Stories of Care

Navigating mental illness together

Description of the coding system of the

Map of Problems

developed for the Erasmus+ project
“Transforming the case stories of families affected by mental illness into learning and awareness raising tools”

Preliminary remarks

This document was developed during the process of identifying problems in the sixty stories produced in the project on the experiences of family members of a person diagnosed with schizophrenia. It was continuously revised as new stories came in and contains the final version of the structure of the map and the definitions of topics identified in the stories.

Since quite a few topics were of a positive character, the term “topics” was used instead of the term “problems” which was used in the submission.

To increase usability and understandability the somewhat theoretical terms “dimensions” and “multi-axial classification” used in the submission are not used here. These terms were used to mean that a specific issue recounted in a story can be characterized as belonging to several “dimensions”, which we call here “Topic groups”. We have identified 26 such “Topic groups”. Each of these has several topics (represented by codes) for addressing specific issues belonging to the specific “Topic group” (altogether 168 such codes). “Multi-axial classification” simply means that these topics (codes) are not mutually exclusive and that a specific issue described in the story can be characterized as addressing several topics and thus receiving several codes. In the text below “topic” and “code” are used interchangeably.

In an annexe to this document the complete structured coding system as such (without definitions) is included.

Abbreviations

FAM ..... A family member who is the main carer of a PAT and the author of a story (also used as plural)
PAT …… A person who was diagnosed with schizophrenia (also used as plural)
SPT…….Specific topics
nsp/oth…Not specified/Other (if related to topics/codes within a topic group)

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Introduction

What is schizophrenia?

Schizophrenia is a mental disorder which usually starts in late adolescence or early adulthood, when the young person is still living in his/her family of origin and starts to become autonomous by building relationships outside the family, starting a job or training for a job and moving out of the family home. When schizophrenia begins this process of becoming autonomous is stymied and the family, usually parents and siblings, are overwhelmed by the problems generated by disease symptoms, the reaction of the closer and wider social network, the information deficit and other problems which are reported in the stories contained in the book of stories. To start with, it is useful to say what schizophrenia is *not*, since many prejudices surround the disease. This is a practical way of also saying what it is.

First, schizophrenia has nothing to do with a split personality, as the word might suggest. The term was coined at the beginning of the twentieth century, when it was a common habit in medicine to use disease terms derived from ancient Greek, with “phren” meaning “mind”, and “schizo” meaning that something which is a harmonious total, is getting loose and not interconnected within in itself. “Being split into two parts” is a layman’s interpretation of the term “schizo”, but not relevant here. Here the incoherence and the loosening of the thread of thoughts, the incongruences between thinking and affect, i.e., a general loosening of the coherence of psychological functioning is, what is meant by “schizophrenia”. Withdrawal from social contacts often occurs, and appears as passivity and laziness, but can be regarded as a kind of coping with the experienced incoherence of psychological processes - which can be often provoked by environmental stress from which the affected person attempts to shield himself/herself by withdrawal (“vulnerability-stress-coping model”).

Second, the meaning of schizophrenia is often reduced to a loss of reality in terms of “hallucinations” and “delusional ideas”, which is also wrong. It is true these symptoms can occur in schizophrenia, and they appear quite often in the book of stories, but according to modern theories they could be assumed as not being at the core of the disease but could be interpreted as “secondary symptoms” following the incoherence in psychological functioning described above, helping the affected person to cope with the uncertainty, by providing some kind of “order” in a delusional idea (albeit often creating fear when delusions of persecution dominate). Also, it has to be stressed here, that hallucinations and delusions (or “psychotic symptoms” as these are called in clinical practice), can occur in many other types of mental disorders, e.g. in organic brain diseases such as dementia, in alcohol delirium, or in mania (delusion of grandeur).

Third, when someone hears “schizophrenia” the idea of a fateful chronic unremitting disease comes to mind. However, many long-term studies show that approximately one third of young people diagnosed with schizophrenia get completely healthy again, and that only one third (or less) have an unremitting chronic course and that the group in between has an episodic course, with a more favourable pattern if medication and psychosocial treatments are well provided and accepted.

The wrong ideas of a “split personality”, of “hallucinations and delusions” being at the core of the disease and the concept of a chronic unremitting course (being equivalent to a kind of “psychological death”) are the source for many problems of stigma and discrimination patients and their family members experience, once the outside world knows of the diagnosis. “Split personality”, hallucinations and delusions are by the general public related to assumed dangerousness, and the idea of chronicity leads to hopelessness and despair.

The collection of stories and its purpose

The aim of the project was to produce a collection of stories from the perspective of family members (FAM) caring for a person in the family diagnosed with schizophrenia (PAT). The stories describe experiences of FAM in dealing with the difficult situation of caring for a PAT, but show also ways of how FAM have coped with the many issues involved in this endeavour. All stories reflect first person experiences.

The purpose of the map of topics

To make the collection of stories easily accessible a coding system has been developed which assists the reader of the collection of stories in identifying stories dealing with specific issues the FAM is interested in. This coding system was originally called “map of problems”, since it helps the reader to find his/her way around in the collection of stories. It was developed during the analyses of the stories by using a qualitative data analysis tool with which specific segments of the stories were coded and received its final structure while more and more stories were coming in for analysis. Since it turned out that not only problems, but also positive issues were contained in the stories the “Map of problems” was renamed into “Map of topics” and is abbreviated as MAP. The MAP will be contained in the final online version of the collection of stories with topic groups and topics linked to stories dealing with specific issues. It has to be kept in mind that all stories are from the perspective of the FAM.

Overview of the topics used in the MAP

The MAP has 168 topics, characterised by specific codes, which are grouped into 26 topic groups, with different numbers of topics for different topic groups. The topics are not mutually exclusive, i.e. specific segments of text tagged in the stories can be characterized by more than one topic. The 26 topic groups are themselves grouped into three clusters, the first relating to behaviour of the PAT (11 topic groups), the second to experiences of the FAM (6 topic groups), the third to specific (other) topics (9 topic groups) (Tables 1 and 2).

The process of developing the coding system

The coding system was empirically developed implying that some adaptations were necessary in relation to a few assumptions in the submission. It was developed in three steps:

Step 1: Specific topics which are relevant for family members of persons diagnosed with schizophrenia were extracted from various sources, including specific literature and the existing documentation of family groups over the last 30 years in the School for Living with Schizophrenia in Vienna. A preliminary coding structure was developed with 30 dimensions and 121 specific codes allocated to these dimensions. For the purpose of easier communication, the dimensions were called “main topics”.

