THRIVING AFTER CRITICAL ILLNESS

Lessons on the essential role of spiritual and family support

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Hospital of the University of Pennsylvania
Why do this work?
“There is no greater agony than bearing an untold story inside you.”

Maya Angelou
Provide Patients a Voice

Lesson 1
“People…sometimes don’t know what you go through. They think that because you are in one piece, everything is fine. But inside I’m all screwed up now.”

ICU Survivor

Cox et al. Critical Care Medicine Oct 2009
THEMES

Pervasive memories of ICU Stay
Day-to-day impact of new disability
Critical Illness defining sense of self
Relationship strain and change
Coping

Cox et al. Critical Care Medicine Oct 2009
STRATEGIES TO ADAPT

Optimism

Hope

Support of Friends and Family

Spirituality

Cox et al. Critical Care Medicine Oct 2009
Patients and families want to understand their illness and the road ahead

Lesson 2
On the day of ICU discharge, the patient’s wife asks
“When will he be himself?
When will he back on his feet?
What should we expect moving forward?
What can we do to help?”

Angus et al Intensive Care Med 2003
“Nobody prepared us for what to expect when we left. When we asked about the quality of life issues, I actually heard one of the doctors say, ‘Well, he’s alive, isn’t he?’”

ICU Survivor

Cox et al. Critical Care Medicine Oct 2009
Post-Intensive Care Syndrome – A Societal (& a UPHS) Threat

- Cognitive impairment
  - 34% impaired at a level of moderate TBI at 12m

- Mental health
  - 22-28% point prevalence

- Physical impairment
  - 27% disabled at 12m

Pandharipande et al NEJM 2013
Desai et al Crit Care Med 2011
Jackson et al Lancet Resp Med 2014

- Among 43 HUP & PPMC MICU survivors contacted 6-9m post-discharge
  - PICS present: 84%
  - PICS worse: 54% self-reported that function was worse

Maley et al Annals ATS 2016
## Challenges in ICU

<table>
<thead>
<tr>
<th>Location</th>
<th>Theme</th>
<th>Patients Reporting [n (%)]</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intensive care unit</td>
<td>Physical weakness</td>
<td>21 (48.8)</td>
<td>“Being in the MICU was scary. I was afraid I would not wake up. I was too weak to make it to the bathroom and […] all over the floor. I felt really embarrassed but everyone was incredibly kind and professional.”</td>
</tr>
<tr>
<td>Cognition</td>
<td></td>
<td>15 (34.9)</td>
<td>“In the beginning, in the ICU, I was very confused and couldn’t communicate with people.”</td>
</tr>
<tr>
<td>Mental health, including anxiety, fear, and nightmares</td>
<td></td>
<td>15 (34.9)</td>
<td>“I can’t remember 2 wk of my ICU stay, which is a challenge. [It’s] hard to get used to the idea that you needed help, that you were essentially handicapped.”</td>
</tr>
<tr>
<td>Difficulties with eating or communication Symptoms, including pain, dyspnea, and insomnia</td>
<td></td>
<td>8 (18.6)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 (14.0)</td>
<td></td>
</tr>
</tbody>
</table>

Maley *et al.* Annals ATS 2016
Cognitive Impairment: What Does It Look Like?

“I felt like I was in a cloud or something. I had no attention span. I couldn’t get past two sentences before I was wondering what I was reading—it didn’t stick. I felt like I was brain damaged.”
- Perspective from a critically ill survivor

“It was like I was married to somebody else...he didn’t remember anything I told him. We went to making lists for everything. I finally told him not to turn on the stove, the washing machine, anything! I was worried he’d burn down the house.”
- Perspective from a caregiver

Jackson et al Crit Care Med 2003
Cox Crit Care Med 2009
Spiritual and Family Support is Vital

Lesson 3
ICU Admissions
4169

Mechanical Ventilation
1778

ICU Chaplain Consults total
248

ICU Chaplain Consults, patient died
199

ICU Chaplain encounters discussed with physician
14

Adapted from Choi et al. J Pain Symptom Management. October 2015
Spiritual guidance and support is underutilized
## Support in ICU

