Bridging psychological and physical health care

Konrad Jacobs, Penny Titman and Melinda Edwards open a special feature on paediatric clinical psychology

Children who have a physical health problem are more likely to successfully manage the challenges presented by their medical condition if their health care addresses both their physical and psychological well-being. Whilst physical health services and psychological services have traditionally been provided by different organisations, paediatric clinical psychologists work across these services to improve both physical and psychological outcomes. This article describes some of the clinical work carried out by paediatric psychologists and the systems within which they work.

How can we use psychological theories and techniques to improve physical and psychological health in children with physical health problems?


www.ppnuk.org: UK Paediatric Psychology network

Children with acute or chronic medical conditions such as these find themselves in unexpected, unfamiliar and unwanted territory. Children often become distressed, angry, sad or worried in relation to their physical condition. Parents in their own right can find it difficult to manage both the child’s emotional response and their own reaction to their child’s condition. Paediatric psychologists (and other psychosocial professionals) help children and their families navigate a way through the difficulties towards a desired solution.

A widely used definition of the field of paediatric psychology is ‘a field of research and practice that has been concerned with a wide variety of topics in the relationship between the psychological and physical well-being of children, including behavioural and emotional concomitants of disease and illness, the role of psychology in paediatric medicine, and the promotion of health and prevention of illness among healthy children’ (Roberts et al., 1984). The challenge for psychosocial professionals working in paediatrics is to maximize health outcomes, minimize the emotional consequences of living with chronic disease and improve the quality of life for children, young people and their relatives (Duff & Bryon, 2005).

Paediatric psychology in the United Kingdom has grown out of various psychological traditions, including adult health psychology, child clinical psychology, educational psychology, developmental psychology and paediatric neuropsychology. We still draw upon all these models to provide our services. Paediatric psychologists became go-betweens between mental and physical health: skilled communicators who hold two different languages, medical and psychological, and who advocate for a psychosocial focus in paediatric medicine. This generally quite amicable relationship (with its ups and downs) between paediatric medicine and psychology has led to a continuing growth of the field of paediatric psychology over the last 30 years. In addition, this growth has been maintained by:

A growing move towards patient-centred care (Edwards & Titman, 2010), as evidenced by Standard 7 of the National Service Framework for Children (DoH, 2004): ‘Attention to the mental health of the child, young person and their family should be an integral part of the children’s service, and not an


afterthought… It is therefore essential for a hospital with a children’s service to ensure that staff have an understanding of how to assess and address the emotional well-being of children.

A The wider availability of (evidence-based) national guidelines (e.g. NICE; Cystic Fibrosis Trust; Arthritis and Musculoskeletal Alliance) which include recommendations for the addition of psychological services in the commissioning of medical services.

A A better understanding of the psychosocial impact of medical conditions on children and families and the fact that users of health care often perceive the psychosocial issues to be as important as the medical issues.

A Validation of the role of psychology in paediatric medicine: interventions improve not just psychological but also health outcomes (Roberts & Steele, 2009; Spirito & Kazak, 2006).

A Psychological interventions that can potentially significantly reduce healthcare costs. A controlled trial of multi-systemic therapy for diabetes demonstrated reduced inpatient admissions and significantly lower care costs for adolescents with poorly controlled diabetes (Ellis et al., 2005). Within an adult context, Chiles et al. (1999) estimated following a meta-analysis of psychological interventions that the medical cost offset was around 20 per cent.

Paediatric clinical psychology in the UK

Clinical psychologists have worked in hospitals with children and families for decades, initially often as a sub-specialty of children and young people’s psychology services. Whilst numbers were low in those days, the field has increased exponentially over the last two decades, and is in fact still growing. Practically all paediatric psychologists are clinical psychologists who have specialised in working with children and young people with clinical health problems. The first paediatric psychology conference in the UK was organised in 1999, in Bath. The Paediatric Psychology Network (see www.pppnuk.org) was established soon after through the efforts of a number of experienced clinicians. The Network became an official part of the British Psychological Society’s Faculty for Children and Young People in 2006. A national survey conducted in 2009 (Edwards, 2010) found that there were approximately 340 paediatric psychologists working in the UK in health care with families of children and young people with acute or chronic illness and disability (230 whole-time equivalent posts), distributed across 90 psychology services. The largest services are based in specialist children’s hospitals, teaching hospitals and linked to healthcare provision providing regional and national services. In other areas, often in district or general hospitals, clinical psychology input is provided as part of a liaison or mental health service, with less dedicated psychology time to health care.

