

# Towards a better quality of life (QoL) for patients with pituitary diseases: results from a focus group study exploring QoL

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## Abstract

**Purpose** Patients treated for pituitary adenomas generally report a reduced quality of life (QoL). At present, the patient's perspective of QoL has not been fully addressed and this, and further insight in potential determinants of QoL in pituitary diseases is required to design strategies to improve QoL. We aimed to define patients' perceived QoL and to identify potential factors they perceive to contribute to QoL.

**Methods** We conducted four independent focus groups of six patients each, per specific pituitary disease (Cushing's disease, Non-functioning pituitary macroadenoma, acromegaly, prolactinoma). In two sessions these focus groups discussed aspects of QoL. Verbatim transcripts were analyzed using a grounded theory approach.

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**Results** The issues raised by the patient groups were compatible with statements and items of available QoL questionnaires. In addition, other QoL aspects emerged, such as visual limitations (*physical problems*); issues with a desire to have children/family planning, fear of collapsing, fear of recurrence, panic, persisting thoughts, problems with an altered personality, anger, jealousy, sadness, frustration (*psychological problems*); and difficulties communicating about the disease, lack of sympathy and understanding by others, and a reduced social network (*social problems*). Next, this study uncovered factors which might contribute to a decreased QoL (e.g. less effective coping strategies, negative illness perceptions, negative beliefs about medicines, unmet needs regarding care).

**Conclusions** This focus group study demonstrated that important disease-specific aspects of QoL are neglected in current pituitary disease-specific questionnaires and elucidated potential factors that contribute to a decreased QoL. Information provided in this study can (and will) be used for developing additional items for disease-specific QoL questionnaires and for the development of a self-management intervention aiming to improve QoL in patients treated for pituitary diseases.

**Keywords** Pituitary adenomas · Acromegaly · Cushing's disease · Prolactinoma · Non-functioning pituitary macroadenoma · Qualitative research · Focus group · Quality of life · Needs · Coping strategies · Illness perceptions · Beliefs about medicines

## Introduction

Patients with pituitary diseases experience considerable physical and psychosocial consequences in the chronic

state of their disease [1]. Persistently impaired quality of life (QoL) was observed in patients in biochemical remission of Cushing's disease (CD) [2–4], non-functioning macroadenoma (NFA) [4, 5], acromegaly (ACRO) [4, 6], and prolactinoma (PRL) [4, 7]. QoL has been reported to improve after successful biochemical treatment, but do not normalize. QoL has been usually assessed by either generic questionnaires (e.g. Medical Outcome Study 36-item Short Form health survey, Nottingham Health Profile), dimension-specific questionnaires (e.g. Multidimensional Fatigue Inventory 20, Hospital Anxiety and Depression Scale) [2, 5, 7–12] or disease-specific questionnaires (available for ACRO [13–15], CD [16–18] and growth hormone deficiency (GHD) [19]). Disease-specific questionnaires have been developed based on semi-structured interviews of individual patients using topics preselected by physicians. Afterwards the emerging topics were checked and modulated by the same physicians. Although patients' experience was included, the development has been controlled by the QoL perception of the physician from the beginning, instead of starting with QoL as formulated by patients.

In contrast, a valuable example of a research method which starts with the patient's perception, is focus groups research. Focus group research incorporates a small number of people (4–8 persons) discussing a particular subject in an informal group discussion. Unlike individual interviews, focus group interviews explicitly use group interaction as part of the method. This method is particularly useful in exploring people's knowledge and experience and can be used to examine not only *what* people think, but also *how* they think and *why* they think that way [20]. Focus group methodology is frequently used to assess health and illness related topics, such as QoL, health care needs and experiences of everyday life in patients with chronic diseases [21–24]. Furthermore, it has been used for the development of disease-specific QoL questionnaires [25, 26] and to identify disease-specific QoL aspects [27–29].

Factors explaining persistently impaired QoL in patients with pituitary diseases are not well established, but are likely to be multi-factorial. Several studies revealed predictors (of aspects) of QoL, such as age, gender, tumor recurrence, non-replaced hypogonadism, non-replaced GHD, visual field deficits, sleepiness, joint complaints, clinical osteoarthritis, radiotherapy and delay of diagnostic process [8, 30–35]. Besides these biomedical predictors, we recently demonstrated that negative illness perceptions correlate with QoL in patients with ACRO or CD [10, 36]. We speculate that also other psychological or social factors can contribute to the persistently reduced QoL, i.e. unmet needs regarding care, which appear to be associated with QoL in other chronic diseases [37].

The primary aim of the present focus group study was to explore QoL as reported by patients treated for pituitary

diseases. In addition, we aimed to identify potential factors that contribute to a decreased QoL. We hypothesized that focus group research would provide ideas complementary to currently available diseases-specific QoL questionnaires, and would elucidate potential factors that contribute to QoL in pituitary diseases. This would give the opportunity to optimize biopsychosocial care for patients treated for pituitary adenomas, aiming to ultimately improve QoL.

