Religious/Spiritual Coping by Parents of Adolescents with Sickle Cell Disease: A Pilot Study

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National Institute of Child Health and Human Development

Parents & Chronic Illness

• What do they contend with?
  – Child diagnosed with illness, but parent bears stress of caregiving
  – Parents vulnerable to depression, especially in first year post-diagnosis and when child diagnosed at <1 year (Quittner, et al., 1992; Dewey & Crawford, 2007; Glasscoe, 2007)

• What do they report is helpful?
  – Parents of children with autism report (Tarakeshwar & Pargament, 2001)
    • behavior modification
    • disease self-education
    • religion
Religion vs. Spirituality

- **Religion**: the search for significance in ways related to the sacred
- **Spirituality**
  - Individualized search for that which gives transcendent meaning to life
  - Some differentiate spirituality from institutional aspects of religious tradition
- May be an academic distinction (74% of respondents considered themselves “spiritual and religious”) (Zinnbauer et al., 1996)

Religious/Spiritual Coping

- The search for significance, in ways related to the sacred, in times of stress.
- Based on work of Folkman and Lazarus (1984)
  - Appraisal of threat and resources
  - Thoughts or actions in response to threat
- Religious Coping can manifest as means of gaining:
  - Control
  - Comfort or Intimacy

Religious Coping and Positive Health Outcomes

• Religion as helpful
  – Inverse relationship between religious beliefs and depressive symptoms in mothers of children with cancer (Elkin et al., 2007)
  – Lower mortality following open-heart surgery (Oxman, et al., 1995)
  – Less depression in elderly hospitalized men (Koenig, et al. 1992)
  – Better function and treatment compliance after heart transplant (Harris RC, et al. 1995)

Religious Coping and Negative Health Outcomes

• Religion as harmful
  – Discontent with congregation and or Deity linked to negative affect (Brant & Pargament, 1995)
  – Negative reframing
    • Illness as God’s punishment was strongest predictor of depression & psycho-social disability (Pargament et al. 1998 & 2008)
    • “Always associated with poorer outcome” in a review of 40 studies (Burke et al., 2004)
Sickle Cell Disease

• Sickle Cell Disease is a genetic, life-shortening chronic disease affecting 1 out of every 500 African-Americans
• Mortality rate about 3 per 1000 person-years (Shankar et al., 2008)

Sickle Cell Disease

• Sickle-shaped red blood cells occlude blood vessels
  – Decreased oxygen
  – Pain
  – Infection
  – Stroke
  – Slowed growth & delayed sexual maturation
• Many adolescents manage well, but some experience anxiety, depression, low social activity and school disruption—which all impact their parents!
  Mitchell et al., 2008
Religion/Spirituality and Sickle Cell Disease

• Organized religiosity associated with fewer negative pain experiences and lower psychiatric disturbances in 50 SCD outpatients (Harrison et al., 2005)

• Prayer was significant method of mothers’ coping with their child’s SCD (Wilson & Miles, 2001)
  – Semi-structured interviews; 14 mothers of infants with SCD
  – Prayer emerged as core theme
  • 12 mothers personally prayed
  • 2 mothers described ministers’ prayers as helpful

Purpose of Study

This study had two specific aims:

1. Describe religiosity, spirituality, and religious/spiritual coping of parents of adolescents with sickle cell disease

2. Describe relationship between religious/spiritual coping and health-related quality of life
Measures

• Demographic and clinical characteristics
• Religiosity (e.g., importance of religion, frequency of prayer)
• Religious Coping (Brief R-COPE\(^1\))
  – 14 items, each scored 0-3
  – 2 subscales
    • Positive religious coping
    • Negative religious coping
  – “…ways you have coped with your child’s SCD since s/he was diagnosed…”
\(^1\)Pargament, K., 1997

