Coping with alcohol use disorders: a consumer’s perspective

Anja Bischof, Miriam Brandes, Tjorven Stamer, Hans-Jürgen Rumpf, Gallus Bischof

University of Lübeck, Department of Psychiatry and Psychotherapy
Conflict of interest

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Background

• Treatment utilization of specialized care in addictive disorders is rather low compared to other psychiatric disorders (SAMHSA, 2018; NCS-R, 2004)

<table>
<thead>
<tr>
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<th>Adults (18years+)</th>
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<tbody>
<tr>
<td>Addictive disorders</td>
<td>19.2%</td>
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<tr>
<td>Depression</td>
<td>64.8%</td>
</tr>
<tr>
<td>Anorexia Nervosa</td>
<td>33.8%</td>
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<tr>
<td>Any psychiatric disorder</td>
<td>43.3%</td>
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• Treatment of specialized care for addictive disorders increases recovery rates (Cunningham, 2005; Dawson, Grant et al., 2006)
Predictors of treatment utilization

- Severity of the disorder, psychosocial problems caused by consumption (Dawson, Goldstein et al., 2012)
- Impairment of the overall level of functioning and psychiatric co-morbidity (Rehm, Manthey et al., 2015)
• Structural factors (Mojtabai, Chen et al., 2014)
  ▪ Financial obstacles
  ▪ Limited accessibility

• Obstacles based on attitude (Schuler, Puttaiah et al., 2015)
  ▪ Self-perception: Treatment isn’t necessary
  ▪ I want to solve this alone

• Stigmatization (Schuler, Puttaiah et al., 2015)
  ▪ In particular: females with AUDs (Verissimo and Grella, 2017)
Perceived Need for Substance Use Treatment among People Aged 12 or Older Who Needed but Did Not Receive Specialty Substance Use Treatment in the Past Year: 2018

- 392,000 Felt They Needed Treatment and Made an Effort to Get Treatment (2.1%)
- 573,000 Felt They Needed Treatment and Did Not Make an Effort to Get Treatment (3.0%)
- 17.9 Million Did Not Feel They Needed Treatment (94.9%)

[Image]
Reasons for Not Seeking Help

• Intervention studies with the aim to increase treatment utilization were not successful so far (Glass, Hamilton et al., 2015)

• Compliance and Outcome can be improved if shared-decision-making concepts are applied (Friedrichs, Spies et al., 2016)
  ➢ Condition => Willingness to change behavior/Consideration of treatment seeking

• Knowledge of reasons for not seeking help (RFNSH) is insufficient
  ➢ Development of questionnaires without affected persons
  ➢ Filling out a questionnaire with RFNSH requires preceding consideration of treatment seeking
    ➢ If not: Assessment of reflective knowledge, not RFNSH
  ➢ Loss of information caused by reduced assessments and standardization
The ART-COPE Study

- ART-COPE: *Alcohol-related treatment: a consumer’s perspective*

- Aims
  - Identification of processes of coping with alcohol use disorders
  - Identification of hindering and possibly facilitating factors for specialized treatment for alcohol use disorders from the perspective of alcohol addicted individuals

- Conducted by: Research group S:TEP, University of Lübeck
- October 2018 – July 2020
- Qualitative study design
Recruitment and Sample

• Sample of individuals with a medium to severe AUD with and without treatment utilization

• Recruitment within the AERIAL Study 2016-2017 (Addiction: Early Recognition and Intervention Across the Lifespan)
  ▪ Research sites: Lübeck, Greifswald, Tübingen
  ▪ Patients aged 18 to 64 in general practices and general hospitals were systematically screened

• ARTCOPE: Sumscore of at least 20 points in the AUDIT
  ▪ 39 written informed consents
  ▪ Late start of the study (different funding source)
    ➢ 2/3 not reached (contact data invalid, no permanent residence, no address research possible) or deceased
    ➢ Severity of disorder!
  ▪ Additional recruitment strategies: local gps, health department, day-care hospitals...

• To date: 13 interviews realized
Methods

1. Telephone screening for inclusion criteria
2. Narrative interviews
3. Protocol of interviews via memos
4. Verbatim transcription
5. Systematic comparison of cases
Narrative Interview

• Narrative-generating initial question on the history of the consumption patterns/the development of the dependence
• Selection of additional questions if topics are not mentioned in the main storyline of the participants
  • Where necessary: Perception of existing treatment and self-help services from the perspective of participants and possible barriers or attractors for treatment seeking
• Other important topics from the perspective of participants
Analysis

• Based on Reflexive Grounded Theory (Breuer, Muckel et al., 2018) with the software MAXQDA
  • Open coding
  • Iterative cycle discussion process
  • Selective coding

• Inductive generation of a categorical system

• Theory development
Sample characteristics

- n = 13
- Moderate to severe alcohol use disorder

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<tbody>
<tr>
<td>Female, n (%)</td>
<td>6 (46.2)</td>
</tr>
<tr>
<td>Age, M (SD)</td>
<td>44.1 (13.1)</td>
</tr>
<tr>
<td>School &gt; 10 years (%)</td>
<td>30.1</td>
</tr>
<tr>
<td>DSM-5-criteria, M (SD)</td>
<td>8.1 (2.5)</td>
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Interim analysis scheme

