

Why do I have to suffer? Symptom management, views and experiences of patients with a cPTSD: A Grounded Theory

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Patientennah – Engagiert – Vernetzt

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Overview

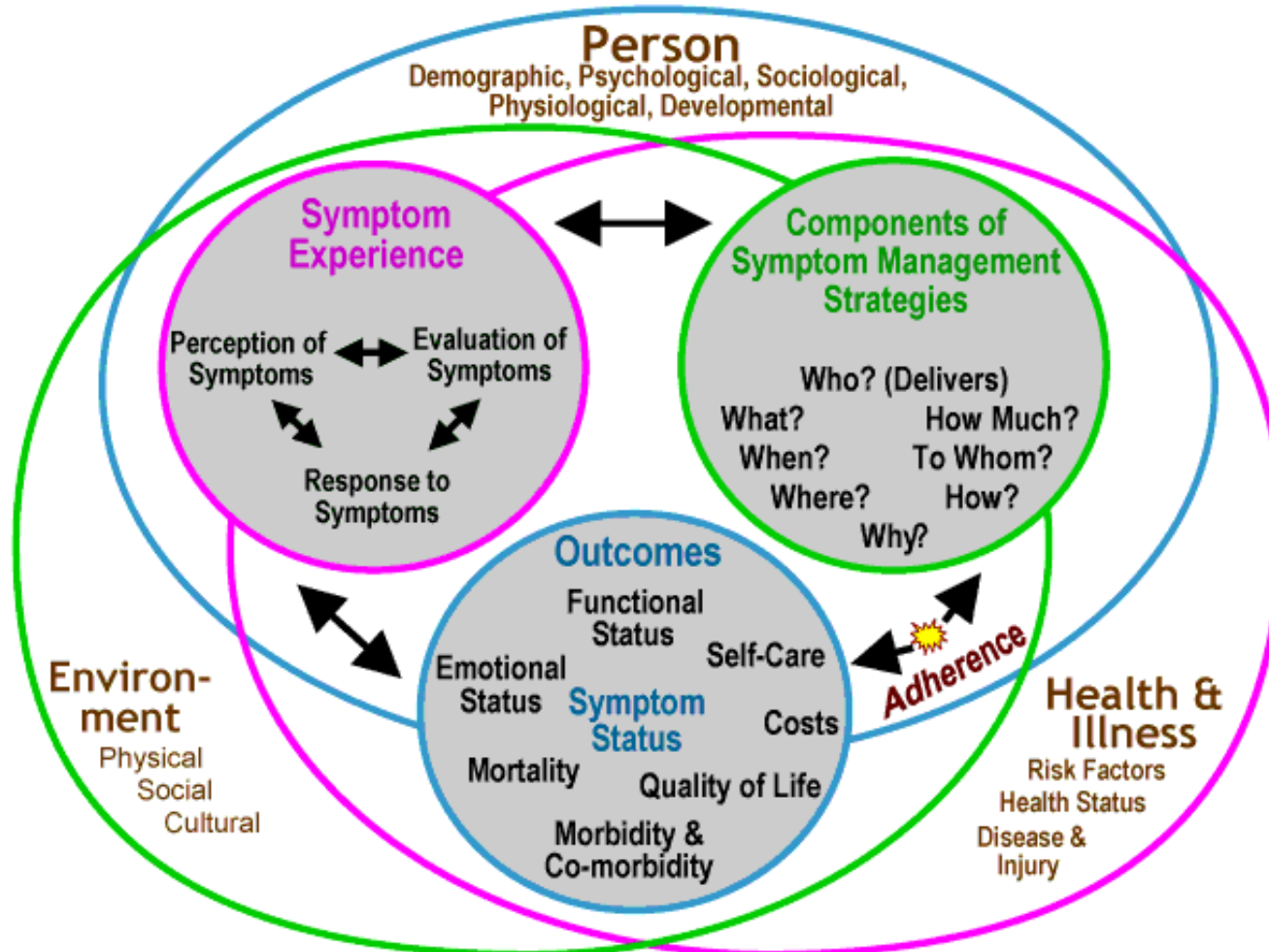
- Introduction
- Background
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Introduction

- In 2018, the World Health Organization (WHO) is expected to approve ICD-11 as the official new version.
- It is proposed to diagnose a complex posttraumatic stress disorder (cPTSD) by the core criteria of PTSD and by the presence of at least one symptom from the domains: a negative self-concept, problems in interpersonal relationships, emotional dysregulation.
- Symptoms are discussed in the literature as a common reason for seeking treatment.
- Dealing with the resulting difficulties is often left to the patients and their relatives.

