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Disrupted everyday life in the trajectory of low back pain: A longitudinal qualitative study of the cross-sectorial pathways of individuals with low back pain over time

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ABSTRACT

Background: Low back pain is a leading cause of disability and sick days worldwide. This type of pain has a fluctuating and recurrent nature, and affects all aspects of a person's life, with profound psychosocial consequences.
Objectives: This study aims to explore the everyday life of individuals with low back pain over time and across various contexts.
Design: A longitudinal Grounded Theory study with the concept, *conduct of everyday life,* as the theoretical framework.
Settings: The study was conducted in Denmark, and participants were sampled from a regional spine centre in a hospital context.
Participants: Twenty-seven individuals with low back pain referred to a hospital for assessment and treatment for herniated discs were sampled. Participants were divided equally between women and men 37-71 years old.
Method: Participants were followed through interviews and participant observation for 6–18 months. They were interviewed at least twice, at the beginning and end of the study period. The interviews took place in participants' homes. Data consisted of transcribed interviews and field notes.
Results: Two themes, "*When 'support' systems become disrupters"* and "*Adapting to a new life",* describe important elements of the participants' conduct of everyday life through a period of low back pain and the time after. The first theme explains how healthcare and sickness benefit systems play an existential role in the individual's life during a period of low back pain. These systems made extensive, often conflicting, demands on participants, which challenged their everyday lives. The systems and their diverse needs could take precedence over other concerns, challenging participants' social self-understanding. In the second theme, we identified three typical patterns of how participants adapt to living with a potential exacerbation of low back pain over time: 1) *Resignation,* 2) *Balancing* and 3) *Ignoring.*

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Conclusions: From the participants' perspectives, healthcare and sickness benefits systems are supportive, but they often disrupt everyday life due to extensive and conflicting demands. Individuals with low back pain must continually adapt to everyday life. Therefore, professionals should support a balanced pattern of adapting to life with recurrent and fluctuating low back pain.

What is already known about the topic?

- Low back pain is the leading cause of disability worldwide, with multiple contributing factors.
- Living with low back pain can be a significant burden for the individual, affecting all aspects of life.
- Most studies of individuals with low back pain focus on specific parts of their lives, but the challenges individuals experience span several contexts and relationships.

What this paper contributes?

- Individuals with low back pain experience conflicting demands and lack of coherent cross-sectoral communication with healthcare and sickness benefit systems.
- Healthcare and sickness benefit systems have conflicting demands on individuals with low back pain. This dissonance causes frequent disruptions on how individuals cope and adapt to their condition.
- Three typical and predominant patterns are defined regarding adaptation to everyday life with fluctuating low back pain: resignation, balancing and ignoring.

1. Introduction

Low back pain is the most common disability worldwide, affecting more than 7% of the population (Hartvigsen et al., 2018). In addition to being a health issue, low back pain is also a substantial economic burden. Direct and indirect annual costs for treatment, including sick leave and early retirement, add up to EUR 892 billion (= 0.38 % of BNP) in Denmark alone (Flachs et al., 2015).

Living with low back pain is a burden, which some describing it as putting “life on hold” (Saunders et al., 2018, Ryan and Roberts, 2019, Bunzli et al., 2013). The pain affects a person's ability to take part in daily activities like work, family time, and other social activities (Holt et al., 2015, Setchell et al., 2017, Holopainen et al., 2018). Since low back pain has a fluctuating nature (Kongsted et al., 2016), individuals can experience repeated and unexpected flare-ups, which have an adverse effect on their daily lives (Tan et al., 2019).

The most profound challenges discussed in existing literature fall under three categories:

1) *The impacts of low back pain on daily living*
2) *Incoherent healthcare*
3) *Psychological strain*

1.1. The impacts of low back pain on daily living

Severe low back pain can have wide-ranging consequences for everyday life (MacNeela et al., 2015). Persistent pain may lead to social isolation Van Griensven (2016), which can have several causes, including withdrawal from social interactions due to pain, low physical functioning, or short temper (Bunzli et al., 2013). These limitations make it difficult to continue regular activity with family and friends. Consequently, relationships may change or end, which increases the individual's sense of social isolation.

Low back pain also profoundly affects social roles, giving individuals a negative self-perception (Saunders et al., 2018, Ryan and Roberts, 2019, Snelgrove et al., 2013, Bailly et al., 2015, Cummings et al., 2017). Lower physical functioning that comes with low back pain can limit an individual's ability to take on leisure activities and household tasks that once defined them (Cummings et al., 2017), and lack of intimacy can also contribute to changed relationship roles (Bunzli et al., 2013, Snelgrove et al., 2013, Bailly et al., 2015, Froud et al., 2014, Kawi, 2014, Stensland and Sanders, 2018). Scepticism and mistrust by friends and family, who feel the condition is psychological, compound these challenges (Ryan and Roberts, 2019, Bunzli et al., 2013, Bailly et al., 2015, Damsgaard, 2016). This may result in a feeling of stigmatisation (Bunzli et al., 2013, Froud et al., 2014, Stensland and Sanders, 2018, Snelgrove and Liossi, 2013, Darlow et al., 2015).

