

Biographical Disruption, Social Inequality, and the Role of Capital in Post-Surgical Recovery for Pancreatic Cancer Patients

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Abstract

This qualitative study examines the impact of pancreatic cancer surgery on patient identities and the role of various capitals in managing illness and regaining quality of life. Eight Danish participants, who underwent pancreatic surgery, are subjected to in-depth interviews with focus on inequality, coping mechanisms and the use of resources. The study draws on Michael Bury's concept of 'biographical disruption' and Pierre Bourdieu's capital- and field theory to understand how the disease and its treatment affect patient lives. Findings indicate that surgery significantly disrupts patient lives, affecting their self-image, daily activities and social roles. Participants employed coping strategies, including physical rehabilitation and social support, to restore their biographies. Despite facing severe challenges, participants generally reported good quality of life. The study contributes to the understanding of the critical role of social and cultural capital, health capital and cultural health capital in navigating healthcare fields and improving long-term quality of life.

Keywords

Biographical disruption; Bury; Bourdieu; Inequality in health; Health capital; Cultural Health capital; Pancreatic cancer; surgery

Background and Introduction

Globally, the incidence of Pancreatic cancer (c. pancreas) is rising with surgery being the only curative treatment (Lancet Gastroenterol Hepatol, 2019), viable in only approx. 20% of patients (Patient's Handbook, Nov. 2022; The Danish Cancer Society, Nov. 2022). Due to more gentle surgery and advances in tracing and treatment, survival rates have improved substantially over the last 10-20 years increasing the current 5-year survivability rate in case of radical surgery to approx. 43% (Kolbeinsson, Chandana, Wright, Chung 2023; Patient's Handbook, Nov. 2022).

The consequences of full or partial removal of the Pancreas can be loss of control, altered expectations for the future and effects on the positioning in life for the individual (Dengsø et.al 2018; Taylor 2021), which according to among others the WHO is defining for a good quality of life (WHOQOL 28.04.23). Psychologically, cancer surgery in the Pancreas can increase the risk of anxiety and depression (Akizuki et al. 2016; Tung 2019), and physically, the risk of i.e. Diabetes, indigestion, pain, diarrhea and loss of weight (Dengsø et al 2018). In a review of 23 studies, chronic pain was found among 50% of patients increasing the risk of eating problems and social limitations as well as the risk of anxiety and depression in relation to other types of cancer (Cipora 2023). One study found that fear of relapse was present in 1/3 of patients who had surgery for c. pancreas (Petzel et al. 2012) and that this was associated with anxiety and low quality of life. Although the risk of relapse diminishes over time there was no correlating drop in the fear of relapse four years post surgery (Petzel et al. 2012). In a study of quality of life among curative and palliative people with c. pancreas (Beesley et al. 2016) half experienced anxiety regarding the future and 41% experienced physical limitations and concern regarding the ability to participate in social relations. Simultaneously, 69% experienced having needs which were not handled professionally and approx. 2/3 recalled not having been given information pertaining to dealing with the disease or its side effects (Beesley et.al. 2016). In addition, not all patients experience the same course of diagnostic and treatment (Larsen K, Hansen GI 2014; Olsen, Kjær, Dalton 2019).

In Denmark, regional inequality regarding preventive efforts, waiting time, adherence to cancer packages, and the right to diagnosis is seen in both municipalities and regionally (Status of the Health Care Sector 2015). For instance, in 2014, only 64% of all lung cancer patients in the North Jutland Region went through the cancer package within the prescribed time compared to 87% in the South Denmark Region, and waiting time for rehabilitation after hospital discharge varies from 3 to 32 days between municipalities (Status of the Health Care Sector 2015). Furthermore, within the diagnosis and treatment of c. pancreas, regional differences are seen in survival over time from the start of the cancer package:

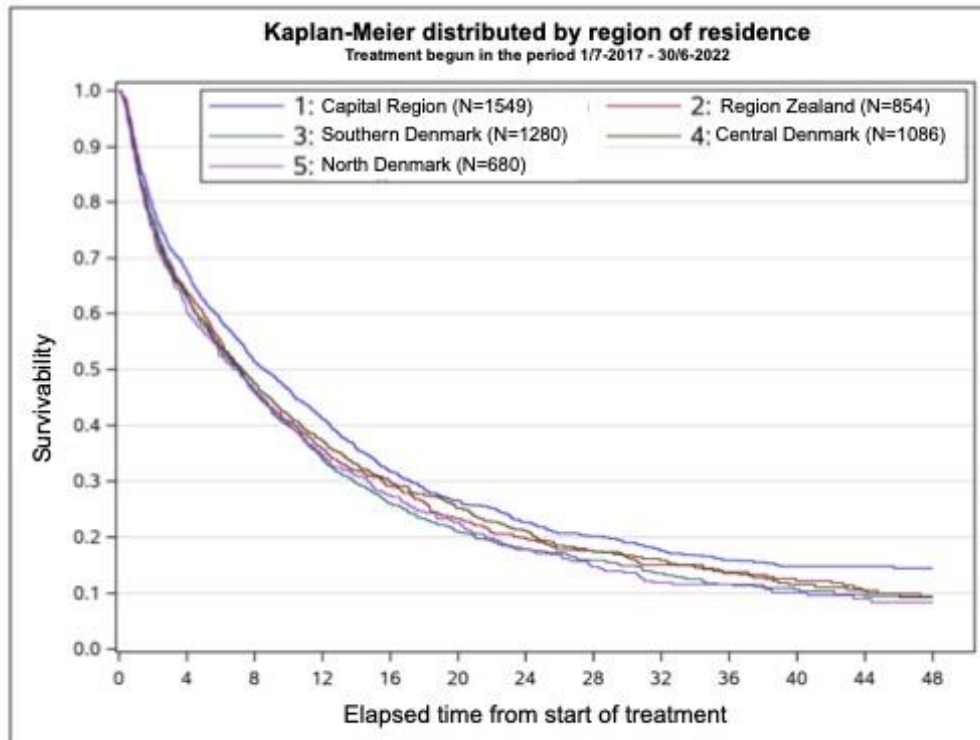


Figure 1: Survival per region over time from treatment start ($n=5449$). Log-rank test: $p=0,0010$, Danish Pancreas Cancer Group 2022.

