Spiritual Palliative Care
Dr. Jochen Becker-Ebel
Palliative Care Definition: Components of Care

WHO 2002 (see: Indian Primer, page 4)  
Others (see: India Primer, page 10)
Example: UG Curriculum MBBS / nurses

A five modules some 160 pages curriculum for MBBS and a similar for nurses were handed in to the respective councils for approval and inclusion in the UG studies in 2013.
II. WHO and other Definitions

**Physical Pain:**
- (doctors, nurses, physiotherapist)

**Social Pain:**
- financial, existential, relational (social workers)

**Psychological Pain:**
- emotional, (therapists, psychologists)

**Spiritual Pain:**
- religious, existential, spiritual, (spiritual counselors)
WHO definition on palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
I. Religion and Death: Buddha

Buddha seeks liberation through overcoming death.
Religion and Death: Christ

**Jesus** liberates believers through his death on the cross.
Religion and Death: Ramana

Ramana Maharshi`s experience: “I said to myself mentally: ‘Now that death has come. What is it that is dying? This body dies. But is the body I?’. . . The body dies but the Spirit that transcends it cannot be touched by death.”
Conclusion on religion and death

Religion and Spirituality try to overcome (physical, body-related) death and pains. They do not focus intensely on the pre-final period of life. Therefore they do not give elaborate on precise answers in their central statements on spiritual palliative care.
Cure / healing

Most believers seek cure/healing when they pray. They want to overcome sickness.
The Tibetan Book of Death gives help for those within the final moments of life or in first moments after death: “liberation through hearing during the intermediate state”.

Bardo Thodol
Ars Moriendi

In 15\textsuperscript{th} century the Christian “\textit{Art of Dying}” gave believers a more positive view on the process of dying and wanted to help them overcome fear and despair through faith, rituals and prayer.
Near Death Experiences

Whether lack of oxygen or reality: Some person draw faith through near-death experiences and so they overcome fears.
Conclusion

Religion did not elaborate intensely on the “art of dying” and the help for pre-final patients and relatives in their religious and spiritual needs.

Only after palliative and hospice care and clinical pastoral counseling movement came up some 50 years back religious and spiritual teachers put their mind into it on a structured way.
Definitions on spirituality / religion

**Spirituality** is what gives a person’s life meaning, how he views the world he finds himself in and this may or may not include a “God” or religious conviction.

**Religious care** relates more to the practical expression of spirituality through a framework of beliefs, often pursued through rituals and receiving of sacraments.
Roll of spirituality in palliative care

Figure 3: Lung cancer – physical, social trajectories and psychological, spiritual trajectories from diagnosis to death. Source: [24]
Literature Overview 2010

Spiritual Care at the End of Life: 
a systematic review of the literature:

www.abdn.ac.uk/cshad/documents/SpiritualCareattheEndofLife.pdf
http://edoc.ub.uni-muenchen.de/5433/1/Bauer_Stephan.pdf:

a) Religious believers do have in general LESS fear connected with dying - but only active believers with prior personal exposure to the topic.

b) Religious/spiritual persons with first exposure to an incurable cancer situation have MORE fear connected with dying than non-believers.

Munich University appointed a professor for Spirituality within Palliative Care in 2010.
<table>
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<tr>
<th>Quality Indicator</th>
<th>Metric</th>
<th>Suggested Tools</th>
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<tr>
<td><strong>3. Outcomes</strong></td>
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| **3.A - Clients’ spiritual needs are met.**<sup>16</sup> | Client-reported spiritual needs documented before and after spiritual care | - Spiritual Needs Assessment Inventory for Patients (SNAP)<sup>17</sup>  
- Spiritual Needs Questionnaire (SpNQ)<sup>18</sup> |
| **3.B - Spiritual care increases client satisfaction.**<sup>19</sup> | Client-reported satisfaction documented before and after spiritual care | - HCAHPS #21<sup>20</sup>  
- QSC<sup>1</sup> |
| **3.C - Spiritual care reduces spiritual distress.**<sup>22</sup> | Client-reported spiritual distress documented before and after spiritual care | - "Are you experiencing spiritual pain right now?"<sup>21</sup> |
| **3.D - Spiritual interventions increase clients’ sense of peace.**<sup>22</sup> | Client-reported peace measure documented before and after spiritual care | - Facit-SP-Peace Subscale<sup>23</sup>  
- "Are you at peace?"<sup>24</sup> |
| **3.E - Spiritual care facilitates meaning-making for clients and family members.**<sup>25</sup> | Client-reported measure of meaning documented before and after spiritual care | - Facit-SP-Meaning Subscale  
- RCOPE<sup>26</sup> |
| **3.F - Spiritual care increases spiritual well-being.**<sup>27</sup> | Client-reported spiritual well-being documented before and after spiritual care | Facit-SP |
III. Spiritual need assessment

<table>
<thead>
<tr>
<th>HOPE*</th>
<th>FICA†</th>
<th>SPIRIT‡</th>
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<tbody>
<tr>
<td>H  Sources of Hope</td>
<td>F  Faith</td>
<td>S  Spiritual belief system</td>
</tr>
<tr>
<td>O  Organized religion: level of identification or participation</td>
<td>I  Importance/Influence of faith or spirituality</td>
<td>P  Personal belief system</td>
</tr>
<tr>
<td>P  Personal spirituality and Practices</td>
<td>C  Community: identification or participation in spiritual or religious community</td>
<td>I  Integration with a spiritual community</td>
</tr>
<tr>
<td>E  Effect on medical care and end-of-life issues</td>
<td>A  Address/Apply: how to address patients’ spiritual or religious concerns</td>
<td>R  Ritualized practices and restrictions if any</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I  Implications for medical care</td>
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<td></td>
<td></td>
<td>T  Terminal events planning</td>
</tr>
</tbody>
</table>
Assessment tools (Indianised) (1:1 interview)

