GLOBAL JOURNAL OF
Community Psychology Practice
PROMOTING COMMUNITY PRACTICE FOR SOCIAL BENEFIT

Re-Empowering Family Members Disempowered by Addiction: Support for Individual or Collective Action?

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Key words: Empowerment, disempowerment, addictions, family members' experiences, 5 steps method.

Recommended citation:
Orford, J. (2012). Re-Empowering Family Members Disempowered by Addiction: Support for Individual or Collective Action? *Global Journal of Community Psychology Practice,* 3(1), 59-64. Retrieved XXXX, from http://www.gjcpp.org/.

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Abstract

Just under one hundred million is a conservative estimate of the number of adults whose lives are adversely affected by the alcohol or drug addiction of close relatives. Including children in the figures would add tens of millions more. The particular qualities of the experience of having to cope with excessive drinking or drug taking in the family, in combination, can make it a unique and highly stressful and disempowering experience. A programme of research over a number of years has 1) explored in detail the nature of affected family members' experiences, and 2) developed and evaluated a method for helping affected family members in their own right. Work in Mexico, England, among indigenous Australians, and in different regions in Italy has suggested the existence of a common core of disempowered experience for family members, with some cross-cultural variations. Predominant cultural norms – individual, familial collective, or community collective – are amongst the factors that modify the core experience. A method of supporting affected family members – the 5-step method – has shown promise in a number of countries. Its emphasis is upon listening carefully to a family member's story, providing relevant information, discussing coping dilemmas, and building social support. The method is flexible enough to be used in brief forms (including booklet and web forms), with anyone affected by or concerned about another person's addiction, and it can be used in a wide variety of settings including primary care and other community settings. Examples will be given of the ways in which it can re-empower family members by building their confidence to cope effectively.

Families and addiction: disempowerment on a large scale globally

It is well understood that the prevalence of substance use disorders is on a colossal scale – of the order of 15 million people with drug use disorders globally and 75 million with alcohol use disorders, according to the World Health Organisation (Obot, 2005). What is not so well appreciated is the toll that such a problem, on such a large-scale, takes in terms of family health. This paper is about an experience that is shared by tens of millions of people around the world. It is the experience of living in a family in which one of the members of the family is consuming alcohol or taking illicit drugs to an extent that is seriously harmful to the family. The chief protagonists are the wives, husbands or partners, mothers or fathers, sisters or brothers, adult daughters or sons, aunts or uncles, and other close kin who are affected by the excessive drinking or drug taking. This group is referred to throughout the paper simply as *family members*. The problem drinkers or drug takers about whom they are concerned are referred to as their *relatives*.

Whereas the direct contribution of alcohol and drug problems to global ill-health is recognised, the indirect contribution to the global burden of ill-health caused by the stress on affected family members remains largely hidden and unacknowledged. That burden falls particularly heavily on women and increasingly in low to middle income countries.

Our research group at the Universities of Birmingham and Bath in England, in collaboration with colleagues in Mexico, Australia and Italy, has carried out a series of studies involving, between them, interviews with around 800 family members affected by their relatives' alcohol or drug problems (Orford et al., 2005, 2010a). Although the experience of being such a family member varies in certain ways according to socio-cultural group and other factors, we have concluded that there is a common core to that experience which is recognisable everywhere. That common core of experience can be summarised as follows. Family members affected by addiction face a form of chronic stress that impacts upon them at a number of different levels. It includes daily hassles of an unpleasant kind as well as relationships that deteriorate over what may be a very lengthy time span. The situation

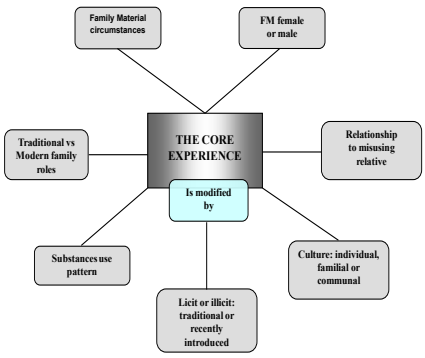
contains a number of threats, to oneself, the home, and the family, particularly to children, and perhaps to the whole community. There is much uncertainty for family members. Part of that uncertainty is how to understand and account for the deterioration in family life which is happening, which appears to be caused by the excessive behaviour of a loved one who seems to be threatening his or her own health and well-being as much as that of the family. How to respond to the relative and his or her drinking or drug taking, in ways that reconcile the needs of the family, the relative and the family member her/himself, poses a number of agonising dilemmas. Should a family member put up with it, stand up to it, or withdraw and seek a degree of independence? Those are perhaps the main options, but those apparently simple questions only begin to reflect the complexity of a family member's struggles for meaning and action.

