

[This is a draft for a draft for a paper and by no means complete in terms of introduction, literature, results, discussion, etc.]

Prevalence, functioning and treatment needs of family members affected by Addiction in Germany: Findings from the Burden, Expectancies, Perspectives of Addicted individuals' Significant others BEPAS study

Bischof, G., Berndt, J., Bischof, A., Besser, B., Rumpf, H.J.

Dpt. of Psychiatry and Psychotherapy, University of Lübeck

*Corresponding author: Gallus Bischof gallus.bischof@uksh.de

Abstract

Background: Family members affected by addiction (FMA) have been found to report elevated levels of stress and strain. The present study gives an overview on the prevalence of FMAs, their functioning and perceived treatment needs in Germany using a mixed-methods approach.

Methods: In the German Health Update survey GEDA, being an FMA was assessed in a representative sample of 24.824 residents aged 15 years or more. In addition, health-related variables were assessed using standardized instrument. Functioning and treatment needs were assessed in a sample of 100 FMAs recruited from self-help groups, addiction services and by proactive screening in the general health system using standardized instruments and qualitative interviews. Qualitative data were analyzed following Grounded Theory.

Results: In the general population, 9.5% of respondents reported being an FMA. Compared to non-FMAs, they reported significantly higher levels of depression and ill-health. Qualitative data showed that origins of stress varied by type of addiction, gender and relationship status towards the addicted individual. Stigmatization, lack of availability and information on treatment offers were reported as

being barriers for help seeking. Treatment needs most often endorsed were receiving behavioural guidelines for coping with the problem behavior of the addicted individual.

Conclusions: FMAs are a substantial group in the general population that is characterised by ill-health and has not been adequately addressed by the addiction treatment system. Treatment offers and policy measures should address barriers towards help seeking and provide evidence-based interventions addressing the needs of FMAs.

Background

Substance abuse and substance-related disorders affect not only consumers but also their social environment. It is assumed that, depending on the specific addictive behavior, the overall societal costs incurred, such as the damage to third parties may be considerable (Nutt, King et al. 2010), some of which are comparable to direct costs. In empirical research on the effects of addictions and problematic substance use, damage to third parties (Harm to Others, HTO) was mostly analyzed for immediate consequences such as Fetal Alcohol Syndrome, substance-associated traffic accidents, substance-induced violence, or the effects of parental addiction on children (Bellis, Quigg et al. 2015, Rossow 2015). Population-based HTOs have been increasingly used in population-based studies for over 10 years (Casswell, Harding et al. 2011, Laslett, Room et al. 2011, Laslett, Rankin et al. 2017) and were endorsed by WHO in 2010 as a priority component of the Global Strategy to Reduce the Harmful Use of Alcohol " (WHO 2011). For other substances and gambling, initial findings on HTO are also available (Taylor, Mackay et al. 2012, Svensson, Romild et al. 2013, Lund, Sundin et al. 2015). A distinction needs to be made between studies that directly assess the negative effects of third-party substance use, and studies that determine if those interviewed have a person with a problematic intake of substances in their social environment. Results on HTO, mostly based on epidemiological research, have shown high rates of negative experiences within the past 12 months due to substance use, e.g. for alcohol alone between 25% and 53% (Moan, Storvoll et al. 2015). Acute exposure such as noise pollution, fear of being intoxicated, physical harm or insult, as well as destruction of property by intoxicated persons are usually recorded. Most studies consistently showed that people reporting to

have suffered from HTO were younger, more often single and even more frequent risk users and / or intoxicants (Seid, Grittner et al. 2015). Furthermore, studies targeting individuals with substance-related problems or problematic substance use found a high proportion of respondents who said they knew someone with problematic substance use, but on the other hand, they did not experience this as specifically stressful (Marmet and Gmel 2015). These findings indicate that studies on HTO often capture rather situational experiences of individuals exposed to someone else's problematic consumption patterns with largely varying clinical significance. However, more complex social impacts, such as consequences for the social environment over a long period of time, have been taken into account only marginally (Orford 2013). Qualitative studies indicate that other factors, such as concerns about relatives are additional sources of stress (Orford, Natera et al. 2005), which can also contribute to chronic stress and depressive developments, especially when levels of human resources and resilience factors are low (Orford, Velleman et al. 2010).

Negative effects of addictions on the health of relatives have been consistently demonstrated. In Family Members affected by Addiction (FMAs), increased rates of victimization, injuries, mood disorders and anxiety disorders, a reduced overall health status, significantly increased medical treatment costs and productivity losses were demonstrated compared to people with comparable life situations without addicts (Dawson, Grant et al. 2007, Orford, Velleman et al. 2013, Salize, Jacke et al. 2014). Insurance data from the US also shows that the significant increase in general medical treatment costs of FMAs compared to individuals not affected by addiction in the family (FMNAs) are associated with the abstinence of addicts of the reference population, i. e., evidence suggests that increased morbidity and treatment needs are a direct consequence of the addiction present in the family (Ray, Mertens et al. 2009, Weisner, Parthasarathy et al. 2010). However, the overall social health effects on relatives can not yet be assessed satisfactorily since there are no representative figures on the number of relatives of addicts and their health impairments.

The focus of the project "Burdens and Perspectives of Affected Addicts (BEPAS)" was an extended understanding of the strain of FMAs, their support needs and possible barriers to help-seeking using a

multi-methodical approach. This should include the development of an integrative model for the conceptual understanding of the psychosocial situation in terms of burdens and resources of addicts. Another aim was to include FMAs with special regard to gender, the type of relationship and the form of addiction in order to allow drawing conclusions on subgroup-specific burden and needs. In addition, specific expectations and barriers regarding the use of professional assistance should be explored from the point of view of those affected. Within the framework of the representative survey German Health Update GEDA (in cooperation with the Robert Koch Institute), the extent of the problem, the health impairment as well as the use of medical care services by relatives were to be determined. In addition, qualitative data of FMAs recruited in self-help groups and addiction-related treatment/counseling settings were contrasted to FMAs identified via systematic screening in primary health care in order to identify treatment barriers and needs in FMAs currently not involved in help-seeking.

