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Using a Delphi process to determine optimal care for patients with pancreatic cancer

Elizabeth A. Burmeister, Susan J. Jordan, Dianne L. O'Connell, Vanessa L. Beesley, David Goldstein, Helen M. Gooden, Monika Janda, Neil D. Merrett, David Wyld, Rachel E. Neale for The Pancreatic Cancer Clinical Working Group.

Abstract

Aim

Overall 5-year survival for pancreatic cancer is ~5%. Optimising the care that pancreatic cancer patients receive may be one way of improving outcomes. The objective of this study was to establish components of care which Australian health professionals believe important to optimally manage patients with pancreatic cancer.

Methods

Using a Delphi process, a multi-disciplinary panel of 250 health professionals were invited to provide a list of factors they considered important for optimal care of pancreatic cancer patients. They were then asked to score and then rescore (from one (no importance/disagree) to 10 (very important/agree) the factors. The mean and coefficient of variation scores were calculated and categorised into three levels of importance.

Results

Overall 63 (66% of those sent the final questionnaire; 25% of those initially invited) health professionals from 9 disciplines completed the final scoring of 55 statements/factors encompassing themes of presentation/staging, surgery and biliary obstruction, multi-disciplinary team details and oncology. Mean scores ranged from 3.7 to 9.7 with the highest related to communication and patient assessment. There was substantial intra- and inter- disciplinary variation in views about MDT membership and roles.

Conclusion

Overall the opinions of Australian health professionals reflect international guideline recommended care; however they identified a number of additional factors focusing on where patients should be treated, the importance of clear communication and the need for multi-disciplinary care which were not included in current clinical practice guidelines. Differences in priorities between specialty groups were also identified.

Introduction

Pancreatic cancer is the 10th most commonly diagnosed cancer in more developed regions of the world. In Australia it is the 6th most common cancer diagnosis and the 4th leading cause of cancer related death.[1] People diagnosed with pancreatic cancer have the poorest prognosis of any cancer. One-year survival is currently 15% and five-year all-stage survival for pancreatic cancer in Australia is 5.2%, which mirrors other western countries.[2, 3] Current projections suggest that it will be the second leading cause of cancer death within 10 years as survival from other cancers improves.[4, 5]

Provision of optimal care increases the likelihood of desired health outcomes.[6, 7] To facilitate this clinical practice guidelines/recommendations for pancreatic cancer have been published in Europe[8-11] and the USA.[12] However, the extent to which health professionals in the field agree with the guidelines, and if they consider all elements of the guidelines equally important is not known. In addition, guidelines may not cover some clinical situations or aspects of care that health professionals believe to be necessary for optimal management.[13] Assessing the elements of care

that specialist clinicians consider to be important for patients with pancreatic cancer and assessing whether these elements are evidence-based could assist in the modification of guidelines and/or identify areas where system changes or clinician education could help to improve patient outcomes.

One way of harnessing the opinions of a group of specialists is to use a Delphi process. This method has been used to facilitate clinical consensus in a variety of medical situations.[14-16] It begins with open-ended questions soliciting information from a panel of experts in the field.[17] This is followed by ranking or scoring of the derived statements by the panel according to set criteria. The combined resultant scores/rankings are fed back to the panel members who are then invited to re-score the statements. The process is conducted anonymously, preventing domination of individuals and iterations of the scoring and feedback process repeated until consensus is reached or negligible change in scores is noted.

The aim of this study was to use a Delphi process to establish components of care which Australian health professionals believe are important to optimally manage patients diagnosed with pancreatic cancer.

Methods

The Delphi process

We used the literature, personal contacts and professional groups, including the Australian Pancreatic Cancer Genome Initiative [18] and Cancer Council Australia, to identify health professionals involved in the care of pancreatic cancer patients from across Australia. We emailed these clinicians inviting them to participate and also asked them to nominate other clinicians who may be interested in participating. The panel consisted of surgeons, medical oncologists, radiation oncologists, gastroenterologists, palliative care specialists, nurses, allied health professionals, interventional radiologists and general practitioners. These experts were initially asked (online) to "...list all/any factors you consider important in the care of patients with suspected or confirmed pancreatic cancer." They were also asked about their specialty and years in practice.

The responses to the open-ended question were used to develop the quantitative questionnaire. Each response was grouped with those of similar themes and we eliminated duplicate statements. This process was done independently by two authors (EB and RN) and a structured list of statements was developed. Where possible, statements were used as written by participants. Some statements with similar inferences required merging to avoid duplication; these were discussed within the study team to avoid corrupting their original meanings.

Via email, we invited panel members to complete the quantitative questionnaire. They were asked to rate the importance of, or their level of agreement with, each statement on a scale of one (no importance/disagree) to 10 (very important/agree). Panel members could record 'no opinion' for statements they felt were beyond their scope of expertise. We provided the mean and median scores for each statement from the initial questionnaire to those who had responded to either the open-ended question or the first quantitative questionnaire and asked them to re-score the statements in light of this information.