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The most prevalent model for these services is for psychology to be based in the hospital setting and to be integrated within the various multidisciplinary health teams. The advantage of this model is that it increases the visibility and presence of psychology within the healthcare environment and encourages psychological thinking within healthcare teams. It also improves communication between team members and facilitates joint working, both clinically and in research. When psychological services are seen as part of the healthcare team and part of the holistic care the team offers, it makes psychological services more accessible and acceptable to children and families. This can be particularly important when families might be ambivalent about the need for, or social acceptability of, receiving psychological help.

The survey showed there were at least 26 medical areas or specialties that had some dedicated psychological input, covering a wide range of acute, chronic and palliative conditions, with the greatest input to specialist medical services such as oncology, cleft lip and palate and diabetes. It was evident that there was little equity or uniformity to the distribution of psychology services in health care across the UK.

Historically, services have developed according to the interests and value placed on psychological care by paediatric medical consultants, or by local healthcare targets, financial opportunities or bids. Increasingly, services are being developed as a result of hospitals meeting standards of care set by Department of Health policies or national guidelines indicating good practice. In addition, parent and local (or national) support groups have also exerted influence, or provided funds to develop psychology posts. The Scottish Government has made some financial investment in the development of paediatric psychology services in Scotland over the last three years as part of a National Delivery Plan.

What do we do?

Paediatric clinical psychologists, like many other clinical psychologists, work both directly with children and families, and indirectly, by providing consultation and supervision to other professionals. In some specialties, such as cleft lip and palate, cystic fibrosis and bone marrow or organ transplant, psychological assessment is carried out as part of an agreed treatment protocol and is considered a routine part of the management of the child’s health condition. The aim of protocol-based assessments is to identify children and families likely to be at increased risk of developing psychological difficulties, in order to offer preventative intervention, or to identify those children and families who are likely to need increased input.
during medical treatment. This approach can also help normalise psychological input and may improve uptake of psychological intervention.

The sorts of referrals made in child health settings do not always fit easily into the diagnostic categories used for child mental health difficulties:
1. Preparation for medical procedures
2. Promoting adherence to treatment
3. Symptom management, for example pain management
4. Managing trauma, including working with siblings and other family members
5. Bereavement work and support for grief and loss
6. Preparation and support for transition to adult services
7. Assessment and management of medically unexplained symptoms
8. Assessment and management of anxiety or low mood

Very few children referred with issues like these would reach the threshold for diagnosis of a psychiatric disorder as defined in ICD 10 or DSM IV. This prompted Kazak (1997) to say: 'Families facing serious paediatric illness are essentially ordinary families facing extraordinary stressors.'

Most paediatric psychologists work by developing a formulation (based on gathering information from a variety of sources) about why the child or family has developed the current difficulties, identifying risk factors, any trigger events that may have precipitated the current situation, and any maintaining factors. A collaborative intervention plan is then developed with the child, the family and the medical team, based on the knowledge of the medical condition and any evidence-based interventions that are relevant to the child's difficulties. For example, with Michael who we met at the start of this piece, it would be important either to observe a session where he is given his injection or to get a very detailed description from all of those involved for a clear shared picture of how this situation is managed, and what factors contribute to the escalation of his difficult behaviour.

Whilst injections are inherently unpleasant for children, the current situation is becoming increasingly traumatic for all members of the family and this is probably contributing to the avoidance and anxiety that accompanies each procedure. His parents may have very different beliefs about how to manage these situations, which are likely to be linked to their beliefs about the illness and treatment and their own emotional reaction to Michael's difficulties.

