

Diagnostic Experiences and Diagnosis Coping in Patients with Pancreatic Cancer

An Empirical Study Focusing on the Qualitative Realities of Lives of People Affected

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Introduction

Every year, up to 19,000 people in Germany are diagnosed with pancreatic tumors, more than 95% of them with adenocarcinoma – the most aggressive type with the highest cancer-specific mortality and a 5-year survival rate of approx. 10%.^{1,2} Delayed diagnosis is associated with a worse outcome.¹

Symptoms are often non-specific.

For about 80% of patients, only palliative therapeutic regimes are possible at the time of diagnosis.¹

"Now you're standing there. In the middle of the week. Something like that. First you could pull out trees and now (...), now you have CANCER."
(A74Ew_29-29)

Purpose

This empirical study³ focuses on individual diagnostic experiences and coping strategies. For this reason, choosing a qualitative research approach was adequate.

Factors that influence successful coping are identified. Furthermore, it is investigated whether already known coping models can be applied to patients with pancreatic cancer.

Methods

After a call to participate in cooperation with a nationwide self-help group (SHG; Fig. 1), theoretical sampling was based on sociodemographic and disease-specific parameters. Twelve participants were recruited and completed approx. 60-minute problem-oriented, guided interviews. Conversations were digitally recorded and then content-semantically⁵ transcribed. One interview could not be transcribed due to technical difficulties. In another case, it became obvious during the interview that the participant had a benign tumor of the pancreas, not an adenocarcinoma. Thus, the interview had to be excluded from the analysis.

The ten remaining data sets were finally evaluated based on the Grounded Theory Methodology according to Strauss and Corbin⁶ using MAXQDA 12. Data saturation was achieved regarding the living environment and situation of people affected, but not regarding coping. The credibility and dependability quality criteria of qualitative research could be fulfilled; transferability and confirmability could be partially fulfilled.

