Mental health in a children's hospital - detection and access to effective care – with some examples from epilepsy

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Summary

• Mental health needs of children with long term health problems are elevated:
  – Common psychiatric disorders are even more common in this population

• We have to be creative and flexible about how we detect and treat these mental health problems
  – Some research examples with potentials for community roll-out

  Some tips along the way of how to do research as a full-time clinician and have fun…….
WELLBEING

ADJUSTMENT

PROCEDURAL FEARS

EMOTIONAL AND BEHAVIOURAL SYMPTOMS

MENTAL ILL HEALTH
Tip 1

• Find great mentors
Background: Isle of Wight, 1970

- Epilepsy and CNS disorders are major risk factors for psychiatric disorders.

Isle of Wight 1970

A population survey of mental health problems in children with epilepsy

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'It is noted that the 10-year rise in pediatric hospitalizations in US children’s hospitals is 5 times greater for children with versus without a psychiatric diagnosis. Strategic planning to meet the rising demand for psychiatric care in tertiary care children’s hospitals should place high priority on the needs of children with a primary medical condition and cooccurring psychiatric disorders.'

Presence of a psychiatric disorder at 5 year follow-up associated with reduced quality of life

Presence of seizures not associated with reduced quality of life

Tip 2

- Find a focus – but don’t be scared of changing
- You will have interesting groups of patients who will give you ideas and can help you discover things
Children with epilepsy are at an increased risk of psychopathology compared to the general population (Machin et al., 1999). The present study aimed to determine the psychopathology rates in children with temporal lobe epilepsy and to compare these rates with those of a control group.

Methods: A case-control study was conducted involving 60 children with temporal lobe epilepsy and 60 age- and sex-matched controls. Psychopathology was assessed using the Child Behavior Checklist (CBCL) and the Strengths and Difficulties Questionnaire (SDQ). The rates of psychiatric diagnosis were compared between the two groups.

Results: Forty percent (40/60) of children with temporal lobe epilepsy had one or more psychiatric diagnoses pre-operatively. Post-operatively, 41/57 (72%) of children had one or more psychiatric diagnoses, with some gaining and some losing a diagnosis.

Discussion: The results suggest that temporal lobe resection may have a significant impact on the psychopathology rates of children with temporal lobe epilepsy. Further research is needed to investigate the long-term effects of temporal lobe resection on mental health outcomes.

Conclusion: Temporal lobe resection is an effective treatment for children with temporal lobe epilepsy, leading to a decrease in psychiatric symptoms in some cases. However, some children may experience an increase in mental health problems post-operatively.

References: Machin et al. (1999).
Mental health disorders in children and young people with epilepsy:

Identification and treatment

The context

Prevalence estimates of mental health disorders in people with neurological conditions such as epilepsy is 50% or greater compared with 10% in the general population (Sillanpää et al., 2016)

“The psychological needs of young people with epilepsy should always be considered”

Mental health problems can impact more on physical health problems than the physical health problem itself (e.g. Thapar et al., 2005)

Mental health problems may impact upon the quality of life more than physical health problems (Baca et al., 2011)

Mental health problems may impact upon the physical health problem itself (e.g. Thapar et al., 2005)

Mental health problems may impact upon the physical health problem itself (e.g. Thapar et al., 2005)
The problem

- ‘Contemporary standards of practice fail to integrate screening and treatment of the comorbidities into routine clinical care’ (Asato, Caplan & Hermann, 2014)

- Mental health disorders in the context of neurological illnesses often remain undiagnosed and under-treated (e.g. Ott et al., 2003)
  - Community epilepsy sample
  - 60% had DSM-IV diagnoses
  - >60% received no mental health treatment

- Paediatricians are said to ‘despair’ at accessing psychological therapies (Smokou et al., 2015) despite such interventions being paramount to optimising outcomes

And...

- There are no strong evidence-based interventions for mental health disorders in this group of young people

- There are only 10 studies in children with mental health disorders and physical illnesses

- Only 2 of which were with children with neurological conditions (epilepsy)
Tip 3

• You have identified a problem from your clinical work
• It can be a long road to design and implement a research plan…..
• ….find great colleagues and get some money

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  – Epilepsy Action
  – NIHR
  – Beverley Alexander Charity
The solution?