The course of the disease is very well documented from a medical point of view, focusing on prevalence, treatment (Patient's Handbook, Nov. 2022; Kolbeinsson, Chandana, Wright, Chung 2023) and challenges regarding general quality of life (Johansen et al. 2022; Scholten et al. 2019; Cloyd et al. 2017; Laitinen et al. 2017; Heerkens et al. 2016; Belyaev et al. 2013; Rees et al. 2013), physical symptoms (Pulvirenti et.al. 2019; Arvaniti et.al. 2018), anxiety and depression (Akizuki et.al. 2016; Tung et.al 2019) in relation to the disease. However, very few or no studies examine how the long term consequences (> 6 years) of c. pancreas and surgery affect identity and biography. Furthermore, we lack knowledge of how inequality in financial, cultural and social resources may affect how a patient handles the course of the disease and rehabilitation as well as how these factors affect the general quality of life in the social space. The analysis in this article constitutes the sociological part of a larger study, which additionally focuses on how relations to health care personnel, hopes for the future and the sensation of freedom affect the quality of life, inspired by the sociological concept *biographical disruption* (Michael Bury) (Bury 1982) and central concepts of capital and field (Pierre Bourdieu) (Bourdieu, Chamboredon, Passeron 1991).

The purpose is to bring to light in what way surgery and treatment of cancer in or near the pancreas affects the biography of a patient as well as how disease and treatment is experienced as a break in existence/identity. In addition, to examine how the various capitals work as a foundation and resources for patients as well as the effect of these factors on quality of life in general.

Theory and Method

Bury is concerned with how chronic disease is experienced as a rupture in identity, everyday life and expectations for the future (Bury 1982; Bury 1991). He uses the phrase Biographical Disruption to understand the experience of rupture as well as how identity adapts to illnesses which affect all aspects of life (Bury 1982; Hubbard G, Kidd L, Kearney N 2010). Bury points to three areas where biographical ruptures become particularly evident: the assumption of being able to take things for granted, our self-image/identity and the need to mobilize resources. The patient seeks a gradual redefinition of a sense of self and an adaptation of an identity including illness through the use of cognitive, action-oriented and personality-related tactics, which Bury defines as: Coping, Strategy and Style (Bury 1991). The success of this adaptation depends on personal and social resources as well as the cultural and social fields the patient is part of (Bury 1982; Bury 1991). Bourdieu's concepts of capital describes economic capital, cultural capital (education) and social capital (family, friends, network) (Bourdieu, Chamboredon, Passeron 1991; Lund, Christensen, Iversen 2011). This study is also inspired by the development of the concept of cultural health capital (Shim 2010) which constitutes a specific capital valued in healthcare institutions and within the healthcare field (Collyer 2018). The healthcare field can be defined as a structured social space where diverse actors (e.g., professionals, institutions, and patients) struggle over resources, authority, and legitimacy, influenced by power relations and shaped by cultural, economic, and symbolic capital. In this field, doxa represents the unquestioned beliefs about healthcare roles, legitimacy and prestige medical hierarchies with cancer on the top (Hindhede, Larsen 2019). Finally health capital (Larsen, Cutchin & Harsløf 2013; Larsen et al. 2020) is integrated. It concerns a more general individual investment in the body, such as physical training, attention to diets/nutrition, surgical interventions, use of pharmaceutical products and investment in the mental body. We also include an item on reading frequency tying the mental body to embodied cultural capital (Bourdieu 1986). This capital is similar to cultural health capital but involves more differentiated investments recognized broadly in the social space and social fields (Larsen et al. 2020).

Study Design

The study has a qualitative design focusing on a theoretically inspired analysis of the individual participants' own experience of how their illness affected their identity and biography as well as how their collected resources affect their abilities/opportunities for handling the course of their disease and preserve/regain quality of life.

Individual, in-depth, and semi-structured interviews are used to obtain nuanced answers about experiences with the illness, disruption of biographies, and which resources (capitals) the participants have been able to activate and use during the course of the disease. The analysis is abductive, meaning it occurs in an interplay between a deductive approach inspired by theories and an inductive approach, i.e., a searching and exploratory approach (Malterud 2018, Ch. 13).

Inclusion and Exclusion of Participants

Inclusion of participants over 18 years, who, due to cancer or precancerous conditions in the pancreas, bile ducts, or duodenum, have had surgery, with resection of the entire or parts of the pancreas a minimum of six months ago. Additionally, patients who have undergone adjuvant chemotherapy must have completed it and must currently be disease-free. Participants with various comorbidities and sequelae from the illness are also included. Ten participants showed interest. Due to cancer recurrence, two participants were excluded.

