

Family conflict in dementia: prodigal sons and black sheep

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SUMMARY

Objective To describe family conflict in cases of dementia referred to the Guardianship Tribunal of New South Wales, Australia.

Method The file notes of 50 cases of family and systems conflict in cases of dementia presented to the Guardianship Tribunal were examined. Demographics, MMSE score, and type and severity of dementia were recorded. The documents and evidence presented to the Tribunal were coded and subjected to thematic analysis to identify the themes of the conflict, the protagonists and the position of the person with dementia with respect to the conflict.

Results Family conflict was most commonly seen in mild to moderate dementia. Conflict occurred most frequently between siblings (with a group of siblings allied against a 'black sheep' member) and involved other systems such as service providers in 25% of cases. The person with dementia was usually involved in the conflict or in alliance with one or other of the family members in conflict, especially when paranoid ideation was fuelled by family members. Common themes included accusations of neglect, exploitation, lack of communication or sequestration of the person with dementia. No family had received family therapy prior to the application; conciliation during the hearing was successful in 30% of cases. Legal transactions such as Powers of Attorney were frequently made and frequently revoked by persons with dementia involved in family conflict.

Conclusion Dementia may be a great family divider, particularly when there are cracks in family solidarity. The understanding of family conflict in dementia has ramifications for both clinical and medico-legal practice. These findings may encourage family-centered interventions which address family dynamics and interpersonal conflict. They may also assist in capacity assessments of persons with dementia who change legal documents because of family conflict. Copyright © 2006 John Wiley & Sons, Ltd.

KEY WORDS — family; conflict; dementia; medico-legal; elderly

BACKGROUND

Preventing and addressing family and systems conflict remains an overlooked yet potentially critical component of clinical care in dementia. Academic and clinical attention has been directed mostly to caregiver stress or burden (Brodaty and Hadzi-Pavlovic, 1990; Brodaty and Green, 2002; Pinquart and Sorensen, 2004; Schulz and Martire, 2004; Depp *et al.*, 2005) and usually the focus has been on the effect of family conflict on the primary caregiver, rather than on the family system as a whole and the

intra-familial dynamics (Mittelman *et al.*, 1996; Mitrani *et al.*, 2005).

Strawbridge and Wallhagen (1991) found that 40% of 100 adult child caregivers were experiencing relatively serious conflict with another family member, usually a sibling, and usually because they failed to provide sufficient help to the caregiver. In addition to lack of support and acknowledgement of the caregiver, other sources of conflict include: (i) differences around issues of impairment (e.g. seriousness of the patient's disability); (ii) disagreements over the amount and quality of attention given to the patient by the other family members; and (iii) the process of institutionalisation (Pearlin *et al.*, 1990; Gaugler *et al.*, 1999).

Secondary role strains such as conflict between the caregiver and other family members affect caregiver

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mental health and perceived burden (Pearlin *et al.*, 1990; Strawbridge and Wallhagen, 1991). Conflict stemming from family members' attitudes and behaviours towards the caregiver has been associated with caregiver depression while conflict involving family members and their attitudes towards the patient has been linked to caregiver anger (Semple, 1992). Family conflict predicted post-placement depression among wives who had institutionalised their husbands (Gaugler *et al.*, 1999). Further, the way families deal with conflict may affect the amount and type of care that is provided to the patient with dementia. For example, families who used a focused decision-making style and positive conflict resolution methods provided more help than families who did not use these methods (Lieberman and Fisher, 1999).

Demonstrating the cross cultural relevance of such issues, a study of 17 people with dementia of unstated severity and their primary caregivers in South India found that family conflict was commonly encountered amongst caregivers, and that caregiver strain was exacerbated by lack of support and, sometimes, criticism from other family members. Themes of conflict identified included allegations of lack of support from other family members and allegations of neglect and harm (Shaji *et al.*, 2003).

