

Mapping the Knowledge on Coping Processes in Patients with Pancreatic Cancer: A Scoping Review Protocol

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ABSTRACT

Background: Pancreatic cancer is one of the malignant diseases with the highest cancer-specific mortality. At the time of diagnosis, life expectancy is often already very limited, as it is usually discovered late and in an advanced stage. Coping with cancer is a complex process. Coping strategies of patients with pancreatic cancer probably differ from those of other malignancies. Yet to date, there exists no pancreatic cancer-specific coping model.

Objective: The objective of this scoping review is to explore and characterize the academic literature related to coping processes in patients with pancreatic cancer.

Methods/Design: The JBI's three-step search strategy, combined with the Arksey and O'Malley framework, will be used to identify articles via PubMed/MEDLINE, CINAHL, Cochrane Library, Google Scholar, CAMbase, CareLit, CC Med, Scopus, and PsycARTICLES (Arksey & O'Malley, 2005; Peters et al., 2017). It follows the PRISMA guidelines for scoping reviews (Tricco et al., 2018). Primary and secondary studies and reviews which report on coping with pancreatic cancer (adenocarcinoma) in adults in English or German language will be included in this scoping review, regardless of publication date or study design.

Discussion: This scoping review will add new insights on coping with pancreatic cancer by summarizing current knowledge, and identifying research gaps. Findings may be used as a foundation for future research.

Systematic review registration: Open Science Framework (<https://osf.io/ug3sf>).

Keywords: Pancreatic cancer, Pancreatic adenocarcinoma, Coping, Adaptation, Cancer survival, Scoping Review, Protocol

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1. Background

Pancreatic adenocarcinoma, which causes 95% of pancreatic cancer cases, is among the malignancies with the highest cancer-specific mortality (Oettle et al., 2018). This disease has an overall five-year survival rate of only approximately 10% in Germany (Robert Koch-Institut & Gesellschaft der epidemiologischen Krebsregister in Deutschland e.V., 2017). In only approximately 15–20% of cases, a potentially curative therapy (R0 resection) with a five-year survival rate of approximately 20% may be considered (Ducreux et al., 2015). The median survival time in advanced stages depends on the extent to which the tumour has grown and spread; regarding locally advanced cancer, the average survival time is less than one year (Huang et al., 2018), but new treatment regimens may extend the time to approximately two years (Suker et al., 2016). Regarding metastatic pancreatic tumours, the most prevalent stage at diagnosis, the average survival time is less than six months (Huang et al., 2018). Patient and institutional factors may influence care delivery and outcomes (Gagliardi et al., 2016).

Pancreatic cancer – like many other tumour diseases - suddenly and unexpectedly plunges those affected into a fundamental life crisis. A cancer diagnosis is an enormous emotional shock and is equivalent to a catastrophe, or a "disruptive event" (Bury, 1982), as the diagnosis impacts different dimensions of patients' lives, including psychological, social, physical, and spiritual dimensions (MacDonald, 2001). Patients never forget the day of their diagnosis (Federspiel & Schiffner-Backhaus, 1999).

To understand the processes that patients go through when confronted with a serious illness and to make these processes comprehensible and tangible to outsiders, several adaptation models have been developed in recent years in various disciplines. Frequently applied approaches include the adaptation model proposed by Roy (Roy & Roberts, 1981), the trajectory model developed by Corbin and Strauss (Corbin & Strauss, 1991), the illness constellation model of Morse and Johnson (Morse, 1991), and the shifting perspectives model created by Paterson (Paterson, 2001).

Since the mid-1980s, research on disease behaviour has shifted to research on coping behaviour. Lazarus and Folkman (Lazarus & Folkman, 1984) provided probably the best known definition of coping with disease. According to their definition, coping is "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). This definition largely encompasses what is now subsumed under the term "coping" (Schüßler, 2000). Coping is a complex process and is determined by various socio-cultural, psychological and medical variables (Barroilhet Díez et al., 2005).