Step 2: The first 24 stories received from HPE and AT were successively coded with the coding structure developed in step 1. Based on the experiences of the pilot study the coding structure was adapted – the 30 main topics were reduced to 26 and the 121 codes were extended to 191. The adaptation included a) collapsing main topics and codes, b) adding new codes and c) renaming main topics and codes.

Step 3: In the process of coding all 60 stories with the system developed in step 2 a refinement of the coding system was performed, including rewording of codes and omission of codes that were not used in

a single story. In addition, almost all specific codes that were only used once were merged with the code ‘unspecified/other’ in the respective main topic.

Table 1: General outline of the coding system

Cluster	Number of topic groups	Number of topics
A Behaviour of PAT	11	54
B Experiences of FAM	6	45
C Specific topics (SPT)	9	69
Total	**26**	**168**

Table 2: The 26 topic groups and numbers of topics in each group.

Clusters	Names of topic groups	Number of topics
Cluster A: PAT 11 Topic groups, 54 topics	PAT_1 Psychotic symptoms	6
	PAT_2 Disorganised/Incoherent behaviour	3
	PAT_3 Inactivity/Blunting	4
	PAT_4 Other psychopathological symptoms	6
	PAT_5 Strange behaviour (not aggressive)	6
	PAT_6 Aggressive behaviour	5
	PAT_7 Self-harm	5
	PAT_8 Blaming others (not delusional)	3
	PAT_9 Insight into illness/Compliance with therapy	5
	PAT_10 Being stressed by external factors	3
	PAT_11 Disease course	8
Cluster B: FAM 6 Topic groups, 45 Topics	FAM_12 Distress	12
	FAM_13 Care dilemma: more or less care/control vs. more or less freedom	8
	FAM_14 Other challenges	8
	FAM_15 Appraisal of others	7
	FAM_16 Positive attitudes	7
	FAM_17 PAT moves out of home of FAM/back to home of FAM	3
Cluster C: SPT 9 Topic groups, 69 Topics	SPT_18 Relationships within the family of PAT/FAM	10
	SPT_19 Employment, Education, Finances of PAT/FAM	5
	SPT_20 Physical health of PAT/FAM	9
	SPT_21 Services and Professionals	12
	SPT_22 Therapy-related issues	6
	SPT_23 Causal assumptions/theories	7
	SPT_24 Information deficits	4
	SPT_25 Stigma, Discrimination, Wider social network, Public realm	9
	SPT_26 Legal issues and police involvement	7
Total number of topics		**168**

The classification provided here, is only one of many possibilities how the topics addressed in the family stories can be ordered and arranged. It is a pragmatic classification which can help the reader of the collection of stories to orient himself/herself to find stories, which deal with specific topics and might be of interest to him/her.

Description of Topics (11 PAT, 6 FAM, 9 SPT)

It is recommended to get familiar with the complete description of each topic group and its topics, because it is important to understand the relationship between the topics in their contexts.

All topics are numbered using a hierarchical numbering system with the first and the second digits representing the 26 topic groups (from 1 to 26), and the digits after the period a running number for each topic (e.g., 18.1 Conflict within family). One reason for numbering the topics is that they can thus be easily identified when translating the coding system into German and Romanian.

The first topic of each of the 26 topics groups has the running number .0 and is used when it is clear that a text segment of a story belongs to a topic group, but the description is too general (= not specified) or the issue described is not represented by a specific topic ("other"). For instance, if for the topic group "PAT_1 Psychotic symptoms" the story only says that psychotic symptoms were present without specifying what they are, the topic "PAT_1.0 nsp/oth 'Psychotic symptoms'" should be used, because "not specified" is included in this topic; in this case no comment is necessary. If, however, a specific psychotic symptom, which is not contained in the specific psychotic symptoms 1.1 to 1.5, is mentioned in the story, the topic "PAT_1.0 nsp/oth 'Psychotic symptoms'" should be used and a comment about the specific psychotic symptom is to be added. In the case of "PAT_1 Psychotic symptoms" this could be the psychopathological phenomenon of "thought insertion".

It has to be repeated here that the topics are not mutually exclusive, in other words, a specific text in a story could receive more than one code (topic).

CLUSTER A: PAT – Behaviour/symptoms of patient and disease course (11 topic groups; PAT_1 to PAT_11)

11 topic groups cover behaviours of the patient (the PAT), including what psychiatrists call psychopathological symptoms, as described by the family member who tells the story (FAM). For easier orientation they are all preceded by "PAT" (which is followed by a bullet point number running from 1 to 26, enumerating all 26 topic groups). These 11 PAT topic groups can be grouped as follows:

- 4 Psychopathological symptoms (PAT_1 to PAT_4)
- 4 Behaviours of the PAT in terms of actions taken (PAT_5 to PAT_8)
- 1 Insight and compliance with therapy (PAT_9)
- 1 Being stressed by external factors (PAT_10)
- 1 Development of the disease (PAT_11)

PAT_1 Psychotic symptoms (6 topics)

1.0 nsp/oth “Psychotic symptoms”
1.1 Hallucinations
1.2 Delusion of persecution FAM included
1.3 Delusion of persecution FAM not included
1.4 nsp Delusion of persecution
1.5 Non-persecution delusion

The term “psychosis” is not clearly defined in psychiatry. Pragmatically it can be regarded as describing a syndrome where “reality is misjudged” because of psychotic symptoms, which are mostly defined as hallucinations or delusions. (It has to be noted that these symptoms may also occur in organic brain disorders.) Hallucinations are “sensory perceptions” without a substrate in the physical reality and can concern all five main sensory qualities (hearing, seeing, tasting, smelling, touching) which connect us to the outside world. Hearing voices is the most typical hallucination in schizophrenia. Sometimes voices are talking about the patient, sometimes they can be of an imperative character, i.e., telling the PAT to perform certain actions. Delusions are “wrong ideas” about reality which are maintained despite evidence to the contrary. The content of delusions can have different topics (persecution, jealousy, grandeur, etc.). For schizophrenia delusions of persecution are typical. Sometimes PATs assume they are (also) persecuted by their own family members, which is an especially complicated issue for the family members (Topic “Delusion of persecution FAM included”. If it is clear that the family members are not regarded by the PAT as being involved in persecution, the topic is “Delusion of persecution FAM not included”). If the story does not allow this distinction and speaks only of delusions of persecution in general this is coded with “nsp Delusion of persecution”. If delusion ideas are mentioned but the content is not “persecution” the topic is “Non-persecution delusion”. Finally, it has to be mentioned that psychotic symptoms *may* occur in schizophrenia, but on their own they are not sufficient for making this diagnosis. Psychotic symptoms can also occur in organic brain disorders (such as dementia, alcohol delirium). In psychiatric texts the terms “positive symptoms” or “plus symptoms” are used as (approximate) synonyms for psychotic symptoms, since they can be regarded as existing “in addition” to normal psychological functioning – in contrast to “negative” or “minus” symptoms (see below PAT_3 Inactivity/Blunting).

