A pilot study to assess the efficacy of the Flinders Program of Chronic Condition Self-management on the health and wellbeing of haemodialysis patients

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Abstract

Background

Currently there is limited research into the effects of self-management interventions amongst haemodialysis patients. The Flinders Program of Chronic Condition Self-management (Flinders Program) is a structured program providing a consistent, reproducible approach to assess self-management behaviours, identify problems, set goals and develop care plans.

Aims

To assess the efficacy of the Flinders Program on patients' health, wellbeing and self-management behaviour.

Methods

A 24-week longitudinal pilot study was undertaken on the effect of the Flinders Program with 13 haemodialysis patients at Latrobe Regional Hospital. A six-weekly review was conducted to monitor participants' progress and motivate them to improve self-management skills. Self-management skills, quality of life and dialysis clinical outcomes were measured at the beginning, during and at the completion of study.

Results

Participants' access to allied health services was significantly increased. Improvements in clinical measurements (increased urea clearance, improved systolic blood pressure, reduction in fluid retention), quality of life (increased Kidney Disease and Quality of Life — Short Form scores), and aspects of self-management skills Partners in Health Scale) were reported. Although few changes reported were statistically significant, every participant made a clinically important improvement in at least one measure.

Conclusion

Clinically important improvements for individual participants were identified. Further study is needed to determine the sustainability of the Flinders Program in haemodialysis patients. A randomised controlled trial with a large sample size and long-term follow-up is recommended.

Keywords

Self-management, quality of life, Flinders Program, haemodialysis, dialysis clinical outcomes.

Introduction

End-stage renal disease (ESRD) is a chronic condition that affects the physical, social, emotional and cognitive aspects of a person's life (Tsay & Hung, 2004). Curtin *et al.* (2002) showed that quality of life is severely compromised in ESRD. In addition to dialysis treatment, patients are expected to comply with medication, and with dietary and fluid restrictions (Krespi *et al.*, 2004). However, compliance with treatment plans has been identified as a major problem (Kaptein *et al.*, 2009).

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Tsay and Hung (2004) showed that 33–50% of haemodialysis patients were non-adherent with treatment regimens, resulting in suboptimal dialysis therapy and increased morbidity and mortality (Loghman-Adham, 2003).

Krespi *et al.* (2004) reported that one reason for poor adherence to treatment is a lack of sense of ownership. Haemodialysis patients in their study described treatment guidelines as externally imposed, frustrating rules that could be avoided. Indeed, haemodialysis patients wanted more involvement in their own care and to maintain control of their lives (Linqvist *et al.*, 2000; Thorne *et al.*, 2000). Curtin *et al.* (2002) found that all long-term dialysis survivors reported active self-management as the key to their success in living a long and healthy life on dialysis.

Self-management is defined as: "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition … to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life" (Barlow *et al.*, 2002, p. 178). While traditional patient education offers information and technical skills, self-management education teaches problem-solving skills; patients continually monitor symptoms, and can use action plans to solve problems in order to achieve goals (Bodenheimer *et al.*, 2002; Lorig & Holman, 2003).

There is strong evidence of the positive effect of self-management in a wide range of chronic diseases (Lorig *et al.*, 2006), which suggests that self-management interventions in haemodialysis may also be beneficial (Kaptein *et al.*, 2007). However, there is limited research in the effect of self-management intervention among haemodialysis patients (Kaptein *et al.*, 2007; Tsay & Hung, 2004). The National Kidney Foundation Kidney Disease Outcomes Quality Initiative (NKF KDOQI) (National Kidney Foundation, 2010) suggested self-management in ESRD is an important field for future research.

The Flinders Program of Chronic Condition Self-management (Flinders Program) is a structured program providing a consistent, reproducible approach to assess self-management behaviours, identify problems, set goals and develop care plans (Flinders Human Behaviour & Health Research Unit, 2010). It involves the application of the Partners in Health (PIH) Scale and the Cue & Response interview (C&R) to identify patients' self-management skills and problems. The patient and health care provider collaboratively set goals and care plan with the Problem & Goals (P&G) assessment and Self-management care plan.

The Flinders Program has been extensively researched among diabetes, arthritis and COPD patient groups (Flinders Human Behaviour and Health Research Unit, 2013). Smitham and Lawn (2010) have used motivational interviewing; however, to date there has been no study reported using the Flinders Program among haemodialysis patients.

The aim of this study was to investigate the effect of the Flinders Program at improving self-management as measured by: number of visits to primary health care services related to management of kidney disease, self-management skills, quality of life and dialysis clinical outcomes.