Another central challenge to identity involves a lack of *attachment to the labour market* because of the periodic variability in functional impairment (Bunzli et al., 2013, Bailly et al., 2015, Froud et al., 2014, Ashby et al., 2012). Due to these work-life challenges, low back pain could challenge financial security (Froud et al., 2014, Darlow et al., 2015), which can create financial barriers and hinder participation in leisure time activities (Ashby et al., 2012).

1.2. Incoherent healthcare

Many individuals with low back pain seek treatment from the healthcare sector. Healthcare interventions generally recommend staying active and continuing work (Foster et al., 2018). Treatment often involves several cross-sectoral contacts, and many individuals experience a lack of cohesiveness in the support they receive (Petersen et al., 2020, Ryan et al., 2020). Individuals with low back pain often feel frustration and a mistrust when interacting with healthcare systems (Stewart et al., 2012). Their expectations related to a diagnosis or cure are often not fulfilled (Bunzli et al., 2013), and they feel that they must coordinate their treatment themselves (Stewart et al., 2012). These challenges are often compounded by a lack of clear, consistent and personalised information (Lim et al., 2019), which leads them to restrict activities out of fear of worsening low back pain (Snelgrove et al., 2013, Cummings et al., 2017, Darlow et al., 2015).

1.3. Psychological strain

Concerns about the future, persistent pain, and changes in social roles can have severe psychological consequences, including symptoms of depression and anxiety (Ryan and Roberts, 2019, Bunzli et al., 2013, Setchell et al., 2017, Van Griensven, 2016, Cummings et al., 2017, Kawi, 2014, Strom et al., 2018). For some, this psychological strain becomes intolerable and leads to suicidal thoughts or attempts (Ryan and Roberts, 2019, Strom et al., 2018).

Overall, low back pain is a complex life-changing condition complicated by contributing psychosocial and contextual factors (Hartvigsen et al., 2018). The condition affects individuals' lives across all social and structural contexts. Most qualitative studies on LBP look at individuals with non-specific low back pain. Few studies have a longitudinal design with a focus on trajectory across contexts (Snelgrove et al., 2013, Sanders et al., 2015).

More extensive research is needed on how individuals with low back pain live across contexts like home, work, leisure, and healthcare, and how the complexity of so-called 'support' systems integrate with and affect private life. Research is also needed on how individuals manage their condition emotionally across social and structural contexts and extended time periods (MacNeela et al., 2015).

This study aims to explore the lives of individuals with low back pain across various contexts over time through extensive in-depth interviews and observations. The result is a unique insight into the pervasive effects of living with low back pain.

2. Methods

This study's point of departure is a grounded theory methodological framework focusing on processes and temporality (Charmaz, 2014). In an abductive process, creative and reflective work with data led us to adopt a critical psychology theoretical perspective in the last part of the analysis. We chose *conduct of everyday life* as a theoretical concept to gain insight into the first-person perspective on the trajectory of low back pain.

2.1. Theoretical perspective: the conduct of everyday life

Conduct of everyday life is a theoretical concept from critical psychology that investigates how individuals partake in local social contexts like home, work and healthcare settings over time. The focus is on understanding the dilemmas, issues, and conflicts individuals face in their everyday lives (Dreier, 1999, Dreier, 2008, Holzkamp, 2013, Schraube, 2016). These factors make the concept well suited for exploring the challenges facing individuals with low back pain.

The concept of *conduct of everyday life* is understood as the actions and social self-understanding by which individuals organise their daily lives in and across various social *contexts of actions* that influence each other. Contexts of action are anchored in time, space and everyday life situations where individuals gather, like when a patient consults a doctor because of a low back issue (Dreier, 1999).

In this theoretical framework, individuals are conceptualised as participants having positions, relationships, scopes of possibilities, and personal concerns in various social contexts of action in everyday life. Personal concerns are what matter for the individual. Some are related to and pursued in specific contexts, and others are pursued across two or more action contexts. Individuals organise their everyday lives in and across all relevant action contexts. They are not omnipotent agents. They are influenced by societal structures and must negotiate their participation with co-participants in and across contexts of action. Different participants also have different concerns, which can cause conflicts.

Individuals fill their everyday lives with meaningful activities, like working or getting out of bed. These activities are taken for granted until they are disrupted by something like severe low back pain. Changes can range in severity and may involve ongoing work to understand oneself and other individuals in light of a new life condition (Dreier, 2008, Holzkamp, 2013, Schraube, 2016). This identity work influences how an individual conducts their everyday life.