Analyses

The mean and coefficient of variation (CV) were calculated for each statement using the scores for all participants and also stratified according to specialty. The CV is the ratio of the standard deviation (SD) to the mean and gives the relative magnitude of the SD; it was multiplied by 10 for ease of reporting.

Using a priori criteria each statement was categorized based on the mean score and CV as follows:

Mean 9 - 10; CV < 4: very important

Mean 6 – 8.9; CV < 4: moderately important

Mean 1- 5.9; CV < 4: unimportant

Any mean; CV \geq 4: unable to agree.

We used analyses of variance (ANOVA) to assess differences between the specialty groups.

Ethics

The Human Research Ethics Committees of the QIMR Berghofer Medical Research Institute and the University of Queensland approved this study. Completion of questionnaires was considered to imply consent.

Results

In June 2013, 250 health professionals involved in the care of pancreatic cancer patients were invited by email to complete the initial open-ended question (Figure 1). Of these, 78 (31%) replied and suggested a total of 380 overlapping items that they considered important in the care of pancreatic cancer patients. These were reduced to 55 items that encompassed the following themes: presentation and staging; surgery and biliary obstruction; the management team (including multi-disciplinary team (MDT) details); oncology; and other (such as enrolling patients in clinical trials and establishing a national pancreatic cancer prospective database). The list of 55 items was then sent to the original 250 health professionals, irrespective of whether or not they responded to the first open-ended question. Following scoring of the initial items, the statements were resent to the 96 health professionals who had responded during round 1 or round 2. Of these, 63 (66% of those sent the final questionnaire; 25% of those initially invited) rescored the items.

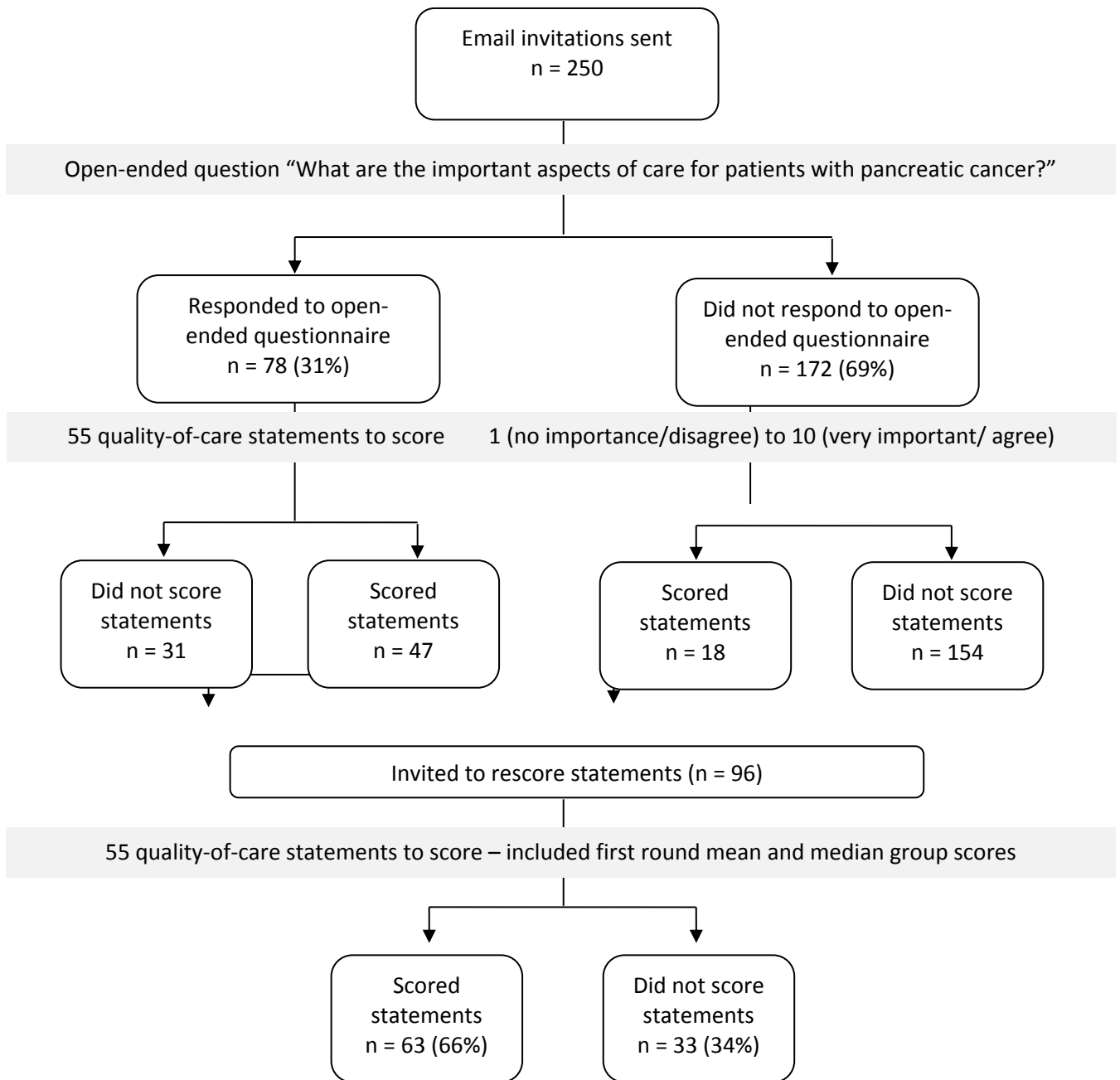


Figure 1: Consort diagram for the number of health professionals participating in the modified Delphi process