Maercker et al. (2015), Hermann et al. (1992), Dodd et al. (2001), Miaskowski, C., Dodd, M., & Lee, K. A. (2004)

Theoretical background



Dodd et al. (2001), Miaskowski, C., Dodd, M., & Lee, K. A. (2004)

Qualitative aims

- The purpose of this study is to explore and to reconstruct the views, perceptions, experiences, facilitations as well as barriers of the participants for symptom management in everyday life.

Setting, recruitment and method

- Ward for psychotraumatology inpatient treatment, Canton Zürich, CH
- Theoretical sampling, n = 11 participants
- 4.1.2017 – ongoing
- Grounded Theory (Corbin and Strauss, 2008)
- In depth-interviews 45 min - 75 min audiotaped and verbatim transcribed
- MAXQDA 12® Software

Theoretical sampling ongoing

Name	Gender	Age	Occupation	Trauma experience
Mary	f	40	Former nurse	1, 2, 3, 6
Celia	f	60	Former teacher	1, 2, 3, 6
Paula	f	22	Former teacher	1, 2, 3, 6
Max	m	34	Former military	1, 2, 3
Susanne	f	58	Former nurse	1, 2, 6
Peter	m	30	Economics student	1, 2, 5
Marta	f	48	Former smith	1, 2, 6
Sonja	f	48	Former airport employee	1, 3, 4
Paul	m	46	No diploma	1, 2, 6
Yuki	f	47	No diploma	1, 2, 4
Laura	f	38	Former bank employee	1, 2, 3, 4

Early Childhood Trauma = 1, Sexual abuse = 2, Physical abuse = 3,
Domestic violence = 4, School Violence = 5, Neglect = 6

Analyses

- Line-by-line Coding

347 P: Jaaa also ich habe auch ganz fest Angst gehabt mich dem zu stellen und und ääähm. Ja. Jaaa und ich bin aber froh gewesen habe ich
348 diesen Schritt gemacht. Ja. Obwohl noch nicht alles aaaaaahm ääähm aufarbeitet ist also ja. Aber ääähm ich will dran bleiben ja. Ja. Ja.
349

Angst vor der Vergangenheit,
Erleichterung um den Schritt zur
Therapie, noch Traumatmas
vorhanden dran bleiben