PAT_2 Disorganised/Incoherent behaviour (3 topics)

2.0 nsp/oth „Disorganised/Incoherent behaviour“
2.1 Incoherent speech/Confused thoughts
2.2 Inability to organise daily life

In several stories the behaviour of the PAT, including what he/she says is characterised as “disorganised” or “incoherent”. Some psychiatric schools of thought regard “cognitive symptoms” (without an organic brain disorder) as typical for schizophrenia, manifesting themselves, for instance, as incoherence of speech. In the stories family members occasionally use the term “confused thought” or similar. The topic “Incoherent speech/Confused thoughts" should be used for characterising this phenomenon. Such “confusion” may also lead a PAT to their “Inability to organise daily life”. This “symptom” is placed here out of convenience, although its causes (in addition to thought disorder) can be manifold (see, e.g., PAT_3 Inactivity/Blunting).

PAT_3 Inactivity/Blunting (4 topics)

3.0 nsp/oth „Inactivity/Blunting““

3.1 Withdrawal

3.2 Neglect of personal hygiene

3.3 Neglect of household chores

It is not infrequent that PATs become inactive, often manifesting itself in "Withdrawal", such as staying in bed the whole day. Inactivity may manifest itself specifically in "Neglect of personal hygiene" and "Neglect of household chores". In psychiatric terminology these behaviours are also called "negative symptoms" or "minus symptoms", since something which is normally present in people (activity) is missing. Another interpretation of inactivity is that PATs, who experience psychotic symptoms and confusion or are oversensitive to noises/to too many people, use withdrawal as a self-protective mechanism. (They have to keep a difficult balance between "overstimulation" and "understimulation"). Inactivity of the PAT is especially challenging for family members since its interpretation is extremely difficult - is the PAT not able to be active or could he be active and does not want to? Formulated in a catchphrase the question is whether the PAT is "bad" (= unwilling) or "mad" (= sick). This challenging situation for the FAM is defined in FAM_13 Dilemma challenges below.

PAT_4 Other psychopathological symptoms (6 topics)

4.0 nsp/oth "Other psychopathological symptoms"
4.1 Depressed mood/Crying
4.2 Anxiety
4.3 Agitation/Restlessness
4.4 Manic mood/behaviour
4.5 Sleep/Day rhythm disturbances

When a psychiatrist interviews a person to arrive (by using also other types of information) at a diagnosis a whole array of pathological symptoms is checked. All kinds of such symptoms can also occur in a PAT but are usually not seen as specific for schizophrenia. The most frequent are "Depressed mood/Crying", "Anxiety", "Agitation/Restlessness", "Manic mood/behaviour", and "Sleep/day rhythm disturbances", which are provided as topics here. In some cases, a PAT may have received the diagnosis of schizoaffective disorder, which is regarded as belonging to the "schizophrenia spectrum". There, in addition to "typical schizophrenic symptoms" as covered by PAT_1, PAT_2 and PAT_3, also mood symptoms regularly occur (such as "Depressed mood" and "Manic mood/behaviour").

PAT_5 "Strange behaviour" (not aggressive) (6 topics)

5.0 nsp/oth "Strange behaviour (not aggressive)"
5.1 Yelling/Screaming
5.2 Getting lost/Not coming home/Not reachable
5.3 Talking to oneself
5.4 Locking oneself up
5.5 Throwing objects out of the window

Here behaviour of the PAT is contained, which is judged by the FAM as "strange" but not as aggressive and is not covered by other PAT topics (e.g., also psychotic symptoms can be regarded as "strange" but should not be included here as such). Apart from the "not specified/other" topic, five self-explaining topics are available here: "Yelling/Screaming", "Getting lost/Not coming home/Not reachable", "Talking to oneself", "Locking oneself up" and "Throwing objects out of the window".

PAT_6 Aggressive behaviour (5 topics)

6.0 nsp/oth „Aggressive behaviour“
6.1 Angriness/Rage
6.2 Threatening/Attempting aggressive acts
6.3 Violence against objects
6.4 Violence against people

Here, apart from the “not specified/other” topic, four self-explaining topics are available: “Angriness/Rage”, “Threatening/Attempting aggressive acts”, “Violence against objects” and “Violence against people”. Actual violence may have legal consequences in terms of criminal or civil law, e.g., compensation for damages (to be coded in addition to topics of SPT_26).

PAT_7 Self-harm (5 topics)

7.0 nsp/oth „Self-harm“
7.1 Medication overdose/Self-mutilation/Attempted suicide
7.2 Dangerous/Risky behaviour
7.3 Announcing/Threatening suicide
7.4 Suicide

This is a difficult category. The topic “Medication overdose/Self-mutilation/Attempted suicide” should be used for situations where it is clear that a “suicide was attempted” and also for situations where a “medication overdose” or a “self-mutilation” are reported without a clear indication that this behaviour is “suicidal”. In some stories “Dangerous/Risky behaviour” is reported without a clear suicidal intent, but which may result in self-harm. “Announcing/Threatening suicide” and “Suicide” are topics which describe factual behaviour.

PAT_8 Blaming others (not delusional) (3 topics)

8.0 nsp/oth „Blaming others (not delusional)“
8.1 Blaming family members
8.2 Self-blame

Thinking in causal assumptions about the factors leading to certain phenomena seems to be a widespread feature of human reasoning. Questions such as “Why has this disease occurred?”, “Why does it affect me?” are frequent in families with a PAT. They are mostly asked by FAM (see SPT_23 below), but they may also be asked by a PAT and they often imply blaming or accusing persons. Here, apart from the “not specified/other” topic two topics are provided: “Blaming family members”, meaning that a PAT blames the FAM respectively his/her other family members of being responsible for the disease. This topic is only to be applied for situations where the PAT has some insight that he/she suffers from schizophrenia, and not if the blaming is part of a delusion of persecution which includes a family member as persecuting the PAT (see “PAT_1 Psychotic symptoms”). The topic “Self-blame” is to be used if the PAT blames himself/herself for certain activities in the past, possibly but not necessarily related to the cause of the disease. Such self-blaming occurs more often if a person is in a depressed mood (to be coded also under PAT_4).