That experience is very disempowering. Affected family members talk about being worried, preoccupied with thinking about the relative and the problem, feeling nervous and panicky, irritable and quick tempered, low and miserable, annoyed and resentful. It is common for them to feel failures themselves or to feel de-valued. Some say they feel alone facing the problem. Others feel frightened. It is not uncommon to hear thoughts of suicide expressed. There are few things more demoralising than witnessing at close hand a person you love, whose life is closely entwined with your own, and who you know is capable of many good things, apparently being taken over by a seemingly senseless attachment to such a harmful form of consumption. This sense of demoralisation is compounded if, at the same time, the addiction poses a threat to the family member's safety or is undermining of family functioning.

Culture modifies the core experience.

The experience of being a family member affected by a close relative's addiction might be called a 'variform universal', to use a term from cross-cultural psychology. Despite there being a common, relatively invariant core to the experience, individuals, families and communities are positioned differently in relation to substance use and misuse, and their varying positions significantly modify the core experience (see Figure 1).

Figure 1: MAIN MODIFIERS OF THE CORE FAMILY MEMBER EXPERIENCE



One of the factors that we believe acts as a modifier is the traditional versus modern arrangement of marital and family roles. An illustration comes from one of our studies in England which was with Sikh wives married to men with drinking problems. Most were first-generation immigrants to Britain, and all had had arranged marriages. On a cultural assimilation scale, wives reported eating mainly Asian food, wearing traditional clothes, and speaking Punjabi most of the time. Most regarded Britain as their home country, but many were still against intermarriage and felt different from indigenous English people. What they said about the ways they had coped suggested that most had moved from a position of inactive resignation to the problem, had often stood up to their husbands, for example by expressing anger towards them or by pouring their drink away, and had often achieved a measure of independence. The evidence showed, however, that despite these changes, they continued to show a relatively high level of tolerance towards their husbands' drinking. All the Sikh wives continued to feel a sense of practical obligation toward their husbands that often involved behaviors that might be described as *tolerant-sacrificing*, such as cleaning up after them when they had been drinking or putting them to bed when they were drunk. Our earlier work with white English and Mexican family members had suggested at least five variations on the theme of independence. Some of these seemed more possible than others for the Sikh wives. For example, while 'not worrying' − one aspect of independence − was something that the Sikh women said they were achieving to a greater extent than previously, 'getting away' and 'doing what I want to do' were limited. Wives were not able to get out of the house for

extended periods because of their duties as wives and mothers. Although some wives had learned to put themselves before their partners, they still mostly continued to put the needs of other family members before their own (Ahuja et al., 2003).

A way of correcting the neglect of affected family members.

Many family members affected by addiction have told us in the course of our research that they had never previously spoken about the problem in the detail which the research interview allowed. Most had received only minimal help from health or social services and it was not uncommon for the help or advice received to be described as having been unhelpful. On the basis of what we have learnt about the experiences of family members coping with addiction, we have developed an approach which we term The 5-Step Method (see Figure 2). We have now used this method in a number of studies. Three of our studies have taken place in the primary health care setting; the method is used by a variety of primary care health professionals, including doctors and nurses (Copello et al., 2000, 2009). Another of our recent studies focused on Black and Muslim families using ethnic minority community services (Orford et al., 2010b). The method has been used in primary care, and other community care settings in Mexico (Natera et al., 2010) and in Italy (Arcidiacono et al., 2009). We believe there are a number of attractions of the 5-Step Method: it is a low cost intervention which can be delivered in a number of different formats and is easily adaptable for different primary care and community settings.

Figure 2: THE 5-STEP METHOD FOR HELPING AFFECTED FAMILY MEMBERS

1. Listen non-judgementally
2. Provide information
3. Discuss ways of coping
4. Explore sources of support
5. Arrange further help as needed (including the involvement of the addicted relative)

Using standard questionnaires, it has been a consistent finding that family members' symptoms of ill-health reduce following receipt of the 5-Step Method. More detailed analysis, based on interviews with participants in these studies, suggests that a number of transformations take place for family members, the principal ones being as follows:

1. *Focus on own life and needs*. The most frequently mentioned type of change referred to is an increase in independence or distance from the relative's problem drinking or drug taking. This is most commonly referred to in terms of an increased focus on oneself and one's own needs.
2. *Being assertive*. Family members speak of being more assertive with their relatives, by communicating more directly with the relative than previously, by being more directive in arranging alternative activities, or by being firmer in maintaining a course of action.
3. *Calming down*. Family members explain how sessions have helped them become less emotional in their interactions with their relatives; finding a different way of dealing with the anger and frustration caused by the drug misuse, acting more calmly, and seeing the positive effects of this change on the drug user's behaviour.
4. *Achieving a better understanding of the problem and seeing the links with one's own health*. Family members speak of gaining an understanding about their relatives' drinking or drug taking, or a realisation of the links between the drinking or drug problem and their own physical or mental health. An important element of this is experiencing a reduction in self-blame: for having been a cause of the drug problem, for not having dealt with it, or for having taken action such as asking the drug-using relative to leave home.

