

Catherine M. Burns
Dorothy H. Broom
Wayne T. Smith
Keith Dear
Paul S. Craft

Fluctuating awareness of treatment goals among patients and their caregivers: a longitudinal study of a dynamic process

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C. M. Burns (✉)
School of Social Administration
and Social Work, Flinders University,
GPO Box 2100,
Adelaide 5001, South Australia
e-mail: Catherine.Burns@flinders.edu.au
Tel.: +61-8-82012206
Fax: +61-8-82013760

D. H. Broom
National Centre for Epidemiology
and Population Health,
Australian National University,
Canberra, ACT 0200, Australia
e-mail: Dorothy.Broom@anu.edu.au

W. T. Smith
Centre for Clinical Epidemiology and
Biostatistics, University of Newcastle,
Newcastle, NSW 2305, Australia
e-mail: Wayne.Smith@newcastle.edu.au

C. M. Burns · K. Dear
Medical School,
The Australian National University,
Frank Fenner Building 42,
Canberra, ACT 0200, Australia
e-mail: Keith.Dear@anu.edu.au

P. S. Craft
Medical Oncology Unit,
The Canberra Hospital,
GPO Box 11,
Woden, ACT 2606, Australia
e-mail: Paul.Craft@act.gov.au

Abstract Background: Because increasing numbers of people now survive for months or years with advanced cancer, communication between patients, service providers, and family caregivers often continues over long periods. Hence, understanding of the goals of medical treatment may develop and change as time elapses and disease progresses. This understanding is closely related to the “awareness of dying,” which has been studied in both qualitative and quantitative research. However, when both a patient and family caregiver are involved, the question of “awareness” becomes more complex. A recent longitudinal study reported on patient and caregiver knowledge of treatment goals, but no comparison of such knowledge using matched interview schedules and paired data analysis has been provided. This report examines patterns of awareness and factors associated with these patterns.

Materials and methods: One hundred sixty-three patients with incurable cancer and their nominated principal family caregivers (136) were recruited from The Canberra Hospital Oncology Services. Participants’ understanding of the treatment goals were measured by interview questions at weeks 1 and 12. **Results:** One-third of both patients and caregivers understood that the treatment goal was not curative; however, not all patient and caregiver pairs had the same

understanding. In 15% of pairs, both patient and caregiver believed that the goal of treatment was curative, while another 13% said that they did not know the aim of the treatment. Thirty-nine percent of pairs registered incongruent responses in which only one member of the pair understood that the treatment was not intended to cure the disease. Over time, a few respondents changed their perception of the treatment goals toward accurate clarification. Bivariate analysis using an awareness variable, constructed for the purpose, showed that in 6 months before death, at least one person in 89% of pairs understood that the treatment was noncurative. Time-to-death, gender, and place of residence were also important predictors of knowledge. **Conclusions:** Discrepancies between patients and their caregivers may complicate the delivery of effective care when patients are seriously ill. Misunderstanding or uncertainty about treatment goals will obstruct proper informed consent. Health professionals providing care for families dealing with advanced cancer must recognize that the discussion of treatment goals is a dynamic process, which may require them to extend their communication skills.

Keywords Knowledge of treatment goals · Advanced cancer · Family caregiver · Awareness of dying

Introduction

Advanced cancer care is now a subspecialty where patients may not be cured, but ongoing monitoring and intermittent drug therapy can enable disease control. This worldwide trend, accelerated by clinical innovations, has introduced a new language of “partial” or “durable remissions.” Patients now receive advanced cancer treatments in outpatient settings, they are now aware of their diagnosis and are encouraged to participate in their treatment decisions [1]. However, research is still sparse on the extent of patient knowledge of treatment goals, although such knowledge is vital to informed consent.

A growing literature is clarifying clinical practices in delivering prognostic information, patient understanding of prognostic information, and cultural differences in preferences and understanding. But attitudes toward disclosure of prognosis show a much greater variability than in the disclosure of diagnosis. Doctors worldwide acknowledge difficulties in discussing prognosis with patients, particularly in the transition from curative to noncurative treatment, and cultural differences as well as geographic differences are pronounced [2–8].

