The Somatising Adolescent and their Family

Department of Adolescent Medicine
The Children's Hospital at Westmead

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- Referring doctors
- Participating families

Occupational Therapist

Adolescent Physicians

Clinical Psychologist

Department of Adolescent Medicine

Artists

Psychiatrist

Social Workers

Clinical Nurse Consultant

Common Symptoms and Diagnoses

Unexplained symptoms

Sore throat/ cough

Dizziness

Headache

Chronic pain

Chronic fatigue syndrome

Tiredness

Shaking/twitching

Limb or joint pain

Fibromyalgia

Recurrent abdominal pain

Nausea

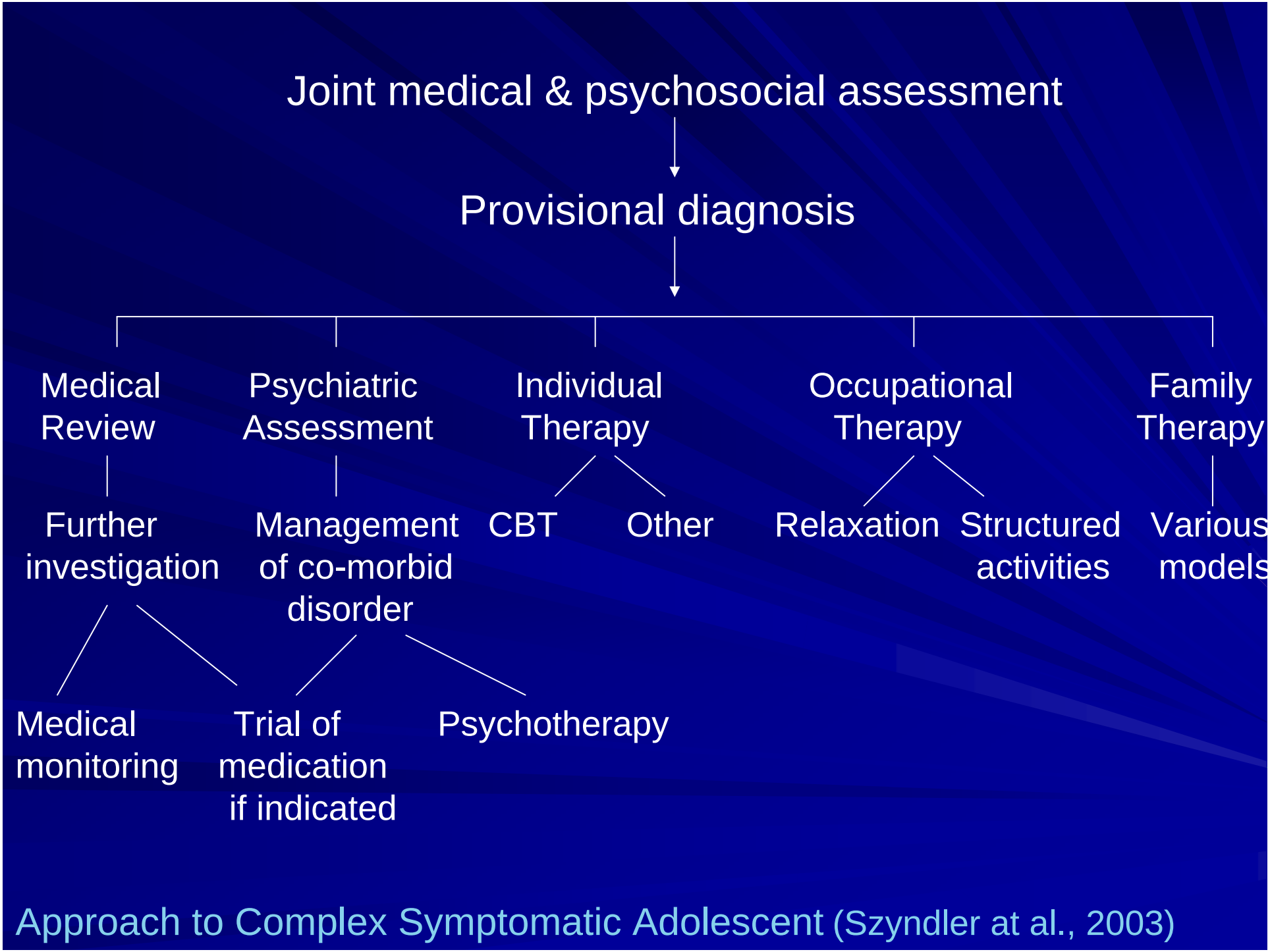
Pseudo-seizures

Somatoform disorder

Multi-Disciplinary Rehabilitative Approach

- Tailor treatment to patient's needs
- Improve quality of life by gradually increasing participation in daily activities
- Reduce number of unnecessary medical investigations

