

CHAPLAINS' WORK WITH FAMILIES OF CRITICALLY ILL CHILDREN

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Goals of the project

- ▣ Understand the initial work that chaplains do with families of critically ill children.
- ▣ Build a successful chaplaincy research team.

Children's Mercy Hospital

- ▣ 300 bed tertiary care center.
- ▣ Large NICU, PICU, trauma center.
- ▣ Approximately 160 deaths each year.
- ▣ Dept of Chaplaincy started in 1987
 - 7 full-time, 3 part-time chaplains, 24/7 coverage
 - Administrative responsibility after deaths:
Communicate with the ME, local OPO, request CMH autopsy, coordinate body release.

Overview of our project

- ▣ Pre-study interviews with chaplains
- ▣ Observation of cases
- ▣ Presentation to interdisciplinary panel
- ▣ Thematic analysis
- ▣ Post-study interview with chaplains
- ▣ Follow-up interview with parents

Analysis (Ongoing)

- Case 1
Inter Disciplinary Group
- Case 2
Inter Disciplinary Group
- Case 3
Inter Disciplinary Group
- Case 4
Inter Disciplinary Group
- Case 5
Inter Disciplinary Group
- Case 6
Inter Disciplinary Group
- Case 7
Inter Disciplinary Group

Pre-
Project
Chaplain
Interviews

Health
Care
Provider
Interviews

Post-
Project
Chaplain
Interviews

Parent
Interviews

Chaplain Documentation Review

Chaplain pre-study interview: attitudes about research

What do you think of the research project that we
are doing now?

“What do you think of the research project?”

- ▣ Nervousness about being observed or “hovered over.”
- ▣ Letting go of ego.
- ▣ Skepticism about researchers.
- ▣ Concern that observation would interfere with the quality of interactions.

THE COMPLEX ROLE OF THE ETHNOGRAPHIC OBSERVER

David McDaniel

The Observer

- ▣ CPE and training in ethnography
- ▣ On-the-job training in research methodology
 - Introduced to families as a researcher
 - Preliminary verbal consent
 - After 24-hours, I sought formal “full” consent.
- ▣ Observed encounters over 72 hours.
 - What was said, how it was said, the context and mood of the encounter, non-verbal communication, and what was NOT said

The Observer as Researcher

- ▣ Detailed descriptive report
- ▣ Interviews with health care providers
- ▣ Interdisciplinary review panel
- ▣ Papers for publication

Observation as pedagogy

- ▣ Observing enhanced my skills
- ▣ Able to see and hear other chaplains
- ▣ No such opportunity in CPE
 - Supervisors/colleagues rarely witnesses chaplain in action
 - Verbatims are main teaching tool
- ▣ Why don't we observe more?
 - Too obtrusive;. Patient/Family might not be as open.
 - Desecration of a "sacred space."
 - Chaplains' discomfort.

Key lessons from observation

- ▣ Tangible Objects are very important
 - Prayer shawls, recorded books, teddy bear, toys, etc.
- ▣ Physical interaction builds trust
 - Eye contact, physical contact, especially in prayer
- ▣ Chaplains initiate and often define prayer rituals
 - “Would you like to pray or do you want me to pray?”
 - “What are specific things you want prayer for?”

THEMES FROM CASE REPORTS

John D. Lantos MD

Recurrent themes in case reports

- ▣ Complex concepts of hospitality
- ▣ Offering and needing support
- ▣ Journeying with families
- ▣ Prayer as connection and healing
- ▣ Embodiment of the divine

Hospitality

- ▣ The chaplain extends hospitality – welcomes family to their temporary new home.
- ▣ Family then extends hospitality by inviting the chaplain to be part of their family's life.

Support

- ▣ “We are here to support you emotionally and in your own spirituality.”
- ▣ “Kids are often afraid. They want to know who you are, but they don’t want you messing with them. Support, with kids, can mean many different things.”

Journeying with

- ▣ “I planned to walk with them during all of Erick’s hospitalization. It could take us through the valley of the shadow of death.”
- ▣ “One of my roles is to journey with people – walking with them and providing a caring presence. Sometimes I lead them as I try to anticipate needs and provide information early in a family’s stay.”

Prayer as connection and healing

I met a young couple in the ER. Their child was dying. I didn't know anything about their religious background. I said to them 'Is it ever helpful for you to pray?' They said it was. So I just prayed. I didn't ask them what they were ahead of time, I just prayed. Their child died. A bad death. Lots of blood.

Prayer as connection and healing

I was amazed when they asked me to do the funeral, but I had been there at that particular time and that's why they wanted me there. It turned out they were Unitarian Universalism and, of course, I used Jesus' name. I apologized. They said 'no, we were just so glad someone was there and would do a prayer for us. Don't worry about it.'

