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ORIGINAL ARTICLE

Exploring advance care planning awareness, experiences, and preferences of people with cancer and support people: an Australian online cross-sectional study

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Abstract

Purpose To explore advance care planning (ACP) awareness, experiences, and preferences of people with cancer and support people of someone with cancer, in Australia.

Methods Descriptive analysis and independent group *t* tests were used to examine data from a national, online cross-sectional survey.

Results Of 705 respondents (440 people with cancer, 265 support people), 48.5% of participants had heard of ACP prior to the survey and 65% had discussed their values or preferences with someone. Significantly more people aged under 65 years had discussed their preferences than their older counterparts. Most (93%) discussions occurred with family or friends, but only 3.7% occurred with a health professional. A total of 33% had documented their preferences, with support people, women, and people aged under 65 years significantly more likely to have signed a legal document appointing someone to make medical decisions on their behalf. Views varied about the preferred timing of ACP and end-of-life care discussions (38.3% when cancer is incurable compared to 20% at diagnosis). Only 3.0% did not want to discuss ACP at all. Topics discussed were significantly different based on cohort, gender, age group, treatment status, and region.

Conclusion Despite increasing community awareness of ACP, understanding remains low amongst cancer patients and support people, who generally rely on discussions with family and friends rather than health professionals. ACP should be introduced early across multiple interactions with health professionals, discuss a broad range of ACP relevant topics, and involve the cancer patient and their support person.

Keywords Advance care planning · Advance care directive · Oncology · Survey · Caregiver · End-of-life care

In 2019, approximately 144,000 new cases of cancer were diagnosed in Australia, being an average of 395 people every day [1]. In the same period internationally, there were an estimated 18.1 million new diagnoses of cancer and 9.6 million cancer deaths [2]. The risk of cancer increases with age, with approximately 80% of all cancer internationally being diagnosed in people 50 years or older, and in high-income countries 60% of all new cancer diagnoses occurring in people over the age of 65 [3]. Cancer is a leading cause of death in Australia, with almost 50,000 deaths estimated for 2019 [1]. The year following diagnosis and the last year of life are the most resource-intensive periods of cancer care [4]. An Australian study found that overall healthcare costs were significantly higher amongst those who died from cancer than any other causes, with 40% of costs expended in the last month of life [5].

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People with cancer often face complex and difficult decisions related to treatment and end-of-life care planning in the last year of life [6]. However, cancer patients may experience impaired decision-making capacity due to delirium, particularly those who are older and hospitalised. Up to half (28–48%) of patients with advanced cancer experience delirium on admission to hospital, 90% of whom will experience delirium in the days before death [7]. Despite a reported preference to die at home, most older people with cancer die in hospital [8]. Few older people with cancer receive palliative care in hospital (15%) or are admitted to a hospice (4%) [8]. In addition, older people with cancer are less likely to receive information about their illness and understand the implications of available treatment options, compared to their younger counterparts [9].

Advance care planning (ACP) is a process of planning for future health and personal care. ACP helps identify a person's values, preferences, and/or substitute decision-maker (SDM), to inform medical treatment decision-making for a time when that person cannot make or communicate their decisions [10]. Ideally, outcomes of ACP discussions are documented in legally binding advance care directives (ACDs). The goal of ACP is to align the care the person receives with their preferences. ACP has known benefits for the person, their families, and health service providers. Patients who discuss their preferences for end-of-life care and/or complete ACDs are more likely to choose less aggressive treatment [11] and receive care which is consistent with their preferences [12]. In general medical settings, ACP is associated with improved outcomes at the end of life, including reduced hospitalisation, increased likelihood that the person will die in their preferred setting, and reduced stress, anxiety, and depression in surviving loved ones [13, 14].

In Australia, ACP uptake and ACD completion is recognised as a priority within national policy including the National Optimal Care Pathways for oncology and the National Palliative Care Strategy 2018 [15]. Nevertheless, uptake remains low in Australia and internationally [16–19]. A 2019 Australian national ACD prevalence study reported that only 27% of older people (aged ≥ 65 years) with a cancer diagnosis had documented their preferences in an ACD [20]. Similarly, a study from 2020 reported that although 58% of participating cancer patients self-reported having completed an ACD, only 30% of participants had at least one ACD in their record [21].

Delivering ACP for people with cancer is a complex and dynamic process that requires personal, emotional, social, and legislative factors to align for it to be integrated into routine cancer care [22–25]. A range of patient, healthcare provider, and system-level barriers impact ACP uptake, including the unpredictable disease trajectory, equivocal treatment options, and poor understanding of prognosis [26, 27]. The values and needs expressed by cancer patients and their response to ACP differ from other patient populations, with many advanced cancer patients more likely to seek life-prolonging treatment than patients with chronic obstructive pulmonary disease or heart failure [28]. Within their own cohort, patients with advanced cancer also vary in their willingness to participate in ACP discussions [6]. Other barriers to ACP in cancer treatment settings include lack of patient comprehension and awareness of ACP, insufficient physician training in end-of-life communication, clinician lack of time for ACP conversations and challenges in determining the appropriate time, and a lack of clarity around whose role it is to initiate ACP conversations in people with cancer [6, 29–35].