PAT_9 Insight into illness/Compliance with therapy (5 topics)

9.0 nsp/oth „Insight into illness/Compliance with therapy“
9.1 Insight into illness
9.2 No insight into illness
9.3 Compliance with therapy (if emphasized)
9.4 Non-compliance with therapy

Once the PAT has received the diagnosis of schizophrenia/psychosis and therapy (especially pharmacotherapy) is suggested by professionals, this issue becomes relevant. In many instances the diagnosis is preceded by a certain (sometimes very long) period of changed behaviour which is difficult to interpret for the FAM (“Is it just a life crisis or something else?”; see PAT_11 Disease course below) and in this period of insecurity PAT_9 is mostly not relevant. “Insight into illness” and the contrary “No insight into illness”, as well as “Compliance with therapy” and “Non-compliance with therapy” are issues as soon as the professional psychiatric system has intervened for the first time. Non-compliance with medication is a frequent problem, which is often responsible for conflicts in the family (see SPT_18 Relationships within the family of PAT/FAM) and may also throw the FAM into doubts about what the appropriate way of action is, finding the balance between being directive and letting go (see FAM_13 Care dilemma: more or less care/control vs. more or less freedom).

PAT_10 Being stressed by external factors (3 topics)

10.0 nsp/oth “Being stressed by external factors”
10.1 Problems/Stress with job/education
10.2 Problems/Stress with partner

A pragmatic model of understanding the relationship between a PAT and his/her environment is the vulnerability-stress-coping model. It starts from the observation that psychotic symptoms are often triggered by stressful environmental situations because PATs have a heightened vulnerability and are thus oversensitive to environmental stress, and that on the other hand “withdrawal” (see PAT_3 Inactivity/Blunting) may have a protective function in this respect (but may become dysfunctional if it becomes excessive – where a PAT would need some stimulation again). The model uses the image of a ”walk on a tightrope between overstimulation and understimulation” which a PAT must steadily perform. FAMs often perceive the stressors and the stress reaction of a PAT and for this case, apart from the “not specified/other” topic, the following self-explaining topics are available: “Problems/Stress with job/education” and “Problems/Stress with partner”.

PAT_11 Disease course (8 topics)

11.0 nsp/oth „Disease course“
11.1 Premorbid problems
11.2 Premorbid inconspicuousness
11.3 Acute onset
11.4 Insidious onset
11.5 Episodic course
11.6 Unremitting ("chronic") course of disease
11.7 Stabilisation period

Typically, the first manifestation of schizophrenia occurs in late adolescence and early adulthood when a young person is in transition from youth to adulthood, which per se is a difficult period in life. For a long time, the view has prevailed that schizophrenia has a chronic deteriorating course. This opinion goes back to the first name of the disease, which was dementia praecox. It has however always been clear, but not reflected in common knowledge, that a PAT can have a whole spectrum of disease courses, from complete lifelong remission after the first episode to catastrophic deterioration. Also, the onset of schizophrenia can have many different forms, with the two ends of a spectrum between "acute onset" and "insidious onset". The issue whether a PAT was already affected premorbidly by some kind of mental abnormality or not is another relevant issue, not only for research but also for FAMs who tell their stories and wonder how and why schizophrenia found its way into their family. Reflecting the above considerations, in addition to the "not specified/other" topic seven topics are provided: Two on the premorbid development of the PAT - "Premorbid problems" and "Premorbid inconspicuousness", two on the type of onset - "Acute onset" and "Insidious onset", and two on the course of the disease – "Episodic course" and "Unremitting course". These characteristics are not often contained in the stories and the decision to code them is sometimes only indirectly possible. In some stories the FAM stresses that a "Stabilisation period" occurred (often jointly with an episodic course).

CLUSTER B: FAM - Experiences of the caring family member (6 topic groups; FAM_12 to FAM_17)

The topics in this cluster describe experiences, emotions of and actions taken by the family member who cares for the patient diagnosed with schizophrenia and who is the author of a story (FAM). The 6 topic groups included in this cluster can be grouped as follows:

- 3 Experienced distress (FAM_12), dilemmas (FAM_13) and other challenges (FAM_14)
- 1 Appraisal of actors the FAM dealt with (critical or positive) (FAM_15)
- 1 Positive experiences including "positive resignation" (FAM_16)
- 1 PAT moving out of/or back to the home of FAM (FAM_17).

FAM_12 Distress (12 topics)

12.0 nsp/oth „Distress"
12.1 Depressed mood/Crying
12.2 Exhaustion/Burnout/Overburdened/Reached limits/Stressed
12.3 Despair/Hopelessness
12.4 Helplessness, powerlessness
12.5 Uncertainty/Doubts
12.6 Anxiety/Fear/Worry
12.7 Sleep disturbances
12.8 'Shock'
12.9 Anger
12.10 Psychosomatic symptoms
12.11 Feelings of guilt/Self-accusation/Shame

In this topic group, the FAMs describe their emotional experiences. For the topics mainly terms employed by the FAMs themselves were used. They are basically self-explaining and include, apart from the "not specified/other" topic: "Depressed mood/Crying", "Exhaustion/Burnout/Overburdened/Reached limits/Stressed", "Despair/Hopelessness", "Helplessness, powerlessness", "Uncertainty/Doubts", "Anxiety/Fear/Worry", "Sleep disturbances", "'Shock'", "Anger", and "Psychosomatic symptoms". Feelings of guilt, coded here as "Feelings of guilt/Self-accusation/Shame", may arise because a FAM thinks a) that he/she is responsible in terms of being a cause of the disease (in this case also use the topic SPT_23.0 nsp/oth "Causal assumptions/theories"), or b) that he/she has made mistakes in dealing with the PAT in terms of the care dilemma (More or less care and control? - in this case also use a topic of the topic group FAM_13 Care dilemma: more or less care/control vs. more or less freedom), or c) if the feelings of guilt relate to having initiated an involuntary hospital admission, also use topic SPT_26.1 Involuntary hospital admission.

FAM_13 Care dilemma: more or less care/control vs. more or less freedom (8 topics)

13.0 nsp/oth Care dilemma
13.1 Dilemma protection vs. intrusion
13.2 Pressurizing PAT to do/not to do something
13.3 Letting go, more autonomy for the PAT
13.4 Feelings of responsibility
13.5 Doubts about own behaviour towards the PAT
13.6 Distance to PAT increasing
13.7 PAT Behaviour "bad" or "mad"?