Since the proposal of Lazarus and Folkman's definition, dealing with a disease has been linked to a success criterion: patients dealing with their disease as successfully as possible to cope with it. Furthermore, it can be stated that coping models attempt to categorise patients into two groups: those with successful coping processes and those without them. In summary, one could also distinguish "good" from "bad" coping. However, this approach unnecessarily prevents a close look at the various ways of dealing with one's own illness (Franke, 2012). Nevertheless, coping with illness is currently usually seen as a transactional process: The perception of, evaluation of and response to a disease have an effect on the state of the disease, its perception and coping, and coping with a disease is considered to be multidimensional and characterized by various conditions (Schüßler, 2000).

As Halldorsdottir and Hamrin stated, it is important that health professionals develop a better sense of what it means to go through existential human experiences from a patient's perspective. This sense might enable health professionals to better handle being confronted

with patients' pain, shame or existential experiences (Halldorsdottir & Hamrin, 1996). Therefore, a study describing the cancer experience from the patient perspective should serve to increase awareness and understanding of this experience among health professionals (MacDonald, 2001).

Although the coping strategies of cancer patients have been studied (Carver, 2005; Stanton et al., 2005) and some disease-specific models, e.g., models for lung or breast cancer, exist (Mehrabian et al., 2015; Mosher et al., 2015), limited research has focused on pancreatic cancer patients. A corresponding model for coping with pancreatic cancer is still lacking, although there is already much evidence on some influencing variables and procedures (e.g. on pancreatectomy, see Lounis et al., 2019; Scholten et al., 2019). This is particularly noteworthy, as the currently available theories and models cannot simply be applied to pancreatic cancer.

It is quite possible that the coping strategies of pancreatic cancer patients differ from those of other cancer patients, as pancreatic cancer patients are usually confronted with the fast progress of their disease due to late detection at an advanced stage and intensive medical treatments (McGuigan et al., 2018). In many cases, pancreatic cancer patients must deal with major changes in their health status within a short time before, during and, in some cases, after treatment, which often have a restrictive effect on their living conditions (e.g. Herman et al., 2019).

It should be noted that those affected have many informational and supportive care needs regarding symptom management and communication with health care providers. They worry about loved ones and the uncertainty of the future (Beesley et al., 2016).

As Jia et al. stated, cancer-related depression is a frequent psychological disorder in people suffering from pancreatic cancer. Its incidence is significantly higher among pancreatic patients (78.0%) than among patients with other gastrointestinal malignancies, such as liver cancer (60.0%), gastric cancer (36.0%) or colorectal cancer (19.2%). Additionally, depression significantly lowers the Quality of Life (QoL) of pancreatic cancer patients (Jia et al., 2010). The quality of life of people with pancreatic cancer is also worse compared to patients with other types of cancer (Bauer et al., 2018).

Patients must adjust to and deal with these challenges, but it is unclear whether and in what ways coping processes are possible due to the often limited life expectancy associated with this type of cancer. It can be assumed that in many cases, patients have no or only very short stable phases due to the abovementioned short survival times. Furthermore, only a few people with pancreatic cancer enter a chronic phase, while there are increasing numbers of survivors of other types of cancer (Miller et al., 2019; Parry et al., 2011; Phillips & Currow, 2010).

In a recent meta-review published in 2019, Laidsaar-Powell et al. analysed current strengths and evidence gaps in qualitative research on adult cancer survivors (2019). They found that breast and gynaecological cancer survivors are strongly represented in current research. Gaps in evidence synthesis include reviews for other common cancers (e.g., lung, colorectal and melanoma, and haematological) as well as survivorship topic areas. In particular, Laidsaar-Powell et al. identified no systematic reviews of the survival of people with pancreatic cancer published between 1950 and 2018. To use the experiences of cancer survivors as a basis for guiding the development of interventions and giving others insight into the experiences and challenges of cancer patients, more research is needed.

In August 2020, an exploratory scan of previously published reviews on coping processes in patients with pancreatic cancer in PubMed, CINAHL and Cochrane Libraries yielded no results. The search strategy applied is shown below in Table 1.

Table 1. Exploratory scan on previously published (scoping) reviews on coping processes in patients with pancreatic cancer.