Method

This study was a 24-week longitudinal study involving provision of the Flinders Program to patients attending the haemodialysis unit at Latrobe Regional Hospital. All participants were assessed at entry and completion of the intervention period. This study received approval from the Latrobe Regional Hospital Human Research Ethics Committee.

Subjects

Adult patients attending regular haemodialysis who met the inclusion criteria were invited to participate in the study. Participation was voluntary.

Inclusion criteria were: all adult patients diagnosed with ESRD and treated as an outpatient with haemodialysis for at least three months, with the ability to read and write in English, who provided informed consent. Patients hospitalised with an acute illness or with a concurrent psychiatric disorder and those patients unable to give consent were excluded.

A power analysis suggested that there were insufficient patients attending the dialysis unit (n=36) to run a randomised controlled trial with a reasonable probability of achieving statistically significant changes in scores on the outcome measures. The study design of choice was, therefore, a pre- and post-intervention assessment of participants. Rather than achieving statistically significant changes in group scores, the interest was in the number of participants that achieve a minimum clinically important change in their score on each measure, defined as a change of half of the standard deviation of the group mean score at commencement (Norman *et al.*, 2003).

Intervention

In the initial contact, participants completed the Kidney Disease and Quality of Life — Short Form (KDQOL™-SF) (Kidney Disease Quality of Life Working Group, 2010). A care plan was developed by implementing the Flinders Program. The assessment tools used in the Flinders Program were the PIH

(12 self-rated domains with a nine-point likert scale, 0=the best response to 8=the worst response) the C&R, (dialogue between patient and health professional) a P&G assessment and a care plan.

During the care planning process, needs were identified and referrals made to the multidisciplinary team and services as required. The researcher reviewed the care plan and monitored progress with participants every six weeks.

Data collection

At the commencement and conclusion of the study, participants completed the KDQOL-SF and PIH for evaluation of quality of life and self-management skills. The KDQOL-SF (Hayes *et al.*, 1995) was used to determine scores of three summary measures of health-related quality of life: Mental Component Summary (MCS), Physical Component Summary (PCS), and Kidney Disease Component Summary (KDCS). Clinical data including: routine monthly blood results (potassium, phosphate, albumin, parathyroid hormone [PTH] and urea clearance), average interdialytic weight change, post-dialysis mid-week weight and pre-dialysis mid-week standing blood pressure were collected throughout the study period. The same data, collected in the three months pre-intervention were averaged to give pre-intervention scores. These data are part of usual care.

Data analysis

The analyses of interest were the amount of change in scores from baseline for the PIH Scale and KDQOL-SF, and the number of patients who achieved a change equivalent or greater than the minimally important clinical difference, defined by Norman *et al.* (2003) as half a standard deviation of the mean score for the group at baseline. This has been selected instead of focusing on the results of paired sample t-tests (or the appropriate non-parametric equivalent), because of the small number of available participants.

For other measures, the analysis focused on the number of participants maintaining a value within normal range over the last six weeks of the program. McNemar's test was used to assess the statistical significance of the number of participants who were normal/outside normal (stable/unstable) in PTH at the start of the program, compared to the number who were normal/outside normal at the conclusion. Paired sample t-tests were used to compare the amount of time participants had normal blood values for potassium, phosphate and albumin.

All data analysis was undertaken using SPSS version 19 (2012).

Results

Thirty-six patients attended Latrobe Regional Hospital Dialysis Unit during September 2010. Out of 29 eligible patients, 13 patients gave consent to participate in this project. All participants completed the study. The baseline characteristics of the participants are shown in Table 1.

Table 1: Participant characteristics at baseline

Number of patients	13
Mean age in years (SD)	65.3 (14.2)
Gender: male/female	7/6
Living situation: live alone/live with family or friend	7/6
Level of education: primary/secondary/tertiary	4/6/3
Transport availability: Own transport	3
Transport provided by family/friend	3
Transport provided by volunteer driver	7
Mean number of co-morbidities (SD)	6.3(1.9)
Mean number of medications (SD)	10.5 (3.8)
Mean duration of dialysis in months (SD)	20.3 (14.3)
Experience of peritoneal dialysis:Yes/No	3/10

Quality of life — KDQOL–SF scores

Baseline scores for the KDQOL-SF were compared with other studies that had used the same scale (Table 2). All components of the KDQOL-SF are scored between 0 and 100, with a higher score indicating a better quality of life. After the intervention, MCS and total KDCS were improved (Table 3).

Participants rated their self-management skills in the beginning and at the end of the intervention with PIH. Each item of the PIH is scored between 0 and 8, with a lower number indicating more active involvement in self-management of health. Results and changes from pre- to post-program are shown in Table 4.

