

PSYCHOLOGY AND ILLNESS BELIEFS

Asthma from the patient's perspectiveAbir Al-kalemji, MD, PhD¹, Helle Johannesen, PhD², Karin Dam Petersen, PhD³, David Sherson, MD¹, and Jesper Baelum, MD¹¹Department of Occupational and Environmental Health, Odense University Hospital, Odense, Denmark, ²Institute of Public Health, Research Unit Health, Man & Society, University of Southern Denmark, Odense, Denmark, and ³Department of Business and Management, Danish Centre for Healthcare Improvements, Aalborg University, Aalborg, Denmark**Abstract**

Background: Asthma is a chronic disease with considerable burden on health and economy. Despite growing knowledge about causes and treatment, many patients have uncontrolled asthma, activity and social limitations and reduced quality of life (QOL). Coping with asthma could be developed in a social and scientific context and influenced by personal experience. **Objective:** To investigate the asthmatic's perspective on asthma and how coping mechanisms with this disease were influenced by health professionals and networks. **Methods:** Asthma and QOL questionnaires were sent to 1191 individuals, who had participated in a population-based clinical study in 2004. Of the 7271 responders (72.7%), 10 chronic asthmatics (4 males and 6 females) with different asthma severity grades were recruited to in-depth interviews. The results were interpreted according to selected theories, especially Antonovsky's salutogenic theory on how comprehensibility, manageability and meaningfulness contribute to sense of coherence and successful coping with stressor/disease. **Results and conclusion:** Asthma comprehensibility was limited by both the lack of structured information about asthma diagnosis, treatment and prognosis and insufficient follow-up. The informants experimented with what worked and developed individual ways to accomplish satisfactory management. They adjusted their own medication and sometimes stopped prophylactic medicine as they did not detect an immediate effect. Many informants put their asthma into perspective, comparing it to what could have been worse. The unnoticeable development of asthma had probably triggered a gradual adaptation making it more complex for asthmatics to estimate severity. This together with their relative view of asthma might have led to gradual and uncritical accept of bothersome symptoms and reduced the need to seek professional advice or make important changes, e.g. eliminating exposure to irritating agents at work. Avoidance was a recurrent phenomenon as the asthmatics tended to drop physical activities with others instead of improving treatment. Several stated that they did not like to flash their asthma. They had concerns about being labelled as 'inadequate'. Physicians are urged to consider these tendencies and underlying the some of the mechanisms of 'living with asthma' in order to achieve proper asthma treatment and insure their patients' wellbeing.

Keywords

Asthma, asthmatic's perspective, coping, in-depth interview, quality of life, qualitative research

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Asthma is a chronic disease with considerable health-related, social and economic consequences. Its prevalence has been increasing during the last decades [1–5], especially in younger age groups (15–54 years) [4]. Despite growing knowledge about causes and treatment, many patients have uncontrolled asthma, which is associated with more absenteeism, frequent emergency department use, significant socio-economic burdens and reduced quality of life (QOL) [6–9]. Greater asthma severity is associated with worse QOL, especially in women

and unemployed [10–13]. The presence of depressive or anxiety symptoms is closely related to dyspnoea and poor asthma control [14,15]. Gender has an independent influence on QOL as female asthma patients are more likely to report dyspnoea, poorer control and reduced QOL [16]. Furthermore, asthmatics with occupational asthma are more psychologically distressed and have worse QOL compared with non-occupational asthmatics [17,18].

The association between asthma and reduced QOL is thus influenced by several factors [19,20]. However, little is known about how persons with asthma view their asthma and cope with it. A qualitative study of 62 patients attending an emergency department for asthma investigated these patients perspectives and concluded that asthma affected personal and family life, employment and finances [21]. Another study identified two main groups of asthmatics, the deniers and the

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accepters. They differed fundamentally in their readiness to accept asthma identity, in their beliefs about the nature of their problem and the meaning of the medication prescribed for it. There was a marked difference in their self-presentation strategies and patterns of medication use, particularly prophylactic medication [22]. Vulnerable patient groups often faced poor material circumstances and chaotic lives, impacting on their capacity to manage their illness and on their ability to derive benefit from primary care [23].

Obviously, there are differences in how asthmatics experience asthma. The idea of this study is to illuminate the asthmatics' comprehension of their condition and adaptation mechanisms to symptoms and treatment as well as to the physical and social limitations induced by asthma. Coping with asthma is assumed to be developed in a social and scientific context and influenced by personal experience. Qualitative research is thus needed to understand the asthmatics perspective, reflections, observations, judgment and experience with their disease. Personal experience is often characterised as being anecdotal, ungeneralisable and a poor basis for making scientific decisions. However, it is often very powerful in changing clinical practice [24].

The objective of this study is to investigate: (1) the asthmatic's perspective on asthma and how it was influenced by health professionals; (2) how asthmatics cope with asthma and how these coping mechanisms are effected by personal experiences, clinical information and interaction with colleagues and family?

Theory

Investigating individuals' perspective on a disease and how they deal with the challenges it provokes can be based on the salutogenic model concerning health, stress and coping, introduced by the Israeli-American sociologist Aaron Antonovsky. The salutogenic model presents the concept of "sense of coherence" (SOC) as a global orientation to the environment as comprehensible, manageable and meaningful. If this is achieved, then the individual will be able to cope successfully with stressors/diseases: "When the stimuli deriving from one's internal and external environments are structured, predictable and explicable, and the resources to meet the demands posed by these stimuli are available, and these demands are challenges worthy of investment and engagement, then the person would be able to achieve SOC" [25, p. 19].

Successful coping with stressors is thus achieved when the world is seen, to a greater or lesser extent, as *comprehensible* (the cognitive component), *manageable* (the instrumental component) and *meaningful* (the motivational component). Complex messages are potential noise rather than information. On the other hand, Antonovsky argues that complexity can be perceived as a possibility of choice, flexibility, adaptive change and autopoiesis (a systematic reorganisation of life after living through chaos), in persons with good resources [26].

According to Antonovsky illness may be viewed as lack of success. Failure is almost inevitable when there is a discrepancy between an individual's aspirations and the limited opportunities. A feeling of failure is found in all societies and coping mechanisms are not dependent on culture but exists in human nature and is universal [27].

Operationalization of these concepts of coping with a stressor-like asthma would open up for interpreting how asthmatics view and deal with their condition. Comprehension and manageability of asthma depends never the less on the information received from their health care providers: "The physician plays a unique role as the sole authority granting legitimation for the sick role and helps coping with the illness. It places a special burden on the physician particularly in a social context to try to understand the patient's way of coping in the particular social context" [27].

Responsibility for the day-to-day management of chronic disease ultimately resides with the affected individual. Success or failure of medical management and the resulting health outcomes are a direct result of the individual's awareness of his or her disease and the appropriateness and effectiveness of responses to that awareness.