Construction of Empirical Data

Thematical analysis according to Braun and Clarke (Braun, Clarke 2006) is used in the analysis and considered in the development of the interview guide to approach data flexibly, allowing for confirmation/denial of theoretical assumptions and exploring a qualitatively under-explored area inductively.

Interview Guide

The first interview was conducted as a pilot but included in the analysis as the interview guide was not significantly changed afterwards (*Appendix 1*). Concurrently with the interview, participants filled out a specially prepared course chart. The idea was to visualize descriptively to what extent the disease affected the queried focus areas and when the impact was most/least pronounced. This aimed to target future clinical treatment to times when the benefit could be maximised (*Appendix 2*).

Before the interviews, participants received general information about the background of the study, its purpose, and themes the interview would cover. The interviews lasted 54 min. – 129 min. and were conducted by the primary author. Since the participants live all over Denmark, four interviews were completed in person and four were done using online video calls. All interviews were recorded and transcribed by the primary author (Braun, Clarke 2006).

Recruitment

Participants were recruited through a patient association as recruitment ensuring maximal variation proved challenging in hospital settings. (Malterud 2018, Ch. 6). Eight people met the inclusion criteria and agreed to participate. None of the participants were known to the authors prior to the interview. Participants were encouraged to speak freely about their experiences and ongoing participant checks were performed by asking for clarification of statements. Concurrently with the analysis, each interview was reduced to about two-page summaries, which were sent to and approved by the participants (Malterud 2018, Ch. 20; Braun, Clarke 2006).

Ethical Considerations

The participants were informed that their participation was voluntary and would have no consequences for their treatment. Everyone was informed that they could cease

participation at any time. Every participant provided informed consent (Declaration of consent April, 2023).

Since the interview potentially could touch upon previous traumatic experiences every participant was offered the opportunity to contact the primary author if needed. No negative emotional reactions to the interview where registered.

Theoretical-Empirical Analysis

Initially, all interviews were read focusing on commonalities, unique statements and the condensation of meaning into immediate themes. According to Braun and Clarke NVivo was used systematically to code deductively based on theory as well as inductively through exploratory coding for emerging themes (Braun, Clarke 2006). Both literal and latent significance of statements were noted in this process. All quotes from each code were read through and relevant codes were merged into initial themes, which emerged either from significant statements or from factors implicitly expressing health behavior/coping. Each theme’s justification was assessed based on internal homogeneity and external heterogeneity ensuring the exhaustion of each theme. For each quote it was defined how it was important for the theme and how it represented the data as a whole. Simultaneously, telling sub-themes were created to structure the content within each theme. Finally, the argument for each theme’s justification and validity is presented with telling quotes from the participants (Braun, Clarke 2006). This article focusses on two sociological themes: Identity disruption and the desire for restoration and inequality in resources in an equality-oriented healthcare field as well as their inherent sub-themes:

| Themes | Sub-themes |
|--|--|
| I: Identity Disruption and the Desire for Restoration | Work Activity |
| | Diabetes |
| | Trying to Find Yourself |
| | Illness Course and Impact on Quality of Life |
| II: Inequality in Resources in an Equality-Oriented Healthcare Field | Social Capital; Friends are Vital in an illness Course |
| | Cultural Capital; Knowledge and Illness Understanding |
| | Exchanging Capitals |
| | Investment in Health Capital – The Body Must Recover |

Results

Participants

The participant group consists of four males and four females aged 57-79 years with an average of 68 years. Four participants have had total pancreatectomy and four participants Whipple’s operation between the years 2013-2021. Five have received chemotherapy and five participants have developed diabetes as a result of surgery. Three have a long cycle higher education, one has a medium cycle higher education and four have a vocational

education. Five participants are retired, two are in early retirement partially due to the course of the disease and one is still working. All participants have near relatives in the form of a spouse/children.

| Participant characteristics | |
|------------------------------------|-------|
| Number | n = 8 |
| Sex | |
| - Male | 4 |
| - Female | 4 |
| Age | 57-79 |
| Place of residence | |
| - Capital Region | 3 |
| - The Region of Zealand | 1 |
| - The Region of Southern Denmark | 2 |
| - Central Denmark Region | |
| - North Denmark Region | 2 |
| Marital status | |
| - Married/cohabitants | 7 |
| - Widow | 1 |
| Education | |
| - Long cycle higher education | 3 |
| - Medium cycle higher education | 1 |
| - Vocational education | 4 |
| Occupation | |
| - Retired | 5 |
| - Early retirement | 2 |
| - Working | 1 |
| Type of surgery | |
| - Total pancreatectomy | 4 |
| - Whipple's | 4 |
| Year of surgery | |
| - 2013-2015 | 1 |
| - 2016-2018 | 4 |
| - 2019-2021 | 3 |
| Chemotherapy | |
| - Yes | 4 |
| - No | 4 |
| Diabetes | |
| - Yes | 5 |
| - No | 2 |
| - Diabetes before c. pancreas | 1 |
| Enzyme substitution required | |
| - Yes | 7 |
| - No | 1 |

Table 1: Participant characteristics

Themes I:

Identity Disruption and the Desire for Restoration

Generally, the participants experienced the illness course as a biographical disruption to their lives, their identity-creating activities, their self-images, and predictable daily life. Most of the participants described how their identity was affected to a greater or lesser extent, especially around the diagnosis and the following three to six months. A couple of participants still experienced affected identity at the time of the interview and had doubts that they would ever fully restore their biography:

Everything has changed. You don't go through something like this without paying a high price. It's both, well it's on all parameters that ... erhm, you just don't because the body has received such punishment that erhm ... I'll never have my life back. I just won't. (D3).