Our clinical experience suggests that in addition to being based on allegations of neglect, harm or unequal distribution of care, family conflict is often fuelled by longstanding sibling rivalries or perceived unfair distribution of financial support or inheritance or control of money. Dysfunctional alliances may be formed between disgruntled family members, often involving the person with dementia (and sometimes service providers); this has not been investigated formally. Such alliances form a fertile ground for legal disputes about wills, powers of attorney, financial management and guardianship.

An application for guardianship or financial management is often the end point of family breakdown for families in conflict. The principal role of the Guardianship Tribunal is to hear and determine applications for the appointment of guardians and financial managers of adults with impaired decision making, the most common cause of which is dementia. The need for such applications usually arises when there are no informal proxy decision-makers (i.e. family or friends) or when there is conflict between the informal decision-makers.

We aimed to explore the phenomenon of family and systems conflict in dementia using case records from 50 cases of family conflict heard by the Tribunal. Starting with this broad exploratory goal and using

grounded theory we set out to look for emergent themes related to who was in conflict, the nature of the conflict and the involvement of the person with dementia in the conflict. Our research objective was to enhance theoretical knowledge and clinical practice in this poorly understood and difficult clinical area. By offering insights into family conflict we aimed to facilitate the use of family-centered interventions in dementia beyond education and support and to enhance understanding of the changes in family alliances that often occur during the course of dementia and the potential legal ramifications of these.

METHOD

When applications are made to the Tribunal, information and documentation attesting to the person's disability and need for a proxy decision-maker are gathered. This information includes reports from the treating doctors (often specialists involved in the patient's care), neuropsychologists and other community or hospital-based service providers such as Aged Care Assessment Teams and hospital social workers, documenting the cause and severity of the dementia and associated neuropsychological and functional deficits. In addition, it is not unusual for family members to write lengthy letters to the Tribunal presenting their point of view. After the hearing the Tribunal issues an Order and Reasons for Decision that provides details of the evidence and opinions provided by the various parties, the Tribunal's observations of the family and the person with dementia and any attempts at conciliation.

All cases of dementia presented (i.e. including both applications and reviews) to the Guardianship Tribunal between May 2004 and December 2004 were identified and case records examined to identify 50 consecutive cases of family and/or systems conflict. Family conflict was defined as conflict between any family members involved in the life of the person with dementia (i.e. both first degree relatives and/or nieces, nephews, grandchildren) and/or involving the person with dementia. Systems conflict was defined as any conflict between the family and non-familial carers or service providers (including hospital staff).

Age, gender, size of the person's estate and dementia details including Mini Mental State Examination score (MMSE), specialist's rating of dementia severity and type (if known) were recorded.

Standard qualitative analysis techniques (Rice and Ezzy, 2004) were used to interpret the data. The documents and evidence presented to the Tribunal were coded and subjected to methods of grounded theory

and thematic analysis (Rice and Ezzy, 2004) by the first author (CP) (R1) to identify the themes of the conflict, the protagonists and the position of the person with dementia with respect to the conflict. Standard techniques for ensuring interpretative rigour and validity of the analysis included: (i) triangulation using multiple information sources including written notes by family members, letters and documents from health care professionals and the observations of Tribunal members involved in the cases studied; and (ii) providing direct quotes and examples (Rice and Ezzy, 2004).

While it has been argued in the literature that claims to objectivity in qualitative research based on traditional inter-rater reliability checks may be flawed (Armstrong *et al.*, 1997; Rice and Ezzy, 2004), it can still be useful to ensure that similar themes (albeit often packaged differently) have been identified by two independent observers (Rice and Ezzy, 2004). A second rater (HB) (R2) independently coded the data and identified themes from a random sub-sample of 13 cases. We defined agreement on the theme (e.g. conflict over money; care arrangements; placement) as the same rating, except if there were three or more themes we required concordance on at least two themes. We defined agreement on the protagonists as the same rating, except if there were three or more protagonists we required concordance on at least two protagonists. We agreed completely on theme in 11/13 cases (85%), partially on one and not on one; consensus ratings are presented in the paper. We agreed on the protagonists in all 13 cases (100%). The type of analysis (i.e. thematic analysis which involved the inductive identification of codes from the data rather than pre-identification of codes) precluded the use of kappa to assess agreement.

