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Title: What Skills Do Primary Health Care Professionals Need to Provide Effective Self Management Support? : A Consumer Perspective.

Authors:

First and Corresponding Author -
Sharon Lawn PhD MSW DipEd BA
Flinders Human Behaviour and Health Research Unit
Flinders University
Room4T306 Margaret Tobin Centre
PO Box 2100, Adelaide, South Australia, 5001
Ph: 61 8 8404 2321
Fax: 61 8 8404 2101
Email: sharon.lawn@health.sa.gov.au

Malcolm Battersby PhD FRANZCP FACHAM MBBS
Flinders Human Behaviour and Health Research Unit, Flinders University

Helen Lindner PhD BA BSc DipEd PGradDipBehStHlthCare FAPS
Australian Psychological Society

Rebecca Mathews PhD BBS(Hons) MAPS
Australian Psychological Society

Steve Morris BSc BA
Australian General Practice Network

Leanne Wells MPP BA
Australian General Practice Network

John Litt PhD MSc(ClinEpid) FAFPHM FRANCGP BS MB
Department of General Practice, Flinders University

Richard Reed MD MPH
Department of General Practice, Flinders University

Abstract**Objective**

This research aimed to identify the skills required by primary health care (PHC) professionals to provide effective chronic condition prevention and self-management (CCPSM) support, according to the perceptions of a sample of Australian consumers and carers.

Methods

Qualitative data was collected and integrated from a focus group, key informant interviews and National Stakeholder meetings and a National Workshop, supported by an extensive literature review.

Results

With the exception of health professionals specifically trained or currently working in this area, consumers and carers perceive there is a lack of understanding, competence and practice of CCPSM support among PHC professionals.

Discussion

The PHC workforce appears not to have the full set of skills needed to meet the growing burden of chronic conditions on the health system. Recommendations include education and training that focuses on improved communication skills, knowledge of community support resources, identification of consumers' strengths and current capacities, collaborative care with other health professionals, consumers and carers, and psychosocial skills to understand the impact of chronic conditions from the person's perspective.

Keywords: Patient-Centred Care, Primary Health Care, Chronic Condition Self-Management

Words: 5046 (excludes table)

Introduction

Chronic conditions are recognised as being among the most common and costly to the health system. In Australia they accounts for nearly 70% of all health care spending (NHPAC, 2006). This burden on health systems in internationally recognised (WHO,2002). Chronic conditions are also among the most preventable health conditions. Early detection and treatment and active collaboration with the patient can delay complications and disability (Glasgow, Orleans, Wagner, Curry & Solberg, 2001) and is most effective within systems that are integrated and support self-management by the person (Wagner, Austin & Von Korff, 1996a). The global shift in health policy towards more ‘patient-centred’ care has necessitated increased focus on self-management models that more actively engage people with chronic conditions. Chronic condition self-management (CCSM) support by health professionals has been investigated across a broad range of conditions. Importantly, current evidence suggests that patients with effective self-management skills make better use of available health services, have enhanced self-care and show clinical benefits, particularly with conditions such as diabetes and hypertension (Barlow, Turner & Wright, 2000; Chodosh, Morton, Mojica, et al., 2005; Warsi, Wang, LaValley, et al, 2004).

Global trends in disease incidence and prevalence indicate that considerable change is required for health systems to be responsive and flexible to meet the changing health needs of the population (Pruitt & Epping-Jordan, 2005). The World Health Organisation has identified a number of competencies required by health professionals and systems to deliver effective care to those with chronic conditions, including patient-centred care, partnering, and adopting a public health perspective. Empowering individuals towards adopting self-management strategies, where appropriate, feature significantly in these competencies (WHO, 2005). Public health models of

care are a response to the increased prevalence of chronic illness and associated systems pressures created by the estimated 6.8 million Australians who have a chronic condition (AGDOHA, 2006). In addition, there are recognised workforce limitations in terms of this care; for example, the limited amount of time General Practitioners (GPs) have to devote to individual patients impacts on the type of care they can offer (Schoen, Osborn, Huynh, Doty, Peugh & Zapert, 2006). More integrated and multidisciplinary care systems are needed in order to respond to these increased health care demands (Mann, Gaylord & Norton, 2004).