Embodiment of the divine

- ▣ “Holy listening.” I really liked that that term to describe what we do because it’s listening, yes, but it’s listening with an ear toward being that vessel, the conduit of the divine.
- ▣ You are there as a channel through which God’s love, presence, and hope come through as you meet this family in this initial period.

Embodiment of the divine

- ▣ That term that I used was 'listening to the lament.' That's really what we're doing when we talk about holy listening, listening to allow the lament.

THE CHAPLAIN TEAM: RESPONSES TO RESEARCH

Jennifer Hunter RN, PhD

University of Missouri-Kansas City
School of Nursing & Health Studies

Pre- and Post-Project Chaplain Interviews

- ▣ Chaplains' evaluations of whether the study aims were met
- ▣ Thoughts of what might have been done differently in the research design
- ▣ Areas of new growth and insight gained by the chaplains in relation to the study.

Aim 1: To identify how chaplains respond to parents who are faced with a life-threatening crisis in their child.

Yes, and No...

Cases provided less intensity within the first 72 hours than expected.

“I was surprised that a lot of the cases were somewhat surface level. I wonder if part of it was because none of the children were actively dying at that moment. So there weren’t too many significant, deep, intimate crises.”

The study did provide a good view of the “hospitality phase.”

“Holy listening, listening with an ear toward being that vessel - the conduit of the divine, being a nonjudgmental presence - I think all of those things highlighted what we do as we meet families in that initial period.”

Aim 1: To identify how chaplains respond to parents who are faced with a life-threatening crisis in their child.

Yes, and No...

But failed to reveal the depth of relationship that happens over time between chaplains and families.

“I feel only a tiny bit of what we do is reflected in this study. My patient is still here eight months later. None of that long-term walk with them is reflected. And then none of what we do with the immediate crises of deaths and traumas and running to code blues is reflected.”

Aim 2: To identify commonalities and differences that exist in how chaplains provide assistance to parents.

Yes

Similarities and differences between chaplain styles were identified.

“It seemed like there was a different element in each person... so I was glad we all had access to each other’s record and could think about how somebody else did something.”

“We all write things differently, we all process things differently, even our reflection – there was a lot of difference in the reflection.”

“There’s a huge difference in how we approach different people.”

Aim 2: To identify commonalities and differences that exist in how chaplains provide assistance to parents.

Yes

“I frequently used touch. There are other chaplains here who would rarely, if ever, use touch.”

“Mary used a lot of humor that worked for her, whereas some of the rest of us wouldn't necessarily do that.”

“Julie was pretty direct with that family. I could never say that or do that. For me, timing has to be different – I need to feel that I've gotten through that hospitality phase, that they've really chosen to make that connection with me. Everybody's timing may be different.”

**Aim 3: To examine how chaplains understand
and incorporate their theoretical and
theological conceptual frameworks into the
work that they do.**

Not so much....

“I don’t know that we really showed that or talked about it. It’s in some of the reflections and the write-ups, but I would say just on the very surface level.”

“I think part of it is it is just so integrated that it’s just there. I don’t often think, for instance, ‘oh, I’m really relating this to the family system theory’ and yet I’m informed by that.”

“I think that was most brought out in the interdisciplinary panel conversations.”

Aim 4: To build a cadre of chaplains who are capable of conducting research.
Cadre might be an extreme word...

“I think there are definitely some that have the interest.”

“I think being a part of a research team or even kind of a lead person would be fascinating.”

“Not every chaplain is geared towards research and not every researcher makes a good chaplain. You have to have each other, to work well with each other, and to advance.”

If you knew what we know now, what would you do differently?

- ▣ Observe a longer term relationship between chaplain and family.
- ▣ Choose more acute traumas or more specific focus for observation.
- ▣ Not try to keep one chaplain with a particular family. Misses the richness of the team's ability and willingness to hand off to each other.
- ▣ Add someone from Child Life and Social Work to the IDG.
- ▣ Increase the level of IDG critique, but without the boss present.

Areas of Chaplain Growth from study experience

“Getting a Glimpse” into others’ styles led to changes in practice

“It’s been ten years since I was in any kind of supervised training where we looked at each other’s dialogues; this provided a glimpse in to what our colleagues conversations are like.”

“I learned new phrases that I use now.”

- ▣ *‘Would you like me to pray with you now or to remember you in prayer?’*
- ▣ *‘What are you hoping for – what are you wanting - right now?’*
- ▣ *‘What are you specifically asking prayer for?’*

“And also when we pray, I try to incorporate those words into the prayer so it’s not just my prayer but it’s a communal prayer.”

“Getting a Glimpse” into others’ styles led to changes in practice

“My experience? Invasion of privacy. It was just uncomfortable. I was very nervous about it.

. . . But this experience was eye-opening to me to see how everybody functions. And you know what? That was valuable! Very, very much so, because that piece is very limited.

