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Shame and Loss
narrative and identity in families with a member suffering from mental illness

David W Jones

This paper investigates the impact that shame can have on people’s sense of identity and how this can be a major factor in exacerbating feelings of loss. Whilst acknowledging the considerable contemporary theoretical interest in the affect of shame, attention is drawn to the methodological difficulties inherent in studying shame. It is argued that shame is an important aspect of human experience but is one that provides a challenge not only to quantitative methods, but also to conventional qualitative methods of enquiry. A methodology based on psychodynamically-informed interviews and analysis is therefore utilised.

Extracts of interviews with families (drawn from a larger study of the impact of serious mental illness on families) are used to argue that the shame of having a family member suffer from mental illness can very directly threaten people’s sense of identity. Shame, it will be argued, helps us understand the well-recognised phenomenon of ‘chronic grieving’ amongst relatives of people with severe mental health problems. Shame keeps people out of the dialogue with others through which new narratives of self might be developed. Theoretical links between this construct of shame and chronic grieving can be made with observations of the associations between shame and depression.

Introduction
This paper is concerned with reaching a better understanding of people’s experiences of shame. After many years of neglect, the past two to three decades have witnessed an upsurge of interest in shame within mainstream psychology (Gilbert, 1998), psychoanalysis (Broucek, 1982; Chasseguet-Smirgel, 1985; Kingston, 1983; Rizzuto, 1991) and sociology (Giddens, 1991; Vogler, 2000). Despite this growth, there are difficulties in studying shame within traditional disciplinary contexts. It will be argued here that shame needs to be understood as a psychosocial concept. It is paradoxically a very intimate and private emotion, yet is also hard to conceive of without the external world: an essential aspect of shame is the feeling of being judged by a real or imagined other. The study of shame has been beset by difficulties of definition and methodological problems that are arguably connected to this mercurial and paradoxical nature of shame: hidden, private and yet inconceivable without culture (Heller 1985).

I came by an interest in shame through carrying out interviews with people who had a family member suffer from serious mental illness. Shame was not something I was looking for when I started. I was interested, however, in ‘stigma’, as the ‘outward’ mark of difference (Goffman, 1963). This was an issue that has been thoroughly explored in relation to those who have been diagnosed as suffering from mental illness themselves (Scheff, 1975 for example). There were good grounds for thinking that families would experience stigma (Wahl and Harman, 1989) which would be significant in that it might well inhibit them from seeking help and support. I found, however, that this stigma was more complex – for one thing it was difficult to get people to talk about. This obstacle to communication pointed the way to the affect of stigma – shame. Two particular issues will be dealt with in this paper: the methodological difficulties of studying shame and the impact that shaming experiences can have on people’s sense of identity which might well provide some explanation for the commonly observed phenomenon of ‘chronic grief’.

Relatives and Mental Illness: Chronic Grief
Many writers and researchers have now drawn attention to the apparently difficult bereavement process that relatives of people with severe mental health problems are involved in (Atkinson, 1994; Cree, 1975; Davis and Shutz, 1997; Lanqueter, 1988; Macgreggor, 1994; Spaniol, Zipple and Lockwood, 1992; Wasow, 1995). A number of explanations have been put forward to explain why this grief should be so difficult to move through. Davis and Schultz suggest that the presence of ‘reminders of loss, or the discrepancy between “the world that is with the world that should be” (Parkes, 1988:5) were blatant and frequent’
(1997:375). It has also been argued that feelings of guilt will inhibit the grieving process, as people may feel they do not deserve to get over it (MacGregor, 1994). This also might be an example of what MacGregor (1994) refers to as ‘disenfranchised grief’; that is grief that is not understood or acknowledged by the wider community. Whilst these factors no doubt have some relevance, the case will be made that feelings of shame can inhibit the dialogue that can be so important to people in ‘updating’ the narrative of their lives and assisting them to find new meaning in the post-loss circumstances.

Conceptualizing Shame

Despite the growing interest in shame, this is an area still dogged by major conceptual differences between theorists (see Gilbert, 1998, and Pattison, 2000, for reviews). No attempt will be made to address these differences here, since it may well be that, as Pattison (2000:39) argues ‘approaches to shame are mostly disparate and incommensurable’. I suggest that part of the difficulty is due to the longstanding divide between the ‘social’ and ‘psychological’ academic disciplines. Shame needs to be understood as belonging to neither one nor the other, but can only be understood within the context of an interaction of both.