By this topic group a dilemma is covered which shows up often in families with a PAT. Since the young person, the child of the parents, is about to become a young adult but is handicapped by the disease symptoms, parents are torn between their tendency to help and protect their child and the frequent wish of the child to become autonomous (the situation is even more complicated if the child includes the parents into his/her delusion as persecutors, see PAT_1). This dilemma can be described with the extremes of "overprotection" and "neglect". FAMs describe this dilemma in several terms, which, in addition to the "not specified/other" topic, are included here in seven self-explaining topics. They are: "Dilemma protection vs. intrusion", "Pressurizing PAT to do/not to do something", "Letting go, more autonomy for the PAT", "Feelings of responsibility", "Doubts about own behaviour towards the PAT", "Distance to PAT increasing", "PAT Behaviour "bad" or "mad"?". Several of these topics can be used for one and the same behaviour if thought to be appropriate.

FAM_14 Other challenges (8 topics)

14.0 nsp/oth "Other challenges"
14.1 Fear of suicide of PAT
14.2 Fear of violence of PAT
14.3 Fear of new episode/deterioration
14.4 Fear that PAT will not be able to lead an independent life
14.5 Need to adapt family life to the new situation
14.6 Managing a dangerous situation
14.7 Parentification

Here specific fears of the FAM concerning several possible challenging events and situations are included, such as suicide, violence, a new episode in a period of stabilisation, and concern about the PAT's future in case the FAM will not be able to care anymore for the PAT or even dies. Apart from the "not specified/other" topic, the following seven self-explaining topics are provided here: "Fear of suicide of PAT", "Fear of violence of PAT", "Fear of new episode/deterioration", "Fear that PAT will not be able to lead an independent life" (especially, when FAM thinks of the situation that he/she will not be able to care for the PAT anymore), "Need to adapt family life to the new situation", "Managing a dangerous situation", "Parentification" (Reversal of child-parent role).

FAM_15 Appraisal of others (7 topics)

15.0 nsp/oth "Appraisal of others"
15.1 Praises/Understands PAT
15.2 Pities PAT
15.3 Praises other family member
15.4 Praises services/system
15.5 Criticises PAT
15.6 Criticises services/system (e.g. "not taken seriously")

In quite a few stories FAMs express either criticism of or satisfaction with services, professional staff, the PAT, and others involved in handling the disease. This represents a positive trend in the status of FAMs who are becoming more self-confident, especially when they are members of self-help organisations or have had positive counselling experiences (as is the case in many stories; such positive experiences should be coded with "FAM_16.4 Help/Relief received through counselling" in FAM_16 Positive attitudes). In addition to the "not specified/other" topic the following self-explaining topics are available for this topic group: "Praises/Understands PAT", "Pities PAT", „Praises other family member", "Praises services/system", "Criticises PAT", "Criticises services/system (e.g. "not taken seriously")". If another family member is criticised in a story the topics "SPT_18.2 Withdrawal of non-caring family member" and "SPT_18.5 Other family member does not understand the disease" in the topic group "SPT_18 Relationships within the family of PAT/FAM" can be used.

FAM_16 Positive attitudes (7 topics)

16.0 nsp/oth "Positive attitudes"
16.1 Supports PAT in coping with the disease
16.2 Positive resignation
16.3 Situation of relief
16.4 Help/Relief received through counselling
16.5 Hope/Confidence that future will be better
16.6 Looking after oneself/Taking care of oneself

Other than one might expect, many stories also contain positive experiences, probably not least because many FAMs whose stories are contained in the "Book of stories" have received counselling. Quite a few have arrived at a "positive resignation", i.e., they have accepted the diagnosis and are not hoping for a miracle anymore, but have realistic expectations of small changes or stabilisation, and have learned how to optimally assist the PAT in coping with the disease. Taking care of themselves and not sacrificing themselves for the child is obviously an important topic for learning how to arrive at a positive resignation. In addition to the "not specified/other" topic the following six topics are provided here "Supports PAT in

coping with the disease", "Positive resignation", "Situation of relief", "Help/Relief received through counselling", "Hope/Confidence that future will be better", "Looking after oneself/Taking care of oneself".

FAM_17 PAT moves out of/back to the home of FAM (3 topics)

17.0 nsp/oth "PAT moves out of/back to the home of FAM"
17.1 PAT moving out of the home of FAM
17.2 PAT moving back to the home of FAM

A final topic group concerns the often conflict-laden issue of whether the PAT stays in the home of the FAM or moves to a separate flat, or vice versa. The topic is often related to the dilemma described in FAM_13 or to conflicts within the families (SPT_18). Apart from the "not specified/other" topic the two following topics are provided here: "PAT moving out of the home of FAM", "PAT moving back to the home of FAM".

CLUSTER C: SPT - Specific topics not covered by Cluster A and Cluster B (9 topic groups; SPT_18 to SPT_26)

The following nine issues addressed in the stories have been identified as main categories.

- Relationships within the family of the FAM (SPT_18)
- Employment, Education, Finances of FAM and PAT (SPT_19)
- Physical health of the FAM and the PAT (SPT_20)
- Services and professionals encountered (SPT_21)
- Therapy-related issues (SPT_22)
- Causal assumptions about illness and efficacy of therapies (SPT_23)
- Lack of information on diagnosis, treatment and other disease related issues (SPT_24).
- Stigma, discrimination and social networks (SPT_25)
- Legal issues and police involvement (SPT_26).

SPT_18 Relationships within the family of PAT/FAM (10 topics)

18.0 nsp/oth "Relationships within the family of PAT/FAM"
18.1 Conflict within family
18.2 Withdrawal of non-caring family member
18.3 Criticism of FAM by other family members
18.4 Other family member is under stress
18.5 Other family member does not understand the disease
18.6 Other family member has mental problems/disorder
18.7 Thoughts of or actual separation/divorce (FAM)
18.8 Support of FAM by other family members
18.9 Involving extended family members in care for PAT

Here events and situations concerning the relationships within the family of the PAT are coded. It is quite understandable that, given the very special new situation of a "normal" young person turned into someone with a mental illness, all kinds of "Conflicts" can arise in the family. Parents may have different opinions about what to do, which (in extreme situations) can lead to "Thoughts of or actual separation/divorce". Given that often one FAM takes on the task of caring for the PAT (if the PAT is a son or a daughter it is mostly the mother), "Withdrawal of non-caring family member" may happen, leaving the whole burden of care to the FAM; also "Criticism of FAM by other family members" can occur. A reason for those two behaviours of other family members – as viewed by the FAM telling the story - may be that an "Other family member is under stress", that an "Other family member does not understand the disease", or that an "Other family member has mental problems". "Involving extended family members" is an option of trying to defuse complex family situations. Also, the contrary to conflicts may occur, when the FAM expressively reports getting "Support by other family members".