All of these little things, learning people’s body language and what it means, it’s very valuable to me as a chaplain to see how other people interact. Very valuable.”

Insights into knowledge limitations

“We could grow in knowing what framework and what theories are guiding us... to be able to more clearly articulate what I’m about, besides just saying, ‘I’m a spiritual and emotional support person.’”

“I’m more aware of spiritual assessment now. Cerner’s assessment is a few check-boxes. I think I need to be a better listener and find out what peoples’ definition of spirituality is – not just sacraments and rituals, but how do they deal with the world that they can’t prove. I thought I needed a goal when I went into the room. I learned that my goal is to find out what my goal is!”

Insights into knowledge limitations

“Before this project, I didn’t know that there were so many research projects out there on chaplaincy. I went to that meeting when all the researchers from the grant came – and they started talking about different research projects going on – it was amazing! I didn’t know that existed. I didn’t know how much research was done to get us connected to JCAHO, our governing board. And actually to meet some of the people that had been in the research – that was really interesting. So I think this project has helped me to understand the importance of research in chaplaincy and where it might go in the future.”

I’ve been in chaplaincy since 2000, so that’s 13 years – and this is the first time, this year, is the first time that I really understood the importance and the impact. We just interviewed a new chaplain who just finished CPE. She talked about a research project that her class had done. I thought ‘hmm’, now she has that research background at the very beginning. I’ve been here 13 years and am just now doing it.”

Increasingly inquiring minds!

Future research thoughts

- ▣ More interviews with parents.
- ▣ Study how we interact with the children.
- ▣ Liminality – how do people learn to live in a place like that?
- ▣ Examine the impact of benchmarks (i.e. 20 patient visits/day.)
- ▣ Dealing with collective grief
- ▣ Explore tension between support/hospitality and the need to push people just a bit – to help people understand what is within them.

Summary

- ▣ Chaplains were willing (with some reticence) to participate in a very demanding research study.
- ▣ The study partially met its aims, teaching us what we might do differently next time.
- ▣ Chaplains highly valued opportunity to share their work and gain knowledge and skills from each other.
- ▣ Most grew in their knowledge of research and their value of evidence-based practice.
- ▣ They envisioned ideas for more research – but also recognized that research is no small task. It cannot simply be added to their current workload; rather, time must be allotted.

FOLLOW-UP INTERVIEWS WITH PARENTS

Dane Sommer, Dmin, BCC
Children's Mercy Hospital

What did you think of the chaplains?

- ▣ Telephone interviews with parents
- ▣ 1-3 months after discharge
- ▣ Semi-structured interview, open-ended questions about interaction with chaplains:
 - What did they remember?
 - What did they like?
 - What did they dislike

Key themes

- ▣ An “embedded” theism.
 - ▣ Chaplain support was crucial.
 - ▣ Prayer helped.
 - ▣ Chaplain as “divine presence.”
-
- ▣ Many parent comments mirrored the chaplains’ own assessments.

EMBEDDED THEOLOGY

Families shared descriptions of their spirituality that fit with a THEISTIC understanding of God.

THEISM is built on a belief that God's is actively and personally present in the world.

God's characteristics are power, wisdom and presence.

Comments reflecting theism

- ▣ “[God] wouldn’t give me something I can’t handle.”
- ▣ “[My baby] was made just for me.”
- ▣ “At first I wondered why this was happening, and then I realized this was God’s plan.”
- ▣ “I found comfort in knowing that God would take care of everything.”

Comments reflecting theism

- ▣ “God is in control of everything that happens.”
- ▣ “Our nation would be a better place if everyone would acknowledge God’s power.”
- ▣ “God healed our baby and God healed our family through this [crisis].”

Chaplains offered support

- ▣ “[It was] comfortable to talk to her.”
- ▣ “She always came to see me at the right time.”
- ▣ “Her presence made things less stressful.”
- ▣ “She was there for me.”

Prayer helped

- ▣ “It was comforting to know that she was praying for me, but we never prayed together.”
- ▣ “It was great knowing that someone else was here that would pray for my son.”
- ▣ “Her prayers were the only thing that enabled me to get through [the crisis].”
- ▣ “She gave us comfort by praying with us.”

Embodiment of the divine

- ▣ “She was just like an angel.”
- ▣ “She continually reminded me that God was part of what was happening to us.”
- ▣ “She helped us to feel God’s presence.”
- ▣ “[She] represented God.”

CONCLUSIONS

Chaplain's tools

- ▣ Time
- ▣ Advanced communication skills
- ▣ Liturgical expertise
- ▣ Knowledge of hospital systems

Chaplains' work

- ▣ Difficult to categorize
- ▣ Goal of specific interventions is to build a trusting relationship
- ▣ Both humanization and deification of the hospital experience.
- ▣ “...the mental aerobics of helping others to slowly take in and come to terms with life-changing news.”