


Pancreatic Cancer From the Patient Perspective: The Time to Act is Now

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Abstract

Pancreatic cancer is a disease requiring urgent attention from governments and policymakers. Recently, a state of emergency has been declared for this cancer—being the fourth most common cause of cancer deaths in the European Union, it has the lowest survival rate of all common cancers. One of the major reasons pancreatic cancer is associated with such poor outcomes is because it is usually diagnosed at a late stage. Also, investment in research for effective targeted therapies is lacking. This is the perspective of a white paper developed by Digestive Cancers Europe, an umbrella organisation representing European patient organisations. It has been developed after consultation with pancreatic cancer patients, representatives of cancer patient organisations and leading pancreatic cancer healthcare professionals. The purpose of the paper is to highlight the key urgent unmet needs in pancreatic cancer from the patient perspective, ultimately with a view to improve patient care and outcomes in this very challenging disease.

Keywords

cancer, medical education, patient engagement, patient feedback, quality of life, quality improvement

The voice of pancreatic cancer patients has gone unheard for too long.

There is a wealth of information about patient experience and preferences in other digestive cancers. But in comparison, there is a stark lack of focus on the experience and needs of those with pancreatic cancer.

Sadly, a key reason there are fewer prominent patient voices in pancreatic cancer compared to other cancers is that it has the lowest survival rate of all common cancers, with an average life expectancy at the time of diagnosis of 5 months (1). Around 92% of patients die within 5 years of their diagnosis (2). Very little progress has been registered in improving survival rates in pancreatic cancer (3).

Digestive Cancers Europe (DiCE)—a European umbrella organisation of national members representing patients with digestive cancer—aims to help amplify the voice of those affected, evidence their needs, and urge governments and policymakers to take urgent action on their behalf. Recently, both a paper published by the United European Gastroenterology and an editorial in the *Lancet Gastroenterology Hepatology*

have declared that pancreatic cancer is “a state of emergency” (4,5). Pancreatic cancer is the fourth most common cause of cancer death in the European Union, accounting for around 90,000 deaths in 2020 (6). Factors that may increase the risk of pancreatic cancer include smoking, obesity, diabetes

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mellitus, chronic pancreatitis, and a family history of pancreatic cancer (7). The incidence is expected to rise in the future, partly driven by the increase in obesity and type 2 diabetes mellitus (8). Obese people (body mass index of 30 or more) are about 20% more likely to develop pancreatic cancer (7), while long-term type 2 diabetes mellitus is associated with a 1.5- to 2.0-fold increase in the risk of pancreatic cancer (9). Chronic pancreatitis, which significantly increases the risk of pancreatic cancer (10), is a major public health issue worldwide, with alcohol consumption an important risk factor (11).

Meanwhile, it is thought that up to 10% of pancreatic cancer cases are linked to genetic conditions (12). Individuals with mutations in the BRCA2, PALB2, p16, STK11, ATM, PRSS1, and HNPCC genes are associated with a significantly increased risk for pancreatic cancer (13).

One of the major reasons pancreatic cancer is associated with such poor outcomes is because it is usually diagnosed at a late stage. Surgery is the only potential curative treatment for the disease, but at least 85% of new diagnoses are not candidates for surgery and present a locally advanced or metastatic disease (14). When surgery is not an option, chemotherapy may increase life expectancy and quality of life (15), but has resulted in only small improvements in overall patient's survival (16). New treatment methods such as targeted therapy and immunotherapy need to be further investigated. There are treatments available for patients with certain gene mutations—patients with germline BRCA1/2 mutations for example may benefit from platinum-based chemotherapies or treatment with a PARP-inhibitor (17). However, the overall 5-year survival rate for pancreatic cancer is still very low, at less than 10% (18).

Table 1. DiCE's 10 Recommendations for Improvement in Pancreatic Cancer Patient Outcomes.