I can pull myself up: Nice clothes, hair done, pointy shoes on, and off I go with a bag, greeting everyone and being sparkling and happy ... My old self ... but when I get out and sit in my car ... ptsssss ... I'm just shattered. So, I can pull myself up for it, but it drains me afterwards. (D7)

Work Activity

The careers of the participants have shaped their biography and been a significant part of their identity. Those who had voluntarily retired had not experienced the illness course as a disruption to this part of their identity, whereas those forced into early retirement due to ailments described being pulled out of a valued and identity-creating daily life previously taken for granted:

Well, it does because I was pulled out of the job market and the life I had before I got sick... uh... It was... In a few days, everything was changed... uh yeah... So, it has changed everything, and you never get your life back... [...] It has changed the identity in that way that I became an early retiree. (D3)

Predictably, the road back to a restored identity has been longer for these participants, since adaptation to a new life is largely a social construction and the degree of success partly depends on the demands for "normal function" in the social and cultural fields the participant usually participates in, and whether this can be met by the individual:

I can't do the same as I could before... it's... it's a big slap in the face... um... I don't have the power I had before... Uh... and endurance and such... I don't have what I had before... and I think it's a bit... No, not a bit. I think it's quite annoying. (D7)

Diabetes

For three participants in particular, getting diabetes, which is often seen after the operation, took a lot of focus. For one, this was due to worries about a future where he cannot feel and react to low blood glucose, and for another, frustration over difficult-to-regulate blood glucose in connection with activities:

That's perhaps one of the areas where I also have a little... fear of what might happen in the future [...] if I were to become demented, then – it's possible I can feel it, but it's not certain I can react to it [...] that thing where I at some point risk not being able to control it myself... that can worry me a bit. (D4)

The most annoying thing is something like gardening. I'm a lot in the garden, and... um... yeah, the blood sugar can either find to rise or fall... And it annoys me that I can't control it. I spend a lot of time in the garden, and... um... yeah, the blood sugar can either rise or fall... And it annoys me that I can't control it. I want to control it, you know. (D5)

For the third participant, the idea of having diabetes has been hard to reconcile with his identity and a challenging factor in social contexts. Consequently, diabetes has been perceived, especially immediately after surgery, as a significant biographical disruption, which the participant gradually managed to restore: "Pancreatic cancer is a... a terrible disease and that... I've actually only recently realized that fact. Actually realized it, I mean. Really, I wasn't aware... so I thought diabetes was completely awful!" (D1). All three participants reported that diabetes was not a hindrance to their activities and did not affect them to an extent that reduced their quality of life.

Trying to Find Yourself

Becoming a cancer patient has been shocking for most participants and has had more severe consequences than they had expected or felt prepared for. Several have been forced to redefine themselves within new boundaries, both physically, mentally, and cognitively. Participants sought information and drew on experiences from fellow sufferers in their search for meaning. They managed to compensate for lost resources by mobilizing others and adapting to the new role. A few participants still find it difficult to find a place for the illness course and its consequences in their identity and self-image: "A picture was taken of me where the whole dining table is filled and packed with medicine and junk. Absolutely crazy! And I just look at it and say, 'Is this my new everyday life?' ... And it is!" (D7). For D7, the biographical disruption has primarily influenced his self-image and social appearance. D7 described himself as an extrovert who used to take up space in a room – through both a large physique and large amounts of energy. This attitude has been valuable capital within his cultural and social field, and large parts of D7's identity were tied to this role and appearance, which explains why the focus of rehabilitation primarily lay in regaining his self-image and energy:

The most important thing is to get in gear... during the course of an illness like that... you absolutely must get in gear! So I told myself every day: take a shower! do your hair! shave! put on regular clothes! Your self-image must be as you remember it, because looking like a homeless person, it just won't do. Looking like crap... uh... it's a downward spiral. The opposite – going upwards – is a lot better. (D7)

For most participants, focus during the illness course has largely been on physical rehabilitation, with the side benefit of regained identity over time having followed the healing process. Others have had to fight more and have regained abilities and repaired biographical disruption through, among other things, significant episodes with feelings of personal victory: "To think that I got to the point where I actually tried to participate in a regular class and not just a rehabilitation... (class), but I actually went into 'The Real World'. That was huge. That was really huge!" (D3).

The course of the illness was experienced as a disruption of life for all participants but in different ways and with varying strength. Those who felt the greatest disruption of identity were affected by multiple factors determining their biography, such as work ability, cognitive abilities, and altered appearance in social contexts. By the majority, getting diabetes is perceived as a practical challenge, but this was more present in a single participant who, especially initially, felt diabetes as an invasion of identity. The course of the illness was experienced as a minor disruption of life among the retired participants, who focused on restoring physical capacity and attributed more of the discomfort and functional limitations to their age.

Illness Course and Quality of Life

The majority of participants described an effect on their identity, especially around diagnosis/surgery, with gradual improvement over time. The illness course's impact on social relationships was expressed differently and varies from positive, in the form of closer relationships with neighbors, fluctuating throughout the course of the illness, or not affected at all. Overall, life was most affected by the course of the illness immediately after surgery and up to two years thereafter, which may indicate a need for healthcare professional follow-up regarding a patient's requirements in terms of individual support and guidance (*Appendix 2*).