The ambulatory setting has returned family caregiving to the center of advanced cancer care. But the literature has still to unravel many hidden aspects of the caregiving role and how caregivers as “health producers” may define their tasks, organize themselves, and then act when confronting family illness [9]. Reports have demonstrated the relationship of patient’s physical and psychological health with that of the caregiver’s health which, in turn, impacts on unmet patient need [10–12]. A recent prospective study in the Netherlands also found that a peaceful death was helped by the promotion of family involvement in patient care [13]. The importance of professional home-care support was highlighted in a recent Israeli study that found that deaths occurred at home for 80.3% patients with access to support services but only for 20.5% of those without such support, underscoring the importance of the palliative home-care support team. Those who were professionally supported expressed greater satisfaction with the caring experience in spite of the heavier financial and emotional burden than the group who did not receive home-care support [14].

A national Swedish study recently found that the length of time a wife was aware of her husband’s terminal cancer varied considerably, influenced by the information and psychological support she received. Those women who knew for only a short time of the impending death of their husband showed greater morbidity than those who knew for a longer period [15]. Australian research confirms that less than half of the patients with advanced cancer and their caregivers correctly understood the aims of the patients’ treatment [16, 17]. Caregiver gender differences were marked, with women more likely than men to understand

that their family member’s treatment was palliative not curative [17].

In Australia, findings from a qualitative study report that it was not always easy to meet the informational needs of both patients and caregivers, but stressed that consistency, openness, and provision of specific information are required for care of the patient. Findings emphasized the benefit of a trusting relationship with at least one health professional to encourage discussion and clarify the patient and caregivers’ understanding. Investigators noted that there was value in having separate discussions with the patient and the caregiver [18, 19].

Glaser and Strauss’ (1967) theory of awareness among dying patients, their families, and medical personnel continues to form our understanding [20]. In the UK, a large retrospective investigation in 1991 replicated a 1969 study of family caregivers’ perception of peoples’ awareness of dying [21]. “Closed awareness” had been the common pattern in 1969, where knowledge of dying was kept hidden from the dying person by both family members and the health team. By 1991 however, “open awareness” of dying between patient, family, and health professionals was common among patients with cancer and their relatives, although it is less for other diseases. In recent years, theorists have suggested that open awareness could be more finely graded, and they have proposed three steps that now occur: a time of “suspended” awareness, then a phase of “uncertain” awareness, and finally a testing of reality with an “active” open awareness [22].

Similarly, Mamo [23] drew attention to the emotional content of terminal illness suggesting this emotional work performed by dying patients and their families is entwined with the cognitive processing of knowledge. Clinical qualitative research identified three specific strategies that family members use to manage their emotional struggles in this period: hoping for a cure, pretending to the patient that things were better than they were, and then preparing for death, for example, by notifying relatives of the seriousness of the situation [24].

A UK clinical report, measuring patient perception over 8 weeks, found that the proportion of patients who were certain they were dying remained remarkably level at between 38 and 48%; about 50% thought it was possible, while a few were noncommittal. However, more relatives than patients were aware throughout the last months of life [25]. Hinton [25] noted individual differences in awareness in progress over time—where awareness remained stable, decreased, or for some, fluctuated—rising, falling, and rising again over some weeks.

Thus, the literature has begun to clarify that awareness of dying for the patient and their families is a dynamic process. But no paired analysis of responses from a survey of both parties has yet to be undertaken, so there has been no opportunity to investigate how congruence or discrepancies between members of pairs might contribute to changes in awareness.

Research on the knowledge of treatment goals in advanced cancer remains slender, with no study other than the Canberra survey examining caregivers' understanding. No research has yet identified whether changing awareness is also possible before the terminal illness stage, when patients are living with their advanced cancer. This period may now last for some years.

Therefore, aims of this paper are:

1. To compare advanced cancer patients with their caregivers with regard to their knowledge of treatment goals.
2. To consider how this knowledge may change over time.
3. To examine response patterns to determine if an "awareness continuum" was identifiable.
4. To investigate associations between "awareness" and a comprehensive range of sociodemographic variables for both respondents, together with patient clinical characteristics and caring characteristics of caregivers.

Materials and methods

Study population

The Canberra Cancer Quality of Life Project, an observational study, was designed to document the experience of patients with advanced cancer and their caregivers. The study randomly selected 237 patients over 18 years of age from The Canberra Hospital. All patients had a diagnosis of incurable malignant disease with symptoms attributable to their disease or anticipated as likely to occur within a 6-month observation period. One hundred eighty-three agreed to participate (77%); however, one withdrew and one died, leaving 181 patients at enrolment in 1996. Caregivers were described as "a carer or support person, e.g., a spouse/partner, other relative or friend who gives you physical and/or emotional support." Caregivers were nominated by 167 (92%) of whom 136 agreed to participate. Patients were followed until March 2003 to record deaths, at which time seven only remained alive. All participants gave written informed consent. The Australian Capital Territory Health and Community Care Ethics Committee gave their approval.

