

# INTEGRATED PSYCHOSOCIAL AND SUPPORTIVE CARE NEEDED FOR PATIENTS WITH PANCREATIC CANCER

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## Abstract

Pancreatic cancer is acknowledged as one of the most challenging diseases in the 21st century. Despite the recent focus on research and novel therapies, by 2030 pancreatic cancer is projected to be the second leading cause of cancer death after lung cancer. With incidence and mortality rising against the trend in other cancers, the importance of a whole team approach to achieve best quality of life and care is critical. Recent Australian research has reported significant unmet needs for psychosocial and supportive care for people affected by pancreatic cancer. Nihilism has been identified as a problem in pancreatic cancer that affects clinicians, patients, carers and families. This can lead to loss of hope and people becoming disengaged from care, resulting in increased distress, poor quality of life and signs of demoralisation. Meaning-centred therapies can help with reducing demoralisation, improving existential wellbeing, increasing dignity and legacy building. Effective interventions can ease the existential distress that is often experienced at end of life and help family members during the grieving process. Essential in providing optimal care for patients and caregivers is timely and appropriate discussions about the importance of palliative care in managing symptoms and improving quality of life. Early integration of psychosocial and supportive care is recommended to achieve best quality of life and relieve suffering.

Pancreatic cancer is a challenging disease from both clinical and research perspectives.<sup>1,2</sup> The literature constantly reminds us that survival in pancreatic cancer has not improved in contrast to other cancers.<sup>3</sup> The relative five-year survival rate is the lowest of all solid cancers, at less than 5%.<sup>4</sup> The overarching burden of pancreatic cancer is expected to increase, with Australian and US data projecting a rise in incidence and associated mortality leading pancreatic cancer to becoming the second highest cause of cancer death by 2030, surpassing breast, prostate and colorectal cancers.<sup>5,6</sup> Individuals diagnosed with pancreatic cancer have poor quality of life and demonstrate a lower level of functioning across the five domains of the EORTC QLQ-C30 and a higher symptom burden, particularly for digestive symptoms (EORTC QLQ-Pan26).<sup>7</sup> The substantial literature on all aspects of pancreatic cancer research, treatment and care never fails to note that consequences for those diagnosed still remain grim.

## Patients exhibit high levels of distress

Distress is recognised as the sixth vital sign in cancer, as a diagnosis of any cancer is associated with physical and psychological challenges.<sup>8</sup> Adjusting to and coping with

the demands of treatment and the disruption to personal and occupational lives, for both the individual and their family, can place a significant emotional burden on all involved. Emotional distress associated with diagnosis can be a major factor that affects an individual's quality of life and the ability to make well informed decisions. A consistent finding from research is that a diagnosis of a poorer prognosis cancer produces the highest rates of distress.<sup>9</sup> In pancreatic cancer, people diagnosed often demonstrate the highest rates of anxiety and depression and record a higher percentage (27%) of psychosocial distress than those with other cancers (21%).<sup>10</sup> Because of the short survival time and the elevated levels of distress, it is imperative that assessment and intervention be prioritised, and psychological strategies appropriate for this population are identified and utilised to support patients and families early on in the care trajectory.

Psychosocial supportive care is recognised as a complex multidimensional construct that includes informational, emotional and physical support, social integration, esteem and support of others.<sup>11</sup> As is the case in pancreatic cancer, when cure is not an outcome, and treatment options are readily exhausted, psychosocial

and supportive care needs are likely to increase for both patients and caregivers. The benefits of psychosocial support have been linked to lower levels of distress and improved outcomes in other cancers. Lutgendorf and colleagues demonstrated in a recent study that psychosocial support conferred a significant survival benefit for women diagnosed with ovarian cancer.<sup>12</sup> For people affected by pancreatic cancer, awareness and early assessment of psychosocial distress and meeting supportive care needs are critical to help achieve best quality of life to end of life, and to relieve carer burden.

