WHAT IS THE DISTINCTIVENESS OF PEDIATRIC CHAPLAINCY AND WHAT ARE THE IMPLICATIONS OF THIS FOR TRAINING AND DEVELOPMENT?

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Workshop B3 Objectives

This workshop will be presented by spiritual care practitioners from the USA and UK, offering the opportunity to compare and contrast approaches and practice. It draws on a systematic literature review based on four key databases across a range of disciplines that sought to identify the distinctiveness of padiatric chaplaincy. The findings have relevance to different foci of spiritual care and the training implications.

Participants will be able to:

- Articulate four areas of distinctiveness of padiatric chaplaincy
- Identify specific developmental and training implications of this distinctiveness in relation to spiritual care
- Be aware of the key steps involved in systematic literature reviews

Questions, hypotheses, needs

- Are there, should there be, differences between adult and children's hospital chaplaincy services?

- If so, then this would shape and influence the style of work, training needs, competencies, standards, resources and research

- What might the distinctiveness of your type of chaplaincy be?

Research Method Summary: Systematic Literature Review

Stage 1 Identify literature through database and other searches

Stage 2 Screening

Stage 3 Inclusion and exclusion criteria

Stage 4 Thematic analysis

Based on approach by Booth et al (2012).

Stage 1a Database Search

- Databases selected on advice from experts in the field:

Proquest Medline, Cumulative Index of Allied Health Literature (CIHNAL), Psych info, American Theological Library Association (ATLA)

- Key words identified from research question:

These focused on the type of chaplaincy: paediatric, hospital, children, chaplain and the type of work: spiritual, pastoral and religious Boolean and truncated search approaches were used which included using "and" with various terms such as chaplain and child as well as * to ensure that all the related words were found thus religio* so religious, religion and religiosity were all found

Table 1 Databases and Search Terms

Search terms	Proquest Med line	CINHAL	Psychinfo	ATLA	Heritage Database St John's College (Books)
Chaplain* paediatric*	48	14	6	19	0
Chaplain* Child*	55	31	42	88	10
Famil*paediatric* chaplain*	18	10	2	1	0
Chaplain* child* spirit	34	12	11	13	1
Chaplain* child* religio*	39	4	9	19	4
Chaplain* child* pastoral	56	3	12	0	43
Hospital* Child* religio*	1	0	100	24	2
Hospital* child* pastoral	12	0	5	39	1
Hospital* child* spirit*	138	0	60	9	1

Stage 1b Other Literature Search

- Books on chaplaincy and related issues some of which were identified through databases
- Official documents relating to chaplaincy from UK Board of Healthcare Chaplains and networks of paediatric chaplains in UK and USA.

Stage 2 Screening

- At this stage type of literature was identified

eg article, peer reviewed journal article, book, book chapter, report, conference paper etc

and relevance for the study before inclusion and exclusion criteria were applied

- 926 articles and 62 books were identified at this stage

Stage 3 Exclusion and Inclusion Criteria

Exclusion:

- Material tangential to paediatric chaplaincy which would not give information on distinctiveness.
- Material about maternity services (pregnancy, miscarriage, still birth) as these services not usually found in standalone children's hospital.
- Material solely addressing adult hospital chaplaincy or other types of chaplaincy.

Inclusion:

- Multidisciplinary perspectives
- All geographical areas and no date restrictions
- All articles authored by a paediatric chaplain

96 pieces of relevant literature remained.

Stage 4 Thematic Analysis

- A narrative rather than statistical approach to synthesis was used focusing on words and text (Popay et al 2006).

- The preview, question, read, summarize (PQRS) approach was adopted to explore the material (Cronin et al 2008). No further quality assessment of the material was done as there is so little in the field it was helpful to include everything found.

- Coding was done as part of this and words used were:

- adolescence, advocacy, assessment, bereavement, cultural, education, end of life, ethics, family, literature review, multidisciplinary, organs, palliative, religious, self, special circumstances, spiritual care, staff care.

- These were then synthesised into four themes: supporting and working with families, spiritual care of children, multidisciplinary working, staff support/self-care.