Little is known about the awareness, experiences, and preferences of Australian cancer patients and support persons regarding ACP. A systematic review identified a lack of patient ACP comprehension and awareness, recommending further research [6]. Support people, whether they be family, friends, or anyone with a significant relationship, typically provide physical, social, or psychological support to a person with cancer and are often involved in decision-making [34, 35]. This manuscript describes the results of a large-scale Australian study exploring ACP awareness, experiences, and preferences of people with cancer and support people for someone with cancer. This work aims to provide more clarity regarding ACP processes in Australian oncology settings to enable widespread uptake across the cancer system.

Methods

A national online cross-sectional study was conducted to examine awareness, experiences, and preferences of ACP for Australians aged 18 years and older with cancer and support person for someone with cancer. The study was approved by Austin Health Human Research Ethics Committee, Melbourne, Australia (reference number: HREC/57061/Austin-2019).

Sampling

An opt-in panel was used whereby adults who had voluntarily signed up to a recruitment agency register, Dynata (www.dynata.com), were invited to complete the survey through invitations and advertisements on the company's website. At the time of the survey, the estimated number of registrants on the company's Australian panel was 1,000,000. Participants were provided information about the project and were informed that consent was implied by completing the survey. Eligible participants were individuals with a current or past cancer diagnosis, and those who acted as a support person for someone with a current or past cancer diagnosis. The first two demographic questions were used to sort participants into one of two groups: a person with cancer or a support person for someone with cancer. All eligible participants were then asked to respond to the remaining survey items. The survey completion took between 15–30 min and data collection occurred over 13 days during November 2019. At survey completion, participants were thanked and given information on accessing support, if required. Participants were reimbursed for the inconvenience (i.e. time taken) to complete the survey by receiving reward points, which were administered by the recruitment agency.

Materials

Survey items were developed following a literature review [15] and research team discussion. Following a pilot with 10 respondents from the target population, item phrasing was refined based on participant feedback about item clarity. The survey used a combination of Likert-type scales, multiple choice, and open-ended responses.

The final survey included 15 demographic questions and 32 questions related to ACP and end-of-life care. Where relevant, definitions of ACP and related terms were included to assist participants. Demographic questions included ten questions adapted from categories used by the Australia Bureau of Statistics (ABS) [36] and five questions about cancer diagnosis and treatment plan.

The 32 ACP questions were grouped into four sections:

> Section 1: six questions asking whether a participant had ever spoken to anyone or documented their "goals, values, beliefs, or preferences," who these discussions had occurred with, and how they had heard of ACP.
> Section 2: thirteen questions examining current perspectives of ACP. An example included whether they valued life-prolonging treatment, pain management or being alert towards end-of-life.
> Section 3: twelve questions examining topics discussed with participants during their cancer experience, and which of those topics they would like to be discussed (if any). Examples included life expectancy and ACP.
> Section 4: a single open-ended item for any additional comments related to ACP.

Information from sections 1, 2, and 4 are included in this paper. Results from section 3 are reported elsewhere.

Data analysis

Data were cleaned, and variables re-coded as needed before conducting analyses. Participants who did not complete at least 20% of questions related to ACP were excluded from the analysis. After exclusions, values were present for all but three responses to demographic questions, so no further records were excluded. Descriptive analyses were conducted using SPSS V26.0 (IBM) to examine the demographic profile of participants and their current knowledge and experiences with ACP. Independent *t* tests and Levene's test for homogeneity of variance were used to identify statistically significant differences between dichotomous groups. Dichotomous groups explored were cohort (person with cancer/support person of someone with cancer), gender (male/female), age group (18–64 years/65+ years), treatment stage (currently receiving cancer treatment/not currently receiving cancer treatment), and region (metropolitan/non-metropolitan). Statistical significance was set at $p < .05$. Where Levene's test produced a significant result ($p < .05$), values reported reflect *t* values where equal variances are not assumed. Only significant differences between groups are reported.

Results

Of the 1596 people who started the survey, 791 were eligible to participate as either a person with cancer ($n = 503$) or support person of someone with cancer ($n = 288$). In total, 705 participants (62% persons with cancer, $n = 440$; 38% support people, $n = 265$) completed at least 20% of survey items related to ACP and were included in the analyses (completion rate 89%).