Finally, we attempt to obtain knowledge about how persons with asthma view their position as asthmatics in interaction with their network, family and colleagues. Ian Hacking, a Canadian philosophy of science professor, discussed the meaning of classification of human nature: "Classifications can change our evaluations of our personal worth, of the moral kind of that person we are. Sometimes this means that people passively accept what experts say about them, and see themselves in that light. But feedback can direct itself in many ways" [28, p. 131].

Hacking argued that human nature is laden with values and that there is a regular attempt to strip people of their intrinsic moral value by biologizing or medicalizing them. Classifying people can change how they think of themselves and change their self-worth, even influencing how they remember their past. People behave differently and react in different ways to being classified by adopting certain stereotypical patterns of behaviour. This generates new casual knowledge that in turn becomes part of what can be known about the person, who changes again as a reaction to the new gained knowledge. This is what Hacking calls the "looping effect". Biologizing human kinds does not make them immune to looping effects [29]. Once diagnosed with a disease normality is brought into perspective. The concept of normality is partly responsible for viewing any deviation as unusual. This study will illuminate how asthmatics navigate in the abnormality spectrum and react to being classified as having asthma.

Methodology and methods

This study is part of a large Danish study on Risk Factors for Adult Asthma described elsewhere [2]. Briefly, 10 000 Danes aged 20–44 years received a mailed asthma screening questionnaire in 2001–2003. Among the 7271 (72.7%) valid respondents, 1191 asthmatics and controls were recruited to clinical investigations in 2003–2006. In November 2010, those clinically examined were sent an asthma screening questionnaire and the 15D, a generic, multidimensional, standardised, self-administered evaluative tool assessing QOL across 15 dimensions: mobility, vision, hearing, breathing, sleeping, eating, speech, elimination, usual activities, mental function, discomfort symptoms, depression, distress, vitality and sexual activity. In total, 778 (67%) returned valid

responses of which 181 persons (23%) had current asthma. Asthma severity, psychiatric co-morbidity, female gender and smoking were identified as independent contributors to reduced QOL. These results are described further in our first paper [30].

Interview subjects

We went through the list of the 181 persons with current asthma and invited those with chronic asthma and varying asthma severity to participate in in-depth interview. The selection stopped when 10 persons (4 males and 6 females) accepted to participate. The data were collected from July 201 to February 2013. Asthma severity was estimated from the responder's answers to the screening questionnaire and graduated according to Pekannen's criteria [31] including symptom severity, symptom frequency and asthma medication. Depressive and anxiety symptoms as well as other co-morbidities were self-reported in the 15D questionnaire. Data on occupation, medication and civil status were collected during the interviews. A sample size of 10–15 persons was indicative and the interviews with 10 persons with asthma were found comprehensive. Thus, additional interviews were not likely to add significant contributions.

The informants were first contacted by phone, informed of the research and invited to participate. They all agreed and were sent a confirming letter that further explained the research. The first author in this article performed the interviews, which took place at a less clinical environment (own home or work places except in one case at the hospital for practical reasons) as more familiar surroundings were anticipated to give a more comfortable base for openness.

The interview process was mainly based on Steiner Kvale's seven steps [32]: thematization, design, interview, transcription, analysis, verification and reporting. Our study was explorative. We therefore used a semi-structured interview guide including questions covering the two main themes/objectives on asthma perception and coping in order to give the participants an opportunity to jump in with further information or new topics whenever they felt inclined. When dealing with sensitive issues as inner thoughts, beliefs and disease coping, unstructured interviews are suitable as they allow adaptation and flexibility according to the informant's individual insights [33].

The interview was initiated by explaining once again about the study and asking simple questions about age and occupation to achieve a gentle start. Some of the techniques that were used during the dialogue were encouraging the informant to talk freely by nodding or confirming mutterings and probing when the answers were unclear or unexpected. In places of doubt, the informant was asked to clarify the statement to avoid misleading interpretations. Only neutral probes that did not suggest answers were used. All interviews were recorded and transcribed for later discussion, validation and analysis of the results in cooperation with the co-authors. "To achieve the transition from consultation to research interview, clinical researchers need to monitor their own interviewing technique, critically appraising tape recordings of their interviews and asking others for their comments" [34].

Research ethics

The study was approved by the local Scientific Ethics Committee and registered with the Danish Data Agency. All participants were thoroughly informed about the research by phone and subsequently sent an informative letter. They all provided oral consent.

The study did not provoke ethical concerns as the participants were involved in the cohort since 2003 and were well informed about the study purpose. As part of the study involved their own feelings and concerns with asthma, some ethical concerns are worth mentioning as follows.

Confronting people with deeper thoughts on their disease can be overwhelming and confusing. It was therefore important to consider any questions or challenges the interview may have risen. It was our strategy to extract information without an attempt to make judgments or corrections. The interviewer was a doctor, who was prepared for any concerns the might emerge during the dialogue. It was a challenge to keep the researcher's perspective during the whole conversation trying to extract as much information as possible and then to shift to a doctor's role at the end of the interview to provided further insight and relief about thoughts and concerns that arose during the dialogue. This ethical dilemma was solved by leaving the interviewee with unanswered questions or unchallenged concerns during the session and providing advice after the interview was complete. The researcher's own position as a health professional had probably created some bias as some medical areas were implicitly understood and left unquestioned. An 'outsider' would probably have sought more details. On the other hand, being a doctor facilitated covering many aspects of asthma and going deeper into uncovered issues and matters of concern for the participants as many details, like medication type, side effects, inhalator techniques, diagnostic tests and guidelines for asthma management were familiar and lack of such knowledge would require more time leaving less opportunity to explore the study objectives.

After the interview, it was important not to abruptly leave the individual after 1 h and a half of a serious conversation including intimate thoughts, fears and challenges and to show appreciation for the participation. The informants were also offered study results with a Danish summary, when available.

Analysis

The interview data were transcribed and thematically organized into categories/concepts that were in line with the objectives mentioned in the 'Introduction' section.

In order to insure analytic rigour all relevant information regarding the purpose of this study was included in the analysis to guard against selectivity. It was also important to ensure that single information points were quoted to avoid generalization. As the interview data generated many relevant quotes, they were organised in boxes according to their relation to the two objectives of the study and referred to in the analysis. Citations were used directly in the result section when emphasis was needed to support interpretations. The names are fictive to ensure anonymousness. Some citations were abbreviated to facilitate the meaning without redundant expressions. The results were analysed, interpreted and

discussed against the theoretical frame in the respective sections.

Cross-examination and consensus was extracted from comparing different quotes. Information on asthma severity from the interview was compared with the answers to the screening questionnaire based on Pekannen's criteria.

All relevant data and quotations were presented for the co-authors and discussed until a consensus on interpretation was reached. This process allowed analytical rigour and the incorporation of deviant cases into the emerging thematic constructs. Original evidence was presented to clarify links between what was stated, interpreted and concluded. The phenomena under study was integrated into their social context. No particular or unique influences were identified, like serious co-morbidities that could influence their view of asthma or lack of cognitive functions that could prevent meaningful dialogue.