Table 2.1 Sources, Themes, Literature Type

	Supporting and working with families	Spiritual care of children	Multidisciplinary working	Staff support/ self-care	Total
Articles (A)	13	9	7	2	31
Peer reviewed articles (APR)	40	32	28	8	108
Book (B)	7	6	6	3	42
Book chapter (BC)	5	5	4	2	16
Report (R)	2		1		3
Invited commentary (IC)	1	1	1		3
Dissertation Thesis (D)		1			1
Conference paper (CP)		1			1

Table 2.2 Sources, Themes, Literature Type

	Supporting and working with families	Spiritual care of children	Multidisciplinary working	Staff support / self-care	Total
Qualitative (QL)	27	15	20	3	65
Quantitative (QT)	8	7	4		19
Case study (CS)	8	7	3		18
Expert opinion (EO)	18	19	13	8	58
Systematic literature review (SLR)	2	2	2	1	7
Literature review	1	1	2	1	5
Mixed Methods	3	3	3	2	11
Concept analysis	1	1			2
Total	68	55	47	15	185

Themes Identified

Theme 1: Relating to and supporting families including Palliative, end of life and bereavement care

Theme 2: Relating to and supporting children and young people

Theme 3: Chaplaincy as part of a multidisciplinary team

Theme 4: Staff support and self-care of paediatric chaplains

Theme 1: Relating to and supporting families

- In paediatric chaplaincy more work may happen with families because:

  The patient is not always able to talk for themselves

  Parents are very often present during visits

  No restrictions on visiting hours

- 71% literature related to the role of chaplain in palliative, end of life and bereavement care

Theme 1: Some Key Findings

- Looking after families benefits the child (Burleigh 2011)
- Significant numbers of parents may suffer from fear and anxiety (Feudtner et al 2003)
- Spirituality and faith facilitates coping for families (Grossoehme et al, 2008b, Schneider and Mannell 2006).
- Chaplains help families get religious, spiritual and cultural needs met (Seltz et al 2008)
- Connectedness, particularly with family is significant for sick children (Bull 2013)
- Praying with infants positively impacts parent (Eichmann 2000)
- Chaplains should be integral part of the paediatric palliative team – presence important (Robinson et al 2006, Lyndes et al 2012)
- Chaplaincy is a vital part of bereavement care (Seidl 1989, Zelcer et al 2010)
- Chaplains can support the work of nurses in spiritual care (Cadge 2013)

Feudtner et al (2003)

They found that "among parents, 60-80% were estimated to have felt fearful or anxious, had difficulty coping with their child's pain or other symptoms, sought more medical information about their child's illness, questioned why they and their child were going through this experience, asked about meaning or purpose of suffering, and felt guilty" (2003:67).

USA reflections

- Though all Chaplains deal with the families of patients, there is a real difference between Patient Autonomy and Parental Authority
- Guilt and remorse in parenting can be so strong!
- The theodicy for suffering children is difficult to develop/maintain for many
- With children, what is "stolen" by death is not the past, but the future
- I have my own children: I fear for them; I worry that I will lose it emotionally (where is the place for my own tears?)
- There are usually more visitors to contend with when a child is the patient; the crowds and their emotions can be overwhelming
- Anger at the "injustice" of sickness and injury to children. The world isn't supposed to work like this. Children are innocent and should not have to suffer. Adults most often suffer self-inflicted injuries, but children suffer from the poor decisions of adult caregivers. We struggle to keep our anger under control (esp. with abuse cases) and remain professional, staying out of the blaming cycle and/or avoiding becoming an investigator.
- And there is also the injustice that minority children in the US are 7.7 times more likely to sustain a burn or gunshot wound, 7 times more likely to be struck by a car, 6 times more likely to be intentionally injured and over twice as likely to die from their injuries as white children.

Issues in Supporting families

Parental authority vs. [adult] Patient autonomy

     1. A type of surrogacy

         Capacity and Competence

     2. Treatment decisions

         Parents are generally seen as loving, caring and wanting best for their children

         When does the state step in?

     3. Research participation

         Can parents objectively make best decision for child?

     4. Religious considerations

         JW Parents asking for no blood for their minor child

Theme 2: Relating to and supporting children and young people

- 58% literature related to this
- Area where there is most research done by paediatric chaplains

Theme 2 Some Key Findings

- Don't treat paediatric patients as mini-adults – there are many differences to the adult experience eg influence of peers, parental guilt, play and education (Speck 1995, Weinstein 2001)
- Siblings may need extra support (Speck 1995)
- Spiritual distress may be an issue for sick children (Pridmore and Pridmore 2004)
- Children have spiritual and sometimes religious needs and all healthcare professionals should be involved in meeting them (Campbell 2006, Bull and Gillies 2007)
- Care needs to be age and developmentally appropriate and chaplains need a good understanding of development theories (Grossoehme 1999, Fosarelli 2012)
- Children with a faith need to explore their concept of God in relation to their illness and also their self-concept (Cater 1963)
- Specific paediatric spiritual assessment tools are necessary (Grossoehme et al 2008a)
- The particular needs of adolescent patients need to be taken into account, particularly in relation to autonomy (Freyer et al 2006)
- Play and storytelling are tools which help children engage with feelings and needs (Schooley 1974)
- Need to explore suffering and theodicy (Sommer 2012)