• Spirituality (FACIT-Sp\(^2\); 12 items)
  – “How true each of the following has been for you over past 7 days?”
  – Total and 2 subscales
    • Peace and meaning
    • Faith
• Health-related Quality of Life (PedsQL Parent\(^3\); 23 items)
  – “in the past one month, how much of a problem has your teen had with…?”
  – Total and 4 subscales
    • Physical functioning
    • Emotional functioning
    • Social functioning
    • School functioning
\(^2\)Peterman, A., et al., 2002
\(^3\)Seid, M., et al., 1999
Measures

- Complementary/Alternative Medicine (CAM) questions
  - “How often has your child used one of the following modalities to manage his/her SCD symptoms?”
  - “Would you consider using any of these types of treatment with your child to help with managing your child’s SCD symptoms?”
  - 5 modalities: Guided Imagery, Prayer, Meditation, Yoga, Relaxation

Recruitment

- 6th Annual Sickle Cell Research & Education Day
  - Joint venture between Divisions of Hematology/Oncology and Behavioral Medicine/Clinical Psychology at CCHMC
  - Participation
    - 96% of SCD families from clinic attend
    - 286 persons (total family members and patients)
    - 100+ volunteers (families, nurses, physicians)
    - 72 eligible 11-19 year-old with SCD from 68 families
Recruitment

- Parents of eligible teens (11-19yo)
- When adolescent presented for study, parent invited to complete parent study simultaneously
- 100% participation by parents who were offered [N=26]
- Trained interviewers obtained consent, provided questionnaires
- Paid $35 cash
Results: Demographics (n=26)

- Mean Age: 41 yo (sd 8.2)
- Race: 25 (96%) African-American
- Gender: 24 (92%) female
- Religion:
  - 15 (58%) “Protestant”
  - 5 (19%) “None”
  - 6 (19%) “Other,” specifying, “Nondenominational”
  - 0 “Catholic,” “Jewish,” or “Muslim”
Religious and Spiritual Characteristics

- 100% reported belief in God
- 96% said religion “very important” or “important”
- 85% reported use of prayer to cope with SCD daily
- 35% meditated at least weekly
- 23% attend services at least weekly; 57% monthly
- 73% consider themselves a “very” or “moderately” religious
- 88% consider themselves a “very” or “moderately” spiritual

Positive Religious Coping

“quite a bit” and “a great deal”

<table>
<thead>
<tr>
<th>Activity</th>
<th>% (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Looked for stronger connection with God</td>
<td>23 (89%)</td>
</tr>
<tr>
<td>Sought God’s love and care</td>
<td>23 (89%)</td>
</tr>
<tr>
<td>Asked forgiveness for my sins</td>
<td>18 (69%)</td>
</tr>
<tr>
<td>Tried to see how God might be strengthening</td>
<td>17 (66%)</td>
</tr>
<tr>
<td>Tried to put my plans into action with God</td>
<td>16 (62%)</td>
</tr>
<tr>
<td>Focused on religion to stop worrying</td>
<td>14 (54%)</td>
</tr>
<tr>
<td>Sought help from God in letting go of anger</td>
<td>13 (50%)</td>
</tr>
</tbody>
</table>
### Negative Religious Coping

**“Felt punished by God for lack of devotion”**

<table>
<thead>
<tr>
<th>Response</th>
<th>N</th>
<th>Percent</th>
<th>Cumulative %</th>
</tr>
</thead>
<tbody>
<tr>
<td>a great deal</td>
<td>3</td>
<td>12%</td>
<td>12%</td>
</tr>
<tr>
<td>quite a bit</td>
<td>2</td>
<td>8%</td>
<td>20%</td>
</tr>
<tr>
<td>somewhat</td>
<td>6</td>
<td>23%</td>
<td>43%</td>
</tr>
</tbody>
</table>