Methods

GEDA-study

As part of a cooperation with the Robert-Koch-Institute, three questions on the stress situation of relatives of addicts could be integrated into the Germany-wide Health in Germany (GEDA) Survey, in order to estimate the overall prevalence of FMAs in the general population. Participants were asked whether they had an family member suffering from addiction, whether the addiction had persisted within the last 12 months or had been overcome more than 12 months ago, the specific type of addiction and the status of relationship towards the addicted individual. Using the GEDA data, the stress situation of relatives could be determined on the basis of a representative sample. The survey took place from November 2014 to July 2015. About 20,000 people were interviewed who live in Germany and were at least 15 years old at the time of the survey. For this purpose, all persons drawn on the basis of a residents' registration office sample were invited to participate. Within the scope of this survey, a representative sample of N = 24,824 persons in 2 waves was comprehensively questioned by means of standardized questionnaires on health impairments, health behavior and utilization of medical services, including the PHQ-8 as a measure of depression (Kroenke, Strine et al. 2009). The

questionnaires could be processed online (Self-administered Questionnaire-Web SAQ-Web) or by mail via paper-pencil (SAQ-Paper). The participant flow for the total sample is shown in Table 1. The response rates were calculated according to the standards of the American Association of Public Opinion Research (AAPOR, 2016). Of the 24,824 questionnaires, 11,253 were collected via SAQ-Web (45.3%) and 13,571 via SAQ-Paper (54.7%). The response rate 1 (number of completed questionnaires divided by all contacted persons including those with unknown availability) was 27.6%, the refusal rate was 6.7%. The refusal rate results from the number of persons who refused to participate in an interview or who dropped off the interview. A detailed description of response rates by age group and gender is shown in Table 2.

Table 1: Participant flow of the GEDA-study

	N	%
Total Sample	92.771	100
Not eligible (NE)	2.802	3
Adjusted total sample	89.969	100
Completed Interviews (I)	24.824*	27,6
Eligible, not interviewed		
Refusal or drop off (R)	6.041	6,7
No contact (NC)	65	0,1
Other reasons (O)	1.260	1,4
Eligibility unknown, Not interviewed		
Person or adress unknown	57.669	64,1
Unknown other	110	0,1

*11.253 SAQ-Web und 13.571 SAQ-Paper-Interviews

Table 1: Response rates stratified according to age and gender.

Age group	Men		Women		Total sample	
	N	Response (%)	N	Response (%)	N	Response (%)
15-17	397	24,5	437	27,4	834	25,9
18-24	951	22,4	1396	35,0	2347	28,5
25-34	1322	22,7	1800	32,1	3122	27,3
35-44	1603	21,1	2183	28,8	3786	25,0
45-54	2372	26,3	2897	32,2	5269	29,2
55-64	1693	30,1	1980	33,2	3673	31,7
65-74	1692	35,4	1692	31,9	3384	33,6
>= 75	1226	25,9	1183	15,7	2409	19,7
15+	11256	25,9	13568	29,2	24824	27,6
18+	10859	26,0	13131	29,2	23990	27,7

BEPAS-study

The project “Burden, Expectancies, Perspectives of Addicted individuals’ Significant others (BEPAS)” was a model project with a mixed-method-approach over 24 months. For the interviews PB was gained through two different recruitment strands, on the one hand with the help of cooperating self-help groups and addiction counseling centers, and on the other hand through proactive screening in medical practices and hospitals. The recruitment through cooperation partners of the self-help took place by means of a theoretical-sampling approach, i.e. the cooperation partners were asked to specifically recruit relatives with certain characteristics (for example, with regard to gender and dependency of the addicted person). The study was not publicly advertised to ensure greater sample heterogeneity. It should be avoided that the sample would primarily consist of heavily burdened partners of people with alcohol dependence. In the second recruiting strand, the proactive approach allowed PB to be recruited, which had hitherto had no contact with the addiction help system or self-help. In the proactive recruitment, participants aged 18 to 64 in three general practices and one general hospital were screened consecutively with an i-Pad in the context of another research study. In every setting, the screening was conducted over eight weeks. If the screening was positive (i.e. the participant had a family member with an addiction problem), informations about the BEPAS study were handed out and informed consent for study participation was requested. The study procedures were carried out in accordance with the Declaration of Helsinki. The study was approved by the ethics committee of the University of Luebeck, Germany. Overall, the BEPAS sample consisted of 100 participants, 66 recruited in self-help groups and counseling services, and 34 recruited in general practices and the general hospital. In terms of gender, 78 participants were female.

Analysis

The evaluation of the GEDA data was carried out with the SPSS module Complex Samples in order to be able to take weightings into account. A weighting factor was deployed which corrects deviations in the sample from the German population structure. All analysis were carried out using SPSS 22.0.

The qualitative interviews were based on a manual following the “Stress-Strain-Coping-Support Model” by Orford and colleagues which covered a detailed description of the addiction problem, strains for FMAs, Coping mechanisms, perceived psychosocial resources as well as desires and needs concerning treatment offers. Analysis of qualitative data was based on the Grounded Theory (Glaser and Strauss 1999) and followed an iterative process between assessment and analysis: At regular and frequent intervals, team meetings took place to develop a system of categories. Interviews were not transcribed but rated based on the audio files and the protocols of the interviewers by different coders and discussed in case-conferences. In case of interrater-differences, the categories in question were discussed in the team. The final coding of the interviews is therefore based on at least two ratings, in

some cases on three to six ratings. Cohen's kappa was fair for 22 categories, moderate for 65 categories, substantial for 63 categories and almost perfect for 25 categories.