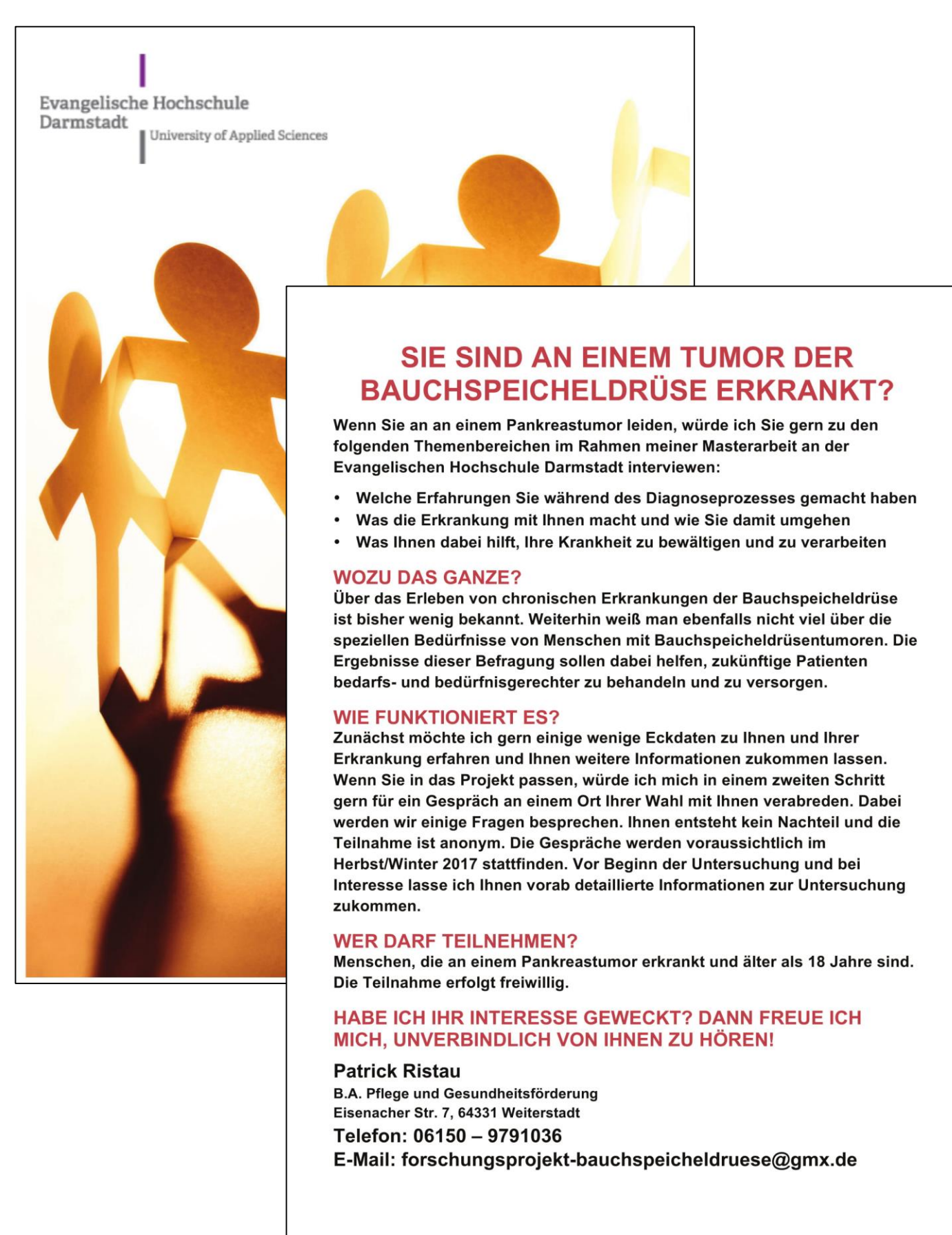


Fig. 1: The call for participants was made online⁴ and via flyers distributed in the group meetings of the SHG. Own illustration.

Ethical Issues and Conflicts of Interest

The Ethics Committee of the German Society of Nursing Science (DGP) assessed ethical and legal admissibility of the research project (request 17-017). There was no project funding. There are no conflicts of interest.

Results

Treatment processes vary, but overall they are sluggish and unsatisfactory.

Patients often complain about an **inadequate flow of information** and a lack of consideration of their own interests in further diagnosis and therapy planning.

The **help and support services offered by hospitals** seem to be little known or poorly accessible. Services are not tai-

lored to the individual needs of patients. Inpatient rehabilitation is often perceived as

inappropriate.

Supply disruptions often occur across sector boundaries: After the inpatient treatment, which is often perceived as a burden, the care of many patients is delayed or breaks off. In some cases, **experienced GPs can avoid this break.**

Following hospital treatment, self-help groups often play a major role in informing and training patients in the absence of health care professionals.

As a result of their illness, those affected are confronted with a multitude of challenges and big questions of life. In many cases, patients suffer from **multi-factorial determined social isolation.**

Coping is often difficult and probably impossible due to rapid disease progression. Currently published theories are not easily applicable.

"So it happened like this in many situations, that I just always got different information. And it was never so certain: What's going on now, right? And that went on - to the end."
(B69Aw_15-15)

"The only thing I mentioned at the hospital: There's all kinds of help in the hospital. But you have to ask for it by yourself. Inform yourself about it."
(L66Lm_37-37)

"Mrs. T. has been our GP, right across the street. That's really great in our case. And she reacted very quickly and immediately made an appointment for a CT scan."
(F75Aw_20-20)

Conclusions and Recommendations

Services provided by professional players in the health care system must be geared more closely to the **individual patient needs**. Shared Decision Making should be used wherever possible. In addition, patients want permanent contacts with sufficient time for their concerns. They wish for interpersonal care and attention from health care professionals.

"I'd HIGHLY have to talk to my GP. But he's least interested anyway. (...) He SKIMS EVERYTHING. (...) I also asked him: 'If there's something wrong with me now, will you visit me at home?' Then he answered: 'NO.'"
(P66Aw1_215-215)

The high demand for information needs to be addressed adequately. Therefore, **contact with self-help groups** is essential and should be structurally engaged and promoted. Relatives may benefit from special offers.

"And I say, 'You know, the woman [in the SHG] has time. She has [answers to my] questions. You can come up with questions. She knows an answer, a PLAUSIBLE answer. And she takes the time that maybe doctors cannot take.'"
(A74Ew_106-106)

References

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