

Self-Management and the Reform Context

In response to the escalating burden of chronic illness in Australia, the Council of Australian Governments instigated the Better Health for All Initiative¹ in line with the 2005 National Chronic Disease Strategy (NCDS).² Central to these policy initiatives is the promotion of patient self-management and better preventive care through increased patient support to act on risk factors.^{3,4}

The NCDS defines self-management as “active participation by people in their own health care”.² According to Barlow et al (2002)⁵ ‘self-management’ refers to:

‘the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and life-style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one’s condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established.’

Patient self-management involves the development of skills by people living with chronic illnesses to manage their risk factors, monitor their diseases, make effective use of services and medications, and also cope with the impact of disease on their lives.^{6,7} To do this, patients need to be empowered to self-manage their health and to attain the knowledge and skills to make the most effective use of the health care system.⁸

Self-management is a collaborative activity between individuals living with chronic disease and their healthcare practitioners.⁹ The Kaiser Model of Stratified Care according to Patient Need¹⁰ and the Wagner Model of Chronic Care concerning self-management and patient decision-making support¹¹ are two widely used models of care that support the promotion of patient education and collaboration between patients and health care professionals for effective self-management.

An often overlooked aspect of patient self-management is the important role family carers play in facilitating the self-management activities of chronically ill patients by working in partnership with both the patient and health professionals.^{7,12} This role, however, is now entrenched in chronic illness policy both internationally and in Australia. For example, the NCDS embeds informal carers and families in a partnership with the patient, service providers and the health system.² The NSW Chronic Care Program and the ACT Chronic Disease Strategy encourage active participation of the patient’s family and informal carer in self-management activities. Both policies recommend that informal carers have input into decision-making regarding health promotion, behaviour modification, goal setting, lifestyle adjustments and the negotiation of treatment and care plans for the patient.^{13,14} There is a clear expectation at a policy level that the self-management process will include family carers working in partnership with patients to manage chronic illness.

The Serious & Continuing Policy & Practice Study

The Serious and Continuing Illness Policy and Practice Study (SCIPPS) is a five-year National Health and Medical Research Council funded study which commenced in 2006 with the following aims:

- to improve the health outcomes of those suffering from chronic illness,
- to reduce unnecessary hospital admissions of this group, and
- to develop more effective preventive strategies.

Stage 1 of SCIPPS involved a qualitative study of patient (and carer) experience of living with and managing, and health professional experience of managing, chronic illness. Patients recruited to the study were aged 45 – 85 and had one or more of the following chronic conditions – chronic heart failure (CHF), diabetes, and chronic obstructive pulmonary disorder (COPD).

This research was supplemented by epidemiologic reviews of the index conditions within the Australian environment and literature reviews of the experience of people living with CHF, as well as a policy diffusion study.

Stage 2 of SCIPPS built on results of the qualitative study and included surveys of older adults living with chronic conditions, evaluations of models of chronic disease management, and a study focusing on Indigenous Australians living with chronic conditions.

SCIPPS Findings

Findings discussed in this section are detailed in the following publications:

- Jowsey T, Jeon Y-H, Dugdale P. Glasgow NJ, Kljakovic M, Usherwood T. Challenges for co-morbid chronic illness care and policy in Australia: a qualitative study. *Aust New Zealand Health Policy* 2009; 6: 22.
- Jeon Y-H, Essue B, Jan S, Wells R, Whitworth JA. Economic hardship associated with managing chronic illness: a qualitative enquiry. *BMC Health Serv Res* 2009; 9: 182.
- Yen L, Gillespie J, Jeon Y-H, Kljakovic M, Brien J, Jan S, Lehnbohm E, Pearce-Brown C, Usherwood T. Health professionals, patients and chronic illness policy: a qualitative study. *Health Expect* 2011; 14(1): 10-20.
- Jowsey T, Gillespie J, Aspin C. Effective communication is crucial to self-management: the experiences of immigrants to Australia living with diabetes. *Chronic Illn* 2010; 1-14.
- Essue B, Jowsey T, Jeon Y-H, Mirzaei M, Pearce-Brown C, Aspin C, Usherwood T. Informal care and the self-management partnership: implications for Australian health policy and practice. *Aust Health Rev* 2010; 34: 414-422.