For the purposes of this paper, shame is defined as the painful and aversive feeling that follows as someone judges that their own self is being, or will be, judged as unacceptable. Piers and Singer (1953/1971) produced an early formulation of shame, many of the themes of which have been developed in more recent psychoanalytic accounts (Broucek, 1982; Chasseguet-Smirgel, 1985; Kingston, 1983; Rizzuto, 1991) and biological approaches (Gilbert and Mcguire, 1998). This formulation provides a link between the often hidden and intimate emotion of shame and wider cultural processes. Piers and Singer drew a distinction between guilt and shame in psychoanalytic terms. They saw guilt being produced from tension ‘between ego and super-ego’ whilst shame arose from ‘tension between the ego and the ego-ideal’. The distinction between ego-ideal and super-ego was not made by Freud, but by others since then (see Chasseguet-Smirgel, 1985 for review). Guilt, according to Piers and Singer, resulted from a perceived transgression of some internalised behavioural boundary, whereas shame came when a person feels that they are being found wanting in comparison to their own idealised self. Piers and Singer’s view of the role of the ego-ideal in the life of shame throws light on these relatives’ experiences. Piers and Singer are consistent with traditional psychoanalytic accounts of the ego-ideal, agreeing that it is formed in large part through identifications with parental objects. They go further than this and suggest that the ego-ideal is far more adaptable and open to much later influences. Identifications with siblings and peer groups are likely to have a part in the continuing formation of the ego-ideal. There are definite parallels here with more sociological and social psychological notions of identity that stress the importance of social interaction in the constant construction of selfhood (Berger and Luckman, 1967; Bruner, 1990; Harré, 1998). Indeed there are now many converging theoretical constructs emphasising the central importance of interaction to the development of selfhood. Daniel Stern’s (1998) meticulous work on child development emphasises the dialogic nature of non-verbal interaction between parents and very young infants – arguing that these interactions are vital to the development of an individual sense of self. As the child matures and develops the capacity for language, verbal interactions will build ‘a sense of verbal self’. There is now growing theoretical interest in the importance of dialogue and narrative in the construction of selfhood (Gregg, 1995; Hermans, Rijks and Kempen, 1993; Lysaker and Lysaker, 2001). Wyatt (1986) and Schafer (1992) suggest that the therapeutic efficacy of psychoanalysis is through its ability to support the patient through refashioning their own personal narratives in ways that help them experience a more coherent sense of themselves (see McLeod, 1997 for a review of the use of narrative approaches in a range of psychotherapy schools).

If shame disrupts interaction and dialogue then it seems likely that it will interrupt the process through which people can continue to refashion their sense of self. Anthony Giddens suggested something similar in arguing that shame threatens identity because it is ‘essentially anxiety about the adequacy of the narrative by means of which the individual sustains a coherent biography’ (Giddens, 1991: 65). A plausible explanation for these relatives becoming stuck in experiences of chronic grief may be the impact of shame on their interactions with others. If interaction occurs it may allow people’s sense of themselves and their relationship to the ‘ill’ family member to grow and change. I will argue that there was evidence during the interviews of shame inhibiting the dialogue that could update the narrative of people’s lives. It is this link between shame and the ability to update and refashion ourselves that suggests more general links between experiences of shame and depression.
Shame, Chronic Grief and Depression

Whilst the links between shame and depression remain the source of some debate (Sloman, 2000; MacDonald and Morley, 2001), correlations between depressive symptoms and self-reports of shame have consistently been found (Tangney, 1993 for example). Andrews, Qian and Valentine (2002) suggest that shame may have a causal role in depression. Scheff (2001) argues that the roots of depression lie in a lack of secure social bonds and that shame is like an alarm ‘a response to threatened or severed bonds’ (Scheff, 2001:218). I will argue here that there may well often be a link between shame and depression. This link can be better understood in terms of the role that shame plays in stifling the dialogue, which can be necessary to the creation of new meanings that may help an individual find their way out of depression.

The proposition here is that people’s sense of selfhood is dependent on them having a narrative of that self that needs to develop and change. I will argue that Giddens (1991) is right to identify shame as causing a rupture in this process since shame leads people to withdraw from dialogue and interaction with others which is a crucial mechanism through which the narrative of the self can be developed. This formulation offers a helpful way of understanding certain psychological aspects of the experiences of those who have suffered shame amidst loss.

