

Open Research Online

The Open University's repository of research publications and other research outputs

Families and Serious Mental Illness: Working with Loss and Ambivalence

Journal Item

How to cite:

Jones, David W. (2004). Families and Serious Mental Illness: Working with Loss and Ambivalence. British Journal of Social Work, 34(7) pp. 961–979.

For guidance on citations see [FAQs](#).

© 2004 BASW Trading Ltd.

Version: Accepted Manuscript

Link(s) to article on publisher's website:
<http://dx.doi.org/doi:10.1093/bjsw/bch123>

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online's data [policy](#) on reuse of materials please consult the policies page.

oro.open.ac.uk

Families and Serious Mental illness: Working with loss and ambivalence.

Introduction

This paper is written to promote a fuller understanding of the experiences of people who have a family member diagnosed with serious mental illness. Working in partnership with families and carers is increasingly being seen as an important issue in social work and allied professions (Oppong-Tutu 1997). It is central to the Care Programme Approach which provides guidelines for the community care of people with long term severe mental health problems (DoH 1995a; Downing and Hatfield 1999). In England, the *National Service Framework for Mental Health* (DoH 1999) stipulates that carers have their needs assessed on an annual basis and that they be provided with a written care plan). There appear, however, to be obstacles to the successful collaboration between professionals and families. There is a long history of findings from Britain (Creer 1975, Mills 1962, Shepherd et al. 1994; Strong 1997), the U.S.A (Hatfield 1987; Terkelson 1987; Wasow 1995; Winefield and Harvey 1994; Zolik et al. 1962) and Sweden (Pejlert 2001) that relationships between families who have a member diagnosed with mental illness and mental health professionals who are working with them can be poor. This state of affairs might partly be explained by some of the models of mental illness that have informed practice. Early psychoanalytic models (Fromm-Reichman 1948; Tietze 1949) and early family therapy models (Bateson et al. 1955; Lidz and Lidz 1949; Selvini-Palozzoli et al. 1978) were quite explicit in laying the blame for serious mental illnesses at the door of the families (these ideas were notably influential on R.D Laing's early work¹, - Laing 1965; Laing and Esterson 1964). Whilst the influence of these models may have dwindled somewhat (as evidence that familial behaviour did cause serious mental illness failed to appear - Hirsch and Leff 1975), it will be argued that there are still aspects of the experiences of families that are not always well understood.

Examples from several case-studies, drawn from a wider study of the experiences of a multi-cultural group of families (Jones 2002), will be used to illustrate some salient aspects of their experiences that focus on their feelings of loss and the resultant feelings of ambivalence. It

1 Whilst Laing revised his view of the family as being chief suspect in the cause of mental illness (Laing 1967) his many followers did not (see Sedgwick 1982 for a detailed review of Laing and his influence).

will be argued that loss is a central experience amongst families who have a member suffer from serious mental illness and that there are features of families' behaviour and attitudes that need to be understood in this context. I believe that some of the particular lessons learned from this research are worthy of consideration by those working with families. Some important aspects of the families' experiences were often difficult for them to articulate, and the negative feelings that might have been most apparent (such as feelings of anger and shame) were often entwined with more positive feelings.

There is a theoretical convergence on the idea that bereavement can be understood as a dual process (Curren 2001, Stroebe and Schut 1999). On the one hand the bereaved must come to terms with absence itself and on the other they must construct new meanings amidst their current circumstances. Engaging in dialogue about their feelings and circumstances can be a crucial way that people can build new meanings (Bonanno and Kaltman 1999, Walter 1996). It is suggested here that professionals working with families could do much to facilitate these processes of dialogue. In order to do this, they would need to be aware of the complicated nature of some of the feelings that family members may have and the therefore complex grief process. The first part of this paper will describe three aspects of the losses experienced by family members that need to be understood by professionals who are working with families. The relatives' losses can be described as complex and ambivalent in at least 3 respects:

Firstly, this is a complicated bereavement since the loss here is not straightforward. The person has, after all, not died they are still around however much altered. It often feels to relatives as though to move on from the loss would be a betrayal of the person that they feel has been lost. Secondly, whilst anger is often a common concomitant of loss itself, it has been identified as a prevalent complicating factor in grief when it is felt towards the object of the bereavement. Anger, for various reasons, is often present, and is particularly difficult to accommodate since it feels so wrong to be angry with someone who is also seen as the victim of an illness. Feelings of guilt can therefore be considerable. Thirdly, through the stigma attached to mental illness, families often feel shame, which itself can be a very difficult emotion for people to acknowledge, and yet can directly stop people seeking help. The presence of shame draws attention to the potential importance of sensitive professional intervention in this area. The second part of the paper will consider some of the implications of this complex loss for professionals who work with families. It may be that professionals are in a good position to support these families, because they often feel so isolated.

Appreciation of the complex emotional tasks that face relatives can help to understand the commonly observed phenomenon of 'chronic grief' (Atkinson 1994, Davis and Shultz 1997) and the array of emotions, some of which such as anger, which if not properly understood can be seen in a negative light (see the large literature on the phenomenon of 'expressed emotion', Leff 1994 for example). It is important to be aware that these apparently negative emotions are often entwined with other more positive feelings of love and commitment. It is argued that professionals can support families by promoting dialogue that can help relatives build an understanding of events that overcome some of the consequences of the chronic grieving they experience.

Methodology

Participants

Two slightly different means of identifying relatives who had a family member suffer from serious mental illness in an urban area of North London were used:

1. relatives of people who had been admitted to a psychiatric unit for a continuous period of at least six months in the past 2 years.
2. relatives of a random sample of people who had been referred to a community psychiatrist (they had also had experience of hospital treatment).

