

Exploring the needs of cancer patients across the patient pathway via Macmillan electronic Holistic Needs Assessment data

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Background

Holistic Needs Assessments (HNAs) enable care providers to deliver tailored care and support to people with cancer, addressing their individual concerns through dedicated conversations and care planning.

Despite intention to offer patients HNAs across the entire care pathway, data from the Macmillan Cancer Support electronic-HNA (eHNA) platform shows a much higher proportion are completed at initial diagnosis than at later stages.

Variation in concerns across the care pathway could provide insight into changing needs beyond the initial diagnosis.

Methods

Exploratory analysis highlighted variation in type and frequency of concerns raised across 10 discrete pathway stages, within HNAs submitted through the Macmillan Cancer Support eHNA platform in 2023.

Zero inflated negative binomial regression (ZINB) models then analysed variation between initial diagnosis and other pathway stages. The ZINB model was chosen to account for the high number of eHNA records where the patient had not selected any concerns in the assessment, by modelling two processes simultaneously: a binary model estimating the probability of an excess zero, and a negative binomial model governing the count distribution.

The ZINB model was first run on total number of concerns raised, and then on the number of concerns raised across 5 domains separately. Models were adjusted for confounding by characteristics including age, sex, cancer site, ethnic group, region and organisation type.

Conclusion

These findings emphasise the importance of assessing patient concerns across the entire care pathway. eHNAs during treatment can highlight unmet need including adverse physical symptoms.

The higher number of eHNAs completed at initial diagnosis may be attributed to

Results

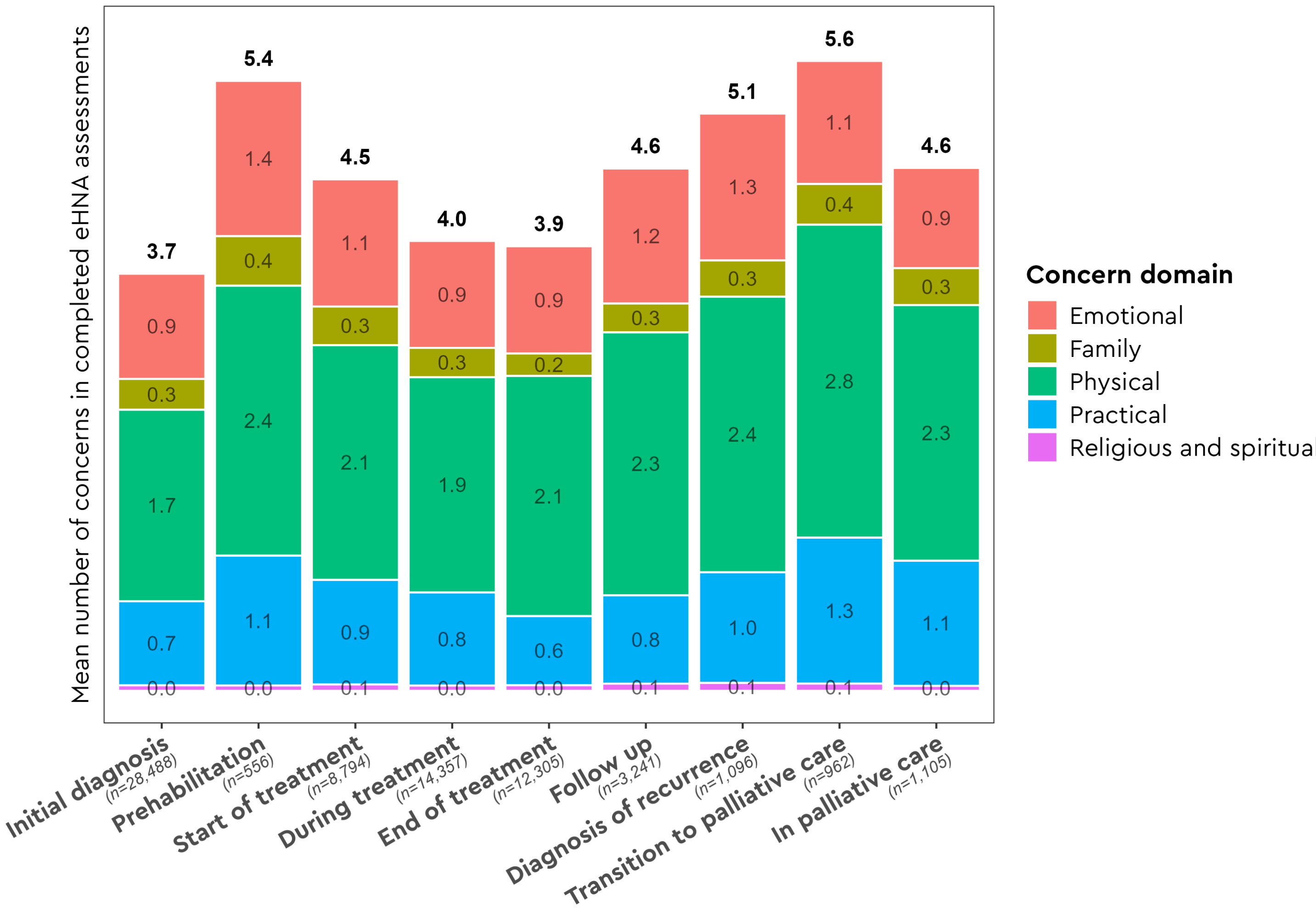
Exploratory Analysis

- 40% (28,496) of completed eHNAs were conducted at the point of initial diagnosis.
- At the point of initial diagnosis, the mean number of concerns raised was 3.7 (95% CI: 3.6-3.8), lower than all other stages combined (mean: 4.2, 95% CI: 4.1-4.3), as well as each individual stage.
- 'Worry fear or anxiety' was the most reported concern at initial diagnosis (19.8% of assessments) but was superseded by 'tired, exhausted or fatigued' from the start of treatment through to follow-up. 'Money and finance' was reported in 16.5% of assessments at initial diagnosis and became more prevalent in pathway stages up until the end of treatment.

Statistical Modelling

- After adjusting for confounding, the ZINB model found a higher rate of total concerns were raised at initial diagnosis than all points of the care pathway other than diagnosis of recurrence and transition to palliative care.
- Patients diagnosed with recurrence raised concerns at an 18% (95% CI: 7%-29%) higher rate than those at initial diagnosis.
- Physical concerns were more frequently raised across all stages of the patient pathway than initial diagnosis, particularly at transition to palliative care (IRR 1.28, 95% CI: 1.15–1.42).

Mean number of concerns raised in completed Macmillan Cancer Support eHNA assessments across the cancer care pathway



performance targets based on offering HNAs at this stage. While effective in improving uptake, these targets may be overshadowing the importance of conducting assessment at other key points, particularly at diagnosis of recurrence, where concerns are highest.

To better support patients, HNAs should be embedded as a process throughout the care pathway. This ensures evolving concerns, especially those relating to symptoms during treatment, are identified and addressed, supporting more responsive and equitable patient care.