

British Association of General Paediatrics

1202

'IS IT TIME TO ACT? A QUALITATIVE STUDY OF THE ACCEPTABILITY AND FEASIBILITY OF ACCEPTANCE AND COMMITMENT THERAPY FOR ADOLESCENTS WITH CHRONIC FATIGUE SYNDROME

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Background Paediatric Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) is severely disabling and relatively common. Over 15% of children do not recover by 12 months. Cognitive Behavioural Therapy for fatigue is one of the only approaches with consistent evidence for improving function and quality of life. Acceptance and Commitment Therapy (ACT) is a suggested alternative therapy. It is effective in paediatric chronic pain and functional syndromes, but has not yet been used trialled in paediatric CFS/ME.

Objectives We aimed to determine whether ACT is an acceptable and feasible treatment approach for children who are still disabled by CFS/ME after 12 months of treatment. This study is part of pre-trial work to inform the development of an effectiveness randomised controlled trial (RCT) of ACT.

Methods A qualitative design, using semi-structured interviews and focus groups was adopted. We recruited children (inclusion criteria: diagnosed with CFS/ME; not recovered after one year of treatment; aged 11–17 years), their parent/carer and healthcare professionals (HCPs) from one specialist UK paediatric chronic fatigue service. Interviews and focus groups were audio-recorded, transcribed verbatim and analysed using thematic analysis to identify patterns in the data.

Results Twelve adolescents, eleven parents, and seven HCPs were interviewed. All participants thought ACT was acceptable and feasible, and welcomed it as a new possibility for recovery. Participants identified reasons why ACT might be efficacious: the pragmatic approach with acceptance and compassion are valued in chronic illness; the focus on values provides motivation and direction; psychological and physical needs are both addressed; and normalising difficulties is a useful life-skill. Some adolescents preferred ACT to CBT-f as it encouraged acceptance of (rather than challenging) thoughts. However, HCPs were concerned patients might associate 'acceptance' with 'giving up' and called for clear explanations of the goals of ACT to be given to patients and parents. Interviews highlighted differing views on who might benefit from ACT and at which point during treatment it should be offered. It was agreed that ACT should be part of an individualised treatment plan that should be made on a case-by-case basis. Most adolescents said they would consent to a RCT of ACT but a key barrier to recruitment was reluctance to be randomised.

Conclusions Adolescents with CFS/ME, their parents and HCPs from a CFS/ME service thought ACT was an acceptable, feasible, and potentially efficacious treatment approach. They support a RCT of ACT, and most would consent to partake in a trial. We recommend trialling ACT in paediatric CFS/ME.

Children's Cancer and Leukaemia Group

1203

NEUROBLASTOMA AND RETINOBLASTOMA AND IN CHILDREN AND YOUNG PEOPLE – A SYSTEMATIC REVIEW OF PRESENTATION SYMPTOMS AND AWARENESS AMONGST FUTURE DOCTORS

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Background In seeking evidence for the Child Cancer Smart (<https://www.cclg.org.uk/childcancersmart>) campaign to enhance public and professional awareness of children, teenagers and young adult (CTYA) cancers, a series of systematic literature reviews of symptomatology of common cancer clusters of childhood are being conducted to synthesis evidence for clinical guideline development and educational materials for target populations.

Objectives (1) To systematically review the literature published between 2010–2020 regarding presenting signs and symptoms of neuroblastoma and retinoblastoma in children (<18 years of age).

(2) To assess the level of knowledge and awareness of symptom awareness amongst medical students in 4th or 5th years (Clinical Phase CP2-CP3) at the University of Nottingham.

Methods Medline and Embase databases were searched from January 2010 – July 2020. Keywords included 'neuroblastoma', 'retinoblastoma', 'diagnosis', 'signs(s)', 'symptom(s)', 'presentation(s)'. References were restricted to 'all child'. All papers discussing tumour presentation were included. Pooled proportions (%) of children with each sign or symptom at diagnosis were estimated. An online questionnaire survey was carried out in October 2020. Medical students who were in their clinical placement (CP2–3) during the study period were invited to take part in the survey.