An example from the Muslim arm of our ethnic minority study is that of a wife living with her husband and three children. Her husband's drug use, of over ten years' standing, meant that they were struggling financially much of the time. Her relationship with her husband, although basically satisfactory, at times left her feeling very low. She thought it had affected the children. She said she had no support from her in-laws. She was given a self-help manual in Urdu which accompanied the 5-Step sessions. As a result, she put in a lot of hard work in

trying to help her husband reduce his drug use and successfully implemented some changes. She started to manage his heroin intake, helping him reduce his spending on drugs from around £100 a day to about £20. Her husband started to take methadone. She also rebuilt connections with her in-laws. The home environment gradually improved and this had a positive effect on the children, reflected in their improved school work.

From individual to collective action.

But I want to bring this presentation round to an issue which is crucial to community psychology: how to foster *collective* action on issues which are more usually treated as individual, personal and private ones. The origins of the 5-Step Method lie in clinical and counseling work with people with problems of substance misuse, and dissatisfaction with the failure of that work to acknowledge the impact of such problems on family health. The work has largely been with individual affected family members. It is clear, however, that this work touches on issues that are of central interest in community psychology. For one thing our work with minority indigenous and immigrant groups has shown us how coping with alcohol and drug problems is both a personal-private and public-community matter. This forced itself on our attention in a study with Aboriginal family members in Australia. Perhaps partly due to the more public nature of family life in remote indigenous communities in Australia, and perhaps partly due to the controversial nature of alcohol policy in the Northern Territory – for example rural communities could opt to be 'dry' – during interviews with indigenous family members it was not possible to draw a clear line between private and public, personal and community. Similarly, when interviewing affected family members in the Pakistani-Kashmiri Muslim community in England, a dominant theme was the large, close-knit family and community networks which existed, offering great potential for positive social support but at the same time threatening greater exposure and dishonour to the family.

The majority of family members who have taken part in our studies have been women, most mothers and partners, but also including sisters, aunts and other female family members. The disempowerment experienced by women in our work – but also often experienced by affected male family members – and the re-empowering changes often associated with taking part in the 5-Step Method, appear very similar to those described by others who have contributed to work in community psychology, emancipatory public health, or women's health studies. For example, the Listening Partners programme described by Bond et al. (2000), for poor, rural mothers in the USA talks of, '… growth of self, voice, and mind among all participants…', as a result of a programme of meetings using 'reflective dialogue' which gave participants the experience of expressing themselves, knowing that they have been heard, and seeing or hearing their own words reproduced and acknowledged. Kar et al. (1999) reviewed reports of case studies from across the world in which women had been empowered in one of four areas: basic human rights, equal rights for women, economic enhancement, and health promotion. A conclusion conclusion was:

> Several innovative and well-regarded community development models… hold that *community empowerment, especially empowerment of women*, is the key to successful programs for social change that affect the quality of life and health of poor and powerless families and communities.

A question that remains for me, therefore, is how our programme, which also embodies empowerment principles and has the potential to empower large numbers of women (and men) affected by alcohol and drug misuse, can move towards a more collective, community-oriented way of working. Interestingly, one of the 40 case studies of women's empowerment identified by Kar et al was Mothers Against Drunk Driving. Other examples of collective action started by family members and others affected by substance problems include neighbourhood action projects and local or regional policy campaigns. An example of the former was Voice of Southmead, an action project in a relatively poor area of Bristol, England. According to Brent (2009), in the course of this project, 'the concerns of the families of drug users moved into the public realm and were no longer treated as a private shame'. One of the interesting features of that campaign was the involvement of men alongside women. An example of policy campaigning was provided by Marshall and Marshall (1990) in their book *Silent Voices Speak: Women and Prohibition in Truk*. During that campaign in the late 1970s to the mid 1980s women took the lead in maintaining a concerted and successful campaign, against considerable opposition, to have one jurisdiction in the Pacific Islands opt for 'dry' status.

The challenge, if this type of work is to move from individual to collective action, lies in the largely

hidden nature of the problem. In all our studies it has been difficult and time consuming to recruit samples. Although the numbers of individuals and families affected are in the tens of millions world-wide, the problems remain largely private ones, unspoken about in public; the mothers, wives, fathers and other family members affected by addiction problems rarely have an effective collective voice. Helping them find that voice remains a task for the future.

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