Results

GEDA-study

Prevalence rates for the total sample and for men and women are shown in Table 3. Of the 24,450 respondents who provided valid data on the presence of a relative's addiction, a total of 9.5% of all respondents reported to be FMAs by an ongoing addiction, 4.4% of the total sample reported to be FMAs by an addiction not active anymore in the previous 12 months. Women were significantly more likely to report being an FMA. Overall, among FMAs, 79.3% (95% CI 77.2-81.2) had only one relative with addiction problems, 14.1% (95% CI 12.5-15.7) named 2 relatives, another 4.6% (95% CI 3.7-5.6) identified 3 relatives. Four to seven relatives (maximum multiple choice due to item formulation) each reported less than 2% of the sample.

Table 3: FMAs in the general population

	Men (n=11147) (95% CI)	Women (n=13393) (95% CI)	Total (N=24450) (95% CI)
FMA actual	8,4 (7,7-9,1)	10,7 (10,0-11,3)	9,5 (9,1-10,0)
FMA remitted	4,1 (3,6-4,6)	4,7 (4,3-5,2)	4,4 (4,1-4,7)
No FMA	87,5 (86,7-88,3)	84,6 (83,9-85,4)	86,1 (85,5-86,6)
Relationship to IP (lifetime)*			
Partner	1,3 (1,1-1,6)	2,6 (2,3-3,0)	1,9 (1,7-2,1)
Child	3,2 (2,8-3,6)	4,8 (4,3-5,2)	4,0 (3,7-4,3)
Parent	1,2 (0,9-1,4)	1,7 (1,4-2,0)	1,4 (1,3-1,6)
Sibling	2,6 (2,2-3,0)	2,8 (2,5-3,2)	2,2 (2,0-3,0)
Other	5,7 (5,1-6,2)	4,9 (4,5-5,4)	5,3 (5,0-5,6)
Type of dependence (lifetime)*			
Alcohol	9,8 (9,1-10,5)	12,6 (12,0-13,3)	11,2 (10,8-11,7)
Cannabis	2,2 (1,8-2,7)	2,4 (2,0-2,8)	2,3 (2,0-2,6)
Other illegal Drugs	1,6 (1,4-2,0)	1,8 (1,5-2,1)	1,7 (1,5-1,9)
Prescription drugs	0,9 (0,7-1,2)	1,0 (0,9-1,3)	1,0 (0,8-1,2)
Gambling	1,0 (0,8-1,3)	1,1 (0,9-1,4)	1,1 (0,9-1,3)

Others	0,8 (0,6-1,1)	0,9 (0,7-1,1)	0,9 (0,7-1,0)
--------	---------------	---------------	---------------

* multiple entries possible

Sociodemographic and stress-related factors are shown in Table 4. FMAs of IPs with current dependence are significantly younger and more often female, followed by those with relatives with remitted symptoms. The average age was highest in FMNAs. Since these variables are associated with stress factors, analyses were controlled for age and gender. Consistently, FMAs faced with ongoing addiction reported the lowest health indicators, followed by FMAs faced with remitted addiction. FMAs reported lower life satisfaction, poorer subjective health, lower overall self-efficacy, and higher PHQ-8 sum scores compared to FMNAs. In addition, relatives reported lower overall social support and were more likely to ever have been diagnosed with depression. The odds ratio of ever having been diagnosed with depression compared to FMNAs was 2.2 (95% CI 1.9-2.5) in the group of relatives of people with current symptoms and 1.9 in the group with remitted symptoms (95% CI 1.6-2.3).

Table 4: Sociodemographic and stress factors according to recency of addiction

	CD* (n=2.286)	RD* (n=1.091)	NA* (n=21.163)	P**
Alter (SE)	39,8 (0,39)	44,3 (0,64)	50,0 (0,15)	<.001
Female (%)	56,9	54,2	50,1	<.001
Satisfaction with life (SE)	6,8 (0,06)	7,1 (0,08)	7,5 (0,02)	<.001
Subj. Health status (SE)	2,5 (0,02)	2,3 (0,03)	2,2 (0,01)	<.001
PHQ-8 Sum (SE)	5,9 (0,15)	5,0 (0,18)	3,8 (0,04)	<.001
Self-efficacy (SE)	9,1 (0,06)	9,1 (0,09)	9,3 (0,02)	.002
Sociale support low (%)	23,7	19,5	17,3	<.001
Ever Depression diagnosed (%)	19,9	18,5	11,0	<.001

* Current dependence CD; Remitted dependence RD; No AFM NA

**Adjusted for age and gender

Non-overlapping categories were established in relatives without consideration of the remission status and statistically controlled by age, gender and remission status using multivariate methods to analyze differential stress factors as a function of dependency and relationship status. For the variable relational type, relatives in partnership with the IP were classified as "partners", parents without affected partner as "parents", children without affected partner or children "children" and all other forms of relationships as "others". The results for relationship type are shown in Table 5.

Parents of addicted children and partners of addicts were significantly older. In terms of gender distribution, the proportion of women in the group of partners was highest, and lowest in the category

of "other relationships". The groups did not differ in terms of the proportion of IP, whose dependency remained in the past 12 months. Furthermore, partners and children of addicts reported more frequently of their IP being addicted to alcohol, while parents reported more cannabis addiction and dependence on other illicit drugs. In addition, children were significantly less likely to report gambling problems than the other groups and the dependence on other illicit drugs except cannabis. Controlling for age, sex, and addiction only resulted in a group difference in life satisfaction that was least pronounced among partners and highest in parents.