- Axial Coding

Liste der Codes

277

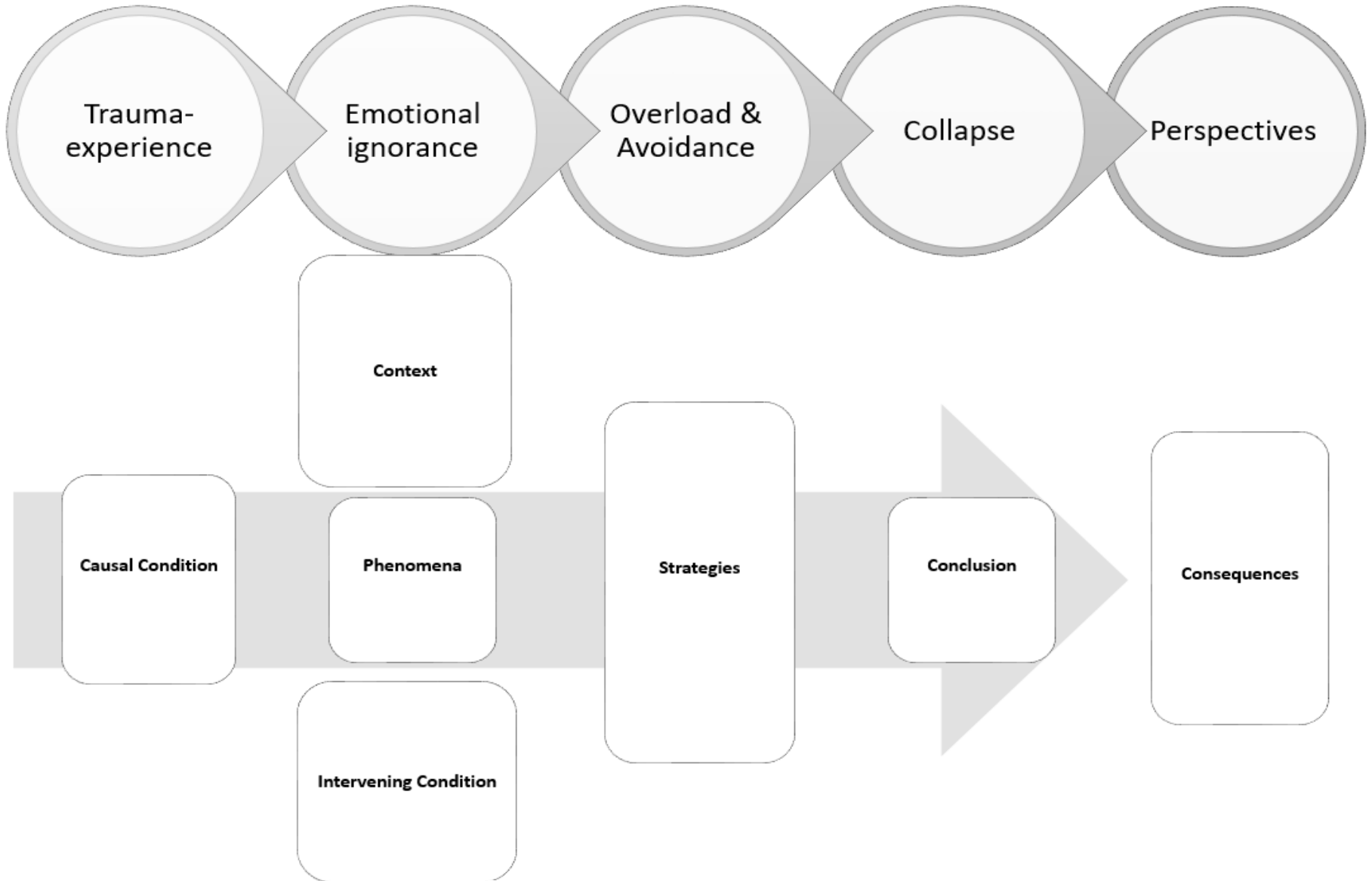
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Selbstbild
Emotionen
Selbstbild
Barrieren
Konsequenzen
Erleichterungen
Konsequenzen
Konsequenzen
Erleichterungen
Barrieren
Selbstbild
Adhärenz
Erleichterungen
Soziale Interaktionen
Bedeutung kPTBS
Erleichterungen

107 Unter Druck setzen
108 Rücksichtnahme schön
109 Funktionieren wollen
110 Verständnis tut der Seele gut
111 Vielseitige Krankheit
112 Zuhause weniger angespannt sein
113 Plötzliche Wut
114 Anspannung durch Selbstvorwürfe
115 Geborgenheit als Unterstützung

- Selective Coding

Results: Process for symptom management



Trauma experience

- This phase describes the **Causal Condition**
- All of our participants had a story of early childhood trauma and at least two of the following types of traumatic experience: sexual abuse, physical abuse, domestic violence, school violence or neglect.

“ So I got the information about soldier's illness. From the American media... But I did not know that it can also develop after physical or sexual abuse” Max, 34

“It started in my childhood, then many bad things happened in my life. I don` t know why I still have to suffer.” Paul, 46

Emotional ignorance

- This phase describes the main **Phenomena**, and the participants view of not knowing about their symptoms.

“I thought it was my personality and I was just weak and useless. Now I know my symptoms were the cause for so many reactions” Sonja, 48

*“It's like being like a ping pong ball blown by a hair dryer. It does with me what it wants, it shoots me to the right to the left or up or down. I have no influence on it.”
Mary, 40*

- and trying to suppress.

