

The Cancer Treatment Helpline – a retrospective study of the NHS Tayside Experience

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Abstract

Background: Treatment related toxicity and delays in the management of this toxicity can impact cancer patient outcomes. In Scotland, a national cancer helpline was established to provide triage assessment for patients receiving systemic anticancer therapy (SACT) in an attempt to minimize delays in toxicity management. In this article we describe the use and impact of the helpline in our region over the last 5 years.

Methods: Patients who contacted the NHS Tayside cancer helpline between the 1st January 2016 and 31st December 2020 were retrospectively identified. Patient demographics as well as the reason and outcome of each call was recorded. A descriptive analysis was performed.

Results: 6,562 individual patients received SACT and 8,397 calls were recorded during the time period. Median age of callers was 63 years (range 17-98) and 59.2% were female. Use of the helpline increased by 83.6% between 2016 and 2020, driven by an increase in in-hours calls. 41% of calls required review by a healthcare professional only, 24% required review and admission and the remaining 35% telephone advice only. The majority of cases (85%) were either assessed or advised solely by oncology. The proportional use of General Practitioner services has decreased.

Conclusions: The helpline provides a way for patients to report symptoms directly to their clinical team and receive appropriate specialist advice at an early stage. We demonstrate that most of these calls can be managed solely by our oncology team. This system can reduce pressure on other parts of the local health system.

Highlights

- To our knowledge this is the first report on the use and health service impact of a Cancer Treatment Helpline within NHS Scotland
- We have observed an increase of 83.6% in calls over the last 5 years
- The majority of calls can be dealt with solely by Oncology
- The helpline has led to a decrease in the proportion of patients contacting their General Practitioner

Introduction

The global cancer burden is increasing annually. By 2030 it is predicted that there will be 4 million people in the United Kingdom (UK) living with cancer¹. Despite advances in cancer management, patients still experience a range of short and long-term treatment related side effects, which can result in significant morbidity and mortality².

In the UK, patients with cancer presenting to their local hospital as an emergency were historically admitted under general medical or internal medicine teams. This was despite a lack of experience in

managing treatment related toxicity and the limited presence of specialist oncology support in smaller hospitals. In 2008, the National Confidential Enquiry into Patient Outcome and Death (NCEPOD)³ found deficiencies in the management of cancer patients admitted to hospital as an emergency; 49% of patients were deemed to have had less than optimal care and 27% of deaths were adjudged to have been hastened or caused by systemic anticancer therapy (SACT). The report highlighted contributing factors relating to both the communication and organization of emergency care.

As a result, the National Chemotherapy Advisory Group (NCAG) was established⁴. They proposed that each hospital with an Emergency Department (ED) should have an acute oncology service (AOS) with the goal of approaching emergency cancer presentations in a more systematic way. The primary purpose of an AOS is to coordinate the management of patients who fall into one of three categories: those with cancer related symptoms, those with cancer treatment toxicity, those requiring investigation and diagnosis of a new undiagnosed cancer.

In Scotland, in response to the NCEPOD report, a Short Life Working Group was established and developed a dedicated 24-hour Cancer Treatment Helpline (CTH) which made use of the existing NHS24 general helpline. At the time, it was the only validated service in the UK which utilised competently trained non-clinical staff to triage patients. The availability of the triage service provided a way for patients to directly report treatment related toxicity and receive specialist input in a timely manner. This is important as delays in managing symptoms can impact patient outcomes – the best example of this is neutropenic sepsis⁵.

NHS Tayside is in the North-East of Scotland and serves a population of over 400,000 people. The chemotherapy service and oncology department within NHS Tayside established a triage service in January 2013 with the goal to enhance patient safety and outcomes for those receiving SACT who had symptoms related to their treatment. This service was designed to provide triage assessment through an initial telephone consultation with the goal to streamlining the patient pathway.