The Methodological Challenge of Shame

Despite the growth in interest in the affect of shame, the empirical study of shame still provides major methodological challenges. It is difficult to study since, as many commentators have observed, one of its chief manifestations is to make people withdraw from social connection and dialogue (Tantam, 1998) and to avoid discussing those aspects of life that were experienced as shameful (MacDonald and Morley, 2001; MacDonald, 1998; Merrell, 1958). It is part of the argument here that people who have a family member suffering from serious mental illness are very likely to be ashamed, but may have great trouble discussing those feelings. Shame often seemed to emerge in quite overt ways during interviews with families about their experiences of living with mental illness. It was in the dynamic space of the interview itself where the shape of shame could be felt, and in the ostensible breaks in communication that shame could be heard. It is therefore important that methodological techniques that are able to apprehend such communications are explored. This study uses data gathered from qualitative in-depth interviews with families. The methodology utilizes principles from traditional qualitative interviewing alongside assumptions, drawn from psychodynamic theory that significant aspects of people’s experiences may not be expressed directly (Hollway and Jefferson, 2000; Jones, 1998).

Method

Two different means of identifying potential participants in an urban area of North London in the UK were used –

i) 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.

ii) Relatives of another group consisting of a random sample of people referred to a Community Psychiatrist. The grounds for including this group were that a decision had been made somewhere that these were people who would be requiring long-term support.

In both groups, participants were from families of people who had at some time received a diagnosis of schizophrenia, or bipolar affective disorder who were below the age of 55, and were not being resettled as part of the repARATION programme. Thirty-four families were interviewed. In terms of ethnicity, they reflected the multicultural area of North London in which the study was based (King et al. 1994). Over half the samples were from an ethnic minority, mainly of African-Caribbean origin. Most of the interviewees were parents, but siblings were also interviewed.

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 this, I was influenced by a strong tradition of phenomenologically informed qualitative research which developed originally in sociology (Bogdan and Taylor, 1975; Glaser and Strauss, 1967; Schutz, 1954/1967; Silverman, 1985), the themes of which are to be found in more recent work in psychology (Harré, 1981; Hollway, 1989; Potter and Wetherell, 1987 and Smith, Jarman and Osborn, 1999). There have been, however, well recorded difficulties with including the emotional worlds of individuals within the findings of this tradition of qualitative research (as discussed by Craib, 1995; Kleinman, and Copp, 1993; Oakley, 1981; O’Connell and Laydor, 1994 for example). The difficulty perhaps emerges because the emotional issues are not necessarily manifest in the transcripts of interviews or in the overt behaviour of the people studied. Since I was particularly interested in examining the emotional impacts and understandings of events it was also necessary to utilise ideas with roots in psychodynamic thought (Hollway and Jefferson, 2000; Hunt, 1989; Jones, 1998). Simply put, these were based on the understanding that a research interview is an event that entails communications occurring at covert and emotional levels.

The interviews and the analysis
A number of techniques can be employed in a research setting which are based on ‘the assumption of association’ (Jones, 1998), techniques that draw on the psychoanalytic concept of free association (Sandler, Dare and Holder, 1973). In other words, the assumption is made that the language people use and the connections that people make between topics can be taken as indicating the emotional significance and meaning of experiences for people in ways that they may not themselves 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, facial expression, or posture is used that may suggest an alternative to the overtly intended meaning. The emphasis on the communication of emotional states demands that researchers be able to monitor their own emotional reactions during interviews, since such non-verbal communication often takes place on such a level. Such monitoring has been referred to, in social research, as reflexivity (Kleinman and Copp, 1993) or as counter-transference in the psychoanalytic literature. Counter-transference can broadly be defined as the experiences of the analyst that occur in the presence of the patient. It was originally seen as some kind of a blockage in the analyst where he/she was failing to understand the unconscious communication of the patient. This blockage was construed as some neurotic reaction within the analyst that suggested the analyst needed further psychoanalysis. Since Freud’s original use in 1910 the concept of counter-transference has been refined and developed particularly by the British school of object relations (Bollas, 1987; Kohon, 1986; Raynor, 1990). Paula Heimann’s (1950) paper was seminal in drawing attention to the communicative aspects of counter-transference. By careful and critical monitoring of their own feelings evoked in the analytic setting an analyst may gain useful insight into the unconscious dynamics taking place and therefore into the internal world of the patient. Samuels (1993) suggests that it is through this notion of counter-transference that depth psychology might make its greatest contribution to political and social analysis. Counter-transference feelings represent a point of contact between the analyst/researcher and the subject of research. This notion was particularly useful in this study in throwing light on one mother’s experience of shame, as will be discussed later.³

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 from them 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. The ideas about the significance of shame came partly from experiences within, and reflections upon, the interviews themselves. These ideas developed further through reading and discussion with others. The results of these processes are subjective interpretations of the interview material. This clearly poses 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 refer to the interview material below.

