AFINet Project 3: Preliminary Report

Background

Relatives of people with addictions are a high-risk group for the development of health problems. For example, increased rates of victimisation, injuries, affective and anxiety disorders, reduced general health, significantly increased medical treatment costs and productivity losses have been demonstrated among relatives of addicts compared to age- and gender-matched controls (1-3). Insurance data from the USA also show that the significantly increased medical treatment costs of relatives of addicted persons equalise again with the reference population when the addicted person achieves abstinence, i.e. there are indications that increased morbidity and treatment needs are a direct consequence of the addiction of the relative (4, 5). Population data from Germany show that 9.5% of the population report having at least one addicted relative with acute symptoms (6).

There are indications from international studies of effective interventions for relatives with regard to the reduction of their own stress as well as with regard to a favourable influence on the course of the disease of the addicted person (7-9). According to a review by Copello et al. (7), the existing services for relatives of addicted persons can be divided into three different approaches according to their goal orientation:

1. interventions with the aim of increasing the addicted person's readiness for or compliance with treatment

2. involving the relatives in the ongoing treatment of the addicted person, or

3. interventions that are primarily oriented towards the needs of the relatives.

Corresponding interventions have so far hardly been mentioned in policy documents on addiction problems; for example, the treatment guidelines on addiction diseases analysed in the context of the study "Position papers and guidelines on relatives of addicted persons" (POLAS) only found references to the effectiveness of treatment offers with inclusion of relatives in relation to the outcome measures of addiction treatment, but not references to treatment offers with relatives independent of the addicted person (10). Accordingly, intervention offers that address relatives independently of treatment of the addicted person are not covered by the guidelines. Thus, the guidelines do not contain any statements on treatment offers for the large group of relatives who are also affected.

In view of the high prevalence figures, the accessibility of relatives through addiction support services has been low up to now; moreover, almost exclusively partners and parents (mostly mothers) find themselves in the addiction support system. In Germany, the share of treated relatives in the outpatient addiction counselling and treatment system was 7.3% in 2017 (11), which corresponds to about 23,500 treated relatives. In addition, the major German addiction self-help and abstinence associations associated with the German Addiction Counsil (DHS) report a decline in the numbers of relatives seeking help within the last 20 years from once 30% to now 19% (12). This could also be compensated by a better integration of relatives by the professional addiction support and a stronger referral to self-help as a long-term support network.

From the perspective of the relatives, aspects such as feelings of shame and guilt, fear of stigmatisation, but also doubts about the effectiveness of the existing services were expressed as significant barriers to use (6). From the point of view of addiction counsellors, a lack of or insufficient refinancing concepts was mentioned, and networking and further training were mentioned as possibilities for improving care, in addition to destigmatisation (10).

However, it remains largely unknown which kind of help offers are available in different countries. Aim of the AFINet project #3 therefore was to identify treatment concepts and offers in different countries by an expert panel.

Methods

The assessment of the care situation in an international comparison was carried out via a semi-structured online survey in English, which was iteratively developed by the board of Trustees of the Alcohol and the Family International Network (AFINet; www.afinetwork.info) and then sent to all members of the AFINet network. In addition, researchers in the field of family-based interventions were personally contacted by the project team. The survey was intended to find out, among other things, the treatment concepts implemented in each case, the offer structure in terms of the number of possible treatments as well as individual and group offers, the financing of corresponding offers as well as the availability of online-based treatment programs. For this purpose, the study was presented at the first AFINet congress in Newcastle (http://www.afinetwork.info/afinet-conference) in September 2018 and support for the international survey was solicited. Furthermore, an article was written for the AFINet newsletter, which appeared in April 2019.

For the international expert survey, an initial attempt was made to develop a semi-standardised questionnaire, which was distributed in the core group of the AFINet board and discussed in regular telephone conferences. It became apparent that due to the diverging care structures, concepts and locations of work with relatives (e.g. focal points in addiction support vs. self-help vs. family and social welfare; state vs. charitable vs. privately organised support structures), a standardisation of the survey was not feasible without a substantial loss of information. In addition, all Trustees reported that no systematic recording of services for AFMs from their countries was available.

The option of an independent qualitative study recommended by the majority of the Board had to be rejected due to lack of resources. As a consequence of the discussion processes, an open questionnaire was generated, which was supplemented with a sample report on the situation of work with relatives in Germany (cf. Appendix). This was sent to all members of the network (n>200) together with a sample report for Germany. In addition, further experts were asked who had published on the topic. In those cases where the expert interviews contained links to online documentation, these were checked and, if necessary, the authors of the reports were consulted. The same was done if estimates differed greatly from the average estimates.

