Spiritual needs of patients with chronic illness

What do they need and how do they get it?

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Structure of the presentation

• Needs: Definitions and Pathways
• Psychosocial and spiritual needs
  – Unmet needs in different populations
  – Associations with health-related and psychological variables
• Who cares for unmet spiritual needs?
• Outlook
Background

• In response to chronic illness and life threatening diseases, patients are confronted with the question of meaning and purpose in life – what is it that gives hope and confidence?

• For several patients, their spirituality/religiosity (SpR) is a relevant resource to cope.

➤ Although an increasing number of patients reject institutional religiosity, particularly in secular societies, several still do have specific SpR needs which are in most cases neither addressed nor recognized in our health care system.
Wishes, Needs, Desire

Subjective experience of a lack → attempt to compensate

• Material vs. immaterial needs
• Conscious vs. latent needs

• Motive (as an individual trait → need for achievement) vs. Motivation (as a current state → „I need your help now“)

- Essential need: Air to breath
- Nice-to-have Wish: Gold-Card without any limit
- Insatiable desire: Experience of „Incompleteness“ → absolute attention
Human Needs
an idealistic hierarchy
Abraham Maslow (1943)

1. **Physiological** (breathing, nutrition, sleep, etc.)
2. **Safety** (personal and financial security, health etc.)
3. **Belongingness** (friendships, family, intimacy, acceptance, etc.)
4. **Esteem** (self-esteem, confidence, social status, respect, etc.)
5. **Self-Actualization** (creativity, realization of potentials, etc).

- The basic needs appear to be more important than the higher level (secondary) needs.
Existence, Relatedness and Growth
Clayton Alderfer (1972)

Because the hierarchical structure was very idealistic, Alderfer modified Maslow’s model in terms of his Existence, Relatedness and Growth (ERG) Theory:

✓ **Existence**: survival, security, etc.
✓ **Relatedness**: friendships, intimacy, etc.
✓ **Growth**: self-realization, creativity, etc.

These three categories have no hierarchical structure, and their importance may vary inter-individually.
Primary and secondary needs in a hospital?

• Because patients with chronic diseases or elderly have restricted possibilities to develop in terms of self-realization, creativity and productiveness, and because respect and esteem are experienced only in rare cases…

• higher needs for relatedness with friends and family - and maybe also a connection with the own religious tradition - would be the consequence when growth needs can not be fulfilled any longer.
Putative pathways of action within a modified Vulnerability-Stress-Model.

Challenges

Predispositions

Resources

Coping behavior

Health status

Stressors (life events, illness)

Environmental

Centrality of SpR

Individual disposition

Social
(religious community; relation to God)

Religious Coping Strategies

Spiritual Needs

Individual (self-esteem, meaning making, values, health behavior)

Non-religious Coping Strategies

Psychological

(Physical)

© Arndt Büssing - modified according to Zwingmann, Klein and Büssing, Religions (2011), and Zwingmann and Klein, Spiritual Care (2013)
Spiritual needs are those essential requirements, expectations or purposes related to the non-tangible sacred or the immaterial soul which would contribute to attain optimal well-being but are not satisfied at a given situation.
Psychosocial or spiritual needs?

- **Psychosocial needs** of patients refer to:
  - **physical issues and treatment** (i.e., physical impairment, fatigue, sleep disturbance, side-effects)
  - **psychological and social** (i.e., emotional distress, depression, loss of sense of control, affected body image, impaired social function and relationship, etc.)
  - **informational and support** (i.e., management of illness, prognosis, treatment options and side-effects, support groups, complementary therapies, etc.).


- **Spiritual needs** are “the needs and expectations which humans have to find meaning, purpose and value in their life”.
  - “Such needs can be specifically religious, but even people who have no religious faith or are not members of an organized religion have belief systems that give their lives meaning and purpose”.

