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Self-Management Support (SMS) from a Chronic Disease Worker in a Rural Primary Health Service, a Pilot Study

Ervin K[1]*, Koschel A[1] and Campi S[2]

[1]Department of Rural Health, University of Melbourne, Graham St, Shepparton, 3630, Australia
[2]Violet Town Bush Nursing Centre, Cowslip St, Violet Town, 3669, Australia

Abstract

The benefits of self-management in chronic disease have been proven and are a recommendation by the peak body for primary care in Australia. In a region of rural Victoria Self-Management Support (SMS) programs have had limited success due to a lack of implementation by trained staff? In this study a small rural health service trained and supported staff to provide SMS care and evaluated the effect compared to usual general medical practitioner (GP) care.

All clients (over the age of 18) allocated a GP care plan at local consenting medical clinics and those receiving SMS care at the rural health service were invited to participate in a survey using the Patient Assessment of Care for Chronic Conditions survey (PACIC). The PACIC is a brief, validated patient self-report instrument to assess the extent to which clients with chronic illness report care that is patient-centred, proactive, planned and includes collaborative goal setting; problem-solving and follow-up support. Responses were compared using non-parametric testing to determine differences between the SMS group and the patients from the GP group (usual care).

Overall the SMS group reported higher frequencies of always or often receiving care that supported a patient centred, planned approach to chronic disease management. In particular for client involvement in making the plan, choosing their own goals, having a written list, understanding how their own self-care influences their condition and post visit contact. Client feedback supported the provision of the SMS program.

Keywords: Chronic disease; Self-management support

Introduction

The prevalence of chronic conditions is increasing in Australia with more than half of the population aged 65-84 years having five or more long term conditions, which now contributes to 80% of disease burden in Australia [1-3]. It is imperative that successful models of care are implemented to manage the growing burden. There is a growing consensus that clients have a more active role to play in defining and reforming healthcare, particularly in chronic disease management, where clients monitor and manage the majority of their own care, related to their illness, day-to-day [4-6]. Benefits of self-management support programs have been provided and are recommended by the Australian Institute for Primary Care [1,7-9].

In Australia, people with chronic or terminal conditions present for six months or longer are eligible for a General Practitioner (GP) management plan. The management plan provide financial rebates for GPs to manage chronic or terminal medical conditions by preparing, coordinating, reviewing or contributing to plans for ongoing care. The rebates for GPs recognise the increased time required to structure and co-ordinate the often complex care required for these clients [10].

Clients with chronic conditions often require multiple service providers in addition to their GP care. Self-management support (SMS) programs are delivered by health care staff trained in delivering SMS. There are many models of self-management strategies currently in use in Australia including Stanford, Flinders, motivational interviewing, and health coaching [11]. Key principles of SMS includes; shared decision making, which encompasses formulating health goals, using planned evidence based care, improving support and access to resources to assist in self- management and systematic monitoring of the patients health status at agreed intervals [12].

Previous research in SMS in the area under study had been limited to staff implementation of SMS training [13,14]. The findings from these studies highlighted difficulty in implementation of SMS related to staff's perception that current service delivery models did not accommodate SMS and the difficulty in changing clinician practice from traditional information provision models to shared decision making with clients [13-16].

A new model of primary health care in rural Victoria, Australia, undertook provision of a chronic disease worker (CDW) with a component of the role to accept referrals from GP's for clients with chronic conditions. The CDW utilised the GP care plan to implement the required care and coordinate referral to various providers, while at the same time build self-management skills with each client. The CDW had previously undertaken training in SMS for chronic disease. This pilot project aimed to explore the difference between clients receiving care under the usual General Practice care plan model versus that receiving self-management support from a CDW.

Methodology

The area of the study was three small townships with a total combined population of 9,486 people, located in one shire and serviced by one community health and wellbeing program as a consortium. The shire has a known ageing population with high rates of chronic disease [17-19].