### Communication difficulties predict high levels of unmet need

Evidence suggests individuals with pancreatic cancer and their carers have unmet needs in many areas, not only in psychosocial and supportive care, but also having unmet information needs. These findings are reported in both a recent qualitative study and also by the largest population-based study to date in Australia.<sup>13,14</sup>

Beesley and colleagues reported that along with high levels of physical need including pain, fatigue and difficulty managing daily activities, almost all participants reported having a psychological need that was currently unmet by services, half at moderate-to-high levels.<sup>13</sup> High levels of unmet need for information about managing the effects of pancreatic cancer were also identified, supporting the earlier finding by Gooden.<sup>14</sup> Both studies also reported perceived difficulties in communication with clinicians that led to people experiencing feelings of isolation and 'abandonment'. Communication difficulties were found to have contributed to distress in both patient and carer groups.<sup>14</sup> Maintaining good communication and managing perceived difficulties encourages continuity and engagement with care.<sup>15</sup> Australian guidelines are available to promote best practice regarding communicating prognosis in advanced illness and end-of-life discussions to minimise distress and ensure patients and families feel supported.<sup>16</sup>

### Nihilism versus hope

The reputation and reality of pancreatic cancer projects a pervasive nihilism that can have a negative impact on clinicians, nurses, health professionals, patients and families. The problem of therapeutic nihilism, defined as the lack of belief in the value and/or efficacy value of therapy, has been flagged in the literature in relation to pancreatic cancer care.<sup>1</sup> What has not been acknowledged is the potential for this nihilism to inadvertently directly affect the provision of care. Experiencing nihilism leads to a loss of hope for patients and families.

A recent study found that in the face of hopelessness, communication between clinicians and patients/families was often less than ideal and as a result, continuity of care was disrupted.<sup>14</sup> This meant that opportunities were missed to have discussions around key issues such as supportive care needs and the importance of

palliative care and timely referral into services. Typically the responsibility to introduce formal conversations around palliative care rests with clinicians. A new study has reinforced the key role of oncology nurses in continuing the conversations, negotiating futility and managing the emotions and tensions around transitioning to palliative care.<sup>17</sup> Delivering effective integrated person-centred care requires a shared approach, with the responsibility for monitoring and managing psychosocial or existential distress assumed by the whole cancer care team.

Though the ideal is early integration of palliative and psychosocial services, these services may not be available or easily accessible to all, particularly for those in regional areas. Phillip and Collins recently asserted that successful integration of palliative care relies on the importance of engagement with communication, a willingness to have these difficult conversations, rather than access to quality services.<sup>18</sup> Regardless of access to services, giving time to patients and families is critical. Checking-in with them regarding their existential feelings and fears can promote the demystification of palliative care, and reframe the conversation to one of providing hope for best quality of life to end of life.

### Risk of demoralisation

The twin effects of lack of continuity of care and nihilism, in conjunction with a lack of hope, have been identified as key factors that make the daily struggle with pancreatic cancer much harder. In the face of hope destroyed, people have exhibited signs of demoralisation,<sup>14</sup> and it is critical to sustain hope in advanced cancer.<sup>19</sup> Hope can be reframed as hope for quality of life, hope for a pain-free death, hope for research to benefit future generations and hope for support to enable well-managed caregiving and importantly, to avoid demoralisation.

Demoralisation is defined in the oncology literature as a state beyond distress whereby the greatest risk is considered to be in people affected by advanced cancers.<sup>20</sup> Demoralisation is distinguished from depression in that it is characterised by hopelessness, helplessness and loss of purpose and meaning in life.<sup>21</sup> Social isolation may also intensify feelings of distress and this is exacerbated particularly in situations where people have low social support.<sup>22,23</sup> People affected by pancreatic cancer who are struggling with high unmet needs for psychosocial and supportive care become socially isolated, as efforts to maintain activities of daily living become more difficult. Caregivers who express feelings of isolation have also been found to demonstrate signs of demoralisation as they struggle with their carer burden.<sup>14</sup> Reducing social isolation, by ensuring continuity of care and providing social support by linking people affected by pancreatic cancer into support services, is critical to improve quality of life.

