

The Prevalence and Types of Advance Care Planning Use in Patients with Advanced Cancer: A Retrospective Single-Centre Perspective, Australia

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Running Head Advance Care Planning use in patients with advanced cancer

Key Points

Question What is the prevalence and types of Advance Care Planning use in patients with advanced cancer in Gold Coast University Hospital, Australia?

Findings This retrospective audit of 320 patients found low Advance Care Planning invitation and utilisation rates, especially in the patients who received chemotherapy in their last 2-weeks of life. In the oncology setting, completion of Acute Resuscitation Plans and Advance Health Directives significantly differed between the control, <2-weeks, and 2–4 weeks groups, identifying the <2-weeks patient group as the lowest utiliser.

Meaning The low utilisation of Advance Care Planning in patients with advanced cancer decreases the scope of recognising their preferences at end-of-life care that indicates a need for an embedded framework along with education and training for the staff and patients.

Abstract

Background: Advance Care Planning (ACP) has been reported to be of value in maintaining patients' autonomy and dignity; reducing patient and family anxiety; improving end-of-life care and reducing futile interventions. But in Australia participation rate in advance care directives is 14%, and research is limited on ACP invitations and uptake among the patients with advanced cancer (PwAC). This study identifies the prevalence and types of documented ACP discussions in PwAC who died within two or four weeks of receiving chemotherapy.

Methods: A retrospective audit was conducted in Gold Coast University Hospital, Australia, and the records of 339 patients were examined and 320 patients were found eligible. Descriptive statistics were calculated in SPSS. The difference in ACP invitation and utilisation between three groups [control, <2-weeks, and –4 weeks] was measured by the Kruskal-Wallis test and Chi-square (or Fisher-Exact) test. Post-hoc follow-up pair-wise comparisons were performed. Adjusted prevalence ratios were estimated using two logistic regression models, and the significance of the coefficients was assessed using Wald test.

Results: Of the 320 PwAC [male: 55%; median age: 65 years], 227 (71%) received ACP invitation, and among the invited patients, 89% used Acute Resuscitation Plan; 54% used Enduring Power-of-Attorney; and 20% completed Advance Health Directive. From 7.5% [n=24] of the patients who received chemotherapy in their last 2-weeks of life, 42% had not received an ACP invitation, 29% didn't have Acute Resuscitation Plan and only 4% completed Advance Health Directive. There were significant differences among the Control, <2-weeks, and 2–4 weeks groups in completing Acute Resuscitation Plan (p=0.003) and Advance Health Directives (p=0.045). A significant difference was also observed between control and <2-weeks groups in number of days since Acute Resuscitation Plan used. Completing an Acute Resuscitation Plan was associated with a lower risk of dying within two-weeks of chemotherapy (OR=0.246; p=0.008).

Conclusions: The low rates of ACP invitation and use in PwAC, especially who received chemotherapy in 2-weeks of dying confirm a need of embedding and regular revisiting the ACP framework in cancer care and educating staff, patients, and their family caregivers to increase the uptake.

Keywords: Advance Care Planning, Advance Health Directive, Enduring Power of Attorney, Acute Resuscitation Plan, Palliative Chemotherapy, Futile Treatment.

Background

Advance care planning (ACP) is widely reported to be of value in maintaining the patients' autonomy, reducing patient and family anxiety, improving end-of-life care and reducing futile or unwarranted intervention [1]. In Australia, terminology and its application vary across states and territories, but ACP generally involves Advance Care Plans; Advance Care Directives; Statement of Choices; Advance Health Directives; Enduring Powers of Guardianship and/or Attorney; and Acute Resuscitation Plan [2, 3]. It is recommended older adults begin ACP early, even when they are healthy, but individuals should particularly be encouraged to participate in the process when diagnosed with a life-limiting or chronic illness [4]. Evidence shows both invitations to ACP and completion of documentation are effective, for example, Houben et al. (2014) reported that increased documentation and discussions about care preference was correlated with patients' wishes being met [5]. Therefore, the ACP becomes integral to the care, communication and treatment plans for patients and their families and carers [4].

In 2011, the Australian government released a national framework on ACP that recommended they be part of hospital admissions/care protocols; accordingly, the country's states/territories circulated guidelines to increase the patients' ACP uptake [6]. Despite such efforts, national data suggests the use of ACP and frequency of end-of-life discussions have not kept pace, with 14% of Australians having a completed Advance Care Directive [2]. A 2017 literature review identified the ACP prevalence of 12.7% in a retrospective USA study undertaken in 2015 assessed ACP practice with the largest international sample size of 24,291 [8]. Research is limited on ACP uptake in Australia, meaning there is a lack of evidence to assist hospitals and governments to understand the impact of ACP initiatives, especially for cancer patients [7].