<table>
<thead>
<tr>
<th>Theme</th>
<th>Patients Reporting [n (%)]</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Facilitators of Recovery</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support (spiritual, family)</td>
<td>13 (30.2)</td>
<td>“While in the hospital, the chaplain who came was extremely helpful. And the fact that he kept coming back meant a lot.”</td>
</tr>
<tr>
<td>Information, engagement, and reassurance provided by staff</td>
<td>10 (23.2)</td>
<td>“My religious faith was very helpful.”</td>
</tr>
<tr>
<td>Postdischarge services (physical therapy, home nursing)</td>
<td>9 (20.9)</td>
<td>“You have to have support from family and friends, otherwise it’s very hard to recover.”</td>
</tr>
</tbody>
</table>
Opportunities on Ward

<table>
<thead>
<tr>
<th>Theme</th>
<th>Patients Reporting [n (%)]</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical ward</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dependence, including inability to feed</td>
<td>14 (32.6)</td>
<td>“Feeling weak. I didn’t even have the strength to feed myself.”</td>
</tr>
<tr>
<td>one’s self</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptoms, including pain, dyspnea,</td>
<td>14 (32.6)</td>
<td>“Trying to move and ambulate. Trying to remember what happened. Dealing</td>
</tr>
<tr>
<td>insomnia, and loss of appetite</td>
<td></td>
<td>with the pain.”</td>
</tr>
<tr>
<td>Physical weakness</td>
<td>12 (27.9)</td>
<td>“Overcoming the loneliness of being in the hospital.”</td>
</tr>
<tr>
<td>Mental health, including anxiety, fear,</td>
<td>12 (27.9)</td>
<td>“Floor nurses and doctors don’t have as much time to spend with you and</td>
</tr>
<tr>
<td>PTSD, loneliness, abandonment, and</td>
<td></td>
<td>can’t really spend the same time listening to the patient to figure</td>
</tr>
<tr>
<td>difficulty coping</td>
<td></td>
<td>out what is wrong. It makes the patient less involved in their care.”</td>
</tr>
</tbody>
</table>

Maley et al. Annals ATS 2016
Communication is Essential
Even When Patients Cannot Speak
Lesson 4
How?
<table>
<thead>
<tr>
<th>CHRISTIAN</th>
<th>JEWISH</th>
<th>BUDDHIST</th>
<th>ISLAMIC</th>
<th>HINDU</th>
<th>JAIN</th>
<th>SIKH</th>
<th>OTHER</th>
<th>NONE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protestant (Baptist, Methodist, Episcopal, Presbyterian, Lutheran, Pentecostal, etc.)</td>
<td>Reform</td>
<td>Zen/Chan</td>
<td>Sunni</td>
<td>Hindú Dharma</td>
<td>Jain Dharma</td>
<td>Sikh Dharma</td>
<td>Unitarian-Universalist</td>
<td>Spiritual but not religious</td>
</tr>
<tr>
<td>Catholic</td>
<td>Conservative</td>
<td>Theravada</td>
<td>Shia</td>
<td>Hindu</td>
<td>Jain</td>
<td>Sikh</td>
<td>New Age</td>
<td>Agnostic</td>
</tr>
<tr>
<td>Jehovah’s Witness</td>
<td>Orthodox</td>
<td>Vajrayana/Tibetan</td>
<td>Sufi</td>
<td>Hindu</td>
<td>Jain</td>
<td>Sikh</td>
<td>Bahá’í Faith</td>
<td>Atheist</td>
</tr>
<tr>
<td>Mormon</td>
<td>Reconstructionist</td>
<td>Pure Land/Nichiren</td>
<td>Other</td>
<td>Other</td>
<td>Other</td>
<td>Other</td>
<td>Pagan (Wiccan, etc.)</td>
<td>Humanist</td>
</tr>
<tr>
<td>Eastern Orthodox</td>
<td>Renewal</td>
<td>Soka Gakkai (SGI)</td>
<td>Other</td>
<td>Other</td>
<td>Other</td>
<td>Other</td>
<td>Other</td>
<td>Other</td>
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<tr>
<td>Other</td>
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<td>Other</td>
<td>Other</td>
<td>Other</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I DON’T KNOW</th>
<th>I PREFER NOT TO SAY</th>
</tr>
</thead>
</table>