The survey instrument for this report was completed by 163 (90.1%) respondents at entry. The interview was repeated 12 weeks after entry for 122 of these patients. Of the 41 not interviewed at 12 weeks, 22 had died, 5 were close to death, and 14 were no longer available. There were 136 caregivers interviewed at week 1, and 92 were interviewed at week 12. Caregiver loss to follow-up, 42 in total, was due to the deaths of 18 patients. Among the remaining 24, most were Australian, living in the nonmetropolitan area, were the child of the parent-patient, and more likely to be aged under 50. They included five, where patients were seriously ill.

Measures

Study details have been reported elsewhere [16, 17, 26]. In brief, patients and their caregivers completed interviewer-supervised questionnaires at baseline and again 12 weeks later. These questionnaires included sociodemographic details of patients and family caregivers, clinical characteristics of patients, and information about caregiving including secondary supports. Nursing and medical staff obtained clinical data at interview and through case-notes reviews. Death details were retrieved both from case notes and the National Death Index at the Australian Institute of Health and Welfare (Canberra, Australian Capital Territory).

In this report, we sought to determine knowledge of treatment intent, whether respondents understood that the illness was life-threatening, and what were the specific goals of the treatment.

In particular, we asked whether the goals of treatment were to monitor illness, to improve quality of life, to control illness, or to cure the disease. Paired responses were used to evaluate levels of congruence between a patient and their caregiver. A variable, namely, "awareness of treatment goals," was created to evaluate the overall perception of treatment intent. The criteria was as follows:

1. *Full Awareness* Both respondents understand that the treatment was not intended to cure.
2. *Partial awareness* One member of the pair correctly understood that the treatment was not curative.
3. *Non-awareness*:
 - (a) *Misperception* Both members of a pair believed that the treatment would cure the disease.
 - (b) *Confused* Both members indicated that they did not know whether treatment aimed to cure or not, or one member of the pair indicated that they did not know, while the other said that they believed treatment would cure.

Statistical analysis

These were undertaken using SPSS 11.5 software [27]. The statistical significance of associations was assessed using the Pearson chi-square and McNemar's test for nominal variables and the Kruskal-Wallis test for ordinal variables.

Findings

Patient and caregiver characteristics

Detailed reports of the characteristics from the study have been published previously [16, 17, 26] and are summarized in Table 1. In brief, key characteristics reported that one-third of the patients enrolled were over 70, and another third were between 60 and 69 years of age. The age

Table 1 Sociodemographic and clinical characteristics of patients who responded to the survey

Characteristics	Percentage (N=163)
Sex	
Female	86 (52.8)
Male	77 (47.2)
Age	
<40	6 (3.7)
40–49	18 (11.0)
50–59	36 (22.0)
60–69	49 (30.1)
>70	54 (33.1)
Marital status	
Never married	10 (6.1)
Married/cohabiting	116 (71.2)
Widowed	20 (12.3)
Divorced	14 (8.6)
Separated	3 (2.3)
Place of birth	
Australia	104 (64.2)
UK/New Zealand/Canada/USA	30 (18.5)
Europe	17 (10.5)
Asia	9 (5.6)
Other	2 (1.2)
Residence	
Metropolitan	136 (83.4)
Nonmetropolitan	27 (16.6)
Performance status	
Able to carry out normal activities without restriction	2 (1.2)
Ambulatory—capable of light work, restricted with strenuous activity	68 (42.9)
Ambulatory—capable of self-care, but unable to work	57 (34.2)
Resting in bed/chair more than half of the waking hours, only capable of limited self-care	25 (19.3)
Totally confined to bed/chair, not capable of any self-care	9 (2.5)
Diagnostic groups	
Breast	40 (24.3)
Lung	31 (19.0)
Gastrointestinal	22 (13.5)
Lymphoma/myeloma/leukemia	18 (11.0)
Prostate	13 (8.0)
Ovarian	10 (6.1)
Other	29 (17.8)
Sites of disease	
Persistent or recurrent local/regional disease	51 (31.3)
Metastases	112 (68.7)
Psychosocial classification	
Crisis, 90 days from diagnosis	40 (25.6)

Table 1 (continued)