“ Sometimes it was so intense, I was so desperate. I knew there was something else ... Something that makes me react in an other way than other humans do. I put it away as well as I can.” Celia, 60

Emotional ignorance

- The **Context** identifies important issues such as frequency of symptoms, intensity of symptoms, duration and social situation.

“So I have had symptoms almost every day since childhood. In school the others thought I was insane and I thought the same. For four years I know that I’m not crazy.” Max, 34

- The **Intervening Conditions** describe facilitations as well as barriers of the patients for symptom management in everyday life.

“The body sensations are very unpleasant. Or suddenly sweaty hands. Very wet soles, aaaaahm. The tension in my back is also really troublesome. These whole body things, they make it more difficult” Sonja, 48

“But I think such a good friend is already nice. It makes it easier... Just to know there is someone and I don’t feel alone anymore.” Paula 22

Overload / Avoidance

- In this phase the category **Strategies** illustrates the efforts of the participants to cope with their symptoms, for instance with dissociation or persistence.

" I did not know what it was... that tension. I was just not here... often... I did not know my body" Mary, 40

- Or through a function mode and social disclosure.

"Distraction I think, and later with 18 functioning mmmh mmmh at 16 I started to work in a hospital. Shift work was a great distraction. For many years I had just two days a month off. Yeah..." Susanne, 58

Overload / Avoidance

- Other categories like caring relatives or managing the lack of control characterize further strategies of the participants.

“Do not give up and again and again two or three days without sleep and then work again. My wife had to take over many things. That was helpful” Peter, 30

“I just scratched myself to the bone, just to bring me down. My parents... They thought it was a skin disease. That I had a persistent exema.” Marta, 48

- Or the struggle with social disclosure and substance abuse.

“But yeah but yeah somehow I had nothing so.... I went through addiction, I then started with alcohol and other drugs. I also preferred to be alone, to ameliorate the whole thing.” Sonja, 48

Collapse

- The phase points out the possible **Conclusions**, collapsing and feeling exhausted through strategies used by the affected persons.

“A total incapacity for work and to manage my life” Peter, 30

“For a long time I did not consider myself ill. For me it was... I can still do everything. Until I noticed nothing worked anymore. Because it is very exhausting.” Paula, 22

Perspectives

- This phase specifies the **Consequences** of the process for instance, surviving, hope, social disclosure, inpatient treatment or suicidality.

“Because yeaah it is difficult to describe it. It is liberating. Because yeaah I now know where the problems lie and I can work on them.” Yuki, 47

“From the age of 22 to 33 it just did not exist. It worked unconsciously through nightmares... I suspect. When I was 33 it broke out again and I had a break-down and nearly killed myself.” Susanne, 58

Process for symptom management

Trauma-
experience

Emotional
ignorance

Overload &
Avoidance

Collapse

Perspectives

Causal Condition

- . forms of abuse in childhood
- . cumulative trauma

Context

- . frequency of symptoms
- . intensity of symptoms
- . social situation
- . duration

Phenomena

- . not knowing about symptoms
- . trying to suppress

Intervening Condition

- . relative dynamics
- . medication
- . other abuses
- . therapy
- . somatic symptoms
- . adherence

Strategies

- . function mode
- . caring relatives
- . managing lack of control
- . social disclosure
- . substance abuse
- . persistence
- . dissociation

Conclusion

- . collapse
- . feeling exhausted

Consequences

- . surviving
- . hope
- . social disclosure
- . suicidality
- . inpatient treatment

Discussion

- The participants did not know about their symptoms or their diagnosis for many years.
- The process of symptom management is extremely exhausting for the participants and they feel left alone with it.
- Inpatient treatment has been described as necessary for being able to engage with their therapy and their feelings.
- The results can serve as focal points to develop and research new interventions for improving symptom management and their quality of life.

Limitations

- Theoretical saturation has not yet been achieved.
- Possible bias through inpatient treatment.
- Personal experience and knowledge may influence the conclusions related to research problem.
- Investigation of causality not possible.

Thank you!

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