Religious/Spiritual Coping among Young Adults with Cancer

Rebecca H. Johnson, MD
Medical Director, AYA Cancer Program
Mary Bridge Hospital/ MultiCare Health System

Background

• Clinical observation from a pastor: “young adults struggle the most”
• Among adults:
  – Religion and spirituality are important in navigating the cancer experience
  – 70% of patients want to discuss religion and spirituality with their physicians and nurses
  – Religious/Spiritual (R/S) coping:
    • Positive R/S coping: a resource
    • R/S struggle:
      – Common
      – Associated with adverse physical, social, spiritual, emotional, outcomes including post-traumatic stress, fear of recurrence
      – Anger towards God is associated with poorer adjustment to cancer


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Background

Among AYAs with cancer:
– No previous quantitative studies about R/S coping in young adults 18-39 years old in active treatment for cancer
– Suggestion of higher incidence of anger toward God in young compared to older adults


R/S Coping Measures: The Brief RCOPE

• 14-item “gold standard” measure of R/S coping with major life stressors
• Predominantly used in adults; also healthy YA college students
• Positive and negative coping subscales
• Scored 0 “not at all,” to 3 “a great deal”

Pargament K et al. (2011) Religions
Positive R-COPE subscale:

- Measures secure relationships with the Divine
  - Sense of connectedness
  - Secure relationship with the Sacred
  - Sense that life has a greater meaning

→ Among adults with cancer: an important and positive emotional resource

Negative R-COPE Subscale

- Measures tensions and struggle with the Divine
  - Within oneself: feeling unloved or abandoned by God/Higher Power
  - Interpersonal: feeling abandoned by one’s R/S community

- Robust predictor of health-related outcomes
- Any degree of response predicts adverse physical, social, spiritual, and emotional outcomes among adults with cancer
Religious and Spiritual Struggles Scale (RSS)

- Newer
- More spiritually inclusive; less theistically oriented
- 26-items in 6 domains: divine, demonic, interpersonal, moral, ultimate meaning, and doubts
- 5-point Likert scale


Religion and Spirituality (R/S) among AYAs

- U.S. AYAs reported to be less religious than older adults, but equally spiritual:
  - “Experiencing a deep sense of wonder,
  - Thinking about the meaning of life,
  - Feeling gratitude”

- AYAs facing physical and mental health struggles describe religion/spirituality as important in coping with illness


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R/S coping in other populations: military veterans

• Among veterans with combat exposure (mean age 36), those with R/S struggle had:
  – More post traumatic stress symptoms
  – Higher risk of suicide (after controlling for other variables)

Mental health among AYAs with cancer

• Moderate to severe post-traumatic stress symptoms in 44% one year after diagnosis
• Compared to healthy peers, increased risk for:
  – Lower QoL
  – Depression requiring hospitalization
    • Elevated risk persists for years
  – Suicide
    • Attempted (HR=4.0)
    • Completed (HR=2.6)
• 40% endorse unmet needs for mental health and support group services
• Could R/S struggle contribute to psychosocial outcomes?

Purpose

Among YAs during the first two months after cancer diagnosis:

– Describe the prevalence and nature of R/S coping and struggle
– Describe the associations between:
  • R/S coping (Brief R-COPE)
  • R/S struggle (Religious and Spiritual Struggles Scale, RSS)
  • These variables and:
    - depression
    - quality of life
    - demographic characteristics

Eligibility

• 15-39 years of age
• Diagnosed with cancer of any type 2 to 8 weeks prior to study enrollment
• Expected to remain on treatment for at least 12 weeks following study enrollment
• Able to speak, read, and write English to complete study measures
• Physical and cognitive capacities to complete measures
Setting

- Participants recruited from the Pacific Northwest:
  - 10 community-based clinics providing care to adults with cancer
  - 1 community pediatric hospital-based clinic providing care to adolescents with cancer

Questionnaires

- Administered using REDCap survey
- 2-8 weeks after diagnosis
- Completed by participants on personal mobile device or computer via an emailed link
- Estimated time for completion <30 minutes
Self-report measures

- R/S Coping (Brief R-COPE)
- R/S Struggle (RSS, Religious and Spiritual Struggles Scale RSS)
- Depression (PHQ-8, Personal Health Questionnaire Depression Scale)
- Quality of life (MQOL, McGill Quality of Life Questionnaire)
- Spiritual/religious identification and practices (investigator developed questions, 2 questions from Duke University Religion Index (DUREL))
- Intensity of treatment experience (investigator developed questions)
- Demographic characteristics (age, ethnicity, race, gender, education, occupational status, marital status, parental status, cancer diagnosis)