Characteristics	Percentage (N=163)
Chronic, >90 from diagnosis and <60 days from death	106 (67.9)
Terminal, 60 days from death	10 (6.4)
Specific therapy within 1 month of enrolment	
Supportive care only	27 (16.6)
Chemotherapy and radiotherapy	20 (12.3)
Radiotherapy only	48 (29.4)
Chemotherapy only	46 (28.2)
Hormonal manipulation	22 (13.5)
Time to death	
>6 months	53 (34.2)
<6 months	102 (65.8)

distribution for caregivers was younger, with half aged between 50 and 70. While the proportions of men and women among patients were roughly equal, more of the caregivers were women (64%). In keeping with the patient age profile, the rate of widowhood was high—12.9%. Another 70.6% were married or living in a de facto relationship and proportionally more caregivers than patients were currently married (86%). Two-thirds of the respondents were Australian-born, with others from UK, Europe, and Asia. One-fifth (19.8%) of the patients had tertiary qualifications, and another 36.7% had completed year 12 or equivalent. The Cancer Services in The Canberra Hospital also served the rural area, and 17% resided in nonmetropolitan areas (Table 1).

The clinical characteristics of the patients were fairly similar to many oncology outpatient services (Table 2). All patients had advanced disease: 29.8% had persistent or recurrent/local or regional disease, while 70% had metastases. Numbers were almost evenly distributed for source of enrollment between Medical and Radiotherapy Oncology, with a small number (11.6%) being enrolled as inpatients. Treatment therapy for the majority was radiotherapy and chemotherapy in equal proportions. A few patients (5.5%) received either combined chemotherapy and radiotherapy or hormonal manipulation (13.3%). The remaining patients were provided with supportive care only (16.6%).

At enrollment, a quarter of the patients (24.5%) were still employed. Using the course of illness indices [16, 17], we found that a number of the patients were ambulatory: 40.3% capable of light work and 34.8% were unable to work but still capable of self-care. Poor functional status (ECOG 3 and 4) was identified for one-fifth either resting (17.1%) or confined to bed/chair (5.5%; see Table 1). Baseline measurement indicated one-third (32.5%) of the patients were within 6 months of death, while another third (36.8%) was more than 2 years from death, including a proportion who survived for 3–5 years. The psychosocial

Table 2 Sociodemographic characteristics of caregivers who completed the week 1 survey, by relationship to patient

Characteristics	All caregivers, N=136 (%)	Caregiver was spouse ^{a,b} , N=97 (%)	Caregiver not spouse, N=36 (%)	Significance (Chi-squared or Mann–Whitney <i>U</i> test)
Sex				$\chi^2=13.4$, $df=1$, $p<0.001$
Female	88 (65.4)	53 (54.6)	32 (88.9)	
Male	48 (34.6)	44 (45.4)	4 (11.1)	
Age				$\chi^2=28.1$, $df=4$, $p<0.001$
<40	19 (13.2)	5 (5.2)	13 (36.1)	
40–49	23 (17.1)	13 (13.4)	9 (25.0)	
50–59	36 (27.1)	29 (29.9)	7 (19.4)	
60–69	32 (24.0)	28 (28.9)	4 (11.1)	
70+	25 (18.6)	22 (27.7)	3 (8.3)	
Marital status ^b				$\chi^2=40.4$, $df=3$, $p<0.001$
Never married	8 (4.7)	0 (0.0)	8 (22.2)	
Married/cohabiting	116 (88.3)	93 (97.9)	20 (55.6)	
Widowed	5 (3.1)	1 (1.1)	4 (11.1)	
Divorced	5 (3.9)	1 (1.1)	4 (11.1)	
Place of birth				$\chi^2=6.2$, $df=5$, $p=0.292$
Australia	97 (71.3)	65 (67.0)	30 (85.7)	
New Zealand/USA/UK/Canada	19 (14.0)	17 (17.5)	1 (2.9)	
Other Europe	12 (8.8)	9 (9.3)	3 (8.6)	
Asia	5 (3.7)	4 (4.1)	1 (2.9)	
Other/unknown	3 (2.1)	2 (2.0)	0 (0.0)	
Place of residence				$\chi^2=0.6$, $df=1$, $p=0.507$
Metropolitan	112 (84.3)	80 (85.1)	29 (80.6)	
Nonmetropolitan	21 (15.7)	14 (14.9)	7 (19.4)	
Relationship to patient ^b				$\chi^2=111.6$, $df=2$, $p<0.001$
Spouse	96 (70.6)	94 (96.9)	0 (0.0)	
Child	26 (16.9)	1 (1.0)	25 (69.4)	
Other/unknown	14 (12.5)	2 (2.1)	11 (30.6)	
Living in same household as patient				$\chi^2=74.1$, $df=1$, $p<0.001$
Yes	110 (80.2)	96 (99.0)	12 (33.3)	
No	26 (19.8)	1 (1.0)	24 (66.7)	
Secondary supports for caregiver ^c				
No one	23 (16.2)	19 (19.6)	4 (11.1)	$\chi^2=1.3$, $df=1$, $p=0.310$
Daughter/s	70 (48.5)	58 (59.8)	12 (33.3)	$\chi^2=7.4$, $df=1$, $p=0.011$
Son/s	56 (39.7)	48 (49.5)	7 (19.4)	$\chi^2=9.8$, $df=1$, $p=0.003$
Sister/s	22 (19.8)	18 (18.6)	4 (11.1)	$\chi^2=1.0$, $df=1$, $p=0.432$
Brother/s	18 (12.5)	9 (9.3)	9 (25.0)	$\chi^2=5.5$, $df=1$, $p=0.025$
Mother	12 (8.8)	8 (8.2)	2 (5.6)	$\chi^2=0.3$, $df=1$, $p=0.728$
Father	7 (5.1)	3 (3.1)	3 (8.3)	$\chi^2=1.7$, $df=1$, $p=0.343$
Other male relative	22 (14.7)	8 (8.2)	13 (36.1)	$\chi^2=15.3$, $df=1$, $p<0.001$
Other female relative	16 (11.0)	8 (8.2)	8 (22.2)	$\chi^2=4.8$, $df=1$, $p=0.037$
Visit doctor together				$Z=2.7$, $p=0.006$
Yes, often	72 (52.9)	57 (58.8)	13 (36.1)	
Yes, a bit	42 (30.9)	29 (29.9)	12 (33.6)	
No	22 (16.2)	11 (11.3)	11 (30.6)	
Employment status				$Z=-0.2$, $p=0.832$
Retired	40 (29.9)	31 (32.6)	9 (25.0)	
Stopped work to care	39 (29.1)	24 (25.3)	13 (36.1)	
Working	55 (41.0)	40 (42.1)	14 (38.9)	
Stopped work				$Z=-1.1$, $p=0.279$