## Conceptual framework of Spiritual Needs related to the ERG model


<table>
<thead>
<tr>
<th>Categories of spiritual needs</th>
<th>Needs according to the ERG model</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Peace</strong></td>
<td><strong>Existence</strong> (Safety)</td>
</tr>
<tr>
<td>(inner peace, hope, balance, forgiveness, distress, fear of relapse, etc)</td>
<td></td>
</tr>
<tr>
<td><strong>Connection</strong></td>
<td><strong>Relatedness</strong></td>
</tr>
<tr>
<td>(love, belonging, alienation, partner communication, etc.)</td>
<td></td>
</tr>
<tr>
<td><strong>Transcendence</strong></td>
<td></td>
</tr>
<tr>
<td>(spiritual resources, positive / negative relationship with God / Sacred, praying, etc.)</td>
<td>Growth</td>
</tr>
<tr>
<td><strong>Meaning / Purpose</strong></td>
<td></td>
</tr>
<tr>
<td>(meaning in life, self-actualization, role function, etc.)</td>
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</tbody>
</table>
Spiritual needs are diverse and yet similar - and they are addressed most likely in a palliative situation -

- **US patients with cancer**: help to deal with fear, to find hope and meaning in life, to find spiritual resources, and to talk with someone about peace of mind, and life and death. 
  Moadel et al., *Psychooncology* (1999)

- **French patients at the end of life**: reinterpretation of life, search for meaning, connection to the world, self and others, vital energy, ambivalence to the future, confrontation with death, relationship to transcendence.

- **Taiwanese patients with advanced cancer**: hope for survival and peaceful mindset, meanings of life and dignity, reciprocal human love, and facing death peacefully.
  Hsiao et al., *J Clin Nurs.* (2011)
• Spiritual needs are **not** an exclusive topic at the end of life

• Right at the start of the course of disease these needs may appear – and need to be addressed and supported

➢ Thus, our research focuses on patients with chronic (not primarily fatal) diseases
• Definitions
• Psychosocial and spiritual needs
  – Unmet needs in different populations
  – Associations with health-related and psychological variables
• Who cares for unmet spiritual needs?
• Outlook
Spiritual Needs in patients from Germany

Spiritual Needs Questionnaire (SpNQ)

Büssing et al., Pain Medicine (2013)

N= 392
67% women, 33% men
age 56 ± 14 y
68% living with partner
61% Christian denomination, 36% none
86% chronic pain disorders, 14% cancer

** p < 0.001; * p = 0.004 (ANOVA)
Spiritual Needs in patients from Germany

*D. Spiritual Needs Questionnaire (SpNQ)*


- N = 285
- 49% women, 51% men
- Age 61 ± 13 y
- 73% Christian denomination, 25% none
- 100% cancer

**Religious Needs**

**Existential Needs**

**Inner Peace**

**Giving / Generativity**

**SpNQ 1.2 Score [0-3]**

* p < 0.05 (ANOVA)

** p < 0.01; ** p < 0.001 (ANOVA)
Spiritual Needs in patients from Shanghai

Spiritual Needs Questionnaire (SpNQ)

Büssing et al., J Integr Med (2013)

N=168
39% women, 61% men
age 51 ± 16 y
93% living with partner
77% no religious affiliation,
34% various Religions
66% cancer,
34% other chronic conditions

* p<0.05 (ANOVA)
Spiritual Needs in patients from Poland

Spiritual Needs Questionnaire (SpNQ)

Büssing et al., J Relig. Health (2014)

- N=275
- 74% women, 26% men
- age 56 ± 16 y
- 54% living with partner
- 100% Catholics
- 35% cancer, 66% other chronic conditions

**Graph:**
- SpNQ Polish [0-3]
- Religious Needs
- Existential: Relief
- Existential: Meaning
- Peace Needs
- Giving / Generativity

* p < 0.05 (ANOVA)
**Spiritual needs of German soldiers**

- **Spiritual Needs Questionnaire (SpNQ)**

- n=824; 93% men, 7% women

<table>
<thead>
<tr>
<th>Reaction</th>
<th>Religious Needs</th>
<th>Existential Needs</th>
<th>Inner Peace</th>
<th>Giving/Generativity</th>
</tr>
</thead>
<tbody>
<tr>
<td>SpNQ Score</td>
<td>PCL-M &lt; 30</td>
<td>30-44</td>
<td>45-50</td>
<td>&gt; 50</td>
</tr>
<tr>
<td><strong>p &lt; .0001</strong></td>
<td><strong>p &lt; .0001</strong></td>
<td><strong>p &lt; .0001</strong></td>
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</tbody>
</table>

