental or learning difficulties, either in addition to (e.g. an autistic spectrum disorder) or associated with (e.g. Down's syndrome, Di George Syndrome) their health needs. Sometimes the stigma and bullying extends to siblings, who can experience high levels of behavioural and emotional distress.

*'When my sister got it I was really scared
'cos the Doctors said you can die from cancer.'*

As with all children and families, there are many factors which either help develop resilience or increase vulnerability. Recognising the uniqueness and the strengths of CYPF and intervening early, in relation to vulnerabilities, maximises both physical and emotional wellbeing and enables C&YP to achieve their full potential.

Medical diagnosis is not always straightforward and physical symptoms can be accompanied by and/or exacerbated by psychological reactions. Children and young people with 'Medically Unexplained Symptoms' (MUS), for example, pain syndromes or chronic fatigue, often have associated causative or maintaining psychological factors. These youngsters often see multiple medical teams, have unnecessary investigations and, in some cases, even surgery in the search for a diagnosis. A well co-ordinated, psychologically informed care pathway reduces unnecessary use of resources, worry and potential harm. Presenting an acceptable alternative formulation or 'diagnosis' that illustrates the interaction between psychological factors and physical experience, to the CYPF, can lead to some resolution of the difficulties and facilitate return to normal life.

Another group who benefit from a psychological service are those admitted to hospital following acute illness or physical trauma. They include C&YP with encephalitis or meningitis; severe burn injuries or road traffic accidents; or those admitted to neonatal or intensive care units and whose survival is precarious. The threat of an infant not surviving can interfere with bonding. One-third of children (and their parents) admitted to paediatric intensive care (PICU) have symptoms of Post-Traumatic Stress Disorder (PTSD) after discharge and one-in-10 go on to develop clinically significant PTSD (Colville, 2008; Lewis et al., 2014).

Psychological interventions to reduce distress and increase coping help CYPF make sense of their experiences and can significantly reduce the risk of trauma from PICU admission or surgical treatment (Kazak et al., 2006).

With advances in medical science, many more young people with chronic and/or life threatening conditions (e.g. Childhood Cancers, Cystic Fibrosis, End Stage Renal Failure and Complex Cardiac Conditions) are now surviving into adulthood. If the psychological needs of this population, and those who care for them, are not identified and treated, they can exacerbate medical symptoms and problems that persist into adulthood. For example, high levels of anxiety and/or low mood influences adherence to treatment (Gray et al., 2012). This leads to worsening of the illness or condition in the short and sometimes longer-term, increased hospital visits, reduced independence, further anxiety, low mood and learned helplessness.

Sadly, despite the increasing numbers of C&YP surviving, many will require palliative care. Attending to the psychological needs of the C&YP and their families can help achieve a 'good death' and for bereavement to be a little more bearable.

Health care staff, including doctors and nurses, and those in the wider MDT such as physiotherapists, dieticians, speech therapists and hospital social workers, all have a role in delivering psychosocial care. Through joint-working, consultation, supervision and teaching by clinical psychologists, staff benefit from time to reflect on and make sense of a C&YP's or family's presentation. This also helps staff to reflect on their own beliefs, attitudes, behaviours and emotional wellbeing and how these impact on their work with CYP&F's, helping them to deliver more compassionate, patient-centred care (European Association for Children in Hospital; EACH Charter).

In the paediatric services described below, the knowledge and skills of the clinical psychologists, embedded in medical multi-disciplinary teams, not only facilitates access to highly specialist intervention and indirect delivery of psychological interventions through the MDT, it also enables system-wide prevention, early identification and remediation of difficulties in a non-stigmatising setting.

Depending upon the complexity, severity and rarity of the CYP's condition, some CYP will be cared for solely in a specialist tertiary hospital, some in a District General Hospital and many will have shared care between both of these and/or community paediatrics. In order to ensure that all CYP with physical health needs have access to a timely and holistic service, it is important that the psychological service model facilitates the integration of physical and psychological need, as well as hospital and community care.

Many of NHS England’s service specification documents advising commissioners about specific medical specialties recommend that a clinical psychologist (with specialist training in paediatrics or clinical health psychology) is central and embedded in the MDT. In Scotland the National Delivery Plan (2009) highlighted that psychological services should be an integral part of children’s medical health care. Various condition-specific guidelines have gone further and specified the level of psychological care recommended to meet patient need, for example, BPS (2013) and PPN (2008). For the past 30 years, in most of the large paediatric centres in the UK, and some in the community linked to local hospitals, clinical psychologists have developed successful, evidence-based and effective services in this way. Significant gains, including financial, can be achieved by co-locating psychological and physical health services (King’s Fund, 2012). However, there continues to be considerable disparity in service provision across the UK. Opportunities exist for imaginative new models with integrated pathways between tertiary, DGH and community services.