Demographics

Participants were generally representative of Australian population as per Australian Bureau of Statistics data [36]. However, they were less likely to be female ($n = 344$, 49% compared to 51%) and were older; with a median age of 64 years (Australian population median age 37 years; see Table 1). Participants were also more likely to have been born in Australia ($n = 542$, 77% compared to 67%) and less likely to speak a language other than English at home ($n = 48$, 7%) compared to the Australian population (22%).

The most common diagnoses for participants were prostate ($n = 108$, 25%), breast ($n = 77$, 18%), and skin ($n = 51$, 12%) cancers. This reflects the most common cancers amongst the Australian population [1]. Many participants reported that either they or their family members were no longer receiving cancer treatment ($n = 275$, 39%). Twenty-six percent ($n = 182$) of participants reported they or their family member had been referred to palliative care.

Awareness of ACP

As shown in Table 2, 49% ($n = 342$) of participants had heard of ACP prior to taking part in the survey ($n = 206$, 47% of people with cancer; $n = 136$, 51% of support people). Of those who had heard about ACP, this information came most often from a health professional ($n = 159$, 31% total; $n = 101$, 23%

Table 1 Demographic characteristics of participants (*n* = 705)

Characteristic		Person with cancer (*n* = 440) *n* (%)	Support person (*n* = 265) *n* (%)	Total (*n* = 705) *n* (%)
Age (years)	18–29	6 (1.4)	30 (11.3)	36 (5.1)
	30–39	36 (8.2)	42 (15.8)	78 (11.1)
	40–49	32 (7.3)	35 (13.2)	67 (9.5)
	50–59	49 (11.1)	47 (17.7)	96 (13.6)
	60–69	128 (29.1)	60 (22.6)	188 (26.7)
	70–79	157 (36)	43 (16.2)	200 (28.4)
	80+	32 (7)	6 (2.3)	38 (5.4)
	Invalid response	0 (0)	2 (0.8)	2 (0.3)
Gender	Male	273 (62.0)	88 (33.2)	361 (51.2)
	Female	167 (38.0)	177 (66.8)	344 (48.8)
Country of birth	Australia	334 (75.9)	208 (78.5)	542 (76.9)
	Other (please specify)	106 (24.1)	57 (21.5)	163 (23.1)
Speaks any languages other than English at home	Yes (please specify)	20 (4.5)	28 (10.6)	48 (6.8)
	No	420 (95.5)	237 (89.4)	657 (93.2)
Jurisdiction	ACT	10 (2.3)	5 (1.9)	15 (2.1)
	NSW	132 (30.0)	86 (32.5)	218 (30.9)
	NT	1 (0.2)	3 (1.1)	4 (0.6)
	QLD	105 (23.9)	49 (18.5)	154 (21.8)
	SA	33 (7.5)	24 (9.1)	57 (8.1)
	TAS	11 (2.5)	8 (3.0)	19 (2.7)
	VIC	103 (23.4)	67 (25.3)	170 (24.1)
	WA	45 (10.2)	23 (8.7)	68 (9.8)
Location	Metropolitan			496 (70.4)
	Rural			201 (28.5)
	Remote			8 (2.0)
Religion	Buddhism	14 (3.2)	7 (2.6)	21 (3.0)
	Christianity	270 (61.4)	149 (56.2)	419 (59.4)
	Hinduism	5 (1.1)	5 (1.9)	10 (1.4)
	Islam	2 (0.5)	4 (1.5)	6 (0.9)
	Judaism	2 (0.5)	1 (0.4)	3 (0.4)
	No religion	134 (30.5)	86 (32.5)	220 (31.2)
	Other (please specify)	5 (1.1)	6 (2.3)	11 (1.6)
	Prefer not to answer	8 (1.8)	7 (2.6)	15 (2.1)
Highest level of education	Years 1–6	2 (0.5)	2 (0.8)	4 (0.6)
	Years 7–10	79 (18.0)	32 (12.1)	111 (15.7)

Table 1 (continued)