Table 2 (continued)

Characteristics	All caregivers, N=136 (%)	Caregiver was spouse ^{a,b} , N=97 (%)	Caregiver not spouse, N=36 (%)	Significance (Chi-squared or Mann–Whitney <i>U</i> test)
Full time	11 (8.7)	7 (7.5)	4 (11.1)	
Part-time	4 (3.2)	2 (2.2)	2 (5.6)	
Special (paid) leave	18 (14.3)	14 (15.1)	4 (11.1)	
Leave without pay	6 (4.0)	1 (1.1)	3 (8.3)	
Not applicable	93 (69.8)	69 (74.2)	23 (63.9)	
Average weekly assistance over past month				Z=-2.4, p=0.016
0–10 h	24 (17.4)	16 (17.8)	8 (24.2)	
11–30 h	31 (24.0)	18 (20.0)	12 (36.3)	
31–100 h	40 (33.1)	29 (32.2)	10 (30.3)	
>100 h	31 (25.6)	27 (30.0)	3 (9.1)	

^a“Spouse” includes partner or cohabiting.

^bThree caregivers, who were identified by the patient as their spouse, did not record this as their relationship.

^cMore than one response was allowed.

classification identified that at the beginning of the study, one-fifth (19.4%) was in the “crisis phase” (Table 1) [16, 17].

The relationships between caregiver and patients were diverse: 71.5% of caregivers were married to the patient, 17% were daughters, with another 8% either relatives or friends, and 3% were parents (Table 2). One-fifth of patients lived alone, but a third of nonspouse caregivers lived in the same household as the patient. A quarter of the caregivers had taken leave or quit work as a result of their caregiving role. They were supplying substantial amounts of care: more than 80% had given an average of over 10 h weekly in the past month, the majority invested more than 30 h weekly, and 25% undertook over 100 h weekly. The extent of caregiving was determined by the relationship, with spouses investing the highest levels of care (Table 2). Most caregivers (87%) attended patient consultations and 62% did so regularly.

Comparison of patient/caregiver knowledge

Comparison of patients and their caregivers in their understanding of the goals of treatment was undertaken using 117/129 pairs at week 1 and 84/90 pairs at week 12. Variations in number of pairs at each time result from missing data on certain items. A large majority of pairs (75%) concurred at baseline that the illness was life-threatening, while a small number (4.1%) of pairs had both of the members agreeing that it was not. Just over a fifth of the pairs displayed incongruence in their belief that the illness was life-threatening (Table 3).