The Impact of co-Morbidity on Patients Ability to Self-Manage

Fifty-two patients and 14 informal family carers participated in the SCIPPS qualitative study into the experience of living with chronic illness. Most of the patients interviewed by SCIPPS for the qualitative study had co-morbid conditions; several carers did, too. Of the 52 patients interviewed, 45 patients (87%) indicated they had more than one chronic illness. Furthermore, without being prompted, 55 of

the 66 patients and informal carers interviewed raised co-morbidity as a complicating factor in their experience of chronic illness; in response to prompting, a further two patients discussed co-morbidity as a complicating factor. Focus group discussions of health care professionals (n=63) found that health care professionals thought co-morbidity was a major determinant of the capacity of patients to self-manage their chronic illness.

Patients, informal carers and health care professionals found that co-morbidity influenced the capacity of patients to self-manage their chronic illness by reducing patients' capacity to:

1. act on risk factors - patients and informal carers reported co-morbidity created barriers to patients acting on risk factors (defined as variables known to increase a person's risk of illness or deterioration).

Health care professionals reported that co-morbid conditions reduced the usefulness of rehabilitation; premature withdrawal of patients from rehabilitation programs due to co-morbid conditions was costly, as was extended participation in programs, which was perceived as creating further resource restraints in a system already under considerable strain. This perception explained why health care professionals deterred people with multiple conditions from staying in rehabilitation programs

2. recognise the signs and symptoms of illness and of exacerbations - co-morbidity made it difficult for patients to recognise signs and symptoms of the index condition, especially early warnings of an exacerbation. Learning about the features of both their index condition and co-morbid conditions took much longer and was much more complicated than simply learning about the features of a single condition. Patients indicated they learnt how to recognise signs and symptoms of exacerbation by applying information gained through various sources (written sources, conversations with health care professionals, friends and family) to their personal experience in a process of trial and error.

Health care professionals agreed with patients and informal carers and thought the difficulty recognising signs and symptoms of exacerbations was a particular problem for people with limited health knowledge. They added that when patients did correctly identify new symptoms they did not always know how to respond and so ended up in hospital or suffered unnecessarily at home. For example, when a patient with both heart disease and lung disease develops swollen ankles they have to decide if they think this symptom is due to their heart condition or their lung condition, and then what to do about it - should they call the doctor, should they do nothing and watch and wait, or should they go to hospital?

3. manage medication – patients found managing medication for their numerous conditions to be complicated, time-consuming, inconvenient and confusing. They raised concerns of insufficient knowledge about drug-interactions and side effects. Many patients had limited knowledge and understanding of their medication and were not able to differentiate between them. However, patients noted the complex process of finding suitable medications to manage their conditions often required good communication with health care professionals, which in turn depended upon patient awareness of signs and symptoms of their several conditions.

Health care professionals raised other elements influencing medication compliance (patient honesty or recall/forgetfulness about medications they were actually taking; financial constraints and the cost of filling scripts). Several health care professionals indicated that medication management and non-compliance were particular problems with patients with mental illness. Health care professionals also suggested that lack of awareness by health care professionals and patients concerning risks involved in using multiple medication brand names could lead to patients unknowingly taking doses higher than prescribed or doubling up unawares, taking the same drug prescribed using a different brand name.

Recommendations

To facilitate self-management, patients will benefit from increased access to information that addresses the links between co-morbid conditions.

Health care professionals suggested that better access to mental health care providers could improve medication management for patients with co-morbid mental health problems.

Patients, informal carers and health care professionals suggested that the capacity to manage medication could be improved through increased education, patient engagement and good communication between patients and their health care professionals.

Confirmatory or Novel?