***Corresponding author:** Kaye Ervin, Department of Rural Health, University of Melbourne, Graham St, Shepparton 3630, Australia, Tel: 61439722510; E-mail: ervink@humehealth.org.au

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Recruitment

The chronic disease worker identified all clients from the local community health service receiving SMS. The researcher provided a plain language statement describing the study, a survey and a reply paid envelope to all clients receiving SMS, which was mailed out by the administrative staff, two months post visit. The CDW was blinded to the survey to prevent change in practice which may have biased results.

Practice nurses at the medical clinics in the three townships agreed to identify and mail out a plain language statement describing the study, a survey and a reply paid envelope to clients with a GP care plan for chronic conditions. The practice nurses were not blinded to the survey in order to gain compliance with recruiting for the research study. The surveys took approximately 10 minutes to complete and were voluntary. All surveys were returned by reply paid post to the researcher.

Sample Size

All clients (over the age of 18) allocated a GP care plan at consenting medical clinics were invited to participate in this study. This was estimated to be approximately 27 clients. This was the usual care group (GP). In the SMS group an estimate of approximately 36 people were expected to be eligible to participate.

Evaluation Tool

Clients were surveyed using the Patient Assessment of Care for Chronic Conditions (PACIC) survey. The PACIC is a 20 item survey which asks clients opinions about their contribution to their care and treatment, the provision of information, collaborative goal setting, person-centred care planning and referral networks. The PACIC is a brief, validated patient self-report instrument to assess the extent to which clients with chronic illness receive care that aligns with the chronic care model-measuring care that is patient-centred, proactive, planned and includes collaborative goal setting; problem-solving and follow-up support [17].

The PACIC tool consists of five scales and an overall summary score, each having good internal consistency. The PACIC is only slightly correlated with age and gender, and unrelated to education. It is only slightly correlated (r=0.13) with the number of chronic conditions. The PACIC demonstrates moderate test-retest reliability (r=0.58 during the course of 3 months) and is correlated moderately, (r=0.32-0.60, median=0.50, P<0.001) to measures of primary care and patient activation [17].

The PACIC is a practical, client-level assessment of the chronic care model implementation. It is suggested as the preferred tool for evaluating the chronic care model, and demonstrates significant positive correlation with improved client outcomes such as medication adherence, improved rates of exercise, quality of life, reduced hospital admission and self-rating of overall health [18,19].

SMS Intervention

The proposed SMS intervention supports and enhances the goals set by clients as part of their GP care plan. The aim of the SMS intervention is to provide a healthcare environment that delivers information in a way that supports; patient- centred care, health literacy, evidence based practice, timely referrals and healthcare recommendations that are appropriate to the clients health conditions. Clients receive an initial assessment including six areas for current best practice management. The assessment is focused on relevancy of needs, in terms of capacity, including financial, physical and cognitive needs. Clients self-rate how they are managing in each of these areas. The six areas addressed are;

1. Manage medications effectively
2. Engage in specific treatment activities
3. Monitor and act on symptoms
4. Attend services and appointments
5. Manage triggers and risk factors
6. Manage healthy lifestyle factors

Current health behaviours are assessed using the stages of change model and goals are set by the client and documented in a personal self-management plan. Goals are reviewed at subsequent visits with the CDW. When the client feels that they are managing in these areas and can continue working on their health care goals themselves they are discharged from the self-management program.

Analysis

The study utilised a survey with both quantitative questions and the ability to record open ended comments. The qualitative comments are reported as recorded with no thematic analysis undertaken, given the brevity of responses.

Quantitative data analysis was limited to descriptive statistics and describing trends. Data was analysed using Stata, fishers exact testing for categorical variables and Mann Whitney U tests for continuous responses. Power to detect a difference was calculated using results of participants for the GP and SMS groups, resulting in a power of 50% to detect a difference. Given this power and the small sample size non parametric testing, Monte Carlo, was undertaken to detect potential differences. Qualitative comments are presented as client feedback.

Results

Survey responses were collected from 15 clients (55.5%) in the GP group and 23 (95.8%) in the SMS group. In the SMS group seven clients were referred to other services for care, one client was deceased and three clients refused to participate in the SMS program.

