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EBN Opinion Article

Title: Meaning making And Generativity In Children and Young people with Life limiting conditions (MAGICYL)

EBN engages readers through a range of online social media activities to debate issues important to nurses and nursing. EBN Opinion papers highlight and expand on these debates.

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This month's opinion draws on an EBN Twitter chat that focused on dignity therapy and meaning-making activities for children and young people with life limiting conditions. Access the blog at <http://ow.ly/oKnz30mSBxq> and <http://ow.ly/JLnr30mSBAG> for a summary of the chat.

Background

In the UK there are just under 50,000 children and young people (CYP) living with a life-limiting condition (LLC). For these CYP there is uncertainty around prognosis and the longevity of their lives. The impact of LLCs on CYP, parents, brother and sisters and the wider family is considerable. Improving well-being throughout their shortened life journey requires care that also addresses the psycho-social and spiritual needs of CYP and their families.¹ In adult palliative care settings, research has found that helping people make sense of their lives is as important as managing disease symptoms.² Dignity Therapy (DT), based on the Dignity Conserving Model of Care,³ is a brief psycho-therapeutic intervention that assists individuals with shortened life expectancies to explore the meaning and purpose of their lives.⁴ During DT, trained professionals encourage people to discuss valued memories, accomplishments, roles, life lessons, and hopes for significant others. Interviews are recorded, transcribed, edited and returned to the patient, who can then add to the document. A generativity (or legacy) document is co-developed from the person's narrative. Many people share these documents with significant others, providing opportunity for meaningful conversations that can assist future bereavement processes. Dignity is fostered when an individuals' physical, emotional and spiritual needs are understood, valued and met.⁵ In the context of LLC, there is often an assumption that as the condition progresses there is an increased dependence on others; dignity, or sense of dignity can then be lost. Evidence suggests DT is well received in adult settings, and can reduce anxiety, and depression, and improve an individual's overall quality of life by promoting a sense of purpose and preserving dignity.^{2,6,7}

A recent review found only four studies that had explored DT and related meaning making interventions with young people: one focused on young people (7-17 years), another three studies included young people but mean ages were 50-70.² DT and related meaning making interventions

can improve wellbeing, and support families. However, further work is needed to develop and evaluate DT for younger populations and establish whether DT can address and meet the psycho-social and spiritual needs of CYP with LLC and their families.

The MAGICYL team came together through a shared passion that the dignity of every individual across care settings and the lifespan is central and a core value to care delivery. With expertise in advocacy for CYP with LLC, palliative, psycho-therapeutic and nursing, spiritual care, the MAGICYL team hope to develop DT based interventions for CYP with LLC.

Key messages from the Twitter Chat (#ebnjc)

A twitter chat led by the MAGICYL team explored opinion around DT and its potential for development in order to meet the psycho-social and spiritual needs of CYP with LLC. A range of issues were debated during the chat but two key themes emerged that have importance in relation to the nature and purpose of potential DT based interventions for CYP with LLC:

Valuing the individual

The chat involved a range of people from different backgrounds, who identified that DT is highly relevant for CYP with LLC but that therapeutic approaches must be tailored to the individual to meet their needs, wishes and hopes. CYP with palliative care needs are often involved, albeit to varying degrees, with their end of life care planning. There appears to be different approaches to this process and the extent to which the CYP feel that their voice is heard. DT could be aligned with the end of life care planning process, to move beyond consideration of clinical care pathways and thinking about wishes. An adapted DT, could assist professionals to explore with CYP their perceptions of the value in their lives lived so far and to think about what creative methods could be used to document their experiences. To this end, DT has the potential to make the CYP themselves feel valued and to enter a process that could be enriching and heighten perceptions of quality of life. A DT based intervention for CYP may also assist in meaning making, supporting family communication and enhancing perceptions of the self and purpose for the CYP. Figure 1 highlights some of views that were shared around valuing the individual.

Figure 1: Valuing the individual

The image shows a screenshot of a Twitter chat conversation. It features three tweets from different users. The first tweet is from Lucy Watts MBE MUniv (@LucyAlexandria) dated Sep 19, 2018, discussing the relevance of dignity therapy for CYP with LLCs and mentioning various creative methods like videos, music, and art. The second tweet is from Dr Michael Tatterton RN (@MJTatterton) dated Sep 19, 2018, agreeing with the previous point and emphasizing the need for tailored approaches. The third tweet is from Alison Rodriguez (@ARodriguez339) dated Sep 19, 2018, discussing communication difficulties between CYP parents and professionals. A reply from Claire Carswell (@ClaireCarswellx) is also visible, replying to Lucy Watts.