1. Co-morbidity diminished patients' ability to act on risk factors - CONFIRMATORY

This finding has been noted in the literature.^{15,16,17}

Recommendations

Future management strategies and guidelines should be informed by dialogue between patients and health care professionals as well as lessons learnt in studies addressing specific co-morbidity clusters.¹⁸⁻²¹ One solution to the challenge of maintaining an exercise regimen would be for cardiac and pulmonary rehabilitation programs to undergo redesign, catering to the needs of COPD and CHF participants with common co-morbid conditions such as arthritis.

Policy interventions that offer incentives to rehabilitation programs could effectively initiate the required changes to increase the programs' capacity to meet more common combinations of co-morbid conditions. The success of this solution will depend on the increased understanding of co-morbidity among health care professionals and increased communication among specialties.²¹ Existing initiatives such as the Chronic Disease Management Medicare items facilitate communication among specialties and increasing their uptake will benefit patients with co-morbid illness.²²

2. Co-morbidity made it difficult for patients to identify signs and symptoms of an exacerbation of an index condition – CONFIRMATORY BUT NOVEL REASON

Kerr, Heisler, and Krein et al. (2007)¹⁷ found complications occurred when patients prioritised the self-management of one condition over another. However, our findings suggest it is the complexity of the

knowledge required and the confusing nature of the symptoms that prevent patients from recognising physical and psychological changes.

Recommendations

The ability to recognise signs and symptoms of each illness is an important aspect of self-care and care planning^{23,24} and patients may benefit from policy that promotes patient health knowledge through self-management planning. Much written patient information provided in primary care settings is disease-specific. Many non-government organisations are orientated towards single diseases or organs (e.g. Diabetes Australia or the National Heart Foundation). Recent policies such as the 2005 NCDS focus on common single conditions rather than co-morbidity. All these observations reflect the dominant disease silo orientation of current Australian policy and practice.^{23,25}

3. Co-morbidity interfered with patient capacity to manage their medications and adhere to medication regimens – CONFIRMATORY

This was made worse by polypharmacy, poor medication literacy or confusion about regimens, and financial pressure.²⁶⁻²⁹

Recommendations

Patients may benefit from medication education and services that address these complications.^{28,30} In Australia this has been addressed through a pharmacist in-home patient medication review as part of a GP care plan called the Domiciliary Medication Management Review (DMMR). This review has had slow uptake across Australia because of pharmacist workforce shortages, pharmacists needing to be accredited before they can access the item, insufficient financial incentives for doctors, insufficient collaboration between pharmacists and GPs and insufficient promotion of the item.³¹ These factors need to be addressed to support the needs of patients who have co-morbid conditions.^{31,32} None of the participants in our study mentioned the DMMR, which might reflect the initiative's shortfalls.

Research is now needed to address how best to manage specific combinations of illnesses that are known to be co-morbid and highly prevalent. This kind of research may suggest modifications to the existing chronic care models and will inform policy initiatives at national and state levels that aim to improve patients' capacities to act on risk factors, knowledge of signs and symptoms, and capacity to manage medication.

Compliance Failures and the Ability of Patients to Follow Recommended Treatment and Self-Manage – Health Care Professionals Views

Focus groups of doctors, nurses, allied health staff and pharmacists (n=88) discussed health professionals' reactions to patients' and informal carers' perceptions of health issues which related to the difficulty managing their chronic illness in three areas: economic hardship;³³ the complexity associated with managing co-morbid conditions;³⁴ and multiple competing demands inherent in balancing illness and its management with the desire to lead a normal life.³⁵ Health care professionals often saw the patient experience as a series of failures relating to compliance or service fragmentation. Their comments on compliance failures had particular relevance to self-management.

The view of most health care professionals was that medication and other treatment costs were frequently prohibitive. They believed that these costs led to compliance problems with patients

rationing their treatments, selectively filling prescriptions, storing partly used courses of medication for later use and, at times, sharing medications with relatives and friends.

Cost was also seen as a factor in patients' abilities to effect lifestyle changes. Most focus groups identified the prohibitive costs of individually-focused preventive health, such as gym membership and weight loss programs. Nurses and allied health staff saw patients making choices between rival necessities: tradeoffs between paying essential bills, buying good quality food and paying for medicines. They and hospital specialists recognized that these difficulties were made worse by the perceived higher cost of purchasing recommended healthy and special food.