## Methods

### Subjects

Patients were recruited from the outpatient clinic of the department of Endocrinology and they were selected by their consultant endocrinologists. Patient selection was based on pre-specified criteria aiming at a focus group composition that would be representative for the chronic situation of the specific pituitary disease (and its sequelae) with respect to: (1) age, (2) gender (almost equal distribution of men and women, except for the CD group considering the high prevalence of CD in females), (3) time since diagnosis and (4) degree of medical complaints as estimated by the consultant endocrinologist, including a mix of cured and medically treated patients, if applicable, and a mix of patients dealing with hypopituitarism and those having normal pituitary function. Four groups were formed each consisting of six patients (CD, NFA, ACRO, PRL), see Table 1. Group size and composition were chosen according to the published guidelines for focus group research [38].

The diagnosis and state of biochemical remission were confirmed in all patients, following previously described criteria [7, 39–41]. All patients gave written informed consent. The Medical Ethical Committee of the LUMC approved the research protocol.

### Study design

The focus group meetings were chaired by a health psychologist (moderator), experienced in group discussions who took the role of an independent moderator (NGAK) [42–44]. The investigator (CDA, psychologist) and a research intern (EK) observed both meetings, but did not participate in the discussions. All four groups met twice for a focus group discussion of ~2 h each. The first meeting had the primary aim to get acquainted and to ensure a safe and confidential group setting in which everybody felt comfortable to speak and act freely. Patients were asked to introduce themselves, then the discussion continued with open-ended questions raised by the moderator about spontaneously reported issues. For example, when one

**Table 1** Demographic characteristics of pituitary patients (N = 24)

	Acromegaly (n = 6)	Cushing's disease (n = 6)	Prolactinoma (n = 6)	NFA (n = 6)
Age (years)	48.6 (36–65)	42.4 (25–58)	44.5 (34–54)	49.2 (27–64)
Gender (M/F)	3/3	2/4	3/3	3/3
<i>Education</i>				
Low	0	1	0	0
Medium	2	1	2	2
High	4	4	3	4
Unknown	–	–	1	–
Duration of follow-up (years)	6.5 (2–19)	10.3 (1–23)	9.6 (2–20)	5.2 (1–12)
<i>Disease severity at time of diagnosis</i>				
Tumor size (micro/macro)	2/4	6/0	2/4	2/4
Visual field defects	1	0	2	4
<i>Treatment</i>				
Radiotherapy	0	1	1	1
TSS	5	6	1	3
Current suppressant medication	4	–	4	–
<i>Hypopituitarism</i>				
Any axis	0	5	4	6
ACTH	0	3	2	3
GH	0	1	0	4
LH/FSH	0	1	0	2
TSH	0	3	1	4
ADH	0	0	0	1

Data are presented as median (IQR) or number

Education classification: *low* elementary school, preparatory low-level applied education—*medium* preparatory middle-level applied education, higher general continued education, preparatory scientific education, middle-level applied education—*high* higher professional education, scientific education. *TSS* Transsphenoidal surgery  
Current suppressant medication: Acromegaly (somatuline, somavert, sandostatine, octreolin), Prolactinoma (cabergoline, parlodel, norprolac)

participant spontaneously reported to be depressed sometimes, the moderator asked the other group members: “Are there moments when you feel depressed?” Based on the discussion of this first meeting, a topic list was formulated which was used during the second meeting (Appendix 1). During both meetings the moderator used open-ended questions. These Dutch focus group discussions were audio-taped and typed out verbatim.