Characteristic		Person with cancer (*n* = 440) *n* (%)	Support person (*n* = 265) *n* (%)	Total (*n* = 705) *n* (%)
	Years 11–12	78 (17.7)	55 (20.8)	133 (18.9)
	Certificate III/IV	77 (17.5)	46 (17.4)	123 (17.4)
	Diploma/advanced diploma	75 (17.0)	41 (15.5)_	116 (16.5)
	Bachelor's degree (including honours)	69 (15.7)	52 (19.6)	121 (17.2)
	Graduate diploma/graduate certificate	23 (5.2)	11 (4.2)	34 (4.8)
	Postgraduate degree (Masters, PhD, Doctorate)	37 (8.4)	26 (9.8)	63 (8.9)
Current employment status	Full-time	80 (18.2)	74 (27.9)	154 (21.8)
	Part-time	55 (12.5)	62 (23.4)	117 (16.6)
	Casual	16 (3.6)	11 (4.2)	27 (3.8)
	Retired	255 (58.0)	81 (30.6)	336 (47.7)
	Not employed	34 (7.7)	37 (14.0)	71 (10.1)
What type of cancer have you been diagnosed with?	Brain cancer	14 (3)		
	Breast cancer	77 (18)		
	Bowel cancer	28 (6)		
	Leukaemia or lymphoma	40 (9)		
	Lung cancer	20 (5)		
	Pancreatic cancer	6 (1.4)		
	Prostate cancer	108 (24.5)		
	Skin cancer	51 (11.6)		
	Uterine cancer	7 (1.6)		
	Other (please specify)	82 (18.6)		
	Prefer not to answer	7 (1.6)		
Which statement best describes you or your family member's current treatment status	Newly diagnosed	43 (10)	22 (8.3)	65 (9.2)
	Currently receiving cancer treatment and aiming for cure	129 (29)	84 (31.7)	213 (30.2)
	Currently receiving cancer treatment and not expecting cure	43 (10)	57 (21.5)	100 (14.2)
	Considering cancer treatment options	23(5)	12 (4.5)	35 (5.0)
	No longer receiving cancer treatment	191 (43)	84 (31.7)	275 (39.0)
	Prefer not to answer	11 (3)	6 (2.3)	17 (2.4)
Have you or your family member ever been referred to palliative care?	Yes	92 (21)	90 (34.0)	182 (25.9)
	No	338 (77)	163 (61.5)	501 (71.4)
	Unsure	7 (2)	12 (4.5)	19 (2.7)
	Missing	3 (1.0)	0 (0)	3 (1.0)

people with cancer; *n* = 58, 22% support people), followed by family or friends (*n* = 138, 27% total; *n* = 86, 19.5% people with cancer; *n* = 52, 20% support people), with these two categories accounting for more than half (59%) of all responses. Other information sources included traditional media (*n* = 50, 10%), social media (*n* = 29, 6%), or a legal

Table 2 ACP awareness and experience of people with cancer and support people (*n* = 705)

Topic		Person with cancer (*n* = 440) *n* (%)	Support person (*n* = 265) *n* (%)	Total (*n* = 705) *n* (%)
Have you ever talked to anyone about your goals, values, beliefs, or preferences in case you become seriously ill or unable to make your own decisions?	Yes	291 (66.1)	165 (62.3)	456 (64.7)
	No	134 (30.5)	90 (34.0)	224 (31.8)
	I cannot remember	15 (3.4)	10 (3.8)	25 (3.5)
Who have you spoken to about your goals, values, beliefs, or preferences? (*n* = proportion of participants who answered yes to the previous question)	Husband/wife/partner	161 (36.6)	89 (33.6)	250 (54.8)
	Children	58 (13.2)	33 (12.5)	91 (20.0)
	Brother/sister	20 (4.5)	9 (3.4)	29 (6.4)
	Other family	11 (2.5)	15 (5.7)	26 (5.7)
	Friend	18 (4.1)	10 (3.8)	28 (6.1)
	Doctor	12 (2.7)	5 (1.9)	17 (3.7)
	Other health professional	4 (0.9)	1 (0.4)	4 (0.9)
	Other (please specify)	7 (1.6)	5 (1.9)	11 (2.4)
Ever written down your goals, values, beliefs, or preferences in case you became seriously ill or unable to make your own decisions	Yes	149 (33.9)	84 (31.7)	233 (33.0)
	No	286 (65.0)	176 (66.4)	462 (65.5)
	I cannot remember	5 (1.1)	5 (1.9)	10 (1.4)
Ever signed a legal document to appoint someone to make healthcare decisions on your behalf if you were unable to make your own decisions	Yes	202 (45.9)	86 (32.5)	288 (40.9)
	No	229 (52.0)	173 (65.3)	402 (57.0)
	I cannot remember	9 (2.0)	6 (2.3)	15 (2.1)
Prior to this survey, had you previously heard of advance care planning?	Yes	206 (46.8)	136 (51.3)	342 (48.5)
	No	210 (47.7)	113 (42.6)	323 (45.8)
	Unsure	24 (5.5)	16 (6.0)	40 (5.7)
If yes, from which of the following source(s) did you learn or hear about advance care planning? (*n* = proportion of participants who answered yes to the previous question)	Family or friends	86 (19.5)	52 (19.6)	138 (27.2)
	Health professional (e.g. nurse, doctor)	101 (23.0)	58 (21.9)	159 (31.4)
	Traditional media (e.g. TV, radio, newspaper, magazine)	35 (8.0)	15 (5.7)	50 (9.9)
	Social media/technology (e.g. Facebook, Twitter, website, smartphones)	15 (3.4)	14 (5.3)	29 (5.7)
	Legal professional	38 (8.6)	21 (7.9)	59 (11.6)
	An event (please specify)	9 (2.0)	7 (2.6)	16 (3.2)
	Other (please specify)	11 (2.5)	9 (3.4)	20 (3.9)
Number of sources heard advance care planning from	Single source	146 (33.2)	102 (38.5)	248 (72.5)
	2 sources	42 (9.5)	28 (10.6)	70 (20.5)
	3 sources	11 (2.5)	6 (2.3)	17 (5.0)
	4 sources	3 (0.7)	0 (0)	3 (0.9)
	5 sources	4 (0.9)	0 (0)	4 (1.2)