Specialties of the participants invited included surgery (n = 56; 22%), medical oncology (n = 43; 17%), allied health and nursing (n = 40; 16%), gastroenterology (n = 29; 12%), palliative care (n = 28; 11%), radiation oncology (n = 13; 5%), and others (n = 41; 16%) which included interventional radiology, general practice, gerontology and medicine (Figure 2). The response proportion to the final questionnaire ranged from 10% (other) to 54% (radiation oncology). The specialties of the final questionnaire respondents were: 22% - medical oncology, 18% - surgery, 19% - palliative care, 18% - allied health and nursing, 11% - radiation oncology and 6% from each of gastroenterology and others. Seventy-six respondents to the initial open-ended questionnaire (97%) described their clinical experience. Of these 12, (16%) reported more than 20 years treating patients with pancreatic cancer and treating more than ten patients each year. The majority of respondents treated more than 10 patients each year (n = 43, 57%) and years of experience were reported as less than 10 years, 10 to 20 years and more than 20 years by 30 (39%), 25 (33%) and 21 (28%) clinicians respectively.

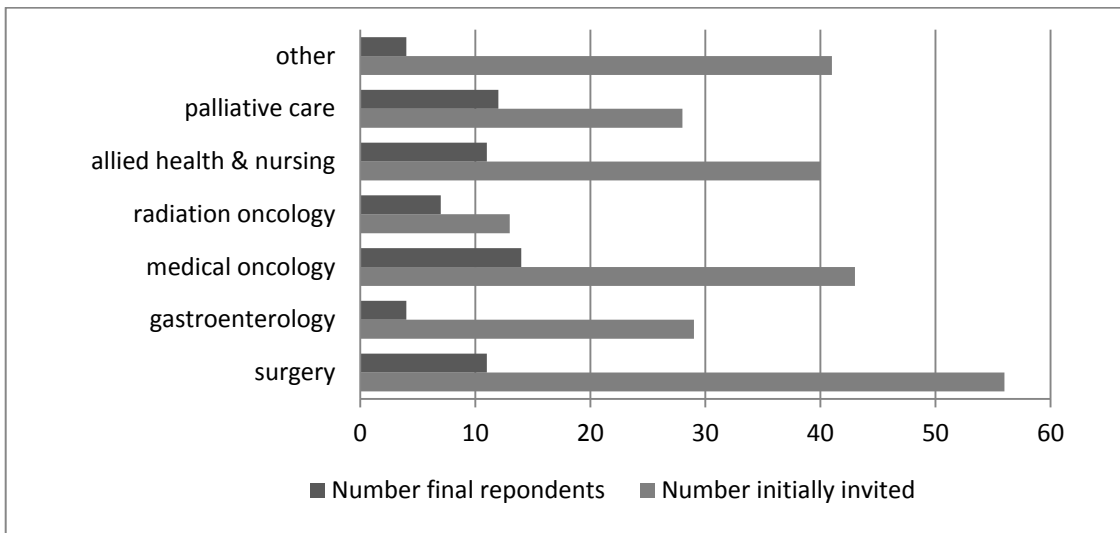


Figure 2: Numbers of invited and final responders by specialty

Based on the initial scores, 8 of the 55 statements (15%) were classified as very important and 33 (60%) as moderately important. The CV was greater than 4 for 14 (25%) statements, including 8 that were considered unimportant. No items where the CV was less than 4 were classified as unimportant. Only two statements “All patients should have a full physical examination, geriatric assessment if elderly, assessment of comorbidities and performance status prior to any treatment” and “Patients should be fully aware of the risks and benefit of interventions prior to any treatment” were given a moderately-high or higher score by all participants.

The mean scores for almost half the statements (n = 24; 44%) increased between surveys but were unchanged for 17 statements (31%), and decreased for 14 (25%) statements. The majority (n = 30; 55%) of CVs remained the same between surveys; 11% (n = 6) increased and 35% (n = 19) decreased between surveys.

Statements scores according to clinician specialty are displayed below within thematic categories and by score of importance (Table 1).