Primary health care services involvement

The number of allied health services accessed increased from 1.1 (1.7) to 2.0 (1.9) ($p = 0.053$). The correlation between change in health care service access and change in self-management skills (as assessed by PIH scores) was assessed using Spearman's *rho* (Table 5) and the correlation with health-related quality of life (as assessed by the KDQOL-SF) was assessed using Pearson's

r (Tables 6a and 6b). Improvements in self-management gave lower PIH scores, whilst increased use of services resulted in a higher number of appointments. Negative correlations show the areas where an improved PIH item score was associated with a greater use of health services.

Clinical outcomes

There was significant improvement in interdialytic weight changes and management of systolic blood pressure (Table 7). There were no significant changes in blood results (potassium, phosphate, albumin, PTH and urea clearance). However, every participant made a clinically important improvement in at least one measure.

Discussion

Krespi *et al.* (2004) suggested that one of the reasons for poor

Table 2: Comparison of the KDQOL™-SF mean scores in different dialysis populations

	MCS	PCS	KDCS			
			Symptoms/ Problems	Effects of kidney disease	Burden of kidney disease	Total score of KDCS
Latrobe Regional Hospital (pre-intervention)	42.9 (13.1)	42.7 (10.0)	71.5 (16.1)	63.0 (30.7)	50.0 (29.0)	61.5 (23.1)
United States (Mapes *et al.*, 2003)	46.5 (11.8)	32.7 (10.6)	-	-	-	63.2 (13.7)
Europe (Mapes *et al.*, 2003)	42.7 (11.8)	35.5 (10.5)	-	-	-	62.8 (12.5)
Japan (Mapes *et al.*, 2003)	44.5 (11.5)	41.7 (9.0)	-	-	-	65.5 (11.8)
Korea (Park *et al.*, 2007)	-	-	76.7 (16.7)	67.3 (19.1)	28.3 (23.5)	-
Philippines (Bataclan & Dial, 2009)	-	-	77.0 (8.3)	77.5 (8.9)	45.0 (37.9)	-
Netherlands (Korevaar *et al.*, 2002)	-	-	76.4 (16.1)	74.7 (18.6)	47.3 (25.6)	-
UK (Carmichael *et al.*, 2000)	-	-	69.9 (20.7)	42.8 (17.3)	79.3 (20.2)	-

Note: All scores are mean (SD)

Table 3: MCS, PCS and the KDCS scores

	Pre-intervention	Post-intervention	p	Mean change	Number of patients with clinically important positive change
MCS	42.9 (13.1)	48.0 (11.0)	0.184	5.1 (12.5)	4
PCS	42.7 (10.0)	41.8 (9.5)	0.709	–0.8 (7.36)	2
KDCS — Symptoms/ problems	71.5 (16.1)	72.6 (17.5)	0.807	1.0 (14.4)	4
KDCS — Effects of kidney disease	63.0 (30.7)	69.5 (28.7)	0.099	6.5 (12.5)	3
KDCS — Burden of kidney disease	50.0 (29.0)	55.7 (33.4)	0.523	5.8 (30.1)	1
KDCS — Total score	61.5 (23.1)	65.9 (25.0)	0.334	4.4 (15.2)	4

All scores are mean (SD)

Table 4: Mean PIH scores pre- and post-intervention

PIH item	Pre-intervention	Post-intervention	p	Mean change	Number of patients with clinically important improvement
Knowledge of condition(s)	4.4 (2.6)	4.3 (2.8)	0.782	–0.2 (2.0)	2
Knowledge of treatment	4.2 (2.4)	4.9 (2.4)	0.145	0.8 (1.7)	0
Ability to take medication and carrying out treatment	7.0 (2.2)	7.2 (2.0)	0.674	0.2 (1.3)	1
Involvement in decisions about my health	4.7 (3.3)	6.0 (3.0)	0.180	1.3 (3.2)	1
Ability to access services	5.6 (2.4)	6.0 (3.0)	0.596	0.4 (2.6)	2
Attending appointments	6.9 (2.5)	6.9 (2.5)	1.000	0.0 (3.2)	1
Understanding and checking early warning signs and symptoms	6.1 (2.5)	3.3 (3.7)	0.029	-2.8 (3.9)	7
Managing early warning signs and symptoms	7.0 (1.8)	6.1 (3.0)	0.438	–0.9 (3.9)	5
Ability to manage the impact of the condition on my physical activities	5.9 (2.2)	5.6 (2.6)	0.474	–0.3 (1.6)	2
Ability to manage the emotional aspects of my life	5.8 (1.8)	5.8 (2.1)	0.891	–0.1 (2.1)	3
Ability to manage the social aspects of my life	5.3 (2.6)	6.5 (2.3)	0.111	1.2 (2.3)	1
Progress towards adopting habits that improve my health	6.4 (1.6)	6.2 (2.5)	0.775	–0.3 (3.0)	3
Average PIH score all items	5.8 (1.4)	5.8 (1.6)	0.846	-.1 (1.1)	5

