The Perspective of Pituitary Patients on Work According to the Expanded ICF Model: a Qualitative Study

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Abstract

Purpose: As the majority of patients with pituitary disease are of working age, their health situation may negatively impact their functioning at work. However, work participation can also be influenced by contextual (environmental and personal) factors. The aim of this qualitative study was to investigate the pituitary patients' perspective on their functioning at work and on contextual factors contributing to work-related problems using the expanded International Classification of Functioning, Disability and Health (ICF).

Methods: Semi-structured interviews, focusing on contextual factors influencing work ability and experience, were conducted with eight patients with different types of pituitary adenomas (Cushing's disease, prolactinoma, acromegaly, non-functioning adenoma). Following the steps of an experiential thematic analysis, forty categories were identified, which were organized into eleven themes according to the expanded ICF.

Results: Patients reported various problems in work-related activities and work participation. Influencing environmental factors included type of employment, perceived job security, financial security, relationships with colleagues/managers, collaboration with others, physical vs. mental work, managing position, flexibility at work, corporate culture, and physical work environment (*work-related*), and traveling distance to work, financial savings, and (non)professional support (*other environmental factors*). Influencing personal factors included professional ambition, sense of duty, motivation, job satisfaction, feeling of fulfilment (*work-related*), and personality, acceptance, coping styles, and lifestyle (*general personal factors*).

Conclusion: Patients with pituitary disease report several contextual factors that influence their functioning at work. Healthcare and occupational health professionals should be aware of these factors to improve patients' well-being and functioning at work, ultimately aiming to improve quality of life.

Introduction

Pituitary adenomas are rare benign tumors of the pituitary gland, which can cause physical, but also cognitive and psychological symptoms[1]. As a result, many patients report a decrease in health-related quality of life (HRQoL)[1, 2]. Surgery is the first-line tumor treatment for most pituitary adenomas, while medication is an option in some patients. Hypopituitarism, if present, requires individualized endocrine replacement therapy[3–5]. These treatments, however, fail to restore HRQoL in a substantial subset of patients, even if the disease is biochemically under control[6–9].

As the majority of patients with pituitary adenomas are of working age[10, 11], pituitary-related health complaints can also affect functioning at work. A qualitative focus group study[2] by our group, aiming to explore pituitary patients' HRQoL, revealed that patients experienced changes in their functioning at work due to the disease, for instance because of difficulties in concentrating and collaborating with others. Previous quantitative research has shown that pituitary diseases pose a substantial burden on patients'

work and financial status[12–22]. A recent study[12] among 241 patients with a pituitary tumor showed that 72% had a paid job, of whom 41% reported health-related absence from work in the previous year, and 39% experienced a negative impact of their health-related problems on their work. Especially mental demands were reported to be troublesome[12]. Other authors reported that work-related problems in patients with pituitary disease were mainly related to a lack of energy[17] and that patients who retired because of their disease were older and had more comorbidities than those returning to work after treatment[15].

Although these studies demonstrated substantial work-related problems in pituitary disease, no studies have been dedicated to the patients' perspective on contextual (environmental and personal) factors that may influence their work ability and to how these patients can be supported in order to improve their functioning at work.

To facilitate a systematic approach towards work ability, a number of theoretical frameworks are available, that mainly aim to describe the impact of work on health (e.g., Job Demands and Resources model[23], the model of work load and work capacity[24]). These models are helpful for occupational health professionals to support people at their work, in order to prevent illness caused by a disbalance between their job demands and their carrying capacity. However, in the evaluation of work-related problems in patients with pituitary disease (and other chronic diseases), the consequences of the disease itself for the patients' carrying capacity should be considered as well. In order to bridge the gap between the approach of occupational health professionals on the one hand, and healthcare professionals (such as endocrinologists) on the other hand, the expanded International Classification of Functioning, Disability and Health (ICF) was developed[25, 26]. The original ICF[27] is a well-known biopsychosocial framework used to describe an individual's health and functioning. It consists of two parts: the part Functioning (negative: Disability), including the two components 'Body functions and Structures' and 'Activities and Participation', and the part Contextual Factors, including the two components 'Environmental factors' and 'Personal factors'[27]. In the expanded ICF, work can be classified under 'Activities and Participation', but also as an 'Environmental factor', since it may affect all three levels of functioning (i.e., body functions/structures, activities, participation)[25]. In this expanded ICF, environmental and personal factors are elaborated in order to show that work-related activities and work participation can be influenced by different contextual factors (related or unrelated to work)[25, 26].

Considering the substantial burden of pituitary disease on participation at work, the aim of the present study was to investigate the perspective of patients with pituitary disease on their functioning at work using semi-structured interviews, in particular focusing on the contextual factors (work-related or not) contributing to work-related problems. The expanded ICF was used to classify themes and categories. This expanded ICF for pituitary disease will facilitate the communication between healthcare professionals and occupational health professionals. This will improve understanding of work-related problems, and facilitate work-related interventions for patients with pituitary disease ultimately aiming to improve HRQoL.