### Negative Religious Coping

**“Wondered what I did for God to punish me”**

<table>
<thead>
<tr>
<th>Response</th>
<th>N</th>
<th>Percent</th>
<th>Cumulative %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somewhat</td>
<td>6</td>
<td>23%</td>
<td>23%</td>
</tr>
<tr>
<td>quite a bit</td>
<td>0</td>
<td>0</td>
<td>23%</td>
</tr>
<tr>
<td>A great deal</td>
<td>3</td>
<td>12%</td>
<td>35%</td>
</tr>
</tbody>
</table>
## Negative Religious Coping

**Wondered whether God abandoned me**

<table>
<thead>
<tr>
<th>Response</th>
<th>N</th>
<th>Percent</th>
<th>Cumulative %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somewhat</td>
<td>1</td>
<td>4%</td>
<td>4%</td>
</tr>
<tr>
<td>Quite a bit</td>
<td>1</td>
<td>4%</td>
<td>8%</td>
</tr>
<tr>
<td>A great deal</td>
<td>1</td>
<td>4%</td>
<td>12%</td>
</tr>
</tbody>
</table>

**Decided the devil made this happen**

<table>
<thead>
<tr>
<th>Response</th>
<th>N</th>
<th>Percent</th>
<th>Cumulative %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somewhat</td>
<td>4</td>
<td>15%</td>
<td>15%</td>
</tr>
<tr>
<td>Quite a bit</td>
<td>0</td>
<td>0</td>
<td>15%</td>
</tr>
<tr>
<td>A great deal</td>
<td>1</td>
<td>4%</td>
<td>19%</td>
</tr>
</tbody>
</table>

**Questioned God’s love for me**

somewhat, quite a bit, a great deal  \( N=4 \)  15%

**Questioned the power of God**

somewhat, quite a bit, a great deal  \( N=4 \)  15%

**Wondered whether church abandoned me**

somewhat, quite a bit, a great deal  \( N=3 \)  12%
Spirituality

- Mean scores:
  - Total Score 32.8 (6.4)
  - Meaning/Peace 20.6 (3.5)
  - Faith 12.2 (3.5)
- Comparable to scores of adults with chronic illness

Quality of Life and Religious Coping

- Fair positive correlation between positive religious coping and higher emotional well-being ($r = 0.34; p=0.08$)
  - No significant correlation between positive religious coping and either total HRQoL score or other subscales (physical, school, or social functioning)
- No significant correlations between HRQoL and negative religious coping.
Use of Mind-Body CAM for Symptoms

<table>
<thead>
<tr>
<th>Method used to Manage Symptoms</th>
<th>Never used</th>
<th>Used about Once</th>
<th>About Once per Week</th>
<th>A few Times per Week</th>
<th>Once a Day or More</th>
<th>Would Consider Using in the Future (% yes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relaxation or Biofeedback</td>
<td>1</td>
<td>2.7</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>85%</td>
</tr>
<tr>
<td>Guided Imagery</td>
<td>1.6</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>77%</td>
</tr>
<tr>
<td>Prayer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4.0</td>
<td>5</td>
<td>88%</td>
</tr>
<tr>
<td>Meditation</td>
<td>1</td>
<td>2.2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>77%</td>
</tr>
<tr>
<td>Yoga</td>
<td>1.7</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>58%</td>
</tr>
</tbody>
</table>

Limitations

- Small sample size
- Cross-sectional
Conclusions

• Religious/spiritual issues relevant to these parents
  – Mothers reported high religiosity
  – Mothers report frequent positive religious/spiritual coping
  – Prayer most frequently used CAM modality for symptoms
• Further investigation is warranted among parents of adolescents with chronic diseases:
  – Negative religious/spiritual coping persists
  – Supporting use of positive religious coping that may result in improved emotional well-being

Future Research

• Examine negative religious coping and outcomes in parents of child with chronic illness
• How does religious coping change over disease trajectory?
• Upcoming K23 proposal to NIH (June, 2009)
  – Use of Religion and Religious Coping by families dealing with chronic diseases of childhood
Thank you!

Questions/Comments?

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