2.2. Study context

The study took place in the Central Denmark Region. Assessment and treatment of low back pain in this region is coordinated by a treatment programme (Kallestrup et al., 2012). General practitioners can refer patients with low back pain for specialised assessment and treatment in a hospital, paid for by a state-supported universal healthcare programme. During periods of severe low back pain, many individuals will go on sick leave for varying periods. During sick leave, Danish citizens get sickness benefits and must comply with legal demands (Bekendtgørelse af lov om sygedagpenge, 2020), including meetings with caseworkers, medical treatment, and a promise not to delay treatment.

2.3. Participants and data collection

Participants were recruited from a regional spine centre, including a medical and surgical outpatient clinic. The researcher involved in the sampling (CBR) was a non-clinician nurse and had no prior relationship with participants.

2.3.1. Theoretical sampling of participants

Inclusion: Individuals referred for assessment for herniated discs.

Exclusion: Individuals not able to speak fluent Danish.

Forty-one participants were theoretically sampled (Charmaz, 2014) to represent the participants assessed in the medical/surgical centre regarding patient gender and age. All patients were over 18 years old. A secretary from each unit selected participants among patients referred for assessment over 18 months. Participants were not excluded because of ethnicity. Out of the 41 participants, the researcher collected longitudinal data on 27, which became the study's sample. The 27-participant sample consisted of 13 women and 14 men aged 37-71 years (mean: 51 years). All participants were Caucasian. Nine had just experienced their first episode of low back pain. The rest were having recurrent episodes of low back pain (see Table 1).

2.3.2. Theoretical sampling of data

The researcher (CBR) planned to collect longitudinal data on participants' trajectories and experiences for at least six months to understand their trajectories during the duration of their current episode of low back pain. Data were collected on each participant up to and including six months after their last hospital visit. This period was based on clinical experience and guidelines (Kallestrup et al., 2012), which indicate that most individuals with acute low back pain will have pain subside within six months. For some participants, the acute phase lasted longer, which our design took into account by prolonging the follow-up period. The researcher followed up with patients for 6–18 months, with a nine-month average (see Table 1). The theoretical sampling process resulted in various data, including audiotaped interviews and field notes from participant observation during consultations and telephone interviews.

Each participant was interviewed at the start and end of the study, with an average of 2.6 interviews per participant. The number of interviews depended on the following: 1) participants sampled in the first part of the study period were followed more closely to get a deep and nuanced understanding of individuals' trajectories with low back pain. Theoretical sampling later reduced this need. 2) Some participants were more eager than others to share their experiences.

CBR conducted data collection for all 21 participants at each time point, and a research assistant conducted data collection for six participants. Researchers collected data from November 2016 to January 2019.

2.3.3. Interviews

All but one interview was conducted in participants' homes. The exception was conducted in a private hospital room. Only the interviewer and the interviewee were present for the interview. Each participant's first interview was conducted approximately one week after consultation in the spine centre. This interview was guided by research interest in low back patients' trajectories and their everyday lives before and during a period of low back pain. Field notes from former consultations allowed researchers to ask specific questions about each participant's trajectory.

The first interview started with an open-ended question: "*Will you please share your experience of your trajectory, starting from your first encounter with low back pain*?". Later interviews were initiated with an open-ended question: "*How have you been since we last spoke?*". Participants were then asked about topics from previous interviews and how their lives were at that time. CBR noted ongoing reflections, preliminary analyses and dialogue with co-authors in memos. This led to modifications of the interview guide and informed theoretical sampling to develop the emerging themes.

2.4. Analysis

Three research assistants made verbatim transcripts of all audio-recorded interviews. The first author manually coded transcripts and field notes using NVivo 12 software to manage and retrieve data (QSR International, 2020). Researchers used an abductive approach and a constant comparative method to conduct the analysis on four levels (Charmaz, 2014). This involved repeatedly listening to recorded interviews and re-reading transcripts and field notes.

For the first level, CBR inductively coded and continuously compared data and codes in a flexible abductive process to produce theoretical ideas. Codes included "important activities", "consequences of low back pain", "who am I", "helpers", and "demands".

On the second level, CBR made a case description from eight participants' complete data sets. Case descriptions were compared and discussed by LH and CBR to produce analytic ideas. For example, researchers found changes in what participants considered to be valuable activities during their trajectory. This was followed by a comparative analysis of how these activities changed over time within each participant and across data.

Level three was an abductive process, informed by the two first levels of analysis. Here, researchers incorporated the theoretical concept "*Conduct of everyday life*" as an interpretive framework (Dreier, 1999, Dreier, 2008, Holzkamp, 2013, Schraube, 2016) to create a plausible theoretical interpretation of data (Charmaz, 2014). Researchers found that the concept suited the theoretical explanation of emerging ideas (Charmaz, 2014) in light of knowledge gaps concerning how low back pain and the support system influences individuals' everyday lives. These theoretical explanations were tested on the complete data set by asking central questions: *What are the participants doing in their daily lives*? *What were their primary concerns*? *In which action contexts did the participants participate*? *How did they pursue their concerns in and across various action contexts*? *How did participants understand themselves when participating*

Table 1
Participants and data collected in the study period.

