

Caring for family carers in general practice

A more proactive approach by GPs would help to ease the burden on family carers

IN AUSTRALIA, up to 2.3 million people are involved in informal care of children, adults and older persons with disabling chronic and terminal conditions.¹ Their role includes managing medications, therapies and medical emergencies; providing supervision and emotional support; and assisting with personal care, mobility and household tasks.¹⁻³ While caring can provide considerable satisfaction and strengthen relationships, carers often feel exhausted, isolated and burdened by their responsibilities.^{1,3,4} In a recent survey of carers, 58% reported their physical health had been adversely affected, a third said they had sustained a physical injury, and over half reported depression, anxiety, high levels of stress and other impacts on their mental health.²

There have been many calls for general practitioners to be more proactive in addressing the support needs of carers,³⁻⁶

and carers have identified how this may be accomplished (see Box).

A 1998 editorial on family carers in Australia³ called for strategies to raise health professionals' awareness about carers, to keep them abreast of programs available to carers, and to encourage them to be more proactive in helping carers to obtain support. Since then, there has been limited apparent progress in Australia (unlike Britain, where there has been considerable interest in the primary care team's designated responsibility for addressing carer needs⁷).

Projects conducted through Divisions of General Practice to inform and educate doctors, to promote carer self-identification and discussion⁵⁻⁶ and to promote collaborative referral with regional carer respite services⁵ showed encouraging outcomes, but have failed to attract further funding from government.

What carers would like general practitioners to do⁶⁻⁸

- Recognise their carer status and care responsibilities and include them in care planning and decision-making. Avoid assumptions about carer's capacity, confidence and willingness to provide home care.
- Provide plain-language information to the carer on the patient's condition, prognosis, treatment, care needs and management (including behaviour management).
- Provide information and referrals relevant to carers (eg, in-home and residential respite care options, counselling, peer support groups, financial entitlements, self-care and coping strategies). Give referrals to carer associations and state-wide condition-specific bodies as a starting point.
- Discuss and, where appropriate, assess the carer's own physical and psychosocial health needs.
- Engage other family members in understanding and sharing care responsibilities.
- Recognise grief and loss on cessation of caring.

Carer associations have also acted by providing various resources. The GP information kit, Carer Checklist and Carers Profile assessment tools (trials in New South Wales) are time-efficient and pave the way for discussion of carer issues.^{7,7} In Victoria, individual carers are encouraged to raise issues and to give their GPs a tailored service-provider kit, but this approach lacks systematic coverage. In South Australia, a GP working group is seeking to collaboratively explore various approaches, including GP education and involvement of practice managers.

Government initiatives have focused on raising GPs' awareness of community services and referral pathways (eg, the Commonwealth CareLinks and Victorian Primary Care Partnership⁸). Supporting tools initiated by governments include service directories, consumer assessment and service coordination templates, referral mechanisms (both printed and Web-based) and consumer/carer charters.

The full potential of information technology has not yet been harnessed. For example, including a "carer status" field in patient records would prompt early identification of care responsibilities. Software could also alert GPs to provide information or follow-up, and could even include (or electronically link to) carer fact sheets and resources, such as those produced by the national carer organisation Carers Australia.

Even GPs committed to working with carers can face considerable barriers to implementing a proactive approach. The patient may not agree to the carer participating in the consultation, or the carer may be reluctant to discuss how he or she is managing, especially if the patient is present or the carer perceives the GP to be too "busy" or very medically focused.^{4,5,7,10} Either the patient or the carer may be reluctant to accept external assistance.^{5,6,10} The carer may forgo his or her own health checks or treatment plan because of the pressures of caregiving.² Finally, in addition to lack of training, information and resources,^{5-7,11} GPs have to cope with increasing demands, time constraints and inadequate remuneration,^{5,7,9-11} problems that are often difficult to overcome.

The Enhanced Primary Care (EPC) Medicare Benefits Schedule items provide an opportunity to focus on carers and partly address the issue of remuneration for GPs.¹²

With the patient's consent, carers can be formally included in care planning and case-conferencing activities. This enables GPs and other healthcare workers to hear carers' views on how well they and their patients are managing at home. GPs and carers can then jointly consider options for coordinated support. Where carer wellbeing is an issue, staff of regional carer respite services (or other workers assisting the carer) can usefully be involved.⁶ Health assessments, another EPC item, should also include screening for carer issues.

However, GPs may still need to grapple with the thorny issues of consent, conflict and reluctance — interpersonal issues arising in the relationships between patients and carers and between patients/carers and their doctor.