Note: All scores are mean (SD)

Table 5: Correlations between change in allied health input and change in PIH scores

	Number of health care appointment	Number of allied health appointment	Number of community rehabilitation admission
Average PIH score	–0.256	–0.253	–0.331
Q1: Knowledge of condition(s)	–0.353	–0.469	–0.306
Q2: Knowledge of treatment	0.010	–0.132	–0.211
Q3: Ability to take medication and carry out treatment	0.280	0.282	0.640★
Q4: Involvement in decisions about my health	–0.480	–0.594★	–0.482
Q5: Ability to access services	–0.595★	–0.712†	–0.515
Q6: Attending appointments	–0.701★	–0.677★	–0.580★
Q7: Understanding and checking early warning signs and symptoms	0.018	0.055	–0.140
Q8: Managing early warning signs and symptoms	0.248	0.291	0.168
Q9: Ability to manage the impact of the condition on my physical activities	0.151	–0.128	0.100
Q10: Ability to manage the emotional aspects of my life	0.491	0.525	0.358
Q11: Ability to manage the social aspects of my life	0.078	–0.279	0.167
Q12: Progress towards adopting habits that improve my health	–0.256	–0.166	–0.331

★: $p < 0.05$

†: $p < 0.01$

Table 6a: Correlations between change in allied health input and change in KDQOL scores

	Dietitian	Physio-therapist	Occupation-al therapist	Social worker	Speech pathologist	Allied health assistant	Number of allied health appoint-ments
SF-12 — PCS	0.148	–0.108	–0.219	–0.047	–0.508	0.221	–0.042
SF-12 — MCS	0.371	0.408	0.432	–0.047	0.264	0.340	0.364
KDQOL — Symptoms	0.087	0.027	0.134	0.301	–0.068	0.080	0.157
KDQOL — Effects of kidney disease	0.370	0.531	0.509	0.467	0.242	0.409	0.587★
KDQOL — Burden of kidney disease	0.756†	0.685★	0.624★	0.151	0.125	0.763†	0.709†
KDCS	0.025	0.629★	0.607★	0.595★	0.323	0.128	0.701★

★: p <0.05 †: p ≤0.01

Table 6b: Correlations between changes in number of health services accessed and change in KDQOL scores

	Number of health care appointments	Number of allied health services accessed	Number of community rehabilitation admission
SF-12 — PCS	–0.052	0.144	–0.017
SF-12 — MCS	0.387	0.257	0.215
KDQOL — Symptoms	0.166	0.436	0.270
KDQOL — Effects of kidney disease	0.618★	0.568	0.631★
KDQOL — Burden of kidney disease	0.724†	0.592★	0.542
KDCS	0.680★	0.686★	0.617★

★: p <0.05 †: p ≤0.01

Table 7: Changes in interdialytic weight and blood pressure pre- and post-intervention

	Pre-intervention	Post-intervention	p value	Mean change
Interdialytic weight changes (kg)	1.49 (0.85)	1.41 (0.55)	0.683	–0.08 (0.68)
Percentage of patients with <2 kg weight gain between dialysis session	37.1 (4.9)	62.9 (4.9)	<0.001	
Systolic blood pressure (mmHg)	158.2 (18.7)	151.9 (18.6)	0.035	–6.271 (9.54)
Normal SBP%	19.2 (23.4)	26.9 (28.4)	0.291	
Diastolic blood pressure (mmHg)	77.7 (11.4)	76.3 (10.6)	0.114	–1.442 (3.05)
Normal DBP%	23.1 (17.7)	25.0 (19.3)	0.678	

All values are mean (SD)

adherence is a lack of sense of ownership. Indeed, haemodialysis patients wanted more involvement in their own care and to maintain control of their lives (Linqvist *et al.*, 2000; Thorne *et al.*, 2000). During the intervention, participants identified their issues using the Flinders Program tools. Care plans were developed with participants, based on their goals. These care plans were different to their routine care plans, which were developed by nursing staff, based on the individual's dialysis care needs.

After the program, all aspects of the KDQOL–SF component summary scores were improved. One-third of participants made clinically important improvement in MCS and KDCS — effects of kidney disease. Initial measures of MCS were low compared to data from international studies (Table 2); however, the post-intervention MCS of our group (Table 3) improved to be higher than shown in data from other studies.