Health Care Professionals Linked Compliance to Health Literacy.

Health care professionals linked compliance to health literacy – the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.³⁶ They saw formal learning as crucial to the patient's ability to make appropriate management decisions.

As part of improving health literacy, nurses, allied health staff and GPs described one of their roles in terms of motivation and behavioural change. They concentrated on having patient recognize the seriousness of his or her condition, manage risk factors and change behaviour. GPs pointed out that patients were often not effective in navigating care. If they were, it would allow more efficient use to be made of health resources by allowing doctors to spend more time treating illness and less on facilitating connections for the patient. One focus group discussed the importance of recognizing people's different learning styles and abilities and their varying needs for knowledge at specific times as factors in successful self-management. They wanted more support to act as teachers and mentors in patient self-management.

Confirmatory or Novel? CONFIRMATORY

All but a small group of health care professionals, irrespective of background, identified social and economic issues as key elements in patients' compliance. Most of the professionals believed that compliance would improve with more adequate pensions and safety net arrangements for pharmaceuticals and necessary aids. The international literature on chronic care recognises the effect of these financial barriers.³⁷

The Impact of Economic Hardship on Patients Ability to Self-Manage

Patients (n=52) and informal carers (n=14) experienced ongoing financial pressure due to high costs involved in the treatment and management of chronic illness (i.e. out-of-pocket costs), often accompanied by existing economic constraints and lack of support resources. Other treatment costs and the need to make home modifications or purchase necessary assistive equipment for disease management also resulted in financial pressure.

Financial pressure resulted in patients having a limited capacity for health-related decision making and for engaging in other desired pursuits. For example, participants were often unable to follow their management plans or proactively engage in secondary prevention activities due to financial

constraints. Some patients prioritised essential treatment options and/or medications (i.e. some prescriptions were not filled or compliance with medication regimes was compromised).

The affordability of additional necessities required for the management of the illness, such as healthy food, exercise and gym memberships and joining social activities, was also raised as a concern by patients and informal carers interviewed. A common view among participants was that maintaining a healthy life-style is more expensive. Participants reported limiting discretionary spending, cutting back on more expensive, healthier foods and reducing participation in regular exercise programs at a gym.

Factors that influenced economic hardship

Among other factors influencing economic hardship, interviews of patients and informal carers showed that a lack of knowledge of self-care added to economic hardship, resulting in costs to both participants and the health care system. The level of health literacy, in terms of patients' and informal carers' awareness of the system and services, also played an important role in the ability to access subsidies, income support or other available benefits (e.g., free oxygen, community transport or taxi vouchers).

Confirmatory or Novel? CONFIRMATORY

Earlier qualitative studies of chronic illness experiences³⁸⁻⁴¹ support what has been found in our study regarding the kinds of economic hardship associated with managing chronic illness. These include the individual's compromised ability to afford not only essential treatment and medication but also to maintain a healthy lifestyle and quality of life. In the 2008 Commonwealth Fund International Health Policy Survey, 36% of Australian participants (n=593) reported access problems (accessing physicians, filling prescriptions, or getting recommended test, treatment or follow-up) because of cost.⁴² The NOUS-Menzies Centre for Health Policy's national survey (n=1,200) conducted in 2008 confirmed these findings: those reporting financial stress were more likely to skip a medical test or treatment recommended by a doctor, were more likely to fail to collect a prescription or skip doses of medicine, and were less likely to access dental services when necessary.⁴³

The Ability of Immigrants from Non-English Speaking Backgrounds to Self-Manage Diabetes

An analysis of a subset of the SCIPPS qualitative data of individuals living with diabetes (n=32; 25 patients and 7 informal carers) explored how the experiences of immigrants from a non-English speaking background living in Australia, compared with the experiences of non-immigrant Australians, influence their ability to self-management their condition. This analysis found the points of difference between the two groups concerned:

- self-management support
- access to health services
- language and communication

- control; and
- the drive and ability to fulfill the roles of ‘expert patient’ and ‘good patient’.

