

**INVESTIGATING THE DEVELOPMENT, DELIVERY
AND OUTCOMES OF INTERNET BASED HELP FOR
FAMILY MEMBERS AFFECTED
BY ADDICTION PROBLEMS**

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ABSTRACT

The aim of this dissertation was to investigate the feasibility of developing, delivering and outcome of the internet delivery of evidence based manualized intervention, for family members. Family members are often the ones to start feeling the negative effects of a loved one's misuse of alcohol of drugs and service delivery though expanding to recognise the needs of family members, is not yet fully addressing these needs. The 5-Step Method which was developed based on the Stress-Strain-Coping-Support Model offers a way to work directly with family members in addressing their needs. There is evidence available suggests that when the 5-Step Method is delivered in other formats, in a variety of settings, by various health care professionals; that it does lead to positive changes for the family member. The challenge of the 5-Step Method therefore was to make it more widely available. The internet offers an option through which this intervention may be made available to family members. Results of the internet delivery of this intervention show that family members found it acceptable, easy to use, and helpful. It did lead to changes in the way family members cope, as well as reductions in the impact and symptoms. These results suggest that the internet is a viable medium for the delivery of this intervention for family members. The implications of these findings are further discussed with suggestions for future research.

DEDICATION

This dissertation is dedicated to my Father Dr Joe, who though is not alive to see it was confident that I would take this journey; and to my mother Akon Ibanga, who lived to make sure I did.

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General Overview

The main aim of this thesis is to investigate the feasibility and effectiveness of delivery of an evidenced based intervention via the internet to family members (FMs) who are concerned about someone else's alcohol or drug use. The person for whom they are concerned about shall be in the course of this work usually be referred to as a "relative". Many of the alcohol or drug services in their current state focus almost solely on the relative who is using alcohol or drugs, and the family members are brought in only if they are seen as crucial in increasing the likelihood of the relative's engagement or retention in treatment (Copello & Orford, 2002; Velleman & Templeton, 2002). Family members are often not seen as clients in their own right (Copello & Orford, 2002; Reagan et al. 1983). There are currently a number of treatment options for involving family members that are evidence-based, these options however do not appear available to family members in the routine service delivery. This highlights the existing gap between research evidence and practice in alcohol and drug treatment (Institute of Medicine, 1998; Lamb, Greenlick & McCarty, 1998; Marinelli-Casey, Domier & Rawson, 2002; McLellan, 2002). As proposed by Owen (2001) our attention should be directed more to transporting these existing research-based interventions to settings where family members would benefit from their availability. This thesis explores the internet as an option for developing and disseminating evidence based intervention, thus making it more available to end users.

Part I consists of two chapters and it sets the scene for the rest of the dissertation by first looking at the theoretical models for understanding of addiction and the family in Chapter 1. Chapter 2 then looks at the internet as an option for delivering an intervention. In Chapter 1 various models of understanding are discussed pointing to the role of Health Care Professionals (HCPs) in working with families and how under these orientations they are likely to view, relate or interact with FMs. Treatment options that have evolved based on the

understanding derived from these models are further discussed. An argument is made here for the theoretical position adopted in this thesis and the accompanying 5-Step Intervention that is suggested by this position. This chapter further examines the availability of interventions that involve family members arguing on the need to consider other channels through which family members may be offered help.

Chapter 2 presents the internet and associated technology as offering an alternative for delivery of an evidence based intervention. It proceeds to look at the reported advantage of using this medium to reach family members then methodological issues, potential difficulties, and effectiveness of these internet interventions are discussed. With limited research of online interventions with family members or their relative with an alcohol and drug misuse problem, this review looked at a broad range of online psychological interventions.

Part II is made up of Chapter 3 which draws on the work of the Alcohol Drugs and Addiction Research group (Orford, Templeton , Copello ,et al. 2009: Orford, Templeton, Copello, Velleman, & Ibanga, 2010), in working with whole organizations to implement the 5-Step Intervention. This chapter presents the results of interviews of Health Care Professionals that were conducted 6 months after the start of the project. It elaborates on the experience of HCPs in using the 5-Step intervention and related interventions to work with family members of alcohol or drug misusers. Potential problems and their implications for dissemination are discussed. It presents the argument for investigating other ways of disseminating this intervention to reach family members in need.

Part III consist of Chapter 4 & 5. In Chapter 4, the feasibility of internet delivery of the 5-Step Intervention is explored. The web-format of this intervention is developed and piloted with family members (trial participants) referred by Health Care Professionals from 4 participating organizations. The acceptability, usage pattern and effectiveness of delivery in this controlled conditions is assessed. Chapter 5 examines the transportability of this intervention to real-life settings where family members access the site and use the programme (spontaneous registrants) without prior contact with a Health Care Professional. Characteristics and usage pattern of trial participants and FMs who registered spontaneously are reported. As the measures used in this study was similar to other studies evaluating this intervention in other formats, it was possible to compare the characteristics of the FMS in the Web-based 5-Step programme with those who have presented for treatment in other formats of this intervention.

Part IV is made up of Chapter 6 which collectively summarizes the results of this work. The limitations of this work is discussed as well as the implications of the findings and direction for future research.

CHAPTER 1

LITERATURE REVIEW

1.1 Introduction

The effect of alcohol and drug misuse is well documented. Some of these include the reported cases of children born with Foetal Alcohol Syndrome (Bandstra, Morrow, Mansoor, & Accornero, 2010; Mancinelli, Binate, & Secant, 2007), or other complexities (Elgin, Briary, & Laagered, 2007) as a result of mother's drinking during pregnancy. Others highlight the role of alcohol and drugs in occupational and road traffic accidents that endanger the lives of other members of the community (Freeborn & McManus, 2010; Gel, Ammeter, Gavel, Calms, Mersin & Deepen, 2006), the alcohol and drug related crimes that disrupt neighbourhoods, leading to heightened levels of unrest (Conrad, 2010; Miller, Levy, Cohen, & Cox, 2006), as well as the burden that it places on the health care delivery system, to name a few. The negative consequences of alcohol and drug misuse thus come with economic and social costs, more than half of which are borne directly or indirectly by non-alcohol or drug misusing members of society (Bamberg, 2006). The user is said to bear some of this cost but, even when the cost is borne by the users, it is often transferred to members of his/her family (U.S. Department of Justice, 1992). As Copello, Templeton, & Powell (2010) point out, the shift can take the form of family members having to make financial contributions towards the user's upkeep, assisting in childcare, alternative accommodation, running errands, or accompanying or being engaged in the treatment process. If, for instance, the alcohol or drug misusing person loses his or her job, it would have implications and cost for other members of that family (Burton-Phillips, 2007).

The position of the immediate family members and the accompanying experience or impact of the relative's drinking or drug use is of particular concern in this research. Orford, Copello, Atkinson, Velleman, and Templeton (2005), and Orford, Velleman, Copello, Templeton and Ibanga, (2010a), in interviewing family members, found that living with a relative who is misusing alcohol or drugs was reported to be unpleasant and extremely stressful. This was irrespective of the person's age (Forrester, Copello, Waissbein, & Pokhrel, 2008), gender (Philpott & Christie, 2008), or ethnicity (Ahuja, Orford & Copello, 2003; Orford, Templeton, Copello, et al., 2009). These experiences are quite similar across different countries and cultures (Arcidiacono, Velleman, Procentese, Albanesi & Sommantico, 2009; Orford, Natera, Copello, Atkinson, Tiburcio, Velleman, et al., 2006; Orford, Natera, Velleman, Copello, Bowie, Bradbury, et al., 2001; Orford, Templeton, Copello, Velleman, & Bradbury, 2001). Family members often found themselves worrying about family finances, the relative's physical health and mental state and the subsequent effects it may be having on his/her job, or social settings, possible desertion by the relative, potential problems with the police or eventual imprisonment (Orford, Copello, Velleman, & Templeton, 2010).

The chapter is a review of the literature on addiction and the family, looking closely at the theories and models that proffer an understanding of addiction in the family. It will highlight the role of the family member, which would have a bearing on how health care professionals (HCPs) refer and relate to family members of alcohol and drug misusing relatives. This will shed light on the role of the therapist and the possible reluctance that they would have in working with family members. The review will start by examining earlier models which view alcohol as a family pathology, then proceed to more recent models which look at the latter as a source of stress for family members. This section concludes by discussing one of the variants of the stress model: the Stress- Strain-Coping-Support model

(Orford, 2001; Orford, Natera, Copello, Atkinson, Velleman, Templeton, et al., 2005; Orford, Copello, Velleman, & Templeton, 2010) which is the position adopted in this work. This model views the family member as someone needing help in their own right.

This will then proceed to examine existing treatments involving family members that have largely evolved based on these theoretical models of understanding addiction and the family. The availability of these treatment options in current service delivery will be considered, highlighting some of the variables that are a barrier to their implementation in routine service delivery.

Because of the nature and course that alcohol or drug misuse presents, family members often experience these stressors as intense and ongoing. Prolonged exposure to high levels of stress and related trauma of this nature places these family members at a higher risk of both mental and physical ill health (Svenson, Forster, Woodhead, & Platt, 1995). This is in accordance with the clinical literature, which has suggested that family members of drinking or drug using relatives experience higher levels of depression, anxiety and somatic complaints (Halford, Bouma, Kelly, & Young, 1999; Kahler, McCrady, & Epstein, 2003; Tempier, Boyerb, Lambert, Mosier, & Duncan, 2006) and are likely to utilize health services more frequently (Lennox, Scott-Lennox, Holder, 1992; Lipscomb, Dement, & Li, 2003; Miilunpalo, Vuori, Oja, Pasanen & Urponen, 1997; Ray, Mertens & Weisner, 2009; Woodside, Coughy & Cohen, 1993) with higher total rates of health care cost (Ray, et al., 2009), high rates of marital separation and divorce (Nace, 1982) as well as low levels of marital satisfaction (Halford, Price, Kelly, Bouma, & Young, 2001; O'Farrell & Birchler, 1987; Zweben, 1986), increased interpersonal conflicts (McCrady, Epstein, & Kahler, 1998), intimate partner violence (Cunradi, Caetano, & Schafer, 2002; Leonard, 2005;), and a greater risk of physical abuse and violence, with children being particularly vulnerable (Caetano,

Nelson, & Burundi, 2001; Murphy, O'Farrell, Fals-Stewart, & Freehand, 2001; Orford, et al., 2005; Velleman, Reuber, Klein, Templeton, & Moesgen, 2008).

The actual number of family members that are affected by someone else's alcohol or drug misuse is however not known. The estimate of the number of children that are affected by parental drug use in the United Kingdom is 250,000 to 1,000,000 while that for parental alcohol misuse stands at 1-3.5 million (Abe our Child Care Trust, 2002; ACMD, 2003; Manning, Best, Faulkner, Titherington, 2009; McNeill, 1998). The attempt at estimating the number of adults affected by someone else's alcohol or drug misuse is however still in its preliminary phase. Copello, Templeton and Powell (2009) present the first attempts at estimating the numbers in the UK that, at minimum, would be affected by a relative's drug use. From the model developed they estimated that the total number of family members affected range from 140,000 (for those within drug treatment services), to 1.4m for those in the general population. Copello and his colleagues acknowledge that these are conservative estimates reflecting the minimum possible number of affected adult family members that are significantly affected by familial drug use. They under-estimate the actual numbers of family members affected, as the model used only family members that were currently living in the same household as the user, and were themselves not using drugs; where parents and siblings were included, it was only those living with the user; and it was only one of the parents or siblings in each case, even in instances where there were two parents or more than one sibling in the same household. It does not take into account the ripple effect (both internal and external), that occurs with drug use in certain networks (Barnard, 2007; Orford, Natera, Copello, Atkinson, Velleman, Templeton, et al., 2005; Orford, Templeton, Patel, Copello, & Velleman, 2007; Templeton, Zohhadi & Velleman, 2007). This work limits itself to narrow definitions of dependence and problematic use, though as noted elsewhere (Velleman & Templeton, 2003), the negative effects are experienced at lower levels of a relative's alcohol

and drug misuse. These individuals would be excluded in these estimates. Secondly, its focus is limited primarily to opiates, cannabis and cocaine/crack; other illegal drugs for which dependence could develop are excluded.

Despite the limitations evident in this work, it is the first attempt at actual numbers of family members that may be affected by someone else's alcohol or drug misuse. And it provides a basis for arriving at more accurate estimates of these numbers. Currently there are no estimates of the number of family members affected by alcohol misuse; this work provides a framework with which making such estimates may be approached. In the absence of exact figures for affected family members, it could be assumed that, with the greater prevalence of alcohol misuse in society, a comparatively larger number of family members would be affected. Furthermore it could be assumed that this number is large enough to warrant attention.

Increasingly, family members are gaining greater recognition (Copello, Templeton, Orford, and Velleman, 2010). At the governmental level the negative effect on families is acknowledged, and steps are being taken to change policy to one that is supportive of family members in this situation. Previously, however, many of the services available were focused almost solely on the user (Copello & Orford, 2002). These services tended to channel their resources more into direct screening, identifying, and intervening, briefly or otherwise, for the individual with the alcohol or drug problem (Orford, Natera, Copello, Atkinson, Tiburcio, Velleman, 2006). Only very few approaches involve family members; where they do, the family members are seen only as an adjunct to treatment (Velleman & Templeton, 2002, Copello & Orford, 2002). They are thought to be crucial in increasing the likelihood of engagement, or retention of the drug using relative in treatment.

The process of adopting interventions that include family members or see them as clients in their own right has been slow. The slow adoption by government bodies, local authorities, local services and therapists has been attributed to a variety of factors which can be grouped into two main categories. First is the absence of conceptual models of understanding alcohol, drugs and the family dynamics (Copello & Orford 2002; Orford et al., 2005); second are factors centring around the Health Care Professional's (HCP) self-efficacy, attitudes and skills, and possible support within the workplace (Bastford, Rohe, & DePompolo, 2003).

1.2 Theoretical Models of Alcohol, Drugs and the Family

Over the years, there have been a number of theoretical perspectives that have attempted to conceptualize the role and experience of the family members where someone in the family is using alcohol or drugs problematically. Velleman, Copello, and Maslin (1998) look at six different perspectives on addiction and the family: codependency; family systems; psychodynamic; community; feminist, and community psychologist perspectives. A case study approach was adopted, with practitioners from these different orientations giving a perspective on the case.

Conceptualizations of alcohol, drugs and the family can be grouped into three main categories: family pathological, family systems or stress model. These are briefly describe in Table 1.1

1.2.1 Family Pathology models were the earliest models of addiction and the family. They were influenced by the psychodynamic traditions predominant at the time, (Price 1945; Bullock & Mudd, 1959). Irrespective of which of these family pathology models is being considered, the common thread is the focus on the spouses (usually wives) of the alcoholics (men). Emphasis lay greatly on discovering personality traits and characteristics that seem peculiar especially to wives of drug abusing husbands.

Table 1.1. Theoretical Models of Addiction and the Family

Model	Variations	Assumptions
Family Pathology	Disturbed Personality (Price 1945; Bullock and Mudd, 1959).	Wives of alcoholics were thought to have married these men to resolve their own neurotic conflicts (Lewis, 1937; Whalen, 1953). Wives were thought to have had knowledge of drinking of potential partner prior to marriage and this information plays a crucial role in her decision to take the relationship further.
	Decompensation	Husband's drinking problems offers stability to the marriage (Paulino & Mcgrady, 1977). These women were seen as discouraging their husband's efforts to reduce or remain abstinent (Ballard, 1959; Rae and Forbes, 1966). Husband's attempts at recovery would lead to a heightened level of distress for their wives – they were in this process said to decompensate (Futterman 1953; Igersheimer, 1959).
	Codependency	The partner and the chemically dependent person were thought to relate in such a manner that they reinforced a pathological need for each other. It is hypothesised that the inability to experience intimacy when relating with a significant other would cause the partner to behave in ways that would encourage drinking. Family members themselves are thought to be suffering from a pathological condition – codependency - and therefore in need of some form of treatment. Some authors (Cermak, 1986; Subby, 1987; Wegsheider-Cruse, 1985; Wright & Wright, 1991) make reference to co-dependence as a personality deficit, while some others (Shaefer, 1986; Young, 1987) have described it as a disease.
Family system	Communications Model	Focuses on the communication patterns found within family systems, specifically on the role of inputs and outputs in communication and the consistency between these in explaining family communication patterns in functional and dysfunctional families (Watzlawick, Beavin, and Jackson 1967). Posits that the patterns in dysfunctional families are a contributory factor to the addiction being experienced
	Family environment	Examines the social contexts and structures in which families find themselves and their interaction with those contexts and structures (Minuchin, 1975). Families are systems of interconnected and interdependent individuals, none of whom can be understood in isolation from the system; over time the family members develop patterns of interacting
Stress Model	Hills Crises Theory	Family passes through four stages in adjusting to the crises of alcoholism namely: onset of crises, disorganization, immediate reactions and readjustment (Hills, 1949). Identifying which stage family members are in is important in determining how to involve them in service delivery
	(Jackson and Kogan, 1954)	Neurotic traits, affective symptoms and psychosocial disturbances observed among wives of alcoholics are coping mechanisms developed to maintain family functioning and stability.
	Stress-strain-coping-support model	When a member of the family drinks to a point where it is causing concern to other members, it signifies the onset of stress, and over time family members would begin to show signs of strain. These family members often try adopting various coping strategies; these strategies may not address the effects of stress on their own health. To alleviate the effects of stress and strain experienced by family members, it is crucial that they are able to receive positive social support. This support could be from within or outside the house, friends or concerned significant others as well as professional services (Orford, et al., 1994, 1998, 2001, 2005, 2010).

There is however no evidence from research that supports this proposition that being diagnosed with a personality disorder is eminent among members of a family in which there is addiction (e.g. Gomberg, 1989). As noted elsewhere, what is deemed pathological may often fall under what could be considered as culturally or socially inappropriate behaviour for women (Haaken, 1993; Krestan and Bepko, 1991; Raven, 1994).

Additionally, the nature of the relationship that existed between the husband and wife was not addressed in these models (Edwards, Harvey & Whitehead, 1973; Nace, 1982; Royce, 1981). None of the variants offer an explanation for men that were married to alcoholic women (Orford et al., 2005), nor do they take into account the changing nature of families, where individuals may be cohabiting or in same-sex unions. The focus is on the role of the women and viewed with negative stereotypic representation, these women are said to play a major role in perpetuating what (alcoholism) was considered a disease. This negative representation of family members may have contributed to their reluctance to turn for help or the embarrassment that family members experience when a relative is seen to have an alcohol or drug problem.

1.2.2 The family systems models focus on the connectedness, interrelation and interdependence of all members of the family, allowing families to be viewed as a unit (Anderson & Sabatelli, 1999). These models, by throwing some light into the potential effects that the family may have on the individual, highlight the need for the involvement of family members in delivery of treatment for alcohol or drug problems, they however still resemble the family pathology model. The family systems models have been criticized (Goldner, 1989; Yllo, 1993) as not fully addressing the issue of gender inequality; they assume equality of the influence of the genders. The systems model either overlooks or understates gender inequality which is crucial in the explanation of family dynamics that may

be disruptive to the family. In the explanation of family violence, for instance, it assumes joint responsibility between the perpetrator and the victim. It removes the focus from the characteristics, motivations, and attitudes of the perpetrator of the violence, making him less responsible for his or her actions (Whitchurch & Constantine, 1993; Finkelhor, 1984).

Studies that have compared alcoholic and non-alcoholic distressed families (Becker & Miller, 1976; Liepman, Nirenberg, Doolittle, Begin, Broffman, & Babich, 1989; Mitchell, 1958) have not found dysfunctional processes that are peculiar to 'alcoholic families'. A broader perspective is the need to include cultural and broader contextual issues that influence families.

1.2.3 The stress model differs from both the family pathology and family systems models in that it focuses on the FM; it steers away from laying blame on the FM, who at this time may already be overwhelmed by guilt arising from a number of related sources. The first variant of this model, the Hills Crises theory, was developed originally to explain the stress experienced by families who had been separated as a result of war, but was later adapted in the conceptualization of alcoholism as a developing crises. This theory postulates that when crises of problematic alcohol misuse of one of its members arise, the family passes through four stages, namely: i) Onset of crises; ii) Period of disorganization; iii) Immediate reactions to the crises; iv) Readjustment process. Identifying which stage family members are in is considered important, as it was central in determining the level and nature of intervention that the family required.

The most recent variant of the stress model proposed for understanding drug use in the family is the Stress-Strain-Coping-Support model (SSCS: Orford, 2001, Orford et al., 2005; Orford, Copello, Velleman & Templeton, 2010). Unlike other models, this model focuses on the

family member and offers ways in which the family member may be supported through the process of gaining an understanding and developing an effective way of responding that would alleviate the stress that accompanies living with someone who is misusing alcohol or drugs. The centre of focus is the family member of the user and he/she is treated as a person in need of help in his/her own right.

The assumptions of this model are: first that the family members of alcohol and drug misusing relatives are under a high level of stress; secondly that there is a strong association between the level of stress experienced by the FM and the degree of strain (Arciadono et al. 2009; Orford et al., 2010). The signs of strain can be seen in the higher levels of health care utilization shown by family members of alcohol and drug misusing relatives (Lipscomb, Dement, & Li, 2003; Pollack & Ringen, 1993; Weisner, Logsdon, & Shanahan, 2000). The model postulates that the stress-strain relationship is influenced by two factors: namely the methods of coping adopted by the family member and the nature of support that the family member can access in relation to facing these circumstances.

When family members are faced with the alcohol or drug misuse of a relative, they engage in a number of behaviours (irrespective of their effectiveness) in responding to it. These behaviours are collectively referred to in the model as "coping". Orford et al. (1998, 2001) postulate that there are three broad forms of coping adopted by family members. These include engaged, tolerant-inactive and withdrawal coping. The family member is said to engage when he or she is actively trying to change the relative's behaviour either through being supportive, assertive, controlling, or emotional. When, however, the responses involve more accepting, sacrificing and inactive behaviours, they are said to be adopting tolerant-inactive coping strategies. Withdrawal strategies on the other hand are ones in which the person engages in activities which reduce interaction with the alcohol or drug misusing

relative. Of these three modes of coping the tolerant-inactive strategies are associated with higher levels of symptomatology. It has been suggested that changes in coping would lead to an alleviation of stress, and thus strain. Orford et al. (2005; 2010) postulate that the reduction in the tolerant-inactive and engaged coping, with an associated increase in withdrawal coping would lead to better outcomes.

The second factor that affects the stress-strain relationship is the nature of support accessible to the FM. Where the FM has access to positive social support - from other FM, close friends, relations, work colleagues, or HCPs, this can potentially alleviate the stress and strain experienced by FMs (Cohen & Wills, 1985). Conversely, the absence of this support or exposure to unsupportive sources can also complicate the FM's situation, leading to greater levels of stress and strain.

The theoretical propositions of this model as well as the expected outcomes of an intervention have been supported by research. Change has been reported in the ways that family members cope, (usually from being withdrawn and tolerant to being less tolerant and engaged (Copello & Orford, 2002; Howells & Orford, 2006). Additionally this intervention significantly reduced symptoms of stress for family members; this is even in situations where the user refuses to engage in treatment (Copello, 2002). Notable also was that there were positive outcomes for the health care professionals that trained in and involved in the delivery of this intervention; they reported an increased level of confidence and a more positive attitude in working with family/network members of alcohol or drug misusing relatives (Templeton, Velleman, Copello, Krishnan & Orford, 1999).

Evidence from research perspectives that evaluate the stress model point out that most women who live with an actively drinking or drug misusing spouse experience intense stress,

resulting in a higher level of psychological and psychosomatic symptoms. Existing evidence points to these symptoms being related to the drinking of the spouse, as their frequency of occurrence is seen to reduce when spouse's alcohol consumption or drug use reduces, or as seen in some cases when the woman has terminated or walked out on the relationship (Bailey, Haberman, & Alksne, 1967; Bailey, 1962). As noted by Jacob and Seilhamer (1982) and Orford (1984), research on this and other aspects of marriages complicated by a drinking problem is more consistent with the stress victim perspective on alcohol and the family than with the disturbed personality.

1.3.4 Summary of findings on Models

When taken as a whole these models suggest a reciprocal relationship between alcohol/drugs and related marital problems and family functioning (Roberts & MacGrady, 2003). Some of these models highlight that problematic alcohol or drug use can lead to high levels of conflict and stress within family relationships (Emmelkamp & Vedel, 2002; Marshal, 2003). The drug use is seen to affect roles played by different members of the family, family rituals, routine communication, finances and other family systems and processes (Brennan, Moos, & Kelly, 1994; Grzywacz & Marks, 1999; Holmila, 1988; Mcleod, 1993; Orford, 1990, Orford et al., 1998; Velleman 2002, 2004). In some of the other models, the levels of marital and family distress can trigger the relative's craving for, or relapse to, drinking and drug use (Cummings, Gordon, & Marlatt, 1980; Fals-Stewart, Klostermann, Yates, O'Farrell, & Birchler, 2005; Maisto, McKay, & O'Farrell, 1995; Moos & Moos, 1984; Orford & Edwards, 1977).

Existing evidence lends credence to this view of reciprocity between alcohol use and marital or family functioning. Marital and family problems may for instance trigger drinking or lead to relapse for an abstinent drinker (Maisto, McKay, & O'Farrell, 1998). Conversely many individuals with a drinking problem have extensive marital and family problems (O'Farrell &

Birchler, 1987). Additionally positive marital and family adjustment is related to positive treatment outcomes (Moos & Moos, 1984; Orford & Edwards, 1977). By implication, therefore, an individual's drinking problem could be triggered by a negative marital and family environment, and if the marital or family functioning improves, drinking may reduce as a consequence.

The models of alcohol, drugs and the family reviewed here have, over the years, progressed from considering family members as having some personality disorder or neurotic conflict (which marriage to an alcoholic helps to resolve) to ones that look for causative factors in the (family), and further to ones that look at the family member as a possible victim of circumstances. The stress perspective, particularly the Stress-Strain-Coping-Support model, provides the premise for looking at the family member as responding to a stressful situation in which they find themselves. Unlike other models it does not pathologize the FM or views him/her as responsible for the alcohol or drug use of the relative. It also differs from previous conceptualizations of alcohol or drug use within the family as it focuses solely on issues that relate to the family member and sees the family member as someone that needs attention in their own right. It focuses on the individual family member with suggestions as to how health care professionals may work with individual FMs. It allows for the family member to be seen alone and not in the context of group or even when the alcohol or drug misusing relative is not present. This lends itself to interventions that could adopt a self-help format where the individual can initiate, seek and receive treatment as an individual in their own right.”

The models reviewed thus far have implications for interventions that involve family members of alcohol and drug misusers in treatment. The stress model, for instance, is different from the other two models in that the primary outcome of interest is that which relates to, or has to do with, the family members. The other two approaches – the family

pathology and the family systems - are more concerned with the alcohol or drug misusing relative, and treatment approaches that emerge from or are rooted in these models focus on the alcohol or drug misusing relative. In the next section we will be looking at some of these treatments.

1.3 Family based approaches in treatment of substance misuse

There are a number of approaches that do involve family and other network members. They vary largely in terms of their scope or optimal focus; for some the primary focus is on individual issues around the drinker or drug user, others on the relationship and issues surrounding the family or network; for others still the focus is on the peculiar needs of the family members. Copello, Velleman and Templeton, (2005) have used the preponderance of the focus on any of these three outcome needs to suggest categories for the different family based alcohol treatments. It must be mentioned however that many of these interventions fall neatly into one of the suggested categories; a relative few however do overlap. These categories include:

- Work with family members to engage relatives in treatment.
- Work jointly with family members and their alcohol or drug use as well as improving the relationship between family members and users.
- Responding to the need of family members in their own right.

Fig. 1.1 below has a list of these interventions and the different categories they would fall into. A more detailed description of each of these and evidence supporting them is provided in the following section.

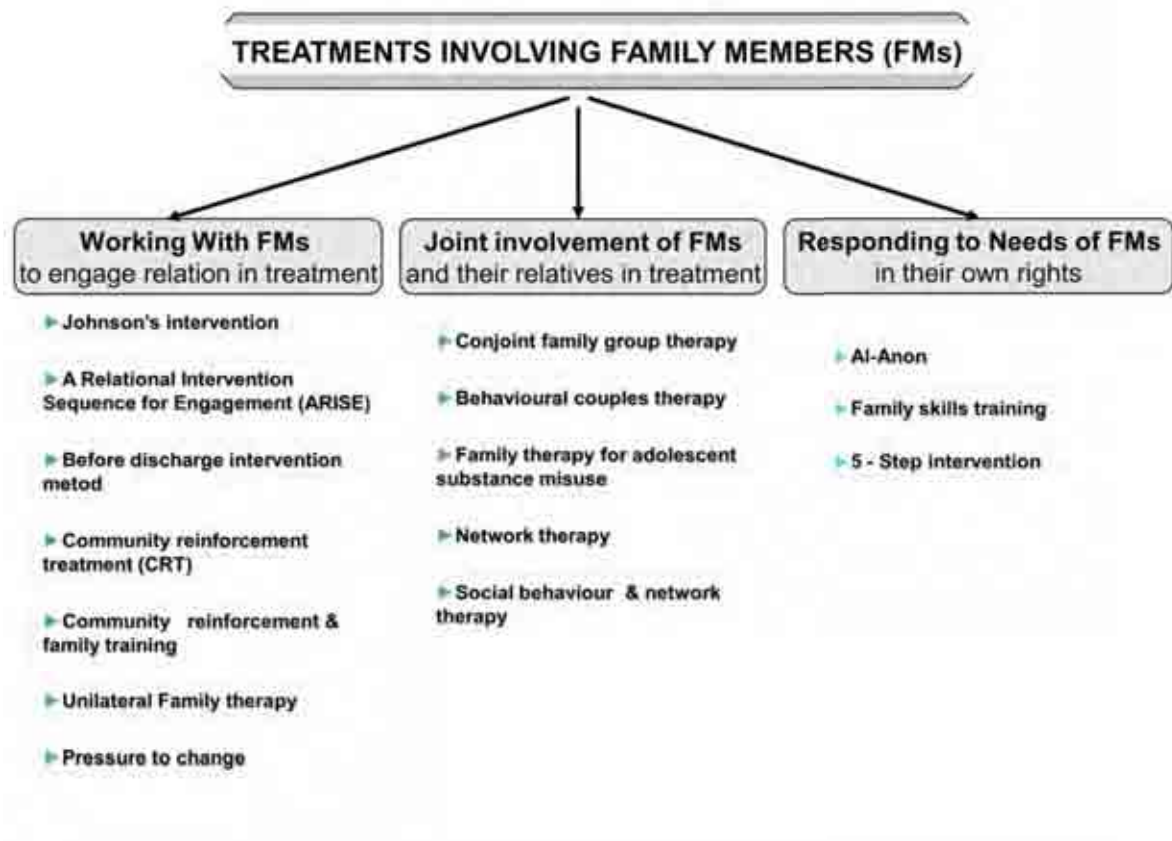


Figure 1.1. Categories of substance abuse treatments involving family members

1.3.1 Working with Family Members to Engage Relatives in Treatment

The focus of interventions in this first group is working together with family members with the main purpose of getting the alcohol or drug misuser into treatment. These interventions emerge mainly in an attempt to address a prevailing problem of engagement and retention in treatment of those misusing alcohol and drugs. Frances, Miller, and Gallant (1989) report that only small fractions (5-10%) of the people who drink to levels that are considered harmful, actually access treatment in a given year. Other researchers have stated that a great majority never do so through the course of their entire life (Nathan, 1990; Shapiro, Skinner, Kessler, Von Korff, German, Tischler et al., 1984). An additional problem is that some of those who are actually able to access treatment are not retained, with many of them dropping

off at the earlier stages and never completing the treatment (Conner, Shea, Mcdermott, Grolling, Tocco, & Baciewicz et al., 1998). Engagement and retention of problematic alcohol or drug misusers has been linked to better recovery outcomes (Stark, Campbell, & Brinkerhoff, 1990). It is therefore crucial that researchers identify and address the issues that may contribute to the higher drop off rates in this condition.

As family members are significant to the alcohol or drug misusing individual's network, and as they are usually the first to begin experiencing the negative effects of the alcohol and drugs use of a relative, they are in a peculiar position to help the person see the negative effects of their alcohol or drug use and to take action in addressing it (Resnick & Resnick, 1984). It is thought that they have leverage with the drinking or drug using relative and that they can be therapeutically assisted to get the drinker or drug using relative into treatment. There are a number of interventions where the core aim is to get the user into treatment, these include:

- Johnson's Intervention (JI)
- A relational intervention Sequence for engagement (ARISE)
- Before discharge intervention method (BDIM)
- Community reinforcement and family training (CRAFT)
- Unilateral family therapy (UFT)
- Pressure to change (PTC)

These approaches believe that family members have leverage and can be therapeutically assisted to encourage or facilitate the entry into treatment of the loved ones whose drinking or drug use is causing them concern (Thomas & Santa, 1982). Their attention and energy is thus directed to changing the behaviour of the drinker through working with member(s) of the family and network who are cooperative (Hunt & Azrin, 1973; Meyers & Smith, 1995; Smith, Meyers & Delany, 1998). They differ slightly in how they choose to work with

family members and the tools used. JI, for instance, initially works with network members in the preparatory process leading up to when they will confront the drinker with the negative consequences they have been experiencing as a result of the family member's drinking. The confrontation is geared towards helping the person work through the denial and consequently be ready to receive help. The Before Discharge Intervention Method (BDIM) adopts methods to work with families whose relative has been admitted for detoxification for the first time. The therapist takes family members through the process of confronting the relative a few days prior to discharge. This allows for the clinician to assess the effect of the delivered messages and gives time to resolve any complications that may have arisen.

For another two of these interventions – Pressures to change (PTC) and A Relational Intervention Sequence for Engagement (ARISE), a full-scale confrontation of the person by his family and network members is avoided. The choice rather is to adopt a progression model, gradually increasing levels of confrontation (Barber & Crisp, 1995; Barber & Gilbertson, 1996, 1997). The others - Community Reinforcement Treatment (CRT) which was later enhanced to the Community Reinforcement and Family Training (CRAFT) and Unilateral Family Therapy (UFT) - work with the family members, improving the interactions between them. In CRT and CRAFT family members are trained in the use of reinforcement to get drinkers to engage in service. These interventions aim at restructuring aspects of everyday life in such a way that abstinence is encouraged.

There are contradictory findings with regards to the confrontational approaches which show family members as being resistant and opting out of the intervention without reaching the final stage at which they confront the user (Leipman, Nirenberg, & Begin, 1989; Lewis, 1991; Loneck, Garrett, & Banks, 1996), with some being concerned that it may have a negative effect on their relationship with the chemically dependent person (Barber &

Gilbertson, 1997; & Rollnick, 1991; Miller & Wilbourne, 2002; Strupp, 1989). In comparison to client centred non-confrontational approaches they were found to lead to poorer outcomes (Finney & Monahan, 1996), and in some cases led to the opposite effect of triggering and increase in alcohol and drug use (Allen, Sprenkel, & Vitale, 1994; Gordon & Miller, 1992). They also seem to fall short of alleviating the problems that the family members of chemically dependent people were experiencing, even after the user was engaged in treatment (Barber & Gilbertson, 1996, 1997; Barber & Crisp, 1995). The less confrontational approaches yield better higher rates of engagement for the user (Sisson and Azrin, 1986) and positive outcomes for family members (Miller, Meyers, & Tonigan, 1999). CRAFT is one of the few interventions that have been subjected to a number of methodologically rigorous investigations. It has been found to be more effective than many others in getting initially resistant alcohol or drug misuser to engage in treatment (Meyers Miller, Smith, Tonigan, 2002; Miller, Meyers, & Tonigan, 1999).

1.3.2 Joint Involvement Of Family Members

In the second category of interventions, the Health Care Professional (HCP) works jointly with both family member(s) and the alcohol or drug misusing individual. Both are usually present in the session and the practitioner works with them, looking at their relationship and issues surrounding the family or network. Interventions that could be grouped under this category include:

- Conjoint family therapy
- Behavioural couple's therapy (BCT)
- Family interventions for adolescents
- Network therapy (NT)
- Social behavioural and network therapy (SBNT)

Typical sessions in any of these would involve the family member and the user; in certain instances separate sessions are advised to resolve issues with the hope of progressing or returning to joint sessions. The focus of these sessions go beyond just getting the drinking or drug using relative into treatment therapy to building support for reduction drinking or maintaining abstinence.

Although these interventions have a common approach in that joint sessions are held with family member(s), they differ slightly in the focus of these joint sessions. In BCT, for instance, the primary focus is on the reduction of marital distress (Hahlweg & Markman, 1988), as well as helping the spouse to learn new coping skills to facilitate and maintain abstinence (Noel & McCrady, 1993; O'Farrell, 1995); this differs from conjoint family therapy where FM and relatives are given assignments dealing with key therapeutic themes. This may include exercises such as listing the factors that attracted each partner to the other, expectations or needs from the other partner and resentment (Epstein and McCrady, 1998; Zweben, Pearlman, & Li, 1988).

NT and SBNT focus on galvanizing the network members' desire to help the patient. They incorporate strategies that have been found effective in other interventions; thus they include aspects of Community Reinforcement (Azrin, Sisson, Meyers, & Godley, 1982), Behavioural Marital Therapy (O'Farrell & Fals-Stewart, 2003); Motivational Interviewing and aspects such as behavioural skills training and medication monitoring by a significant other. These interventions seek to create a social environment outside of the health care services that would be supportive of change (Copello, Templeton, Krishnan, Orford & Velleman, 2000; Copello & Orford, 2002).

In regards to adolescent substance misuse issues, there are a number of options of family-based interventions. Some of these include: Multidimensional Family Therapy (MDFT: Liddle, Dakof, Parker, Diamond, Barrett, & Tejada, 2001), Functional Family Therapy (FFT: Alexander, Pugh, Parsons, & Sexton, 1999; Waldron, Slesnick, Brody, Turner, & Peterson, 2001), Family Behaviour Therapy (FBT: Azrin, et al., 1994), Brief Strategic Family Therapy (BFST: Santisteban, Coatsworth, Perez-Vidal, Kurtines, Schwartz, LaPierre, et al., 2003; Szapocznik, Kurtines, Foote, Perez-Vidal, & Hervis, 1986), and Multisystemic Treatment (MST: Henggeler, Pickrel, & Brondino, 1999). As Austin, Macgowan, and Wagner (2005) point out in their review of these interventions, they may differ slightly in their clinical application and focus but are quite similar in other regards. All the listed interventions approach substance abuse of adolescents as a family problem, deriving their roots to a large degree from the family systems model (Muck, Zempolich, Titus, Fishman, Godley, & Schwebel, 2001). Additionally, all focus on multiple interdependent domains of adolescent and family functioning (e.g., individual, family, community, and other extra familial systems). These domains are all considered critical in the therapeutic process. For each adolescent the risk and protective factors in each of these domains is considered (Liddle, et al., 2000), with the therapists working simultaneously with the information in each of these domains focusing on specific issues peculiar to that adolescent and his family.

