

Caring for people with dementia

The focus should be on what can be done rather than on the lack of a cure



RESEARCH, p 258

Murna Downs professor in dementia studies, Bradford Dementia Group, University of Bradford, Bradford BD5 0BB
m.downs@bradford.ac.uk

Barbara Bowers associate dean for research and Helen Denne Schulte professor, School of Nursing, University of Wisconsin, Madison, WI 53792-2455, USA

Competing interests: None declared.

Provenance and peer review: Commissioned; not externally peer reviewed.

BMJ 2008;336:225-6

doi: 10.1136/bmj.39429.434907.80

In the accompanying prospective cohort study, Xie and colleagues show that people can live for several years after being diagnosed as having dementia and many are already frail at the time of diagnosis.¹ The authors estimated survival times after the onset of dementia in 438 people according to age, self reported health, disability, and severity of cognitive impairment. The estimated median survival time from the onset of dementia was 4.1 years (interquartile range 2.5-7.6) for men and 4.6 years (2.9-7.0) for women. Survival between the youngest (56-69 years) and oldest people (≥ 90 years) differed by nearly seven years. Sex, age of onset, and disability significantly predicted mortality in the presence of dementia. The study shows that dementia is a terminal condition, the course of which unfolds with coexisting age related impairment and ill health. The study provides clear evidence that people with dementia need coordinated care and support from a range of professionals and practitioners from diagnosis to death to ensure maximum quality of life and prevent unnecessary disability and suffering.

During the past 30 years, substantial advances have been made in understanding how best to support people living with dementia. Until recently, dementia was viewed as a “living death” about which little could be done beyond custodial care. In November 2006, the National Institute for Health and Clinical Excellence together with the Social Care Institute for Excellence published the first guideline on the care of dementia.² It proposed pathways to tackle the social and medical aspects of living with dementia. The guideline is a first step towards rectifying the fact that the United Kingdom fails to provide adequate care for people with dementia despite evidence that well organised care reduces disability.^{3 4}

Doctors occupy a unique vantage point for ensuring optimal quality of care for people with dementia and their families. Both the patient with dementia and their carer—many of whom live together—need to be provided for. Doctors have a part to play in promoting quality of care from diagnosis until death, through assessment of changes in cognitive functioning—such as memory, day to day functioning, and behaviour—alongside identification and treatment of comorbidities. Referral to specialist psychological and psychosocial services is integral to provision of high quality care.⁴

Many people with dementia and their families wait years for a diagnosis, and some never receive one.⁴ Primary care doctors often defer the diagnosis because they think it is futile—that the condition is not treat-

able, it carries stigma, and it will leave people feeling hopeless.

Doctors have a part to play in responding to concerns about changes in cognition including memory, behaviour, and day to day functioning. This requires comprehensive assessment to identify the underlying cause, which may include pain; infection; dehydration; side effects of drugs; or unmet psychosocial needs, such as lack of human contact or meaningful engagement.⁵ Assessing and treating the cause may reduce inappropriate use of tranquilising drugs.⁶ Doctors also need to assess and treat comorbidities; this may prevent unnecessary admissions to hospital and associated excess disability.⁷ People with dementia are more likely to be admitted to hospital and to have longer stays in hospital than people without dementia,⁷ which may reduce quality of life and cognitive and functional ability.⁷ Promoting awareness of the many psychosocial supports and services that can improve quality of life may help to counteract doctors', patients', and carers' sense of futility.

Health care and social care for people with dementia and their families is most effective when provided in partnership with organisations in the private and voluntary sector, such as the Alzheimer's Society.⁴ Research from the US shows that much of the distress experienced by people with dementia and their families can be prevented when primary care works closely with geriatric nurse practitioners and community and voluntary services.^{8 9} Working in partnership with people with dementia and their families is now the expected norm.

In planning care and support, doctors need to pay as much attention to the essential human worth of a person with dementia and their retained capacity for relationships, pleasure, communication, and coping as they do to deficits and dysfunction.¹⁰⁻¹² They also need to be aware of the growing evidence base for therapeutic intervention and effective support to minimise disability and promote optimal quality of life.^{2 4}