Ethics approval and permission to carry out the study were obtained from the Guardianship Tribunal and confidentiality of subjects was maintained by removal of all identifying data.

RESULTS

Demographics

Details about gender, age, dementia type and severity, and estate size are presented in Table 1.

The applicants for guardianship or financial management were children of the person with dementia in 64% of cases, a health care professional (e.g. social worker or Director of Nursing) in 18%, a friend or solicitor in 6%, or a spouse in 2%. Data were missing in 10% of cases.

Table 1. Demographics of the person with dementia ($n = 50$)

Variable	Frequency [#]
Age (mean \pm SD)	79.8 (6.81)
Range (yrs)	59–92
Female	33
No. protagonists in conflict (mean (SD))	3.84 (1.06)
Size of the estate (\$AUD)	
< \$100,000	8
\$100,000–\$1million	31
> \$1million	7
Unknown	4
Type of dementia	
Alzheimer's Disease	21
Vascular Dementia	14
Combined	6
Other	3
Unknown	6
MMSE (mean \pm SD)	18.85 (5.81)*
Severity	
MMSE > 24	5
MMSE 18–24, or rated mild by specialist	18
MMSE 10–17, or rated moderate by specialist	21
MMSE < 10 or rated severe by specialist	4
Unknown	2

[#]All percentages are double the frequency because $n = 50$.

*MMSE not available for 17 cases.

The protagonists

Conflict most frequently involved siblings. (Table 2) In ten of the twelve cases of multiple sibships, several siblings were in alliance against one 'black sheep' carer sibling. In seven cases of sibling conflict the black sheep was significantly troubled with mental illness or burden including: schizophrenia or severe paranoid personality disorder ($n = 2$); substance abuse disorder ($n = 2$); major depression ($n = 1$) or 'overburdened' or 'unable to cope with caring' ($n = 2$); one of whom reluctantly conceded that he needed help 'before I do something'). In all seven cases the carer was male, unemployed, and, save for one case, single and living with the person with dementia.

In 26% of cases there was some involvement of service providers in the conflict and in 12% of cases the conflict was solely between service providers and the family. In the latter cases the conflict was based on lack of communication and judgemental stances adopted by service providers (e.g. regarding family's misuse of finances or the family's neglect of their ageing relative).

Themes of the conflict

Overall, conflict was most often based on accusations of inadequate care, financial exploitation (either

Table 2. Nature of family and systems conflict in dementia

	Frequency [#]
Who is in conflict?	
Sibling vs sibling	27
Other intra-familial	9
Family vs agency	6
Person with dementia versus family	5
Family vs friend/'bystander'	3
Themes of conflict*	
Inadequate care	23
Money/financial exploitation	23
Lack of communication or sequestration	21
Placement/Where the person with dementia should live	15
Underestimation of the diagnosis	9
Paranoid ideation of the person with dementia	13
Risk	5
Position of person with dementia with respect to the conflict*	
Involved or allied	37
Inconsistent	13
Distressed 'trying to keep the peace'	7
Neutral, uninvolved	9

[#]All percentages are double the frequency because $n = 50$.