Intervening at different levels

Figure 1 (below) illustrates a whole systems approach to service provision. The inner semi-circle demonstrates what is provided and the outer semi-circle to whom. A comprehensive psychological service aims to utilise expertise to enhance the quality of experience of all CYPFs, and improve the psychological competence of staff and provide governance for psychological interventions delivered by non-psychology staff. It should also educate and skill up front line staff across agencies

and along the whole patient pathway, by providing training, consultation and psycho-education. Finally for the minority of CYPF’s who require highly specialist psychological intervention, this should be easily accessible to CYP and their families and delivered in a timely fashion. The service CYP receive should be flexible and adaptive. Each element of this model is discussed below.

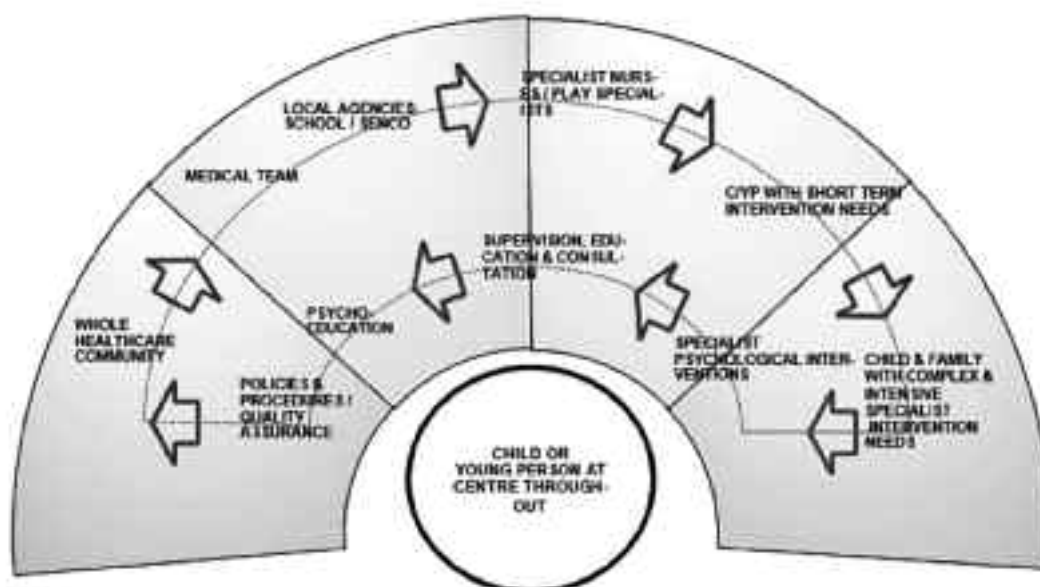
Care pathways

For psychological provision to be effective, care pathways should address a CYPF’s psychological needs across the entire journey, between medical specialties, from hospital to community, and all involved agencies. Good communication, joint working and regular liaison between professionals, and between families and professionals, is one of the key components of best practice identified by a variety of charities representing children and families, for example, in Action for Sick Children’s Charter.

Whole systems approach

Repeated hospitalisation and invasive procedures put CYP at increased risk of developing procedural anxiety and post-traumatic symptoms (National Child Traumatic Stress Network, 2005). Putting psychological wellbeing at the heart of CYP services can ensure that harm is reduced and improve CYP’s experiences of health care, which will, in turn, influence their interactions with health services in the future (Doyle, 2013). A positive experience of treatment and care is rightly viewed as an important health outcome in itself (Evans, 2014).

Figure 1: Psychological Services Model (Griggs & Mercer, 2015).



Prevention and support, online and community resources

CYPF routinely seek information from the **internet**. It is important that this is of high quality. Clinical psychologists can and do contribute to the development of accessible **psycho-education**, for example, 'MindEd', a universally available e-learning portal. Clinical psychologists also contribute information to online support groups for specific conditions, organised by parents and young people or condition-specific charities, which can be particularly useful for CYP with rare conditions.

The use of **technology-based therapy interventions** has increased in popularity with both internet and telephone-based interventions (Chi & Demeris, 2014). Innovative practice includes: a home-based behavioural health intervention for managing adherence in Type 1 Diabetes (Adkins, 2006); computerised CBT for chronic pain (Velleman et al., 2010); and the Hospital Passport Coping Kit rolled out nationally across Scotland. The latter, soon to be available as an app, teaches CYPF and staff psychological strategies to reduce hospital and procedure related anxiety, improve communication and involve them more effectively in decision making.

