

How much does your drinking affect family members and close others?

– Preliminary results from online questionnaires

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Introduction

The A-Clinic Foundation is a non-governmental organization and a non-profit service provider operating in Finland. It's treatment and rehabilitation services, substance abuse prevention and expert services help to reduce substance abuse and other psychosocial problems. The central office is involved in national and international activities in the fields of prevention, information, development and training. The NGO activities are mainly funded by grants from The Funding Centre for Social Welfare and Health Organisations (STEA).

The Childhood and Family -team at A-Clinic Foundation consists of 4 online services/work activities:

- 1) *Fragile Childhood* has started in 1986 as a series of projects and is nowadays a permanent form of work. It has persistently sought new innovative ways to prevent and diminish harms caused to children due to adult's excessive drinking. Ways to work are i) Providing direct support and help (mainly online) to young people and adults who suffer from parental alcohol abuse; ii) Training and motivating professionals who work with children, young people & families to meet the needs for help & support iii) Raising awareness in society (through social media presence, campaigning) and iv) Increasing the child (and childhood) sensitivity in the treatment services.
(www.lasinenlapsuus.fi/en)
- 2) *Shadow World* is a web service maintained by Fragile Childhood targeted for young, 12–22 year-olds. It provides 10–12 weeks professionally guided anonymous online peer support groups, counselling service and 1 to 1 chats. Shadow World has gained a European Commission E-Inclusion Award in 2009. (www.varjomailma.fi/english)
- 3) *AddictionLink* is the Finland's most popular site on addiction and substances with some 210 000 different visitors each month. It is intended for substance abusers, their families and friends and all those interested in objective information on substances and addiction. It features e.g. a personalized area with a calendar function and an electronic version of the AUDIT-test which provides an immediate feedback to the user. (www.addictionlink.fi)
- 4) *YouthLink*: A web site targeted to young people (12–20 year-olds) with themes ranging from substances, gambling, gaming, internet use and depression to bullying. This year 2018 It's counselling service has got 339 questions up to October.

A-Clinic Foundation has 20 years' experience in running online services. There is a huge demand by family members and close others affected by alcohol abuse to find help & support. Following the core ideas of the 5-Step Method (AFInetwork.info), especially from the point of view of COAs (children of alcohol abusers) and ACOAs (adult children of alcohol abusers), these people:

- ✓ want to have a chance to tell what it is or was like for them (and to share this with peers)
- ✓ want reliable information (and to exchange information with peers);
- ✓ wish to find coping strategies for themselves (also self-help tools) ; and
- ✓ to find further help and support in real life or online (for many online services are sufficient)...

... In order to overcome challenges posed in their everyday life.

About the prevalence

There are 5,5 million inhabitants in Finland (for comparison, in Sweden there is roughly 9,9 million). In the very recent survey, in English called the Drinking Habit Survey conducted in 2016 by The National Institute for Health and Welfare (THL in Finnish) there are 460 000 Finns for whom family members or close other's problematic drinking has caused *severe* problems in their lives during the past year (THL 2018).

There are 65 000 – 70 000 children under 18, whose at least one parent, has a *severe* substance abuse problem (Raitasalo et al 2016). This is 6% of the underage population. One third of adults using substance abuse related treatment services has underage children. From cohort study, we know that children under 18, who have a mother with a substance use disorder, do have higher risk for accidents, hospital visits, psychic disorder (F80-F89), or to be taken into custody (Raitasalo & Holmila 2012). In Sweden the figures are much the same; 5% of children have at least one parent who has substance use disorder according to Swedish general population survey (Elgan et al 2016; Raninen et al 2015).

In the very recent (unpublished) research survey, conducted by a commercial research agency (sample representative of population) and commissioned by A-Clinic Foundation, 7 % of the young of age 16 to 20 answered they have *often* experienced harms due to parental drinking (22 % experienced harms sometimes). Our previous surveys have provided similar figures. Every fourth Finn has experienced harms in childhood due to parental drinking (Lasinen lapsuus 2016).

In addition to valid screening tests, other simple tools are needed

The starting point for developing these questionnaire tools comes from the Finnish legislation. *The Act on Welfare for Substance Abusers* (from 1986) clearly states that services must also be provided for family members and close others based on their need. In Finland, the local authorities can provide services independently or together, or outsource them to other local authorities, the third sector or private service providers (THL 2018). The reality seems to be that 1) family members do not easily get referrals for the services and 2) the situation of the family members is not systematically checked with the patient in treatment. The system of specialised services for substance abusers (and family members) is undergoing changes as a result of the ongoing – and dragging – national social welfare and health care reform. (See also Dr. Pitkänen's presentation in this conference.)