Area	Recommendation
1. Awareness	Raise awareness of pancreatic cancer and potential 'red flags' to drive earlier diagnosis
2. Screening	Screen high-risk populations and accelerate referral times
3. Information	Ensure patient information is clear, timely and contains hope
4. Centres of excellence	Ensure that patients are only treated in high-volume specialist centres
5. HCP relationship	Ensure continuity of care for patients, supported by a MDT
6. Treatment	Ensure patients can proactively participate in their own care
7. Support	Ensure patients have access to essential psychological, nutritional and pain relief support as needed
8. Patient organisations	Create environment for national patient organisations to flourish
9. Research	Increase levels of research and funding for pancreatic cancer
10. Data availability	Practice good data collection and sharing

In an area with such significant unmet needs, the challenges may be great, but they can also be seen as opportunities—the scale of the potential impact of any improvements could be significant for patients.

DiCE talked to patients who have survived pancreatic cancer from several European countries including Poland, France, Portugal, UK, and Sweden. DiCE also spoke to patient organisation representatives from 5 countries and health care professionals from 4 countries across Europe including Germany, Sweden, Spain, and Austria. The objective was to collect comprehensive feedback from different perspectives on how these improvements could look like. Based on these discussions and additional research, a 10-point plan has been developed, which represents the patient perspective on what is urgently required to improve overall survival and quality of life.

A 10-Point Plan of Action

The appalling patient outcomes associated with this disease speak for themselves. Not enough progress has been made in this area.

DiCE is calling for action across 10 key areas to help improve awareness, prevention, diagnosis, treatment, and proper management of patients with pancreatic cancer (see Table 1). These action points are in line with the recent political declaration for actions against cancer (19).

1. Awareness: Raise awareness of pancreatic cancer and “red flags” to drive earlier diagnosis

Despite being one of the leading causes of cancer death, there is a general lack of awareness of pancreatic cancer.

This must be urgently addressed because late-stage diagnosis is a major reason for the appalling mortality rate in pancreatic cancer.

It is vital that the public and general practitioners (who act as a gateway to diagnosis and care) are aware of the common symptoms—particularly “red flag” symptoms, such as new-onset diabetes, dysphagia, loss of appetite, weight loss, abdominal or back pain, or abdominal distension (see Figure 1).

2. Screening: Screen high-risk populations and accelerate referral times

A specific screening programme is proposed for individuals with a strong family history of pancreatic cancer and/or genetic susceptibility of developing the condition.

In addition, there is a need to accelerate referral times to ensure patients have the best possible opportunity for effective treatment, including surgical resection.

3. Information: Ensure patient information is clear, timely, and contains hope

Every European citizen has the right to the most accurate information and to be proactively involved in his/her care.