(Szyndler et al., 2003)



Approach to Complex Symptomatic Adolescent (Szyndler at al., 2003)

Research on Rehabilitative Treatment Approaches

- Lack of high quality evidence (Calvert & Jureidini, 2002)
- Available literature generally supports a rehabilitative approach (Garalda, 1996)
- Chalder (1999) found a multi-disciplinary rehabilitative approach is beneficial for chronic fatigue syndrome (CFS)
- However, Rangel et al. (2000) found no link between treatment and recovery in CFS

Study Aims

1) Does adolescent quality of life improve with our intervention?

Hypothesis:

- There will be a significant improvement in adolescent physical and emotional functioning after the first 4 months of treatment
- However, for many families it will take considerably longer (up to 12 months) for functioning to return to average levels.

Family Processes

- Based on a review of the literature, Garralda (1996, 2000) suggests the following risk factors are important in families:
  - Psychological distress
  - Health problems
  - Modelling of illness behaviour
  - Reinforcement of illness behaviour
  - Emotional distance
  - Closeness around health issues

Family Oriented Approach

- Engage all family members from initial assessment
- Attempt to involve all family members throughout treatment
- Offer family therapy if indicated

Research on Family Oriented Approaches

- Family involvement in treatment reduces relapse (Sanders et al., 1994; Chalder, Tong & Deary, 2002)
- No evidence about the mechanism by which family involvement improves efficacy
- No evidence on whether family oriented approaches impact on family functioning

Study Aims

2) a) Does family functioning improve with our intervention?

   b) Do changes in family functioning impact on improvement in quality of life?

Hypotheses:

- Significant improvements in family functioning will occur after 12 months of treatment.
- Those families whose functioning improves will experience greater increases in adolescent functioning.

Family Health Beliefs

- Families often focus on physical symptoms and are reluctant to discuss psychosocial issues
- Could the patient and family's beliefs about their condition impact on treatment outcome? (Szyndler et al., 2003)

Family Health Beliefs: CFS

- Adult literature
  - Making more physical attributions about symptoms is associated with worse physical functioning (Taillefer, 2002; Chalder et al., 2003)
- Child & adolescent literature
  - Children whose parents refuse to accept the possibility that psychological factors contribute to their symptoms have poorer outcomes (Garralda & Rangel, 2001)

Medical Family Therapy Model

- Assumes no biomedical event occurs without psychosocial consequences, and no psychosocial event occurs without some biological features.
- Aims to shift from an “Either-Or” way of thinking about causes that polarises families and doctors/therapists to “Both-And” thinking.
- Allows for a link to gradually be drawn between physical and psychological factors, without placing unnecessary strain on engagement.

(Watson & McDaniel, 2000)

Study Aims

3) a) Do adolescent and family health beliefs change with our intervention?

   b) Do changes in health beliefs impact on improvement in quality of life?

Hypotheses:

- Adolescents and their families will be more open to the role of psychosocial factors in their illness after 4 and 12 months of treatment.

- Those families who make these changes in their beliefs will experience greater improvements in adolescent functioning.

Subject Criteria

- Adolescents aged 12-17 years presenting to AMU with a chronic or relapsing pattern of unexplained physical symptoms

  (e.g. pain, dizziness, fatigue, nausea, sore throat, pins and needles, cough, shaking/twitching)

- The symptoms should be interfering with daily functioning

  (e.g. school attendance, social activities, self-care)

Questionnaires

- Administered to adolescents and parents at initial assessment, 4 months & 12 months.
- All questionnaires have been extensively validated and have good to excellent psychometric properties.
- Quality of life
  - Child Health Questionnaire (CHQ) (Landgraf & Ware, 1999)
  - Assesses functioning at home, school and social settings.
- Family Functioning
  - McMaster Family Assessment Device (FAD) General Functioning Scale (Epstein et al., 1983).
  - Evaluates families according to the McMaster Model of Family Functioning across 5 domains (Novack and Gage, 1995).
- Family Health Beliefs
  - Illness Perception Questionnaire (IPQ) (Weinman et al., 1996)
  - Assesses beliefs about illness in five domains.