DATABASE	SEARCH STRATEGY	FILTERS APPLIED	RESULTS	PAPERS MATCHING THE ScR'S QUESTION
PubMed	((((((("pancreatic neoplasms"[MeSH Terms]) OR ("pancreatic neoplasm*")) OR ("pancreatic malignanc*")) OR ("pancreatic adenocarcinoma")) OR ("pancreatic tumor*")) OR ("pancreatic tumour*")) OR ("pancreatic carcinoma")) OR ("pancreatic cancer")) AND (((behavior, coping[MeSH Terms]) OR (behaviors, coping[MeSH Terms])) OR (adaptation, psychological[MeSH Terms])) OR (coping))	Review, Systematic Review	8	0
CINAHL	((pancreatic neoplasm* OR (pancreatic malignanc*)OR (pancreatic adenocarcinoma) OR (pancreatic tumor*) OR (pancreatic tumour*) OR (pancreatic carcinoma) OR (pancreatic cancer)) AND ((psychological adaptation) OR (coping))) AND (review)	none	3	0
Cochrane Library	((pancreatic neoplasm* OR (pancreatic malignanc*) OR (pancreatic adenocarcinoma) OR (pancreatic tumor*) OR (pancreatic tumour*) OR (pancreatic carcinoma) OR (pancreatic cancer) OR (MeSH descriptor: [Carcinoma, Pancreatic Ductal] explode all trees)) AND ((psychological adaptation) OR (coping) OR (MeSH descriptor: [Adaptation, Psychological] explode all trees))	Cochrane Reviews	1	0

As a result, conduction of a scoping review seems appropriate to summarise knowledge on the coping processes in people with pancreatic cancer, as it can be used to map the key concepts that underpin a field of research (Arksey & O'Malley, 2005). Therefore, the following research question is intended to answer:

What is currently known about coping processes in patients with pancreatic cancer?

The scoping review outlined in this paper aims to explore the knowledge on coping processes in patients with pancreatic cancer. The methodological approach, objectives, search strategies, selection processes, and reporting are described in the following sections.

2. Methods/Design

2.1 Protocol design

This scoping review protocol was prospectively registered in the Open Science Framework to guarantee good scientific practice and transparency regarding both the research process and the future findings. The protocol can be found there at <https://osf.io/ug3sf>. It is reported in accordance with the reporting guidelines outlined in the Preferred Reporting Items

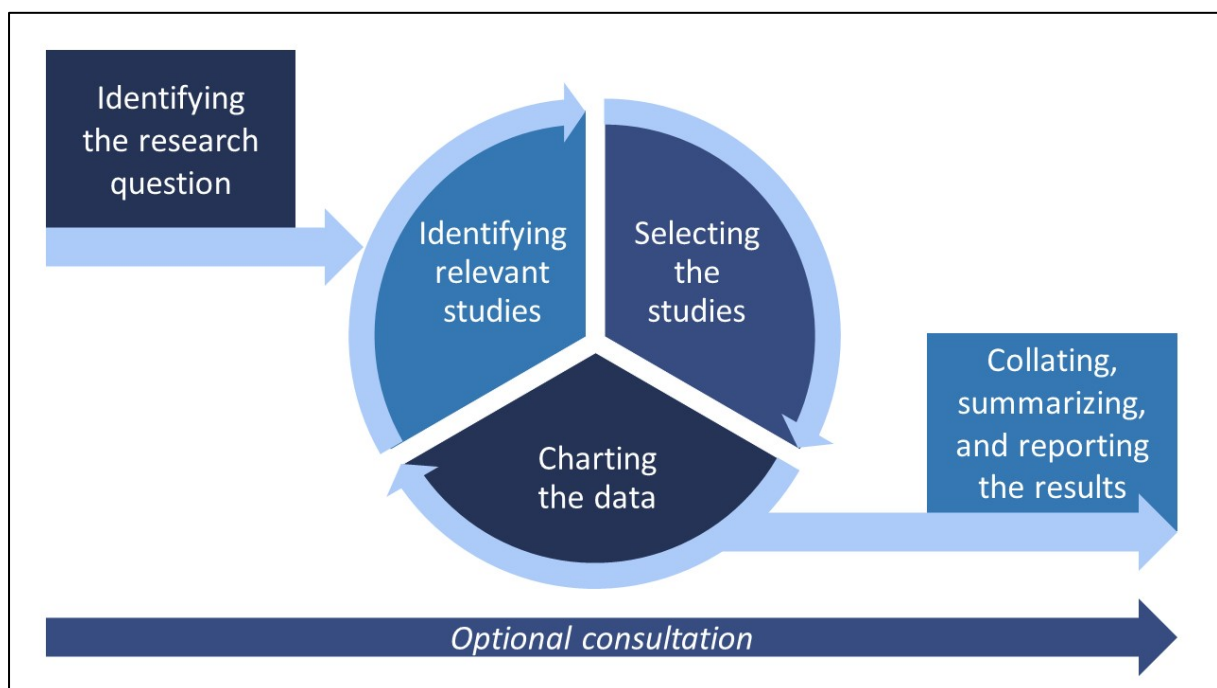
for Systematic Review and Meta-Analysis Protocols (PRISMA-P) (Moher et al., 2015) statement and the PRISMA Extension for Scoping Reviews (PRISMA-ScR) (Tricco et al., 2018). This study does not require ethical approval, as the scoping review methodology is based on the collection and review of data from publicly available sources instead of the collection of new data from humans.

