

# THRIVING AFTER CRITICAL ILLNESS

Lessons on the essential role of spiritual and family  
support

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# 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

# STRATEGIES TO ADAPT

Optimism

Hope

Support of Friends and Family

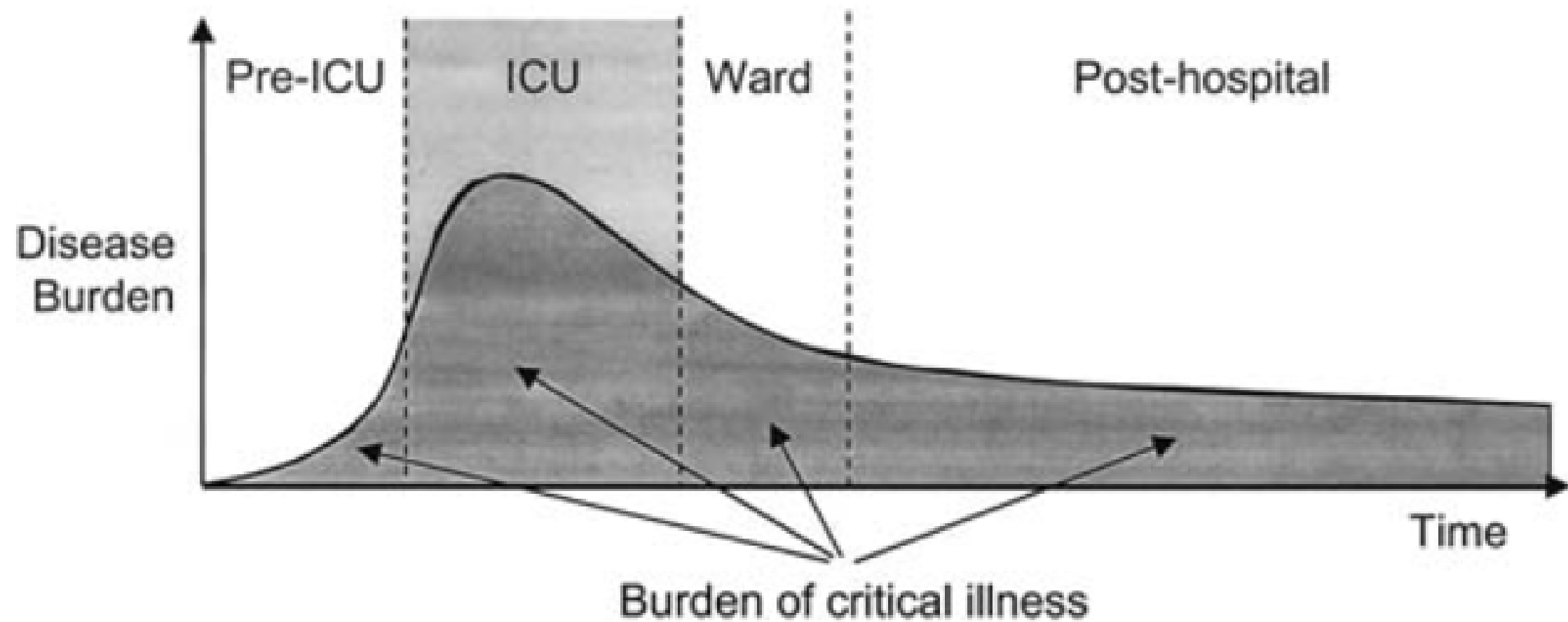
Spirituality

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

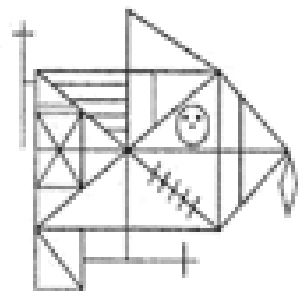
Maley et al Annals ATS 2016



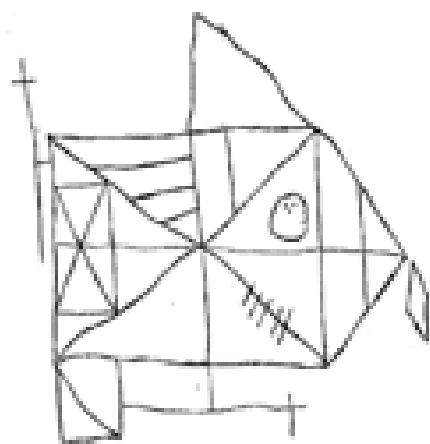
# CHALLENGES IN ICU

| Location  | Theme  | Patients Reporting [ <i>n</i> (%)] | Examples  |
|---|--|------------------------------------|---|
| <b>Recovery Challenges across the Continuum of Care</b> |  |                                    |   |
| Intensive care unit                                     | Physical weakness                                      | 21 (48.8)                          | “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.” |
|   | Cognition  | 15 (34.9)                          | “In the beginning, in the ICU, I was very confused and couldn’t communicate with people.”   |
|   | Mental health, including anxiety, fear, and nightmares | 15 (34.9)                          | “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.”  |
|   | Difficulties with eating or communication              | 8 (18.6)                           |   |
|   | Symptoms, including pain, dyspnea, and insomnia        | 6 (14.0)                           |   |