Weinstein 2001

- Adult patients usually speak for themselves, either directly or through advanced directives, while children rarely do. For adults, quality of life is often the number one issue, while with children, patients see quantity of life as paramount. Adults usually suffer in silence when they receive an injection, but kids can't always do that, so we as care givers must get accustomed to hearing screaming and crying in the halls. …further, I have not meet met a child or teenager yet who knew what a chaplain did, so they have no pre-conceived notions about us. We can't look into the eyes of a suffering child and remark 'all things happen for a reason', because it's not true (2001:132).

Pridmore & Pridmore (2004)

Their main findings are around meaning and fulfilment, negotiation and the rights of the child, ethnicity and religion, learning environment, assessment criteria and the reciprocal nature of the relationship between the patient and the professional. They also helpfully identify the concept of spiritual distress, spiritual development models and personal well-being in sickness.

Grossoehme (1999)

Suggests that "the most fundamental ways in which children are different from adults is that they use a different vocabulary to describe their experiences. They feel emotions as readily as adults but do not know the same words to describe what is going on inside them" (1999:8).

He goes on to highlight that therefore our pastoral care should be shaped by the age and development level of the child.

USA reflections

- Children are not small adults
- Children are not sweet little angels
- Children are smarter than we think
- Children have robust beliefs
- We must operate within the bounds of the parents' religious and spiritual beliefs
- We must recognize and honor adolescents' emerging sense of self and need for growing independence

Issues in Relating to children / YP

Consent vs. Assent (at what age does the patient's decision count?)

      1. Treatment decisions

                Knee/ankle replacement (APH): teen vs. parents

                Forced chemo (CT, VA): teens

                St. Jude, National Children's (D.C.) go as low as 7yo

                Canada has no lower age limit

      2. Research participation

                Does the child's voice count?

                Story from Mark Brown at St. Jude?

      3. Religious considerations

                Baptized JW teen: do we honor her choice based
                on religion?

Theme 3: Chaplaincy as part of a multidisciplinary team

52% literature discussed this area

Theme 3 Key Findings

- Chaplains see their contribution as being around wholeness, presence and healing (Cadge et al 2011)
- Chaplains are sometimes seen as integral part of the team (Robinson et al 2006, Freyer et al 2006, Michelson et al 2011, Rudd et al 2013)
- Others discuss chaplains co-opted where necessary (Wallace et al1995)
- Medical staff need to understand what chaplains do (VandeCreek et al 2007)
- Chaplains need to engage with language of outcomes (Lyndes et al 2012)

Lyndes et al (2012)

Lyndes et al (2012) discuss the barriers for the different values and "language of outcomes" and suggests that for Chaplains to become even more integrated Chaplains need to learn to translate their language (2012:74).

Issues in MD working

Mutual Pretense in pediatrics (from Myra Bluebond, PhD, Yale: "The Private Lives of Dying Children")

1. Roles (PT, family, doctor, nurse, others)

Child: to grow up to adulthood

Parent: to protect and nurture child to grow to adulthood and have their own family

Medical team: to heal, to eliminate threat to child's growth to adulthood

2. Telling the truth

Child's angry last words to Mom: "You lied to me!"
Parents of angry oncology patient daughter (APH)

Parents did decide to tell her she was dying

Mom's excellent talk with her later: "What is it like to have a baby?"

Theme 4: Staff support and self-care of paediatric chaplains

- This is the theme with least literature in the review with 17% of items being relevant.

However, from experience it is an important part of the role and this may suggest it is an

under-researched area, particularly when noting the amount of literature which may be

classed as expert opinion.

