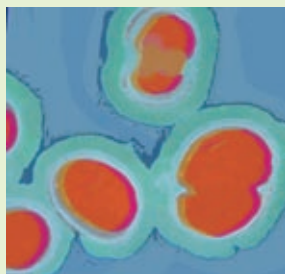




# MAKING A DIFFERENCE



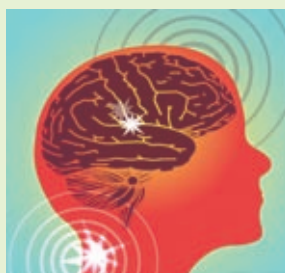
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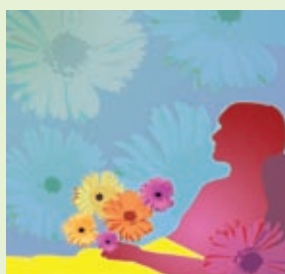
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# Running the gauntlet to improve patient care

Several topics turn the spotlight on areas that are less than glamorous and are perhaps all too often passed over, even as their impact on individual lives and society increases

This supplement is the result of a gauntlet thrown down, and picked up, during a dinner in London just over a year ago. The gauntlet thrower was Don Berwick, president of the Institute for Healthcare Improvement in Boston. What, he asked, was the BMJ Publishing Group really for? What were we trying to achieve? In reply, I and our chief executive, Stella Dutton, were quick to quote the *BMJ*'s mission, which ends with the crucial words "to improve outcomes for patients." Fine, said Don, but how about being more specific: which outcomes, what patients, by how much?

We took his suggestion seriously. Why not target a few important healthcare problems, taking a quality improvement approach and focusing on the evidence on how to make a difference in these areas? But how to choose which issues to tackle among the many millions of pressing healthcare challenges facing the world? We turned in the first instance to *BMJ* readers. In May 2007 we asked you to tell us what information was most needed to improve the quality of care of patients in clinical practice. From your many rapid responses we harvested more than 200 ideas. After categorising these and matching them against the priorities of national and international bodies, we created a shortlist of 12. With the help of an expert panel (see <http://makingadifference.bmj.com>) we cut these down to six.

Inevitably the choice of topics is subjective rather than scientific, but the six we have ended up with are interesting. Several turn the spotlight on areas that are less than glamorous and are perhaps all too often passed over, even as their impact on individual lives and society increases. Two topics deal with problems of old age: multiple illness and adverse drug reactions. Two deal with palliation: of chronic

pain and in dying from non-malignant disease. The remaining topics deal with two very different but serious and growing public health challenges: drug resistant infections in the developing world and excessive drinking in young women. You will no doubt find important gaps in what we have chosen. But if this initiative proves useful we can expand it further.

On each of the six topics we've invited leading commentators to write the pairs of articles that make up this supplement. One article in each pair aims to describe the importance of the problem in terms of its health and societal impact. The other looks at the available evidence on quality improvement initiatives to tackle the problem. Perhaps inevitably, several of the quality improvement articles conclude that the evidence is inadequate and more research is needed, but the authors do lay out what they think are the priorities for future research. One key priority is to develop new and better research methodologies for evaluating quality improvement initiatives.

We need to choose one or two of these topics to focus on over the next year, on which we will create and compile content across the BMJ Group's portfolio of products: the *BMJ*, *BMJ Journals*, *Clinical Evidence*, *Best Treatments*, and *BMJ Learning*. How will we know whether we have made a difference? We probably won't in any scientific sense. But we will be looking for ways to evaluate the effect of the initiative. On this, as well as on the topics themselves, we would welcome your thoughts.

Fiona Godlee, editor, *BMJ*  
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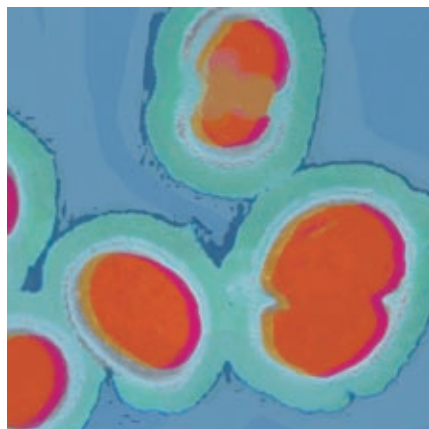
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## Drug resistant infections in poor countries

Resistance to drugs in many common childhood infections is a growing problem in the developing world, says **Zulfiqar Bhutta**. Effective programmes to combat resistance are within reach in developing countries, argue **Ralph Gonzales and colleagues**, but we must move swiftly

## A major burden on children

Around the world an estimated 10 million children under the age of 5 years die each year, the vast majority (90%) in a mere 42 countries. Of the major causes of death among children, infections such as newborn sepsis, diarrhoeal disorders, pneumonia, meningitis, and malaria are major killers. While much is known about the role that poor availability of interventions has in childhood morbidity and mortality in developing countries, much less is known about the contribution of antimicrobial resistance—but it is likely that the contribution of resistant infections is significant. In a prospective study of 1828 children with signs of systemic infections in Tanzania, the mortality from Gram negative bloodstream infection (44% of the deaths) was more than double that from malaria (20%) and Gram positive bloodstream infections (17%), and antimicrobial resistance was found to be a significant risk factor for mortality. A literature review has underscored the importance of hospital acquired resistant bacterial infections among newborn infants in developing countries.

The emergence of antimicrobial resistance is recognised as a major contributor to excess morbidity and healthcare costs in developed countries. In poorer countries, limited laboratory

facilities and the lack of robust, population based surveillance systems has meant that information on the effect of antimicrobial resistance on health outcomes is restricted to a small number of infections. Emerging drug resistance in malaria, recognised for many years, has now resulted in many traditional drugs such as chloroquine becoming completely ineffective. An evaluation of trends in malaria treatment in sub-Saharan Africa has shown that continuing use of ineffective chloroquine treatment has contributed to excess malaria mortality. The case fatality rate for malaria fell as an increasing proportion of children received an effective treatment regimen: adjusted malaria case fatality rates were 5.1% in 1992 and 3.3% in 1994, and the corresponding percentages of children who received effective therapy were 85% in 1992 and 97% in 1993-4.

The increasing resistance of *Streptococcus pneumoniae* and *Haemophilus influenzae* to drugs has an effect on pneumonia mortality that is less well recognised, largely because of the difficulty in isolating the organisms from the bloodstream. In a prospective study of children in 5000 Bangladeshi urban households who had invasive pneumococcal disease, the

## A shrinking window of opportunity

Certain principles of effective quality improvement interventions are universal. Relevant stakeholders must believe that it is worth while to remedy the deficiency in quality, that the benefits of change outweigh the costs, and that change is possible. The threat of antibiotic resistance and its coevolution with particular patterns of antibiotic use are also universal.

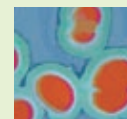
Unfortunately, the public health agendas of few countries have prioritised the problem of antibiotic resistance. This is especially true in less developed countries, where antibiotics are often overused and misused by formal and informal healthcare providers and by patients, who are often able to obtain antibiotics without a prescription. Few policy makers, few members of the general public, and unfortunately too few medical schools and health professionals recognise the urgency and implications of the problem. Instead, pharmaceutical policies often focus on scaling up and ensuring access to drugs, including broad spectrum antibiotics, without considering rational use.