- 1 Xie J, Brayne C, Matthews FE. Survival times in people with dementia: analysis from population based cohort study with 14 year follow-up. *BMJ* 2008 doi: 10.1136/bmj.39433.616678.25.
- 2 National Institute for Health and Clinical Excellence/Social Care Institute for Excellence. *Dementia: supporting people with dementia and their carers in health and social care*. 2006. www.nice.org.uk/guidance/cg42.
- 3 Knapp M, Prince M, Albanese E, Banerjee S, Dhanasiri S, Fernandez JL, et al. *Dementia UK*. London: Alzheimer's Society, 2007.
- 4 National Audit Office. *Improving services and support for people with dementia*. London: Stationery Office, 2007.
- 5 Cohen-Mansfield J. Non-pharmacological management of behavioural problems in persons with dementia: the TREA model. *Alzheimer's Care Quarterly* 2000;1:22-34.
- 6 Margallo-Lana M, Swann A, O'Brien J, Fairbairn A, Reichelt K, Potkins D, et al. Prevalence and pharmacological management of behavioural and psychological symptoms amongst dementia sufferers living in

- care environments. *Int J Geriatr Psychiatr* 2001;16:39-44.
- 7 Silverstein NM, Maslow K, eds. *Improving hospital care for persons with dementia*. New York: Springer, 2005.
 - 8 Callahan CM, Boustani MA, Unverzagt FW, Austrom MG, Damush TM, Perkins AJ, et al. Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial. *JAMA* 2006;295:2148-57.
 - 9 Vickrey BG, Mittman BS, Connor KI, Pearson ML, Della Penna RD, Ganiats TG, et al. The effect of a disease management intervention on quality and outcomes of dementia care: a randomized controlled trial. *Ann Intern Med* 2006;145:713-26.
 - 10 Kitwood T. *Dementia reconsidered: the person comes first*. Buckingham: Open University Press, 1997.
 - 11 Normann HK, Norberg A, Asplund K. Confirmation and lucidity during conversations with a woman with severe dementia. *J Advanced Nursing* 2002;39:370-6.
 - 12 Clare L. *Neuropsychological rehabilitation and people with dementia*. Hove, East Sussex: Psychology Press, 2008.

Cardiovascular risks of calcium supplements in women

Increased risk of myocardial infarction outweighs the reduction in fractures

RESEARCH, p 262

Graeme Jones professor of rheumatology and epidemiology, Menzies Research Institute, Hobart, Tas, Australia 7000
Tania Winzenberg postdoctoral research fellow, Menzies Research Institute, Hobart, Tas, Australia 7000
g.jones@utas.edu.au

Competing interests: None declared.

Provenance and peer review: Commissioned; not externally peer reviewed.

BMJ 2008;336:226-7
 doi: 10.1136/bmj.39463.394468.80

Calcium is an important component of bone, and a sufficient intake of calcium is needed for bone homeostasis. Calcium supplements can reduce the risk of fractures in elderly women who are deficient in calcium and vitamin D, but data on the risk of adverse effects on cardiovascular outcomes have so far been inconclusive. In their accompanying paper, Bolland and colleagues report a preplanned secondary analysis of their randomised controlled trial of calcium supplements in 1471 postmenopausal women. They analysed the effect of calcium supplements on myocardial infarction, stroke, and sudden death.¹

Calcium and vitamin D supplements have been shown to reduce the risk of hip fractures in elderly institutionalised women who are deficient in calcium and vitamin D.² More recent large trials based in the community have been negative, but this may have been the result of poor adherence,³ which is particularly important for calcium to be effective. Benefit has been shown only in analyses restricted to women who adhered to treatment for total fractures,⁴ hip fractures,⁵ and forearm fractures.⁶ A recent meta-analysis suggested an overall 12% decrease in the relative risk of fracture.³ If we assume that the average incidence of fracture in women aged 80-84 years is 4% each year, then the number needed to treat (NNT) for five years to prevent one fracture is 42.⁷

Calcium supplements have generally been thought not to be harmful. Patients often complain of constipation,⁶ and the risk of renal calculi is slightly increased.⁵ Possible positive effects on obesity and cholesterol have implied a protective effect on cardiovascular outcomes. However, calcium based phosphate binders are associated with increased vascular calcification in patients about to undergo dialysis.⁸ The potential mechanisms of arterial calcification are many and complex,⁹ but biologically plausible mechanisms support the role of calcium. Under certain stimuli, vascular smooth muscle cells may undergo a phenotypic switch to bone-like cells,⁹ and in the presence of high amounts of calcium these may be capable of producing vascular calcification.

So what does the analysis by Bolland and colleagues tell us? The data were not totally consistent, but if most weight is placed on the verified events (from medical records alone as well as a search of a national database of hospital admissions), women tak-

ing calcium had a significantly higher risk of cardiovascular disease (relative risk 2.12, 95% confidence interval 1.01 to 4.47, P=0.047), especially myocardial infarction (1.49, 0.86 to 2.57, P=0.16). The equivalent risks for stroke were 1.42 (0.83 to 2.43, P=0.21) and 1.37 (0.83 to 2.28, P=0.23), respectively. The survival curves started to diverge after about two years, indicating a slow onset of effect.