Methods

Participants

Patients were recruited from the outpatient clinic of the Center for Endocrine Tumors Leiden of the Leiden University Medical Center (LUMC) and were selected by their consulting endocrinologist and/or neurosurgeon. All patients were of working age and were currently employed or had had a paid job at the time of diagnosis. Patient selection aimed at forming a representative, mixed group of patients regarding sex, employment status and tumor type. Two patients (one male, one female; one employed, one partially employed or unemployed at the time of the interview) of each tumor type (Cushing's disease, prolactinoma, acromegaly, non-functioning adenoma (NFA)) were asked to participate. Since it has been recommended to include six to ten participants for the interactive data collection method using interviews[28] in order to reach data saturation, we aimed to include a total of eight patients in this study. Data saturation was considered when after eight patients no new topics were raised. All patients gave written informed consent prior to participation and the research protocol was approved by the institutional Medical Ethical Committee before the interviews started (P17.142).

Study design and data collection

The consolidated criteria for reporting qualitative research (COREQ) were used for the design and reporting of this study[29]. With each patient, an individual semi-structured interview was conducted by CDA (MD, psychologist, female) and DJL (MD, male), who were both not involved in the patients' clinical care. These interviews took place between September 2017 and March 2018 in person (n = 6) or by phone (n = 2) and were performed based on a predefined topic list (Supplement 1) focusing on problems at work and potential barriers and facilitators for functioning at work. Conversations were recorded and typed out verbatim.

Data analysis

Transcripts were analyzed following the steps of an experiential thematic analysis as described by Braun and Clarke (2013)[28]. Two independent researchers (MM, BS) carefully read and reread the transcripts in order to get familiar with the data and independently performed open coding (bottom-up) of the transcripts using ATLAS.ti version 8.4 (ATLAS.ti Scientific Software Development GmbH, Berlin). The open coding was discussed in the research team (MM, BS, DJL, CDA), after which complete coding was performed (MM, BS). Discrepancies were discussed until consensus was reached. Based on the theory of the expanded ICF model, categories and subcategories were formulated (top-down) and reviewed. Categories and subcategories were defined and renamed after which the analysis was finalized. Since this study focused on the patients' current and perioperative situation, statements relating to the situation prior to their diagnosis were not considered.

Results

Eight patients participated in individual semi-structured interviews (Table 1). Their median age was 56.8 years (range 40.7 to 63.8) and four patients were female (50%) (for privacy purposes, all individual patients will be referred to with male pronouns). For further clinical, sociodemographic- and work characteristics, see Table 1.

Table 1
Patient characteristics

	Total group (N = 8)
Age, median (range)	56.8 (40.7–63.8)
Gender: female, N (%)	4 (50%)
Type of pituitary adenoma, N (%)	
Non-functioning adenoma	2 (25%)
Acromegaly	2 (25%)
Cushing's disease	2 (25%)
Prolactinoma	2 (25%)
Time since diagnosis, years (median, range)	6.8 (1.1–27.4)
Surgical treatment, N (%)	8 (100%)
Time since surgery, years (median, range)	5.6 (0.3–25.8)
Received substitution therapy for pituitary deficiency, N (%)	4 (50%)
Education level, N (%)	
High	7 (88%)
Intermediate	1 (13%)
Low	0 (0%)
Current work status, N (%)	
No paid job	3 (38%)
Working < 20 hours per week	1 (13%)
Working 20–40 hours per week	2 (25%)
Working ≥ 40 hours per week	2 (25%)
Current type of function, N (%)	
Managing position	2 (25%)
Mainly mental	5 (63%)
Mainly physical	0 (0%)
Employed	2 (25%)
Self-employed	3 (38%)
No paid job	3 (38%)

	Total group (N = 8)
Type of function at time of diagnosis, N (%)	
Managing position	5 (63%)
Mainly mental	8 (100%)
Mainly physical	0 (0%)
Employed	7 (88%)
Self-employed	1 (13%)
No paid job	0 (0%)

After eight interviews, no new issues were raised and data saturation was reached. Forty categories were identified from the transcripts, which could be organized into eleven themes following the theory of the expanded ICF model (Fig. 1, Table 2). Under each ICF theme, the categories and subcategories pertaining to that theme are printed in bold.

Table 2

Themes and categories identified in the interviews, categorized according to the International Classification of Functioning, Disability and Health (ICF)

Theme	Category	Subcategory	Quotes
Body functions and structure (impairments)	Physical complaints	Fatigue	'It's a type of fatigue that I cannot describe in other words than complete exhaustion.' (NFA1)
		Malaise	'I have the feeling that I am less fit; it feels like a bad hang-over. The strange thing is that this feeling often improves over the course of the day.' (ACRO2)
		Speech problems*	'In the beginning, when the acromegaly was still active, one colleague that apparently didn't know what I had said to me: "Why are you talking like you're drunk?"' (ACRO1)
		Joint problems	'Some days, my body is so painful and stiff when I wake up, that I can barely get out of bed.' (ACRO2)
	Cognitive complaints	Concentration problems	'I think what bothered me most at work the past few years was my inability to focus.' (ACRO1)
		Lack of alertness	'I just do not have the clarity of mind that I need at work.' (ACRO2)
		Sleep problems	'After a while, I started to fall asleep during meetings.' (NFA1)
		Short-term memory problems	'I can't remember things. I have to write it down.' (PRL1)
		Lower speed of information processing	'I have a slow start in the morning.' (CUSH1)
		Less creativity*	'I find it hard to acknowledge that I no longer have some of the qualities of an entrepreneur. I don't have a lot of energy or new ideas anymore; I'm less creative.' (CUSH1)
		Feeling of overstimulation	'I couldn't handle the external stimuli. I would either get angry or walk away.' (PRL2)

ACRO, patient with acromegaly; CUSH, patient with Cushing's disease; NFA, patient with non-functioning pituitary adenoma; PRL, patient with prolactinoma. Numbers indicate which patient said a certain quote.