#### Data analysis

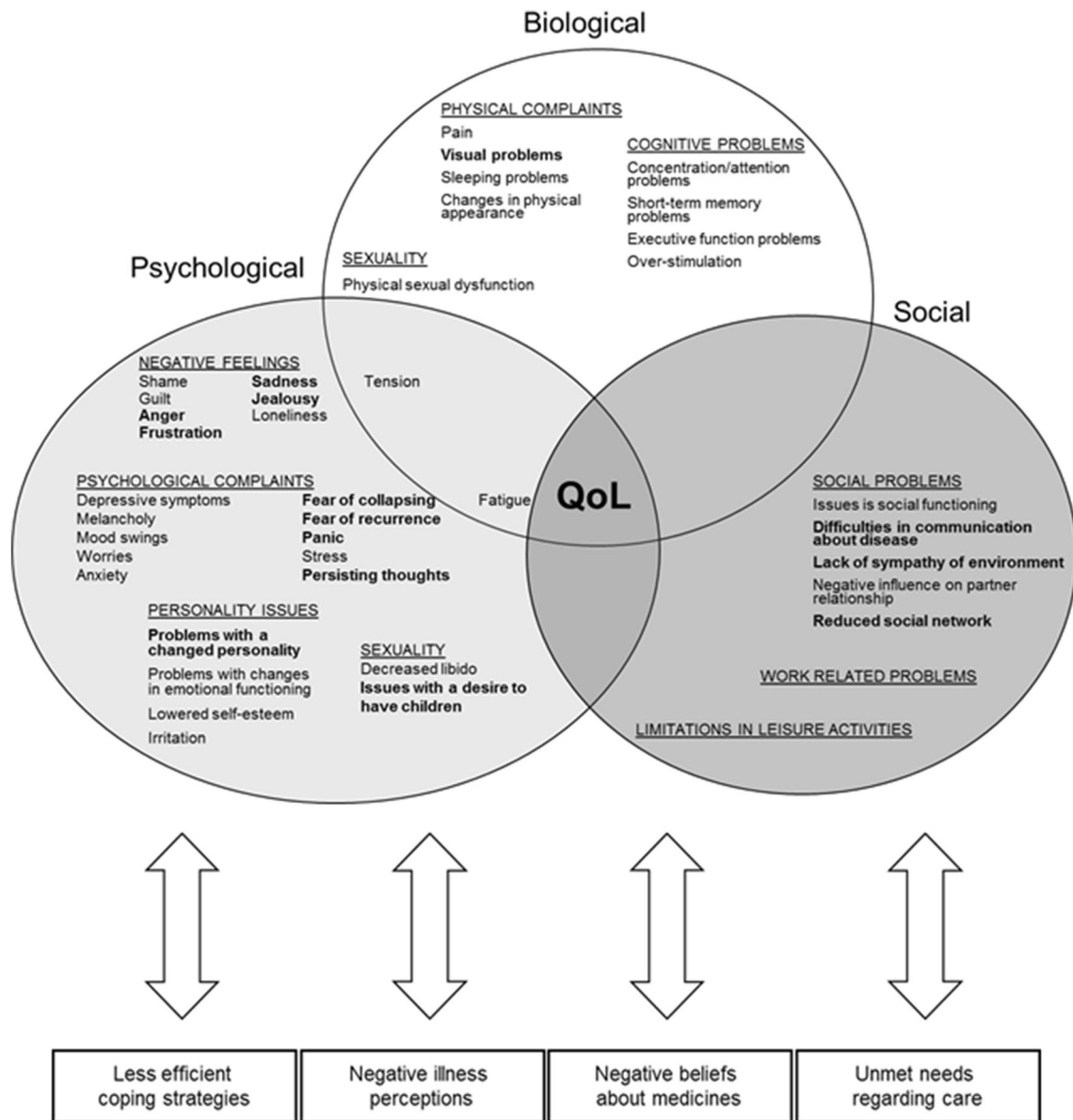
Transcripts were analyzed following the steps of a grounded theory approach [45]. First, two researchers (NDN endocrinologist, CDA psychologist) listened to the recorded discussions and carefully read and reread the transcripts. These two researchers independently performed open coding of the transcripts for each disease separately, using Atlas.ti 6.2 software. Discrepancies between coding were discussed and coding of transcripts of all groups as a whole was checked. As a result, categories were inductively identified from the data. In the second phase an axial coding method was performed, which is used to reflect on the properties of the categories (i.e. are categories

applicable?) and to consider the relationships between the different categories (i.e. how are categories linked to each other?). The biopsychosocial model [46] was deductively used to reformulate categories. In the last phase data was integrated around the established categories and it was conceptualized how these categories may be integrated into a theory.

#### Results (Fig. 1; Table 2)

All patients were present during both focus group meetings, except one patient of the PRL-group who was absent during the second meeting, due to personal circumstances.

From the transcripts thirteen main categories of issues were identified. Nine categories corresponded to the biopsychosocial domains of QoL [47] (physical complaints, cognitive problems, sexuality, personality issues, psychological complaints, negative feelings, social problems, work related problems and limitations in leisure activities). Four alternative categories were identified that might contribute to QoL (less effective coping strategies, negative illness perceptions, negative beliefs about medicines, unmet needs



**Fig. 1** QoL in patients with pituitary diseases, as perceived by patients. Bold additional aspects which are not included in available disease-specific questionnaires

regarding care). Figure 1 presents the overlap and connections between the biological, psychological and social categories and the possible influence of the alternative categories. Table 2 summarizes the identified categories and the similarities and differences between the respective pituitary diseases, together with some representative quotes. Newly raised aspects are further elaborated below. Topics which are not included in available disease-specific QoL questionnaires [13–19] are highlighted in bold.

*Physical complaints* were fatigue, physical pain, sleeping problems, changes in physical appearance and **visual problems**. Fatigue was the most profound physical complaint in all groups. The cause of fatigue was not easily

explained and it was attributed to their pituitary disease, their job or impaired sleep. The fatigue was both physical and mental. In addition, lowered muscle strength and impaired physical condition were reported. Sleeping problems were reported in all groups (except PRL). For example, difficulty with falling asleep due to persisting thoughts (CD)<sup>Q1</sup>, or difficulty staying asleep due to sleeping in blocks of 2–3 h (NFA). A long lag time after awakening was also reported (ACRO)<sup>Q3</sup>. Visual problems, such as tunnel vision, were reported (NFA), and the severity was related to fatigue. Some patients had problems sleeping in total darkness because of disorientation due to the visual impairment.

