Child and adolescent psychotherapy with children and young people in hospitals and their families

Introduction

Child and adolescent psychotherapists working in hospitals are usually based within departments of psychological medicine at the hospital, offering a service in the areas of paediatric and adolescent medicine. Models differ but most usually child psychotherapists work within the medical teams, functioning as an integral part of the multidisciplinary medical specialities. This is termed paediatric liaison. Ideally the psychological services or CAMHS should comprise or include child and adolescent psychiatry, clinical psychology and child and adolescent psychotherapy and family therapy.

Child psychotherapists working in hospitals perform a variety of functions. These include assessing and working with children and young people individually or with parents or other family members to address the emotional impact of the illness on the child and those around them; signposting the needs of the child and family to hospital staff; and supporting the staff who are involved with the patient and their family, including doctors, ward nurses, clinical nurse specialists, physiotherapists, dieticians, speech and language therapists, hospital play specialists and other clinical and support staff.

Children living with long-term physical illness are twice as likely to suffer from emotional or conduct disorders. [1]

[1] Parry-Langdon N (Ed) (2008) three years on: survey of the development and emotional wellbeing of children and young people. Office for National Statistics.

Flexible working

Infants**,** children and young people may be seen on hospital wards, in clinics, accident and emergency, radiotherapy rooms, operating theatres or day care and out-patients departments. The work may be long or short-term. The input of child psychotherapists is highly valued in all aspects of paediatric liaison.

For example, accident and emergency services including deliberate self-harm and acute psychiatric presentations; general paediatric and adolescent medicine including somatising illness; chronic conditions such as asthma, dermatology, rheumatology, diabetes, HIV, Sickle Cell Disorder; Thalassaemia, Crohns disease, endocrine and urology problems; surgery; neonates; children's and young people's cancer, including radiotherapy; and intensive care. In some hospitals a child psychotherapist may be employed to provide dedicated input into a specific medical service, for example a paediatric chronic pain clinic or a paediatric burns unit.

"I never thought the sessions could help but they did. It makes you realise that other things affect you as well as the physical things that you need to address as well."

Young person seen in hospital

As well as working with the emotional impact of serious or longstanding illness, child psychotherapists are well positioned within paediatric liaison settings to address the emotional context of an illness and sometimes somatising or psychosomatic presentation. There is considerable overlap between children with medically unexplained symptoms and long-term conditions, with both being significant risk factors for chronic mental and physical ill health in adulthood.[2] In addition, approximately 10 per cent of children and young people frequently experience somatic symptoms not fully explained by medical assessments yet which cause significant impairment.[3] The need for psychological support for children and families in this area has been well recognised within the National Service Framework:

"CAMHS Paediatric Liaison (CAMHS-PL) is concerned with providing a bridge between acute paediatrics and psychiatric and psychosocial care. This is an essential service for the ill child, siblings, parents and carers in cases where the presenting illness has a psychological component, or where psychological distress is caused as a result of the illness. Too often CAMHS-PL have insecure funding, with no local champions and are therefore vulnerable. However in London for example, virtually all CAMHS offer some out-patient referral, consultation and emergency service to their local paediatric service, though not necessarily a dedicated PL service."[4]

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[2] Ben-Shlomo Y, Kuh D. (2002) A life course approach to chronic disease epidemiology: conceptual models, empirical challenges and interdisciplinary perspectives. *Int J Epidemiology 31:285-93*

[3] Garralda ME (2010) 'Unexplained physical symptoms' in Trivedi HK (ed) *Child and Adolescent Psychiatric Clinics of North America* 19, 199–209

[4] Promoting the Mental Health and Psychological Well-being of Children and Young People. Report on the Implementation of Standard 9 of the National Service Framework for Children, Young People and Maternity Services. Department of Health/DfES 2006

Case example:
A 15-month-old child was referred as he could not swallow solid foods despite extensive tests that showed no physical reason for this difficulty. The child psychotherapist met the mother and child and they talked about the child's feeding patterns. The mother explained that there had been considerable domestic violence from the child's father but that he no longer lived with them. The child psychotherapist enquired if the child had been hit which he had not. However, the child psychotherapist also wondered about how fearful the mother may have felt and asked if the child ever coughed when feeding. The result was dramatic - the mother explained that she had been choked by her partner to the point where she felt she might die. She asked the psychotherapist to "feel the lump" in her throat and became very distressed. The child psychotherapist gently wondered if this terrifying experience was relived every time her child "choked" or coughed as he fed. The mother was hugely relieved feeling that something had been understood. The next time the child psychotherapist met with the mother and child he had begun to eat food that was a little lumpy.