Results and discussion

Ten eligible participants (6 females and 4 males) accepted our invitation for in-depth interviews. All interviews succeeded in covering the study questions as all informants were willing to talk freely. Both men and women were informative about their asthma. Women though were slightly more expressive of their concerns, but men reached the same level of openness as their female counterparts as the dialogue continued. The variety of participants regarding asthma severity, gender, age (ranging from 36 to 52 years), education, occupational status and psychiatric co-morbidity (Table 1) made it possible to get a nuanced picture of everyday life with asthma.

Asthma comprehensibility

Our first objective was to investigate the asthmatic's reflection on asthma and how their view of this disease was developed in conjunction with information from their doctor. Interview data suggested that the asthmatics narratives on asthma were retrospective, closely related to the onset of symptoms, diagnosis and treatment. Asthma debut was typically linked to a specific episode that highlighted their asthma symptoms, like pneumonia, measles and other viral infections, allergic contact to animals, "diagnosis confirmation", etc. However, during the interview, most of them recalled difficulties with physical activities and breathing problems at an earlier stage, actually several years before their condition was diagnosed, illustrating the tendency for asthma to develop unnoticed (Box 1): "I got asthma in 2003, or probably 2002. I was always sick at the time; had often viral infections and runny nose. I got pills against allergy that did not help (...) The specialist told me then that I had allergy-related asthma (...) It started maybe earlier, when I got my daughter in 1995. I had breathing problems when I played with her (...) Oh, maybe I had asthma at much earlier stage, in 1987 when I worked as cook as I barked each time I was exposed to steam etc." (Liona)

Asthma was mainly diagnosed by general practitioners (GP). Almost all our interview-participants experienced the doctor's messages as short and closed: "You have to live with it" and "You will grow from it". They were not offered follow-up with simple diagnostic tests like measuring peak

Table 1. Sociodemographic characteristics, asthma severity, medication and co-morbidities.

Name (fictive) and age	Occupation	Marital status	Asthma severity (Pekannen's criteria)	Asthma medication	Anxiety/depression	Other co-morbidities
Stan (36)	Engineer	Married with children	Moderate (5)	Beta2-agonist inhaler	None	Muscular-skeletal and skin disease
Ken (37)	Works at a piggery	Married with children	Moderate (5)	ICS and Beta2-agonist inhaler	None	Muscular-skeletal disease
John (38)	Academic IT-manager	Married with children	Mild (2)	None	None	None
Linda (39)	Teacher	Married with children	Severe (6)	Long-acting beta2-agonist and ICS	Depression	Muscular-skeletal disease
Frankie (43)	Unemployed	Single	Severe (6)	Beta2-agonist inhaler	None	Muscular-skeletal disease
Anna (45)	Prepare books	Single	Mild (4)	Beta2-agonist inhaler	Anxiety symptoms	Epilepsy
Liona (45)	Smith	Married with children	Moderate (5)	Beta2-agonist inhaler	Depressive symptoms	Muscular-skeletal disease
Sharon (46)	Postman	Married with children	Moderate (4)	None	Both	Muscular-skeletal disease
Lesley (48)	Finance manager	Married with children	Severe (7)	Beta2-agonist inhaler and ICS	None	Muscular-skeletal disease, concussion
Pamela (52)	Early retired	Single	Severe (6)	Leukotriene inhibitor, ICS and Beta2-agonist inhaler	Both	Neurological disease, obesity

ICS, Inhalation corticosteroids.

Box 1. Asthma comprehension: narratives on asthma debut, symptom perception and experience of the doctors' information about asthma.