Table 5: Sociodemographic and stress factors according to type of relationship

	PA* (n=504)	PT* (n=320)	CL* (n=944)	OT* (n=1.632)	p
Age (SE)	50,0 (0,87)	57,9 (0,99)	35,8 (0,49)	38,6 (0,46)	<.001
Weiblich (%)	69,0	58,8	60,3	49,2	<.001
Aktuelsymptomatik (%)	68,9	67,3	67,4	69,0	.879
Type of dependence (lifetime)*					
Alcohol	84,2	60,2	91,6	77,4	<.001
Cannabis	14,9	32,1	8,4	18,4	<.001
Other illegal Drugs	10,5	19,3	5,6	15,1	<.001
Prescription drugs	8,8	5,0	9,9	5,5	.002
Gambling	9,5	8,3	4,8	8,6	.030
Other	5,6	11,1	5,4	6,0	.035
Satisfaction with life (SE)	5,9 (0,22)	6,6 (0,24)	6,2 (0,21)	6,4 (0,20)	<.001**
Subj. Health status (SE)	2,6 (0,06)	2,5 (0,08)	2,4 (0,7)	2,4 (0,6)	.211**
PHQ-8 Sum (SE)	8,4 (0,45)	7,9 (0,47)	8,1 (0,44)	7,8 (0,41)	.288**
Self-efficacy (SE)	8,7 (0,21)	8,8 (0,23)	8,8 (0,20)	8,9 (0,18)	.590**
Sociale support low (%)	24,4	23,3	22,9	21,4	.386**
Ever Depression diagnosed (%)	22,5	25,0	21,3	16,7	.247**

*(Partner PA, Parents PT, Children CI, Others OT)

** Adjusted for age, gender and type of addiction

In a next step, non-overlapping categories for the type of dependency form were formed to analyze the influence of different forms of addiction. For this purpose, the six different forms of dependency recorded in the GEDA questionnaire were used and, if more than one dependency form was affirmed, an additional variable "multiple dependency" was formed. This was the second most frequently named category after singular alcohol problem. Sociodemographic and stress factors are shown in Table 6.

Table 6: Sociodemographic and stress factors according to type of addiction

	AL* (n=2.231)	CA* (n=138)	ID* (n=96)	PD* (n=64)	PG* (n=72)	SO* (n=127)	MD* (n=650)	p
Age (SE)	42,9 (0,39)	38,7 (1,82)	41,4 (1,84)	45,7 (2,80)	42,6 (2,08)	36,2 (2,0)	37,5 (0,78)	<.001
Female (%)	58,1	48,7	52,3	42,5	49,9	57,3	54,6	.206
Current symptomatic (%)	64,4	74,0	54,2	77,7	74,1	80,8	79,0	<.001
Relationship to IP (lifetime)**								
Partner (%)	14,4	5,6	6,7	19,9	15,6	10,9	13,5	.114
Child (%)	33,2	6,5	9,2	32,6	18,2	17,6	27,8	<.001
Parent (%)	6,6	24,1	21,1	6,0	15,6	24,8	14,7	<.001
Sibling (%)	15,1	33,8	21,2	16,4	20,1	17,2	31,0	<.001
Other (%)	35,0	32,2	43,4	28,7	35,6	34,3	51,4	<.001
Satisfaction with life (SE)	6,5 (0,29)	6,1 (0,36)	6,5 (0,33)	6,4 (0,39)	6,5 (0,43)	6,2 (0,37)	6,1 (0,52)	.255***
Subj. Health status (SE)	2,5 (0,8)	2,5 (0,1)	2,5 (0,11)	2,4 (0,11)	2,7 (0,13)	2,3 (0,10)	2,6 (0,7)	.005***
PHQ-8 Sum (SE)	6,7 (0,65)	7,2 (0,74)	6,4 (0,73)	6,7 (0,95)	7,7 (0,82)	6,9 (0,77)	8,2 (0,55)	.003***
Self-efficacy (SE)	8,5 (0,28)	8,4 (0,36)	8,6 (0,34)	8,5 (0,39)	8,8 (0,40)	8,4 (0,35)	8,3 (0,26)	.458***
Sociale support low (%)	20,2	29,0	15,4	25,4	32,8	21,3	27,3	.460***
Ever Depression diagnosed (%)	17,4	17,6	12,2	30,0	25,4	18,0	26,4	.442***

* (Alcohol AL, Cannabis CA, other. Illegal Drugs ID, Prescription drugs PD, Pathological Gambling PG, Others OT, Multiple Dependence MD)

** multiple entries possible

*** Adjusted for age, gender and type of relationship

Relatives of addicts with a singular problem with cannabis and other illicit drugs as well as people with multiple addictions were significantly younger. In addition, members of people with singular problems of "other illegal drugs" reported more often that the problem was more than 12 months ago. There

were marked differences in the relationship status between the groups: people with cannabis, other illicit drugs and multiple forms of dependency were more likely to be parents, siblings and "other relatives". For relatives of people with "other drugs" dominated parents and "other relatives".

In multivariate analysis, with control of age, sex, type of relationship and timeliness of symptoms, people with multiple dependency reported significantly higher levels of depression, and those with "other substance use" reported better subjective health than other relatives.

BEPAS

About one-third of the total sample was recruited via a proactive screening in doctors' offices. This sub-sample of the pro-actively recruited relatives (PA) was at the time of the interview with two exceptions still not in contact with the addiction help system and thus largely untreated. Two of the PA reported having had contact to an addiction counseling center, no-one reported to have had contact with a self-help group.

There were clear differences between the PA and the Reactively recruited FMAs from the addiction treatment system/self-help groups (RA) with regard to the type of relationship and the type of dependency, so that the two groups could only be compared to each other in a limited manner by multivariate methods. Many of the PAs participated as adult children of addicted parents, while the RAs mainly consisted of partners and parents. In comparison to the RA, they also significantly less often lived together with the addicted family member. As a result, the frequency of contact and the proximity of the relationship with the addicted family member were lower. These differences in the relationship type were taken into account when comparing the two sub-samples. In addition, differences in the type of addiction were also apparent. The PA reported less often being exposed problems and effects of pathological gambling, cannabis use and other illegal drugs. The proportion of alcohol, cannabis and drug-dependent IP in the PA was higher. While parents of cannabis-consuming children were not represented in PA, children of alcohol-consuming parents were rarely found in RA. Overall, 56% of PA reported problematic alcohol use in IP (compared to 37% in RA), followed by multiple addictions (29% vs. 42% in RA), cannabis and pathological gambling (6% each vs. 18% and 0% in RA).