The benefits of child psychotherapy

The task of the child psychotherapist - who plays no role in the medical care of the patient - is to try to reflect with the patient (and/or parent) on their experience, their capacity for adaptation to the reality of their illness, treatment and prognosis, and to enable the expression of fear, anger, anxiety and sadness.

The hope is to minimise the psychological effects and foster the capacity for resilience. The belief is that being able to make sense of the experience helps the child's or adolescent's coping mechanisms. The training of Child Psychotherapists, at the core of which is their own analysis, enhances their capacity to meet and bear the intensity of such emotions. For other children and parents the condition may be chronic, such as cerebral palsy or diabetes. The on-going psychological strain can be immense & may lead to such problems as the adolescent diabetic patient who does not comply with the daily treatment regime or the parent racked by anxiety who allows their child no freedom. The Child Psychotherapy training helps develop an understanding of how resistance and internal conflict can bring about apparently irrational behaviour.

Containment of unbearable feelings is a crucial part of the work - with the parents as much as with the patient. This can happen through the naming of feelings and emotions and the notion that some of the previously un-nameable fears may become tolerable and acceptable to the patient and their family.

In addition, one of the most important parts of the work of the child psychotherapist is to offer support through supervision, teaching and consultation across all agencies involved with the child patient's care. This includes medical and non-medical staff. Child psychotherapists are trained to work with all levels of complexity, and are experienced in working over long periods of time if necessary. They are not daunted by the depth or

complexity of the child's problem and in hospital work can play an important role in supporting the child, the parents and the medical team to endure the often harsh treatment and achieve a satisfactory outcome. On some occasions in which the child has died, helping staff accept and understand their responses requires sensitivity and skill of a high order.

The child psychotherapist represents and speaks out for the child or young person's emotional and psychological perspective in multi-disciplinary team meetings where medical staff often have to face traumatic and difficult situations and decisions.

Current issues in the field

Child psychotherapists work in different areas and specialities across a wide number of hospitals. Children and adolescents attending for hospital treatment face a barrage of difficulties that can affect parents and the whole family. For example, in paediatric and teenage cancer care the impact on the child and his family is profound. These families need continuing containment and therapeutic input throughout their child's illness and treatment. Often children who have had to endure long and harsh treatments require support to return to normal life, including school and peer interaction, or to digest the traumatic experience and sometimes life-changing effects of surgery, radiotherapy and chemotherapy. The availability of psychological support for patients and families at the end of a child's life is crucial and can greatly facilitate staff's management of these painful events. Long-term follow up can strengthen and support families after such a bereavement has happened.

Children who have been diagnosed with chronic conditions such as diabetes, epilepsy, HIV, sickle cell disorder, thalassaemia, skin conditions, asthma, endocrine, urological or rheumatology problems require support to come to terms with and manage conditions

that are life long and which can isolate them from their peers, often involving their future sexual interactions and reproductive capacities. Children with burns and other disfigurements are helped by the work of a child psychotherapist who can listen to and accept the distress of an injured child which can in turn allow the child to feel that their voice has been heard and responded to without judgement or a need to rush to solutions.

This allows the process of digestion of a fact and a way to endure and manage the difficulty. As about 50 per cent of burned children are under the age of two, it is recognised that for this group, most of the work will be done with parents. This work aims to lessen the effects of trauma for both the children and their parents.

"The sessions help me really well and I have someone outside of my family and friends to talk to and it's only between me and that person. It also gets me out because I don't go out anywhere anymore but I want to change that lifestyle because I need some space out of the house and I want to meet new people."