SPT_19 Employment, Education, Finances of PAT/FAM (5 topics)

19.0 nsp/oth „Employment, Education, Finances of PAT/FAM"
19.1 FAM loss of income/Financial burden
19.2 PAT education & work
19.3 PAT cost of therapy & health insurance
19.4 PAT financial issues

This topic group relates to both the PAT and the FAM and covers issues concerning education, the workplace, and financial problems. Given the early age of onset of schizophrenia, school and educational issues usually relate to the PAT. Work issues on the regular labour market may concern the PAT ("PAT education & work"; occupational rehabilitation services – should be coded as SPT_21.6) as well as the FAM, and here the work issues are mostly related to financial problems ("FAM loss of income/Financial burden"). "PAT cost of therapy & health insurance" and financial problems involving directly the PAT ("PAT financial issues") are additional topics provided here.

SPT_20 Physical health of PAT/FAM (9 topics)

20.0 nsp/oth "Physical health of PAT/FAM"
20.1 FAM Medical condition/disability
20.2 PAT Medical condition/disability
20.3 PAT Increased alcohol consumption
20.4 PAT Cannabis use
20.5 PAT nsp/oth Substance use
20.6 PAT Excessive nicotine use (smoking etc)
20.7 PAT Excessive coffee consumption
20.8 PAT Medication side effects

The topic group "Physical health" comprises all medical conditions and physical disabilities of the FAM and the PAT ("FAM Medical condition/disability", "PAT Medical condition/disability") mentioned in the stories. Substance use is covered by three topics, since in PATs the use of cannabis ("PAT Cannabis use") and alcohol ("PAT increased alcohol consumption") is frequently reported in the stories. Also "PAT excessive nicotine use (smoking etc.)" and "PAT excessive coffee consumption" can be coded here, in

addition to a more general topic “PAT nsp/oth Substance use”. “PAT Medication side effects” are also coded here as physical health issues.

SPT_21 Services and Professionals (12 topics)

21.0 nsp/oth “Services and Professionals”
21.1 Ambulance, emergency and crisis services
21.2 Hospital
21.3 Outpatient/Mobile service
21.4 Day structure
21.5 Supported living facility
21.6 Occupational rehabilitation services
21.7 Forensic services, prison, probation services
21.8 Psychiatrist
21.9 Physician other
21.10 Psychologist/Psychotherapist
21.11 Other staff (nurses, etc.)

Here services and professionals mentioned in the stories are coded. If experiences with these services and professionals are appraised, either negatively or positively, the topics of the topic group “FAM_15 Appraisal of others” are used. Apart from the “not specified/other topic”, the self-explaining topics for services used here are “Ambulance, emergency and crisis services”, “Hospital”, “Outpatient/Mobile service”, “Day structure”, “Supported living facility”, “Occupational rehabilitation services”, “Forensic services, prison, probation services”. For professionals four topics are provided: “Psychiatrist”, “Physician other”, “Psychologist/Psychotherapist”, “Other staff (nurses, etc.)”.

SPT_22 Therapy-related issues (6 topics)

22.0 nsp/oth “Therapy-related issues”
22.1 Medication oral
22.2 Medication depot injection
22.3 Medication nsp
22.4 Substitution programme
22.5 Psychotherapy/Psychoeducation

As far as different types of therapies are concerned medication is a frequent topic in the stories. “Medication oral” and “Medication depot injection” are provided here as two different topics, since the problem of compliance (see above “PAT_9 Insight into illness/Compliance with therapy”) is often discussed in families (see above “FAM_13 Dilemma challenges”) potentially leading to conflicts (“SPT_18 Relationships within the family of PAT/FAM”). It matters in many ways whether medication is prescribed in an oral form to be swallowed every day or as a depot injection to be administered every second week or even less frequently, especially in terms of compliance (if oral, then PAT can decide to take the medication or not and therefore might prefer oral medication; if depot injection, the PAT cannot get rid of the medication and might not prefer depot injections). In addition, “Medication not specified” can be coded. “Substitution programme” (in case of substance abuse) and “Psychotherapy/Psychoeducation” are further topics used here.

SPT_23 Causal assumptions/theories (6 topics)

23.0 nsp/oth “Causal assumptions/theories”
23.1 Initial symptoms interpreted as due to a puberty crisis
23.2 Initial symptoms interpreted as due to drug use
23.3 Initial symptoms interpreted as due to concealed criminal activities
23.4 Cause of schizophrenia is psychological
23.5 Cause of schizophrenia is biological/genetic
23.6 Theories why a specific therapy/intervention works

When the family is hit by schizophrenia (a disease more difficult to understand than most other diseases), - it is quite understandable that a search for causes begins, and one’s own behaviour is not seldom in the focus (see “FAM_13 Dilemma challenges” > “FAM_12.11 Feelings of guilt/Self-accusation/Shame”; “PAT_8.2 Self-blame”), - a search for information starts (today mainly on the internet). In fact, today still little is known about the complexities of potential causal factors for schizophrenia, and most researchers follow their own preconceived theories. However, since a basic human drive for searching for causes exists, in some stories, ideas about the “Cause of schizophrenia” show up (typically “Cause of schizophrenia is psychological” but also “Cause of schizophrenia is biological/genetic”), as well as “Theories why a specific therapy/intervention works” (these topics might be illustrated by a comment). Such theories might also be put forward by the PAT (when blaming the FAM’s behaviour for his/her disease, see PAT_8 Blaming others). A specific issue is the attempt of family members to explain changes in the behaviour of the PAT before the time the diagnosis of schizophrenia is made. For this issue three topics are provided: “Initial symptoms interpreted as due to a puberty crisis”, “Initial symptoms interpreted as due to drug use”, “Initial symptoms interpreted as due to concealed criminal activities”.