When directly comparable incidence rates for myocardial infarction and stroke are used in 80-84 year old women, the number needed to harm (NNH) for five years is 10-17 and 26-28, respectively.¹⁰ Both are considerably less than the NNT, which indicates that the risks greatly outweigh the benefits in an elderly population. Indeed, the absolute risk of fracture would have to be four times that of cardiovascular disease for the NNT to be less than the NNH. This would be met only in women with a very high risk of fracture, in whom guidelines recommend more effective treatment anyway. These estimates are subject to wide confidence intervals and they contrast with the absence of increased cardiovascular risk in the women's health initiative study in younger postmenopausal women, although poor adherence in that study may contribute to this.⁵

These adverse findings need to be replicated by re-examining the databases of other large trials for cardiovascular end points, especially in people with good long term adherence. Until then, the use of calcium supplements as monotherapy in elderly people does not seem to be justified, except possibly in women with very low calcium intakes. Data suggest that it may be safe to use supplements to prevent osteoporosis in younger postmenopausal women. Caution is necessary, however, given the need for long term use to maintain the benefit on bones and the likely time lag between treatment with calcium and adverse cardiovascular events.

The place of calcium as co-therapy with other treatments for osteoporosis—such as bisphosphonates and strontium—is less clear. None of these agents has been shown to be effective without co-administration of calcium and vitamin D. The literature on dialysis provides a rationale for the use of bisphosphonates to prevent arterial calcification,¹¹ so these agents may offset one of the harmful effects of calcium. The recent report of decreased mortality caused by cardiovascular disease starting about 18 months after treatment with zoledronic acid is consistent with this hypothesis.¹²

Furthermore, these patients are at much higher risk of fracture, so the NNT would be lower. It therefore seems reasonable to continue supplementation in people taking bisphosphonates.

- 1 Bolland MJ, Barber PA, Doughty RN, Mason B, Horne A, Ames R, et al. Vascular events in healthy older women receiving calcium supplementation: randomised controlled trial. *BMJ* 2008 doi: 10.1136/bmj.39440.525752.BE.
- 2 Chapuy MC, Arlot ME, Doboëuf F, Brun J, Crouzet B, Arnaud S, et al. Vitamin D3 and calcium to prevent hip fractures in the elderly women. *N Engl J Med* 1992;327:1637-42.
- 3 Tang BMP, Eslick GD, Nowson C, Smith C, Bensoussan A. Use of calcium or calcium in combination with vitamin D supplementation to prevent fractures and bone loss in people aged 50 years and older: a meta-analysis. *Lancet* 2007;370:657-66.
- 4 Prince RL, Devine A, Dhaliwal SS, Dick IM. Effects of calcium supplementation on clinical fracture and bone structure: results of a 5-year, double-blind, placebo-controlled trial in elderly women. *Arch Intern Med* 2006;166:869-75.
- 5 Jackson RD, LaCroix AZ, Gass M, Wallace RB, Robbins J, Lewis CE, et al.

- Calcium plus vitamin D supplementation and the risk of fractures. *N Engl J Med* 2006;354:669-83.
- 6 Reid IR, Mason B, Horne A, Ames R, Reid HE, Bava U, et al. Randomized controlled trial of calcium in healthy older women. *Am J Med* 2006;119:777-85.
 - 7 Cooley H, Jones G. A population based study of fracture incidence in southern Tasmania: lifetime fracture risk and evidence for geographic variations within the same country. *Osteoporos Int* 2001;12:124-30.
 - 8 Russo D, Miranda I, Ruocco C, Battaglia Y, Buonanno E, Manzi S, et al. The progression of coronary artery calcification in predialysis patients on calcium carbonate or sevelamer. *Kidney Int* 2007;72:1255-61.
 - 9 Wallin R, Wajih N, Greenwood GT, Sane DC. Arterial calcification: a review of mechanisms, animal models, and the prospects for therapy. *Med Res Rev* 2001;21:274-301.
 - 10 Simons LA, Simons J, Friedlander Y, McCallum J, Palaniappan L. Risk functions for prediction of cardiovascular disease in elderly Australians: the Dubbo study. *Med J Aust* 2003;178: 113-6.
 - 11 Ariyoshi T, Eishi K, Sakamoto I, Matsukuma S, Odate T. Effect of etidronic acid on arterial calcification in dialysis patients. *Clin Drug Invest* 2006;26:215-22.
 - 12 Lyles KW, Colon-Emeric CS, Magaziner JS, Adachi JD, Pieper CF, Mautalen C, et al. Zoledronic acid and clinical fractures and mortality after hip fracture. *N Engl J Med* 2007;357:1799-809.