Lucy Watts MBE MUniv @LucyAlexandria · Sep 19, 2018
Dignity therapy is most certainly relevant for #CYP with LLCs. Finding meaning in life, finding outlets & discovering talents but also creating items that form part of your legacy - be it videos, music, written work, art, whatever it may be - can make a huge difference #ebnjc

Claire Carswell @ClaireCarswellx
#ebnjc are there any particular concerns or barriers for providing DT for CYP with LLCs?
4 7:24 PM - Sep 19, 2018

Dr Michael Tatterton RN @MJTatterton
I agree, and think a range of approaches is key @josmith175 - a 'one size fits all' approach just wouldn't work! #ebnjc

Jo Smith @josmith175
Also way we engage with CYP needs a range of approaches #ebnjc
twitter.com/ARodriguez339/...

Alison Rodriguez @ARodriguez339
#ebnjc some of the adult focused questions may not be appropriate. There is also a mutual protectiveness that exists between CYP parents and professionals. Talking openly can be difficult and difficult to allow. We also need to consider those who have communication difficulties

Claire Carswell @ClaireCarswellx
Replying to @LucyAlexandria
#ebnjc are there any particular concerns or barriers for providing DT for CYP with LLCs?
4 7:28 PM - Sep 19, 2018

Being remembered

The second theme related to being remembered. If CYP can share their views about the lives they have lived and conceptualise this in their own way, they then also have a mechanism to harness their special memories. This could provide, some level of control over how CYP reflect on life, what they want to share with others and in what ways, and how they would like to be remembered. A DT based intervention could provide CYP with the space and means to communicate around what are generally perceived to be challenging and difficult topic areas. Sometimes in current practice end of life care conversations may not take place or take place very late in the illness trajectories. To be supported in creative ways, to discuss the wishes of CYP alongside issues of legacy and how they would like to be remembered, could possibly ease the existential worries that can burden families and CYP. Figure 2 provides some valuable insights into the theme of being remembered.

Figure 2: Being remembered

The image shows a screenshot of a Twitter chat conversation. The main thread starts with a tweet from Claire Carswell (@ClaireCarswellx) replying to @MJTatterton and @LucyAlexandria, discussing the importance of asking sensitive questions. Lucy Watts MBE MUniv (@LucyAlexandria) replies, sharing a personal experience of how a designated therapy (DT) based conversation was transformative and liberating. Alison Rodriguez (@ARodriguez339) asks if others would benefit from a designated intervention. Lucy Watts MBE MUniv replies, explaining that her generativity-style thoughts have been documented in care plans and through video, writing, and planning. Linda Milnes (@LindaMilnes_UOL) thanks Alison Rodriguez, noting how DT could enhance young people's lives and relationships. Alison Rodriguez replies to Linda Milnes, explaining that in DT, individuals share their legacy documents with chosen family and friends, allowing their thoughts and memories to transcend beyond the immediate family.

Claire Carswell @ClaireCarswellx · Sep 19, 2018
Replying to @MJTatterton @LucyAlexandria
Giving people permission and broaching sensitive subjects are powerful things. People can be so relieved to just be asked the question #ebnjc

Lucy Watts MBE MUniv @LucyAlexandria
Exactly. Someone asking me what mattered to me & how I wanted to spend my life & how I want to be remembered was transformative. It was done at the same time as my advance care planning & made that "difficult conversation" even more liberating, as everything was included #ebnjc

Alison Rodriguez @ARodriguez339
#ebnjc do you think others would benefit from a designated intervention that is DT based? You have been really proactive but I dont think all CYP get these opportunities. Activities maybe undertaken but not so much openness as to why @LucyAlexandria

Lucy Watts MBE MUniv @LucyAlexandria
Replying to @LucyAlexandria
2/2 My generativity-style thoughts have been documented in care plans & my wishes & goals I have been supported to fulfil these, such as through video, through writing & through planning my #digitallegacy. It's been a natural part of my #palliativecare #ebnjc

Linda Milnes @LindaMilnes_UOL
Thank you @ARodriguez339 this is fascinating and I can see how DT could enhance YPs limites lives, value who they are and maybe strengthen relationships #ebjn

Alison Rodriguez @ARodriguez339
@LindaMilnes_UOL #ebnjc in DT as it stands individuals share their legacy document with people of their choosing. This maybe family and/or friends. Through the process of adult DT thoughts and memories and words of wisdom can transcend beyond immediate family twitter.com/LindaMilnes_UO...

Were next?

The findings from the focused review¹ and the varied types of information gathering so far, including the Twitter chat, establishes support for the amendment and development of DT therapy for CYP with LLC. The MAGICYL team have also undertaken face to face consultation work with CYP and professionals to explore recommendations for development. Central to the work of MAGICYL team is having a young person ambassador, the lead author (LW) of this OPINION

article, to guide future activities ensuring they meet the needs of CYP. The next step for the team is to explore wider family perceptions, especially how DT could be developed for younger children and those with communication difficulties. A protocol for the development of a digital intervention, with the support of NIHR MedTech Devices for Dignity is being designed for young adults aged 18-24 years and we are seeking external funding. A further study is planned to harness the creative practices already undertaken in hospice care facilities to facilitate a DT based intervention for adolescents and younger children.

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