**Table 2** Overview of QoL categories in different diseases and illustrative quotes

Category	Subcategory	Illustration of complaint	Reported by				Quotes	Nr
			CD	ACRO	PRL	NFA		
<i>Biological</i>								
Physical complaints	Fatigue*	Fatigue was the profound physical complaint. Lowered muscle strength and impaired physical condition were also reported. The nature of fatigue differed between the four pituitary diseases: either strange intense fatigue which took them by surprise and could disappear in just half an hour (PRL), severe fatigue requiring a two hour nap in the afternoon (CD) or extreme chronic tiredness with a “shaking” body (ACRO).	x	x	x	x		
	Physical pain	Physical pain was especially reported by the ACRO-group, which included headaches, a tickling and inflamed sensation of the whole body, arthralgias with red thick joints. CD and NFA patients also reported joint complaints.	x	x		x		
	Sleeping problems	Sleeping problems were reported, for example, difficulty with falling asleep due to persisting thoughts (CD) <sup>Q1</sup> , or difficulty staying asleep due to sleeping in blocks of 2 to 3 h (NFA). The perception of interrupted sleep was not always negative, since some patients liked easy waking in the morning <sup>Q2</sup> . A long lag time after awakening was also reported (ACRO) <sup>Q3</sup>	x	x		x	It takes time before I can get to sleep because I have to organize my thoughts first; thoughts about what is yet to happen and what I have to do On the one hand I think it is quite nice. I used to be able to sleep and wake up only when the alarm rang. Now I don't have the feeling that I'm lying down If I am awakened in the morning because something has to happen, then my whole system becomes disrupted; I might as well forget the rest of the day	Q1 Q2 Q3
	Changes in physical appearances	Changes in physical appearance were reported, with main feature weight gain. The ACRO-group experienced coarsening of appearance, with features as a bigger mouth, nose and cheeks, large spaces between teeth, big hands and feet being perceived as very negative <sup>Q4</sup>	x	x		x	My appearance has changed, and it has not had a positive effect on me. I don't like the fact that my face has changed	Q4
	Tension*	Both physical and psychological tension were reported <sup>Q19, Q20</sup>		x			When thinking about the things that I have to do, my whole body becomes tense	Q19
	<b>Visual problems</b>						x	

**Table 2** continued

Category	Subcategory	Illustration of complaint	Reported by				Quotes	Nr
			CD	ACRO	PRL	NFA		
Cognitive problems	Concentration/attention problems	Concentration and attention problems and problems with mental focusing were reported by all groups. Concentrating was reported to be energy consuming.	x	x	x	x		
	Short-term memory problems	Short-term memory problems were reported with word-finding problems and difficulty remembering names, while the long-term memory was generally intact.	x	x		x		
	Executive function problems	Executive dysfunction was reported, such as decreased ability to formulate sentences, problems with multitasking, lowered processing speed and decreased ability to orientate <sup>Q5</sup> . Problems in keeping up with the speed of conversations were mentioned (ACRO) <sup>Q6</sup>	x	x		x	When I was in an unfamiliar city, I walked through a shopping mall and I went in and out of shops, I couldn't really remember from which part I came or how I should walk back. After the operation, things go better, but it is still different to the situation before the operation	Q5
	Over-stimulation	A feeling of overstimulation was experienced and they mentioned difficulty to deal with large crowds.	x				When I am in a conversation, I want to keep up with the conversation, but I notice I just cannot	Q6
Sexuality	Physical sexual dysfunction	Physical sexual dysfunction such as erectile dysfunction was reported (PRL). Some male and female patients of the ACRO-group reported inability to get an orgasm. Patients reported menstruation problems (i.e. chronic menstruation), which interfered with sexual activity (NFA). (New) relationships were perceived to be affected by physical sexual dysfunction.		x	x	x		
<i>Psychological</i>								
Psychological complaints	Depressive symptoms	Current depressive symptoms were discussed.	x			x		
	Melancholy	Melancholy was reported, which was perceived to be caused by physical complaints.	x	x		x		
	Mood swings	Mood swings were discussed <sup>Q7</sup>	x			x	Within a short period of time your feelings fluctuate	Q7
	Worries	Some groups reported worries in relation to physical complaints and the possible progression of these complaints in the future <sup>Q8</sup>		x		x	I sometimes feel like an elderly-person, how will it be in ten years time? I worry about that	Q8

**Table 2** continued

Category	Subcategory	Illustration of complaint	Reported by				Quotes	Nr
			CD	ACRO	PRL	NFA		
	Stress	Patients perceived more stressful events than before the diagnosis, but also a higher sensitivity to stress, most pronounced in the CD- and ACRO-group.	x	x	x	x		
	Fatigue*	Both physical and mental fatigue are reported.	x	x				
	Anxiety	Patients reported (some) anxiety and panic attacks, associated with unexpected situations (CD) <sup>Q9</sup> , or in relation to orientation problems (ACRO) <sup>Q10</sup>	x	x				
	<b>Fear of collapsing</b>		x	x		x		
	<b>Fear of recurrence</b>		x	x	x	x		
	<b>Panic</b>		x	x			When friends invite me to go to the city, I already panic and I think “O no” then I have to do this and that the next day	Q9
							I panic terribly, when I am in the city or wherever I am. When I come out of a store I don’t know whether I left the shop on my right or on my left. For instance when I am in a big shopping mall, I will stay at the same point when my friend goes to look at something	Q10
	<b>Persisting thoughts</b>		x				If I forgot to buy butter, then I have to immediately return to the stores to buy it, even though there’s no need for it, because otherwise I would not be able to sleep a wink	Q11
Sexuality	Decreased libido	Decreased libido was discussed <sup>Q12</sup> , although the cause was not unanimously attributed to the disease, but also to aging, a negative self-image, shame, physical pain and as a side effect of medication. The awareness of a decreased libido resulted in the fact that sexual intimacy was not initiated by the patient and therefore gave tension between partners <sup>Q13</sup>	x	x	x	x	I don’t have the need to have sex My libido is decreased; at a certain moment you come to a point that you doubt your relationship	Q12 Q13
	<b>Issues with a desire to have children and family planning</b>			x		x		