While Australian-born participants with diabetes reported feelings of confusion about self-management activities, immigrant participants from non-English speaking language backgrounds with diabetes reported feelings of confusion about management of their health as a result of communication barriers.

English Fluency and Communication

Many participants demonstrated a desire to be viewed as proactive and ‘good patients’ and to gain the skills and knowledge necessary to be viewed as ‘expert patients’. They described their interest in self-management activities, their active engagement in support groups and pursuit of health information, and compliance with the instructions of healthcare providers. Immigrant participants found these two roles of good patient and expert patient harder to achieve when they found information confusing, or when health care professionals were more authoritarian giving firm directions on diabetes management without checking the patient’s level of comprehension.

Participants who did not speak fluent English reported lacking confidence in their ability to communicate with healthcare providers and to seek information about managing their illness. On occasions when interpreters were not made available, participants reported becoming confused and unable to manage. Difficulties in accessing health information limited their sense of control, empowerment and agency in the management of diabetes.

To defuse these communication barriers, some immigrant participants reported seeking health professionals who spoke their native language. Most relied on family members who interpreted for them during health consultations and translated written information from pharmacists and doctors that could be absorbed at their own pace, this included information about medication.

Patient Evaluations of Experiences with Health Care Professionals and Implications for Self-Management

Immigrant participants were less willing than the Australian-born participants to discuss—and criticize—the details of encounters with health services and were slower to criticize both health care professionals and services than were the Australian born participants. The result of this was that Australian born participants demonstrated more agency and control over the management of their illness through the questioning and critical evaluation of health professionals.

Navigating the Health System

While all participants found the health system to be a frustrating maze, immigrants from a non-English speaking background were more likely to find it impenetrable.

Self-Management Support

A crucial dimension of self-management is support from family members, and an absence of family support is a considerable barrier to participants’ ability to manage. An absence of family support was

more prevalent among immigrant participants. Immigrants who could not turn to family members were more dependent on their designated family informal carers (usually their spouse), and among other roles often relied on them to act as interpreters at medical appointments.

(NB: Previous SCIPPS work showed that both groups experienced difficulty in balancing their illness with the rest of their life, had a high prevalence of co-morbid illness, expressed difficulty in accessing health services and health information, and experienced uncoordinated care from health services.³⁴⁾

Confirmatory or Novel? CONFIRMATORY

Effective communication is an essential ingredient in self-management strategies. The findings in this study support and build on those of Manderson and Kokanovic concerning cultural and language barriers to effective management of diabetes. Barriers to communication fundamentally influenced a person's willingness and ability to try to control the management of their illness, as did a person's informal and formal support to an extent not found among the Australian-born participants.⁴⁴⁻⁴⁶

Furler and colleagues noted that English speakers were more ready to seek professional support to adopt self-management strategies.⁴⁷ Our study findings indicate that this was also true for our Australian-born participants. However, the experience of migration combined with communication barriers created confusion at all stages. It prevented most of our immigrant participants from effectively utilizing support from health professionals, navigating the health system, finding useful information concerning self-management and thereby fulfilling the roles of expert and good patient.⁴⁸

Recommendation

It is essential that diabetes information be provided in a form that is easily understood by people for whom English is not the first language. Furthermore, immigrants need support in learning how to apply this knowledge in a way that will help to ensure beneficial health outcomes and enhance self-management.⁴⁹ There is clear evidence that improved self-management contributes to a reduction in health service utilization,⁵⁰ but self-management hinges upon good culturally appropriate communication and the implementation of health information as well as informal support.

The Role of Informal Carers in the Self-Management Partnership

An analysis of interviews of informal carers (n=14) showed that informal carers play a vital role in the self-management partnership with their care recipient. They assume a range of complex tasks and responsibilities, which can have a serious impact on their health and well-being as well as that of the care recipient. The key roles contributing to the self-management partnership with the care recipient are:

- home helper
- lifestyle coach
- advocate
- technical care manager
- health information interpreter.