- "I was 18 years old when I was diagnosed with asthma. It was discovered during a pneumonia episode (...) Yes, maybe my asthma started before. As a child, for example, I remember when being in fights, I could not breathe when the other kids jumped on my chest, but not vice versa; they had no problems when I sat on top of them." Frankie
- "I was 18 years old when I got asthma ... when I gave birth to my daughter in 1988. I do not think I had asthma as a child (...) but I've always been a little heavy, always the last to arrive." Lesley
- "Actually, I got asthma after I've had measles (...) when I was 6 years old. I was hampered in my movements. I could not do the same things as everyone. I got quickly tired." Linda
- "The first time I found out that I had asthma, I got pills that didn't really help. Then I got an inhaler and that's it" Frankie
- "Never really thought about asthma. I just had to live with it. In a sense it was ok because you had an explanation." Pamela
- "It was horrible to be diagnosed with asthma and allergy towards animals. I loved animals (...)" Sharon
- "I remember the first time I was diagnosed with asthma. I got pretty sad (...) I thought I was a superwoman who could do everything; work, study, be a mother etc." Lesley
- "I was teenager. It was horrible that I could not get enough air. My mother took me to the doctor and I was examined with skin prick test. And then I just got Bricanyl (rescue medication)... I thought about it a lot for approx. 5 years... what's the deal with that Bricanyl? I thought my asthma could get worse. But I believed that I could grow out of it. Today I don't really think of it." Ken
- "I got asthma in 2003, or probably 2002. I was always sick at the time; had often viral infections and runny nose. I got pills against allergy that did not help (...) The specialist told me then that I had allergy-related asthma (...) It started maybe earlier, when I got my daughter in 1995. I had breathing problems when I played with her (...) Oh, maybe I had asthma at much earlier stage, in 1987 when I worked as cook as I barked each time I was exposed to steam etc." Liona
- "Asthma is like being in a bad physical condition because of lack of exercising. I normally coughed after exercise (...) I just did not take it seriously; I thought it was silly. But later on when I was more bothered from my asthma I could see it was a disease." Liona
- "My symptoms are generally few. So I do not think about it. Can't remember exactly how it started but there was a period with great difficulty in breathing. And so I got some medicine and I have been able to keep the symptoms down since." Stan
- "I was 10 years old. I had problems with shortness of breath. I was prescribed Ventoline (rescue medication) and Pulmicort (ICS) and it helped (...) I did not get much information (...) I would have appreciated some follow up to give a status on my asthma. But the doctors never offered that (...) Yes, I monitored my peak flow when I was younger. The doctor never looked at the measurements. I am not sure what they were supposed to be used for (...) Our neighbours died from COPD, I believe this disease is kind of 'super-asthma'." John
- "I did not really receive information about my asthma or how to control it. I just call my doctor whenever I need to renew my medicine. He never asks about my asthma (...) Once I was given the "red" inhaler and it gave me horrible palpitations so I stopped taking it. The specialist got mad and told me that I should take it. No way, I thought. The palpitations were frightening (...) Bricanyl gives me no problems at all. I stopped taking my Pulmicort many years ago because I did not notice any effect even though the doctor measured an improvement by 10 %. Recently I was told by some researcher that I have COPD (...) Maybe I have never had asthma (...)" Liona
- "I am insanely interested in understanding what the causes of asthma are. I think it's a strange disease. There is something hereditary, but what the hell it is that triggers it. Is that the way you live? I look at my son and the flu triggers his asthma. During the spring it disappears. There must be something with humidity. There are many factors that have an influence. What is it in our lifestyle? What are we doing wrong? Is it something we eat? Is it the lack of exercise? Is it genetic? I read about it occasionally, if there are any new publications. I do so in periods out of curiosity. I do not think I've read something unique yet. It is not like pressing a button and then you get an answer. I am not concerned, just curious. I like to understand the reason for things (...) When you know the cause then you might do something to adapt better. Perhaps the next generation will have less asthma if you can get to the bottom of it and find the cause of this disease. There are many diseases which are lifestyle-related. Changes in our everyday lives can change a whole lot. But sometimes people don't want to or just adapt foolishly." Stan
- "I would like to get a thorough investigation at the hospital (...) to get answers to whether I could stop taking medication. It's expensive and I could probably do without. I often thought that it is meaningless to continue taking the inhalers (...) My asthma was not real asthma, it is overwork asthma. Not like a guy from my class who had to gasp for breath what ever that kind of asthma is (...) When the doctor told me that I had asthma, I was not happy. I had a classmate who had real asthma (...) but I was told that I could grow out of my asthma. And I think I have. Why I still take asthma medication, I honestly don't know." Ken
- "No, I do not go to control or measure the PEF. The doctor has not offered those tests." Lesley
- "The doctors said that it was more risky actually taking medication with corticosteroids. I did not detect any difference after one month of taking Pulmicort, and as it is probably dangerous, I stopped" Frankie
- "Back then the doctor said when he gave me the asthma diagnose: "you have to learn to live with it". That's it. I remember that I was told that most people grow out of asthma, I just had to wait and see, the doctor said." Sharon
- "Yes, for many years I woke up at night with a feeling of breathlessness. But not the last 10 years. All I have is just overwork asthma and it's not the worst thing you can get (...) I have been exposed to dust for many years, I think about it a lot... I'm afraid it is not healthy." Ken
- "My knowledge of asthma comes from personal experience (...) I once participated in a project and had to answer a questionnaire about asthma. I wrote that asthma felt as if something was sitting on my chest and pressing and that I can't breathe properly. It helped me to put into words how I really felt. No one else has ever actually asked me about that, or what I think. I was left to myself to find out what it was. Oh well, today you can Google everything." Linda
- "The doctors could perhaps give a little pep talk every now and then and inform asthma patients more positively about asthma. They should inform that medicine can provide opportunities and that you get medicine because you're sick but it helps you get better and open up for opportunities (...) Teenagers in particular need better information." Linda
- "I think doctors should turn asthma into something positive. Instead of just saying "now you've got asthma and you have to avoid a lot of things", then perhaps they should say: "we need to find out how you can manage your disease and enjoy your sport and the underlying possibilities". If a teenager is asked to stop playing football or what ever, it's awful! (...) I saw my asthma as a limitation. The doctors should have treated me sufficiently so I could be with animals, even just for a little bit, without endangering my health off course. But it's also all about quality of life. Your world can fall apart when you are deprived the things you like the most." Sharon
- "Having dogs keeps me active as I take a walk with them on regular basis. If I was told to get rid of them, then I might have suffered from other damages to my health." Pamela
- "Today children know much more about asthma ... they are more taken care off by the system (...) They must be happy (...) I felt lost in asthma." Pamela
- "I had a doctor as a child, who was simply amazing in taking care of me, listening to my parents and my needs, and encouraging me (...) Afterwards I had worse doctors that did not believe that asthma was a problem. One doctor told me to run 10 km to overcome asthma like an elite patient he had, but there is a difference between a professional athlete with asthma and a 16-years old, slightly overweight girl! I walked away and was devastated because I felt something was wrong with me and that it was my fault that I had those extra kilos. I was a teenager and very easily influenced. I could not even run 500 meters, for god sakes!" Linda
- "I don't need explanations on how the medicine works. I just want to know if it works. And since in 99.5% of the time I can't tell the difference if I take the Pulmicort or not, I don't need such medication. If I woke up every night because of asthma or felt discomfort every time I ran, then I would take the medication, no doubt!" Stan

flow or lung function. As no instructions were received concerning the prophylactic effect of inhalation corticosteroid (ICS), this important medication was not used regularly. The “invisible” therapeutic effects of this preventive medicine gave less motivation to take it: “I just want to know if it works. And since in 99.5% of the time I can’t tell the difference if I take the Pulmicort (ICS) or not, I don’t need such medication. If I woke up every night because of asthma or felt discomfort every time I ran, then I would take the medication, no doubt!” (Stan). In one case, the participant got the impression that the ICS is dangerous: “The doctors said that it was more risky actually taking medication with corticosteroids. I did not detect any difference after one month of taking Pulmicort, and as it is probably dangerous, I stopped” (Frankie).

In some cases, asthma diagnosis provoked a feeling of defeat and confusion rather than clarification: “I just remember the first time I was diagnosed with asthma. I got pretty sad (...) I thought I was a superwoman who could do everything; work, study, be a mother, etc.” (Lesley), “I felt lost in asthma” (Pamela), “It was horrible to be diagnosed with asthma and allergy to animals. I loved animals” (Sharon) and “I was a teenager. It was horrible that I couldn’t get enough air. My mother took me to the doctor (...) I just got Bricanyl (a Beta2-agonist inhaler) (...) I thought about it a lot for approx. 5 years...what’s the deal with that Bricanyl? I thought my asthma could get worse. But I believed that I could grow out of it. Today I don’t really think about it” (Ken).

These citations confirm the importance of sufficient information and care provided by the physicians at this stage, where the person experiences a shift from being healthy to sick. However, this transition was not successfully supported by health professionals and invoked a feeling of being “left to oneself”. The greater the difficulty in integrating information, the greater the danger of confusing outputs, conflicts of interests, differing interpretations of reality and navigating in the asthma condition: “When things make no sense and are not predictable, it is difficult to expect that needs will be fulfilled” [35, p. 126]. The lack of insight in asthma’s effects on daily life, treatment and prognosis provoked a feeling of chaos and frustration which in turn compromised the comprehensibility of asthma: “Comprehensibility refers to the extent to which one perceives the stimuli that confront one, deriving from the internal and external environments, as making cognitive sense, as information is ordered, consistent, structured, and clear, rather than as noise-chaotic, disordered, random, accidental, inexplicable” [25, p. 16].

Acknowledging the centrality of the patient allows her or him to take ownership of the disease.

When the encounter with a health professional is limited to one-way communication, the patient is deprived the chance to teach clinicians about the realities of living with chronic disease and about taking control of their illness in important and potent ways in order to get a more central role in their own health and achieve comprehensibility. However, in several cases, our informants took a more passive position: “The sick role legitimizes a greater measure of passivity that is generally acceptable in an active value context he is

required to accept, passively and submissively, instructions, medicines, and other forms of treatment administered by professional personnel or members of his family” [27]. They expected that their doctor would offer an examination if necessary: “I would have appreciated some follow-up to know my asthma status. But the doctors never offered that” (John). “I didn’t really receive information about my asthma or how to control it. I just call my doctor whenever I need to renew my inhalers. He never asks about my asthma” (Liona).