Table 1: Final scores for all statements by specialty

		Surgery	Gastro- enterology	Medical Oncology	Radiation Oncology	Allied Health & Nursing	Palliative Care	Other	Total
	n†	Mean (Coefficient of Variation)							
Presentation and Staging (n = 13 statements)									
^a All patients should have a full physical examination, geriatric assessment if elderly, assessment of comorbidities and performance status prior to any treatment	59	8.9 (2)	10.0 (0)	9.2 (1)	9.1 (1)	9.0 (2)	9.3 (2)	8.8 (2)	9.2 (2)
^a Standard guidelines for staging should be developed	60	8.5 (3)	10.0 (0)	9.4 (1)	9.1 (1)	9.3 (1)	8.6 (2)	8.8 (2)	9.1 (2)
^b All patients should have a triple phase/ pancreas protocol CT scan for staging	55	9.5 (1)	10.0 (0)	8.9 (1)	9.0 (1)	9.3 (1)	7.6 (4)	8.5 (2)	8.9 (2)
^b All patients should have an initial TNM stage recorded	59	7.9 (3)	10.0 (0)	9.1 (1)	8.6 (2)	9.1 (1)	8.4 (2)	8.3 (2)	8.7 (2)
^b Standard guidelines should be developed to determine which patients would benefit from transfer to a tertiary centre	61	8.2(2)	10.0 (0)	7.7 (3)	9.0 (1)	8.5 (2)	8.7 (2)	6.5 (2)	8.3 (2)
^b Tissue diagnosis should be obtained where possible	59	7.2 (3)	6.2 (8)	8.9 (2)	9.1 (1)	8.9 (2)	8.3 (2)	8.3 (2)	8.3 (3)
^b All patients should have access to ERCP and EUS facilities	57	7.4 (3)	10.0 (0)	8.2 (2)	7.9 (2)	9.2 (1)	7.8 (3)	7.8 (3)	8.2 (2)
^b A laparoscopy should be performed if resectability is uncertain	52	7.1 (4)	9.5 (1)	8.0 (3)	8.7 (1)	8.0 (1)	7.9 (2)	6.8 (2)	7.9 (2)
^b All patients presenting with ongoing epigastric/back pain should have a CT as part of the initial investigations	58	8.0 (3)	8.0 (4)	7.6 (3)	7.7 (1)	8.2 (2)	8.5 (1)	6.0 (2)	7.8 (2)
^b General practitioners should coordinate the initial workup	59	7.3 (2)	7.0 (3)	6.4 (3)	5.9 (4)	7.1 (4)	7.2 (3)	7.3 (2)	6.8 (3)
^c If disease appears to be localised a PET scan should be performed	56	5.1 (4)	8.4 (3)	6.1 (5)	7.7 (2)	7.4 (3)	8.4 (2)	6.8 (3)	6.9 (4)
^c All patients should have an EUS	56	6.2 (5)	6.6 (6)	6.4 (3)	5.4 (4)	7.2 (3)	5.5 (4)	5.0 (6)	6.1 (4)
^c All patients presenting with ongoing epigastric or back pain should have a CA19.9 blood test	56	5.9 (6)	4.0 (8)	4.6 (7)	4.3 (6)	5.3 (2)	5.3 (4)	4.5 (1)	4.9 (6)
Surgery and biliary obstruction (n = 9 statements)									
^a All patients with a small lesion and technically resectable disease plus adequate performance status should be offered a resection	57	9.2 (1)	10.0 (0)	9.1 (1)	9.3 (1)	10.0 (0)	8.8 (1)	8.7 (2)	9.2 (1)
^a Resectability should be assessed and surgery performed by surgeons who perform more than 5 pancreatic surgeries per year	53	8.7 (2)	10.0 (0)	8.7 (2)	9.3 (1)	9.2 (2)	8.8 (1)	8.5 (2)	9.0 (2)
^b Surgery should take place in tertiary institutions where > 15 resections are performed annually	57	7.5 (4)	10.0 (0)	8.4 (2)	9.0 (1)	9.4 (2)	8.5 (2)	8.5 (2)	8.6 (2)
^b Biliary obstruction should routinely be managed endoscopically in non-resectable patients	50	8.2 (3)	9.0 (2)	8.6 (1)	8.4 (1)	8.3 (1)	7.5 (2)	8.0 (2)	8.2 (2)
^c Patients with resectable disease should not be stented prior to surgery unless surgery is delayed	42	5.7 (5)	9.6 (1)	5.6 (5)	7.5 (2)	9.0 (0)	7.1 (3)	7.0 (0)	6.8 (4)
^c A self-expandable metallic stent (SEMS) should be used instead of a plastic stent if biliary drainage is indicated prior to surgery	36	5.7 (6)	7.2 (5)	6.9 (3)	6.5 (2)	9.0(-)	6.8 (3)	5.5 (1)	6.6 (4)
^c Potential for coeliac plexus block should be discussed before any surgical procedure	41	3.3 (6)	6.6 (5)	5.9 (4)	5.5 (6)	9.0 (-)	7.2 (2)	7.0 (-)	5.8 (5)
^c Biliary obstruction should be managed surgically if performance	48	5.2 (4)	2.2 (8)	4.5 (3)	4.8 (3)	5.5 (1)	5.7 (4)	6.0 (5)	4.8 (4)