The scoping review will review the existing literature on coping with pancreatic cancer. It will be guided by the methodological framework outlined by Arksey and O'Malley (Arksey & O'Malley, 2005). This framework defines the following six stages to be considered when developing a scoping review:

1. Identifying the research question,
2. Identifying relevant studies,
3. Selecting the studies,
4. Charting the data, and
5. Collating, summarising, and reporting the results.

Stages 2, 3 and 4 proceed as an iterative process. Throughout the entire process of the scoping review, it may be necessary and useful to seek optional expert consultation or consultation with relevant stakeholders. The process of the scoping review is shown in Figure 2 based on the framework of Arksey and O'Malley (Arksey & O'Malley, 2005).

Figure 1. Process of scoping review. Own illustration according to Arksey and O'Malley 2005.



The stages and how they will be applied in the proposed scoping review are discussed below.

Stage 1. Identifying the research question:

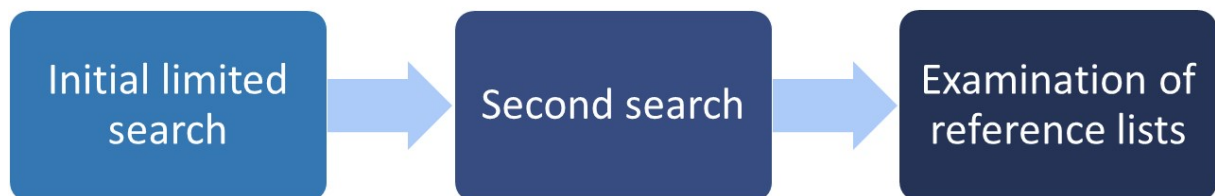
Based on an initial scan of the existing literature and the presentation of results in the background section, the following research question was developed: *What is currently known about coping processes in patients with pancreatic cancer?*

This question will be answered through the scoping review outlined in this paper. The aim of the scoping review is to summarise knowledge on the coping processes in people with pancreatic cancer and to disseminate research findings in medicine and health sciences through scientific publications and presentations. Gaps in the current research literature on coping with pancreatic cancer will also be identified. The results will be used as a foundation for developing methodological ideas and theoretical approaches to future research studies on coping with pancreatic cancer (Arksey & O'Malley, 2005; Coughlan & Cronin, 2017; Peters et al., 2017).

Stage 2. Identifying relevant studies:

The three-step search strategy recommended by the Joanna Briggs Institute (JBI) will be applied in this scoping review (Peters et al., 2017). This strategy is illustrated in Figure 3.

Figure 2. Three-step search strategy according to the JBI (Peters et al., 2017).



As a first step, the PubMed, CINAHL, and Cochrane Library databases will be searched. Titles, abstracts, and index terms of the hits retrieved will be analysed regarding possible search terms.