Young person seen in hospital

Premature infants and their parents can be supported during difficult and sometimes traumatic neonatal treatment. Child psychotherapists are especially well suited to this work because of their intensive and in-depth training in the area of infant mental health. Follow up of this group of children is important as they can be left with lifelong health difficulties as well as the emotional impact of such a difficult start in life, including the interference of the early all-important mother-child attachment. Feeding difficulties can be addressed in the early years preventing later, more entrenched, problems. These are but a few examples of the nature of the work undertaken by child psychotherapists in hospital settings.

Case example:

A four-year-old boy had been sent for emergency radiotherapy treatment for a brain tumour but because the hospital was unable to offer a general anaesthetic slot due to a rapid need for treatment it was necessary for him to manage radiotherapy while still awake. The child psychotherapist was called and found a very distressed child, mother and grandmother. The mother was shouting at the boy trying to implore him to behave. It was apparent to the child psychotherapist that the mother was unable to contain her child's distress and realised that in this state of mind the child was unable to receive the necessary support from her. The child psychotherapist asked for a break and if the grandmother might attend to the child while she spoke to the child's mother. The mother was then able to tell the story of the child's journey to diagnosis and the child psychotherapist was able to listen and comment in a way that acknowledged the huge trauma this mother had experienced. She was able to support the mother to feel able to return to her child in a more integrated state and not to the mother who he felt reflected his own feelings of panic. The child had his treatment successfully and the child psychotherapist continued to support the family throughout their time at the hospital.

The National Service Framework (NSF), NICE and other guidance

It is only in the last two to three decades that child psychotherapy has become more commonplace in hospitals, providing liaison work in paediatric departments. Hospital-based mental health services for children lagged behind those of adult services. There is now much wider recognition of the emotional and psychological needs of children and young people who present in hospitals with chronic or severe illness.

This is reflected in key government documents. **The final report of the National CAMHS review DCSF 2008** states:

> "7.59 Physically disabled and chronically ill children and young people are also at particular risk of experiencing mental health problems, yet they do not always receive the support and care that they require. Reasons for this include a lack of CAMHS involvement on paediatric wards (paediatric liaison service); differences in the culture, structures and working practices of medical staff dealing with physical disorders and those dealing with mental disorders; a tendency to overlook the impact of physical illness on mental health and vice-versa; a lack of expertise; and difficulties in co-ordinating services where child mental health and paediatric services fall under different employing trusts, which is the case in many areas of the country."

National Service Framework 2004: "The National Service Framework for Children, Young People and Maternity Services (September 2004) requires child psychotherapists to be part of every CAMHS team."

For example, **NSF for Children Standard (9) for Hospital Services** stresses the importance of a joined up, collaborative team where Child psychotherapists are integrated into medical multidisciplinary teams. It states:

> "Attention to the mental health of the child, young person and their family should be an integral part of any children's service and not an afterthought… It is essential for a hospital with a children's service to ensure that staff have an understanding of how to assess and address the emotional wellbeing of children, and are able to identify significant mental health problems, and that there are robust liaison arrangements in place to secure CAMHS input."

The **NHS Commissioning Board 2013** highlights the importance of commissioning CAMHS services when commissioning specialised hospital services for women and children. "All paediatric patients should have access to appropriately trained paediatric trained dieticians, physiotherapists, occupational therapists, speech and language therapy, psychology, social work and CAMHS services within nationally defined access standards."

The **Joint Commissioning Panel for Mental Health 2012** in its guidance for commissioners of liaison mental health services to acute hospitals states "child and adolescent mental health services to general hospitals should be provided by specialist multidisciplinary CAMHS liaison teams, but current provision is patchy and further investment is required."[5]

The **NHS Confederation 2012**[6] Highlights the long term health gains of investing in emotional and psychological well being for patients with long-term conditions and medically unexplained symptoms: "Living with a severe physical illness impacts on young people themselves, their emotional and social development, and their families.

Two reviews (Child and Adolescent Psychotherapy: A Systematic Review of Psychoanalytic Approaches, Dr Eilis Kennedy 2004 and Process and Outcome Research in Child, Adolescent and Parent-Infant Psychotherapy: a Thematic Review Edited by Dr Eilis Kennedy and Nicolas Midgley 2007) reported that psychotherapy input reduces the psychological and emotional impact on these children, young people and their families.