		Surgery	Gastro- enterology	Medical Oncology	Radiation Oncology	Allied Health & Nursing	Palliative Care	Other	Total
	n†	Mean (Coefficient of Variation)							
status and prognosis are satisfactory in non-resectable patients									
‡Potentially resectable patients should not have a tissue biopsy prior to surgery	46	5.3 (5)	3.6 (11)	4.5 (5)	3.4 (4)	4.5 (2)	5.3 (4)	6.0 (5)	4.7 (5)
Oncology and Other (n = 14 statements)									
^a Patients should be fully aware of the risks and benefit of interventions prior to any treatment	63	9.6 (1)	10.0 (0)	9.7 (1)	9.0 (2)	10.0(0)	9.7 (1)	9.3 (1)	9.7 (1)
^a Patients should be advised of the limitations of chemotherapy	61	9.5 (1)	10.0 (0)	9.5 (1)	9.1 (1)	9.9 (0)	9.6 (1)	9.0 (2)	9.5 (1)
^a Careful attention to pain control is important, using nerve blocks if required	58	8.3 (2)	10.0 (0)	9.1 (1)	9.1 (1)	9.9 (0)	9.6 (1)	9.3 (1)	9.3 (1)
^b All patients should have a collaborative generalist/ specialist care model	61	7.4 (4)	9.0 (2)	8.7 (1)	9.0 (1)	9.9 (0)	9.3 (1)	8.8 (1)	8.8 (2)
^b Entry into a clinical trial should be considered for all patients	57	7.7 (3)	8.8 (2)	9.4 (1)	9.1 (1)	9.5 (1)	8.3 (3)	8.3 (2)	8.8 (2)
^b Apart from surgery, all treatment should occur as close to the patient's home as possible	62	9.3 (1)	9.8 (0)	8.7 (2)	7.1 (3)	9.7 (1)	8.7 (3)	7.3 (4)	8.8 (2)
^b All pancreatic cancer patients' details should be entered into a prospective database	60	9.1 (2)	9.8 (0)	8.4 (2)	8.7 (1)	8.7 (2)	8.3 (2)	8.0 (2)	8.7 (2)
^b Tissue should be routinely banked	51	9.2 (1)	9.2 (1)	8.9 (1)	6.8 (5)	9.8 (1)	7.1 (4)	9.0 (1)	8.5 (2)
^b All patients should be offered adjuvant therapy post operatively, assuming performance status is adequate	52	7.7 (4)	8.0 (3)	9.0 (1)	7.9 (2)	9.3 (1)	7.5 (2)	7.5 (1)	8.1 (2)
^b Creon prescription should be considered for all patients	51	9.0 (1)	6.2 (5)	8.0 (2)	6.8 (4)	8.8 (1)	7.9 (2)	6.5 (3)	7.9 (3)
^b All patients should have access to new drugs	59	7.2 (3)	8.2 (2)	7.9 (2)	7.7 (3)	8.9 (2)	7.2 (3)	7.5 (2)	7.7 (3)
^b Borderline resectable cases should be considered for neo-adjuvant therapy	51	6.8 (4)	8.8 (1)	6.9 (3)	8.0 (2)	9.0 (1)	7.3 (2)	8.0 (0)	7.5 (3)
^b Biomarkers should be used as prognosis and management tools	51	7.7 (3)	7.8 (4)	7.4 (3)	7.2 (3)	8.7 (1)	6.6 (3)	8.5 (2)	7.4 (3)
^b All patients should have access to conformal radiotherapy	52	6.2 (3)	8.3 (3)	6.6 (4)	8.9 (1)	7.5 (3)	7.5 (2)	7.0 (0)	7.2 (3)
MDT and Referrals (n = 19 statements)									
^a All patients with potentially resectable disease should be referred to an hepato-biliary surgeon	59	9.9 (0)	8.2 (5)	9.6 (1)	9.7 (1)	10.0 (0)	8.7 (2)	7.8 (3)	9.3 (2)
^a Tumour resectability should be assessed by a MDT at a tertiary hospital	60	8.4 (2)	10.0 (0)	9.3 (1)	9.1 (1)	9.6 (1)	8.4 (1)	7.7 (3)	9.0 (1)
^b MDT meetings should include palliative care specialists	63	8.5 (2)	7.2 (4)	8.2 (2)	8.9 (1)	9.6 (1)	9.3 (2)	9.0 (1)	8.7 (2)
^b Symptom management should be discussed at MDT meetings	63	6.8 (4)	9.0 (2)	7.7 (3)	8.9 (1)	9.5 (1)	9.2 (1)	8.8 (1)	8.5 (2)
^b Each patient should have a care-coordinator assigned with an individualised treatment/ clinical plan	62	7.8 (2)	9.6 (1)	8.2 (2)	8.7 (1)	9.5 (1)	8.3 (1)	8.0 (3)	8.5 (2)
^b Tertiary hospital MDTs should be involved in the care of patients from smaller centres (via video-conferencing etc if necessary)	62	8.9 (1)	10.0 (0)	7.8 (2)	8.9 (1)	9.4 (1)	8.1(2)	7.3 (2)	8.5 (2)