As a second step, all databases (PubMed, CINAHL, and Cochrane Library, Google Scholar, CAMbase, CareLit, CC Med, Scopus, and PsycARTICLES) will be scanned with the keywords and index terms identified. These scientific databases were chosen for their relevance to specific professions, because they reflect the multidisciplinary nature of the phenomenon of interest, and because they are freely accessible or can often be accessed by researchers through their universities. No date limits will be imposed on the search strategy. Boolean terms, such as “AND”, “OR” and “NOT”, will be used to separate and combine keywords when applicable. An example search strategy for PubMed and results of a pilot search run carried out on August 15, 2020 are illustrated in Table 2. Optional consultation by a librarian might be sought to improve the search strategy.

Table 2. Draft of the PubMed search strategy.

SEARCH NUMBER	SEARCH TERMS/COMBINATIONS	RESULTS OF A PILOT SEARCH RUN IN AUGUST 2020
#1	"pancreatic neoplasm"	74,048
#3	"pancreatic adenocarcinoma"	7,290
#4	"pancreatic tumor*"	7,497
#5	"pancreatic tumour*"	1,259
#6	"pancreatic carcinoma"	7,690
#7	"pancreatic cancer"	38,833
#8	"Pancreatic Neoplasms"[Mesh]	76,159
#9	((("pancreatic neoplasm*") OR ("pancreatic adenocarcinoma") OR ("pancreatic tumor*") OR ("pancreatic tumour*") OR ("pancreatic neoplasms"[MeSH Terms]) OR ("pancreatic cancer"))	91,933
#6	behavior, coping[MeSH Terms]	127,203
#7	behaviors, coping[MeSH Terms]	127,203
#8	adaptation, psychological[MeSH Terms]	127,203
#9	"coping"	55,392
#10	"disease burden"	14,617
#12	((((behavior, coping[MeSH Terms]) OR (behaviors, coping[MeSH Terms])) OR (adaptation, psychological[MeSH Terms])) OR ("coping")) OR ("disease burden")	170,189
#13	(((((("pancreatic neoplasm*") OR ("pancreatic adenocarcinoma") OR ("pancreatic tumor*") OR ("pancreatic tumour*") OR ("pancreatic neoplasms"[MeSH Terms]) OR ("pancreatic carcinoma") OR ("pancreatic cancer")) AND (((behavior, coping[MeSH Terms]) OR (behaviors, coping[MeSH Terms]) OR (adaptation, psychological[MeSH Terms])) OR ("coping")) OR ("disease burden"))	107
FILTERS	none	

As the third and last step of this stage, the reference lists of the included studies will be browsed for potential additional studies. The search will be limited to the reference lists of those articles that have been included in the scoping review.

The Population, Concept, Context (PCC) framework, which is recommended by the JBI, (Peters et al., 2017) will be used to align the study selection with the research question.

Table 3. PCC framework based on recommendations by JBI (Peters et al., 2017).

PCC ELEMENT	DEFINITION
P – POPULATION	Adults with pancreatic cancer (adenocarcinoma) at any stages and with any therapeutic goals
C – CONCEPT	Coping with pancreatic cancer
C – CONTEXT	Including all study designs on coping with pancreatic cancer in English or German language, no restrictions on setting or date or study design

Stage 2 inclusion and exclusion criteria:

To be included in the scoping review, papers will need to report on people coping with pancreatic cancer. As approximately 95% of the cases of pancreatic cancer are pancreatic adenocarcinoma (Oettle et al., 2018), it can be assumed that the articles will also refer to this type of cancer unless clearly stated otherwise. Journal papers will be included if they are written in English or German language. Papers on quantitative, qualitative and mixed-method studies will be included as well as those on primary or secondary studies and reviews to include all available knowledge on the research topic knowledge (e.g., coping with therapy effects within the context of drug approval and side effect studies and spirituality and faith within the context of qualitative studies).

Papers will be excluded if they do not align with the conceptual framework or if they focus on another (pancreatic) disease. Furthermore, studies that clearly focus on tumour entities other than pancreatic adenocarcinoma will be excluded. In addition, letters, comments, opinions, discussion papers, websites, etc., that have not been published in journals as well as studies that do not have an abstract available will not be considered.

There will be no limitations on the timeframe or study design and no restrictions regarding therapy goals or strategies.

In addition to the inclusion criteria, the exclusion criteria are listed in Table 4 below.

Table 4. Inclusion and exclusion criteria.