Research evaluating joint involvement of family members in treatment shows that, when compared to individual alcohol counselling, interventions that involve family members produce better results. For instance, they lead to higher rates of engagement of the drinker (Santisteban et al., 1996; Slesnick and Prestopnik, 2004; Szapocznik, Perezvidal, Brickman, Foote, Santisteban, Hervis et al., 1988), increased days of abstinence (Austin, Macgowan, & Wagner, 2005; Becker and Curry, 2008) as well as broader outcomes of better marital adjustment (Fals-Stewart, Kashdan, O'Farrell, & Birchler, 2002; Fals-Stewart, Birchler, &

Kelley, 2006; Helberg & Campbell, 1974; Hunt & Azrin, 1973; Kelley & Fals-Stewart, 2002), family satisfaction, cohesion, and reduction in open conflict (Copello, et al., 2002, 2006).

Most of these interventions are however very intensive and the logistics of arranging joint sessions must be taken into consideration. As they are currently set up, the family or network is often the client; the focus of the session surrounds issues about the drinker. In these interventions family members are not seen as the clients in their own right. It is only in the third category of interventions discussed below that family members are considered to have peculiar needs and attempts are made to address them.

1.3.3 Responding To Needs of Family Members

In this last category of interventions the focus is solely on the family members as needing treatment in their own right. The outcomes of interest in these interventions are primarily those that relate to the family member, though the secondary outcomes of change in behaviour of the alcohol or drug misusing relative are sometimes measured. Many of these interventions are designed to be carried out with family members even when the alcohol or drug misusing relative is not present in the session. The interventions in this category include the following:

- Al-Anon
- Family Skills Training
- 5-Step Intervention

Al-Anon and other mutual help groups (Alateen, Nar-Anon, Adult Children of Alcoholics (ACA), Families anonymous, and Al-Anon Facilitation Therapy) provide separate interventions for family and other network members rather than the person with the alcohol

or drug problem. Often this is done in the absence of the person with the drinking or drug problem. These groups are reported to be among the most used resources to support family members and friends of alcohol or drug misusing individuals (Cermack, 1989; Room, 1973; Room and Greenfield, 1993), as well as being the intervention that therapist and professionals will use in working with family members or will refer family members to (Miller, Meyers & Tonigan, 1999).

Evaluative research shows that this intervention is not effective in getting the drinkers to enter treatment (Barber, 1996). These mutual help groups have, however, been found to be effective in reduction of family members' personal problems (Barber & Gilbertson, 1996), depression, anger, family conflicts (Miller, et al., 1999), as well as improvements in self-esteem (Kingree, 2000), and family cohesion (Miller, et al., 1999),

Family Skills Training Programme: One programme that is considered here is the Strengthening Families Programme. This has its origins in a methadone maintenance clinic where the parents in treatment indicated a desire to improve their parenting skills so they could provide a healthier environment for their children to grow up in and hopefully not pick up their drug taking habits (Kumpfer, DeMarsh, & Child, 1989). It must be noted that at this time that the available evidence confirmed that a number of maladaptive parenting factors do place young people at risk of experimenting with alcohol or drugs (Quinn, Kuehl, Thomas, Joanning, & Newfield, 1989; Bennett, Wolin & Reiss, 1987). These factors include poor parent-child communication (Kafka & London, 1991; Wills, Vaccaro, & McNamera, 1992), high frequency of conflicts with parents (Maltzman & Schweiger, 1991; Dembo, Williams, Wish, Dertke, Berry, Getreu, et al., 1988), and not being adequately supervised or monitored by parents (Dishion, Patterson, & Reid, 1988; Reifman, Barnes, Dintcheff, Farrell, & Uhteg, 1998). It is believed that if these parents were to received parental skills training, it would

make a significant difference in these children, reducing the number that would actually go on to experiment with alcohol or drugs.

The original goal of SFP was to reduce risk of children with substance abusing parent(s) experimenting with drugs themselves. It was targeted at children in primary schools who were considered to be at high risk. It consists of 14 highly structured sessions each lasting 2 hours. In the first hour parents and children work independently of each other in separate rooms, learning their skills or roles independent of the other. In the second hour, they are brought together for structured activity, giving opportunity to put the learned skills into practice. Randomized control trials (DeMarsh & Kumpfer, 1985; Kumpfer & Alder, 2003) suggest that each component of this intervention targets different outcomes. The children's skill training targets their competence, while parents' skills training reduces conduct disorders and the family session improves communication and relationship within the family. The full programme has been reported as more effective than either of the components alone. (Gottfredson, 2006).

Evaluation of this approach has demonstrated that SFP is robust at improving youth's competence and social skills, parenting skills and family relationships – effectively, it eliminates the risk and increases the protective factors for children at risk of substance misuse. SFP has been culturally adapted and found effective for African-American children (Aktan, Kumpfer & Turner, 1996; Brody, Murry, Gerrard, Gibbons, Molgaard, McNair, et al., 2004; Brody, Murry, Kogan, Gerrard, Gibbons, Molgaard et al., 2006), Pacific Islander, American Indian, and Hispanic families of 6- to 12-yearolds, as well as for pre-teens and teens (Kumpfer, 2001; Kumpfer, Molgaard, & Spoth, 1996; Spoth, Redmond & Lepper, 1999), and several other cultural groups (Aktan, 1995; Aktan, Kumpfer & Turner, 1996; Harrison, Proskauer, & Kumpfer, 1995; Kameoka, 1996; Whitbeck & Smith, 2001). Most of

these studies reported positive effects, especially when the programs were implemented with high-risk families by a single sponsoring agency (Kumpfer, et al., 2004).

Recruiting and maintaining families in treatment is challenging, often needing incentives to be applied. Additionally, implementing this intervention comes with a high overhead cost for personnel. The cost results from having three programmes (a parent, a child, and a family skills training) run simultaneously where at least two trainers are needed in each of the separate sessions.

The 5-Step Method: The SSCS model postulates a strong positive relationship between the level of stress and strain experienced by family members of alcohol or drug misusing relatives and states that this relationship is influenced by two factors: the method of coping adopted by FM and the availability of social support (Orford et al., 2005, 2010). By implication, if these two factors change in any way, this change may have consequences for the level of stress and strain experienced by family members.

The 5 Step Method which has its roots in this theoretical model is designed in such a way that it attempts to modify/influence these two factors (Copello et al., 2010). The method attempts to help the individual to first of all examine and change the strategies adopted in coping with the alcohol or drug misusing relative. The method also explores the support that the FM is currently accessing, seeing how to either expand this support network, or get more positive support from already existing network. It sets about this by first seeking a clear understanding of the FM's situation, through the process of validating his or her experience, as they often feel alone in the discovery that their relative is misusing alcohol or drugs (Step 1). The level of knowledge is said to be a contributory factor to the stress experience, and providing adequate knowledge may go some way towards relieving some of the stress and the strain

caused by this (Step 2). It then examines the individual's coping activities (Step 3) and possible alternative ways in which the individual could respond, before proceeding to examine the support available (Step 4). Lastly it looks at sources through which additional support could be accessed by family members (Step 5).

As an intervention it was designed with due consideration to the existing structures of the primary care setting for which it was designed to be implemented. This creates room for its ready and easy adoption by practitioners in these settings (Orford, Templeton, Patel, Copello, & Velleman, 2007; Orford, Templeton, Patel, Velleman & Copello, 2007). The 5-Step Method is flexible in its application; the practitioner may work sequentially through each of the steps with the family member or may work randomly depending on the felt needs of the FM. Again, the amount of time spent on each phase would depend on the practitioner's assessment of the presenting issues and peculiar needs of the FM. As the focus of this intervention is supporting the FM in their own right, it allows for practitioners to work with family members even when the alcohol or drug misusing relative is not present, or has refused treatment.

Based on the theoretical propositions of the SSCS model, the 5-Step Method seeks to make changes in the way the people respond to alcohol or drug use within the family. Of the three modes of coping identified by this approach, tolerant-inactive coping and engaged coping are associated with higher levels of symptomatology. Orford et al. (2005; 2010) postulate that a reduction in the tolerant-inactive and engaged coping, with an associated increase in withdrawal coping, would lead to better outcomes. In withdrawal coping, the FM engages in activities that involve reduction in the interaction with the alcohol or drug using relative.

The 5-Step method thus creates opportunities in which family member can explore ways in which they are currently responding to the alcohol or drug misusing member of the family and related issues. It further more encourages them to look at alternative ways they could respond to the different situations they face and how these responses may lead to better outcomes for them. Often in doing this the family members are found to reduce their use of engaged and tolerant-inactive coping strategies while increasing the use of those of withdrawal coping (Copello, Templeton, Orford, & Velleman, 2010). They often report reduction in tolerant and engaged ways of coping and an increase in more independent activities; which is associated with reduced symptoms (Velleman et al, 2008)

Research evaluating this intervention has shown that it does lead to significant reductions in physical and psychological symptoms for the FM, as well as changes in the ways that FMs cope with the alcohol or drug problem (Orford, Templeton, Patel, Copello, & Velleman 2007a). Changes have also been observed among the professionals that have been trained to deliver the intervention. These professionals report a greater level of confidence, self-esteem, knowledge, legitimacy and a positive overall attitude in delivering the intervention (Copello, et al., 2000; Templeton, et al., 1999; Orford, Templeton, Patel, Velleman, & Copello, 2007).

Though originally designed for implementation in the primary care setting, there is evidence of its effectiveness when delivered outside of this setting (Howells & Orford, 2006; Templeton, Zohhadi, & Velleman, 2007; Orford, et al., 2009, 2010). Its delivery in different cultural settings has also been evaluated (Arcidiancono, Velleman, Fioretti & de Georgio, 2007; Sainz & Rey, 2003; Velleman, Reuber, Klein, Templeton & Moesgen, 2008), leading to statistically significant reductions in symptoms of distress for family members.

Self-help versions of this intervention have been developed and evaluated. In a randomized controlled trial, Copello, Templeton, Orford, Velleman, Patel, Moore, et al., (2009) compared a full intervention with 5-sessions of face-to-face consultation with a brief intervention which consisted of one face-to-face meeting with the practitioner who then introduced the self-help manual. In this instance the self-help manuals were given to family members to take home and work on at their own pace. Results obtained showed that the use of self help with minimal contact with health care professionals was comparatively as effective as a full intensive version of the 5-Step intervention. Delivery in other formats is currently being evaluated (Templeton, et al., 2009, 2010). There was however no statement or measure regarding the pattern of usage of the self-help manual by those in this group. This would have helped to highlight potential relationships between degree of exposure to the intervention and improved outcome.

1.4 Availability of Treatment Interventions for Family Members.

Collectively, the interventions reviewed present strong evidence in support of alcohol and drug treatment services that involve family members as well as services that cater for the needs of the family members as clients in their own right. Despite the well documented efficacy and effectiveness of some of these approaches, they are not readily available to whole families or individual members of these families (Backer, 2000; Backer, Barlow, Levitt, & Bufka, 1999; Morgenstern, 2000; Wilson, 1998).

Current research on the availability of such services or the extent to which they are provided in different organizations is scant. Earlier work by Moore and Buchanan, (1964) examining 231 mental hospitals with specialized programmes for the treatment of alcohol misuse found that only 2% included family counselling. Later work by Gerard and Saenger (1966) points out that even in cases where there is evidence that family members reside with their alcohol

or drug using relative, it was in only 30% of such cases that family members were ever seen in treatment.

Regan et al. (1983) focused specifically on services that indicated that they were family oriented in their treatment of alcohol misuse. They were interested in assessing the reason for contact, nature and involvement of these agencies with alcohol misusers and their families. Services assessed were categorized as either being alcohol-specific, or having a more general orientation (mental health centre, hospitals, family service agencies, etc.). These agencies differed greatly with respect to staffing and the conceptual models of alcohol misuse that serves as the organization's guiding framework. Results from their study showed that the nature of contact or services offered to family members depended on the organizational setting (e.g., outpatient settings were more likely to offer conjoint treatment than hospitals or more intermediate settings), patient characteristics, and staffing patterns. For the most part, contact with family members, irrespective of the organizational setting, involved referring them to other types of treatment, especially Al-Anon and Alateen (Reagan, et al., 1983; Salinas, 1991).

It would thus appear that, irrespective of the treatment agency, family members were most likely going to be referred to other centres. This may be reflective of the present conceptualization of the organizations' mandate, where family members are thought to fall outside of the mandate of these organizations. Making these referrals, however, is an indication of a recognition that family members are in need, even if they do not view themselves as being responsible for meeting those needs. The effects of organizational characteristics and staffing patterns on the extent of family services offered was however not replicated in Salinas' (1991) study; they observed similar trends where most family members were given referrals to Al-Anon or Alateen and conjoint couple interview in inpatient

programmes. Outside of these, very few marital and family services were provided to those who were eligible.

In a more recent study, Copello and Orford (2002) assessed patient contact within a two day period across a number of organizations in the UK. They found that of 174 patient contacts only 2.8% of the family members were seen as clients in their own right and a further 1.7% received couples intervention.

Fals-Stewart and Birchler (2001) in their work obtained results that were equally not encouraging. From a randomly selected sample of alcohol and drug treatment programmes in the US, they interviewed a total of 398 practitioners, directors, counsellors (one from each organization). They found that 27% of those interviewed reported offering some form of couples-based counselling. The counselling provided was described in terms of a general couples counselling with a disease model orientation. The couples were typically seen for an average of 3.1 (SD 2.4) sessions. Less than 5% of those interviewed reported offering behavioural-oriented couples therapy to their married or cohabiting clients; none reported specifically providing Behavioural Couples Therapy. A very small percentage (3%) indicated having heard of BCT prior to the initial interview. When they were given brief descriptions of the intervention and supporting evidence, 71% indicated that they would not be willing to use this approach with the couples in their organization. As Orford, Templeton, Copello et al. (2009) posit, services that are thought to be family friendly may actually be discouraging the involvement of family members.

We could conclude that, despite evidence in support of the effectiveness of a number of family based interventions, their adoption by alcohol and drug agencies and related services has been slow. Availability of these treatment options for family members in routine service

delivery is the exception rather than the rule. We thus have a situation where therapeutic interventions are being created, modified and positively evaluated for different populations but are not being used in treatment, a situation which Owen (2001) equates to throwing a party which no one is attending. There is acknowledgement in the literature of the large gap that exists between research evidence and practice in alcohol and drug treatment (Institute of Medicine, 1998; Lamb, Greenlick, & McCarty, 1998; Marinelli-Casey, Domier, & Rawson, 2002; McLellan, 2002), and efforts should be directed to developing mechanisms to transport existing research-based interventions to settings where family members can routinely benefit from their availability. This transfer however is not without its complexities or difficulties (Institute of Medicine, 1998), some of which are elaborated on below.

1.5 Barriers to the transfer of evidence based alcohol treatment research to routine practice.

A number of studies which have assessed the readiness of organizations to adopt new evidence based interventions point to the fact that, like patients who are at various levels of change, the organizations and practitioners working in them may themselves be at different stages in their willingness to adopt and use new evidence-based treatments in their practice (Backer, 1998; Lehman et al., 2002).

Often these evidence based interventions do not take the peculiarities of the alcohol or drug agencies or related services into consideration in their design process. The organizations' interest may be more determined by other factors like the ease of implementation or how it fits with the clinicians' beliefs, or what they are already doing, as well as its cost-effectiveness and response to clinician-expressed need (i.e. market driven). The barriers to specific practices require more study, and perhaps must in some way be integrated with the approaches for translation that are eventually favoured.

While research focuses on factors such duration of stay, severity of the problem, and other factors that will contribute to the effectiveness of the treatment, the services are more concerned with the economics of managed care; cost effectiveness and ease with which it can be implemented within the current organizational structure (Simpson, 2002). Often these market driven concerns can overshadow the concerns for the needs of the service users (McGovern, Fox, Xie, & Drake, 2004). For many of these therapeutic techniques, achieving positive treatment outcome is dependent on the therapist adhering to the treatment protocol (Henggeler, Pickrel, & Brondino, 1999). This is possible if the practitioners are adequately trained in necessary skills and supervised in the delivery of this intervention (Willenbring, Kivlahan, Kenny, Grillo, Hagedorn, & Postier, 2004). Training, however, is time-intensive and potentially costly. Not many organizations are funded at a level where they can afford to release and train the required number of practitioners for the required period, to implement any new intervention.

This on its own may prove to be an insurmountable challenge. Even where practitioners desire to receive training in delivery of these new interventions, opportunities are not always present to do so. In addition, they may lack incentives as the organizational structure may not be set up in such a way as to accommodate change in the desired direction. These organizations may not have the funding or a reimbursement system in place that would encourage or support change. As several authors (e.g., Barlow, Levitt, & Bufka, 1999; Fals-Stewart & Birchler, 2001; Wilson, 1998) have argued, some of the interventions are not ones that practitioners would be willing to administer with appropriate patients in their services.

An additional problem is with the intensity of training often required in order to deliver the intervention at the required standard. It is often also time-consuming and logistically difficult

to arrange in the “real world practice setting”. If we look at standard BCT, for instance, a practitioner would need to provide 15-20 couple sessions to deliver this intervention adequately. Most practitioners are already overwhelmed by caseloads and long waiting lists and would be less willing to take up an intervention that would at the onset appear to further contribute to lengthening the waiting period. It is in recognition of this time consuming nature, that briefer versions of some these interventions are being developed and evaluated. (BCT, SBNT, 5-Step). Acceptability of these briefer interventions is still to be assessed.

Copello and Orford (2002) point out that commonly held belief about family members being there to support their relative in treatment services, are a barrier for the adoption of treatments that may focus specifically on involving family members either in the treatment process of their loved ones or as clients in their own right. Closely related to this is the treatment philosophy of the implementing agency. One of the oldest and commonly held philosophies by a number of treatment agencies and programmes is the disease model of treatment (Fuller & Hiller-Strumhofel, 1999). Where a treatment programme is rooted in another philosophy, it conflicts with the disease model and practitioners are somewhat hesitant to accept these new treatments (Fals-Stewart & Birchler, 2001).

In summary, even if a treatment is efficacious and established by evidence to be effective, there are barriers to its being implemented by frontline practitioners. The relevance of the intervention to frontline practitioners must be demonstrated. For various organizations, the barriers may be specific, requiring more studies on how to surmount them. What is evident is that traditional methods of providing and disseminating this evidence (materials, manuals) through conference, journal articles and newsletters to frontline staff are not adequate in getting organizations to change their culture and adopt new research based interventions (Brown, 2000). This is just the first step in a much more complex process of transfer from

research to practice (Simpson, 2002). Identification of problems of transferring of research and finding solutions has led to the production of conceptual models of the diffusion process, some of which are discussed in chapter three.

1.6 Conclusion

In this chapter a review of existing models of understanding of alcohol and drugs in the family, along with treatment approaches that emerged from these varied models, was discussed. Available evidence shows that treatment options which involve FMs are more effective in increasing engagement rates and result in broader outcomes, than individual based treatment for the user. As noted by Copello et al. (2005), at the minimum, family members are provided with an opportunity to be heard and are allowed to express their fears in ways that they previously had not been able to in front of a specialist.

Copello et al. (2005), and Orford (1984) have raised issues with regards to many of the studies evaluating these interventions, Only a very few have been tested using a randomized control design, which would allow for making confident assertions about the effect of the interventions and related factors. Most of the research evaluating these interventions have not been methodological rigorous, many are feasibility studies with low number of respondents, some lack control groups or where they did, they were not matched; for some others the follow-up rates were low. These shortcomings affect the generalization and general conclusions that can be made about the effectiveness of some of these interventions. There is a need for more studies to examine the validated delivery of these interventions in a variety of settings, cultures, types of family members, presenting problem/ clients (alcohol or drug type), or health profession delivering the intervention.

From the evidence of evaluative studies of interventions that involve family members presented here, we can tentatively state that those involving FMs can be effective and often result in better recruitment and retention of users in treatment, as well as greater success evidenced by the longer periods of abstinence or moderation in drinking. They also tend to have broader outcomes as they go beyond the user to benefit other members of the family and social network. Some of these interventions that involve family members are quite promising and with the evidence gathered, they should be made available in routine service delivery. There would still be the issue of determining core therapeutic components of these interventions, and which of them work best for which family members, or under what settings and which are more accepting or in need of modifications for use in a variety of cultural settings. These questions can be answered by a programme of research in real-life settings to ascertain what works in which conditions and environments.

As Drummond, (1997) pointed out, these interventions may have strong evidence supporting them, but may still have questions as to their transportability and availability in routine service delivery. A number of evidence based treatments have been developed but are currently not being used by HCPs in working with clients. For some interventions the time and cost-intensive nature makes it practically impossible to transport without modification to real life service delivery settings. Some developers have tried to address this issue by modifying the interventions or developing briefer versions that would require much less time for delivery (Chick, Lloyd, & Crombie, 1985; Chick, Ritson, Connaughton, Stewart & Chick, 1998; Heather, 1995; Kristenson, Ohlin, Hulten-Nosslin, Trelle, Hood, 1983). For one of the reviewed interventions – ‘the 5-Step Intervention’ - specific consideration to the environment and structure of the implementing organizations was given in its development. This possibly is why practitioners in these organizations report it as easy to implement and family members

see those organizations as being the right organizations from which it should be delivered (Orford et al., 2007 a,b).

The current health care environment however introduces another dimension in which health care interventions might reach end-users, in this case family members. The growing culture of self help and self management, evident in the proliferation of motivational books and self-help manuals, has encouraged an increasing number of people to take active steps in seeking answers to addressing their health care issues. This may take place without the person ever seeking the attention of a health care practitioner, or they may seek such attention somewhere along the process of a resolution. Government, in its argument for a stepped care model, acknowledges and encourages these treatment options that are less intensive (defined by input or time involvement of health care practitioner) as a first line of action. Progress to a more traditional engagement of health care professionals is possible where this fails to alleviate or fully resolve the issue.

This environment then presents yet another option for reaching family members with evidence based interventions. It is suggested by the author that, rather than work with the existing structures of health care providers and tailoring interventions to fit these structures, one can work with family members. One should use the structures that family members already have in place and are using in regards to their well-being, and tailor interventions to work with due consideration to these structures. As family members are increasingly using the internet and related technology to seek solutions to health issues that they are currently experiencing (Sillence, Briggs, Harris, Fishwick, 2007), this provides an opportunity to channel health interventions through channels that family members are already using. The scope of this dissertation is to evaluate the feasibility and effectiveness of using the internet

as an alternative to disseminating an evidence-based intervention to family members of alcohol or drug misusers.

CHAPTER 2

Web-based interventions: A review

2.1 Introduction

The advent of computers and related information technology, and the changing culture of help seeking offer innovative alternative routes for accessing self-help interventions (Andersson & Carlbring, 2003; Smith & Senior, 2001). Using these evolving technologies, self-help is now being offered on CD-ROMs, stand-alone computers, palm-tops, or through the internet. With the recognition of the potential that the internet presents, researchers have been evaluating it as a channel through which evidence based treatments might be disseminated more widely. The increasingly diverse range of treatment conditions being addressed by web interventions is evidence of the demand for, and appreciation of, this new medium for delivering such interventions. Currently a wide range of internet interventions is now available for various mental health and behavioural conditions. They include treatment for depression (Christensen, Griffiths, Korten, 2002; Clarke, Reid, Ebanks, O'Connor, Debar, Kelleher et al., 2002; Donker, van Straten, Riper, Marks, Andersson, & Cuijpers, 2009), anxiety (Newman, Consoli, & Taylor, 1997, 1999), post-traumatic stress disorders (Lange, Rietdijk, Hudcovicova, Van de Ven, Schrieken, & Emmelkamp, 2003; Litz, Engel, Bryant, & Papa, 2004; Rugerrio, Resnick, Acierno, Coffey, Carpenter, Ruscio, et al., 2006) smoking cessation (Schneider, Walter, & O'Donnell, 1990), obsessive-compulsive behaviours (Robinson & Serfaty 2003), and specific phobias as well as panic disorders (Devineni & Blanchard, 2005; Kenwright, Marks, Gega, & Mataix-Cols, 2004; Marks, Shaw, & Parkin 1998; Klein, Richards, & Austin, 2006; Titov, Andrews, Choi, Schwencke, & Johnston, 2009), weight loss (Tate, Wing, & Winett, 2001; Winett, Roodman, Winett, Bajzek, Rovniak, & Whiteley, 1999), headaches (Strom, Pettersson, & Andersson, 2000), and diabetes management (McKay, Glasgow, Feil, Boles, & Barrera, 2002), to name but a few.

Governments' acceptance of this means of delivery of interventions can be seen in the US in the calls for bids for funding put out by The National Institutes of Health and other government agencies which are actively encouraging the development and evaluation of interactive web-based health interventions. In an updated guideline for treating tobacco use and dependence, web interventions are recommended (Fiore, Jaen, Baker, Bailey, Benowitz, & Curry, 2008). In the UK, several internet based interventions, such as Beating the Blues, and Fear Fighter, have been recommended for use by the National Institute for Health and Clinical Excellence (NICE). In this way the governments of these countries are publicly recognising the value of web interventions and are seeing them as feasible and acceptable means of delivering treatment.

Given the relative paucity of research that focuses on the internet or computer based interventions for family members, or that addresses issues of substance misuse, this review will take into consideration internet programmes which target other mental health conditions. Though the reviewed studies will not focus solely on family members of someone using alcohol or drugs problematically, they will provide a useful perspective on the acceptability, feasibility, and efficacy of internet intervention that would be developed targeting this population.

2.2 Advantages of internet delivered interventions

There are certain features of internet interventions that make them attractive for delivering psychological interventions. It is particularly appealing for some people who do not wish to use traditional face-to-face delivery settings and would rather seek help in other formats (Low, Charanasomboon, Lesser, Reinhalter, Martin, Jones et al., 2003; Winzelberg, Classen, Alpers, Roberts, Koopman, Adams, et al., 2003; Zabinski, Celio, Wilfley, & Taylor, 2003). It removes the social barriers of self disclosure, creating a situation where people are more

willing to disclose information that could be potentially embarrassing (Brennan & Rippich, 1994; Grant, 1997; Proudfoot, Swain, Widmer, Watkins, Goldberg, Marks, 2003; Taylor & Luce, 2003). Some people just show a preference for communicating and interacting via a computer rather than with the clinicians (Carr & Ghosh, 1983).

Harvey, Churchill Crawford, Brown, Mullany, Macfarlane, et al. (2008), reported that young people are likely to turn to health websites when they are unable to confide in others, do not have friends they feel close enough to turn to and discuss the issues, are afraid that a GP might inform their parents, or are just too embarrassed to discuss the problem. Other conditions where people have been more willing to disclose information on the internet include people living with AIDS (Brennan, Ripich, & Moore, 1991; Brennan & Ripich, 1994; Flatley-Brennan, 1998), individuals with alcohol and drugs, sexual problems (Cunningham, Sobell, Sobell, Agrawal, & Toneatto, 1993; Grant, 1997), HIV risk factors (Locke, et al., 1992), issues with diet, eating disorders or suicidal feelings (Proudfoot, et al., 2003; Taylor & Luce (2003), and women with breast cancer (Gustafson, Wise, Mctavish, Taylor, Smalley, Wolberg, et al., 1993). Internet delivered interventions thus have the potential for lowering the barriers that are experienced when individuals are accessing help in more traditional face-to-face therapist formats.

The borderless nature of the internet also allows for addressing the physical and geographical barriers that would otherwise be present in accessing routine treatment services (Cudney & Weinert 2000). Physical attendance in this instance is not required and the individual can access this service from the comfort of his or her own or friend's home, library, internet café or stand alone computers in primary care centres or other hotspots. In this way an individual conveniently avoids the logistics of scheduling and travelling to or from these face-to-face consultations or sessions with the professional. The around-the-clock availability of these

programmes provides a flexibility that enables individuals to participate in or use these interventions with little or no disruption to their routine activities. Some programmes, for instance, provide asynchronous communication, where the users can post questions to the health care professional at any time of the day. Winzelberg (1997) in one study found family members posing questions to the health care professional during the late hours of the day, well outside working hours, and receiving a response sometime within the following 24 hour period. Often these internet programmes allow individuals to use the programme at their own pace; in this way it empowers users, allowing them some sense of control over their condition (Amichai-Hamburger, 2008).

From the service delivery perspective, its advantage lies in the uniform and consistent delivery of therapy which an internet delivered intervention allows, in contrast to delivery in face-to-face formats by clinicians or other practitioners. Because the programme elements can be systematically manipulated, it is easy to monitor their effects on a large population, identify weaknesses or shortcomings and make changes and re-evaluate. Opportunities for improvement with time are inherent in the medium as it is relatively easy to incorporate new concepts while at the same time dropping those that have not been found helpful. Reprogramming computers is a much cheaper option than training and retraining professionals in the light of new discoveries about what works best.

Additionally, the interactive capabilities of the internet offer opportunities for the individual to be given personalized (tailored) feedback (Budman, Portnoy & Villapiano, 2003). An individual could for instance be given an idea of how his or her responses stand along others who have responded to the questionnaire or where he/she would fall on the continuum of people with similar demographic characteristics. Tailoring has been found to allow for a more engaging and personalized experience, the programme is rated more positively and

people are more likely to return to or complete the programme, which itself increases the efficacy of the programme (Ryan & Lauver, 2002). As stated earlier, these programmes contribute to empowering the individual; in doing so they fit in nicely with current strategic policies in health policy which strive to empower individuals for active personal involvement and responsibility with regards to their health (Cappelen & Norheim, 2006; Tritter & McCallum, 2006).

Another growing concern is in regards to the unintended but potentially harmful effects of delivery of intervention on the internet. These include internet addiction, which is currently attracting a lot of research attention (Roman, 2009; Christakis & Moreno, 2009), as well as exposure to sexual solicitation, harassment or cyber bullying (Guan & Subrahmanyam, 2009). Factors that place one at risk of these potentially negative consequences of internet use are not yet known. There has additionally been no reported experience of any of these negative consequences as resulting from participation in an online intervention. This is again something that the therapist must contend with in working with this medium. Face-to-face interventions allow the therapist to monitor the effects of different aspects of the intervention on the individual. The practitioner is able to identify any negative consequences earlier in the therapeutic sessions and suggest a course of action. Many online interventions do not currently have means of monitoring for possible negative reactions to the intervention process and therefore are not equipped to respond in ways that would address them. There may be a need for future web interventions to be linked with the individual's current service provider where available, and where the onset of potential negative effects is recognised they could be referred or their practice informed.

Its ability to reach the desired target population however is dependent on access – which may be related to methodological issues such as recruitment follow-up procedures, and engagement of the site, as well as design issues (e.g., therapist involvement in delivery of the

intervention, satisfaction / acceptability, addictive or stand-alone, and content tailoring). While ongoing research seeks to establish the efficacy of online treatment, it is equally important to consider these and other related factors.

2.3 Methodological Issue

2.3.1 Recruitment : One of the great strengths of the internet is the vastness of its reach. Interventions delivered through the internet have the potential to reach a much wider population of individuals than any of the technologies currently available. A couple of intervention programmes illustrate the potential of the internet to transverse the geographic divide. These include the stop smoking site (www.dejardefumar.ucsf.edu or www.stopsmoking.ucsf.edu) that successfully recruited a final sample of 17,579 participants from 157 different countries (Barrera, et al., 2009) and the depression intervention programme (www.moodgym.anu.edu.au), which reported participants from 62 different countries (Christensen, Griffiths, & Jorm, 2004).

It is often thought that recruiting participants in a programme through the internet is much easier than recruiting using other more traditional methods. This prediction may result from the increasing majority of people that use this medium to communicate and gain information. Researchers have, however, reported that using this medium to recruit is difficult (Koo & Skinner, 2005; Im & Chee, 2005). Internet programmes, particularly those in primary care settings that recruit through the contact with health care professional or general practitioner, have tended to yield high levels of enrolment into the programme and higher follow-up rates. However, a number of open programmes suffer from very low uptake rates, sometimes getting response rates as low as 3% (Koo & Skinner, 2005). In a pilot of panel participation for “Value of Health”, Stein, Dyer, Crabb, Milne, Round, Ratcliffe, et al. (2006), contacted

5,320 potential participants using the electoral roll. A total of 23.6% responded to the initial invitation letter, but only 5.5% were willing to participate. Those that actually participated made up 2.1% of those initially approached.

Attempts have been made to better understand this low uptake of internet based research programmes. Glasgow, Nelson, Kearney, Reid, Ritzwoller, Strecher, et al. (2007) examined uptake in relation to the method used. They found a letter targeting members with chronic illness was more effective eliciting enrolment than letters directed to general members. When looking at the group of general membership, they noted in this group those who received personal letters had higher rates of recruitment (2.4%) than those than those who saw the announcement of the programme in the newsletter (1.7%). The findings lend credence to the earlier work of Spittaels and De Bourdeaudhuij (2006) who examined the effect of handing out flyers or pasting them in strategic locations. They found that people being handed the flyers with face-to-face contact resulted in more people (46%) registering and participating on the site than did those who saw the flyers posted in strategic locations (6%), without contact with health care practitioners.

There is also the special challenge of recruiting a representative sample, as the internet sample may be already biased. Evidence available shows that internet users are a demographically select group who have internet access, are computer literate, and prefer these channels of communication (Hassani, 2006; Marks, Cavanagh, & Gega, 2007; Robinson, Flowers, Alperson, & Norris, 1999; Selywn, 2006). There are still many who do not have access or do not desire to access the internet. It is in this context that recruiting ethnic minorities poses a challenge (Klemm, Hurst, Dearholt, & Trone, 1999; Pautler, Tan, Dugas, Pus, Ferri, Hardie, et al., 2001). They are less likely to be computer literate and are less likely to have access to the internet to be aware of interventions that may be recruiting

through internet forums, organizational web-pages or email request; as such they are not in a position to benefit maximally from such interventions. According to Monnier, Laken, and Carter (2002) individuals who are older, less educated or of an ethnic minority (especially women) are less likely to have used the internet. In order to reach these populations there is a need to put in place strategies that would identify and recruit from potential pool of ethnically identified individuals (Im & Chee, 2005).

2.3.2 Engagement/ Retention: Even where you do achieve high levels of recruitment, there is the issue of utilization or exposure/dosage of the internet programme that people receive. A substantial proportion of people have been found not to use, or to use the programme sparingly, after signing consent to participate. The low utilization of internet programmes reported has led Eyesench (2005) to coin the phrase ‘non-usage attrition’, describing this phenomenon.

Though some interventions (Hester, Squires & Delaney, 2005; Stevens, Funk, Brantley, Erlinger, Myers, Champagne, 2008), have reported utilization rates of 80% or more completing the programme, quite a number have reported low rates. For instance Christensen, Griffiths & Korten, (2002) evaluated site usage of an internet programme for depression and anxiety. They used the number of visits to the sight as a measure of the number of sessions. Although this is acknowledged as an imperfect measure, as some people may visit the site more than once, it does give some indication as to the amount of web traffic generated by the site. Over a period of 181 days the site recorded 817,284 hits. The programme consisted of 5 modules, each taking 35-45 minutes to complete. They found however that people on average spent 9.47 minutes on the site. Slightly less than 10% spent 31 or more minutes – the approximate time needed to complete one of the modules.

Verheijden, Jans, Hildebrandt, and Hopman-Rock (2007) examined utilization of a web-based behaviour change programme for healthy body weight and lifestyle. They found that only 940 of 9774 (9.6%) participants who completed the baseline test actually used the site more than once. Similar rates of non-utilization have been reported by Farvolden, Denisoff, Selby, Bagby, & Rudy (2005). In recording longitudinal effectiveness of a 12 week internet programme for panic disorders, they found a number of people dropping off with progressive sessions; thus 54.78% dropped out after the first session, 68.22% stopped by the fourth session, with only 1.03% of the participants actually completing the programme.

Programme utilization however seems to be mediated by a number of factors. One is whether it is in the context of a trial format or an open format. Trial formats have shown to lead to greater rates of participation and completion than open formats (22.5% vs. 0.5%) in a programme consisting of 5 modules (Christensen, 2005). Andersson, Carlbring, Holmstrom, Sparthan, Furmark, Nilsson-Ihrfelt et al. (2006) observed low programme adherence rates in an internet cognitive behavioural treatment programme for school phobia, Andersson et al. (2006) obtained a 62% completion rate. In a later study of this programme, (Carlbring, Gunnarsdottir, Hedensjo, Andersson, Ekselius, Furmark, 2007), adherence rates jumped to 93% and this was attributed to the additional component of weekly telephone calls that were made to the participants. As this was not a direct comparison it is difficult to conclude that the increased adherence was as a result of the inclusion of these weekly phone call reminders.

Titov et al. (2009) overcame this barrier by randomizing participants into groups that received or did not receive telephone reminders within the same intervention research. With 163 volunteers they tested an enhanced internet cognitive behaviour therapy for school phobia. Results obtained showed that those who received telephone reminders had a significantly higher adherence rate; 81% as compared to the 68% for the group that did not.

Prompts, telephone and email, have been found effective in other studies of sustaining ongoing internet programme usage (Stevens, et al., 2008).

Several studies have taken a further step to compare differences in adherence and how it affects the outcomes of internet intervention. In an internet smoking cessation program, Strecher, Shiffman, and West's (2005) results point out that the number of web pages opened by the participant was not a good predictor of 12-week cessation. Palermo, Wilson, Peters, Lewandowski, & Somhegyi (2009) in an internet family delivered cognitive-behavioural therapy for children and adolescents with chronic pain found that the majority of those that were randomized to the internet delivery showed high rates of adherence with 77 % of the children completing all eight modules of the programme. On the other hand only 54% of the parents completed all the modules. They found however that the outcomes of treatment were not related to the number of modules that were completed by the family. This is similar to Stevens et al.'s (2008) research that did not find any difference. Notable is that adherence in this study was also high (81% vs. 68%).

Lower adherence rates have been obtained elsewhere; in Pretorius, Arcelus, Beecham, Dawson, Doherty, Eisler et al.'s (2009) study of an internet bulimic symptomatology reduction programme, participants completed an average of only 3 of the possible 8 web-based sessions. Christensen, Griffiths, Korten, Brittliffe, & Groves (2004) examined difference in adherence between trial participants and spontaneous internet users. They found that spontaneous users of the internet programme complete comparatively fewer modules than trial participants. Only 15.6% of the spontaneous users went beyond the second module, while 66% of the trial participants completed two or more modules. Results indicated that the spontaneous users showed similar levels of improvement. Unlike previously quoted work, however, Clarke et al. (2002) report significant differences in

outcome between those who used the programme less with those who visited the site more often.

These results are in line with Christensen, Griffiths, & Farrer's (2009) review of adherence rates for randomized controlled trials of internet interventions for anxiety and depression. They report that adherence in the context of internet delivered randomized controlled trials is somewhat similar to that which is seen in other non-internet based interventions such as those for depression and anxiety. But they do dramatically differ from open access internet interventions. When comparing open access internet interventions with face-to-face treatment settings, adherence rates are not too different. Reported non adherence rates are high in face-to-face interventions, where as many as 70% of the patients terminate therapy after the third session, with hypothetically none completing the required 10 sessions of treatment. Turks & Meichenbaum (1991) report 20-80% of the patients discontinuing their participation in stress, exercise and smoking cessation programmes. These rates are comparable to the non-adherence to antidepressant medication treatment regime which also ranges from 20-80% (Sabate, 2003).