It is worth noting that I am deliberately drawing an artificial boundary around the psycho-social space in order to make some particular points about the significance of the impact of shame. Many issues could be brought up to explain why particular individuals experience shame – notably concerning people’s biographies and social factors.
such as gender and ethnicity. This study is focused on the impact that shame itself can have.

Extracts from three different interviews will be introduced and explored. The first will be used to make the case for understanding relatives’ experiences of stigmatization in terms of the emotion of shame. The interview illustrates the very direct impact that shaming experiences can have on people’s sense of identities. The second example will illustrate how one common manifestation of shame is to make people withdraw from dialogue. This withdrawal from dialogue, it will be argued, has made it very difficult for this particular mother to find new meanings that could accommodate the losses she has experienced. She is stuck in ‘chronic grief’. The third example is of a family that appears to have been able to maintain a dialogue amongst each other, including the person suffering mental illness. They have been able to talk about both the experiences of stigma and of loss. This capacity was manifest in the interview. This dialogue has allowed the narrative of their lives, and their sense of themselves to develop. The loss they feel through having one of their number suffer from mental illness is not denied, but becomes part of the narrative through which they are able to understand themselves and their identities.

1. Stigma, Shame and Identity

Jason Manula was an interviewee who was able to offer useful insight into the links between stigmatisation and psychological processes of shaming. Jason had a brother who had a long history of psychiatric hospitalisation with a diagnosis of bipolar affective disorder. At one point Jason described going to the hospital to talk to staff about what was going on in order to garner support (1). He used very strong language (2), to describe his frustration that even though he has made revelations about himself and his family, there was no real response (3):

DJ: Do doctors and other people talk to you about what they think?
JM: Do the doctors? No, not at all. No they don’t … you’re the first person who has spoken to me about this, and normally when I have taken him to a hospital I have really tried to explain what it’s like (1) I’ve tried to, in some cases, even exaggerate a little but just to make them take notice but, you know, it’s so frustrating you know you walk away thinking ‘Why the fuck (2) did I go in there in the first place? Why did I reveal all those personal things about myself and my family if they’re not going to be responsive?’ (3) OK they have a lot on their plates, that’s how I justify some of their actions but I just . . .

As the interview continued, the meaning of the strong language (4) with its suggestion of humiliation (and so perhaps with shame) becomes clearer. Jason actually swore only on these two occasions (in the excerpt above and below) when he was describing his feelings about talking about his brother’s difficulties. Jason described himself as becoming reluctant to confide in others because he would be revealing something that others might find unacceptable. Jason is aware of a dilemma here in that in cutting himself off from people he may be less able to help his brother this time (5):

DJ: Have you had people that you can talk to, turn to for support?
JM: Er . . . Friends, immediate friends. But even then after a while you don’t want to encroach on their privacy, you don’t want to take them for granted. And furthermore they begin to feel “I’ve heard this crap before” (4). And also I don’t particularly want to go to people to relate this same thing year in year out “Oh another crisis in the family”, this type of thing; I mean people get fed up. And this time, as I said, I’m going through my own personal sort of problems as well, in terms of marriage and divorce etcetera . . . And I’ve cut myself off from lots of people. I’ve fewer people to relate to this time now, at that level (5). And I think that’s probably why this time I’m not even taking this illness on board.

When I asked Jason directly about his feelings of embarrassment he articulated concerns about his identity being damaged. He assumes that people will perceive that his ‘image’ (6, 8) is flawed if people know about his brother. Jason feels that people will see traces of his brother in him (7), there is a stumble over words at this point emphasising the doubt about where the precise boundary between himself and his brother lies. If his brother has weaknesses, then so must he ‘deep down’ (9):

DJ: You mentioned feeling embarrassed 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 especially to people I don’t know very well. And also we all project a certain image (6) 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 . . . of him in you as well (7) 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 . . . (8) 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 (9) as well and some people want you to talk about it, but you don’t want to . . .