	INCLUSION CRITERIA	EXCLUSION CRITERIA
POPULATION	Adults living with pancreatic carcinoma	People with all other types of (pancreatic) diseases
LANGUAGE	English or German	All other languages
TYPE OF ARTICLE	Primary and secondary studies and reviews	Unpublished studies or studies with no abstract available, commentaries or opinions, letters, discussion papers, websites
STUDY FOCUS	Studies that report on the coping of people with pancreatic cancer	All other types of studies
TIMEFRAME	<i>No limitations</i>	
STUDY DESIGN	<i>No limitations</i>	

Eligible articles will be imported into Citavi 6 for Windows 10. This software will allow the identification and removal of duplicates through the comparison of titles and, if necessary, abstracts. The software will also be used for managing records, keeping track of articles, and producing a list of references to be included in the final review report.

Stage 3. Selecting the studies:

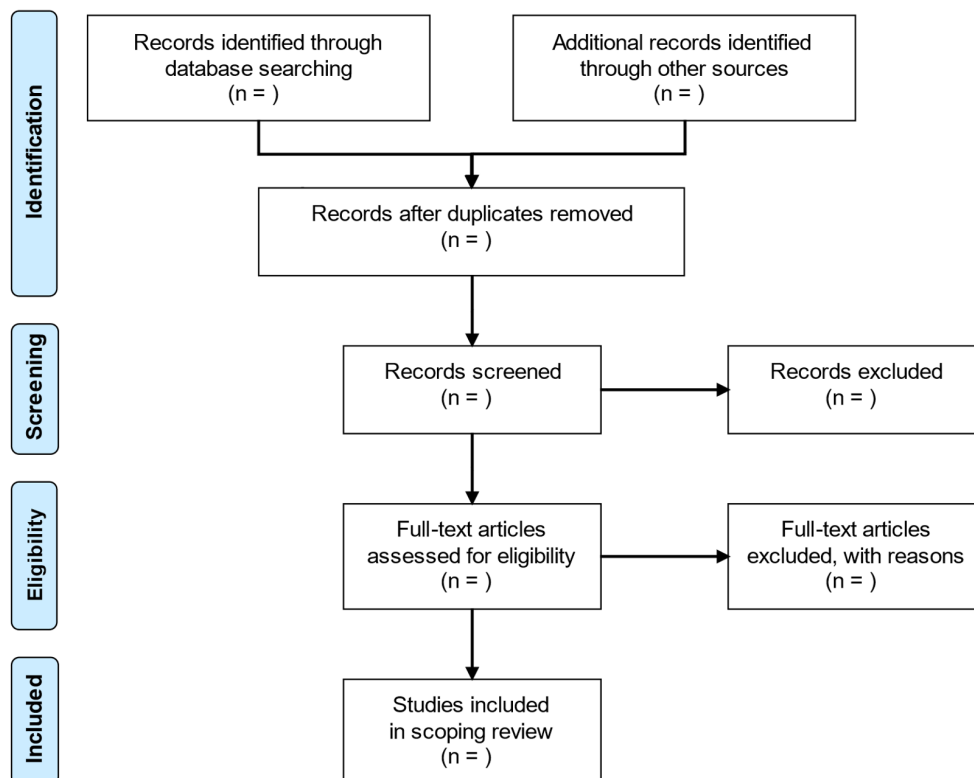
The articles will be systematically selected through a three-stage procedure.

Stage 1: The titles and abstracts of all articles identified in the search will be stored electronically in Citavi 6.5 and reviewed by the first author. For this purpose, a previously prepared checklist will be used. To validate the selection process, at least 10% of the articles will be reviewed by another independent reviewer. This process will continue until the two reviewers have reached a common understanding of how to apply the inclusion criteria and resolved any disagreement on the inclusion of publications.

Step 2: Next, the remaining articles will be stored electronically in Citavi 6.5 in full text and evaluated in detail according to the inclusion and exclusion criteria by the first author. As in step 1, the checklist will be used. Furthermore, another reviewer will second-screen articles in the same manner as described above until all disagreements have been resolved and both authors have reached full agreement on the application of the inclusion criteria.

