Patterns in prioritisation of emotional concerns following cancer diagnosis: insights from 25,000 Holistic Needs Assessments

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Background

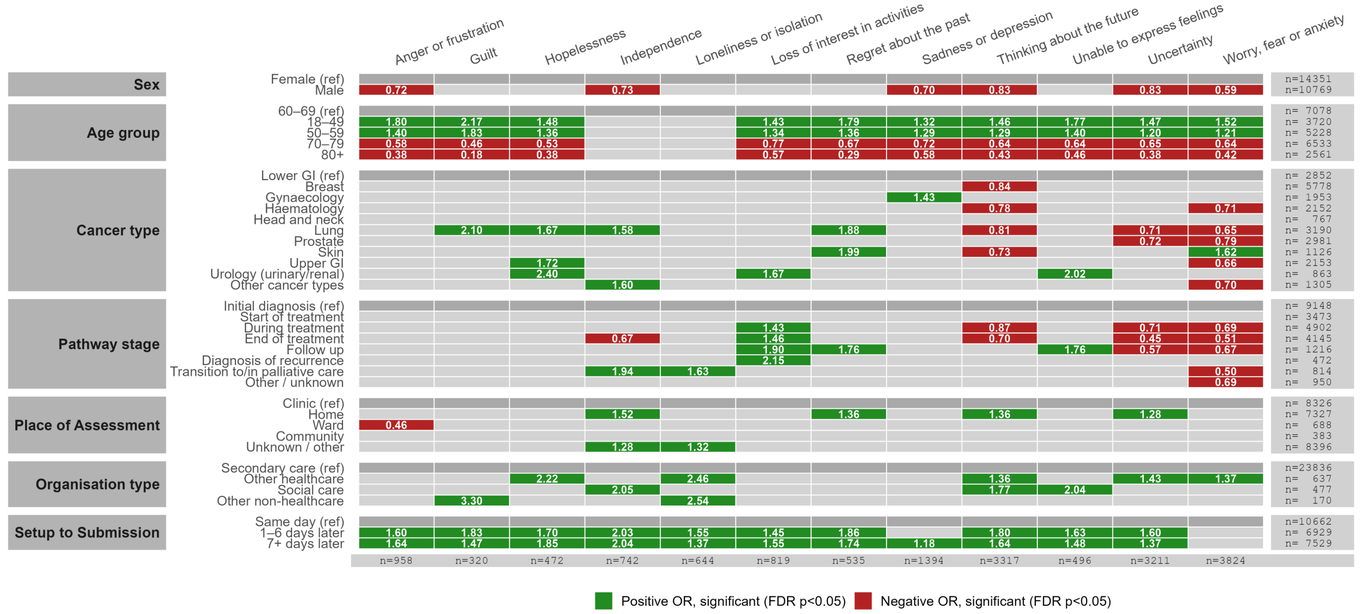
Holistic Needs Assessment (HNA) and care planning is a person-centred approach that enables people with cancer to identify and communicate the concerns most important to them.
An HNA includes a checklist of concerns that the service user reviews to identify those relevant to them, by assigning a score from 1 to 10. The selected concerns and their scores inform a therapeutic conversation and care plan focussed on addressing these concerns.
Emotional wellbeing is a frequently reported concern, recorded in a third of HNAs; however, the groups of people most likely to report emotional concerns and the service contexts that support this are not well understood.
This study uses data from Macmillan Cancer Support's electronic Holistic Needs Assessment platform to explore demographic and system factors associated with Leading Concern Propensity (LCP), the likelihood of a given concern being the highest or joint-highest scoring within a submitted HNA.

Methodology

Of 120,708 eHNAs initiated in 2023, 46,435 were submitted with at least one scored concern. This analysis includes 25,121 submissions from patients, after excluding those with missing sex or cancer type data, or with a paper-based mode of completion.
As there can be variation in respondents' interpretation of the HNA concern rating scale, leading concern propensity (LCP) was used to mitigate bias. This metric ensures that only the concern of greatest, or joint greatest importance to the respondent is included.
Twelve logistic regression models, one per emotional concern, were fitted to estimate associations with LCP. All models included the same predictor set: sex, age group, cancer type, care pathway stage, place of assessment, organisation type, and setup to submission time. AIC comparison indicated that random intercepts for delivering organisation (n = 136) did not improve model fit, so a single-level structure was retained.
Benjamini-Hochberg false discovery rate correction was applied across all predictors to account for multiple testing.
The Macmillan eHNA platform supports ethnicity and additional comorbidities (cancer and non-cancer) inputs when submitting an HNA, however there was insufficient completeness of this data to support imputation.

Results

The leading concern propensity (LCP) of each emotional concern was associated with a distinct set of patient characteristics and service contexts.
Across emotional concerns with statistically significant demographic effects, females and those aged under 60 years were most likely to rank emotional concerns as their highest or joint highest concern (that is, to have the highest LCP) while those aged 70 years and older were least likely to do so, after adjusting for potential confounders.
Place of assessment had a statistically significant effect on LCP for 6 of the 12 emotional concerns after adjusting for potential confounders; of which, LCP was higher when HNAs were conducted at home compared to in secondary care, and LCP for 'Anger or Frustration' was lower when HNAs were conducted in inpatient ward settings.
Where pathway stage had a statistically significant effect on LCP after adjusting for confounders , 'Thinking about the future', 'Uncertainty', and 'Worry, fear or anxiety' were less likely to be recorded as the highest or joint highest concern at all subsequent pathway stages relative to initial diagnosis. Conversely, 'Loss of interest in activities' showed a progressively increasing effect on LCP at each subsequent pathway stage, from the treatment phase onwards through to follow-up and, where applicable, diagnosis of recurrence, compared to initial diagnosis.



Limitations

HNA and care planning is designed to be tailored to individual patient needs and the health system context and is not designed for research. For this reason, neither the data collected nor the study population are optimised accordingly, meaning the study population is not fully representative of the broader cancer population. All available variables were modelled and tested for inclusion; however, patient characteristics such as ethnicity, health literacy, deprivation are likely confounders but could not be included due to absence or insufficient data. Note: ethnicity and deprivation have been analysed separately using linked datasets.

To find out more about this research visit: www.macmillan.org.uk/about-us/what-we-do/research/evaluation-reports

Implications

Although many secondary healthcare organisations have introduced HNA and care planning into their processes, variation in how these are offered and delivered to patients may be influencing how patients engage with the assessment and the patterns of concerns they submit.
Certain emotional concerns will be the highest or joint-highest scoring among all submitted concerns more commonly when HNAs are submitted at home, suggesting that offering this mode of assessment is essential for participating organisations. Patients who are female and younger are more likely to score emotional concerns highly, which is consistent with findings around emotional distress following cancer diagnosis in other contexts.
We note that social care organisations have an important role to play in the emotional support of people with cancer and with expanded use of HNA within these contexts may lead to a wider cohort of individuals supported.