professional (*n* = 59, 12%). Most people (73%) reported receiving information from a single source. A greater proportion of those who had been referred to palliative care had heard of ACP prior to the survey (61% compared to 36%). No significant differences in ACP awareness were found for cohort, gender, age group, treatment status, or region.

Experiences with ACP

Two-thirds of participants, 65% (*n* = 456), had discussed their goals, values, beliefs, or preferences with someone (Table 2). Of these, 93% (*n* = 424) had occurred with family or friends (55% with a partner, *n* = 250; 20% with children, *n* = 91; 6%

with a sibling, *n* = 29; 6% with other family, *n* = 26; 6% with friends, *n* = 28 6%). Only 17 (4%) people with cancer and support people had discussed their goals, values, beliefs, or preferences with their doctor. Across groups, significantly more people aged below 65 years reported having talked to someone about their goals, values, beliefs, or preferences in case they become seriously ill or unable to make their own decisions when compared to people aged 65 years and over (see Table 3 for all significance measures).

One-third (*n* = 233, 33%) of participants reported they had written down their healthcare preferences, and 41% (*n* = 244) reported they had signed a legal document to appoint someone to make their healthcare decisions on their behalf, should they become unable to make their own decisions. Significantly more support people, women, and people aged below 65 years reported having signed a legal document to appoint someone to make healthcare decisions on their behalf if they were unable to make their own decisions as compared with people with cancer, men, and those aged 65 years and over (see Table 3 for all significance measures).

Preferences about ACP

Participants with cancer had different views about the preferred timing of ACP discussions (Table 4). Almost half of people with cancer (42%, *n* = 185) stated that they would prefer the first ACP conversation with their doctor to occur when their cancer becomes incurable. Approximately one-third (*n* = 140, 32%) of participants with cancer preferred to raise these conversations themselves at a time of their choice, whilst a further 16% (*n* = 72) of people with cancer felt the discussion should occur when they were first diagnosed. For support people, 32% (*n* = 85) wanted ACP discussed when cancer became incurable, 27% (*n* = 72) when the person with cancer decided to raise the matter, and 26% (*n* = 69) at diagnosis. Only 3% (*n* = 21) of participants did not want to discuss ACP and end-of-life care at all (*n* = 17, 4% of people with cancer; *n* = 4, 1.5% of support people).

Most participants (90%) had at least one of the ten topic options listed discussed with them, and the results were similar for both people with cancer and support people (Fig. 1). However, a minority of those (8% of people with cancer and 15% of support people) had discussed all ten listed topics and the mean number of topics discussed was 5 (*S.D.* = 3.052). The topics discussed least often were assistance to complete an ACD (70% not discussed), followed by end-of-life care and dying (58% not discussed) and ACP (57% not discussed).

Significant group differences were present in terms of the topics people had had discussed with them by health professionals. For brevity, all significance measures are presented in Table 3. A significantly greater proportion of people who had cancer had discussed pain management with someone compared to support people. Significantly more people aged 65 years and over had discussed life expectancy, assistance to complete an ACD, and the potential future stopping of cancer treatment compared with those aged under 65 years. Significantly more people not currently receiving treatment or the support people of those not receiving treatment reported having a health professional discuss ACP, assistance to complete an ACD, end-of-life care and dying, life expectancy, pain management, quality of life and values, and whether or not to attempt CPR or go to intensive care with them compared to those who were currently receiving treatment or the support people of those currently receiving treatment. Significantly more people living in non-metropolitan regions than metropolitan regions had assistance to complete an ACD discussed.

People with cancer expressed a need to have more discussion around quality of life and values, pain management, and life expectancy. Support people also identified a need for more conversation around these topics as well as end-of-life care and ACP specifically, although these differences were non-significant.