Jason feels that his own identity is very directly threatened by his brother’s condition. Jason is aware of the dilemma that he needs the support of others, but is becoming more reluctant to seek that support because of the threat to his identity that such exposure entails. The next example is someone who, I argue, has been deeply affected by shame which has helped to keep her in a highly unresolved grief.

2. Shame and Withdrawal from Dialogue

Mrs Land was in her late 50s and her son, who had been in and out of hospital with severe mental health problems since his late teens, was in his early 30s. I will suggest here that Mrs Land is very affected by feelings of shame yet is not able to acknowledge them at all. It was through analysis of my own reactions during the interview (the counter-transference) that I was led to an understanding of the powerful impact of shame. I argue here that shame was manifest during the interview itself, so that dialogue about her son was severely limited. This formulation of the impact of shame on the dialogue is, I suggest, not merely relevant for understanding the interview itself, but could also be construed as operating in the rest of her life. There was evidence that she had withdrawn more generally from any kind of dialogue about her son. This makes it difficult for her to reach any new understanding of her son’s current condition. Instead, she is stuck with her memories of him as a healthy and successful child and teenager, which do not connect with how her son is now. This means it is hard for her to have a real relationship with her son. At the time of interview she had not visited him in hospital for over 6 months.

When I first tried to broach the subject of stigma, the dialogue between us quickly became attenuated (1), but Mrs Land instead talked of not needing other people since she withdraws into her family (2):

DJ: [Do you feel able to talk about Brian, to either friends, colleagues …]
ML: [Only my sister …]
DJ: [You don’t talk to other people?]
ML: [No… (1)]
DJ: [Why is that?]
ML: … [I don’t have any friends … I only have my colleagues here at work, because I involve myself in my family (2). I find contentment with my family. I don’t need to go out and find someone to talk to because I involve myself with my family . . .]

A little later on in the interview I pushed the point about her perhaps feeling that stigma has affected her, and she denies it on the grounds that she does not bother trying to discuss mental sickness with anyone (except for someone similarly affected):

DJ: [Do you think, maybe, that the difficulties with Brian made you more private?]
ML: [No I was always a quiet person … although I’m happy go lucky – I’ll walk around the office and I’ll sing and I can talk to people and I can discuss my family with them … but when it comes to … understands, but I wouldn’t discuss it with … I found the person that I am able to talk to, so I am able to talk to her.]

When I yet again tried to ask her more directly about any possible feelings of being stigmatised (3) Mrs Land became quite hostile in denying any experience like this. She certainly seemed to perceive my questions as aggressive. In fact I was aware that I did become quite defensive and almost confrontational at this point. After the interview I had to think hard about what had happened here and consider what the counter-transference issues were. It was certainly unusual (I think, unique) for me to get into a confrontation with the people I was interviewing – who I was normally allowing to ‘tell their own story’. I might have had some reason to be confrontational, perhaps annoyed that Mrs Land was not agreeing with me about my idea about the significance of stigma. I think instead that we did act out something about her rela-
tionship to her son and to the outside world. Briefly in the interview I did become part of the hostile world that she thinks cannot understand and care for her son. I become part of the hostile world that she shelters from. To an extent, this could be seen as an example of ‘projective identification’ (Bollas, 1987; Hinshelwood, 1989). Perhaps Mrs Land has projected the hostile feelings that she has about her son onto me, and I have responded by helping her to act out this split – she has good thoughts about her son whilst I, and the rest of the world, have bad ones. At the end of the extract, I think that some of the anxiety and shame that Mrs Land struggles with emerged (4) as she brings up the possibility that others might see her son as a ‘loony’:

DJ: Do you think people might look at you differently (3) …
ML: No.
DJ: if you told them about Brian?
ML: No. It doesn’t bother me. To me mental sickness, and any illness, is an illness to me.
DJ: But I know other people say, they think other people will look at them differently, that others will look down on them?
ML: No. No. I don’t feel that at all, I’m proud of my son.
DJ: I know you are, but I’m just saying that I know other people have said to me that they are reluctant to talk to friends and colleagues about their son or daughter because they think that they will be looked down on.
ML: No. You see I feel confident enough that if I spoke to anyone about my son I’m able to get across to them. Whereas there wouldn’t be any of that, I don’t believe that people would think that, because I know my own ability that when I start talking to someone they were able to understand. It’s just the same to me as explaining to someone how to mend broken bones if I knew how to do it, and that’s how I talk to people… I’ve never found anyone yet, haven’t met anyone yet who’s been biased. I mean you hear about it, but I’ve never met anyone. And I feel that if I did meet somebody that I would talk them around it, so that they would understand, so I don’t feel that someone’s going to think my son’s a loony (4), in layman’s language, so it doesn’t bother me.