Zinc supplements for severe cholera

Are simple, well tolerated, and could save money as well as lives

RESEARCH, p 266

Marzia Lazzerini paediatrician, Department of Paediatrics, and Unit of Research on Health Services and International Health Institute of Child Health, IRCCS Burlo Garofolo, 34137, Trieste, Italy
lazzerini@burlo.trieste.it

Competing interests: None declared.

Provenance and peer review: Commissioned; not externally peer reviewed.

BMJ 2008;336:227-8
doi: 10.1136/bmj.39434.517431.80

In the accompanying paper, Roy and colleagues report that zinc supplementation has an additional benefit over antimicrobial treatments in reducing the duration and severity of cholera in children.¹ The study was carried out in Bangladesh, where cholera is endemic.

Cholera is a common disease in many countries of the world. About 230 000 cases in more than 50 countries are reported globally, but the World Health Organization estimates that official notifications make up only 5-10% of the real burden of cholera.² This means that as many as three million cases and more than 100 000 deaths occur each year.^{2 3}

Cholera may be undetected for various reasons. About 80-90% of episodes are of mild to moderate severity. Therefore, without performing routine culture for *Vibrio cholerae*, the infection is difficult to distinguish clinically from other causes of acute diarrhoea, including traveller's diarrhoea. Also, until recently economic repercussions such as restrictions to food exports and losses to tourism have acted as strong disincentives for reporting.^{2 3}

Several major outbreaks have occurred since 2005, and reported cases have doubled in the past three years, with a threefold increase in the absolute number of deaths. Almost all deaths occurred in Africa. Case fatality varies from about 1% to 4%, but in some regions—such as Angola's provinces, mortality reached 30% in 2006. Children and women of childbearing age are the most susceptible to contracting and dying from the disease. People who are malnourished are, as always, more vulnerable.^{2 3}

The treatment of cholera has changed little in recent decades. The mild form can be treated with oral rehydration. Rice based solutions decrease stool output more than those based on glucose.^{3 4} Solutions with reduced osmolarity produce similar clinical outcomes to standard solutions.⁵ About 15-20% of patients have severe life threatening dehydration and need intravenous fluids. Most patients will recover even without

antibiotics if hydration is maintained. Nevertheless, antibiotics (ciprofloxacin or azithromycin as a single dose or 12 doses of erythromycin) reduce the duration and severity of disease, and they can minimise the use of services and resources.^{2 3} However, resistant strains are common and treatment protocols should be adjusted accordingly.^{2 3} Antisecretives—drugs that reduce gut secretions of ions and water, such as racecadotril—have no effect.

What does zinc add to the current treatment of cholera in children? In Roy and colleagues' study, significantly more children receiving zinc supplements than controls recovered on the second day (40 (49%) *v* 26 (32%), *P*=0.03) and on the third day (66 (81%) *v* 56 (68%), *P*=0.03).¹ On average, diarrhoea lasted for eight hours less in children taking zinc and their stool production was reduced by 200 mg a day. No excess vomiting was reported in this study, which is not the case when zinc syrup is not flavoured to mask its metallic taste.

Is this effect clinically relevant? At first glance this small benefit seems negligible. But imagine the potential effect at the International Centre for Diarrhoeal Disease Research, Bangladesh, where about 34 100 patients had cholera in 2005. During the epidemic season, the treatment ward is extended with tents to accommodate more than 500 patients each day. Under these circumstances, a 10-15% reduction in children being admitted to hospital would save lives.³ The cost of zinc treatment for three days is around \$0.14 (£0.07; €0.1).¹ The average cost of full treatment for one patient with severe cholera is estimated at \$15.³ Therefore, reducing hospital stay might even save money.