Discussion

This Australian study provides new evidence demonstrating similar findings between cancer patients and support people of someone with cancer for their awareness, experiences, and preferences regarding ACP. Half of the participants reported awareness of ACP, most commonly hearing about it from a health professional, family member, or friend. Two-thirds of participants reported discussing their values and preferences with someone. Few participants reported having these discussions with their doctor, despite many having learned of ACP from a health professional. People aged under 65 years were significantly more likely to have discussed their preferences with someone than those aged 65 years and over. A third of respondents reported having documented their preferences for medical treatment, with more support people, women, and those aged under 65 years having signed a legal document appointing an SDM compared with people with cancer, men, and those aged 65 years and over. This result contrasts with other Australian literature that found no association between age and ACD preparation [19] and may indicate this significant difference is related to the younger mean age of support people than a genuine age difference.

Nearly half of all participants reported an awareness of ACP, but most participants reported wanting more information on a range of topics regarding ACP and end-of-life care. However, less than a quarter of people with cancer felt ACP discussions should occur when they were first diagnosed but rather when cancer becomes incurable. This suggests that participants have a limited understanding of the principles of ACP and the importance of early ACP. The identification of a person's values,

Table 3 Statistically significant dichotomous group differences in survey items related to ACP (n = 705)

			Levene's test		*t* test for equality of means					
Item		Group category	*F*	Sig.	*t*	*df*	Sig. (2-tailed)	Mean diff.	Std. error diff.	Cohen's *d*
Have you ever signed a legal document to appoint someone to make healthcare decisions on your behalf if you were unable to make your own decisions?		Cohort*	19.942	0.000	−3.426	581.036	0.001	−0.138	0.040	0.526
		Gender*	24.795	0.000	−2.218	700.249	0.027	−0.088	0.040	0.528
		Age group*	6.573	0.011	4.153	701.934	0.000	0.164	0.039	0.524
Have you ever talked to anyone about your goals, values, beliefs, or preferences in case you become seriously ill or unable to make your own decisions?		Age group*	7.928	0.005	2.065	701.675	0.039	0.086	0.042	0.554
Have you or your family member ever been referred to palliative care?		Cohort*	43.880	0.000	2.478	464.479	0.014	0.098	0.040	0.481
		Age group*	174.003	0.000	−5.500	614.252	0.000	−0.195	0.036	0.473
		Treatment status*	29.907	0.000	−2.452	610.341	0.015	−0.091	0.037	0.476
Topics discussed	Advance care planning	Treatment status*	8.517	0.004	−2.276	648.759	0.023	−0.102	0.045	0.582
	Assistance to complete an advance care directive	Gender*	6.218	0.013	2.883	700.484	0.004	0.124	0.043	0.571
		Age group*	54.503	0.000	−2.027	661.853	0.043	−0.087	0.043	0.572
		Treatment status*	13.660	0.000	−3.305	652.535	0.001	−0.143	0.043	0.564
		Region*	7.526	0.006	−2.084	407.172	0.038	−0.097	0.046	0.573
	End-of-life care and dying	Treatment status*	5.893	0.015	−2.757	660.051	0.006	−0.118	0.043	0.558
	Life expectancy (how long you are likely to live)	Age group	1.211	0.271	−2.148	700	0.032	−0.098	0.046	0.604
		Treatment status	1.849	0.174	−2.911	685	0.004	−0.134	0.046	0.599
	Pain management	Cohort	0.712	0.399	2.130	702	0.034	0.097	0.046	0.585
		Treatment status	3.781	0.052	−3.375	685	0.001	−0.149	0.044	0.577
	Potential future stopping of cancer treatment	Gender	0.223	0.637	2.409	702	0.016	0.107	0.045	0.590
		Age group*	13.256	0.000	−2.251	698.034	0.025	−0.100	0.045	0.591
	Quality of life and your values	Treatment status	1.578	0.209	−3.053	685	0.002	−0.138	0.045	0.590
	Whether or not to attempt cardiopulmonary resuscitation (CPR) or go to intensive care	Treatment status*	4.108	0.043	−2.115	656.366	0.035	−0.094	0.045	0.582

*Values reported reflect *t* values where equal variances are not assumed based on Levene's test for equality of variances

Table 4 Participants' preferences regarding timing of their first conversation about ACP and end-of-life care (*n* = 705)

