• The Hospice Movement
• Within the Systems Psychodynamic approach, Open Systems Theory as applied to children’s hospices, its strengths and challenges
• Reflections and further thoughts
THE HOSPICE MOVEMENT

“You matter because of who you are. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die.” Dame Cecily Saunders

www.stchristopher’s.org.uk
www.hospiceuk.org
THE DISCIPLINE AND CULTURE OF PALLIATIVE CARE

- Dying people need dignity, compassion and respect
- Effective pain management
- Rigorous scientific methodology in the testing of treatments
- Focus on patient not disease
- From seeking always to cure to providing palliative care
- A right to a pain free death, supporting the family to achieve this.
WHAT’S DIFFERENT ABOUT CHILDREN’S PALLIATIVE CARE?

“Palliative care for children is an active and total approach to care, from the point of diagnosis, throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person, and support for the whole family. It includes the management of distressing symptoms, provision of short breaks, end of life care and bereavement support after death for as long as it is needed. Palliative care can be introduced at any point throughout a child’s life; it is completely individual. Some children may require palliative care from birth, others only as their condition deteriorates.”

World Health Organisation 1998
ELIGIBILITY CRITERIA

Category 1
Life-threatening conditions

Category 2
Conditions in which premature death is inevitable

Category 3
Progressive incurable conditions

Category 4
Irreversible, non-progressive, severely disabling conditions
AND DIAGNOSIS IS ONLY PART OF THE PROCESS

- Spectrum and severity of the disease
- Subsequent complications
- Needs of the child and family
- Likely impact
THE QUALITY OF CARE AND SUPPORT ARE CRITICAL

THIS APPLIES TO ALL ELEMENTS OF THE SYSTEM: IMPORT, CONVERSION AND OSTE NSIBLE OUTPUT.
THE IMPORT PROCESS - BUILDING TRUST

- Referrals, self/paediatrician
- Admission and review criteria
- Initial stays (overcoming family anxiety; building trust)
- Agreed location, route, and accommodation arrangements
- Scope of care, and psychosocial support for the whole family/circle
- Links to client's paediatrician and other professionals
- Early development of Care Plans
THE CONVERSION PROCESS: A SPECTRUM OF CARE

- Specialised palliative care for babies, children and young people (BCYP) with life limiting conditions (LLC)
- Advanced Care Plans
- Short breaks
- Outreach/In reach
- Step-down care
- Special approaches
  - The technology dependent child
  - Management of Challenging Behaviours
  - Other Complex Needs
HOLISTIC SUPPORT (THE UNACKNOWLEDGED CONVERSION PROCESS)

- Across the Boundary activities for children and young people (CYP), e.g. outings & visits
- Education to 25 and Life Skills Development, through Education & Healthcare Plans (EHCP) and advocacy
HOLISTIC SUPPORT CONTINUED – CHILD SUPPORT

Though not commissioned to do so, children’s hospices support therapeutic interventions by helping the child and young person (CYP) to:

- Work better at school
- Learn how to manage symptoms & pain, achieving a balance between psychosocial support and physical well-being
- Grow relationships between staff and CYP and their families
- Use of Assistive technologies and the role of Lifelites
- Consider the possibilities around transition, including helping the parents to let go
HOLISTIC SUPPORT (THE UNACKNOWLEDGED CONVERSION PROCESS)

- Across the Boundary activities for children and young people (CYP), e.g. outings & visits
- Education to 25 and Life Skills Development, through Education & Healthcare Plans (EHCP) and advocacy
- Supporting therapeutic intervention
- Staff/family relationships, helping families cope to avoid separation, possibly even divorce
- Cultural, Religious and Spiritual Support
- Siblings are a special case
Children’s hospices also support siblings, why?.

- They need familial love and a sense of belonging but are frequently overlooked in favour of the ill child. They also need to be valued, trusted, understood and safe but instead feel guilty and isolated.
- At school, they are discriminated against and bullied or abused and regarded as freakish because of their life limited sibling.
- They need to have control over their lives and build resilience; instead, they feel at the mercy of the family’s needs and lack self-confidence. This may develop into long-term educational difficulties.
- Possible recorded disorders include depression, self-harm, eating disorders, PTSD, ADHD, generalised anxiety disorder (GAD) and physical ill-health.
END OF LIFE CARE AND BEREAVEMENT SUPPORT (THE OSTENSIBLE OUTPUT PROCESS)

- Anticipating grief and loss and other difficult conversations
- Pain and symptom management to ensure a dignified ending
- Care in special bedroom prior to transfer to funeral director
- Bereavement support, open access to garden of remembrance
- Rituals: Photos, pebbles and commemorations
SO, IN SUMMARY, WHAT IS IT ABOUT THIS PROCESS THAT MAKES THE DIFFERENCE?

- Is it because the hospice itself is so aesthetically pleasing?
- The quality of the conversion process is the foundation of the everyday life of a children’s hospice. And everyone who works there is party to the process, regardless of their own stated responsibilities.
- It is like a benevolent virus, infecting everyone with the desire to bring “life into the years” of each child.
- *This is the primary process of an organisation, not its aim, but rather something without which its stated aims are unlikely to be achieved* David Armstrong (2005)
- In a children’s hospice, while its aim may be to deliver high quality palliative care and support, its primary process is the “building of happy memories”
WELL-BEING OF THE WORKFORCE – POSITIVE EXPERIENCES

- Making a difference for child and family
- Providing individualised care
- Time and space not afforded in hospital
- Care not cure approaches
- Team working
- Constant support and guidance from management
WELL-BEING OF THE WORKFORCE – POSITIVE EXPERIENCES

- Making a difference for child and family
- Providing individualised care
- Time and space not afforded in hospital
- Care not cure approaches
- Team working
- Constant support and guidance from management
WELL-BEING OF THE WORKFORCE – CHALLENGES

- Mixing EoLC, complex care and short breaks
- Controlling own grief
- Appropriate medicines for symptom control and pain management
- Keeping specialisations within generalised care
- Communications –
  - Training
  - Interrelationships between hospital, hospice, and community settings
  - Learning by experience
  - Difficult conversations
WELL-BEING OF THE WORKFORCE – COPING STRATEGIES

- Outside work outlets
- Faith
- Mindfulness
- Peer to peer support (activities like “too busy to stop”)
- Organisational support, including 1:1 staff counselling
- Formal debriefing
- Role playing
- Psychological self-care
REFLECTIONS AND FURTHER THOUGHTS
POSSIBILITIES FOR ONGOING RESEARCH

Further support for families, including improved funding and psychosocial support.
* Workforce Well-being in furtherance of the QUB Study.
* Beyond the CQC Report, what really counts as doing well or doing badly?

Possible research topics –
* Samples of patient experiences in different settings to understand what does count as doing well and badly
* Qualitative comparisons between different hospice approaches/ overlap in care
* Relationships: staff/BCYP; staff/families; clinical staff/support staff/volunteers
* Possibility of a group relations experience at executive level

* McConnell and Porter BMC Palliative Care (2017)
COMPARISON OF PRESENTING ISSUES AT THREE CHILDREN’S HOSPICES ON APPOINTMENT AS CEO
Contact Information

David Strudley CBE FRSA FCMI
Former Chair Together for Short Lives UK Transition Taskforce
Vice President Acorns Children's Hospices
Trustee Lifelites
Associate Lecturer Children and Families Centre, University of Worcester
Associate Director Forum Academy

t: 01905 796 933
m: 07969 639 012
Email: david.strudley@togetherforshortlives