Why would zinc help treat cholera? Zinc is a catalytic or structural component of more than 200 human enzymes. It is involved in immune competence, resistance of skin and mucosa to infection, and development of the nervous system. Nutritional zinc deficiency is a common problem in developing countries, and giving

zinc to children improves growth and the treatment and prevention of acute respiratory infections.^{6 7}

The beneficial effects of zinc on diarrhoea and cholera have a biologically plausible explanation. Zinc restores the integrity of the mucosal barrier and the activity of the enzymes in the brush border of enterocytes.⁸ It directly affects ion channels—it blocks potassium channels in the basolateral membrane and thus inhibits chloride secretion induced by cyclic AMP.⁹ Animals deficient in zinc show high fluid losses in response to cholera toxin,¹⁰ while zinc supplementation in humans reduces cyclic AMP concentrations in enterocytes, promotes ion absorption, and substantially reduces ion secretion induced by cholera toxin.¹¹ Finally, zinc also enhances the production of antibodies against intestinal pathogens, including cholera, and increases the numbers of circulating T cells in children.^{8 12}

In conclusion, the results of the study by Roy are consistent with previous studies in diarrhoea.¹ WHO and Unicef already recommend 10-20 mg of zinc a day for all children with diarrhoea. The current trial adds to our knowledge that zinc has a beneficial effect even in severe cholera, in children in hospital with high purging rates (both high frequency and volume of diarrhoea). The benefit of zinc in cholera may be small, but it is far from negligible in countries where the disease is endemic. Treatment is simple, has no serious adverse effects, and may even save money.

- 1 Roy SK, Hossain MJ, Khatun M, Chakraborty B, Chowdhury S, Begum A, et al. Zinc supplementation in children with cholera in Bangladesh: a randomised controlled trial. *BMJ* 2008 doi: 10.1136/bmj
- 2 WHO. Cholera, 2006. *Wkly Epidemiol Rec* 2007;82:273-84.
- 3 Sack DA, Sack RB, Chaignat CL. Getting serious about cholera. *N Engl J Med* 2006;355:649-51.
- 4 Fontaine O, Gore SM, Pierce NF. Rice-based oral rehydration solution for treating diarrhoea. *Cochrane Database Syst Rev* 1998;(4):CD001264.
- 5 Murphy C, Hahn S, Volmink J. Reduced osmolarity oral rehydration solution for treating cholera. *Cochrane Database Syst Rev* 2004;(4):CD003754.
- 6 Bhutta ZA, Bird SM, Black RE, Brown KH, Gardner JM, Hidayat A, et al. Therapeutic effects of oral zinc in acute and persistent diarrhea in children in developing countries: pooled analysis of randomized controlled trials. *Am J Clin Nutr* 2000;72:1516-22.
- 7 Aggarwal R, Sentz J, Miller MA. Role of zinc administration in prevention of childhood diarrhea and respiratory illnesses: a meta-analysis. *Pediatrics* 2007;119:1120-30.
- 8 Shankar AH, Prasad AS. Zinc and immune function: the biological basis of altered resistance to infection. *Am J Clin Nutr* 1998;68:447S-63S.
- 9 Hoque KM, Rajendran VM, Binder HJ. Zinc inhibits cAMP-stimulated Cl secretion via basolateral K-channel blockade in rat ileum. *Am J Physiol Gastrointest Liver Physiol* 2005;288:G956-63.
- 10 Roy SK, Tomkins AM, Ara G, Jolly SP, Khatun W, Chowdhury R, et al. Impact of zinc deficiency on vibrio cholerae enterotoxin-stimulated water and electrolyte transport in animal model. *J Health Popul Nutr* 2006;24:42-7.
- 11 Canani RB, Cirillo P, Buccigrossi V, Ruotolo S, Passariello A, De Luca P, et al. Zinc inhibits cholera toxin-induced, but not Escherichia coli heat-stable enterotoxin-induced, ion secretion in human enterocytes. *J Infect Dis* 2005;191:1072-7.
- 12 Albert MJ, Qadri F, Wahed MA, Ahmed T, Rahman AS, Ahmed F, et al. Supplementation with zinc, but not vitamin A, improves seroconversion to vibriocidal antibody in children given an oral cholera vaccine. *J Infect Dis* 2003;187:909-13.

Coaching to support patients in making decisions

Needs to be tailored to individuals, and integrated with existing health systems

Annette M O'Connor professor, University of Ottawa, School of Nursing, Ottawa, ON, Canada K1H 8M5
aocconnor@ohri.ca

Dawn Stacey assistant professor, University of Ottawa, School of Nursing, Ottawa, ON, Canada K1H 8M5

France Légaré assistant professor, Laval University, Department of Family Medicine, Quebec, QC, Canada G1K 7P4

Competing interests: AO has received grants from a US not for profit Foundation for Informed Decision Making (FIMDM). FIMDM has a licensing agreement with Health Dialog, a commercial company that markets patient decision aids and health coaching services.

Provenance and peer review: Commissioned; not externally peer reviewed.