No reason to assume that standard evidence based protocols won’t work

So start with these……

Start with a case series to determine feasibility/acceptability

Progress to pilot trial

Then full RCT

Automation…….
How do we identify them? A modernised screening process

Using The Development and Wellbeing Assessment (DAWBA; Goodman et al., 2000) in GOSH neurology clinics

Thank you very much

Progress to full DAWBA

rest of DAWBA
What is the DAWBA?

• DAWBA = Development and Well-Being Assessment

• Standardised assessment of mental health and well-being

• Incorporates an emotional and behavioural symptom screen: the Strengths and Difficulties Questionnaire (SDQ)

• Generates DSM and ICD psychiatric diagnoses

• Validated in epidemiological and clinical settings

• [www.dawba.info](http://www.dawba.info) for a demonstration of the online DAWBA system

Searchable database of DAWBA publications

343 publications from 29 countries:

[http://dawba.info/py/dawbainfo/e0.py](http://dawba.info/py/dawbainfo/e0.py)

Main findings

• High rate of uptake for screening 639 SDQs were completed

• 353 (55%) of these met criteria for continuation to the full online mental health diagnostic assessment (DAWBA)

• In those who progressed to the DAWBA:
  69% had at least one mental health disorder
  - 170 DAWBAs were completed
    (48% of those eligible)
Tip 4

• Don’t give up on getting published

Treatment

• Evidence-based protocols with clinical judgment using an empirically derived algorithm

• Designed to be adapted for a diverse range of children and problems and has a modular design

• Suitable for guided self-help
Guided self-help

• Easier for families who already have a lot of medical appointments

• Economical and increases access
  (Williams & Martinez, 2008)

• With guidance, as efficacious as face-to-face therapy for anxiety and depression
  (Cuijpers et al., 2010)

• Effective in adults with physical illnesses
  (Cuijpers et al., 2008)

What Not to Do

Thank you! Take your instructions. Don’t criticize.

One-on-one time is not the time to teach your child anything new, like how to build something higher or draw something better. If you just pay attention and provide lots of description or praise, your child will learn a lot. It’s never a good idea to give backhanded compliments, like, “I think you’re having a real creative time. Why couldn’t you do this more often?”

Sticking with It

Your child will be mad at you if you don’t. Help him understand his anger.

This may sound like a lot, but it will get the best results and be the most rewarding in the long run. After the first week, try to have one-on-one time 3 to 4 times each week. You may want to spend one-on-one time with the other children in your family once you find things are going well with this child. One-on-one time should become a part of your regular routine. You shouldn’t have to stop once you start doing this together, and over time, probably won’t want to.

Examples of Ways to Show Approval

NONVERBAL

Hug
Pats on the head or shoulder
Affectionate rubbing of hair
Placing arm around child
Smiling
Giving a thumbs-up sign
A wink
High-five

VERBAL

“I like it when you...”
“It’s nice when you...”
“That was terrific the way you...”
“Great job!”
“Nice going!”
“Terrific!”
“Super!”
“Fantastic!”
“Wow, I never knew you could do that!”
“Beautiful!”
“Wow!”
“What a nice thing to do.”

“...you did that all by yourself. Way to go!”
“I am very proud of you when you...”
“...I always enjoy it when we...”
Case 1

- 12 year old boy. Focal epilepsy. Autism spectrum disorder

1. Not having a tantrum or being able to accept when you say no
2. Being able to stop things mid-routine without having a tantrum/getting upset
3. Being able to choose food or have food chosen) from a menu at a restaurant without getting upset

- Strategies:
  - Behaviour

Results: Goal Based Outcomes
Impact of intervention on goals (n=28)

Mean goal rating

Week

Qualitative results (n=27 interviews)

• “I found the phone interviews fine, it didn’t take up too much time and I could carry on with my life after”

Practicalities of telephone treatment

• “honestly it’s changed our lives”

Outcomes of the intervention

• “obviously they don’t need to know the ins and outs of epilepsy but… got to understand that having epilepsy must be like you’re walking on a frozen lake, waiting for it to crack”

Extent of adaptation needed
Summary so far…

- Standard psychological/behavioural interventions have beneficial impact on diagnosis, goals and symptoms

- No need for major adaptation of standard evidence based treatments and families considered the strategies to be suitable

- These methods are adaptable to the specific needs in even a severe epilepsy surgery group

- 5yr year NIHR Programme Grant

The MICE Study (Mental health Intervention for Children with Epilepsy)

- As a result of pilot: intervention telephone based but fully integrated within epilepsy services

- Who can deliver the intervention and knows about epilepsy?