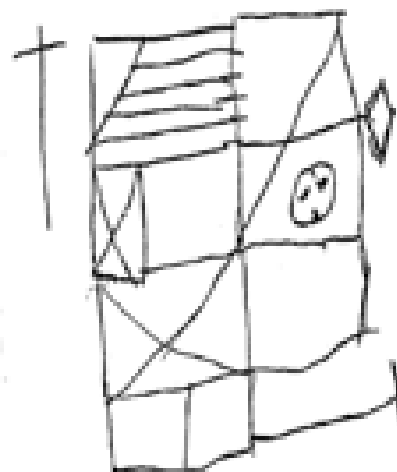
# Cognitive Impairment: What Does It Look Like?



asked to copy above picture, results below:



Near normal rendition by unimpaired 69 y/o  
pulmonary embolus survivor



Moderate to severely impaired 89 y/o  
Pneumonia survivor



Severely impaired 72 y/o ARDS survivor

*"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

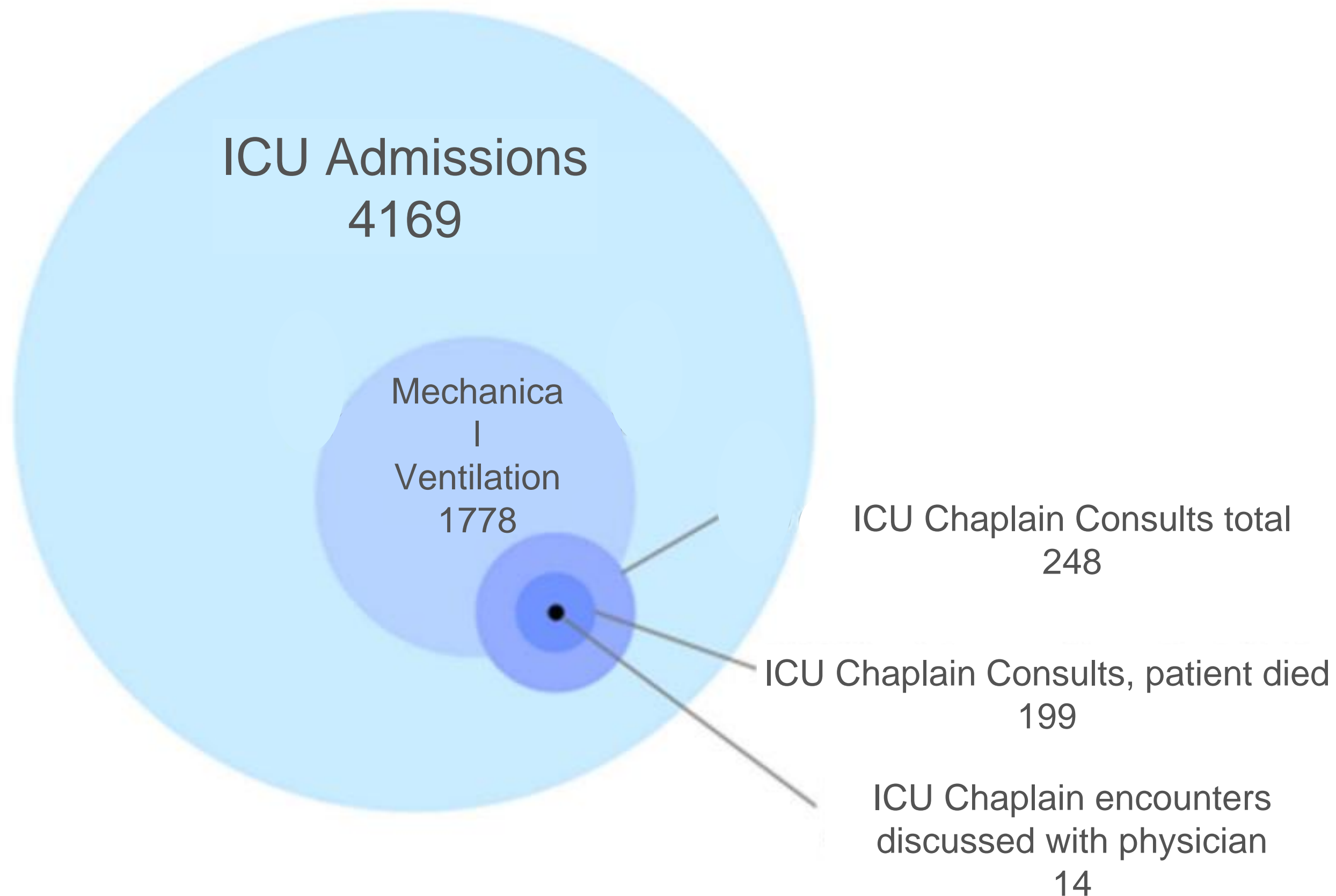
Jackson et al Crit Care Med 2003

Cox Crit Care Med 2009

# Spiritual and Family Support is Vital

## Lesson 3





# Spiritual guidance and support is underutilized

# Support in ICU

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



# Opportunities on Ward

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

# Communication is Essential Even When Patients Cannot Speak

## Lesson 4

How?



























MY RELIGION/SPIRITUALITY IS:

| CHRISTIAN  | JEWISH  | BUDDHIST  | ISLAMIC   | HINDU   | JAIN   | SIKH  | OTHER                   | NONE                        |
|--|---|---|---|---|--|---|-------------------------|-----------------------------|
|          | <br>יהודים |  | <br>الإسلام |                              |   |  | Unitarian-Universalist  | Spiritual but not religious |
| Protestant<br>(Baptist, Methodist, Episcopal, Presbyterian, Lutheran, Pentecostal, etc.) | Reform  | Zen/Chan  | Sunni<br>أهل السنة  | हिन्दू धर्म<br>हिंदू धर्म<br>ਹਿੰਦੂ ਧਰਮ<br>हिन्दूधर्म<br>ہندومت<br>இந்து<br>ಹಿಂದೂ ಧರ್ಮ<br>ಹಿಂದೂಮತಮು<br>ഹിന്ദുമതം | जैन धर्म<br>ਜੈਨ ਧਰਮ<br>જૈન ધર્મ<br>जिन मत<br>சமணம்<br>ಜೈನ ಧರ್ಮ<br>ಜೈನ ಮತಮು<br>ಜৈನಮತಂ | ਸਿੱਖੀ<br>ਸਿੱਖ ਧਰਮ   | New Age                 | Agnostic                    |
| Catholic   | Conservative  | Theravada   | Shia<br>شيعة  |   |  |   | Bahá'í Faith            | Atheist                     |
| Jehovah's Witness  | Orthodox  | Vajrayana/Tibetan   | Sufi<br>تصوّف   |   |  |   | Pagan<br>(Wiccan, etc.) | Humanist                    |
