Bereavement Care Needs of Pediatric Providers

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CCSP/Palliative Care Seminar
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Pediatric healthcare providers
What we know

- Pediatric clinical settings are rarely equipped to provide health care providers the opportunity to acknowledge feelings of grief and loss.

- Providers caring for kids through their illnesses are repeatedly bereaved.

- Little, if any, support is provided to them after their patients die.
And this can lead to:

- Burnout
- Relationship strain
- Compassion fatigue
- Symptoms of PTSD
- Poor health
- Depression
- Emotional distancing/withdrawal
Stages of Grief

“NORMAL” FUNCTIONING

Shock and Denial
- Avoidance
- Confusion
- Fear
- Numbness
- Blame

Anger
- Frustration
- Anxiety
- Irritation
- Embarrassment
- Shame

Depression and Detachment
- Overwhelmed
- Blohs
- Lack of energy
- Helplessness

RETURN TO MEANINGFUL LIFE

Acceptance
- Exploring options
- A new plan in place

Dialogue and Bargaining
- Reaching out to others
- Desire to tell one's story
- Struggle to find meaning for what has happened
LPCH Study

• 54% reported that adequate support was not provided
• “No place to discuss their experiences, were required to immediately put aside their grief and return to work, and were troubled by painful experiences”

MB’s Dissertation

• 48.5% reported support was inadequate
• Healthcare providers’ own emotional distress was the second most frequently raised challenge in working with pediatric patients
• On-the-spot consultation rated most helpful and most likely utilized type of support
• Formal courses would be helpful, but more likely to attend one-time workshop (e.g., grand rounds)
Why do we care about this?

• NC Children’s Hospital offers some support but many providers are unaware of or reluctant to use these resources

• Comprehensive palliative care teams provide support for health care providers
How can we provide support?

• We proposed a research study
  • Two aims:
    • Explore grief and bereavement support needs of pediatric health care providers
    • Design a program of emotional support for pediatric health care providers
  • Funding: Children’s Promise Junior Faculty Research Grant
Study methods

• First...
  • Survey of pediatric HCPs
    • Utilized existing surveys and literature on HCP needs to design 15 minute web-based survey
    • Multiple choice and open-ended questions
    • “Recruitment” by email to listservs of HCPs
    • Summary statistics, thematic analysis of open-ended questions
Study methods continued

• Second...
  • Focus groups with providers
    • Developed questions using results of survey
    • Recruitment via survey, flyers
    • Conducted by expert facilitator, recorded and transcribed
    • Thematic analysis conducted by research group
### Survey - demographics

<table>
<thead>
<tr>
<th>Respondent characteristic (total # respondents: 250)</th>
<th>N (%) or median (range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Years of employment at NCCH</td>
<td>5 (0.1-36)</td>
</tr>
<tr>
<td>Years of practice as a pediatric HCP</td>
<td>10 (0.5-36)</td>
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<tr>
<td>Occupation</td>
<td></td>
</tr>
<tr>
<td>Nurse</td>
<td>112 (45%)</td>
</tr>
<tr>
<td>Faculty MD</td>
<td>34 (14%)</td>
</tr>
<tr>
<td>Resident/fellow MD</td>
<td>35 (14%)</td>
</tr>
<tr>
<td>Psychosocial (social worker/clinical care manager, recreational therapist/child life specialist, psychologist, pastoral care)</td>
<td>30 (12%)</td>
</tr>
<tr>
<td>Other</td>
<td>35 (14%)</td>
</tr>
<tr>
<td>Practice setting(s)</td>
<td></td>
</tr>
<tr>
<td>Inpatient</td>
<td>164 (67%)</td>
</tr>
<tr>
<td>Outpatient</td>
<td>126 (51%)</td>
</tr>
<tr>
<td>ICU</td>
<td>108 (44%)</td>
</tr>
<tr>
<td>Ever experienced death of a pediatric patient</td>
<td>206 (84%)</td>
</tr>
</tbody>
</table>
Survey – provider experience

Acting as a mentor or role model to trainees/coworkers
Discussing DNR status with patients/families
Discussing transition from curative treatment to end of life care
Pain management for dying patients
Managing symptoms of dying patients
Coordinating the care of dying patients
Communicating with dying patients' families
Communicating with dying patients

Less experienced
More experienced
Survey – provider experiences

• Most difficult experience caring for seriously ill children

1. Emotional distress of families
2. Own emotional distress
3. Communication with patients/families
4. Child’s environment
5. Feeling medically helpless

• Most difficult experience caring for dying children

1. Own emotional distress
2. Emotional distress of families
3. Relationships with patients
4. Communication with families
5. Coordinating care among health care providers
Survey – provider experiences

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  4. Communication with families
  5. Coordinating care among health care providers
Survey – provider support

- What type(s) of support do you seek for yourself?
  - None: 68%
  - Colleagues, family/friends, relaxation, exercise, spiritual/religious

- What are barriers to seeking support for yourself?
  - Lack of time, others don’t understand/don’t want to talk, stigma, confidentiality