BMJ 2008;336:228-9
doi: 10.1136/bmj.39435.643275.BE

An essential component of high quality clinical care is an informed and engaged patient.¹ Although some patients have the necessary confidence and skills to participate in their care, others or their families need coaching to develop their skills. Over the past 15 years, health coaching has been evaluated in research interventions and is now provided mostly in call centres or management programmes for chronic conditions in North America, Europe, and Australia.

Coaching develops patients' skills in preparing for a consultation, deliberating about options, and implementing change. Trained facilitators, who are supportive but do not make decisions for the patient, coach patients before or after an encounter with a clinician. Coaches are often nurses, but they may also be other health professionals or trained patients. Coaching is provided face to face between individuals or groups, or over the telephone, email, or internet. Human interaction is usually involved, but automated coaching using telephone or e-tools is evolving.

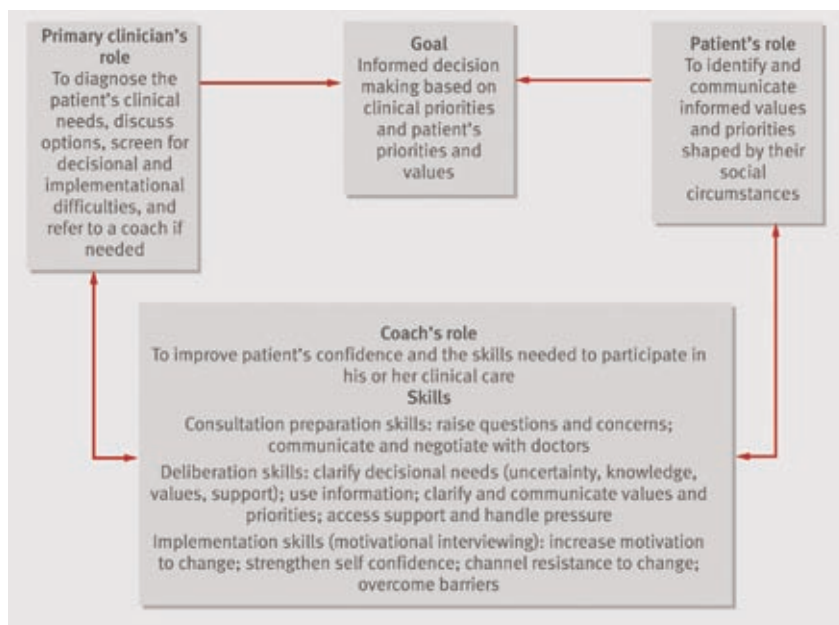
Coaching can be used for chronic conditions where the challenge lies in finding common ground between clinical and personal priorities and implementing changes. It is also useful for preference sensitive decisions (such as treatments for prostate and breast cancer, back pain, benign prostatic hyperplasia, benign uterine bleeding,

and osteoarthritis), where the challenge lies in choosing the option that matches the patients' informed values.

The figure illustrates the coach's potential role in supporting the clinical encounter. The clinician and patient work together to reach informed decisions about the plan of care, on the basis of the patient's clinical needs, priorities, and values. The clinician's expertise lies in diagnosing and identifying treatment options according to clinical priorities, whereas the patient's role is to identify and communicate their informed values and priorities shaped by social circumstances. Coaches are involved when the patient's confidence and skills in preparing for consultations, deliberating about options, or implementing changes need to be developed.¹⁻³

What is the evidence that coaching is effective in these three domains? A recent review of seven systematic reviews of coaching and question prompts that are designed to prepare patients for consultations showed that these interventions had positive effects on patients' knowledge, information recall, and participation in decision making.¹ The effects on satisfaction and treatment outcomes were inconsistent, however.

In terms of deliberation about options, the review included 10 systematic reviews of "patient decision aids," which explain options, clarify values, and



Roles of coaches in collaborative care and shared decision making

provide structured guidance or coaching in deliberation and communication. Decision aids improved patients' participation, increased knowledge of their treatment options and probable outcomes, and improved agreement between patients' values and subsequent treatment decisions. The use of discretionary surgery decreased without apparent adverse effects on health outcomes. However, the intensity of structured guidance or coaching in decision aids varied widely.⁴ One trial evaluated the separate contribution of coaching relative to a video decision aid alone or usual care for menorrhagia.⁵ Women who had additional coaching to help them express their preferences had greater satisfaction and reduced hysterectomy rates; service costs were also lower.