*Not mutually exclusive categories.

through control of money or manipulation of a will and failure to communicate with other family members or sequestration of the person with dementia. (Table 2). Twenty-five of the 27 cases of sibling conflict were based on clear rivalry and battles for control over care and the future of the parent/s and two solely on finances. The position of carer appeared to provide some adult children with an opportunity to jostle for favor with parents who may have: 'always favored one child or the other'. The child who was traditionally favored was the one with difficulties (as described above), perceived by the family as the runt of the litter, who ended up caring for the parents. A typical case scenario involved an adult male child carer living at home, zealously guarding the intimate relationship with his mother or both parents and leveling accusations of lack of interest and involvement at his other sibling/s. Siblings in turn would accuse him of failing to communicate and being neglectful and ill-equipped to deal with the onerous task of caring. Sometimes such accusations arose from a non-carer child living overseas or interstate. In 33% of cases involving siblings, there was obvious competition about who was acting in their parents' best interests and who was the 'better child'.

Conflict over money, the theme in 23 (46%) of cases, was based on accusations that the family member with financial control over the person with

dementia was taking liberties with that person's money and over spending on himself or herself and/or inadequately meeting the needs of the person with dementia. In ten of the 23 cases this was based on a longstanding arrangement between the person with dementia and the family member, and had long been associated with hostility in other family members. In all but three of the 23 cases, accusations of financial abuse were intermingled with other disputes and accusations. For example, one sibling accused: 'mum's too vulnerable to her favourite daughter who's had her hand in the till all the time... I was the one who made her well'.

Underestimation of the diagnosis was another source of conflict. In such cases one family member (often the carer) colluded with the person's lack of insight and denial of the illness. There was a collusion that 'there's nothing wrong' or 'we don't need help', so that others (i.e. previously trusted and loved children) who offered support or suggested services were perceived by the person with dementia as intrusive and threatening their autonomy. For example, two previously adored daughters were accused by their mother of being: 'interfering bossy boots'.

Position of the person with dementia

The person with dementia was frequently involved in the conflict and had formed alliances with certain parties to the conflict while holding hostile or antagonistic beliefs about other parties, at times culminating in refusal to see certain family members or friends (Table 2). Such alliances were changeable and inconsistent in 26% of cases, which further fuelled family conflict. In one-third of the cases there was no past history of major conflict between the person with dementia and the family member with whom the person with dementia was now in conflict (as determined by histories provided by the protagonists in the case records).

Alliances between the person with dementia and the protagonists were always associated with accusations of undue influence with regards to signing legal documents, forming adverse opinions of various family members ('he poisoned her about us') or accepting their input into care. When the person with dementia suffered paranoid ideation and was involved in the family conflict, their suspiciousness and paranoid ideation was fuelled by hostile family camps who fed accusations of financial abuse or 'just wanting to dump' the person with dementia into a nursing home. The following four typical cases illustrate this:

- (i) a mother aligned herself with her son against two daughters previously given Powers of Attorney and interpreted their desire to organise community supports for her as: 'they just want the house'. When asked how she knew this, she replied: 'their attitude'.
- (ii) an elderly lady became estranged from her sister and niece over many years because she believed that they were trying to poison her, trying to steal her house and telling people that she was a lesbian. Those who supported her did not check the veracity of her allegations or understand their origin and were outraged by the alleged behaviour of the sister and niece.
- (iii) a father was estranged from his daughter towards whom he had developed paranoid delusions. His son was accused by his sister and her friends of: 'feeding his father's delusions . . . telling dreadful lies'.
- (iv) two siblings had previously reported a 'good and close' relationship until their mother developed paranoid delusions about her daughter stealing \$200 000 from her. These allegations, although proven untrue, were believed by the son who abused alcohol.

Wills and Powers of Attorney were changed according to the particular alliance favoured at the time. Sixty percent of the persons with dementia had given Powers of Attorney to parties involved in the family conflict prior to the hearing and 24% had made changes to previous appointments revoking previous appointments or appointing new Attorneys during the period of conflict. Three persons with dementia each appointed three different attorneys within 12 to 18 months!