Participants generally felt fortunate, privileged, and grateful to have come through such severe illness courses and still be disease-free today, two to ten years after the operation. Many experienced taking less things in life for granted, finding meaning in minor things, and having a greater focus on being present: "The life change that happens in such a course; You become grateful for everything, every little thing." (D3).

D6 described her quality of life and joy of life today as being higher than before the illness course due to a newly acquired ability to let go of household chores, live in the moment, and for instance take trips around the country, which she greatly appreciated: "I think I live more, I live life more intensely now than I did before... there are things you... really appreciate doing... that is... you have a - in a way... you get a freedom to say to yourself, 'Just do it if you feel like it'." (D6).

Participants experienced a growing zest for life and hope for the future despite going through an illness course with poor prognosis. They generally possessed personal characteristics, capital and resources with which to handle challenges and concerns effectively thereby not letting the course of the illness dictate their identity or quality of life. The course of the illness has reduced the certainty of a predictable future but has also given the majority an increased awareness of further appreciation and enjoyment of life. Generally, they maintained hope by choosing to believe in a positive future and by trusting the abilities of healthcare professionals as well as ongoing improvements in treatment.

Themes II:

Inequality in Resources in an Equality-Oriented Healthcare Field

Social Capital; Friends are Vital in an illness Course

As a whole, participants had considerable resources to draw on regarding their management of illness and the illness course. For instance, many had substantial social capital in the form of family members who provided support and care and, for some, acted as spokespersons in the healthcare field. Several participants had close relationships through board work and sports, as well as close relationships with friends. Due to the shared framework of understanding, many formed significant bonds with fellow patients, expanding their networks and making it possible to draw on their resources: "In the board we have, where I have met the other patients, the relationship automatically becomes stronger [...] and it's... again, those life witnesses around a course and an illness we share. So yes, it clearly provides more." (D2). Support from a partner, siblings, or adult children has been of varying nature but for the individual it has been of great or decisive importance in getting through the course of the illness:

Well, if I didn't have the family I have... I wouldn't have been able to manage this... I wouldn't. (D3).

My girlfriend was a tremendous help because one thing was, she relieved me – I didn't have to pull the cord all the time, I could just tell her, 'I really need a popsicle now... uh... I'm so thirsty'... So, the process at the hospital... it was a crucial part of getting strong very quickly. (D7).

For most, social capital in terms of help and support from friends and networks has changed over time. Today, several participants in this study prioritize close relationships highest and have sorted out friends due to, among other things, lack of support when it was needed most: "Well... people I thought were close to us were conspicuously absent during a really tough period... And that sticks. It sticks in here today (points to the chest) [...] You get a different relationship with some people." (D3). Simultaneously, other significant relation-

ships have been strengthened, and new ones formed. For several participants, being able to mirror their illness course in the experiences of fellow sufferers has provided a benchmark for what to expect and strengthened their comprehensibility, manageability, and meaningfulness in the course of their own illness:

I was so happy the day I came in [...] there was a guy in that ward... and he was standing up, and he said he had been operated on three weeks ago... And then I thought, 'Wow... well... he can, he can walk'. (giggles). (D1).

I have got some other networks I would say, on Facebook, so it's... It's a completely different world where... I get a lot... of information and help and... there are also some... there are some really good groups... So, I think Facebook is brilliant. (D5).

The social relationships of the participants have been of great importance for their quality of life throughout the course of their illness. Especially in the form of support, help, and guidance from the closest relations but also in the form of new communities with a shared framework of understanding. Some experienced disappointment, which at the time may have negatively affected their quality of life, but many have also become more reflective and chosen to sort out their relationships to only associate with those who matter most. The social capital of participants has provided access to benefits in the healthcare field, which presumably has affected quality of life positively.

Cultural Capital; Knowledge and Illness Understanding

The amount and type of cultural capital is expressed differently among the participants. Three participants had a high level of education, providing them with substantial cultural capital in their work-related fields. Parts of this capital had application in the healthcare field, i.e. understanding of the illness and the ability to make superior choices for the patient on a qualified basis. The remaining participants had either short or medium length levels of education and possessed other types of cultural capital. Several participants possessed cultural health capital, either by themselves or through relatives, thereby managing to play according to the rules of the game within the healthcare field. "Yes, I think... they did what they had to, and I followed suit. I showed up for everything and all appointments because... uh... that has to be the prerequisite for them to have control over me, that... At least I do what I'm told." (D7). Two participants were able to exchange the cultural health capital of relatives; a retired oncologist and a nurse, for communication and knowledge with possible gain of benefits in the healthcare field as a result: "I also have a daughter who is a nurse, so she has been with me all the way through and supported me and, if there was something I had doubts about, she could step in and... talk about things." (D6). The disadvantage of drawing on the cultural health capital of relatives appeared in one participant's experience in which healthcare professionals mainly addressed the relative, making him feel uninformed and overlooked:

So, it was her (oncologist sister) who talked a lot with them and stuff, so it wasn't... I would say, I actually didn't talk much with the doctors, which surprised me a bit... That they didn't... uh... but it may be that they talked... with others... Uh... yeah, I had actually expected to – to hear more. (D5).

The other participant also often felt overlooked and uninformed and often depended on support from his nurse-trained daughter to understand the context of the treatment: "When you are hospitalized [...] you don't always feel that... that you get to be part of everything. Some decisions are made over your head... that you perhaps didn't expect and also don't always understand." (D6).