	Gender/Age	Sick leave during study period	Followed for x months	Audio recorded interviews	Telephone interviews	Field notes	Field notes from consultations[*]	Surgery during study period	First episode/recurrentlow back pain	Dominant coping behaviour
I1	M/forties	Yes	18	4	2	3	7 (M/S)	Yes/1	Recurrent	Balancing
I3	M/forties	Yes	16	3	2	8	4 (M/S)	Yes/2	Recurrent	Balancing
I5	M/forties	Yes	16	3	2	5	6 (M/S)	Yes	Recurrent	Ignoring
I6	F/forties	Yes	8	2	0	1	1 (M)	No	Recurrent	Balancing
I7	M/fifties	Yes	6	2	0	2	1 (M)	No	Recurrent	Balancing
I8	M/sixties	Retiree	9	2	0	3	2 (S)	No	First	Balancing
I9	M/sixties	Self-employed - short hours	8	2	0	1	1 (S)	No	Recurrent	Balancing
I10	F/sixties	Retiree	8	1	1	2	1 (S)	Yes/1	First	Balancing
I11	F/thirties	Yes	7	2	1	2	3 (S)	No	First	Balancing
I12	F/fifties	Yes	9	2	1	2	2 (S)	Yes	Recurrent	Ignoring
I13	F/forties	Yes	6	1	1	3	2 (S)	No	First	Balancing
I14	M/forties	Yes	12	2	1	5	3 (S)	Yes/1	Recurrent	Resignation
I15	M/fifties	Yes	7	2	1	1	1 (M)	No	Recurrent	Balancing
I16	F/thirties	Yes	6	2	1	1	6 (M)	No	First	Resignation
I18	F/fifties	Yes	12	2	0	2	1 (S)	No	First	Resignation
I20	F/fifties	Reduced hours	6	2	0	3	1 (S)	No	Recurrent	Balancing
I21	F/fifties	Yes	11	2	0	4	4 (S)	No	First	Balancing
I24	F/thirties	Yes	6	2	0	1	1 (S)	No	First	Resignation
I27	M/fifties	Yes	12	2	0	2	1 (S)	No	Recurrent	Balancing
I28	M/fifties	Yes	9	2	0	2	1 (S)	No	Recurrent	Balancing
I33	M/forties	Self-employed - flexible hours	9	2	0	3	1 (M)	No	Recurrent	Ignoring
I34	F/sixties	Yes	7	2	0	3	1 (S)	Yes/1	Recurrent	Balancing
I35	M/fifties	Yes	7	2	0	2	1 (M)	No	Recurrent	Resignation
I37	F/fifties	Yes	6	2	0	2	1 (M)	No	Recurrent	Balancing
I38	F/forties	No	7	2	0	3	1 (M)	No	Recurrent	Balancing
I39	F/seventies	Retiree	6	2	0	4	1 (M)	No	Recurrent	Resignation
I40	M/sixties	Yes	6	2	0	2	1 (M)	No	First	Balancing

[*] S: Surgical outpatient clinics, M: Medical outpatient clinics

in the different action contexts? In this part of the analysis, researchers used constant comparison to compare participants' daily life descriptions within each of their trajectories over time. Two themes were then constructed based on each participant's major concerns in different action contexts. The first theme describes demands from 'support' systems and how they influence daily life in the first part of their trajectory. The second theme describes three patterns of adaptation in everyday life after periods of low back pain.

On the fourth level of analysis, these themes were challenged by reading, re-reading and discussing emerging interpretations and data. During this process, researchers used deviant cases to challenge their analysis (Charmaz, 2014).

Throughout all study stages, memos were written to prompt analysis, capture creative thoughts, and follow up on instincts (Charmaz, 2014). CBR and LH jointly conducted interpretations of the data with MTH, LDB and LBJ. The authors, all female, have backgrounds in nursing, anthropology, and physiotherapy. CBR, LH, MTH and LBJ have PhDs and are experienced in qualitative research.

2.5. Ethical considerations

The Danish Data Protection Agency (j. No. 16-02-580-16) approved the study, and researchers observed all of the agency's regulations regarding data storage throughout its duration. According to Danish regulations, this research type is not required to undergo an ethical review for approval. The regional Research Ethics Committee was notified of the project (j. no. 615763) and had no objections.

Potential participants were invited to the study by letter before their clinic consultation. Potential participants were approached in the waiting room of the outpatient clinic. If interested, they were taken to a separate room, where they received further information, including the study's goals and the head researcher's background (CBR). They then provided written informed consent to be included in the study.

Before interviews, participants were again informed about the study's goals, the researchers, and their rights. All data were anonymised, stored and handled in full confidentiality.