Discrepant perceptions were also common in responses to questions about the aims of the treatment: almost half (43%) offered differing perceptions as to whether the therapy was monitoring the illness; over a quarter (27%) recorded differing views as to whether the goal was to improve quality of life and one fifth of pairs (19%) did not agree the treatment goal was to control illness (Table 3). Very high proportions of pairs (39%) reported incongruent responses to whether the treatment aim was to cure or not.

Table 3 Level of congruence in paired analysis of perception of treatment at weeks 1 and 12

Aim of treatment	Congruent responses								Incongruent responses (%)	
	No. of pairs		Yes (%)		No (%)		Don't Know (%)		Week 1	Week 12
	Week 1	Week 12	Week 1	Week 12	Week 1	Week 12	Week 1	Week 12		
Monitor illness	117	85	41.0	50.6	7.7	4.7	7.7	8.2	42.7	36.5
Improve Quality of Life	121	86	65.3	70.9	2.5	0	4.9	7.0	27.3	22.1
Control Illness	127	90	75.6	76.6	3.1	4.4	2.4	3.3	18.9	15.4
Cure Illness	117	84	15.4	14.3	33.3	32.1	12.8	13.1	38.5	40.4
Aware Illness was Life Threatening	129	84	75.0	80.9	4.1	4.8	n/a		20.8	14.3

One-third of the patients and their caregivers, however, understood treatment was not curative in intent, while a few pairs (15%) both believed treatment would cure, and a smaller number (13%) both reported they did not know the aim of treatment (Table 3).

Awareness of treatment goal

Using the awareness variable constructed to analyze responses to the question whether treatment aim was “to cure,” one-third (33.3%) of the 117 patient and caregiver pairs were aware that the treatment goal was noncurative (full awareness; Table 4). A second category comprised almost another third (29%) who were “partially aware.” Among these 34 pairs, the distribution comprised 23 pairs, where the *patient* correctly understood the treatment goal, while 15 of their caregivers said they did not know, and eight caregivers thought that the treatment was curative. Where it was *the caregivers* who correctly understood that the treatment was noncurative (11 pairs), six of the patient family members did not know, and five thought that the treatment was going to cure them.

Over a third (37.6%) of the respondent pairs were categorized as non-aware, that is, neither patient nor caregiver appreciated the real purpose of the treatment. However, only 15.4% of the whole sample (18 pairs) completely misconstrued treatment goals, believing that the goal was to cure. Other respondents were confused (26 pairs in total). Within this group were 15 pairs whose members both said that they did not know what was happening, while of the remaining 11 pairs, seven patients and four caregivers thought that treatment was curative.

Table 4 Response to treatment aim “to cure” at baseline (patient/caregiver pairs, N=117)

Caregiver	Patient				Total (%)			
	No (%)	Don't know (%)	Yes (%)	Total (%)				
No	39	33.3	6 ^a	5.1	5 ^a	4.3	30	25.6
Don't know	15 ^a	13.6	15 ^b	12.8	7 ^b	5.9	50	42.7
Yes	8 ^a	6.8	4 ^b	3.4	18 ^c	15.4	37	31.6
Total	30	25.6	62	53.0	25	21.4	117	100.0

Bold indicates that both members of the pairs understood that the treatment was not curative.

^aOne partner has a correct appraisal of treatment intent, answering that the treatment intent was not to cure.

^bBoth indicate that they do not know the purpose of the treatment, or one says they do not know and the other party believes that the treatment intent was to cure.

^cBoth partners answered that the treatment intent was curative.

Bivariate analysis

Bivariate analysis confirmed the importance of the interplay of gender and patient/caregiver relationship in predicting understanding of both patients and the caregivers ($p < 0.03$; see Table 5). Caregiver–patient pairs with a male patient were much less likely to misperceive the goals of treatment than were pairs with a female patient ($p < 0.03$). Furthermore, more than a quarter of the pairs with a male caregiver misperceived treatment goals, whereas twice as many pairs with a female caregiver registered confusion ($p < 0.03$).

Living outside the metropolitan area was associated with different awareness levels: 50% of nonmetropolitan patients ($p < 0.02$) were confused compared to 17% of metropolitan patients. A similar response was reported by caregivers living in nonmetropolitan areas, where 47% said they did not know whether the treatment was curative in intent or not, compared with 17% of caregivers in the metropolitan areas ($p < 0.03$). Significantly higher proportions of patients classified as “confused” were also much more likely to have local or regional disease rather than metastatic disease ($p < 0.03$).