In October 2015, NHS Tayside adopted the Cancer Treatment Helpline, a national cancer helpline established in conjuncture with NHS Scotland and NHS24. Unwell patients presenting out of hours are now diverted to the CTH, while those presenting in hours continue to contact the local oncology service directly. During the initial telephone triage assessment, a suitably qualified healthcare professional triages callers using a series of questions from the UKONS guidelines. Based on the triage outcome, the patient can either be managed over the phone, reviewed in the oncology department, seen by a general practitioner (GP) in the community or admitted to the Accident and Emergency department (ED). Out-of-hours, patients are redirected to the national NHS24 phoneline.

In this article we provide a descriptive analysis of the use of the CTH in NHS Tayside over a 5-year period (1st January 2016 -31st December 2020) and discuss the impact it has had on the wider NHS in our region.

Methods

Patients

Patients who contacted the NHS Tayside CTH between the 1st of January 2016 and the 31st of December 2020 were retrospectively identified from existing paper call logs.

The date, time, and outcome of each call were recorded along with the primary reason for the call. The reason for the call and the symptoms experienced by the patient were graded according to the UKONS triage tool ⁶. The time of the call was recorded as in-hours (8am-5pm on Monday to Friday) or out of hours (5pm-8am on Monday-Friday and all-day Saturday and Sunday). The outcome of the call was recorded as advice given, oncology review, NHS24 contact, paramedic/emergency department (ED) attendance or general practitioner (GP) review. If the outcome resulted in a hospital admission, this was also recorded.

Electronic records were reviewed to complete data collection including confirmation of patient age, type of malignancy and systemic anti-cancer therapy being received at the time of call. Treatment was classified as either chemotherapy, immunotherapy, tyrosine kinase inhibitors, combination therapy or other therapy. Combination therapy included combinations of same or different class drugs. Other therapy included radiotherapy (alone or in combination with chemotherapy), anti-oestrogen (exemestane, fulvestrant), CDK4/6 inhibitors (ribociclib, abemaciclib, palbociclib), PARP inhibitors (olaparib, niraparib), bisphosphonates (pamidronate, zoledronic acid), targeted therapy (trastuzumab, pertuzumab, cetuximab, trastuzumab emtansine, bevacizumab, panitumumab, olaratumab), anti-androgens (enzalutamide, abiraterone), mTOR inhibitor (everolimus), somatostatin analogues (lanreotide) and dexamethasone. Treatment data was unavailable for 2016 as it was not recorded on the paper logs at that stage.

All patient data was anonymised and collected in a password protected database on secure NHS computers. Local Caldicott ethical approval was obtained prior to data analysis.

Statistics

A descriptive analysis of patient demographics, the number of calls and the outcomes of each call was performed to assess differences between 2016 to 2020. Comparison of age of caller was compared between years using a two-sided unpaired t-test using Microsoft Excel.

Patient and Public Involvement

Patients were not involved in this retrospective study.

Results

The total number of calls to the CTH between 1st January 2016 and 31st December 2020 was 8397. The median age of callers was 63 (range 17-98) and 59.2% were female. From the data, we observed that,

5463 (65.1%) of calls required the patient to be reviewed in person, whilst 2917 (34.7%) received advice only. During the same time period 6,562 individual patients received SACT in Tayside (**Table 1**).

Use of Cancer Treatment Helpline

The total number of calls to the CTH has gradually increased year on year, with an increase of 83.6% since 2016 (**Table 1**). Over the same time period, the number of patients being treated has increased by 15.4%. The number of in-hours calls to the CTH has also increased year on year from 530 in 2016 to 1421 in 2020, which corresponds to an increase in the proportion of calls. In the same time period, the number of OOH calls has remained relatively constant (**Table 2**).

Year	2016	2017	2018	2019	2020
Number of patients who received SACT	1212	1254	1285	1412	1399
Total Number of Calls	1137	1433	1773	1967	2087
Year on year increase (%)	-	+26.0%	+23.7%	+10.9%	+6.1%

Table 1. Total number of calls to the NHS Tayside CTH between 2016 and 2020. Percentage year on year increase indicates the change from the previous year. SACT – systemic anticancer therapy.