What will really help to create change and foster effective quality interventions to tackle resistant infections in developing countries? Strategies in such countries require changes at the levels of policy, the institution (including healthcare pro-

viders), and the individual. Quality improvement strategies to improve the behaviour of providers and patients do exist in developing countries, but their success depends on government and stakeholder support.

To increase government and stakeholder involvement and accountability, it is important to establish national programmes that publically report rates of antibiotic use and resistance. Although the World Health Organization (WHO), the Pan American Health Organization, and others have promulgated useful recommendations for hospitals and communities around the world to combat antimicrobial resistance, few developing countries have been able to implement these recommendations fully. When resources are limited, assuring access to drugs tends to overshadow the quality of their utilisation. The international community should partner with developing countries to perform the initial cycles of measurement and to design systems to link the data with information to the public on the effect of the problem on population health, personal health, and the economy. Such measurement should occur across several countries in close proximity to harness “peer pressure” and foster better practices.





incidence of the disease was 447 episodes per 100 000 child years, and the rates of resistance to penicillin, co-trimoxazole, chloramphenicol, and ciprofloxacin were, respectively, 3%, 82%, 15%, and 24%.

Such evidence of the failure of co-trimoxazole has led to the recommendation to use amoxicillin to treat pneumonia in primary care settings, but as yet few health systems in the poorest countries have the extra funds needed to implement these recommendations widely. This is akin to the need for combination therapy for effective malaria treatment and to second line treatment for drug resistant tuberculosis in children, both looming realities in public health systems in sub-Saharan Africa. In South and South East Asia a major burden of childhood bacteraemic infections is related to typhoid fever, as well as the infections listed above. Over the last two decades the prevalence of

## Antimicrobial resistance results in a much higher economic burden on the health systems of poor countries

multidrug resistant typhoid has steadily increased in Asia, and with the widespread use of generic ciprofloxacin and cephalosporins resistance to these second line antibiotics has steadily grown. Increasing antimicrobial resistance results in a much higher economic burden on the health systems of poor countries, because of the higher likelihood of treatment failure and of complications associated with such infections.

Several factors are associated with the rise of resistance to common infections in developing countries, including the global spread of drug resistant clones as travel becomes easier and local antimicrobial pressure on common organisms. This second factor may be related to inappropriate prescribing of antibiotics, the unregulated availability over the counter of these drugs, and (for reasons of affordability) inappropriate dosages and duration of treatment.

Increasing public awareness, improving standards of care, and the appropriate regulation of the use of such antimicrobials are all important steps. A recent evaluation of the effect of the Swedish national programme for the surveillance of antibiotic use and resistance and the

implementation of rational antibiotic use showed that antibiotic use among outpatients fell from 15.7 defined daily doses per 1000 people in 1995 to 12.6 per 1000 in 2004. The largest reduction (by 52%) was noted in children, with no measurable negative consequences on admission rates for common upper respiratory infections. However, examples of successful application of such interventions in developing countries are few.

What are the main challenges with regard to antimicrobial resistance in common childhood infections in developing countries? We need better information systems defining the magnitude of the problem and training programmes to optimise treatment with antibiotics. As we need to balance antibiotic "access" as well as "excess," measures to regulate antibiotic availability must be accompanied by strengthening workforce capacity and drug supplies in dysfunctional health systems. The crisis of increasing antimicrobial resistance to serious and common childhood bacterial infections is a reality in developing countries, and solutions are urgently needed.

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Performance measurement and accountability are potent inducers of behavioural and systemic change in organisations. For example, accreditation agencies and funders now require hospitals in the United States to publically report performance and outcome measures, a policy that has triggered an explosion of quality improvement activity in US hospitals. An excellent template for the annual measurement and comparison between countries of consumption of antimicrobials and resistance rates has been developed by the GRACE project in Europe ([www.grace-lrti.org/portal/en-GB](http://www.grace-lrti.org/portal/en-GB)). Similar utilisation and resistance profiles for developing countries are needed, and efforts are under way to accomplish this in Latin America through a partnership between research institutions, government agencies, and WHO.

Many lessons from quality improvement interventions in health care in wealthier countries can be applied elsewhere. Various frameworks and theories have been found useful for diagnosing contextual factors and developing strategies to change specific policies, organisational practices, and the behaviour of providers and individual consumers. For example, education and decision support, when part of a comprehensive effort, have been useful in HIV prevention, tuberculosis management, and tobacco control, as well as in appropriate antibiotic use. The literature also shows that

quality improvement initiatives that lack local champions and stakeholder support will face formidable challenges to success.

Strategies that work in one place must be assessed for their applicability to other settings, and programmes must be tailored to countries' unique circumstances. Formative research into social factors and practices in specific regional and local contexts, such as how the public and professionals make decisions to recommend, procure, and use antibiotics, is indispensable to achieve change. For example, we found that most patients (62%) purchasing antibiotics in Mexican pharmacies without a prescription reported acting on the recommendation of a clinician. Thus, in Mexico, education campaigns to reduce unnecessary antibiotic use must target doctors as well as the public. Nevertheless, educating the public is crucial, as patients often misuse antibiotics regardless of whether they were bought over the counter or were prescribed.

In developing countries, access to antibiotics without a prescription is commonplace. Here the priority should be to change regulatory policies related to antibiotic procurement and to enforce these policies. This includes creating an infrastructure for surveillance, communication, and effective sanctions. For example, in Chile a mass media campaign preceded enforcement of regulatory measures making

antibiotics available by prescription only, resulting in a 35% decrease in antibiotic consumption. It may be useful to emphasise the repercussions that are unique to antibiotic use: in contrast to other drugs the consequences of an individual using antibiotics extend to that person's family and community. Finally, we need to use data and the media to challenge the perception that providing access to antibiotics without a prescription somehow helps to compensate for the lower access to doctors in poorer countries.

The window of opportunity for combating antibiotic resistance continues to shrink. Much work remains to be done in most countries, but particularly in developing countries. We believe that effective programmes to tackle resistant infections are tenable and within reach of the constrained resources of developing countries. The major barriers are the political and public will to set up the systems that can bring about change. Partnerships among national and international stakeholders will help.

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## Multiple health problems in elderly people

With ever increasing pressure on doctors' time, **Iona Heath** wonders whether primary care really meets the needs of elderly people at all, while **John Wasson** suggests ways for doctors to improve the care of older patients that don't require extra resources or staffing

## Never had it so good?

What does it mean to be old? What is the relation between ageing and illness? How does the subjective experience of multiple and compounding illnesses relate to the medical model and the taxonomy of disease? These questions become more pressing as an ever greater proportion of the population survives into extreme old age, and as the postwar baby boomers—those who “never had it so good,” as Harold Macmillan put it—begin to draw their pensions.

Globally the proportion of people aged  $\geq 60$  years is growing very fast. It is expected that by 2025 a total of about 1.2 billion people will be in this age group. By 2050 this number will have risen to two billion, 80% of them in developing countries. The older population itself is also ageing. Currently 69 million people are aged over 80, and although this age group now accounts for only 1% of the world's population (and 3% in developed countries), it is the fastest growing segment of the population.