SPT_24 Information deficits (4 topics)

24.0 nsp/oth “Information deficits”
24.1 Information deficits about the diagnosis of schizophrenia/psychosis
24.2 Information deficits about how to react to symptoms/strange behaviour of PAT
24.3 Confusion about information, especially on the internet

A reason why causal speculations are not uncommon (see SPT_23 above) is that information is often not available to the FAM or not in a non-confusing away (“Confusion about information, especially on the internet”). It is not even communicated to the FAM that causal information is very scanty, specifically on the “Diagnosis of schizophrenia/psychosis”. Family members also complain that they don’t receive information on “How to react to symptoms/strange behaviour of PAT” (often FAMs get such information not from professionals, but from FAM self-help and counselling organisations). Other specific information deficits mentioned could be coded under “not specified/other “Information deficits”” (e.g. on medication or other biological therapies, potential genetic causal factors, available services, legal issues). In this case they should be described in a comment.

SPT_25 Stigma, Discrimination, Wider social network, Public realm (9 topics)

25.0 nsp/oth “Stigma, Discrimination, Wider social network, Public realm”
25.1 Observed stigma in public domain (including media)
25.2 Discrimination experiences
25.3 Secrecy in order to avoid stigma and discrimination
25.4 Being blamed from wider social network and other external sources
25.5 Engagement in fighting stigma & discrimination
25.6 Embarrassing behaviour of PAT in public
25.7 FAM Social network is reduced
25.8 Support by wider social network (e.g. neighbours)

This topic group comprises issues where the wider social field or the general public are involved. It comprises several different experiences. Several topics are available for stigma and discrimination experiences, namely “Observed stigma in public domain (including media)”, “Discrimination experiences”, “Secrecy in order to avoid stigma and discrimination”, “Being blamed from wider social network and other external sources” and for active involvement of the FAM in anti-stigma activities (“Engagement in fighting stigma and discrimination”). Also included here is “Embarrassing behaviour of the PAT in public” (e.g., concerning behaviour as described in “PAT_5 Strange behaviour (not aggressive)” and “PAT_6 Aggressive behaviour”), which can give rise to stigma and discrimination in an uninformed public. Furthermore, the topic “FAM Social network is reduced” is included here – FAMs often reduce contacts with other people because of fears of stigma and discrimination (hiding the problem of having a PAT as family member). The topic “Support by wider social network” is used for positive experiences with people in the wider social network. If a story specifically mentions that the social network is getting larger again, it should be coded under “nsp/oth “Stigma, Discrimination, Wider social network, Public realm”” and described in a comment.

SPT_26 Legal issues and police involvement (7 topics)

26.0 nsp/oth “Legal issues and police involvement”
26.1 Involuntary hospital admission
26.2 Police/Fire brigade involvement
26.3 Criminal law issue
26.4 Civil law issue
26.5 Guardianship
26.6 Legal aspects of social benefit/health insurance

This topic group comprises several self-explaining topics relating to legal issues and also police/fire brigade involvement (which imply often legal aspects). Apart from the “not specified/other” topic the following topics are provided here: “Involuntary hospital admission”, “Police/Fire brigade involvement“, “Criminal law issue”, “Civil law issue”, “Guardianship”, “Legal aspects of social benefit/health insurance”.

Annexe: Complete list of topics/codes

26 Topic Groups 168 Topics
PAT_1 Psychotic symptoms
PAT_1.0 nsp/oth "Psychotic symptoms"
PAT_1.1 Hallucinations
PAT_1.2 Delusion of persecution FAM included
PAT_1.3 Delusion of persecution FAM not included
PAT_1.4 nsp Delusion of persecution
PAT_1.5 Non-persecution delusion
PAT_2 Disorganised/Incoherent behaviour
PAT_2.0 nsp/oth "Disorganised/Incoherent behaviour"
PAT_2.1 Incoherent speech/Confused thoughts
PAT_2.2 Inability to organise daily life
PAT_3 Inactivity/Blunting
PAT_3.0 nsp/oth "Inactivity/Blunting"
PAT_3.1 Withdrawal
PAT_3.2 Neglect of personal hygiene
PAT_3.3 Neglect of household chores
PAT_4 Other psychopathological symptoms
PAT_4.0 nsp/oth "Other psychopathological symptoms"
PAT_4.1 Depressed mood/Crying
PAT_4.2 Anxiety
PAT_4.3 Agitation/Restlessness
PAT_4.4 Manic mood/behaviour
PAT_4.5 Sleep/Day rhythm disturbances
PAT_5 Strange behaviour (not aggressive)
PAT_5.0 nsp/oth "Strange behaviour (not aggressive)"
PAT_5.1 Yelling/Screaming
PAT_5.2 Getting lost/Not coming home/Not reachable
PAT_5.3 Talking to oneself
PAT_5.4 Locking oneself up
PAT_5.5 Throwing objects out of the window
PAT_6 Aggressive behaviour
PAT_6.0 nsp/oth "Agressive behaviour"
PAT_6.1 Angriness/Rage
PAT_6.2 Threatening/Attempting aggressive acts
PAT_6.3 Violence against objects

PAT_6.4 Violence against people
PAT_7 Self-harm
PAT_7.0 nsp/oth "Self-harm"
PAT_7.1 Medication overdose/Self-mutilation/Attempted suicide
PAT_7.2 Dangerous/Risky behaviour
PAT_7.3 Announcing/Threatening suicide
PAT_7.4 Suicide
PAT_8 Blaming others (not delusional)
PAT_8.0 nsp/oth "Blaming others (not delusional)"
PAT_8.1 Blaming family members
PAT_8.2 Self-blame
PAT_9 Insight into illness/Compliance with therapy
PAT_9.0 nsp/oth "Insight into illness/Compliance with therapy"
PAT_9.1 Insight into illness
PAT_9.2 No insight into illness
PAT_9.3 Compliance with therapy (if emphasized)
PAT_9.4 Non-compliance with therapy
PAT_10 Being stressed by external factors
PAT_10.0 nsp/oth "Being stressed by external factors"
PAT_10.1 Problems/Stress with job/education
PAT_10.2 Problems/Stress with partner
PAT_11 Disease course
PAT_11.0 nsp/oth "Disease course"
PAT_11.1 Premorbid problems
PAT_11.2 Premorbid inconspicuousness
PAT_11.3 Acute onset
PAT_11.4 Insidious onset
PAT_11.5 Episodic course
PAT_11.6 Unremitting ("chronic") course of disease
PAT_11.7 Stabilisation period
FAM_12 Distress
FAM_12.0 nsp/oth "Distress"
FAM_12.1 Depressed mood/Crying
FAM_12.2 Exhaustion/Burnout/Overburdened/Reached limits/Stressed
FAM_12.3 Despair/Hopelessness
FAM_12.4 Helplessness, powerlessness
FAM_12.5 Uncertainty/Doubts
FAM_12.6 Anxiety/Fear/Worry
FAM_12.7 Sleep disturbances
FAM_12.8 'Shock'
FAM_12.9 Anger
FAM_12.10 Psychosomatic symptoms