**Table 2** continued

Category	Subcategory	Illustration of complaint	Reported by				Quotes	Nr
			CD	ACRO	PRL	NFA		
Personality issues	Problems with changes in emotional functioning	Changes in emotional functioning were reported, for instance being more sensitive to emotions (CD) <sup>Q15</sup> , having extreme emotions (PRL) <sup>Q16</sup> , or a flattened affect with less fantasy (e.g. daydreaming, fantasizing) (ACRO) <sup>Q17</sup>	x	x	x		I get very emotional very quickly. Someone saying “boo” to me is sufficient to make me cry. It can also be of happiness	Q15
							When I was angry, I became furious. When I had to laugh, I laughed hysterically	Q16
							Fantasizing about future plans or about nice things is decreased	Q17
	Irritation	In general patients reported to be less patient and to experience more irritability.	x	x		x		
Lowered self-esteem	A lowered self-esteem was reported, either initiated by the disease or already present before the diagnosis. The current experienced insecurity was mainly caused by functional limitations <sup>Q18</sup>	x	x		x	It is your awareness of your limitations that thwart you and makes you act insecure	Q18	
	<b>Problems with a changed personality</b>		x	x	x	x	I am having difficulty with the fact that I have changed mentally and psychologically	Q14
Negative feelings	Tension*	Both physical and psychological tension <sup>Q19, Q20</sup>		x			The whole day I am tensed	Q20
	Loneliness	Loneliness was reported in connection with fatigue or depressive symptoms.	x			x		
	Guilt	Guilt was reported and this was especially felt in their partner relationship, since patients sometimes felt they were less able to pay attention to their partner or because of the decreased sexual libido.	x			x		
	Shame	Patients reported shame because of physical sexual dysfunction, but also because of being ashamed of their body during sexual activity.		x		x		
	<b>Anger</b>		x			x	At first, I was really angry at my body. A failure in my body has let me down	Q21
	<b>Jealousy</b>			x			I envy friends who look feminine and I envy friends when they get children	Q22
	<b>Sadness</b>		x	x			I have gone through a lot of sorrow in the last couple of years. All this because I discovered that I wasn't myself anymore and I couldn't do things that I could do	Q23
	<b>Frustration</b>		x	x		x		



**Table 2** continued

Category	Subcategory	Illustration of complaint	Reported by				Quotes	Nr
			CD	ACRO	PRL	NFA		
<i>Social</i>								
Work related problems			x	x	x	x		
Limitations in leisure activities			x	x		x		
Social problems	Issues in social functioning	Patients reported issues in social functioning. They felt insecure and nervous in social situations <sup>Q24</sup> . Moreover, they experienced some difficulties with social contacts <sup>Q25</sup>	x	x			I get tensed when I have to go to a birthday party. If I go then I have to socialise and do fun things—that is something that I find difficult. It is actually too much for me to cope	Q24
							If I see 6 people waiting to pay near the cashier, I will not even enter the shop. I would rather go another time than wait impatiently in the line	
							I have difficulty with social contacts. If the friendship does not work out, I don't bother anymore, it's an unpleasant vicious circle	Q25
	Negative influence on partner relationship	The whole process of diagnosis frequently had a negative influence on the partner relationship and some marriages had fallen apart during the time of diagnosis <sup>Q28</sup> . Also after treatment, relationships were negatively influenced by changed personalities and decreased sexual activity and libido. In addition, patients also reported negative influences on their family.		x	x	x	He made the best of a bad bargain. Perhaps none of this would have happened if part of the care plan included teaching the partners of patients the effects the disease can have on someone's psychology. As a result, my partner could have had a better understanding with regards to this	Q28
	<b>Reduced social network</b>		x	x			I had a large network of friends and relatives, but in the meantime I lost 98 % of those people	Q29
							I have lost no one with whom I have discussed my disease as they have sympathy for my situation	Q30
	<b>Difficulties in communication about disease</b>		x	x	x	x	Sometimes I walk a bit strange because of problems in my cartilage. Then I tell people that it will disappear sooner or later and that it was a result of doing too much sport	Q26
	<b>Lack of sympathy of environment</b>		x	x		x	My employer has all the brochures, but he puts them on a pile. He would prefer it if I quit the job and that I be replaced by someone who is healthier and who is able to earn money for him	Q27