Burdens and coping mechanisms of untreated relatives

Looking at the comorbid diseases of IPs, it is striking that the PA had to deal more with somatic diseases and dementia and less with IP's psychotic diseases and ADHD. Here, the high proportion of children of addicted parents of this subsample may have played a role. Above all, older addicted family members in addition to their alcohol and drug use often were struggling with severe physical complaints, mostly associated with a longer history and chronicity of addiction. This problem is reflected in the pronounced concern of the children for the health of their addicted parents. In this respect, PA had to deal less with

financial problems of the IP, as they did not take over responsibility for their addicted family members concerning financial issues as children or siblings. The general burden on the family, social and professional life was less pronounced, because only a relatively small share lived with the addicted person. Also, the problem of finding a common way of dealing with the addicted family member within the family or partnership was less relevant. However, some specific stresses and strains were more pronounced in Pas, like a high proportion reporting parentification and neglect during their childhood. This distinctive feature is likely to be primarily related to the high number of children of addicted parents.

"There were also very strange things happened and there I was so sad, my parents have offered me eggnog when I was five years old. So when I think about it from today's perspective, it's so crazy, they offered it to me to make me feel better again [...] I see my mother lying on the bed, my father was also completely drunk, my mother lying on her bed anyway, she drank so much that she was really sick. At the age of five, I was totally on my own, so to speak, I thought my mother was dying. [...] For example, I had to go through occupational re-training on my own, because at the age of 10 I was considered grown up. So, everyone sat with their parents and I was sitting there alone somehow. I'm surprised that nobody ever stumbled over it. [...] It was bad for me to sit there, everyone had their parents, but I did not thought of this as strange, it was pretty normal. "

(Daughter, 47 years, alcohol)

Similar to the case described above of the daughter of an alcoholic mother, stress situations were frequently reported that had long since disappeared and hardly had any influence on the everyday life of FMAs. Their reports concerning experiences of violence often referred to events that were very distant. However, in some cases, the memories were still a burden. There was no significant difference between RA and PA in terms of exposure to verbal violence and IP aggressiveness. There were also very few differences regarding the deviant behavior of the IP in the form of threats and vandalism. In terms of physical violence, about one out of every four PA reported such experiences, which is slightly more often than in RA.

"My father used to be that way, that he came home at night, totally drunk, and then rioted, rioted, beat everything up. In principle, my mom says now, he probably lost all his money in gambling, then came home, and had to do something so that no-one approached him and therefore he really made a fuss. Two to three times the police had to come, but then it is really a massacre, he breaks everything, beats everything "

(Daughter, 27 years, alcohol and pathological gambling)

In addition, the emotional unpredictability of the addicted family member seemed to be an important burden in PA, while financial problems or withdrawal of the IP from everyday affairs played less of a role. The greater distance to the IP is also likely to be a main reason that effects on a psychosomatic

level are lower compared to RA: Depression, sleep problems and, above all, the feeling of stress were significantly lower. However, PA reported twice as often that the addiction problem had a negative impact on the health of other family members. In other words, in many cases, other family members were obviously burdened and possibly more heavily burdened.

On the cognitive-affective level, the PAs were less burdened overall. There were fewer worries about the future of the addicted family member, presumably because no parents were among the PA sample, and worries about the future were particularly pronounced in the parents of addicted children in the RA sample. The fear of relapse also seemed to play less of a role. The same was true for feelings of guilt. Since most of the PA did not live with the addict and had limited influence on their addictive behavior, feelings of blame were less pronounced. However, some stress components were more pronounced in PA, such as pronounced concerns about the health of the addicted family member. These concerns were particularly pronounced in the group of children and siblings, which made up over two-thirds of the PA. In addition, the type of addiction may play a role here. As the PA were mostly concerned with the effects of alcohol, health problems were very prevalent in their addicted family members. On the one hand, children of alcoholic parents worried about the physical decline caused by consumption, but also often expressed the fear of possible accidents and falls in the IP in intoxicated state. RAs were more commonly concerned with cannabis use and pathological gambling, two forms of addiction less associated with physical discomfort.

"My biggest burden or fear is that someday someone will call and say there's something wrong with my dad. [...] That then I have to take care of a person to whom I actually had no contact for years, and who may then still have an alcohol problem. [...] On the one hand, I care that something happens to him, on the other hand, that I have to deal with the topic even more".

(Daughter, 39 years, alcohol)

It was also noticeable that the PA felt more pity in the face of the state of the IP. The usually more distant relationship with the IP meant that the problems were more from the perspective of an outsider and less related on their own. Accordingly, attempts to cope with the addiction were less pronounced. In particular, control mechanisms played a relatively minor role. Monitoring and control of the consumer's behavior did not take place in most cases because separate households or predominantly telephone contact did not allow this. Many PA reported that over the years, they had developed an emotional distance from the IP and a sense of resignation. Especially among children of addicted parents, the problems were already existent for such a long time, most of them did not believe in possible coping mechanisms to face the addiction. Almost one-third of the PA said in the interviews that they had come to terms with the addiction of the IP or accepted it. Especially siblings reported an increasing acceptance concerning the addictive behavior of their sister or brother. There were also

those who saw no problem in the (usually alcohol) consumption of the affected family member since the beginning. For these PA, consumption was neither a burden for the addicted individual nor for other relatives as long as certain consequences (e.g. job loss, crime or physical impairment) did not happen.

"We tried everything imaginable, we were with many doctors. At some point you have to find a way that both sides can come to terms with. It's just like that now, I enjoy the time I still have with him. He is old enough. [...] I know that it does not help. He just needs it. We just hope it's going to be okay for a long time. "

(Foster daughter, 30 years, alcohol)

Barriers in getting help from untreated relatives

Overall, the burden of the PA appeared to be lower. Accordingly, some felt no need to seek help and were fine to deal with the topic on their own. For others, support from family and friends was sufficient and served as a kind of substitute for professional assistance. However, there were also a number of severely affected PAs who expressed very personal and specific support needs. The barriers that have kept this group from seeking help and their needs are discussed in more detail below. Some of the PAs referred to the support they needed earlier, but at the time of the interview no longer felt a personal need for support. These retrospective descriptions were taken into account in the evaluation of the needs of untreated FMAs.