As indicated here, the problem of adherence is not limited to internet programmes; it would however be vital in understanding utilization patterns as they relate to internet programmes. It would be helpful knowing the degree of exposure that is effective and which (if any) components of the intervention are important as relates to behaviour change. It would be of interest, for instance, to know why individuals on average stopped using the internet programme after the third session. Would it have been that they were no longer experiencing symptoms and therefore no longer needed the programme, was it that they no longer found the site useful, or was this was due to motivational factors like the sessions being too long? Sproull, Subramani, Kiesler, & Walker (1996) call for basic research on how various

elements of the website may be changed (e.g. addition or change of colours used, addition of sound, or video and how this may affect the outcomes), or it may be necessary to confirm Glasgow et al.'s (2007) finding that they are not related to patient characteristics. Research of this nature would lay the groundwork for a greater understanding of adherence with internet programmes. We may arrive at similar conclusions as Rozanski, Bollman, & Lipman (2001), that attrition as experienced in these programmes is more a reflection of the general problem of internet behaviour, where individuals tend to spend a short time (an average ranging from 0.6 to 6.7 minutes) on websites they visit.

2.3.3 Follow-up: The low follow up rate obtained with internet interventions is an emerging concern. Sheehan and McMillan (1999) note that responses to email internet surveys end up with lower response rates than other traditional survey methods; this is later confirmed in Cook, Heath, and Thompson's (2000) meta analysis of internet surveys; they found that the mean response rate for 56 internet surveys without missing data was 34.6% (SD=15.7%). These low rates become even more pertinent when we are evaluating an internet intervention, which requires that the individual does not just log in to the programme but also uses the programme and at some future point provides follow-up information.

Regarding concerns about low follow-up rates, Eyesench (2005) posits that a 'Science of Attrition' is needed to explain and understand the low levels of utilization and subsequent follow-up of participants in many of the internet programmes. Eyesench (2005) highlights that the internet allows us to make clear distinctions between two separate yet interrelated phenomena; low or non-utilization of the internet programme and follow-up. He coined the two phrases 'non-usage attrition' and 'drop out attrition' to describe these two related phenomena.

Non-usage attrition in itself is said to be related to an often experienced loss of participants at follow-up in internet research. It may be that the loss at follow-up is an indication of the participant's earlier loss of interest in the programme, therefore stopping using it. We are thus dealing with two similar yet very distinct phenomena: 'non-usage' and 'drop out' attrition. The internet allows for the possibility of a variety of responses to a programme. For instance we could have a situation where there is non-usage of the programme and high drop out. Or it could be one of non-usage and low drop out. Similarly, we may find situations of high programme usage with high dropout or the desirable research situation of high programme usage and low drop out. The ability to differentiate usage and follow up data in this manner is only possible because of the internet's capabilities to monitor and track usage with greater detail and precision than is possible with other traditional clinical trials. High fidelity maintained in these studies relates to the fact that the internet interventions are delivered in a standardized and uniform manner to all the participants. (Christensen & Mackinnon, 2006).

Some internet programmes have experienced low follow-up rates. Cunningham, Humphreys, Kypri, & van Mierlo (2006) for instance had a follow-up rate of 27.28% completing follow-up at 3 months, in an internet programme for problem drinkers. Rothert, Strecher, Doyle, Caplan, Joyce, Jimison, et al. (2006) randomized participants in a weight management programme into two treatment arms: tailored and non-tailored (controls) in a six-week weight management programme. The participants were then followed up at month 3, 6, and 12 months after baseline; they were sent email reminders at each point. The participants were classified as non-responders if after a period of 3 weeks they did not respond to any of the 21 email reminders. Of the participants that provided baseline information, only 31% followed up at month 3, with 21% at month 6 and 15% responding to a 12-month survey. There was no difference in the rate of attrition in the different treatment arms.

In a landmark research by Etter (2005), 11969 smokers were recruited to participate in an internet based smoking cessation programme. These participants were randomized into two groups: one which experienced the original web-based programme and the second group which experienced the modified version. He also notes a large number of dropout attrition with 35.4% providing follow-up information on the whole. Those in the modified arm had lower rates of follow-up than in the original web programme arm (31.6% vs. 39.2%). Despite the high attrition rate, it was still possible to detect significant differences between the two interventions.

A few studies (Couper, et al., 2007; Lange, et al., 2003) have tried to follow-up the non-respondents to find reasons why they did not provide follow up information. Lange et al. followed up a group of non respondents in an internet based programme for post traumatic stress. Of the 44 non respondents, 18 (41%) gave technical reasons for not being able to provide follow-up information, 13 (29.5%) reported that they found writing about the stressful life events a bit burdensome and the remaining 13 (29.5%) indicated a preference for face-to-face treatment sessions. If these last two categories were to be collapsed and considered under issues related to the intervention then 26 (59%), would fall into this category.

Couper et al. (2007) followed a sample consisting of 380 non-respondents to follow-up in an internet programme for weight management. Technical problems (accessing or submitting the survey, email or computer problems or did not receive or remember email message or treated it as spam) was the reason given by 51.8% of those sampled. 37.8% gave reasons related to the intervention (e.g., lack of interest or lack of effectiveness of intervention, did

not have time or badly timed, etc.), the remaining subjects either did not give reasons or they indicated not remembering why they did not respond to the earlier follow-up. These findings receive support from other available information on non-responses, though this information comes from separate data and not from the nonresponders as a group. Some of the reasons indicated in this research included issues of motivation (Titov, Andrews, Schwencke, Drobny, Einstein, 2008a), preference for drug medication and or interfering medical conditions (Klein, Richards, & Austin, 2006), issues related to timing (Andersson, Strömngren, Ström, & Lyttkens, 2002; Carlbring, et al., 2007; Cuijpers, van Straten, & Anderson, 2008; De Graaf, Arntz, Riper, Metsemakers, Evers, Severens, Widdershoven, et al., 2009; Spek, Nyklícek, Smits, Cuijpers, Riper, & Keyzer, et al., 2007; Warmerdam, van Straten, Twisk, Riper, & Cuijpers, 2008), perceived lack of improvement (Lange, van de Ven, Schrieken, & Emmelkamp, 2001; Titov, Andrews, & Schwencke, 2008b), as well as improvements in condition (Patten, 2003; Warmerdam, et al., 2008).

There have been efforts to increase the follow-up rate on internet programmes. Bersamin, Paschall, Fearnow-Kenney, & Wyrick (2007), for instance, look at the effects of the inclusion of monetary incentive. They gave \$10 cash for each survey and a cheque of \$50 if they completed at least 3 of the 5 units of College Ale. They were able to arrive at a follow-up rate of 59.48% of the college students who participated. In response to the low follow-up rate they were experiencing. Glasgow et al. (2007) sent follow-up letters to those individuals who had provided a mailing address with \$10 cash; this boosted their follow-up rate from 22.3% to 47.6%.

Verheijden, et al. (2007) found that those who did not provide follow up information said they would be interested in participating if a bonus or reward was given for participation. This is confirmed later in the findings of Su, Shao and Fang (2008), that material incentives

are still the more effective incentives. There is however a problem of how this could be delivered to participants, particularly in open access research which may span across various countries. Further research is needed for us to clearly understand which internet incentives (existing or yet to be discovered) hold greater value for which population and how best these incentives could be timed and delivered in an internet programme.

The format adopted in following up the participants should also be given considerable attention, Brennan, Moore & Symth (1995) found that approximately half of the respondents in their study showed a preference for receiving hard copies of the online questionnaire which they filled in and returned by postal mail to the researchers. It should be mentioned that this may have been due more to the fact that participants in this research included those in the older age bracket, 75 years of age, who at this time were not thought to find internet technology as user friendly. Thus if the option for filling in hard copies and returning by post was not included it may have led to higher attrition rates for this group.

The potential of attrition to selectively affect certain populations raises the question of the validity of the measure obtained, and the confidence in the conclusions and generalizations that can be made from the data. In other treatment formats, attrition is analyzed using the intent to treat approach where all participants in the trial are analyzed. The extent to which this is undertaken in large randomized control trials is however not known (Eysenbach, 2005). Using the intent to treat analysis with the high attrition rate that is peculiar to internet interventions increases the likelihood of not detecting true differences that may exist. In a rejoinder to this article, Christensen and Mackinnon (2009) note that these classical analysis of variance methods, which allow for estimations of the effect of an intervention under the intent to treat model, throw little light onto the causes or consequences of attrition. They posit the need for a model that would allow for an accurate estimation of the effects of an intervention despite high attrition rate.

2.4 Design and delivery issues

2.4.1 Therapist involvement and internet tools use: Internet based interventions use a variety of methods in the delivery of the intervention – both in terms of content of the website and procedural aspects of the interventions. For one, they differ in regards to the extent to which contact with the therapist is required. At one end are internet interventions that adopt formats that closely resemble traditional forms of treatment where the user is online at the same time as the practitioner and have more or less what would be regarded as a regular treatment session; this may also be performed in either the individual or group format. Various terms have been used to describe the interventions that adopt this delivery format, these include: e-therapy, online therapy, cyber therapy. These sessions delivered in real-time may take the form of ‘chat room’ conversations, audio conferencing (sometimes with video-conferencing facilities). An example of such programme is eGetgoing, which is an online rehabilitation programme for adults that are new to recovery from substance misuse or returning after relapse. This programme has been accredited by the USA Joint Commission on Accreditation of Healthcare Organisations and Commission on Accreditation and Rehabilitation facilities. In this programme a group of about 10 participants login to an online one hour session twice every week. These meetings are led by therapist and held live using the interactive audio- and video-conferencing capabilities of the internet. Usually this treatment phase lasts for 6-12 weeks, depending on whether it is a primary or basic treatment session. This is then followed by 12 weekly online group after-care meetings. This also has facilities for text based group chat with other alumni participants. Another website, ABCs of Internet Therapy (www.metanoia.org), presents a centralized listing of certified therapists offering online consultation services as well as a guide to help the individual in making a choice of which therapist to use for their issue. Various ethical and legal concerns have been raised in regards to internet interventions that are delivered in this manner. Another site with counselling alternatives is www.asktheinternettherapist.com. Here the client has options to

choose from a list of qualified counsellors as well as the mode or channels of counselling that would be preferred (e.g., email or chat, audio or visual therapy). These internet interventions are similar to face-to-face settings in regards to the demands they place on the therapist, and the high level of involvement that is required by the therapist. Some other online therapeutic programmes are however not run by certified professionals but rather host peer-led sessions. Many of these sites are set up by helping agencies to provide an alternative form of support for their clients. An example of this would be groups working with the 12-Step principles. A directory of these sites is in the AA's big book www.aabigbook.com.

At the other end are interventions that adopt a guided self-help approach, where the individual independently works through the programme, with little or no contact with a practitioner. For some of the programmes that adopt this design, information on how to contact the therapists is usually provided; contact is however seldom made by users. In cases where they do have contact, it is usually for the practitioner to introduce the individual to the programme, giving basic instructions or login codes/ access keys where this is required. They may also be offered ongoing email or telephone support through the process.

Programmes delivered in this format use a variety of online tools and techniques to enhance the information that the individual receives. Some for instance may include animations, colour schemes, audio- or visual instructions/clips, rollover images, modelling presented in video interviews, audio files that the person can listen to online or download and use at a later time, facilities to 'ask the expert' questions, pop-up windows with messages that would serve as reinforcers, the ability to post information or comments on a bulletin board, chat with others in similar situations (Stinson, Wilson, Gill, Yamada, & Holt, 2009). An internet programme may use one or all of these methods, some with assignments that the participants are required to complete. Many of these assignments provide feedback to the individual,

sometimes the assignments are such that non-completion makes it difficult for the person to proceed to the further stages of the programme. These programmes vary in their range and intensity; some are more informational, presenting educational material in a non-interactive format. Others, however, are more interactive, providing feedback to the individual based on their responses, and may also direct the individual to assignments based on these responses (Tate & Zabinski, 2004).

An example of a programme that adopts the self-guide approach is Moodgym (<http://moodgym.anu.edu.au>). This is designed to allow the individual work independently of the therapist in the prevention and treatment of his or her depression. The individual is encouraged to work sequentially through five modules of the programme. Each module takes approximately 40 minutes to complete, but the user is allow the flexibility of skipping sections and proceeding as they wish. These modules cover issues of dysfunctional thinking patterns that the person may have adopted, description of various types of dysfunctional thinking, how to overcome this dysfunctional thinking pattern, lessons in relaxation and simple problem solving. The programme includes exercises and assessments that the individual is required to complete at different stages, as well as relaxation tapes which the individual is encouraged to download and use in helping them to relax.

Another self-help programme that utilizes some of these named tools is Fear Fighter (www.fearfighter.com) which has been designed for use in the treatment of panic/anxiety and phobias as well as co-morbid anxiety with depression or obsessive compulsive disorders. The programme encourages the individual to identify a specific problem and guides him/her through a process of repeated self-exposure to the feared situation in order to work through the fear. In different versions of this programme the individuals will also have scheduled

therapeutic helpline support from the therapist. On average this is approximately for one hour over the 10 week treatment period.

2.4.2 Acceptability and satisfaction of participants with internet interventions: The acceptability of internet interventions has been measured in a variety of ways including: the readiness or willingness of people to use these interventions, satisfaction with using these interventions, information that they post when using the interventions, and the extent to which the interventions meet their expectations. This however is not a well researched area (Kalthenthaler, Sutcliffe, Parry, Beverly, Rees, & Ferriter, 2008).

Dow, Scott, Amodha, Wise, & Hill (2008) look at the feasibility of an internet programme for rural carers. Fourteen carers recruited to use the intervention rated this approach as practical and acceptable. It is notable that most had little or no knowledge of computer and internet usage, with 64% rating themselves as not being confident in using email. At post intervention follow-up 93% reported increased confidence in their email and internet use, with the intention of continuing to use them. Similar encouraging results have been obtained by Chambers, Connor, McGonigle and Diver (2003) who recruited care givers to use multimedia software that aims at enhancing the caregiver's ability to cope; these caregivers made positive and enthusiastic comments with regards to the programme content. The caregivers rated the usability features of the programme (e.g., appearance and navigation) quite highly.

Looking at the uptake of computer-guided cognitive behaviour therapy, Fear Fighter, by rural participants in Scotland, Hayward, MacGregor, Peck, David and Wilkes (2007), concluded that the high uptake was an indication of the acceptability of this medium for use in treatment. Only 24% of those approached refused to participate. Of those that participated in

the programme 97% indicated being satisfied with the e-help they received from the programme.

Pretorius, et al. (2009) had participants rate various aspects of the internet delivered cognitive behaviour therapy for adolescents with bulimic symptomatology. Many of the participants reported that they liked the convenience of its being online and they felt the information provided was helpful. They also indicated that the provision for email support gave the feeling that someone cared about them, and that the message board gave the feeling of belonging to a group. Some, however, found the sessions were not personal and were a bit repetitive. And they did not like the fact that the workbook included had fonts that were large in addition to not having prompts to guide you through the assignments. They also did not like the talking commentary that was on each page, even though this was a function that was optional and they could turn off.

There are some programmes that do contain features that participants find not easy or difficult to use. Nijland, van Gemert-Pijnen, Boer, Stehouder, and Seydel (2008) conducted in-depth interviews to examine how participants perceived the user-friendliness of the programmes and problems they encountered in using them. Some of the reported problems encountered included inadequate navigational structures, limited search options, absence of feedback features, or insufficient tailoring of the messages to patients' needs,. They also found that care givers doubt the reliability of the computer-generated information and the efficiency and effectiveness of secure email consultation, as well as the legal and ethical concerns of the potential use of emails sent.

Similar dissatisfaction has been noted with other online programmes. Anhøj (2004) found that, though participants were quite enthusiastic about the online life style change programme

(LinkMedia-Heart), they only used the programme a for short time period, and reported that the programme did not fit into their daily lives. Some felt the programme had a complex navigational structure, while others felt that the programme's feedback was too elaborate and detailed without adding much to the knowledge the already had. Similar findings have been reported with internet smoking cessation programmes. Some users have indicated that they find some of the sites confusing and unhelpful (Etter, 2006). It has been suggested by some (Carey, Wade, & Wolfe, 2008) that prior experience with computers and users' confidence in usage may be a determining factor in deriving benefits from online intervention programmes.

Another aspect of internet intervention that gives an indication of its acceptability and preference for this channel for delivery of the intervention is the ability of computer mediated communications in accessing information that may not be presented in other formats. In comparison to face-to-face interactions, the anonymity of computer-mediated communications leads to higher levels of self-disclosure. (e.g., Chiou, 2007; Joinson, 2001; McKenna & Seidman, 2005; Newman, Consoli, & Taylor, 1997). This is more so in areas considered sensitive, such as experiences of blackouts from alcohol consumption, sexual disorders, or suicidal intent (e.g., Appleby, 2001; Leider, 1999; Miller & Gergen, 1998; Stern, 2000; Yeaworth, 2001).

In a recent study, Butler, Villapiano, and Malinow (2009) examined disclosure of personal information using the Addiction Severity Index (ASI). A total of 142 participants from a substance abuse treatment were recruited for this study, and a counterbalancing order was used in the administration of ASI. Thus half of the individuals responded to the questions in a self-administered computer-mediated sessions. After 3 to 5 days they were again required to respond to the questions, this time administered by an interviewer. This order of administration was reversed for the other half of the participants. When composite scores

for each of the 7 domains were compared it showed that greater addiction problem severity was reported in the computer-mediated administration than in the interviewer administered sessions. It must be mentioned though that this is not always the case and there are instances where people engage in greater depth of self-disclosure in a face-to-face situation than a computer mediated session (Mallen, Day, & Green, 2003).

It is possible, as Buchanan, Paine, Joinson, and Reips (2007) argue, that when computer mediated communication leads to greater level of disclosure it may be attributable to the absence of visual cues or, as broadly stated by Piazza and Bering (2009), that the absence of historically reliable cues, (e.g., inflections in voice, face non-verbal cues) creates anonymity leading the individual to be less concerned about the image he/she is projecting and thus more willing to relay personal information which would have otherwise been concealed.

2.4.3 *Adjunctive or stand-alone treatments:* In delivery of some web-based programmes, they are designed to function as stand-alone treatments in themselves that participants use without the involvement of the clinician. Still others function with varying degrees of clinical input. In their delivery of a cognitive behaviour therapy for childhood anxiety, Spence Holmes, March, and Lipp (2006) found it effective to combine an internet delivery programme (CLIN-NET) with treatment in the clinic. Thus the child had 5 internet delivered sessions and 5 face-to-face sessions. In this way the internet programme was used as adjunctive to face-to-face treatment. Delivery in this way can free up the therapist's time. This is more pertinent if the computer application offers something that is not readily available in standard face-to-face interventions. Such an instance is in the use of virtual reality therapy (Garcia-Palacios, Hoffman, Carlin, Furness, & Botella, 2002; Harris, Kemmerling, & North, 2002; Wald & Taylor, 2000), to promote the gradual exposure of the

individual to anxiety provoking stimuli in a way that may not be feasible in standard therapeutic encounters.

Additionally there are features of internet programmes and tools that may be applied as an adjunct to treatment, e.g., email being used as an adjunct to post or to send reminders for participants to complete assignments or enable contact with therapist (Yager, 2001, 2003), or bulletin boards that enable individuals in treatment to post and receive responses to questions between treatment sessions. Participants have reported these as providing an increased sense of accountability often associated with increased adherence (Tate and Zabinski, 2004).

2.4.4 Tailoring vs. non-tailoring: The way that health messages have been presented over the years has changed (Davis, 2007). This is described in Kreuter, Strecher and Glassman's (1999) paper as having moved from generic messages – ones that are not individualized in any format and focus more on the health issue as it affects the general population, towards messages that target specific populations and more recently to messages that are personalized. The current perspective is that health information that is customized to suit the needs, interests and other characteristics of different individuals is more effective (Kreuter, Farrell, Olevitch, & Brennam, 2000). Messages of this nature are said to be tailored. Depending on the theoretical framework used, tailoring will take into consideration one or several characteristics of the individual, including: person's age, gender, race, health condition or status, risks factors, motivation, information needs, etc. (Lustria, Cortese, Noar & Glueckaluf, 2008).

Noar, Benac & Harris, (2007) carried out a meta-analysis of 50 studies of the effectiveness of print-based (pamphlets/leaflets, newsletters/magazines, letters, and manuals/booklets) tailored information for a number of health behaviours. They found that interventions that

had the largest effect size were those that used pamphlets/leaflets ($r=.168$) and the least manuals and booklets ($r=.039$). On the whole the weighted mean effect size for the effectiveness of tailored messages in leading to improved outcomes was a little less than small ($r=.074$). A larger effect size ($r=.058$) was seen when the no treatment control group was excluded and comparisons made only with those interventions with generic or targeted messages. They suggested that similar effects are likely in internet interventions, and with its potentially limitless capabilities this would have far reaching implications.

A variety of these methods have been used for tailoring messages in internet programmes. In some dietary programmes, for instance, the individual is given feedback which compares his responses to the current recommended levels (De Bourdeaudhuij, Stevens, Vandelanotte, & Brug, 2007; Winett, Anderson & Wojcik, 2007); some programmes compare individuals with similar conditions, background, race, age, gender, etc. (Kypri & McAnally, 2005; Oenema, Tan & Brug, 2005), or compare an individual's current situation/position to previously set goals (Booth, Nowson, & Matters 2008; Winett, et al., 2007), or relates this to the individual's stages of change (Irvine, 2004; Vandelanotte, De Bourdeaudhuij & Sallis, 2005). In various internet programmes a variety of these tailored approaches are used. Often depending on the responses that the person has given in response to the questions, they might be assigned particular treatment options (Collins, Murphy & Bierman, 2004, 2005).

The findings on the effects of tailoring in internet intervention programmes have however been inconsistent. Earlier investigations of the effects of tailoring on a number of health risk behaviours (Kypri and McAnally, 2005) found that tailored feedback messages led to significantly higher rates of compliance for individuals in taking recommended portions of fruits and vegetable, than for individuals who were exposed to minimal contact. The effect of tailored feedback was however not significant for drinking behaviour, at the 6 months follow-

up. Other researchers (Cook, Billings, Hersch, Back & Hendrickson, 2007; De Bourdeaudhuij Stevens, Vandelanotte. et al., 2007; Revere & Dunbar, 2001; Spittaels, De Bourdeaudhuij, Brug & Vandelanotte, 2006) have obtained similar results where tailored information interventions led to more significant improvements in healthy dietary intake, than a generic intervention or no prevention group. But, as reported in De Bourdeaudhuij et al.'s (2007) study, tailored information was not significantly better than the generic information condition. Spitael, De Bourdeaudhuij, Brug, and Vandelanotte (2006) showed that it can lead to individuals being more attentive and willing to discuss the information more, but it did not lead to differential increases in physical activity.

In a later study, Portnoy, Scott-Sheldon, Johnson, and Carey (2008) conducted a meta-analysis of 75 randomized controlled trials published between 1988–2007 and did not find evidence in support of tailoring activities, irrespective of whether this was at the individual or group level. Others have reported on positive outcomes of tailoring in internet interventions. In their review of randomized control trials of computer delivered dietary information, Neville, O'Hara, and Milat (2009) found evidence in support of tailoring. In 10 of the 13 papers reviewed tailoring was compared to a no treatment or waiting list control, or a comparison generic group receiving information. They found that web-based programmes were more effective than print materials in producing improvements in the areas of diet and nutrition but were not more effective in reducing stress or increasing physical activity. Where there is evidence supporting tailoring it may relate more to the depth of the tailored message, as high depth messages have been related to (Strecher, McClure, Alexander, et al., 2008). It is possible that the higher depth of tailoring would to participants to perceive the message as being personally written for them and therefore be more willing to act on these messages (Strecher, Shiffman & West, 2005).

As highlighted by Lustria et al. (2009), web delivery of interventions provides multiple options for both tailoring and delivering tailored messages to the participants. But tailoring in these internet interventions is still in its infancy (Bock, Graham, Whiteley & Stoddard, 2008). There is a need for future research efforts to focus on identifying key features that would make for effective tailoring for various health conditions or interventions as well as the differential effects of tailoring on health outcomes and what possible mediators exist.

2.5 Ethical Issues

In the face-to-face interventions it is expected that ethical standards are maintained in the interaction between therapist and service user. Critical in this is that the individual has given informed consent, has been assured of privacy of the information being given, informed of the duty of warning third party of harm and that the therapist will maintain professional boundaries (Kanani & Regehr, 2003). These and other ethical principles and guidelines are very well established in the more traditional forms of treatment but they do not cover situations that arise with online interventions. The internet by its very nature presents situations in which the clients (and therapist) could conceal, falsify or impersonate identities; it opens up many ethical and legal issues that need addressing.

Even in instances where informed consent has been obtained from the individual there is no way of accessing the individual's capacity to give informed consent in the absence of a face-to-face communication. It has been argued elsewhere that consent obtained in the traditional forms are also not perfect and it would not be correct to demand that electronic consent should be subjected to a much higher standard. Where online signatures or photographs are required it is recommended that some form of encryption and digitization tools be used to protect them.

The unregulated nature of the internet makes it possible for almost anyone, irrespective of their level of competence, to offer such service online. Various programmes for instance are being developed by individuals with programming skills and limited clinical knowledge and experience; this can lead to violations in regards to the competence of programmes and therapist adherence to professional standards. Other related ethical concerns would include the extent to which licensing requirements are in place, and legal issues of professional insurance and negligence. In many instances internet programmes have difficulty closely monitoring the effects of the programme hence early detection of unanticipated negative effects and the ability to provide emergency assistance is in question.

There are also issues that relate to the interventions' heavy reliance on what is regarded as fragile technology (broadband capabilities, electricity supply - which is erratic in various countries and areas), as well as difficulties of billing and collection of fees where required. There are for instance issues of anonymity and confidentiality that need to be addressed. This may be difficult to be adequately ensured, in the light of servers that are reportedly being hacked and patient information being accessed by others outside of those handling the information. Having technical information about the server that is hosting the programme does provide some information as to the risk of it being hacked. Acknowledgably no server is hack-proof, but some have proven to be more secure than others.

Whitefield and Williams (2004) report that many practitioners are concerned with who is responsible for the patient while the patient is making use of the these internet interventions, with a number of them indicating that they would not want to take responsibility for the patient who is interacting with a computer in this way. This absence of ethical and legal guidelines for internet interventions is acknowledge and being discussed (Chen, Effler & Roche, 2001; US Department of Health, 2001). In some areas there are local principles that

are accepted and adopted, there are however currently no accepted universal standards for dealing with the legal and ethical issues of internet interventions (Bier, Sherblom & Gallo, 1996).

2.6 Effectiveness of internet interventions

One of the main question that evaluative research attempts to answer is how effective these programmes are in addressing the problems that they set out to address. At a deeper level the potential factors that may mediate the effectiveness of these internet intervention programmes are investigated. The published work of Murray, Burns, See, Lai, and Nazareth (2005) is an earlier review of interactive health communications applications (IHCAs) and their effects on people with chronic diseases. In 24 identified studies they found IHCAs had a significant positive effect on knowledge, self-efficacy and clinical outcomes.

Weinstein (2006) on the other hand reviewed weight loss programmes delivered over the internet and found that in 7 of the 8 studies there were significant positives. The effect size however was low. It is showed that it was as successful as face-to-face traditional treatment programmes in producing some initial weight loss. The number of studies included in this review was however small and limited subjects to all white, educated females thus making generalization difficult.

In a more recent publication, Cuijpers, van Straten, and Andersson (2008) examined the effectiveness of internet administered CBT for health problems in a total of 61 studies. They however excluded studies that focused on lifestyle such as smoking, obesity, nutrition, etc. They found Internet-delivered interventions to be promising though they reported effect size smaller than those obtained by Spek, Nyklícek, Smits, et al. (2007) in their meta-analysis of internet interventions for anxiety and depression. Speck and colleagues examined a total of

28 randomized control trials arriving at a mean effect size of moderate to large (0.40 to 0.60). Yet still higher mean effect size (0.62-0.66) has been obtained in other meta-analytic studies of internet interventions for anxiety (Hirai & Clum, 2006; Reger & Gahm, 2009).

Similarly, Amstadte, Broman-Fulks, Zinzow Ruggiero, and Cercone (2009), in their review of the effectiveness of internet interventions for traumatic stress related mental health problems, came to the conclusion that internet interventions for anxiety and depression yield effect sizes that are comparable to those attained in face-to-face interventions. They also report, however, that those that target alcohol and cigarette smoking have lower effect size. This lends credence to Bewick, Trusler, Barkham, Hill, Cahill, and Mulhern's (2008) review indicating that web interventions that focus on reduction of alcohol consumption are generally well received; their effectiveness however appears to yield inconsistent results. Myung, McDonnell, Kazinets, Seo, and Moskowitz' (2009) metanalysis of randomized controlled trials for internet smoking cessation programmes provides evidence for selective effectiveness of the programme. They report that the evidence is sufficient for supporting internet smoking cessation for adults but at one month follow-up it does not lead to any significant increase in abstinence rates for adolescents.

The general conclusion arrived at in these reviews is that internet interventions do lead to positive outcomes. Most of these reviews however were limited to specific health conditions or populations, or where they were broader considered a relatively small number of publications. There have been two more comprehensive and extensive meta-analytic studies that throw more light on the effectiveness of internet interventions. In the first of these studies, Portnoy et al. (2008) present a meta-analysis of 75 published randomized control trials of computer delivered interventions for health promotion and behavioural risk reduction. They looked at not just internet interventions but ones delivered in stand-alone

computer software packages. Results obtained showed that certain factors were more predictive of positive outcomes in computer delivered interventions. Computer delivered interventions were more likely to improve knowledge if the participants were women, young, and had prior computer experience. Improvements in self-efficacy were likely when more women or younger participants were sampled, or delivered to via the internet. They also noted that it led to modification of health behaviours in some contexts. They, for instance, note that improvements in online smoking cessation and alcohol reduction programmes were more successful if the researchers sampled more users or the participants had greater exposure to the programme. Likewise the smoking programmes showed greater degrees of success when they were delivered without a motivational component via a CD-ROM, instead of the internet, to a group of young participants. They did not however find evidence supporting computer delivery interventions that sought to improve physical activity, weight loss, or self-management of diabetes.

Barack and Suller (2008) carried out a more detailed review examining the factors that moderate the effectiveness of internet interventions. They expanded their search to include unpublished literature, and arrived at a total of 92 studies with a client pool of 9764 that received treatment. They found an average weighted mean effect size (ES) or .53 which is equivalent to a medium effect. It should be mentioned that this did vary greatly and depended largely on the health condition being treated. On average PTSD and panic and anxiety disorders had higher ES (0.80 to 0.88) while ES for weight loss was lower (0.17).

They examined other possible mediators of effectiveness of internet treatments. They found that the more interactive sites had significantly higher ES (0.65) than more static non-interactive web-pages (ES = 0.52). This finding contradicts Bock et al.'s (2009) later finding that could not distinguish the degree of informational detail or interactivity that was optional

in smoking cessation sites. This difference may have resulted from their limiting their focus to only online smoking cessation programmes.

Barack et al. further examined the moderating effect that additional supplements would have on the effectiveness of the intervention. They found that using email as a supplement or a discussion forum did not contribute to the effectiveness of the intervention. Additionally the use of two other supplements (audio and chat features) to the main treatment, were actually associated with diminished effectiveness of the intervention. Lastly a few of the reviewed studies compared internet interventions with face-to-face traditional treatment formats for the problems. Internet interventions showed effect size that was similar to those of face-to-face treatments for these conditions

The mode of delivery of intervention was also crucial in determining the effectiveness of the interventions. Those programmes that were delivered in an open-access format, which permitted anyone to login and use as desired had a smaller ES (0.48) than those that were closed – allowing only authorized or pre-screened individuals (ES of 0.68). When the nature of communication was examined, it showed that there was no significant difference in ES if the communication occurred synchronously or asynchronously.

Age of participants was also found to have a moderating influence. Results showed a U shaped curve between age and effectiveness; those who benefited most from interventions were those between the ages of 19 -39 years. Those who were either younger or much older were less effectively treated with internet interventions. Newer research published after the date of the collection of research used by Barack et al. (2008) shows that the influence of age as a mediating factor on the effectiveness of internet interventions might be related more to the health condition under consideration, or that the observed difference may have been due

more to the digital divide and disparity, which has reduced substantially (Carpenter & Buday, 2007). The newer studies show that internet interventions are effective in treating anxiety (Spence, et al., 2006), stress management (Van Vliet, Andrews, 2009), and depression (Nelson, Barnard & Cain, 2006) in young people. Similarly, the newer interventions have been found to effectively treat people in the older age brackets (Hill, Weinert & Cudney, 2006; Lorig, Ritter, Laurent & Plant, 2006; Marziali & Donahue, 2006).

2.7 Availability and accessibility of internet interventions:

As with all new interventions developed in a research environment and subjected to randomized controlled trials, there is the issue of transporting it for use in routine clinical or community settings. The fact that there is sufficient evidence to suggest that an intervention should be made available for those who might wish to use it, does not necessarily imply that it will be readily or speedily adopted by practitioners for use among their patients. There is a need for an understanding of the processes required for transporting web-based interventions from a trial format with pre-screening and granting of access for selected individuals to having the intervention in an open format in which it is freely accessible. In part this is related to the issue of recruitment of participants to open formats of interventions with its attending problems. Recruitment in open format interventions has experienced rates of uptake that are as low as 1%. The issue of transporting these web programmes from a research setting to a clinical or community setting may also be affected by the attitude of practitioners towards the programmes and their willingness to make referrals.

In recent times the NICE recommendation of the use of computer delivered CBT interventions and upsurge in the number of such interventions now available, would point to the interest in computer delivered CBT (CCBT). Evidence at other levels does not seem to support this. Whitefield & Williams (2004) sampled 500 of approximately 800 therapists

accredited with the British Association for Behaviour and Cognitive Psychotherapies (BABCP). A total of 329 (65.8%) therapists responded to questions concerning their knowledge and use of computerized therapies. They found that a large percentage of these therapists (67.2%) could not name any of the computerized interventions that were currently available for treatment of mental health problems. Only 2.4% of the practitioners indicated using CCBT with their clients. Only 5 practitioners indicated using it as an alternative to practitioner contact. It must be noted however that a high number of these practitioners (90%) did not rule out their using it in future, with (80%) stating that they see themselves using it as a supplement to their current treatment approaches. When asked what they felt needed to change to enable them use the internet intervention programmes, the two highest responses were the need to learn more about computerized treatment (61.7%) and the need for training in how to use the programmes (54.3%). It is evident that, as Moore (1999) states, moving an intervention developed in an academic research environment to be adopted and used in a large scale in the real-world is a huge endeavour.

2.8 Discussion

Because of the sparse research on internet interventions for family members at one end and alcohol/drugs at the other, this review looked at internet interventions that were developed to address other conditions, drawing from this to guide the present research. Evidence so far available on internet interventions would at its best represent pioneering efforts in the use of this medium to deliver evidence based interventions. As pointed out, it presents the advantage of delivering an intervention in ways that minimize the barriers currently experienced by people trying to access help. As the digital divide continues to close, and more people gain access to the internet (Pew Internet and American Life Project, 2005; Fox, 2004; Internet World Statistics 2009; Yates, 2007), the internet intervention can become a powerful tool for addressing health inequalities. It would be easier to reach people who are

geographically isolated as well as those who cannot or do not seek face-to-face treatment. In low resource countries where specialist care may be absent it would be even more crucial as it would provide access to treatment that would not otherwise be available.

For individuals to derive these potential benefits is however, dependent on various factors, the most important of which is its ability to reach across the existing digital divide to those who may be targeted to receive these intervention programmes, some of who may not have the degree of access required to fully benefit from the intervention programme. There is then, for instance, the challenge of reaching ethnic minorities with internet interventions, a population that has proven hard to access in other formats of treatment. Im and Chee (2005) suggest the adoption of mixed methodology in recruiting participants for internet programmes.

Currently demographic differences still exist among people who show a preference for using or consulting the internet for health related information, or simply prefer the internet to face-to-face options of interacting (Hassani, 2006; Marks, Cavanagh & Gega, 2007; Robinson, et al., 1999; Selywn, 2006). There will be a need to tease out the characteristics of people who participate in online activities and their motivations for doing so as well as coming to a better understanding of those who may be weary of the internet showing a preference for other formats. This knowledge could then serve in devising recruitment strategies that would be more inclusive, leading to a more representative sample of the general population. This will be particularly important in developing an intervention to meet the needs of existing clients. If they demographically differ from family members that were recruited to participate in previous evaluations of the 5-Step Method in other formats it would point to the fact that the programme would be meeting the needs of a completely different and possibly previously hidden population of family members.

The literature reviewed (Chambers et al., 2003; Dow et al., 2008; Hayward et al., 2007), shows that a high degree of acceptability and satisfaction has been reported when using the internet for various intervention programmes. Even with the high degree of acceptability and satisfaction, there is a major challenge of low utilization and follow-up. The degree or level of utilization reflects the degree of exposure/intensity of dosage of intervention that the individual experienced. Optimal dosage of internet interventions must be defined, and systematically monitoring of this should be built into the intervention. Once it has been defined and so monitored, one can confidently attribute various observed effects to different elements of the programme that have been manipulated. It will be possible to identify the optimum duration/exposure to intervention for each health condition while taking into account symptom severity as well as being able to determine the degree of therapist involvement required.

Both Christensen and Mackinnon (2006), and Eysenbach (2005) highlight the urgent need for a broader debate on the 'science of attrition', calling for the development of a comprehensive model for a theoretical understanding of this process with a statistical model that can be used to accurately estimate the effectiveness of internet interventions while taking into account the high rate of attrition that is seen in many internet programmes.

For many critiques, an internet intervention should be considered effective only when it offers the basic minimum that people receive in face-to-face standard treatment sessions. While this may be the gold standard, this comparison and desire may actually be out of place (Ritterband & Tate, 2009). Internet intervention, for instance, provides help for individuals who may have no other source of help, either by choice, because they are geographically removed from where they can access help, or because there is a clear shortage of certified practitioners that can offer the help they need. Despite the evidence that some online

interventions yield outcomes that are not different from those of face-to-face treatment (Barak & Suler, 2008) they exist as a supplement to face-to-face treatment and do not seek to replace it. They allow for various flexible arrangements of how and where they can be put to use in routine practice, whether it is administered to those on the waiting list, used as an adjunct to treatment or as a standalone treatment (Whitefield & Williams, 2004). Thus, rather than attempting to replace face-to-face therapeutic sessions, it allows for the broadening of the scope giving a variety of options that the practitioner can use. Internet intervention may not be suitable for everybody, but it may suit many people in a variety of situations, especially those who do not wish to use the traditional consultation formats that are available (Barak, Klein & Proudfoot 2009; Griffiths, 2005).