No attempt was made to initiate a dialogue with health professionals about own thoughts and concerns: “I had a doctor as a child, who was simply amazing in taking care of me, listening to my parents and my needs, and encouraging me (...) Afterwards I had worse doctors that did not believe that asthma was a problem. One doctor told me to run 10 km to overcome asthma like an elite patient he had, but there is a difference between a professional athlete with asthma and a 16-years old, slightly overweight girl! I walked away and was devastated because I felt something was wrong with me and that it was my fault that I had those extra kilos. I was a teenager and very easily influenced. I could not even run 500 meters, for god sakes!” (Linda), and “I think doctors should turn asthma into something positive. Instead of just saying ‘now you’ve got asthma and you have to avoid a lot of things’, then perhaps they should say: ‘we need to find out how you can manage your disease and enjoy your sport and the underlying possibilities’. If a teenager is asked to stop playing football or whatever, it’s awful! (...) I saw my asthma as a limitation. The doctors should have treated me sufficiently so I could be with animals, even just for a little bit, without endangering my health off course. But it’s also all about quality of life. Your world can fall apart when you are deprived the things you like the most” (Sharon).

Asthma manageability

As mentioned in the previous section, asthma comprehensibility was limited by lack of important elements like ordered, consistent, structured and clear information on asthma. This, we argue, opened up for individual interpretations and managements as Antonovsky states that complexity can lead to choice and adaptive changes leading to autopoiesis, an extraordinary capacity for system reorganization after experiencing chaos. Attitudes to life’s challenges seemed to play an important role. In several cases, the informants linked asthma management to the way they tackled any other problem in general (Box 2). Many stated that it was a matter of trying to live as normally as possible. Statements such as “You make your peace with it” and “You get to accept the fact that you have a disease and just go on” were consequently used: “I resigned myself to asthma. It’s something you just have to live with for the rest of your life. You must adapt to it and find out what you can do and what you cannot do” (Linda).

According to Antonovsky, realism and accept of stressor/failure is a way of dealing with it:

One may be fully aware that life involves failure and frustration. The important thing is that one has a sense of confidence, of faith, that by and large, things will work out well, not that things will have a Hollywood happy ending.

Box 2. Manageability and meaningfulness: coping mechanisms based on personal attitudes, self-management, and putting asthma into perspective.

- "I'm not good at being sick. First of all, I don't have a good understanding of disease and secondly, I get a bad conscience if I stay home from work (...) I could go to work with 39, 0°C. It is illegitimate to call in sick because of asthma. It's just silly, right? Once my colleague called in sick due to an allergy attack and I thought: how silly. Just get over it" Lesley
- "I am very independent in solving problems. I always figure something out (...) Many times I take things as they come (...) I don't like to take medicine on daily basis - I am too distracted to do so - unless I could detect a considerable improvement. My rescue medicine works just fine." Frankie
- "I took asthma diagnose easy. I didn't really know what asthma was. I was just happy that I did not have allergies to dogs (...) It is horrible to think of those who wear oxygen masks and can not breathe. It concerns me. When I get asthma attacks, I wonder how much my health is deteriorating. But then again, I haven't done anything to make it worse. I have not smoked much, just a little bit in my youth, and thus I have not destroyed something. But I often think of the passive smoking that I've been exposed to through my family..." Pamela
- "No, I am not bothered from my asthma. Not at all, not like a guy I knew who had asthma. It was much worse when he was gasping for breath, whatever this kind of asthma is. My asthma has never been that bad, not at all." Ken
- "I don't have concerns about the feature or the risk of having to wear oxygen masks. I've come to terms with my asthma. Off course asthma was stressful for me because it has limited me from doing what I wanted (...) Psychology played probably a roll because I mentally felt more limited. You just think you can not, even though you may be able to. However, asthma is not the worst thing you get compared with other chronic conditions. I actually think that I've gotten off easily." Linda
- "I was pretty upset when I got asthma diagnosis (...) I thought I was Superwoman, who could be a mother, a student and work a few hours (...). But I got on with my life (...) I have smoked until I was 18 and then I stopped because I coughed a lot. My uncle had a bad bronchitis and I didn't want to end up like him sitting with a breathing apparatus." Lesley
- "Asthma has not affected my quality of life. Life goes on. What's the use of crying? It's all about moving on. There is nothing to do about asthma. One must find a way to live as good as possible." Pamela
- "I resigned myself to asthma. It's something you have to live with for the rest of your life. You must adapt to it and find out what you can do and what you cannot do." Linda
- "I think my asthma is just a mild one ... compared to my brother in-law. His asthma is really bad, mine is just silly (...) Our neighbours died from COPD, I believe this disease is kind of 'super-asthma'." John
- "I was not bothered by my asthma. I used to be a nerd s a child and fat so I did not play football. I'd rather sit in front of the computer ... my anti-asthma medication worked just fine." John
- "I cough a lot during the winter and antihistamine pills helps. I adjust my asthma medication by increasing and decreasing the dose when ever it's necessary. Yes, I have heard of Peak Flow Meter (PEF) through others. My grandmother had COPD, and I've tried her PEF out of curiosity to see the differences between when I felt bad and when I got better (...) My doctor sees me for asthma control only once a year." Pamela
- "When ever I had a cold, I have cheated and taken a bit of my son's asthma medication." Sharon
- "Sometimes I just medicate myself. I always do. I just call my doctor and say that I need more Bricanyl and Pulmicort and I simply get it (...) Some times my sleep is disturbed, I wake up a lot, sometimes with chest tightness (...) No, I do not get regular checks or measure PEF. The doctor has not offered that." Lesley
- "I've been close to an asthma attack once when our car broke down (...) It was freezing and we had to push our car. I couldn't breath. I couldn't do anything. My tears dropped. I thought I was going to die. It was the worst I have ever experienced (...) I have heard of asthma attacks and horror stories (...) But I didn't know it could be so bad. I couldn't take medication. I focused on breathing and cooling myself down, then I could take Bricanyl quietly. After half an hour, I was back again. Yes I guess I panicked. I got respect for asthma (...) if you do not have that self-control and can keep yourself calm then you are on the death road." Linda
- "I could provoke asthma just by thinking about it." Frankie
- "When I am happy, I don't think much of my asthma, but when I am sad, my asthma symptoms bother me." Linda
- "I don't know what starts what. When I cannot breath, I panic and it gets worse (...) My father calls me to distract me. He knows that I feel safe when I talk to someone. If I get asthma attack during the night, my dogs are there and they poke me to ensure that I am ok (...) When I have a cold, I sleep in a sitting position (...). I am depressed sometimes (...) It affects me a lot when I can not breathe." Pamela
- "Psychology had probably an influence because I mentally felt more limited by asthma. You just think you can not, even though you may be able to." Linda
- "No I don't see any relation between my mood and asthma." Lesley
- "Not really, I don't think that asthma has anything to do with the psychological state", Ken and Stan
- "I don't need to go to asthma school. Others need it more. But I would like to know if asthma is hereditary because I have 3 kids." John
- "Asthma School is not an option for me, it is too radical. I have formed my own picture of my illness and if the teachers want me to make fundamental changes in my life, like going to bed at a certain hour or eat certain food then I would just think: "go to hell "Frankie
- "I don't think I need to go to asthma school (...) I'm not sick enough to do so and there are probably others who need it more. I have made my peace with asthma. Actually I think I have enough knowledge about it." Linda
- "I really don't think I need to talk to others about asthma. I had a friend at school that had asthma and we talked about it. When I needed to know more, I just asked my mother. I've come to terms with the fact that when there are symptoms I just take Bricanyl (...) I know what needs to be known about asthma and I'm not afraid of it. Due to my educational background, I find information when needed. My source of information is the doctor, pamphlets, my mother and own analyzes and experiences. I can not help but to experiment with things, cross limits, and build knowledge (...) it's certainly important for me to exercise, but I would never take asthma medication unless I get an attack." Stan

