

UNIVERSITY *of York*

This is a repository copy of *Palliative care for teenagers and young adults - the need for more evidence*.

White Rose Research Online URL for this paper:
<https://eprints.whiterose.ac.uk/177747/>

Version: Accepted Version

Article:

Fraser, Lorna Katharine orcid.org/0000-0002-1360-4191 and Ziegler, Lucy (Accepted: 2021) *Palliative care for teenagers and young adults - the need for more evidence*. *Palliative Medicine*. ISSN 0269-2163 (In Press)

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk
<https://eprints.whiterose.ac.uk/>

Palliative Medicine

Palliative Care For Teenagers and Young Adults - the need for more evidence

Journal:	<i>Palliative Medicine</i>
Manuscript ID	PMJ-21-0319
Manuscript Type:	Invited Editorials
Date Submitted by the Author:	08-Jul-2021
Complete List of Authors:	Fraser, Lorna; University of York, Dept of Health Sciences Area 2 Seebohm Rowntree Building Ziegler, Lucy; University of Leeds, Leeds Institute of Health Sciences, School of Medicine
Keywords:	teenagers and young adults, palliative care, decision making
Abstract:	no abstract - invited editorial

SCHOLARONE™
Manuscripts

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Blank Author checklist

For Peer Review

Palliative Care For Teenagers and Young Adults- the need for more evidence

Lucy Ziegler¹, Lorna K Fraser²

¹ Academic Unit of Palliative Care, University of Leeds, UK

² Martin House Research Centre, Dept of Health Sciences, University of York, UK.

“Doesn’t everything die...at last and too soon? Tell me, what is it you plan to do with your ONE wild and precious life?” Young people with life limiting conditions and their families won’t need Mary Oliver’s words to remind them that life can be short, and that for hopes and wishes to be fulfilled, it is usually necessary to make a plan.

Teenagers and Young Adults, aged 13-24 years, have different healthcare needs than either children or adults due to their biological, psychological and social developmental changes.¹ These young people with life limiting conditions are a heterogeneous group including those diagnosed with a life limiting condition in childhood.² Many of these young people will have developmental delay, while others will be diagnosed with conditions such as cancer or organ failure which do not usually affect cognitive function. This collection of studies published in Palliative Medicine demonstrate the complex challenges of meeting the needs of a population that is increasing in size and complexity² in relation to active engagement in care decisions, including the planning of end-of-life care.

Some young people with life limiting conditions are capable of contributing to planning, discussions and decision-making about their treatment.^{3,4} Studies of young people undergoing heart transplant³ or bone marrow transplant⁴ successfully engaged young people and their families in discussions about treatment, however discussions focussing on end-of-life care occurred much less frequently, even when that treatment carried a high risk of failure or the young person was known to be approaching the end of their life.

Barriers to active participation in end-of-life planning include a lack of rigorous high quality evidence about how to involve young people in care planning and decision-making, and opportunities for staff training.^{5,6} Where highly-standardised protocol-driven patient pathways exist, such as through cancer services, these pathways can limit the opportunity for patient participation in decision-making.⁷ If treatment proves ineffective and the young person and their family want to take an active role in decision making about end of life care the established dynamic between the young person and their family and the clinician needs to shift, sometimes quickly from the clinician leading the decision making. Further service level challenges to active participation in decisions about care include poor communication around the transition to adult services. However, adult services may be unable to meet young peoples’ emotional needs or support them to realise their aspirations.⁸ Integrated models of care, where palliative care co-exists alongside disease specific care, may help young people exercise choice. However for patients with Cystic Fibrosis despite an ‘integrated model,’ high symptom burden usually led to in-patient end-of-life care and death in hospital⁹ irrespective of the young person’s preferences.

The discourse summarised here is ongoing, the studies are small scale and do not represent the diversity of groups of young people with life limiting conditions, however there is growing evidence to support a more collaborative approach to end-of-life care planning, not just between young people, their families and clinicians but in terms of the wider collaboration between specialist palliative care and the other specialities.. What is still far less clear is how best to achieve this collaborative approach.

1
2
3 Future research needs to focus on identifying key decision points within care pathways, and
4 opportunities to work collaboratively with young people and their families . We also need to explore
5 how to integrate palliative care earlier and how to support clinicians to have timely and
6 compassionate conversations about end-of-life care with young people and their families. Getting it
7 right for everyone is a challenge given the diverse nature and needs of younger people with life
8 limiting illness. One approach will not be appropriate for all, but it is clear that a collective research
9 effort is needed with young people and their parents at the very heart of it.
10
11

- 12
13 1. Michaud PA, Suris J.C, and Viner R The adolescent with a chronic condition : epidemiology,
14 developmental issues and health care provision. World Health Organization 2007
- 15
16 2. Fraser LK, Lidstone V, Miller M et al [Patterns of diagnoses among children and young
17 adults with life-limiting conditions: A secondary analysis of a national dataset](#) Palliative
18 Medicine 2014 28:6, 513-520
- 19
20 3. Cousino M, Miller VA, Smith C et al [Medical and end-of-life decision making in adolescents'
21 pre-heart transplant: A descriptive pilot study](#) Palliative Medicine 2019 34:3, 272-280
- 22
23 4. Needle JS, Peden-McAlpine C, Liaschenko J et al ["Can you tell me why you made that
24 choice?": A qualitative study of the influences on treatment decisions in advance care
25 planning among adolescents and young adults undergoing bone marrow transplant](#)
26 Palliative Medicine 2019 34:3, 281-290
- 27
28 5. Tobler D, Greutmann M, Colman JM [End-of-life care in hospitalized adults with complex
29 congenital heart disease: care delayed, care denied](#) Palliative Medicine 2011 26:1, 72-79
- 30
31 6. Hughes B, O'Brien MR, Flynn A et al [The engagement of young people in their own advance
32 care planning process: A systematic narrative synthesis](#) Palliative
33 Medicine 2018 32:7, 1147-1166
- 34
35 7. Day E, Jones L, Langner R et al [Current understanding of decision-making in adolescents
36 with cancer: A narrative systematic review](#) Palliative Medicine 2016 30:10, 920-934
- 37
38 8. Kirk S, Fraser C [Hospice support and the transition to adult services and adulthood for
39 young people with life-limiting conditions and their families: A qualitative study](#) Palliative
40 Medicine 2013 28:4, 342-352
- 41
42 9. Bourke SJ, Doe SJ, Gascoigne AD [An integrated model of provision of palliative care to
43 patients with cystic fibrosis](#) Palliative Medicine 2009 23:6, 512-517
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60