From both groups, families of people who had at some time received a diagnosis of schizophrenia, or bipolar affective disorder who were below the age of 55 were contacted by myself. The average age of the initial patient group (11 women and 23 men) was 33. A total of 47 family members were interviewed: 15 mothers, 8 father, 8 brothers and 8 sisters.

Interviews

Relatives were interviewed usually in their own homes. The purposes of the study were explained: I was being funded by the Health Authority and I was interested in the families of

people who used the psychiatric services, as I felt that the involvement and responsibility taken by families was not always recognised by professionals and service planners. People were given an assurance about confidentiality; that if I used something they said to illustrate a point I would not use their real name, and that identities would be disguised. If people agreed to take part, I then asked if they would mind being tape-recorded. Interviews were typically around 1.5 hours long, with a range between 45 minutes and 2 hours.

In depth, relatively unstructured, interviews were the chosen method of investigation. There are two major methodological strands to the study. Firstly I wanted to try and understand the perspectives and experiences of the families, in line with a strong tradition of phenomenologically informed qualitative research which developed originally in sociology (Bogdan and Taylor 1975; Glaser and Strauss 1967; Silverman 1985, 1993), the themes of which are to be found in more recent work in psychology (Hollway 1989; Potter and Wetherell 1987; and Smith, Jarman and Osborn 1999). However, since I was also interested in understanding the emotional aspects of those experiences, which have not always been handled as well by these sociological methods (Craib 1995; Johnson 1975; Kleinman and Copp 1993) it was also necessary to utilise ideas with roots in psychodynamic thought (Hunt 1989; Hollway and Jefferson 2000). Simply put, these were based on the understanding that a research interview is an event that entails communications occurring at covert, unconscious and emotional levels.

The interviews and the analysis

A number of techniques can be employed in a research setting which are based on, to coin a phrase, *the assumption of association*, (Hollway and Jefferson 2000; Jones 1998) which draw

out the essence of the psychoanalytic concept of ‘free association’ (Sandler, Dare and Holder 1973). The assumption is made that the particular words that people use and the connections that people make between topics can be taken as indicating the emotional significance of events in ways that people themselves may not be able to express. This implies paying particular attention to what people bring spontaneously to an interview; what words and thoughts are associated together; or what tone, or what facial expression, or posture is used to describe things that may suggest an alternative to the overtly intended meaning.

All the interviews were fully transcribed and then analysed using two distinct methods. Certain discrete topics such as people’s views on medication or direct experiences of stigma were initially explored through a systematic process. All mentions of the topic were gathered together. All extracts could then be compared and themes developed rather in the manner of grounded theory (Glaser and Strauss 1967). Other issues, however, emerged from what I am calling *integrative analysis*. Here, no meaningful distinction can be made between the process of data collection and data analysis. This was analysis that was an integration of experiences within the interviews and was being shaped by reflection, reading and discussion between interviews. Such methods clearly pose a challenge for judging the reliability and validity of the findings. In an attempt to address these concerns I have tried to use quite long quotations from interviews, and use a system of numeric notation to show why I am making those interpretations. Numbers appearing in the text usually refer to the interview material below (the occasional exceptions are noted). Ultimately the interpretations are made here in the spirit of dialogue, and their value will be judged by the resonance they find in the worlds of the readers (Rorty 1980). The ethics of this interviewing, which clearly have much in common with therapeutic approaches have been explored elsewhere (Jones 1998). It is argued that care needs to be taken in this kind of interviewing. Particular care needs to be

taken with those whose experiences are still quite 'raw', or 'deep' in Langer's term (Langer 1992) and that it may be potentially harmful to challenge the narratives of those who have more processed memories. All names have been changed and details altered in order to disguise the identities of the interviewees.

1. The Complex Loss

It is very important to understand that families who have had a member experience serious mental health problems perceive that there has been a great change in their family member. This change has been experienced as loss, as has been observed in other studies of families' responses to mental illness (Davis and Schultz 1997; MacGregor 1994; Wasow 1995). This short extract from an interview with Mrs Karajac illustrates the prominence of the experience of loss. Mrs Karajac's daughter was in her mid-twenties and began to have serious difficulties over ten years previously (reaching a crisis when she was taking her GCSE exams at 16 years of age). In response to a very general question (1) Mrs Karajac told me about seeing former friends of her daughter and the pain she feels in realising what she has lost.

DJ: How do you think it has changed your life? (1)

MK: It's made me a bit bitter . . . Especially when I'm walking in the street and I look at people who were going to school, and I think of her . . . [] . . . I look at the friends, [her] friends that I used to know. When I meet [them] in the street and hear how old they are and how are they doing and I think . . . So then I am really sort of bitter, but then I think what's the use? . . . She's not going to change . . . I try to forget about it.

This short extract points us towards the first of three particular complicating factors that will be considered: the difficulty of adjusting to the loss of a person who has not actually gone away but is seen as if they are someone else.

1.1 The Fear of Betrayal

Mrs Karajac had a sense of loss because, in her own mind, her daughter had become a different person and has been unable to keep up with her former school friends (having

relationships, jobs and perhaps a family of her own). Bruce and Schultz (2002) refer to this kind of loss as 'non-finite', since it is constantly being re-newed as different life points are reached (see also Creer 1975, Wasow 1995 who emphasise this in relation to the families of those with serious mental illness), whilst her daughter is actually still a real physical presence. This dilemma is reflected on by another interviewee, Mrs Mansell, whose own experience as a bereavement counsellor (2) allowed her a perspective on her own feelings about her husband who had a long history of serious psychiatric illness. Although she felt that her husband had changed completely (and she has separated from him) she felt unable to move on through a process of grief (1) and have another relationship because there was no space within her for another relationship (3) because her husband was physically still around (4):

DJ: How do you feel about Alfred now?