Much attention has been given to the family members in the substance use disorder treatment services and there are many service providers who are specialised in family rehabilitation. However, it can be stated that getting treatment, help & support for family member is quite random and unequal across the country. The need for tools to bring the family members' or close others' situation to light is clearly stated in the research (e.g. Itäpuisto 2016, Perälä et al 2016).

Despite knowledge exists, there is lack of understanding of the necessity in including the whole family into treatment when parents suffer from substance use disorder (SUD) (Wangensteen et al 2018; Alexanderson & Näsman, 2017; Gullbrå et al., 2016; Selbekk & Sagvaag, 2016). Parents with SUD often receive welfare support or treatment, but family members do not get the same attention (Wangensteen et al 2016). Child protection services do, of course, focus on the children, but it is argued they offer little attention to the relationship between children and parents or to the family as a whole. In their study focusing on children of parents with SUD in Norway, Wangensteen et al (2018) stated that "professionals may think that, as long as children are physically safe and no longer exposed to substance use, relational support is no longer necessary." From professional experience, it can be said, this applies to Finnish context, too.

It is important to highlight, it is not the aim to develop an AUDIT-like test for close others. Unlike AUDIT and other valid screening tests (see table 1) these two questionnaires do not score the answers, but like AUDIT it is developed to provide interpretation and customized feedback. These questionnaires can be used for screening in a sense, that it can identify anyone who is at risk of having a specific health condition due to family member's excessive drinking. It is stressed that these questionnaires under development are tools for diminishing and preventing harms caused by drinking to family members and close others.

Questionnaire tools can serve as a starting point for strengthening the coping strategies and finding appropriate support for the close others. Questionnaires do not measure whether alcohol misuse can be considered as a disorder or can it be defined as a dependency problem. The amounts and frequency of the drinking are irrelevant or at least secondary. The overall target is to draw attention to the situation and needs for help& support for close others, as they are entitled to this, in their own right.

Screening tests for alcohol use identify those who may have an alcohol use disorder or are at risk of experiencing problems of alcohol use. These screening test focus mainly on user him/herself and less on harms to others. Screenings can be conducted by a variety of health officials, it can be offered through face-to-face interview and/or as self-administered paper or electronic format. There are many alcohol screening tools available (some listed briefly in Table 1). Some focus on alcohol use patterns (amount and frequency) while other on alcohol-related problems, or both. Most known and widely in use is the AUDIT, and extensions/ variations of it, developed in the context of World Health Organization.

Table 1 . Examples on different types of tests used for screening alcohol use and risks

Acronym	Name	No	Origin	Purpose
AUDIT & AUDIT-C	Alcohol Use Identification Test	10	WHO (1992)	a simple method of screening for excessive drinking and alcohol use disorder.
FAST	Fast Alcohol Screening Test	3		An alcohol harm assessment tool designed for use in emergency department (for past 12 months)
Alkohol-E	AUDIT Extended version		Berman et al (2004)	Concentrating on alcohol related problems, also on friendship and families, and motivation for change
CAST 30	Children of Alcoholics Screening Test	30	Pilat & Jones (1981)	A true or false-item scale designed to identify individuals who have lived with an alcoholic parent.
CAST 6	Shortened version from CAST 6	6	Hodgings et al (1993)	
CAGE	Cut down – Annoyed– Guilty – Eye-opener	4	(1968)	Screening alcohol problems over a lifetime.
SAAST	Self-Administered Alcoholism Screening Test	35		Self-Administered Alcoholism Screening Test

Hodgins et al (1993) have developed a a shortened version, CAST-6 of the longer Children of Alcoholic Screening Test (CAST-30) and tested it to be as valid in screening the ACOAs. Instead of asking with a single question such as, "has the drinking of either parent created a problem for you?", a semi-structured interview brings up more COAs, especially those who are reluctant to disclose parent's problem (Stout et al 1992; Biek 1981). Interviews along with the multiple questions consider the entire life experience of the child. Similarly, with these questionnaires that are being developed here, instead of asking, "How much of a problem the drinking is for you?" the practitioner has a chance to draw a much more vivid picture of the current situation or how it has been for the close others. And for the family member and close other, it opens a new horizon of possibilities to elaborate how much of a problem it (still) is.

Questionnaires under development

A-Clinic Foundation's Fragile Childhood has developed two questionnaires (see Attachment), which are currently being piloted in paper format in services of various kind. Service units and organisations participating in the piloting are from child & family clinics (The current national system reaches 99,8 % of children born in Finland), outpatient substance treatment clinics, outpatient and inpatient family rehab unit and NGO called Carers Finland. The challenge has been all along to make these questionnaire forms generic, yet simple enough.