Home helper

Activities that informal carers assisted with or managed entirely included: self-care, household finances, transportation, grocery shopping, scheduling paid support services, and household chores. Many of these responsibilities required informal carers to take on new roles in their relationship and develop new skills, and the number of activities the informal carers managed increased according to the care recipients' stage and severity of illness. If the care recipient required a particular diet, informal carers had to develop an understanding of what was required in the new diet and develop an ability to physically provide the diet at the required times.

Lifestyle coach

Informal carers encouraged and supported their care recipient to adhere to the dietary and exercise requirements recommended by health care professionals. This involved producing the specified diet at the appropriate time and ensuring that it was consumed and encouraging, supporting and monitoring the care recipients' efforts to exercise and modify risk behaviours.

Advocate

This role involved acquiring information on behalf of the care recipient about healthcare options and eligibility criteria for social support benefits and subsidies. This role was essential when the care recipient was very unwell and unable to manage medical encounters on their own, or unable to participate in decision-making.

This role was a source of tension between health care professionals and informal carers when health care professionals did not include informal carers in treatment decision-making.

Technical care manager

All participants reported their involvement in managing, overseeing or conducting technical aspects of the care recipients' care. The quasi-medical care included: operation of medical equipment such as supplementary oxygen concentrators; carrying out testing procedures such as monitoring blood glucose levels; and medication management, including filling prescriptions; identifying and raising issues with health care professionals and ensuring adherence to the prescribed medication regimen. This role required specific skills and knowledge in order to carry out the tasks correctly, including an ability to trouble-shoot problems as they arose in the home. Over time, informal carers learnt to recognise signs of exacerbations.

Health information interpreter

A core responsibility reported by the majority of informal carers was interpreting health information. This was particularly necessary when the care recipient had impaired memory, difficulty understanding treatment and self-management processes, or was critically ill. Informal carers were also responsible for facilitating communication with health care professionals when the care recipient was not fluent in English (n = 6). In instances, both care recipients and health care professionals relied on informal carers to function simultaneously as an English language interpreter and a health information interpreter. The regular use of formal interpreters was not reported by culturally and linguistically diverse (CALD) participants. In fact, most of these participants were not aware that this

service could have been organised on their behalf. Informal carers generally attended all appointments with health care professionals and were involved in health decision-making.

Juggling takes its toll: the negative impact of being a member of the self-management partnership

Informal carers faced common changes in their own lifestyle and in their relationships as a result of participating in the self-management partnership. Two negative consequences of juggling the multiple caregiving roles were carer self-neglect and conflict.

Informal carer self-neglect and conflict

The demanding and exhausting nature of caregiving contributed to informal carers neglecting their own needs. This was emphasised when the care recipient had more than one chronic condition, the informal carer had a chronic illness, or when English was not the first language of either person.

Several informal carers were unaware of the support services that were available to them and reported having a limited social support network. The few who were aware of respite care felt that it was not a viable option because of the following factors: the severity of their care recipient's health condition; inadequate access; insufficient information about the available services; and a lack of time to accommodate another service into their already busy schedules.

Conflict arose between informal carers and care recipients as well as between informal carers and health care professionals. All participants reported that their efforts associated with the 'lifestyle coach' and 'home helper' roles were major sources of conflict. Establishing the appropriate level of involvement in the care recipients' self-management activities was difficult. Coaching and monitoring transitioned into enforcement in some cases.

The interactions between informal carers, health care professionals and the care recipient were strained when English was not the first language of the care recipient. CALD participants described difficulty managing encounters where HPs isolated the care recipient by directing their attention and instructions to the informal carer only.

Confirmatory or Novel? CONFIRMATORY & NOVEL

The findings from this study reaffirm existing knowledge about the roles that constitute informal care, particularly in terms of providing assistance with activities of daily living,⁵¹⁻⁵³ performing technical care activities,⁵⁴ interpreting and advocating in health care encounters,^{53,55} and monitoring behaviour.^{51,54,56,57} They also offer new insights into the role that informal carer's play in coaching care recipients through the self-management process.