IM: Part of me has to see him sometimes. One thing is I can't grieve properly (1), if he'd had died you know what to do. Being a bereavement counsellor (2), I know what to expect, what to do and you can perhaps make a new beginning, but with Alfred he's never asked me whether I have a relationship with anybody, I haven't, but he just takes it for granted that I'm here. I don't think I have anything left for another relationship (3), [edit] . . . If I see him, that shows me that he's not dead and that although I'm grieving (I know it's there it's true) I find it difficult to know that he's in the world, he's not dead (4) - why's he not with us?

Mrs Christian was a mother who seemed to be caught in the middle of a visible and active grief. I met with her several times and carried out two recorded interviews and in both she was tearful, angry and upset. Although the interviews were two years apart, it is significant that they were very similar. The first interview occurred 25 years after her son's initial diagnosis with schizophrenia. He had spent the intervening years in and out of psychiatric care. Given the length of time involved, Mrs Christian's situation seems very much to deserve the label of 'chronic grief'. It is interesting that in this exchange, whilst she acknowledged that relatives have been around her to offer support, she has felt isolated by their failure to understand her grief; they have felt as though she should be over it now (2). This is perhaps a good example of what MacGregor (1994) refers to as 'disenfranchised grief' - one that is not readily recognised by the wider community. There follows a significant couple of phrases. Her rhetorical question (3) suggests that she felt 'crippled' by what has happened to her son. This direct reference to her feelings is then denied, instead she referred to her son's 'crippling illness' (4). I think she felt too guilty to complain about the pain that *she*

has felt when she sees him continuing to suffer. Any attempt to move away from the pain that she has would feel like a betrayal of her son (5).

DJ: Do you have people you can turn to?

LC: Yes . I have lots of relatives (1) . . I think sometimes they think, relatives and friends, that you should be used to it now (2). I feel that's what they think, but you don't get used to it, how do you get used to such a crippling (3). . . , watching someone suffering from such a crippling illness (4). It's not on . . it would be turning your back on them (5). You can sometimes stand back, and I do, you know try and be objective, there's still the pain and the hurt is there. . . .

The ambivalence of grief is therefore doubly reinforced. To move on from the grief is not only difficult because it involves a betrayal of the memories of the past (as in 'normal' grief), but is difficult because the person is still around, however much altered. Later in the interview Mrs Christian talked about a cousin (Tom) of her son (Peter), who had become successful in his career. This appears to be poignant because her son had, before his difficulties began, been doing very well in school. Mrs Christian appeared to be upset that her own son did not feel valued anymore (1).

Peter would ask me 'How's Tom doing?', in the early days I found it hard to tell him that he's a journalist and a lawyer, doing very well. Peter would say "He must be very clever", I'd say 'Well, average he works hard for it'. Peter has this thing on his locker on the ward, something like "I am a genius I have a high IQ, if you don't believe me, ask the staff", he used to have it in the hostel as well. I said to him once, trying to get a reaction from him, 'Peter you're not living up to what it says on there, you could do lots of things, you could help yourself more, make life a lot easier for yourself'. "I suppose so he said". 'Why do you put it up there Peter, we all know you're clever anyway?'. He said: "I want people to think that I am a somebody, I'm not a nobody" (1). I said: 'Of course Peter you're important, very important, don't ever forget it. You are a very important person to yourself, to me, to all the people you know'. (2) It's very sad that he thinks that.

As I was struck by this very bold statement about Peter's worth to her and others (2 - *above*) I asked her directly about what he meant to her (1 - *below*). I suspect that her response that Peter means 'everything' to her is an accurate reflection of her feelings (2). The suffering of her son, and her own grief, are major preoccupations. This is hardly a reconcilable loss. On one level her son *is* the same person as the successful schoolboy, but on other levels there is

no link between the past and the present. The significance of the sense of isolation that Mrs Christian has, particularly her acute awareness of the fact that her son is not as valued as perhaps he once was can be understood in terms of the importance of biographical reconstruction following loss (Walter 1996). People can build new meaning for themselves partly by engaging in dialogue about the lost person with others. But Mrs Christian feels let down and isolated by the lack of understanding she experiences around her. What relief she gets seems to come from the contact with members of the National Schizophrenia Fellowship (NSF - a voluntary organisation set up in response to the concerns of carers and families, now re-named *Rethink*), because she feels they understand:-

DJ: What does Peter mean to you? (1)

LC: Everything really (2)I will always fight for Peter, as he's not able to do it himself. I don't care who I upset along the way, I shouldn't have to do this . .[becomes tearful] . .it should have just been there, "Yes we'll try and help him, or find a suitable place for him", [edit]. The Fellowship [National Schizophrenia Fellowship] have been absolutely fantastic, [edit]. you never have to explain to them how you feel, they know exactly how it feels.

The extent of the anger that Mrs Christian felt is also apparent in the above extract. Anger, it has been suggested is partly a 'normal' reaction to loss of any kind (Bowlby 1980), whilst it is still a common complicating factor in grief (Marris 1978; Murray Parkes 1972). I would argue that anger is a prevalent feeling amongst relatives, simply because of the distress caused by the often difficult and unpredictable behaviour associated with mental illness (Creer 1975; Wasow 1995). Unfortunately this is anger that is often very difficult to express because it feels so wrong to be angry with people who are so clearly victims themselves. Anger therefore often emerges quite covertly.