The majority of SMS clients were referred to the CDW by their GP. During the course of six months the CDW completed 98 telephone calls with clients, 14 telephones consults with other service providers, 40 home visits and 13 other visits. Fourteen clients had logistical support as part of care co-ordination needs identified through the SMS process in addition to their SMS management plan and 14 clients were discharged from the SMS management program.

Reasons for referral were for varied health conditions but specifically for opinion, support and management of a chronic condition. Goals were closely aligned with referral reasons with independence and staying at home and increased understanding and knowledge being the most commonly reported goals.

The range of self-reported chronic conditions in the GP group included; cardiovascular, arthritis, spinal injuries, obesity and diabetes. In the SMS group conditions included; cardiovascular, arthritis, spinal injuries, mental health issues and diabetes. The majority in the SMS group were listed as multiple conditions. Table 1 reports on the demographic characteristics of the two groups.

Table 2 presents the results of the PACIC survey for the GP and SMS groups. Client feedback was recorded by the CDW. Responses were

		GP group	SMS group	P value
Age	Median	66.3 years	66.5 years	*0.47
	Range	61-73	55 - 80	
Gender	Male	8 (53%)	8 (35%)	#0.3
	Female	7 (47%	15 (65%)	
Length of time associated with service	1 month or less	1 (6.7%)	5 (21.7%)	^0.002
	1–6 months	2 (13.3%)	14 (60.9%)	
	6–12 months	2 (13.3%)	1 (4.3%)	
	Over 12 months	10 (66.7%)	3 (13.0%)	
Know why they have a care plan	Yes	14 (93.3%)	22 (95.6%)	#0.6
	No	1 (6.7%)	1 (4.3%)	

* Mann Whitney U test
# Fishers Exact test
^ Monte Carlo test

Table 1: Comparison of demographic characteristics.

		GP group	SMS group	P value
Asked for my ideas when we made a treatment plan	None of the time	0	0	0.14
	A Little/Some of the Time	2 (14.3%)	2 (8.6%)	
	Most of the Time/Always	12 (85.7%)	21 (91.3%)	
Helped to make a treatment plan that I could carry out in my daily life	None of the time	0	0	0.03
	A Little/Some of the Time	3 (20%)	1 (4.3%)	
	Most of the Time/Always	12 (80%)	22 (95.6%)	
Given a copy of my treatment plan	None of the time	0	0	0.001
	A Little/Some of the Time	4 (28.5%)	2 (8.7%)	
	Most of the Time/Always	10 (71.4%)	21 (91.2%)	
Asked to talk about my goals	None of the time	1 (7.1%)	0	0.01
	A Little/Some of the Time	3 (21.4%)	2 (8.7%)	
	Most of the Time/Always	10 (71.4%)	21 (91.3%)	
Helped to set specific goals	None of the time	1 (7.1%)		0.06
	A Little/Some of the Time	3 (21.4%)	3 (13%)	
	Most of the Time/Always	10 (71.4%)	20 (86.9%)	
Asked questions about my health habits	None of the time	1 (7.1%)	0	0.09
	A Little/Some of the Time	3 (21.4%)	3 (13%)	
	Most of the Time/Always	10 (71.5%)	20 (86.9%)	
Asked how my chronic condition affects my life	None of the time	0	0	1.0
	A Little/Some of the Time	2 (13.3%)	1 (4.6%)	
	Most of the Time/Always	13 (86.7%)	21 (95.4%)	
Given choices about treatment to think about	None of the time	0	0	0.13
	A Little/Some of the Time	2 (14.2%)	1 (4.3%)	
	Most of the Time/Always	12 (85.7%)	22 (95.7%)	
Asked to talk about any problems with my medicines or their effects	None of the time	1 (7.1%)	1 (4.3%)	0.25
	A Little/Some of the Time	2 (14.2%)	1 (4.3%)	
	Most of the Time/Always	11 (78.6%)	21 (91.3%)	
Given a written list of things I should do to improve my health	None of the time	2 (14.3%)	1 (4.3%)	0.001
	A Little/Some of the Time	4 (28.5%)	0	
	Most of the Time/Always	8 (57.2%)	22 (95.6%)	
Satisfied that my care was well organized	None of the time	0	0	0.11
	A Little/Some of the Time	1 (7.1%)	1 (4.3%)	
	Most of the Time/Always	13 (92.8%)	22 (95.7%)	
Shown how what I did to take care of myself influenced my condition	None of the time	0	0	0.01
	A Little/Some of the Time	3 (21.4%)	1 (4.3%)	
	Most of the Time/Always	11 (78.6%)	22 (95.6%)	
Helped to plan ahead so I could take care of my condition even in hard times	None of the time	0	0	0.07
	A Little/Some of the Time	5 (33.4%)	2 (8.6%)	
	Most of the Time/Always	10 (66.7%)	21 (91.3%)	