Year	Total Calls	In-hours	Out of hours
2016	1137	530 (46.6%)	607 (53.4%)
2017	1433	777 (54.2%)	656 (45.8%)
2018	1773	1085 (61.2%)	688 (38.8%)
2019	1963	1235 (62.9%)	728 (37.1%)
2020	2053	1421 (69.2%)	632 (30.9%)

Table 2. Number of in-hours and out-of-hours calls from 2016-2020. Percentage expressed as proportion of calls according to individual year.

Analysing the data according to the day of the week, the highest number of calls were observed to on a Monday, with a total of 1903 calls (20%) being logged. There was an annual increase in calls on each weekday while number of calls on weekends remained similar. The majority of calls during the day were received in the morning with the greatest number of Monday morning.

Use of CTH according the age

The median age of patients using the CTH was 63 years (range 17-98). There was an increase in the number of calls across all age groups from 2016-2020. There was no significant difference in median age of patient across the years (**Table 3**).

Year	Median (years)
2016	63 (23-85)
2017	64 (17-90)
2018	63 (21-89)
2019	62 (18-98)
2020	64 (18-95)

Table 3. Median age (range) of patients who called the CTH from 2016-2020.

Impact of tumour group and regime

In keeping with the incidence of the common cancers, the use of the CTH was greatest in patients with breast, lung and colorectal cancer (**Table 4**). Most tumour groups had an increase in call number – the exception was prostate cancer.

Tumour group	2017	2018	2019	2020	Total	% change
Breast	295 (21%)	387 (22%)	477 (24%)	465 (22%)	1624 (22%)	58%
Lung	305 (21%)	405 (23%)	413 (21%)	408 (20%)	1531 (21%)	38%
Lower GI	167 (12%)	240 (14%)	264 (13%)	276 (13%)	947 (13%)	65%
Gynae	191 (13%)	183 (10%)	220 (11%)	203 (10%)	797 (11%)	6%
Upper GI	173 (12%)	155 (9%)	170 (9%)	263 (13%)	761 (10%)	52%
Prostate	105 (7%)	101 (6%)	105 (5%)	80 (4%)	391 (5%)	-24%

Table 4. Breakdown of CTH use by tumour group from 2017-2020. Only tumour groups with more than 100 calls in 2017 are shown. The percentage (%) change from 2017 to 2020 is recorded. GI – gastrointestinal.

The greatest number of patients were on a form of combination treatment at the time of their call. Between 2017 and 2020, the largest increase in use of the CTH was seen for immunotherapy and other treatments; 215% and 225% increase respectively. Calls related to chemotherapy, tyrosine kinase inhibitor and combination therapy increased by 21%, 41% and 26% respectively.

Call outcome

Of the 8397 patients that have used the CTH between 2016 and 2020 – 41% required review by a healthcare professional only, 24% required review and admission and the remaining 35% were given telephone advice only (**Table 5**). The majority of cases (85%) were either assessed or advised solely by oncology. Of note, the proportional use of GP services has decreased, while the number of patients being reviewed by oncology has increased by an equal proportion. It is important to note the likely impact of the Covid-19 pandemic on the 2020 data, with an increase in advice and a fall in clinical review.

Year	Advice only	GP/NHS24	Oncology review	ED review	Admission
2016	30%	15%	26%	3%	27%
2017	32%	12%	25%	2%	29%
2018	31%	10%	30%	2%	27%
2019	31%	11%	31%	4%	22%
2020*	46%	11%	20%	4%	19%

Table 5. Outcome of calls to the CTH between 2015-2020. Values expressed as percentage of total calls to nearest whole number. *Covid-19 pandemic.

Discussion

The NCEPOD report in 2008 suggested that failure to provide a robust 24-hour oncology advice service resulted in compromised cancer patient safety³. In response, Scotland established a 24-hour CTH with the aim of providing a direct route of contact for patients to report their treatment related toxicity directly to their clinical team. In this article we describe the use of the CTH in our oncology service in NHS Tayside, as well as the impact it has had on service provision in the wider local health service.