This is why the proviso "as can reasonably be expected" is added. A strong sense of coherence includes a solid capacity to judge reality. [35, p. 127]

The asthmatics experimented with what worked and what did not and developed individual ways to accomplish satisfactory management. Adjusting their own medication was a technique all of our responders used to adapt to symptom fluctuations and keep control of asthma. "Sometimes I just medicate myself. I always do. I just call

my doctor and say that I need more Bricanyl and Pulmicort and I simply get it" (Lesley). This system reorganization, we argue, had some disadvantages. According to the Danish Society of Respiratory Medicine, optimal asthma management would be based on establishing cooperation between the patient and the doctor, informing the patient properly about treatment principles, and offering regular follow-up to monitor severity grade and make treatment adjustment [36]. The physician plays thus a central role in the patient's coping. "The medical institution, with the physician as its central

figure, plays a major role in contributing to patient's effort to cope with failure" [27]. None of our interviewees recalled however that they were urged to follow these recommendations making manageability difficult. "Manageability is the extent to which one perceives that resources are at one's disposal which is adequate to meet the demands posed by the stimuli that bombard one" [25, p. 17]. At one's disposal refers to own control or to resources legitimately controlled by others, likes doctors.

Furthermore, the asthmatics adjusted their medicine according to their asthma attacks. Some of them stopped taking ICS because they did not detect a visible effect. They were not aware of the protective effect encouraging better prognosis. Our finding is not surprising. The difference in the pattern of medication use, particularly for prophylactic medication, is seen in other studies [22] and the lack of asthma control is found in almost 50 % of asthmatics [6,37].

The ability to stay calm and keep cool during an asthma attack was highlighted as an important tool in managing asthma. Panicking was considered as a self-inflicted lack of ability to master self-control. Few asthmatics, especially those with a tendency for anxiety symptoms, stated an association between the psychological state and the way they viewed their asthma symptoms: "When I am happy I don't think much about asthma but when I am sad my asthma symptoms bother me" (Linda). One informant felt that limitations induced by asthma were probably mostly in her head. She felt that having self-control was an important aid in controlling asthma symptoms. Another informant felt that her psychological state could worsen her asthma symptoms as she would react with panic. A third told that he could provoke an asthma attack by simple thinking about it.

Their effort to construct own asthma management was based on "learning the hard way" and they somehow became experts on their own disease. None of our interviewees had considered going to an asthma school, but for different reasons: They had already established their way of living with asthma and did not want new information that potentially could confront them with mistakes in their coping. They did not feel that their asthma was "bad" enough, and did not want to take a place for someone who really needed it. Finally and probably most importantly, they felt it was too late. Asthma knowledge was mainly extracted from the asthmatics' own experience that seemed to be crucial in managing asthma. The manageability and meaning they established became a solid part of their SOC. Once they had developed their own ways, it is difficult to change or challenge them. This suggests the importance of early asthma education and intervention. In a sense, they became their own doctor and their expertise was not negotiable. Their SOC was completed.

Meaningfulness

Analyzing our informants' asthma perspective, we detected a pattern in the meaning our asthmatics attributed to their condition. They typically compared asthma with what could have been worse, e.g. chronic back pain or severe asthma types (Box 2): "Asthma is not the worst thing to get... I actually think I've gotten off easily" (Linda), "No, I am not bothered by my asthma. Not at all, not like a guy I knew who had asthma.

It was much worse when he was gasping for breath, whatever kind of asthma this is. My asthma has never been that bad, not at all." (Kenneth) and "No, asthma does not influence my quality of life. What's the use of crying?" (Pamela).

These citations reflect an attempt to un-dramatize and regain a feeling of being normal instead of being a failure or a victim: "To the extent that one has a high sense of manageability, one will not feel victimized by events or feel that life treats one unfairly. Untoward things do happen in life, but when they do occur, one will be able to cope and not grieve endlessly" [25, p. 18].

Interestingly, there was no consensus on asthma definition as the participants received different names for asthma: allergy-related asthma, overwork-asthma, bronchial asthma etc. Consequently, breaking down asthma into different kinds influenced their understanding of asthma regarding aetiology and severity grade: "My asthma was not real asthma in the sense that it was overwork asthma. Not like a guy from my class who had to gasp for breath whatever that kind of asthma is" (Ken).

However, during the interview process, concerns about possible functional deterioration and how much asthma was bothering them became more prominent: "I sometimes had heavy attacks when I could not breathe and just gasped for breath, it could get so ugly! (...)" (Ken).

The relativistic view of asthma's impact on everyday life might have lead to uncritical accept of bothersome symptoms and made it less urgent to seek professional advice or make important changes, e.g. at work to avoid exposure to irritating agents. In most cases, asthma started at an earlier stage, which probably triggered a gradual and unnoticeable adaptation making it more complex for asthmatics to estimate severity. In fact, their estimation of asthma severity was not necessarily based on symptom intensity, but to what extent they were inhibited by the symptoms. The asthmatic's perception of symptom severity was actually quite different from what we estimated as moderate to severe asthma based on Pekannen's criteria. They felt that their asthma was not that bad. Any limitations that asthma may have imposed were not seen as contributing to a deterioration of daily living making it unnecessary to seek medical help and remaining in a "habitual" status: "A radical change in one's structural situation – in marital status, occupation, place of residence – can lead to a significant modification in one's sense of coherence. But in addition one's sense of coherence, strong or weak, plays a significant role in determining one's choice of remaining in or changing one's structural situation (...) One tends to choose situations that reinforce the level of one's sense of coherence" [35, p. 125].

Achieving a feeling of normality gave them a sense of control: "Meaningfulness refers to the importance of being involved 'as a participant in the processes shaping one's destiny as well as one's daily experience'" [25, p. 18].

Sense of coherence

In summary, SOC was established individually, resulting indifferent asthma coping patterns. The concepts of comprehensibility, manageability and meaningfulness are interrelated in building a sense of coherence. "High manageability is

strongly contingent on high comprehensibility. A requirement for the sense that resources are available to one to meet demands is that one has a clear picture of what those demands are. Living in a world one thinks is chaotic and unpredictable makes it most difficult to think that one can manage well" [25, p. 20]. Our informants adjusted for lower comprehensibility by experimenting with what worked (manageability) and creating their own relative meaning (meaningfulness). Successful coping depends on the SOC as a whole: "The motivational component of meaningfulness seems most crucial. Without it, being high on comprehensibility or manageability is likely to be temporary" [25, p. 22].

