Failure to Respect Informal Carers in the Australian Health System: the Highs and Lows of Social Bonds

by

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This paper will take my four years’ personal experience as a primary informal or family carer as its point of departure. Much scholarship on carers has concentrated on economic aspects, the relations of exploitation and subordination and negative stress effects. However there is also a need to continue to highlight non-economic and positive aspects of the complex social relations in which informal caring proceeds.

The first part of the paper will develop a critical treatment of Scheff’s concepts of social bonds and shame as a context within which to locate informal carers. The second part will develop the contention that informal carers are treated in a derogatory manner by the Australian health system. Now, with the coming of the so-called ‘tsunami’ of chronic illness and ageing, and the diminishing health labour force it is transferring an even greater burden of the growing health work-load onto this over-extended and vulnerable group potentially causing it to decline even faster.

Thomas Scheff: social bonds and shame

I have devised a new concept, ‘do social bonds’, to argue that informal caring is the ‘doing of social bonds’. This concept is broader than a similar concept, ‘doing the family’ because it potentially includes the varied nature of caring activity for example, the magnificent caring carried out by members of the gay and lesbian community and family members in relation to the Aids epidemic. The Sociologist of Emotion, Thomas Scheff, ranging across history, psychology and sociology, developed his concepts of
social bonds (pride as a sign of an intact bond; shame signalling a break in the social bond or relationship) because he found no usable model of a normal social bond in the literature of the social sciences (1990: 5). While human beings require a sense of belonging, i.e. a web of secure social bonds, modern society gives rise to unlimited change and one’s connection to others is never quite safe. The bond has to be constantly tested and renewed if it is to remain intact. Nevertheless there is always the potential for abuse within these relations of solidarity. Scheff’s schema can partly incorporate this with his idea of enmeshment. Social bonds can be too tight and too loose. For example families who define loyalty in terms of conformity engulf their members with bonds that are too tight. In later work he even describes the modern world as having a shocking lack of community and solidarity (2003: 259).

Scheff (2003) discusses shame as a key component of conscience, the moral sense. He defines shame which he also calls ‘bond affect’, as a large family of emotions -- most notably embarrassment (weak and transient) guilt, humiliation (powerful and of long duration) and related feelings such as shyness, even awkwardness. One becomes ashamed by seeing oneself negatively in the eyes of others whether real or imagined. The sense that one has failed to live up to one’s standards would usually signal a threat to one's social relationship with that person. Grief signals a loss of a social bond but it is not a frequent event. By contrast shame, is present or anticipated in virtually all social interaction. In modern society shame is a taboo not talked about (it has gone underground) and leads to behaviour that is beyond awareness. As a result it plays a key function in systems of social control, particularly of groups who have a low status.
However, Scheff’s account of social bonds is too functionalist. He does not acknowledge sufficiently the conflict between social groups with the dominant group about their subordination and marginalization such as women in relation to the family and caring, gays and lesbians, people of colour, immigrants and refugees; the latter groups, to a greater or lesser extent, have to use subcultures not ‘society’ to sustain social bonds. Scheff’s analysis has valuable potential but there is a material side to social bonds beyond language and emotion, and imagining one’s degree of integration. A great deal of hitherto invisible work is involved in the creation and maintenance of some of the central dimensions of social bonds. Hochschild actually defines ‘care’ as an emotional bond, usually mutual between the care-giver and cared-for, a bond where the care-giver feels responsible for other's well-being and does mental, emotional and physical work in the course of fulfilling that responsibility (1995: 333). Scheff fails to acknowledge that women, in the kind of society he is describing, have assumed a much greater responsibility for preserving social bonds through an almost compulsory altruism and even coercion (Folbre and Weisskopf 1998: 183) which, until recently, required them to make their interests secondary. Historically women across a range of societies, have created and reaffirmed social bonds by looking to the physical and emotional needs of children, grandchildren, their parents of origin and in-laws and other kin. Because women have broadened their lives beyond the family, they no longer are so preoccupied. According to Folbre and Weisskopf, we need to develop a new social contract that generates a sense of responsibility for caring labour for all members of society (1998: 188). While we are witnessing a widening of the range of people ‘doing social bonds’ to
heterosexual men, there is a care deficit for a range of reasons including government policies (Hochschild 1995: 332) and longer life expectancy living with chronic illness.

Many aging people and those who are ill would prefer to be cared for, for as long as possible at home by people they are bonded to rather than in the authoritarian, medicalised regimens and nursing cultures of hostels and nursing homes. Home or informal caring for a sick, injured or disabled person can be regarded as one of the highest expressions of the social bond between people. It is important work improving the texture of social relations and even holds society together. Some of the time it generates genuine pride not shame and eschews exploitation. Many do it because it is a crucial social bond in their lives. They accept that death, disability and illness are part of the human condition for others and themselves. Grief is a common emotion during informal caring, anticipating the loss of the valued person. After the person is gone, social bonds will be irrevocably changed, and for older people could be far looser and status lost.