Therapy and conciliation

From the information available, none of the families was involved in family therapy or counselling to address the conflict prior to the application. Obligated to use its best endeavors to bring the parties to a settlement, the Tribunal deemed conciliation successful in 30% of cases. Success was often achieved by finding common ground between family members and relabeling or giving positive connotation to family members' mutual accusations. For example, a typical case of sibling conflict involved a carer son who was accused by his sister, brother and health care professionals of being 'inflexible, secretive and lacking the skills' to care adequately for his mother, with whom he had an 'excessively enmeshed' relationship.

Accusations of the son's incapability were re-labeled by the Tribunal as concern for her welfare and his brother and sister were engaged by the Tribunal in supporting him to obtain respite and pursue his own interests.

An attempt at conciliation was deemed neither possible nor appropriate in 26% of cases due to: (i) absence of crucial family members; (ii) 'entrenched or severe conflict'; or (iii) conflict based on the person with dementia's delusions or lack of insight. In 14% of cases the Tribunal was unsuccessful in bringing the parties to a settlement despite its best endeavors. There was no written reference to conciliation in 30% of cases.

DISCUSSION

This exploratory study is the first to examine the nature of involvement of the person with dementia in family conflict and to describe family conflict in dementia beyond role-specific conflict related to caregiving. Family conflict involved siblings in over half the cases, often based on rivalry, perceived injustices of inequity of care or financial support and conflict between what was perceived as being in the best interests of the person with dementia. Our findings lend support to clinically-based observations of family relations in older life which suggest that having a dependent parent provides an opportunity for siblings to play out a competition to be the best, most caring child (Garner, 2004). The role of carer sometimes allows a previous 'black sheep' to become newly respected for his or her competence or listened to for the first time (Knight, 1986). The provision of care, particularly instrumental care, is said to be independent of attachment (Carpenter, 2001) and the child who takes on the carer role is not necessarily the one who is most securely attached to the parent. Unresolved issues of attachment may emerge (Neidhardt and Allen, 1993) and pre-existing patterns of insecure, anxious attachment may predispose to enmeshment with the ageing, disabled parent.

The carer role offers children a unique—perhaps newfound—position of intimacy with their ageing parent; while lack of communication with other siblings and refusal of services provide opportunities to enmesh further with the parent/s. It has been found previously that more anxious-ambivalent carers report smaller social networks and less satisfaction with the support received than those less anxiously attached (Markiewicz *et al.*, 1997). Conversely, feelings of guilt and ambivalent or avoidant attachment in

less-involved children may be projected as criticism onto the carer. This may provoke carers (particularly in the case of siblings) to reinforce their bond with the parent defensively and may result in sequestration of the person with dementia and duplication or sabotage of care arrangements sometimes resulting in confusion and distress for the person with dementia.

The sizes of the estates involved were not huge, although what is considered a large estate depends on the family's financial circumstances. Conflict over money and its equitable distribution is not unusual in families, regardless of the amount involved because money often represents concretisation of emotional supply and security, and battles over money are often proxy for battles for control within families.

The person with dementia was involved in the conflict in 76% of cases. This is not surprising. Many of the neuropsychological deficits typically associated with common forms of dementia such as: (i) deficits in judgment and working memory (Masterman and Cummings, 1997); (ii) impairment in autobiographical memory (Fromholt and Larsen, 1991; Kazui *et al.*, 2000); (iii) personality change (e.g. apathy and passivity); and (iv) paranoid ideation, may influence the appraisal of relationships and render a person with dementia vulnerable to the influence of others.

Family and systems conflict occurred in all types of dementia, in a pattern approximating the currently established distribution of the causes of dementia (Mendez and Cummings, 2003). Contrary to expectation, in the cases brought to the Tribunal, family conflict occurred most often in mild to moderate dementia, probably because the frequent involvement of the person with dementia in the conflict would be precluded by severe dementia. Alternatively, family conflicts may have already played out by the time the dementia becomes severe.