The New Ways of Working document (Department of Health 2007) also stresses the importance of child psychotherapists being able to work with the most disturbed children and adolescents because of their complex and unique training. Their distinctive contribution can support, supervise and train workers with less specialist training.

Within **NICE guidelines** there is recognition of the important role psychological services have to play at all stages along the patient pathway, including after completion of treatment and into adult life.'[7]

Both the **NSF** and **NICE** guidelines recommend psychological support as part of an "ongoing integrated package of care by a multi-disciplinary paediatric"[8] team in a range of serious or chronic conditions such as depression, diabetes and cancer. Addressing mental health is seen as key in the treatment of children and young people with type 1 diabetes and their families who should be offered "timely and ongoing access to mental health professionals because they may experience psychological disturbances (such as anxiety, depression, behavioural and conduct disorders and family conflict) that can impact on the management of diabetes and well – being" [9]
Crucially, these guidelines highlight that optimal care requires attention to psychological and psychosocial issues that affect management and compliance. They also recognise the links to other conditions such as depression, eating disorders and cognitive or behavioural disorders which may *pre-date the onset of illness*.

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[5] Guidance for commissioners of liaison mental health services to acute hospitals *vol 2* Practical Mental Health Commissioning, p 10. www.jcpmh.info
[6] http://www.nhsconfed.org/Publications/briefings/pages/investing-in-emotional-psychological-wellbeing.aspx
[7] **NICE Guidance - Improving outcomes in children and young people with cancer** (August 2005) (Section 2 pg 73)
[8] **NICE Guidelines for Type 1 Diabetes 4.1-4.8**
[9] Ibid

Similarly, the Diabetes NSF makes several observations and recommendations that recognise the psychological impact of diagnosis and the dangers of poor psychological adjustment as a barrier to effective self management.[10] The provision of psychological support facilitates management and is seen as a cornerstone of diabetes care.[11]

Hence the **NSF Diabetes Careplan** in highlighting the different needs of children and young people to those of adults recognises the need to ensure continued psychological and social development of children and concludes that "The challenge is to develop an early alliance with the child and their family and carers, which will sustain the therapeutic partnership into adulthood."[12] and that "Children and young people should also receive regular surveillance for and where required, treatment of other conditions that are more common in people with diabetes, including mental health problems such as depression and eating disorders".[13]

Other important documents include the **Making Every Young Person with Diabetes Matter** (Department of Health, April 2007) and **Emotional and Psychological Support and Care in Diabetes Report (**from the emotional and psychological support working group of NHS Diabetes and Diabetes UK, March 2010)

"Diabetes may result in additional psychosocial vulnerabilities such as eating problems, social isolation, fear of stigma, depression and psychiatric difficulties, depending upon factors such as coping skills, support and resilience. The long- term implications and life-threatening nature of this condition make the psychological and social challenges particularly complex. For diabetes services to respond to these emotional needs and the varying levels of complexity, psychological provision must be a central component. The challenge is to integrate psychological developmental principles into routine provision for children and young people. Inadequate access to psychology and psychiatry services has been recognized as a significant concern to children/young people with diabetes, their families and staff."[14]

The National Network for Burn Care also argue that a principle requirement is for all children (and their families/carers) to have access to psychological support throughout their pathway - from admission, ward, discharge and follow up which can continue for many years into adult life. [15]

Evidence and research

[10] **Diabetes NSF Standard 3:** "All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process".

[11] **Diabetes NSF Standard 5, 10-12**
[12] **NSF Diabetes Careplan,** p.24, para 24
[13] Ibid, p.29, para 16
[14] **Making every young person with diabetes matter** (Department of Health, April 2007)
[15] **National Burn Care Standard, 2013**

In hospital settings the specific theoretical and clinical foundations date back to the beginnings of child psychotherapy (Ramsden, 2009) through the work of Bowlby (Bowlby, J. (1951) Maternal care and mental health, Geneva: World Health Organisation and (1971) Attachment and loss, vol 1, London: Penguin.) and the Robertsons (Robertson, J (1952) Film: A Two-Year Old Goes to Hospital, London: Tavistock.) and their focus on the impact on young children of separation, maternal deprivation and subsequent work on attachment. The work of Bowlby and the Robertsons
was strongly instrumental in altering paediatric practice. Isabel Menzies Lyth's research later provided a further psychoanalytic view of the social system of the hospital (Menzies Lyth, I. (1959 and 1987). There now exists a large literature on the psychological aspects of illness and hospitalisation in relation to children, young people and their families, based on research and clinical practice.