Participants

- 49 enrolled
  - 4 excluded: did not complete questionnaires
  - 1 participant <18 years: excluded to create homogenous sample of YAs
- Final N=44 respondents aged 18-39 years
  - Mean age 32.1 ± 5.9 years
  - 57% female
  - 68% Caucasian
  - 45% College graduates or held advanced degrees
  - 54% Employed part- or full-time
  - Breast cancer (43%), Lymphoma (34%)
• 64% Christian
• 82% \((n=36)\) identified as religious \((n=4)\), spiritual \((n=10)\), or both \((n=22)\)
• 29% attended church at least a few times/month,
• 61% spent time in private religious/spiritual practice at least a few times/month

Results

• **Positive R/S coping: 89 %**
  – Did not correlate with QoL or depression
• **Negative R/S coping (struggle): 64%**
  – **Correlated with:**
    • Presence of depression
    • Inferior QoL
More Struggle in females and participants in committed relationships

<table>
<thead>
<tr>
<th>Brief RCOPE Struggle</th>
<th>Full Sample (N=44)</th>
<th>No (n=16)</th>
<th>Yes (n=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean SD Mean SD Mean SD p-value</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>32.1 5.9 31.8 6 32.3 5.9 0.76</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>N % N % N % p-value</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>30 68.2% 12 75.0% 18 64.3% 0.69</td>
<td></td>
<td></td>
</tr>
<tr>
<td>College/Advanced degree</td>
<td>20 45.5% 7 43.8% 13 46.4% 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed part/full time</td>
<td>24 54.5% 9 56.3% 15 53.6% 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>In committed relationship</td>
<td>32 72.7% 9 56.3% 23 82.1% 0.09</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>28 63.6% 10 62.5% 18 64.3% 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Breast</td>
<td>19 43.2% 4 25.0% 15 53.6% 0.16</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lymphoma</td>
<td>15 34.1% 8 50.0% 7 25.0%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>10 22.7% 4 25.0% 6 21.4%</td>
<td></td>
</tr>
<tr>
<td>Religious/Spiritual Identification</td>
<td>Religious but not spiritual</td>
<td>4 9.1% 1 6.3% 3 10.7% 0.67</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Spiritual but not religious</td>
<td>10 22.7% 4 25.0% 6 21.4%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Both spiritual and religious</td>
<td>22 50.0% 7 43.8% 15 53.6%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Neither spiritual nor religious</td>
<td>7 15.9% 4 25.0% 3 10.7%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Christian affiliation</td>
<td>28 63.6% 9 56.3% 19 67.9% 0.66</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Attends church at least a few times per month</td>
<td>13 29.5% 4 25.0% 9 32.1% 0.73</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Prays at least a few times per month</td>
<td>27 61.4% 10 62.5% 17 60.7% 1</td>
<td></td>
</tr>
</tbody>
</table>

Positive correlation between RCOPE Struggle and RSS

<table>
<thead>
<tr>
<th>Brief RCOPE Struggle</th>
<th>Full Sample (N=44)</th>
<th>No (n=16)</th>
<th>Yes (n=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean SD Mean SD Mean SD p-value</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brief RCOPE Positive Religious Coping</td>
<td>11.8 7.2 9.5 7.7 13.1 6.7 0.13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RSS Total</td>
<td>1.4 0.36 1.2 0.23 1.5 0.39 0.004</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PHQ-8</td>
<td>6.6 4.6 5.6 4 7.2 5 0.27</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MQOL Total</td>
<td>6.7 1.6 7.1 1.7 6.4 1.5 0.16</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

RSS: Religious and Spiritual Struggles Scale
PHQ-8: Patient Health Questionnaire 8
MQOL: McGill Quality of Life questionnaire

despite focusing on different types of R/S distress

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Females reported significantly higher R/S Struggle, more depression, inferior QoL