| Mormon   | Reconstructionist   | Pure Land/Nichiren  | Other   |   |  |   | Other                   | Other                       |
| Eastern Orthodox   | Renewal   | Soka Gakkai (SGI)   |   |   |  |   |                         |                             |
| Other  | Other   | Other   |   |   |  | I DON'T KNOW  | I PREFER NOT TO SAY     |                             |

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# I FEEL:

|   |   |   |  |
|---|---|---|--|
| afraid<br>     | sad<br>          | angry<br>        | happy<br>         |
| worried<br>    | lonely<br>       | annoyed<br>      | relieved<br>      |
| uneasy<br>     | guilty<br>       | disappointed<br> | excited<br>       |
| terrified<br> | embarrassed<br> | overwhelmed<br> | loved<br>        |
| shocked<br>  | hopeless<br>   | frustrated<br> | comfortable<br> |
| nervous<br>  | helpless<br>   | betrayed<br>   | peaceful<br>    |

# MY SPIRITUAL PAIN IS:

|      |   |   |   |   |   |   |   |   |   |   |    |         |
|------|---|---|---|---|---|---|---|---|---|---|----|---------|
| none | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | extreme |
|------|---|---|---|---|---|---|---|---|---|---|----|---------|

# PLEASE:

|  |  |   |   |   |
|--|--|---|---|---|
| prayer<br>            | blessing<br>          | song<br>               | poetry<br>         | talk with me<br>                 |
| Siddur<br>סדור<br>    | Tanakh<br>תנ"ך<br>    | Tefillin<br>תפילין<br> | candles<br>        | help me with a decision<br>      |
| Christian Bible<br> | Quran<br>القرآن<br> | make an altar<br>    | chanting<br>     | visualization / meditation<br> |
| Communion<br>       | Anointing<br>       | Confession<br>       | Rosary<br>       | read to me<br>                 |
| leave me alone<br>  | get my nurse<br>    | get my family<br>    | hold my hand<br> | sit with me<br>                |