**Table 2** continued

Category	Subcategory	Illustration of complaint	Reported by				Quotes	Nr
			CD	ACRO	PRL	NFA		
<i>Contributing factors</i>								
Negative illness perceptions	Consequences	Patients reported a severe impact of the disease on their lives and told that they had underestimated the consequences <sup>Q31</sup> . They pointed out that factors such as age at diagnosis or duration of active disease prior to diagnosis may have influence the experienced impact. Some considered the influence of the disease on their life, personal development and life choices <sup>Q32</sup>	x		x	x	It has had quite an impact, you have a house, a good job, and all of a sudden you are ill. Meanwhile you have lost your complete life. It controls your life completely, your whole day	Q31
							I was thinking, suppose if I didn't suffer from the disease—would my life have been different? Would it have been better or would I have made other choices? How has my personality developed as a result of my disease and medication?	Q32
	Timeline	Perceptions of a chronic timeline were noticeable in the awareness of the irreversible damage to their body (ACRO) <sup>Q33</sup> . Furthermore, patients reported the experience of physical complaints, such as physical weakness (PRL), physical pain, and joint complaints arriving by fits and starts (ACRO) (cyclical timeline).	x		x		The damage is long lasting. The symptoms in your joint, your mental limitations and other signs which are part of the disease remain with you lifelong	Q33
	Cause	Sometimes there was confusion about the cause of the pituitary adenoma, for example explanations were a fall, medication or congenital <sup>Q34</sup> . Furthermore, patients were wondering when the disease actually started <sup>Q35</sup>	x			x	I find it difficult to decide for myself what the cause is. Has the disease progressed slowly or was it always present?	Q34
							Did I have it already during my puberty? Then I can understand why I was depressive then	Q35
	Cure/control	It was thought that stress played a major role in the origination of the adenoma and/or in the recurrence of the adenoma <sup>Q36</sup>	x				I always have this feeling that stress plays a role in my life. I fear that something might grow	Q36
Identity	Some patients wondered whether certain complaints, such as complaints of fatigue or influenza were caused by their pituitary disease, or that they experienced common complaints. Some refused to attribute certain complaints to their pituitary disease <sup>Q37</sup> . Others said that in a way, the complaints suited them <sup>Q38</sup>	x	x		x	I think it is a kind of excuse, I have to handle it myself. The diagnosis of 'Cushing's Disease' is insignificant	Q37	
						All complaints have a cause, actually it suits me the way it is	Q38	
Negative beliefs about medicines	<b>Concerns</b>		x		x	x	The lower the mess, the better	Q39

**Table 2** continued

Category	Subcategory	Illustration of complaint	Reported by				Quotes	Nr
			CD	ACRO	PRL	NFA		
Less efficient coping strategies	Withdraw		x				I retreat every now and then to recover; I think it is a painful situation	Q40
	<b>Overdoing</b>		x	x	x	x	Some patients preferred to withdraw and to be alone sometimes	
	<b>Problems with acceptance</b>		x	x			I try to do as much as possible; I prefer to rest for two days, instead of taking it easy	Q41
Unmet needs regarding care	<b>Insufficient information</b>		x	x	x	x	I have not accepted it, I am still searching	Q42
	<b>Inadequate cooperation/communication between medical specialties</b>				x	x		
	<b>Absence of recognition for certain complaints</b>		x	x	x	x	I can discuss about my medication and basically everything with my doctor, but we don't really discuss about who I am from the inside	Q43
	<b>Dissatisfaction with other aspects of medical care</b>		x	x	x		The ideal training should teach one how you can keep stress under control,	Q44
							What are the do's and don'ts to keep the disease under control?	Q45
						A psychologist can support those with acromegaly. He/she could prepare us in advance for what to expect	Q46	
						My husband could not go through it alone. He really needed help	Q47	

Bold: QoL which has not earlier been studied and which is not included in a disease-specific QoL questionnaire. Italics: category which is earlier used in other disease-specific questionnaires for pituitary diseases

\* Category was mentioned biologically, as well as psychologically

Bold: category which has not been studied before in patients with pituitary diseases. Italics: category which has been examined earlier (by the studies of Tiemensma et al. [10, 36])

*Cognitive problems* were characterized by concentration and attention problems, short-term memory problems, executive functioning problems and a feeling of overstimulation.

*Sexual problems* were physical sexual dysfunction, such as erectile dysfunction, decreased libido and **issues with a desire to have children**. Some patients reported inability to get an orgasm. Female patients reported menstruation problems (i.e. chronic menstruation), which interfered with sexual activity. (New) relationships were perceived to be affected by physical sexual dysfunction. Decreased libido (all groups) was discussed<sup>Q12</sup>, although the cause was not unanimously attributed to the disease, but also to aging, a negative self-image, shame, physical pain and as a side effect of medication. The awareness of a decreased libido resulted in the fact that sexual intimacy was not initiated by the patient and therefore gave tension between partners<sup>Q13</sup>. A desire to have children and family planning were serious issues for some young women as they felt uncertain

whether it would be possible to conceive at all, or alternatively whether they would be capable of caring for a child.

*Psychological complaints* were depressive symptoms, mood swings, melancholy, anxiety, stress, **fear of collapsing, fear of recurrence, panic and persisting thoughts**. Fear of collapsing was related to situations with higher temperatures and physical strain. Fear of recurrence was reported in all groups and it was provoked by physical complaints (flu-like symptoms or pangs in the head). Fear of recurrence was aggravated by discontinuation of medical treatment and by uncertainty about the cause of the adenoma. Patients reported panic attacks, associated with unexpected situations (CD)<sup>Q9</sup>, or in relation to orientation problems (ACRO)<sup>Q10</sup>. Less established complaints were for instance that patients reported to be unable to let go persisting thoughts about pointless issues (CD)<sup>Q11</sup> and the perception of mental absence, foremost during the 'active' disease period (ACRO).