*Subcategories only mentioned by one patient are included in the table but are not mentioned in the main text.

Theme	Category	Subcategory	Quotes
	Psychological complaints	Problems with a changed personality	'My personality has changed; I have become a different person.' (ACRO1)
		Indifference	'I don't enjoy things the way I used to. Things don't interest me anymore.' (ACRO1) 'Some days, I think: I just don't care anymore.' (CUSH1)
		Frustration	'I notice that everything costs a bit more effort, which is very frustrating.' (ACRO2)
		Feeling of shame	'I feel ashamed that I can't do some things anymore.' (ACRO1)
		Feeling of guilt*	'There were moments when I thought: if I had paid more attention or made a better risk assessment, things would have worked out differently.' (ACRO1)
		Insecurity	'I asked [my colleagues], "Was that speech okay? Because personally, I had the impression that I was struggling, that it was not as good as normally."' (ACRO1)
		Fear	'I was scared that no one would hire me anymore if I opened up about my health problems.' (ACRO1)
		Worry	'In the first weeks of working as a freelancer, I didn't get any sleep. What if something goes wrong? I didn't even have a car insurance.' (PRL1)
		Feeling of failure*	'I have the feeling I'm failing, because I can't do everything I demand from myself.' (NFA2)
		Irritability / impatience	'I have noticed that I get irritated more easily than I used to.' (NFA2)
		Anger	'I was very angry about what had happened to me.' (ACRO1)
		Agitation	'I felt very agitated, especially in the morning. I was always nervous and stressed.' (CUSH1)
		Depressive feelings	'I have been feeling down for the past few weeks.' (CUSH1)
ACRO, patient with acromegaly; CUSH, patient with Cushing's disease; NFA, patient with non-functioning pituitary adenoma; PRL, patient with prolactinoma. Numbers indicate which patient said a certain quote.			
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Theme	Category	Subcategory	Quotes
		Increased emotional instability	'I get upset more easily than other people.' (CUSH1)
Activities (limitations)	Activities cost greater effort: writing, reading, driving, memorizing speeches, networking, working in a busy physical work environment, starting to work early		'Seemingly simple activities, simple things I had been doing for years, started to cost more and more effort over the course of the week.' (NFA1)
	Need to take more time		'You have to allow yourself to take more time.' (PRL1)
	Need to take more rest		'You have to take care that you are rested, by taking a break in time and going to bed early.' (ACRO1)
	Having to redo things		'I really have to read things two or three times, otherwise I miss things.' (ACRO1)
	Inability to assess risks/situations		'Assessing risks is a lot more difficult. You're less able to foresee the consequences of your decisions.' (ACRO1)
	Making mistakes		'In that period, I certainly made mistakes, which they had never seen from me before. That was purely due to extreme fatigue.' (PRL2) 'I noticed that at work, it cost more effort to do things right; it cost a lot of attention. As a result, I have definitely made mistakes. Of course, everyone makes mistakes, but I really think this had to do with it.' (ACRO1) 'I've been wondering, if I hadn't had a problem with my pituitary, had I been more alert and had some things perhaps not gone wrong? In that line of thought, after two, three years, I started thinking: "Is it wise what I'm doing now?"' (ACRO1)
Participation (restrictions)	Absenteeism (sick leave)		'If I'd been employed, I would have taken a day off sometimes. But I couldn't do that, because I was self-employed, with my own projects and my own clients.' (CUSH1)
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Theme	Category	Subcategory	Quotes
	Working less temporarily		'Maybe, they should have given me more time.' (PRL2)
	Working less permanently		'Twenty hours a week is my maximum for now.' (CUSH1) 'A year has passed, and I haven't been able to run my company optimally for a while. If it continues like this, we will get a hard time financially.' (CUSH1)
	Modification of function		'I have given up the managing part of my function.' (ACRO2)
	Job loss		'After five years, I got fired and I really think that had to do with my acromegaly. [...] If you have difficulty concentrating, you give up earlier. And in that competition process during a reorganization, you really need to concentrate and pay close attention.' (ACRO1) 'They fired me and I was fine with that. I couldn't handle my job anyway, physically nor mentally.' (PRL2)
	Presenteeism (decreased productivity)		'It really took me a long time to get back to my old level.' (NFA2) 'In my opinion, I have returned to the level of functioning that I had before my symptoms started.' (CUSH2)
	Problems in maintaining a healthy work-life balance		'I noticed that on workdays, I wasn't able to do anything when I came back home.' (ACRO2)
Work-related environmental factors: terms of employment	Employed vs. self-employed		'An employer will wait and see for a while, but then you have to get going again. You can't take a rest.' (PRL1)
	Perceived job security		'I got surgery in December and it was almost certain that I would have a new job in the new year.' (ACRO1)
	Financial security		'I'm a freelancer, so I'm the only one responsible for my financial security.' (CUSH1) 'I have to make sure I get an insurance somewhere. But that is impossible at the moment, it's too expensive.' (PRL1)

