

The economic impact to Australian patients with neuroendocrine tumours

A Commonwealth Neuroendocrine Tumour Research Collaborative (CommNETs) Project

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Rationale

Little is known about the economic toll of neuroendocrine tumour (NETs) on patients and families. Patients with very high medical expenses can face substantial distress and, among those unable to pay for healthcare, can lead to avoiding medical appointments and poor adherence to medications. This situation is called 'financial toxicity', a broad term that refers to the financial distress or hardship from treatment, specifically for patients with cancer.

To understand the financial burden on patients with NETs, our study addressed three research questions:

- What are the medical expenses and financial impacts of persons with NETs?
- What are the main determinants of higher costs during the first two years after diagnosis? and
- Do those with higher financial strain report poorer quality of life?

The study was set in the Australian health system comprising both publicly-funded government services and private providers.

Timeline of data available for the analysis

Year	Prior to 2013	2013	2013	2014	2014	2015	2015	2016	2016	2017	2017	2018	Total
Quarter	Q2	Q1-Q3	Q4	Q1-Q3	Q4	Q1-Q3	Q4	Q1-Q3	Q4	Q1-Q3	Q4	Q1-Q4	
Data type			Medicare data was received for 4 years over these dates ¹ n= 80								Survey n=205		205 ²
	Time of diagnosis												
Participants with Medicare & survey data	40	8	19	11	2	80							
Participants with survey data only	50	7	21	25	21	124							
Total n	91	15	40	36	23	204							
Categories of within/outside 3 years of time of survey	113 diagnosed >3 years before survey						91 diagnosed within 3 years of survey						204

1. Medicare data is only held for 4.5 years before it is archived and this limited the data retrieved for this analysis.
2. One person was deleted from final analysis for not residing in Australia