Australian Institute of Health and Welfare (2014) identified cancer accounted for three out of every ten deaths in the country, and in 2011, cancer was responsible for 19% of the overall disease burden [9]. Compared to common non-cancer causes of death, cancer has a distinct trajectory of functional decline with a more predictable terminal period, which may be more conducive to ACP and palliative care [10]. Literature suggest cancer care continues to be highly intensive, driven in large part by local practice patterns as opposed to the patients' preferences [11, 12]. Indeed, report published over a decade ago that described an environment of

increasingly aggressive cancer care is mirrored in recent study showing persistent use of hospital-based services near death, despite evidence that aggressive end-of-life interventions may not be associated with better medical or quality of life outcomes [10].

Health status of cancer patients treated with chemotherapy often continues to deteriorate. There are benefits of chemotherapy in terms of symptom control, i.e., palliative chemotherapy [13], but ongoing use of chemotherapy must be balanced with the side effects and toxicity. Studies from North America point to a trend revealing increased use of chemotherapy in the last 2-weeks of life [14, 15, 16, 17, 18]. The benchmark for chemotherapy uses in the last 2-weeks of life was set by Earle et al. (2004, 2008), which states less than 10% of patients should be receiving chemotherapy prior to death [14, 15]. The Adam et al.'s (2014) comparison table identified an Australian, single-centre study that looked at 747 patients who died across two cancer care departments in New South Wales and revealed 8% patients received palliative chemotherapy in the last 2-weeks and 18% for 4-weeks prior to death (where n =398) [19, 20]. Interestingly, the predictor of palliative chemotherapy continuation until the last 4 weeks of life in the study by Kao et al. (2009) was the treating oncologist, yet this was not a statistically significant effect for 2-weeks prior to death [20]. It is, therefore, pertinent that all cancer patients receiving chemotherapy, especially those with advanced stages of disease, should have had in-depth discussions with health staff about their end-of-life care.

As noted earlier, little is known about the invitation and uptake of ACP in the patients with advanced cancer (PwAC). In 2014, a review of 113 studies on the effects of ACP, only 18% (20 studies) reported on complex ACP interventions and only two of them included patients with cancer [1]. The studies were limited in their objectivity, as results were self-reported by next-of-kin after the patients had died. Currently, there exists disparity in the broader community in terms of preferences for end-of-life care including location of death, with 70% of the cohort stating a preference (in surveys) to have end-of-life care at home and yet 70% experience their end-of-life care in hospital [21]. It remains a challenge to determine if the PwAC wishes are being met, if they are not being documented in the first place, ultimately resulting in reduced levels of patient care and autonomy. We, therefore, aim to estimate the prevalence and types of ACP utilisations in PwAC who

have received chemotherapy. Our study also examined the use of chemotherapy and ACP for the subgroups of patients who received chemotherapy up until their last 2-and 4-weeks of life.

Methods

Study design

This retrospective audit examined the ACP documentation contained in the records of 339 oncology patients who received chemotherapy for solid tumours and who died between January 1, 2016 and April 30, 2017.

Settings and subjects

The audit was conducted at Gold Coast University Hospital, Australia, which is a tertiary referral-centre servicing a population of 600,000 and only public oncology service in the region. The audit primarily focussed on oncology patients who were treated for solid tumours. A patient was defined in this study who was seen by oncology team and underwent at least one-cycle of chemotherapy/immunotherapy treatment. Patients with advanced solid tumours were included in this study. Generally, the PwAC would be present as an inpatient and subsequently receive a booking confirmation for chemotherapy treatment in oncology unit. The patients who met the oncology team and did not proceed to chemotherapy/immunotherapy intervention were excluded, resulted in 320 patients who met the inclusion criteria [Figure 1]. The median age of all patients was 65 years, with a range from 21 to 94 years and 55% males.