Theme 4 Key Findings

- Self care education and enhanced spiritual well-being positively affect health of both institution and employee (Charlescraft et al 2010)
- Chaplains involved in soul care for individuals and communities (Charlescraft et al 2010)
- Chaplains need to identify coping and defence mechanisms both for themselves and for others (Hesch 1987)
- Impact of caring is cumulative on staff and chaplains (Cadge 2013)
- Chaplains need to offer care to staff as well as families in traumatic situations (Coffing 2011)
- Some staff feel that they lack skills in offering spiritual or religious care (Cadge 2013)

Charlescraft et als (2010)

On compassion fatigue and paediatric critical care nurses, they conclude

self-care education and enhanced spiritual well-being appear to positively affect the health of the entire institution and the individual employee. ....As chaplains we are called to compassionate care and hospitality, and when we provide a sacred, emotional safe and educative space for individuals and institutions maturation we are practicing the long history of soul care for in individuals and communities"(2010:22).

This is perhaps the most hidden role of a paediatric chaplain.

USA reflections

- Staff debriefings:
  - Sharing food (some restaurants, such as Olive Garden, offer free meals for cases like this)
  - Inviting counselors to speak (EAP, we call them: Employee Assistance Program)
  - Having Administration speak to the group
  - Having the lead physician speak to the group

Observations

- Very little research led by paediatric chaplains on our own discipline
- Some of the differences between paediatric and adult chaplaincy are nuanced because of the distinctiveness of childhood and adolescence as developmental stages
- Adolescents and young people have different needs
- There is still a strong focus on role of chaplain in palliative, end of life and bereavement care, particularly in research
- Awareness raising of the breadth of the role of chaplains for both patients and staff would be helpful
- Chaplains may often have a role across the whole institution – staff care and self care improve the health of both the institution and individuals
- There are significant training needs that chaplains can help address

Triangulation

A survey was carried out through USA and UK paediatric chaplaincy networks:

	More	Same	Less
Religious and spiritual care with children and young people	89.5% (17)	10.5% (2)	0.0% (0)
Supporting the wider family	73.7% (14)	26.3% (5)	0.0% (0)
Staff support	42.1% (8)	63.2% (11)	0.0% (0)
Palliative care for children, young people and their families	89.5% (17)	10.5% (2)	0.0% (0)
Bereavement care for families	76.5% (13)	23.5% (4)	0.0% (0)
Heightened sense of injustice	76.5% (13)	23.5% (4)	0.0% (0)
Dealing with the worst things life can bring	63.2% (12)	36.8% (7)	0.0% (0)

19 people responded

Implications

1. Research and consultations
2. Professional documents
3. Models
4. Training
5. Resources

1 Potential research needs include:

- Comparative research into the spiritual needs of children in hospital and those not ill;
- Effective assessment and intervention models for spiritual care with children;
- Research on the differences of children and adults in coping with illness and disability;
- Overlap with maternity, perinatal and paediatric chaplaincy
- Approaches to measuring efficacy.

2 Professional documents

1. Standards
2. Competencies
3. Capabilities
4. Code of ethics
5. Good practice guidelines

2. Standards and competencies

1. **Paediatric specific religious and spiritual care:**

Be aware of the differentiation of spiritual and religious needs in relation to age, gender, culture, ethnicity, developmental stage, illness, faith and or spiritual development.

Care may need to be offered in the context of the family and an understanding of family systems theory.

Safeguarding needs will be paramount.

Spiritual and religious care may need to be offered through activities and play.