1.2. Loss and Anger

In order to explore the importance of anger I present some quite long extracts from an interview with a man who was remarkably reflective about his feelings and relationship with his daughter. Jacob Doors' 27 year old daughter April had been in and out of psychiatric hospital since her mid-teens. During an extended interview he spontaneously brought up his fears that his daughter might kill herself. His response to my remarking on this fear is given in the extract below. He told me that he has dreams about his daughter dying (1), which

evoke feelings of remorse. Perhaps he had been too busy, wrapped up with his business affairs to have done more for her (2):

DJ: This is something that concerns you particularly, the risk of suicide?

JD: Yes, now that you mention it, yes, yes. It's a bit at the back of my mind now because, she's taking the medication and she appears better, but it is, yes, . it is a worry yes. mmm . . it is a worry. Sometimes I wake up in a dream and think that it's happened (1) and I feel terrible about it. It doesn't happen very often but it does happen. . . I haven't got an awful lot of time for April (2) I've got my work, and if I don't work I won't eat, I'll sort of be bankrupt, I owe about . £35,000 I suppose, plus the mortgage . so right now I'm worth minus £100,000! .[edit]. so I've got to keep going. But it does bother me . I wake up in these dreams "Gosh I wish I'd spent more time with her" and things like that. It does bother me yes. . . There you are . . So yes that is the main . I think you've isolated the . what it's all about, that is the main worry at the bottom of it all.

I wondered if this rumination on the risk of suicide was giving expression to some of the anger that he feels. Perhaps it was allowing him to 'fantasise' about the demise of his daughter, and consider how life might be after her death. During a second interview with Jacob Doors I felt able to inquire more closely, with a cautiously worded question, as to whether he was aware of harbouring aggressive feelings towards his daughter:-

DJ: Some families say, when things are really bad . "Sometimes I wish they had taken that bottle of pills, they said they were going to take", - to kill themselves, things would be easier. Have you ever thought like that?

JD: Er . . I'd say it has crossed my mind, yes. Don't think I've, I don't think I've verbalised it, even in my own head. But erm . yes it has, it has . I have thought about this . rather than the terrible wait, yep. . . . I imagine people feel guilty about it as well. . . . But it is a strain, and a strain is a strain, I mean I've . made it less of a strain by just cutting myself off from April unless it's necessary- to the point of being abrupt, abrupt with her, you know sort of down to earth. It keeps a barrier between me . . [edit]. But yes I can understand someone thinking that, yes, yes.

Thus there may often be an uncomfortable combination of loss and anger that can very directly lead to feelings of guilt. This may not only immediately make the process of bereavement more difficult (Murray Parkes 1972; Marris 1978), but the presence of such feelings towards someone who is seen as a victim of illness may induce feelings of shame

which may make people less likely to seek the help they need. It is shame that will be discussed next.

1.3 Loss and Shame

There is little doubt that relatives of people with mental health problems often experience stigma (Wahl and Harman 1989). Stigma can be considered to be the outward 'mark' of difference (Goffman 1963) that may or may not lead to the feelings of shame (Lewis 1998). A number of salient points about shame need to be noted. It is firstly a highly unpleasant emotion that threatens the coherence of people's sense of themselves as valued people. As Gilbert (1998:30) expresses simply, 'Shame is about being in the world as an undesirable self, a self one does not want to be'. Secondly, shame has a big impact on people's behaviour, most notably making them withdraw and hide from others (Tantam 1998), rather than seeking help and support (Wahl and Harman 1989). Thirdly, people find that experiences involving feelings of shame are often very difficult to talk about (MacDonald and Morley 2001; MacDonald 1998; Merrell Lynd 1958). All this suggests that shame is both an extremely relevant emotion to be aware of when working with families, but also one that is difficult to apprehend (Jones 2002). In the extract below, I used the much softer term 'embarrassment' (1) rather than ashamed. Jason Manula has a brother with long term mental health difficulties. He was able to say that he is aware of the impact of stigma in making him reluctant to talk about his brother's illness (2). He is particularly articulate in spelling out his anxiety that his own identity is threatened by his brother's stigmatised status (3, 4,5):

DJ: You mentioned feeling embarrassed (1) before, is it something you have difficulty talking about to some people, you try and hide it?

JM: Yes I think [in] the majority of cases, people who have a similar problem are embarrassed to talk about it . . . [edit]. . Yes it is embarrassing I don't like talking about it (2) especially to people I don't know very well. And also we all project a certain image (3) out there and once people will connect that flaw with you, they have a certain perception of you. I think some people for example, because when he gets into a very, very bad condition people begin to think that there are traces of you .(4) . . of him in you as well. When they open the door they look at you very closely to see how you look:- are you looking aggressive today or not?! . . I mean it's like little subtleties . .[edit] . I'm not saying it happens on a large, or overt scale but you can see that they seem to think that there is a weak chain in all the sort of image that you

project . strong, confident whatever. Because obviously for your brother to be in that condition means that you can't be as strong as all that. In that you do have a problem deep down (5) as well and some people want you to talk about it, but you don't want to . . .

It is important to be aware that although shame may be hidden it is an extremely powerful feeling that involves a threat to people's sense of themselves. It may well inhibit people from seeking help or revealing some of the ambivalent feelings they may have. It is also important to observe that Jason's feelings of shame stem from the strong identification he has with this brother (explored further in Jones 2002). As he says himself, it is as though his brother were a part of him (4,5 - *above*). Similarly Ami Brodoff (1988:115) movingly describes her feelings invoked in her by her brother (Andy) suffering with schizophrenia:

I felt that the part of me that was emotionally fragile, that sensed I didn't quite belong, despite belonging, had burst from its boundaries in my inner life and found expression in Andy's illness: What I harbored secretly he expressed to the world . . . In his eyes, I saw the disturbing reflection of what I feared I might become.