3. Results

In the longitudinal data analysis process, researchers produced two themes based on participants' major concerns during and following periods of low back pain. The first was, *When 'support' systems become disrupters.* This theme shows how participants experienced significant disruptions in their daily living in the first part of their trajectory. These disruptions were caused by conflicting demands amongst new action contexts, the healthcare system, and the sickness benefit system. These systems' demands could take precedence over other concerns, which challenged participants' social self-understanding. The second theme, *Adapting to a new life,* describes three typical patterns of how participants found an adapted way of living with low back pain over time.

Each theme represents a part of the trajectory, but they should not be seen as linear. Each participant's unique course is affected by pain, physical functioning and new episodes of low back pain.

3.1. When 'support' systems become disrupters

In the first part of the participants' trajectories, the healthcare system and the sick leave system influenced other action contexts in participants' everyday lives. Seen from the participant's perspective, these systems were perceived as necessary support in their new situation. But at the same time, the two so-called 'support' systems produced demands that were seen as causing disruption and strain on participants' daily lives. The following, taken from field notes from a man in his early 40s who was six months into his current trajectory, exemplifies the demands these systems put on participants:

> *Ted says that he is tired and busy. To show me what he was so busy with, he gets up and goes to a bulletin board covered with papers. He says that those are appointments for meetings and consultations that have something to do with his back. [A few weeks later…] We are sitting in a waiting room waiting for him to consult with a doctor at the hospital. He tells me that he is still on sick leave and that he has just been fired. He says that he was busy last week because he had eight appointments related to his back, including appointments with his caseworker, therapists and employer. He indicates that it's hard to live up to obligations that come with having back pain and being on sick leave* (Fieldnotes from interactions with P5).

Healthcare and sick leave systems were perceived as necessary to organise participants' daily lives and deal with concerns regarding pain relief and economic security. Still, these systems have extensive demands. For example, participants did not get to choose the times of their consultations and meetings. This leads to several appointments in various places at various times, affecting the participant's trajectory.

Seen from the participants' perspective, they must comply with these demands, even though they are exhausting. This is because, as participant 13 describes it, "when you are a patient, you are more vulnerable". Participants need the support that they hoped these systems could offer them. But consequently, once meaningful daily activities that are already challenging because of pain became even more difficult because of lack of time and energy.

Participants also experienced that their low back pain was unpredictable, since its intensity fluctuated. Waiting times added to the pain's unpredictability, as participants lacked guidance on what to do while waiting. This lack of knowledge led to frustration and uncertainty.

The healthcare system was structured around fragmented consultations and self-managed rehabilitation that consists of training and scheduled rest. For participants, the primary goal was pain relief. Participants often felt insecure about their prognosis and left behind in the process of understanding and learning to deal with their pain. They expressed that they needed someone who could guide them in the right direction and provide information about their condition, its prognosis, and treatment options.

The sickness benefit system was a new action context in most participants' lives, positioning them as clients needing financial help. Participants worried about being able to work and provide for themselves in the future. If their current jobs were impossible to do because of low back pain, they made plans for a career change. But in the context of the sickness benefit system, they often felt that legislation came before the individual, and that they were suspected of malingering if they could not meet caseworker or employer expectations for returning to work. Participants also experienced legislative limitations that could made alternative careers impossible.

Participation across the two contexts of action, the healthcare system and the sickness benefit system, was characterised by conflicting demands and lack of cross-sectoral communication. Often, healthcare professionals' recommendations were contrary to those of the caseworker in the sickness benefit system, or the employer.

The following is taken from field notes from the second interview with a woman in her late thirties. She wanted to keep her job, but experienced pressure and mistrust from her employer and caseworker.

> *Today, she has had to stay home because of pain due to working too long the day before. It bothers her that there is a contradiction between what the doctor advises and what her job centre and employer expect. She is in doubt about whether or not the job centre knows what is in her medical record. The doctor thinks she should wait until January before she increases her work time (it is now mid-December). But she already works up to 8 hours per day – not the 5 hours that the doctor recommended. She is not part-time help anymore. She is a part of the workforce on equal footing with her colleagues. Her employer says she is welcome to rest during working hours (lying down for a quarter of an hour every 2 h, as recommended by the physiotherapist). But she feels frowned upon when she rests. She has just been to a meeting with her employer, who suggests declaring herself recovered and fit for work. But she is not ready, and she is afraid she will be fired if she does not go back to a full-time schedule* (Fieldnotes from interview with P11).

Participants often felt that they were considered unreliable when they told their employers or caseworkers the medical recommendations they were given, which often included rest during the workday or fewer working hours. This situation often posed a dilemma for participants, who felt forced to choose between pain relief and employment.

Mistrust, lack of guidance, waiting times, conflicting demands, and insecurity often left participants feeling powerless. Consequently, they had difficulties in becoming the self-manager that the system expected them to be. This challenge influenced their social self-understanding. Participants described themselves with negative descriptions like, "*I am not the man I used to be*" (P1). Many described themselves as sad, discouraged, and in doubt.