Finally, we observed that service providers are often involved in the conflict and that family therapy is rarely, if ever, used. Most caregivers would benefit from more understanding and support from their families and possibly from family counselling (Mittelman *et al.*, 1996). Our findings and clinical experience suggest that except for one-off family meetings to plan discharge or community supports—very little is done to address family dynamics and very few families are referred for family therapy. In practice it can be difficult to engage all family members to attend meetings, let alone formal therapy. Additionally, our findings suggest that conflict involving service providers was based on a lack of communication with and neutrality towards family members

precluding any therapeutic systemic intervention. We argue for the need to educate service providers and families about the advantages of such a systemic approach as soon as cognitive impairment is diagnosed.

This study was limited by being based on a case file review and by the information normally available to the Guardianship Tribunal which may have led to an underestimation of the richness of the associations. The data are based only on what has been recorded rather than what has actually been said by families. In this sense, it can only reflect an interpretation of the conflict by the note taker. It would be interesting to compare these results with a qualitative study of family interviews and to assess whether there is a significant difference in the themes that emerge. Further, having been derived only from cases which reach the Guardianship Tribunal, it is likely that the type of family conflict reported here is more overt and marked than is usually seen among family members.

Disagreements happen in all families. To gain a fuller understanding of the nature of conflict in these families would require a comparison of families of older people with and without dementia, and families whose disagreements did not culminate in Guardianship Tribunal applications. Without such controls we are limited in drawing aetiological links between conflict and dementia. However, the observation that conflict was not present prior to the onset of dementia in 33% of cases suggested that presence of dementia might have had a role in precipitating conflict or in escalating disagreements into disputes. This highlights the need to explore pre-existing family relationships when assessing the person with dementia and their family for the first time (Knight, 1986; Neidhardt and Allen, 1993). While we have captured a breadth of family conflict situations, it is by no means exhaustive and other types of family and systems conflict that do not result in guardianship applications have not been described here.

It may be that dementia exposes fault-lines in families, widens pre-existing cracks or creates new divisions in families. The present observational findings need to be clarified prospectively, ideally following a group of subjects with Mild Cognitive Impairment and comparing their appraisal of family members as well as their family relationships over time, and comparing this with an elderly control group, neither of whom has been involved in Guardianship applications. Perhaps such conflict is a feature of many families with ageing parents generally, or those with intense care needs, although the lower frequency of conflict amongst those with severe

dementia seems to suggest a different mechanism involved.

Our findings, although clearly tentative, point to alienation of previously trusted family members during the course of dementia. This suggests a requirement to obtain very careful histories of family relationships when making assessments of capacity to execute legal documents such as powers of attorney, enduring guardianship and wills. The rationale behind changes in such documents should be carefully scrutinised, particularly if there are changes in an established pattern of trusting or favouring certain family members.

There is a gap in formal knowledge about family conflict in dementia care and a need for further understanding in this difficult area of clinical work. Ageism in marriage and family therapy and the paucity of literature addressing family life concerns of older people have been highlighted previously (Van Amburg *et al.*, 1996; Ivey *et al.*, 2000) and are possibly reflected in the training and experience of family therapists (Ivey *et al.*, 2000). Meta-analyses of family therapy indicate it is an effective treatment with an effect size of about 0.65 overall and an evidence base to support its efficacy in schizophrenia, adolescent conduct disorders, substance abuse and domestic violence (Shadish and Baldwin, 2003; Patterson *et al.*, 2004). However, empirical support for family therapy for the elderly is sparse (Mouratoglou, 1997; Garner, 2003) and empirically studied family interventions for persons with dementia have been mainly cognitively-based, although there is evidence that such interventions have a positive effect on carer burden and patient behaviour (Marriott *et al.*, 2000).

Dementia is an area where addressing family dysfunction may have a positive yield for both the patient and the family (Peisah, in press). The altered perceptions of the person with dementia coupled with the pressure of caring placed on the family may uncover unresolved issues and conflicts which can provide a focus for such therapy. The next step after recognition of the family as an integral unit of care in dementia is to refine further the specific ways we can assist families.

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