The research pool on internet interventions is still in its infancy. Despite the limitations often experienced with research at this stage of development of interest there appears to be ample evidence to warrant greater examination of the interventions for different health conditions that use this format. Taken together, research suggests that internet may be an efficacious treatment delivery system. Even in a context where internet interventions have not been shown to provide benefits, there is a need for confirmatory research to be conducted; research should be conducted to examine the effects of demographic variables such as age, gender, educational level, socio economic status and computer literacy influencing recruitment and adherence to treatment. Also more information is needed as to what cultural preferences and barriers exist, how the interventions would be best delivered in various languages, age groups and settings that would make it acceptable as well as factors that would make it attract and maintain potential participants. The evidence of research (Hill, Weinert & Cudney, 2006; Lorig, et al., 2006; Marziali & Donahue, 2006; Nelson, Barnard & Cain, 2006; Spence, et al., 2006; Van Vliet and Andrews, 2009), that counters Barack and Suler's (2008) evidence concerning the U shape curve of internet interventions not being effective for the younger and

older age brackets lends credence to this. There is a great need for work that examines the effectiveness of these programmes across various groups of vulnerable populations that could clarify the effectiveness of these interventions and how they are moderated by various factors.

There is the further issue of the dissemination of internet intervention. As Whitefield and Williams (2004) show, it is not just the putting it on the internet so it will be accessed by patients with that condition, there is a need for practitioners to guide them to these programmes. Currently only very few of these practitioners are aware of these interventions or evidence supporting their usage. Most of these practitioners indicate that to enable them to use these interventions and refer patients to them, they would first of all need to attain greater knowledge of these interventions as well as receive training in how to use them. There is a need for health care service providers to take the lead from other industries, like the banking and commercial sectors, and effectively embracing the use of interactive communications and other internet tools in reaching their clients.

2.9 Conclusion

As shown, internet delivered programmes vary on a number of fronts, from health conditions being addressed to the method or technology that has been put to use in delivering them. As we continue to accumulate evidence of the effectiveness of internet interventions and adjust and develop these interventions in line with evolving software designs and functions, the potential of the internet as a channel for delivering effective interventions programmes will remain immense. As Barak and Suler (2008) suggest, developing effective empirically supported internet interventions is becoming a professional imperative.

On the basis of the inadequacy of existing services that address the needs of family members of alcohol and drug misusers, and the existing evidence of the increasing use of the internet in search of health-related information and help (Sillence, et al., 2007), it can be argued by analogy and suggested that there will be a demand for internet support from people that are trying to cope with the stress and strain that often accompanies having to live with an alcohol or drug misusing relative.

There are two main reasons for the choice of the 5-Step Method. First as an intervention it has been evaluated in face to face formats and adapted for delivery in self-help format. There is evidence for the effectiveness of the intervention in this format (Copello et al., 2009). As a self-help strategy, it was possible to design the intervention in such a way that it could be accessed and used by an individual. Secondly, this intervention has 5 clearly delineated stages with specified activities and exercises that a FM should carry out in the process of working through the stages. The five stages of the intervention included listening and exploring the effects that the alcohol or drug use has had on the family, providing adequate knowledge to the FMs about alcohol or drug addiction, examining the coping strategies adopted and the social support available and lastly looking at further sources of help that the FM may need to access (Copello et al. 2000, 2010). With the help of internet tools and techniques it is possible to render the requirements of the exercise and the activities of each of these steps in a web-based programme. Particularly challenging, in this format however, is how to model helping the FM to explore how the family has been affected by the alcohol or drug use, that would give them the sense of being listened to and understood.

There are also challenges around the recruitment of family members to use the programme. This is cause existing interventions involving family members often approach family members presenting them with roles that are mostly focused on getting the alcohol or drug

using relative into treatment (Copello & Orford, 2002), and therefore are not expose to the concept of their needing professional support in their own right. Coupled with this would be maintaining their engagement through the programme in order to derive optimal benefits. As seen in various other treatment programmes, engagement can be challenging whether it is self-help or face-to-face delivery (Christensen et al., 2004, 2005; Flarvolden et al., 2005; Pretorius et al., 2009; Sabate, 2003; Turks & Meichenbaum, 1991; Verheijden et al., 2006). Other challenges of delivery of this intervention in the web-based format would be how to model different aspects of the programme; such as helping the FM to explore how the family has been affected by the alcohol or drug use, that would give them the sense of being listened to and understood.

This research is an examination of the feasibility of delivering the 5-Step Method in the Web format. This intervention will first be developed and piloted in a trial setting, following which it will be open for access in a community setting where any FM can use it.

CHAPTER 3

Working With Families: Attitudes and Views of Health Care Professionals in Addiction Services.

3.1 Introduction:

In the earlier chapter on families and addiction, the evidence suggested that the 5-Step Intervention should be made available for routine service delivery. However when this has been the case, government bodies, local authorities and local services, have been slow in the adoption of interventions of this nature (Barlow, Levitt & Bufka, 1999; Morgenstern, 2000; Wilson, 1998). The slowness in adopting these practices has been attributed to a variety of factors which can be grouped into two main categories. The first is the absence of a conceptual model of understanding addiction and family dynamics (Copello & Orford 2002; Orford, et al., 2005); second are factors centring on the health care professional's (HCP's) self-efficacy, attitudes and skills, and possible support within the workplace (Basford, et al., 2003).

The previously discussed conceptual model - the Stress-Strain-Coping-Support Model presents an alternative perspective that focuses largely on the experience of family members and their effort to respond to the stress and strain they experience from living with someone misusing alcohol or drugs (Orford, et al., 1998a, b, c, 2001, 2005, 2010). This model led to the development of the 5-Step intervention which was designed to help family members in this situation. The intervention is so called as it consists largely of five Steps, which the HCP explores with the family member. The amount of time spent on each step and the importance of these steps differs according to the needs of each family (Orford, Templeton, Copello, Velleman, Ibanga & Binnie, 2009). Thus this model presents an understanding that should help in the adoption of this intervention for family members.

The second group of factors contributing to the slow adoption of approaches that involve family includes the attitude, skills and confidence of the HCP him/herself (Jacka, Clode, Patterson & Wyman, 1999). Being less prepared to make a diagnosis of substance misuse (Johnson, Booth & Johnson, 2005), or the demand on time posed by the intervention (Aalto et al., 2001) are also significant factors. These are all issues that could be addressed by education or training of the HPC (Anderson, Kaner, Wutzke, Funk, Heather, Wensing, Grol, et al., 2004; Gomel, Wutzke, Hardcastle, Lapsley & Reznik, 1998; Hagemaster, Handley, Plumlee, Sullivan, Stanley, 1993; Kaner, Lock, McAvoy, Heather & Gilvarry, 1999; Silins, Conigrave, Rakvin, Dobbins & Curry, 2007). However, despite the evidence that the attitudes of HCPs may be moderated by training and support, there has been little or no change in the teaching curriculum (Arthur, 1998).

Transferring evidenced based research to practice takes the form of dissemination by researchers to HCPs through workshops, seminars and conferences. In these settings, dissemination efforts are largely hierarchical and unidirectional (Addis, Wade & Hatgis, 1999). Input from the practitioners is generally not considered (Backer, Liberman & Kuehnel, 1986; Simpson, 2002), and in certain circumstances altogether ignored (Ball, Bachrach, DeCarlo, Farentinos, Keen, McSherry, et al., 2002; Foreman, Bovasso & Woody, 2001).

This hierarchical transfer has been criticized by experts in transfer technology. A commonly held perspective of current models that have been discussed is that effectual transfer is not hierarchical but bi-directional. As such, frontline clinicians are tasked to share joint responsibility with the researchers in not just the execution but the planning of how to implement the intervention in the practice setting with the existing structure while still

maintaining the fidelity of the intervention (Fals-Stewart & Birchler, 2001; Liddle, et al., 2006). Whitefield & Williams (2003) suggest that training of teams rather than individuals is more effective in making and sustaining change in work settings, as individuals alone often find it very challenging to bring about or sustain change in these settings. However a crucial factor in all the transfer literature is that frontline staff must be willing to adopt the intervention, and additionally existing structures must be willing and able to support change in order to sustain the new interventions.

Brown & Flynn (2002) proposed that transfer consists of four stages: technological development, transfer preparation, transfer implementation, and transfer stabilization, with the crucial role of the government at each of these phases being highlighted. Simpson (2002) presents four stages in the process model for the transfer of research to practice. These stages include: exposure to the intervention, adoption of the intervention, implementation or trial use, and practice or incorporation into routine use. The first step - Exposure involves the providers becoming aware of the intervention. This could be through newsletters, conferences, treatment manuals, self study or expert consultation. The second stage – Adoption, speaks of the organization's desire or intent to implement the intervention. Once adopted this is followed by its implementation where the intervention is implemented in a trial bases to assess its feasibility and potentials within the organization. The final stage proposed by Simpson (2002) is practice, where the intervention is now incorporated into the organization's routine service delivery. This process of transfer from exploration to practice is said to be influenced by a number of factors which will determine the extent and the fidelity to which the intervention is eventually delivered in the practice setting.

Fixsen, Naoom, Blase, Friedman, and Wallace (2005) proposed a model which incorporates many of the ideas inherent in Simpson's model but extends it to reflect six stages. They

collapse the first two stages of Simpson's model into one. They propose that the first phase of exploration and adoption is the point at which the need for the intervention is identified and prioritized. It is believed that providers must become aware of the intervention programme and see it as meeting the needs of the community, within the available community resource, funding and organizational structures in place. Support for adopting this programme must be sought at the political, financial, state and federal levels. Once a decision has been reached to adopt a programme, the next phase would be installation of the programme. This phase focuses on issues of initial costs of installing the programme. It ensures that the structures necessary for the transfer are on ground: e.g., realignment of current staff, hiring of new staff where this would meet programme requirements, purchase of additional items of equipment where required, and/or changing record keeping systems to meet the new programme. This leads to the third phase of initial implementation, in an environment described by Fisher (1983) as: "full of personnel rules, social stressors, union stewards, anxious administrators, political pressures, inter-professional rivalry, staff turnover, and diamond-hard inertia" (p. 249). However, for many organizations, attempts at implementation may end at this point (Macallair & Males, 2004).

Once the new intervention is fully integrated into routine practice and over time becomes accepted as 'business as usual' for that organization, it is accepted as having reached the fourth stage of full operation. During this stage situations will present that give opportunities for staff to innovate, thus refining and expanding the treatment programme. This is the fifth stage. With time the innovations are then included in the treatment programme and we now arrive at a stage of sustainability where we have a standard model (Winter & Szulanski, 2001).

The final phase described by Fixsen et al. (2005) is that of sustainability. The implementing organization must be able to sustain the adopted approach in the face of the challenges of staff turnover, changing funding streams, and changes in programme requirements. In the present research qualitative interviews were obtained from HCPs in addiction services. In keeping with the literature, rather than training single individuals, staff members were trained as a team on how to engage clients in a more family focused (FF) way. Training included exposure to the Stress-Strain-Coping-Support Model and the 5-Step Method of working with family members that evolved from this model.

HCPs were encouraged to apply the techniques inherent in this intervention in a flexible way depending on the peculiarities/presentation of the case (See Orford, et al., 2009 for a full description of this project). A qualitative analysis of the experience of HCPs (counsellors, nurses, practitioners and health care workers) using the 5-Step Method when working with alcohol or drug misusing clients was carried out six months after the initial training event.

3.2 Aims and Objectives

This study aimed to examine the experience of HCPs who were given training and support in involving families with an alcohol or drug misusing relative in service delivery. A qualitative approach was considered appropriate as it would give an in-depth understanding of the experiences as narrated by health care professionals in their effort to adopt a more family focused approach in their work. It would highlight the transferability of this evidence-based intervention to the real-life setting and the degree or nature of involvement of family members in service delivery.

3.3 Method

3.3.1 Description of Sample

A total of 15 HCPs from this agency were part of the initial training; during the interview period however, 2 could not be reached. One of the HCPs that could not be reached at the time of the interview was on maternity leave; the other had left the organization. Of the remaining 13 HCPs who were interviewed, 9 (69.23%) were female and 4 (30.73%) were male. The roles held by these professionals included: Nurse, Practitioner, Drug & Alcohol Outreach Worker, Counsellor, and Nurse Manager. They had all been working in the organization for periods ranging from 2-11 years (mean=5.92).

3.3.2 Procedure

This was part of a larger programme of research in seeing what is feasible in using interventions based on the Stress-Strain-Coping-Support Model to involve FM in service delivery. With the team that had consent to participate in the project, all members of staff were given an orientation of SSCS and the two interventions. A team approach was adopted in which all staff of the organization were exposed to the SSCS model and training in the delivery of the 5-Step Intervention for FM as well as the Social Behavioural and Network Therapy (SBNT) which, though it focuses on the person misusing the alcohol or drugs, draws on that person's network to build positive support for change. They were then specifically encouraged to work with clients (either new or from their existing caseload) and engage them using the 5-Step Intervention model or that of SBNT and report back on their experience.

3.3.3 Measures

Qualitative Semi-structured interviews were conducted 6 months after the initial project training event with all the 13 HCPs. The interview covered 6 different areas:

- Feelings of the FM in receiving a more family focused service
- Opportunities that presented for working in this way
- Experiences of HCPs (both positive and negative) using this approach
- What difficulties they experienced
- The difference between how they work now and how they worked prior to project
- What they found helpful and what kind of support they thought would be needed in order to continue working in this way.

The researcher had earlier been trained in following the interview guide; where necessary the interviewer probed using open-ended questions to clarify as well as to obtain examples where they were not provided spontaneously. To ensure the adequacy of written report, separate feedback was given on each of the initial 3 reports produced by the researcher, and he was then allowed to proceed with the remaining 10.

These interviews were designed to take approximately 25 minutes; the HCPs were asked to relate their experience in adopting a more family focused approach in their service delivery. The interviewer at the time of interview took detailed notes of the main points that were made including verbatim quotations which illustrated the points. The written reports of these interviews varied between 700 - 1,500 words in length. Orford et al. (1995) suggest that this method yields results that are comparable to transcriptions of interviews and in addition provides very accurate reports, contains sufficient information for in-depth analysis, and has the advantage over full interview transcripts in that it is condensed. It has since been used and refined in several qualitative studies by the Alcohol Drugs and the Family Research

Group (Orford, Rigby, Miller, Tod, Bennet, Velleman 1992, 1998, 2000; Orford, Templeton, Patel, Copello & Velleman, 2007; Orford, Templeton, Patel, Velleman & Copello, 2007; Velleman & Templeton, 2000).

3.3.4 Data Analytic Process:

The detailed report that is produced from the interview process contains verbatim quotes from the interviewee together with notes taken by the interviewer. An approach based on grounded theory was adopted to then analyze the interview data (Charmaz, 1995; Glaser and Strauss, 1967; Strauss and Corbin, 1990). The procedures and techniques prescribed by these authors were used more as a guide and, as suggested by Dieseng (1971), the techniques prescribed were flexibly applied rather than rigidly adhered to.

In order to establish the adequacy of these interviews the first 3 were completed and reviewed by members of the larger project team conversant with this method. This was to examine whether the interview questions covered the breadth of what would be the experience of HCPs when working in a more family focused manner. It was also to help in the identification of possible areas where further probing may be required to enable the participants to report a greater depth of information.

In order to establish an analytical direction the 8 interviews were selected at random and read in detail. Each line in the report was given a number and categories indentified and coded along the margins of the report. The codes were attached to each line or portion of information (in some instances a phrase, others a sentence and still others the full paragraph). This process enabled the researcher to stay close to the data and have confidence that the emerging analysis was grounded in the interview reports of the HCP. Example of codes given can be seen in Table 3.1.

Table 3.1. Examples of codes identified

INTERVIEW TEXT	CODES
1. He reported certain opportunities that presented for doing	Opportunities presented for FF work
2. family focused work. Elaborating on the case mentioned	Focus on family work
3. above he says that the individual was referred for detox,	Referred from detox
4. has a wife and 2 kids, had lost job because of drinking.	Social Network (SN), negative consequences from drinking-loss job
5. In addition to wife, the wife’s sister and partner and a	Members of SN
6. friend all indicated a desire to be part of the support	SN desires to get involved
7. network and to get involved. The immediate family was	
8. also involved in identifying network	SN participate in network identification

When the 8 interviews had been coded in this manner, the researcher proceeded to the next phase in which the remaining 5 interviews were used to explore in detail themes emerging from the initial coding. This process corresponds to what Charmaz (2006) describes as ‘focus coding’. This process helped examine the adequacy of the initial codes arrived at, and helped build a more incisive and complete analytic categorization of the themes that emerged from the data. Connections were made between the categories and integrated into a model. This model aimed at encompassing the most salient features of the reported experience of the HCPs in adopting a more family focused approach in delivery of alcohol or drug misuse services.

Charmaz (2006) warns that care must be taken to avoid the data being forced into preconceived codes and categories or forcing the preconceptions of the researcher into the

data. To ensure that the analysis is grounded in the data and to reduce the potential influence of the researcher's preconceptions, the interview materials and memos were constantly referred to during the writing up. Additionally two colleagues with experience in qualitative analysis were allowed to randomly view the interview data and initial codes as well as the emerging model explaining the experience of HCPs.

3.4 Results:

This section describes the findings of the qualitative analysis of the interviews. The results are discussed in terms of the different categories that emerged from analysis. Some of these categories were further re-grouped into sub-categories. Figure 3.1 below shows a summary of the categories with sub-categories that emerged from this analysis: in some instances the codes used were direct quotes from the HCP. Each of these five broad categories will be discussed separately. They will be illustrated with case examples and direct quotes from the HCPs taken from the interview reports.

3.4.1 Expressed feelings about working with FMs

The HCP's feeling about working with FM was one of the categories emerging from the qualitative interviews. The data pointed towards further division of the category into: the HCP's feelings about working in this way were, and the HCP's perception of how their clients felt about this approach of working with them. These two subcategories are discussed separately below:

a) Health Care Professionals

All the Health care professionals expressed their feelings about adopting this approach in working with their clients. The feelings stated by health care professionals were further subdivided into 3 main groups. The groups that emerged include:

- i. *“It is pleasing and rewarding”*
- ii. *“Gave legitimacy”*
- iii. *“Has been a real struggle”*

There is some overlap between the first two, but they will be presented separately.

I) It is pleasing and rewarding: A number of the HCPs described the feeling of working with FM in positive terms. While one of the HCP describes this in somewhat neutral, more reserved term as having “been okay” (HCP 1), most of the others who described the feeling in positive terms were more forthcoming, saying: “Working in this way was quite pleasing and rewarding, when it is working well, *and people seem to be getting the best out of it*” (HCP3).

Another HCP states that: “It opens the door for more people to deal with the feelings and minimize the effects of the drinking. It makes the sessions more interesting counselling when you are dealing with someone with a drinking problem”(HCP 3) This HCP felt it is: “absolutely great how families are now coming,” and that “It’s a livener, you start with one person, look at the communication between them and this can expand to a number of people that may be seen separately at the initial stage but with the *hope of bringing them together at some stage*” (HCP 8).

One HCP describes enjoying the three way session that arises during consultation when working in this way. In one instance where an agreement was arrived at for a joint session of family member with the relative, the HCP quite felt disappointed when the alcohol misusing relative came in alone for the next session. HCP felt the relative coming alone for that session as an “anticlimax” (HCP 11). In one reported instance the positive feelings that

have developed towards including FMs caused one HCP to limit personal caseload to only those that have evident network, in his words: “the desire now is to take on only caseloads that *have children and/or family*” (HCP 13).

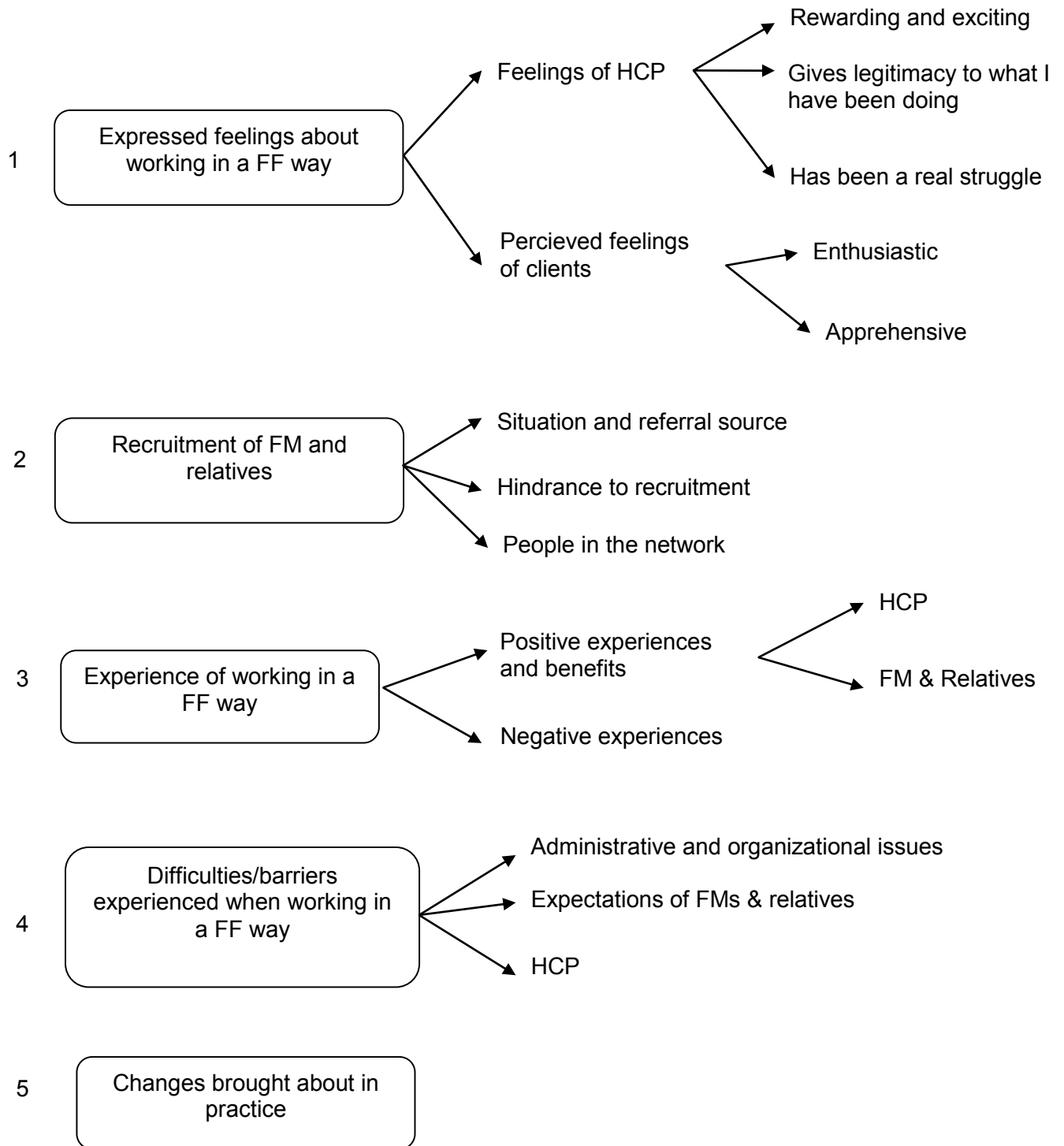


Figure 3.1 Categories and subcategories emerging from the analysis of the interview content

ii) Gave legitimacy: This has been effectively captioned by a worker who has more or less worked in this way due largely to her own personal experience of an ex-husband who drank and how it affected everyone in the family. As a result of this experience, she tends to approach the issue taking the whole family into account. The emerging situation now gives her credence that it is something she can legitimately pursue as an organizational goal and not just a personal one. In her words: "Now that it is being sanctioned, I am encouraged to bring *people in, for one or two sessions. I like the concept*" (HCP 9).

For another worker this approach to working with their clients "...provides you with a basis and a structure with which to work" (HCP 1). This project has not only provided them with this framework, but has also given them "organizational backing" to do so (HCP 13). It is an approach that gave the HCPs permission: "...to really push and ask for relations to come in" (HCP 4).

iii) Has been a real struggle: A few of the HCPs stated that working with clients using this flexible FF approach has not been very pleasant. One HCP states that "The experience has been frustrating" (HCP 11). The HCP was at this point describing attempts to engage the network in the process; having encountered various cases with potential for adopting a FF approach in working with them, it never quite seem to take off. Another HCP in describing the difficulty experienced in attempting to engage potential FM said: "it has been a real struggle" (HCP 2). This was made in reference to the HCP's attempt to keep the mother of a drug using son engaged in the sessions whereas the mother felt that her son had an unhealthy dependent relationship and desired to withdraw her support in order to help her son gain some level of independence. In another instance it was said that "...*the practical*

application (of working in this way) *has however been difficult*' (HCP 1). In elaborating on this the HCP referred to an instance where family members and others affected are eager to participate in the sessions and offer support to the relative who was misusing alcohol, their eagerness however seem to have disappeared once the relative relapsed; they made re-engagement contingent on the relative not drinking.

Another has reported leaving a session: "*feeling 'high and dry' and quite traumatized*" (HCP 6). This was after a series of attempts in getting people to come along with supportive others to the sessions. During the session, there were expressions of differences in goals between the drinker and the spouse with FM desiring abstinence, while the drinker wanted controlled drinking. HCP found herself siding with and defending the drinker, and retrospectively did not think that she had handled the situation well. HCP placed herself in the shoes of the wife and felt that she would probably have responded in the same way, desiring that abstinence should be the goal of the sessions.

b) Perception of client's feelings

I. Clients are apprehensive:

II. Clients are enthusiastic:

i) Clients are apprehensive: statements emerging from the analysis show HCP's perception of some of their clients as being apprehensive about this approach of working. One family member is reported to have questioned what she was doing, in being part of the session as she did not consider herself as having a problem or being a part of the development of the relative's problems.

Several other clients reported as being apprehensive about bringing someone else into the sessions and requested to be seen alone. Some have refused to have joint sessions with FM, with one making his engagement in the service contingent on his never being asked to bring a FM to any of the sessions.

ii) Clients are enthusiastic: The data also shows some “clients are enthusiastic about working in a FF way” (HCP 2). This is seen not just in the fact that they state this but some actively participate in the identification of the relative’s support network, or are eager to be a part of that network offering support for the drinking relative. The relative has been stated by some HCPs to “mentally accept to and grasp this concept and are willing to bring a family member along to be part of their sessions” (HCP 1).

3.4.2 Recruitment

From the data it was seen that a large majority of the HCPs agreed that in the course of normal routing practice many opportunities for adopting a FF way of working do present themselves. We will look at this emerging category under different sub-categories: situations and referral sources, hindrances to recruitment, and contact with people in the individual’s social network.

a) Situation and referral source: A number of referral sources were mentioned in the data. Analysis showed that many of the people recruited were either old clients or individuals that had undergone detoxification sessions. A few were referred by their GP and one by social welfare; another was an arrest-referral. Opportunities also presented for some other FMS, when the HCP made home visits. Still others were invited to be a part of the session if they

came with their drinking or drug using relative for the consultation sessions in the Specialist alcohol and drug service. FM were also given an invitation to see HCP if relative indicated that there were some perceived impacts his/her drinking were having or not having on the FM. Thus some FMs were recruited through their alcohol or drinking relative's contact with HCPs.

b) Hindrances to Recruitment: The data showed HCPs expressing difficulties recruiting clients to work with using this approach. Several mentioned difficulty in "getting people onboard" (HCP 4). Different reasons for this difficulty and hindrance is seen in the analysis of the interview content; they range from the HCPs seeking for a "perfect family for network" (HCP 1) to the HCP's lack of confidence.

According to the HCPs "getting suitable people in right social circumstances can be difficult". (HCP 1). Data shows HCPs consider that some of their clients:

- a) "are so complex and private not liking intrusion" (HCP 3) or "don't welcome anyone else being part of the sessions" and for those cases it would be "...inappropriate to ask FC to *bring a family member*" (HCP 4).
- b) or are "dysfunctional and intellectually unable" (HCP 1) or are just "not suitable" for using the FF approach in working with them.

Closely related to this is that the HCP feeling that the difficulties in recruitment may actually lie more in the way that is being presented in her words: "the invitation is not presented accurately leaving a lot of room in the hands of the relative to decide rather than actively encouraging them to bring someone that could be supportive along to the session" (HCP 4).

The worker stated that: “sometimes when the clients come in, they just want containment and it would appear inappropriate if I were to suggest for them to come along with someone. It would almost be as if I had not heard the things they were saying. I get the feeling that at *those times it is not appropriate to ask*” (HCP 4).

Other hindrances mentioned were linked to the client’s support network. One of the difficulties mentioned is the client’s “lack of social network” (HCP 1). When they do have social support networks these networks are sometimes thought to be inappropriate for recruiting to provide positive social support, as these individuals are themselves misusing alcohol or drugs.

In instances where the client has a social network there are other hindrances such as the client struggling with having them present in their sessions with the HCP. As stated by the HCP: “client struggles with bringing partner along” (HCP 7). Some family members consider the relative coming along or being part of the session at some stage; according to the HCP the FMs see themselves: “...wanting (drinking) relative in sessions but not immediately, still wanting their own time.” Others had adopted a pattern of having “FM for 1-2 sessions then say they want their space” (HCP 7), and in some cases it is that the clients want to have their “space” and time alone and therefore they find as in one instance that the “FM flatly refuses to bring partner” (HCP 7), or “refuses to bring drinker to her session” (HCP 4) and they state that they “*...do not want relative in same session*” (HCP 7).

c) Contact with FM: The qualitative data collected from the HCPs allowed for an examination of the contacts they had with family/network members of drinking relatives that they gave as examples. The relationships of the family/network members to the relative and the number of different people mentioned by the HCP is shown in Table 3.2 below. Where

it is indicated as “listed” it is implied that that individual was listed by the relative (or family member) but that either contact had not been made or this initial contact was made but the person could not be part of any of the sessions and did not have any further contact with the HCP.

Table 3.2. Family/network members given in the examples of contacts by HCP

Relationship	Total
Husband of partner	3 + (1 listed)
Wife/partner	8
Ex-Wife	1
Wife’s sister	1
Wife’s sister’s partner	1
Friend	1
Mother	5
Grandmother	1+ (1 listed)
Father	2
Co-worker	(1 listed)
Daughter	3+ (1 listed)
Son	2
Aunt	1
Uncle	3
Sister	3
Brother	3
Brother’s wife	1
Girlfriend	1
TOTAL	40 + (4 listed)

3.4.3 Experiences of working in a FF way

The data presented in this section relates to the experiences (positive and negative) of HCPs in adopting this approach and what they mentioned as benefits derived from using this approach. These are examined under the separate sections with that of positive experience being further examined first in terms of positive experience and benefits for the HCP and then the benefits for their clients

a) Positive experiences and benefits

i) *Positive experience of HCP:* According to the HCP, “you get another angle which actually *plays out before you*” (HCP 7). This provides you with another side of the story. She feels that the family focused approach provides the health care professional with the possibility of getting a much clearer picture of the true situation of the alcohol or drug misuse and the effect it may be having on both the individual and significant others. It is said that when a family member is brought into the sessions it allows the HCPs “to get two sides of the picture making it more complete,” or that “it stops the isolation where people pull the wool over their own *eyes – it is not always an easy session*” (HCP 8).

This is in line with the observation by another worker that “Having other people in the session is like a reality check. It left me feeling that I knew the woman better after seeing her mother” (HCP 11).

One HCP describes a scene in which she was able to witness issues that may not have been brought out if she were using other intervention methods: “It was a dynamic interaction

that would have been impossible to capture if not in the environment of doing family work and gives more light to the individual circumstance and dynamics of relations or support she may *have*.” (HCP 8).

Another positive benefit derived from FF as described by HCPs: “It is a positive experience when both are able to hear the other and get a positive response as all the others sometimes see is the drinking of the drinker. It is good to see the change in couples, when that happens and to see them behaving differently towards each other.” (HCP 5).

“When the drinker comes in first, he sometimes gets angry when the ‘nagger’ comes in later and it changes information he gave. The initial reaction to this is usually negative, but *eventually it turns out to be positive*.” (HCP 9).

The positive aspect of this approach according to the HCP is that “It takes the onus away from the counsellors as some of the responsibility is dissipated among the family members.” (HCP 10).

In addition to this, it widens the HCPs’ choice of options for intervening with each case. As stated: “Working in this way gives you such a range of interventions; so many different configurations with just one case, which would not be possible in individual counselling.” (HCP 13).

As summarized by one HCP using this approach: “I would rather have as many people as conveniently possible in a session. It is self-evident to me that it is more effective, you can

get as far as and as wide a view with many people than you would get with just one. You would also be addressing the need of more than just one person.” (HCP 13).

ii) Positive experience for clients

Health care professionals spoke of being able to see positive effects of using this approach in working with their clients. Working in this way has, for instance, presented a mediator in the family that the members feel free to turn to; in the words of a worker: “There is a focal person for family to turn to” (HCP 3). For some clients it led to the recognition of the importance of the people in their social network and the role of support they play, leading at times to actively looking at other potential sources of support that they could use. As stated by one worker: “The experience for the client has been positive. Without the mother being brought in to support the client would not have been able to come for the sessions mainly because of issues of trust. The client had come to recognise the importance of the mother in *his social network.*” (HCP 2).

It has in some instances helped family members to gain insight to the effects drinking is having on other members of the family. This has led in some cases to the FM’s realization that they could benefit from some form of counselling in their own right.

In another instance, the relative misusing the substance desired to become engaged with the service or at least being part of the FM sessions. Again, when FM are in the room there is much greater possibility of getting them to work together as a team. But even when not present, the fact that the FM was encouraged to work through her assignments with the drinking relative led in one instance to that relative desiring to become engaged with the service or, at least, be present during sessions with FM. One worker mentions that joint

sessions help to alleviate the fears and misunderstandings that some FMs may have about the service. One worker stated that: "Being present in the room where the sessions are occurring leads to less suspicion from the family member in regards to what may be occurring behind their back." (HCP 13). Furthermore, after the session, she reports that using this approach allows for family members to have "grip time"; she states that: "Having this time in the context of the sessions allows the opportunity for feedback to help them see and make changes...it is a fallacy to avoid that as it will happen anyway but when it happens *in the session it can be managed.*" (HCP 13).

Lastly it has been mentioned that one of the benefits is when the family member's interactions with the relative changes and they are able to make a distinction between the person drinking or taking drugs and the behaviour. This is reflected in the statement that: "It is nice to see the family member being able to see the drinker beyond the drinking" (HCP 5).

b) Negative experiences of working in this way

The data shows that the experiences mentioned by HCPs have not been all positive. Some of the quotes referring to or reflecting these experiences are below.

For instance the fact that you are working with more than one person implies that if they remain engaged you can report working with that number but when they disengage, on the other hand it would mean losing more than one person. As stated by one HCP: "One of the negatives however is that if it does not work then it does not work big time. If you are seeing one person and the person disengages then you are losing one client. If you are seeing five and they disengage then you are losing five clients. And when it does not work you feel real bad. You have to work harder to keep people engaged." (HCP 1).

Additionally the relative and the family members come into the session with different agendas; this presents its own set of difficulties as one worker states "...if you are dealing with *ten family members you can get ten different versions*" (HCP 1).

There have been sessions where the FM member is screaming at their relative and sometimes also at the HCP; in one of such sessions the HCP reported that she: "felt useless in some of the *sessions with the woman screaming at both her and the husband*" (HCP 3).

Again there are instances when: "the drinker just gets into a corner and lets significant other do all the talking and the significant other just talks on and on taking the focus away from the drinker. At times the environment is not so safe to probe and talk about underlying issues, it *calls for a greater amount of sensitivity.*" (HCP 5).

When the FM comes into the session and brings up issues that the relative has either glossed over or has not fully told the truth about the situation, it does lead to some tension, as it demands some sort of response from the HCP. As one HCP puts it: "I find it difficult when there is a partner in the room and they come in and give all the information away that the relative did not want to. I also get to a point where I do not know how far I can share. And then you have to deal with how to view the person with the new information that she was to *embarrassed to say.*" (HCP 7).

Sometimes this process brings up emotional issues that could get in the way. The support network gets lost by both the worker and the client as they attempt to deal with the emotional issues that arise.

There are reports of the worker sometimes becoming the prime target during sessions when both relative and FM come to the session at odds with each other. These instances are described as emotionally challenging, particularly in instances where the parties are not willing to reach a compromise. This situation is however not limited to the face-to-face sessions. It also occurs when they each place a call to the agency, and they sometimes do this in an attempt to get the worker to take sides on an issue. Similarly, when they have an argument, it is usually evident from the feedback that things that were said by the HCP were sometimes brought in.

3.4.4 Difficulties / Barriers to working with FMs

HCPs experienced some difficulties or barriers in working with family members. These barriers include:

- a) Administrative or organizational issues
- b) Client factors
- c) The HCP

a) Administrative or organisational issues: It was mentioned that the logistics of engaging more than one person were challenging, as it can be sometimes difficult to find a convenient time for the significant others that may be working. Because the HCPs are

maintaining contact longer with the relatives and family members it means a reduced caseload which may affect the targets for the whole organization.

Another difficulty stated was the waiting time. One worker states that: “drinkers were enthusiastic to bring in someone from their support network but the time lag between the interview where the network is mapped and actual scheduled session makes clients lose enthusiasm.” (HCP 2). Another difficulty mentioned was with record keeping, particularly recording separate instances of contact. The nature of these contacts with FM and where to keep these records was problematic.

b) Client factors: One HCP talked about the difficulty or frustration experienced in getting relatives to see themselves as in need of treatment. Likewise, relatives sometimes do not see any need to identify significant others that would be supportive. Another difficulty found in the analysis was the changing nature of the client’s network. When meeting clients, particularly in the home setting, people present in the house tend to change from time to time. These people at times may just be visitors to the home, who are subsequently invited by client to participate in the session. This sometimes does not allow the HCP to build on previous sessions but rather leads to the reintroduction of concepts and steps.

Another difficulty experienced is with the timing in which the FM is invited to be a part of the sessions. Because the relative is most likely to have had previous contact with the HCP, the family member that has been invited feels that discussions had occurred in his/her absence and therefore comes into the sessions somewhat on the defensive, or a little apprehensive. As stated by one worker: “The family member has to come and make adjustment, *in order to see that you are not on the relative’s side*” (HCP 13).

Additionally, when family members come for sessions, it is often with expectations which sometimes act as barriers to working in a FF way. One HCP reports: "I feel that sometimes in the family situation the family members expect you to perform some form of magic and make everything turn out nice" (HCP 1); the people present at the centre "...usually come with the hope that something will happen immediately and then it does not happen creates a *short-coming*" (HCP 2).

c) The Health Care Professional: One of the difficulties that they reported revolves around confidence in having more than one person in the room at a time and having to deal with the dynamics of group relationships. One worker states: "It is like from the beginning I tell myself that I can't do it" (HCP3). Approaching sessions with this frame of mind and then experiencing a session that does not seem to go well could lead to becoming more apprehensive with the confidence of the person being undermined even more, as one worker puts it. Another HCP stated that: "As a practitioner the difficulty is in learning and being confident in working in this way. Having few opportunities to do family work is detrimental to developing the skills and this gets in the way of delivering this approach." (HCP 2).

There was a lot of talking going on but without the clients. This experience without everyone present in her words: "...*made me feel more informed, but somehow more powerless*" (HCP 11).