There are 10 questions in both, with given options to choose from "often, sometimes, never, I don't know". (Questions are translated by the paper Presenter in the attachment). The main idea is to provoke one to think about the consequences of the drinking. There are separate questionnaire forms targeted for "Drinker" and for "Close other". Forms are not necessarily to be filled jointly, but in some cases, it might be possible. Also, it is advised, Drinker fills the form individually for each family member. Close other might also have several alcohol abusers close to him/her (e.g. both parents). It is also possible to answer the questions retrospectively, looking back to one's childhood or if the Drinker has been abstinent for some time.

Following the questionnaire (in paper format) there is a short feedback per question and space provided to fill-in own thoughts or things that come up in the discussions with the counsellor. It is possible to use the questionnaire individually apart from a session. In the end, there are links to further information about what help & support is available.

What is wished to accomplish is to make the misuser to think of the consequences of the drinking for the family member or close other and through that prevent and diminish these harms. From the close other's point of view, the aim is to give often "the silent one a voice", a possibility to bring up to light how the drinking affects everyday life. Through that the coping strategies can be strengthened and harms can be prevented or diminished. These questionnaires are both tools for practitioners as well as self-help assessments (especially online version).

Next phase: to go on-line

Two questionnaire forms will be coded in the electronic interactive formats by the end of 2018. These forms will function in a way that as user go along answering, a short feedback is given after each question. In the end, user may print or save the answers along with the feedback. Forms will be accessible from the Addiction Link and Fragile Childhood websites.

Addiction Link has a long history of providing interactive online tests for personal use in the field of substance use and addictions. Alcohol Use Disorder Identification Test (AUDIT) was published online 15 years ago. All the online filled forms are stored on the A-Clinic Foundation's internet server. The online version of the AUDIT in AddictionLink has been filled in the years 2003 –2016 569 416 times. A research of AUDIT's online use was conducted in 2016 (Elovainio et al 2016). Data consists of 34 000 answers from women and 49 000 from men.

Other online self-assessment tool, extended AUDIT (Alcohol-E) has been developed in Karolinska Institutet in Sweden (Berman et al 2004). It was translated to Finnish and published in electronic format, online in AddictionLink in 2014. The electronic version has been completed 1289 times in the year 2017. To the question: "Alcohol has destroyed my family-life" of all the online responders 98 (8 %) has replied "completely", 131 (10%) "considerably", 140 (11%) "to some extent".

It is estimated that a third of the AddictionLink visitors (from a total of 210 000 monthly) are family members or close others. Therefore, we can expect a remarkable number of users filling in these question forms. Naturally, there are several limitations on the validity. Keeping that in mind, the accumulating large

data will provide interesting insights for research purposes. These will be reported in the near future in the AFINet context as the online versions were not produced yet by the time of this paper was written. Analysing data gives a fine opportunity to elaborate knowledge on alcohol harms to family members and close others. It can draw a more detailed picture, for example, on how different subgroups of family members and close others experience drinking and how much experiencing (and causing) harms pass down through generation. The question on what type of help & support one would wish to have should also be included in the online questionnaire.

Two main points

- 1) Family members and close others suffering from alcohol abuse are not getting help & support they need, because their situation is not recognized in the service system.
- 2) In addition to valid screening tests for alcohol use, there is demand for easy and simple tools and self-help (online) assessments for both practitioners and family members & close others to bring their situation to light.

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ATTACHMENT

Questions for the Drinker (Often, Sometimes, Never, I dont know)

1. Do *You* think your drinking is excessive?
2. Does She/He comment your drinking?
3. Have you ever failed to do something you promised or planned to do, because of the drinking?
4. Has your family member seen you drunk?
5. Have you been arguing at the consequence of your drinking?
6. Have you been hiding your drinking from your family member?
7. Have you hurt your family member mentally or physically?
8. Has your family member or someone else asked you to stop or cut down the drinking?
9. Has your family member been feeling ashamed, an outsider or less worthy?
10. Has your family member experienced fatigue, depression anxiety?

Questions for the Family Member / Close other

1. Do You think *His/Her* drinking is excessive?
2. Do you comment His/Her drinking?
3. Has He/She failed to do something promised or planned to do because of the drinking?

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Etc...

Background questions:

Sex: male, female, other, I don't want to tell

Age:

What is your relation to the person in question?

Did you experience harms in your childhood home due to parental drinking?