*Personality issues* were problems with changes in emotional functioning, lowered self-esteem, irritation and **problems with a changed personality**. Patients (all groups) reported a personality change to some degree<sup>Q14</sup>, for example they experienced to be less approachable, more tolerant and more peaceful to other people, or more conscious of their feelings.

*Negative feelings* were tension, loneliness, guilt, shame, **anger, jealousy, sadness and frustration**. Patients reported to be more sensitive to anger (CD, NFA). Furthermore, they felt anger towards their own body<sup>Q21</sup>. Jealousy was noticed, i.e. due to the inability to do what healthy friends can do (ACRO)<sup>Q22</sup>. Sadness was associated with fatigue or emerged because someone was not feeling his usual self (CD)<sup>Q23</sup> and they reported to cry more easily. All groups (except NFA) felt frustration facing the persisting physical and cognitive complaints, especially when their medical doctors or the social environment turned a deaf ear to their complaints.

*Social problems* were issues in social functioning, negative influence on the partner relationship, **difficulties communication about their disease, a lack of sympathy of environment and a reduced social network**. All groups reported difficulty communicating about their disease, for instance because they did not want to frighten somebody or being looked at with pity. Patients used little tricks to avoid talking about their disease<sup>Q26</sup>. Frequently, patients only told the direct environment about their disease. Patients informed their present employer about their disease, but patients hesitated to tell a new employer, because they were afraid to be rejected for a new job. Unfortunately, patients in all groups (except PRL) often encountered a lack of sympathy, for instance by acquaintances, colleagues and employers<sup>Q27</sup>. However, this lack of sympathy was most of the time resulting from ignorance about the disease. Patients experienced that their social network declined (CD, ACRO)<sup>Q29</sup>. However, in some cases discussing the disease within their social network prevented the loss of friends<sup>Q30</sup>.

*Work related problems* were experienced in all groups. Patients experienced changes in their work situation due to their disease. Some lost their jobs or were (partly) rejected as medically unfit. Reasons for these changes were diminished ability to function, to concentrate and to cooperate. Most patients currently work part-time.

*Limitations in leisure activities* were perceived in their ability to perform sports, due to their physical limitations (all except PRL). In addition, they experienced limitations in social activities, such as going to parties and on trips. They reported that these activities were energy consuming and that they had to take into account the extended resting time afterwards.

*Negative illness perceptions* were reported. Illness perceptions are defined as: “the beliefs that a patient holds

about his/her health problems”, influence how patients respond to their illness. They are conceptualized in the common sense model of self-regulation (CSM) of Leventhal et al. [48]. Illness perceptions in patients with pituitary diseases are previously evaluated by Tiemensma et al. [10, 36]. In general, patients cluster beliefs about their illness around five cognitive components: *consequences, timeline, cause, control/cure and identity* [48]. All components were spontaneously mentioned during the focus group discussions.

*Negative beliefs about medicines* were reported. Beliefs about medicines can be grouped into two major categories, beliefs about the *necessity* of prescribed medication and *concerns* about the potential aversive/side effects [49]. In these discussions, **concerns about medications** were most dominant. Patients reported negative experiences with medication (e.g. negative effect on mood) and they reported beliefs about the use of medication changing their personality (PRL). Patients in the ACRO-group experienced the use of injections as awful. Some patients reported that they disliked the use of hydrocortisone, and therefore preferred to take a low dose<sup>Q39</sup>.

*Less effective coping strategies* used by patients were withdraw, **overdoing activities** and **problems with acceptance**. Some patients felt it was difficult to let go feelings of frustration and reported the need for alcohol intake to relax (ACRO, NFA). All groups reported that they overdo their activities<sup>Q41</sup>. Some patients reported problems with acceptance of the disease and its consequences (ACRO, CD)<sup>Q42</sup>.

*Unmet needs regarding care* were **insufficient information, better cooperation and communication between medical specialties, absence of recognition for certain complaints and dissatisfaction with other aspects of medical care**. The most prominent unmet need regarding care was insufficient information about the disease at diagnosis and during active disease (all groups). For instance, information about the adverse effects of medication (effect on personality), physical complaints, psychological complaints, cognitive complaints, sexuality and the ability to have children. They would have liked to be better prepared with regard to the impact of the disease and the overall short- and long-term consequences of being a patient with a pituitary disease. Furthermore, patients agreed that medical specialties should better cooperate and communicate together and that other medical specialists than endocrinologist should be better educated about pituitary adenomas (e.g. gynecologists, general practitioners).

All groups experienced absence of recognition for certain complaints by medical professionals, i.e. lack of response to complaints of sexuality, fatigue, and other physical complaints. Psychological, social and personal issues were hard to discuss<sup>Q43</sup>.

To some degree patients were also dissatisfied with other aspects of medical care (CD, ACRO, PRL), since they reported a need for stress-management<sup>Q44</sup> and lifestyle recommendations<sup>Q45</sup>. In addition, there was a need for special care of physiotherapists, dietitians, medical sports experts and psychologists<sup>Q46</sup>. Support was not only needed for patients, but also for their partners according to patients<sup>Q47</sup>.