3.4.5 Changes brought about in practice

Many of the HCPs indicated changing several ways in which they work. One mentions that there has been a change in focus, and that the focus is no longer solely on the alcohol or drug misusing relative. The worker mentions that they are more drawn now to see each person in the family in their own right as someone that needs to be seen, and to help them find a place in the family that they are comfortable with. In her words: "...I now see the family as broad...and explore how they can help each other...Now are able to see the family member *as clients in their own right.*" (HCP 3).

Previously, there was a feeling of breaching confidentiality by talking to the person's FM, but now they appear much more confident in doing so and do not see confidentiality being breached. One HCP states: "I would feel disloyal initially if I were to speak to the family members, but now I am more confident and won't lose the individual" (HCP 3). Furthermore the HCPs find themselves encouraging people to contemplate and bring someone along, particularly if they talk of a relationship that is being affected by the drinking.

Further changes have been made in the way HCPs interact with clients. More time is spent in the initial assessment for investigating the support network of clients. As mentioned by one of the HCPs: "Previously this is something that we would gloss over, or not given thought to at all. It has led to exploring the network more for networking possibilities" (HCP 2).

One worker mentions: "...I would end up spending more time with client than I otherwise would have. This may mean I would have to work with a reduced case load" (HCP 7). One worker states: "Prior to now what I would do is to detox the patient and pass them on to the counsellor, now I keep people in my books for 2-3 months post detox. In a way this is

positive as it allows me to give them a family approach which I would not be sure they *would get if I referred them.*" (HCP 1).

As mentioned by one HCP she now makes active use of the network diagram to help explore potential people in the support network that the client can draw on for support. The worker feels that this is a useful tool if client is willing to work through the issues that are brought up in the process of drawing this network diagram.

3.4.6 Ways they feel they could be supported further

Different ways in which HCPs could be supported in continuing to work in this way, or that have been helpful in adopting this approach to working with clients, was one of the categories that emerged from the quantitative analysis. The factors mentioned in the data were grouped in terms of whether they constituted external or internal forms of support.

a) External forms of support

A majority of the HCPs mentioned they found the frequent meetings with the research project team quite helpful as captured in the statement of one of the HCPs: "The continued presence of the Project team members made them keep 'the involving family members' on the agenda and it makes it that one strives to work at something to have something to report during the sessions" (HCP 6). Or that "Just having a presence rather than waiting and checking up every 6 months has been good" (HCP 2), as well as the available option of counsellors being able to ring up any of the members of the research team to discuss crucial cases or problems.

A few HCPs mentioned that having had previous training in related areas (e.g., couples therapy, family work) had been helpful. Additionally it was mentioned that it would have been very helpful if they had more contact with other teams that were working with clients using this approach. One worker mentioned incorporating a one-to-one session for the HCPs to discuss the projects with a member of the research team was particularly helpful for her, and felt it would be quite helpful if this was built into the project. She suggested that having the manual would also be helpful; after people have read through there could be a session of questions and answers. The HCPs have mentioned feeling that there is a need for more training and practice to deliver this approach, and particular cases they have handled (which posed some difficulties) only seemed to further “*cement*” these thoughts.

b) Internal support

Several issues came up relating to internal sources of support that had been helpful or would be useful if they were to continue working in a FF way. One worker mention the need to have home visits arranged in such a way that two HCPs (or a social work assistant) would be available to do them. The current situation was having a student on placement to do this but when they are not there or available, then making these home visits does become problematic. For her: “Just listening to people relate their own experience would have been very helpful it might have been in that process I may have learnt something in regards to what others are doing to get the family member of relative to commit to having someone come along as my not being able to do so may have something to do with my approach.” (HCP 4).

For difficult cases, the Community Alcohol Team as a whole had been helpful, as they always shared these cases and others would contribute ideas on how to handle the situation.

Monthly clinical supervision was also mentioned to be something they found very helpful as it "...provides a place to take issues to" (HCP 2). Also mentioned as helpful was having a supervisor who is keen on getting HCPs to use this approach.

3.5 Exploration of Emerging Model.

A model for understanding the experience of HCPs in working with FMs emerged from the categories in the data. A diagrammatic representation of the emerging model is presented in Figure 3.2. Recruiting and working with clients in a FF way immediately brings up a number of issues, which affect the willingness of HCPs to recruit or work with clients. HCPs for instance had different levels of skill, comfort, desire and prior experience of working with family members of alcohol or drug misusing relatives. For a majority of the HCPs, working in this way was a new experience; only a few mentioned having previous experience of working with FMs. Even these few reported that the project provided them with a better understanding or grasp of the processes and concepts which they were using. It additionally gave them legitimacy and organizational backing for working in this way. For many that had not had prior experience of working in this way, it would arouse some anxiety, or feelings of uncertainty. These then may have been further heightened if they had difficulties in recruitment or in the actual work itself.

Expressed feelings about working with FMs

The HCPs participating in this project came with a variety of preconceptions and feelings ranging from being positive or excited to fear and apprehension. These feelings were either

confirmed or challenged as they proceeded in working with FMs. For those that were eager to work in this way, they were willing to recruit and engage FMs. However for a number of HCPs willing to engage FMs, the initial experience was one of being frustrated. Some set out to look for a “perfect family” with the right social circumstances to work with or had actually started the process of recruiting FMs. Other expressed difficulty in fully engaging the FMs in the process, leading to the reported frustration. Nevertheless, they expressed that, if used flexibly, the approach could be applied to most of their clients.

Those HCPs who were apprehensive about adopting the FF way of working were less willing to engage FMs, worrying that the user’s relative, in their words, would be “lost in the process” and that they were not confident that they had adequate training to have more than one person in the consultation sessions at the same time, thus influencing the HCP’s willingness and efforts at recruiting and working with FMs.

Difficulties/barriers experienced while working in an FF way

Irrespective of whether HCP was excited or apprehensive about working in this way, they encountered a number of difficulties and barriers as they proceeded to recruit and engage FMs. A major barrier to overcome was with the recruitment of FMs. As stated above, some of the HCPs were looking for a “perfect family for networking” or individuals that are in the “right social circumstances”. In seeking for clients that would fit the concept, HCPs did not present the option to involve family members to all they were in contact with. Also when they thought the person’s situation was considered “too complex” or that the user had other conditions such as mental health conditions, they were hesitant to offer this flexible approach. It was also reported that when this offer was made, it was often not done with accuracy nor was it thought to be appealing enough for the FMs or the user to take it up.

These barriers, both for the client and the HCPs, are ones that may be overcome with education and making HCPs aware that the flexible approach is not so much looking for clients in which the pure form of 5-Step interventions could be used, but rather a flexible approach where tools derived from this approach could be used to gain better understanding and render help to FMs in their various situations.

Besides having the HCPs acquire a greater understanding and training in delivering this approach, their FM would need to become more knowledgeable and aware of the available help. The ability to actively encourage FMs in taking up this approach would however depend on the HCP's confidence and belief in the approach. This confidence, as mentioned by a couple of HCPs, is something that would improve with the opportunities they have in working with FMs, using this approach.

The HCPs' ability and willingness to wade through these barriers to a point where they feel positive and willing to recruit and work with a FM depended on the perceived support of the organizational team as well as the clinical supervision received and support offered by project team members in the bi-weekly meetings. Many reported that having a supervisor who was keen on involving FMs in service provision was very helpful. This was in addition to the availability of telephone access to support the bi-weekly meetings with project team. As mentioned these meetings "*provided a place to take issues to*". What was also found helpful was having been trained and encouraged to work as a team in becoming more family focused. This created an environment where caseloads were shared and issues raised with colleagues to enable them to get another professional perspective. This is captured by one of the HCPs that was not part of the initial group meetings: "Just listening to people relate their own experience would have been very helpful; it might have been in that process I may have learnt something in regards to what others are doing to get the family member or relative to

commit to having someone come along as my not being able to do so may have something to do with my approach.” (HCP 4).

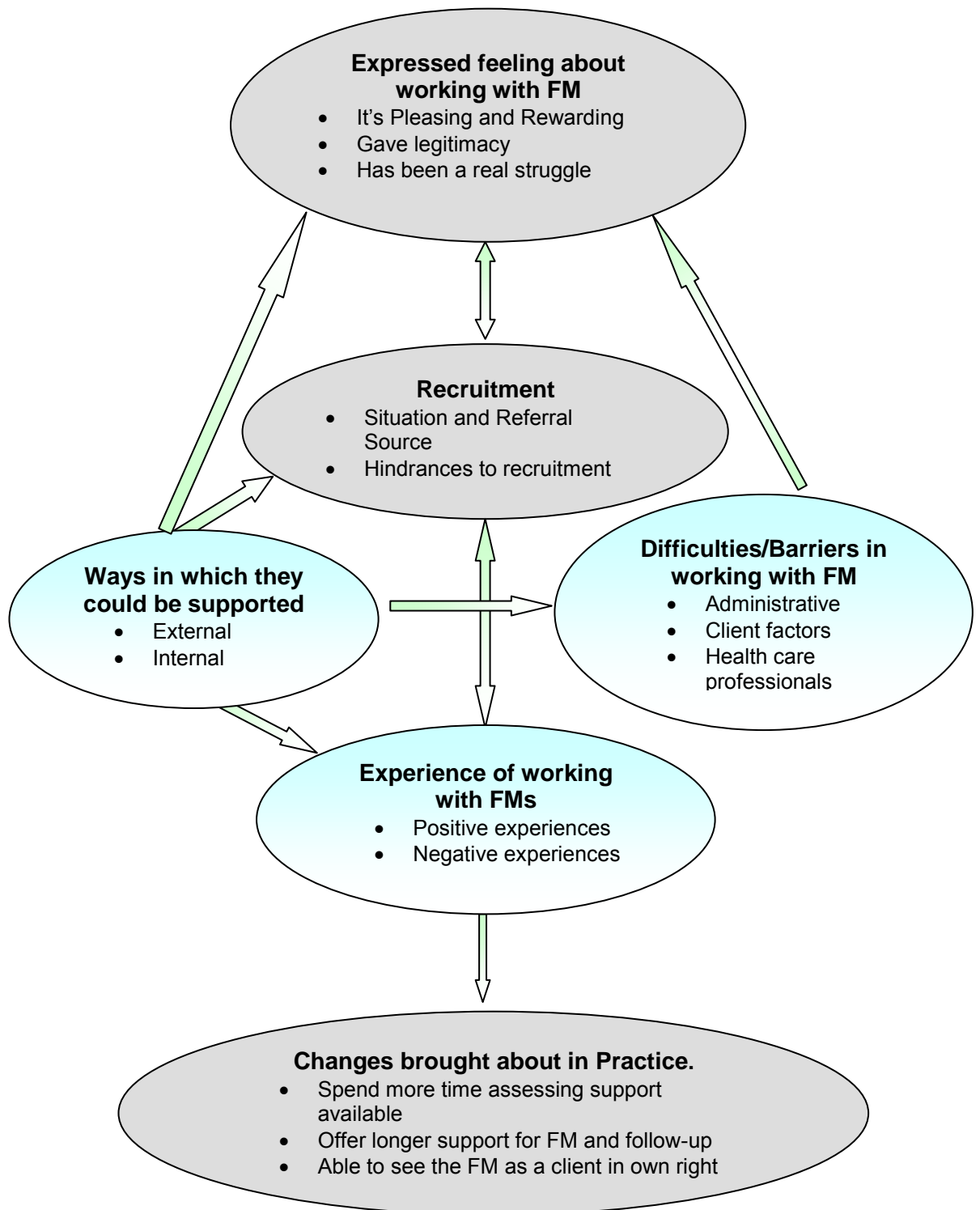


Figure 3.2. A model of factors affecting adoption of evidence based

Benefits of working in a FF way

When HCPs were able to recruit clients and work with them using this approach they came to experience the benefits of the approach. Such benefits included the ability to address the needs that extend beyond the alcohol or drug misuser. The needs of the other individuals in the family were also being addressed. As an approach, they reported that it brought greater benefits than the methods previously used.

It was reported for instance that this approach in working with FMs allowed them to observe “dynamic interaction that would have been impossible to capture using any other approach”, thus giving the HCP “a more complete” picture of the situation. This alone helped to fully highlight the impact of the situation on everyone involved and stops the relative using the alcohol or drugs from pulling “the wool over their own eyes”.

In addition to this, they also report that “It takes the onus away from the counsellors” and places it more on the side of the clients, creating an environment for greater “team work”, thus empowering the clients to take active steps to improve their situation.

Changes evident in practice

Largely due to the experience of these benefits both in therapeutic practice and on client population, many of the HCPs showed evidence of a change in the way they now worked with their clients. As such they incorporated a detailed assessment of the person’s support network at the initial intake interview. The HCPs also appeared to have moved through a phase of being apprehensive and lacking in confidence in adopting this approach to one in which they developed a more positive attitude and were confident or comfortable having

more than one person in the consultation session. As a result, they were now actively encouraging alcohol or drug misusing clients to come along with someone else for the consultation sessions.

The HCPs that participated in this project attributed the change in their practice largely to the support (both external and internal), that they received. External support in the form of fortnightly meetings with the project team provided an avenue to discuss the project and specific cases/scenarios currently being handled and possible options of how to proceed. In addition to these fortnightly meetings, HCPs had telephone access to the members of the research team.

The internal support that was thought to be crucial was that of a supervisor who was keen to have this approach implemented in the organization. Another significant factor mentioned was that of being in an environment where the organization as a whole adopted this way of working with clients. This all helps to keep the project high on the agenda of the organization. It also allowed for HCPs within the organization to obtain peer support and as such, compare notes and seek advice about cases from each other. The model put forward here to explain the obtained data will however need to be tested further with larger numbers and needs to be interpreted within the context of quantitative studies.

Dissemination is crucial for the adoption of evidenced based intervention programmes that target vulnerable and hard to reach populations. Important factors suggested by models of transfer were taken into consideration. Thus 'organizational sign-up' was required to participate in this project (Orford, et al., 2009). Ensuring organizational structures that would support change (McGovern, et al., 2004), in the desired direction, was also necessary, as was a team training approach where all members of staff were given adequate training and supervision. To ensure ease of transfer of evidence-based intervention to real life settings,

the hierarchical or unidirectional approach from research to practitioner was avoided (Addis, Wade & Hatgis, 1999). At all stages of the development and transfer the input of HCPs was actively sought rather than ignored (Ball, et al., 2002; Foreman, Bovasso & Woody, 2001). As this transfer process involved greater levels of collaboration, coupled with the intervention being designed with due consideration to the operating environment, it was expected that, unlike the findings of Fals-Stewart and Birchler (2001), more HCPs would be willing to use the intervention in working with FMs. The bi-directional nature of the transfer in this instance allowed for the implementation of the intervention within these organizational settings while still maintaining the fidelity of the intervention (Liddle. et al.. 2006).

However, in addition to these research findings, the HCPs that took part in this study report that crucial to their adopting and continued use of this intervention in working with family members, was the support they received. This was both in terms of organizational or institutional structures in place that supported changing in this direction and the meetings with researchers where practical issues of implementation could be discussed. In the absence of this level of support, the level of change observed, such as where one HCP reports a preference for, and only takes up, cases that have FMs, would not be possible.

It is important to consider some of the limitations of this work. It for instance focused only on the qualitative reports of HCPs' experience and their perception of the experience of family members; FMs were not approached to be interviewed. Again the number of HCPs interviewed was small, thus generalization to other HCPs may be difficult. Considering that these HCPs were drawn from addiction services, they constitute a specialist group of workers that already have experience of working with clients in regards to alcohol or drug misuse, and may have had a higher level of motivation for a change in service delivery; this may not be reflective of other health care professionals.

However, despite these limitations, this study does provide insights into the experience of a small number of participants. It provides insight to the barriers that may exist for professionals and what could be done to enhance the adoption of this and similar interventions in organizational settings. It suggests that to arrive at a point where the HCPs are comfortably and confidently working with FMs as clients in their own right, there is a need for training of HCPs, and more importantly for those trained to implement the intervention to have organizational structures in place that would support working in this way. A crucial part of the follow-on from training is access to continued support as they begin to adopt this approach with their clients. It is worth noting that this level of organizational support or supervision is not available to HCPs in the current health care delivery system.

This work additionally sheds some light on the focus of health care professionals when working with family members either alone or alongside the alcohol or drug misusing relative. In this work the most reported incidence and trend was that the health care professionals, though they recognized the needs of the family members, were still largely focused on the user and how to reduce or moderate the behaviour of the user with the help of the FM, and in that way reduce some of the negative effects being felt by FMs. Seldom was it focused on solely meeting the needs of the FM outside of the alcohol or drug misusing relative. The needs of FMs are therefore still left relatively unaddressed. Thus, even if there were adequate numbers of trained HCPs, there would still be the question of how many family members are able to access these services and, of those that do access it, how many are actually being seen as clients in their own right.

With the increase in the quest for maintaining one's health and increasing help-seeking behaviour that is occurring via the web, investigating the feasibility of the delivery of this

intervention for FMs on the internet is important. It would present an option from which they could choose of how they would wish to manage the experience of addiction in the family.

CHAPTER 4

Quantitative and Qualitative Pilot Study of an Internet Based 5-Step Intervention.

4.1 Chapter Rationale

In the previous chapter HCPs were trained in the delivery of the intervention and provided qualitative reports of their experience. Results showed that the 5-Step intervention provided them with a framework for understanding addiction within the family and was incorporated into the routine service delivery of the organization. The delivery of this intervention has been found effective in various settings: in primary care settings (Copello, et al., 2000; Orford, Templeton, Patel, Copello & Velleman, 2007; Orford, Templeton, Patel, Velleman, & Copello, 2007), in specialist settings (Copello et al., 2000a,b; Howells & Orford, 2006; Templeton, Zohhadi & Velleman 2007; Orford, et al., 2009), and in a group format (Templeton, et al., 2009). It has also been evaluated among black and minority ethnic (BME) communities (Orford, Copello, Simon, Waheed, et al., 2009) and in different countries and cultures (Arcidiacono, Velleman, et al., 2007, 2009; Sainz & Rey, 2003; Velleman, et al., 2008). Positive results of earlier studies of face-to-face delivery of this intervention led to the development of a self-help manual version.

4.2 Introduction

Despite the evidence of effectiveness of the 5-Step intervention, and the fact that HCPs can be trained in the delivery of this intervention, in reality the intervention is still out of reach for the majority of family members that could benefit from it. As pointed out in Chapter One, there are a number of interventions that involve the family members in the treatment of the relative, yet only three of these interventions see family members as people in need of

support in their own right and as such set out to work with FMs. These interventions included the AI-Non, Family Coping Skills Training and the 5-Step Method. Even with the interventions that exist, the review shows that these are currently not widely available to family members in routine service delivery (Backer et al. 2000; Copello & Orford, 2002; Morgenstein, 2000; Orford et al. 2009), a gap therefore exists between the proven effectiveness of the intervention and their availability in routine clinical delivery.

By implication when family members are exposed to alcohol or drug use problems of a relative, they are often at a loss as to where to go to receive treatment or help. Commonly most attend or report at their GP practice with health related complaints (Halford et al. 1999, Kahler et al. 2003; Ray et al. 2009), the symptoms they present are often not identified as being linked to the stress of living with a relative who is misusing alcohol or drugs. A need was therefore identified for designing support that took into consideration how and where family members may turn for help, and providing or making this help easily accessible through the channels that they use. In this case the web, which has increasingly become a place where people go to search information for health related issues, provided this option (Harvey et al. 2008; Sillence et al. 2007).

Results of interviews with HCPs in chapter 3 show that professionals need training and support of an intensive nature to feel comfortable to work with family members as clients in their own right. As reported elsewhere, health and social care professionals who are trained in delivering family based interventions are in short supply (DoH, 2001); these factors were considered and led to the need to design a web-support programme that could function as a fully automated system with minimal or no input from health care professionals, but which could also be used as an adjunct to treatment.

From the available evidence, it was predicted that family members would respond like average web surfers who commonly alight on a site and click on interesting pages in any order in which they appeal to him or her or are relevant to the condition/ situation. As the literature does not provide conclusive evidence as to specific features of the internet that are effective for all populations, there is a need for basic research that examines the feasibility of delivering internet interventions for family members of alcohol or drug misusing relatives.

The remainder of this chapter looks at the development and overview of the web-based support programme (www.alcoholdrugsandfamilies.nhs.uk) and the results obtained from piloting this programme.

The 5-Step Method contrasts with other models of intervention that involve family members of alcohol or drug misusing relatives in its focus on responding directly to the needs of family members, and unlike other models it can work with a single member of the family, even in the absence of the alcohol or drug misusing relative. The steps that need to be taken when supporting the FM are clearly described. It is an intervention that has been developed in a self-help format (Copello et al., 2009), therefore lending itself for further adaptation for internet delivery.

With the ever increasing number of people that have access to the internet (Internet World Statistics, 2009) and are, through it, searching for health-related topics (Murero, D'Ancona & Karamanoukian, 2001; Tatsumi, Mitani, Haruki & Ogushi, 2001; Powell & Clarke, 2002), the internet presents itself as an option for which dissemination of an automated 5-Step intervention is possible. This has the potential to reach a far greater number of family members than any of the other more traditional channels of delivery of this intervention.

To date, a wide range of internet interventions is available for other mental health and behavioural conditions. These include treatment for anxiety (Newman, et al., 1997, 1999),

depression (Christensen, Griffiths & Korten, 2002; Clarke, et al., 2002), smoking cessation (Schneider, Walter & O'Donnell, 1990), obsessive-compulsive behaviours (Robinson & Serfaty, 2003), and specific phobias as well as panic disorders (Devineni & Blanchard, 2005; Kenwright, et al., 2004; Marks, Shaw & Parkin, 1998; Marks, Mataix-Cols, Kenwright, et al., 2003; Klein & Richards, 2001), weight loss (Tate, Wing & Winett, 2001; Winett, et al., 1999), headaches (Ström, Pettersson, & Andersson, 2000), and diabetes management (McKay, et al., 2002), to name but a few.

The existence of this increasingly diverse range of treatment conditions being addressed by internet interventions is evidence of the demand for and appreciation of this new medium for delivering such interventions. The National Institutes of Health and other government agencies in the US are actively encouraging the development and evaluation of interactive web-based health interventions. In the UK, several internet-based interventions such as 'Beating the Blues' and 'Fear Fighter' have been recommended for use by the National Institute for Health and Clinical Excellence (NICE). In this way the governments of these countries are publicly recognising the value of web interventions and are seeing them as feasible and acceptable means of delivering treatment.

4.3 Study Rationale and Aim:

The internet is thus set to play a revolutionary role in how health care is delivered in the future. Hence there is a need to position alcohol and drug treatment services in general, and treatments that support family members of alcohol and drug misusing relatives in particular, in such a way that they can make full use of this medium. This work stands out in that it is the first in making an accessible web format for an intervention that is grounded in theory and

based on evidence. Secondly, it focuses on support for family members as people in need of help in their own right.

The literature on web based interventions contains a varied range of studies based on different research designs and evaluations reporting different results. Given that this was the first attempt to develop and evaluate an internet based study for FMs of alcohol or drug misusers, it was decided in the first instance that a pre and post design, supported by a qualitative exploration would be used in order to evaluate the feasibility and pilot of this intervention. A randomized design was considered but it was felt that, whilst this would be suitable at a later stage, it was not the appropriate design for this early phase. In the present studies test measures were collected at baseline and 3 month follow-up. The 3-month post intervention period was chosen to allow comparison of the results obtained in this study with previous studies evaluating the 5-Step intervention in other formats. The remainder of this chapter looks at the development and overview of the web-based support programme (www.alcoholdrugsandfamilies.nhs.uk) and the results obtained from piloting this programme.

4.4 Objective

- i. The aim of this study is to investigate the feasibility of internet delivery of the 5-Step intervention. The specific research questions are:
- ii. What is the FMs' evaluation of this format of delivery; this will be in terms of their overall satisfaction, appearance of the web site, ease of navigation, viability of the links, difficulties encountered and helpfulness of the site. The acceptability of the intervention would justify it being released more widely.
- iii. Are there any difficulties in using collecting baseline and follow-up responses online from FMs on the validated questionnaires?

- iv. Did use of the programme lead to desired changes for FMs?

4.5 Method

4.5.1 Design

The design involved the pilot cohort follow-up study of family members accessing the internet based intervention where they were followed up 3 months after registering on the site. Both quantitative and qualitative measures were obtained.

4.5.2 Sample

Family members were recruited through two main procedures. The first route was conducted through ongoing referral from HCPs in four organizations (two specialist alcohol and drug agencies, and two Primary care surgeries), the second was through a one-time event, organized to provide computer access and technical support to family members that were interested in taking part in the trial. The flow of FMs through the study is shown in Figure 4.1.

The criteria for inclusion of a FM in analysis were:

- Individual must be a FM who considered themselves sufficiently affected and/or concerned about the alcohol or drug use of a relative
- FM must had been in contact with the relative in the last six months
- The problematic drinking or drug taking incident(s) had occurred within the last 6 months.

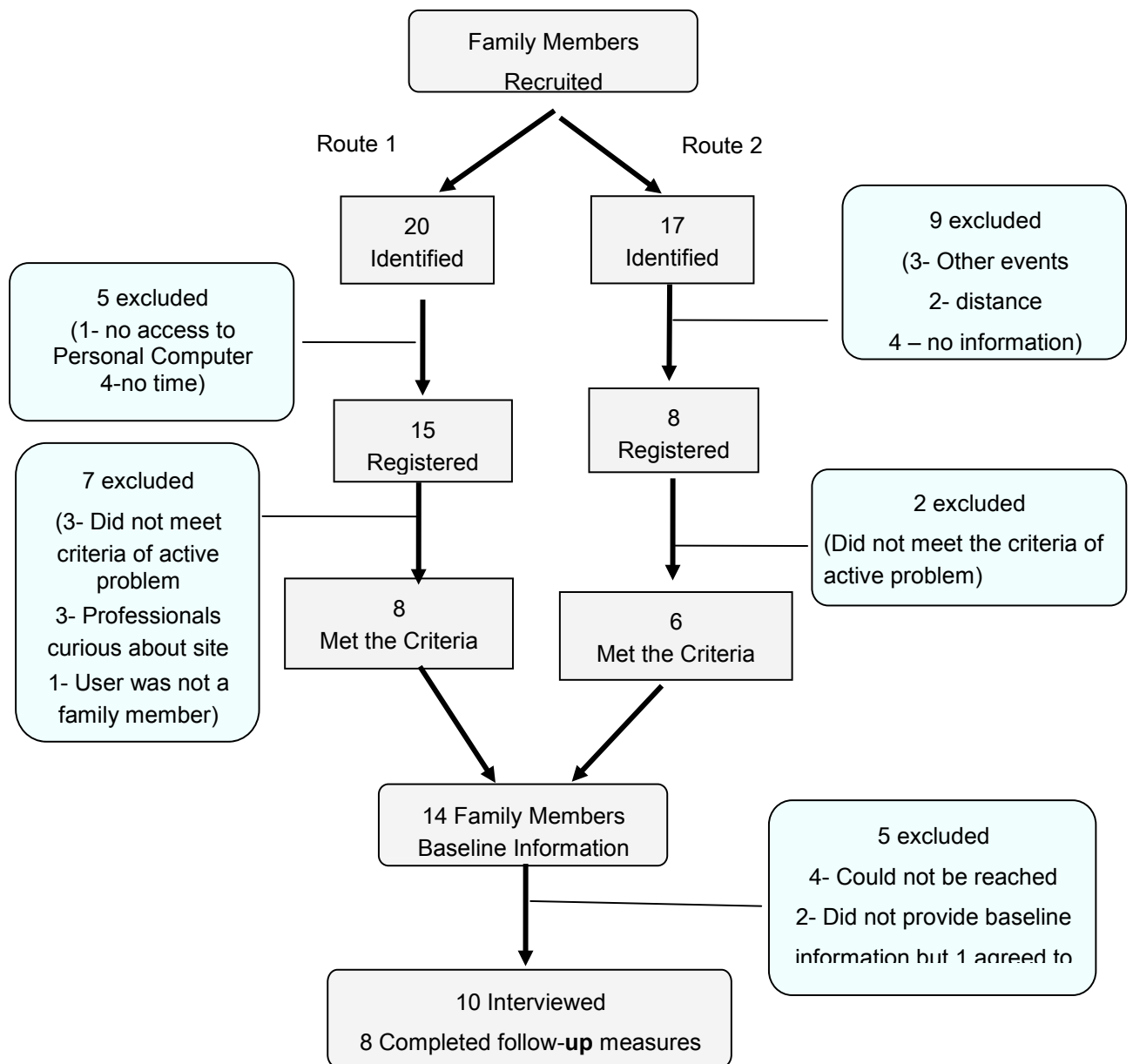


Figure 4.1: Flow of participants through the pilot

Route One: This first recruitment route was ongoing through the four organizations. FMs were identified by key workers in the NHS trust/GP surgeries and Specialist Drug Services.

Through this ongoing recruitment route 20 FMs had indicated their interest in taking part. Of these 20 FMs, 15 successfully logged in and registered on the programme. The 5 FMs that did not register were followed up four weeks later to see if they were experiencing difficulties and if they were able to login. Results of this showed that one did not login because they were not able to access a computer, while the remaining four had not logged in to use the programme as they could not find the time to do so. They still maintained their interest and desire to be a part of the programme.

Out of the 15 people recruited through this route 8 were included in the analysis. Three were excluded as they did not meet the criteria for inclusion in the study. Baseline information provided showed that their relative's problem had not been active in the past 6 months. One individual was excluded because he was not a family member. Three others were excluded as they were practitioners that had registered on the programme to view it for future recommendation to their clients.

Route Two: The second route by which FMs were recruited to participate in this trial was through a one-time event. Invitations were given through various educational organizations for FMs to come for a workshop that specifically advertised the internet intervention programme. As part of the workshop they were given access to a computer terminal from which they could log in to the web-based programme and, if required, receive technical support while doing so. Invitation letters were sent out to staff of three universities within the locality as well as students of one of these universities. The email sent out invited participants who were concerned about someone else's drinking to a "two-hour workshop for family members". It was held within the university where they had access to a computer terminal and support in logging in to the web-based programme. Posters and pamphlets were

also printed and strategically placed in the University, and leaflets sent to the staff of four primary schools and three secondary schools.

Reasons for not attending the workshop were obtained: two FMs reported that they lived in towns that were far away and could not get permission from work to attend, one was ill; two had conflicting activities. The remaining three could not be reached to provide information. Out of the total of 17 that indicated a desire to be a part of the workshop, a total of 8 FMs attended. Two of these were later excluded from analysis as they did not meet the criteria because their relative did not have an active alcohol or drug problem (defined as an alcohol or drug taking episode within the last 6 months). Among those that did not attend the workshop two eventually registered on the programme and therefore were counted among those that came through the first route.

4.5.3 Procedure

The HCPs in their course of work identified potential family members and invited them to participate in the evaluation of the web-based programme. These family members were identified in the surgery when they presented with symptoms caused by a relative's drug and alcohol problematic use. They were then invited to participate in the trial of the web-based intervention. Similar to those who attended the workshop, they were given the information leaflet and the registration code that they needed to enter to gain access to the intervention. When they logged in to the website, they were taken through the registration process. This included reading the information sheet describing the intervention online, providing consent, filling baseline questionnaires and choosing a username. At the end of registration a password was sent to the individual's email box. He/she could then use this password to access the intervention programme.

4.6 Description of the website

The homepage contained general introductory information about the broader Alcohol, Drugs and the Family (ADF) project. From the home page there are links to collaborating organizations, and scientific publications as well as other sources of help which family members may find useful. The website is developed as a fully automated one: the contact with the Health Care Professionals was for referral purposes and to obtain a registration code that the person required to access the site (see Figure 4.2).



Figure 4.2 Welcome page of the www.alcoholdrugandfamilies.nhs.uk website.

Thus, when family members were seen by practitioners or members of the research project team, they were informed that they could have the option of accessing support online while working through the programme at their own pace. These family members were then given a pamphlet they could take with them that provided information about the programme and what

was required of them. Once they arrived at the site and input the registration code they had received, they were then taken through a registration and consent procedure. This required reading through the information page about the work and what to expect. Links from this to the privacy policy that is operated on the site were provided. Once this information sheet was read, the individual was required to give informed consent for further participation.

Once consent was given, the participants provided basic demographic information about themselves, current situation and the nature of their relative's problem. They were then required to respond to a series of validated questionnaires that provided baseline measures. Once registration was completed a password was sent to their given email account; there were provisions for the participants to change this password to one that was easier for them to remember. FMs could then use the password to access the intervention programme.

4.6.1 Site Content: The web-based intervention was adapted from the 5-Step self-help manual. The pages of the self-help manual were converted into a web format using available technology. The content of the web programme is thus very similar to what can be found in the self-help manual in book format.

The programme itself is arranged in five different modules (See Fig 4.3) which correspond with the five steps of the 5-Step Method. In the first module the FM is led to explore the nature of stress that the relative's use of alcohol or drugs has had on the family and how this affects other family members as well as the health issues that the FM may be experiencing. The second module is based on the premise that not having knowledge negatively affects ability to cope, and it sets out to provide this knowledge for family members.

The site itself was modelled after the 5-Step Intervention's Self-Help Manual. It consists of 5 modules, with exercises in each of these modules (a total of 13 exercises in the programme). These exercises record and update the FM's responses.

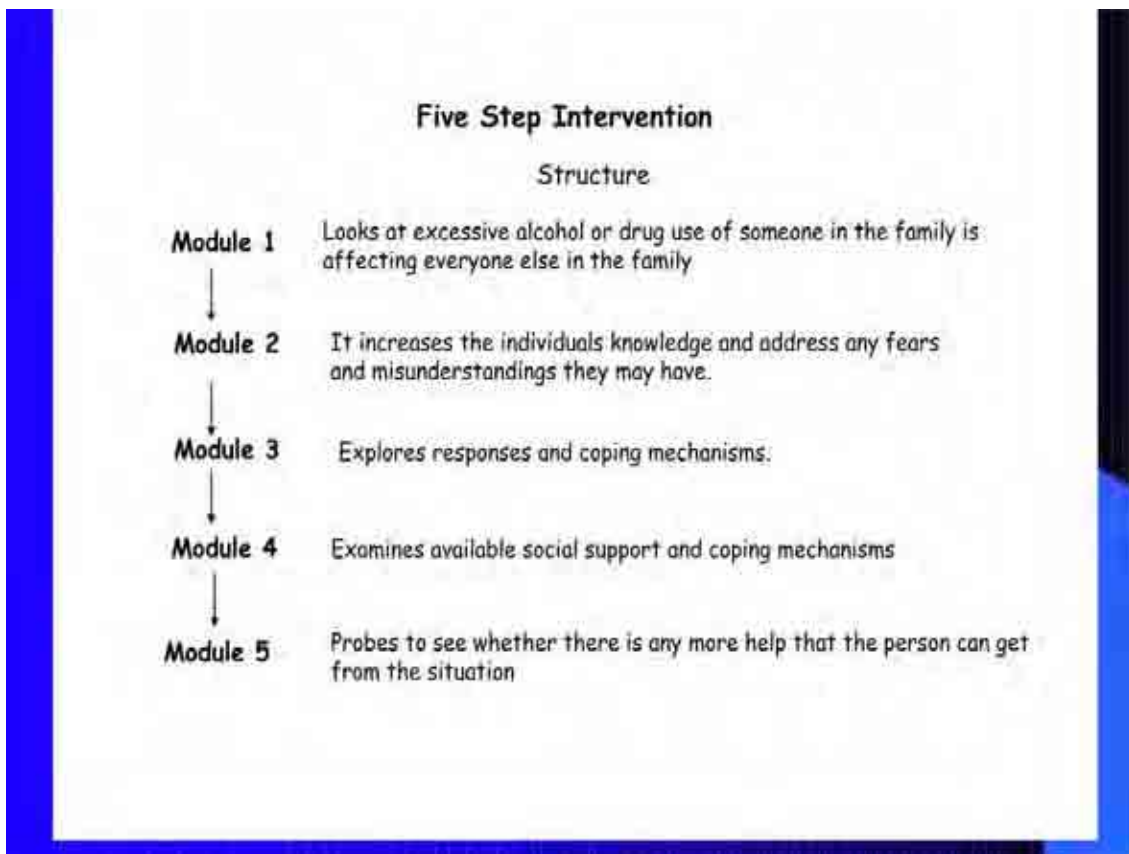


Figure 4.3. Modules of the Web-based 5-Step Intervention.

4.6.2 Internet sessions: The sessions are designed in such a way that they could be taken in any order that the person desires. Family/network members are advised to proceed through each of the stages/modules sequentially. They are however, not forced to do so as the programme will allow for entry at any level. The programme itself is arranged in five different modules to reflect the steps of the self-help manual. Thus the five modules were

broken down into a series of activities and exercises. Details of this are shown in Figure 4.4. The programme included a total of 13 different exercises scattered throughout the 5 modules of the programme.

In some places links to other resources were provided. For example, the section on getting additional help in module 5 provides hyperlinks to other sources of help and treatment that are available in the UK and elsewhere. These are sources both for the alcohol and drug misusing relatives as well as for the family members themselves, since many family members are particularly concerned about where they can get help for their relatives.

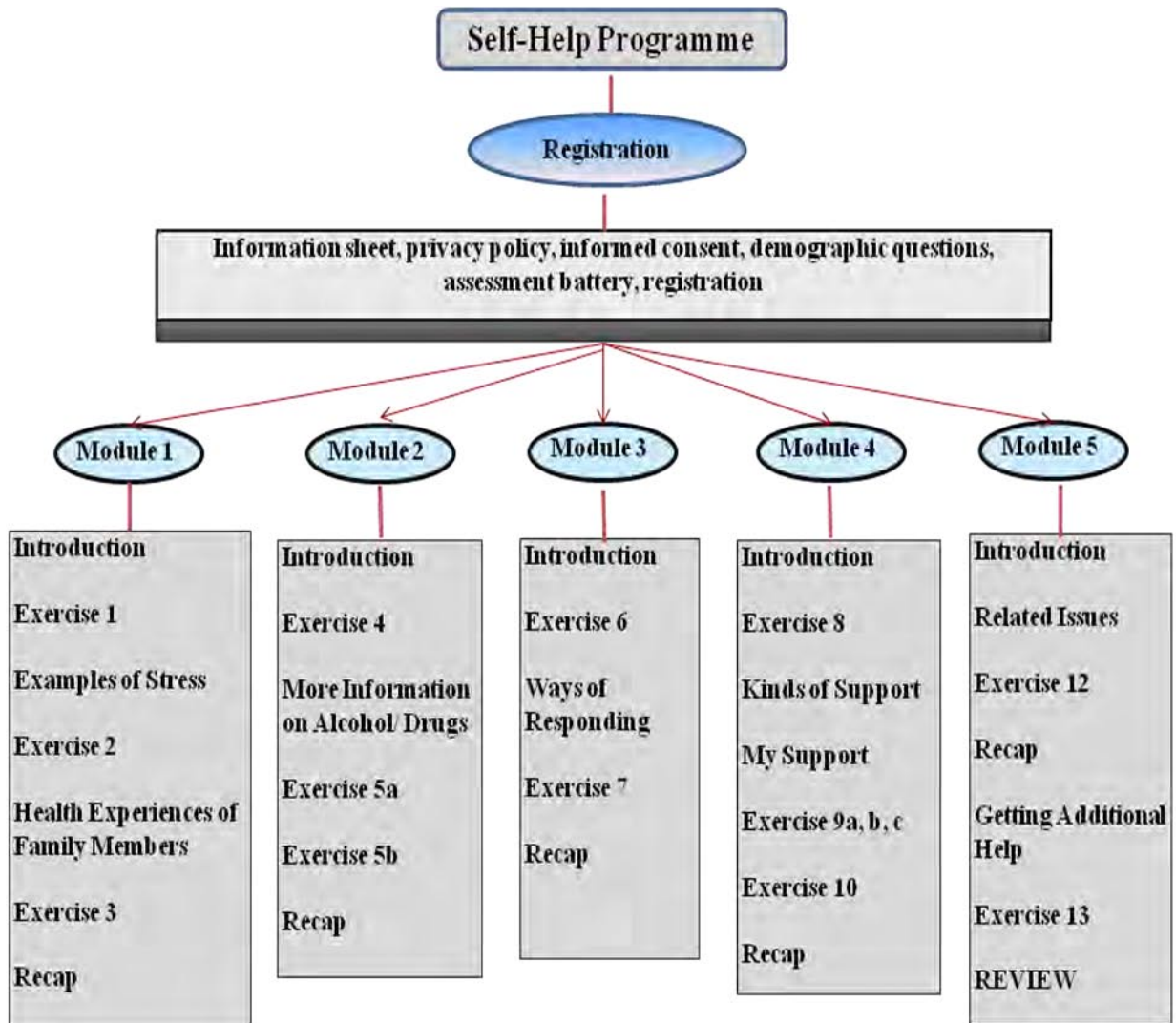


Figure 4.4. Layout of the web-based intervention programme

There is also a series of exercises and assignments for the family member to complete in each module. Typically each module starts with a description of issues to be covered. It then presents an exercise or exercises designed to help the family members gain insight into how the topic relates to her or his particular situation and possible actions that could be taken to change that situation. Typically these exercises come in one of two forms; either a tick box form or one in which the family member types in a response to the question posed. Figure 4.5 illustrates an exercise on increasing one's support. When these are typed in and submitted they are uploaded and the family member can view his or her responses. They can repeat the process if they wish. Their previous responses are all available to family members at any time that they login to the programme again.