The main hurdle in finding professional help in both groups (PA as well as the RA) was fear of stigmatization. Some pointed out the bad image of FMAs in the public discourse. As FMA, one would have to deal with rejection and people would quickly turn away from one. Compared to depression as another psychic disorder, addiction is much more associated with shame. There is no lobby for addicts, therefore it is even more difficult for relatives to receive empathic understanding. In part, FMAs reported that friends and acquaintances did not want to get to know their addicted family members. Outsiders would wonder how someone could volunteer to spend time with an alcoholic and fall for addicts again and again. Therefore, conversations involving addiction were partially avoided by the FMAs. FMAs are often accused of weakness, because they have "enabled" the addiction.

"By the way, the one doctor who gave the lecture last week said: 'We have no lobby for addiction help'. [...] Depression is really on everyone's lips, but addiction? Addiction? [...] So I think it's quite, very difficult for relatives or for those affected, then there to get out, so because it is then shameful, much more shameful, for example, as a depression, because not so recognized. "

(Daughter, 47 years, alcohol)

Partly unpleasant questions were feared by addiction counselor, like to what extent the addiction was indirectly supported or what AFMs have been done to effectively cope with it. One FMA reported

figuring to be watched by friends while visiting an addiction help facility. This idea was so embarrassing to her that she had never dared to make her way into addiction counseling. In addition, some were worried about disclosing details of privacy to strangers. Also, the idea of having to sit in a self-help group and having to face the private problems of others was perceived as difficult. Some feared being pulled down by the fate of others.

Another important aspect that served as a barrier to finding help is time. The time required to visit addiction counseling centers or self-help groups, including the arrival and departure times, caused some relatives not to take advantage of support services or to cancel them early. Partly conflicting consultation times with work commitments were mentioned. Some reported to have other, more important things in between, or to have set other priorities. Some reported that their desperation was simply not enough to seek professional help. Furthermore, several FMAs were not even aware that there is specific help for them and so far did not think about looking for help offers. "I do not really know how the help system works, I have to admit," reported the daughter of an alcoholic father. She would have found proactive information helpful. Another daughter saw a significant barrier in the lack of provision of services for children of addicted parents.

"The help system did not work for me. But it's still like that, for example, group offers for children of addicted parents are still very rare. For example, I was totally scared when I heard that there is not an offer in B. [City], not a single, in such a big city. "

(Daughter, 47 years, alcohol)

Additional uncertainty in the search for professional help contributed to doubts about the severity of consumption. When relatives felt unsure if the substance use behavior of their family member met the criterion of a serious addiction, they were less inclined to seek help. The sister of a drug addict reported her general doubts about the competence of the help system, since her mother did not feel welcome there as an FMA when she was seeking help. Advice regarding the need to withdraw from the addicted family member would have been of little help to them. On searching the Internet, she found mainly information she did not perceive as helpful. She reported that information from doctors and psychiatrists about treatment offers for relatives would have been helpful. The communication behavior of psychiatrists and lack of specific information for FMAs made it difficult to find adequate coping strategies to deal with the situation. The mother of an addicted daughter also expressed fears that she would have to break with her daughter through professional help. Advice from addiction counselors could come between her and her daughter, for example if she were asked to stop giving money to the child. For some FMAs, seeking help was associated with personal weakness and was avoided if it was not absolutely necessary. Some FMAs also reported their inclination to solve problems on their own.

Support needs and wishes of untreated relatives to the help system

The perceived support needs of PA were very heterogeneous. Some did not see any need for treatment for FMAs in their own right and focused exclusively on treatment for the addicted family member. Some of them found it difficult to understand their personal needs and wishes, and many supported rather general preventative measures that currently had little or no effect on their personal situation. Others had a variety of ideas on how to improve their personal situation. Several of the FMAs began to think about personal needs concerning professional support for the first time during the interview. Some reported they simply never were asked about their needs, like the niece of a cannabis-dependent uncle: "I have been waiting for this question all my life".

Similar to the case of the RA, the PA mainly wanted to have a reliable contact person, someone who could give concrete help in dealing with the addictive behavior of their family member. Some wanted a trustful person, who could objectively assess and guide them through difficult situations at home. They hoped to learn guidelines on what should (and shouldn't) be addressed in certain situations.

"For example to receive instructions on how to behave properly. This is always the most important issue for me. 'How do I do it right? How do I do it wrong? Can I let him fall? I know such things as gossip 'yes, they must first be in the dirt and recognize it themselves'. But that's all hearsay, so I would like to know from a competent person, although I do not even know if those are competent people or if they have only personal experiences or if one simply exchanges experiences. I would imagine that there is at least enough to help you realizing that you are not alone. [...] Yes, that somebody just shows me the way and says, either there is no point in keeping still now, for example, and if it [drinking behavior] does not change, tells me "you do not have to have to feel guilty if you put a 70 year old on the street".

(Female partner, 55 years, alcohol)

There was also a desire to receive help from "experts" who have already experienced and survived a similar situation. A sister of drug-addicted brothers hoped by conversations with a counselor to learn skills, influence cognitive processes and be able to mentally free herself from concrete problem situations. Also a kind of mediator, where FMAs and their addicted family members could show up together was rated as helpful. Above all, help in the context of a four-eyes conversation seemed to be the most preferred setting. The idea of a group discussion was a frightening for some. In addition, mediation and intervention within the whole family could be helpful with the addict.

