Diagnostic Experiences and Diagnosis Coping in Patients with Pancreatic Cancer

An Empircial 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.

Results

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



"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)

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

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. 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"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)

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

"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) 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**.

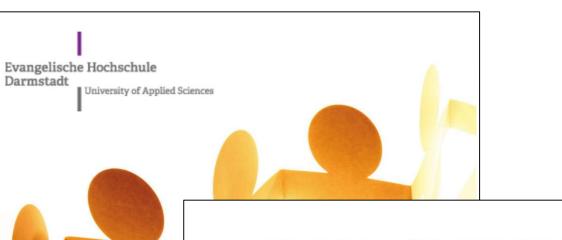
Following hospital treatment, self-help groups often play a major role in informing and training patients in the absence of health care professionals.

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.

"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)

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 problemoriented, 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



SIE SIND AN EINEM TUMOR DER BAUCHSPEICHELDRÜSE ERKRANKT?

Wenn Sie an an einem Pankreastumor leiden, würde ich Sie gern zu den folgenden Themenbereichen im Rahmen meiner Masterarbeit an der Evangelischen Hochschule Darmstadt interviewen:

Welche Erfahrungen Sie während des Diagnoseprozesses gemacht haben
Was die Erkrankung mit Ihnen macht und wie Sie damit umgehen
Was Ihnen dabei hilft, Ihre Krankheit zu bewältigen und zu verarbeiten

WOZU DAS GANZE?

Über das Erleben von chronischen Erkrankungen der Bauchspeicheldrüse ist bisher wenig bekannt. Weiterhin weiß man ebenfalls nicht viel über die speziellen Bedürfnisse von Menschen mit Bauchspeicheldrüsentumoren. Die Ergebnisse dieser Befragung sollen dabei helfen, zukünftige Patienten bedarfs- und bedürfnisgerechter zu behandeln und zu versorgen.

WIE FUNKTIONIERT ES?

Zunächst möchte ich gern einige wenige Eckdaten zu Ihnen und Ihrer Erkrankung erfahren und Ihnen weitere Informationen zukommen lassen. Wenn Sie in das Projekt passen, würde ich mich in einem zweiten Schritt gern für ein Gespräch an einem Ort Ihrer Wahl mit Ihnen verabreden. Dabei werden wir einige Fragen besprechen. Ihnen entsteht kein Nachteil und die Teilnahme ist anonym. Die Gespräche werden voraussichtlich im Herbst/Winter 2017 stattfinden. Vor Beginn der Untersuchung und bei Interesse lasse ich Ihnen vorab detaillierte Informationen zur Untersuchung zukommen.

WER DARF TEILNEHMEN? Menschen, die an einem Pankreastumor erkrankt und älter als 18 Jahre sind. Die Teilnahme erfolgt freiwillig.

HABE ICH IHR INTERESSE GEWECKT? DANN FREUE ICH MICH, UNVERBINDLICH VON IHNEN ZU HÖREN!

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

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

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.

"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) "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.

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.

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