Exchanging Capitals

Different types of capital will always be intertwined as well as reinforce and compensate each other, exemplified by D4. Due to a long education and high position as well as network/friends in the healthcare field, D4 possessed strong social, cultural, and economic capital: Through D4's employer D4 was offered health check-ups including CT-scans every two years. Despite the fact that seven out of eight participants took enzyme supplements due to malabsorption, only D4 described having the degree of malabsorption assessed. D4 was the only participant granted an insulin pump, and currently, six years after surgery, D4 had an open offer to contact the surgeon bypassing the general practitioner if needed:

I feel treated very well – but I have also realized that not everyone shares that experience. There are large differences. I could be selfish and be happy that I have fine conditions, but I am sad that the others don't also have that. That's how it should be, right? (D4).

Similarly, D2, due to a long municipal career, was equipped with high social and cultural capital, which opened doors not accessible to everyone:

I kept saying: 'I want a scan of that liver!', and 'can't you...?'... I then had to use the back door to (Region) and then they took me in... and I can do that today because I... meet them so much in everyday life, but if a patient from (City), for example, or where they don't have so much... Our region just isn't good for our patient group. They just aren't... (D2).

In another region, many years of job-specific work experience and strong social capital in the family gave D3 resources to fight for more than a year for sufficient diagnosis and treatment. Post-surgery follow-up was insufficient, and in this region, high social and cultural health capital could not be converted to the same expediency in treatment or the same post-surgery possibilities:

There is no follow-up for us living out here [...] so that means I was discharged – Well, someone did call... um... once when I got home, but otherwise there was *nothing*. So, I was *totally* left to my own devices with a stomach that didn't accept food at all, and I went to the toilet 30 times a day, and it just poured out of me (D3).

Overall, this study involved a rather privileged group of patients. Economic capital is important but not vital given the free treatment available in Denmark. However, as shown in this study, the ability to draw on resources including social and cultural capital remains of great significance for patients. The ability to navigate a healthcare field which is often opaque, as well as understand and present arguments to healthcare professionals, health institutions, employers, private and public actors is crucial for diagnosis, treatment and rehabilitation when illness is on the agenda.

Investment in Health Capital – The Body Must Recover

For seven out of eight participants, physical activity has been a significant part of their lifestyle, both consciously to promote health and to a higher degree unconsciously because they appreciated nature, the activity, the community that arises around sports, and the image associated with an active body. Participants knew the importance of being in good shape and invested effort in keeping the body as strong as possible: "I mean, I think I will keep in good shape, but I also love to ride my bike, so... And love to ski, yes... so it... I just started skipping because I don't know, they say my blood pressure is too high. I'm not sure, I... I try to lower it." (D1). After the course of the illness, the investment in health capital for many has meant a broader focus on health-promoting behavior through reduced alcohol consumption and smaller, healthier meals, perhaps even consumed with greater enjoyment and gratitude than before: "In the old days, we would have a glass in the middle of the week. Now, we are quite strict and drink only on Friday, Saturday, Sunday [...] and we are fine with that." (D4).

Health capital includes materialised, institutionalised, and corporeal dimensions (Larsen, Cutchin & Harsløf, 2013). Beyond patients' own investments, such as exercise and diet, they benefit from accumulated health capital they have not directly built. Surgical success draws on broader expertise and resources, including surgical technologies, medical knowledge, and pharmaceuticals. Patients gain from health resources within the Nordic welfare state, materialised in technologies, hospitals, and procedures, and institutionalised through professional expertise (Larsen, Cutchin & Harsløf, 2010).

Discussion

We summarize that the participants in the study experienced pancreatic cancer as a significant biographical disruption which affected their identity, daily activities, self-image, and routines. According to Michael Bury's concept of biographical disruption, such life-changing illnesses create a rift in an individual's narrative, forcing them to renegotiate their self-understanding and normality (Bury 2001). The illness forced the participants to redefine their identity within new boundaries and mobilize resources to compensate for lost abilities (Bury 1991). Many of them were actively engaged in physical activities and

personal appearance to maintain a positive self-image and counteract the biographical disruption. External factors, such as early retirement due to illness, further complicated the ability to regain identity, creating challenges in adapting to new circumstances and roles in the lives of the participants. Diabetes, a common condition after surgery (Dengsø et al. 2018), presented ongoing challenges, requiring constant monitoring and adaptation. This affected daily lives and future health, further contributing to the ongoing sense of biographical disruption. The journey toward regaining biographies involved small victories and resumption of social and physical activities, which provided significant milestones in rebuilding self-understanding.

The study shows that participants generally had considerable resources, especially in the form of cultural (health) capital and social capital, which played crucial roles in their illness management and rehabilitation processes. It is implicit in several interviews that participants were relatively privileged and had a high degree of respect for authority and trust in healthcare professionals and generally fit the role of the "good patient," which can be beneficial during the course of the illness (Shim 2010; Sodemann 2018). Participants with large amounts of cultural capital in the form of higher levels of education used their knowledge and skills to better understand their medical conditions and make informed decisions. This cultural capital provided them with better care access and made navigating the healthcare field easier. Investment in health capital, such as focusing on physical activity and a healthy lifestyle, was an integral part of the lives of most participants before and after the diagnosis as well as crucial for their physical and emotional well-being.

It does not appear in the interviews whether the physically active participants have directly been able to convert their health capital into benefits in the healthcare field, and no one mentioned whether their lifestyle had been addressed positively or negatively. But the appearance of an active body signaling engagement and ability to invest in one's own health gives latent value within the healthcare field, which potentially may have resulted in benefits (Larsen 2021, Ch. 2).