I suggest that shame was being revealed through this confrontation, and that shame was keeping Mrs Land out of dialogue with me and perhaps anyone else (she suggests in the interview that she does not talk to anyone). The next question referred her to the past and it is clear that Mrs Land felt more comfortable in this territory. Mrs Land made reference to having ‘tape recordings’ of her son (5) as a child. This otherwise odd reference seems to express how the memory of Brian as a child is trapped as an isolated memory in her mind. These memories are not connected to how Brian developed as a teenager and then an adult, or who he is currently. I was given a list of his past achievements:

DJ: Did he use to be very different?
ML: Oh yes I’ve got tape recordings of him as a child (5), he was so happy go lucky, joking and he’s very, very talented. He taught himself to play the guitar; he’s even written his own music. And he went for exams to play guitar, he was disillusioned because he put himself up at such a level that was too high for him, he graded himself to a grade seven, in fact he was probably a grade five. He went for music lessons, he went. He was working. He was working up at [a shopping centre] he was an electrician. He qualified as an electrician within three years rather than five. And yet he was not interested in his school but he qualified as an electrician after 16, and he wrote this music. He even took music lessons with [guitarist], you’ve heard of him? … So he’s not stupid, not a stupid boy, he’s very, very sensitive.

The next question addressed the present (6), which was more problematic for Mrs Land. Although her son is in his 30s, Mrs Land seemed to be describing a relationship a mother would expect to have with a young child. She takes him out shopping and buys him some clothes as he became like his old self (7) – rather like a child in asking ‘Now what shall we do now mum?’ (7).

DJ: So he does talk to you now? (6)
ML: Yeh. Uh, I went to see him and all he would say was “yes, no, I’m alright, don’t worry about me”, for several weeks and then I arranged to take him out and buy him some clothes and I took him to the shop and all he wanted was a pair of shoes (6). I took him to the shop and bought him these trainers and when he came out of there for a brief moment he was his old self (7), “Now what shall we do now mum?”, I said “Well what would you like to do?” And he said, “Oh I don’t know anything you’d like to do”, so he was back to his old self with me, alone…

Perhaps this remained an unresolved situation because there has been a major rupture in the narrative that Mrs Land has about herself and...
her relationship with her son. She is not able to renegotiate a different narrative, so she is confined in a somewhat unreal relationship with her son where it is difficult for her to construe him as anything other than a little boy. It is as though his childhood is stuck on audio-tape, and there is no connection between these memories and the adult Brian who has a lot of problems. There seems to be no meaningful framework in which this can be understood. The stifling effect of shame was very evident even during the interview itself. It is serving to keep Mrs Land out of dialogue with anyone about Brian as he was now.

An interview with a family where feelings of shame have not obstructed dialogue will now be presented. It is argued that this process of dialogue, which was very alive during the interview, has been instrumental in facilitating relationships between family members (including the person with mental health difficulties).

3. Dialogue and the Renegotiation of the Narrative
Mrs Peters was in her 60s and had a son who had had a diagnosis of schizophrenia for over 20 years. She was talking here with her daughter Carol Peters. When they were asked about stigma, they were quite unusual in talking quite freely about having felt stigmatized. Mrs Peters told me first of all that she experiences stigma within the family (1). To other members of the family it is as though Donald had disappeared from the story of her family. Carol talks about feeling stigmatized in the past and suggests that her own ‘acceptance’ of the situation has reduced her own feelings of being stigmatized (2). Mother and daughter then go on to make bitter contrast between the large amount of publicity and funding that AIDS has received with the attention given to mental illness. The link that was made here to AIDS (3), with its associations to sexuality, death and shame (Kaufman 1989) is surely poignant. This angry aside perhaps does indicate a certain amount of ‘splitting’ (Klein 1946) which Alexander et al. (1999) suggest is characteristic of shame experiences. Some of the anger and ambivalence that Carol and her mother may feel towards Donald, is safely channelled to an external target – AIDS.