		Surgery	Gastro- enterology	Medical Oncology	Radiation Oncology	Allied Health & Nursing	Palliative Care	Other	Total
	n†	Mean (Coefficient of Variation)							
^b MDT meetings should include allied health professionals	61	7.4 (4)	9.0 (1)	7.8 (3)	8.7 (1)	9.1 (2)	8.8 (1)	9.0 (1)	8.4 (2)
^b All patients should be presented to a MDT	63	7.1 (5)	10.0 (0)	8.1 (2)	8.9 (1)	9.7 (1)	7.3 (4)	7.3 (1)	8.3 (3)
^b Patients requiring diabetes management should be seen by a diabetic educator	63	7.8 (3)	9.4 (1)	8.8 (1)	7.6 (2)	9.1 (1)	7.3 (3)	8.3 (2)	8.3 (2)
^a All patients should be offered psychosocial support	62	6.7 (3)	9.4 (1)	8.0 (3)	6.7 (3)	8.8 (3)	8.6 (2)	7.8 (3)	8.0 (3)
^b All patients should see a medical oncologist	58	8.2 (3)	7.6 (4)	8.1 (2)	8.0 (2)	8.3 (4)	7.2 (4)	7.8 (3)	7.9 (3)
^b A specialist HPB surgeon should be the initial/primary specialist unless the patient has obvious metastases	57	7.7 (3)	7.6 (3)	7.6 (2)	6.6 (4)	8.1 (3)	6.4 (3)	7.3 (3)	7.3 (3)
^b All patients should be referred to a dietitian soon after diagnosis	61	6.5 (3)	8.2 (4)	7.9 (2)	7.1 (1)	7.8 (4)	7.0 (2)	6.3 (2)	7.3 (3)
^c All patients should be referred to a social worker	60	5.9 (4)	7.0 (4)	6.4 (4)	5.0 (3)	6.9 (5)	6.6 (2)	7.3 (3)	6.4 (4)
^c All patients should be referred to a physiotherapist	60	4.9 (6)	4.3 (5)	5.1 (4)	3.8 (3)	5.1 (4)	4.9 (5)	5.0 (3)	4.8 (4)
^c All patients should be referred to an occupational therapist	59	4.3 (7)	5.8 (7)	4.8 (5)	4.7 (4)	4.1 (5)	5.3 (4)	4.8 (2)	4.7 (5)
^c Patients should only be referred to palliative care when they have confirmed metastatic disease	59	6.7 (3)	4.2 (8)	5.4 (4)	6.5 (2)	7.1 (4)	5.5 (5)	7.0 (3)	6.0 (4)
^c Only patients who are potentially suitable for resection should be presented to a MDT	61	5.1 (7)	1.2 (4)	4.3 (6)	2.0 (5)	1.8 (7)	4.3 (5)	4.8 (4)	3.6 (7)
^c On diagnosis all patients should be referred to palliative care	61	2.7 (10)	2.8 (8)	3.6 (5)	3.1 (5)	4.6 (6)	6.1 (5)	4.3 (7)	4.0 (6)

CV = coefficient of variation PET = Positron emission tomography; EUS = Endoscopic Ultrasound; MDT = Multi-disciplinary team

^a all agree important (9 +); ^b all agree moderately important (6 - 8.9), ^c unable to agree (CV ≥4) † Number of observations/respondents with an opinion "Other" specialty group includes interventional radiologists, general practitioners and physicians.

Presentation and Staging:

Almost 25% of the statements derived from the initial open-ended question related to presentation and staging (n = 13; 24%). The need to conduct a full physical assessment prior to treatment and to develop standard staging guidelines were both rated as very important. The panel did not reach consensus about the value of positron electron tomography (PET) scans, endoscopic ultrasounds (EUS) or carbohydrate antigen 19.9 (CA19.9) as staging tools, with evidence of variability in the rated importance of these statements both between and within specialty groups. Palliative care specialists rated the value of PET scans more highly than surgeons (mean scores 8.4 and 5.1 respectively, p = 0.03) and had a lower CV (2 versus 4).

Surgery and biliary obstruction:

The 9 statements related to surgery and biliary obstruction had the fewest responses with some high proportions (9 – 91%) of the allied health, nursing and “other” groups indicating no opinion due to lack of expertise in the area. Amongst those who did respond, the statements "all patients with a small lesion and technically resectable disease plus adequate performance status should be offered a resection" and "Resectability should be assessed and surgery performed by surgeons who perform more than 5 pancreatic surgeries per year", were classified as very important. Consensus was not reached for 5 statements. Allied health /nursing and palliative care specialists rated the statement “Potential for coeliac plexus block should be discussed before any surgical procedure” much higher than the surgical specialists (scores 9.0, 7.2 and 3.3 respectively, p = 0.02).