- As not previously trained in mental health intervention, need to make tailoring to epilepsy explicit – epilepsy specific module/examples
Design

• 4 phases:
  – 1. Development of epilepsy-specific module
  – 2. Training services to deliver the intervention
  – 3. Randomised Controlled Trial, with quantitative and health economic evaluation
  – 4. Qualitative outcome and process evaluation

Development informed by…

• Theory/literature, Patient and Public Involvement Research Advisory Groups, Health Professionals Advisory Groups, Qualitative interviews
Tip 6

• Make as many friends as you can along the way – but don’t occasionally be afraid of being bloody-minded……

Psychological Wellbeing and Mental Health Drop-In Centre at Great Ormond Street Hospital for Children

Research project funded by Beryl Alexander Trust
PSYCHIATRIC HELP $5

THE DOCTOR IS IN

THE DOCTOR IS IN
BACKGROUND

AIMS

• Evaluate the usefulness of a Psychological Wellbeing and Mental Health Drop-In Centre at GOSH

• Evidence-based interventions for emotional and behavioural difficulties

• Children, siblings, parents and carers at GOSH only
BACKGROUND

FOCUS:
– Early intervention
– Subthreshold cases
– ‘Low intensity’ evidence-based, stepped care
– Liaison and referral
– Integration with existing services not duplication of involvement
Progress: evaluation of need cont.

- Symptom severity:
  - 75% young people in clinical range on SDQ
  - 50% parents – caseness for anxiety
  - 30% parents – caseness for depression

- Conclusions:
  - Unmet need
  - Common mental health difficulties (*anxiety, sleep, behaviour*)
  - Potential for low-intensity interventions

Progress: total numbers for phase 1

[Diagram showing the flow of participants through the phases of the study, starting from Consent (n=128) and ending with Intervention completed (n=63).]
Progress

- https://gospsychmed.wixsite.com/drop-in-centre

Official Project Launch

On the 22nd January we officially launched the Lucy Booth Drop-In Centre with a grand opening in the reception of GOSH.
Tip 6

• Have fun

Progress: feedback to date

“This is fantastic” (Dermatology)

“Great initiative” (Paediatric Endocrinology)

“It sounds great” (Clinical Genetics).

“A wonderful initiative” (Developmental Epilepsy / Sturge Weber clinics)

“Good luck… Let me know if there are any issues arising that I can help with” (Psychological Services)

“I believe this service to have an immense positive effect.” (Parent)

“I believe this service is an exceptional idea to help children move forward.” (Parent)

“I imagine it would be of interest to other families I am in touch with […] Are you looking to only recruit families known to GOSH?” (Stroke Association)
Present focus: main phase of study

– Treatment outcomes
– Impact on mental and physical health
– Participant satisfaction
– Cost-effectiveness

2018

Psychiatric team of the year - children and adolescents: Psychological Medicine Team, Great Ormond Street Hospital

This team puts ‘No Health Without Mental Health’ into practice by fully integrating physical and mental health care in a children’s hospital. Early detection and effective treatment of mental illness in children with physical illness is also the subject of their clinical research programs. Accessible, cost-effective and flexible stepped care models are evaluated with the aim of wide dissemination.

The judges said, “Although we had a number of truly excellent submissions this year, the judges were unanimous in their decision regarding this winner. This application was judged to have outstanding contributions in all domains. This is a model team, exceptionally led and productive both clinically and academically. We were impressed by the team’s commitment to providing accessible, effective, evidence-based treatments for improving the mental health of children and young people with physical health problems with a number of innovative projects and research studies.

For example, the Lucy Project was set up as a self-referral Mental Health and Psychological Wellbeing Drop in Centre at Great Ormond Street Children’s Hospital, an excellent example of breaking down barriers and increasing access to help for children and families.”
Conclusions

• Integrating physical and mental health care optimises early detection and intervention
  – Emotional & behavioural problems are common
  – Mental health problems contribute to overall level of disability
  – All children must have easy access to effective, evidence based treatments for psychiatric disorder
  – Preliminary evidence suggests detection and integrated treatment in childhood improves prognosis
  – Need for further research and treatment trials