

Quality of care in frail older people: the balance between receiving and giving

The focus on providing essential medical and social care for frail older people often leaves them feeling unable to contribute. But building in reciprocity could help preserve social inclusion and foster autonomy, dignity, and quality of life, say **Myrra Vernooij-Dassen, Sheila Leatherman, and Marcel Olde Rikkert**

Average and maximum life expectancy are now higher than ever in most of the developed world and still rising. However, it is not ageing itself, but the sharply increasing age related prevalence of frailty and multimorbidity that is the major challenge for healthcare. A fundamental problem is that healthcare services are designed for frail elderly patients without really asking them what they need and want. One of the most basic but often neglected human needs is reciprocity—the ability to give something in return for receiving.¹ We summarise the emerging evidence that reciprocity is an important means of improving health and wellbeing in frail elderly people and argue that taking it into account in health interventions will help older people feel included in their own care.

Frailty in social relations

Estimates of the prevalence of frailty among people aged 65 or older living in the community vary from 6% to 17%.^{2–3} Frailty as a concept has been defined as loss of resources in several domains of functioning, including physical, psychological, and social.^{3–5} An important characteristic of frailty is the high risk of decreasing functional performance in the near future. Consequently, frailty threatens dignity and autonomy by reducing a person's control over his or her life.⁶ Dignity refers to the importance of not being perceived as a burden to others as well as continuing to be useful.⁷ Dependency caused by frailty directly challenges the normal balance in life between giving and taking—and thereby social inclusion, a key factor in wellbeing.⁸

Importance of reciprocity

According to Gouldner, reciprocity is a universal element in sustaining human relationships and comprises two interrelated minimal demands: people should help those who have helped them and people should not injure those who have helped them.¹ This norm of reciprocity imposes obligations only when the individual is able to reciprocate. It therefore does not apply with full force in relations with people who are physically or mentally impaired.¹ Nevertheless, people retain a genuine wish to give. We found that half of frail older patients receiving palliative cancer care per-

ceived it to be a problem that they could not be of use to others.⁹

Indirect evidence exists that reciprocity is a factor explaining the differences between effective psychosocial interventions and those showing no beneficial effects. Effective psychosocial interventions focus on the needs of both patient and caregiver and provide them with tools to adapt their interactions to the specific situation, including their life expectancy, functional deficits, and competencies.^{10–12} These interventions consider reciprocity by providing subtle support that does not diminish self esteem and by allowing the patient to give back. For example, a review of psychosocial interventions for patients with cancer found that behavioural therapy and group support in which people were encouraged to interact with and support each other, as compared to usual care not including such encouragement, significantly reduced depression.¹¹

Another example of reciprocity as a key factor for successful interventions is a community occupational therapy intervention for dementia patients and their caregivers. Instead of taking over all the tasks of frail older people, this intervention stimulates caregivers to help patients function better through using their remaining capacities. Caregivers are coached in valuing the achievements of patients and their attempts to give.¹³ Tools used in this process include assessment of needs and preferences, assessment of competencies and deficits, and shared decision making on goals. A randomised controlled trial of this occupational therapy intervention showed significant improvements in daily function (interview for deterioration of daily activities in dementia: -11.7 ; 95% confidence interval -13.6 to -9.7) and caregiving competence of families (sense of competence questionnaire: 11.0 ; 9.2 to 12.8) compared with the control group.¹³ Moreover, the quality of life of patients and caregivers' health status significantly improved.¹⁴

The evidence on psychosocial interventions is mixed: reviews show both improvements in the quality of life and the failure to show effects.^{10–12} A failure to show effects may not only be due to

methodological problems, such as low numbers of participants, but also reflect unintended consequences of receiving care.

Although psychosocial care is usually provided with the best of intentions, it is often not appreciated as such. Bolger and Amarel provided experimental evidence that social support is often ineffective because of the emotional costs of receiving support: dependency threatens self esteem.¹⁵ The evidence suggests that use of interventions that allow reciprocity and don't diminish frail older people as individuals may improve the effectiveness of social and healthcare services. This warrants further research and testing.