Much of the responsibility for monitoring patient records and maintaining information resources can be delegated to the practice manager or an allied health professional. For example, practice nurses have effectively undertaken health assessments¹³ and are well positioned to provide carer health education, service referral and coordination. A counsellor or carer-support worker attached to a general practice can assist with identifying carer needs and making referrals, as well as helping the carer to develop skills and to work through emotional or relationship issues.⁶

The Better Outcomes in Mental Health Initiative¹⁴ is relevant to assisting carers who are experiencing severe stress, anxiety or depression. The initiative provides incentive payments for mental health needs assessment, planning and review activities to doctors who register interest with their local Division of General Practice and receive training. We believe that including educational material on carer mental health issues in training packages would enhance this initiative.

Given the absence of clear strategies and leadership on this issue over the past four years, the development of clinical practice guidelines and policy positions by governments and peak practitioner bodies is needed. The evolving Commonwealth-funded Primary Health Care Research Evaluation and Development Strategy¹⁵ provides an ideal opportunity to prioritise collaborative research in this area. The demonstration of the benefits to carers, those they care for, and the community generally, of an overtly aware and interventionist clinical approach is well overdue.

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Clinical trials and “real-world” medicine

Trial evidence best informs real-world medicine when it is relevant to the clinical problem

CONTROLLED CLINICAL TRIALS provide the most reliable evidence of whether treatments are effective, particularly when the effects of treatment are moderate. Without such trials, ineffective treatments or, even worse, harmful interventions may be accepted in medical practice. Yet medical practice is often not based on clinical trial evidence, because the evidence is considered not relevant or does not exist. Real-world medicine must not only consider the effectiveness of specific treatments, but must do so in the context of patients who have multiple problems and who are often already receiving many different treatments in a setting different from that tested in the trial.¹

Throughout the history of medicine, many treatments have been considered effective until well-controlled trials demonstrated otherwise.² Some recent treatments based on observational data that have been discredited by randomised controlled trials include hormone replacement therapy to prevent coronary heart disease events,³ vitamin supplements to prevent lung cancer⁴ or cardiovascular disease events,⁵ and arthroscopic surgery for osteoarthritis of the knee.⁶ Although data from observational studies may be of value,⁷ these data may sometimes suggest a harmful outcome for treatments that are known, from controlled trials, to be effective, such as blood pressure treatment.⁷

Applying trial results to individual patients

Although clinical trial evidence for the introduction and use of new drugs is widely accepted, the “real-world” uptake is often erratic. For patients with coronary heart disease, the merits of statins, angiotensin-converting enzyme (ACE) inhibitors, β -blockers and aspirin are well recognised from clinical trial evidence, yet these treatments are still significantly underused.⁸ The gap between evidence and practice is even wider in other areas.

Evidence is an essential part of good medical practice, but it is not the only information needed for clinical decision-making. Real-world medicine may ignore clinical trial evidence if it does not seem relevant to the clinical problem at

hand or if the benefit is uncertain. A drug that shrinks a cancer is not necessarily useful unless it also improves the patient’s quality of life or prolongs survival. A treatment that lowers blood pressure or cholesterol has value only if these outcomes are translated into meaningfully fewer cardiovascular events, without a penalty of increased adverse effects.

Hence, evidence from trials is most applicable in practice when the design and the outcomes chosen are directly relevant to real patients, the trials are undertaken against a background of standard medical care, patients in trials are broadly representative of patients in the real world, and evidence from trials is integrated with individual patient characteristics for meaningful risk–benefit assessment.

Absolute differences in risk (or numbers needed to treat) are recognised as most relevant to decision making; yet clinical trial results are often reported as changes in relative risk. For example, recent clinical trial results of breast cancer risk in women taking hormone replacement therapy appeared exaggerated if the increased risks were considered in relative rather than absolute terms. Treatment resulted in a 26% relative increase in breast cancer, which equated to an absolute increase of just 0.08% per year.³ Nevertheless, the relative treatment effect is of value if applied appropriately (by combining it with the individual’s baseline risk), providing a better guide to the absolute effect of treatment in specific patient groups.¹

Participation

Despite the need for high-quality clinical trials, few patients participate in them, even in areas where trials are common. For example, less than 5% of eligible patients participate in most cancer trials⁹ and less than 10% in many cardiovascular trials.¹⁰ Low participation rates raise concerns that the results from trials apply only to select groups of patients. Scant participation is not necessarily a problem if patients are representative, but patients in trials are often narrowly selected because of the eligibility criteria, the setting, or the patients agreeing to participate. Strategies such as public