Referrals and Multi-disciplinary team (MDT):

Over a third of the survey statements (n = 19; 35%) referred to when and where treatment should occur, and which specialists should be involved. The statements "all patients with potentially resectable disease should be referred to a hepato-biliary surgeon" and "tumour resectability should be assessed by a MDT at a tertiary hospital" were thought very important with overall mean scores of 9.3 and 9.0 respectively.

No overall or within-specialty consensus was reached for the statement “On diagnosis all patients should be referred to palliative care” (CV = 6). There was a significant difference in the scores between palliative care and surgical specialists with mean scores of 6.1 and 2.7 respectively, (p = 0.03). Similarly, the panel did not agree on which patients should be presented at MDT meetings, with high inter- and intra-specialty variability.

Although surgeons and gastroenterologists had significant variation within their specialty groups (p < 0.001) they thought it less important that “MDT meetings should include palliative care specialists” and that “symptom management should be discussed at an MDT” than allied health, nursing and palliative care specialists (p = 0.02).

Oncology and Others:

All the 14 oncology and "other" statements were classified as moderately or very important with participants able to reach consensus and ranking none as unimportant.

The statements that “patients should be fully aware of risks and benefits of interventions prior to any treatment” and “patients should be advised of the limitations of chemotherapy” were the highest scoring statements with total mean scores of 9.7 and 9.5 respectively and little variability across specialty.

Radiation oncologists regarded access to conformal radiotherapy as more important than other health professionals. Surgeons scored the statement "all patients should have a collaborative generalist/specialist care model" lower than all other health professional groups. This difference between surgical and allied health/nursing specialists was statistically significant ($p = 0.03$).

Gastroenterology, palliative care and allied health and nursing specialists rated the statement “careful attention to pain control is important, using nerve blocks if required” more highly than surgeons ($p = 0.03$).

Discussion

We used a Delphi process to identify factors that health professionals from a range of disciplines consider important in the care of patients with pancreatic cancer. As expected, many of the items rated as important are consistent with existing evidence-based clinical guidelines, but there were also items rated as important by health professionals that are not considered by guidelines. Furthermore, for some consensus-based or expert opinion-based items included in guidelines agreement on the importance of these between the health professionals we surveyed was not reached. We also found that the rating of particular issues varied substantially by clinical discipline.

Clinical guidelines have been developed by peak bodies in Europe and the USA, most notably the National Comprehensive Cancer Network (NCCN)[12] and the European Society for Medical Oncology (ESMO),[9, 11] which describe clinical pathways from diagnosis to treatment for patients with pancreatic cancer. In Australia no national clinical practice guidelines have been developed that are specific to the care of patients with pancreatic cancer.

Comparing current guidelines with the opinions of clinicians working in the field identified some areas requiring further clarification, in particular the diagnosis and staging of pancreatic cancer. Respondents in this study rated highly the need for development of standard guidelines for staging. This was underscored by the very high variability in responses about the value of PET, CA19.9 and EUS. Lack of clarity about PET is also apparent in the guidelines, with NCCN stating that it is unclear if PET is useful and ESMO guidelines recommending PET not be used. Both organisations recommend that CA19.9 should only be used in treatment monitoring and that EUS be used as an adjunct to a pancreatic protocol computerised tomography (CT) or magnetic resonance imaging (MRI) only in those without biopsy-proven metastases. The high variation in scores for EUS amongst our participants may result from the inclusion of the words “all patients” in the statement as those with confirmed metastases would not benefit from the procedure.

It is notable that of the 55 items derived from panel members’ responses, approximately half related in some way to access to treatment, where treatment should occur or who should be involved in different treatment aspects. This may be a recognition that pancreatic cancer patients require highly specialised care and the provision of treatment at specialist centres might improve outcomes. This could also reflect the substantial geographical dispersion of the Australian population and the

finding of a trend towards poorer survival in rural and remote areas.[19] The study participants agreed that patients should be managed as close to home as possible, but that standard guidelines should be developed to determine who would benefit from transfer to a tertiary centre. Improved access through video-link to tertiary centres was also considered important. Telehealth aims to remove barriers to accessing medical services for residents of rural and remote Australia,[20] and there are International and Australian recommendations around its use.[21] The Queensland state Department of Health estimates that use of Telehealth would reduce health costs by 30% [22] and is currently under-used throughout Queensland.[23]

Access to specialist surgical management was particularly highlighted. There was high agreement that all patients with potentially resectable disease should be assessed by a hepatobiliary surgeon, ideally as part of a multidisciplinary team. The need for multidisciplinary assessment of resectability is specifically stated in guidelines[12] and has been shown to improve surgical mortality rates[24] but it is unclear to what extent this currently occurs. Respondents also agreed that pancreatic cancer resections should occur in high-volume centres, reflecting guideline recommendations although definitions of high-volume vary across guidelines. The cut-off recommended by our panellists was consistent with the NCCN guidelines (15 surgeries/year). However, the National Cancer Institute (NCI) guidelines classify hospitals carrying out > 5 resections/year as high-volume and the British Society of Gastroenterology (BSG) guidelines[25] do not give a value, but rather recommend that surgery be carried out in 'specialist centres'. The evidence available suggests different values (range 5 - 19) for high-volume classification.[26, 27] Few data support a role for surgeon volume independent of hospital volume,[27, 28] probably because these are highly correlated, but our participants nevertheless felt pancreatic resections should be undertaken by surgeons performing more than 5 per year. These data clearly show that clinicians feel that centralisation of surgical care for pancreatic cancer is important. In the USA, hospital volume for pancreatectomies more than tripled between 2000 and 2008 with the median volume increasing from 5 to 16[26] whereas in Australia volume is increasing but resections are still performed in low-volume hospitals.[29, 30]