<table>
<thead>
<tr>
<th></th>
<th>Female (N=25)</th>
<th>Male (N=19)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>RSS</td>
<td>Mean 1.5</td>
<td>Mean 1.2</td>
<td>0.03</td>
</tr>
<tr>
<td></td>
<td>SD 0.4</td>
<td>SD 0.2</td>
<td></td>
</tr>
<tr>
<td>PHQ-8</td>
<td>Mean 8.6</td>
<td>Mean 4.1</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td></td>
<td>SD 4.5</td>
<td>SD 3</td>
<td></td>
</tr>
<tr>
<td>MQOL Total</td>
<td>Mean 6.1</td>
<td>Mean 7.4</td>
<td>0.005</td>
</tr>
<tr>
<td></td>
<td>SD 1.4</td>
<td>SD 1.6</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>N 11</td>
<td>N 1</td>
<td>0.006</td>
</tr>
<tr>
<td></td>
<td>% 44.0%</td>
<td>% 5.3%</td>
<td></td>
</tr>
</tbody>
</table>

92% with depression were female

Respondents with depression had significantly higher R/S struggle (p=0.007)

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### Results by Diagnosis

#### Female vs. male

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain tumor</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Leukemia</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Breast</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>Testicular</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Cervical</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Colon</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>25</td>
<td>20</td>
</tr>
</tbody>
</table>

#### Not depressed vs. depressed

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Not Depressed</th>
<th>Depressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain tumor</td>
<td>2 6%</td>
<td>0</td>
</tr>
<tr>
<td>Leukemia</td>
<td>2 6%</td>
<td>0</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>12 36%</td>
<td>3 25%</td>
</tr>
<tr>
<td>Breast</td>
<td>12 36%</td>
<td>7 58%</td>
</tr>
<tr>
<td>Testicular</td>
<td>3 9%</td>
<td>0</td>
</tr>
<tr>
<td>Cervical</td>
<td>0</td>
<td>1 8%</td>
</tr>
<tr>
<td>Colon</td>
<td>2 6%</td>
<td>1 8%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>33 100%</td>
<td>12 100%</td>
</tr>
</tbody>
</table>

#### No R/S struggle vs. struggle

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>No Struggle</th>
<th>Struggle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain tumor</td>
<td>1 6%</td>
<td>1 4%</td>
</tr>
<tr>
<td>Leukemia</td>
<td>2 12%</td>
<td>0</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>8 47%</td>
<td>6 23%</td>
</tr>
<tr>
<td>Breast</td>
<td>4 24%</td>
<td>14 54%</td>
</tr>
<tr>
<td>Testicular</td>
<td>1 6%</td>
<td>2 8%</td>
</tr>
<tr>
<td>Cervical</td>
<td>0</td>
<td>1 4%</td>
</tr>
<tr>
<td>Colon</td>
<td>1 6%</td>
<td>2 8%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>17 100%</td>
<td>26 100%</td>
</tr>
</tbody>
</table>

Of patients with R/S Struggle:
- 71% were female
- >50% were females with breast cancer

### Limitations

- **Design**
  - Cross-sectional design
  - Variable initial time point (2 to 8 weeks after diagnosis)

- **Setting and Sample**
  - Small sample size
  - Geographic region noted for low religious identification
  - Sample homogeneity (Caucasian, female, educated, breast cancer)
  - High proportion of young women with breast cancer (43% of sample)
    - Worse HRQoL among young women recently diagnosed with breast cancer (vs. young women with other cancers)
    - Depression rates >2x higher among young women than young men


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Conclusions

• **Among YAs with cancer:**
  • More than half experience R/S struggle
  • Female>Male
  • Any degree of R/S struggle was associated with depression, decreased QoL

Conclusions

• High frequency of R/S struggle validates need for pastoral care in the AYA multidisciplinary care team

• How to determine who is struggling?
  • **Systematic use of screening tools?**
    • R/S struggle is not picked up by standard tools;
    • Only 25% of adults endorse distress on NCCN thermometer
  • **Or is a conversation with clinician preferable?**
    • Adults who ask for consults tend to have low struggle (low need for support) and high spiritual needs
    • Should this topic be raised proactively with young adults?
Next Steps

• Clinicians should:
  – Recognize the high frequency of R/S struggle in AYAs
  – Normalize the experience when talking to patients
  – Make appropriate referrals

• Develop and test a clinical screening tool for R/S struggle
  – Brief, acceptable, sensitive/specific
  – Clinically relevant cut score

• Explore covariates: Is there a phenotype of YA females with breast cancer at highest risk for depression and R/S struggle?

Thank you