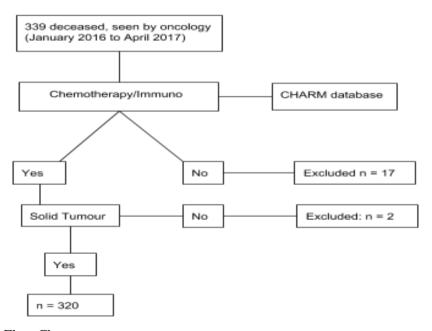


Figure 1. Method Flow Chart

Data collection

Data was collected from hospital administration records; electronic medical records (EMR); and the chemotherapy pharmacy treatment database ('CHARM'). Specifically, the researchers retrieved data about how many PwAC had completed Advance Health Directives, an invitation to participate in any ACPs, a documented Advance Resuscitation Plan, a nominated default decision maker or Enduring Power-of-Attorney. Data was also collected for type of cancer, treating oncologist, date of last chemotherapy and place of death.

The spreadsheet was constructed in Excel with the first column pertaining to patient identification. Data extracted from the electronic medical record for entry into the spreadsheet included the following patient characteristics: gender, age, date of death, presence of a documented Advance Health Directive, of an Enduring Power-of-Attorney, an Acute Resuscitation Plan and an invitation to ACP. Place of death was also extracted from individual EMR. The database CHARM was used to obtain the variable of last chemotherapy treatment date and this was also recorded. The type of cancer and treating oncologist was obtained via EMR notes and cross-referenced with the CHARM database.

The ACP information was not always in the allocated section of EMR. In this case, a search of clinician notes (both inpatient and outpatient documentation) and social worker notes was undertaken. This process was repeated for the Enduring Powers of Guardianship and/or Attorney and invitation to ACP variables. Similarly, the Acute Resuscitation Plan was sometimes scanned into the EMR. If not, the aforementioned subsections of EMR were searched to confirm documentation of Acute Resuscitation Plan completion.

Data Analysis

Continuous variables were summarized using means and standard deviations. Categorical variables were summarized as counts and percentages. Percentages were calculated in SPSS after excluding the missing values. The percentage of the missing values did not exceed 5% for any of the variables. The PwAC were grouped into three cohorts [control, <2-weeks, and 2–4 weeks] to understand whether ACP invitation and participation had occurred in the context of treatment futility. The Kruskal-Wallis test was therefore used to compare the distribution of continuous variables between the groups to test whether the distribution was

significantly different. Chi-square (or Fisher-Exact) test was used to compare the categorical variables between the three groups. In both cases, post-hoc follow up pair-wise comparisons were performed if the initial test results were significant to compare each pair of groups. Bonferroni correction was used to adjust the p values.

Two binary logistic regression models were developed:

- 1. Model 1: Compare the 2-weeks cohort to the control cohort (rest of the cohort excluding the 2-4 weeks group).
- 2. Model 2: Compare the 2–4 weeks cohort to the control cohort (rest of the cohort excluding the 2-week group)

Before performing logistic regression, days since Acute Resuscitation Plan and days since ACP were log transformed. Odds ratio was calculated, and the significance of the coefficients was assessed using Wald test. Likelihood ratio test was performed to assess whether the constructed models (which includes the independent variables) were significantly better than the null model.

Ethics

Ethics approval for the audit was granted by Gold Coast University Hospital and Health District Human Research Ethics Committee [Project Number: HREC/17/QGC/200]. The PwAC were de-identified and their hospital identification numbers were used to ensure privacy. The de-identified data was stored in a spreadsheet format on a computer with password encryption and kept at the hospital for analysis and comparison.

Results

Table 1 illustrates the types of ACP invitations and their uptake by the PwAC. About 71% (n=227) of the total patients received ACP invitation. Of them, 20% completed an Advance Health Directive; 89% had an Acute Resuscitation Plan; and 54% had an Enduring Power-of-Attorney. From 7.5% of the PwAC who received chemotherapy in their last 2-weeks of life, 42% had not received an ACP invitation, 29% didn't have an Acute Resuscitation Plan and just 4% had an Advance Health Directive.

Table 1 also shows the significant difference with respect to types of ACPs use between the three groups [Control VS <2-weeks VS 2–4 weeks]. The proportion of individuals who completed an Acute Resuscitation

Plan was significantly different between the three groups (p=0.003). Post-hoc comparisons showed that the proportion was higher in the control groups compared to the <2-weeks group only, but not the 2–4 weeks group. The proportion of PwAC who completed an Advance Health Directives was significantly different between the three groups (p=0.045). Post-hoc analysis showed results similar to those noted with Acute Resuscitation Plan. Patients treated by one particular oncologist were significantly higher in the <2-weeks group compared to the control group, but not in the 2–4 weeks group. The proportion of males was higher in control group compared to the <2 weeks group and the 2–4 weeks group. The proportion of patients treated with immunotherapy was not significantly different between the three groups (p=0.794). The location of death was not significantly different between the groups (p=0.759). And the types of cancer was not significantly different between the groups.