CYPF meet multiple professionals in both community (e.g. GPs, Health Visitors and School Nurses) and hospital settings (Physicians, Surgeons, Physiotherapists, Orthodontists, Hospital Play Specialists and Nurses). All professionals have a role to play in maximising psychological wellbeing, and providing compassionate care. All professions' core training should, therefore, include education about psychological issues, including developmental theory and how to identify both resilience and vulnerability factors.

Supervision and consultation: A clinical psychologist can support front line clinicians in their role, and enable them to safely use psychosocial strategies for managing common difficulties such as adherence and procedural distress, improving overall patient centred care (e.g. Child in Mind, 2002; NHS Education for Scotland, 2010).

'Psycho-social' meetings: The aim of a psycho-social meeting is to formulate the CYPF's presenting difficulties, co-ordinate and evaluate interventions and manage risk. Psychologists help the MDT to consider a wide range of psychological, social, emotional, cognitive, developmental and systemic factors and generate hypotheses to plan and test out different ways of working with the child and family. Sometimes the presenting concern is about difficulties in the communication or relationship between CYPF and the staff team and the psychologist will then use the formulation to facilitate a resolution and help everyone to move forward.

Staff wellbeing and stress has been directly linked with families' experience of care, staff sickness and absence, and retention of staff (Care Quality Commis-

sion (CQC), NHS Employers, 2009). Staff who are confronted with issues of life and death, reduced quality of life, and children in pain and distress are at risk of feeling burned out and disempowered, and working with emotionally overwhelmed families and stressed colleagues can diminish the professional's own capacity to cope (Gehring et al., 2002). The importance of staff support and training for coping with stress is well established (Board & Ryan-Wenger, 2000) and both doctors and nurses view multi-disciplinary team supervision from psycho-social colleagues as essential in coping (Gehring et al., 2002). The importance of creating a caring culture is reported by Berwick (2014). The consequences of not doing so are tragically illustrated by Francis (2013).

Promoting good psychological care as part of Trusts' policies, procedures and pathways enhances the CYPF's experience, governance and helps the organisation to meet CQC standards. For example, embedding evidence-based and developmentally appropriate approaches to consent to treatment, managing distressing behaviour, procedural anxiety and preparation for surgery. Some national multi-disciplinary pathways require psychological and/or cognitive assessment at key points; for example, pre-transplant (kidney, heart and liver), pre-surgery for epilepsy or Bone Marrow Transplant.

Development of a coherent policy and practice in the **process of transition to adult services** is crucial. The best timing for transition depends on the course and phase of a YP's condition, their psychological, social and cultural uniqueness and their preparedness in terms of level of dependence and motivation. There are particular challenges for YP including a need to understand their condition and treatment and to develop skills in managing complex medical regimes and consultations without their parents. YP also need to co-ordinate their own care, which might involve multiple medical teams in multiple settings. They also have normal developmental tasks and transitions such as going to college, university or starting work. These all occur in the context of what is a particularly challenging period of adolescent brain development, emotional responses to leaving long established relationships with their paediatric team and developing a relationship with both their GP as their care co-ordinator and the adult medical team(s).

'I wish someone had advised me to get to know my GP before I moved to the adult hospital.'

Targeted help: prevention and support

Screening for vulnerability: Many specialties (e.g. Diabetes, Asthma, and Cystic Fibrosis) annually review the children in their care on standardised measures to

identify and remediate early difficulties. Providing holistic care including psycho-social interventions is central to the SIGN guidelines for both diabetes (2010) and asthma (2011). Often this screening and early intervention is provided by health professionals under the supervision of the clinical psychologist.

Anticipating vulnerability: CYP who have experienced brain trauma, for example, due to accidents, tumours or lack of oxygen, are at risk of falling behind at school and struggling with peer relationships. Cognitive assessment can help identify and remediate cognitive deficits by ensuring that schools have the information to support learning and reduce the potential negative impact on a CYP's education and quality of life. Anticipating additional functional vulnerability can be done by the whole team through psychosocial meetings that identify problems in coping, parenting stress, sibling distress and so on.

Admission to PICU or surgical treatment are potential stressors for the whole family. Timely psychological interventions help CYPF make sense of their experiences and can significantly reduce the risk of trauma (Kazak et al., 2006). The NICE guidelines on PTSD (NICE, 2005) recommend screening those at risk of PTSD one month after their experiences. These CYP may not meet criteria for mental health services until the problem becomes more entrenched and intractable.