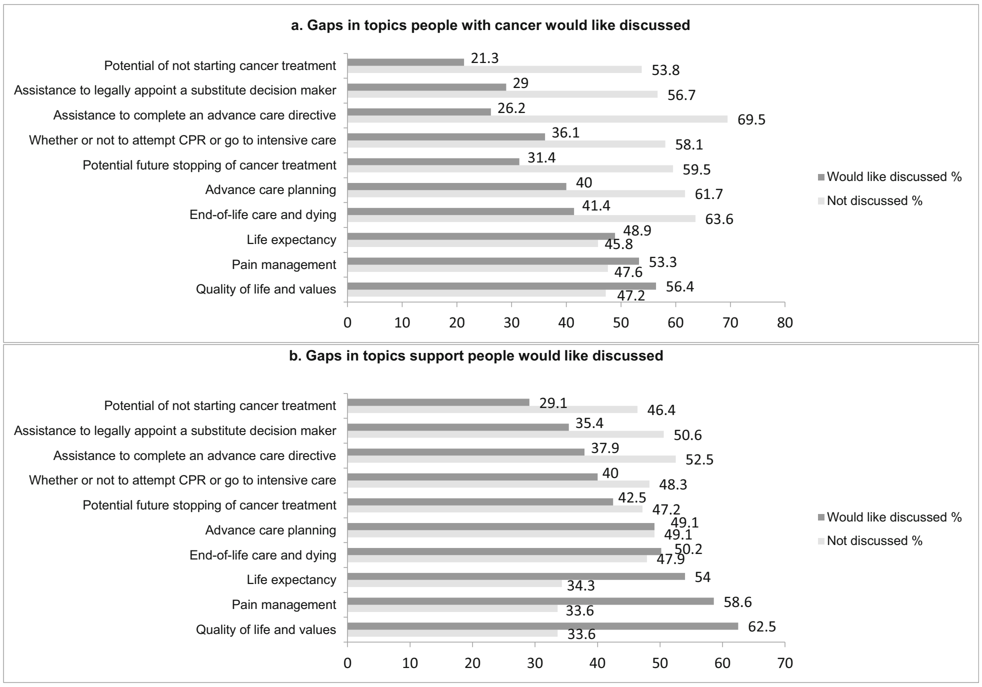
Timing preferred	Person with cancer (*n* = 440) *n* (%)	Support person (*n* = 265) *n* (%)	Total (*n* = 705) *n* (%)
At diagnosis	72 (16.4%)	69 (26.0%)	141 (20.0%)
When cancer becomes incurable	185 (42.0%)	85 (32.1%)	270 (38.3%)
When doctor decides to raise the matter	26 (5.9%)	35 (13.2%)	61 (8.7%)
When patient decides to raise the matter	140 (31.8%)	72 (27.2%)	212 (30.0%)
Would not want to discuss it at all	17 (3.9%)	4 (1.5%)	21 (3.0%)

preferences, and/or SDM for a time when there is a loss of capacity is relevant to all cancer patients and not just those requiring end-of-life care. Other research has also shown that ACP awareness may not indicate an adequate understanding of ACP's concepts and utility [22, 37]. Cancer patient loss of decision-making capacity can occur during cancer treatment, particularly during periods of delirium or surgery [7]. Patient engagement and information provision beyond awareness are required to achieve the potential benefits of ACP.

Most participants reported hearing about ACP from a health professional, family member, or friend, with the majority receiving this information from only one source. Cancer patients reported that ACP, assistance to complete an ACD, and understanding end-of-life care and dying were the most common topics not discussed with them. Support people reported that assistance to complete an ACD, including legally appointing a SDM, and whether or not to attempt CPR or go to intensive care were the most common topics not discussed. Yet approximately half of them reported wanting discussions regarding ACP and quality of life and values. Few wanted to wait until the doctor raised the matter, with more preferring to raise ACP themselves. These findings differ from past international studies showing that oncology patients usually prefer doctors to initiate ACP conversations [38–40]. These differences may imply societal changes regarding the willingness of people with cancer to initiate and participate in ACP conversations or differences in attitudes of Australian cancer patients and their support people compared with other areas of the world. Given this result, Australian health professionals have an important role to play in information provision and regularly offering the opportunity for ACP discussions as part of quality cancer care. International literature also suggests that ACP needs to be an ongoing conversation raised at various time points with people with cancer and their support people [22, 35].

ACP conversations are valuable in their own right with two-thirds of participants reporting having talked to someone about their goals, values, beliefs, and preferences for healthcare. Whilst half expressed having discussed this with

Fig. 1 Identification of gaps in topics discussed with people with cancer and support people (*n* = 441 people with cancer, *n* = 265 support people)



family/friends, only 4% reported having a conversation with their doctor. This finding is different from other studies, where 11% of participants in an Australian study [41] and 29% in international literature [40] reported discussions with their doctor. The reasons for this difference are unclear. Both cancer patients and support people reported gaps in the information provided by their doctors. Treating practitioners should be actively involved in ACP and offer key information like prognosis and treatment intent [42] and ensure that cancer patients' preferences align with the medical treatment they are receiving [12]. Including support people in conversations can also positively impact uptake and participation in ACP [6, 22, 41, 43].

Despite awareness of and engagement in conversations regarding ACP, few people complete ACP documentation with only a third of study participants reporting having documented their goals, values, beliefs, or preferences for medical treatment and a slightly higher proportion having appointed a SDM. These findings are consistent with other Australian national ACD prevalence studies that found an ACD prevalence of 27–30% for cancer patients [20, 21]. Interestingly, more support people, women, and people aged under 65 years reported having completed documentation appointing a SDM than men, people with cancer, and those aged 65 years and over. Research shows that informal caregivers are typically women and older adults [44, 45]. As such, this result may reflect a greater likelihood of these groups having experienced stress related to decision-making on someone else's behalf, and a wish to reduce that burden for others.