Figure 4.5. Exercise on increasing one's support

4.7 Measures

The measures used in this study were similar to those used in evaluating the intervention in other formats (Arcidiacono et al., 2009; Ahuja et al., 2003; Copello et al, 2000, 2009; Krishnan & Orford 2002; Orford et al., 2001; 2005; Templeton et al., 2007; Velleman, 2008). These measures included: the Family Member Impact Scale (FMI), Symptoms Rating Test (SRT) and Coping Questionnaire (CQ). Evidence of the validity of this scale is seen in their sensitivity to change over time (Orford et al., 2005, 2010). Also assessed was information regarding FMs' age, gender, ethnicity, and religious orientation as well as the age, gender and their relationship with the relative for whom they were concerned. Using similar measures in both the online version studies and other formats allows for comparison of results.

The Family Member Impact (FMI) scale. The family impact scale consists of 16 items which measure the perceived impact that alcohol and other drug use by a relative is having on the family member or the family as a whole. Questions in the FMI include: "Does your relative have very changeable moods?", "Have family's finances been affected?" and "Are you worried that your relative has neglected his/her appearance or self-care?" The individual is asked to choose one of the four possible fixed response options, either: "Not at all", "once or twice", "sometimes", or "often" and these are scored 0, 1, 2, and 3, respectively. The highest total score obtainable on this scale is 48. There are two subscales within the Family Member Impact Scale; one of these measures "worrying behaviour" and the other is "active disturbance".

Coping Questionnaire (CQ) The coping questionnaire is designed to assess ways in which family members have been coping with the problem drinking or drug taking relative over the previous 3 months. It consisted of 68 questions, some of which in its original format were limited to measuring only the effect of the husband's alcohol problem on the wives. This

version has been used in various studies both within and outside the UK (Hayashi, 1978; Mcgrady and Hay, 1987; Holimila, 1997). This scale has been adapted a number of times making it now relevant for husbands and other family members. It also extends beyond drinking to also cover a relative's drug use. This adapted version is also much shorter with only 30 questions. Examples of questions in this scale include: "Have you started an argument with your relative about his/her drinking/drug use?", "Have you sat down together with your relative and talked frankly about what could be done about his drinking?", "Have you pleaded with your relative about his/her consumption of alcohol/drug use?". Possible responses to questions in this scale are: "No", "Once or twice", "Sometimes" and "Often". These responses are scored 0, 1, 2, and 3 respectively. The highest total score obtainable on this scale is 90. This version is reflective of the three moods of coping: engaged, tolerant-inactive, and withdrawn (Holmilla, 1997; Orford, et al., 1998b). These three modes of coping are subscales within the coping questionnaire.

The Symptom Rating Test (SRT) was developed by Kellner and Sheffield (1973). It has been used in assessing the extent of physical and psychological ill-health in the general population. It is brief, consisting of 30 listed symptoms of which the respondent indicates the frequency that he/she has experienced the symptoms within the past 3 months. These symptoms, for example include; "Feeling dizzy or faint", "Feeling tired or lack of energy", and "Feeling nervous". There are 3 possible responses that the family member can choose from; "Never", "Sometimes" or "Often". They are scored 0, 1, and 2 respectively. The highest possible score that a person can have on this scale is 90. Orford, Templeton, Velleman and Copello (2005) describe in detail the reliability and validity of these scales.

Other measures that were taken in the course of this study relate to the internet behaviour of the visitors to the site. Thus information was sought in relation to:

- Time spent on step/page

- Page viewing history.

At the end of the 3 months, post registration qualitative interview data was obtained on the experience of family members in their use of the web-based intervention programme. Family members were also required to provide quantitative responses by filling follow-up questionnaires.

4.8 Semi-Structured Interview

Qualitative data was also obtained through semi-structured telephone interviews. The interviews included the following topics:

- i. Recruitment prompt: How did family/network member hear about the project?
- ii. Pattern of usage prompt: How would they describe their experience in using this web-based intervention?
- iii. Impact the site had prompt: What did family or network member find most useful in this intervention, or what are some of the things that they gained in participating in this web-based intervention?
- iv. Suggestions prompt: What suggestions would they like to give for improvements or changes they would like on the site to make it more friendly and useful?

Of the initial 14 family members that registered on the site, 10 (71.43%) granted follow-up interviews about their experience with the website. Of the remaining five FMs one refused to be interviewed and four could not be reached. The method adopted here is one that has been used and refined in previous qualitative studies by the Alcohol Drugs and the Family Research Group (Orford, et al., 1998, 2000, 2007a, 2007b; Velleman, 2000). Experience has shown that this method does provide very accurate reports and contains sufficient information for in-depth analyses. The condensed nature of this method has the advantage over full interview transcripts (Orford, Templeton, Velleman & Copello, 2010).

A grounded theory based approach was adopted in analysing six of the interview data. Rather than code each line of the report, parts of it were coded with the actions of events that occur or are represented in the information being defined. Following Charmaz' (2006) suggestion, focus coding was employed in the remaining four interviews. This helped to examine the adequacy of the initial codes arrived at, and allowed for a more incisive and complete categorization of the data.

4.9 Follow-up protocol

There are two aspects to the follow-up of family and network members that took part in piloting this site. Quantitative data was gathered 3 months post intervention by the FM filling out the post intervention set of questionnaires which are similar to those used at baseline. Qualitative data about family members' experience in using the site was gathered through brief telephone interviews. The family members were contacted by email, post, or phone depending on the channels of communication that had been stated as convenient by the FM at the point of registration.

Three months after registering onto the programme, email and telephone reminders were sent to the individuals who had desired to be contacted using the particular means. These reminders were accompanied with the web address and instructions on how to log back into the 5-Step Internet intervention. If they had forgotten their password they could request a new one to be automatically generated. Once they logged in to the programme it automatically took the person through the follow-up questionnaires. The telephone calls and email reminders were repeated until the completion of follow-up for each of the participants. If they did not respond to this email after a certain number of weeks, they were then sent another email. An electronic copy of the follow-up questionnaire was sent asking them to respond and send back as an attachment, or to print and post it to the project contact.

4.10 RESULTS OF QUANTITATIVE DATA

4.10.1 Characteristics of family members

There were 14 FMs that met the criteria for inclusion in the analysis; the mean age of FMs was 44.93 years (SD=13.96), ranging from 28–73 years. The data obtained allowed for an examination of the demographic characteristics of the registrants. This is presented in Table 4.1 along with the demographic characteristics of family members that had experienced the delivery of this intervention in other formats and other settings. The results showed that almost all the registrants (13 (92.9%)) were female, and there was a large percentage 12 (85%) of relatives.

Table 4.1 shows the occupation of FMs included in the analysis. The largest percentages of registrants (35.7%) were in full time employment. This was followed by students (28.6%), those looking after the home, retired or permanently sick or disabled. Each of these made up 7.1%. Family members were asked to tick the main problem that their relative has.

Results from the data (see Table 4.1) show a slightly higher number reporting concerns about drugs (42.9%), as compared to alcohol (35.7%), and a smaller percentage (21.4%), reporting their relative has a problem with both. The table shows that a high percentage (17.4%) of FM state that the duration of drug or alcohol misuse of their relative has been more than 10 years.

Table 4.1: Demographics of participating family members and their relatives.

Characteristics	Internet Programme (n=14)	Face to face intervention (n=42-51)	Self Help Manual (n=88-92)
Gender of family member			
Male	1 (7.1%)	6(11.8%)	14 (15.2%)
Female	13 (92.9%)	45(88.2%)	78 (84.8%)
Gender of User			
Male	12 (85.7%)	NA	NA
Female	2 (14.3%)	NA	NA
Age of FM	44.93 (SD 13.97)	44.2 (SD 14.4)	45.1 (SD 12.9%)
Age of User	36.21 (SD 11.21)	37.1 (SD 15.2)	35.82 (SD 12.9)
Relationship of User to FM			
Parent (Father/Mother)	2 (14.3%)	3 (5.9%)	5 (6.6%)
Husband/Male Partner	5 (35.7%)	22 (43.1%)	38 (41.3%)
Wife/Female partner	-	5 (9.8%)	10 (9.8%)
Sibling	2 (14.3%)	-	-
Child	5 (35.7%)	18 (35.3%)	33 (35.9%)
Other	-	3 (6%)	6 (5.5%)
Main Substance of misuse			
Alcohol	5 (35.7%)	29 (56.9%)	55 (59.8%)
Drugs	6 (42.9%)	21 (41.2%)	30 (32.6%)
Alcohol and Drugs	3 (21.4%)	1 (1.9%)	6 (6.5%)
Other	-	-	1 (1.1%)
Living with relative	11(71.4%)	38 (76%)	65 (71%)
Duration of the problem			
3-5 years	3 (21.4%)	Mean duration = 8.7yrs (SD 7.7)	Mean Duration = 8.9yrs (SD 7.3)
6-9 years	1 (7.1%)		
>10 years	10 (71.4%)		
Occupation of FM (n=15)			
Full time employment	5 (35.7%)	19 (38.8%)	45 (50%)
Part time employment	1 (7.1%)	22 (44.9%)	28 (31.1%)
Looking after home	1 (7.1%)	-	-
Retired	1 (7.1%)	-	-
Student	4 (28.6%)	-	-
Permanently sick or disabled	1 (7.1%)	-	-
Other	-	8(16.3%)	17 (18.9%)

Note: In the face-to-face and self-help version, duration of problem was reported in actual number of years. The means and standard deviation are presented in comparison to the web format.

4.10.2 Follow-up rate

The first attempts following up the family members using this protocol proved difficult as many did not respond to the email messages inviting them to return to the site to fill in the questionnaire or to indicate a convenient time in which a brief interview of their experience with the programme could be given. Two FMs responded to the second reminder and filled in the question online. The protocol was then reviewed and the initial email was sent to interview or schedule a convenient time that the researcher could call back and interview the FM. This led to another 8 FMs providing follow-up data. Five FMs requested a hard copy by post, and two filled in the questionnaire as an attachment to their returned email. Thus a response rate was obtained of 57.14%.

4.10.3 Site use of statistics

Website usage statistics were also recorded. The data showed that 11 (78.6%) of the 14 people that went through the process of registration returned to make use of the 5-Step internet intervention modules. The interest was focused on the frequency and pattern of usage of the site along with the time that the individual spent on each of the modules of the programme. Table 4.2 shows the time (in minutes) spent by each of these 11 FMs on the different modules of the programme that they accessed.

Monitoring logins of these 11 FMs shows that 7 (50%) went on to view the 2nd module. The 3rd, 4th and 5th module was viewed by 4 (28.57%). The amount of time spent on each of these modules was also recorded. The average amount of time spent showed the most to be on first module on strain, followed by the third module which examines the different ways that family members respond.

Table 4.2 Duration of Relative's Problem and Time (minutes) spent by FM on each step of the web programme

S/N	Duration of problem	Module 1	Module 2	Module 3	Module 4	Module 5
1	3-5 yrs	11.50	1.28	3.30	3.19	2.58
2	3-5 yrs	36.55	0.28	-	-	-
3	6-9 yrs	35.20	5.49	-	-	-
4	>10yrs	6.13	-	-	-	1.44
5	>10yrs	17.24	3.30	5.07	7.51	9.58
6	>10yrs	11.28	1.21	-	-	-
7	>10yrs	13.26	0.10	0.04	9.03	3.33
8	>10yrs	11.21	-	-	-	-
9	>10yrs	0.37	-	-	-	-
10	>10yrs	11.51	-	-	-	-
11	>10yrs	19.44	6.09	4.07	1.06	-
	Mean	13.55	2.43	12.48	5.20	4.35

The pattern of usage of the programme was also examined. Family members were encouraged at the beginning to progress sequentially through the programme, starting at step one and working up. They were, however, not forced to do so and could in reality access the

steps in any order that they desired. All participants seem to have progressed sequentially through the programme as arranged on the site. Most of the FMs did this in one day and afterwards never returned to it. For one of the participants that went to Step Two, evidence shows that they did the first two steps in day one and then repeated this process when logging in 5 days later. A second participant seemed to constantly return to the different exercises in step one and two of the programme.

Three out of four of the participants that completed the programme did so in one day and did not return to it. Two, however, completed the programme in one day but returned again within the week to go over the programme proceeding sequentially but being slightly more selective with the pages viewed and spending less time on each of the viewed pages. The greatest frequency of participants returning to the programme was 3 days. This was by a FM that stopped at step two. FMs used 3 days to cover aspects of Step One and Step Two, appearing to go over these steps at each login. The login was separated by an initial period of 4 days then followed by 1 week.

4.10.4 Baseline scores on assessment measures

A total of 14 family members successfully registered for the pilot phase of the programme; all 14 FMs provided baseline data. Of the 14 family members, 10 (71.43%) granted follow-up interviews about their experience with the website. Three month follow-up measures were provided by 8 (57.14%) FMs.

Baseline scores obtained in this pilot were compared with baseline scores of FMs in other formats of this intervention (see Table 4.3). The baseline scores on the scales and subscales

of the three validated questionnaires fell within range of that obtained in other studies. The scores on coping with withdrawal were slightly higher than those of the other studies.

Table 4.3. Comparison of baseline scores of participants of internet programme and other formats

	Internet Program me Pilot (N=14)	Italy ^a (N=113)	Italy ^b (N=51/ 52)	SW ^c Engla nd (N=1 34)	Mexic o ^c (N=16 3)	Englan d ^d PCPI (N=27)	England e PCPII (N=136)	Engla nd ^g AWP (N=20)
Total Impact	32.2 (10.3)	24.9 (10.8)	NA	NA	NA	NA	NA	29.0
Worrying behaviour	21.1 (8.5)	16.6 (7.5)	NA	NA	NA	NA	NA	18.6
Active disturbance	11.1 (2.8)	8.3 (4.3)	NA	NA	NA	NA	NA	10.8
Total Coping	51.4 (15.0)	NA	43.1 (15.5)	NA	NA	NA	NA	53.1
Engaged coping	12.4 (5.8)	24.2 (9.7)	30.5 (6.9)	20.6 (9.7)	22.2 (9.7)	28.3 (7.8)	26.9 (7.9)	26.4
Tolerant coping	26.4 (10.4)	10.8 (5.5)	14.2 (5.2)	9.3 (5.7)	9.5 (5.5)	13.5 (5.6)	14.6 (5.5)	14.0
Withdrawal coping	13.1 (5.4)	8.6 (4.5)	7.4 (3.39)	10.9 (5.3)	9.2 (5.6)	10.9 (4.9)	7.0 (4.0)	11.8
Total symptoms	30.0 (10.8)	26.2 (12.3)	32.9 (9.9)	27.5 (11.2)	25.0 (13.0)	31.2 (10.8)	33.7 (12.1)	28.9
Psychologica l Symptoms	20.5 (7.0)	16.9 (7.8)	20.8 (5.9)	18.0 (7.3)	15.6 (8.4%)	20.2 (7.8)	21.66 (7.8)	18.9
Physical Symptoms	9.5 (1.4)	9.4 (5.3)	12.1 (4.9)	9.5 (4.6)	9.4 (5.5)	11.0 (4.7)	12.06 (5.3)	9.9

Mean (SD) Note : NA= Not available ; ^aArcidiacono et al. (2009) ^bVelleman et al. (2008b); ^cOrford et al. (2001, 2005b);

^dCopello et al. (2000); ^eCopello et al. (2009); ^fTempleton et al. (2007).

To explore any potential differences, it was also possible to compare follow-up completers with non-completers. An independent t-test was used to compare baseline scores on the questionnaires (see Table 4.4). There was no significant difference between those that provided follow-up information and those that did not.

Table 4.4. Mean baseline scores of those who did and those who did not provide follow-up information (n=14).

	Non- Completers (n=6)	Completers (n=8)	t	df	Sig.
Total Impact	35.8 (6.3)	30.22 (11.7)	-.973	12	.350
Worrying behaviour	24.0 (4.5)	19.56 (10.0)	-.932	12	.369
Active disturbance	11.8 (1.9)	10.67 (3.3)	-.701	12	.497
Total coping	54.6 (11.0)	49.67 (17.2)	-.574	12	.577
Engaged coping	26.4 (8.9)	26.44 (11.7)	.007	12	.994

Changes in scores between baseline and follow-up were also examined using a paired t-test with an intent-to-treat analysis. In this instance those who did not provide post intervention scores were given the same score as they had at baseline and analysis carried out. As seen in Table 4.5, there were changes in the scores between baseline and follow up. There was a slight reduction in all measures except for withdrawal coping where there was an increase. Significant differences were found in the pre-post intervention scores on the total coping score $t=1.729$, $df=13$, $p<.05$), and the engaged coping subscale ($t=2.371$, $df=13$, $p<.02$).

Table 4.5. Pre and post intervention scores (Mean and Standard Deviations) for participating family members (n=14)

	Baseline	Follow-up	t	df	Sig. (1-
	Mean (SD)	Mean (SD)			tailed)
Total Impact	32.2(10.3)	32.2(10.5)	.000	13	.50
Worrying behaviour	21.1(8.5)	21.0(8.4)	.158	13	.44
Active disturbance	11.1(2.8)	11.2(3.5)	-.221	13	.41
Total Coping	51.4(15.0)	45.8(16.3)	1.729	13	.05
Withdrawal coping	12.4(5.8)	13.2(4.5)	-.565	13	.29
Engaged coping	26.4(10.4)	22.6(10.5)	2.371	13	.02
Tolerant coping	13.1(5.4)	11.5(5.9)	1.242	13	.12
Total symptoms	30.0(10.8)	27.5(12.7)	1.146	13	.14
Psychological Symptoms	20.5(7.0)	18.4(9.3)	1.363	13	.10
Physical Symptoms	9.5(1.4)	9.1(4.9)	.345	13	.37

4.11 Results of Qualitative Analysis

This section presents the findings of the qualitative analyses of the interview of family members of alcohol or drug misusing relatives. The data presented in this section refers to their evaluation or assessment of the web-based programme. The responses are discussed under five main categories that emerged from the analysis of their responses. These include:

- Ease & usability of site
- Site content
- General opinion and feeling about the web-based programme
- Site impact
- Desired changes or additions to the programme

4.11.1 Ease and usability of site

Many of the family members that provided qualitative information variously state that the programme was not difficult to use. As one family member stated: "I felt it was pretty straightforward to follow". or, as stated by another "it is straightforward to complete, easy to follow". Another said, "It makes it that one...could move easily from one session to another without difficulty". Even in situations where the family member thought of himself as not being confident in surfing the web and not too computer literate, the member reported that the programme was not difficult to follow. In his words: "It was initially awkward but found the steps easy to pick up once you get the hang of it".

A few family members, however, did report difficulties with the login registration and venue that they used to access the programme. They also reported being logged out when the programme was left unattended for a period of time. These two main problems of

registration and the venue which some used to log in to the programme are discussed later in this chapter.

4.11.2 Venue of login

There are three different venues that FMs mentioned that they used to log in to the programme; these included their home, library, and workplace. There were certain issues mentioned by FMs that were interesting. Two of the family members that used the programme at work stated that they tried using this programme during their lunch break. Both stated that this was difficult to do. For one it was the issue of having to share the break with going out for something to eat or stepping out to smoke a cigarette. For the other FM it was the constant movement of people in and out of the office during the break, some of whom she needed to attend to. Thus she found that the disruption of not being able to concentrate doing the programme and the fact when the programme is left unattended for a period it tends to log the person out to be a bit of a problem. She mentioned that the option of doing it at home would have meant that it would compete with other chores like cooking, cleaning up or attending to the children. She, however, never attempted doing at home as she did not want her other child to see what she was accessing or that she was using the programme. These competing interests may make using the programme difficult for some family members.

4.11.3 Site Content

In terms of the specific content of the web-page programme a family member stated that she “gained more information, the information presented was clear accessible and easy to sift through”. Some mentioned that the questions caused them to think more and feel as if

someone is supporting you and knows what you are going through. In the words of one family member, “It was quite helpful being able to put down what you were thinking in the exercise after getting on... it does not present you with a ‘yes’ and ‘no’ situation but asks you questions and requires you to think further than this which actually is quite revealing”.

“Good to think that there is not a set way of coping. But that the programme makes you look at what you are doing and if it is actually working for you”.

“It was good in the way it talks about dependency and the effects of the drugs in detail”.

The felt it was a resource that people could keep returning to for help which previously was not there: “With the ups and downs one has with the addict it is nice to have something that *one can go back to that is available and check with*”.

4.11.4 General opinion and feeling about the web-based programme

For most of the FMs that were interviewed the site was generally described in positive terms. They used various terms saying it is “very useful, interesting, definitely informative, having face validity with the great CBT issues in it, helpful”, and that the experience was “real good”. One family member described it as “*absolutely wonderful*”.

4.11.5 Site Impact

Several ways are mentioned in the interview by family members on how the site impacted them. For one family member “The site went into how you feel and really makes you open up, it is nice to let it all out”. Another family member summarizes the feeling that comes after using the site saying: “In using this site you get the feeling that you are not alone that someone understands what you are going through”. Yet another family member, describing the impact that the programme had on him, stated that “It was a therapeutic experience online *for me*”.

A more detailed description of its impact was given when a family member stated: “The programme helps challenge me to think about the specifics of what I think or feel about the issues. Providing answers to questions asked in the programme caused me to pause and think how I might feel or put into words. It is kind of difficult to put into words but it was *generally positive*”.

On another level it is not so much the specific impact it had or potential of impact that it can have, but that it does offer support that is available by just logging in to the internet to use at one’s convenience. This is more so as resources of this nature may not currently be available to family members. One family member elaborated on this by stating: “...just knowing that there *is something out there is helpful*”.

Some of the effects reported were quite unexpected as one of the family members who also drinks states that the programme helped keep her “*straight and narrow*”. The programme made her more aware of her actions and the potential effects around her own drinking. She felt that it was a programme that needs returning to, “*like having a bit more each time.*”

This family member stated that the programme made her more aware of the effects of her own drinking and her understanding and responding to her husband; she also reported that her husband over the period changed and is more positive, spending more time at home.

Though one family member mentioned its impact or effects as something that currently does not fit her needs, she still evaluates or talks positively about the programme. In her words the programme, “Never felt that it gave me actual practical support...at the moment it is not something that fits my needs, as I would prefer face to face contact and support.

Nevertheless, I do feel that the website is a clever and worthwhile innovation". We could conclude as stated by one of the family members that "Many things are now online and people search online for a lot of things and a way to provide help on the internet is the way forward....*Having it online (might be) is obviously the way to go*".

4.11.6 Desired changes and additions to the programme

Another category emerging from the analyses of the qualitative data was that of desired changes or additions that family members would like in the programme. Many liked the programme as it was and could not think of any way in which it would be changed or that they would like it changed. However, a few pointed out certain aspects of this programme that one could consider changing or including if it were to be further developed. One was the desire to lengthen the period that you would be kept logged in to the programme if you were to leave the keyboard untouched for a while.

Others hoped that there would be a way that it could offer more practical support to family members. In one case the family member stated that it just did not have the kind of support that she needed and did not think that it was something that she needed at this stage. She said, "I imagine that in future people would be able to liaise with others online that are in the same situation they are in and get questions answered. And this would make available so much *needed social support that is just not always available....*"

4.12 DISCUSSION

This pilot work (or study) set out to develop a site whereby selected FMs would commit to participating in the pilot and provide both baseline and post intervention responses on a set of standardized questionnaires, and qualitative feedback of their experience with internet delivery of the 5-Step Method. Results of the pilot are discussed below.

Analysis of the qualitative interviews show that many family members reported that the site was not difficult to use, and navigating through the various modules of the programme was easy. They also stated that the site presented a clear, easy to understand message. Almost all of them reported it as being very informative, interesting, and useful with some stating that it is a resource that they wish to return to. In the words of one of the FMs, "With the ups and downs one has with the addict it is nice to have something that one can go back to that is available and check with". This becomes more pertinent as one family member points out that sometimes resources and help are just not available for family members. "I think it to be a useful system. Though I did not have opportunity to use the system much but I imagine that in future people would be able to liaise with others online that are in the same situation they are in and get questions answered. And this would make available much needed social support that is just not always available with every door being closed on you wherever you go".

The design aimed to make for easy navigation; the results of the qualitative analysis in fact does point to the ease of navigation which FMs found with the site. Even in the case where the family member was not confident with his ability to navigate the web, he reported that "...the steps are easy to pick up once you get the hang of it". The programme, however, seems not to be "sticky", as a majority of the family members using it seem to log in once, going through the programme briefly, and after they log out, never seeming to be able to get back to the site to use it again. This, however, may reflect more the internet behaviour of individuals reported by Rozanski, Bollman & Lipman (2001) where individuals enter a website that is of interest, spend a brief time (an average ranging from 0.6 to 6.7 minutes) then proceed to another site and do not return to the first site. There may be a need for

further development of this site to design it in such a way that it will encourage people to return frequently. As new internet tools become available and technological advances continue, the site can become even more user friendly.

Overall it appears that family members did find delivery of the intervention on the internet acceptable. Many mentioned the programme to be useful and something that should be made more widely available. It has been seen to have validity and gives one the online therapeutic experience, many of which said that it leaves them with the feeling that someone understands their situation and the stress they experience.

Uptake and adherence to the internet intervention programme showed decline from the first module to the 3rd module where it then levelled off. People were able to use it at their own pace, some going through it in one day and others separating their experience over several days. It would appear from the data that FMs spent a lot of time on the first module. Those who then progressed to view the 3rd module seem to spend time in this module also. The first module looked more at the issue or experiences of FMs who have a relative who is misusing alcohol or drugs while the least amount of time was spent on the second module which provided information on alcohol and drugs. Module 3 looked more closely at family members' responses, challenging the family member to consider possible effects of previous responses while also thinking of alternative ways to respond. Only 27.27% of the FMs that used the site actually progressed through all 5 modules of the programme. This low utilization rate with internet interventions is not uncommon (Christensen et al., 2002; Farvolden et al., 2005; Verijden et al., 2006). Low utilization or completion rates, however, have been found to not affect outcome (Palermo et al., 2009; Stevens et al., 2008).

Baseline demographic information as well as pre-post intervention responses on a set of standardized questionnaires was obtained. The results point to FMs in the online version being reflective of FMs in other formats. As in the face-to-face and self help formats (Copello et al., 2009), a large percent of the participants were females, and the relative causing concern was most often male. These findings are expected as recruitment of participants in the online intervention was referred through their contact with HCPs - the same setting in which other studies had been conducted. These questionnaires were used in the previous researches evaluating the 5-Step Intervention. It was, therefore, possible to compare responses of participants in the internet delivery of this intervention with those of the face-to-face or self-help delivery. The results show that the FMs in this pilot study had similar scores in filling these questionnaires online as compared to the paper and pencil format in other studies (Ahuja, 2003; Orford et al., 2001, 2002, 2005; Krishnan & Orford, 2002; Copello et al., 2000, 2002). The similarity of the online version to the paper and pencil formats demonstrates that there is a close match between the two versions, and on the basis of this finding we would be in line to suggest that the online version of the questionnaire, broadly speaking, measure the same constructs. And it does demonstrate that the web-based version closely matches the paper and pencil version, having acceptable psychometric properties.

An intent-to-treat analysis using a paired t-test examined the changes in pre to post intervention measures. The changes that were observed were in the expected direction as predicted by the Stress Strain Coping Support Model (Orford et al., 1998, 2001, 2005). There were trends towards the reduction of symptoms and impact of alcohol and drugs as reported by the family member. The reduction in scores between baseline and 3-months post registration was evident in all scales with the exception of the withdrawal. Significant difference was, however, only seen in changes in the engaged coping subscale. Previous

research points to this kind of coping (engaged coping) as being unhealthy (Hurcom et al., 1999). These changes would suggest a positive impact of the intervention.

There were, however, a number of difficulties experienced in the pilot phase of the work. During follow-up of the FMs, the protocol was reviewed to address the non-response of FMs to email reminders asking them to return to the site to fill in their responses online. With the change in protocol they were now first requested by phone to talk of their experience in using the internet programme. During this interview they were then given the option of returning to the site and filling in the follow-up measures or having it sent as a file attachment to be filled and emailed back or to have a hard copy sent to them along with a pre-paid envelope in which to return their responses. A majority (66.67%) of the FMs preferred having the hard copy sent to them. This preference for hard copies lends credence to the findings of Sheehan and McMillan (1999) and Cook, Heath & Thompson's (2000) studies of internet surveys having lower response rates than other traditional survey methods. This is a point that may be of relevance to follow-up measures that are collected online after a period of initial engagement of participants in web-based researches. There is a need to understand some of the issues that may be involved in the collection of follow-up data on this platform.

The change in protocol for follow-up at this pilot phase had the effect of lengthening the period. Instead of the stipulated 3 month period the follow up period ranged from 4-6 months. Koski-James, Cunningham, Tolonen, & Bothas (2007) found in their work with alcohol and drug misusers that the effects observed at month 3 tended to disappear at the 6 and 12 month follow up period. Thus the non-significance of the results obtained for most of the measures in this pilot, may have been due more to a gradual reduction or disappearance of an effect after 3 months, than the non-existence of a significant difference.

Availability on the internet does not automatically equate to accessibility. This was brought out in the case of the worker who desired to access the intervention but could not as a result of intrusions in the office and not wanting to be noticed by other members of the family at home. There will be people who desire to use the intervention but whose life situation may make it difficult for them to do so. The internet may meet the needs of accessibility for many but may not be the convenient means for some.

Other shortcomings have, however, been pointed out in that it does not provide the face-to-face practical support that some are seeking. A future development of the site that takes this into consideration may have this as an add-on to the programme. This may actually address the problem of the “stickiness” of the site and would lead more people to log in and stay logged in for longer periods of time or log in more frequently than as was experienced in this phase of the study.

Despite these shortcomings, however, this pilot presents evidence of the acceptability of the delivery of an intervention for FMs using this medium. Its capabilities to be used in collecting baseline information is shown, as well as its potential for changes in the desired direction for FMs. The results of this pilot beg the question of wider availability, and it could be that, as stated by one family member. And though as stated by one of the family members in this pilot: *“Having this [support] online is obviously the way to go”*, there is a great need for research in identifying the various delivery options of the internet programme that lead to greater engagement and subsequent outcomes; and patterns of usage and demographic characteristic that would allow for FMs to derive optimum benefit from the use of this support programme.

CHAPTER 5

A TRIAL TESTING THE WEB-BASED 5-STEP INTERVENTION FOR FAMILY

MEMBERS

5.1 Introduction

In the previous chapter a pilot study was described. It examined the delivery in a trial or control setting where the FMs needed to first contact health care professionals (HCPs). Based on the HCP's assessment of the FM they would provide them with information and an access code that would enable them to access the web-based support programme. The aims of the pilot study included:

- The development of a web-based 5-Step programme

- Establishing the feasibility of delivery in this format to family members

- Pilot testing the procedures and measures used in further studies

- Obtaining views of family members through qualitative exploration.

Results obtained from the pilot point to the intervention being desired by FMs and easy to use as a standalone programme with little or no support. In this chapter FMs will be provided 'open access' to this intervention in a more traditional or 'real world setting' where they will be able to access the site without contact with HCP. This phase will help to understand the issue of this intervention's transportability from controlled clinical settings to community or non-traditional settings. It was thought that opening up the website such that it could be accessed without restrictions and evaluating its use would give greater insight into the acceptability and use of this medium to gain support, as well as into its effectiveness in providing support that FMs find useful.

5.2 Method

5.2.1 Sample

During this open access phase of the research, the earlier restriction placed on participants that required a registration code to gain access was removed. Thus individuals did not have to be in contact with any HCP to gain access to the programme. They did not have to be referred to the programme, it was more widely advertised through self-help groups and organizations across the UK which were thought to have contact with family members of alcohol or drug misusing relatives, and through a limited number of general practices. Where possible, web links to other web programmes were created, making it possible for people to reach the site via those routes. Although access to the site was now open, we were still interested to learn how the programme was used. This resulted in 1,488 hits on the site from 1,174 unique visits (first time visitors) to the site. Fig 5.1 gives details of the flow of FM through the internet intervention programme between March 2008 and September 2009.

5.2.2 Measures: Participants were required to provide anonymized information with regards to their situation. This included the age, gender, relationship of the family member to the problem drinker or drug user (wife, husband, mother, etc.), as well as the extent of the problem and length of time that the family member had been living with the problem. In addition to questions asking for demographic information, three validated questionnaires were used. These questionnaires were similar to those used in the previous studies evaluating the effectiveness of this intervention in other formats and had been tested in the pilot of the web format. The pilot of these questionnaires in the web format did show that it was sensitive and could pick up changes in FM. Evidence suggested its use to gather information for evaluation of the progress of the family member in the programme via the Family Member

Impact Scale (FMI), Coping Questionnaire (CQ) and Symptom Rating Test (SRT) (Orford, et al., 2005).

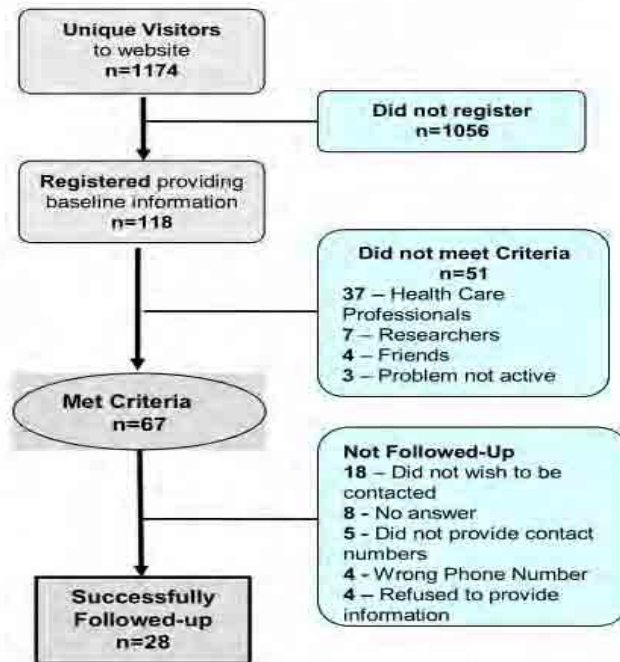


Figure 5.1 Flow chart of family members through the open access programme

All measures taken were completed and submitted online. The non-response to initial email reminders by FMs in the pilot study led to the consideration for FMs at month 3 to be reminded by phone and to request for them to talk about their experience in using the internet intervention programme. FMs were encouraged to give answers to two of the standardized questionnaires over the phone. Where the individual did not respond to email reminders to return to the site to provide these responses, the option of providing answers via a telephone interview was explored.

Other measures taken relate to the cumulative internet behaviour of all of the visitors to the site. Thus, information was obtained in regards to the following:

- Site hits by day, month, geographic area
- Pages visited
- Time spent on each page/module
- Search engines used by visitors to access the site.

5.2.3 Qualitative Semi Structured Interviews: Three months after the registration of family members during the restricted access phase, semi-structured interviews were conducted. These interviews were designed to take 15-20 minutes during which FMs reported their experience related to their use of the programme. Detailed notes of the main points that were quotations of family members which illustrated the points made. Where necessary, the interviewer probed using open-ended questions to clarify as well as to obtain examples where they were not provided spontaneously (detailed information of this method is described in Orford, Templeton, Velleman & Copello, 2010).

5.3 RESULTS

5.3.1 Overall Site Usage Statistics:

Measures were taken of the usage of the site by the family members. The interest was focused on seeing the frequency and pattern of usage of the site along with the time that a person spent on each of the pages/steps of the programme. These data were collected for all individuals who reached the site and all the pages that were visited, however brief and cursory the visits. Overall a total of 1488 visits were made to the website within a period of

18 months after going live; these were generated from 35 different countries with a majority coming from the UK. Of these 1,174 were made by first time visitors to the site. The total number of times pages were viewed reached 10,000. In terms of the source for the generated traffic, 41% came as direct traffic while 19% came as referrals from other sites and the remaining 40% from search engines.

5.3.2 Demographics of Registrants: Within the study period there were a total of 1,174 first time visitors to the site. 67 of these visitors registered to use the self-help programme; this represented a registration rate of 5.7% of those visiting the site for the first time. Data collected shows that of the 67 family members that registered to use the programme, a total of 48 (71.64%) actually visited and used the programme. The usage patterns of these family members are presented in Figure 5.3. Of those who did use the site, 37 (77.1%), viewed the programme through in one day and did not return to the programme before follow-up. The remaining few returned to the site on other days, most using it on two or three different occasions. In one instance there is a record of a FM logging in to use it on 9 different days.

Of those who visited the site a total of 67 family members moved beyond the initial introductory pages of the website, and registered to use the self-help programme. This required the family member to give consent, provide registration baseline information, and be allocated a user identification record on the database. The demographic information of participants in the open access phase is presented in Table 5.1 alongside those obtained in the trial or pilot as well as other formats of evaluation of this intervention.

Age and gender: The age range of FMs who registered to use the site was between 17 and 64 with a mean of 44.5 years. They were largely females with 57 (85.1%) female. And the relative that was causing concern was usually male - 58 (86.6%) were male.