'Jason' is a 3-year-old boy who was attacked by a guard dog on his grandparents' farm. His grandmother managed to get the dog away from him, but Jason had extensive and serious bite injuries to both legs and arms and needed skin grafts. Jason needed to stay in hospital for at least three weeks. The role for psychology was initially to provide information for all concerned, including the treating team, about what should be expected as a 'normal' reaction to trauma for a 3-year-old child, and also to consider the trauma to his grandmother. Further work was planned to meet with the family to facilitate the adults to express guilt, anger, and anxieties about what had happened, and to address how to repair and restore their previously good relationships. Information about building an account of the incident that is honest and age-appropriate was provided for Jason, which could be developed over time as his understanding progressed. Individual work with Jason was arranged to help him to cope with the immediate emotional impact of his scars. This work took three sessions, with feedback from staff that the boy and family were more settled and ward staff found it easier to give treatment and so were less stressed.

Many expectant parents are aware that their child will be born with a specific genetic syndrome or some form of disability. Some only become aware at birth. A number of these babies' lives are perilous and they will need surgery and/or neonatal intensive care. Early psycho-social interventions can facilitate bonding and parent-child interaction, thus influencing infant brain development and reducing stress (McCusker et al., 2007). Opportunities for parents and siblings to make sense of their experiences and express complex or negative emotions can reduce the long-term traumatic impact of these events and improve adjustment to bereavement.

Finally, there are increasing numbers of CYP with Medically Unexplained Symptoms. By working closely with the medical team, a psychological assessment can help staff and CYPF to develop an alternative narrative for symptoms, drawing on a bio-psycho-social model. This serves not only to reduce unnecessary further testing but also introduces the idea that psychological factors play a role in maintaining their symptoms, thereby helping the CYPF gain control and return to normal functioning.

'Stefan' is a 14-year-old with Ehlers-Danlos Syndrome, which affects connective tissues and some organs. During one year, he presented 61 times to A&E with partial dislocations, and tens of times to each of the medical specialties whose care he was under. He was referred to a paediatric clinical psychologist who helped him make sense of when the dislocations occurred, what factors in his early experience and current situation played a part in his presentation, and to develop coping skills. Within four sessions he was back at school full time; six months on he had no further admissions to A&E.

Specialist help for highly complex needs

Timely access to specialist intervention: When clinical psychologists are embedded in, or closely linked to, the medical MDT a '**whole systems approach**' can be developed, providing preventative interventions and improving access through timely assessment and intervention on the ward or in clinic. Moreover, embedding a psychologist in the team reduces any stigma associated with accessing support. Presenting problems can be understood as a normal response to CYP's experience, treatment or condition and the whole team can support a therapeutic intervention.

There is a rapidly growing evidence base for the efficiency and effectiveness of psychological interventions in paediatric populations such as Cognitive Behavioural Therapy (CBT), Motivational Interviewing, Family Therapy, and Acceptance and Commitment Therapy

(BPS, 2009; NHS Education for Scotland, 2012, 2015; Spirito & Kazak, 2006, and <http://www.societyofpediatricpsychology.org/evidence>). Their impact can also save money across the local, regional and national health services by addressing adherence issues, reducing demands on services (for example, when CYPF are anxious about their condition or where anxiety symptoms mimic or exacerbate medical symptoms) and reducing the need for unnecessary treatment or investigations. Furthermore, NICE promote a number of therapies for the treatment of anxiety, depression, behavioural difficulties and PTSD, all of which can co-occur with long term conditions or hospitalisation. These interventions include CBT, Parent Training and Systemic Therapy. Although much of the research is with physically healthy populations, these interventions also have utility and efficacy in paediatric settings (Fonagy, 2015).

'Amina' is 16-years-old with multiple Arteriovenous Malformations (AVMs) problems with blood flow. She has a 10-year history of increasing social anxiety and social isolation. Amina has a distinctive appearance and needs to manage curious questions and teasing from others, in addition to comments about her religion and culture. She has missed school due to multiple surgical procedures and so has had limited opportunities to socialise. Her family is socially isolated within their community. Amina now doesn't recognise faces (prosopagnosia) and her surgeon needs to check for cerebral AVM. Prosopagnosia is also likely to contribute to social anxiety. If cerebral AVM is diagnosed then this may have implications for life expectancy and/or deteriorating neuropsychological function. A culturally sensitive assessment, including neuropsychology, and psychological intervention, was required in order to develop a psychological formulation to point to an intervention plan.

Assessment of risk; for example, a young person with diabetes can self-harm by manipulating their insulin, resulting in frequent hospitalisation and intensive care. A child undergoing potentially life-saving, but painful treatment with multiple side effects might (understandably) refuse treatment.

'Paula', aged 15, has Leukaemia; her parents are divorced and argue constantly. Paula's 13-year-old sister has started to self-harm. Paula won't get out of the car at the hospital, refusing chemotherapy. The Oncologist wants to sedate her and is talking to legal services.