FICA /SPIR Interviews (European Journal of Cancer Care 15, 238–243)

- **Spirituality**: Would you describe yourself as a believing/spiritual/religious person?
- **Place**: What is the *place* of spirituality in your life? How important is it in the context of your illness?
- **Integration**: Are you *integrated* in a group of spiritual believers/religious family?
- **Role**: What *role* would you like to assign to your doctor (or nurse or therapist) in the domain of spirituality?
Examples - SPIR interview

• **Spirituality**: ‘I am a believer in a broad sense. Whether it helps, I do not know.’

• **Place**: ‘I find strength in my belief. Then I do not feel so alone.’ ‘God chooses strong people to deal better with the illness.’

• **Integration**: ‘Although brought up in a strict religious background, I have nothing to do with institutional church.’

• **Roll**: ‘I am glad that somebody is interested in such personal subjects.’
Spiritual palliative care in (future) India

- Who are the “carers”?
- Will karma-concept, traditional rituals, holy places refuge help?
- Which impact has the religious diversity?
- What influence has “alternative healing”?

There is more to listen, hear and learn on this.
IV. What can we do ???

1. Pray
2. Rituals

Recite holy texts, give Ganga-water / Tulsi leaf

Bless, holy ointment, Eucharist
3. Speak and listen
4. Meditate
5. Be present, be still, wait
How to teach Spirituality in Palliative Care courses

Dr. theol. Jochen Becker-Ebel
Adjunct Professor for Palliative Care
IAPCON 2016 at Pune – Sunday Feb. 14th 9.30 am in Session 6A

Empathy, Compassion and Spirituality: Need of the hour in medical teaching
Why to teach? – Patient, family & own needs

• God? ..... divine punishment/abandonment
• Self? ..... extinction of being/self
• Certainty? ..... “home”, foundation, “beyond”
• Why me? ..... meaning of sickness/pain
• Meaning? ..... loss
• Life balance? ..... negative
What to be taught? (..in India)

• Definitions & Spirituality as contribution to care
• Diagnosis: spiritual/existential needs of patient & help
• Done by each team member
• Own spirituality, rituals, mediation for care & self-care

All seems to be quite difficult and is often not done.
2. Palliative Care teaching in India (Raj 2012)
http://ebookbrowse.net/teaching-palliative-care-in-india-m-r-rajagopal-ppt-d419648038

Palliative care practice needs..

• Heart (Attitude)
• Head (Knowledge)
• Hands (Skill)
Heart - part of learning

- emphasise with the patients emotional needs
- improve one’s own communication skill
- understand one’s own role in groups / teams
- Reflect on one’s own work behaviour/ethics
- find one’s own strength

http://directfrommelissa.blogspot.in/
Suggestions on: QoL, additional therapies

1. **supportive therapies: play**
2. music therapy: body tambura
3. Acupressure / Mediarupress®
4. Yoga: mudras, hatha yoga, take a minute™, pranic healing, laughter yoga
1. Supportive therapies: play

2. Music therapy: body tambura

3. Acupressure / Medikupress®

4. Yoga: mudras, hatha yoga, take a minute, pranic healing, laughter yoga
1. supportive therapies: play

2. **music therapy:** singing

3. Acupressure / Mediakupress®

4. Yoga: mudras, hatha yoga, take a minute, pranic healing, laughter yoga
Suggestions on: QoL, add. therapies 3

1. supportive therapies: play
2. music therapy: body tambura
3. Acupressure / Mediakupress®
4. Yoga: mudras, hatha yoga, take a minute, pranic healing, laughter yoga
Suggestions on: QoL, add. therapies 4

1. supportive therapies: play
2. music therapy: body tambura
3. Acupressure / Mediakupress®
4. mudras, hatha yoga, take a minute, pranic healing (Help Age) laughter yoga
Teaching means: not only know theory and practice, but... during teaching to cope with:

- emotions of the students
- outbreak of emotions, tears, grief,
- resistance, non-cooperation, anger
- „knowing better“ or „have reason why this should not be done“
- students’ lack of palliative practice
- conducting difficult group processes
How (not) to teach?

NOT: By long talks (all will sleep)

But: Through interaction methods
Rituals at teaching/conference (as sample)
Work Impressions of 2016

KMC Attavar, Mangalore, Manipal University 3rd batch
Yenepoya University, Mangalore, College of Nursing; 3rd batch
Karunashraya with Bengaluru Network: NIMHANS, KIDWAI, St. Johns, NH, HCG a.o. for MD, nurses & counsellors: 1 day comm. course
Background: Patients (caretakers) of Geriatric Palliative Care Ward, KMC Attavar, Mangalore
Spirituality through Action Methods: Preparing the work

Starting the work

Being prepared
The „Persons in need“ and the „Carers“
Preparing the stage
Communication (students = trainers)
The „Play of Gods“
V. Accompanying the “inner growth”

Monika Müller, a German Spiritual Palliative Care Pioneer meets Mr. B., a baker from profession, five days after hospital admittance with an unclear diagnosis.