Table 5.1. Demographics of participating family members on the internet programmes, face-to-face and self help manual

Characteristics	Web Based Programme Pilot (n=14)	Web Based Programme Open Access (n=67)	Face to face intervention ¹ (n=47- 51)	Self Help Manual ¹ (n=88- 82)
Male FMs	1 (7.1%)	10 (14.9%)	6 (11.8%)	14 (15.2%)
Female FMs	13 (92.9%)	57 (85.1%)	45 (88.2%)	78 (84.8%)
Male relatives	12 (85.7%)	58 (86.6%)	NA	NA
Female relatives	2 (14.3%)	9 (13.4%)	NA	NA
Age of FM	44.93(SD 13.97)	44.54 (SD 10.21)	44.2 (SD14.4)	45.1 (SD 12.9)
Age of User	36.21(SD 11.21)	39.93(13.32)	37.1 (SD 15.2)	35.82 (SD=12.9)
Relationship of User to FM				
Parent (Father/Mother)	2 (14.3%)	4 (6%)	3 (5.9%)	5 (6.6%)
Spouse/ Partner	5 (35.7%)	33 (49.3%)	22(43.1%)	38 (41.3%)
Sibling	2 (14.3%)	6 (9.0%)	-	-
Child	5 (35.7%)	19 (28.4%)	18 (35.3%)	33 (35.96)
Other	-	5 (7.5%)	3 (6%)	6 (5.5%)
Main Substance of misuse				
Alcohol	5 (35.7%)	42 (62.7%)	29 (56.9%)	55 (59.8%)
Drugs	6 (42.9%)	12 (17.9%)	21 (41.2%)	30 (32.6%)
Alcohol and Drugs	3 (21.4%)	13 (19.4%)	1 (1.9%)	6 (6.5%)
Other	-	-	-	1 (1.1%)
Living with relative		37 (54.3%)	38(76%)	65 (71%)
Duration of the problem				
1-6 months	-	1 (1.5%)		
7 11 months	-	2 (3.0%)		
1-2 years	-	6 (9.0%)	X=8.7	X=8.9 (SD 7.3)
3-5 years	3 (21.4%)	16 (23.9%)	(SD 7.7)	
6-9years	1 (7.1%)	9 (13.4%)		
>10 years	10 (71.4%)	33 (49.3%)		
Occupation of FM				
Full time employment	5 (35.7%)	39 (56.7%)	19 (38.8%)	45 (50%)
Part time employment	1 (7.1%)	11 (16.4%)		
Looking after Home	1 (7.1%)	3 (4.5%)	22 (44.9%)	28 (31.1%)
Retired	1 (7.1%)	6 (9.0%)	-	-
Student	4 (28.6%)	2 (3.0%)	-	-
Permanently sick or disabled	1 (7.1%)	6 (9.0%)	-	-
Other	-	1 (1.5%)	8(16.3%)	17 (18.9%)

Occupation: As shown in Table 5.1, a little over half of the registrants were in full time employment (56.7%), followed by those in part-time employment (16.4%), with smaller numbers in other categories.

Relationship to the Relative: Table 5.1 shows the relationship of family members to their drinking or drug misusing relatives. The most frequent relationships were those where the misusing relative was a spouse or partner (half the sample) or an offspring (just over a quarter).

Alcohol or drugs or both: As table 5.1 shows, the majority (62.7%) indicated that they were concerned about their relative's drinking, a further 19.4% were concerned about drinking in combination with drug misuse. Slightly less than one in five stated that the problem was drugs alone.

Duration of problem: Table 5.1 shows a breakdown of responses of family members to the question, "How long do you feel that your relative has had problems with drugs and/or alcohol?". Nearly half reported that the problem had been in existence for 10 years or more and a further third for three to ten years.

Housing situation: Family members were asked how long they had been living with their relatives (4 response options), or, if they were not living in the same household, how frequently they were in contact with the relative (4 options). Table 5.1 shows that 54.3% of

family members indicated living in the same household with the user. Of the 25 who did not live with family members (information not available in 5 cases) they were required to state how often they were in contact with family members. Results show that 12 (48%) indicated seeing the alcohol or drug misusing relative at least once or more a week, while a further 8 (32%) reported seeing their relative 1-3 times a month. Others were less frequently in contact with family members.

Table 5.2. Source of Information about Website

SOURCE	n
Friend	3 (4.5)
Web search	34 (50.7)
Health care professional	9 (13.4)
Leaflet or pamphlet	1 (1.5)
Work colleague	1 (1.5)
Counsellor	5 (7.5)
Newsletter or magazine	3 (4.5)
Conference	1 (1.5)
Other	9 (14.9)

5.3.3 How they came to know about the site: Family members were also asked to indicate the source of their information about the website. The results are summarised in Table 5.2 although the largest number found the site through their own web searches, sources were very varied.

5.3.4 Utilization of the Web Programme: Results obtained also show a drop in the number of modules viewed by FMs as they progressed from the first to the last module. Of the 48 FMs who actually used the programme, 26 (54.2%) went beyond the second module, 20 (41.6%) reached the fourth and 19 (39.6%) viewed pages of the fifth module. The average amount of time spent by participants on each of these modules is shown in the graph below (Figure 5.3). FMs spent an average of 19 minutes and 19 seconds on the first module which dropped to levels of 2 to 8 minutes for the remaining stages.

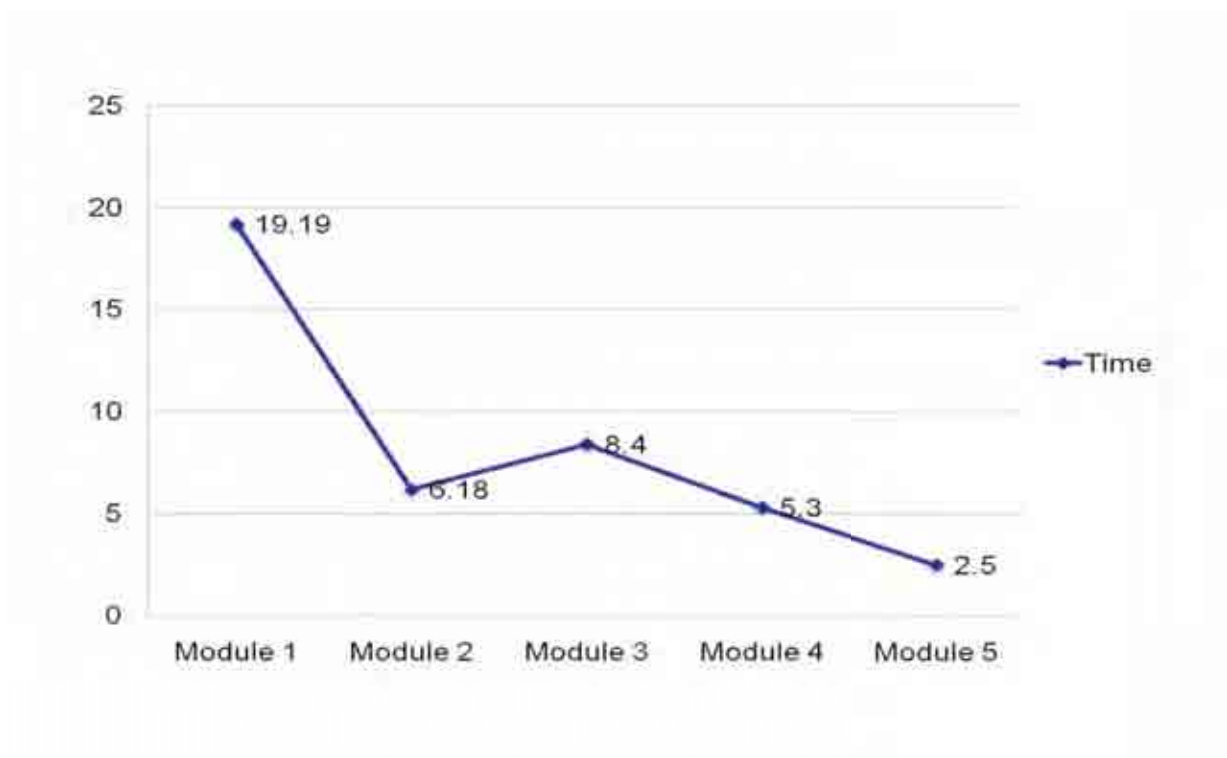


Figure 5.2 Average Amount of Time Spent by Family Members on each Module of Web Programme

5.3.5 Baseline Measures: Responses to the three validated questionnaires - Family Impact Inventory, Coping Questionnaire, and Symptom Rating Test - are presented in Table 5.3. These measures were again compared with results in other formats. The table shows scores obtained in the pilot are similar to the scores for the open access.

Table 5.3. Comparison of Baseline Scores of FMs in the Web-Based Intervention with Samples from Other Formats

	WWW Internet Access (n=67)	Italy ^a (N=113)	Italy ^b (N=51/52)	SW ^c England (N=134)	Mexico ^c (N=163)	England ^d PCPI (N=27)	England ^e PCPII (N=136)	England ^g AWP (N=20)	
Total Impact	32.0 (8.9)	24.9 (10.8)	NA	NA	NA	NA	NA	29.0 (??)	
Worrying Behaviour	20.9 (6.2)	16.6 (7.5)	NA	NA	NA	NA	NA	18.6 (5.4)	
Active Disturbance	11.1 (3.8)	8.3 (4.3)	NA	NA	NA	NA	NA	10.8 (4.4)	^a Arcidiac
Total Coping	48 (14.7)	NA	43.1 (15.5)	NA	NA	NA	NA	53.1 (15.7)	ono et al. (2009);
Engaged Coping	23.0 (9.6)	24.2 (9.7)	30.5 (6.9)	20.6 (9.7)	22.2 (9.7)	28.3 (7.8)	26.9 (7.9)	26.4 (8.2)	^b Velleman et al. (2008);
Tolerant Coping	13.2 (5.2)	10.8 (5.5)	14.2 (5.2)	9.3 (5.7)	9.5 (5.5)	13.5 (5.6)	14.6 (5.5)	14.0 (5.5)	^c Orford et al. (2001, 2005b);
Withdrawal Coping	12.6 (4.5)	8.6 (4.5)	7.4 (3.39)	10.9 (5.3)	9.2 (5.6)	10.9 (4.9)	7.0 (4.0)	11.8 (5.0)	^d Copello et al. (2000);
Total Symptoms	29.7 (11.8)	26.2 (12.3)	32.9 (9.9)	27.5 (11.2)	25.01 (13.0)	31.2 (10.8)	33.7 (12.1)	28.9 (10.6)	
Psychological Symptoms	20 (7.8)	16.9 (7.8)	20.8 (5.9)	18.0 (7.3)	15.6 (8.4)	20.2 (7.8)	21.7 (7.8)	18.9 (6.2)	

^eCopello et al. (2009); ^fTempleton et al. (2007).

5.3.6 Comparison of Completers and Non-Completers: Baseline scores on

assessment measures for completers of the follow-up measures were compared with those of non-completers using an independent t-test (see Table 5.4 below). FMs that completed follow-up had similar baseline scores on the three scales to non-completers.

Table 5.4 Mean Baseline Scores of Those Who Did and Those Who Did Not Provide Follow-Up Information

	Completers (N=28)	Non-Completers (N=39)	t	df	Sig
Total Impact	31.75 (9.61)	32.17 (8.53)	-.193	65	.43
Worrying Behaviour	21.00 (6.61)	20.76 (6)	-.189	65	.44
Active Disturbance	10.75 (4.05)	11.41 (3.63)	.149	65	.24
Total Coping	46.61 (14.67)	48.97 (14.91)	.146	65	.26
Engaged Coping	22.21 (9.70)	23.51 (9.53)	-.700	65	.29
Tolerant Coping	12.96 (5.73)	13.36 (4.89)	-.687	65	.38
Withdrawal Coping	12.00 (4.84)	13.10 (4.22)	-.645	65	.26
Total Symptoms	29.21 (12.72)	30.03 (11.18)	-.647	65	.36
Psychological Symptoms	20.43 (8.24)	19.67 (7.49)	-.546	65	.35
Physical Symptoms	8.79 (5.36)	10.3590	-.544	65	.10

5.3.7 Pre- and Post-Test Measures: After a 3-month post-registration on the site, FMs were sent email reminders encouraging them to return to the site and fill in the questionnaires. None of the family members responded to the first email reminder. Three responded to the third reminder sent. The rest responded to telephone calls requesting them to fill in the questions. Two additional FMs agreed to do this online while the rest had the questions read out to them over the phone for them to provide answers.

Changes in scores between baseline and follow-up were also examined using a paired t-test with analysis. As completers were not significantly different from non-completers in the baseline measures, only those who had provided follow-up measures were used in this analysis. As seen in Table 5.5, there were changes in the scores between baseline and follow-up.

Table 5.5 Pre- and Post-Intervention Scores for Participating Family Members

MEASURES	Baseline		Follow-up		t	Sig.
	n	Mean (SD)	Mean (SD)			
Total Impact	28	31.8 (9.6)	28.7 (11.4)	2.06	27	.03 *
Worrying Behaviour	28	21.0 (6.6)	18.1 (8.2)	2.27	27	.02*
Active Disturbance	28	10.8 (4.1)	10.5 (4.2)	.48	27	.32
Total Symptoms	24	29.1 (13.3)	24.8 (14.7)	1.75	23	.05*
Psychological Symptoms	24	20.1 (8.7)	17.4 (10.1)	1.66	23	.06
Physical Symptoms	24	9.0 (5.6)	7.4 (5.2)	1.88	23	.04*

*p<.05

Initial levels of impact measured by the Family Impact scale show a significant reduction from baseline to follow-up. Other significant changes between baseline and 3-month post-registration were observed in the Worrying Behaviour subscale of the FMI, scores on the Symptom Rating Test (SRT), and the Physical Symptoms subscale of the SRT. Scores on the Psychological Symptoms subscale changed in the desired direction but failed to reach significance ($t=1.66$, $df=23$, $p<.06$). Table 5.5 above provides full details of these findings.

5.4 Patterns and Process of Help-Seeking by Family Members

Qualitative semi-structured interviews were conducted by telephone with family members who indicated that they could be contacted to provide feedback of their experience with the web-based support programme. Of the 67 FMs registered on the site, 18 (26.9%) did not consent to be interviewed, and therefore did not leave telephone numbers through which they could be contacted and did not respond to any of the email reminders to return to the site to provide follow-up information.

Twenty-six of the 49 FM provided qualitative data regarding their experience in using the web-based programme. Elements of the grounded theory approach were adopted in analyzing the feedback provided by family members. As suggested by Willig (2006), line by line coding was used. The aim was to arrive at a greater understanding of the FMs' reported experience in using the web-based support programme. There was no attempt at this stage to generate a model.

Major themes emerging from qualitative analysis of the data included:

- 1) Mitigating circumstances that led family members in search of help and their expectations
- 2) Structure and ease of use of web programme
- 3) 3) Usefulness of the site.

Each of these categories is examined in greater detail in the next section.

5.4.1 Mitigating Circumstances and Expectations: Various FMs, in giving feedback

of their experience in using the web-based support programme, talked about how they were introduced to or found out about the programme. Some were referred by HCPs, most however came to the site via searching the internet. They relayed crisis situations that led them to actively seek help. One family member narrates the realization of the relative's alcohol use as “navigating in a strange land, where you do not know anything, no idea of how to access help as a family member, no knowledge of existing structures, interagency relationships, privacy issues”. She described herself as being “in peculiar situation grabbing at all straws” (FM 6). Often this realization of the problematic use of alcohol or drugs of a relative triggers a FM's desperate search for help. One female narrates coming down in the morning to take the child to school, only to find her husband and his friend on the floor, drunk. In her own words “At that point I needed help on how to cope with this situation”. She had described herself as “...emotionally distraught and was not sure what I wanted. Probably what I was looking for was an easy solution to my problems”.

Others have described a variety of crises situations that triggered their own search for help. As one FM states; “the problem that was so acute and unbearable that I found myself crawling the web for any kind of support” (FM 17). A few mentioned being introduced to this website as convenient, given their inability to attend Al-Anon and desiring support via email. Or, as in one case, a FM felt this was the support that would best suit his need, “as I am severely disabled, (being bedridden) it seemed just the right thing as I could access the support from my laptop while I was in bed” (FM 2).

For many FMs faced with these circumstances, when they are introduced to, or come in contact with the web-based programme, they usually have high expectations and hopes. Several expectations that they have reported include: “Information on how to change the drinker” (FM 22), “Help in getting the relatives into treatment” (FM 6), “Ongoing support” (FM 5), “Advice on how other people in my circumstance were or would cope...forum to give and receive advice” (FM 14), “Getting involved with a group online” (FM 2), “Ability to network with others” (FM18), as well as being able to “ask-the-expert” questions” (FM 20).

5.4.2 Structure and Ease of Use of Web-Programme: The family members interviewed used various terms when describing their experience of the content and structure of the site. Many of these family members reported the programme as being

“well laid out” and “easy to use”. One family member summarizes and encapsulates this by stating that: “I like the way it was structured according to different steps that you could approach sequentially” (FM 12). Yet another FM compares it with other websites, in her words: “The web programme was easy enough to use, not at all complicated like some other sites; it is something that could easily be put to use by young people”. Though seen as easy to use with an understandable structure, it was mentioned as not being engaging enough by one of the family members he felt that the contents and the functions in the site were not ones that would keep him returning to the site.

5.4.3 Usefulness of the Site: This family member that did not find the site engaging was one of the two that also did not find the web programme useful. According to this family member: “The programme sounded good and I thought I would be getting involved with a group online. But from the beginning you get the impression that it is something that you get online and then return to it again after 6 months”. He was expecting to have access through the site to online forums for family members in similar situations. In the absence of this facility, family members’ expectations were not met, leading to the feeling of getting on the site and answering questions, to return a few months later. The second family member reported the website not being helpful in her current circumstances. She said she was in a crisis situation which led her to search the internet in the hope of finding help. In her words: “It did not seem to meet my needs at that time. I was emotionally distraught and was not sure what I wanted. Probably what I was looking for was an easy solution to my problems”. She mentioned that he had since accepted that he was drinking too much and had stopped drinking. She felt that if it was now she was to visit the site that she probably would have ended up feeling differently about it.

Other FMs who provided feedback reported that the web programme was helpful. For some it validated their own experience of living with or being concerned for a family member who is drinking, as well as the simple fact that such a support facility was being made available. As one family member puts it: “My concern for my Dad had led to my having a relapse of my depression and anxiety and a breakdown. I was in search of CBT for myself. This site was in that sense helpful because of the CBT nature. What was helpful for me is the fact that there was something out there that was *available for one to consult*”. (FM 22)

This is stated slightly differently by another FM: “I feel like I was validated and that the feelings I had were not strange but that other people in situations like mine went through similar things. It was nice to have a website that was not solely for the user. Of all the sites I had visited before this was based on the user and what can be done for them, there was none for the FM. So it was nice to have a site that was for me and *not the user*”. (FM 10).

Another family member described it in terms of not conflicting with experiences from other sources: “I found the site very useful. The stuff I had done on the website fitted in well with feelings I was going through or having and what I had found out from other *sources, so this was comforting as there was no conflict*.” (FM 6).

For still another FM, the usefulness derived from using the web-based programme was in terms of its functionality: “I like it as self-help as it allows you to work with it at your

own pace and in your own home if you like". From her experience with Al-Anon groups, as well as individual consultations, she found that "people sometimes cannot get to these group sessions and being able to refer them to this site where they can get support is a great tool" (FM 12). Another family member stated that: "I sometimes dread going home - especially the weekends - and it would be beneficial to just be able to tell someone how I feel even if only electronically. As far as I am aware there is no organization that will do that" (FM 5).

WSome other FMs discussed the usefulness of the web-based programme making reference to certain aspects of the site to illustrate their point. A few family members pointed to the baseline questions asked as being very helpful. According to one FM, she entered the site and filled in the questionnaires, and did not go any further in the programme than this. In her words: "I found this rather helpful rather than having to go for the meeting". She further elaborated on what effects the questionnaires had on her: "It helped me look at things and the way that it could be affecting me and the rest of the family in more detail. It made me feel more knowledgeable in its pointing out how the family has been affected in the process of coping with my daughter's drinking without our having really been conscious of it" (FM 13). For another FM, the experience of using the programme was described as "cathartic". She said that "going through the questions confirmed for me that I was not going mad and that what I was *experiencing was not unusual*" (FM 4).

For the remaining FMs the usefulness mentioned was in relation to the programme content itself. The specific tips given in the website were mentioned by another as being useful: "It provided useful tips in regards to coping I found quite useful. It was the practical things people in that situation should do that I found useful" (FM 9).

Another family member relates as a common experience not being able to get help from her GP; and the site helped her to be able to make decisions which seemed to her healthy. In her words: "It was good to know that what you were feeling was common to many people in a similar situation and that in all this time I was not able to get help from GP. My blood pressure went up and I experienced a lot of stress and anxiety which was related to the drinking of my partner". She also stated that the programme helped her in coming to a decision about the relationship, as she states: "The web support programme was helpful in getting me to move on. I could never get him into treatment as he did not want to stop. I recognised that I can't *help him*" (FM 1).

Still talking about the feelings that were generated by the web-based programme, another family member stated that this was of great help for her, that is: "One of the positive impacts was that it helped me to recognise what I was feeling about having to look after someone that was having a drinking problem and I think this would be quite useful in the initial phases for someone in this situation. It would help them examine their own feelings and how they are really feeling about this...Some people do not want to go to a meeting where they could meet people they recognise or where they may have to talk about things that they would rather not talk about in a group situation: this would be the right programme *for them*" (FM 3).

In the words of one FM: "The programme for me was helpful. It raised awareness that it was affecting us. It was a realization that was not quite there. It was like get out and

let it go.” Additionally, “it also allowed me to see that there are some of the things that we were doing that may seem good but that was not *the right thing*” (FM 18).

This aspect of the web programme: “*Helping one to look at one’s reactions and how it may negatively be contributing to the situation*” was highlighted in the response of another family member who stated: “What I liked about it is that the site did not apportion blame to any of the parties, rather it looked at the issue, bringing out the emotional aspects of living with someone with a problem which the others (websites) did not”. Furthermore: “It helped me to look at how I reacted to my partner and how that reaction may actually have been making him drink more. It set me thinking and looking at the different ways that I was responding to him. It was particularly helpful getting me to temper my reaction and to look to see where I was making it worse. This site served as something I could turn to during difficult times” (FM11). Her concluding remark was: “I found the website very helpful, far more helpful than what I have *found anywhere else*” (FM 11).

5.5 Discussion

Results of the pilot of this intervention showed that FMs found the 5-Step Internet Intervention easy to navigate, and useful. The intervention in this format showed it had the potential to bring about change in the desired direction. They suggested that it was a resource that should be made more widely available. This study was a follow on from the pilot to explore the transportability of the intervention from the controlled trial to a “real-life setting” This web-based programme was unique in that it focused on the family members rather than the alcohol or drug misusing relatives. Vernon, (2010) reviewed literature on computer based alcohol problem services that are designed for

the general public and all of the evaluated interventions solely for the alcohol or drug misusing relative. Whilst a few programmes do target family members and concerned others, these tend to be sites that provide information about alcohol or drugs or where to get help. The 5-Step internet intervention programme discussed in this chapter is the first manualized, evidence-based approach for supporting family members that has been developed in a web format. The main focus of this work was to explore its viability in using available internet technology to further disseminate this intervention.

Results obtained in the open access phase of the web-based programme showed that FMs who registered to use the programme were demographically similar in many ways to family members in the pilot phase, and by implication with FMs in the Copello et al. (2009) study of the face-to-face and self-help manual versions. A majority of those seeking support were females (85.1%) as compared to males (14.9%). These percentages were little different from the ones obtained by Copello, Templeton & Powell (2009) using face-to-face sessions or the self-help manual versions. Also, as in other formats, the concern of FMs in the web-based support programme was often about the alcohol or drug use of a male relative (Velleman et al., 2008). What was evident in the web-based programme were some siblings - 6 (9.0%) - of the alcohol or drug misusers; this group was absent in studies of this intervention in other formats. Here they were concerned for relatives' drinking and did log in to use this web-based programme. This may have been because siblings did not see themselves as being in a position to access help in the traditional service delivery settings. It is possible that they did not see themselves as primarily responsible for the drinking or drug using relative and therefore may have lacked opportunities or they may be too embarrassed to use these opportunities if they were available ((Low, Charanasomboon, Lesser, Reinhalter, Martin, Jones et al., 2003; Winzelberg, Classen, Alpers, Roberts, Koopman, Adams et

al., 2003; Zabinski, Celio, Wilfley & Taylor, 2003). The internet on the other hand presents a different format; as it is being used to seek for answers for a variety of issues (Murero, et al., 2001), using this medium to search for an understanding of the alcohol or drug misuse of a sibling would not be out of place.

The percentage of FMs who reported living with the user was also slightly smaller than in the face-to-face and self-help versions (Copello et al., 2009). Though approximately one-third of the FMs did not live with the alcohol or drug misusing relative, they were still very concerned and affected by these relatives. Of the FMs who did not live with them, over 60% were in contact with their relatives three or more times a month.

Family members who participated in the internet intervention programme also differed from those included in studies using other formats with regard to employment status. A larger percent of web-based programme users indicated being in some form of employment: 75.1% as compared to 39% and 50% in the face-to-face and self-help manual versions (Copello et al., 2009). This difference may be as a result of the logistics of planning or attending face-to-face sessions, which may make it more difficult for people in employment to participate. The increased number of those in gainful employment accessing the web-based programmes may also be reflective of economic forces, with those in employment either being able to access the internet in their work place or being able to purchase home computers with broadband services, giving them greater access to internet programmes. Being in gainful employment may thus simply indicate availability of financial resources (Pew, 2004). This suggestion seems to be supported by the fact that over half of the participants reported obtaining information about the web-based programme through using different internet search

engines. This is similar to the overall data looking at recorded website visits which showed that the site received an average of 78 new visitors for each of the months that it was made available. Half (50.7%) of these site hits were generated from the use of search engines or through links from other websites. Many of the FMs who registered indicated that the problem was one that they had been experiencing for ten or more years, implying that it is a problem for them which have not been adequately addressed. The fact that the searches of FMs arriving at the site originated from 35 different countries supports Barrera et al. (2009) and Christensen, Griffith & Jorns' (2004) findings which point to the limitless nature of internet programmes in their ability to reach across geographic divides and the potential impact that this can have in delivering support to FMs.

FMs who registered on the site during the open access phase also provided answers to questionnaires online. Their online baseline scores were compared with those obtained when these scales had been used in the paper and pencil format with family members in other studies (Arcidiacono, Velleman, Procentese, Albanesi, and Sommantico, 2009 ; Copello et al., 2000, 2009; Orford et al., 2001, 2005; Templeton et al., 2007; Velleman et al., 2008). The similarity of these web-based baseline data to those obtained in other formats suggests that the online version of the questionnaires works satisfactorily and that the problems faced by FMs who use the web format are similar to those included in other studies using more traditional formats. Only one difference stands out: a slightly higher baseline score for the web group on the withdrawal coping subscale, suggesting greater opportunities for these individuals to withdraw from the situation. It could be that this, with more FMs in this sample indicating they were working, reflects the availability of financial resources as well as outlets in which they could be involved in

things outside of the home and situation. Increased resources may include home assets (like computers and internet access) that may play a part in giving avenues or options for activities that could allow FMs to withdraw more than may be possible for others. This of course would need to be further investigated using larger numbers of FMs who turn to the internet seeking help.

When the data on web programme utilization was examined, it was noted that a significant minority, 19 (28.36%), did not return to the site after providing baseline information, and hence, did not view the content or make use of the support programme. The remaining 48 (71.64%) returned and made use of the programme, showing patterns of usage similar to those that have been reported in other studies of pilot study. The FMs seem to spend time on Step One then it drops sharply; they view the 2nd module briefly but spend a little more time on the 3rd module which focuses on the individual's coping responses. Many of them logged in and selectively viewed different pages of the programme over one day; a few of the FMs spread this over a two to three day period, or very occasionally longer. In total, 19 (38.78%) of those who registered proceeded through to the fifth module of the web programme. Again, this is somewhat similar to the findings of others using web programmes for other problems (Pretorius, Arcelus, Beecham, Dawson, Doherty, Eisler et al., 2009; Christensen, Griffiths, Korten, et al., 2004). Eysenbach (2005) has argued for a 'science of attrition' that could lead to a better understanding of this process within internet based research and intervention programmes. But it must be kept in mind, as Christensen, Griffiths & Farrer (2009) point out in their review, that the adherence rates that are observed in internet interventions are not much different from those in some face-to-face interventions, where as many as 70 percent of the patients terminate therapy by the fourth session.

Changes in scores between baseline and the 3-month follow-up showed that individuals who registered for the programme and used it improved, both in terms of the reduction of the impact that the alcohol and/or drug use of a relative was having on them and probably on the rest of the family. The reduction was significant for Total Impact scores and scores on the “Worrying Behaviour” subscale of the Family Impact Inventory (FMI). Significant changes were also observed with the measures of the Symptom Rating test. There were significant reductions between pre- and post-intervention measures of the Total Symptoms, as well as the Physical Symptoms, subscale. Though the score on the Psychological Symptoms subscale reduced between the two time periods, it failed to reach significance ($t=1.66$, $df=23$, $p<.06$).

Notably, the pattern of usage showed that quite a number of people filled the questionnaire and did not return to the site to use the programme, and that of those who did return to the site, a majority did not finish the programme. It may be that some of these individuals dropped off after taking the first “dose” and seeing notable improvements no longer felt they needed to continue with the web-based programme. Results of the qualitative analysis of the feedback from family members points to this possibility. As one family member stated, she did not return to the programme after filling in the questionnaire, but that in filling the questionnaire she found it “rather helpful, rather than having to attend any (Al-Anon) meeting”. As the availability of support of this nature for family members appears limited, where some report “not getting help from their GP”, any support that the family member then receives is seen in the context of its scarcity and is greatly appreciated. As one family member put it, “What was helpful, was knowing that there is something out there that was available *for*

one to consult". As mentioned by one of the family members, this, of all the sites visited, was the only one meant for the family member. She talks of it as being "nice to have *a site that was for me and not the user.*"

In various ways, the FMs speak of the web-based programme as one that validated their experience. It let them know that their situation was not unusual and that other people, who were in a similar situation, were having these same experiences with the alcohol and drug misuse of their relative. For those that went into doing the exercises, it helped them to look at their own behaviour and how it may have been negatively contributing to the situation and the changes that they needed to make.

In this open access phase, the family members reported searching for help particularly as a result of a crisis; they often began the search somewhat desperate for answers. This, itself, is usually triggered by some event . This is in line with the current trends in internet usage; where people pose questions for others to answer, they seem to have the expectation that there would be such facilities, forums or ask-the-expert functions in the programme that would aid them resolve the crises for which they have found themselves in (Sillence, Briggs, Harris & Fishwick, 2007). Arriving at the site without these functions would have led, as one family member commented, to the site being seen as non-engaging or not interactive enough and, therefore, the user does not see themselves returning to the site frequently to use it. As this web programme is not currently set to run with these functions, it may be worth considering including them in future developments of the site. This may greatly affect the usage patterns, with more people going through more modules of the programme. With potentially greater exposure, there is the hope to achieve results with a greater level of significance.

5.6 Limitations

In the present study we chose not to use intensive recruitment strategies such as direct emailing, target communication, radio, newspaper or TV adverts as we wanted to mimic the real-life implementation as much as possible. Nevertheless, the low response and participation rate may have reduced the external validity of our results and should be taken into account when considering larger scale implementation.

In addition, we were faced with the difficulty that recruiting FMs for internet based programmes can pose. Providing an evidence-based intervention online for easy access to those in need does not necessarily translate to large numbers of people using the programme. There is a need for a greater understanding of the factors related to recruitment and usage of internet intervention programmes by family members of alcohol and drug misusers. Some of these factors may be related more to the individual and others may be programme issues.

Additionally, because the participation of FMs was voluntary, there is the issue of self-selection. It is possible that the family members who participated in this web-based support programme were those who are highly self-motivated, actively seeking for support, and therefore may benefit more than FMs who are not so motivated. The findings of a positive effect of the web-based programme should thus be generalized with caution as it may in reality only be reflective of FMs who are highly motivated,

rather than the general population of FMs who are affected by a relative's alcohol or drug misuse.

There was a low response rate of family members to the request to return to the site to provide post intervention measures. Most of them ended up providing answers to the questions over the telephone. Thus, all the baseline questions were administered electronically while most of the follow-up questionnaires were collected over the phone. Though these responses have been taken to lead to similar results, differences in responding to questions via these channels have been noted by other researchers (Buchanan, 2002; Emmelkamp, 2005). Using telephone interviews also raises the question of whether these responses were more differentially affected by socially desirable responses which may have led to significant results observed. Because the telephone was then used in the follow-up of family members, those who did not provide telephone contact details were lost in the follow-up and those who provided wrong numbers, or who may have moved house or job, were no longer reachable with the provided details. There is a need to consider ways in which to commit FMs to the programme in order to ensure a higher response rate, either in terms of incorporating features that would encourage them to return more frequently to the site than had been seen in this research programme, to incorporate the provision of this information where the web programme is used as an adjunct to other treatment programmes (Yager, 2001, 2003), or to have a professional collect both or at least the post intervention responses to questionnaires.

Another limitation is that these measures are taken across a time span and we do know that the cycle of alcohol and drug misuse within the family tends to fluctuate, becoming

more intense at one time as opposed to another. It may be that the obtained data reflects the fluctuation and not the effects of the use of the internet intervention programme.

5.7 Conclusion

This research into providing internet delivered intervention for FMs brought up certain issues. For one, an obvious yet often overlooked problem with internet-based services is that there may be periods over which the programme becomes unavailable, either because the programme is being upgraded or due to the server being 'down' (for example, when it is being worked on). At these times the programme becomes inaccessible to participants; though it is usually for brief periods, this could prove to be significant. In this instance, the period of time when the programme was unavailable was much longer, spanning approximately five months. Hence, although a key advantage in designing an intervention which would be accessible to family members via the web was its 24/7 unlimited accessibility, this in reality was not the case.

There is an additional need to investigate other ways in which the programme could be used to maximize the possible benefits that FMs can derive from the programme. For instance, one could investigate whether using this approach where the individual works through the web module and then adding brief consultation sessions with a health practitioner to discuss progress would give the added impetus needed to increase FM adherence to the programme. On the other hand, sessions with a practitioner could be arranged such that some were in a face-to-face format while others made use of the computer modules, or the computer could be located in a primary healthcare centre with times scheduled for the FM to use the programme. As stated by Tate and Zabinski (2004), this would increase the sense of accountability for FMs which could lead to an

increase in adherence and utilization. Whether such modifications would make for greater adherence to the project needs to be studied. Also whether regular reminders (email, phone, postal) would be welcomed by family members, and whether this improves adherence and the effectiveness of the programme needs to be the subject of future research.

In summary, this initial work provides important evidence of the viability and potential of using the internet to support family members of alcohol or drug misusing relatives. It points to the fact that family members on their own are seeking for some support for their situation, and that they are using the internet to try and access that support. There appears to be a general agreement among family members interviewed that this programme is useful and something that more family members should have access to. It has been seen to have face validity and gives one the online therapeutic experience which many have said leaves them with the feeling that someone understands their situation and what they are going through. With the advances in technology and internet-based tools, there are now opportunities to modify this web-based support programme, taking into consideration some of the suggestions from FMs. The site could be made to be more interactive and incorporate either forums or bulletin boards where FMs could pose queries that could be answered by other registered members or the administrator. There is a need to further investigate these various delivery options and how they would increase the retentive capabilities of the site, increasing the likelihood of FMs returning more frequently to the site than has been currently reported.

CHAPTER 6

FINAL DISCUSSION AND CONCLUSIONS

In the review of the theoretical understanding of addiction and the family, the models that exist focus on the family member as either pathological or disturbed in some way or, by systems of interacting with the user, is contributing to the alcohol and drug misuse. The Stress-Strain-Coping-Support Model stands apart in that it views the family members as experiencing stress that leads to the strain and as a result grappling with personal understanding of the situation and making efforts to cope with the situation. This perspective allows for an intervention that could focus solely on the needs of family members, whether or not the user is engaged in treatment; the 5-Step Intervention takes this perspective. Research evidence suggests that this intervention is effective for family members and can be delivered in a variety of settings, by a variety of Health Care Professionals (HCPs) or in a self-help format. This intervention however is not widely available. The programme of research that is reported in this dissertation looked at the experience of HCPs in working with family members, interviewing them after participation in an action research project. This was followed by a pilot of the internet intervention, lessons from which were carried forward in exploring the transportability of the intervention in a “real world setting”. This final chapter collectively considers the findings reported in the various studies documented in this dissertation. It summarizes the results and looks at the implications, suggesting future research in this area.

6.1 Summary of Results

The first study in chapter three looked at the adoption of the 5-Step Method by health care professionals (HCPs) in their provision of services for family members of alcohol or drug misusing relatives. After a six month period following their initial training, qualitative interview data of their experience of working with family members was obtained.

These HCPs were found to have different levels of skills, comfort, desire and prior experience of working with family members of alcohol or drug misusing relatives. For a majority of the HCPs, working with family members was a new experience. The few that mentioned having worked with family members prior to this reported that the project however provided them with a better understanding or grasp of the processes and concepts which they were using. A large majority of the HCPs who participated in this project, reported changes in the way they now work with their clients, as exposure to the 5-Step Method allowed them to be more willing to recruit and work with FMs. To get to this point HCPs appear to have passed through a phase of being apprehensive and lacking confidence to one of having confidence or feeling comfortable working with FMs.

This study provided insight into the barriers that may exist for professionals as well as what could be done to enhance the adoption of these and similar interventions. It appeared, for instance, that the format of training whole teams suggested by Whitefield and Williams (2003) allowed for building in organizational support of the nature that was evident in this work. It appears that this level of support is needed for changing and sustaining change in the adoption of evidenced-based interventions by HCPs. Where

this support is absent, and the barriers remain insurmountable, the need for investigating other channels through which interventions may be delivered becomes imperative (Macallair & Males, 2004). It must be noted however that in this study where the HCPs were trained in the delivery of services to family members, they often did this in the context of the relative's addictive behaviour, thus focusing largely on the user; the FM was not often seen as a client in their own right. Thus the needs of family members are still unaddressed. These findings call for alternative means through which this intervention might be made available to FMs.

The second study examined the feasibility of delivering this intervention in another format, namely a web-based format. This was a controlled delivery where potential FMs were directed or referred to the site through their contact with HCPs; this enabled testing of the ease of use of the system, its appeal and acceptability by FMs. Additionally it allowed for the examination of the data collection protocol and the sensitivity of the instrument on this platform. Quantitative results of the pre- and post-registration measures showed trends for change in the expected direction.

Qualitative analysis of the semi-structured feedback provided by family members three months post-registration showed that they found the website easy to use and follow, and that the contents were "very useful", "interesting", "informative" and had "face validity". It was reported that "it did not present you with yes or no answers but allowed you to think further in terms of what you are going through". Also, "it makes you look at ways in which you are coping and whether this way is working *for your situation*".

