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Anxiety, depression and quality of life in people with pancreatic cancer and their carers

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ABSTRACT

Background: People with pancreatic cancer have high levels of anxiety and depression and reduced quality of life (QoL), but few studies have assessed these outcomes for patient-carer dyads. We therefore investigated these issues in an Australian population-based study.

Methods: Patients with pancreatic cancer ($n = 136$) and many of their carers ($n = 84$) completed the Hospital Anxiety and Depression Scale (HADS) and Functional Assessment of Cancer Therapy QoL questionnaire at a median of three months after diagnosis. Overall QoL and well-being subscales (physical, social, emotional, functional) were compared with general population norms. Intraclass correlation coefficients were used to compare anxiety, depression and QoL scores of patients and their respective carers.

Results: Fifteen percent of patients and 39% of carers had HADS scores indicative of anxiety and 15% of patients and 14% of carers of depression, respectively. Overall, 70% of patients and 58% of carers had QoL scores below the Queensland population average. Patients' anxiety, depression, overall QoL, social, emotional and functional wellbeing scores were significantly related to those scores in their carers. Among patients and carers, accessing psychological help was associated with elevated anxiety. Not receiving chemotherapy was associated with elevated depression among patients and younger age was associated with poorer outcomes in carers.

Conclusions: More carers had symptoms of anxiety than patients with pancreatic cancer, but symptoms of depression were similarly common in patients and carers. Further research is needed to assess whether interventions to reduce patients' distress could also improve QoL among carers, or whether carer-focussed interventions are required.

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1. Introduction

Pancreatic cancer is the fourth most common cause of cancer death in more developed regions of the world [1]. There have been no major improvements in survival in the last several decades and 5-year survival remains poor at less than 5%. A recent study

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estimated that in Europe alone, 610,000–915,000 quality-adjusted life-years are lost to pancreatic cancer annually [2]. Thus, optimizing patients' quality of life (QoL) must be a major focus of care.

There are relatively few studies outside clinical trials that have assessed depression, anxiety or QoL in people with pancreatic cancer. Those that have generally had small sample sizes [3–5] or were focused on particular patient groups such as those who had undergone surgery or who had been diagnosed with advanced disease [4,6–8]. Most previous studies have found that depression [9–11], anxiety [12,13] and poor QoL [3,14] are more common in pancreatic cancer patients than in other cancer populations.

A cancer diagnosis inflicts significant emotional burden on people caring for patients (most commonly partners, relatives or friends) and has a detrimental effect on carers' QoL that can persist even after the person with cancer has deceased [15]. Caring for people with pancreatic cancer is likely to pose particular challenges due to the extremely poor prognosis with which these people and their families are confronted. Four studies, three small and one larger, have focused specifically on carers of people with pancreatic cancer [12,16–18]. These studies show that carers experience feelings of crisis and being heartbroken at the time of the person's diagnosis, difficulties in providing supportive care, including finding appropriate ways to provide adequate nutrition. Many carers also report finding it difficult to understand information and to be a conduit of illness-related information to other family members. The lack of opportunity to de-stress, given the multiple tasks required and when a person's health rapidly declines has also been found to be burdensome for carers.

Although these previous studies highlighted the association between patients' and carers' wellbeing in a qualitative way [16–18], or examined burden separately for patients and carers [12], none of these studies quantified the association between patients' and their immediate carers' wellbeing and few have assessed associations between demographic or clinical variables and patient-reported outcomes. These research gaps are addressed in the present study, which collected data from patients enrolled in a population-based pancreatic cancer case-control study and eligible carers of these patients. We hypothesized that patient and carer self-reported wellbeing would be significantly associated. We expected that carers of patients with greater severity of anxiety and depression, or low quality of life may also experience greater reduction in their own mental health and quality of life.

2. Methods

2.1. Ethical approval

All study components were approved by Human Research Ethics Committees of the QIMR Berghofer Medical Research Institute and participating hospitals and were in accordance with the 1964 Helsinki declaration. Informed consent from participating patients and carers was obtained.