Today: Some Preliminary Results

- Data from a group of adolescents and their mothers at initial presentation and 4 month follow-up
- 33 adolescents: 9 males and 24 females
  (Ratio is consistent with Offord et al (1987))
- Age range: 12-17 yrs (M = 14.8, SD = 1.3)
- Time to follow-up: 12-24 wks (M = 17.5, SD = 2.7)

Quality of Life (CHQ)

- Focussed on selected subscales

  Rated by both adolescent and mother:

  - Physical functioning
  - Limitations to role (school/socialising) due to physical health
  - Self esteem
  - General health

  Rated only by mother:

  - Emotional impact of adolescent's health on mother

Quality of Life (CHQ)

- Adolescent and mother's ratings were significantly below Australian norms* on all subscales at initial assessment

- For adolescents, after 4 months there were significant improvements in
  - Physical functioning ($p < 0.001$)
  - Physical impact on role ($p < 0.001$)
  - General health ($p < 0.01$)
  - Self esteem ($p < 0.01$)

* Waters et al., 2000, 2001

Quality of Life (CHQ)

- For mothers, after 4 months there were significant improvements in their ratings of
  - Teen physical functioning ($p < 0.001$)
  - Teen physical impact on role ($p < 0.001$)
  - Teen self esteem ($p < 0.001$)
  - Emotional impact of teen's health ($p < 0.001$)
- Ratings were still significantly below Australian norms at 4 months, with the exception of adolescent-rated self-esteem.

Conclusion

1) Does adolescent quality of life improve with our intervention?

   Yes, there were significant improvements in adolescent physical and emotional functioning after 4 months.

   However, most scales were still significantly below average at this stage.

Family Functioning (FAD)

- At initial assessment
  - Adolescent ratings of family functioning were not significantly different from US norms for a clinical population* (seeking help for family difficulties)
- After 4 months
  - No evidence from t-test of significant improvements in adolescent or mother ratings of family functioning
  - However, adolescents are now rating their families as significantly more functional than US clinical population.

