

When, and how, should we talk about palliative care concepts with adolescents and young adults with cancer?

An international Delphi study.

Ursula M. Sansom-Daly, Holly Evans, Lori Wiener, Abby Rosenberg, Meaghann Weaver, Anne-Sophie Darlington, Fiona Schulte, Louise Sue, Susan Trethewie, Ruwanthi Amanda Fernando, Toni Lindsay, Anthony Herbert, Maria Cable, Jennifer Mack, Richard J Cohn, Antoinette Anazodo, Claire E. Wakefield, on behalf of *The Global Adolescent and Young Adult Cancer Accord End-of-Life Study Group*.

BACKGROUND

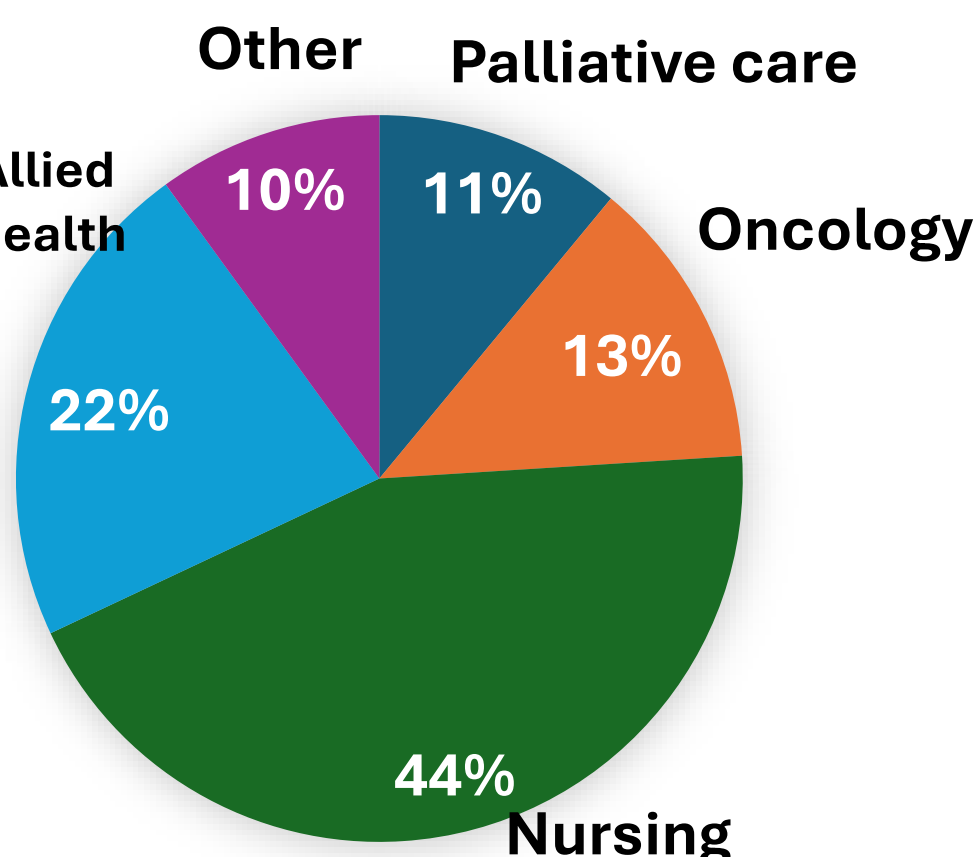
Adolescents and young adults (AYAs) with cancer are not consistently being introduced to palliative care concepts to reduce suffering, due to barriers experienced by health professionals (HPs).^{1,2,3}

AIM

We explored HPs' practices and perspectives, regarding introduction of palliative care concepts with AYAs with cancer in an online survey. HPs were recruited via snowball methods from >30 international professional organisations and networks (see published protocol).⁴

Study 1

Examined palliative care communication among 148 AYA oncology HPs in Australia, New Zealand and the UK.