Step 3: The first author will refer any articles about which he is uncertain regarding their inclusion to a supervisor for review. The research output derived from the various steps will be illustrated in a PRISMA flow chart (Moher et al., 2009). A draft is presented in Figure 1. Methodological quality will not be evaluated in accordance with the scoping review methodology (Peters et al., 2017).

Figure 3: Draft of the PRISMA flow chart (Moher et al., 2009).



Stage 4: Charting the data:

Key pieces of information from the abstracts of the selected articles will be collected and organised. Standard data items will be extracted and reported. These items will include bibliographical information (author, title, journal, year of publication, and language), objectives of the paper, target population and setting, type of study, and country/region where the study was conducted. A draft of the data charting form is shown in Table 4.

Table 5. Data extraction framework.

CATEGORY	SUB-CATEGORY	DESCRIPTION
BIBLIOGRAPHICAL INFORMATION	Author	
	Title	
	Journal	
	Year of publication	
	Language	
OBJECTIVES OF THE PAPER		Description of the study objectives
TARGET POPULATION		E.g., specific age groups, gender, therapy regime
SETTING		E.g., inpatient/outpatient, palliative/curative
TYPE OF STUDY		Qualitative, quantitative or review (and possibly specification)
COUNTRY/REGION		Where the study was conducted
MAIN FINDINGS		Main findings or key points of the paper

To ensure that the coding framework is consistently applicable, the framework will be pilot tested on a sample (20%) of the included studies. Additional categories may emerge during this process. If so, the categories will be modified, and the data extraction framework will be revised. Questions arising during pilot testing will be discussed among the researchers, and possible disagreement will be resolved through team consultations. Missing data may be found in some eligible abstracts. This will be resolved and documented in consultation with team members. The authors of those articles will be contacted via e-mail or ResearchGate if possible in an attempt to obtain the required details. If the authors contacted do not respond to the request within two weeks, the study in question will be noted as having unavailable information. Nevertheless, the study will be included in the results with an appropriate reference to the unavailable information.

Stage 5. Collating, summarising, and reporting the results:

The scoping review outlined in this protocol aims to map the current knowledge of coping in people with pancreatic cancer. The analysis of the data collected using the data extraction framework will help to obtain a deeper understanding of coping processes and the challenges that people confront due to their illness.

The scoping review will present a narrative report of the existing literature. In addition, core results and findings will be presented in a table according to the data extraction framework shown above.

The analysis will provide information about both the existing knowledge and current research gaps and offer an outline of the published research rather than an assessment of the

quality of the relevant studies. It might also provide an overview of existing interventions to support coping processes or possible assistance in overcoming challenges for those affected.

4. Discussion

Within this protocol, we have presented our planned scoping review, which will summarise the present knowledge on the coping processes of people with pancreatic cancer and will aim to identify current gaps in research.

A possible limitation of our approach is that only English and German language articles for which an abstract is available will be included in the scoping review.

The publication of scoping review protocols in advance increases transparency in the description of study methods and enhances the value of results. It also enables peer reviewers and other researchers to make critical comments. The authors will conduct this study as described here but will consider any proposed methodological refinement regarding the objective and purpose of the review in an appropriate manner.

A dissemination of research findings on coping with pancreatic cancer in medicine and the health sciences through the submission of an article for publication to a scientific journal, participation in conferences and presentations will help increase awareness and empathy and provide better care for those affected.

The identification of gaps in the current research literature may provide a foundation for developing methodological ideas and theoretical approaches for future research studies on coping with pancreatic cancer, and could help to improve the quality of care for patients by developing targeted interventions.

List of Abbreviations

JB	Joanna Briggs Institute
PCC	Population, Context, Concept
PRISMA	Preferred Reporting Items for Systematic Review and Meta-Analysis
PRISMA-P	Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols
PRISMA-ScR	PRISMA Extension for Scoping Reviews
QoL	Quality of Life

Declarations

Ethics approval and consent to participate: Not applicable.

Consent for publication: Not applicable.

Availability of data and materials: Not applicable, as no datasets were generated for the development of this protocol.

Competing interests: The authors declare that they have no competing interests.

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Authors' contributions: PR conceived the study, developed the protocol, and drafted the manuscript. COR and AB contributed to the manuscript content according to their fields of expertise. All authors read and approved the final manuscript.

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