These complex and deep emotions may well inhibit people from discussing their feelings with others. It will now be argued that professionals may play a constructive role in allowing some of these difficult feelings to be acknowledged and for new understandings of situations to emerge.

2. Helping Families Find Meaning.

It would be hard to deny that relatives experience the illness of their relative as a loss (Davis and Schultz 1997; MacGregor 1994; Wasow 1995). The model of grief that is being assumed here is one that supposes that cognitive reconstruction is necessary as people build new systems of meaning and that dialogue can be an important means of facilitating this reconstruction. The following section will focus on how professionals working with families can facilitate these processes of dialogue by being sensitive to the complex bereavement.

Mr Johnson, whose adult son had had a diagnosis of schizophrenia for a number of years, described how important he felt communication with others has been to him. His choice of the word balance is suggestive of the shifts of views, the new meanings that can emerge through dialogue:

DJ: Some families find it difficult because other people don't understand mental illness and they're are frightened of it, think its strange- find it difficult to talk about . have you found that?

MJ: Well you find that some people find the easy way out and it doesn't work.

DJ: You mean not talking about it?

MJ: Yeah, not talking about it. Thinking that it should be a private affair and all that- doesn't work. You have to tell the people that work among the people what the people is like or what they have to cope with and so on. And they [and] you get a sort of balance between the two, the two communities that are looking after these people. You get a certain amount of balance with the nurses, a certain balance with the doctors, a certain amount of balance with the social worker you get certain balance with the welfare officer. Its balance like that . .

2.1 Allowing negative feelings to be part of the dialogue

If dialogue is important, it must be a dialogue that is able to incorporate the negative feelings that relatives often have. These feelings are after all part of the new reality. It may well be quite difficult for professionals to accept these negative feelings without challenge. Molly Quinn, who maintained a supportive relationship with her sister who had serious mental health problems, told me how the understanding of close friends had been invaluable. She had been able to express very negative feelings such as *'I wish she was dead'*, whilst not being made to feel guilty since they understood her feelings. One very clear way that negative feelings may be allowed into the dialogue was through discussion of diagnosis and prognosis.

The multi-cultural nature of the sample served to reinforce the significance of the fact that the people interviewed almost universally held an essentially medical view of what happened (in line with findings by Angermeyer and Matschinger 1996; Furnham and Bower 1992). It is important to note that they did not necessarily refer to specific diagnoses or pin their faith on

medical intervention and cure, but they did believe some *thing* had happened. There had been some external force of 'illness' that changed their relative. For those professionals in the mental health field, who are well versed in theories about the negative consequences of psychiatric labels and pessimistic beliefs about mental illness for identified patients (Goffman 1961, Scheff 1975) such views might be difficult to accept. The common psychological function of the idea of 'illness' needs to be understood, however. The idea of illness can provide a safe target for a lot of the aggressive feelings that people may have. Kinsella et al. (1996: 27) quote a sibling's succinct advice: 'Separate the illness from the person and say it's alright to hate the illness and it's best to love the person'. Jason Manula was able to articulate very clearly that he felt angry with the *illness* (1), which goes some way to protecting his positive feelings toward his brother (2):

. . . And I hate this illness (1), because it leaves me unsettled, it leaves me frightened it leaves me uncertain. I mean every time I hear the door now I always think is it him? Or is it the police bringing me bad news? -when he's ill. When he's well he'll come and visit me once a week, we'll sit, we'll cook, have a few beers we'll go out on a Friday night, enjoy ourselves go out, go over to his . . . and relate like brothers. (2) .

The psychological utility of such labels for the families needs to be understood. I would suggest that the absence of a medical view can cause difficulties. Mallon (2000, cited in Jones 2002: 136), for example, reports a daughter of a woman with a diagnosis of schizophrenia, who had entirely cut off contact with her mother. She reflected herself on being unable to see her mother as different from the 'illness':

'Y'see I don't see her as *sick*, I see her as just my mother. I can't go, "Oh, she had an illness like someone with a broken leg", you know, I just can't do that, it was just . . . it was all bundled together'.

Diagnoses provide meaning, in spite of the very negative connotations that they carry. A good example of this arose in an interview with Mrs Karajac (referred to earlier) concerning her daughter. Despite the rather negative prognosis that she was hearing from the psychiatrist (2), what he says seems to have provided some meaning to her in that it fits with her experience (3):

DJ: You said before that Dr B. has talked about schizophrenia, has he said much about that, what it might mean?

MK: He told us that they have to have the medication because they hear voices and they listen to these voices . . . that she will get frightened .[edit] . He said that the medicine would not make her better but just make her sort of more quiet . . (2).

DJ: That's what Dr B. said?

MK: Yes make her more quiet.

DJ: How did you feel about him saying that?

MK: I was not happy at all, but you have to take it that's a fact. We had come to the conclusion that it is true because the more we go on the more we realise that it isn't getting better it's getting worse. (3)

2.2 The difficulty talking about negative feelings

Having stressed the likelihood of negative feelings, it may of course be important to bear in mind that these feelings are often coexisting with other more positive feelings (Joyce et al. 2000). As discussed in Section 1.2, anger often emerges from feelings of loss and sadness. As discussed in Section 1.3, to feel 'ashamed' of someone is often a signal that people are quite strongly identified with them, or at least feel close to them. It may be useful to be aware of those negative emotions, to allow them to be expressed, but there may be little to be gained from directly exposing or challenging them. For example, Mr Ajani was, quite unusually, direct about his feelings of stigma (1). What is interesting, however, is that as I pursued the emotional implications of this for him (2), it results in fairly rapid denial of any emotion and the attempt to terminate discussion on the topic (3) which I felt unable to resist (4) :

DJ: Do you find it easy to talk to other people outside of the family about what's going on?