Social capital including networks, family and friends were vital in navigating the healthcare system and managing the illness. Many experienced a change in 'who' acted as help and support for them which, according to Mette Ryssel Bystrup, is a natural process in a rehabilitation course (Bystrup et al. 2022). Friends you no longer share interests with easily fall away, while new relationships can form and existing ones grow stronger (Bystrup et al. 2022).

The study highlights the significant role cultural and social capital play in shaping the experiences and outcomes in managing pancreatic cancer for the participants. It illustrates the complexity of biographical disruption and restoration within a sociological framework, showing how these resources impact the illness experience and the ability to restore a meaningful existence with a good quality of life.

Cancer as Biographical Disruption

The theory of illness as biographical disruption was originally developed for chronic patients but has proven applicable in several types of cancer, such as breast cancer (McCann et al. 2010; Trusson, Pilnick, Roy 2016), urological cancer (Neris et al. 2020)

and prostate cancer (Schultze, Müller-Nordhorn, Holmberg 2020). In a qualitative study, Hubbard et al. describe how mainly disease-free individuals with different types of cancer continue to experience the illness as a biographical disruption both psychosocially and physically up to five years after diagnosis (Hubbard, Forbat 2012). Another qualitative study shows how colorectal cancer can be experienced as a biographical disruption without necessarily affecting identity (Hubbard, Kidd, Kearney 2010). In a qualitative study of biographical disruption among women aged 70-80 with breast cancer or gynecological cancer (Sinding, Wiernikowski 2008), Sinding et al. describe how a long life with periodic adversity, comorbidity, and the feeling of having achieved what they wanted in life can mitigate the experience of cancer, so the course of the illness does not feel like a biographical disruption but as an expected part of a long life (Sinding, Wiernikowski 2008). The oldest participant in this study had a similar experience of the course of the illness. With several cancer courses and a deceased spouse behind her, c. pancreas related surgery was perceived more as yet another bump in the road rather than biographical disruption. Overcoming this illness too has led to increased gratitude for life.

Social and Regional Inequality in Denmark

Social inequality in health is multi-causal, with mutually reinforcing factors. Inequality relies on conditions during childhood and youth, lifestyle, level of education, area of residence, and social relations (Larsen, Hansen, 2014). The participants in this study all possess resources and varying capital and, in other words, do not represent the typical image of social inequality among low and high-positioned patients (Social Inequality in Health and Illness 2020).

Findings in this study highlight the existence of regional inequality in diagnosis and demonstrate that residence can have a decisive impact on the experience of the rehabilitation course despite strong resources and varying but significant capital. In the cancer package for pancreatic cancer 2016 (Cancer packages 2016; Danish Pancreas Cancer Group 2011), which was in effect when most study participants were operated on, follow-up every six months for at least two years after completing treatment is recommended, which far from matches the experience of every participant in this study. However, focus on individual needs and patient involvement is clearly sharpened in the latest cancer package from SST 2021 (Cancer packages 2021). The preparation of an individual follow-up plan after surgery is now a requirement. The patient must be offered follow-up every three months in the first year. Then every six months for a five year period (Cancer packages 2021). Consequently, one can hope that patients operated on for c. pancreas today and in the future will experience receiving support according to need rather than place of residence.

Quality of Life

Generally, participants maintained a strong belief in and pursuit of a future and an identity where neither the illness, its consequences, nor the prognosis had a dominant place in their lives. Over time, discomforts became manageable and accepted as part of life. Some gained new insights, appreciated small things, and one described improved quality of life.

Thoughts about cancer were only present daily in the participant who was most recently operated on and who may have yet to fully adapt to the new life. Otherwise, concerns about the future involved practical matters such as employment opportunities. The participants were generally able to push away worries about illness or recurrence and found comfort in the security of having the necessary resources available, which in itself can reduce the fear of the future (Gannik 2005, Ch. 5). In 2021, a systematic review of 35 studies examined the quality of life post-surgery for pancreatic cancer (Toms et al. 2021). In most included studies, no change in quality of life was seen in either the short or long term, except for cognitive function, emotional, and social factors, which in the long term proved to be better than baseline (Toms et al. 2021).

The reason for the unchanged quality of life in general may be found in the fact that among the 15 different measurement tools, only four were disease-specific, and the quality of life may be poorly captured in this specific patient group. Another qualitative study (n=20) examines the psychological consequences of c. pancreas six months to six years post-surgery (Taylor et al. 2021). Here, similar to the findings of this study, the urge to return to life before the course of the illness was great, and a positive attitude seemed crucial. The majority of participants had changed priorities to spend more time on what they found most precious (Taylor et al. 2021). The findings differ from this study in that these participants largely felt their lives were controlled by doctors and disease concerns. Some experienced that household roles had changed, and social relationships were hindered due to sequelae (Taylor et al. 2021). The reasons for the different findings may be that participants in this study did not experience challenges with eating/drinking in social contexts and that they are resourceful and rich in social capital. They have largely experienced support from the most important people throughout the course, promoting their rehabilitation and quality of life.