A referral is made to clinical psychology to assess the situation, provide a holistic formulation and make recommendations about interventions. A treatment package is designed which can both assist the treating team with their care plan and also support the family to improve their communication and relationships, develop parenting strategies to keep the girls safe, provide positive coping strategies for managing procedural distress, and help Paula to explore her feelings and choices.

Providing containment at times of great anguish also forms part of the specialist inter-vention for the most distressed and vulnerable CYP and families, and supports front line staff in their role. When a child or YP's life is threatened it is important to take account of the very personal, potentially religious, existential and spiritual aspects of the despair and anguish this engenders. The focus here is in 'being with' rather than 'doing to' and takes a very skilled practitioner. Through modelling, teaching and consultation, this knowledge and skill can be disseminated to the wider staff team, who can support CYPF and triage more complex presentations.

Core components of a psychological approach

One of the crucial over-riding principles is taking a '**whole child and whole family approach**', and patient-centred approach (*Future in Mind*, 2014; Healthcare Quality Strategy for NHS Scotland, 2010; Getting It Right For Every Child (GIRFEC), 2009). Children and young people with a long-term condition are children first, with their own unique interests, needs, hopes and aspirations.

Assessment

In the physical health settings, a thorough assessment takes into account bio-psycho-social and treatment factors in the development and maintenance of the presenting problem and explores strengths, motivation and coping strategies in both the individual CYP and their family. For example:

Parenting and family factors – parenting capacity and style, plus inter-generational attachment issues. Nature of the family; for example, two parent household, single parent, step-family with shared care of the child, and foster or adoptive parents, availability of extended family members for support, and the quality of relationships.

Social factors – the child and family’s culture, religion, spiritual beliefs, economic situation, school, college and work context, extended family and neighbourhood support. Sexuality factors are also considered if relevant.

Psychological factors – CYPF’s previous experiences of hospital and illness, levels of stress/distress, anxiety, low mood, ability to tolerate change and ambiguity, cope with setbacks, their health beliefs and attitudes, coping strategies, locus of control, ability to articulate/assert concerns, and developmental stage of child and family. The young person’s and parents’ level of understanding (and wish to know or not) about their condition and prognosis.

Biological factors – impact of the illness on the child’s mobility and independent living skills, and/or cognitive functioning; the physical and mental health of other family members.

Condition-related factors – prognosis and predicted course (e.g. progressive loss of mobility), nature of treatment which could be painful and traumatic, anticipated surgery, and frequent hospitalisations, complex medical regimens.

Wider system factors – for example, relationships with medical team, experience of communication and mutual understanding across professional networks including health, education and social care.

The assessment can include the use of standardised questionnaires such as anxiety or self-esteem scales. It can also involve a neuropsychological/cognitive assessment to determine whether a child or young person’s presentation or behaviour is due to impaired function in systems such as attention, memory, perception or impulse control.

Formulation

Taking a holistic view as described above and carefully listening to the uniqueness of the child and family can in itself be therapeutic and allows everyone to take stock in a context which often only focuses on the latest physical symptom. Collaboratively considering these interacting factors leads to a shared psychological formulation of the difficulties, which draws on psychological theory and research and provides a number of hypotheses and treatment options. These can be shared with the MDT, where appropriate, to promote a shared understanding and intervention. Making sense of the interplay between psychological and physical wellbeing normalises the experience and gives CYPF a sense of control over the condition. The hypotheses proposed can be tested and a reformulation of the difficulties are shared as situations change and develop.

Within agreed boundaries of confidentiality, this coherent psychological explanation can: help the CYPF

feel understood and contained; encourage collaborative work and consistent team approaches; challenge unfounded beliefs; reduce negative staff perceptions; and minimise disagreement and blame within and between teams, thus increasing understanding, empathy and reflection.

‘No one has ever understood me before... (crying).

I can see there are reasons why I feel the way I do and why I’m so afraid, I’m not crazy.’

A young woman’s experience of a formulation.

Psychological formulations offer coherent psychological explanations of the presenting difficulties, in multiple contexts. Rather than reducing a person’s experience to a category, or diagnosis, a psychological formulation functions to communicate the complexity of their difficulties in an understandable way (Mason, 2014).

Intervention and treatment plans

One of the biggest challenges for practitioners working in medical settings is that, due to time constraints (a clinic visit or inpatient stay), they may have to assess, formulate and treat a presenting difficulty within a single session. It takes a very skilled and experienced practitioner to do this competently.

