Psychological Management in Sickle Cell Disease

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Outline

Psychological Challenges & Issues

Paediatric Interventions

Adult Interventions
Outline

Sickle Cell Disease causes much distress to patients & families

Poses significant challenges

Psychosocial problems may be present

Result from impact of symptoms on daily lives patients & families
Cognitive Challenges

Family must learn about illness
cause
prognosis
complications

Family must revise expectations for child
daily life
present & future
Emotional Challenges

Coming to terms with the illness
- uncertainties
- disease process

Thoughts & feelings about outcome
- fears & anxieties
- hoping & praying
Behavioural Challenges

Changes in family life
- treatment
- hospital visits

Preservation of family function
- daily roles & limitations
- other members – eg. siblings
- income
Individual Challenges

Identity & Role
- active able independent
- to passive dependent

Social Support
- Isolation from family & friends

Future
- career or family plans
Ideal Model of Care

- Hospital & Community
- Age Appropriate
- Evidence Based
Paediatric Issues

Cognitive Impairment
- strokes, silent strokes
- attention, executive function, learning

Educational Problems
- loss of schooling
- academic achievement

Nutrition & Growth
- body image
- puberty
Adolescent Issues

Personal
- severity & chronicity of illness, limitations
- coping strategies, skills

Interpersonal
- family & peer relationships
- attitudes to health services & professionals

Adherence
- treatment & healthcare
- health beliefs & illness perceptions
Adolescent Needs

Transition in Care
- paediatric to adult
- readiness to transfer

Competence for Self-Management
- adequate knowledge
- self-efficacy

Independence Maturity & Responsibility
- confidence with age
- parents relinquish care
Challenges in Interventions

- Pain & Symptom Management
- Enhance Coping Ability
- Support Adherence to Treatment
- Reduction in distress & emotional problems
- Quality of life Improvement
Child & Adolescent Interventions I

Psychoeducation
- groupwork
- patient education
- coping skills
- creative arts eg. artwork, music

Family
- problem solving
- parents, family eg. siblings
Psychoeducation

- Psychoeducational App for children & adolescents
Child & Adolescent Interventions II

Cognitive Behavioural Therapy (CBT)

- coping skills
- emotional support
- self-help materials – manual, video

Coping with Sickle Cell Disease & Pain

A Self-help Manual for Children
Child & Adolescent Interventions III

Neuro-Educational

attention/concentration
executive function
memory & learning
processing speed/psychomotor
IQ (Not focus)
special needs plans (EHC)
extra tuition
Cognitive Behavioural Therapy

- long-term coping skills
- behaviour modification
- emotional distress
- self-help materials – manual, video

A SELF-HELP MANUAL

COPING WITH SICKLE CELL DISEASE AND PAIN
Adult Interventions - II

Neuropsychology

Attention/Concentration
Executive Function
Memory
Processing Speed
IQ (Not focus)
## Sickle Cell CBT Studies

<table>
<thead>
<tr>
<th>Patients</th>
<th>Children: N=65</th>
<th>Adolescents: N=46</th>
<th>Adults: N=59</th>
<th>Adults: N=35</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Intervention</strong></td>
<td>Individual: 6 Sessions CBT vs Art Therapy vs Attention Placebo</td>
<td>Group: 8 Sessions CBT vs Attention Placebo vs None</td>
<td>Individual: 6 Sessions CBT (manual assisted) vs None</td>
<td></td>
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<tr>
<td><strong>Outcome</strong></td>
<td>Reduced Healthcare Utilisation*</td>
<td>Reduced Emotional Pain Component</td>
<td>Reduced Anxiety</td>
<td>Improved Coping</td>
</tr>
</tbody>
</table>

Thank You!