The World Health Organization and many national governments are promoting the concept of “active ageing,” which portrays ageing as a positive experience and promotes continuing

participation in social, economic, cultural, and civic activities. The concept is based on rights rather than on need and seeks to move away from a view of elderly people as frail and dependent. All this is to be applauded, but it may conceal a worrying reluctance to acknowledge the inevitable reality of death and dying. All bodies must die and find ways of doing so.

Age is a fundamental cause of disease, working through a multiplicity of causal pathways to generate multiple risk factors and multiple disease outcomes. All clinicians are familiar with this process, by which treating one disease in a frail, older person often means that symptoms reappear through another pathway. As the treatment of disease slowly becomes more effective, an ever greater proportion of the population survives with multiple compounding chronic diseases. The commonest of these are cardiovascular disease, stroke, diabetes, cancer, chronic obstructive pulmonary disease, musculoskeletal conditions, and mental illness (including dementia), occurring in many different combinations. The orthodox medical view is that these are distinct and definable conditions each of which carries a different prognosis and

## Adapting what is known

Multiple health problems are not unique to older persons; they are, however, more prevalent in this group. Furthermore, as a person ages, what was once a reasonable choice in treatment may be less appropriate, even harmful. In making clinical decisions about the health of older patients and in quality improvement for managing care, what are the trade-offs between benefit and risk? What are the opportunities for, and the barriers against, putting such knowledge into practice?

A 78 year old woman with complex health problems visits her doctor. Although in younger patients clinical recommendations may include screening mammography or intensive control of diabetes, this woman may not actually live long enough to benefit from these interventions. The issues that are most important to her may bear little relation to the bioclinical problems her doctor has been trained to diagnose and treat. Collaborative decision making by clinicians and older patients such as this woman is almost always made in a grey zone of unavailable evidence and divergent expectations. Yet tools are becoming available to help weigh the trade-offs between treatment benefits and competing risks. As these tools become more

sophisticated and easier to use in the everyday clinical setting, they will help in clarifying the choices that must be made by older patients with multiple health problems.

The environment in which care is offered and decisions made—the system of “usual care”—is often bad for health. Its toxicity may be a consequence of too many health workers providing fragmented care, too many drugs having adverse side effects, or too much intensive treatment leading to dangerous complications. And usual care suffers by being fast paced, reimbursed according to volume, and focused too much on what the matter is with the patient, rather than what matters to the patient. Many alternatives to this usual care are better, but most of these add additional workforce—nurses, case managers, “coaches,” and “teams”—in bewildering combinations called disease management, case management, transition management, and geriatric evaluation and management. Other effective alternatives to usual care, such as routine telephone calls to the patient from an identified primary care clinician, need no additional workforce.

That there are so many things wrong with the usual care and so many ways to improve it raises an obvious question: why hasn't qual-



requires different treatment. However, people who live with multiple diseases, physical and mental, experience them simultaneously and inseparably. The patient with diabetes and depression and congestive cardiac failure does not have these conditions in separate compartments of her life. She has all three inseparably and, if she is also lonely and frightened, all of this is a single condition.

The problem is that in health care the specialist medical view predominates. And, as a direct result, multiple diagnoses lead almost inevitably to polypharmacy as each condition is treated in perverse isolation from the others. Research findings are extrapolated from younger age groups and interpreted overoptimistically in the context of what inevitably are limited life expectancies. As a direct result, older people are taking an ever increasing number of prescribed drugs, but because of diminished physiological reserve they are also more susceptible to adverse drug reactions and interactions. Nevertheless, the all too easy accusation of age discrimination means that the limited time available for older people to derive clinical benefit is not seen as a legitimate reason for “underprescribing.”

Systems of “quality improvement” that involve payment for performance, such as the UK Quality and Outcomes Framework (QOF), apply standards with no allowance for age and systematically encourage overtreatment of hypertension and type 2 diabetes, to the detriment of patients. Many preventive treatments in old age may simply change the cause of death and not its date. The energetic treatment of cardiovascular risk factors is effective in reducing cardiovascular mortality but does not prolong life and increases the likelihood of a diagnosis of cancer or dementia.

Old people themselves have different priorities and can find the epidemiological perspectives of healthcare professionals to be intrusive and inappropriate. Most elderly people are very aware of death and know that it must be faced and negotiated: “The big event of old age—the thing which replaces love and creativity as a source of drama—is death” (the author Diana Athill).

Many frail older people have a rapidly diminishing appetite for technological health care and a proportionately increased need for sensitive, gentle, hands-on physical care: a

need that is easily compromised by the very real fear of becoming a burden. At present, medicine seems to have limited means of marking this transition, but such means are urgently needed, because the continuing emphasis on individual diseases leads, usually inadvertently, to undertreatment, overtreatment, or mistreatment—and often all three.

Tragically, the global trends of commodification, privatisation, and fragmentation in health care mean that the dimensions of care most needed by frail elderly people become less and less accessible. Yet multiple illnesses can be coherently managed only by a personal generalist physician who is able to provide continuity of care for the patient’s whole experience of illness, while at the same time remaining alert to those diagnostic possibilities that are readily remediable. But how, within a market system, can unprofitable need for time intensive and hands-on personal care from a known other ever be given commensurate priority?

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ity improvement already resulted in better usual care for older persons with multiple health problems?

One reason commonly given for the persistence of poor care is that most studies of successful interventions for elderly patients, when compared with usual care, have not provided clear evidence of cost savings. However, saving costs seems a poor reason for not improving care, and indeed many of the attributes of good quality care may not require extra staff or money. In fact, within the range of usual care about a fifth of older patients with multiple health problems are already receiving the high levels of access, continuity, communication, and self management that are associated with successful alternatives.

The fact that these crucial attributes of quality care are already available to some patients raises a second question: can this high quality care be generalised to more patients?

**The prevailing culture has to change to enable breathing room from oppressive volumes of consultations and paperwork**

An affirmative answer to this question is provided by one innovative US example of a quality improvement project: an online collaboration involving a group of primary care practices across the country ([www.ideal-medicalpractices.org](http://www.ideal-medicalpractices.org)). In these practices, the percentage of older patients with complex health problems who are attaining attributes of high quality care as listed on the website is more than twice that in non-participating practices, even though they receive no special reimbursement.

The thrust of future research into quality improvement for older patients with multiple health conditions should be directed towards two objectives. The first is research into how to adapt and adopt what is known. The existing literature on quality improvement demonstrates numerous ways to improve health care for these patients through timely assessment of “what matters,” easy access to care, continuity of care with an identifiable clinician, and understandable, relevant information and support for condition management and collaborative decision making. Although no particular setting, patient population, or disease mix will be identical to those reported in the published literature, many essential elements are constant. For example, it is not surprising to clinicians that their patients’ confidence in self

management, financial status, and managing pain and psychosocial problems affects their healthcare outcomes. What is surprising is that clinicians don’t systematically evaluate these factors when assessing older patients and placing them into categories for the delivery of planned care. Technologies and methods are already freely available to help busy health professionals capture these valuable opportunities.