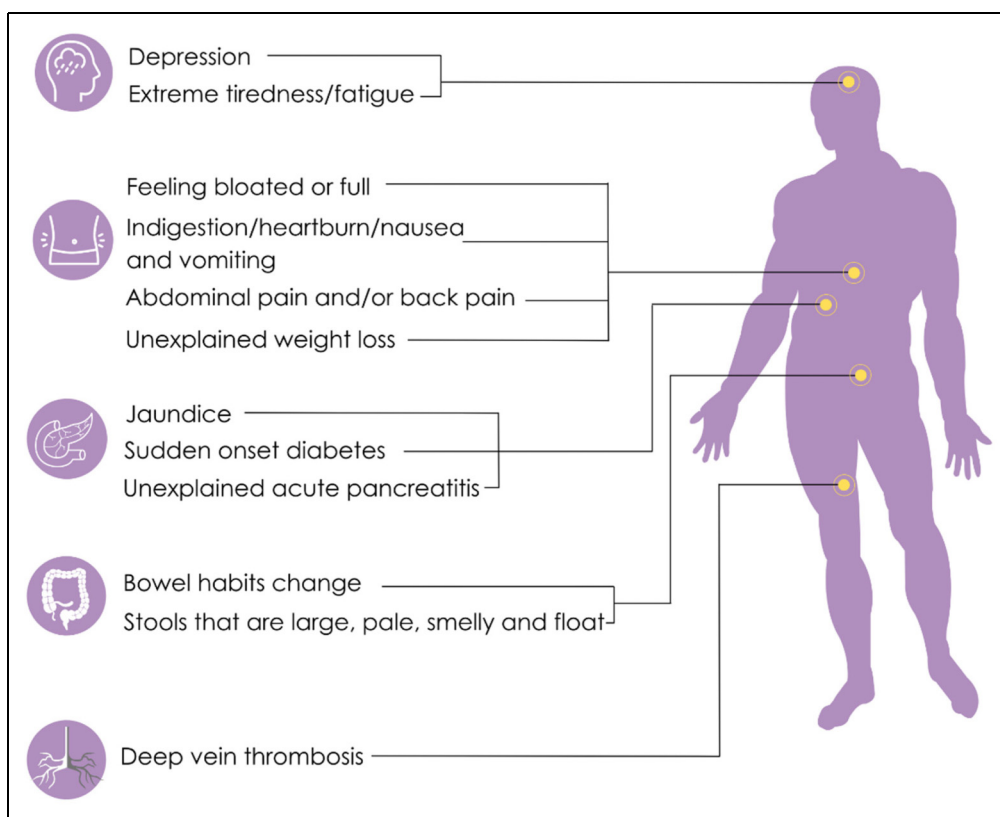


Figure 1. “Red flag” signs and symptoms of pancreatic cancer.

Information should be clear and timely, and in a tone that offers hope in the context of the facts. Too much publicly available information on pancreatic cancer is very bleak for newly diagnosed patients (and their loved ones) to read.

4. Centres of excellence: Ensure that patients are only treated in high-volume specialist centres

Diagnosis and management of pancreatic cancer is more complex than most other diseases and it involves multiple clinical investigations and tests from different specialists. This is why referral to a high-volume specialised centre under the management of a multidisciplinary team (MDT) to determine the best treatment plan for each individual is so essential.

5. Health care professional relationship: Ensure continuity of care for patients supported by MDT

Pancreatic cancer is a complex disease requiring a multitude of different healthcare professionals (in an MDT). However, having an element of relationship continuity is highly valued by both patients and clinicians, and it may lead to more satisfied patients and staff, reduced costs, and better health outcomes.

6. Treatment: Ensure patients can proactively participate in their own care

Patients should have the right to access all information regarding their state of health and to proactively participate in decision making regarding their treatment. They should have all realistic options open to them—which may include surgery, chemotherapy, and/or participating in clinical trials.

It is also important to ensure patients are constantly assessed by the MDT/tumour board as the situation can change very quickly.

7. Support: Ensure patients have access to essential psychological, nutritional and pain relief support as needed

Pancreatic cancer and its treatment can lead to a range of other problems for which patients need, but don't always receive, support.

Many people with pancreatic cancer have high levels of anxiety and depression and reduced quality of life. Many suffer from significant weight loss, sometimes from cachexia (multifactorial syndrome defined by an ongoing loss of skeletal muscle mass). Pain in the abdomen (belly) or back is common. Patients should receive support as standard for these common issues.

8. Patient organisations: Create environment for national patient organisations to flourish, including via proper funding

Cancer patient organisations play a significant role, from raising awareness, providing guidance, and advice to patients, to acting as an advocate and champion.

However, in part due to the high mortality of pancreatic cancer and thus the lack of survivors, there are very few pancreatic cancer patient organisations in Europe. Lack of funding and support is also a major issue.

It is essential that national patient organisations are given all the support required to start and to flourish and to play an active role in patient care.

9. Research: Increase levels of research and funding for pancreatic cancer

There are still many unanswered questions about the biology and aetiology of pancreatic cancer; in particular, the discovery of biomarkers that will aid earlier detection of pancreatic cancer and a more precise definition/understanding of “high-risk populations.”

There is a need to encourage international exchanges to improve our knowledge of the disease. Funding also needs to be urgently increased.

10. Data availability: Practice good data collection and sharing

Only a few countries have established clinical registries capable of benchmarking pancreatic cancer care and there is little historical pan-European cooperation on establishing comparable indicators. This needs to change.

Conclusion

There is no common cancer with so many areas of urgent unmet need as pancreatic cancer.

The appalling patient outcomes associated with this disease speak for themselves. Not enough progress has been made in recent years.

DiCE is calling for governments and policymakers to act now across all 10 key areas to help improve awareness, diagnosis, treatment, and management of patients with pancreatic cancer.

The time for action is now.

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