Clarity of understanding improved in the last 6 months of life. As death approached, none of the pairs continued to believe that the treatment goal was to cure: only 11% were confused, 38% reported partial awareness, and half of all pairs were fully aware. There was a linear development toward clarity in awareness. The number of those who were fully aware more than 2 years from death was only 18%; when death was between 1 and 2 years away, a quarter of pairs understood, with increasing numbers (45%) recording accurate appraisal at 6–12 months from death. In the last 6 months of life, at least one person in 89% of patient/caregiver pairs was aware that treatment was noncurative (Table 5).

Finally, among the pairs who were “non-aware” and were classified as confused, high numbers of caregivers stilled worked, in contrast to those “fully aware” pairs, where a high proportion of caregivers had stopped work in order to provide care ($p < 0.002$; Table 5).

Table 5 Distribution of levels of awareness at baseline (n=117 pairs)

Full awareness	Partial awareness ^a	Non-awareness	
		Confused ^b	Misperception ^c
39	33.3%	34	29.0%
26	22.2%	18	15.4%

^aOne partner has a correct appraisal of the treatment intent, answering that the treatment was not curative.

^bBoth indicate that they do not know the purpose of the treatment, or one says they do not know and the other party believes that the treatment intent was to cure.

^cBoth partners answered that the treatment intent was curative.

Changes over time

Cross-tabulations at week 12 indicated that overall levels of awareness remained similar to baseline—one-third were fully aware, 28.6% recorded partial awareness, 14.3% continued to have misperceptions, and 25% were confused (Table 6). Bivariate analysis at week 12, however, found few statistically significant associations; only site of disease continued to be predictive ($p < 0.03$; Tables 7 and 8).

Using the 77 pairs available for a cross-tabulation of weeks 1 and 12, we found that only one pair who was fully aware at baseline moved to incorrect perception. The improved awareness of individual respondents led to a reclassification of some pairs into the partial awareness category at week 12. But ten respondent pairs remained confused at week 12, and seven pairs continued to believe treatment was curative.

Discussion

To our knowledge, no previous research has been undertaken that compared knowledge of treatment intent among patients and their caregivers. Our findings are novel and must therefore be seen as exploratory. The discrepancies in perception were pronounced in many responses to the goals of treatment, and strikingly so with regard to perceptions regarding noncurative intent. These global results suggest similar findings to those of qualitative researchers, indicating oncologists may still be engaging with their patients or family caregivers, but not patients and caregivers together [9, 10]. Recent research acknowledges the distinct needs of caregivers and patients in aged and end-of-life care [18, 28].

Our most important finding may well be the discovery that in the last 6 months of life, at least one member in 89% of pairs became aware that treatment was noncurative. It suggests that the Canberra healthcare team may have been responding to changing awareness and need, hopefully, in harmony with the readiness of the patient and their family. Further research exploring this dynamic could be insightful

Table 6 Bivariate analysis of paired levels of awareness at week 1

Characteristics	Patient/caregiver level of awareness pair ($n=117$)				Significance
	Aware	Partially aware	Non-aware Confused	Misperception	
Sociodemographic characteristics of patient					
Sex					0.03
Male	35.1	36.8	22.8	5.3	
Female	31.7	21.7	21.7	25.0	
Residence					0.02
Metro	35.4	31.3	17.2	16.2	
Non-metro	22.2	16.7	50.0	11.1	
Clinical characteristics					
Site of disease					0.03
Local/regional only	28.6	37.1	31.4	2.9	
Metastatic	35.4	25.6	8.3	20.7	
Time to death					0.003
<6 months	51.4	37.8	10.8	0.0	
0.5–<1 year	45.0	10.0	35.0	10.0	
1–<2 years	25.0	29.2	29.2	16.7	
>2 years	18.2	31.8	18.2	31.8	
Sociodemographic characteristics of the caregiver					
Sex					0.03
Male	36.6	24.4	12.2	26.8	
Female	31.6	31.6	27.6	9.2	
Residents					0.03
Metro	35.4	31.3	16.7	16.7	
Non-metro	21.1	21.1	47.4	10.5	
Occupation					0.002
Working	19.1	34.0	31.9	14.9	
Retired/unemployed	20.6	38.2	20.6	20.6	
Stopped work to care	61.8	14.7	11.8	11.8	