Table 1. Descriptive statistics for categorical variables (n = 320)

			< 2 Weeks (n = 24)	< 2 – 4 Weeks (n = 27)	Control (n = 269)	p
Advance Care planning	AHD (%)	1 (4.2) ^a	3 (11.1) ^{a, b}	59 (21.9) ^b	0.045*	
		EPOA (%)	10 (41.7)	10 (37.0)	151 (56.1)	0.08
		ACP (%)	14 (58.3)	19 (70.4)	196 (72.9)	0.316
		SOC (%)	3 (12.5)	2 (7.4)	32 (11.9)	0.877
		ARP (%)	17 (70.8) a	22 (81.5) a, b	246 (91.4) b	0.003*
		Gender (Male) (%)	9 (37.5)	10 (37.0)	156 (58.0)	0.024
		Immunotherapy (%)	5 (20.8)	5 (18.5)	46 (17.1)	0.794
Doctor (%)		Doctor 1	8 (33.3) ^a	4 (14.8) ^{a, b}	32 (11.9) ^b	0.0138*
Death location (%)		Hospital (inpatient)	19 (82.6)	19 (76)	199 (76.2)	
		Home	4 (17.4)	6 (24.0)	42 (16.1)	0.759
		Hospice (8 bed facility)	0 (0.0)	0 (0.0)	16 (6.1)	
		RACF (Nursing Home)	0 (0.0)	0 (0.0)	4 (1.5)	
Cancer (%)		Breast	3 (12.5)	3 (11.1)	18 (6.7)	0.379
		CNS	0 (0.0)	0 (0.0)	11 (4.1)	0.54
		Genito-urinary	2 (8.3)	3 (11.1)	31 (11.6)	1
		GI	6 (25.0)	7 (25.9)	92 (34.5)	0.527
		Gynae	3 (12.5)	1 (3.7)	9 (3.4)	0.093
		Head & neck	0 (0.0)	1 (3.7)	10 (3.7)	1
		Lung	8 (33.3)	6 (22.2)	51 (19.1)	0.241
		Melanoma	0 (0.0)	1 (3.7)	7 (2.6)	0.757
		NEC/NET	0 (0.0)	0 (0.0)	5 (1.9)	1
		Other	0 (0.0)	0 (0.0)	10 (3.7)	0.826
		small cell lung	2 (8.3)	3 (11.1)	19 (7.1)	0.61
		Unknown primary	0 (0.0)	2 (7.4)	4 (1.5)	0.149

Different superscripts indicate that the groups are significantly different from each other

ACP = Advance Care Plan; AHD = Advance Health Directive; EPOA = Enduring Power of Attorney; ARP = Acute Resuscitation Plan;

SOC = Statement of choices invitation RACF = Residential Aged Care Facility

Hospice = 8 bed facility not attached to the hospital (not a palliative care unit)

Table 2 shows that there was a significant difference in the number of days since Acute Resuscitation Plan between control and <2 weeks group, meaning that the Acute Resuscitation Plan often filled out by the oncology team as the patients' condition deteriorates and they approach end-of-life. There was also a significant difference between the <2-weeks and the 2-4 weeks group. However, there was no significant difference in the days since Acute Resuscitation Plan between the control group and the 2-4 weeks group. Results show that there were no significant differences between the three groups with respect to age or days since ACP.

Table 2. Descriptive statistics for continuous variables (n = 320)

	Control (n=269)	< 2 Weeks (n=24)	2-4 Weeks (n =27)	p
Age	67.00 [58.00, 73.00]	68.00 [55.75, 74.00]	62.00 [55.50, 73.00]	0.661
Days since ARP	17.50 [6.00, 54.75] ^a	3.00 [2.00, 8.00] ^b	10.00 [7.00, 13.00] ^a	<0.001*
Days since ACP	41.50 [15.25, 101.75]	66.50 [17.00, 115.75]	57.00 [30.00, 94.00]	0.494

Different superscripts indicate that the groups are significantly different from each other

Table 3a. Predictors of death within two weeks of chemotherapy $(R^2 = 16.7\%)$ [<2-week group vs cohort]