The Australian primary health care (PHC) sector comprises health professionals drawn from medicine, nursing and allied health, often complemented by a broad range of semi-professionals, community support and health promotion groups. What they all espouse is a commitment to promoting health, wellbeing and improved basic quality of life for people in their community. However, the efficacy of chronic condition prevention and self-management (CCPSM) support depends on the development of interdisciplinary collaborations, integrated care planning across disciplines and service systems, and quality of the care relationship. Notions of dignity and respect between consumers, carers and workers are central to the success of these processes.

In 2007 the Flinders Human Behaviour and Health Research Unit (FHBHRU) in conjunction with the Australian General Practice Network (AGPN), Australian Psychological Society (APS) and the Flinders University Department of General Practice undertook a national project for the Australian Government Department of Health and Ageing investigating training needs and information options available to the PHC workforce to support CCPSM. The motivation to assess training needs arose from the Australian National Chronic Disease Strategy (AGDOHA, 2005), with recognition that significant workforce changes and specific skills development would be

required to support the system's shift towards greater chronic condition management. Additional drivers for the investigation included awareness of an ageing population, reported workforce pressures, outdated clinician attitudes and practices, inequities in access to services, shortage of PHC professionals in rural and remote areas, and inadequate coordination and integration of services. Australian State, Territory and Federal governments have jointly invested in the Australian Better Health Initiative (ABHI) to start this health system refocus of the health system, to promote good health and reduce the burden of chronic disease. This paper aims to identify the skills required by PHC professionals to provide effective self-management support to those with a chronic illness, according to the perceptions of a sample of Australian consumers and carers. Therefore, it reports on one aspect of the larger workforce research and consultation.

Methodology

Consumer and carer views were sought via a focus group, key informant interviews, and key consumer and carer stakeholders' input to a cycle of three sequential National Reference meetings, designed to inform, build and validate the project's findings from a broader methodology involving workforce survey, training organisation audit, focus groups and key informant interviews across all stakeholder groups. Each method used to gather consumer and carer data informed and built on the next as part of a cyclic process of checking, interpretation and verification of meaning of the issues raised by consumers and carers. Participants were asked questions about:

- Their understanding of the meaning of CCPSM support
- Their personal experience of receiving PHC services support for chronic conditions;
- What would improve the services they received from PHC professionals; and

- What skills they thought the PHC workforce needed.

These areas of interest were determined by the project team in consultation with the National Reference Group and informed by existing literature.

Focus group procedure

Consumers and carers with exposure to Stanford Course training were specifically targeted because they were assumed to have heightened awareness of CCSM, health system issues and training skills generally, and could therefore provide highly informed feedback. A purposive sample of eight consumers and carers were recruited for the focus group following a call for expressions of interest, mediated through the SA Council on the Ageing (COTA). This organization coordinates Stanford training for South Australia and keeps a statewide database of trainers in this peer-led group-based CCSM program (Lorig, Ritter, Stewart, et al, 2001). Focus group participants were sent a letter of invitation, consent form and a brief project overview stating the project aims. A sitting fee plus travel expenses were paid for their participation in the two hour focus group. All eight participants identified themselves as consumers; that is, having a chronic condition. Four participants also identified themselves as carers for someone with a chronic condition. Three men and five women from across metropolitan Adelaide participated, ranging in age from 48 to 82 years. All participants had more than one chronic condition which varied in nature and severity and included physical and mental health conditions. All participants identified having a GP and regular contact with other PHC service providers such as community nurses, physiotherapists, dietitians and diabetes educators.