Policy Problem: The level of participation in self-management and care that is implicit in both policy and practice guidelines,⁵⁸⁻⁶⁰ expected from health care professionals⁶¹ and demonstrated in this study, comes at a cost to the informal carer and is disproportionate to the support that is available to informal carers and which they are eligible to receive. Despite the health system's reliance on informal care as an additional model of community support, informal carers continue to occupy a marginalised role in the care partnership because they have limited access to practical, emotional and financial support that is appropriate to their needs.

Policy Implications

There are implications for three policy spaces: access to support, demand for support and appropriateness of support. This research also identifies an important implication for practice in terms of how best to integrate and respect the informal carer role in health care encounters.

Appropriateness of Support

The results of this study suggest that informal carers need targeted skills-based programs that assist with the development of confidence and competence to carry out the caregiving roles associated with the self-management process, including:

- how to provide self-care to another person
- obtaining health information
- coping with role reversals
- maintaining relationships with family
- conflict resolution
- advocacy in a health care setting
- appropriate coaching and monitoring.

This has been echoed in the House of Representatives' report in their inquiry into better support for informal carers, which calls on the government to develop a national training and skills development strategy for informal carers that takes into account the multitude of skills that are required by diverse informal carers along the entire care trajectory.⁶²

The effectiveness of targeted skills-based training programs for informal carers has been demonstrated for other illnesses that are reliant on self-management in the home.^{63,64} Although developing training programs to enhance informal carers' capacity to effectively facilitate the range of self-management activities stands to professionalise informal care, such a strategy would reflect a more accurate understanding of the actual needs of informal carers who are currently performing these roles, often with insufficient training or support. Non-profit organisations and peak informal carer bodies could play a greater role in offering such skills-based programs as they are not currently the focus of existing programs and services offered by the Commonwealth or States and Territories.

Respecting the role of the carer in health care encounters

The inclusion by health care professionals of informal carers in the care partnership and health encounters remains limited.^{54,55,65,66} It is important to develop the confidence of informal carers to engage with health care professionals to advocate on behalf of the care recipient. However, an equal dedication to training health care professionals to refine their strategies for working with informal carers and provide opportunities for their input into decision-making is overdue. Bearing in mind the care recipient's right to privacy, this could involve discussing the mutual expectations held by the health care professional, the patient and the informal carer, soon after the diagnosis of the chronic condition. This would make explicit the informal carers' contribution to the care and self-

management partnership. Dow discusses the usefulness of such an open contract in order to eliminate some of the uncertainty about the informal carer role in home rehabilitation.⁶¹ This could provide an opportune time to discuss support needs, and skills development opportunities.^{65,67}

More research is required to gain a better understanding of possible models of cooperation that would best support the care partnership that is enshrined in chronic illness management policy and practice guidelines.

Future research should draw on studies of informal carers using purposeful sampling to gain an in-depth understanding of the experience of providing care for these index conditions, including informal carers' support needs and the barriers to accessing currently available programs and services. Although many of the informal carers had co-morbidity themselves, we did not explore the experience of co-caring within relationships, which may have an impact on the roles that informal carers conduct as part of the self-management partnership. This is an area that warrants further research.

Conclusion

We identify three policy implications that are priorities for improving the support available to informal carers. Access to services remains limited due to rigid eligibility criteria that serve to underestimate and undervalue the contributions that informal carers make to the self-management partnership. Informal carers in a self-management partnership are a hidden group that needs to be actively targeted, recognised and supported. Informal carers also need access to support services that are appropriate to *their* needs, including assistance to develop practical skills and core competencies to better perform their caregiving roles. Furthermore, at a practice level, the empowerment of informal carers must happen in parallel with the training of health care professionals to work effectively with them in order to minimise the conflict that can overshadow the care partnership. This research is an important input into current reforms to the health and aged care systems as it provides evidence-informed direction on how to achieve a positive caregiving experience for informal carers.

Recommendations

Increased inclusion by health care professionals of informal carers in the care partnership and health encounters. While we are beginning to see inclusion of informal carers in Government policies and budgets, more support for informal carers is called for. Informal carer payments need to more closely reflect the actual 'work' of caring.

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