One-third of participants reported they would like assistance to complete an ACD and/or appoint an SDM. Significant differences were present between groups in terms of which topics had been discussed with them. In particular, significant differences were present for discussions of assistance to complete an ACD and the potential future stopping of cancer treatment. These results highlight a need for greater consistency in the type of information and assistance given to oncology patients and their support people regarding ACDs. Further exploration of the factors contributing to cohort differences related to ACP conversations with health professionals is also warranted.

Our findings have important implications for future oncological care. It is both recommended and essential that people with cancer have the opportunity to engage with ACP throughout their cancer journey [24, 35]. These findings are particularly important given the risk of loss of capacity at times during their illness and towards the end-of-life [7]. To achieve this, people with cancer need early access to information regarding ACP [37]. Health professionals play an important role in ACP, as evidenced by this study, people often access information from their doctors. However, health professionals often report they lack knowledge, and skills in ACP, discussion of prognosis, and end-of-life care [6, 35, 40]. Thus, incorporating ACP, end-of-life care, and communication skills education into health professional cancer training programmes is fundamental. In conjunction with this, these findings demonstrate a desire for assistance in completing ACD documentation, consistent with other Australian and international findings [37, 40, 41, 46]. Given that people with cancer often discuss their preferences with their support people, who may also be required to make decisions on behalf of their loved ones, there is need for information, support, and education on ACP and the role of support people.

In addition to supporting conversations, policy and practice should promote ACD completion, given that documentation increases the likelihood that preference concordant with care will occur [47]. One important area for consideration is for organisations to directly identify whose responsibility it is to initiate ACP discussions with oncology patients. Studies assessing prospective interventions that address ACP in an oncology setting show significant variability in terms of who conducts the ACP session [23]. Improvements in ACP delivery have implications across cancer services, systems, and policy and are likely to lead to improved end-of-life outcomes for people with cancer, their family, and health professionals [13, 14, 24, 48] and may have positive financial implications for the healthcare system [5, 24].

Study strengths include a large sample of participants with a cancer diagnosis and support persons for someone with cancer with representation from all Australian jurisdictions. The sample included people with the common types of cancer in Australia and approximately equal gender representation. However, similar to other studies, [22, 40, 41, 43], our cohort was mainly Caucasian and well-educated, limiting generalisability to other populations. Use of an opt-in panel may mean individuals who are open to engaging in ACP discussions were over-represented in the sample. Self-reporting may also have impacted results through misreporting due to lack of knowledge or inaccurate recall. Limitations were also present in the design of the survey tool and prevented further analysis of important areas of research such as cancer stage or reason for no longer receiving cancer treatment and topics discussed directly with health professionals. Future studies exploring these factors as well as studies including culturally and linguistically diverse populations may provide key information about the experiences of ACP in other cancer populations that can be translated into practice.

Conclusion

ACP aims to encourage people with cancer to plan for future healthcare and make their values and preferences for medical treatment known and/or appoint an SDM(s). This study demonstrates an alignment in awareness, experiences, and preferences of both the cancer patient and the support person of someone with cancer.. However, differences in experience and preferences related to ACP were identified for gender, age, treatment status, and region. Despite Australian legislation and policy supporting ACP and increasing community awareness, understanding appears to remain low in the cancer population. There is a lack of ACP discussion with health professionals despite a desire for more discussion. People with cancer tend to rely on conversations with family and friends rather than discussions with their care providers. Efforts to promote the uptake of ACP in cancer care should occur early, across multiple interactions with health professionals, include a broad range of topics, and involve both people with cancer and their support people. Healthcare professionals play an important role in helping cancer patients communicate and document their preferences for care to ensure that people receive care consistent with their preferences.

Authors' contributions Linda Nolte (senior author) contributed to the conceptualization of the study, acquisition of funding, and final approval of the manuscript. All authors contributed to study design. Data collection and analysis were performed by Helena Rodi, Marcus Sellars, and Ashley Macleod. Manuscript development and writing were led by Helena Rodi in consultation with Karen Detering and Linda Nolte. All authors commented on previous versions of the manuscript and approved the final manuscript.

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Data availability The corresponding author should be contacted directly for any queries related to the availability of data and material.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethics approval The study was approved by Austin Health Human Research Ethics Committee, Melbourne, Australia (reference number: HREC/57061/Austin-2019).

Consent to participate Participants were informed that consent was implied by completing the survey, which was voluntary and anonymous and allowed participants were able to withdraw from the survey at any time.

Code availability Not relevant to this study.

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