Growing up in Palliative Care
Is there a Prescription for Transition?

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1. Background

The number of children in the UK living with life-limiting conditions is increasing annually, leading to more surviving into young adulthood and beyond (Figure 1).

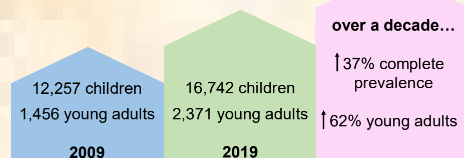


Figure 1: Children (0-21y) and young adults (19-21y) with life-limiting illness in Scotland.

Transitioning from paediatric to adult palliative care services around age 16 is a complex process, requiring coordinated multidisciplinary support for patients, caregivers, and healthcare professionals.

Despite the emphasis by NICE on "*purposeful and planned transitions*" to adult services, the reality often falls short of this ideal.

"unfathomable" healthcare system to navigate

"absolutely no continuity" between service-providers

Important interventions have been identified to aid transition but there is still a gap in addressing prescribing and medicine administration.

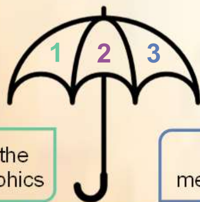
This is despite recognition that healthcare professionals are unfamiliar with symptoms in young adults with life-limiting illnesses.

2. Aims / Objectives

AIM

To provide evidence-based recommendations for a medicine education framework for healthcare professionals navigating the transition journey with young adults who have a life-limiting condition.

Objectives



identify the demographics

profile medicine use

collate underlying diagnoses

...in those children that are eligible for or have already transitioned from paediatric to adult palliative care services.

3. Methodology

Caldicott guardian approval was obtained from CHAS to review electronic patient notes.

CHAS provides palliative care to children up to 21 with life-limiting conditions across Scotland.

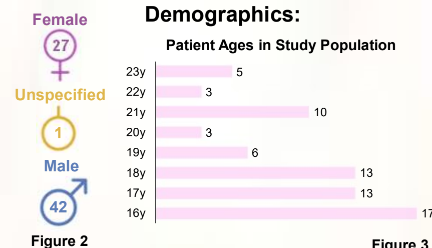
Electronic data filters:
young adults that had transitioned (≥19y)
young adults preparing for transition (≥16y)
August 2021–23 dates inclusive

70 case-files returned:
51 young adults ≥ 16 years
19 young adults had fully transitioned

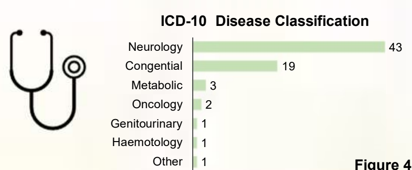
Thematic analysis:
1. Demographic information
2. Diagnoses
3. Medication charts/Kardex

4. Results

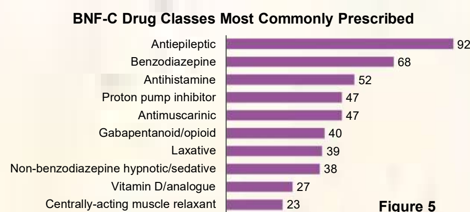
Demographics:

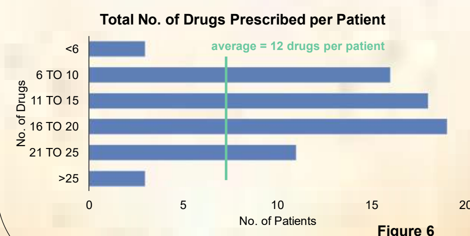


Diagnoses:



Medicine Profile:





5. Discussion

Observation	Reflection
60% male, 39% female patients **(Figure 2)**.	Representative of the population supported by CHAS.
27% (19 patients) had congenital illnesses, whilst the remaining 73% (51 patients) were distributed among other categories **(Figure 4)**.	Somewhat reflects the broader paediatric palliative care population in Scotland, where 37% of diagnoses are congenital and 63% fall into other categories.
Of those with non-congenital illnesses, 85% (43 patients) had recorded diagnoses of neurological origin **(Figure 4)**.	Deviates from the distribution of non-congenital illness observed in the wider paediatric palliative care population, in which neurological, oncology, haematology and perinatal conditions are approximately evenly proportionate.
A significant pharmaceutical burden was observed with an average of 12 drugs prescribed per patient, ranging from 3 to >25 **(Figure 6)**.	Polypharmacy, whether appropriate or not, is prevalent in this population, as also observed in the broader paediatric population in receipt of palliative care.
94 classes of drugs were identified with the 10 classes most often prescribed represented in **Figure 5.**	The classes of drugs prescribed are reflective of the symptoms associated with neurological conditions i.e. seizures, dystonia, spasticity, myoclonus, pain and insomnia.

6. Conclusion

To ensure better care for young adults with life-limiting conditions transitioning into adult services, healthcare leaders should ensure that their staff have access to a medicine education programme, given the lack of familiarity with this patient population.

Proposed evidence-based education framework:

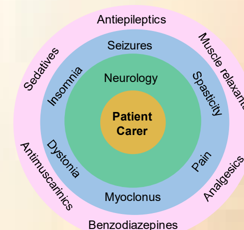


Figure 7: Educational Framework

Young adults and their carers should co-design the programs to provide valuable insights into prescribing and medicines administration.

More research on the appropriateness of polypharmacy in young adults with life-limiting conditions is needed.

References
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3. NOYES, J., PRITCHARD, A., REES, S. *et al.* (2014). *Bridging the Gap: Transition from Children's to Adult Palliative Care.* [online]. Available from: https://research.bangor.ac.uk/portal/en/researchoutputs/search.html [Accessed 17 Oct 2023].