

## Coding tree

### (The meaning of living with severe chronic obstructive lung disease: a qualitative study)

| Main Categories   | Codes  |  |
|---|--|--|
| Stigma COPD   | CC: Acknowledging personal responsibility for illness  |  |
|   | C: Visibility of disease (oxygen device)   |  |
|   | AS: Look for causes of COPD  |  |
|   | CQ: Open handling of disease   | Fighting against the disease   |
|   | CQ: Confronting oneself and others with disease  | Consciousness of being ill<br>Consciousness of being at the end of life<br>Acceptance of the disease |
|   | CQ: Denying responsibility   |  |
| Increased social isolation                                    | CC: Restriction of mobility  |  |
|   | CC: Physical complaints / limitations  | Headaches<br>Breathlessness<br>Speaking is strenuous   |
|   | C: Being dependent on support  |  |
|   | AS: Outbreak of social isolation   | Contact with self-help group   |
|   | CQ: Need for attention   |  |
| Insidious decline conveys only a gradual feeling of being ill | CC: Routine during crises gives the feeling of general routine                                   | Treatment outside the crisis routine   |
|   | CC: Progressive course   |  |
|   | CQ: Lack of feeling ill  |  |
|   | C: Fear of what might come   |  |
|   | C: Social integration  |  |
|   | AS: Slow implementation of care  |  |
|   | AS: Using one's own initiative in influencing the disease?                                       | Change of lifestyle<br>Own initiative in medical care  |
|   | AS: Delaying medical interventions   |  |
| CQ: Hardly any confrontation with one's own mortality         | Depressive attitude / resignation  |  |
| Disease as a factor that determines everyday life (Dominance) | CC: Physical complaints / limitations  |  |
|   | C: Being dependent on support  |  |
|   | AS: Social withdrawal  |  |
|   | CQ: Monotony   |  |
| Uncertain feeling of being ill                                | CC: What does COPD mean) (finding the right treatment)   | "and at that time, nobody knew what COPD was"  |
|   | CC: Perception of physical signals and ability   |  |
|   | C: Convalescence   |  |
|   | AS: "There's nothing else wrong with me" (healthy interpretation of one's own disease situation) |  |
|   | CQ: Trivialisation   |  |
|   | CQ: Trusting (having to trust) conventional medicine   |  |

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| Trusting (having to trust) conventional medicine | CC: Hope of a cure / optimism for an improvement to the general condition                              |  |
|  | C: Convalescence / positive experience of care   |  |
|  | C: Knowledge about the disease / treatment (also one's own disease experiences)                        |  |
|  | C: Setbacks in treatment   |  |
|  | C: Perceived errors in medical care  | Communication not patient-appropriate<br>Negative experience with professional care<br>Dissatisfaction with the clinical care  |
|  | AS: Decision to avail of conventional medical competencies   | Coordination of medical aids and processes   |
|  | CQ: Treatment problems create fear   |  |
|  | CQ: Stability of the general condition enables one to avoid confronting the seriousness of the illness |  |
| Maintenance of normality                         | CC: Need for independence  | Freedom of movement in home environment  |
|  | C: Control of symptoms   | Own ability to influence the illness   |
|  | AS: Exhausting physical limits   |  |
|  | CQ: Optimism / hope (of a cure)  |  |
|  | CQ: Trivialisation   | ... as a strategy<br>... of the severity of the illness<br>... of the symptoms<br>... of the symptoms by relatives   |
|  | CQ: Emotional separation   |  |
|  | CQ: Optimism / hope of a cure and an improvement to the general condition                              | Active hope<br>Passive hope<br>Hope of a cure with conventional medicine   |
| Being dependent on support                       | CC: The body can no longer manage  | Powerlessness<br>Omnipresence of the disease<br>Frequent rests required during the course of the day   |
|  | C: Limitation due to (medicinal) side effects and symptoms   | Environmental factors / air conditions influence the symptoms<br>Physical reserves of energy decline<br>Speaking is strenuous<br>Constipation<br>Nocturnal restlessness<br>Breathlessness<br>Headaches |
|  | AS: Restructuring of everyday life (redistribution of tasks)   | Change in social roles<br>Responsibility of the families   |
|  | CQ: Dependency on personal (carer) and technical support (technical aids)                              | Medical home visits are necessary  |
|  | CQ: Functional and social dependency   | Support with<br>... meals<br>... daily motivation<br>... personal hygiene<br>Underlying family conflicts   |
|  | CQ: Increase in social isolation   |  |