The second area is research into how to overcome the most conspicuous barrier to the improvement of care: the current healthcare culture. The current culture induces dysfunctional workforce expectations, unwanted variation in practice patterns, ineffective training venues, counterproductive payment incentives that are often based on inappropriate measures, and excessive technological imperatives. Only in a very few clinical practices are measures of “what matters” to the patient really at the centre of care. At a minimum, the prevailing culture has to change to enable breathing room from oppressive volumes of consultations and paperwork so that the few motivated health professionals implementing patient centred, collaborative care can become the many.

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## Excessive drinking in young women

The growing problem of binge drinking among young women is one that must be dealt with at a societal level, says **Ian Gilmore**. Nevertheless, doctors can make a difference at an individual level, and **Brenda Reiss-Brennan and colleagues** describe one US quality improvement intervention in primary care

## Not just a “lifestyle disease”

Are we now seeing the undesirable consequences, for instance in drinking and smoking habits, of female emancipation? As women quite rightly seek greater opportunities for equality in the workplace and in other aspects of life, we see signs of them falling prey more and more to so called lifestyle diseases. Young women are all too commonly seen huddling outside enjoying a cigarette; and while lung cancer rates fall overall, they continue to rise in women.

Women are also conspicuously heading for equality in their drinking habits. In the most recent British general household survey, 42% of men and 39% of women aged 16 to 24 years had exceeded safe recommended daily limits in the previous week, with over half of those drinking heavily or “bingeing.” The United Kingdom has the heaviest drinking young women in Europe, nearly 40% of whom admit to having drunk six or more units in one session in the previous week.

Does it matter that our young women are having fun? Most get away without harm and will probably settle down. But those who do not escape harm may have their life changed fundamentally under the influence of alcohol.

Most first consensual sexual experiences and unwanted pregnancies occur in this way, and the distinction between rape and sex regretted the next day can become blurred when women are drunk. Genitourinary clinics see drink as the biggest factor in unprotected sex and sexually acquired infections. Some young women will be scarred for life through drunken brawls and arguments. In Scotland about 30% of women committing violent crime are drunk.

Of course, the victims of accidents need not be drunk themselves: alcohol is responsible for much third party or collateral damage. In England and Wales, over half of victims of violence perpetrated by a stranger judged the attacker to be under the influence of alcohol. This is particularly an issue in domestic violence, where again at least half of perpetrators are likely to have been drinking. It is remarkable how damage to the health of third parties was such a tipping point for public opinion on the issue of smoking in public places, yet alcohol is hugely more serious in this regard.

Teenage girls and young women are unlikely to be receptive to arguments about serious organ

## Reducing harm through quality improvement

The concept of harm reduction has evolved over nearly 90 years from its beginnings in the 1920s, when it applied to drug misuse in adult populations. Applying the concept to adolescent groups at risk is relatively new, requiring that the concept be adapted appropriately.

Adolescent harm reduction spans a wider array of harmful behaviours than are discussed in the literature: substance misuse, multiple sexual partners, violence and weapon carrying, non-use of helmets when cycling, skating, or snowboarding, riding with a driver who has been drinking, and suicide plans. But the main contributor to death from injuries in people in the United States under the age of 21 is underage drinking.

Young women are “outdrinking” their male counterparts of the same age and are more likely to experience adverse health consequences. Such behaviour may undermine neurological brain development, predispose to adult dependency, and increase mortality. The strong association between drinking and having multiple sexual partners “underscores the need to educate young people about the effects of alcohol on partner choice and the risk of infection with sexually transmitted diseases,” as one study put it.

Harm from drinking often involves others; among young women this other will often be an unborn child. Fetal alcohol syndrome is the leading cause of brain damage in children in the United States. Young girls are now drinking and smoking like boys and are more likely to be depressed and to attempt suicide. In primary care the complexity of these risky behaviours among young people often goes undetected, owing to lack of time, of access to effective treatment, and of coordinated and adequately funded resources in the community to reduce harm.

A growing number of patients with serious mental illness and substance misuse report being treated in primary care or emergency rooms. Despite the availability of evidence based treatment for these disorders, many patients and families do not receive effective treatment in real world settings. One strategy to help remove such barriers is to re-engineer the processes of care delivery, using an evidence base of changes that lead to improvements in the quality and efficiency of care.

Our organisation, the non-profit Intermountain Healthcare (<http://intermountainhealth->

Longer versions of all the articles in the Making a Difference supplement, including references and figures, are at <http://makingadifference.bmj.com>

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damage in years to come, and so it is important to highlight dangers that are more immediately relevant to them. It is now apparent that fetal alcohol syndrome, where babies are born with severe brain damage and a typical physical appearance, is but one end of a spectrum (fetal alcohol spectrum disorders); and less obvious behavioural disorders such as attention deficit hyperactivity disorder may result from exposure to alcohol in the womb. Unfortunately exposure in early pregnancy is likely to be important, and so far no safe threshold has been identified. Thus the only safe advice is for women to avoid alcohol if they seek to become pregnant—tough advice where every celebration now seems to have alcohol at its core.

Alcohol misuse remains the most important cause of death from chronic liver disease

## Alcohol is our favourite drug, and it is distressing to see young women pressured into misusing it

(cirrhosis), the prevalence of which has grown startlingly in women, particularly in the 35–44 year age group (sevenfold in the last three decades) but also in even younger women. This reflects the early age when heavy drinking starts. Particularly striking is the emergence of the syndrome of alcoholic hepatitis (not always associated with histological cirrhosis), where the patient is febrile, deeply jaundiced, and often has ascites and other features of decompensation of liver function. Histologically this can be indistinguishable from non-alcoholic fatty liver disease, and it has been suggested that alcoholic hepatitis may be a “double hit” of alcohol on top of a fatty liver, often associated with obesity, which would explain the rapid increase in the disease. Certainly the burden of harm is seen disproportionately in the most disadvantaged in society, a striking example of health inequality that remains unexplained.

What can be done to turn this tide of alcohol related health harm in young women? We know that telling them to behave better will not work. England's national alcohol harm reduction strategy of 2004 relied heavily on

voluntary partnerships with producers and retailers of drink, linked to public education and information. Sadly, these initiatives have palpably failed. This should not surprise us too much, because the best predictor of alcohol related health damage is per capita consumption, and it can hardly be in the industry's interests to have falling sales. Hence we need to fall back on the tools that have an international evidence base: mainly price and availability. Alcoholic beverages have never been as cheap in real terms as they currently are—particularly those sold in off-licences and supermarkets—nor as available.

Although approaches to increase price and reduce availability smack of the “nanny state,” it is simplistic to dismiss alcohol dependence and physical damage as lifestyle diseases, somehow down to the individual's free choice and nothing to do with the state. Cheap drink is available and heavily promoted. Alcohol is our favourite drug, and it is distressing to see young women pressured into misusing it.

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care.org/xp/public/about-intermountain/), became increasingly concerned that primary care resources were not being used effectively to treat patients with mental health conditions. Its medical leaders were influential in establishing the mental health integration (MHI) quality improvement programme. Over the last decade Intermountain has implemented MHI throughout 68 primary care clinics to identify patients with mental health or substance use disorders and to treat them and refer them to additional services. MHI makes available a clinical team and offers financial support to the primary care doctor.

Sustained results show that MHI leads to improved functional status in patients and improved satisfaction and confidence among physicians in managing mental health problems as part of routine care at a neutral cost.