MrA: No, not that sort of thing in a society, in my society you don't talk about that sort of thing.

DJ: Why is that?

MrA: Because people would take the mickey out of you, you see what I mean? (1)

DJ: People would look down on you?

MrA: Yeah.

DJ: That makes it difficult?

MrA: Yeah . And they can't help you can they? It's only the authority that can help you, there's no amount of prayer that can help. You just don't talk about it, you want to remove this thing . what happened. Whatever they say you just can't cure it, it's still around.

DJ: But do you think that that has made you feel isolated . . (2)

MrA: No, no . in the first place there is no need, because I am not a mixer, I don't have to carry on telling people that this happened to me because that doesn't solve my problem, they can't solve my problem because talking to me would not have removed the problem. It's just like when you have the habit of smoking, you've got a problem . you can say 'Oh I've got this problem' when you've said that, the problem is still with you. Why bother? It isn't worth it. . . . Any other questions? (3)

DJ: I think that is everything. (4)

This was not necessarily a very premature end to the interview (it had been about 40 minutes long at this point and Mr Ajani had said quite a lot about what had happened to his son). However, it does seem likely that Mr Ajani felt very uncomfortable about any exploration of his feelings of shame and isolation that may have led behind the experience of stigma (as discussed earlier, in section 1.3, people are reluctant to discuss their feelings of shame). This example emphasises that to directly draw attention to the negative feelings may not necessarily be constructive. Instead what might be borne in mind is the fact that those strong negative feelings are themselves attached to feelings of loss, guilt and very often love. I was very struck by an interview with Penny O'Reilly who had come across as rather flippant and dismissive of the difficulties that her two brothers had had. For example, when asked about the treatments one of her brothers had been offered, she commented:

. . . I don't think Andrew would benefit from group therapy. He'd bloody bore you to tears!

[laughing] They'd all bore you to tears honestly, unless people have emotional [problems], group therapy helps with emotional [problems] or drink problems, not mentally ill people I don't think.

'Cos they start talking, bore you to tears about voices and that sort of stuff . . . um so I can't see

how else they can really help him, apart from medication, he takes drugs I don't know whether he takes them in tablet form, liquid form, injection I haven't a clue.

On hearing this, it would be reasonable to conclude that Penny O'Reilly might not make a reliable source of support for her brothers. However, guessing that she had deeper feelings for her brothers (she had, after all, agreed to be interviewed, and she had talked about them for quite some time) I commented on her feelings of responsibility which had not openly been discussed (1). The positive contrast I made with others who are not able to maintain a relationship unleashed a considerable amount of her feelings of responsibility and affection which had not been expressed but were very clearly present underneath the more dismissive and (perhaps guilty) feelings:

DJ: You obviously do feel quite responsible, a couple of times you've used the word 'ought' about visiting . (1).

PO: I do feel very responsible, they are my responsibility, yep absolutely.

DJ: Where do you think that comes from? Not everyone feels that.

PO: Don't they?

DJ: No, plenty of families eventually give up, cut themselves off.

PO: Oh I think that's . . . mmmm . . . it must be because I'm a nice person [laughing] . . . I can't. . . I just don't understand why . . . Well I can understand why yes, it depends on the sort of things that they've been up to - I mean you can be at the end of your tether and they can be really nasty and . . . I'm not saying Andrew or Sean in particular, but I would say that, er . . . you know you could get one that would come in and beat you up and smash up the house and take your money. You'd want to wash your hands of somebody like that, but er . . . I do feel it's my responsibility and a duty as well

I mean - they're my flesh and blood it's as simple as that and I like them. It just seems strange that people wouldn't do that or would cut themselves off, it's a pleasure - you know if I actually catch Andrew and he's quite funny sometimes it's, you know, it's nice ..

Conclusions

Professionals who work with families of people experiencing serious mental illness need to be aware of the uncomfortable feelings with which relatives may be struggling. They are involved in a bereavement process that is complicated by the presence of feelings of anger, guilt and shame. Perhaps too often in the past, the presence of these negative feelings have been observed and have been assumed to be a sign of some underlying family pathology (as witnessed by the large number of family therapy models that proliferated in the latter half of the 20th century). Indeed the presence of critical emotions in families has given rise to a considerable volume of 'expressed emotion' research (Leff 1994). Whilst expressed emotion researchers have not blamed families directly, critics of the approach have still argued that '[h]igh EE and low EE are seen as labels that once again depict families as "good families" and "bad families" - usually the latter' Hatfield (1987:61). This paper has reviewed three perspectives on the experiences of relatives that can delay resolution of the grief and may produce negative feelings:

- This is a complex bereavement in that although relatives do feel that they have on one level lost someone - they may feel reluctant to accept that loss as they feel they are betraying that person who has been lost, since that person is still actually around ('non finite grief', Bruce and Schultz 2002).
- Families may often feel anger towards people with mental health problems. Anger can be a significant impediment to a process of bereavement.
- Feelings of shame that often emerge through association with such a stigmatised state as mental illness can stop people finding help, support, and the dialogue with others that can be helpful to building new meaning in changed circumstances.

Professionals may have a number of contributions to make in helping families come to terms with some of the complex feelings that they have. Firstly when working with families they can allow space for negative feelings to be acknowledged in a non-critical atmosphere. At the same time, however, whilst it is important that professionals be aware of the presence of these negative feelings, and where they may stem from, it is often not necessarily a good thing to directly draw attention to them. Such direct exposure of such negative feelings might trigger additional feelings of shame. It may also be helpful to bear in mind that these negative feelings of anger and shame are very often attached to feelings of loss, love and commitment. Secondly professionals can work to set up and encourage relative support groups (Sheridan and Moore 1991). In a mutually supportive and non-critical atmosphere those complex feelings can be heard and be come to terms with.