Spiritual care may need to be offered in a multidisciplinary context.
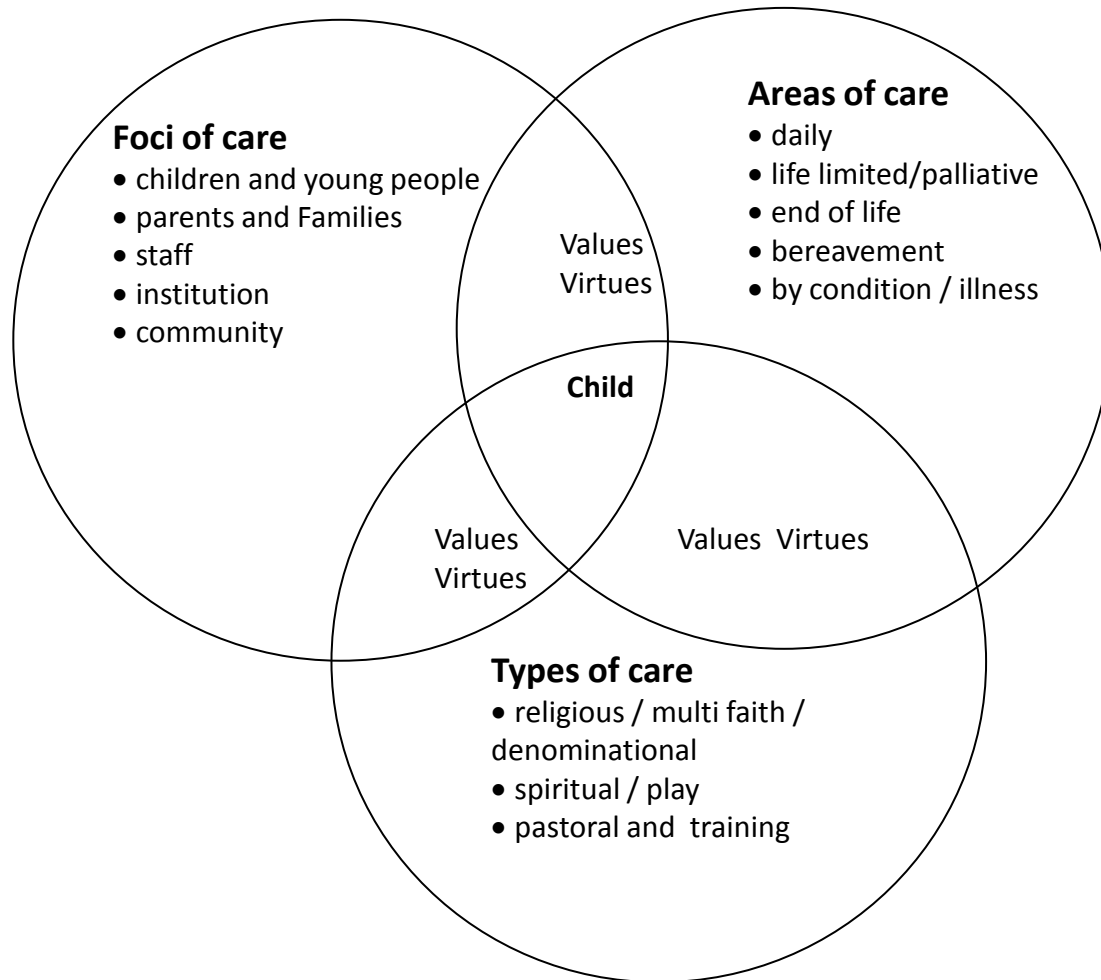
There is an inherent injustice in child death.

Autonomy and transition are key issues and autonomy may be inverted with illness.

2. **Paediatric specific standards:**

Distinct and separate support for varied family members being aware of issues relating to blended families.

Direct access for children and young people to chaplaincy services according to age and development level.

3. Integrated Model of Paediatric Chaplaincy

Foci of care
- children and young people
- parents and Families
- staff
- institution
- community

Areas of care
- daily
- life limited/palliative
- end of life
- bereavement
- by condition / illness

Values
Virtues

Child

Values
Virtues

Values Virtues

Types of care
- religious / multi faith / denominational
- spiritual / play
- pastoral and training

4. Training Modules

1. Introduction to paediatric chaplaincy and multidisciplinary work
2. Spiritual care of sick children and young people
3. Working with families in a paediatric healthcare setting
4. Staff care and self-care for paediatric chaplains
5. Paediatric chaplaincy team leadership
   CPE?

5. Resources

Multi faith, spiritual and pastoral care

Day to day, palliative, EOL and bereavement

1. Patients: Neonates, babies, children and young people

2. Families: parents, siblings, grandparents

3. Wider community: training and equipping to look after children and families

Conclusion and Recommendations

There are six areas in particular which would support the development of the paediatric chaplaincy as a discipline and enhance its distinctiveness. These are:

1. Religious, spiritual and pastoral support for families with sick children.
2. Bereavement support for families after the loss of a child including the development of pathways.
3. Spiritual and religious care of sick, disabled and palliative children and young people.
4. Integration of chaplains into multidisciplinary research teams
5. Intentional staff support programmes
6. Chaplain's self-care and training including a robust theodicy

Additional Implications and Developments

1. Chaplains to have a robust theodicy and help other HCS to have the same
2. Developing chaplains from research illiterate to literate to competent
3. Explore how chaplains can become more integrated and a part of MD teams
4. Build vocational security: we are like but unlike other disciplines
5. Make a commitment to the local community to support and resource them in caring for sick children and their families

Next steps:
More research on paediatric chaplaincy

- Test chaplaincy taxonomy for paediatrics

- Appropriate assessment and interventions tools tested for validity and reliability

- Develop and test models, resources and pedagogy

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