There was no statistically significant change in self-management behavior as measured by change in PIH scores. However, more than one-third of participants made a clinically important improvement in "understanding and checking early warning signs and symptoms", "managing early warning signs and symptoms" and their overall average PIH scores (Table 4).

In terms of clinical outcomes, since the average blood results were within normal range prior to the intervention, instead of comparing the absolute value of pathology results pre- and post-intervention, it was more meaningful to compare the percentage of time in which blood results fall in the normal range. There were improvements in the amount of time that phosphate and albumin levels were within the normal range. The statistically significant increase in the percentage of patients with less than 2L fluid gain between dialysis sessions suggests a better adherence to fluid restriction. In addition, systolic blood pressure was statistically significantly improved. The percentage of patients with normal systolic blood pressure and diastolic blood pressure were also increased. These changes suggest an improvement in compliance with treatment plans.

A major part of self-managing chronic illness is knowing when and where to find resources and services for assistance (Lorig *et al.*, 2006). A systematic literature review showed that a multidisciplinary team approach results in better clinical outcomes (Black *et al.*, 2010). In this patient sample there was a clinically important increase in the number of allied health services accessed following the implementation of the Flinders Program. This increase is correlated to a better health-related quality of life as shown in the improved KDCS in the sub-scales of Burden of kidney disease and Effects of kidney disease. The Community Rehabilitation Service is a goal-orientated and interdisciplinary service. The increase in community rehabilitation services accessed was moderately correlated to higher scores in Effect of kidney disease, and overall KDCS. Among all the allied health services accessed, the increased involvement of dietitian, physiotherapist, occupational therapist and allied health assistant were moderately to strongly correlated to the improved KDCS (Table 6a).

Considering the participants attend the dialysis unit three times per week, with substantial treatment time, attending additional appointments places an extra burden on participants. Accessing additional services becomes difficult within the health services' working hours. Incorporating therapy and consultation during dialysis treatment when feasible may relieve the time spent on attending appointments. However, the health service would need to support the provision of additional services, particularly during evening dialysis sessions.

Limitations

This study involved patients attending the dialysis unit at Latrobe Regional Hospital. Since there were insufficient patients to run a randomised controlled trial, a pre- and post-intervention assessment was conducted. The small number of participants in this study is a significant limitation. There may be a bias towards participants who were better at self-managing their health and being willing to take part in this study. Those who did not participate were not asked for a reason.

This study shows that the implementation of the Flinders Program resulted in improvement in some clinical outcomes, various areas of self-management skills and kidney disease quality of life. Kidney disease is a complex medical condition. Curtin *et al.* (2002) stated that due to the serious morbidity episodes, it is difficult to maintain the status quo in kidney failure and make progress towards goals. Our participants had a poor physical health as reflected by a higher number of co-morbidities compared to other studies, lower pre-intervention mental health component score and kidney disease component score. In addition, with a short duration of the program, significant changes are difficult to achieve. Therefore, the study focused on results that reflect clinically important levels of positive change.

A six-weekly review was conducted as part of this study to monitor participants' progress and motivate them to improve self-management skills across the duration of this study. The sustainability of the Flinders Program without a regular review is unknown. There was no dropout in this study. However, the acceptability and feasibility of this approach among haemodialysis patients from the perspective of patients and staff is unknown.

Recommendations

In order to assess the sustainability of the Flinders Program it would be useful to have a six-month review of the status of participants. A randomised controlled trial with a large sample size is needed to further investigate the efficacy, acceptability and feasibility of the Flinders Program. Based on the amount of changed achieved in KDQOL–SF score in this pilot study, the approximate sample size needed to be likely to find real changes at 80% power and an alpha of 0.05 is 74 participants. This may need to be a multi-centre trial to gain sufficient participants to have a reasonable expectation of being able to achieve statistically significant changes.

Conclusions

This study showed that the implementation of the Flinders Program and development of a care plan with patients significantly increased the access of participants to allied health services. Improvements were identified in: urea clearance, blood pressure, quality of life and aspects of self-management skills, along with decreases in fluid retention.

Importantly, every participant made a clinically important improvement in at least one measure.

Abbreviations

C&R Interview	Cue and Response interview
ESRD	End-stage renal disease
KDCS	Kidney Disease Component Summary
KDOQI	Kidney Disease Outcomes Quality Initiative
KDQOL-SF	Kidney Disease and Quality of Life —Short Form
MCS	Mental Component Summary
NKF	National Kidney Foundation
PCS	Physical Component Summary
P&G Assessment	Problem and Goals Assessment
PIH Scale	Partners in Health Scale
PTH	Parathyroid hormone

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