2.2. Participants

This study was nested within the Queensland Pancreatic Cancer Study (QPCS), a population-based case-control study which examined genetic and environmental risk factors for pancreatic cancer. Full details of the study design and participant recruitment have been reported previously [19,20]. Briefly, patients aged over 18 years with histologically diagnosed pancreatic adenocarcinoma or pancreatic cancer diagnosed clinically between January 2007 and June 2011 were eligible to participate. Given the high case fatality for this disease, the study used a rapid ascertainment approach recruiting patients as early as possible after diagnosis

through a state-wide network of clinicians in hospitals and private practices. With their doctors' permission, the Queensland Cancer Registry approached patients who had not been identified through this network. Approximately 30% of all people diagnosed were recruited.

We reviewed medical records of participants to capture clinical information about their pancreatic cancer and treatment and about their co-morbidities. A co-morbidity score was calculated using the Charlson index and participants were categorised into three groups according to their score: low (score equal to zero), medium (score equal to one) and high (score equal to two or more) comorbidity burden.

Starting in July 2009 newly recruited QPCS participants were invited to also participate in a sub-study of patient-reported outcomes involving the completion of a self-administered questionnaire, which is the focus of this report. Of the 351 eligible QPCS participants recruited after July 2009, 29 did not consent to being approached to participate in future studies, 8 died before being invited to participate in the sub-study, 10 were more than 8 months post-diagnosis and thus outside the protocol timeframe, and 50 were considered by the research nurse to be too sick to be approached. Of the 254/351 (72%) patients who were approached, 57 (22%) refused, 23 (9%) died shortly after receiving the questionnaire, we lost contact with five patients (2%) and 33 (13%) consented but did not return the questionnaire. Thus data from a total of 136/254 participants (54% of those approached; and 38% of those potentially eligible) were used in this analysis.

We asked participants in the sub-study to nominate a carer who we could also invite to participate. Of the 136 participants, 21 did not nominate a carer, 16 carers refused to participate and 15 agreed to take part but did not return the questionnaire. In total 84/136 (62%) carers' questionnaires were completed.

2.3. Outcome measures

The hospital anxiety and depression scale (HADS) was used to assess patients' and carers' psychological distress [21]. The HADS is appropriate for both clinical and non-clinical populations [21–24]. It has been validated against clinical interview, and its sensitivity and specificity for depression and anxiety in cancer patients is good to excellent [25,26]. All questions are answered on a four-point Likert scale (0–3). Seven items form a depression scale and seven items form an anxiety scale (both scales range from 0 to 21). A score of 8–10 in each subscale indicates symptoms consistent with borderline depression or anxiety, while a score of 11 or greater indicates symptoms consistent with a likely state of depression or anxiety [23]. However, the HADS does not differentiate between different subtypes of anxiety or depression, and patients with elevated HADS scores need to be reviewed by a clinician for further differential diagnosis. In the present study internal reliability of the anxiety and depression scales were good with Cronbach's alpha coefficients of 0.88, and 0.85, respectively.

The Functional Assessment of Cancer Therapy (FACT) was used to assess patients' and carers' QoL [27]. Patients with pancreatic cancer completed the 27-item FACT-general (FACT-G) and an 18-item hepatobiliary-specific subscale which, together with the FACT-G, forms the FACT-Hep [28]. Carers completed the 21-item general population version of the FACT (FACT-GP) [29], which, by prorating the available items to the FACT-G subscales, generates scores compatible to the FACT-G [30]. All questions were answered on a five-point Likert scale, ranging from "not at all" to "very much". The FACT-G and FACT-GP consist of four subscales which measure physical well-being (PWB; range 0–28), social well-being (SWB; range 0–28), emotional well-being (EWB; range 0–24) and functional well-being (FWB; range 0–28). Together the subscales add

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