Soldiers with PTSD symptoms after traumatic missions had significantly (p<.0001) higher **Inner Peace needs** (F=29.3) and **Existential Needs** (F=21.1).
Spiritual needs of elderly living in retirement / nursing homes

n=100: mean age 84 ± 7 years; 82% women, 18% men
self care abilities: 28% independent, 27% largely independent, 45% only with help


Compared to patients with chronic diseases, the needs categories of elderly show similar pattern, but are much lower!
Spiritual needs of elderly from the North and the South of Germany differ strongly

**North: Schleswig-Holstein** (n=100)
- age: 84 ± 7 years
- 82% women, 18% men
- 84% Christians (pred. Protestants)
- Religious Trust: 38 ± 29
- Life satisfaction: 68 ± 13

**South: Bayern** (n=112)
- age: 83 ± 7 years
- 76% women, 24% men
- 92% Christians (predom. Catholis)
- Religious Trust: 68 ± 23
- Life satisfaction: 67 ± 13


Man Ging, Öven-Uslucan, Frick, Fegg, Büssing (submitted for publication)
Elderly were attended – but felt alone

• During the assisted interviews, several started to weep because they were never confronted directly with their inmost perceptions, and they never were invited to talk about these perceptions and needs.
  – Often the interviewees regarded these talks as `liberating´, pleasant and enriching.
• The interviewees´ comments indicate that most feel connected with their family - nevertheless they fear to burden their family with their own troubles, fears and worries.
• The individual statements made clear that closer relations or confiding talks with other residents were rare; often they felt an impersonal, cool and egoistic atmosphere among the residents.
• Complicating was the fact that relations to close friends are reduced because several of them are already deceased or were unable to come to visits.

Erichsen & Büssing, Evidence-based Complementary and Alternative Medicine (2013)
• Definitions
• Psychosocial and spiritual needs
  – Unmet needs in different populations
  – Associations with health-related and psychological variables
• Who cares? – Spiritual care
• Outlook
Existential Needs were weakly associated only with Escape from illness – but not with pain disability or pain symptoms

<table>
<thead>
<tr>
<th></th>
<th>Religious Needs</th>
<th>Existential Needs</th>
<th>Inner Peace</th>
<th>Giving / Generativity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life Satisfaction (BMLSS-10)</td>
<td>.174**</td>
<td>-.151**</td>
<td>-.141**</td>
<td>.065</td>
</tr>
<tr>
<td>Escape from Illness (Escape)</td>
<td>.055</td>
<td>.212**</td>
<td>.137</td>
<td>.070</td>
</tr>
<tr>
<td>Pain Disability Index (PDI)</td>
<td>.087</td>
<td>.126</td>
<td>.084</td>
<td>.091</td>
</tr>
<tr>
<td>Symptom Score (VAS)</td>
<td>-.148</td>
<td>-.004</td>
<td>-.087</td>
<td>-.027</td>
</tr>
</tbody>
</table>

** p < 0.01 (Pearson)

Spiritual Needs correlated predominantly with patients’ positive and strategy associated interpretations of illness

<table>
<thead>
<tr>
<th>Interpretation of Illness (IIQ)</th>
<th>Religious Needs</th>
<th>Existential Needs</th>
<th>Inner Peace</th>
<th>Giving / Generativity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Threat / Enemy</td>
<td>.227**</td>
<td>.165**</td>
<td>.187**</td>
<td>.196**</td>
</tr>
<tr>
<td>Interruption of life</td>
<td>.114*</td>
<td>.231**</td>
<td>.294**</td>
<td>.120</td>
</tr>
<tr>
<td>Punishment</td>
<td>-.056</td>
<td>.044</td>
<td>.119</td>
<td>.069</td>
</tr>
<tr>
<td>Weakness / Failure</td>
<td>-.014</td>
<td>.193**</td>
<td>.170**</td>
<td>.005</td>
</tr>
<tr>
<td>Relieving break from life</td>
<td>.149**</td>
<td>.301**</td>
<td>.158**</td>
<td>.110</td>
</tr>
<tr>
<td>Call for Help</td>
<td>.361**</td>
<td>.258**</td>
<td>.212**</td>
<td>.240**</td>
</tr>
<tr>
<td>Challenge</td>
<td>.205**</td>
<td>.255**</td>
<td>.124</td>
<td>.067</td>
</tr>
<tr>
<td>Value</td>
<td>.332**</td>
<td>.424**</td>
<td>.253**</td>
<td>.199**</td>
</tr>
</tbody>
</table>

** p < 0.01 (Pearson)

Existential and Inner Peace Needs of patients with fibromyalgia were predominantly associated with affected mental health and impact of pain.