According to one of the family members, situations may arise in the course of living with a user that cause you to search for answers, and the web programme was thought to serve as resource that is readily available, which one could go back to check. Overall, there appears to be a general agreement among FMs that this programme is useful and should be accessible to more FMs. It has been seen to have face validity and gives one the online therapeutic experience, which many have said leaves them with the feeling that someone understands their situation and what they are going through.

Building on the lessons learnt from conducting the pilot, the third study expanded to test the transportability of the web-based 5-Step Intervention to a community and other non-traditional settings. During this open access phase, the initial restrictions in place during the controlled trial were removed. Family members could now access the programme without prior contact with any HCP. The site could thus be accessed by anyone in the general population who so desired. When family members accessed and used the programme, they provided baseline measures and were followed up three months post-registration. FMs also provided feedback in a telephone interview of their experience in using this web-based programme. Low uptake rate was observed, similar to previous studies of open access programmes (Koo & Skinner, 2005; Stein, et al., 2006).

Results obtained in this phase showed that a majority of those seeking support were females (85.1%) as compared to males (14.9%). These percentages were similar to those seen by Velleman et al (2008) in their work in Italy, and Copello et al. (2009) in their randomized control trial of the delivery of this intervention in the face-to-face and the self-help manual formats. Also, as in studies using other formats, the concern of

FMs was about a male relative's alcohol or drug misuse. The notable difference between delivery in this format and other formats was the presence of siblings; 6 (9%) of the users who had registered to use the programme. Additionally, there was a comparatively larger number of FMs that were in employment and participated in the web-based format in comparison to the Copello et al. (2009) study.

The rate of follow-up attrition was high; this was similar to some of the earlier reviewed web-based studies. Attrition was, however, higher in the later study of spontaneous public registrants as compared to the pilot study, (58.21% versus 35.71%). In the earlier (controlled) instance the rates of completion of follow-up falls within that reported in the evaluation of other web-based interventions (Cunningham, Humphreys, Kypri & van Mierlo, 2006; Etter, 2005; Rothert, et al., 2006). Similarly, public (spontaneous registrants) have been found to have higher rates of attrition than trial participants recruited by HCPs (Christensen, Griffiths, Korten, Brittliffe & Groves, et al., 2004).

Feedback from interviews with FMs points to participating in the web-based programme as being something that validated their experience. It let them know that their situation was not unusual and that other people who were in a similar situation were having these same experiences with the alcohol and drug misuse of their relative. For those FMs who proceeded to do some of the exercises, they reported that it helped them to look at their own behaviour and how it may have been negatively contributing to the situation and the changes that they need to make.

6.2 Implications

Several implications arise from this work. As pointed out by other researchers (Keeley Williams & Shapiro, 2002; Whitfield and Williams, 2004; Orford, et al., 2009, 2010), professional organizations are often slow in adopting new evidenced-based approaches. For HCPs in the first study, an analysis of the qualitative data provided suggested that at baseline HCPs did not feel they were adequately trained to work with family members and were not confident to do so. This is similar to Jacka et al.'s (1999) findings of lack of confidence causing HCPs not to engage or involve FMs in service delivery. In line with suggestions from previous research (Hagemaster, et al., 1993; Gomel, et al., 1998; Kaner et al., 1999; Anderson et al., 2004; Silins et al., 2007), we find that when they were provided with training they were willing to recruit and work with family members and made changes in their delivery of service in the desired direction (Orford et al., 2009). These changes seem possible however because the model of dissemination suggested by Simon et al. (2002) and Fixsen et al. (2005) was adopted where there was a bi-directional working together of researchers and HCPs to ensure fidelity in the delivery of the intervention within the existing organizational structure. Thus at one end is the evidence that transferring this intervention to real-life settings is feasible, but at the other is the realization that the positive results of transfer evident were possible because of the extent of the support and continued supervision made available to HCPs throughout this project. By implication the absence of organizational infrastructures that would encourage this method of working with FMs, as well as training and initial support for HCPs, would mean that the adoption of this intervention in service delivery will be slow. Consequently, more FMs will continue to be deprived of needed specialist help unless other channels are adopted for disseminating this intervention.

The underlying assumption for the use of the internet in the dissemination of this intervention is that this is a platform that FMs are already using to seek health related information and help (Mead et al., 2003; Pew, 2002; Rozmovitis & Ziebland, 2004) and support (Rotondi, Sinkule & Spring, 2005). It would thus have face validity and be readily accepted by FMs. This seems to be supported by the data pointing to the traffic generated by the site. Many of the FMs in this study point to mitigating circumstances as triggering their search for help and more than half do so through internet search engines. One of the mentioned expectations they had in coming to the site was that they would be reaching a forum or network of other FMs in similar situations where they could receive advice and support.

The rates of recruitment and uptake of this programme by family members and their commitment to the completion of suggested modules in this programme is similar to those for other internet interventions (Etter, 2005). This demonstrates that the availability of an evidence-based approach does not equate to full-scale adoption or utilization by those who may be in need. A small percentage (5.7%) of the visitors to the site proceeded to register to use the web-based programme. This is higher than the 2.1% participation rate reported by Stein et al. (2006) and, as noted by Koo & Skinner (2005), rates of 3% are reported in many open internet intervention programmes.

Closely related to the low-uptake of this programme by FMs was the notable high rate of attrition. In the pilot FMs were required to obtain a registration code from HCPs; in this instance follow-up was higher in comparison to the open access phase (64.29% and 41.79% respectively). These differences in attrition between the community participants and participants in a controlled (pilot) setting have been noted elsewhere

(Christensen, Griffiths, Korten, Brittliffe & Groves et al., 2004). There is a need to investigate characteristics of family members that may be related to their enrolment, engagement and retention in follow-up. For internet interventions that span across several countries, identifying and administering what may be considered rewards for participating in these programmes becomes a challenge. As stated by Sabate (2003), however, one must note that the obtained are comparable to non-adherence rates for antidepressant treatment regimes which range between 20%-80%. In addition, even with the low utilization rate, it was still possible to detect significant differences between baseline and 3 month post-registration measures.

It may be that the potential users are not aware of this site or that they are not motivated to access it. Or it may be that they do get to the site, but as is the nature with many of the individuals who search for online information, they tend to stay for a brief while on one site before exiting it for another more compelling site. When studying the recruitment and uptake in other formats of self-help programmes the rates have been dependent on factors such as the degree to which they are able to engage participants, length of the programme, text used in recruitment, marketing strategy, variations in characteristics of study population, incentives that are used, and sponsorship. None of these strategies have been isolated as a guarantee for a good response rate in these formats. In web-based intervention programmes, studies of these strategies are sparse. This has raised a need for studies highlighting the characteristics and motivation that people have when they register to use internet self-help programmes versus those who would prefer to have a face-to-face interaction with the health care professional as well as those who do not wish to seek treatment.

One of the advantages of the internet is its potential to reach a large population of FMs that may be in need. Barrera et al. (2009) record traffic to the stop smoking website as originating from 157 different countries, while Christensen, Griffith & Jorns, (2004) report that of the moodgym website for depression standing at 62 different countries. In this study website traffic generated shows as coming from 35 different countries though the majority of traffic was from the United Kingdom. This traffic was generated in the absence of active recruitment efforts. The generated traffic points to the fact that family members are searching for help, and disseminating this support programme using the internet and related technology should be investigated. The availability of this support programme on the internet would give FMs access to support, particularly in countries that do not have HCPs to deliver interventions or where government policies are not supportive of interventions for FMs. The internet lowers the bar for reaching FMs in these countries; it has shown that it can reach a vulnerable group that may not currently have access to the internet interventions (Low et al., 2003; Winzelberg, 2003; Zabinski et al., 2003). In this work it was seen that siblings who were availing themselves of the web-based support did not participate in other formats of delivery in this intervention. Groups of this nature could easily be missed by providers of traditional health services.

Inherent in the expansive nature of the internet and its ability for people in different countries to access help is the need to evaluate the adaptability of this support programme to various cultures. There would be a need to investigate the ease and pattern of usage that people from different cultural backgrounds would adopt, and whether the findings obtained in this work could be generalized to those settings. Would we, for instance, find the results of increased withdrawal coping in settings where there are large family networks, where kinship ties play a major role in daily life

of the people? Would they respond in the same way as this sample which was derived more from settings with smaller family units? Would they derive the same benefits from using this programme as obtained in the current study? Would cultures that promote self-help fare better or present different usage patterns than cultures that do not? With an increase in the numbers of people using this programme in these countries, clusters may emerge allowing us to answer some of these questions.

This research effort, though it is an initial work, points to the potential of the internet in delivering this evidence-based, manualized intervention. In the pilot or controlled condition, when FMs needed to contact a HCP or project team member to gain access to the site, it led to greater follow-up rates and potential for increasing engagement. In this format, HCPs were in a position to refer as well as serve as potential monitors of usage of the web-based intervention. Though in the controlled setting FMs reported finding the web-based programme helpful in general terms, very few mentioned how they made use of the programme and the specific nature of changes that it helped them accomplish. There were also observed modest reductions in pre- to post-intervention scores on the Family Member Impact scale and the Symptom Rating Test. This, though, was limited in the open access phase which involved a larger number of family members in the sample.

This work points to the fact that the realization of a relative's problematic use of alcohol or drugs by a family member often triggers a desperate search for help by FMs. Some of them have described this as having to navigate a strange land of grabbing at straws, being emotionally distraught and not really knowing what one is searching for.

Closely related to this is that this pilot and initial open access phase have shown the web-based format can potentially reach people who cannot or will not avail themselves of traditional services. As mentioned, some people would rather not have to sit and talk to another person in a face-to-face or group session about the problem, either because of embarrassment that is felt or possibly, if the using relative has not seen it as a problem, the FM's attendance at such sessions, if discovered, could lead to difficulties in their relationship. One of the issues mentioned in this work was the inability of some FMs to attend Al-Anon meetings or these sessions due to conflicting activities as well as physical limitations in doing so. Also seen was the groups – siblings, who were not showing up in the other evaluations of this approach. It thus holds within it the potential for reaching these vulnerable groups.

The lack of access to treatment and support for FMs in traditional service delivery is evident in the reports of some participating FMs that this web-based support programme was their first exposure to anything that was just for them. For some, it was their first time receiving help of any kind. Others reported how comforting it was, stating that the knowledge that such help was available validated what you were experiencing. Still others reported that, compared to other programmes, this experience was the best yet for them.

6.3 Limitations of the Findings

There are a number of limitations in this study that need to be acknowledged. A major limitation is that the sample size was relatively small and restricted to participants who were English speaking, had the necessary computer skills, were actively searching for help for this, mostly through the internet, and were additionally prepared to use a self-

help module in addressing or finding solutions to the problems that they faced. These individuals may have had a preference for types of treatment that is not shared by the general population. By virtue of the population from which they were selected, they are likely to have been from a higher socio-economic group. Research from other works show that higher education is associated with the uptake of complementary or alternative treatments (NICE, 2004). Care must be taken in generalizing the findings of this study to other populations.

Secondly there was no control group which would have allowed for us to rule out the other contending factors such as the mere passage of time which may be said to account for the observed differences in between baseline and three month post registration. The difficulty however in having a comparative treatment group is that FMs of alcohol and drug misuse are currently not receiving treatment as clients in their own right. As postulated by the assumptions of the 5-Step Intervention, just having someone that would listen is what some of them report in their first exposure to the 5-Step Intervention. It is possible as mentioned by a few of the FMs in their interview, just answering the questions was therapeutic, giving them the sense that someone understood. This would imply that taking baseline measures alone would be actually entering step 1 of the 5-Step Module in which the FM is given the opportunity to “say it like it is”. These considerations need to be worked through in designing a true comparative control group for testing the effectiveness of the intervention.

It must be pointed out that the method adopted for gathering qualitative data did not rely on recording and transcription, but on detailed note taking and writing up of reports soon after - usually within a 24 hour period. A number of reservations have been raised

with this method: the first centres on how the data is gathered and the second relates to the content of the gathered information. In the first case, some have suggested that this method might be experienced as disruptive by the interviewee, and also that the interviewer's note taking may interfere with his ability to listen and probe, leading to possible missed opportunities to probe for deeper understanding or meaning at different parts of the interview.

Issues relating to the content question the extent to which the information reflects the interviewee's experience. The interviewer, in listening and taking notes, is thought to already be sifting the information to determine what is relevant and therefore to be quoted and later included in the writing up of the report. In the absence of recordings of the interview, much depends on the details that the interviewer is able to capture in the notes and later report. The method relies heavily on the accuracy of the interviewer's report in reflecting what was said by the interviewee. If there are shortcomings in these notes there are no recordings that one can rely on or refer to for clarity; any data lost at this stage would be irretrievable.

The purpose of the qualitative information gathered in this study was not conversational analysis of the discourse, for which full transcription would have been required (Willig, 2008); rather the purpose was giving understanding and meaning of the experience of FMs; note taking was therefore considered adequate (Orford et al., 2005). This method has been used in previous research evaluating this intervention. When this was used, FMs, rather than finding it intrusive, as suggested, reported that the note-taking during the interview made them feel that their opinions and experiences were of value (Velleman & Templeton, 2003). Furthermore, when trained in both interviewing and

report writing, interviewers report finding the techniques required quite easy to master (Orford, Templeton, Velleman & Copello, 2010). Important however is that the method involving detailed note taking yielded results which are in line with methods based on full transcription (Ahuja, Orford & Copello, 2003; Orford et al., 2005). With the availability of such training and supervision and the pragmatic advantage of its use of fewer resources (e.g., it avoids the time cost and difficulty of listening to recordings and making transcriptions; Orford, Templeton, Velleman & Copello, 2010), it was the method of choice for this study.

The data obtained in this study, however, did not seem to provide an in-depth understanding of the intervention itself, or the specifics within this intervention that these FMs or clinicians were relating or affected by, and thus raised issues as to the adequacy of the method used in gathering the data. This is particularly evident with FMs who participated in the web-based interventions. This lack of specific in-depth information regarding how family members experienced the website may however have resulted from the fact that many of the FMs using the intervention did not proceed far into the programme and therefore made statements that were more general, rather than referring to specifics of the programme which they found helpful.

The Stress-Strain-Coping-Support model suggests that the relationship between the level of stress and the degree of strain experienced is affected by both the coping strategies adopted and the positive support that the individual can access. It was thus expected that, as FMs proceeded through the 5-Step Method evolving from this theoretical perspective, they could be helped in examining ways in which they have been responding to the situation and led to consider other responses; this could reduce

the degree of strain experience. Similarly, improved access to positive support from others could also reduce the degree of strain experienced. The results of this study suggest that modest changes in baseline and post intervention measures were observed even with the limited exposure that some FMs had to both the modules that seek to change coping responses and those which focus on increasing accessibility of positive support. This raises the need to consider the adequacy of this theory in explaining change. It could be as suggested (Orford, Copello, Velleman & Lorna, 2010; Personal communications) that there is another factor – ‘making sense’ - which is descriptive of a the sense of understanding that the individual is believed to arrive at in terms of the effects that the relative’s alcohol or drug use has on the family in general and specifically on the family member.

Closely related to this is the need to test the impact of each of the 5-Step modules to see the specific contributions that they each make to the outcome. A more detailed study is required to obtain information on not just the effects of any of the separate modules of the programme, but also the required length or depth of exposure that is needed for obtaining optimal effect.

This model further suggests that there are four stages through which a person should pass which would help alleviate the stress and strain of living with an alcohol or drug misusing relative, the first being that of being listened to, or exploring the effects that substance misuse has had on the family as a whole and specifically on the FM. This may be a challenge in the self-help manual and web-formats where this seems to be broached by the questions that the person is made to answer serving as avenues for the person to examine and come to terms with the realities of how the family has been

affected. This could be further achieved by creating a more accessible channel of communication for FMs with an 'expert'. Given the functionality of the web and the fact that this communication with the expert may occur synchronously (when both are present on different computer terminals at the same time - reflective of the day-to-day life communication) or asynchronously (where it takes place over a period of time) it may be worth examining the effect this may have on FM exposure and willingness to return frequently to the site, and the furthermore what effects this may have on other outcomes of this support programme.

Given the low uptake and usage of the site it may be worth investigating whether changes in the design and the delivery of this web programme could lead to improved uptake and engagement. Results obtained were similar to that of Christensen, Griffiths, Korten et al. (2004) who found that, when compared to trial participants, a lower percentage of those who register spontaneously in an open access phase engage and go through all the modules of the programme. This seems to agree with the suggestion by Tate & Zabinski (2004) that recruiting through HCPs may increase the FMs' sense of accountability and hence greater levels of adherence. In the future delivery of this intervention there would be a need to investigate how varying degrees of contact with HCPs would affect the outcomes (Spence, Homes, March & Lipp, 2006). It may be that using it as an adjunct to treatment, where internet sessions are supplemented with face-to-face sessions with the HCP, would lead to increased accountability and hence greater likelihood of programme completion.

Furthermore there are a variety of existing as well as newly developed internet tools and techniques which may be included and which may lead to greater uptake and

engagement with the site. There would be a need to investigate if such additional components like weekly telephone calls (Carlbring et al., 2007), —ask the expert, video interviews, audio files (Stinson et al., 2009), or the provision of interactive feedback in varying degrees and forms (De Bourdeaudhuij et al., 2007; Irvine, 2004; Kypri & McAnally, 2005; Portnoy et al., 2008; Tate & Zabinski, 2004) would have an effect on programme uptake and adherence, and the possible effects of the increased adherence on outcome (Palermo et al., 2009; Stretcher, 2005). There is also the question of the possible effects that the inclusion of incentives, either in the form of bonuses or rewards, may have on the use and outcomes (Verheijden et al., 2007; Su et al., 2008). The challenge of including incentives however will be to find ones that are valued universally and can be delivered to FMs irrespective of the country from which the programme is being accessed.

As pointed out in several of the reviewed papers, research into the factors affecting the use of web-based programmes for different conditions by different people is still in its infancy, yielding varying results (Amstade et al., 2009; Barak et al., 2008; Bock et al., 2008; Myung et al., 2009; Portnoy et al., 2008; Reger & Gahm, 2009). As pointed out by Sproull et al. (1996) there is a great need for basic research on how different elements of the website may change and their effects on the outcomes for the users, as well as on identifying user characteristics that may be related to outcomes (Glasgow et al., 2007). The focus of future research efforts in this direction would lead ultimately to identifying several of these factors and to the design of an effective support programme for FMs of alcohol or drug misusing relatives.

It must also be noted that not all family members agreed to be followed up; some refused to provide follow-up measures, suggesting that we should exercise some level of caution in the interpretation or ability to generalize the results obtained. It should, however, be noted that there were no systematic differences between the completers and non-completers on the variables that were measured. Closely related to this is the high level of attrition between baseline and follow-up at three months post-registration, again leading to the need to be cautious regarding the validity of the results (Eysenbach, 2005; Koo & Skinner, 2005). There was a loss of FMs to follow-up in the controlled phase (35.71%) where access was limited to those who were referred by HCPs; this loss was much higher (58.71%) in the open access phase. The greater retention of those in the controlled setting may point to sample differences that, though difficult to characterize, may mask the differences in the outcomes that were obtained.

Baseline measures on the different scales (FMI, CQ and SRT) were obtained online. Though this was the preferred mode for collecting the three months post-registration responses, most family members did not return to the site to fill in the questionnaire on being reminded but preferred to give responses to the questions over the telephone. Psychometric properties of the questionnaires administered over the internet may be different from those administered over the telephone. It may be that respondents were more honest and revealing when responding online to the questionnaire, leading to a reported higher level of symptomatology. By implication therefore, the change of scores between pre- and three months post-registration may have more to do with the psychometric properties of the channels of administration than due to the actual effects of participating in and receiving support from the programme.

Another limitation of this study is the absence of a control group. The observations of significant pre- to post-intervention changes in scores on measured variables can only be taken as peripheral support for the effectiveness of this web-based support programme. Though the data that was collected included a variety of variables (e.g., country, ethnicity, duration of problem, etc.), the sample was not large enough for any comparisons to be made. Because of the small scale of this work, it was also not possible to determine which of the intervention components were most effective, or for which FMs. Also, for ethical and practical reasons, FMs were not prevented from accessing other forms of help. These additional services, therefore, could have been potential confounders, though, as mentioned by many family members, support for them is hard to access.

Finally, this work shares the low exposure rate which is common to other internet-based programmes (Crutzen, De Nooijer, Candel et al., 2008). The observation of pre and post intervention measures on the Coping Questionnaire can only be taken as suggesting support for the effectiveness of this web-based programme. As many family members dropped out the programme without progressing to 3rd and 4th modules that focus on coping and support, there is a need to examine other possible explanations for the obtained results.

6.4 Further Research

Due to the limitations experienced in this work there is a need for further research in order to provide conclusive evidence on the effectiveness of this web-based support programme. There is a need to include a comparison condition or control group. There

is a need for collection of information from a larger group of FMs to allow for a close examination of individual characteristics as they affect responses to exposure to the web-based support programme. Comparing this to other formats or combination of formats for administering the 5-Step Method would help to answer questions about the cost effectiveness of this web-based version. Furthermore, the follow-up period of three months was brief. Future research may seek to determine the duration of the beneficial effects derived from participating in the programme. This would entail longer follow-up periods.

The low utilization rates of the website by family members suggest a need to look at how this might be improved. That most FMs dropped out without accessing the coping and support model implies that they may not have been exposed to the full package or possibly derived the full benefit. With the model effects obtained in the coping strategies and measure of family impact and symptoms, it would be of interest to know if increased utilization (adherence) rates would lead to differences in outcomes. This is more so as the reviewed literature points to variations in this effect depending on the condition studied (Clarke et al., 2002; Christensen et al., 2004; Palermo, 2009; Stretcher, 2005). Furthermore, the challenges of creating a sense of being listened to in this programme should be examined. Such could be the inclusion of internet tools such as a bulletin board which would allow for family members to post questions on the internet programme to which other family members or the moderator could respond or comment, or the inclusion of an 'ask-the-expert' function, which would allow for family members to pose questions and get responses from healthcare professionals, or the creation of chat forums within the programme, where family members could get online to communicate synchronously with other family members logged in to the programme

at that time. In the present study family members reported that they were expecting facilities of this nature in the web programme; it would be interesting to see if this would lead to greater sense of FMs' feelings of being listened to and supported (Pretorius et al., 2009), leading to better outcomes which would contradict Barack et al.'s (2009) findings.

There is also the need to investigate other modes of delivery of this intervention, where the level of contact with the HCP may be varied to observe what effect this may have on FMs' willingness to take up and engage with the programme, and the potential effects that this would have on the outcomes. In this light it would be worth investigating experiences and outcomes for FMs when varying face-to-face sessions with a HCP and individual computer sessions.

The observation of changes in reported measures even with low utilization rates, as experienced in this study, points to the need for information on the specific effects of any of the separate steps of the programme, as well as the required length or depth of exposure that is required for optimal benefits to be derived from any of the steps. It would also be necessary to investigate whether differences in the sequence in which the steps are taken would play any part in the outcome. To adequately investigate this, there is a need to examine the effects of differing the content and sequence of presentation of the intervention steps, which was outside the scope of this paper. As participants are encouraged to use these modules in any way they like, which is similar to the practice for many websites, there will be a need to closely monitor their engagements with each of the modules. Furthermore, there will be a need to examine possible additional effects that any booster session may have on the outcomes obtained.

6.5 Conclusion

Despite these limitations, the present research has a number of strengths. It is the first effort at providing an online manualized evidence-based approach for family members of alcohol and drug misusing relatives. This programme relies heavily upon psycho-educational content, providing text information about the impact of alcohol and drugs on family members and looking at a variety of ways people have tried to cope with this. It would be thought to fall into what would be considered the first generation of computer intervention programmes. While in its current form, it does show preliminary evidence of its effectiveness and acceptability, although there are barriers to it being taken up which may limit its usage if not addressed. This includes taking into consideration some of the expectations that FMs have expressed in their learning about the intervention, and incorporating this into the programme. There is, for instance, room for improvement by updating it with technological developments within this area. As more and more people are turning to and using internet communities for support, there is a need to investigate how support forums, notice boards and ‘ask-the-expert’ functions may be built into the programme. This is more relevant when one considers that developing and utilizing a supportive network is a practice suggested by the 5-Step Method itself.

Despite the limitations and shortcomings, this work holds promise for a potential channel through which family members of alcohol or drug misusing relatives may be able to have access to help. Further research is however needed to establish demographic characteristics of family members that are better placed for deriving these benefits as well as the mode of delivery that would encourage engagement of FMs with

the programme for the desired period in order to derive better outcomes. With the health care systems in many developed countries changing in ways that encourage self-help and self-responsibility, this programme is capable of providing this much needed tool for the self-delivery of an evidence-based support that could be put to use in various ways by health care professionals.

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APPENDICES

APPENDIX 1

Information Sheet

Web-Based Intervention for Family/Network Members of Alcohol or Drug Misusing Relatives

This program has been developed by a team of researchers and clinicians from the University of Birmingham, University of Bath and the NHS. It offers support to people who are affected by or worried about a relative's drinking or drug misuse. This information sheet explains more of what it is about. **We hope that you will take time to read through this information before you decide on participating.**

What is the Purpose of this Program?

Previous work done by the Alcohol Drugs and the Family (ADF) Group has shown that when a relation develops an alcohol or drug problem it has a significant negative impact on family life in general, and on other individual members of the family.

ADF group has formulated a way of looking at how alcohol and drugs affect that family, and have gone further to offer this self help intervention as a means through which the effects that the relative's problematic drinking or drug use on other members of the family can be address. This program has been made available in different formats and the results have all been encouraging. Now we are offering this help in a web-based format to people we think might find them useful, we want to find out how effective it is to offer it in this format. To do so we will be asking the people using it a set of questions before and after they have registered and used the program, this is in addition to asking them to be interviewed by a researcher afterwards.

Do I have to take part?

You can choose whether or not you want to take part in this program. Feel free to discuss this with friends, colleagues and /or your GP before making your decision. If you do want to take part then you will be required to fill in the consent form. If you do decide to take part and at any stage you change you mind, you can withdraw from the program.

What will happen if I decide to take part?

If you decide to take part in this program the healthcare professional will give you a pass code. You will be required to enter the pass code when you login to as a new user. Once you login you will be provided with in informed consent form to fill. You will then be required to complete 3 questionnaires online. These questionnaires usually take about 20 minutes and they are about:

- The effects of your relatives' misuse of alcohol or drugs has on you and other members of the family
- Ways in which you have been responding to or managing it.
- Your general health

You can then access this source of help from the computer at home, work , library or wherever you find is convenient for you. Work through each of the steps of the program at your convenience. We have found that it each step takes an average of one hour to complete. For someone that is who is consistent in working through the program he should be through within a 3 month period.

3 months after you have registered on this program, you will be contacted by email (or by post or telephone where you have indicated you want to be sent reminders by this means), and you will be asked to complete the questionnaires again, additional questions will be asked about the

support that you have received. This is to help us see if this intervention has an effect and to see the trends that may exist.

What are the possible benefits of my taking part?

Previous research we have conducted using this approach points to its being effective in helping family members. Reports from other researches have it that when family members have been included in service provision, as this program does; it leads to other benefits like the alcohol or drug misusing relative seeking and staying in treatment.

We hope that you will benefit from this program and further more that it may have the suggested effect of your alcohol or drug misusing relative seeking and staying in treatment. We cannot however guarantee this. Nevertheless you will, through your participation help us to learn how to improve on using this format to support family members who are affected by this problem.

How might taking part harm me?

This method has not been known to cause physical harm. Reading about and answering questions or doing exercises focused on the difficulties that you are experiencing may cause discomfort and might be upsetting. The methods used here are designed to help you improve the situation. If you do experience distress, inform your doctor, nurse or counsellor who will offer you support to help you cope with this.

What happens when I have completed the program?

After the three months period, when it is expected that you would have finished going through the program and you have filled in the questionnaires the second time, you will continue to have access to the intervention. You should feel free to return at any time to any of the sections that you found helpful or that you feel you need to go over again.

What will happen with the information I give?

All information provided by you in the course of this work will be strictly confidential. We are bound by the Privacy Act 1988 which lays down a set of Information Privacy Principles, which makes us obligated to treat all information gathered from the participants in this project with respect and to take all possible measure to ensure that your confidence is never breached. Further information about this you can read on your [privacy statement](#).

Will my taking part in the study be kept confidential?

The answers to the questions that you provided will be kept confidential. The program will give you an identification code number that will not be known to people outside of the research team. We will ask you to provide an email or address and telephone number so that a researcher can contact you to arrange an interview. This does not have to be a home address and telephone number and the interview does not have to be at home and it may be over the telephone.

Who to contact for further information/

If participants experience difficulties they were encourage to use the contact information on the site to contact either the Chief Investigator Akanidomo Ibanga or the project secretary.

APPENDIX 2

CONSENT FORM

Web-based Intervention for Family /Network. Members of Alcohol or Drug Misusing Relatives.

Please indicate in the box below your informed consent to participate in this intervention program by ticking in the appropriate box. Once you have ticked the relevant boxes click on the "submit" button or press <enter> to send the form.

1 I confirm that I have read and understand the information sheet dated 18/07/2006 (version 2) for the above intervention program. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3 I agree to my GP being informed of my participation in the study

4 agree to take part in the above study.

SUBMIT

APPENDIX 3

FAMILY MEMBER IMPACT QUESTIONNAIRE

16-item form

FAMILY MEMBER IMPACT QUESTIONNAIRE

16-item form

SCORING KEY

Score each item:

Not at all	=	0
Once or twice	=	1
Sometimes	=	2
Often	=	3
Don't know*		
Items 3, 6, 7	=	1
All other items	=	2

*If there are more than 3 don't knows, do not score the questionnaire

FOR TOTAL IMPACT, sum all items

FOR WORRYING BEHAVIOUR, sum items 3, 4, 8, 9, 11, 12, 13, 14, 15, 16

FOR ACTIVE DISTURBANCE, sum items 1, 2, 5, 6, 7, 10

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Section A. Ways in Which You Have Been To your knowledge, have any of the following happened **in the last 3 months, as a result of your relative's drinking/drug use** (Click in the box that is the most appropriate answer for you).

	Not at all	Once or twice	Some times	Often	Don't know
1. Does your relative have very changeable moods?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Does your relative communicate badly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Does your relative steal or borrow money and not pay it back?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Have the family's finances been affected?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Does your relative pick quarrels with you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Has your relative sometimes threatened you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Have people outside the family had to get involved?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Does your relative come and go at irregular or awkward times?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Does your relative's drinking/drug use get in the way of your social life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Has your relative upset family occasions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Does your relative fail to join in family activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Has your relative been late or unreliable?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Are you worried that your relative's ability to work or study has been affected by the drinking/drug use?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Are you worried that your relative's physical health has been affected by the drinking/drug use?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Are you worried that your relative has neglected his/her appearance or self-care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Are you worried that your relative's mental state	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX 4

SYMPTOM RATING TEST

30 items

Source: Kellner, R. and Sheffield, B. (1973). A self-rating scale of distress, *Psychological Medicine*, 3, 88-100.

SYMPTOM RATING TEST

30 items

SCORING KEY

Score each item:

Never	=	0
Sometimes	=	1
Often	=	2

For TOTAL SYMPTOMS, sum all 30 items

For PSYCHOLOGICAL SYMPTOMS, sum the following 18 items: 3, 5, 8, 9, 10, 12, 13, 15, 17, 18, 19, 20, 22, 23, 24, 25, 26, 28

For PHYSICAL SYMPTOMS, sum the following 12 items: 1, 2, 4, 6, 7, 11, 14, 16, 21, 27, 29, 30

Section C. Ways in Which You Have Been Feeling (These questions are asking about ways that you have been feeling in the last 3 months)

	Never	Sometimes	Often
1 Feeling dizzy or faint.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 Feeling tired or lack of energy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3 Feeling nervous.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4 Feeling pressure or tightness in the head.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5 Feeling scared or frightened.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6 Poor appetite.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7 Heart beating quickly or strongly without reason (throbbing or pounding).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8 Feeling that there was no hope.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9 Restless or jumpy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10 Poor memory.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11 Chest pains or breathing difficulties or feeling of not having enough air.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12 Feeling guilty.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13 Worrying.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14 Muscle pains, aches or rheumatism.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15 Feeling that people look down on you or think badly of you.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16 Trembling or shaking.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17 Difficulty in thinking clearly or difficulty in making up your mind.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18 Feeling unworthy or a failure.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19 Feeling tense or 'wound up'.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Never	Sometimes	Often
20 Feeling inferior to other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21 Parts of your body feel numb or tingling.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22 Irritable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23 Thoughts that you cannot push out of your mind.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24 Lost interest in most things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25 Unhappy or depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26 Attacks of panic.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27 Parts of the body feel weak.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28 Cannot concentrate.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29 It takes a long time to fall asleep, or restless sleep, or nightmares.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30 Awakening early and not being able to fall asleep again.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX 5

COPING QUESTIONNAIRE

30-item form

Copyright: Alcohol, Drugs, Gambling and Addiction Research Group, School of Psychology, The University of Birmingham

COPING QUESTIONNAIRE

Short 30-item Form

SCORING KEY

Score each item:	NO	=	0
	ONCE OR TWICE	=	1
	SOMETIMES	=	2
	OFTEN	=	3

FOR TOTAL (CQ-TOT) COPING, sum all 30 items

FOR ENGAGED COPING SUB-SCALE (CQ-E), sum score for items:

1, 5, 6, 7, 9, 11, 13, 16, 17, 19, 21, 25, 26, 28

FOR TOLERANT COPING SUB-SCALE (CQ-T), sum scores for items:

3, 4, 10, 14, 20, 23, 24, 27, 30

FOR WITHDRAWAL COPING SUB-SCALE (CQ-W) sum scores for items:

2, 8, 12, 15, 18, 29 and subtract scores for items 5 and 22:

and then add 6 (to ensure all values for CQ-W are positive)

(N.B. – Item 5 contributes positively to CQ-TOT and CQ-E, but negatively to CQ-W)

COPING QUESTIONNAIRE

Section B. Things You Do Because of Your Relative's Drinking/Drug Use.

Again, the questions are asking about what has happened **in the last 3 months**. (If you don't see your relative any more, please read the questions as you will be able to answer all of the questions, even if the answer is 'no').

	No	Once or twice	Sometimes	Often
1. Have you refused to lend your relative money or to help your relative out financially in other ways?				
2. Have you put the interests of other members of the family before your relative?				
3. Have you put yourself out for your relative, for example by getting him/her to bed or by clearing up mess after him/her when he/she has been drinking/using drugs?				
4. Have you given your relative money, even when you thought it would be spent on drink/drugs?				
5. Have you sat down together with your relative and talked frankly about what could be done about his/her drinking/drug use?				
6. Have you started an argument with your relative about his/her drinking/drug use?				
7. Have you pleaded with your relative about his/her consumption of alcohol or drugs?				
8. When your relative was under the influence of drink/drugs, have you left him/her alone to look after him/herself or kept out of his/her way?				
9. Have you made it quite clear to your relative that his/her drinking/drug use was causing you upset and it had got to change?				
10. Have you felt too frightened to do anything?				
11. Have you tried to limit your relative's drinking/drug use by making some rule about it, for example forbidding drinking/drug use in the house or stopping your relative from bringing drinking/drug using friends home?				
12. Have you pursued your own interests or looked for new interests or occupation for yourself or got involved in a political, church, sports or other organisation?				
13. Have you encouraged your relative to take an oath not to drink or use drugs?				
14. Have you felt too hopeless to do anything?				
15. Have you avoided your relative as much as possible because of his/her drinking/drug use?				

	No	Once or twice	Sometimes	Often
16. Have you got moody or emotional with your relative?				
17. Have you watched your relative's every move or checked up on your relative or kept a close eye on him/her?				
18. Have you got on with your own things or acted as if your relative wasn't there?				
19. Have you made it clear that you won't accept your relative's reasons for drinking/drug use, or covered up for him/her?				
20. Have you made threats that you didn't really mean to carry out?				
21. Have you made it clear to your relative your expectations of what he should do to contribute to the family?				
22. Have you stood up for your relative or stood by your relative when others were criticising him/her?				
23. Have you got in a state where you didn't or couldn't make a decision?				
24. Have you accepted the situation as a part of life that couldn't be changed?				
25. Have you accused your relative of not loving you or of letting you down?				
26. Have you sat down with your relative to help your relative sort out his/her financial situation?				
27. When things have happened as a result of his/her drinking/drug taking, have you made excuses for your relative, covered up for your relative or taken the blame yourself?				
28. Have you searched for your relative's drink/drugs or hidden or disposed of it/them yourself?				
29. Have you sometimes put yourself first by looking after yourself or giving yourself treats?				
30. Have you tried to keep things looking normal, pretended all was well when it wasn't or hidden the extent of your relative's drinking/drug use?				

APPENDIX 6

Summary of Research Protocol

This research sets out to assess the feasibility of a web-based delivery of the 5-Step Intervention for family/network members of relatives with an alcohol or drug problem. The face-to-face delivery of this intervention, in the primary care and specialist drug agencies, has been evaluated, as well as the delivery in a self-help book format. Results of these evaluation studies have shown that it can lead to positive changes for family members at pre- and post-intervention.

For this study 50 family members shall be identified and recruited directly through their own contact or indirectly through the contact of their drinking relative with specialist drug agencies and GP surgeries that are currently involved in a broader project of "Involving the Family Members" in service delivery. The other channel, through which recruitment shall take place, is through contact with a member of the research team.

At recruitment the participants will be given information sheet, the web address, and a login pass-code by key persons at the participating organisations. They will be encouraged to login to the intervention at their convenience. At login the individual will be taken through a process of registration. This involves:

- Choosing a user name and password
- Answering a few questions about their peculiar circumstances and relationship with the relative.
- Giving informed consent to participate in this research project online, and
- Filling out a battery of standardised self-report measures.

Once these requirements for the registration process are met, they will be allowed access to the intervention itself. The intervention itself is arranged in 5 modules, reflecting the book format of the self-help. Each person will work through the intervention at their convenience and in a manner that suits their situation. They shall again be sent email reminders at 3 month post intervention to fill the post intervention questionnaires. Also at post intervention, a select few of the family/network members will be interviewed to gain knowledge on their experience in using this web-based intervention.

APPENDIX 7

Semi-Structured Post Intervention Interview Guide

A semi-structured interview will be conducted at the end of the intervention for selected participants. This is estimated to be 3 months after registration, on the internet site. The interview itself will last approximately 20 minutes over the telephone or face-to-face, at the preference of the participant. The topics to be explored during this interview include:

1. *Recruitment*: How did family/network member hear about the project? How was the family/network member identified and recruited to participate in the project? Did the participant discuss this with others prior to consent to participate in the intervention?
2. *Pattern of usage*: How did family/network member use the intervention? What pattern was adopted in working through the intervention? How would they describe their experience in using this web-based intervention? Family/network members views on the content, appearance and navigation through the intervention site. Were there other sources of help or other websites consulted at this time?
3. *Impact* the site has had: What did family or network member find most useful in this intervention, or what are some of the things that they gained in participating in this web-based intervention? What was not achieved for family/network member and what limitations did they experienced?
4. *Suggestions*: What are some of the difficulties that family/network member had in regards to using the intervention? What suggestions would they like to give?