Multidisciplinary care has become the accepted standard for cancer patients and has been shown to improve treatment access and timeliness.[7] [31] However, systematic review evidence suggests there is substantial variability in the way MDT meetings are incorporated into patient care[32] and this is reflected in our data, which show that clinicians value multidisciplinary care but vary in their views about the function of MDTs in the management of patients with pancreatic cancer. For example, in contrast to other specialties, surgeons were less likely to agree that all patients should be presented to MDTs and more likely to indicate that only potentially resectable patients should be presented to MDTs. The NCCN guideline also suggests that only patients without metastatic disease be presented at MDT meetings. However, The European Partnership for Action Against Cancer (EPAAC) recommend in their MDT policy document[33] that MDTs co-ordinate cancer care at all stages. While there was strong consensus among our panellists across all specialties that palliative care specialists should be present at MDT meetings, the presence of allied health professionals was not consistently rated as important by surgeons. This may reflect the fact that surgeons lead most MDT meetings and may prioritise surgical and medical issues over psychosocial concerns.[34] EPAAC guidelines emphasise the need for MDTs to address the supportive care and psychosocial needs of their patients. They also emphasise the need for coordination across different disciplines to achieve continuity of care. While our Delphi process identified the importance of care coordination, the reality is that in Australia there is considerable variability in the way that the coordination role is

implemented.[35] Adopting system-wide policies regarding MDTs and care coordination may be one way of improving the management of patients with pancreatic cancer.

The two top-scoring items in our study related to patient communication. Both items emphasised the importance of ensuring that patients are aware of the risks, benefits and limitations of treatment. While this should be standard in all clinical situations, it is particularly important for patients with pancreatic cancer where surgery can result in significant morbidity and, even with successful resection, median survival is poor at ~20 months.[36] In addition, current chemotherapy regimens have limited survival benefit and a USA national cohort study showed that about three quarters (69 - 81%) of patients with advanced cancer did not understand that the chemotherapy they were receiving was unlikely to result in cure.[37]

Up to 75% of patients with advanced pancreatic cancer report pain and it is one of the major factors adversely affecting quality of life.[38-40] The need to manage pain was one of the highest-scoring items on the survey, but there was a lack of consensus about whether coeliac plexus neurolysis (CPN) should be discussed before embarking on any surgical procedure. CPN can prevent pain development for up to 6 months post-operatively[41] and, while some studies suggest that CPN may not offer greater pain relief over opioid analgesia, it has fewer side effects.[40] The NCCN guidelines do suggest that CPN should be considered at the time of palliative surgery.

A major strength of this study was the robust method we used to elicit opinions from experts in pancreatic cancer management.[42, 43] Key features of the Delphi process we used included: (1) the multi-disciplinary panel drawn from a wide range of medical and allied health fields; (2) each health professional rated the quality-of-care statements anonymously, limiting the potential for a single individual to dominate the proceedings; (3) we provided structured feedback, where following the first round of ratings the panel received the ratings from the entire group; (4) it was iterative, with two rating rounds allowing panel members to change their minds after deliberation;[16] (5) it was internet-based and therefore less costly than other methods such as focus groups.

The study has two key limitations. Firstly, although a broad range of specialist clinicians participated, response rates were highly variable and some specialties (notably gastroenterology) were under-represented. For ethical reasons we were unable to capture detailed information about the non-responders so it is difficult to determine the representativeness of the final sample in terms of factors such as location of practice and years of experience. Secondly, some statements did not fully portray the clinical variability that underlies decisions about care. This particularly applies to those statements which commenced with the words "All patients". While the statements had been transcribed verbatim following responses to the open-ended questionnaire and to amend them would have resulted in a deviation from the Delphi method, some items may have scored more consistently had they been worded differently.

This work shows that, for the most part, clinicians' opinions reflect clinical guideline-recommended care, albeit with some exceptions. However, clinicians identified a number of additional factors that are not incorporated in pancreatic-cancer specific guidelines, with a particular focus on where patients should be treated, the importance of clear communication and the need for multidisciplinary care. The lack of agreement about which patients and clinicians should be included in MDT meetings reinforces the notion that further in-depth investigations are required to identify the optimal composition and schedule of MDT meetings to improve and standardise practice in this

area. Similarly, clinicians support the need to develop policies about transfer to tertiary centres and implementation of Telehealth to ensure that all patients with pancreatic cancer receive optimal multidisciplinary coordinated care.

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