- How adequate is support for providers at NC Children’s Hospital?
  - Exceptional: 9%
  - Mostly adequate: 30%
  - Somewhat adequate: 48%
  - Not at all adequate: 13%
Survey – provider support

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Majority feel current support is inadequate
Survey – provider support needs

• What would be helpful in your work with seriously ill or dying children?
  1. Expert consultation
  2. Debriefings
  3. Formal course in palliative care
  4. One-time workshop
  5. Educational materials
  6. Facilitated peer support groups
  7. Supportive gifts

• Which of these would you likely use?
Focus groups

- 42 participants, 8 focus groups
- Questions:
  1. How does caring for seriously ill children affect pediatric health care providers?
  2. How does caring for children who die affect pediatric health care providers?
  3. How is loss acknowledged within the Children’s Hospital?
  4. What makes it difficult to acknowledge/cope with loss?
  5. What resources would be helpful to pediatric health care providers?
Focus groups – provider needs

1. Feelings and coping
   “I think it makes you really sad and has a cumulative effect, like you can’t forget the kids that you’ve seen, but in some ways (through experience) you get better at helping the families too…”

2. Communication
   “Families have totally different goals. Sometimes our goal is something very different from what they are expecting. We don’t always have the fortitude to say, ‘it is my strongest recommendation that we do not continue therapy’.”

3. Relationships (with families and fellow providers)
   “It would be nice to have colleagues who you could actually talk to about this stuff. You know there is not anybody in the hospital who has not been touched by it at some point.”

4. Education and support
   “I think (the field of) palliative care is at least attempting to address that, while you can’t do much about the outcome, there can be some control over the process. There is something you can do to be helpful, supportive and positive.”
Provider recommendations

• Education for health care providers
• Consultation with palliative care providers
• Coordination between inpatient and outpatient providers
• Standardized follow-up with families (bereavement care)
• Debriefings
  • Open-ended, multidisciplinary meetings to discuss cases
What’s next at NC Children’s Hospital?

- Pediatric health care providers report varying education/training in palliative care
- Desire additional support
- And, understand and/or appreciate the (potential) positive impact of a pediatric palliative care team

“Education and support would be helpful. It’s just a matter of figuring out when and how to do it.”
What’s available now via CSCT?

- **Education**
  - CAPC, IPPC, ELNEC
    - “Lunch and learns”
  - Residency program Noon Conferences
    - Prevent “just in time” training
    - Promote support from each other
    - Also desire for interdisciplinary support/mentoring

- **Rounds with Children’s Supportive Care Team (CSCT)**

- **Team and staff consultations to CSCT**
  - Pager: 216-6793
“Pictures, parties, and proms”

Thanks to Children’s Promise Grant
What else might we do?

- **Code Lavender**
  - For patients, families, or caregivers who need additional support
    - Wholistic approach including pastoral care, reiki, touch therapy, aromatherapy, music therapy, social work, guided imagery, and nutrition and wellness services

- **Collaboration with Duke Children’s Hospital**
  - Pediatric Quality of Life Program
    - Pediatric Pain and Palliative Care Program
    - November, February, May at UNC
      - Staff support for coping with loss

- **Bereavement Support for Families**

http://experiahealth.com/codelavender
Schwartz Rounds

• Case or theme-based interdisciplinary discussion
• 1x/mo, lunch provided, possibly CE credits, ACGME
• 8-12 committee members, with non-physician facilitator
  • Including: chaplain, psychology, PICU faculty, nurse managers, outpatient nursing, ethics committee members, social work, RT/CL

• *Goals*: compassion for patients and each other, insight into others’ thoughts/emotions, care for self
Schwartz Rounds

Benefits include:

- "Increased insight into social and emotional aspects of patient care; increased feelings of compassion toward patients; and increased readiness to respond to patients’ and families’ needs."
- Improved teamwork, interdisciplinary communication, and appreciation for the roles and contributions of colleagues from different disciplines.
- Decreased feelings of stress and isolation, and more openness to giving and receiving support."

Schwartz Rounds

- Adult Schwartz Rounds at UNC

- First Pediatric Schwartz Rounds in NC!
  - January 10th, 2013 at noon, NCCH Conference Room 1
Conclusions

• Pediatric providers experience a variety of emotions when caring for children, ranging from joy to grief

• Taking care of ourselves and each other is as important as taking care of our patients

• We’re hoping to improve the care provided to our staff and amongst our staff via
  • Education
  • Supportive Care Team consults
  • Parties, proms, and pictures
  • Collaboration with Duke’s Palliative Care Team
  • Bereavement follow-up
  • Schwartz Rounds
Thank you! And thanks to...

- NC Children’s Hospital Pediatric Palliative Care Committee
- Children’s Promise
- NC Children’s Hospital staff
- Rob Sellers, MS 1
- Diane Yorke, RN, PhD, PNP
References


• SIOP (2000). Guidelines for recognition, prevention, and remediation of burnout in health care professionals participating in the care of children with cancer. @cms.onlinebase.nl/userfiles/c1iccppo/file/Guidelines%20for%the%20Recognition.pdf