• Coping with the disorder
  ▪ Congruency
  ▪ Incongruity

• Treatment
  ▪ Attractors
  ▪ Barriers
Coping with the disorder

• Congruency
  ▪ Disease-immanent: Consequences of consumption, craving, repression, etc.
  ▪ Milieu
  ▪ Regulation of emotions / self-medication
  ▪ Co-morbidity
  ▪ Need for autonomy
  ▪ Loneliness => no reasons for change
  ▪ Alleged control over consumption
  ▪ Social comparison: others drink more
  ▪ Concealing (Coping with shame)
  ▪ Reduction (Coping)

• Incongruity
  ▪ Life event
  ▪ Direct negative consequences
  ▪ Feared negative consequences
  ▪ Social comparison: Others are more successfull
  ▪ Treatment for other primary diseases
  ▪ Social pressure
  ▪ Shame
Coping with the disorder

• Congruency
  ➢ Disease-immanent: Consequences of consumption, craving, repression, etc.

„And if you have an alcohol blood level of under 1 per mille, you get all jittery or if you have something to take care of and... or in town and you want to / either you postpone your appointment, or you don’t go there. Or you have to do everything as fast as possible and most of all you want to go home. Because you want to drink, that’s it.“

- PB 59.000.051, 35 years

➢ Not being able to take care of things, to change, to seek treatment because of the disorder itself
Coping with the disorder

• Congruency
  ➢ Milieu

  „In pubs, everyone boozed and I have grown up in a pub. Even when I couldn’t even walk, still sitting in a baby buggy, I could already pour a beer.“

  - PB 80.000.024, 51 years

➢ Not even thinking of change or treatment because of the social environment => drinking is normal
Coping with the disorder

• Congruency
  ▪ Loneliness => no reasons to change

„It wasn’t so bad financially, but I wasted EVERYTHING on drink. Somehow, this was my only purpose in life. Anyway, everything else was GONE. My kids were gone, I had no responsibility for anyone. I had no tasks, no one needed me.“

- PB 27.000.188, 42 years
Treatment

• Attractors
  • Solution for acute problems
  • Support by others
  • Not being alone
  • Out of everyday life
  • More information/
  • Individually adjusted help
  • Empathy + Care in the preparation phase

• Barriers
  • Disease immanent: Lethargy, comorbidity, lack of energy
  • Lack of social network
  • Lack of availability
  • Provision for pets
  • High administrative demand/mental overload
  • (Self-) Stigmatization
  • Loss of autonomy
  • Negative experiences with other services (gp, self-help group, therapy, etc.)
  • Doubts on effectiveness
  • Negative experiences of others
Treatment

• Barriers
  ➢ Disease immanent: Lethargy, comorbidity, lack of energy

„... when you are drinking that much, you don’t participate in life anymore. You are only focussing on alcohol. And than you have to go to the drug counseling service and to the pension fund and fill out the forms and have all the papers together and gather together everything and then most people give up. You say yourself: forget it, kiss my a...“

- PB 59.000.051, 35 years
Treatment

• Barriers
  ➢ High administrative demand/mental overload

„You know, it’s the middle of the month and you live on social welfare, and you haven’t enough money to go to the clinic... and you have to pack your things and what to do with the cat? How can you manage all this in 12 hours?“

- PB 59.000.051, 35 years

➢ Structural barriers:
  ➢ Financial hurdles, no transport options, who cares for the cat while he’s away
  ➢ Waiting list, treatment spot on call
Treatment

• Barriers
  ▪ (Self-) Stigmatization

„... you heard how they talk about alcoholics. And I was worrying. As I said, that everyone knew and that they babble and slander about what a bad person I am and so. No, it was really important for me what others thought. “

- PB 51.000.044, 51 years
Limitations & preliminary conclusions

• Low Generalisability

• ARTCOPE:
  ➢ gives new impulses
  ➢ assesses what standardized questionnaires didn’t
  ➢ the participants themselves set the focus
  ➢ expands knowledge on lacking motivation to change and barriers for treatment seeking
  ➢ provides insight into the function of alcohol

• RFNSH are not related to the content of treatment

Maybe: Life circumstances (Congruency) have too much influence => CRA or CRAFT approaches may have a better outcome than counselling
THANK YOU :)
Coping with the disorder

• Congruency
  ➢ Regulation of emotions / self-medication

“Alcohol was like an antidepressant for me, my depression was gone. I always had a little bit depressions. And the anxiety was gone. And afterwards, I drank out of boredom. And it became more and more [...] when I started to drink, I realized: hey cool, you are cheerfull again, a better self-confidence...”

- PB 59.000.051, 35 years
Treatment

• Barriers
  ➢ Lack of availability

„And then the ’Blue Cross’ was recommended to me. But the Blue Cross was only in [Name of City] and ... of course that was too far away."

- PB 19.000.058, 48 years