

## ORIGINAL ARTICLE

# A qualitative study of patient and clinician attitudes regarding surveillance after a resection of pancreatic and peri-ampullary cancer

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## Abstract

**Background:** After surgical resection of pancreatic adenocarcinoma, most patients will develop recurrence within 2 years. Intense follow-up is often recommended; however, its impact on survival is unknown. Patient and clinician attitudes towards follow-up were qualitatively assessed along with the perceived benefits and challenges.

**Methods:** A semi-structured interview guide was developed. Purposive sampling identified patients who were in active surveillance or had developed recurrence. Clinicians involved in patient care were also interviewed. Interviews were conducted until saturation was reached and themes were derived using standard qualitative methods.

**Results:** A total of 15 patients and seven clinicians were interviewed. Patient themes included a limited understanding of disease prognosis, a desire for reassurance, a desire to know if and when recurrence occurred and minimal difficulties with follow-up. Clinician themes included expectation that patients are aware of the recurrence risk, a desire to provide reassurance, support for intense follow-up and perceived patient challenges in follow-up. Overall, the dominant theme was one of disconnect between patients and clinicians in the understanding of the disease and its prognosis.

**Discussion:** Patients have an intense need for reassurance and obtain this through follow-up appointments with their oncologists. Consequently, they express few difficulties with the process. Clinicians recognize this desire for reassurance. Patients' understanding and expectations contrast starkly with clinicians' perspectives regarding prognosis.

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## Introduction

Pancreatic ductal adenocarcinoma is the 12<sup>th</sup> most common cancer in Canada and the United States; however, it is the 4<sup>th</sup> leading cause of cancer death.<sup>1,2</sup> While surgery remains the only potentially curative treatment, after resection the 5-year survival rates remain

low at 5–27%.<sup>3–6</sup> Unfortunately 80% of patients with pancreatic cancer will develop a recurrence within the first 2 years after a resection, for which there are no curative treatment options.<sup>7–9</sup> Palliative chemotherapy improves survival in those with a good performance status; however, the median survival after recurrence only ranges from 6 to 12 months.<sup>10</sup> Clinical trials are therefore strongly recommended and best supportive care remains a valid option<sup>10</sup> for those who are not fit for chemotherapy. There is no compelling evidence to suggest that early detection of recurrence or early initiation of treatment impacts survival.

Some clinicians advocate for intensive surveillance after a resection of pancreatic cancer owing to the high risk of recurrence.<sup>10–12</sup>

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The National Comprehensive Cancer Network (NCCN) recommends a history and physical examination, laboratory investigations (including Ca19-9) and computed tomography (CT) every 3 to 6 months for the first 2 years and then annually.<sup>10</sup> No randomized controlled trials have evaluated the benefit of intensive follow-up and data from observational studies have been conflicting.<sup>11,13</sup> A recent analysis suggests that a less intensive protocol with no routine imaging is the most cost-effective surveillance protocol.<sup>14</sup> It should be noted that none of these studies evaluated the benefit of follow-up in the setting of clinical trials, where there may be other potential benefits to an intensive follow-up plan. However, given the lack of strong supporting evidence towards a follow-up protocol, current guidelines are poorly followed.<sup>15</sup>

Intensive surveillance carries the potential for harm. Patients undergoing follow-up testing exhibit significant anxiety and fear of cancer recurrence, with a substantial impact on quality of life.<sup>16–18</sup> False-positive test results followed by additional invasive testing may perpetuate harm to the patients undergoing intensive surveillance.<sup>19</sup> Beyond individual patient harm, there are resource consequences to intensive follow-up and surveillance.<sup>19–22</sup>

In spite of the high risk of recurrence, the intense follow-up strategies, and the potential consequences of such regimens, no qualitative study has previously investigated patient understanding and the impact of surveillance on patients with pancreatic cancer. This study sought to assess patient and clinician experiences, expectations and attitudes towards surveillance after resection of pancreatic and peri-ampullary cancer.

## Patients and methods

### Participants

Patients were recruited from a specialized Hepato-pancreato-biliary clinic at the Odette Cancer Centre (OCC), a tertiary cancer centre at Sunnybrook Health Sciences Centre (SHSC), from November 2012 to March 2013. Consecutive eligible patients who had undergone surgical resection of pancreatic or peri-ampullary adenocarcinoma with curative intent and were undergoing surveillance or had developed recurrence were identified for inclusion in the study. No patient was enrolled into a clinical trial as none was being conducted during the study period. No standardized patient education material, support group or follow-up protocol was available during this period. In keeping with the qualitative research design, the sample size was expanded as necessary until redundancy on core issues, known as saturation, was observed.<sup>23–26</sup> Informed consent was obtained from each participant prior to the interview. No additional educational materials were given to patients beyond that required to obtain informed consent. This study was approved by the SHSC Research Ethics Board.

### Data collection

Each patient completed a questionnaire to supply demographic and general follow-up information. Pathological information was obtained through retrospective chart review.

Qualitative methodology and Content Analysis (CA) directed the generation of the interview guide, data collection and data analysis. Data collection was accomplished through private semi-structured interviews to encourage honest opinions and allow for discussion of sensitive issues.<sup>23</sup> Patients were encouraged to bring a support person, such as a family member; however, the family member was not interviewed. A single trained researcher (E.C.), who was not involved in the clinical care of these patients, conducted all the interviews using a semi-structured interview guide. The interview guide was piloted during the first three interviews.<sup>23</sup> The interview guide was adjusted to ensure all areas of interest were addressed. Interviews were conducted once per participant.

All clinicians in radiation oncology, medical oncology and surgical oncology involved in treating pancreatic adenocarcinoma, except for those directly involved in this study, were invited to participate. Semi-structured interviews were conducted with the clinicians by a single interviewer (E.C.) using a different interview guide.

The interviewer made notes concerning important interactions, mood or tone of responses, and any other non-verbal behaviour for both sets of interviews.<sup>23</sup>

### Statistical analysis

Interviews were transcribed verbatim and CA was used to analyse the data. This is an iterative approach which involves multiple readings of the transcripts; simultaneous data collection and analysis generates a coding schema reflecting unique ideas.<sup>25–28</sup> Constant comparative analysis of the schema allowed similar concepts to be grouped together into larger themes driving the research towards an overarching theory or theme construction.<sup>24–28</sup> Interviews were coded independently by three investigators (E.C., R.D. and F.C.W.), findings were discussed with the entire research team and consensus of interpretation was achieved. One dominant theme or overarching theory was identified. Descriptive statistical analysis of participant demographics and clinical characteristics was performed.

## Results

### Patient characteristics

Seventeen patients were invited to participate in the study; however, one patient was excluded after the interview owing to a different histological presentation (intraductal papillary mucinous neoplasm) and one patient declined to participate as a result of physical discomfort. Fifteen patients were included in the analysis. The median time from pancreatic cancer resection to the interview was 247 days (range 41 to 1140). Patient demographic and follow-up data are included in Table 1. Three patients had been diagnosed with recurrence whereas the remaining 12 had no evidence of disease. Patient pathology and treatment data are included in Table 2.

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