The primary care environment presents opportunities and challenges for reducing harm in young female drinkers. Alcohol dependence and underage drinking are complex family health problems and are intensely personal and isolating issues for girls and young women. It is an opportune consultation in which teenagers' health risks are uncovered and wellness can be promoted. Although guidelines are available, the routine screening of young women for harmful behaviours varies widely among primary care doctors.

The MHI assessment begins with a common screening toolset administered by the family doctor, who determines, with the patient and family, the severity of the mental health concerns. It includes comprehensive, self reported measures of family history and relational support, environmental stressors, use of substances, depression, anxiety, and bipolar and attention deficit disorders.

The results determine whether the doctor continues routine treatment or triages the patient to the MHI psychologist, psychiatrist, or psychiatric nurse practitioner for prompt consultation. The team includes a nurse care manager, who provides support and feedback to the doctor, the patient, and the family. The care manager also provides education and information and links the patient to community resources, if this will benefit the patient.

The team members use harm reduction strategies to improve education and to provide treatment for alcohol misuse. They also facilitate the involvement of families and community resources in social support and reinforcement of abstinence. Strategies that are tailored to the preferences of patients and communities are more likely to result in positive behaviour change.

Intermountain's MHI database identified 123 263 patients across all age groups, 45% of

whom were women (55 568). The data show that 25 945 girls and women aged <39 were being treated for substance misuse and that 9107 had comorbidity of depression and substance misuse. Of those with a diagnosis of substance misuse, 420 (1.6%) were 18 years old or younger.

Adopting a harm reduction approach to help young female drinkers and their families will require quality improvement interventions that provide institutional support for the primary care doctor to deliver care that is matched to the family's and community's social, financial, and cultural healthcare preferences for wellness. Higher levels of social capital exert strong protective effects against alcohol misuse and harm.

Intermountain's MHI programme is one example of a quality improvement intervention that tackles social capital needs and such barriers as failed access and limited, fragmented treatment choices, which many families face when trying to find help.

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## Management of chronic pain

The burden of chronic pain for those who have it and their families is substantial, says **Henry McQuay**, and these patients deserve better.

**Dawn Stacey and colleagues** describe an example of quality improvement in practice for one group of people with chronic pain, those with osteoarthritis

## Help and hope at the bottom of the pile

Chronic pain is common—but it isn't sexy. People who through no fault of their own have their lives demolished by pain deserve our help. The Pain in Europe survey found that 19% of almost 50 000 people questioned in a poll had chronic pain, defined as pain of at least moderate severity occurring almost every day for at least six months. One in five of these people had pain for more than 20 years, and most had pain for more than five years.

The main causes are back pain and arthritis, and the incidence of chronic pain increases with age. Our populations are ageing. In the United States the number of people aged 65 years or older will have almost doubled by 2025 to 63 million, from 37 million in 2006, and there will be a third of a million Americans over the age of 100 years by 2020.

Chronic pain has a substantial impact on quality of life. A Dutch study that analysed eight large datasets by quality of life factors ranked different medical problems. Musculoskeletal conditions (including arthritis and back pain) had the most severe effect on quality of life. This impact of everyday pain on quality of life is something that has yet to be fully appreciated

by those who organise our health services and allocate resources.

Most normal or nociceptive pain can be managed with conventional painkillers, from paracetamol through to morphine, with the more powerful painkiller added for more severe pain. Most pains wax and wane, and flexible prescribing takes time to explain. Problematic pains include severe pain on movement with little pain at rest, leaving patients oversedated with painkillers when they are not moving. Problematic side effects of the drugs include drowsiness and constipation, a major burden for elderly people.

Perhaps the most testing pains are those that result from nerve damage, the neuropathic pains. Peripheral nerve damage from surgery, trauma, back pain, and the classic post-herpetic neuralgia, painful diabetic neuropathy, and trigeminal neuralgia often respond poorly to conventional painkillers and need the unconventional drug classes, the antidepressants and the antiepileptics. Titrating these drugs to maximise pain relief and minimise side effects is fiddly but necessary.

## Improving shared decision making in osteoarthritis

Common treatments for osteoarthritis include physiotherapy, bracing, pharmacotherapy, and joint replacement surgery. When treatments are proposed that increase the risk of harm (such as non-steroidal anti-inflammatory drugs, opioids, or surgery), patients' values concerning potential benefits and harms need to be considered. However, clinicians find it difficult to judge patients' values, which are also often based on unrealistic expectations. Therefore tools that improve the shared decision making process are important.

Shared decision making is a process in which the patient and clinician together reach an informed decision 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; the patient's role is to identify and communicate their informed values and personal priorities, as shaped by their social circumstances.

Patient decision aids are tools that prepare patients for consultations by explaining options, quantifying risks and benefits, helping patients to clarify their values, and providing structured guidance in deliberation and communication. A

review of 10 systematic reviews of patient decision aids found that they improved patients' participation, increased their knowledge of treatment options, realigned their expectations, and improved the match between their values and subsequent treatment decisions. The aids also reduced the overuse of elective surgery (for herniated disc, for example) without apparent adverse effects on health outcomes. Another study showed the potential for patient decision aids to reduce inequalities among ethnic groups. The Cochrane inventory of patient decision aids ([www.ohri.ca/decisionaid](http://www.ohri.ca/decisionaid)) uses international standards to rate their quality. Decision aids for osteoarthritis treatment are available online, in brochures, and on DVD.

In 2006, patient decision aids were accessed more than eight million times, mostly through the internet. Ideally, these tools should be linked to clinical care processes, but practitioners report several barriers to implementation: inappropriate content for their patients; forgetting to offer them; inadequate time; content that was too complex or too simple; and cost. Practitioners are more likely to use patient decision aids if they have a positive effect on patients' outcomes

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Most chronic pain is managed with drugs in primary care. Obstinate pains—pains that resist drug control at acceptable levels of side effects—may need other treatment options, from injections through to a multidisciplinary pain management programme. The necessary skill mix includes nursing, psychology, drug expertise, and injection options and physiotherapy.

The imperative to provide this tier of expertise is humanitarian and economic. Patients with chronic pain who are managed poorly will bounce around the healthcare system, becoming more and more exasperated and consuming considerable

**Chronic disease comes low on the political priority list, and chronic pain just gets forgotten. The burden for the sufferers, their families, and society is substantial**

resources. Well managed pain contains this excess use of resources, saving an estimated £1500 (€1900; \$3000) per patient per year. Set against the background of the large economic burden of chronic pain, the cost of this tier of expertise is marginal.

An estimate of the financial burden of musculoskeletal illness in the United States argued for \$50bn, and the indirect costs of back pain in the United Kingdom are estimated at £11bn. Certainly, chronic pain increased costs for payers by more than double, in comparison with matched controls without pain (\$C4200 (£2070; €2600; \$4100) versus \$C1800 a year), an excellent Canadian database survey found. There are also financial implications for the person with the pain, reduced household income being the most obvious example.

No one thing will improve this situation. We need more and better basic research, the most tangible products of which are likely to come from the major drug companies. But there have been pitifully few new painkillers in the past 30 years.