Another systematic review assessed the evidence on implementing change. The combined effects of 72 trials of motivational interviewing in patients with various diseases showed no effect on cigarette smoking or glycated haemoglobin values, but significant positive effects were found for body mass index, total blood cholesterol, systolic blood pressure, blood alcohol concentration, and standard ethanol content.³ Single encounters of 15 minutes' duration were effective in 64% of studies, but more than one encounter had a greater likelihood of positive effects. Interventions by doctors were effective more often (80% of studies) than interventions by other health-care providers (46%).

So how can coaching be implemented in practice? Health coaches are most commonly found in call centres or peer support programmes. This improves access and coverage but usually lacks continuity or linkage with primary care or specialty care practices. Linkage to care may make it easier to identify and document cases, to tailor the coaching to the patient's clinical needs, and to have the patient's own doctor reinforce the skills patients acquire through coaching.

Some centres have embedded coaching into clinical care processes. In California, trained volunteers provide a consultation planning programme, which includes coaching in raising questions and concerns and in communicating and negotiating with doctors.⁶ In the United Kingdom, nurse specialists are trained to administer decision aids and provide coaching for patients having difficulty deciding about treatment for prostate cancer and benign prostatic hyperplasia.⁷ At the Dartmouth Hitchcock Medical Center in the United States, patients receive decision support using automated computerised methods⁸; highly distressed patients are automatically referred to support personnel. Patients view decision aids and are prompted by computers to elicit their knowledge, values, preferences, and unresolved decisional needs. Decisional needs are summarised electronically and sent to the doctors to "close the loop" on decision making with each patient. Also, the clinical service and the public receive aggregated quality reports on decision making.^{9, 10}

Although many healthcare providers are being trained in motivational interviewing, its use in daily clinical practice is limited.³ The future of coaching lies in a blend of human and electronic interfaces based on people's specific needs. Patients' electronic self reports of their clinical and decisional needs, which are completed at health centres or via the internet, could serve as prompts for planning consultations and trigger access to coaching.

Coaching in preparing for consultations can improve patients' participation and inform their decisions. In turn, motivational interviewing can improve some health outcomes. However, many operational barriers need to be overcome before there is widespread implementation of coaching that is linked to clinical care and tailored to patients needs.¹¹

- 1 Coulter A, Ellins J. Effectiveness of strategies for informing, educating and involving patients. *BMJ* 2007;335:24-7.
- 2 O'Connor AM, Légaré F, Stacey D. Risk communication in practice: the contribution of decision aids. *BMJ* 2003;327:736-40.
- 3 Rubak S, Sandbaek A, Lauritzen T, Christensen B. Motivational interviewing: a systematic review and meta-analysis. *Br J Gen Pract* 2005;55:305-12.
- 4 O'Connor AM, Stacey D, Entwistle V, Llewellyn-Thomas H, Rovner D, Holmes-Rovner M, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2003;(2): CD001431.
- 5 Kennedy AD, Sculpher MJ, Coulter A, Dwyer N, Rees M, Abrams KR, et al. Effects of decision aids for menorrhagia on treatment choices, health outcomes, and costs: a randomized controlled trial. *JAMA* 2002;288:2701-8.
- 6 Sepucha K, Belkora J, Mutchnick S, Esserman LJ. Consultation planning to help breast cancer patients prepare for medical consultations: effect on communication and satisfaction for patients and physicians. *J Clin Oncol* 2002;20:2695-700.
- 7 National Steering Group for Decision Support Aids in Urology. *Implementing patient decision aids in urology. Final report.* 2005. www.pickereurope.org/Filestore/Research/Urology_steering_group_report.pdf.
- 8 Collins D, Sepucha K, O'Connor A, Moore C, Kearing S, Llewellyn-Thomas H. *Can women with early stage breast cancer make an informed choice for mastectomy?* Fourth International Shared Decision Making Conference, Freiberg, Germany, 2007. www.shared-decision-making.org/index.php?article_id=165.
- 9 Dartmouth Hitchcock Medical Center. *Quality reports. Breast cancer performance results.* 2007. www.dhmc.org/qualityreports/list.cfm?metrics=BC.
- 10 Dartmouth Hitchcock Medical Center. *Quality reports. Knee replacement.* 2007. www.dhmc.org/qualityreports/list.cfm?metrics=KR.
- 11 Gravel K, Légaré F, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. *Implement Sci* 2006;1:16.

Presumed consent for organ donation

Is an ethical and effective way of dealing with organ donation shortages

VIEWS AND REVIEWS, p 278

Danielle Hamm ethics adviser,
British Medical Association,
London WC1H 9JP
dhamm@bma.org.uk

Juliet Tizzard deputy head of
ethics,
British Medical Association,
London WC1H 9JP

Competing interests: None
declared.