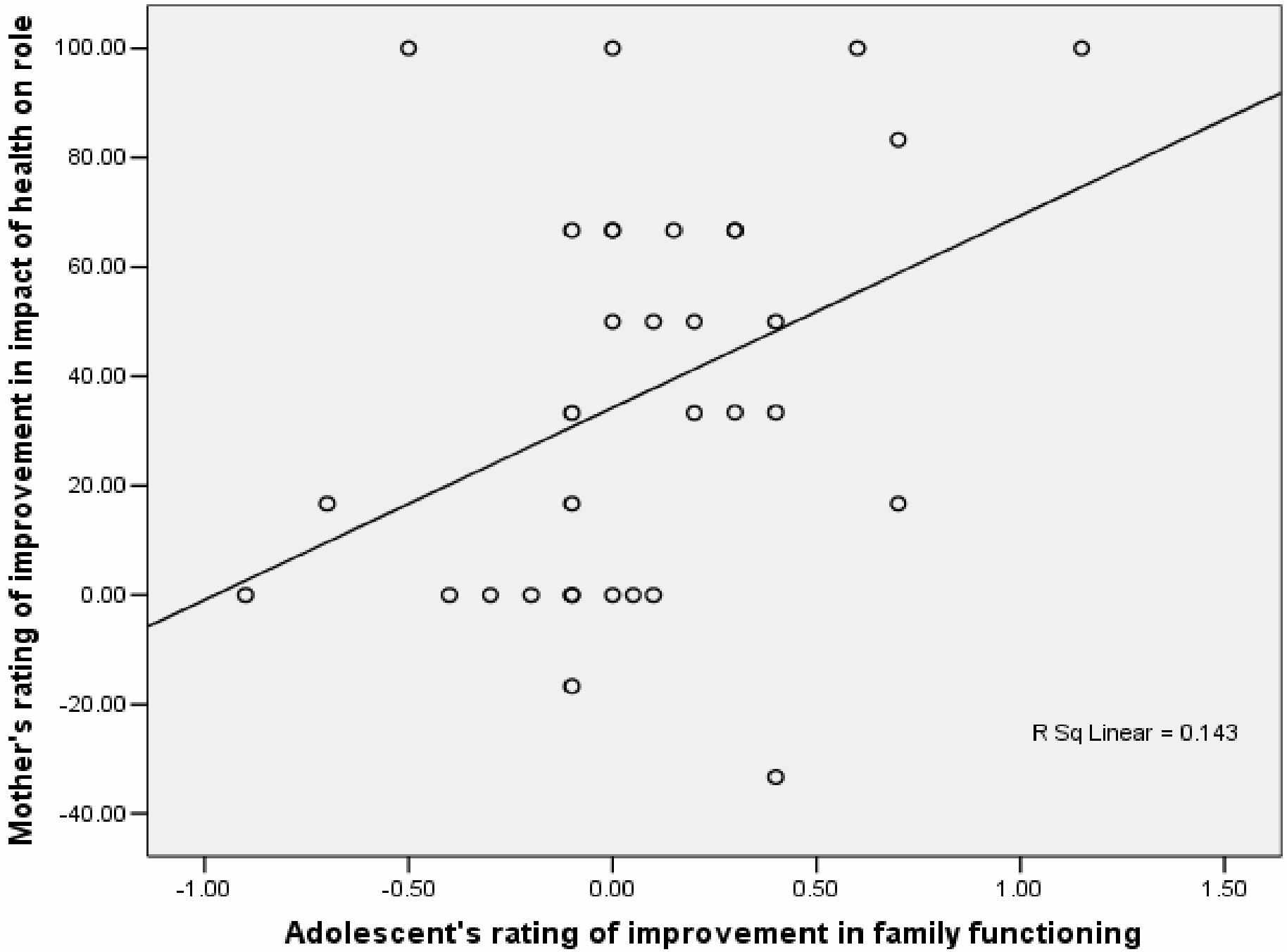
* Miller et al., 1985

Impact of Family Functioning on Quality of Life

- Greater improvements in adolescent ratings of family functioning (initial vs 4 months) predicted greater improvements in mother's ratings of teen physical impact on role.

- Using an MRA (stepwise method), both age and improved adolescent ratings of family functioning were found to be significant predictors of this variable ($F(2,31) = 6.866$, $p < 0.01$). Adjusted R square = 0.268.

Predictor variable	Beta	p
Improved family functioning	0.449	< 0.01
Age	-0.42	< 0.05


Mother's rating of improvement in impact of health on role
100.00
80.00
60.00
40.00
20.00
0.00
-20.00
-40.00
-1.00
-0.50
0.00
0.50
1.00
1.50
Adolescent's rating of improvement in family functioning
R Sq Linear = 0.143

Conclusion

2) a) Does family functioning improve with our intervention?

There is little evidence of this. However, we hypothesised that it would take 12 months to see significant changes in this area.

b) Do changes in family functioning impact on improvement in quality of life?

Yes, improved family functioning is associated with reduced impact of the adolescent's illness on school attendance and socialising. Further impacts may be seen by 12 months.

Health Beliefs (IPQ)

- Focussed on selected subscales and items. All were rated by both adolescent and mother.
  - Belief in the adolescent's personal control over their illness or symptoms.
  - Belief in treatment's control over the illness or symptoms.
  - Belief in the following causes of the illness:
    - Stress
    - Family problems