Key informant interviews and key stakeholder consultation procedure

Key informants from five major consumer and carer advocacy groups in Australia were invited to participate in two National Reference Group meetings and one National Stakeholder Workshop

that considered the cumulative findings of the project over a six month period. These included representatives from the Consumers Health Forum, Carers Australia, The Chronic Illness Alliance, The Australian Chronic Disease Prevention Alliance and the Health Consumers of Rural and Remote Australia Incorporated. These organisations represent the broad network of Australian consumers and carers, the first two being the peak organisations for many subgroups, including advocacy organizations and mental health networks. All have connections with diverse consumer groups, including urban, regional, rural and remote and culturally and linguistically diverse (CALD) consumers and carers. All consumer and carer participants provided fervent and critical input to debates and discussions at national meetings for the project, providing additional written feedback on project findings and one-on-one key informant discussions with the project manager for which extensive notes were taken and email correspondence kept. In addition, the chair of the Consumer Health Forum was formally interviewed by the project manager using the interview guide from the consumer and carer focus group, contextualized to the broad Australian consumer experience.

Data analysis

The focus group discussion was audiotaped and transcribed. Focus group data were analysed using content analysis methodology based on the areas mentioned previously (Newman, 2006). Three reviewers (facilitator, co-facilitator, and project officer) independently coded the data to identify themes and sub-themes that were revealed by the participants' comments then came together to discuss areas of agreement and any discrepancies. The facilitator was an independent consumer/carer academic. The co-facilitator was the project manager who has 23 years clinical experience with nursing and social work qualifications. The project officer provided administrative support and took extensive notes also and came from a nursing background of 25 years. Data from the formal key informant interview were audiotaped and transcribed, then

analysed similarly to focus group data. Outcomes of these processes were taken to the first two National Reference Group meetings as part of process debate and discussion during the project, and to the National Stakeholder Workshop at the conclusion of the project for further discussion, validation and integration into overall consensus data. The project team took extensive notes of these sessions, then met to debrief about the significance and meaning of the discussions. All data sources combined to provide a rich understanding and dense description of the views of consumers and carers. This contributed to and culminated in the development and endorsement of recommendations for addressing the training and information needs of the national PHC workforce.

Results

Focus Group data

1. Understanding of the definition of CCPSM support

The definition of CCPSM support was adapted from the agreed definitions of CCSM and prevention determined by previous work (Battersby, Lawn, Reed, Grimmer, Misan & Heartfield, 2007), the National Chronic Disease Strategy (NHPAC, 2006) and the RACGP guidelines on prevention (2006), that is: ‘CCPSM support is what health professionals, carers and the health system do to assist the person to manage their disease or condition, in order to promote health and prevent illness, detect, treat and manage early signs of disease, and minimise the disabling impact of existing conditions and complications’. All participants concurred with this definition, emphasising the importance of workers’ beliefs, attitudes and active collaboration with consumers and carers when providing CCPSM support.

2. Perceived quality of service and support provided by PHC professionals

All participants reported difficulties with accessing GP and other PHC services in a timely way. Most said they have at most 15 minutes during visits with their GP, which is not enough time to work with the person on the impacts of their illness. One participant commented that “GPs become a product of their system desensitized to the individuals.” Seven of the eight participants said there was little or no preventative care occurring; GPs were not proactive, few had effective recall systems for screenings, there was little or no follow-up planning for chronic condition management, and little time available to discuss issues in a more holistic way, especially mental health and wellbeing issues.

Participants also discussed the current environment of GP services whereby people feel they need an excuse to see the GP, that they are being ‘a burden’ if they do not have a serious problem to present. Participants said this was problematic for prevention, early risk factor identification, and management. All participants endorsed the use of care plans when used by PHC workers and supported a more active role in care planning by practice nurses in GP clinics.

Many participants had changed their GP due to dissatisfaction with the level of service provided. They perceived differences between the ‘old school’ doctors whom they felt were less likely to listen to their views, and the new doctors who they said were more willing to encourage dialogue, involvement by the person in their own care, and to provide comprehensive care. The five female participants all commented on problems accessing female GPs, due to a tendency to work part-time, move between practices, and move in and out of the workforce due to family commitments more frequently than male GPs. Access to specialist allied health services was also reported to be

problematic (eg. psychologists, dietitians) due to long waiting lists and costs. Participants stated that the consequence of the perceived suboptimal care by GP practices was that care had to be managed largely by the person and/or their carer. They worried about the impact of this at a population level and believed more needed to be done to educate the public about self-management of health at a population level as well as training health professionals to practice this way.