Provenance and peer review:
Commissioned; not externally
peer reviewed.

BMJ 2008;336:230

doi: 10.1136/bmj.39475.498090.80

Last year, 1000 people in the United Kingdom died while on the organ transplant list or after being removed from the list because they became too ill. Had a system of presumed consent been in place, whereby adults are automatically registered as organ donors unless they opt out, many of these deaths may have been prevented.

Over the past year, opinion in the UK among the public, media, and politicians has shifted towards presumed consent, and the prime minister has pledged his support of such a system. A public opinion poll taken in October 2007 showed that 64% of respondents were in favour of a soft system of presumed consent, compared with 59% in 2004.¹

Although 90% of the UK population is in favour of organ donation, only 24% has signed the Organ Donation Register.² Currently, when a person's wishes are not known relatives are asked to decide about donation, in the most difficult circumstances, when they are recently bereaved. Not surprisingly, a large number of families—around 40%—opt for the default position, which is not to donate.³

The BMA has advocated a “soft system” of presumed consent since 2000. The system would still retain a role for relatives, opting out would be easy and accessible, and strict measures would be in place to protect vulnerable groups who may not have the capacity to decide for themselves.

Making donation the default position, from which everybody would retain the right to opt out during their lifetime, would make it easier for most people to achieve their wish to donate; it would also relieve relatives of the burden of making the decision.

One of the major concerns people have with a presumed consent system is that individuals will lose control over what will happen to their body after death, and the state will take over. This is not the case. Like the current system, under presumed consent people would retain the choice over whether or not to donate after death. Imperative to any change in legislation would be a widespread public information campaign, which would target sections of society that are hard

to reach. Mechanisms must be in place to ensure all members of the public are informed of their choices and can register an objection quickly and easily—for example, through their general practitioner, post office, or electoral registration forms. As an added safeguard, the system would retain a role for relatives. After death, relatives would be informed that the deceased person had not opted out of donation and, unless they object—either because they know of an unregistered objection by the person or because it would cause major distress to the close relatives—the donation would proceed.

A key question is whether such a system would increase organ donation rates; a growing body of evidence indicates that it would. The relation between presumed consent and donation rates is notoriously hard to understand because of other determinants that affect donation rates. A study in 2006 compared 22 countries over 10 years; it took account of determinants that might affect donation rates, such as health expenditure and number of deaths from road crashes.⁴ It concluded that “When other determinants of donation rates are accounted for, presumed consent countries have roughly 25-30% higher donation rates than informed consent countries.” A study in 2003 found similar results.⁵

Spain consistently has the highest donor rate in Europe. One major difference between Spain and the UK is that it has an exceptionally highly organised and well funded system. The recent report of the UK Organ Donation Taskforce has drawn on the experience of Spain and has centered its recommendations on increasing organ donation rates through improved infrastructure, coordination, and funding. The other major difference with Spain is that it has a system of presumed consent. Although relatives are still consulted, the system of presumed consent, which presents a very positive view of donation, has resulted in a decrease in the number of relatives' refusals.⁴ The UK can learn two lessons from Spain, one regarding improvements to infrastructure—which the BMA welcomes government commitment to—and the other regarding presumed consent.

The Organ Donation Taskforce is currently conducting an inquiry into the practical, ethical, legal, and societal implications of presumed consent. It will report its findings this summer. With at least two people dying every day from preventable deaths we cannot wait any longer to have this debate.

- 1 YouGov. *Organ donation*. 2007. [www.bma.org.uk/ap.nsf/AttachmentsByTitle/XLSorgandonation07/\\$FILE/organandonation07.xls](http://www.bma.org.uk/ap.nsf/AttachmentsByTitle/XLSorgandonation07/$FILE/organandonation07.xls).
- 2 UK Transplant. *Transplants save lives*. 2007. www.uktransplant.org.uk.
- 3 UK Transplant. *Potential Donor audit, 24 month summary report 1 January 2005 to 31 December 2006*. 2007. www.uktransplant.org.uk/ukt/statistics/potential_donor_audit/potential_donor_audit.jsp
- 4 Abadie A, Gay S. The impact of presumed consent legislation on cadaveric organ donation: a cross-country study. *J Health Econ* 2006;25:599-620.
- 5 Gimbel RW, Strosberg MA, Lehman SE, Gefenas E, Taft F. Presumed consent and other predictors of cadaveric organ donation in Europe. *Prog Transplant* 2003;13:17-23.