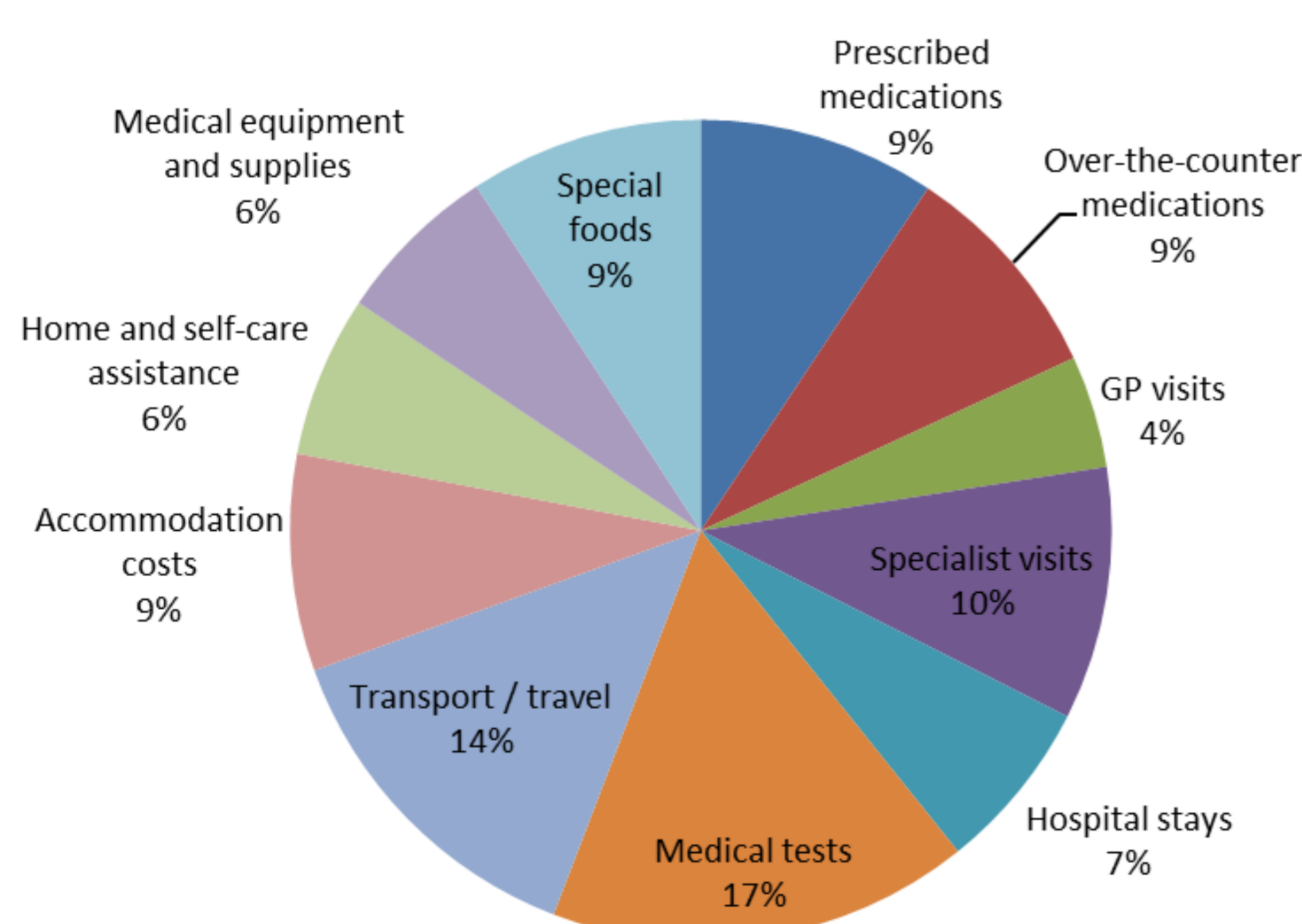
Results

- 204 survey participants – 164 (80%) full, 41 (20%) partial responders
- Mean age of 59 years, 53% married, 59% tertiary educated, 36% from a rural area, 47% retired, average time since NET diagnosis 5.2 years
- 76% had received a somatostatin analogue, 47% surgery, 40% PRRT

Self-reported Out-of-Pocket Medical Expenses (previous 3 months)

- Self-reported mean costs were AU\$1,698 (sd \$2,132) (median \$877)
- These were highest for medical tests (mean AU\$376, sd \$722), travel-related expenses (mean AU\$289, sd \$559), and specialist visits (mean AU\$225 sd \$342).
- Participants with private health insurance paid proportionally more out of pocket than those without insurance for medical tests and specialist visits, and less for transport and travel, and was a key determinant of higher out-of-pocket costs.

Proportion of mean out-of-pocket expenses over past 3 months



Medicare Data on Out-of-Pocket Expenses (over a 4 year period)

- Analyzed for 54 patients who were at least 2 years from their diagnosis
- Mean cost was \$AU6153 per person over 4 years
- Co-payments highest for medical procedures, followed by medicines, doctors appointments, imaging and pathology tests
- Pharmaceuticals were the highest cost to the Commonwealth Government, mean AU\$74,400

Methods

- We undertook an online cross-sectional survey, using a targeted approach through hospital clinics and via NET patient support group Neuroendocrine Cancer Australia.
- The self-reported survey comprised 85 questions (average 30mins to complete) and comprised questions over 8 domains including cancer profile, employment, household finances, out-of-pocket medical expenses (past 3 months), financial toxicity, health insurance, quality of life and socio-demographics
- Two validated surveys measured health-related quality of life (EuroQol-5D-5L) and financial toxicity (COMprehenSive Financial Toxicity – COST - tool).
- Generalized linear models were performed to assess determinants of quality of life and out-of-pocket expenses recorded by Medicare.
- Respondents were also asked to release their Australian Medicare claims data covering the past 4 years, providing information on resource use, health provider charges, Medicare reimbursement, patient contributions to Medicare listed medicines and health services.

Response to Financial Situation and Financial toxicity

- 20% had sought financial advice after their cancer diagnosis
- 40% reporting spending more on cost of treating cancer than expected
- 17% said this caused significant stress to them and their family
- 31% said cost was a consideration in choosing their cancer treatment
- 4% did not proceed with treatment due to cost

Employment and Insurance Expectations

- Of those retired, 44% did so early due to their cancer
- Current workers reported substantial time off work due to cancer
- One third reported cancer had prevented them securing employment and another third had decreased their work hours
- Of those privately insured, insurance did not cover expected expenses in 58%
- Between 2 and 25% had been refused some type of insurance product (eg travel insurance 25%)

Alternative Therapies

- 60% of participants reported purchasing alternative therapies as a result of their cancer at a mean cost of AU\$3,190

Quality-of-Life impacts

- Poorer quality of life scores were significantly associated with a higher financial toxicity score, two or more comorbidities, younger age, not working due to cancer and nausea/diarrhea.

Conclusions

- Deleterious financial impacts were experienced by some patients with NETs, ranging from ongoing and high out-of-pocket expenses to having to retire earlier than desired and refusals of insurance.
- Accessing supportive care services to provide occupational support is likely to be an increasingly important aspect of cancer rehabilitation services for NETs patients.
- Patients with NETs live with metastatic disease for long periods and appropriate assessment and support for issues such as financial toxicity should occur at all stages of their illness journey.