

OPTIMISTIC - Optimising care and support for people with inoperable pancreatic cancer – patient and family carer perspectives

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Aims of research

This research highlights the care experiences of people affected by inoperable pancreatic cancer and explores how their care and support could be optimised. While only patient and family carer (FC) findings are presented here, the study also considered the experiences of HCPs in delivering supportive care to patients and their FCs in order to identify the challenges in providing optimal care.

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Methods

Qualitative research using an intrinsic case study design - the 'case' being the delivery of supportive care for people affected by inoperable pancreatic cancer.

36 semi-structured interviews with patients (13) and FCs (12) - participants interviewed more than once, where possible. 7 patients took part in separate interviews, 6 in joint interviews with their FC.

Participants recruited via 5 NHS sites, specialist charity and social media. Data analysis using Framework Approach (Ritchie and Lewis, 2003) and Fitch's Supportive Care Framework (1994) used as theoretical framework.

Findings from patient and FC interviews

GAPS

Information needs on all aspects of care and across cancer trajectory

Care co-ordination sub-optimal at 3 timepoints – point of diagnosis, transition from active treatment to palliative care, transition to EoL care; and sub-optimal out of acute sector

Few HNAs undertaken so limited assessment of psychosocial and emotional needs

No evidence of fast-track pathways for access to supportive care services i.e. specialist dietetics, psychological support etc.

Primary and community care sectors unable to support these patients effectively without better liaison and information sharing with acute sector specialists

Heavy caring burden on FCs but no evidence of routine assessment of their needs

'...and we were just left with a thousand questions and no answers really.'

'...no doctor had come to the house, no nurse had come to the house, it was really a lot of being left to sort of get on with it a bit.'

Conclusion

The findings demonstrate that people affected by inoperable pancreatic cancer are not receiving optimal supportive care. Several issues are amenable to improvement such as addressing variation in practice, improving poor or suboptimal communication practices, clarifying roles and responsibilities, and improving co-ordination of care. Workforce capacity and staff shortages were identified as significant issues however that require long-term national policy solutions.

Recommendations

Better information provision
Earlier access to CNS
Primary care access to specialists
Enhanced information sharing
Fast-track pathways to services
Increased referrals to community palliative care
Better support for FCs
Enhanced HCP communication skills.