At other times informal caring can be fraught if accompanied by a sense of enmeshment, lack of choice and money, loss of job progression and earnings and the hidden and painful feelings of shame. It needs to be noted that the latter qualities can cut both ways for carer and caree. As a result, activists who are disabled argue for ‘support’ to replace the laden notions of ‘care’, with ‘choice’ and ‘control’ as key concepts of empowerment for adults with a disability, preferring to buy services in the market with the accompanying dignity this can provide (Williams 2001: 478).
Paid carers in comparison to informal carers are actively discouraged from ‘doing social bonds’. As workers they are frequently rotated in an attempt to prevent social bonds from developing. Meagher (2006) advocates we aspire to ‘good enough’ care from paid carers and the necessity to circumscribe their responsibilities for the social and emotional well-being of those they care for.

**Caring and rehabilitation in the home**

So far a theoretical perspective has been outlined to provide a framework to discuss my own experience caring for a stroke survivor with severe heart disease in conjunction with an important Australian study of informal carers (Dow and McDonald 2007) involved in rehabilitation in the home (RITH) programs including stroke.

Despite the fact that stroke is responsible for more disability than other events and nursing home places, it is a ‘Cinderella’ area of medicine and health, being a low-tech area. My partner’s physician commented that stroke was seriously under-researched and that Australian medicine was conservative and slow to use the drug that can stop a stroke if administered within three hours of onset.

Over a nine-month period, Dow and McDonald (2007) interviewed 24 informal carers in Victoria. They were involved in RITH programs aimed to replace hospital beds (beds substitution) to contain the cost and reduce the time that older people spent in hospital by replacing it with home-based acute and sub-acute health services following strokes and
other major events such as bowel cancer operations and amputations. Most were in their 50s and 60s with 21 female and three male carers (13 wives, three daughters two daughter-in-law, a friend, a granddaughter and a niece). For many the assumption of care happened almost involuntarily. It was an ad hoc process where a last-minute decision is made almost by stealth to target the individual who has been visiting regularly. Most carers described the assumption of this huge extra rehabilitation responsibility as ‘It just happened!’ They had little choice about it. It was assumed by others including program staff that the ‘carer’ would take it on.

Seven of the 24 carers were carrying out extra-ordinary levels of quasi-medical care, available 24 hours, getting up several times a night to help the care recipient get to the toilet or to move them to prevent bed sores (2007: 197). Fifteen assisted with rehabilitation activities and six were involved in nursing tasks such as wound care and diabetes monitoring. Staff expected the carer to work as part of ‘the health care team’ and be compliant and cooperative. If they were not, they were labeled ‘difficult’, ‘resistant’ and ‘obstructive’. Their work was often arduous and relentless. Most did not receive any remuneration whatsoever, neither Carer Payment nor Allowance, and those that did thought it was insufficient. No RITH programs had any formal processes of identification, recognition, inclusion or compensation for the carer. The essential knowledge that the carer had about the clients care needs was not routinely sought.

Dow and McDonald are highly critical of these programs. They argue that informal carers are disenfranchised care contractors. They were in a central position in terms of
work and responsibility but in a peripheral position in decision-making power. In their view, the carers are relied on by the state and by hospitals for provision of home-based rehabilitation but they are not considered as members of the rehabilitation team. Their work is largely unrecognized and uncompensated and they have little say in care planning decisions that impact on their lives. They recommend program expectations be made explicit to the carer together with reciprocal rights and entitlements. This could take the form of a written agreement which could be also be used to apply for carer payments.

My own situation was more privileged than those in the Dow and McDonald study. While the stroke happened in a hospital as a result of a heart procedure, because my partner was under 65 he received six weeks hospital-based rehabilitation and further rehabilitation. However in the stroke ward I bridled at how I was treated as a carer either regarded as invisible or a nuisance, ‘seen but not heard’ (Williams 2007). As Dow and McDonald argue we are not recognized as a category. We are lumped in with an amorphous category called ‘relatives’ with the same status as a feckless grandson making too much noise on a visit. I was not permitted to communicate important information from my partner to ‘the health team’. However at the end of the six weeks the entire burden of my partner's care was dumped on me and I was given about one minutes training to deal with it which consisted of the sentence: 'Have you got your Warfarin book?’ This was code for the clear sentence: ‘The Warfarin dose is written in the middle of the book’. Not realizing this (as I had already read the book and implemented soft toothbrush etc) I gave my partner too much of the blood thinner, Warfarin from a broad direction on a pharmacy card. It was daunting at first taking over almost every hospital
function that is carried out by small armies of paid workers in hospitals: cleaners, kitchen and catering staff, nurses who administer medication, implement medical procedures and make beds, other nurses who are in charge of blood collection, for example for INR for Warfarin, and laundry staff at Linen services who wash sheets and towels.