Responding to fear and anguish

Attending to the often existential/spiritual aspects of life threatening illnesses or physical trauma is a key element. The profound fear, anguish and guilt of all family members needs to be acknowledged in a contained way. There are a number of potentially helpful models, including: Acceptance and Commitment Therapy (ACT), Mentalisation, Compassionate Mindfulness and psychodynamically informed psychotherapy. Being trained to work across the life span is crucial, in order that parental distress and despair can be given a voice within a family based approach. Staff responses to the CYPF’s distress need to be processed to facilitate compassionate care.

‘Some people’s lives are long novels. My child’s life is a short story with just as much meaning.’

Responding to emotional disturbance

Psychological interventions to support young people live with their condition or potentially disfiguring trauma is important to prevent additional distress or disability. Regardless of which medical speciality they inhabit, the emotional and psychological response is similar (Fonagy et al., 2015) and there is good evidence that psychological treatments are effective.

'Alice', aged 13, has idiopathic chronic pain syndrome, frequently attends her GP, paediatrician and local A&E. There is no medical treatment for her disability. She has stopped going to school, has limited mobility, disrupted sleep, panic attacks and low mood. Her mother has given up work to look after her and the whole family has adapted to her disability.

The intervention helped Alice learn psychological methods to tolerate her pain, and recognise psychosocial triggers which intensified her pain experience. Anxiety management and self-hypnosis resulted in better sleep, and liaising with her school facilitated her return, initially on a part-time basis.

With additional training and ongoing supervision from the psychological service, **front line staff** (e.g. Nurse Specialists, Physiotherapists and Play Specialists) can deliver some psychological interventions based on Cognitive Behaviour Therapy (CBT) and basic counselling. These approaches include: problem solving, goal planning, anxiety management techniques, psycho-education and good listening skills. Gaining psychological knowledge enhances staff roles and promotes ongoing positive relationships with their patients. These professionals are often best placed to deliver an intervention.

'Michael', aged 6, has recently been diagnosed with an aggressive form of Juvenile Arthritis requiring weekly Methotrexate injections and monthly blood tests. Every time, it takes over two hours for him to have his injections. Michael is frightened. He screams and struggles. His mother becomes upset and tearful while his father gets angry. The Play Specialist requests a consultation from psychology. Following detailed observation of the process, the psychologist advised Michael, his parents and staff on how to approach the procedure to minimise anxiety and trauma. Michael left proudly with his bravery sticker and his parents left feeling more confident.

Embedding and co-locating psychological services within the medical/surgical MDT is recommended in a growing number of NHS England service specifications. Working together facilitates indirect psychological interventions as described above, ensures appropriate governance of psychological treatments and enables triaging of referrals for complex psychological interventions, ensuring efficient and effective use of psychological resources.

Responding to neurological changes

It is important to recognise that neurological changes (caused by, for example, RTA, smoke inhalation, chemotherapy, tumours, multiple surgery, acute illness and progressive neurological conditions) can impact on cognitive ability, personality and behaviour. The effects may develop over time and long-term follow-up is often required. Neuro-psychological (psychometric) assessments, alongside full psychological investigation, can assist the child, family and school to identify significant changes due to neurological impairment. Psychologically informed interventions can be developed to include both the family and school, aimed at improving function to help the CYP achieve their full potential. With an individual learning programme at school and psychological support at home the CYP's experience can be positive.

'Now I understand my child's memory problems and how to help him. I don't blame him or myself for some of his behaviour; it's to do with brain injury... he still needs boundaries though.'

Some specialist centres are developing pathways to address this need. However, lack of resources often means that these vulnerable children do not receive specialist assessments. Misunderstanding of their presentation at school and at home may negatively impact on their relationships, learning and self-esteem.

Responding to behavioural challenges including parenting and sibling work

Many children (with or without physical health difficulties) communicate their distress through their behaviour. Families and parents may find it hard to be consistent with a child with physical health needs or who is potentially dying. Acknowledging parental fear and worry as well as encouraging consistency, boundaries, and routine is important. NICE guidelines refer to various parenting programmes which, if adapted for this setting, can provide guidance. Given the unpredictable nature of chronic conditions, it is unlikely that parents will attend weekly groups so interventions need to be adapted to their needs. Work with individual parents, couples and the extended family can help develop both a consistent and caring approach to managing behaviour.

CYP's distressing or disruptive behaviour on the ward can put themselves or others at risk, for example, pulling at their central line or hitting out at staff. Managing this behaviour needs to be informed by a psychological formulation of the difficulty, so that the CYP is helped to express their desperation in more adaptive ways, and a defined group of key staff along with parents can agree and provide a consistent approach.