Only one participant described their GP service as having a highly effective CCPSM program with:

- Three monthly recalls for review and monitoring of chronic condition care plans
- Completely computerised processes that flag for recall as well as give extensive population-specific data to the practice in order for staff to identify high needs groups and better target services.
- Willingness and commitment to giving long consultations
- Effective use of practice nurses across a full range of activities and clinical input

3. What skills are needed by the PHC workforce?

All participants stated that CCPSM should be a core aspect of all undergraduate, post-graduate and professional development training for health professionals and consumers should be more involved in the planning, delivery and evaluation of that training. More training was seen as needed in basic person-centred approaches, including the following:

- Interviewing skills
- Assessment of consumers' needs

- Communication skills
- Collaboration with consumers and acknowledging their self-management role
- Raising issues with consumers (“learning how to ask”)
- Developing rapport
- Identifying consumers’ strengths and supporting self-efficacy
- Understanding stages of change and consumer motivation or perceived lack of it
- Goal-setting and supporting goal achievement
- Understanding how to use community resources more effectively
- Helping consumers navigate the system

Participants reported that tensions existed when they used different services such as community health staff in addition to their GP. Problems centred on communication, sharing of information, and perceived scepticism about each other’s roles by the different health care providers. Hand held records were endorsed as an effective means for the person to give information to each health care provider. Participants agreed that websites were excellent sources of information, but had limited application in elderly populations and individuals with little internet technology literacy or access.

Key informant interview data

Good communication between health professionals and with consumers was seen as the most important skill to be addressed. Key informants suggested that health professionals receive training that assists them to understand what it is like to be on the receiving end of the current system of care. They advocated for training that helps health professionals to listen to consumers

and carers, and attitudes and values that acknowledge the chronically ill person's experience and expertise.

Knowledge of available support services by health professionals was identified as a gap in the health care system. Key informants said that the consumer is often coming away from acute services or even the GP with little knowledge of what other services do and their usefulness. In addition, they viewed PHC teamwork as essential rather than over-reliance on sole PHC professional input.

Key informants said there needs to be more two-way communication between PHC staff and GPs at community health centers where each party is aware of the other's boundaries. Likewise, consumer support organisations and groups were perceived as undervalued and often denigrated by PHC professionals. Key informants said that health professionals need to understand consumers' and carers' motivation to seek out these alternative supports, viewing them not as a threat to the clinical role of health professionals but a supplement to their existing treatment. In general, key informants felt coordinated care is not occurring and requires improvement with the support of new technologies.

Key informants also stressed that PHC professionals need to think of management and self-management as a continuum of necessary adjustments to change; one that considers the whole journey for the person and their significant others, not just the here and now and in isolation from the person's psychosocial circumstances and environment. Within this context, chronic condition prevention support was reported as the hardest for consumers to get from PHC professionals.

They felt GPs and other health professionals need to understand the whole context of how consumers may or may not follow their advice.

When asked about the different professions and their training needs, one key informant suggested that nurses have a fundamental training issue regarding their professional need to communicate, such as using the computer to check records. The key informant expressed concern that some tasks have become perceived to be more menial such as engaging in 'light' conversation with patients prior to seeing their GP. However, 'chatting' has proved to be a useful informant of the individual's day to day self-management as well as their 'lived experience'. This key informant said that doctors perceive medication record printing for patients as a waste of time and therefore don't inform patients fully by providing them with this written record. Regarding training providers, all key informants stated that consumer representation is patchy and not as inclusive of consumers' perspectives as it should be. They said training tends to be superficially consultative, asking consumers to do 'show and tell' segments within training without fully including or integrating their views. They stressed that involvement of consumers in the accreditation of training courses should be 'a given'. There was strong support for the view that consumers should be involved in the development, delivery and evaluation of training provided to the PHC workforce.

Concern for CALD consumers was clearly expressed by all key informants, who stated that many programs and supports are simply not reaching these consumers. Concern was also expressed about overseas trained doctors who may lack a cultural understanding of Australian populations, and consequently the cultural context to discuss personal issues and to understand the contextual and subtle aspects of such communication. Likewise, in rural areas, key informants stated that

training needs to respond to the ‘community’ where solutions are often worked out locally, mirroring a community development approach that is practical and uses local resources.