Current healthcare and reciprocity

According to a long legal and cultural tradition in the United States and Europe, care should be provided in a way that respects the autonomy and dignity of patients.^{16–17} This is consistent with patients' wishes. Several studies have documented that what patients want from medical care is relief from suffering, help in minimising the burden of families, closer relationships with family members, daytime activities, and a sense of control.^{9–16–18} There is no evidence that frail elderly people want anything different.

However, current healthcare focuses too much on dealing with the consequences of people's frailty and far less on their strengths and wishes to give. The mismatch between what patients really want and what is offered is clearly shown by the poor agreement between the goals of professionals and hospitalised frail patients and their families (κ of interindividual agreement: -0.11 to 0.33). The agreement between patients and professionals on medical goal was 61% ($\kappa=0.12$) and on future planning 49% ($\kappa=0.03$).¹⁹

To lessen this disagreement, we need to pay greater attention to psychosocial competencies and interventions that facilitate the introduction of needs based care. Although some of the interventions may be complex, needs based care can often be achieved by simple steps in daily practice. For instance, if a frail older person is approached with the words: "You need a break, you are always

alone, let's go for a walk," the person may perceive pity. But if the approach is: "I would like to have a walk. Would you like you to join me?" self esteem is not threatened and may even be strengthened. Subtle support reduces feelings of dependency and indebtedness.¹⁵

Skills needed to allow the patient to reciprocate include being able to encourage patients to support other patients, the ability to help patients to use all remaining capacities, the ability to show attention and affection, and the ability to coach caregivers in valuing these attempts to give. As far as we know, these skills are not included in medical or nursing training.

Conclusions

Acknowledging the norm of reciprocity for all citizens can prevent or mitigate the loss of autonomy and dignity of frail elderly people who are dependent on care. Being able to give something back is largely ignored as a basic social need. Although more robust evidence is needed, the perspective of reciprocity provides a new angle to help provide more effective care, especially in the design and implementation of psychosocial interventions.

Of course the importance of imbalance in reciprocity may vary according to personality and may be influenced by the opportunity to pay for care received. However, care for frail older people should include shared decision making, which may even help to limit resources spent by a health-care system with a propensity "to do everything."²⁰

Though the evidence base on the importance of reciprocity is sparse, the early findings argue for paying greater attention in both policy and practice to the role of reciprocity in improving social inclusion and the quality of outcomes for frail older people.

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Accepted: 27 December 2010

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Competing interests: None declared.

Provenance and peer review: Not commissioned; externally peer reviewed

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Cite this as: *BMJ* 2011;342:d403

ANSWERS TO ENDGAMES, p 1091. For long answers go to the Education channel on bmj.com

STATISTICAL QUESTION

Number needed to harm

Answer a is correct.

ON EXAMINATION QUIZ

Schizophrenia

Answer B is correct.

PICTURE QUIZ An odd cause of dysphagia

- The chest radiograph shows dramatic paratracheal and mediastinal widening. The computed tomogram of the chest shows a large superior mediastinal mass with superior vena cava obstruction and a pericardial effusion.
- Lymphoma, thymoma, bronchogenic carcinoma, and metastatic carcinoma.
- Ideally a whole node biopsy should be done if the lymph node can be felt on clinical examination (a third of cases) because this is most likely to yield a definitive diagnosis. Failing that a computed tomography guided percutaneous biopsy, endoscopic ultrasound guided biopsy, or mediastinoscopy with lymph node biopsy may yield a diagnosis. The histological diagnosis influences the choice of systemic treatment used in non-Hodgkin's lymphoma and non-small cell lung cancers so large tissue samples are needed. Computed tomography guided biopsy does not provide large samples and is therefore not the best method for obtaining tissue for diagnosis. The biopsy showed tumour cells with prominent nucleoli and immunohistochemistry in keeping with non-Hodgkin's lymphoma of B cell type.
- Endovascular stents can provide rapid relief of superior vena cava obstruction and can be put in place before tissue diagnosis. In patients with stridor or cerebral oedema, emergency treatment with radiotherapy and stent placement is advocated to reduce the risk of respiratory failure and death. Glucocorticoids are effective in thymoma. Radiotherapy can be used in radiosensitive tumours such as small cell and non-small cell lung cancers. Chemotherapy and radiotherapy are the main treatments in lymphoma; glucocorticoids also play a role. Treatment of metastases is largely limited to symptomatic relief. Corticosteroids should be avoided before material for pathological screening has been collected.