Session 1:
“Why Me?” The Religious/Spiritual Concerns and Resources of Adolescents/Young Adults Receiving Blood and Marrow Transplants

APC Webinar Journal Club V
What Chaplains Do, What Patients and Families Need: Learning from Research
Presented by George Fitchett PhD BCC
and Sr. Patricia Murphy PhD BCC
Five sessions presented on Tuesdays
September 22, 2015, November 10, 2015, January 12, 2016,
March 8, 2016, May 10, 2016
2:00 pm - 3:00 pm Eastern
1:00 pm - 2:00 pm Central
12:00 pm - 1:00 pm Mountain
11:00 am - 12:00 pm Pacific
2 CE hours for 2013
2 CE hours for 2014
Plus reading/study hours

APC Webinar Journal Club V
http://www.professionalchaplains.org/calendar_list.asp

George and Pat and Research at Rush
Our research website:
www.rushu.rush.edu/rhhv
click on Research in Religion, Health & Human Values

RUSH UNIVERSITY MEDICAL CENTER
### Webinar Journal Club Aims

- To help participants use research about what chaplains do, and what patients and families need to critically reflect on their current practice.
- To inform participants about current issues in professional chaplaincy.
- To provide participants with resources that can help them advance their practice and advocate for its importance.
- To help chaplains develop and maintain research literacy, including the ability to critically read research and, where appropriate, apply the findings in their professional practice.

### The State of Research in Chaplaincy

- **Case Studies**
  - allow the reader to observe **specific behaviors** of a chaplain with a single patient and the **outcome of the interventions**.
- **Qualitative Studies**
  - gathers information from a group of people with questions that let respondents reply with their own words. Researchers systematically synthesize the information to find common themes.
Qualitative Research in this study

• A Qualitative Method: Grounded Theory
  – Purpose: Explore a little-known subject by gathering data based on the experience of the participants
  – Data collection: interviews
  – Data analysis: layers of coding processes resulting in key themes
• Longitudinal study
  – Question of whether R/S changed in the process of BMT

Quantitative Research

• Bases information on questionnaires that respondents complete v. their own words;
• Can provide information about the frequency of response (e.g., using Religion or Spirituality to cope);
• Lets the research team explore variables related to the outcome;
• Can explore relations of cause and effect between interventions and outcomes in a large enough sample;
• Can infer results apply to a population.
Research in Chaplaincy

- Chaplains need to gather evidence about
  - chaplain interventions.
  - patients’ stated needs;
  - Specific outcomes of interventions.
- We have chosen articles for this webinar series that move our work towards the goal of evidence-based practice.

What is Evidence-Based Practice?

Evidence-based practice in psychology is the integration of

- the best available research
with
- clinical expertise
- in the context of patient characteristics, culture, and preferences.

Evidence-Based Practice (EBP) Model

- Practitioner’s Individual Expertise
- Best Evidence
- Client Values and Expectations

AMERICAN PSYCHOLOGICAL ASSOCIATION
APA Policy Statement on Evidence-Based Practice in Psychology, 2005
Objectives for this Session

Aims for reading this article through the Webinar journal club:
1. To make chaplains aware the ways that adolescents and young adults turn to religion or spirituality (R/S) to cope with serious illness;
2. To encourage chaplains to use qualitative research to deepen their understanding of their patients’ R/S needs and resources;
3. To help chaplains develop and maintain research literacy, including the ability to critically read research and, where appropriate, apply the findings in their professional practice.

There is research about adults

Adults Use Religion or Spirituality to Cope

For some adults, coping can be related to struggle
• Struggle with the Divine – threatening view of God, feel abandoned by or angry with God
• Intrapersonal – questions, doubts about spiritual matters
• Interpersonal – family, friends, congregation

Canada et al., 2013

Pargament, 1997; Pirutinsky et al., 2011
What about adolescents and young adults?

- The introduction to today’s article gives a succinct summary that is worth reading carefully.
- The authors point out that there is limited information about R/S in younger patients.
- It is important to fill this gap with evidence.

A Case Study

God tells the doctors to pick the right medicine – LeeAnn, a 12 year old girl with cystic fibrosis

Dan Grossoehme, also from Cincinnati’s Children’s hospital, provides evidence of the use of Religious/Spiritual coping through a case study.

(Grossoehme in Fitchett & Nolan, Eds, 2015)
Study Aims

1. to examine how adolescents and young adults (AYA) receiving Hematopoietic stem cell transplant (HSCT) use religion or spirituality R/S to help them cope with their illness and transplant;
2. to examine whether the experience of a (HSCT) led to changes in the AYA understanding of R/S beliefs;
3. To promote evidence-based care interventions for chaplains on the health care team.
Methods: Sample

- 12 Patients aged 15 to 28 receiving HSCT
- at Cincinnati Children's Hospital, well enough for an interview
- Assented or consented

Methods

Qualitative research using grounded theory:

First Interview (n=12)
- Interviewed as close to HSCT as possible;
- Semi-structured Interview: e.g. “How would you describe your faith beliefs today?” p. 1243

Second Interview 1 year after transplant (n = 6)
- Different semi-structured interview: e.g. “Was your way of doing faith changed at all by this experience?” p. 1243

Interviewers: PhD in qualitative research familiar with chaplaincy or chaplain with master’s level training in qualitative methods.