Clinical research and practice are now much

more likely to make a difference, helping to make existing evidence sensible and understandable so that people can use it. The evidence base in pain enables us to assess the relative effectiveness of treatments, for instance in nociceptive and neuropathic pain and indeed in migraine. This evidence does not dictate what analgesic to use for a particular patient but does help us to make choices about treatments on the basis of their effectiveness, propensity for harm, and cost.

Then there's the provision of care. Chronic disease comes low on the political priority list, and chronic pain just gets forgotten. The burden for the sufferers, their families, and society is substantial and merits better treatment.

The mark of a gracious society is how it treats those with least voice. That chronic pain puts people at the bottom of the pile is precisely why we should be agitating on their behalf for a fairer share of the medical resource cake.

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or on the clinical interaction. Orthopaedic surgeons rated the content of patient decision aids for osteoarthritis treatments as good to excellent and were motivated to use them to improve patients' understanding but had concerns about interrupting the flow of clinic work.

Patient decision aids have been implemented successfully in specialist clinics in the United Kingdom and Canada and in specialist and primary care clinics in the United States. Patients with osteoarthritis, for example, use decision aids together with balanced, evidence based information on the treatment options and the likelihood of the benefits and harms of those treatments. The decision aids help patients clarify their values concerning benefits and harms by describing what it is like to experience them. Patients then complete a personal decision form, which elicits their knowledge, values, preferred option, and any unresolved "decisional needs" (for example, uncertainty about their preference, gaps in their knowledge of the options, lack of clarity of their values concerning benefits and harms, and support needs). This information is summarised on a "patient preference report," which is sent to the clinician to "close the loop" on decision making with the patient.

In Canada, patients on the waiting list for a surgical consultation are screened for eligibility by trained general practitioners or physiotherapists before they receive a decision aid and

personal decision form. The Canadian patient preference report (see <http://makingadifference.bmj.com>) lists clinical priorities as determined by self reported pain and functional limitations, the trained screener's assessment of surgical priority, and the patient's preferences and decisional needs. The report is paper based, but one author (NC) has developed a similar computerised report as part of the US Veterans Administration's electronic patient health records.

Using the patient preference report together with patient decision aids has the potential to improve the clinical encounter and to provide the incentive that practitioners need to overcome their resistance to using the aids. For example, when patients arrive at a surgeon's consultation with their preference report, the surgeon can focus on issues of concern to the patient, such as fears of side effects of surgery. Thus the surgeon's time will be used more efficiently, and the care provided is more patient centred, so patients and practitioners are both more likely to be satisfied with the process.

Outcomes such as pain reduction and improved function cannot be the sole quality indicators in treatments that involve trade-offs between potential benefits and harms. In such treatment decisions, the quality of decision making should be defined by how well the chosen treatment option matches the features that matter most to the informed patient. Patient prefer-

ence reports document decision quality as an indicator of the shared decision making process. In addition to monitoring postoperative complications such as infections, these reports can be used by quality improvement teams to monitor the extent to which high quality decisions are achieved and decisional needs met.

Patient decision aids prepare patients for making shared decisions concerning treatment. Patient preference reports that summarise patients' clinical and decisional needs improve communication. With standardised measures and documentation of decisions, healthcare organisations can monitor and include decision quality as another indicator of the quality of their programmes.

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An example of a patient preference report is at  
<http://makingadifference.bmj.com>



## Adverse drug reactions in elderly people

Doctors should pay greater attention to managing the risk-benefit relationship to improve care of patients over 65, urge **Jerry Avorn** and **William Shrank**. The challenge of safer prescribing, says **Anne Spinewine**, lies in shared decision making

## A substantial cause of preventable illness

Patients over 65 years old bear the greatest burden of illness and thus are the greatest beneficiaries of drugs to prevent, ameliorate, or treat conditions. One of the most rapidly growing segments of the population, they consume an ever increasing proportion of all prescribed drugs.

For decades elderly people were excluded from randomised trials of many preventive drugs, reinforcing scepticism over whether they would benefit from treatment of conditions such as hypercholesterolaemia and hypertension. But elderly patients may benefit from such treatments at least as much as their younger counterparts. In fact, because of the higher prevalence of preventable disease in older patients, they often derive greater benefits from such prescribing than younger patients.

For this reason, much primary care has shifted from the treatment of acute illness to the management—often pharmacological—of “risk states” in elderly people, including hypertension, hypercholesterolaemia, and osteoporosis, as well as diseases such as atrial fibrillation, heart failure, and diabetes. Solid evidence from clinical trials indicates that appropriate prescribing can substantially reduce the burden of preventable

morbidity in these conditions. Although such concerns are traditionally seen as a problem of the industrialised world, they are rapidly becoming a major issue facing developing countries as well.

But this benefit comes at a price: the high prevalence of adverse drug reactions in older patients. The problem has several sources. One is the altered pharmacokinetic status of elderly people; they are less able to metabolise and excrete many common drugs, even in the absence of liver or kidney diseases. They may also have altered pharmacodynamic responses, with some receptor systems (such as those for opiates and benzodiazepines) having greater sensitivity with advancing age, and others (such as those for insulin) showing reduced sensitivity. Unfortunately, the under-representation of older patients (especially frail ones) in clinical trials makes it even harder for the prescribing doctor to prevent untoward drug reactions in older patients.

When an elderly person experiences an adverse drug reaction, it may be mistakenly attributed by the patient or doctor to a new disease or (even worse) the ageing process itself. Examples include the parkinsonian side effects of many antipsychotic drugs and the fatigue, confusion,

## The challenge of safer prescribing

Quality improvement for the care of older people has become a priority in many countries. Elderly people consume a large proportion of health care, including drugs, and evidence shows that prescribing to this group is often inappropriate. Inappropriate prescribing occurs in all care settings and at the transition between settings. Negative consequences include adverse drug events, higher costs for the patient and society, and impaired quality of life.

Specific approaches tailored to the needs of frail elderly people are needed. A recent review of ways to optimise prescribing to older people found that geriatric medicine services (involving a multidisciplinary team that includes a geriatrician and other health-care providers with specialised geriatrics training), involvement of pharmacists in care, and computerised decision support can all improve the quality of prescribing to this group in different settings.

Quality improvement strategies are more likely to be effective when there is direct interaction with the prescriber and when the strategies are provided at the time of prescribing. In nursing homes, involvement of nurses in strategies is another important factor. The

effect of educational interventions is mixed, although the lack of training of doctors in geriatrics is often cited as a cause of inappropriate prescribing.

However, widespread diffusion of effective approaches has not yet occurred. As in many other fields, translating research into practice is a delicate task. In the domain of quality improvement for safer prescribing to older people, this is further complicated by a lack of strong data showing the impact of effective approaches on important health outcomes. Also, the question of who should meet the cost of such approaches is a matter for debate. And we lack data on the cost effectiveness of strategies. With regard to computerised decision support systems, we first need systems that have been tailored to elderly patients before they can be implemented more widely.