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Theme	Category	Subcategory	Quotes
Work-related environmental factors: social relationships at work	Issues in the relationship with colleagues		'People don't understand that after the surgery and a period of recovery, the disease isn't over.' (NFA2)
			'Now they know about my situation, they ask me how I'm feeling.' (CUSH2)
			'I'm quite sure that, if I had opened up about it, I would have experienced difficulty with several people at work.' (ACRO1)
Issues in the relationship with manager/supervisor			'If anyone had told my manager what my condition involves, it would have made a huge difference.' (PRL2)
			'He allowed me to take the time I needed to return to work. I found it very pleasant that he wasn't pushing me.' (NFA2)
			'At some point, I had a good conversation with my manager. He said he thought I wasn't doing so well and suggested that I quit managing my own department and start working as his right-hand man.' (NFA1)
Collaborating with others or hiring employees			'I have been thinking about collaborating with a colleague freelancer or hiring someone for a few hours a week.' (PRL1)
Work-related environmental factors: task contents	Physical vs. mental work		'I think it's noticeable that you are physically less able to do things, so it would not be wise [for employers] to offer very physically demanding work.' (PRL2)
		Managing position	'A manager can be fired easily, while someone else wouldn't get fired if they got ill.' (ACRO1)
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Theme	Category	Subcategory	Quotes
	Flexibility		<p>'When I was still working 60%, I divided this over four shorter days. Because I don't sleep well, I start later in the morning.' (ACRO2)</p> <p>'I find it very pleasant that I can determine my own work pace.' (PRL1)</p> <p>'When I'm at the office and I feel very tired, I think: "I don't have any meetings, I'm going to drive home and will work there if I need to."' (ACRO2)</p> <p>'In that case, I take it home with me and work on my laptop in the weekend.' (NFA2)</p> <p>'Because I was the manager, I could do certain things: I didn't have to tell anyone why I wasn't at work.' (ACRO1)</p> <p>'If I was unable to work, I chose not to. In that respect, I was very happy that I didn't have a boss.' (PRL1)</p>
Work-related environmental factors: working conditions	Issues in the corporate culture		'There was no understanding in that company ever, for anything.' (PRL2)
	Busy physical work environment		'If I had shared a room with one other colleague, I would have been able to continue working much longer.' (NFA1)
Other environmental factors: home environment	Traveling distance to work		'Driving to and from work took almost two hours. That was really heavy for me.' (NFA2)
	Financial savings		<p>'I have the great advantage that I don't have to work for the money, because of what I did and built in the past.' (ACRO2)</p> <p>'I am lucky to have a partner with a good job.' (PRL1)</p>
Other environmental factors: social support	Nonprofessional support		<p>'I know that they [my family] are there for me. Although they can't really help me with work, I can definitely discuss things with them.' (CUSH1)</p> <p>'Everyone thinks I have a great life, because I'm not working. But no one really understands, even my family doesn't.' (PRL2)</p>
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Theme	Category	Subcategory	Quotes
	Professional support	Occupational health professionals	<p>'I have good contact with my occupational physician. He gives me the opportunity to return to work at my own pace.' (NFA2)</p> <p>'They bring forward all kinds of opportunities and ideas to solve my problems.' (CUSH1)</p> <p>'My company didn't offer any professional support whatsoever.' (NFA1)</p> <p>'There was no contact: you fill out online forms, which I found extremely complex and cumbersome. And that was all. In my opinion, they didn't do anything.' (PRL1)</p> <p>'I'm not sure whether they understand anything about the life of a pituitary patient.' (CUSH1)</p> <p>'They said to me: "You look fine, you can get back to work." But I couldn't do any work.' (PRL2)</p>
		Endocrinologists	<p>'What really would have helped with work, is expectation management. They told me what I had, that they could treat me and that I would never feel 100% again, but they should have added one more sentence: "Think about the impact this might have on your work situation. Consider whether you should keep working fulltime or should change something."' (NFA1)</p>
		Psychological support	<p>'Conversations about how to find a new balance, about what I can still do and how to deal with the fact that I can't do certain things anymore: that may help.' (ACRO2)</p>
Work-related personal factors	Professional ambition		<p>'I notice that everything costs a bit more effort, which I find very frustrating, because I demand a lot from myself.' (ACRO2)</p>
	Sense of duty/responsibility		<p>'Even when I'm not feeling too well, I just go to work.' (NFA2)</p> <p>'Sometimes, I think: "This is not a wise thing to do", but then again, I have appointments and I don't want to let people down.' (ACRO2)</p>
<p>ACRO, patient with acromegaly; CUSH, patient with Cushing's disease; NFA, patient with non-functioning pituitary adenoma; PRL, patient with prolactinoma. Numbers indicate which patient said a certain quote.</p>			
<p>*Subcategories only mentioned by one patient are included in the table but are not mentioned in the main text.</p>			