Acknowledgements: I am grateful to Professor Shulamit Ramon, Anglia Polytechnic University for her support and guidance of the original project, and to Jo Campling for help in shaping the written project. I am grateful for the comments of 2 anonymous reviewers. Most of all I am grateful to those families who so willingly gave their time and so bravely talked about their lives. This paper is written in the hope that those lives may be better understood.

Bibliography

Angermeyer, M., C. and Matschinger, H. (1996) 'Relatives' beliefs about the causes of schizophrenia.' *Acta Psychiatrica Scandinavica* 93 (3) 199-204

Atkinson, S. D. (1994) 'Grieving and Loss in parents with a schizophrenic child.' *American Journal of Psychiatry* 151 1137-1139.

Bateson, G, Jackson, D., Haley, J. and Weakland , J. 'Towards a theory of schizophrenia.' *Behavioural Science* 1 (4) 251-264

Bogdan, R. and Taylor, S. J. (1975) *Introduction to qualitative methods: A phenomenological Approach to the social sciences*. Wiley: New York.

Bonanno, G. A. and Kaltman, S. (1999) 'Toward an Integrative Perspective on Bereavement.' *Psychological Bulletin* 125 (6) 760-776.

Bowlby, J. (1980) *Loss, Sadness and Depression*. Howgarth Press: London.

Brodoff, A. S. (1988) 'First Person Account: Schizophrenia through a sister's eyes – the burden of invisible baggage.' *Schizophrenia Bulletin* 14 (1) 113-116.

Bruce, E. and Schultz, C. (2002) 'Non-finite loss and challenges to communication between parents and professionals.' *British Journal of Special Education* 29 (1) 9-13

- Craib, I. (1995) 'Some Comments on the Sociology of the Emotions.' *Sociology* 29 (1) 151-158.
- Creer, C. (1975) 'Living With Schizophrenia.' *Social Work Today* 6 (1) p2-7.
- Currer, C (2001) *Responding to Grief: Dying, Bereavement and Social Care*. Palgrave: Basingstoke.
- Davis, D. and Schultz (1997) 'Grief, Parenting, and Schizophrenia.' *Social Science and Medicine* 46 (3) 369-379.
- Department of Health (1995a) *Building Bridges: A guide to Arrangements for Inter-Agency Working for the Care and Protection of Severely Mentally Ill People*. DoH: London.
- Department of Health (1995b) *Carers (Recognition and Services) Act*. HMSO: London.
- Department of Health (1999) *A National Service Framework for Mental Health*. Department of Health: London.
- Downing, A. and Hatfield, B. (1999) 'The Care Programme Approach: Dimensions of Evaluation.' *Brit J of Social Work* 29 841-860
- Fromm-Reichman, F. (1948) 'Notes on development of treatment of schizophrenics by psychoanalytic psychotherapy.' *Psychiatry* 11 263.
- Furnham, A. and Bower, P. (1992) 'A comparison of academic and lay theories of schizophrenia.' *British Journal of Psychiatry* 161 201-10.
- Gilbert, P. and Andrews, B. (1998) *Shame: Interpersonal Psychopathology , and Culture*. Oxford University Press: Oxford.
- Glaser, B. G and Straus, A. (1967) *On the discovery of grounded theory*. Weidenfield and Nicholson: London.
- Goffman, E. (1961) *Asylums*. Pelican Edition. Penguin: Harmondsworth.
- Goffman, E. (1963) *Stigma: Notes on the Management of a Spoiled Identity*. Penguin: Harmondsworth.
- Hatfield, A, (1987) "Coping and Adaptation: A Conceptual Framework For Understanding Families." in *Families of the Mentally Ill: Coping and Adaptation*. Eds Hatfield, A. and Lefley, H. P. (1987) Cassell: London.
- Hirsch, S. and Leff, J. (1975) *Abnormalities in the parents of schizophrenics*. Oxford University Press: London.
- Holden, D. F. and Lewine, R, R, J. (1982) 'How Families evaluate mental health professionals, resources, and effects of illness.' *Schizophrenia Bulletin* 8 (4) 626-633

- Hollway, W. (1989) *Subjectivity and Method in Psychology: Gender, Meaning and Science*. Sage: London.
- Hollway, W. and Jefferson, T. (2000) *Doing Qualitative Work Differently*. Sage: London.
- Hunt, J. (1989) *Psychoanalytic Aspects of Fieldwork*. Qualitative Research Methods, Vol 18. Sage: London.
- Johnson, J. (1975) *Doing Field Research*. The Free Press: New York.
- Jones, D., W., (1998) 'Distressing Histories and Unhappy Interviewing'. *Oral History Journal* 26 (2) 49-56.
- Jones, D., W., (2002) *Myths, Madness and the Family: The impact of mental illness on families*. Palgrave: Basingstoke.
- Jordan, R. and Parkinson, C. (2001) 'Reflective practice in a process for the re-approval of the ASWs: an exploration of some inevitable resistance.' *Journal of Social Work Practice* 15 (1) 67-79.
- Joyce, J.; Leese, M. and Szmukler, G. (2000) 'The Experience of Caregiving Inventory: further evidence.' *Social Psychiatry and Psychiatric Epidemiology* 35 (4) 185-189
- Kingsella, K. B. Anderson, R.A. and Anderson, W. T. (1996) "Coping skills, strengths, and needs as perceived by adult offspring of people with mental illness: A retrospective study." *Psychiatric Rehabilitation Journal* 20 (2) 24-32.
- Kleinman, S. and Copp, M. A. (1993) *Emotions and Fieldwork*. Qualitative Research Methods vol 28. Sage: Newbury Park.
- Laing, R. D. (1965) *The Divided Self*. Penguin: Harmondsworth.
- Laing, R, D. (1964) *Sanity Madness and the Family*. Tavistock: London.
- Laing, R.D (1967) *The Politics of Experience*. Penguin: Harmondsworth
- Leff, J. (1994) 'Working with Families of Schizophrenic Patients.' *British Journal of Psychiatry* 164 (suppl 23), 71-76.
- Lewis, M. (1998) 'Shame and Stigma.' In P. Gilbert and B. Andrews. *Shame: Interpersonal Behaviour, Psychopathology, and Culture*. pp 126-140. Oxford University Press
- Lidz, R. and Lidz, T. (1949) "The family environment of the schizophrenic patient." *American Journal of Psychiatry* 106 p332-45
- MacDonald, J. (1998) 'Disclosing Shame.' In Gilbert, P. and Andrews, B. *Shame: Interpersonal Psychopathology, and Culture*. Oxford University Press: Oxford.