Variable	Odds ratio	Lower 95% CI	Upper 95% CI	Wald stat	P value
Gender (Male)	0.41	0.156	0.99	-1.94	0.053
AHD	0.182	0.01	0.923	-1.63	0.1
ARP	0.246	0.088	0.73	-2.64	0.008*
Oncologist (1)	3.45	1.25	8.97	2.49	0.0128*

Table 3b. Predictors of death within 2-4 weeks of chemotherapy ($R^2 = 5.8\%$) [2-4 weeks group vs. cohort]

Variable	Odds ratio	Lower 95% CI	Upper 95% CI	Wald stat	P value
Gender (Male)	0.44	0.187	0.988	-1.95	0.051
AHD	0.493	0.113	1.51	-1.11	0.266
ARP	0.473	0.169	1.55	-1.35	0.178
Oncologist (1)	1.173	0.32	3.4	0.27	0.787

Table 3a and 3b present the logistic regression analysis results. Males were 59% less likely to die within 2-weeks of chemotherapy compared to the females. Completing an Advance Health Directives was not significantly associated with dying within 2-weeks of chemotherapy (p=0.1). But completing an Acute Resuscitation Plan was associated with a lower risk of dying within 2-weeks of chemotherapy (OR=0.246; p=0.008), the odds of dying within 2-weeks of chemotherapy among the PwAC who completed an Acute Resuscitation Plan was 75.4% lower compared to those who did not. There was a significant difference in

treatment up to 2-weeks prior to death for one particular oncologist. Table 3b reports that males were 56% less likely to die within 2-4 weeks of chemotherapy compared to their counterpart. None of the remaining variables was significantly associated with dying within 2-4 weeks of chemotherapy.

Discussion

The study findings confirmed that the invitation and utilisation of ACP in the PwAC, especially in the patients who received chemotherapy in their last 2-weeks of life have remained consistently low across Australia despite high levels of relevance and applicability. Various studies revealed the importance of ACP documentation in maintaining patient preferences for care [1,5]. Brinkman-Stoppelenburg et al. (2014) outlined the evidence for ACP and its positive impact on patient outcomes [1]. However, not all ACP documents are equivalent and therefore may be less likely to ensure patient outcomes. The Acute Resuscitation Plan was the most completed documented in our study yet contains the least legal power to ensure the PwAC outcomes. The Acute Resuscitation Plan completion is not dependent on the PwAC signatures, but rather involves verification through a hospital doctor only. Rietjens et al. (2016) highlighted the importance of patient engagement in decision making around end-of-life care preferences [23]. A document with greater PwAC involvement may increase the likelihood of achieving their preferences. In terms of the patient preference, the Advance Health Directives requires the greatest patient involvement, has a greater level of legal power (depending on state legislation), yet was the most under-represented document in our study.

As a suite of documents, the ACP process has two main components: i. surrogate decision maker; and ii. documents related to patient preferences. In our study 53% of PwAC had a formally allocated a surrogate decision maker via completion of an Enduring Powers of Guardianship and/or Attorney. Despite advanced oncological illness, approximately half the PwAC in our study did not complete an Enduring Powers of Guardianship and/or Attorney and for those who did it was completed nine weeks prior to death (median time frame). In oncology setting, for the PwAC who are receiving chemotherapy/immunotherapy, there exists a distinct timeframe advantage and occasionally predictable functional decline associated with advanced disease. Such death trajectories allow more time for completion and regular revisitation of documents which should align with treatment goals. It could be assumed that many PwAC who did not formally document a decision

maker may believe that family members or carers were adequately informed of their wishes. Shalowitz et al. (2006) revealed the PwAC surrogate decision makers incorrectly predicted patient preferences in one third of cases [37].

In terms of decision making, it is of note that median time frames for Acute Resuscitation Plan completion in our study were the shortest for the PwAC who died within 2-weeks of receiving chemotherapy. This result was significant in our study but also speaks to the reality of advanced cancer. Hebert and Selby (2014) suggested family members and patients should be provided with an explanation of non-reversible aspects of an illness to help guide resuscitation plans [38]. In the case of progressive/advanced cancer, the ARP is more representative of a change in the goals of care or treatment goals, and discussions are often centred around an upper limit of care. Revisions or alterations in resuscitation plans are therefore more likely to occur when a patient is clearly declining and approaching end-of-life.