Brothers and sisters are often separated from one or both parents for periods of time, while their sick sibling is in hospital. Research indicates that they are often very distressed, experiencing feelings of loss, frustration, anxiety, post-traumatic stress and jealousy. The experience can also have a maturing effect and siblings are sometimes rated as more pro-social than their peers. Distressed siblings should be offered individual or group work before their difficulties become entrenched.

Risk assessment and self-harm

Sometimes distress becomes overwhelming, either relating to the enduring demands of the condition, or associated experiences such as bullying or social exclusion. The young person might self-harm using their condition as a vehicle, for example, manipulating insulin in diabetes, or not adhering to dietary restrictions in renal disease. Risk assessment and psychological formulation informs the intervention with the individual young person, family, medical team and school. This can reduce psychological distress and prevent potentially serious physical consequences of non-adherence and self-harm. A good psychological service will work jointly with the wider mental health system to provide continuity for the CYPF and manage risk where there is a psychiatric presentation in the CYP or parent.

Enhancing complex decision making

Often difficult complex decisions are necessary, for example, potentially life-saving but risky surgery. A psychological approach is crucial, taking account of the child's developmental stage and level of understanding, the parents' perspective and working alongside medical staff; considering all perspectives to ensure agreement with the decision whatever the outcome. Medical staff can benefit from a confidential space to explore their thoughts and feelings formally or informally. Being able to 'off-load' to an experienced clinical psychologist promotes resilience and the medical leader remains resilient, which impacts on the whole team.

For children on long-term pathways (e.g. Cleft palate repair), the psychologist often facilitates discussions with young people about whether they want further elective surgery. This can involve systemic (family therapy) approaches to managing differences of opinion between parents, the medical team and the YP.

Responding to adult mental health

Children look to their parents to gauge their emotional response and contain their own feelings. It is important, therefore, that psychological care extends to parents experiencing clinically significant levels of anxiety and low mood, including PTSD symptoms. Psycho-socially skilled services anticipate this and

provide information and reassurance. If symptoms emerge, psychological treatments address the symptoms and improve coping, thereby improving family wellbeing and long term mental health.

'My daughter has always been a bit shy and awkward, and a bit of a worrier, so I was worried when my grandson became ill that she wouldn't cope. It's good she has support too.'

Ensuring continuation of psychological care

While many tertiary/specialist hospitals have well established paediatric psychology services, follow-up care to maintain progress can be challenging for those CYPF living some distance from the specialist centre. It is important, therefore, to ensure their psychological care continues, either provided by locally-based community or DGH services and/or from the tertiary hospital using telephone calls and video conferencing. There are also internet-based approaches referred to earlier.

Schools are crucial in the wellbeing of children. It is now a legal requirement for schools to support children with medical conditions, both physically and psychologically (Supporting Pupils at School with Medical Conditions, Dept. of Education, 2014; Additional Support for Learning Act Scotland, 2009). Advocacy for the CYP may be necessary to ensure this occurs.

Too often there is no local appropriate psychological service when the child is discharged from, or lives a long way from, a tertiary paediatric centre. Despite national policies and drivers recognising the need for psychological care embedded within physical care ('no health without mental health'), there is disparate and patchy provision of locally-based paediatric psychology services across the UK. This results in **many children and families having no service at all.**

Some of the challenges at local level for this group of CYPF include the increased referral threshold for many CAMHS, not wishing to access a 'mental health' service with its accompanying stigma and mental health record, CAMHS clinic-based mental health clinicians rarely having experience of their medical condition, and a lack of continuity with the CYPs' medical teams.

Outcome monitoring (PROMS PREMS)

A good paediatric psychology service will demonstrate that psychological treatment outcomes are developed in collaboration with the CYPF. These Patient Reported Outcomes take the form of goals, unique to each CYPF and can change over the course of treatment. For some, these may include psychological and behavioural changes such as: being able to understand and tolerate their distress, developing coping strategies for pain management or procedural anxiety, or a more realistic understanding of their condition, and increased

communication within the family. Outcomes may also include concrete changes such as improved blood results for diabetes, fewer hospital admissions or being able to participate more in normal life.

Some goals can be monitored by standardised questionnaires, for example, to evaluate quality of life, self-esteem, anxiety, PTSD symptoms or low mood. These can provide useful feedback to CYPFs as an adjunct to their self-determined goals.

Sometimes the goal might not be to achieve change. For the family the goal could be to talk and be with each other in a developmentally sensitive manner when their child's prognosis is poor and death is imminent.

The CYPF's experience of psychological intervention is crucial and is itself an outcome. Research continues to demonstrate that the therapeutic relationship is key. **Patient Reported Experience Measures (PREMS)** reflect the quality of the experience; and how understood and respected CYPF's felt. In short, was the clinician sufficiently compassionate, qualified and experienced to provide a sense of containment and safety?