* $p < 0.05$ (Pearson chi-square)

The following variables were not significant: Patient age, marital status, place of birth, education levels, disease type, type of therapy, source of selection, ECOG (0–*S), psychosocial classification, Caregiver marital status, age, place of birth, relationship to patient

Table 7 Response to treatment aim “to cure” at week 12 (patient/caregiver pairs, $N=84$)

Caregiver	Patient				Total (%)			
	No (%)	Don't know (%)	Yes (%)	Total (%)				
No	27 32.1	6 ^a 7.1	6 ^a 7.1	22	26.2			
Don't know	8 ^a 9.5	11 ^b 13.1	4 ^b 4.8	39	46.4			
Yes	4 ^a 4.8	6 ^b 7.1	12 ^c 14.3	23	27.4			
Total	22	26.2	39	46.4	23	27.4	84	100.0

Bold indicates that both pairs understood that the treatment was not curative.

^aOne partner has a correct appraisal of the treatment intent, answering that the treatment was not to cure.

^bBoth indicate that they do not know the purpose of the treatment intent, or one says they do not know and the other party believes that the aim of the treatment was to cure.

^cBoth partners answered that treatment intent was curative.

for the evolving theory and practice of end-of-life care, which is highlighting the importance of the art of conversation as central to effective medical practice [29]. Current views emphasize that encounters take place over time and involve the patient, the family, and the medical team [11]. The potential value of an ongoing relationship is suggested by our finding that time to death is associated with increasing clarity of understanding, which may also grant the opportunity to discuss religious and spiritual issues as well as medical and health matters [30].

Timmermans [21], Mamo [22], and Valdimarsdottir et al. [15] all found that the process of developing an awareness of dying is a gradual one for family caregivers. It is characterized by uncertainty and anguish. In our time-from-death analysis, we found those caregivers who had ceased full-time employment had a relatively accurate understanding of the treatment aims. Whether knowledge led to withdrawal from the workforce or whether with-

Table 8 Distribution of levels of awareness at week 12 ($n=84$ pairs)

Awareness	Partial awareness ^a	Non-awareness	
		Confused ^b	Misperception ^c
27 32.1%	24	28.6%	21 25.0% 12 14.3%

Bold indicate that both pairs understood that the treatment intent was not to cure.

^aOne partner has a correct appraisal of the treatment intent, answering that the treatment intent was not to cure.

^bBoth indicate that they do not know the purpose of the treatment intent, or one says they do not know and the other party believes that the aim of the treatment was to cure.

^cBoth partners answered that the treatment intent was curative.

drawal facilitates acquisition of knowledge still remains to be studied. This pattern may be due to gradual clarification with changing disease stage, or greater opportunity to discuss illness with the patient and health care providers, or the opportunity to create with the patient and for themselves, a more emotionally supportive environment.

The reasons why people indicate that they did not know the intent of treatment warrants further investigation. We lacked the data to shed light on this group, either singly or as pairs. Describing this subpopulation in more detail could assist all healthcare providers to understand how they may inadvertently contribute to such confusion. Italian research has confirmed that health system factors reinforce differing approaches to communication, with patients in urban areas much more likely to have a full understanding of their medical condition and to discuss treatment goals openly with their physicians [31]. Research in a geographically large Australian state (Queensland) has identified major life disruptions to family and employment and substantial social isolation. Whether these factors contribute to patient confusion about treatment goals is a matter for further investigation [32].

If samples of sufficient size are drawn, epidemiological frameworks of the kind used in this study could identify more precisely the nature of patient experiences and their understanding of services and information being provided to them and their family. Does a lack of knowledge matter? Seale's large UK study found patients who were aware they were dying were able to stay at home, obtain better hospice and palliative care, and to have their families with them. In contrast, those who were not aware of the seriousness of their condition were more likely to have a rushed emergency admission and to die in a hospital [14]. An equally importantly recent Swedish report confirmed that women who had only a short awareness of their husband's impending death from cancer suffered greater long-term anxiety in widowhood [15].

In summary, these findings confirm a clinical picture already well-recognized, namely, that perception of treatment goals varies among patients and their family caregivers over time. For clinicians, discrepancies between patients and their caregivers may complicate the delivery of effective care and achievement of a “good death.” Recognition of the dynamic nature of the understanding of treatment goals may require physicians to extend their communication skills. We also suggest that this awareness is likely to be influenced by the culture of communication at the larger social and organization level and reflected within the local hospital and community care. The interplay between these social and individual forces is still poorly understood.

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