Findings

Reports of varying length were provided from Austria, Brazil, Denmark, England, Greece, Italy, the Netherlands, Northern Ireland, Poland, Scotland, Sweden and Switzerland. Overall, the reports showed a comparable picture: systematic data were neither available on the basic population of relatives nor on the existing services, and all respondents emphasised that the assessments could not be classified as reliable.

With regard to the structure of services, it became apparent that in most countries, priority was given to work with relatives in the form of services for mostly underage children from families with addiction problems. In Poland, it was also emphasised that publicly refinanced services for adult children from families with alcohol problems are part of the standard care. There are hardly any figures available on the share of children from families with addiction problems reached by corresponding measures; for Poland, where it is assumed that a total of 943,000 children grow up in families with addiction problems, about 32,000 measures are documented annually, which corresponds to a reach rate of about 34%.

The organisation of care showed clear differences between the countries, which, however, could not be systematically surveyed within the framework of the survey due to their complexity (cf. chapter 2.3.). In some countries, the structure of services was rather addiction-specific, while in other countries services for relatives were a component of general mental health care structures. The majority of the services were financed by public funds, in some cases there were parallel care structures for self-payers or mixed-funded services that were refinanced by both public funding and fundraising. Particularly from the UK (England and Scotland), professional help structures were also reported that exclusively address relatives of addicted persons and were founded as non-profit organisations at the instigation of those affected and are refinanced by public funds as well as third-party funds and donations.

The majority reported that publicly financed addiction-specific counselling and care facilities provided free services also for relatives without the involvement of the IP, which, however, were mostly not concept-based services and often limited to a few sessions. In individual countries, such as Italy and the Netherlands, it was stated that services for relatives were mainly limited to relatives of IP who were already in treatment. In these cases, services for relatives of untreated IP were primarily limited to model projects or to smaller, mostly mixed-funded independent non-governmental organisations (NGOs). Several reports also indicated that the availability of such support varied greatly from region to region and depended not least on the commitment of individual actors. With regard to the dissemination of evidence-based services, at least partial coverage was reported in Denmark where, since the inclusion of CRAFT in the treatment guidelines, approximately 30% of (tax-funded) counselling centres currently provide CRAFT-based services, and in Sweden where CRAFT-based services were also considered to be widely available. CRAFT-based services were also reported to be available within the National Health Service in Scotland, although the relative proportion could not be estimated. It was reported from Northern Ireland that extensive training in the 5-Step Method has taken place in the context of outpatient care, although no data on the actual implementation of the procedure is available.

With regard to the content orientation of the corresponding offers, reports from the UK on special bereavement groups for relatives whose IP had suddenly died as a result of the addiction disease as well as the promotion of training measures for dealing with overdoses combined with naloxone prescriptions (cf. chapter 4.1.3.) in Scotland were also remarkable.

Regarding the involvement of relatives in the treatment of IP, it was reported that the majority of treatment facilities offer options for the involvement of relatives, partly also in the form of independent offers without the IP. These offers are more extensive than offers in the context of outpatient care, which exclusively address relatives without the IP. Various countries such as Denmark, Sweden and Northern Ireland also reported that a treatment focus on children, if available, was standard among treated addicted persons.

With regard to self-help offers, Al-Anon or Al-Ateen groups based on the 12-step programmes were offered in all countries participating in the expert survey, which are aimed at relatives or teenagers from alcohol-affected families. Nar-Anon groups, which address relatives of addicts of illegal drugs on a similar basis, were rarely named. In the field of illicit drugs, primarily independent parents' initiatives were mentioned. In all countries, various local self-help groups were also mentioned, some of them with a large reach. According to the feedback, a particularly high use of local self-help groups was found in Brazil (with an estimated reach of about 150,000 families per year) and in Italy, where according to an older survey (Allamani 2008) 53% of treated alcohol addicts are referred after treatment to the Clubs of Treated Alcoholics (CAT), which involve families during and after treatment. This approach has resulted in CAT groups being about four times more common in Italy compared to self-help approaches after AA (13). In Italy as well as in Brazil, the close networking of self-help with the addiction treatment system was pointed out.

The estimates of how many relatives can be reached by the existing offers were consistently in the low range between 1% (Greece) and 4% (Switzerland) of the estimated total group, whereby the number of relatives concerned was mostly estimated by a simple extrapolation of the respective prevalence rates for addiction patients.