<table>
<thead>
<tr>
<th></th>
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<th>Existential Needs</th>
<th>Inner Peace</th>
<th>Giving / Generativity</th>
</tr>
</thead>
<tbody>
<tr>
<td>14 patients; 95% women; mean age: 58 ± 10 years</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fibromyalgia Impact (FIQ)</td>
<td>.137</td>
<td>.237**</td>
<td>.288**</td>
<td>.235**</td>
</tr>
<tr>
<td>Tender points</td>
<td>.129</td>
<td>.069</td>
<td>.115</td>
<td>.156</td>
</tr>
<tr>
<td>Anxiety (HADS)</td>
<td>.061</td>
<td>.326**</td>
<td>.462**</td>
<td>.222**</td>
</tr>
<tr>
<td>Depression (HADS)</td>
<td>-.079</td>
<td>.232**</td>
<td>.294**</td>
<td>-.025</td>
</tr>
<tr>
<td>Escape from Illness</td>
<td>.014</td>
<td>.303**</td>
<td>.390**</td>
<td>.211</td>
</tr>
<tr>
<td>Loneliness (UCLA)</td>
<td>-.126</td>
<td>.196</td>
<td>.237**</td>
<td>.001</td>
</tr>
<tr>
<td>Life satisfaction (BMLSS)</td>
<td>.098</td>
<td>-.136</td>
<td>-.254**</td>
<td>-.032</td>
</tr>
<tr>
<td>QoL – physical (SF-36)</td>
<td>-.153</td>
<td>.029</td>
<td>.063</td>
<td>-.150</td>
</tr>
<tr>
<td>QoL – mental (SF-36)</td>
<td>-.008</td>
<td>-.328**</td>
<td>-.419**</td>
<td>-.119</td>
</tr>
</tbody>
</table>

** p < .01 (Pearson)

Offenbaecher et al., Evidence based Complementary and Alternative Medicine (2013)
Existential Needs and Inner Peace Needs indicate a lack of spiritual wellbeing, while Religious Needs require faith.

<table>
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<tr>
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<th>Existential Needs</th>
<th>Inner Peace</th>
<th>Giving / Generativity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaning subscale</td>
<td>.080</td>
<td>-.302**</td>
<td>-.254*</td>
<td>.226*</td>
</tr>
<tr>
<td>Peace subscale</td>
<td>.126</td>
<td>-.312**</td>
<td>-.355**</td>
<td>.068</td>
</tr>
<tr>
<td>Faith subscale</td>
<td>.654**</td>
<td>-.072</td>
<td>-.108</td>
<td>-.020</td>
</tr>
</tbody>
</table>

** p < 0.01 (Pearson)

Structure of the presentation

• Definitions
• Psychosocial and spiritual needs
  – Unmet needs in different populations
  – Associations with health-related and psychological variables
• Who cares for unmet spiritual needs?
• Outlook
When no one cares…

Killian's Hospital Bed Room. © Jim McKenzie
Who supports unmet spiritual needs of patients with advanced cancer?

- 72% reported that their spiritual needs were supported minimally or not at all by the medical system, and
- 47% minimally or not by a religious community.


- Spiritual support was significantly associated with patients’ (psychological) quality of life.

Medical doctors should know about patients’ spiritual needs!

The majority of German tumor patients wanted their doctor to be interested in their spiritual orientation.

Frick et al., *Eur J Cancer Care* (2006)

Patients with chronic pain diseases would like to talk about their spiritual needs with …

- chaplain: 23%
- had no one to talk with: 20%
- important to talk with medical doctor: 37%


Yet medical practitioners may lack the necessary time, skills or even interest to uncover and address these needs.
Who should care?