DJ: Yes. Often people have difficulty talking outside of the family.
MP: Yes that is quite true, it is still a terrible stigma, there is no doubt about that. I mean I have aunts and things who never mention his name (1). They never ask after him, they ask after the girls, but they will never ask after him. It is a stigma yes it is.

CP: Mmm. I find actually myself, I will talk more freely than I did, I have to say, I suppose because after so many years of going through what we’ve gone through you accept it (2). And it’s just a fact of life, it’s there. And so … yes I do talk about it freely, but I think with certain people you can see a look cross their face because they’re not made aware of it, it’s not something that you know there isn’t a hell of a lot of publicity about it.

MP: Well we didn’t know anything about it let’s face it.

CP: No we didn’t, we didn’t know anything about it, but also it’s not. It’s not the sort of thing that’s trendy to be part of. Do you know what I mean? I can’t explain it, it’s just…

MP: AIDS is of course (3).

CP: Everybody is going on about how ghastly AIDS is.

MP: It is ghastly.

CP: It is ghastly, people are dying of it, but people are also dying …

MP: Six hundred million pounds was given to AIDS at the last …

CP: The trendy charity, everybody is giving to, doing something for AIDS and nobody is doing anything for, let’s face it, an illness which has been around for centuries. AIDS has just only come into being, I mean you know …

So the reference to AIDS suggests that this family is not free of feelings of shame and anger. Despite the presence of these feelings, this family seemed to represent one of the more resolved situations that were encountered during the study. This can be understood as a function of their ability to come to terms with their feelings of shame and to have thus worked further through a process of grief. They have been able to do this by creating a dialogue between themselves and Donald which is able to accommodate their memories about the past, their feelings of loss and shame, alongside an understanding of the current situation. It was striking that the capacity for dialogue was very evident during the interview itself. Of course there were two of them in this interview which may well have helped put them at their ease and be able to talk. Nonetheless I still think that there was evidence of a very constructive dialogue actively going on during the interview. They were batting ideas around, certainly not agreeing with each other or me all the time. We had all, I think, reached a rather different understanding of things by the end of the dialogue.

I had noticed the word acceptance being used earlier in the interview (as in 2, in the above extract). As I was wondering if some sort of
psychological process of 'acceptance' was of significance I commented on this (4). The suggestion was greeted with scepticism (5). It was felt that Donald's own acceptance (6) was more important, and that what was really crucial was that he was able to talk about it (7) – he became involved with them in a process of dialogue:

DJ: It sounds as though your accepting of him becoming somewhat different has been important in being able to cope (4).

CP: Um … yeh. I don't know, I suppose so … Because not that it's important (5), I just think that is something that you have to do, it's not that it's important I just think …

MP: It was when he accepted it, that it was a great milestone, when he accepted that he was ill (6), he didn't for a long time . . .

CP: Yes that's right … He did not. One's been through so much that… there's so much that's gone through and you tend to feel … 'well at what stage did you accept it?' And I suppose one accepted it when he accepted it. It was a big thing for all of us.

MP: In fact you have lost him when he's ill

CP: When he's ill, I mean totally, he's just not there.

MP: … he's not the same at all.

CP: You know they were victimising him and that work were victimising him, the company were victimising him, they wanted to put him somewhere where they wouldn't have to look at him', and all this sort of thing. It was all sorts … Everybody else. And then all of a sudden he just started talking about … the hospital and the fact that he couldn't work and he knew he couldn't work.

MP: And never will work.

CP: And never will work and that really one's got to look at it like he were an invalid. Remember that, when he was going on about "really I'm an invalid" …

MP: Mmmm. Well he does get a disability pension.

CP: Yes. He wasn't going on about the pension but he was going about the fact that he was an invalid.

MP: Well he was quite pleased about that!

CP: Yes. You see this is the thing, you know he's still our brother and that's all there is really.

It needs to be emphasised that this process of dialogue has not eradicated distressing feelings about what has happened. It has instead allowed the unhappiness to be talked about and to become part of the shared narrative of their family. They have their memories of the past when he was a child and well, and they recognise that they have lost something:

CP: It's like a terminal illness of any kind really. You know it's like coping with somebody that's in a wheel chair. One of your children lives in a wheel chair.

MP: As far as I'm concerned I think about him all the time.