© 2015 NewYork Presbyterian Hospital. Symbols were sourced by Wikimedia users Yoskem and are further used pursuant to that Creative Commons Attribution-ShareAlike 3.0 Unported License (http://creativecommons.org/licenses/by-sa/3.0/deed.en).
CHAPLAIN-LED PICTURE COMMUNICATION

- 72% selected a chaplain intervention
- Patients experienced decreased:
  - Anxiety
  - Stress

Berning et al. Annals ATS 2016
Families provide support and need support of their own

Lesson 5
Families Experience PICS with Alarming Frequency

Depression

Anxiety

Post-Traumatic Stress Disorder
Communication as a Means to Mitigate PICS-F

3 months

Formal family meetings (N=10) and palliative care consultation (N=6) were rarely used

Psychological morbidity was common
PTSD 26%
Depression 19%
Anxiety 15%

Multidisciplinary family meetings and palliative care consultation during the ICU stay were associated with improved psychological function

Kross E et al AJRCCM 2015;A3769
The ICU Diary As a Means to Mitigate PICS & PICS-F

ICU diary, written by relatives and ICU staff, was introduced after the 4th ICU day in a med-surg ICU

<table>
<thead>
<tr>
<th>Phase</th>
<th>Severe PTSD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Family</td>
</tr>
<tr>
<td>Pre-Diary</td>
<td>80%</td>
</tr>
<tr>
<td>Diary</td>
<td>32%</td>
</tr>
<tr>
<td>Post-Diary</td>
<td>68%</td>
</tr>
</tbody>
</table>

Garrouste-Orgeas et al Crit Care Med 2012
Jones et al Critical Care 2010

Slide Courtesy of Mark E Mikkelsen, M.D.
The Roadmap to Success: Promoting a culture of resilience
There is Hope

- PICS is common
- Resilience, while correlated with executive dysfunction, anxiety, depression, PTSD, self-care difficulties, and pain, is the norm
- Resilience is “ordinary, not extraordinary”
- How can we promote a culture of resilience amongst survivors and their loved ones?

Maley et al Annals ATS 2016
American Psychological Association

Slide Courtesy of Mark E Mikkelsen, M.D.
Listen to Patient

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<tr>
<th>Support (spiritual, family)</th>
<th>30.2%</th>
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<tr>
<td>Information, engagement, and reassurance provided by staff</td>
<td>23.2%</td>
</tr>
<tr>
<td>Post-discharge services (PT, home nursing)</td>
<td>20.9%</td>
</tr>
<tr>
<td>Staying positive</td>
<td>18.6%</td>
</tr>
</tbody>
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"While in the hospital, the chaplain who came was extremely helpful. And the fact that he kept coming back meant a lot."

"My religious faith was very helpful."

"You have to have support from family and friends, otherwise it’s very hard to recover."

"In the ICU, they treated my wife like one of the team. That was very important to me. They often invited her to rounds."

"I liked feeling like I was part of the decision making."

"Physical therapists were really helpful in getting me up and moving at the hospital and rehab."

"Stay positive. Be motivated."

"After surgery, a woman came in and asked if I would like to hear some music. They brought guitars into my room and played music. I found it to be incredibly uplifting."

Ernecoff JAMA Intern Med 2015
Foster Support

Modified from Maley and Mikkelsen. Crit Care Med. 2015
The Longitudinal Perspective
“It Takes a Village”

Acute Care

- Family
- Friends
- Chaplain
- In-patient clinicians
  - Physicians
  - Nurses
  - Nursing assistants
- Therapists
- Discharge planning

Discharge

Post-Acute Care

- Survivors
- Caregivers
  - Family, Friends
  - Chaplain
- Out-patient clinicians
  - PCPs
  - Consultation
  - Home nursing visits
- Home health aids
- Physical therapists
- Occupational therapists
- Neuropsychologists
- Nutrition
- Social workers

Adapted from Mark E Mikkelsen, M.D.
THANK YOU

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ICU Patients