Results in summary

The researchers considered the skills and gaps identified by consumers and carers, and compared these with those identified by the larger PHC workforce audit project undertaken for the Department of Health and Ageing (Battersby and Lawn, 2008). That audit involved an extensive literature review, a national workforce survey, an audit of training organisations, focus groups with PHC professionals and key informant interviews which identified nineteen core skills of equal significance required by the PHC workforce to effectively deliver CCPSM support.

<insert table 1 here>

Discussion

The consumer/carer focus group and key informant interviews did not assess PHC workers’ skill level or competence in detail. However, they did present some consumers’ and carers’ perceptions about services provided; that is, the end product of the delivery of workers’ skills and competencies. These perceptions are useful for informing potential gaps that could be targeted in the development of training for the PHC workforce and are particularly interesting and concerning coming from consumers and carers who are already understood to be knowledgeable, activated and assertive in their interactions with health professionals due to their involvement in peer-led Stanford groups. Consumers’ and carers’ identification of gaps, primarily in PHC workforce engagement and communication skills, demonstrates that consumers and carers perceive themselves to be largely ‘passengers’ in their own care. This suggests significant shifts in attitude are required by the workforce and training organisations in order to fully engage

consumers and carers and acknowledge them as active and collaborative partners in the process of CCSM (Wagner, Austin & Von Korff, 1996b).

The efficacy of CCPSM support depends on the quality of the collaboratively developed, integrated plan of care across these areas and the quality of the relationships that underlie the process of care giving and care receiving. This includes the development of health workers' belief and trust in the person's ability to self-manage and may require a cultural shift in service philosophy. Pivotal to this shift is the quality of communication between the person and the health professional; open and respectful communication is central to a client-centred approach.

Little et al (2001) surveyed 865 general practice patients on patient centred care using five principle domains to measure patient-centeredness: exploration of experience, understanding the whole person, finding common ground, health promotion, and enhanced relationship involving caring and power sharing. Patients confirmed that health professionals need to focus greater attention in all five domains. These domains could form a framework for training in PHC to support engagement and better outcomes in CCPSM. Clark and Gong (2000) identified that, at least in the area of asthma management (and likely more widely), there is a distinct lack of focus on patient-practitioner partnerships and patient self-management in the training of healthcare professionals. Perceptions of consumers and carers in the current study confirmed these concerns about the way they are viewed by health professionals.

The Picker Institute (Coulter, 2007; Coulter & Ellins, 2006) has provided a useful list of justifications for enhancing people-centred health care that is relevant across the CCPSM continuum. These include:

- Enhancing the person's understanding of the causes of disease and factors that influence health

- Improving self-diagnosis and treatment of minor self-limiting conditions
- Enabling patients to select the most appropriate form of treatment for acute conditions in partnership with health professionals
- Enhancing their capacity to monitor symptoms and treatment effects
- Fostering greater awareness of safety issues and likelihood of reporting them
- Enhanced the patient's learning to manage the symptoms of chronic disease
- Encouraging the patient to adopt health behaviours to prevent occurrence or recurrence of disease
- Empowering patients to effectively critique and provide feed back on the quality and appropriateness of healthcare services

Coulter further states that “Recognising these roles and seeking to strengthen them is fundamental to securing a more patient-centred approach to healthcare delivery” (2007, p.1).

Such an approach suggests core underlying values about patients, as experts in the experience of their chronic illness and its impacts, in addition to knowledge and skills transfer between health professionals and their patients. McCaffery et al (2007) suggests an increased focus on educating consumers to ask for information and involvement in their health care, as part of this overall approach. This has further implications for training of PHC professionals in the art of effective consumer involvement.

Clark and Gong's review (2000) suggested that post-graduate training related to the management of asthma (sponsored largely by professional associations, medical facilities, pharmaceutical

companies, and others) “shows that they focus almost solely on therapeutic recommendations to doctors...the correct choice and administration of drugs, the basic mechanisms of disease, and the use of monitoring devices for patients” with little focus on patient education for effective management by patients (p.574). Problems with effective communication between doctors and patients were also highlighted in many of these studies. Patients reported often feeling like they are wasting the doctor’s valuable time; they often omit details they deem unimportant for the doctor to hear, they are embarrassed to mention things they think will place them in an unfavourable light, they do not understand medical terms, and they may believe the doctor has not really listened and therefore does not have the information needed to make a good treatment decision. Similar concerns were raised by consumers and carers within the PHC workforce project.