Encouraged to go to a specific group or class to help me cope with my chronic condition	None of the time	2 (14.3%)	7 (30.4%)	0.18
	A Little/Some of the Time	6 (42.8%)	3 (13%)	
	Most of the Time/Always	6 (42.9%)	13 (56.5%)	
Referred to a dietician, health educator, or counsellor	None of the time	3 (20%)	8 (36.4%)	0.70
	A Little/Some of the Time	2 (13.3%)	2 (9.2%)	
	Most of the Time/Always	10 (66.7%)	12 (54.5%)	
Contacted after a visit to see how things were going	None of the time	4 (28.6%)	1 (4.3%)	0.04
	A Little/Some of the Time	1 (7.1%)	1 (4.3%)	
	Most of the Time/Always	9 (64.3%)	21 (91.3%)	

Table 2: Comparison of PACIC.

recorded at multiple time points during the SMS program. Responses from clients after the first initial visit included;

- Very helpful and informative, now feeling motivated and wanting to make changes to diet and exercise regime. Information given in a way that you feel like you can actually start to achieve something.
- When asked what the client understands about his diabetes and his management plan. He stated that he has little understanding at present and that the entire doctor said to him was go for a walk 20 minutes 3 times a week to manage his diabetes.
- It has been great to be able to sit and have a talk to someone who can answer all your questions and give you information in a way that is understood. I wish that I had had those years ago. It has been very helpful.

During the program responses recorded included;

- After visiting I have become so much of confidence in processing in my life. It has made me want to continue looking after myself to the fullest and enjoy a future retirement.
- Client states that after setting goals and working on them she now feels more independent, more in control of her life and more settled in the family home. She also stated that she followed up our referral to review her medications and her asthma is being controlled better, she feels a lot better and is less breathless.
- It was very helpful to have someone help me to get on track. The self-management support helped me by explaining what diabetes was and how to manage it. It was helpful to talk through what the dietician and the doctor had said. It made it clearer for me. It was very confusing before that. Lots of appointments and information, etc.

Responses were also recorded from family during the program with the following examples;

- Mum seems more relaxed and less edgy since our service has been in place. The shopping lists are a great idea. This has helped mum manage. Mum is very comfortable talking to you about things. This is a great improvement on her refusing all services and not letting anyone into the home. (all services were reinstated to allow the couple to remain living in their home)
- Wife stated I don't know what you said to my husband but he has now got me buying cottage cheese. He received the information in the mail, that you sent, and he has read over it all very carefully. Since you spoke with him he has had a complete change in his thinking, he realises that he needs to change his lifestyle to improve his health so that he can live longer.

Responses recorded at the point of discharge included:

- Client stated that prior to seeing me she had thought there was no point in living. She now says that she feels like a new woman and her whole outlook has changed. She feels stronger both physically and mentally. She has completely changed her life around in that she is now exercising daily, attending appointments with navigating life, setting boundaries around family relationships, managing pain and making better food choices.
- Got motivated to get back on track and manage my type 2 diabetes. I have lost weight, more motivated, diabetes under better control, feeling better, lot more energy, feeling like I can manage a full day's work and enjoying life more. I feel that I can manage my health now.
- Very helpful, I was able to discuss my concerns and then I was given helpful advice

Discussion

There was a significant difference in response rate between the GP and the SMS group. The GP group relied on practice nurses identifying patients and mailing out the survey. Clients in the SMS group had recent contact with the CDW within 2 months of the survey; however in the GP group contact with the GP may have occurred longer ago than two months. Recent contact may influence a person to respond in comparison to a patient who has not had recent contact; this may explain the difference in responses.