Overall, primarily psychoeducational websites and partly chat offers were mentioned as digital offers. It was also unanimously reported that offers of professional addiction support and also self-help are increasingly also offered virtually as a result of the Covid 19 pandemic, mostly in the form of video conferences or chats, but partly also in the form of anonymous counselling by e-mail or telephone. Occasionally, it was stated that corresponding offers under pandemic conditions take place exclusively virtually (e.g. Scotland), which can be associated with the problem of limited availability of the necessary terminal devices for socially weaker families. Free, interactive computer-based self-help programmes (in which no interaction with therapists or other affected persons is required) have been reported from Sweden (http://anhorigstodet.se/; https://www.beroendecentrum.se/vard-hos-oss/narstaende/stod-via-natet-for-narstaende/) and the Netherlands (www.samennuchter.nl). Furthermore, specific computer-based help offers for children from families with addiction problems were reported from Denmark (https://bopam.dk/) and for parents with addiction problems from the Netherlands (https://www.kopopouders.nl/). There are increasingly online courses for self-payers (e.g. in the USA CRAFT for parents, https://www.cadenceonline.com/, in Germany CRAFT in general: https://www.challenge-a.com ), the quality of which has not been evaluated.

Discussion

For the first time internationally, the EVIFA study attempted to obtain an overview of the degree of implementation of family-related care structures and services. Already in the extensive discussion processes within the framework of the board work of the Addiction and the Family International Network (AFINet), it became clear that best practice models, which could be used as a target for other countries, could not be expected due to the heterogeneous care structures.

Overall, the hypothesis-generating international expert survey points to an international underuse of care for relatives that is far below that of the affected IPs, even in the most positive estimates. Due to the different organisational forms of care, no standardised survey method could be used. However, it became clear that the implementation of evidence-based procedures must be assessed as insufficient. While self-help groups for relatives exist in all countries, the professional offers are described as comparatively heterogeneous. While the majority of offers for relatives are named in the context of addiction or family support or as a component of public health care, there are hardly any systematic surveys regarding the number of relatives reached, the treatment procedures used and the scope of possible help. Exceptions tend to be Denmark and Sweden with a tax-financed care system in which the care of relatives is an integral part of addiction support; in addition, longstanding efforts to establish a stronger family orientation in addiction support seem to be effective here.

The heterogeneity of the care offers also raises a number of open questions. It is unclear, for example, to what extent a stronger integration of family-related care structures in public health measures or mental health services would lower the threshold of utilisation of help measures. It remains unclear to what extent the attractiveness of corresponding offers can be increased through structured treatment offers, as experience reports from outpatient addiction counselling suggest (14).

In the past years, a tendency towards a stronger spread of digital offers has prevailed in various countries, which is currently being intensified by the Covid pandemic. At the same time, it is striking that in contrast to digital intervention offers in other mental health spectrums, hardly any automated intervention tools have been developed so far. Digital programs, which can be processed anonymously, also offer the advantage that, in view of the feelings of shame and guilt often encountered among relatives, a non-binding initial contact with help offers is facilitated. Against the background of the unclear refinancing of family-related interventions, a potential for the improvement of care could be expected here, whereby the effectiveness of corresponding procedures must be evaluated analogously to other health apps. The first fundamentally positive findings are available from the USA (15). However, the results of a study conducted in Sweden (16) did not show any effects, whereby the high drop-out rates in particular proved to be a problem. Further studies are currently underway (17, 18). In parallel, various online-based procedures have been developed in the private sector, the effectiveness of which has not been evaluated and the costs of which are not communicated transparently in some cases. The provision or refinancing of efficacy-tested, generally accessible free programmes seems desirable here.

Also against the background of the uncertain financing situation, self-help offers a possibility of sustainable connection and relief. In Germany, for example, more than 13,000 relatives are reached annually through the group offers of the addiction self-help and abstinence associations united in the DHS, according to the last statistical survey of 2017 (12), whereby mixed groups with relatives and individuals suffering from addiction dominate. In addition, according to the self-description, there are about 600 Al-Anon groups for relatives in Germany (https://al-anon.de) as well as other regional offers. However, the statistics of the addiction self-help and abstinence associations showed a continuous decline in the number of participating relatives in the past 20 years from 30% to 19%, which, in the view of the associations, results in a need for action. The international experience reports indicate that there is still untapped potential through optimised networking between addiction support services and self-help associations.

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