Limitations

Participants represent a limited and potentially biased sample, skewed towards those who are aware of and have participated in CCPSM support training and who therefore may demonstrate more assertiveness with PHC professionals in engagement in their own self-management.

However, given this bias, the findings are argued to equally hold for other less aware consumers and carers; arguably being more significant and concerning. There is also potential bias (7:1) in people who were not completely happy with their care with many having negative experiences.

However, using other sources such as the broad ranged consumer and carer organisation key informants reinforced the findings. These findings also reflect those found by other studies such as Infante, et al (2004). Although rural and remote consumers and carers were represented by individuals as part of the National Reference Group and Workshop, we acknowledge that their views and specific needs may not have been illuminated fully. The metropolitan bias in the focus group membership added to this limitation. Lack of focus on the needs of CALD and Indigenous

consumers and carers was also apparent. These should be the subject of further study due to the unique nature of their experience of receiving healthcare services in the context of larger issues related to access and culture, as examples. Given these limitations, findings should be considered tentatively.

Conclusions

There appear to be fundamental skills gaps that can be used to inform the detailed CCPSM support training needed by the PHC workforce. Based on feedback from consumers and carers it is recommended that training for PHC professionals addresses:

- Communication skills, including listening and asking questions about the consumer's experience of their chronic conditions and management.
- Knowledge of community resources available to support the person and their carers
- Identification of consumers' strengths and current capacities
- Collaborative care with other health professionals, consumers and carers
- Psychosocial skills to understand the impact of chronic conditions from the person's perspective.

We also propose that PHC professionals, managers and training organisations need to involve consumers more in training at all levels, from development through to delivery, evaluation and accreditation of training provided to the PHC workforce.

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Table 1: A Comparison of CCPSM Skills Identified from the Findings of the Audit of the PHC Workforce and Consumer and Carer Focus Group and Key Informants

Audit of PHC Workforce	Consumer and Carer Participants
<p><u>General Person-Centred Skills</u></p> <ol style="list-style-type: none"> 1. Health promotion approaches 2. Assessment of health risk factors 3. Communication skills (including awareness raising and engagement) 4. Assessment of self management capacity 5. Collaborative care planning 6. Use of peer support 7. Cultural awareness/Interpreter service utilisation 8. Psychosocial skills 	<ul style="list-style-type: none"> • Interviewing skills • Assessment of consumers' needs • Communication skills • Collaboration with consumers and acknowledging their self-management role • Raising issues with consumers ("learning how to ask") • Developing rapport • Identifying consumers' strengths and supporting self-efficacy • Valuing the chronically ill person's experience and expertise • Valuing peer support services and using them effectively as an adjunct to health services • Cultural awareness
<p><u>Behaviour Change Skills</u></p> <ol style="list-style-type: none"> 9. Models of Health Behaviour Change 10. Motivational Interviewing 11. Collaborative problem definition 12. Goal setting and attainment 13. Structured problem solving 	<ul style="list-style-type: none"> • Understanding stages of change and consumer motivation or perceived lack of it • Understanding the person's needs holistically, including psychosocial impacts and environmental influences • Goal-setting • Understanding problems and priorities from the consumer's perspective
<p><u>Organisational/Systems Skills</u></p> <ol style="list-style-type: none"> 14. Working in multidisciplinary teams 15. Use of Electronic (or other) recall systems 16. Organisational change techniques 17. Use of Evidence based guidelines 18. Conducting practice based research / quality improvement framework 19. Awareness of community resources 	<ul style="list-style-type: none"> • More collaboration, cooperation, teamwork and sharing of information between service providers and services • Helping consumers navigate the system • Involving consumers and carers more in the planning, delivery, evaluation and accreditation of training • Skills in supporting new technologies • Understanding how to use community resources more effectively