Participants often had milestones that gave them hope for returning to life before episodes of low back pain, such as an appointment with a chiropractor or a date for their first day back at work. Participant 1 says that, *"I became much calmer when I knew that I had a date for my pre-operation appointment. Then I knew when I would get my operation, which meant that I would hopefully get back to work soon."* Being offered surgery was a milestone that brought relief, since both systems understood surgery regimens. Waiting for surgery and the following rehabilitation gave participants a respite from conflicting system demands.

3.2. Adapting to a new life

In the second part of the trajectory, participants' pain subsided, with some fluctuations, and their level of functioning increased. Need for help from the systems naturally decreased. Participants were in a transition period where they negotiated their self-understanding by creating a balance between and daily life and health concerns.

We identified three patterns of how participants pursued the everyday concerns involved in adapting to life with low back pain: 1) *Resignation 2) Balancing and 3) Ignoring.* It was possible to identify elements of all three patterns in each participant's trajectory over time, with one being dominant (see Table 1).

3.2.1. Resignation

For six participants, *Resignation* was a dominant pattern. In this pattern, participants' conduct of everyday life was governed by trying to avoid relapse. Participants viewed themselves as permanently injured. For example, they excluded activities they enjoyed and once gave them a sense of fulfilment in their lives. This could create a loss of meaning, a loss of valuable socialisation, and decreased possibilities in work life. Resignation changed social self-understanding and impacted these participants' daily living in all social action contexts. The following quote exemplifies this from the final interview with a man in his late fifties. His work as a craftsman was central to his self-understanding. Even in his leisure time, he played a central role in renovating family and friends' houses. Family gatherings were primarily physically active and prominent in his life. He also had an extensive social network, where he often took part in physical activities. In interviews, he expressed sadness and frustration at having to stop these activities because of low back pain:

> *Damn it, I've never had a problem with anything before, and then all of a sudden it… You also have to learn to admit that you're just not able to do it anymore. It's problematic, and it's a little difficult. It would have been easier if I had taken early retirement, then it would have come gradually. But this, damn it, just came suddenly. Now it's over. I've always been damn busy with something. Always. I'm not anymore. I can't do anything compared to what I did before. Nothing. I cannot. And it's hard. It's damn hard* [He cried during this interview] (from the final interview with P35).

In this pattern, participants' social self-understanding changed, and they had lost most of their sense of social belonging. They organised their lives around avoiding low back pain and described themselves as being down or depressed. Their daily lives were fundamentally changed and reduced to the most necessary activities, like taking care of the children at home and coping with work tasks. Some participants unsuccessfully tried to establish new activities to substitute for the lost sense of social belonging.

3.2.2. Balancing

We found that eighteen of the participants were predominantly in this pattern. Here, participants adapted to the situation and conducted their everyday lives in a new manner, governed by a wish to return to their regular daily lives. They described regaining control and finding themselves again. Participants also described themselves as capable of living life as usual. Still, it became clear in the interviews, combined with field notes from in-home observations during interviews, that they adjusted their activities substantially, mostly without noticing. Even though they could not do what they did before, they felt they could complete activities that were essential to their social self-understanding. These activities include domestic tasks and leisure activities. Still, participants continually weighed these activities against the risk of relapse. They modified their behaviours by participating in social gatherings for fewer hours, walking slower, or taking rests. The following quote is from the final interview with a man in his early sixties. In the interview, he describes how he had restored his physical function level to where it was before he experienced back pain, with adaptation. *Well, I don't lift heavy things… but otherwise I don't think there is anything. Well, I can do gardening… but digging in the garden, I don't want to risk that* (From interview with P40).

A woman in her late thirties describes it this way:

> I just vacuumed half of the house, because vacuuming is probably my greatest enemy. Yes, then I take a break when I have vacuumed… So, I split things up more than I did before. (from interview with P11).

A woman in her sixties describes how she and her husband now take the bike when they go on a trip, rather than walking. *"I don't walk well, but I bike. . . so we can bike together."* (from interview with P34).

In this pattern, participants adapted their lives while retaining a sense of fulfilment. They felt in control and could attend activities that were a central part of their social self-understanding, while at the same time weighing the risk of relapse.

3.2.3. Ignoring

We found that three of the participants were predominantly in this pattern. Here, participants' aimed to continue as before, despite pain, almost without adapting. Even though participants were aware of reduced physical functioning, they still carried out activities as usual without considering their back pain, e.g., continued 24 h work shifts. They held onto their social self-understanding and carried out daily activities. They knew it was an unsound plan, and consequences included a high level of pain and worries about the future. Still, participants in this pattern could not find other coping mechanisms. The following quote is from the last interview with a man in his early forties. He was used to being in charge of demanding physical tasks at home and work. After his surgery, he maintained this work, even though it involved long working hours and he could not follow post-surgical recommendations for rest and recovery. He also exaggerated his leisure activities: *Now, I'm working hard all day. I have 3,000 square metres of land. I was just going to cut the grass, and my garden tractor broke down, so it was with the hand lawnmower. So last night I was tired as hell [laughs]* (from interview with P5).