My first reaction to the RITH programs was outrage at the enormity of what was being required of informal carers and the way carers were inducted without consultation. Using Scheff’s analysis one could argue that the recurring phrase from carers, ‘It just happened’ suggests the hidden presence of the painful emotion shame, in this case, unacknowledged shaming is occurring through a clear lack of choice in recruitment.

Here are a group of people with a highly developed moral sense, a sense of duty toward their social bonds as one of their many identities. Instead of being respected, they are open to shame from hospital staff when visiting a relative or friend for having the very values which make them admirable members of our community increasing its social solidarity. If they hesitate in the face of the fait accompli they fail to live up to their own standards. They experience in the eyes of the hospital staff member, reflected back to them (whether real or imagined) a threat to the social bond with the loved one or family member. By manipulating their recruitment the hospital staff engages in underhanded disrespect which according to Scheff (1992) gives rise to unacknowledged shame. Shame is not a problem if it is acknowledged as it often is, by an apology, shared laughter; it quickly subsides. It is unacknowledged shame which is pathological and causes trouble because it goes underground. It can re-emerge as anger and the dangerous shame-rage.
This covert disrespect for informal carers is less the individual strategy of the staff member than a product of a deeply authoritarian health system dominated by the science base of medicine. Very few voices have legitimacy in this system and informal carers are not even listed in the pecking order. Medicine’s claims to ‘truth’ in managing illness give a false sense of accuracy when in real terms there is a great deal of indeterminacy about illness and politics about resources.

Dow and McDonald tend to underestimate the extent to which the transferred hospital responsibility is carried out within a bedrock of extra domestic and emotional labour. There is a tendency to import the long-standing perspective of the invisibility of this labour. My partner’s physician said to him rather brutally when he complained of tiredness that he was half a person now. The carer has to manage the missing half of that person for a long time exemplified by a non-usable and later weak right arm and grief over the losses. The carer has to do the missing aspects of the household work both indoor and outdoor, manage repairs and secure the dwelling. Informants themselves can reflect back the invisibility assumption because their unpaid labour is socially devalued. Unfortunately this can be adopted without question by researchers as it is by Dewey, Thrift, Mihalopoulos, Carter, Macdonell, McNeil and Donnan (2002) who decided not to count any household work whatsoever. They quantified informal caring labour at a third of wages and as leisure foregone. However even their conservative estimates valued the total cost at $21.7 million for the first year (once-in-a-lifetime stroke) and $171.4 million over a lifetime.
I found it difficult to see how Dow and McDonald’s informal carers would have any surplus to absorb, on a continuing basis, what is in reality a serious extra rehabilitation hospital function, so they could survive intact over time. We know from other Australian research that informal carers are at risk. Spouse carers have the worst health with 43% reporting major health problems with mothers, younger wives and co-resident daughters clearly distressed from their high intensity caring situations and close kinship bonds (Schofield with Block, Hermann, Murphy, Nankervis and Singh, 1998: 77, 85).

While my initial response had been outrage, I was later amused to note that there is evidence that home-based rehabilitation is functionally effective, if not more effective than hospitals and clients prefer it (Dow and McDonald 2007: 194). These schemes implicitly include informal carers in the labour process which should be recognized by those who devise them. For most carers there is no next hospital shift coming in. Unlike paid workers they do not have regular days off, no guaranteed leave such as long service leave. A minority has access to the unstable vagaries of respite care if they can afford a holiday or break. There needs to be guaranteed leave (preferably paid), appropriate rights and safeguards which could include occupational health and safety.

Conclusion

This paper has used a critical reading of Scheff’s scholarship on social bonds, shame (or ‘bond affect’) and a new concept, ‘doing social bonds’ to argue that informal carers ’do
social bonds’ at a deep level. The concept was used to locate informal carers positively
in important social processes that weave the social fabric into a denser structure where
compassion is paramount. By its very presence it critiques false individualism and
shallow materialism. The concept has the capacity to include all social actors engaging in
informal care work and does not privilege the conventional family structure. Scheff’s
work also enables the common accompanying emotions of grief and shame to be
identified.

The inclusion of informal carers needs to be done with social respect and this means
hospitals acknowledging them as a category and not ignoring their tacit knowledge of the
person, giving individuals the clear option of saying ‘No’ with no moral pressure of any
kind, thus removing the possibility of shaming. They need to be assisted by the state to
survive their important work rather than their goodwill and unpaid labour ransacked by
powerful health interests. These schemes could provide the pathway by which their
essential health contribution is no longer so marginalised.

References

North East Melbourne Stroke Incidence Study (Nemesis)’, Stroke 33: 1028-1033.