Theme	Category	Subcategory	Quotes
	Motivation		<p>'The type of work really helps. I have always had jobs that I really liked, otherwise I can't work.' (PRL1)</p> <p>'In general, I experience less emotions. Consequently, I also have less motivation to do things, because when I have done something, I don't feel the joy of it, I can't be happy with it.' (ACRO1)</p> <p>'More than in the past, I now feel that work is compulsory. Maybe that is because I associate work with the fact that, at the end of a workday, I have too little energy left to do anything else.' (ACRO2)</p>
	Job satisfaction		'I really liked my job. I still do.' (NFA1)
	Feeling of fulfillment		'It gives me a sense of fulfilment that I know that I'm good at what I do and that I'm appreciated for it.' (NFA2)
General personal factors	Personality	Stress tolerance	'I can handle stress quite well.' (NFA2)
		Desire to be active	'One reason to keep working is that I don't want to sit on the sofa thinking about how I'm doing today, which would really make me a patient. In that respect, work is a distraction.' (ACRO2)
		Perseverance	'I just continued; I didn't think: "Take it easy". No, I just continued.' (PRL1)
		Goal-oriented mindset	'I'm practical and goal-oriented.' (ACRO2)
	Acceptance of the consequences of their disease		'Maybe you just have to accept, hard as that may be, that you have to function at a lower level than you did in the past.' (ACRO2)
	Coping style	Decreased ability to cope with pressure	<p>'When I returned to work, I couldn't do anything. I couldn't handle all the pressure.' (PRL2)</p> <p>'In the past, I used to perform well under pressure, whereas now, I have started to perceive the pressure as something negative.' (ACRO2)</p>
ACRO, patient with acromegaly; CUSH, patient with Cushing's disease; NFA, patient with non-functioning pituitary adenoma; PRL, patient with prolactinoma. Numbers indicate which patient said a certain quote.			
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Theme	Category	Subcategory	Quotes
		Dosing activities/energy	'Although it's not always easy, I have learnt not to do too many things on one day, because then I will feel awful the next day.' (ACRO2)
		Indicating one's limits	'If you continue working longer than normally, you will be so tired afterwards, because you have crossed your boundaries.' (CUSH1)
		Planning medication intake around work	'Intentionally, I took my medication before the weekend, because the day after my medication intake I'd better not be working with machines.' (PRL1)
		Writing more down	'When I have to give a speech, I now have to write it down entirely beforehand.' (ACRO1)
		Putting things in perspective	'Work is just work.' (NFA2) 'Everyone has difficult periods at work.' (CUSH2)
		Setting priorities	'I don't have the energy to invest in my professional development. I use that energy now to get some exercise or to do other things that are better for me and my recovery.' (CUSH1)
		Procrastination*	'Procrastinating things may also be a form of escapism. I did that too much with the tasks related to home, when I was still working more.' (ACRO2)
	Lifestyle		'I eat healthy, exercise, and always take my medication.' (CUSH1)
ACRO, patient with acromegaly; CUSH, patient with Cushing's disease; NFA, patient with non-functioning pituitary adenoma; PRL, patient with prolactinoma. Numbers indicate which patient said a certain quote.			
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Body functions and structures (impairments)

Impairments in physical functions and in mental functions were distinguished. Mental functions included cognitive functions (i.e., related to memory, reasoning, and executive functions), and emotional functions (related to emotional processes).

Impairments in physical functions

All patients indicated they experienced physical **fatigue** and some patients reported **malaise**, which they described as feeling unwell. Patients associated this with being less alert, having sleep problems (cognitive impairments), a lower work pace, making more mistakes (activities), and difficulty maintaining a healthy work-life balance (participation). Some patients also experienced **joint problems**, which did not clearly affect work in this small selection of patients that performed mainly mental work.

Impairments in mental functions

Cognitive impairments

Patients mentioned being bothered at work by various **cognitive impairments**. Several patients experienced mental **fatigue**, and **concentration problems** were experienced by all but one patient, resulting in problems with reading and the need to take more time to perform certain tasks (activities). These concentration problems were often associated with a **lack of alertness**, which some patients attributed to their medication. **Sleep problems**, such as daytime sleepiness, sleeping more hours per night, and less and/or fragmented sleep at night, were also reported. Furthermore, several patients experienced **short-term memory problems**, which led to problems with reading, learning new information, and remembering to do certain work-related tasks (activities). Especially patients with Cushing's disease experienced a **lower speed of information processing**, most pronounced in the morning, resulting in a lack of time to do all their work. Finally, some patients reported a **feeling of being overstimulated** at work, particularly in relation to a busy work environment (working conditions).

Emotional impairments

Several patients reported **problems with a changed personality**, in the sense of experiencing changes in different aspects of their personality or having a different self-image. A change of self-image could be caused by physical or psychological changes and was often related to the inability to do certain work-related tasks.

Furthermore, patients experienced a wide range of mood issues and negative feelings that affected their work. Patients reported **indifference** (being less assertive and caring less about things) towards work, which decreased their job satisfaction, work motivation (work-related personal factors), perseverance (general personal factor), and ability to assess risks (activity). They experienced that concentration problems (cognitive complaint) and the resulting lower work performance contributed to this indifference. Moreover, the inability to do things due to concentration problems (cognitive complaint) led to **frustration** and a **feeling of shame**. Several patients felt **insecure** about whether they still liked their job and about their functioning at work, which was related to (a **fear** of) making mistakes (activities). Furthermore, some patients experienced **fear** that they would not be able to find a job anymore if they opened up about their disease and **worried** about their health and the resulting problems at work. Especially self-employed patients worried about their financial situation (personal factor) if they could not work anymore. Finally, several patients reported a greater degree of **irritability and impatience** at work compared to before the diagnosis, which they related to making different risk assessments and to feelings of overstimulation.