It is important to take environmental barriers into account. Some barriers can be specific to the setting of care or even to the country of practice. For example, improving the quality of prescribing of neuroleptics in nursing homes is less likely to occur without an increase in staffing and resources. Direct contact with prescribers





or depression-like symptoms that can result from excessive use of heavily marketed psychoactive drugs. Elderly people are at special risk of such misattributions because of the pervasive cultural assumption that growing older brings with it a collection of inherent and inevitable disabilities. The problem is compounded by the slender preparation that most students receive in geriatrics and in clinical pharmacology. There is ample evidence of the clinical burden of iatrogenic illness in the elderly. Studies of US patients aged over 65 indicate that each year more than 180 000 life threatening or fatal adverse drug effects occur in the outpatient setting, of which over half may be preventable. Another study attributed 6.5% of all hospitalisations in the general population to adverse drug events, a rate that is likely to be higher in elderly people.

Despite these gloomy realities, the most notable aspect of drug induced illness in elderly people is the most encouraging. Once recognised, a side effect of a drug is probably the single most reversible affliction in all of geriatric medicine. Usually, care of elderly people requires the management of conditions with a downward course. But discovering that a symptom

is caused by a drug presents an uncommon opportunity to effect a total "cure" by stopping the offending prescription or lowering the dose. In our own practices we have often seen patients on a seemingly inexorable trajectory towards institutional care whose functional capacity was restored by thoughtful reassessment of their drug regimens. This has led to the useful if overstated recommendation that "any new symptom in an older patient should be considered a possible drug side effect until proved otherwise."

As well as being alert to the possibility of new iatrogenic problems, it is also prudent to reassess a patient's entire drug regimen at least twice a year, including categories often overlooked by patients and doctors: drugs bought over the counter and "nutraceuticals" such as herbal remedies or dietary supplements. Although these products are often devoid of therapeutic benefit, they can impose important toxicities, and their interactions with prescribed drugs are poorly understood. With growing use of the electronic medical record, we can expect that drug regimen review will increasingly be prompted by the computer in the course of routine care. In one computerised system for entering prescription

orders, the system automatically checks all prescribed drugs and dosages against the age of the patient and recommends a lower dose or different drug if necessary.

Non-compliance with prescribed drug regimens can produce a different kind of drug related morbidity. In this "silent epidemic," as much as half of prescribed drugs are simply not taken. Considerable morbidity results from this other kind of drug related illness in elderly people, in which potentially useful treatments are not taken or (because of misplaced therapeutic nihilism) not prescribed in the first place.

Broader systems based and educational approaches are emerging to guide the evidence based use of drugs in older patients so as to reduce their burden of iatrogenic illness while ensuring that needed drugs are prescribed properly. Better attention to managing this benefit-risk relationship will play an increasingly important role in maintaining and improving the health of an ageing population.

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(such as with a clinical pharmacist) is not always feasible in nursing homes, and this can decrease the efficacy of the intervention. In some countries pharmacists do not have access to patients' records. Consequently, a quality improvement strategy that is effective in one care setting cannot be directly transposed to another without adaptation. The same applies to transposition between countries, because of differences in practice environments and culture.

Big improvements in communication at the interface between primary and secondary care are urgently needed too. Many adverse drug events result from problems with communication relating to management of drugs during the transition between care settings. National online databases of drugs dispensed to patients (as in Denmark), to which all doctors and pharmacists have access, should help to tackle such problems. The same should apply to patient records. Such a challenge should be taken up at the national level, although of course steps must be taken to protect patients' privacy. Better communication among prescribers to track changes in treatment and to record the reasons for those changes will also help to avoid the fragmentation of care. This aspect should be included in measures of quality performance.

## Big improvements in communication at the interface between primary and secondary care are urgently needed

Quality improvement strategies for safer prescribing in older people must include shared decision making. The beliefs and preferences of older patients concerning treatment affect adherence and, in turn, the safe use of drugs. Several recent studies have shown the importance of considering patients' wishes, but many questions remain unanswered.

The high prevalence of people with dementia and the need to involve carers in decisions complicate further the task of shared decision making. Furthermore, many prescribers are not familiar with the principles of shared decision making or are reluctant to engage in it because of the extra time needed. Therefore a huge amount of work needs to be done here, from research to implementation. Education and training programmes for prescribers should include sessions on communicating with patients and on involving them in decisions.

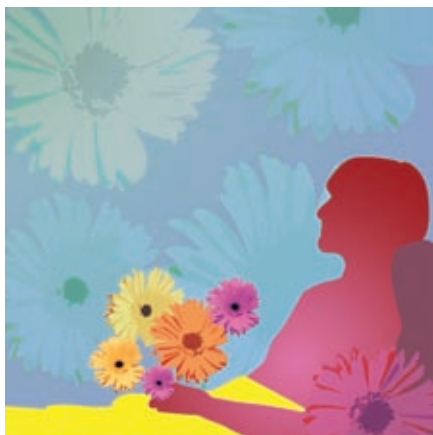
Health authorities should also consider including this dimension of care in quality performance measures.

What are the most urgent of the unanswered research questions? We need more clinical trials that enrol frail elderly patients, to enhance our knowledge of the benefits and risks of treatments in this group. With regard to quality improvement strategies, we need to evaluate the effect of multifaceted approaches on important health outcomes and costs. This is a challenging task that will certainly require multicentre trials with large samples.

It is important that quality improvement approaches are multidisciplinary in nature, use computerised decision support systems that are specific to this age group, and take the patient's view into account.

Meanwhile, national health systems should provide incentives for prescribers to regularly review treatments, develop information systems to facilitate seamless care, and encourage the implementation of multidisciplinary approaches including geriatric medicine services. Quality improvement strategies need to be customised to account for differences in patients, prescribers, and environmental factors.

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## Palliative care beyond cancer

**Scott Murray** and **Aziz Sheikh** say that the lessons learnt from palliative care for cancer need to be applied to other fatal conditions. Healthcare delivery that is tailored to the varying needs of patients with these diseases will be crucial in making a difference, says **Joanne Lynn**

## Care for all at the end of life

We must apply the lessons learnt from cancer (often slowly and painfully) to the growing number of people now dying from non-malignant illnesses. New theoretical insights into the trajectories of decline in a range of long term conditions—together with technical developments that aid the delivery of care in people's own homes and the timeless clinical qualities of listening, compassion, empathy, and inspiring hope—mean that we now have the means to make a real difference to the lives of so many people in the throes of their final illness and to the lives of their loved ones. Getting end of life care “right” lies at the heart of what it means to be a civilised society, and thus prioritising this area needs no apologies.

In 2005 cancer was responsible for a relatively small percentage of deaths worldwide (13%), while other long term conditions caused 47%. By 2030 the annual number of deaths around the world is expected to rise from 58 million to 74 million, with conditions related to organ failure and physical and cognitive frailty responsible for most of this increase. Yet despite these rapid demographic changes, palliative care services typically still cater only for people with cancer. For

example, hospices in economically developed countries currently provide 90% of their care to patients with cancer. Moreover, people dying from cancer usually have needs lasting for weeks or months, whereas those dying from organ failure or old age often have unmet needs that extend over many months or years. It is little wonder, then, that people dying of the “wrong” condition and their carers, whether family, social, or professional, are increasingly frustrated by the major obstacles to accessing appropriate care.

The drive to extend palliative care beyond cancer has so far been hampered by a combination of factors: prognostic uncertainty; funding difficulties (in the United Kingdom influential cancer charities support many hospices and outreach programmes); lack of palliative care clinicians with expertise in non-malignant diseases; and a hitherto relatively weak evidence base in relation to appropriate models of care. Although the empirical evidence base remains weak, we do now have a good theoretical understanding of when and how to intervene in a range of conditions.