There was no difference between age and gender or knowledge of having a care plan between the two groups. The SMS group reported being associated with providing service for less time than those in the GP group, not surprising given it was a new program.

The value of having a CDW is demonstrated in the statistically significant differences in SMS group in relation to the following:

- Involvement of the client when making a treatment plan to carry out in their daily life,
- Being given a copy of their treatment plan,
- Being asked to talk about their own goals,
- Receiving a written list,
- Understanding how self-care influences condition, and
- Being contacted after the visit for follow up.

Broader literature shows that involving the client in their treatment plan and talking about goals results in improved outcomes, both for compliance to the plan and resulting improvements in their condition [20]. Education for clients regarding their conditions and ensuring that

information is understood has been shown in other studies to improve clinical outcomes for clients [21]. In contrast, many other studies show that compliance is poor when clients do not have an understanding of the reasons or the impact that treatment has on their condition [22]. It has long been recognised that time constraints for GP's prevent them undertaking the level of client education required [23]. Given the demands of GP's and the associated costs of extended visits, it makes good economic sense to utilise other health workers to undertake this role.

Although there was no significant difference overall for the remainder of elements assessed however there were some differences in frequency worthy of discussion. Compared to the GP group, clients in the SMS group reported higher frequencies of the following often occurring:

- Assisted in goal setting to achieve improved eating and exercise,
- Being asked about their health habits,
- Asked how their condition affected their life,
- Being given choices about their treatment,
- Being asked to talk about problems with their medications,
- Helped to make plans so they could take care of themselves even in hard times, and
- Recommended specific groups of class activities for those with chronic conditions.

Choices and preferences for clients regarding treatment is a fundamental tenet of client autonomy and self-determination [24]. Involving clients in their care and treatment by elucidating their values and what matters most to them more likely results in better compliance and resultant improved health outcomes [24]. Models of care, where the GP advises the client what to do, without consideration of the clients preferences but based on the GP's expertise, have not been acceptable models of care for some time [25]. The best recommendations in the world are wasted, if the client does not follow them [26]. There is also compelling evidence that patients who are active participants in managing their health and health care have better outcomes than patients who are passive recipients of care [27].

There was no difference between groups for being satisfied that care was well organised or being encouraged to attend community programs. The GP group reported higher frequencies of being referred to an allied health professional compared to the SMS group. This is potentially because the CDW was able to meet the needs of client without referral.

Qualitative responses provided and reported above suggest that the support of the CDW has been invaluable immediately after initial assessment, during the program and prior to discharge. Clients report better understanding of their conditions and support to initiate and maintain changes to poor health behaviours contributing to their conditions. This suggests that CDW's have time to elucidate root-cause behaviour issues which impact on the chronic condition as well as a viable process that addresses the underpinning issues. These positive results demonstrate the usefulness of initiating and maintaining the motivation of clients with chronic conditions.

It should be acknowledged that the sample size was small and power to detect a difference therefore compromised by this; however the qualitative results are consistent with the survey results suggesting that the positive outcomes achieved are valid.

Conclusion and Recommendations

There were several significant differences in the SMS group in relation to CDW support that advocate for the continued use of such health professionals. Where specific items assessed were not statistically different between the GP group and the SMS group the SMS group fared better for consistency in always receiving care compared to mostly in the GP group. Comments provided by clients further support the benefits in relation to initiating change and maintaining change in clients to improve health outcomes.

Previous evaluations of SMS in the Hume region have demonstrated that staff trained in SMS failed to implement the training and therefore achieve improved service delivery and support for clients with chronic conditions [14-18]. Anecdotally, previous poor uptake of SMS is also reportedly a result of the need to make government targets for care delivery and the onerous reporting involved. The framework of support in this project enabled the CDW to work collaboratively with clients at a suitable pace, reflecting a person-centred culture, with resultant better uptake and outcomes. This evaluation demonstrated that staff commitment to service delivery change to support clients with chronic conditions resulted in much improved support for clients. It is the first evidence in the region to demonstrate the benefits of SMS training and achievable implementation.

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