- Macdonald, J. and Morley, J. (2001) 'Shame and non-disclosure: A study of the emotional isolation of people referred for psychotherapy.' *British Journal of Medical Psychology* 74 1-21
- MacGregor, P. (1994) 'Grief; The unrecognised parental response to mental illness in a child.' *Social Work (USA)* 39 (2) 161-166
- Marris, P. (1978) *Loss and Change*. Routledge and Kegan Paul: London.
- Merrell Lynd, H. (1958) *On Shame and the Search for Identity*. Harvester: New York.
- Mills, E. (1962) *Living with Mental Illness: A study in East London*. Routledge and Kegan Paul: London.
- Murray Parkes, C. (1972) *Bereavement: Studies of Grief in Adult Life*. Tavistock: London.
- Oppng-Tutu, A. (1997) 'Working with the mentally ill and their families.' *Mental Health Nursing* 17 (4) 8-10.
- Pejlert, A. (2001) 'Being a parent of an adult son or daughter with severe mental illness receiving professional care: parents' narratives.' *Health and Social Care in the Community* 9 194-204.
- Potter, J. and Wetherell, M. (1987) "*Discourse and Social Psychology: Beyond Attitudes and Behaviour*." Sage: London.
- Rogers, M. (1983) *Sociology, Ethnomethodology, and Experience: A Phenomenological Critique*. Cambridge University Press: Cambridge.
- Rorty, R. (1980) *Philosophy and the Mirror of Nature*. Basil Blackwell: Oxford.
- Sandler, J. Dare, C. and Holder, A. (1973) *The Patient and The Analyst: The Basis of the Psychoanalytic Process* Karnac: London.
- Scheff T.J. (1975) *Labelling Madness*. Prentice Hall Inc. Endelfield Cliff. NJ: USA
- Sedgwick, P. (1982) *Psychopolitics*. Pluto Press: London.
- Selvini-Palozzoli, M., Boscolo, L. Cecchin, G. and Prati, C (1978) *Paradox and counter-paradox. A new model in the therapy of the family in schizophrenic transactions*. Jason Aronson: New York.
- Shepherd, G. Murray, A. and Muijen, M. (1994) *Relative Values: The Differing Views of Users, Family Carers and Professionals On Services For People With Schizophrenia In The Community*. The Sainsbury Centre For Mental Health: London.
- Sheridan, A. and Moore, L. (1991) 'Running Groups for Parents with Schizophrenic Adolescents: Initial Experiences and Plans for the Future.' *Journal of Adolescence* 14 1-16.

Silverman, D. (1985) *Qualitative Methodology and Sociology*. Gower Publishing: Brookfield USA.

Silverman, D. (1993) *Interpreting Qualitative Data: Methods For Analysing Talk, Text, and Interaction*. Sage Publications: London.

Smith, J. A., Jarman, M. and Osborn, M. (1999) "Doing Interpretive Phenomenological Analysis." In *Qualitative Health Psychology: Theories and methods* eds Murray, M. and Chamberlain, K. Sage: London.

Stroebe, M. and Schut, H. (1999) 'The Dual process/model of coping with bereavement: Rationale and Description.' *Death Studies* 23 197-224.

Strong, S. (1997) *Unconditional Love: The Views and Experiences of Parents Living with Children with Mental Health Problems*. The Mental Health Foundation: London.

Tantam, D. (1998) 'The Emotional Disorders of Shame.' In Gilbert and Andrews eds *Shame: Interpersonal Psychopathology, and Culture*. Oxford University Press: Oxford.

Terkelson, K, G. (1987) ' The Meaning of Mental Illness to the Family.' in *Families of the Mentally Ill: Coping and Adaptation*. Eds Hatfield, A. and Lefley, H. P. (1987) Cassell: London.

Tietze, T. (1949) 'A Study of Mothers of Schizophrenic Patients.' *Psychiatry* 12 55-65

Wahl, O.F and Harman, C.R. (1989) "Family Views of Stigma." *Schizophrenia Bulletin* 15 (1) 131-139.

Walter, T. (1996) 'A New Model of Grief: Bereavement and Biography.' *Mortality* 1 (1) p7-25.

Wasow, M. (1995) *The Skipping Stone: Ripple Effects of Mental Illness on the Family*. Science and Behaviour Books: Palo Alto.

Winefield, H. R. and Harvey, E.,J. (1994) 'Needs of Family Caregivers in Chronic Schizophrenia.' *Schizophrenia Bulletin* 20 3 557-566.

Zolik, E.,S., Des Lauries, A., Graybill, J, G. and Hollon, T. (1962) 'Fulfilling the Needs of 'forgotten' families.' *American Journal of Orthopsychiatry* 32 176-185.