Prognostic uncertainty can and does hinder clinicians in thinking and planning ahead. Most

## Reliable comfort and meaningfulness

To live well in the time left to them, patients with fatal chronic conditions need confidence that their healthcare system ensures excellent medical diagnosis and treatment, prevention of overwhelming symptoms, continuity and comprehensiveness of care, advance care planning, patient centred decisions, and support for carers. Hospices and palliative care have improved these dimensions of quality for people dying from cancer. Applying those insights to other fatal chronic conditions could greatly improve the last part of life, although the endeavour entails substantial challenges.

End of life care for elderly people will have to last for a long time: being disabled enough to need daily help now continues for an average of more than two years before death. Patients with non-malignant, long term illness are older and frailer than patients with cancer (as are their carers). Transfers between hospitals, nursing homes, and home care often engender delirium, depression, falls, treatment errors, and pressure ulcers, in addition to the common hospice problems of pain and loss. Entities that are often unfamiliar to hospices—such as social insurance programmes for poor people and disability transportation—will need to be partners in care.

How can we ensure reliable services for all in the last phase of life? Systematic quality improvement and policy reforms will offer reliable and efficient strategies if they focus on the three common patient trajectories: short decline typical of cancers; intermittent exacerbations and sudden death typical of organ system failures; and the slow dwindling course typical of frailty.

For gains to be achieved and sustained, quality improvement requires clear goals, appropriate teams, ways to monitor progress, sequential testing of improvements, and the institutionalisation of improved processes. Local quality improvement has a track record of success in correcting some shortcomings of ordinary care. These include improving pain prevention and treatment (such as by routinely responding at a patient's home within a time period determined by the patient or a family member), developing and implementing advance care plans (deciding whether to attempt resuscitation, for example), and preventing and healing pressure ulcers (one quality improvement programme reduced the incidence of full thickness lesions by 69%). Quality improvement projects can reduce over-treatment near the end of life, improve prognosis and counselling by providing automatic

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patients with heart failure die when they are still expected to live for more than six months, and accurate prognostication is also virtually impossible in people with chronic obstructive pulmonary disease (COPD). Although this uncertainty is frustrating for doctors, its very presence can be a basis for initiating end of life discussions.

Recent work is helpful in identifying critical events and stages when a palliative approach may be introduced. People with progressive chronic illnesses follow three characteristic trajectories (see figure on <http://makingadifference.bmj.com>): a cancer trajectory, with steady progression and usually a clear terminal phase; an organ failure trajectory, with gradual decline punctuated by episodes of acute deterioration and eventually a seemingly unexpected death; and a trajectory of prolonged gradual decline (typical of physical or cognitive frailty).

Hospices provide excellent and accessible care to people with cancer but are not configured to address the needs of patients who don't have cancer. So what can we do? A typical critical juncture in an organ failure trajectory, such as hospitalisation for acute heart failure or an

exacerbation of COPD, should trigger a holistic assessment and care plan for the next stage of the illness. Practical models of care are now being formulated and tested to fit the other two trajectories. Some Scottish general practitioners are, for instance, documenting a care plan for every patient admitted to hospital with COPD. Clinicians are thus alerted to "change gear" from routine chronic disease management to a more personalised palliative care approach, while continuing active treatment. These trajectories thus help us consider what should be done to promote quality of life rather than focus on what can be done, which may lead to futile treatment. A strategic policy overview of these trajectories may also help services to consider all people with serious chronic illnesses equitably, rather than cancer "top slicing" care.

Palliative care for everyone underscores the need for anticipatory personalised care for all people with life threatening illnesses. Technical developments such as video conferencing and remote monitoring devices may help in realising this aspiration, but far more important are the medical vocation's essential clinical skills—active listening, respecting autonomy,

and empathic care—none of which depends on first world infrastructures. These can be implemented anywhere in the world, as long as health services respect the importance of clinicians and patients having time together, ideally in the context of a relationship that allows for personal continuity of care.

Facilitating a good death should be recognised as a core clinical proficiency, as basic as diagnosis and treatment. Death should be managed properly, integrating technical expertise with a humanistic and ethical orientation. We also need research into how best to identify, assess, and plan the care of all patients who are sick enough to die, and we need education that keeps alive our humanity and sense of vocation. This is an enormous challenge in politicised, market driven healthcare models but one that will make an important difference to those most in need.

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A figure showing the three main trajectories of decline at the end of life is at <http://makingadifference.bmj.com>

feedback to clinicians, and implement shared accountability and effective drug reconciliation throughout changes of care settings.

Sustainable excellence requires supportive social policies. Practitioners working in trustworthy arrangements for delivering care must make a living. But powerful economic interests and social forces now encourage the overselling to patients and families of treatments with little chance of success. Citizens and clinicians must encourage political leaders to champion more appropriate policies, such as allocating healthcare payments to reward continuity and comprehensive primary care and ensuring an adequate income in retirement for family members who are carers.

Such reforms will be more efficient when they set out to match eligibility and service patterns to the three dominant patterns in the last phase of life. If palliative and hospice care are available only to those who die in a predictable way in a short time, most people will never qualify, because their timing of death will stay uncertain until very close to the end of

life. A short period of hospice care does meet the needs of many cancer patients, but people with heart and lung failure are better served by having a much longer period of support for self care and rapid response to help people at home in times of crises. In contrast, people with dementia or who are frail are often best served by having many years of support to carers in the family. Delivery systems that are tailored to the usual needs of these groups would enable clinicians to customise care plans to the preferences of individual patients and their families.

The combination of specific innovations from quality improvement, encouragement in the form of payment and regulatory policy, and services tailored to particular groups of patients is a powerful package for reform. In various forms, such a strategy is being pursued in many places: the United Kingdom, Saskatchewan in Canada, and Sweden, and in the United States by Kaiser Permanente, the Veterans Affairs Health System, and Medicare's Quality Improvement Organizations in each state.

Every clinical team can use quality improvement to adapt its own care system to the needs of patients with fatal illnesses. For example, doctors can shoulder the burden of helping patients and families come to a realistic view of the outlook and to collaborate in making plans. Claiming to be sustaining hope, doctors

often offer improbable treatment plans, falsely implying that all will be well if the patient and family go along with them. Instead, an honest appraisal of the situation, the likely course of the illness, and the treatment alternatives would allow the patient, family, and clinicians to negotiate the priorities among various goals, the preferred strategy, and a timeframe for reconsideration.

The ageing of populations will greatly increase the number of sick and dying older people, while smaller families and reduced retirement security will shrink the number of available carers in the family. The coming crisis is obvious. Policy makers and practitioners must learn to support family carers, and local quality improvement and innovation in governmental policy are the right prescriptions.

The dying patient's clinical care team must provide highly skilled diagnosis and treatment. Doctors must be able to promise to prevent pain and dyspnoea near death, for example. Specialist palliative care is well established in many countries, but palliative care skills among those professionals who serve most patients—long term care nurses, home care teams, generalist physicians, and specialist physicians—lag far behind.

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**Local quality improvement  
has a track record of success in  
correcting some shortcomings  
of ordinary care**