Repeated suggestions were made on how public relations could increase the public visibility of help offers. Often, these ideas were voiced by relatives who needed help at a given time, but had no knowledge of existing offers. Public awareness could be improved by distributing leaflets and flyers. It is also important to convey that help is not necessarily associated with costs. Also, hanging posters in doctors' offices and reports in pharmacist magazines could increase reach of FMAs. In addition, a more

sophisticated media coverage of addictions was perceived as desirable. Media should refrain from using negative stereotypes of individuals suffering from addiction like e.g. "drug junkies". Large-scale campaigns using posters, newspaper articles and television reports could bring about changes in the way addiction is perceived and dealt with. In addition, stigma might be reduced by encouraging an open discourse about addiction. Other relatives saw a problem in the alcohol industry itself that, for example, makes money from selling alcopops to adolescents and thus promotes the development of dependencies. Stronger state-driven alcohol control policies were perceived as useful.

As another important starting point for promoting knowledge regarding addiction campaigns in school were mentioned. Pupils should be educated by instructors and leaflets. It is important to recognize early signs of dependency, and information should be provided, inter alia, by individuals who have been affected by addiction themselves. Overall, Pas raised the issue that there are too few help offers for children of addicted parents. For example, the daughter of an alcoholic father reported that at her school, all addiction counseling services were directed only at addicts, but no help was offered to FMAs.

Discussion

The data from the GEDA study allow for the first time an estimate of the prevalence of relatives of addicts in the general population. Of the German general population aged 15 and above, 9.5% said they had a relative with an existing addiction problem in the past 12 months, another 4.4% said they had a relative with a long-term dependency. Extrapolated to the total population aged 15 and above of 71.3 million persons (Federal Statistical Office, 2016), this corresponds to approximately 6.8 million persons (95% CI 6.94-7.13) with an actual dependency and a further 3.1 million persons (95% CI 2.9-3.4) with remitted dependence. In accordance with international findings (Orford, Velleman et al. 2010, Orford, Velleman et al. 2013), FMAs reported higher levels of stress and reduced resources, with FMAs by current addiction having the highest burden, followed by FMAs affected by remitted dependency. Although the relationships do not allow causal conclusions, they suggest a strong association between the recency of the dependence problem and the gravity of stress and strain and correspond to the results of American analyzes on the basis of insurance data, according to which the psychosocial burden of partners of alcohol-dependent men after successful treatment decreases (Weisner, Parthasarathy et al. 2010). Overall, the findings confirm the high public health relevance of the topic.

As expected, alcohol was by far the most popular form of addiction, followed by cannabis and other illicit drugs. It should be noted here that the assessment is self-reported as to whether there is a dependency on one or more relatives, i.e., the figures are not based on a standardized diagnosis of the relatives. Accordingly, they reflect the perception of the subjects, which is likely to express themselves in more or less clearly observable symptoms, depending on the type of addiction. The distribution reflects differences in the prevalence rates of the two disorders in the comparison of the two forms of

alcohol / drug dependence (Pabst, Kraus et al. 2013). The significantly lower mentioning of dependence on prescription drugs compared to the estimated prevalence rates of alcohol and drug addiction was striking, given that the prevalence estimates in Germany suggest similar rates of PD dependence compared to alcohol dependence (Pabst, Kraus et al. 2013). It can be surmised that this form of dependency is more likely to remain undetected by relatives, at least for longer periods, especially if the medication has been prescribed for a long time by a doctor because of existing medical conditions.

The comparisons of the different forms of relationships and the type of dependence were characterized by a pronounced interaction between the two parameters. For example, comparison of FMAs by type of relationship and type of dependency revealed a significant accumulation of drug-related disorders (cannabis, other illicit drugs) for addiction problems in one's own child. Also, drug-related problems, including cannabis, have been reported more often by participants who were either partner or children of individuals suffering from addiction. It can be assumed that, on the one hand, parents, siblings and other family relationships are more sensitive to drug-related addiction problems than to alcohol-related problems. On the other hand, cohort effects may also play a role here, as the addicted family members are assumed to be younger in these two groups, which increases the likelihood of consuming other, including illegal, substances than alcohol. In addition, Swiss epidemiological data suggest that family-related drug-related problems are more onerous, although this study was not restricted to dependency (Marmet and Gmel 2015).

It should be noted, however, that the GEDA data only allow a rough assessment of specific stress factors and effects on the relatives. A survey of further characteristics of the IP or addiction-specific stress reactions of relatives was unfortunately not possible within the framework of the GEDA study. However, findings show that asking specifically for addictive disorders in family members leads to smaller endorsement rates compared to negative experiences due to other's drinking/substance use, survey participant's endorsing addiction problems in the family reveal elevated rates of depression as a clinically relevant issue. Findings suggest that the elements of the Coping-Support-Stress-Strain Model should also be analysed in detail using unselected FMAs recruited from the general population.

For the first time, the BEPAS study investigated the generalizability of findings among help-seeking relatives. As expected, we found that relatives recruited in the help system (including self-help) usually represented partners or parents, while other forms of relationships were clearly underrepresented there. In addition, relatives recruited in self-help reported significantly more often about drug-related problems of their IP. Thus, relatives seeking help represented a particularly high-burdened group within the family, which was expressed multivariate in increased values of the Family Members Assessment Scale and reduced health (despite significantly higher social support). The results correspond to self-selection effects in media-recruited alcohol addicts (Rumpf, Bischof et al. 2000). Accordingly, findings

obtained from relatives of the help system and / or self-help can not be transferred to the whole group of FMAs. Furthermore, due to the more extensive quantitative subgroup comparisons, given the only slight differences between various groups of relatives described in the literature (Orford, Natera et al. 2005), it may be assumed that the restriction to heavily burdened relatives from treatment/self-help group settings or volunteers recruited via media solicitation in previous studies could have led to a bottom effect masking differences between groups.