FAM_12.11 Feelings of guilt/Self-accusation/Shame
FAM_13 Care dilemma: more or less care/control vs. more or less freedom
FAM_13.0 nsp/oth Care dilemma
FAM_13.1 Dilemma protection vs. intrusion
FAM_13.2 Pressurizing PAT to do/not to do something
FAM_13.3 Letting go, more autonomy for the PAT
FAM_13.4 Feelings of responsibility
FAM_13.5 Doubts about own behaviour towards the PAT
FAM_13.6 Distance to PAT increasing
FAM_13.7 PAT Behaviour "bad" or "mad"?
FAM_14 Other challenges
FAM_14.0 nsp/oth "Other challenges"
FAM_14.1 Fear of suicide of PAT
FAM_14.2 Fear of violence of PAT
FAM_14.3 Fear of new episode/deterioration
FAM_14.4 Fear that PAT will not be able to lead an independent life
FAM_14.5 Need to adapt family life to the new situation
FAM_14.6 Managing a dangerous situation
FAM_14.7 Parentification
FAM_15 Appraisal of others
FAM_15.0 nsp/oth "Appraisal of others"
FAM_15.1 Praises/Understands PAT
FAM_15.2 Pities PAT
FAM_15.3 Praises other family member
FAM_15.4 Praises services/system
FAM_15.5 Criticises PAT
FAM_15.6 Criticises services/system (e.g. "not taken seriously")
FAM_16 Positive attitudes
FAM_16.0 nsp/oth "Positive attitudes"
FAM_16.1 Supports PAT in coping with the disease
FAM_16.2 Positive resignation
FAM_16.3 Situation of relief
FAM_16.4 Help/Relief received through counselling
FAM_16.5 Hope/Confidence that future will be better
FAM_16.6 Looking after oneself/Taking care of oneself
FAM_17 PAT moves out of/back to the home of FAM
FAM_17.0 nsp/oth "PAT moves out of/back to the home of FAM"
FAM_17.1 PAT moving out of the home of FAM
FAM_17.2 PAT moving back to the home of FAM
SPT_18 Relationships within the family of PAT/FAM
SPT_18.0 nsp/oth "Relationships within the family of PAT/FAM"
SPT_18.1 Conflict within family

SPT_18.2 Withdrawal of non-caring family member
SPT_18.3 Criticism of FAM by other family members
SPT_18.4 Other family member is under stress
SPT_18.5 Other family member does not understand the disease
SPT_18.6 Other family member has mental problems/disorder
SPT_18.7 Thoughts of or actual separation/divorce (FAM)
SPT_18.8 Support of FAM by other family members
SPT_18.9 Involving extended family members in care for PAT
SPT_19 Employment, Education, Finances of PAT/FAM
SPT_19.0 nsp/oth "Employment, Education, Finances of PAT/FAM"
SPT_19.1 FAM loss of income/Financial burden
SPT_19.2 PAT education & work
SPT_19.3 PAT cost of therapy & health insurance
SPT_19.4 PAT financial issues
SPT_20 Physical health of PAT/FAM
SPT_20.0 nsp/oth "Physical health of PAT/FAM"
SPT_20.1 FAM Medical condition/disability
SPT_20.2 PAT Medical condition/disability
SPT_20.3 PAT Increased alcohol consumption
SPT_20.4 PAT Cannabis use
SPT_20.5 PAT nsp/oth Substance use
SPT_20.6 PAT Excessive nicotine use (smoking etc.)
SPT_20.7 PAT Excessive coffee consumption
SPT_20.8 PAT Medication side effects
SPT_21 Services and Professionals
SPT_21.0 nsp/oth "Services and Professionals"
SPT_21.1 Ambulance, emergency and crisis services
SPT_21.2 Hospital
SPT_21.3 Outpatient/Mobile service
SPT_21.4 Day structure
SPT_21.5 Supported living facility
SPT_21.6 Occupational rehabilitation services
SPT_21.7 Forensic services, prison, probation services
SPT_21.8 Psychiatrist
SPT_21.9 Physician other
SPT_21.10 Psychologist/psychotherapist
SPT_21.11 Other staff (nurses, etc.)
SPT_22 Therapy-related issues
SPT_22.0 nsp/oth "Therapy-related issues"
SPT_22.1 Medication oral
SPT_22.2 Medication depot injection
SPT_22.3 Medication nsp

SPT_22.4 Substitution programme
SPT_22.5 Psychotherapy/Psychoeducation
SPT_23 Causal assumptions/theories
SPT_23.0 nsp/oth "Causal assumptions/theories"
SPT_23.1 Initial symptoms interpreted as due to a puberty crisis
SPT_23.2 Initial symptoms interpreted as due to drug use
SPT_23.3 Initial symptoms interpreted as due to concealed criminal activities
SPT_23.4 Cause of schizophrenia is psychological
SPT_23.5 Cause of schizophrenia is biological/genetic
SPT_23.6 Theories why a specific therapy/intervention works
SPT_24 Information deficits
SPT_24.0 nsp/oth "Information deficits"
SPT_24.1 Information deficits about the diagnosis of schizophrenia/psychosis
SPT_24.2 Information deficits about how to react to symptoms/strange behaviour of PAT
SPT_24.3 Confusion about information, especially on the internet
SPT_25 Stigma, Discrimination, Wider social network, Public realm
SPT_25.0 nsp/oth "Stigma, Discrimination, Wider social network, Public realm"
SPT_25.1 Observed stigma in public domain (including media)
SPT_25.2 Discrimination experiences
SPT_25.3 Secrecy in order to avoid stigma and discrimination
SPT_25.4 Being blamed from wider social network and other external sources
SPT_25.5 Engagement in fighting stigma & discrimination
SPT_25.6 Embarrassing behaviour of PAT in public
SPT_25.7 FAM Social network is reduced
SPT_25.8 Support by wider social network (e.g. neighbours)
SPT_26 Legal issues and police involvement
SPT_26.0 nsp/oth "Legal issues and police involvement"
SPT_26.1 Involuntary hospital admission
SPT_26.2 Police/Fire brigade involvement
SPT_26.3 Criminal law issue
SPT_26.4 Civil law issue
SPT_26.5 Guardianship
SPT_26.6 Legal aspects of social benefit/health insurance