Impact of asthma classification on comprehension and management

Many had problems explaining their asthma to family and friends and avoided 'flashing' asthma to their colleagues and

employer unless their symptoms reached an unbearable level. They had concerns about being stigmatised as "less good" (Box 3): "No I would not just talk about my asthma with others, you become a diagnose, you know (...) I don't want them to think I am a pussy" (Frankie). In some cases, they experienced an altered self-image: "I thought I was superwoman", said Lis, who was disappointed by getting the asthma diagnose.

Avoidance was a recurrent health-related behaviour/phenomenon. Dropping activities that might provoke asthma instead of seeking proper treatment occurred in several cases: "I usually do not take a walk with others because I don't want to slow them down. I feel physical discomfort when I don't have control over my breathing especially when I walk with groups. I like to walk alone" (Pamela).

Asthmatics considered their disease as their own responsibility and did not expect others to be considerate, e.g. by not

Box 3. Classification as asthmatic in conjunction with colleagues and network.

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- "I would hide asthma from my employer. You just don't talk about this stuff. It could have affected my work, especially when I have dyslexia – I would probably not be considered for any job. I don't imagine that colleagues and employers would be that understanding. I used to "secretly" mix glue before I went home from work the day before it should be used in the machine so the irritation from it would be less when I came to work the next day." Pamela
- "I work with welding and I know it is not healthy. I turn the extraction machine on in the morning even though it makes noises and irritates my colleagues. It's my lungs and I have to be careful. But my colleagues don't care and weld nearby without turning their extraction machine on. I couldn't ask them to show respect because they think it is silly. My boss is no better so I can't tell him. (...) But I love my job and I don't want to lose it." Liona
- "I would be open at my workplace about my asthma (...) I don't think that if you have asthma that affects your work activity that your colleagues would be so tolerant on the longer run because then they have to work even more. But if it is just intermittent, I think that they will understand." Sharon
- "When my asthma reached an unbearable level, I talked to my boss and told him that I needed to wear a mask at the piggery." Ken
- "My asthma is unnoticeable and I don't need to tell my colleagues about it. I could imagine that e.g. a carpenter with asthma would not to speak openly about asthma as it is expected from him to be in top physical form." John
- "Some times when my class should do cross-training, with much running and interval training I leave this task to the other teachers. There are usually two or three teachers since we have two or three classes at the same time. I say to them that I'm not in shape for exercising. I don't say that it is because of asthma. I usually make fun of it and say that it's probably me how is going to lie on the floor before the kids." Linda
- "My work has absolutely minimal physical activity. I suppose that I couldn't work with e.g. insulation or dusty places because I have a good deal of allergy (...) No, my colleagues do not know that I have asthma. I have not had the need to tell it (...) There are many who have asthma. It is not a taboo unless you see it as a weakness to have asthma." Stan
- "I have found out that there are different types of asthma. However, people often think that asthma has something to do with animals. They don't understand that I have the three dogs. I have an explanation problem (...) they think I'm just a little hysterical (...) I sometimes doubt myself and think I am probably hysterical" Pamela
- "I could be among people who smoke. I would not bitch about it. I couldn't dream of asking people to stop smoking because of my asthma. I would rather just go away if it bothers me so much." Frankie
- "No, I would not just talk about my asthma with others ... you become a "diagnose", you know (...) I don't want them to think I am a pussy." Frankie
- "Today we have smoking bans and it is so great. My husband used to smoke at home, but when we got kids, he smoked outside (...) I can complain about others smoking but would not ask them to stop." Sharon
- "It can be a little hard to explain to people who have cats and rush to take the cats outside when I come, that the allergens still sit in the furniture and carpets and all places." Sharon
- "Asthma has definitely been a limitation for me. I have not had the same opportunities for development as my classmates. Children's are good at adapting but if you don't play with them because of an asthma attack, they would not ask you again (...) There is a lack of information to the general population, about what asthma". Linda
- "Actually it was not mentally difficult in childhood. Teenagers are more aware of errors and they would think that my asthma is nothing compared to their problems (...) I think many people who do not have asthma may judge you as being in less good shape. It is important today to be in a good shape and almost go to Zumba 30 times a week." Linda
- "When I got asthma diagnose, my parents began to book seats on the plane in the non-smoking area (...) When I got asthma, my mother had apologized that she has smoked near me, but my father still doesn't really understand asthma or take it seriously." Pamela
- "I stopped working at the horticulture because I was allergic and had a rash. I thought to myself that the breathing problems might osculate if I continued working and I might end up being allergic to even a little plant in my apartment." Anna
- "I usually do not take a walk with others because I don't want to slow them down. I feel physical discomfort when I don't have control over my breathing especially when I walk with groups. I like to walk alone." Pamela
- "It is mostly "safe" for me to have asthma symptoms when I am with my family. They don't give me a bad feeling about my asthma. I have felt comfortable doing stuff with them. Once, I was at a family birthday and we were physically active. I didn't feel exposed when I got asthma attack. If you are with strangers it is embarrassing to take medication in front of them. They might think: "what is she doing?!" Asthma has been a problem for me when I was with people I am not acquainted with ... when running after the bus and had to stand in a crowded bus with my inhaler shaking - so embarrassing! I do not take my medication in unknown territory (...) I think it's embarrassing. No, it is not because I think it is a sign of weakness. A friend of mine with asthma would not care and take her inhaler in front of others, as if she wanted attention. I couldn't really understand her (...) Yes, maybe it was good that my classmate was open about her asthma (...) when you are a teen, there is the fear of being different. She did not care and took her inhaler in front of everybody. It is good for people to see it, know what it, hear it and get it demystified." Linda
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smoking when close by or asking for help when physical function was limited by asthma: “I do not think that if you have asthma, that affects your work activity, that your colleagues would be so tolerant in the long run because then they have to work even more. But if it is just intermittent, I think that they will understand” (Sharon).

Taking asthma medication was mostly seen as a private matter that should be done in a safe territory. However, some stated that transparency regarding asthma would demystify the disease and create openness. Others wished that the general population was more knowledgeable about asthma. However, they did not actively take part in spreading knowledge because they often felt they had problems explaining asthma: “People often think that asthma is caused by animals. I have found out that there are different types of asthma (...) It is difficult to explain to others that I have asthma and dogs at my house at the same time” (Pamela).

Other avoidance incidents happened at work. Three subjects told how they had experienced worsening of asthma symptoms due to occupational exposure like dust, welding smoke and glue fume. They chose to accept it and not complain to their employer: “I don’t imagine that colleagues and employers would be that understanding. I used to ‘secretly’ mix glue before I went home from work the day before it should be used in the machine so the irritation from it would be less when I came to work the next day” (Pamela).