Synthesizing: text coded by interdisciplinary team; authors gathered into subject categories; compared codes from two different group of coders; settled on categories after reached saturation.
Results First Interview: Religious/Spiritual Perspectives of Adolescents & Young Adults Receiving HSCT

<table>
<thead>
<tr>
<th>Asking “Why me?”</th>
<th>“I feel like emotional, like why me? (tearful). Like why this point in my life when I’m just about to go off to college . . . and now I can’t go right now.”</th>
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<td>Asking “What will happen to me”</td>
<td>Two participants addressed the question of eternal life by requesting and receiving the Christian rite of baptism.</td>
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<td>Believing God has a reason</td>
<td>“He chose me ’cause I’m strong. I understand what I have to go through.”</td>
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<td>Using faith practices</td>
<td>“And just when I’m in pain and I pray for peace . . . that side effects won’t be too bad.”</td>
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<td>Benefitting from spiritual support people</td>
<td>“My pastor’s wife is one of the biggest helps because. . . she talks to me like I’m normal.”</td>
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Themes for 12 AYAs (age 15-28, 7 female, interviewed 2 weeks pre to 3 months post-transplant; 6 re-interviewed 1 yr post-transplant); Ragsdale et al., 2014

Results Interview 2: Religious/Spiritual Perspectives of Adolescents & Young Adults a Year After HSCT

<table>
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<tr>
<th>Believing God chose me</th>
<th>“It’s just, it made me realize that God is using me in a big way and he’s just using me to touch a lot of lives...”</th>
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<tbody>
<tr>
<td>Affirming that my life has a purpose</td>
<td>“I trust God’s plan more...and I know that He’s got a reason even if it takes forever to figure it out.”</td>
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<td>Receiving spiritual encouragement</td>
<td>“Our heads were just kind of bobbing around, not really knowing what’s going on and the youth pastor came in and he just really kind of put us back in the...kind of relaxed mode...”</td>
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<td>Experiencing faith</td>
<td>“I’ve gotten really close to God. Me and him haven’t always been close and me going through this just opened my eyes and showed me he is a very big part of everybody’s life.”</td>
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Themes for 6 AYAs re-interviewed 1 yr post-transplant); Ragsdale et al., 2014
Religious/Spiritual Perspectives of Adolescents & Young Adults Receiving BMT

“We learned that AYA patients were utilizing R/S far more than we suspected.

Our data . . . suggest that chaplains should be proactive in asking AYA patients about their understanding and use of faith.”

Ragsdale et al., 2014

Discussion with
Judy Ragsdale, PhD, ACPE
and
Mary Ann Hegner, MA, BCC

1. What gave you the passion to explore this question and how did you compile the questions for the semi-structured interviews?
2. What does this study show about what chaplains should keep in mind when working with HSCT AYA patients?

3. We have described this study as a model for chaplain research that could/should be replicated by other chaplains. Do you agree/disagree?
Discussion with Judy Ragsdale, PhD, ACPE and Mary Ann Hegner, MA, BCC

4. What cautions would you give to chaplains who want to conduct a study like this?

Webinar Journal Club V – Future Sessions

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<tr>
<th>Date and Topic</th>
<th>Paper</th>
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<tr>
<td>May 10, 2016 Identifying Chaplain Competencies</td>
<td>Cooper D, Aherns M &amp; Pereira J (2010). The competencies required by professional hospice palliative care spiritual care providers. Journal of Palliative Medicine, 13, 869-875. DOI: 10.10089/jpm.2009.0429</td>
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Make the Most of the Journal Club

• Give us your feedback on the evaluation
• Study the article ahead of time using the Research Article Summary as a guide
• George_Fitchett@rush.edu
• Patricia_Murphy@rush.edu

References


(continued next slide)


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**TRANSFORMING CHAPLAINCY**

Promoting Research Literacy for Improved Patient Outcomes

*Co-led by George Fitchett (Rush) & Wendy Cadge (Brandeis)*

**Core activities**

- 16 Templeton Chaplain Research Fellowships
- Research literacy curriculum development grants to 70 CPE residency program
- Free online continuing education Introduction to Research course for members of chaplaincy organizations

Together these initiatives will create over 800 research literate chaplains strengthening understandings of religion, spirituality and health and transforming chaplaincy as a profession.

Phase 1 – July 1, 2015 - June 30, 2016
Phase 2 – July 1, 2016 – June 30, 2019

[www.researchliteratechaplaincy.org](http://www.researchliteratechaplaincy.org)