# CHAPLAIN-LED PICTURE COMMUNICATION

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



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

12 months



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

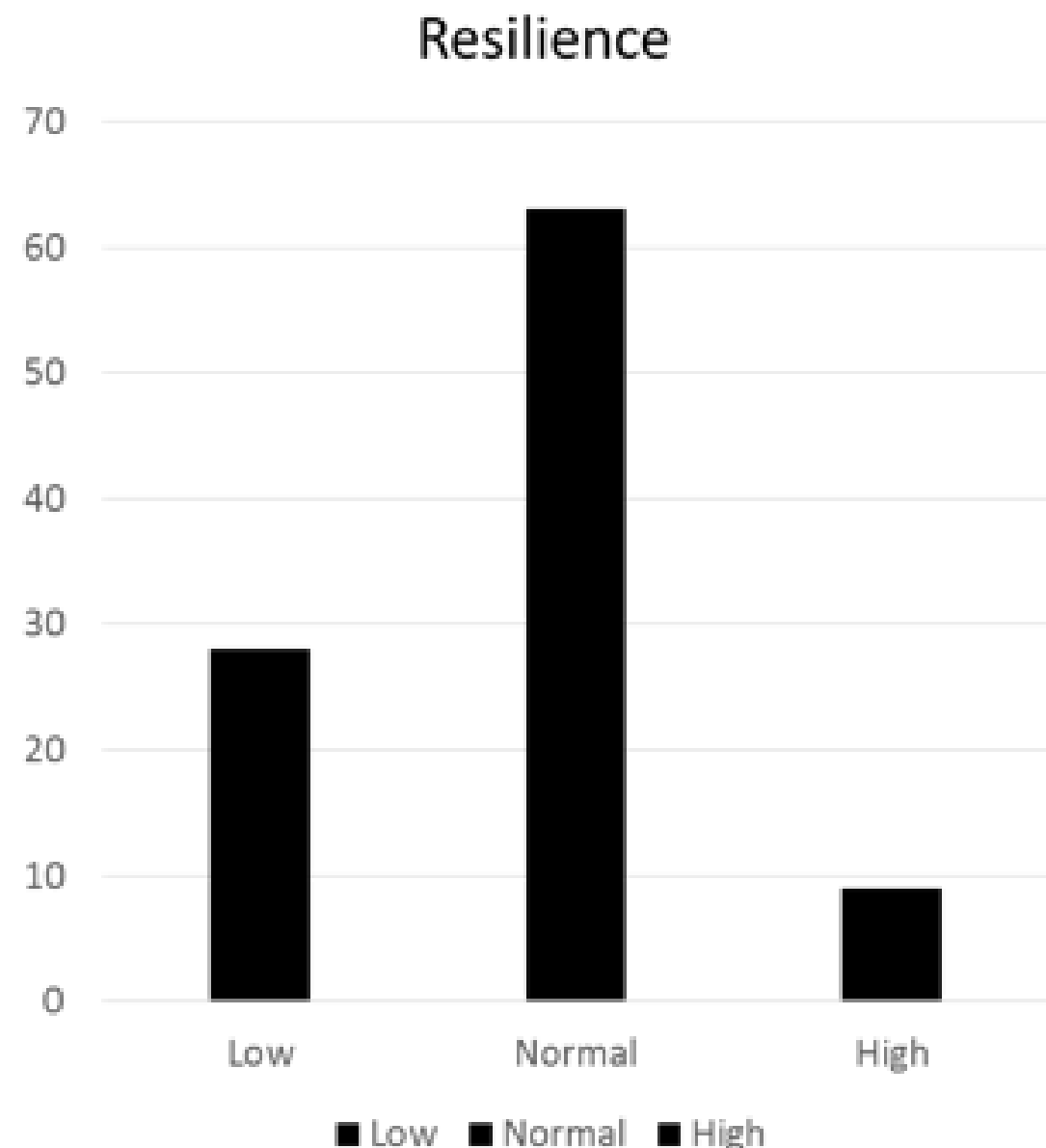
| Phase      | Severe PTSD |         |
|------------|-------------|---------|
|            | Family      | Patient |
| Pre-Diary  | 80%         | 35%     |
| Diary      | 32%         | 21%     |
| Post-Diary | 68%         | 30%     |

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

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



# Listen to Patient

|  |       |
|--|-------|
| Support (spiritual, family)                                      | 30.2% |
| Information, engagement,<br>and reassurance provided<br>by staff | 23.2% |
| Post-discharge services<br>(PT, home nursing)                    | 20.9% |
| Staying positive   | 18.6% |

Maley et al Ann Am Thorac Soc 2016  
Ernecoff JAMA Intern Med 2015

"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."