For some conditions, there is an established evidence base regarding effective interventions, for example, CBT for the management of headache (Spirito & Kazak, 2006) or the use of motivational techniques for addressing difficulties with adherence in adolescents with diabetes (Channon et al., 2007). In some situations it is possible to draw on the use of techniques that have been developed for general difficulties and adapt these to the child's situation. However, in common with many areas of psychological work, the evidence base is still quite limited and clinicians rely on creative adaptation of psychological techniques and clinical experience.

Indirect work often includes attending regular psychosocial or multidisciplinary team meetings, where the psychological and social needs of the children and families can be considered from different professional perspectives. These meetings provide excellent opportunities to influence the team's thinking about families across the spectrum, not just those with high psychological needs, but also those families who are coping well. One of the advantages of these meetings is that this reduces the barriers between physical and psychological models of care and facilitates communication about the child's care (Duff & Bryon, 2005). Many other professionals work with children in hospital (for example, play specialists, physiotherapists, social workers, teachers, etc.); joint case discussion and shared formulation provides an opportunity to enhance every professional's approach and care of the child. When this works well, it provides a forum for planning holistic multidisciplinary interventions and can ensure that a wider range of children and families benefit from a psychological perspective on their care.

Challenges

One of the challenges that needs to be addressed by psychology services is ensuring greater equity and access to psychological support across all illness groups and across all healthcare provision. This can be supported in part by increasing the capacity of a range of healthcare staff in a range of psychosocial interventions and by developing and making available effective psychological resources (leaflets, websites, good practice guidelines, DVDs and other media resources). Greater access to psychological input can also be supported at a more strategic level by communicating more effectively with commissioners about the 'added value' that psychological care brings to health care, in terms of health outcomes, satisfaction with services and well-being, and by contributing to national guidelines and policies about evidence-based and quality indicators for paediatric health care.

Within the NHS, all services are required to meet targets for efficiency and effectiveness, including clinical outcome and cost-effectiveness. The Paediatric Psychology Network is actively exploring and piloting clinical outcome measures that are meaningful and sensitive to the particular challenges of illness and disability in childhood and adolescence. Most outcome measures that are currently available have been developed within child...
mental health or adult health services. Unfortunately, many of these measures have poor face validity for families where children have serious medical conditions, and are not sensitive to assessing change in this context. Some paediatric psychology services in the UK are utilising these outcome measures whilst more tailored ones are being developed. The most informative outcome measures are those that are able to measure change for the individual child based on their goals and needs, and those of the wider system around the child including family and healthcare team. A further challenge is to be able to communicate the effectiveness of the wider psychology roles that are highly valued by healthcare teams, including enhancing team communication and cohesion, consultation, staff support and supervision. Services have often been assessed on measures such as clinical activity, patient satisfaction and patient outcome, with less understanding and focus on this wider systemic role, which is harder to quantify.

There is increasing recognition that psychological input can improve psychological and health outcomes for children with a chronic illness and there is a growing evidence base for the effectiveness of particular psychological interventions in health care. In the current financial climate there is both a clear need and interest in quantifying the cost of illness and medical care and the cost effectiveness/benefits of psychological input. For example, calculating the cost of a surgical procedure that has been cancelled due to a highly distressed child who is unable to cooperate, and comparing this with the cost of specialist psychological support and preparation for the procedure. A cancelled surgery slot amounts to thousands of pounds, possibly a further stay in hospital with the associated costs of rescheduling the procedure, let alone the distress for the child, family and healthcare team and any direct health consequences of a delay in treatment. For other children, the costs of non-adherence can have significant healthcare costs in terms of less effective medical management and impact on health with the likelihood of increased medical appointments to monitor and ensure appropriate treatment. This is an area that has not been tackled sufficiently by paediatric psychologists yet. The challenge for psychology in health care is to be able to provide and evaluate high-quality and evidence-based services as well as understanding the value placed on the service by managers and commissioners, which includes the added value in terms of cost-effectiveness, and to communicate outcome effectively in all of these areas.

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