Dementia: supportive groups for relatives

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We describe two years' experience of supportive groups for the relatives of elderly demented patients, who were inpatients, day patients, and outpatients served by the German Hospital Psychogeriatric Unit. Most patients suffered from dementia.

The impetus for forming a relatives' group came from the obvious need such relatives had for discussion and support; the City and East London district still had inadequate inpatient resources for demented patients, which has led to some patients being cared for at home longer than is desirable. Despite maximum support for the caring relative, one of us (JF) found such relatives would telephone the hospital from time to time saying they could no longer cope. They were always invited to the unit to discuss their problems, which they did, returning home with the problem unchanged but apparently satisfied and willing to carry on caring for their elderly relatives. Nevertheless, further opportunities to ventilate their feelings were needed; a group seemed to offer practical support, being economical of professional time while supplementing other supports and allowing sharing of the practical experience of coping with a demented relative.

Composition and character of groups

A simple letter of invitation to meet in a group and discuss common problems was sent to all relatives. The elderly spouses of patients appeared the most implicated and for these one hour every two weeks at lunch time was chosen for the first group meetings in the hospital library. A second, evening group was started to cater for relatives who worked by day; they were mainly the patients' children or grandchildren. Informality was a feature, no limit was set on numbers, and it was explained that the groups would continue for as long as relatives found them useful. With a slowly changing membership, the groups are still running after nearly two years. The staff members present were a GP vocational trainee working on the psychogeriatric unit, a social worker, and a nurse.

At first, the staff expected that much time would be spent prompting discussion. This expectation proved unfounded, and an immediate and lively exchange of views has been a continuous feature. As experience and confidence have grown some meetings have been held on one of the long-stay wards itself, with considerable success.

The numbers of relatives attending a meeting has varied from two to ten, with an average of six; 40 different relatives have attended in all. Initially, only the relatives of demented patients were invited, but as it became clear that relatives of patients suffering from a functional illness, such as depression, wished to attend, they were also invited.

Common themes

Certain themes arose often enough or seemed so emotionally coloured that they might well feature in any similar group. We

describe some of these themes so that colleagues who choose to start similar groups will know what to expect.

HE'S JUST THE SAME

Relatives look eagerly for similarities and seem reassured when able to say "My husband's just like that." So powerful is the wish to find common ground with other relatives that, at times, relatives of functionally ill patients seemed to convince themselves that their relative was the same as the others. As the prognosis with different patient groups might be quite different, this is an important practical point, and further explanation and reassurance to such relatives concerning the differences in outlook was necessary.

WHAT IS THE CAUSE OF IT?

Most relatives accepted their relative's illness as irreversible and partly age related. A minority seemed to find an uneasy comfort when they had attributed the illness to a concrete cause. Examples were "a knock on the head," "his awful war experiences," or "that anaesthetic he had," and no amount of explanations from staff and other relatives influenced such views. This attitude seemed to be linked with a need to ask "When will he get better?" over and over again. These few relatives seemed to have a generally negative set and appeared to gain least from the group.

HE'S NO SENSE OF TIME

A common and bitter complaint was that a demented spouse would retire to bed very early, having first switched off the television without warning or discussion. Invariably the patient would rise in the early hours, wake his spouse, and demand breakfast "before I get off to work." Relatives found this nocturnal disturbance extremely wearing, and their levels of tolerance were rapidly lowered.

SHE DOESN'T RECOGNISE ME ANY MORE

This phenomenon was often reported in conjunction with the demented spouses "packing to go home" while already in their own home. Related to this was the patients' paranoid mood leading to accusations against loved ones of lying, stealing, and not caring. These themes were among the most emotionally painful and tragic occurring within the setting of dementia. The group could give comfort but the wounds were deep.

ANGER AND RESENTMENT

Anger and resentment were common but rarely directed towards staff, in contrast to the experience of other workers.¹ Nevertheless, the angry belief that "he does it on purpose" was commonly expressed, as was "he's driven all our friends away, hovering over them." In the latter case we found that it was the normal spouses' sense of shame rather than the patients' behaviour that had usually driven friends away.

Two wives, who claimed angrily that their husbands never gave them a moment's rest, had taken on time-consuming "good works"; one finding time to care for an 88-year-old hemiplegic neighbour, the other helping the blind. Both wives were emphatic that they would never let their husbands' needs interfere with their self-imposed caring roles for others; as one commented "it keeps you sane."

MONEY

Surprisingly, the husbands reported more difficulties over money. The demented but overbearing wives seized all the pension and other

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money, hoarding it until they had several hundreds of pounds though refusing to spend anything on housekeeping. The husbands were forced to take the money while their wives' attention was otherwise distracted.

WETS THE CLOTHING, etc

Incontinence was not a major topic. Most relatives saw it as something to be borne philosophically. Those who did mention it seemed to be the more distressed and rejecting relatives.