In this pattern, participants ignored their pain and their risk of relapse by continuing their daily lives. They knew that this was problematic, but they did not see another option in their current situation.

4. Discussion

Our analysis' theoretical departure point is the concept of conduct of everyday life. Here, we explore individuals' daily lives with low back pain in and across various action contexts over time. We discuss our findings in conjunction with existing knowledge while focusing on how a lack of cooperation and conflicting rules across 'support' systems can create conflicting demands on patients. These demands can erode at the integrity of individuals with low back pain and are consequential to their daily lives. Finally, these findings are discussed in light of methodological considerations.

4.1. Lack of cooperation between systems affects integrity

In line with Petersen et al. (2020), this study showed how participants' everyday lives are characterised by fragmented contacts, waiting time, and lack of cooperation between healthcare and social benefit systems. Our findings also show the consequences of this dissonance on participants' everyday lives.

Healthcare professionals recommended time-consuming daily activities like exercise and rest, which is not compatible with the social benefits system's demands to return to work as soon as possible. Reducing hours and incorporating necessary rest was at times impossible to incorporate into work life. This made it impossible to comply with both the healthcare systems' guidance and the sickness benefit system's requirements (Bekendtgørelse af lov om sygedagpenge, 2020). In other words, patients could not simultaneously manage pain and live a self-providing life. This problem was compounded by participants feeling like mistrusted messengers within both systems, which made them feel powerless and misunderstood.

This tension between the individual, the systems' expectations, and possible negative consequences is found in many groups of patients who cope with health issues in their daily lives (Jørgensen et al., 2013, Jorgensen and Fridlund, 2016, Jørgensen et al., 2017, Bastrup, 2012). Jørgensen et al. (2017) found that individuals are significantly concerned with keeping their integrity intact while dealing with health issues. They deal with this via a transitioning process that involves attuning internal and external factors.

Existing research shows that individuals often struggle to maintain their integrity when they experience pain and internal changes (Van Griensven, 2016). Discrepancies between personal values, health status, self-expectations, and external factors are the most predominant trigger points for altering integrity, and the outcome of these discrepancies can either erode at or preserve the integrity of the individual.

Dependence on public systems also threatened the physiological and psychological integrity of participants in our study. Their self-expectations and self-understanding relied on responsibility and financial independence, so they had to adjust to the sickness benefit system's expectations. But by doing this, they were sometimes forced to neglect the healthcare system's advice, which stated that they shouldn't go beyond their limits. This atunement led to a coping mechanism that harmed their physiological and psychosocial integrity. It also pitched the healthcare and sickness benefit systems' integrity against the individual's integrity (Jørgensen et al., 2017).

Healthcare professionals and caseworkers play an essential role in the trajectory, but their goals and requirements often differ from each other. Therefore, legislation and organisational infrastructure requirements between systems must support evidence-based and coherent cross-sectoral support to individuals with low back pain.

4.2. Striving for a balanced adaptation to everyday life

Our study provided insights into three patterns of adapting to daily life following periods of low back pain. Through various coping strategies, creating and adapting to new behaviour patterns can be seen as a way for participants to keep their integrity intact (Bunzli et al., 2013, Jørgensen et al., 2013, Jacelon, 2004, Morse, 1997). Participants that were predominantly in the *Resignation* or *Ignoring* patterns seem to have problems attuning to the tension between personal concerns, daily life, and external recommendations and demands. These difficulties can have crucial long-term consequences.

Those in the *Resignation* pattern show traits similar to those described in other studies (Bunzli et al., 2013, MacNeela et al., 2015). A longitudinal study by Snelgrove et al. (Snelgrove et al., 2013) following individuals with chronic low back pain for two years found the individuals used behavioural-focused coping strategies like living pain, rather than avoiding or deprioritising valuable social activities. Consequently, they restored their valued self and did not focus too much on the future.

Our study showed that the *Resignation* pattern could result in severe psychological implications. Participants in this pattern described themselves as having low mood and symptoms of depression. This possible association between renouncing a valuable life and severe psychological consequences is supported by existing research i.e. (Ryan and Roberts, 2019, Van Griensven, 2016, Strom et al., 2018). Professionals must be aware of this pattern so they can identify early signs of Resignation and integrity-damaging coping methods that could have a negative psychological effect.

In contrast, those in the pattern of *Ignoring* used coping behaviour that seems to preserve their integrity. To some degree, they held on to their self-understanding. Despite the pain, they chose to live as the person they wanted to be. This dichotomy between the past and present self is also found in other studies (Bunzli et al., 2013), which state that that the battle to retain the self can be central and even more distressing than pain itself. For example, one participant continued to work in 24-hour shifts, because the immediate consequence of not doing so was to get fired. But even though it does not always seem reasonable to ignore pain and risk long-term consequences, it can, from a subjective standpoint, be in their best interest Holzkamp (2013). However, this kind of coping behaviour can also have long-term consequences, including long-term severe pain.