Strengths and Limitations in the Empirical Data

Challenges in studying this patient group generally lie in the poor prognosis and many side effects, which limit the recruitment basis and increase the risk of drop-out (Patient's Handbook, Nov. 2022). Patients who are highly educated and possess a large amount of capital will also predominantly have healthiest lifestyle regarding diet, exercise, and smoking and will generally be those who cope best with surgery, chemotherapy, and rehabilitation (Olsen, Kjær, Dalton 2019). Patients with resources and the ability to engage in a patient association and the willingness to participate in research studies will thus easily become a selected group of the strongest patients, which is not necessarily representative of the group of patients with c. pancreas as a whole (Stewart BA, Stewart 2022). In recruitment, participants with any life history and various comorbidities were included. Seen in isolation, statements could have reflected impact on life of surgery for c. pancreas if participants with comorbidity had been excluded. For the two participants with several prior illnesses, it is difficult to distinguish the impact of c. pancreas from the other courses of illness. On the other hand, quality of life turned out to be better for one participant, possibly because yet another illness had been overcome. This nuance would have been lost if comorbidity had been excluded from the start. Furthermore, it would have made

recruitment more difficult and weakened the transferability to other elderly with comorbidity operated for c. pancreas.

Strengths and Limitations in the Method

Validity in data is sought through the four criteria for achieving "trustworthiness": Credibility, Transferability, Dependability, and Confirmability as described by Shenton (Shenton 2004), as well as ongoing reflexivity regarding own impact on data through values, attitudes, and pre-understanding, as described by Malterud (Malterud 2018, Ch. 6). Credibility / Internal validity describes whether findings in data are consistent with the purpose of the study and real-world findings (Braun, Clarke 2006). As a clinical dietitian with experience in diet treatment of c. pancreas patients, the first author came with a pre-understanding regarding illness courses and assumptions about the value of life post-surgery. An open and explorative approach to provide space for the experiences of participants without the influence of personal assumptions has been actively sought.

The atmosphere during the interviews was pleasant and the interviews characterized by openness, instilling trust that the most significant experiences were genuinely elicited. The focused scope on quality of life, reflexivity over own pre-understanding, and nuanced statements given by participants with homogeneous illness courses made achieving good information strength possible (Malterud, Siersma, Guassora 2016). Through an iterative analysis process it is sought to uncover significant and unique experiences through theme formation and representative quotes (Malterud, Siersma, Guassora 2016; Saunders et al. 2018).

Method and/or researcher triangulation could have contributed to more nuances, for instance through observations or a longitudinal approach. All stages in the process were discussed with a supervisor and a colleague/Cand.scient.san. Internal validity was ultimately confirmed as findings in this study generally aligned with existing literature findings.

Transferability has been achieved through describing the method and backgrounds of the participants, respecting anonymity, as transparently as possible to increase external validity. Limitations in transferability lie in the representation of only resourceful participants. More socially disadvantaged patients may have different experiences of how surgery for c. pancreas has shaped their life/quality of life.

Dependability / Reliability refers to whether the method description is sufficiently transparent to allow the study to be replicated. This is attempted by, among other things, using COREQ as a guideline in reporting (Tong, Sainsbury, Craig 2007).

Confirmability / Confirmation concerns whether the study's findings are a result of the experiences of participants rather than pre-understanding and preferences of the researcher. Own impact on data is attempted to be minimized by reflexivity through, among other things, Audit trail (Malterud 2018, Ch. 5), by using telling quotes, and through the iterative approach focusing on context and entirety in the interviews.

Implication in Clinical Practice

This study contributes with the uplifting finding that participants, two to ten years after a pancreatic surgery due to cancer, despite severe illness courses and various sequelae,

experience good quality of life. Disruption of identity has largely been reestablished but cultural and social capital has been crucial for successful rehabilitation. In clinical practice, findings can be used to increase attention to individual needs both in the short and long term. On a more structural level, findings can be used to raise awareness of regional inequality, and one can hope that the more patient-centered focus in the latest cancer package (Cancer packages 2021) will allow room for follow-up of a more individual nature improving long-term management of sequelae significant for quality of life regardless of capital and place of residence.

Conclusion

This study supplements existing literature with a long-term perspective on how changes in life are affected by identity disruption, social inequality and illness management after surgery due to pancreatic cancer and how this effects quality of life. The findings show that the course of the illness is generally experienced as a disruption to identity, including the interruption of work life, and a disruption to life through the interruption of daily activities. Through effective coping strategies and mobilization of the right resources, as identified in this study, it proves possible to restore the biography and in several areas achieve greater gratitude for life and increased quality of life despite potential functional impairment and cognitive sequelae. Findings further show that the interaction between different types of capital was evident, as participants possessing strong social, cultural, and economic capital had better access to healthcare resources which was of significant importance for handling illness, treatment, and rehabilitation courses.

Overall patients in Nordic welfare states draw upon accumulated health capital, materialised in hospitals and technologies, and institutionalised through procedures and professional expertise. But even in a Danish welfare state context, social capitals such as networks and friends have been crucial in the struggle to regain quality of life. Generally, there was a certain inequality in the individual capitals but also significant differences in the institutionalized capital available to patients (within the health care field). This manifested not least in large geographical and regional differences in what was offered in terms of supporting patients after the surgery. Participants are generally rich in capital and resources and have managed to allow neither prognosis nor sequelae to have a prominent impact on their quality of life. Findings in this study thus provide an uplifting picture that it is possible for resourceful and generally "fit" patients to recover and regain quality of life post-surgery due to cancer in/near the pancreas.

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Appendix 1: Interview Guide

<http://praktiskegrunde.dk/2024/appendix-1-Interview-Guide.pdf>

Appendix 2: Course Chart (En)

<http://praktiskegrunde.dk/2024/appendix-2-Course-Chart.pdf>

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