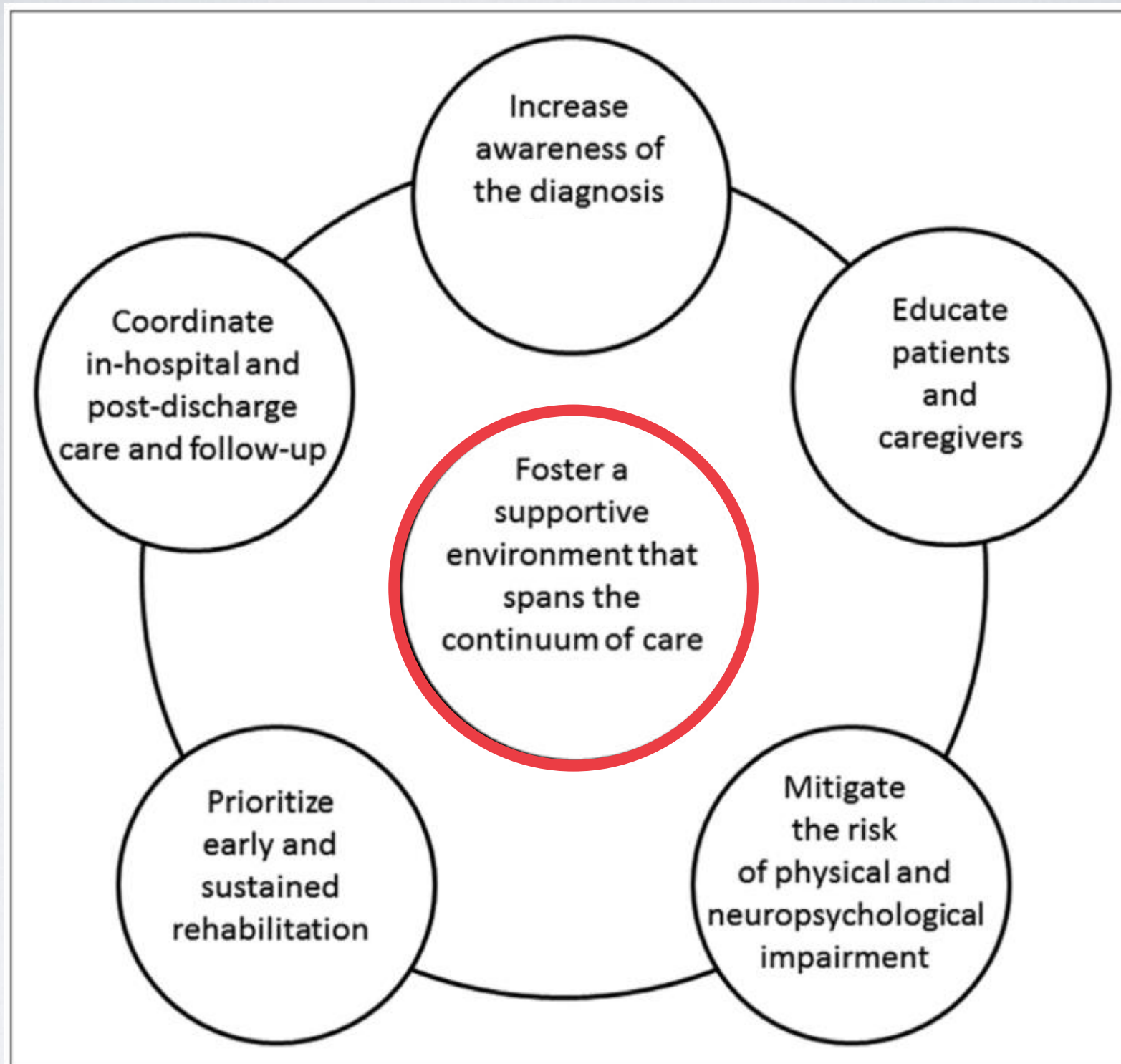
"In the ICU, they treated my wife like one of the team. That was very important to me. They often invited her to rounds."

"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."



# Foster Support

Modified from Maley and Mikkelsen. Crit Care Med. 2015

# The Longitudinal Perspective

## “It Takes a Village”

Acute Care

Discharge

Post-Acute Care

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

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



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