Key publications include:

- Dorothy Judd's book **"Give Sorrow Words"** (1989 Free Association Books) addresses in-depth the topic of terminal illness in childhood, as it affects both the families and professionals. The current research into new developments in approaches to terminal illness is reviewed and discussed.
- **"Psychotherapy with hospitalised children with Leukaemia: is it possible?",** Journal of Child Psychotherapy 16(2); 21-37 by Emanuel, R., Colloms, A., Mendelsohn, A et al (1990) gives a clear exposition of the psychotherapist's role in alleviating the distress of children cancer patients and the need for flexibility in technique in this applied setting.
- Sandra Ramsden's chapter **"The Psychotherapist in a hospital setting"** Handbook of Child and Adolescent Psychotherapy edited by Monica Lanyado and Ann Horne (1999) illuminates, through discussion and clinical examples, the impact of psychotherapeutic work on patients, their families and staff in the complex hospital environment.
- Erskine, A & Judd, D. (1994). **The Imaginative Body: Psychodynamic therapy in health care.** Whurr Publishers Ltd, London
- Engel, G. (1977). The need for a new medical model. *Science* **196,** 129-136
- **Mercer's review** of the research literature indicates that those most vulnerable while hospitalised are those with severe or chronic illness with frequent hospitalisations, particularly early in life. Mercer, A. (1994) **"Psychological approaches to children with life-threatening conditions and their families",** Review of the Association for Child Psychology and Psychiatry 16 (2) 56-63.
- Increased vulnerability in emotional and behavioural developments in children with chronic illness has been demonstrated by Garralda et al (1988) in **"Psychiatric adjustment in children with chronic renal failure"**, Journal of Child Psychology and Psychiatry 29: 79-90.
- The vulnerability of the siblings of ill children has been shown by Lavigne and Ryan (1979) **"Psychological adjustment of siblings of children with chronic illness"** Paediatrics 63: 616-27.
- Looking at one of the questions faced by parents of terminally ill children with malignant disease, that is whether or not they should talk to their child about death, the researchers reported that none of the parents who reported having talked to their

children regretted it (Ulrika Kreicbers et al (2004) **"Talking about Death with Children Who Have Severe Malignant Disease"**, The New England Journal of Medicine Vol 351 No 12.

- Royal College of Psychiatrists:

Improving physical and mental health: Children and young people (2012) http://www.rcpsych.ac.uk/mentalhealthinfo/improvingphysicalandmh/childrenandyoungpeople.aspx Discusses the importance of improving physical and mental health in children and young people with medical illnesses and the increased risk for emotional disorders. "At times, the emotional and behavioral symptoms can be the early manifestation of the medical illness. … Integrated working between general practitioners, generalist and specialist pediatricians, psychologists, child psychiatrists, specialist nursing staff and other professionals is encouraged while looking after young people with chronic physical, neurodevelopmental or life threatening illnesses. This has been particularly emphasized in the care of young people with diabetes, cancer, respiratory conditions and epilepsy."

- **Promoting the Mental Health and Psychological Well-being of Children and Young People.** Report on the Implementation of Standard 9 of the National Service Framework for Children, Young People and Maternity Services. Department of Health/Dress 2006. Louis Appleby, the National Clinical Director for Mental Health, Sheila Shipman, the National Clinical Director for Children's Services, and Naomi Eisenstaedt, the Secretary of State's Chief Advisor on Children's Services at Dress

If you are interested in commissioning a child psychotherapy service in your locality, either via your local NHS CAMHS or via a private provider, please call the ACP office on 020 8458 1609 or at contactus@childpsychotherapy.org.uk. Further briefing papers on the work of child psychotherapists in family courts, in schools, with looked-after children, with parents and carers, with children with disabilities and through long-term work and intensive work are available at **www.childpsychotherapy.org.uk**