HPs that 'usually' or 'always' introduce palliative care concepts regardless of disease status

55% Australian

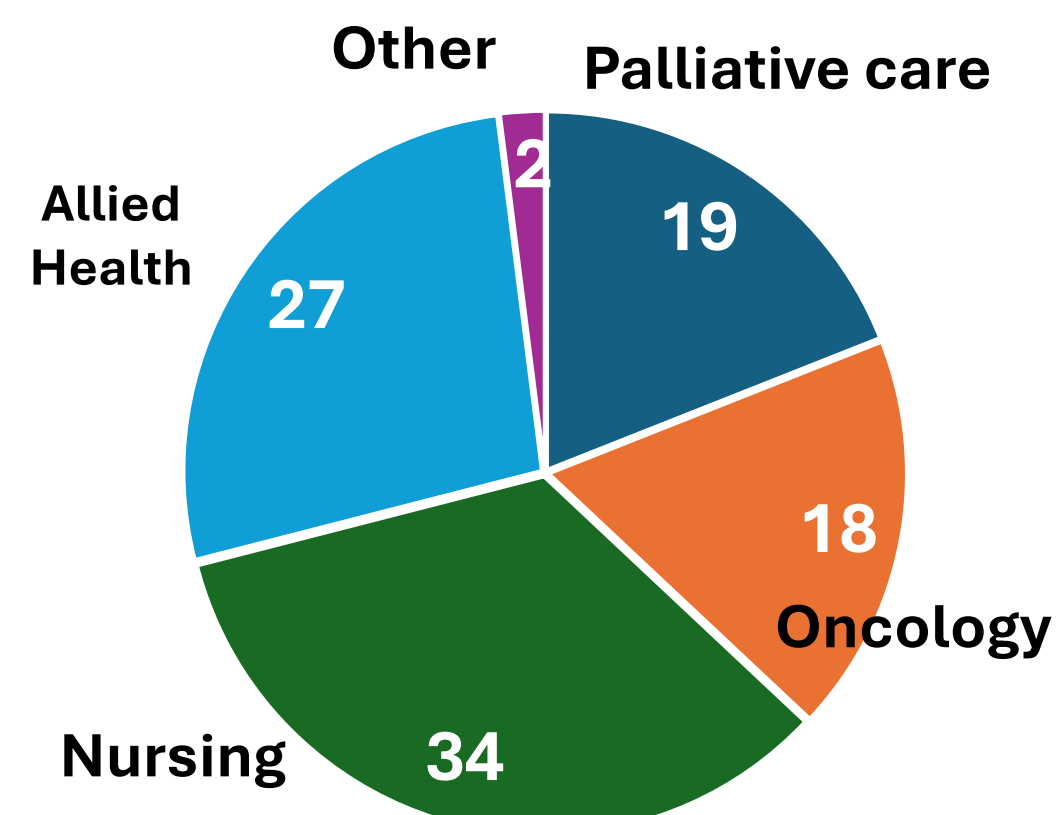
48% UK

20% NZ

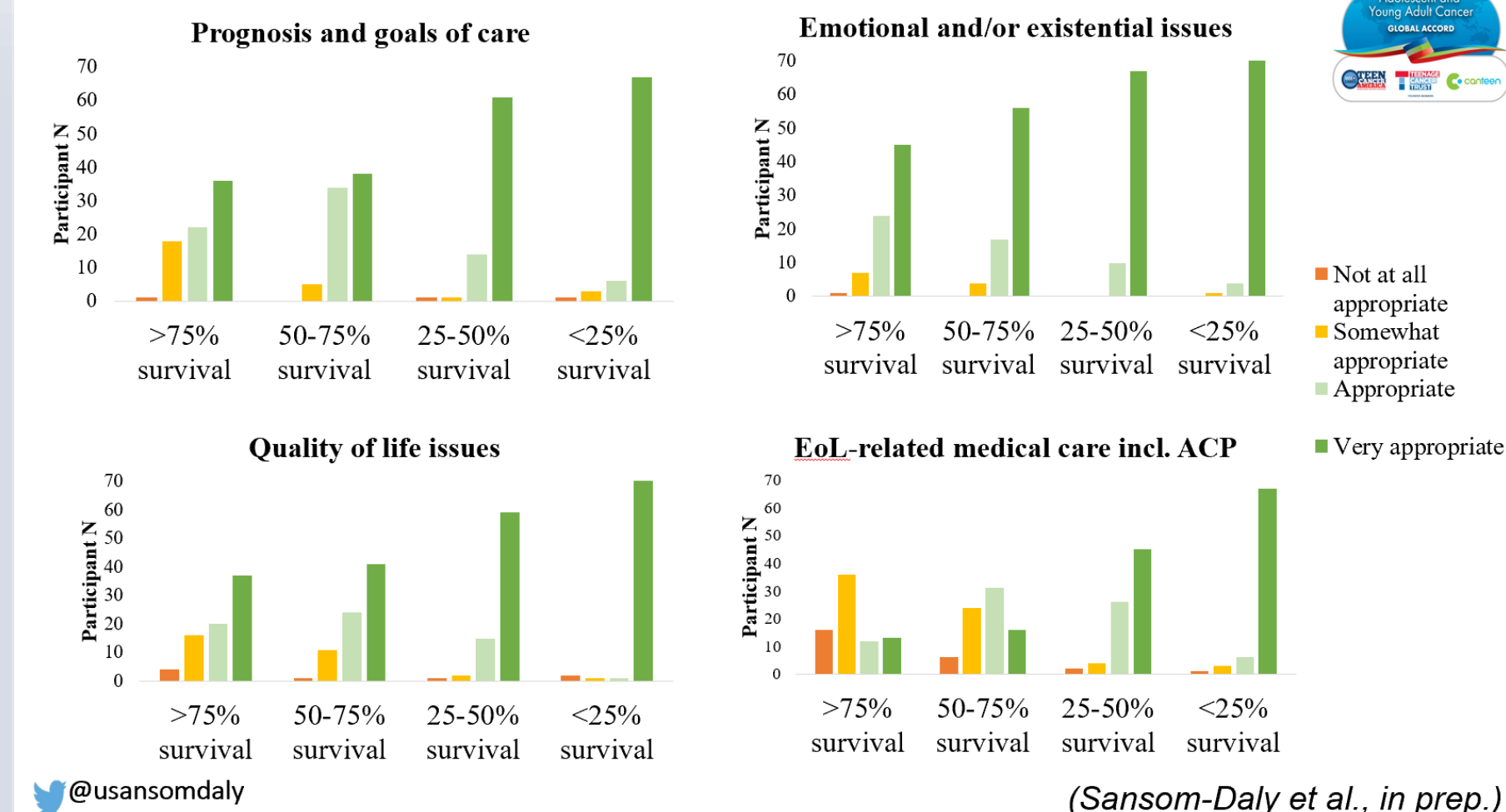
Health professionals need support to navigate communication decisions and approaches across all stages of an adolescent or young adult patient's treatment trajectory.

Study 2

Used a modified two-round global Delphi survey to establish when 248 HPs felt palliative care concepts were appropriate to introduce according to patient prognosis and treatment time-points.



Concluded that some palliative care concepts (e.g., emotional and existential issues) were appropriate across all prognoses and treatment/disease timepoints.



RESULTS

End-of-life-related medical care topics were only considered appropriate to routinely introduce when:

- ✓ Patients have a prognosis of <50%
- ✓ Patient has a second relapse and onwards

Prognosis and goals of care, and quality of life topics were consistently considered appropriate for:

- ✓ Most patients with <75% prognosis, across most of the treatment trajectory

CONCLUSIONS

Several palliative care topics including goals of care and quality of life were considered appropriate across most of the care trajectory, though our data suggests this is likely not occurring as a standard practice.