Our study revealed that the male PwAC were approximately 59% and 56% less likely to die within 2-weeks or 4-weeks of receiving chemotherapy respectively compared with females. While the results were significant, it may also be explained by the types of solid tumours affecting both genders in our study. The literature points to a greater percentage of female-specific cancers that are treated as chronic diseases or maintenance therapies [39]. A study by Nevadunsky et al. (2013) concluded that women with gynaecological malignancies undergo aggressive treatments at end-of-life without any evidence of improved quality of life or longevity [40]. Despite the current study partly supporting the findings of Nevadunsky et al. (2013), there were no statistically significant differences between ACP documentation related to gender.

Barriers to participation in ACP have been investigated by several studies [24, 25, 26]. Michael et al. (2013) suggested a lack of disease specific ACP discussions and outlined the importance of ACP intervention as several discussions throughout the disease trajectory [24]. Optimal time frames for ACP discussions for oncology patients undergoing chemotherapy intervention remain unclear. In particular, studies should look at the time between the initial development of ACP and the subsequent revisions of the plan as suggested for all patients on the end-of-life spectrum as indicated in the consensus guidelines for quality end-of-life care [21].

The quality and content of end-of-life discussions, along with early palliative care involvement has been identified as a significant variable in the development and implementation of ACPs and may require guideline development to ensure a consistently effective approach [24, 26, 27].

This study was limited by a lack of documented hospital admissions in the last-weeks prior to death and the intervention received during this time. Limited data collected on revisions to ACP, i.e., in some cases the Acute Resuscitation Plan or Advance Health Directives were revised several times and the data did not capture this. Statement of choices documentation was not included in the ACP invitations in 2016. However, the study generates evidence for a specific cohort examined and the relevance of ACP implementation in the context of imminent death. Also, it provides pertinent and scarcely available data on the utilisation of ACP in oncology patients that would benefit the practitioners in engaging the patients and their families in ACP.

Impact statement

- ∉ An indication as to which forms of ACP are utilised by Oncology patients with solid tumors;
- Results showing low rate of invitations to participate in ACP and completion of Advance Health
 Directives in patients who died after receiving chemotherapy treatment;

Conclusions

This study revealed that despite government initiatives, ACP prevalence rates are not improving among the PwAC. Of concern are the decreased rates of completion for the PwAC receiving potentially futile treatment in their last weeks of life. Our evaluation of ACP rates in a population of advanced oncology revealed the common form of ACP completion was the Acute Resuscitation Plans followed by Enduring Powers of Guardianship and/or Attorney and then Advance Health Directives. Significantly, Advance Health Directives completion rates in this setting were almost identical to Australian population rates, despite advanced disease.

The study highlights the need for a range of strategies to improve ACP invitation and completion rates: first,

embedding the ACP framework for all patients aged 65 years and over within hospitals; second, ACP

education, training and mentoring for staff; third, engaging social workers in health literacy interventions to

educate patients and their family caregivers about ACP uptake; and finally, revising the ACP documentation

in regular intervals with disease progression. Further research should focus on barriers to ACP completion in

the oncology setting, which may have broader application to the PwAC and ensure patient preferences are

aligned with care received.

Declarations

Ethics approval: This study is approved by Gold Coast University Hospital and Health District Human

Research Ethics Committee [Project Number: HREC/17/QGC/200].

Consent to participate: Not Applicable

Consent for publication: All authors read and approve the submission.

Availability of data and materials: The datasets used and/or analyzed during the current study are available

from the corresponding author on reasonable request.

Competing interests: The authors declared no conflicts of interest.

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Authors' contributions AV made substantial contributions to conception and design, acquisition of data,

analysis and interpretation of data. Responsible for drafting the manuscript and revising it critically for

important intellectual content. AB, GS, AM and MH made substantial contributions to shaping the conception

and design. Involved in drafting the manuscript and revising it critically for important intellectual content. AV

and MH involved in reviewing the manuscript, contribute to developing methodological and oncological

frames, and revising it critically for important intellectual content. All authors read and approved the final

manuscript.

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14

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Figures

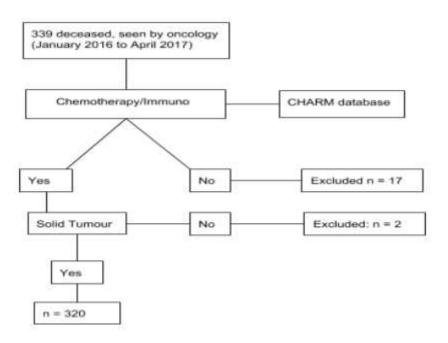


Figure 1

Method Flow Chart