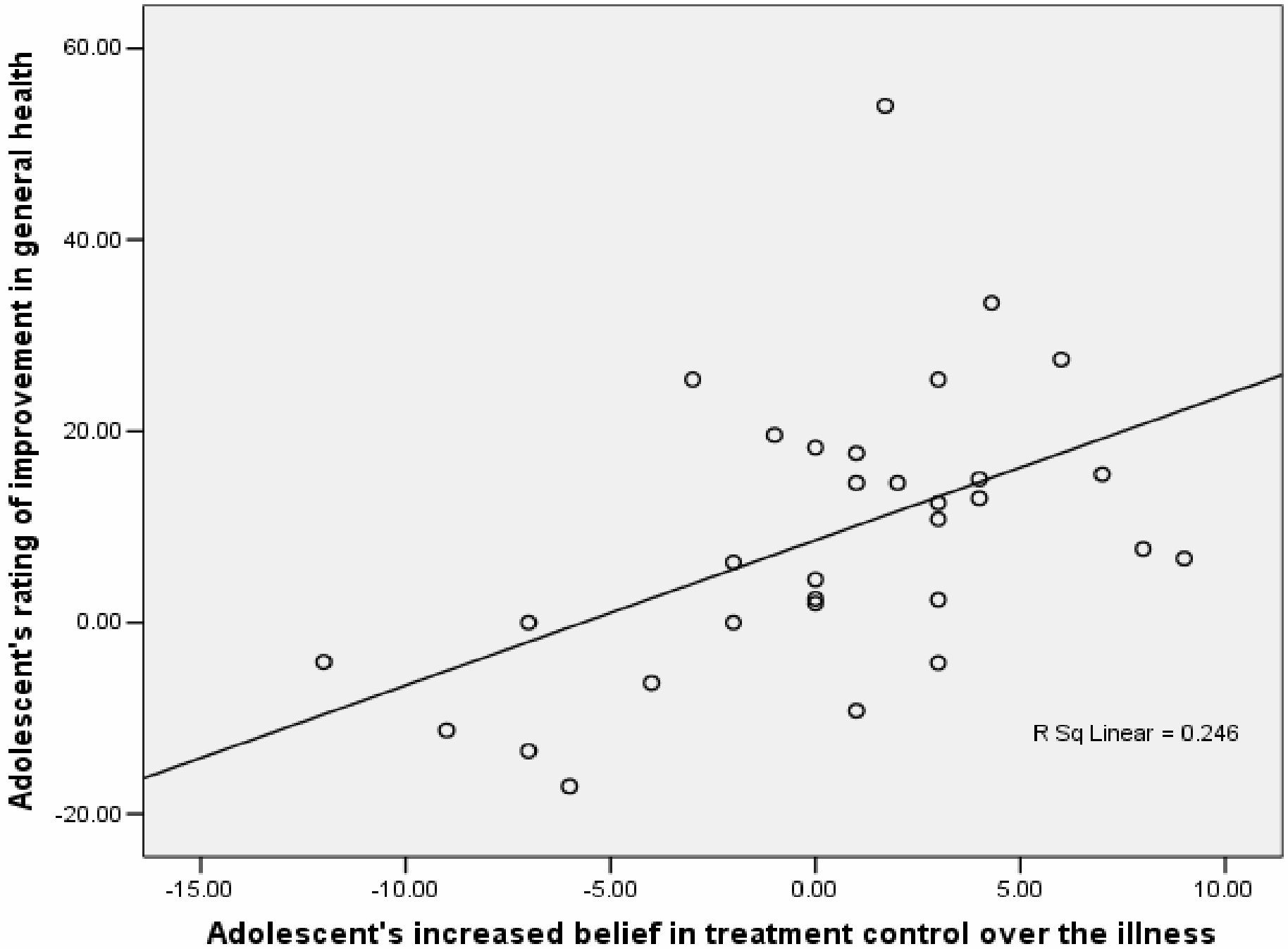
Beliefs About Illness/Symptom Control

- At the initial assessment
  - Mothers had a stronger belief in treatment's control over the illness than in the adolescent's control ($p < 0.05$)
- After 4 months
  - Mothers belief in the adolescent's personal control over the illness had significantly increased ($p < 0.05$)
  - Mothers had equal belief in the role of the adolescent and of treatment.
  - No evidence of significant changes in adolescent beliefs.

Impact of Beliefs About Illness Control on Quality of Life

- Greater increases in adolescent ratings of treatment control (initial vs 4 months) predicted greater improvements in their ratings of general health.
- Using an MRA (stepwise method), increased adolescent belief was found to be a significant predictor, but age was excluded ($F(1,29) = 9.446$, $p < 0.01$). Adjusted R square = 0.220.

Predictor variable	Beta	p
Increased belief in treatment	0.496	< 0.001
Age	-0.25	0.118


Adolescent's rating of improvement in general health
60.00
40.00
20.00
0.00
-20.00
-15.00
-10.00
-5.00
0.00
5.00
10.00
Adolescent's increased belief in treatment control over the illness
R Sq Linear = 0.246

Impact of Beliefs About Illness Control on Quality of Life

- There was a non-significant trend such that greater increases in adolescent ratings of their own control (initial vs 4 months) predicted greater improvements in their ratings of physical functioning ($p = 0.063$).

- There was a non-significant trend such that greater increases in mother's ratings of teen's own control predicted greater improvements in adolescent ratings of self esteem ($p = 0.078$).

Beliefs About Causes

- At the initial assessment
  - Mother and adolescent causal beliefs were similar to each other.
- After 4 months
  - Mothers' belief in stress as a cause had significantly increased ($p < 0.05$).
  - Mothers' belief in stress as a cause was now significantly greater than adolescents' ($p < 0.05$)

Impact of Beliefs About Illness Cause on Quality of Life

- Greater increases in mothers' beliefs in family problems as a cause (initial vs 4 months) predicted greater improvements in adolescent ratings of general health. ($F(1,31) = 7.416$, $p < 0.05$). Adjusted R square = 0.167.