CP: Well you think, like all of us, when we think about. When you think about your family you think about the four of us, you don't think about Donald being somewhere else, you just think about all of us as a unit. And er… I mean …you know my sister and I we sort of. We … I suppose at the beginning you think 'My god I've lost a brother' because that's what it feels like.

MP: In fact you have lost him when he's ill

CP: When he's ill, I mean totally, he's just not there.

MP: ... he's not the same at all.

CP: You know there's the three of you as children and you've all grown up together, you've all gone to school together … all of a sudden he's not there because he's just. It's a completely different person it's not the Donald that you know. And as I say you have to accept it in some form or another, [edit] … It's just a life-long thing really. I mean I think we're all resigned to the fact that this is going to go on for all of our lives and [sigh] we will have to cope with things as and when they come up . . . And it will never be the family that it was, ever again.

There were two of them, which might have made talking easier for them (compared to Mrs Land in the previous example). Despite this, it still seems clear that mother and daughter were able to engage in a very lively dialogue with me about their feelings of being stigmatized, and their feelings of loss. They tell me they that they think an important turning point in their being able to work out a liveable arrangement with Donald was when he and they were able to have a dialogue about the way he was. I think that this capacity for dialogue has been very important in their being able reach a more reconciled place, a place not free of the unhappiness and loss, but where there is space for the real
substantial methodological issue I would want to raise is that shame cannot be properly studied without a psycho-social research methodology like the one used here. On the other hand, shame cannot be fully understood without greater study of both the psychological and the social aspects of the phenomenon.

Shame and Grief

The argument has been made that the shame that was tangibly interfering with dialogue during the interviews could also be having an impact on someone’s ability to use dialogue in other contexts. As discussed in the introduction, there are a number of strands of thought emphasising the importance of dialogue and interaction to the experience of selfhood (Harré, 1998; Stern, 1998; Schafer, 1992). People’s sense of themselves can be constantly replenished by continuing interaction with others. This might be particularly important during periods of loss. New dialogues can create fresh narratives, which themselves might encourage processes of adjustment to loss and change. If shame disrupts those dialogues and interferes with the process of creating new narratives, this would help explain the widely noted phenomenon of ‘chronic grief’ amongst families affected by serious mental illness. It may be that longer-term research tracing how people’s feelings of shame and grief changed over time might help tease out some of the causal factors and the importance of individual differences and contexts (such as the presence of social support or previous biographical experiences).

It may also be useful to think about the more general links that have been made between shame and depression (Tangey, 1993; Andrews, Qian, and Valentine, 2002). The long term work of George Brown and colleagues on the significance of experiences of loss in the aetiology of depression has drawn attention to the significance of loss events that have also involved experiences of humiliation (Brown, 1998; Craig, 1996). These finding have been framed within an evolutionary model that emphasises the loss of rank and status (Gilbert, 1998). The framework used in this study suggests a somewhat different explanation – where shame itself may have a corrosive effect on the dialogue that is required for people to build different meanings for themselves after loss. Experiences of humiliation would be very likely to give rise to these feelings of shame (indeed the distinction is debatable, Patterson 2000). There may also be useful theoretical links to be made here with cognitive models of depression that emphasise the rather negative and
circular thought processes that are associated with depression (Beck, Rush, Shaw and Emery, 1979). These thought processes may well be self-perpetuating if they are not being challenged through dialogue. Such thinking fits with ideas on the need for reconstructive cognitive work following losses and traumas. Walter (1996) emphasises the significance of dialogue to the bereavement process (see also Bonanno and Kaltman, 1999, who argue for the importance of dialogue in ‘cognitive reconstruction’ following loss). If shame does have such an inhibitory impact on dialogue then it is understandable how it could interfere with processes of adjustment following loss and change. Without an ability to update the narrative of their lives, people might well be left stranded in a state of depression.

Notes
1. For reasons discussed about the difficulty that people may have in discussing shame, their reliance on data from self-report questionnaires might be seen as undermining the robustness of the findings.
2. This was to ensure that the sample consisted of families who had a member suffering from serious and long-term mental illness, but whose lives were being led largely in the community. It is this group who have been identified as providing a significant challenge for the successful implementation of community care policy.
4. The sexual and coprolitic language is open to psychoanalytic interpretation in terms of possible infantile roots of shame, connected to experiences of toilet training and body shame (Chasseguet-Smirgel, 1985).

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References