Our data demonstrates that the number of calls received by the CTH has increased by 83.6% over the last five years. This is in keeping with rising incidence of cancer⁷ as well as the availability of newer treatments such as immune checkpoint inhibitors, which provide the option of more lines of therapy for our patients. There was no significant change in the median age of the patients we observed calling the CTH. Interestingly, while the in-hours calls increased (almost trebling), the out-of-hours calls did not, possibly reflecting a hesitancy from patients to phone outside traditional working hours. This is supported by the sharp increase in calls on a Monday, and in particular Monday morning, suggesting that patients were willing to wait to call until after the weekend.

Of the calls to the CTH, 35% were able to receive telephone advice only. 85% were dealt with exclusively by the local oncology team either with telephone advice or in person review. This demonstrates the impact the CTH has had on appropriately directing patients and receiving early specialist care. This has also had a positive impact on other parts of the health service. As the CTH has developed and the team has increased in size and experience, the proportion of patients requiring review by their General

Practitioner has fallen from 15% in 2016 to 11% in 2020, while the number receiving oncology review has increased by the same proportion. This demonstrates a shift in care model. This is also reflected in the triage classification which has demonstrated a reduction in acuity of calls and a move towards a greater proportion of green and single amber calls – suggesting patients are phoning at an earlier stage of their toxicity burden.

It is important to note that there was a change in triage outcome in 2020, which likely represents the impact of the Covid-19 pandemic on SACT delivery in Scotland⁸. During this year, a greater proportion of patients received advice only which may represent not only a propensity to avoid patients coming to a high-risk clinical area but also a tendency for clinicians at the beginning of the pandemic to dose de-escalate, use increased supportive measures and dose delay. All of these measures would reduce incidence and severity of toxicity.

Most tumour groups have observed an increase in call burden – reflecting the increase in number of patients with cancer and improved patient survival as well as the increased number of treatment options available. The exception is prostate cancer, which has seen a reduction. This is likely a result of the introduction of the oral agents abiraterone and enzalutamide, which in general are better tolerated in comparison to chemotherapy and require regular clinical review in the clinic setting.

Likewise, all treatment types have noted an increase in calls. This increase is particularly marked for immune-checkpoint inhibitors which over the past 5 years have been licenced for use in several tumour groups both in the adjuvant and palliative setting.

The strengths of this report are that we have generated a large amount of data over a period of time from the same oncology unit. We have used a standardised reporting form which has enabled consistency in data recording and minimised missing data. Despite this, our report has some limitations. The recording of the patient symptoms using the UKONS tool is open to interuser variability and despite the standardised paper form, we did note some data was missing. The lack of granularity regarding burden of disease must also be acknowledged.

In summary, we provide an overview of the CTH in our region. We believe this is the first report of its kind. We have shown that use of the CTH has increased over the last 5 years and the ability to direct patients to specialist care early has removed pressure on other parts of the health system.

Conclusion

Early reporting and management of treatment related toxicity improves patient's outcomes and quality of life. The CTH provides a way for patients to report their symptoms directly to their clinical team and receive appropriate specialist advice at an early stage. We have demonstrated that most of these calls can be managed solely by the oncology team and that this can remove the pressure on some of the other parts of the local health system. The CTH fits within our local AOS service.

Declarations

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Conflicts of Interest

RDP has undertaken speaking, consulting and advisory roles for Eli Lilly, BMS, Pfizer, Sanofi, Servier; and received research funding (not related to the work in this manuscript) from Astra Zeneca, Roche, MSD, Merck serrano, Eli Lilly, Five Prime Therapeutics, Clovis, Boston Biomedical, and Janssen.

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Author Contributions:

IT and SG analysed the data and drafted manuscript. They are joint first authors.

MT oversaw data collection and edited the manuscript.

RDP edited the manuscript.

MAB designed the project, analysed the data and wrote the manuscript.

All authors approved the final manuscript.

Abbreviations

AOS – acute oncology service; CTH – cancer treatment helpline; ED – emergency department; NCAG – national cancer advisory group; NCEPOD – national confidential enquiry into patient outcomes and death; NHS – national health service; SACT – systemic anticancer therapy; UK – United Kingdom; UKONS – united kingdom oncology nursing society

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