Participants who are predominantly in the *Balancing* pattern seem to keep their integrity intact by balancing aspects of their everyday lives, including personal concerns, fluctuating low back pain, and external factors. Participants in this pattern acknowledged that they needed to learn to live with low back pain.

It is a pattern found in other studies, too (Bunzli et al., 2013). In a longitudinal design by Sanders et al. (2015) following individuals with low back for a year found that individuals with non-specific low back pain realised that they had a recurrent condition which needed to be managed over time. They managed through a combination of self-care, lifestyle adjustments, and realistic expectations about the pain trajectory in their daily lives. The *Balancing* pattern appears to support long-term health and achievement of a fulfilling life.

For most individuals, low back pain is episodic, and many will pass through the described trajectory several times (Kongsted et al., 2016). Our study cannot answer whether individuals will change their coping behaviour over time. Still, a long-term prospective study on healthcare-seeking individuals with low back pain suggests that most individuals follow the same pain trajectory over time (Dunn et al., 2010). In that vein, the coping behaviour we describe in this study could be an individual path of behaviour that is impossible to change. However, healthcare and sickness benefit system professionals should encourage individuals to use healthy coping mechanisms to maintains their integrity. Our study indicates that a central way of doing this is to minimise the systems' conflicting demands and reinforce cross-sectoral coherence. Furthermore, patients' perspectives can advantageously be used to develop future cross-sectoral pathways and legislation.

4.3. Methodological considerations

Our findings should be seen in light of several methodological considerations. Our sampling strategy was to recruit participants diagnosed with a herniated disc in a hospital setting. This led to a sample of participants who were diagnosed and received specialised assessment and treatment. If individuals with other types of low back pain were part of the sample, we might have further enhanced our understanding of the phenomena explored.

For most individuals, being diagnosed with a herniated disc means that specialised treatment is offered for possible recovery. Patients with other low back pain diagnoses might have had different experiences. Still, our sample reflects experiences similar to those described in most low back pain studies that involve individuals with non-specific or chronic low back pain (Bunzli et al., 2013, MacNeela et al., 2015, Froud et al., 2014). This can be explained partly by the assumption that diagnosis does not forecast future outcome (Kongsted et al., 2016). Thus, our findings suggest that despite diagnosis and access to treatment options, living with low back pain can, over time, lead to radical changes in everyday life and extensive identity work.

A significant volume of data from participant observation and interviews was accumulated for this study. Due to theoretical sampling, some participants' trajectories were followed more closely than others (Charmaz, 2014). This could mean that their experiences influenced findings more than results from other participants.

The results should also be understood within a Danish context, which includes a specific healthcare and sickness benefit system. This can affect external validity (Miles and Saldaña, 2014). To address this, we have described the Danish setup in the "study context" section.

We fully acknowledge that the lack of ethnic diversity in the sample may impact results. We recognise that expressions and experiences of pain are also culturally situated, so the culturally homogeneous sample in this study may have limited our study's empirical diversity.

5. Conclusion

In this study, we developed a substantive theory explaining how individuals with low back pain manage their everyday lives across various contexts over time. The first part of their trajectory was characterised by high pain and low functioning, with the main concern being pain reduction. The two 'support' systems, healthcare and sickness benefit, played an existential role in individuals' lives, especially in this part of the trajectory. This study showed that individuals with low back pain often experienced disruption due to conflicting demands arising from different legislative frameworks and lack of cross-sectoral communication. These disruptions had negative consequences for individuals' integrity.

In the second part, when the pain subsided, individuals were concerned about adapting to everyday life. They were in a transition where they negotiated their understanding of themselves by finding ways to adapt to daily life and pursue ongoing concerns.

Researchers identified three patterns of adaptation: resignation, balancing and ignoring. Each individual adapted by using a dominating behavioural pattern. The balancing pattern of behaviour seems to best support long-term health and achievement of a fulfilling life.

More coordinated support from systems involved in the trajectories of low back pain is needed. Further, knowledge about adaptation patterns can guide healthcare and sickness benefit professionals toward strategies that support integrity maintenance and coping mechanisms.

Declaration of Competing Interest

None.

CRediT authorship contribution statement

Camilla Blach Rossen: Conceptualization, Methodology, Data curation, Formal analysis, Funding acquisition, Investigation, Project administration, Writing - original draft. **Mette Terp Høybye:** Conceptualization, Methodology, Writing - review & editing. **Lene Bastrup Jørgensen:** Conceptualization, Methodology, Writing - review & editing. **Louise Deigaard Bruun:** Resources, Data curation, Writing - review & editing, Formal analysis. **Lisbeth Hybholt:** Formal analysis, Writing - original draft, Data curation, Methodology, Conceptualization.

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Supplementary materials

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