FUNDING This work was supported by the *Inaugural AYA Psycho-Oncology Research Acceleration Grant* (2018-2020) funded by the Adolescent and Young Adult Cancer Global Accord. Ursula Sansom-Daly is supported by a Cancer Institute NSW Early Career Fellowship (2020/ECF1163) and was supported by the Leukaemia Foundation of Australia and ESA International to attend this conference (ESA International Dorothy Banks Bursary).



REFERENCES

- Weaver, M.S., et al. Palliative Care as a Standard of Care in Pediatric Oncology. *Pediatric blood & cancer* **62** Suppl 5, S829-833 (2015).
- Weaver, M.S. et al. A Summary of Pediatric Palliative Care Team Structure and Services as Reported by Centers Caring for Children with Cancer. *J Pall Med* **21**, 452-462 (2018).
- Sansom-Daly, U.M., et al. End-of-Life Communication Needs for Adolescents and Young Adults with Cancer: Recommendations for Research and Practice. *J Adolesc Young Adult Oncol* **9**, 157-165 (2020).
- Sansom-Daly, U.M., et al. (2022). Thinking globally to improve care locally: A Delphi study protocol to achieve international clinical consensus on best-practice end-of-life communication with adolescents and young adults with cancer. *PLoS ONE* **17**(7): e0270797.