Other emotions that were reported included **anger, agitation, depressive feelings, and increased emotional instability**, but patients did not perceive a direct relation between these complaints and their work.

Activities (limitations)

Due to fatigue (physical complaint) and cognitive complaints, several patients experienced that activities, specifically **reading, writing, driving to work, memorizing speeches, networking, working in a busy physical work environment**, and **starting to work early** in the morning, **cost greater effort**. As patients were not able to work at the same pace as they used to, they perceived a **need to take more time** to perform tasks, and also reported the **need to take more rest** during the workday. Moreover, patients reported **having to redo things** due to memory and concentration problems (cognitive complaints), particularly while reading texts. Patients also experienced an **inability to assess risks** and to oversee the consequences of their actions at work, which they associated with a lack of alertness (cognitive complaints). Finally, several patients reported **making (more) mistakes**, due to memory and concentration problems, lack of alertness (cognitive complaints), fatigue (physical complaints), and the fact that activities cost more effort. This resulted in a feeling of guilt and insecurity (emotional complaints).

Participation (restrictions)

Several patients reported that the frequency of sick leave (**absenteeism**) had not changed due to their disease. Factors positively contributing to this were flexibility of work times (task contents), financial pressure due to freelance work (terms of employment), and a sense of duty (work-related personal factor).

However, several patients were working less hours than before their disease. Some patients had **worked less temporarily** after surgery during their return to work, slowly increasing their work hours. Some patients **permanently decreased their working hours** in order to cope with their health-related problems at work and to maintain a healthy work-life balance (participation). Due to financial pressure, particularly self-employed patients experienced difficulty working less. In order to be able to keep working, some patients made **modifications to their function** or considered changing jobs.

Several patients reported being dismissed by their employer. Some of them saw a relation between **losing their job** and their disease. They thought their disease had affected their chances of keeping their job and related this to concentration problems (cognitive complaints) and mistakes they had made (activities).

As a result of fatigue (physical complaint) and a lack of alertness (cognitive complaint), some patients perceived a decreased work productivity (**presenteeism**). Others did not notice a decline, although some perceived that regaining their old level had taken a long time. Finally, patients experienced **problems in maintaining a healthy work-life balance**, mainly because they were so tired after a workday that they were unable to do anything at home.

Environmental factors

Work-related environmental factors

Terms of employment

Being **employed by a company or self-employed** affected patients' work experience. A disadvantage experienced by the patient who was self-employed at the time of diagnosis was that he felt forced to start working again shortly after surgery, mainly for financial reasons. Patients who became self-employed just after their diagnosis (one because of a company reorganization, the other because of health complaints) experienced benefits of being self-employed: they could choose their own work rate and did not have to explain their health complaints to an employer.

Patients reported varying degrees of **perceived job security**. Some patients knew they would be able to maintain their job after treatment of their disease, while others were insecure about maintaining or obtaining a job if they told (future) employers about their disease. Patients also had concerns about **financial security**. Particularly freelancers felt financial pressure to work despite their disease and were worried about what would happen if they had to stop working. Some patients experienced difficulties regarding their insurance policy, fearing that they would not be able to get a new insurance due to their disease or being unable to pay the insurance premium.

Social relationships at work

Several patients reported issues in **the relationship with colleagues** due to their disease. Some perceived a lack of understanding from their colleagues, resulting in conflicts and mockery, as well as limited support. Others did experience collegial support after having discussed their situation, which was considered difficult, but helpful by some patients.

Some patients also experienced issues in **the relationship with their manager or supervisor**, such as a lack of understanding. Discussing their situation with their manager led to a feeling of support at work and resulted in solutions for work-related problems for those who did discuss it.

Lastly, several self-employed patients considered **collaborating with others or hiring employees** to be able to keep doing their job.

In order to improve general understanding and support at work, patients recommended making a flyer about pituitary disease that can be taken to work, so that their managers and colleagues can read reliable information about their disease and its consequences.

Task contents

Various task contents influenced patients' ability to function at work, such as the work being mainly **physically or mentally demanding**. The included patients had predominantly mentally demanding jobs and reported that their return to work would have been more troublesome if they had had more physically demanding tasks. Moreover, patients in a **managing position** experienced more flexibility regarding working hours and did not have to justify their absence compared to lower-ranked employees.

In general, **flexibility** at work was considered important. Patients employed by a company that allowed flexible working hours experienced that this was beneficial for their performance at work and for maintaining their job (participation). Likewise, self-employed patients considered the flexibility concerning working pace and working hours as an advantage. Patients also mentioned that the ability to work from home was beneficial.

Working conditions

Issues in **the corporate culture** of a company affected patients' work experience. Several patients perceived that there was no room for employees to discuss their health problems, as they believed this would lead to difficulties at work and they perceived a lack of understanding for any personal issues in their company. Moreover, due to a combination of concentration problems (cognitive complaints) and an overload of stimuli, some patients were bothered by a busy **physical work environment**, such as an open-plan office.