It was surprising, that the majority of our informants stated that “asthma is not something you talk about”. They considered their condition a private matter and did not want to bother others with it. According to Ian Hacking, being labelled as sick can change self-understanding and self-worth. Our informants maintained their self-image by avoiding bringing their asthma ‘out in the open.’ One of the informants began to question herself for exaggerating her symptoms when people in her network called her hysterical. This is a kind of looping effect. Hacking stated that being classified imposes reactions that change our view of ourselves: “Classifying people changes them, and can even change their past (...) Hence ‘we’, the experts, are forced to rethink our classifications (...) To create new ways of classifying people is also to change how we can think of ourselves, to change our sense of self-worth, even how we remember our own past. This in turn generates a looping effect” [29].

We would like to elaborate further on the classification of having asthma as a social construction. Asthma is normally defined by a series of symptoms and tests and intervention is often presented as a unilateral biologized concept. However, the way people react to asthma, adds more insight into how we understand asthma implications. Presenting asthma as a health problem, within a limited framework, should therefore be expanded to include the meaning that the asthmatics add, diversifying our knowledge on this important health problem. Having asthma symptoms and being labelled with a medical confirmed, makes the person adopt certain stereotypical patterns of behaviour, as we have shown: relativism, self-medication, altered self-image and avoidance behaviour. Awareness of these mechanisms helps us understand how asthma imposes changes in everyday life. This in turn expands

our view of asthma with a looping effect that promotes an acceptance of asthma as a psychosocial biogenetic disease.

Advantages and disadvantages of qualitative methods

This qualitative research has complemented the quantitative study adding more insight into areas that are important for dealing with asthma from the patient’s perspective and suggested some explanations to why objective and subjective measures differ. Results from the first part of our study [30] showed that asthma severity and psychological states as well as gender influenced HRQOL.

However, none of the interviewees linked asthma to worse QOL, even those who experienced severe episodes of shortness of breath, night waking and function limitations. First of all, they perceived asthma as something one must live with and not complain about. Second, the informants had their own understanding of what is important for their QOL, like being limited in their work activity or having to avoid animal contact due to allergy. This emphasises that any attempt at operationalization of the concept of quality of life is confronted by the problem of conceptual differentiation between objective and subjective outcomes.

Asthma severity, defined by the questionnaires, was not completely in accordance with how asthmatics viewed their symptoms as we showed earlier. The term “dyspnoea”, as used by physicians and scientists, subsumes a number of distinguishable uncomfortable respiratory sensations experienced by patients. The patient’s experiences during an asthma attack vary, e.g. “chest tightness” or “increased effort” or “inability to take a deep enough breath”. The relationship between stimulus and perception may differ widely within and among patients [38]. According to the informant’s statements, the sensation of breathing problems was most clear when they had an asthma attack. Mild shortness of breath was not interpreted as an asthma symptom and was often explained by being in a bad condition. Thus, focusing on objective criteria for asthma severity can be misleading as the patient’s own comprehension and sensation of symptom intensity should also be addressed as it deepens our understanding of troublesome symptoms.

Furthermore, we assumed that the reason for gender differences regarding QOL was probably due to the nature of the 15D questions. Men did not report many complaints at the beginning of the interview compared to their female counterparts. However, as the dialogue continued, it was obvious how many concerns and thoughts men had. This process does not exist in questionnaires. Another aspect that the quantitative questionnaires did not fully capture was asthma debut. Most of the informants recalled an earlier asthma debut which was different from their answers in the screening questionnaire. As for the psychological state, some of the informants stated that negative mood influenced their view of asthma and energy level in a negative direction, but it was not possible for them to elaborate further on the psychological mechanisms behind. Other informants did not detect any relationship between their mood and the experience of asthma symptoms.

It is reasonable to conclude that the quantitative paradigm, dominant in biomedical research, using methods adopted

from the physical sciences, epidemiology and statistics should not stand alone. Qualitative research gives insights, discoveries, identification, descriptions and explanations that are important to get a holistic understanding of the impact of scientifically generated facts. In many circumstances, the use of both approaches is necessary and complimentary [39].

One of the limitations of this study is the small sample size which limits generalisability. This, however, was not our aim. We did not seek systematic, general and accurate knowledge but rather to discover behaviour patterns, tendencies, make descriptive statements based on individual narratives and give an interpretive inspiration for causality. Different asthmatics have different ways of coping. This is the strength of our study, to be able to formulate different truths about asthmatics, their actions and their sentiments adding more knowledge about how health professionals can reach out to these patients. Another limitation of the small sample size is the risk of missing on asthmatics that might have successful stories about asthma and their encounter with health professional, expanding our analysis to include examples of positive coping mechanisms.

Conclusion

The aim of this qualitative study was to achieve insight into the asthmatics' world in an attempt to understand their perspective on asthma and coping. Asthma comprehensibility was limited by the lack of structured and clear information about asthma diagnosis, treatment and prognosis and lack of follow-up. Consequently, asthma diagnosis provoked a feeling of chaos and frustration. Many felt that they were left to themselves. The informants experimented with what worked and developed individual ways to accomplish satisfactory management. They adjusted their medication and sometimes ceased taking prophylactic medicine as they did not detect a visible effect. Minimal dialogue with health professionals opened up for individual interpretations. Many informants had a relative view of asthma, comparing it to what could have been worse, a way of achieving meaningfulness and regaining a feeling of normality. The unnoticeable development of asthma had probably triggered a gradual adaptation making it more complex for asthmatics to estimate severity. This together with their relative view of asthma might have led to gradual and uncritical acceptance of bothersome symptoms and made it less urgent to seek professional advice or make important changes, e.g. at work to avoid exposure to irritating agents. Avoidance was a recurrent phenomenon as persons with asthma tended to drop physical activities with others instead of enduring better treatment. Several stated that they did not like to flash their asthma. They had concerns about being labelled as "less good". This qualitative study has to some extent unravelled the pattern of asthmatics' coping and sense of coherence adding more insight into how everyday life is influenced by asthma. Health professionals are urged to be aware of the challenges that asthmatics meet in everyday life and engage in a dialogue including (1) assessing asthma debut. It is important to spend time on the history of symptoms, partly to get information about a precise asthma debut and to uncover some of the adaptation mechanisms that might already have started and

address them as they can be difficult to change; (2) Asking the patients about how they cope with their symptoms and what their routines are in order to make adjustments. It is crucial to reach a contract on optimal self-management that meet their needs and at the same time follows recommended guidelines; (3) Sufficient testing and follow up as the patients expect that the doctors offer check up and they only seek professional help when their symptoms reach unbearable level; (4) Talking about how the family supports the asthmatic and how the latter interacts with their network in order to address avoidance behaviour; (5) Discuss working conditions and exposure for irritants. Asthma patients are vulnerable at work and they often chose to avoid confrontation about their asthma; (6) Addressing factors that influence HRQOL, like psychological state, lifestyle and gender. Hopefully these recommendations will help achieve optimal treatment, compliance and quality of life.

Declaration of interest

The authors do not have any financial, consulting or personal relationships with people or organizations that could influence this work.

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