## Discussion

In this focus group study in patients treated for pituitary diseases, we explored QoL as perceived and discussed in representative patient groups. This study puts forward new QoL aspects from the patient's perspective, which are not included in the currently available disease-specific questionnaires, and identified factors which may contribute to decreased QoL.

The primary aim was to explore disease-specific QoL as reported by patients treated for pituitary diseases. Earlier qualitative studies used semi-structured interviews about preselected topics to develop disease-specific QoL questionnaires (i.e. CushingQoL, Tuebingen CD-25, AcroQoL, QoL-AGHDA) [13–19]. These topics can be categorized according to the biopsychosocial approach of QoL: (1) *physical problems*, (2) *psychological problems*, (3) *social problems*. Although the majority of these dimensions also emerged during the focus group discussions, new QoL aspects were also identified.

Newly raised physical issues were the presence of visual limitations, which is indeed a common symptom in patients treated for pituitary adenomas [1], but which is not included in available disease-specific QoL questionnaires. Uncovered psychological problems were issues with a desire to have children and family planning. At present, this issue is not incorporated in existing disease-specific QoL questionnaires, although many patients are of reproductive age. Furthermore, patients reported that they were unable to let go persisting thoughts, and had feelings of panic and fear. The reported fear of recurrence of the adenoma, is also frequently seen in cancer survivors [50] and is usually associated with increased use of health care services (e.g. a greater number of outpatient visits and emergency room visits) [51]. Interestingly, this fear may be neglected by the physician, since they consider adenomas to be benign. Other uncovered psychological problems were the feeling that their personality was changed and feelings of anger, jealousy, sadness and frustration. Additionally revealed social problems were issues with communicating about the disease, facing a lack of empathy of others and a reduced social network. These

physical, psychological and social issues were not included in earlier disease-specific QoL questionnaires. In conclusion, disease-specific QoL as formulated in available disease-specific QoL questionnaires for pituitary diseases could be further elaborated by incorporating the patient's perspective.

The second aim of our study was to identify factors that may contribute to a decreased QoL. Recent papers discussed the presence of negative illness perceptions and ineffective coping strategies [10, 36, 52]. The present study revealed examples of negative illness perceptions and less effective coping strategies, but also negative beliefs about medicines and unmet needs regarding care. We believe that further exploration of the significance of these uncovered factors is relevant for the care of patients with pituitary adenomas, since these factors may affect QoL [10, 36, 37].

Concerns about medication and unmet needs regarding care were not previously described in patients treated for pituitary adenomas. In a study by Horne and Weinman it was found that concerns about adverse effects of medication were significantly associated with non-adherence to medication in patients with asthma [53]. Considering the large part of patients with pituitary diseases that is treated with substitution therapy and medication, our findings suggest that physicians should be aware of, and adequately cope with these concerns. Furthermore, medical experts and other healthcare providers could play a role in meeting patient needs by being aware of the reported unmet needs. This awareness could improve the communication and care for patients treated for pituitary diseases. In addition, the patient's perspective of QoL explored in this study can be helpful for medical experts in their communication with patients, since it describes experiences, rather than numbers provided by QoL questionnaires. Patients reported an explicit need regarding care, such as stress-management, psychological care, and physiotherapy and nutrition and sports recommendations. Experts in these fields could play a major role in meeting this need, for instance by offering self-management interventions (SMI) including these aspects. It is found that SMI's positively affect well-being of patients suffering from chronic conditions (e.g., asthma, diabetes, arthritis, Parkinson's disease) [44, 54, 55]. Obviously, objectives of SMI's differ between various diseases. For instance, SMI's for asthma aim to monitor symptoms and to improve adherence to medication, and SMI's for diabetes tend to focus on lifestyle issues. These differences in focus result in a range of different contents and methodologies in SMI's [56]. The information provided in this study could be used for the adjustment of a SMI for patients treated for pituitary diseases.

There are some limitations to this study, all largely due to general limitations of focus group methodology.

For instance, a dominant participant with his/her own agenda could have influenced the groups discussions. Nevertheless, the moderator aimed to prevent this by giving each patient equal space to speak. Although we aimed at a representative group composition able to reflect a broad range of experiences, a selection bias is inevitable. Moreover, with four different focus groups we considered the number of included patients adequate for conclusions for pituitary diseases in general. There was a considerable overlap in reported issues between the groups, but we also identified differences between the various pituitary adenomas. However, since there was only a single group per specific disease, we were unable to draw firm conclusions about CD, NFA, ACRO, and PRL specific issues. Future quantitative research in a larger group of patients is needed to further evaluate the differences between groups and to determine the importance of each aspect to QoL. This could also give more insight in the potential influence of clinical characteristics, such as the influence of pituitary deficiency, disease severity and duration of follow-up.

In conclusion, this focus group study showed disease-specific QoL as formulated and perceived by patients treated for pituitary diseases. Furthermore, it uncovered potential contributing factors. The information provided in this study can be used for developing additional items for disease-specific QoL questionnaires and for the development of a SMI aiming to improve QoL in patients treated for pituitary diseases.

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