'...really helpful service much needed in long-term situations where your life completely changes.' (Mother)

Many services use the **Experience of Service Questionnaire (ESQ)** which has different sections for children, young people and parents. In addition to answering set questions there is an open-ended section for further comment and advice. Feedback helps services improve and adapt.

'I was listened to and she helps me calm down when I'm panicking.' (9-year-old child)

Finally, it is also important to monitor the outcomes of interventions provided by front line staff, and their experience of supervision and consultation.

Helping the whole service work as well as possible

In order to help the whole service work as well as possible a number of key factors are fundamental.

Listening to CYPFs is fundamental to the whole service working well. Feedback about direct therapeutic interventions, as well as from Children's and Parent's forums or councils should inform service policy, development and co-ordination, thereby improving the patient experience. For example, Kennedy (2010) recommended that CYPF should not have to repeat their 'story' and should have better access to co-ordinated pathways and programmes of care with various appointments in the same place, on the same day.

Accountable leadership at a sufficiently senior level (e.g. Consultant Clinical Psychologist) is required to champion psychological care at the highest level across the organisation or network. This leader should be responsible for the governance of a Paediatric Psychology Service of psychological practitioners, providing psychological care embedded within various medical specialties.

Governance systems to support and monitor psychological care provided by front line staff as well as psychologically qualified staff. Recruitment of appropriately qualified practitioners to provide a skills mix across a broad range of competencies ensures quality. For example, Children's Congenital Heart Services Psychology Standards (BPS, 2013).

Research, evaluation and audit: Research, evaluation and audit in health care settings is informed by psychological theory and the evidence base. Collaboration between medical/nursing researchers, patient participation groups and clinical psychologists can further inform service delivery. For example, a psychological service that takes the evidence that CYPF with visible difference experience bullying and teasing could provide proactive groups to help CYP practice social and emotional coping skills, thereby improving adjustment in the longer term.

Evidencing the cost/savings benefit: In addition to the human cost, there is a clear economic argument for good psychological services; psychological intervention in pain management is a helpful example. Pain significantly impacts on quality of life and brings considerable economic cost for both families and health services alike. Slead et al. (2005) calculated the mean treatment cost per adolescent with chronic pain to be £8000, amounting to a national economic burden of adolescent pain of approximately £3840 million in one year! There is a strong evidence base for the effectiveness of psychological therapies in chronic pain (Eccleston et al., 2014; Fisher et al., 2014), either working alongside medical and physiotherapy interventions or, in the case of medically unexplained pain, on its own.

Conclusions

Most tertiary paediatric centres in the UK have long established psychological services departments led by clinical psychologists, integrated into medical or surgical teams. This is often required to achieve specialist centre status (e.g. Oncology) or Best Practice Tariff (e.g. Diabetes or CF). The evidence-based success of these services is no doubt reflected in the growing number of NHS England commissioning documents and Scottish National Strategies that specify clinical psychology as part of a medical/surgical team. However, this does not apply to all medical conditions and has led to a serious inequality in access to psycho-

logical support. A further issue is that there are only a small number of community-based paediatric psychology teams and some services are only provided on a sessional basis by CAMHS psychologists, which means that highly complex, face-to-face psychological interventions are frequently privileged over preventa-

tive work and consultation. Close working with **commissioners** at local and regional levels to develop **integrated services** across hospital and community settings would deliver **efficiencies and significant savings** in the health economy as listed below.

Outcomes of addressing psychological needs.

- **Improved adherence to treatment** = shorter and fewer hospital stays, reduced risk of morbidity and mortality.
- **Individualised preparation for surgery/ medical procedure** = less anxiety, faster recovery and improves patient flow.
- **Psychological pain management** = less anxiety, less reliance on medication, faster recovery, earlier discharge.
- **Identifying cognitive changes** = better understanding, rehabilitation, behaviour management and education plans plus evaluation of the impact of treatment (e.g. brain tumours, radio and/or chemotherapy).
- **Prevention/reduction in PTSD** due to trauma of injury or repeated (necessary) treatment = better long-term mental health for child and parents.
- **Early intervention for very vulnerable families** = improved adherence, improved physical and psychological health and the development of positive health behaviours.
- **Psychological support for complex decision-making** in relation to surgical and medical interventions = CYPF fully participating in their own health treatment.
- **Psychologically trained and supervised MDT** = broad-based psychological interventions, delivered to more families, leading to fewer referrals for complex therapy.
- **Well supported staff** = better able to care, therefore fewer complaints and increased compassionate working practices.

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