Results The neuroblastoma search strategy identified 5804 titles, 164 papers were reviewed in full, and 24 met the inclusion criteria, describing the symptoms/signs in 6443 children. Symptoms occurred in 5% or more were abdominal/pelvic mass/hepatomegaly (24%), abdominal pain ± GI symptoms (12%), fever (9%), anaemia/pallor (8%), incidental/asymptomatic (6%) and respiratory symptoms±cough, symptoms of spinal cord compression, respiratory distress/dyspnoea and head/neck/cervical mass (5%).

The retinoblastoma search strategy identified 2359 titles, 102 papers were reviewed in full, and 48 met the inclusion criteria, describing the symptoms/signs in 13154 children. Symptoms occurred in 5% or more were Leukocoria (64%), proptosis (7%) and Strabismus (5%).

A total number of 163 medical students took part in the survey. On average respondents mentioned 7.7 symptoms when unprompted, compared to 35.2 symptoms when prompted. Unprompted awareness of abdominal mass or distension was 13% (22/163) or 61% when included additional 78 reported generalised mass/swelling/lump, compared to 98% (159/163) identified abdominal distension or mass when prompted. Unprompted awareness of leukocoria was 16% (26/163), compared to 59% (96/163) when prompted with a symptom list.

Conclusions The systematic reviews will provide evidence of common presentations and will form the basis for clinical guidelines on the assessment and investigation of children presenting with suspected tumours. The results of the awareness survey highlight a potential gap of awareness amongst medical students and further work in other regions and medical professionals will be needed in order to provide more insight on this topic.

(*AC and ET contributed equally to this work)

British Society for Rheumatology

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British Association of Perinatal Medicine and Neonatal Society

1205

FAMILY INTEGRATED CARE FROM THE DELIVERY ROOM: A MULTICENTRE APPROACH

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Background Having a baby requiring admission to a neonatal intensive care unit (NICU) can be very distressing for families and there may be a significant period after birth where parents do not see or hold their baby. Facilitating delivery room cuddles (DRC) allows family integrated care to begin at the earliest opportunity.

Objectives A collaborative project to facilitate cuddles at delivery for infants born <32 weeks gestation, or with congenital anomalies requiring NICU admission, without impacting safety or factors affecting mortality (such as hypothermia or hypoglycaemia).

Methods Education was delivered to all staff attending deliveries to ensure safe facilitation prior to implementing the initiative. Data was collected, across three tertiary units, between 2018 and 2019 for infants <32 weeks gestation. One unit collected data over six months, expanding the initiative to consider DRC for all infants with a congenital anomaly requiring NICU admission.

The decision to facilitate cuddles was at the discretion of the clinical team at delivery following assessment of stability of the infant.

Results 161/224 infants (72%) received DRC. Details of the preterm and congenital anomaly groups are presented in table 1. During DRC, 61% received non-invasive respiratory support and 16% were ventilated. 82% of cuddled infants were normothermic (36.5–37.5°C) on admission compared to 68% of those not cuddled. Rates of normothermia in the cuddled infants were higher than the national average.¹ There was no increase in rate of hypoglycaemia for the cuddled infants.

Of those with congenital anomalies who received DRC, 42% had congenital heart disease, 9% had a congenital diaphragmatic hernia, 27% had another surgical gastrointestinal condition (including gastroschisis and exomphalos), and 9% had renal abnormalities.

Adverse events were mild and infrequent. There was one interruption to the ventilator tubing which was rectified immediately with no change to the infant's vital signs. Two infants had a decrease in temperature promptly recognised; both were normothermic on admission. The most frequent reason for no DRC was maternal general anaesthetic (27/63;43%), followed