- Although it is adequate that board-certified chaplains should assess patients’ spiritual needs and resources (Puchalski et al., 2009),
- one can not ignore that particularly in secular societies more and more non-professionals have to care for specific issues which go beyond their primary expertise.
Professional Neutrality
Curlin et al., Medical Care (2006); Lee & Baumann, Evid Based Complement Alternat Med. (2013)

2,000 US physicians; 39% Protestants, 22% Catholics, 29% other denominations, 11% no religious affiliation
99 German psychiatrists; 71% with religious affiliation; 29% without

Most often stated reasons not to address SpR issues in the clinical encounter:

- **Professional neutrality:** 55% Germany  40% USA
- **Lack of lime:** 34% Germany  48% USA
- **Lack of knowledge:** 15% Germany  26% USA
- **General discomfort:** 3% Germany  23% USA
- **Not my duty:** 22% Germany
The problem of relation and communication

• Patients with inoperable lung cancer and end-stage heart failure and their carers were generally reluctant to raise spiritual issues,

• but many, in the context of a developing relationship with the researcher, were able to talk about such needs.

• Patients with advanced cancer and non-malignant disease were best able to engage their personal resources to meet their spiritual needs when affirmed and valued by health professionals.
…and how do they get what they need?

In most cases not

- because particularly in secular hospitals only a few physicians / nurses do care for these issues
  → the number of those who are aware of their own resources / spirituality and have the necessary competence & compassion is not legion
- because the organizational structures do not support this
  → “Otherwise we had to change our well-organized routine.”
- because during the ever shorter hospital stays the team has to focus on their “main duties”
  → in most cases our patients do not have even have contact to a religious community which might support them at home
Health professionals as facilitators to open `inner doors´

- As medicals doctors, nurses, social workers, psychologists, chaplains, ... – as sensitive beings – we are in charge to help and assist others,
- we have to address their spiritual needs and to respond adequately.
- This remains a challenging task for a modern health care system!

- Yet we need the organizational structures to facilitate this, professional competencies, and compassion to act as `Samaritans´.

What about voluntary work of non-professionals?
Team Spirit = Spiritual Care

- Mind
- Emotion
- Vitalities
- Physis

- relatives
- volunteers
- chaplains
- psychologists, therapists
- physicians, nurses

- physicians,
- nurses
The mystery which deserves respect

All health care professionals have a spiritual core competence, and all contribute with the specific competence derived from their professional qualification.

- This core competence („spiritual aerial“) includes the sensitivity for the `dimension of mystery´ within the daily routine in a clinic, medical ward, etc.

- This `dimension of mystery´ disburdens (at least medical doctors) from ideas of omnipotence to explain, manipulate or control each and everything,

- and facilitates to perceive the sick person as a mystery which deserves respect – despite of all diagnostic procedures and therapeutic attempts.

Büssing und Frick (2014)
How may I help you?

• I am here to respond
  (being present - either silently, smiling, holding hands, talking, nursing,…)

• You are worth the efforts.

We may see Christ, Buddha, …, ourselves in each and every face.
Whom do we face?

• How can we **offer spiritual / pastoral support** when in secular societies up to 50% of patients with chronic diseases regard themselves as R-S-? (Büssing et al., 2009)

  ➢ Several of them still do have spiritual needs, mostly secular forms.

• Who could **offer such support** when several reject the church as an institution, and are not interested in “religious issues”?

  ➢ Do we have to change as caregivers / chaplains?
  ➢ “**Spiritual / Inner Life formation** as part of the professional formation” (Chr. Puchalski)
Predispositions / Resilience

Trained Attitudes / Behavior
SpR → Ethics / Values
- social behavior
- individual health behavior
SpR → life approved resource of hope and meaning

Resources
Family / Community → Connectedness / Belonging

Coping Strategies
Reflection → Change behavior / priorities
Meaning in Life
Interpretation of Illness

Therapeutic Interventions

Palliative Care
Pastoral Care
Empathic Presence

Optimistic Hope

Spiritual Needs
Transcendence / Religion
Meaning
Connectedness
Peace

Education:
- awareness of the own resources
- develop compassion and abilities to reflect

Concept: Arndt Büssing
© Pictures: own and internet
If she can’t fly and help anymore, let’s give her our hands.