Existential wellbeing, increasing dignity and legacy building, are promising ways of reducing demoralisation and enhancing meaning in those with advanced cancer.<sup>24</sup>

A recent review of psychological interventions effective in the treatment of distress in cancer patients, found that meaning-centred therapies can have a significant and positive effect with relatively short-term interventions, whether delivered individually or in groups.<sup>25</sup> A 2007 study on family members' perspectives on dignity therapy found that not only did this intervention alleviate psychological and existential distress in the patient, it also helped family members during the grieving process.<sup>26</sup> These findings suggest that even in the most confrontational of situations, psychological wellbeing, meaning and hope can be positively influenced by certain interventions. Dignity therapy and meaning-centred therapies may be the most effective for those individuals with pancreatic cancer and their families, due to the benefits to be gained in a relatively short amount of time.

## Importance of integrated psycho-oncology and palliative care

Clinical practice guidelines demonstrate strong evidence that end of life psychological interventions can improve mood, coping, sense of personal control, and physical and functional adjustment.<sup>27</sup> Very necessary in this population group is early referral and integration into palliative care, along with the provision of psychosocial support services. Although this is accepted as essential to manage physical, spiritual and psychosocial care in inevitably fatal disease, both studies cited previously found this did not happen for the majority of the people in their studies affected by pancreatic cancer.<sup>13,14</sup> This may be due to the stigma associated with palliative care and its association with the inevitability of death.

Studies have confirmed the negative connotations associated with the term 'palliative care' and demonstrated a preference by oncologists in the US for the term 'supportive care'.<sup>28,29</sup> The study by Rhondali and colleagues highlighted a name change alone did not strongly influence earlier referral patterns to palliative care. Communication difficulties were still acknowledged as a problem in discussing transitioning of care. Best practice is considered to be early integration of palliative care with emphasis on a whole team approach to support patients to achieve best quality of life and help their families manage and understand the care trajectory.

Australia, like many other countries, has a multi-cultural society where norms around death or discussions of death vary widely across cultures. The transition from active care to being supported to live with the dying process is a paradigm shift that is difficult for individuals and families in every cultural context. The risk for patients and families affected by pancreatic cancer, when palliative care is not appropriately engaged, is an undignified, distressing and painful experience of death that can result in ongoing and complex grief for families. The acceptance of palliative care is a key step in providing optimal care for many patients and families across all cultures, with sensitivity required to individual belief-systems. Indeed, it becomes even more

important when evidence suggests that involving palliative care early in the care of metastatic cancer patients can increase mood, quality of life, and may actually extend life in some cases.<sup>29</sup> Conway advocates for working together to move beyond the confines of acute health care, within a broader health promotion approach, to create supportive environments around end of life.<sup>30</sup> The emphasis is on effectively delivering quality of life to end of life through the provision of coordinated cancer care.

## Is quality of life an achievable goal in pancreatic cancer?

Quality of life to end of life is a goal that is achievable for people affected by pancreatic cancer. Providing phase-appropriate support helps to engage patients and their families with the medical and psychosocial support that will facilitate their adjustment process. In the long term it is hoped that genomic research and new biotherapies will achieve the breakthroughs that are needed to prolong disease-free survival and improve outcomes in this disease. In the short term, efforts need to be directed towards supporting best possible quality of life by promoting effective communication that fosters realistic hope for a managed disease process. This would ideally involve integrating psycho-oncology into multidisciplinary care and ensuring continuity of care throughout the disease trajectory, which may ameliorate feelings of isolation and abandonment. Initiating timely and appropriate discussions about the importance of palliative care in managing symptoms and improving quality of life is also an essential part of optimal care for all patients with metastatic cancer.

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