

Title: Cancer care and wellbeing in adolescents and young adults during the COVID-19 pandemic: a UK sarcoma perspective

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Precis: Wellbeing in adolescents and young adults (AYAs) with cancer may be acutely impacted by the pandemic compared to adults, though their concerns likely overlap with healthy AYAs. Loneliness is an important contributing factor to reduced wellbeing in young people during the pandemic.

Keywords: Psycho-oncology, Adolescent, Young adult, COVID-19, Mental health, Sarcoma

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Main text:

Adolescents and young adults (AYAs) with cancer face particular psychosocial challenges which may be amplified by the COVID-19 pandemic. Kosir et al. examined the impact of the pandemic on cancer care and wellbeing in AYAs in an online survey.¹ The authors highlight increased levels of anxiety in AYAs and used qualitative data to provide unique insight into possible contributing factors to reduced wellbeing during the pandemic.

In the first month of lockdown we surveyed 350 sarcoma patients from two London institutions, including 60 AYAs ages 16-39 (52% male).² Consistent with the heightened anxiety found by Kosir et al., AYAs were significantly more likely than adults to report the pandemic had an impact on their emotional wellbeing (60% vs. 38%; $p=0.002$) and had significantly lower emotional functioning (EORTC-QLQ-C30) to a clinically relevant level (mean 63.1 vs. 74.6; $p=0.001$). This indicates that adverse psychosocial outcomes during the pandemic may be more prevalent in AYAs than in adults with cancer.

Based on their qualitative results, Kosir et al. hypothesized that anxiety in AYAs was predominantly driven by health and cancer-related concerns. Conversely, we found no significant difference in the level of worry about potential impact of COVID-19 on health in AYAs versus adults (ten-point scale; mean 5.37 {SD2.66} vs. 5.94 {SD2.50}; $p=0.112$), and mean cancer worry was slightly higher in adults compared to AYAs (mean 5.64 {SD2.5} vs. 4.91 {SD2.8}; $p=0.054$). Modifications to care were similar in AYAs and adults, including the proportion of telemedicine appointments (65% vs. 60%) and

treatment postponements (2% vs. 10%). These data indicate that care modifications, COVID-19 or cancer-related worry may not entirely explain the higher impact on emotional well-being in AYAs.

Kosir et al. reported that half the participants felt more isolated during the pandemic, however, its impact on anxiety was not explored in depth. The UK Office for National Statistics reported a strong association between loneliness and anxiety in the general population during the pandemic.³ In our study, loneliness was higher in AYAs (33%) than adults (22%), despite 92% of AYAs living with others. AYAs reporting loneliness had significantly lower emotional functioning than those not reporting loneliness, suggesting this may be a strong contributor to reduced wellbeing (mean 52.9 vs. 68.1; $p=0.048$). Lower emotional functioning was also seen in lonely adults (mean 54.9 vs. 80.3; $p<0.001$), showing the pervasive impact of loneliness across all ages.

A sense of belonging amongst peers and the ability to maintain connections is important for AYAs to reduce social isolation and emotional distress.^{4,5} Pre-pandemic, AYAs with cancer may have cherished the opportunity to take their chemotherapy infusion in a backpack to the movies with friends. The pandemic has isolated AYAs with longer, more intensive shielding compared to peers. However, widespread social distancing restrictions may have narrowed the AYA-peer gap, as noted by some AYAs in Kosir et al.'s study.

Considering emotional distress in healthy AYAs provides context to the experiences of young people with cancer. A repeated cross-sectional study comparing clinical and community cohorts of young people ages 14 to 28 found that clinical cohorts had slightly higher mental health symptoms but community cohorts experienced greater deterioration during the pandemic.⁶ Similarly, a Dutch study of over 4000 cancer survivors and matched normative participants found slightly higher levels of depression and loneliness in the general population.⁷ These studies suggest that levels of distress may be similar, or even higher, in healthy populations.

The authors acknowledge several limitations to their study, such as the high proportion of females (87%), and participants from different healthcare systems and continents. Female gender is predictive of increased psychological distress across the cancer disease trajectory and has been associated

with higher anxiety during the pandemic.^{3,8,9} A significantly higher proportion of female AYAs in our study reported that COVID-19 had impacted their emotional wellbeing compared to males (76% vs. 45%; $p=0.015$). Additional limitations include the lack of information on cancer type and stage which lead to differing levels of anxiety and health-related quality of life in AYAs.⁹ There was also a high proportion of AYAs (37%) who reported pre-existing mental health conditions and may be particularly sensitive to disruption caused by the pandemic.

Wellbeing in AYAs with cancer may be acutely impacted by the pandemic compared to adults, though their concerns likely overlap with healthy AYAs. Evidence-based interventions such as practical skills sessions that strengthen social support, emotional wellbeing and resilience should be rapidly integrated into care to reduce loneliness.¹⁰ Age appropriate resources are crucial to sustain emotional wellbeing and safety in AYAs during periods of social isolation.

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