Despite the limitations mentioned, several conclusions regarding strategies aiming to improve the situation of FMAs can be drawn:

1. Stigma is an important Barrier for seeking help in FMAs that needs to be addressed
2. Improving visibility of help offers for AFMs and raising public awareness on stress and strain FMAs are faced with might specifically decrease shame and fear
3. Proactive approaches that might be implemented e.g. in primary healthcare might optimize the reach of FMAs
4. Individual needs of FMAs might be addressed by improving networking between different health sectors and providing/implementing person-centered help offers

References

- Bellis, M. A., Z. Quigg, K. Hughes, K. Ashton, J. Ferris and A. Winstock (2015). "Harms from other people's drinking: an international survey of their occurrence, impacts on feeling safe and legislation relating to their control." *BMJ Open* **5**(12): e010112.
- Casswell, S., J. F. Harding, R. Q. You and T. Huckle (2011). "Alcohol's harm to others: self-reports from a representative sample of New Zealanders." *N Z Med J* **124**(1336): 75-84.
- Dawson, D., B. F. Grant, S. P. Chou and F. S. Stinson (2007). "The impact of partner alcohol problems on women's physical and mental health." *Journal of Studies on Alcohol and Drugs* **68**: 66-75.
- Glaser, B. G. and A. L. Strauss (1999). *Discovery of Grounded Theory. Strategies for Qualitative Research*. New York, Routledge.
- Kroenke, K., T. W. Strine, R. L. Spritzer, J. B. Williams, J. T. Berry and A. H. Mokdad (2009). "The PHQ-8 as a measure of current depression in the general population." *J Affect Disord.* **114**: 163-173.
- Laslett, A. M., G. Rankin, O. Waleewong, S. Callinan, H. T. Hoang, R. Florenzano, S. Hettige, I. Obot, L. Siengsounthone, A. Ibanga, A. Hope, J. Landberg, H. T. Vu, T. Thamarangsi, D. Rekve and R. Room (2017). "A Multi-Country Study of Harms to Children Because of Others' Drinking." *J Stud Alcohol Drugs* **78**(2): 195-202.
- Laslett, A. M., R. Room, J. Ferris, C. Wilkinson, M. Livingston and J. Mugavin (2011). "Surveying the range and magnitude of alcohol's harm to others in Australia." *Addiction* **106**(9): 1603-1611.
- Lund, I. O., E. Sundin, C. Konijnenberg, K. Rognmo, P. Martinez and A. Fielder (2015). "Harm to Others From Substance Use and Abuse." *Subst Abuse* **9**(Suppl 2): 119-124.
- Marmet, S. and G. Gmel (2015). *Suchtmonitoring Schweiz - Alkohol - und Drogenprobleme im Umfeld im Jahr 2013*. Lausanne: Sucht Schweiz.
- Moan, I. S., E. E. Storrø, E. Sundin, I. O. Lund, K. Bloomfield, A. Hope, M. Ramstedt, P. Huhtanen and S. Kristjansson (2015). "Experienced Harm from Other People's Drinking: A Comparison of Northern European Countries." *Substance abuse : research and treatment* **9**(Suppl 2): 45-57.
- Nutt, D. J., L. A. King and L. D. Phillips (2010). "Drug harms in the UK: a multicriteria decision analysis." *Lancet* **376**(9752): 1558-1565.
- Orford, J. (2013). *Power, Powerlessness and Addiction*. New York, Cambridge University Press.
- Orford, J., G. Natera, A. Copello, C. Atkinson, J. Mora, R. Velleman, I. Crundall, M. Tiburcio, L. Templeton and G. Walley (2005). *Coping with alcohol and drug problems. The experience of family members in three contrasting cultures*. London, Routledge.
- Orford, J., R. Velleman, A. Copello, L. Templeton and A. Ibanga (2010). "The experiences of affected family members : a summary of two decades of qualitative research." *Drugs: Education, Prevention and Policy*: 44-62.
- Orford, J., R. Velleman, G. Natera, L. Templeton and A. Copello (2013). "Addiction in the family is a major but neglected contributor to the global burden of adult ill-health." *Social Science and Medicine* **78**: 70-77.
- Pabst, A., L. Kraus, E. G. de Matos and D. Piontek (2013). "Substanzkonsum und substanzbezogene Störungen in Deutschland im Jahr 2012." *Sucht* **59**: 321-331.
- Ray, G. T., J. R. Mertens and C. Weisner (2009). "Family members of people with alcohol or drug dependence: health problems and medical cost compared to family members of people with diabetes and asthma." *Addiction* **104**(2): 203-214.
- Rosow, I. (2015). "How well do survey studies capture alcohol's harm to others?" *Substance Abuse: Research and Treatment* **9**(Suppl. 2): 99-106.
- Rumpf, H.-J., G. Bischof, U. Hapke, C. Meyer and U. John (2000). "Studies on natural recovery from alcohol dependence: Sample selection bias by media solicitation?" *Addiction* **95**: 765-775.
- Salize, H. J., C. Jacke and S. Kief (2014). "Produktivitätsverluste, berufliche Einbußen und Unterstützungsleistungen von Angehörigen von Patienten mit Alkoholabhängigkeit vor und nach der Entzugsbehandlung." *Sucht* **60**: 215-224.
- Seid, A. K., U. Grittner, T. K. Greenfield and K. Bloomfield (2015). "To Cause Harm and to be Harmed by Others: New Perspectives on Alcohol's Harms to Others." *Subst Abuse* **9**(Suppl 2): 13-22.

Svensson, J., U. Romild and E. Shepherdson (2013). "The concerned significant others of people with gambling problems in a national representative sample in Sweden - a 1 year follow-up study." BMC Public Health **13**: 1087.

Taylor, M., K. Mackay, J. Murphy, A. McIntosh, C. McIntosh, S. Anderson and K. Welch (2012). "Quantifying the RR of harm to self and others from substance misuse: results from a survey of clinical experts across Scotland." BMJ Open **2**(4).

Weisner, C., S. Parthasarathy, C. Moore and J. R. Mertens (2010). "Individuals receiving addiction treatment: are medical costs of their family members reduced?" Addiction **105** 1226-1234.

WHO (2011). Global Status Report on Alcohol and Health 2011, World Health Organization.