Other environmental factors

Home environment

Some patients experienced **traveling from home to work** as burdensome, as this influenced their energy level. **Financial savings** also affected patients' work experience. Some patients could afford working less (participation), because they had a financial buffer, or a partner with sufficient income (non-professional support).

Social support

Patients perceived different degrees of social support by partners and relatives varied (**non-professional support**). Patients with little social support felt misunderstood by their surroundings and missed talking about their condition.

Professional support was provided by occupational health professionals, endocrinologists, and psychologists. Patients had diverse experiences with occupational health professionals and the Employee Insurance Agency (Dutch: Uitvoeringsinstituut Werknemersverzekeringen [UWV]). Some were satisfied with the care they had received. In their experience, their occupational physician was supportive, acknowledged their complaints, did not exert pressure, and offered sufficient support and practical measures to adapt their work to their health problems. Others perceived little or no support from their occupational physician and reported a lack of actual interventions. In the patients' view, the lack of support originated from a lack of acknowledgement of their complaints, which was caused by a lack of understanding for and knowledge of pituitary conditions.

With regards to support by endocrinologists, some patients perceived a lack of information about their disease and expressed that early expectation management concerning their work situation would have been beneficial. The lack of information had resulted in frustration about their decreased work ability after surgery (emotional complaints).

Most patients had had some form of psychological support during the course of their disease. They found this helpful to cope with work-related problems and frustrations and to create a healthier work-life balance (participation).

Personal factors

Work-related personal factors

Several personal factors reported by patients were strongly work-related. Especially patients with a high **professional ambition** found it difficult to accept that they were not able to do everything they used to do anymore, which resulted in frustration (emotional complaint). Some patients reported that having a great **sense of duty or responsibility** was the reason they continued going to work despite their health complaints.

The patients reported that work was a source of joy or satisfaction, which was a **motivation** to continue despite their health complaints. For some patients, however, the disease and its consequences made them doubt whether they still liked their job. Patients reported that knowing that you are good at your job, making people happy, and getting appreciation for your work resulted in higher **job satisfaction**, a **feeling of fulfilment**, and more motivation. In contrast, physical and mental complaints (e.g. fatigue) contributed to lower job satisfaction and work motivation.

General personal factors

Personality

Patients reported several personality traits that affected their work experience and work ability. Some patients reported having a high **stress tolerance** that enabled them to keep functioning at work despite their disease and having a busy job. For several patients, a **desire to be active** was a motivation to keep working. Moreover, **perseverance** was a character trait that helped patients to keep going to work. Some patients reported that a **goal-oriented mindset** helped them to deal with problems at work.

Acceptance of the consequences of their disease

Several patients experienced **difficulty accepting** their current level of functioning and their changed work situation.

Coping styles

Since their disease, some patients experienced a **decreased ability to cope with pressure** at work. Patients adopted various strategies to cope with their new situation. Several patients reported that **dosing their activities and energy** carefully and **indicating and respecting their limits** was important to cope with their fatigue. One patient carefully **planned his medication intake** on Friday, so that he could recover during the weekend from the drowsy feeling caused by the medication. In order to deal with memory and concentration problems (cognitive complaints), patients reported **writing things down more often**.

Moreover, **putting things in perspective** helped patients in coping with their health-related problems at work. They also perceived that consciously **setting priorities** helped to create structure in their work tasks and helped them improve their work-life balance (participation).

Lifestyle

Several patients modified their **lifestyle** in order to cope with their symptoms, such as a healthier diet, more physical exercise, yoga or meditation, and less alcohol consumption, the latter because some believed alcohol aggravated their attention problems (cognitive complaints).

Discussion

This qualitative study showed that patients suffering from pituitary disease experience limitations in performing work-related activities and restrictions in participation at work (at least partly) as a result of the physical and mental impairments related to their disease. In addition, we identified several work-related and non-work-related contextual factors that influence functioning at work, which can be classified according to the expanded ICF[25].

In this study, several work-related problems were identified that pertain to the part 'Functioning' of the ICF. Due to fatigue and cognitive complaints, patients experienced limitations in activities such as reading and writing and reported making more mistakes at work and needing to take more time for work tasks. These problems were related to changes in work participation, varying from modifications of their work tasks to working fewer hours or even losing their job. Moreover, for many patients, trying to meet the demands at work was at the expense of their functioning at home.

Besides issues in 'Functioning', various 'Contextual Factors' were identified, which could be categorized into environmental and personal factors according to the expanded ICF. Awareness of and attention for these factors by professionals could have a beneficial effect on patients' work experience, absenteeism, and presenteeism. In previous studies, age and comorbidity were reported to affect pituitary patients' functioning at work[15]. Although these factors were not reported by patients in the present study, patients did report several other important contextual factors. For instance, patients perceived a lack of understanding regarding personal or health issues, which not only occurred among colleagues and supervisors, but also among occupational health professionals. This emphasizes the need for awareness of the largely invisible long-term consequences of a pituitary disease. As some patients pointed out, flyers or electronical resources providing information on pituitary disease and its consequences could be helpful to inform employers and colleagues about the disease. Other environmental factors that could be addressed to improve patients' functioning at work are the task contents, working conditions, and factors of the home environment (e.g., travel distance). No heavy physical tasks, sufficient flexibility, a quiet physical work environment, and a job close to home are important to function optimally at work. However, some environmental factors are less influenceable, such as a patient's financial situation. In the Netherlands, self-employed people will experience negative financial consequences if they do not have a disability insurance and work less due to their disease, whereas employed people may be eligible for a