Predictor variable	Beta	p
Increased belief in family problems as cause	0.439	< 0.05

Impact of Beliefs About Illness Cause on Quality of Life

- Greater increases in mothers' belief in stress as a cause predicted smaller improvements in their ratings of teen physical functioning. ($F(1,30) = 4.842$, $p < 0.05$). Adjusted R square = 0.167.

Predictor variable	Beta	p
Increased belief in family problems as cause	- 0.373	< 0.05

Conclusion

3) a) Do adolescent and family health beliefs change with our intervention?

After 4 months, there is evidence that some of the mother's health beliefs changed in the desired direction. However, there is little evidence of the desired changes for the adolescent.

b) Do changes in health beliefs impact on improvement in quality of life?

The evidence was mixed, with causal directions difficult to interpret.

Comments & Limitations

- The findings presented today suggest that adolescent functioning improves significantly after 4 months of our treatment.
- However, the lack of a control group means this improvement cannot be confidently attributed to the treatment.

Comments & Limitations

- The findings offer support for the inclusion of families in treatment as
  - Improving family functioning may help to improve quality of life
  - Mothers' health beliefs may be more amenable to change than adolescents'
  - Therefore, it may be more beneficial to work on changing the mother's health beliefs than the adolescent's
- However, further information is required to examine the full impact of treatment on family functioning and the relationships between health beliefs and quality of life.

Case Study

A 15 year old with persisting fatigue and nausea

Background Information

- Tina was referred to the complex clinic of the Department of Adolescent Medicine in September 2004.

- She was 13 years old at the time and had had a 12 month history of lethargy and intermittent nausea which had followed a flu-like illness.

Background Information

- She was in year 8 at a Performing Arts School where Dance was her major.
- There had been an increase in school absenteeism.
- Referring paediatrician had diagnosed mild hypothyroidism which could contribute to the symptoms.

Background Information

- She was commenced on an appropriate dose of Thyroxine but after one month there was no clinical improvement.
- He thought that her condition did not account for the full clinical picture.
- It was at this point that Tina met the Adolescent Medicine Team, comprised of the Physician, Senior Social Worker and Occupational Therapist.

Question 1

- Based on your clinical knowledge, and the research presented today, what is the important information to obtain during the assessment?

Answer

- Impact of symptoms on daily functioning
- Other possible medical causes
- Family beliefs about symptoms
- Family history of similar problems
- How family responds to symptoms
- General family history and interactions
- General adolescent assessment (HEADSS)

Assessment

- Assessment revealed that the family were very caught up with the physical description of the illness.
- Maternal grandmother, who had accompanied Tina and her mum, believed that Tina had been diagnosed with the same condition that she had been suffering with for many years.

Assessment

- Tina was having difficulty attending school regularly. When there, she was unable to concentrate or participate in all activities.

- She was struggling to keep up with extra dance classes after school. She had previously been dancing five days per week.

Question 2

- Based on this assessment, and the research presented today, what are the key goals/targets for intervention?

Answer

- Improve functioning/return to normal activities using
  - Symptom management strategies (e.g. relaxation training)
  - Graded return to normal activity levels
  - Coordination with school

Answer

- Involve all family members in treatment
- Work to gradually shift family focus from purely physical issues to
  - Recognising a role for psychosocial issues (“Both-And”, not “Either-Or”)
  - Recognising the role the adolescent can play in symptom management
- Regular contact to maintain progress (relapse prevention)

Treatment

- Intervention commenced with the family
- As the mum's beliefs changed and she recognised Tina's role in her recovery, so Tina's general health and wellbeing improved.

Mother's Sample Questionnaire Responses

	Initial assessment	4 months	12 months
Nothing my adolescent does will affect his/her illness	Neither agree/ disagree	Strongly disagree	Disagree

Mother's Sample Questionnaire Responses

	Initial assessment	4 months	12 months
Please indicate how much you agree/ disagree that stress/ worry is a possible cause of your adolescent's illness	Neither agree/ disagree	Neither agree/ disagree	Agree

Conclusion

- The benefit of these changes were evident in Tina's rehabilitation.
- Initially maternal grandmother was a notable voice demanding answers. Once Tina's mother accepted the role that Tina had in her recovery, the grandmother's voice became silent.
- Tina diligently followed the timetable grading her activity.

Conclusion

- Both she and her mother noticed the difference in her general health and emotional well being.
- Tina's school which had been visited at the outset, was in regular contact about her progress.
- Tina was able to attend school for a full day, 5 days a week by the end of that school term.
- She attended the clinic regularly because of the cyclical nature of her symptoms, but has continued to maintain the gains made.

Contact for further information about our project:

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