HE GETS VERY SEXY

Not surprisingly, this topic was infrequently mentioned. What was surprising was how freely and unembarrassedly elderly relatives discussed this topic when it arose in connection with a demented, pathologically libidinous octogenarian. His wife received impressive and sensitive support from the other relatives.

Discussion

In the 1960s in Newcastle some 10% of the elderly population had dementia, which in something over half was moderate or severe.^{2,3} In the 14 years since this work general practitioners have increasingly introduced "at-risk registers." Thus in many practices demented patients and their relatives are becoming less difficult to identify. A reasonable estimate is that the average general practitioner, with a list of 2500, has about 25 families with demented relatives in his care, with regional variations. A health centre with ten general practitioners would serve as many as 250 demented patients and their relatives.

Clearly, a hospital with many elderly patients is an obvious place to hold a relatives' group. A health centre or group practice, however, would be more community based and just as suitable. We have found that no special psychiatric skills are required. A group could be run by an interested general practitioner, health visitor, community nurse, or social worker. We know of groups that have been started by advertising in the local press; a simple advertisement in a health centre or other practice would probably reach the relatives in need.

We found that groups for the relatives of patients with dementia benefit the relatives by support, as well as the opportunity to express resentment and anger by exchange of useful tips and in other, subtler ways. In addition, we have gained much information and insight into the realities of living with dementia. This too has benefited our patients and their relatives. In short, it is worth doing.

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- ¹ Pitt, B, *Psychogeriatrics*. Edinburgh, Churchill Livingstone, 1974.
- ² Kay, D W K, Beamish, P, and Roth, M, *British Journal of Psychiatry*, 1964, **110**, 146.
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Most soft drinks and cordials contain saccharin. Is there a carcinogenic risk from their consumption?

When male rats were fed on diets containing 5.0% or 7.5% saccharin some of them developed bladder stones and bladder tumours. Females were not affected, and no excess of tumours has been seen in males fed on lower concentrations of saccharin in the diet. These dose levels were some 500-750 times more than those normally achieved by humans and vastly higher than those of even a dedicated consumer of saccharin-containing soft drinks. Male mice fed on a diet containing 5% saccharin developed no bladder tumours. The results of tests for bacterial mutagenicity have given essentially negative results, and there is no clear evidence from epidemiological studies suggestive of an increased risk of bladder cancer in humans who consume saccharin. In the USA saccharin is caught by the Delaney Amendment, which renders it illegal to add to food anything that has been shown to induce cancer in appropriate tests. It is arguable whether the feeding of 5.0% or 7.5% constitutes an appropriate test. In Britain and other European countries a more pragmatic view based on common sense has so far prevailed. Common sense dictates that if there is any cancer risk from saccharin consumed in "normal" quantities by humans, it is negligible and can be ignored.

What are the common conditions that cause renal failure requiring dialysis or a kidney transplant?

End-stage renal disease is the ultimate result of many progressive diseases that destroy nephrons. Almost half of the patients who require renal replacement treatment by dialysis or transplantation present at an advanced stage in their illness, and the reconstruction of pathogenic events is thus often conjectural. Furthermore, only a proportion of patients who require dialysis and transplantation receive these treatments, and it is only among patients selected for treatment that an analysis of diagnoses is available. Diagnoses recorded among patients accepted for dialysis and transplantation in Europe and on whom returns were made to the European Dialysis and Transplant

Association Registry are shown in the table.¹ The proportions were compared for 3413 patients accepted in 1970 and 8858 accepted in 1977.

Classification	Per cent 1970	New patients 1977
Chronic renal failure, aetiology		
uncertain	0.4	10.7
Glomerulonephritis	53.1	33.1
Pyelo- or interstitial nephritis	21.5	20.9
Drug nephropathy	3.2	3.7
Cystic kidney disease	7.2	9.5
Heredofamilial	3.8	2.8
Renal vascular disease	4.9	7.5
Multisystem disease	1.1	7.7
"Other"	4.8	4.1

Differences between the proportions in 1970 and 1977 appear to be the result, in part, of changes in diagnostic fashion. In the more recent analyses the aetiology of chronic renal disease was uncertain in one out of 10 patients, and there also appears to be an increasing awareness of the contribution of primary vascular disease. English doctors now diagnose pyelonephritis less often than formerly and less often than their continental colleagues. Little more than 15% of British patients had this classification in 1977. Changes in selection policies are the reason for the increased proportion of patients with multisystem disease. Analgesic nephropathy is a preventable cause of end-stage renal disease and accounts for one in five of Swiss and Belgian patients but is less common in Britain, about 3% of cases. There are other interesting geographical variations in diagnoses of patients accepted for treatment, which may be due to true differences in incidence. Cystic kidney disease and heredofamilial conditions appear to be commoner in Northern than in Southern European countries.²

¹ Wing, A J, et al, *Proceedings of the European Dialysis and Transplant Association*, 1978, **15**, 3.

² Gurland, H J, et al, *Proceedings of the VIIth International Congress of Nephrology*, 1977, p 77. Basle, Karger, 1978.