disability pension if the Employee Insurance Agency judges they have a reduced work ability[30]. Besides these environmental factors, targeting personal factors (e.g. motivation, coping styles, and lifestyle) with psychological support, psychoeducation, and self-management interventions[31] could prove beneficial for patients' work experience and productivity. The focus of psychological interventions in this patient group is on recognition and acceptance of physical and mental changes after diagnosis, and on finding an optimal balance between work demands and available mental and physical resources.

Several aspects of health-related problems at work identified in this study, such as fatigue, a lack of understanding by employers, and concentration and memory problems, have also been reported for other chronic conditions[32–35], including traumatic brain injury[36–38], Q-fever[39], and sarcoidosis[40]. Since pituitary patients report a substantial burden of cognitive complaints on their functioning at work, these complaints, which are often not easily recognized by the patients' environment, require special attention in this population. Targeted interventions specifically aimed at work rehabilitation, such as coaching, cognitive behavioral therapy, and multidisciplinary interventions, have been used previously in other chronic disease populations and could also prove beneficial in patients with pituitary disease[41]. In terms of the ICF, these interventions will mainly address the mental functions and work-related contextual factors.

The qualitative nature of the semi-structured interviews is a major strength of the present study. It allowed for a rich exploration of the patients' perspective taking into account the context and meaning of work-related problems. Semi-structured interview studies, however, also have their limitations, including the risk that answers of participants are influenced by the interaction with the interviewer. However, as the researchers conducting the interviews were experienced with interview studies, the risk of this bias was considered to be low. Furthermore, almost all participating patients were highly educated and had mentally rather than physically demanding jobs, which may limit the generalizability of the results. Despite our intention to include a diverse group of patients, patients with a lower education level were less keen on participating. Moreover, following the guideline recommending to include six to ten participants[28], eight patients were included. This sample size might have been rather small considering the number of different pituitary diseases. However, it should be noted that different pituitary diseases have clinically and symptomatically quite a lot of similarities: many patients are treated surgically, and every tumor type can cause hypopituitarism, requiring hormone replacement therapy. Therefore, it can be assumed that the sample size was sufficient to provide a valuable exploration of pituitary patients' work experiences. Finally, it should be noted that considerable overlap may exist between issues reported under impairments in mental functions, and general personal factors, as described in the expanded ICF by Heerkens et al. (2017)[26].

For future research it would be interesting to develop an ICF Core Set[42], describing the expanded ICF for pituitary disease, based on the results of the present study and taking into account the healthcare professionals' perspective. This would be helpful in clinical research evaluating work-related interventions, but also in clinical care for individual patients by improving communication and collaboration between healthcare professionals (e.g., endocrinologists, endocrine nurses) and

occupational health professionals. Furthermore, future research should focus on the implementation of targeted interventions in pituitary patients, tailored to individual needs, in order to improve well-being and functioning at work.

In conclusion, the expanded ICF model for pituitary diseases described in the present study can bridge the gap between the approach of occupational health professionals and healthcare professionals involved in pituitary disease. Patients with pituitary disease report limitations in activities and restrictions in participation at work, which are influenced by several environmental and personal factors. Healthcare professionals and occupational health professionals should be aware of these influencing factors and should address those that are modifiable in order to provide holistic, multidisciplinary patient-centered care. This can improve patients' well-being and functioning at work with the ultimate goal to improve HRQoL.

Declarations

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Conflicts of interests:

The authors declare that they have no conflict of interest.

Ethics approval:

This study was approved by the Medical Ethical Committee of the Leiden University Medical Center (P17.142) and was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Informed consent:

Informed consent was obtained from all individual participants included in the study.

Data availability:

Data requests can be directed to D.J. Lobatto: d.j.lobatto@lumc.nl.

Author's contributions:

CDA, DJL, and NRB contributed to the study conception and design. Data collection was performed by CDA and DJL. The theoretical framework was discussed and agreed upon by MM, CDA, DJL, TPMVV and YFH. Data analysis was performed by MM. The first draft of the manuscript was written by MM and CDA

and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Figures

Figure 1

The expanded International Classification of Functioning, Disability and Health (ICF) for pituitary disease (modified from Heerkens et al. 2004) * Impairments in physical functions: fatigue, malaise, speech problems, joint problems. ** Impairments in mental functions, cognitive: concentration problems, lack of alertness, sleep problems, short-term memory problems, lower speed of information processing, less creativity, feeling of overstimulation. *** Impairments in mental functions, emotional: problems with a changed personality, indifference, frustration, feeling of shame, feeling of guilt, insecurity, fear, worry, feeling of failure, irritability / impatience, anger, agitation, depressive feelings, increased emotional instability. The boxes 'Functions and structures', 'Activities', and 'Participation' in the grey upper half represent the part 'Functioning', while the white lower half represents the part 'Contextual Factors'.

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