Rehabilitation services for patients undergoing peritoneal dialysis in Hong Kong


Abstract

Aim To examine whether rehabilitation services are provided to patients undergoing peritoneal dialysis in Hong Kong, and the impact of such services on patients’ lives.

Method Semi-structured interviews were conducted with 30 participants. Transcripts were analysed using thematic content analysis. Categories and codes were identified from the first 21 interviews, but questioning continued throughout the process to saturate the categories.

Findings Rehabilitation is not provided to patients undergoing peritoneal dialysis in Hong Kong. Most support services are initiated by patients themselves.

Conclusion To enable these patients to lead productive lives, efforts should be made to provide them with the required medical information to help them make choices. Nurses should provide appropriate training to peer counsellors and regular exercise should be encouraged to allow patients to maintain physical health and mobility. Counselling on finding a purpose through other roles is beneficial for those who cannot return to work.

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Keywords

Dialysis; Kidney disorders; Quality of life; Rehabilitation

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PATIENTS WHO perform peritoneal dialysis are now expected to take more responsibility for the treatment of their illness. This shift in the provision of care from medical staff to the patient can be effective only if the patient is concordant with the treatment regimen.

For optimal physiological and psychological recovery, rehabilitation programmes complement traditional patient education in helping patients maintain or improve their health and will aid their transfer from the predialysis stage to maintenance dialysis (Lorig et al 1999).

The study reported in this article was the first to investigate the availability of rehabilitation services for patients undergoing dialysis in Hong Kong. The findings will help nurses determine how to improve existing rehabilitation services for dialysis patients.

Literature review

End-stage renal disease is a chronic condition in which the kidneys can no longer regulate electrolytes and the acid-base balance, and excrete waste products and water from the blood. Although haemodialysis and peritoneal dialysis are life-saving treatments, they are only partial replacements for the excretory function of the kidney. Patients are faced with complicated and demanding treatment regimens that include dietary and fluid restrictions, and medication schedules. Prolonged survival in patients with end-stage renal disease is associated with various functional disorders in almost all body systems. This has a negative effect on the patient’s quality of life.

In Hong Kong, haemodialysis is usually undertaken by nurses in a health centre while peritoneal dialysis is undertaken by patients at home. As the pressure to control hospital costs has intensified, the need to deliver the best nursing
care in the most economical way has increased. In a study by Lindqvist and Sjöden (1998), quality of life was perceived as being below average by both groups of patients receiving in-centre haemodialysis and home peritoneal dialysis, although the latter reported a higher quality of life than those receiving haemodialysis. Peritoneal dialysis is the treatment modality preferred by patients. A study of 120 patients with experience of haemodialysis and peritoneal dialysis found that, when given the opportunity to choose, 92 patients listed peritoneal dialysis as their first choice. The reasons given were that this treatment allowed them more free time and more freedom, improved their wellbeing and was less troublesome. They did not like having an arteriovenous fistula implanted and being bound to the haemodialysis machine (Galpin 1992).

In-centre haemodialysis treatment is more expensive than home peritoneal dialysis. In March 2005, the Central Renal Committee in Hong Kong reported that the average amount spent per patient annually on haemodialysis was £17,143 pounds compared with £7,143 pounds for peritoneal dialysis (Judith Siu, access to information officer, Hospital Authority, Hong Kong, 2005, personal communication). Patients are increasingly required to administer treatment themselves using peritoneal dialysis. This shift in the provision of care from medical staff to the patient is seen as a viable way of controlling rising healthcare costs. In March 2005, the Hospital Authority, the health body in Hong Kong, saw 3,200 peritoneal dialysis patients, while those receiving haemodialysis numbered only 690 (Judith Siu, access to information officer, Hospital Authority, Hong Kong, 2005, personal communication).

Dialysis is a crucial treatment on which a patient’s life depends. In transferring treatment from the hospital to the home, it must be considered whether patients can adapt to the intrusions on daily life caused by the treatment. Peritoneal dialysis requires patients to repeatedly instil and drain sterile dialysate through an implanted catheter into their peritoneum. Physicians can prescribe peritoneal dialysis using manual exchanges of dialysate fluid (continuous ambulatory peritoneal dialysis) three to four times per day, or automated exchanges in which a cycler is used to fill and drain the peritoneum with dialysate fluid every night (continuous cycling peritoneal dialysis) (Rubin et al 2004). By contrast, haemodialysis is only performed two to three times weekly in a dialysis centre for three to four hours. The non-stop nature of peritoneal dialysis makes it more difficult for patients to separate their treatment from the time when they are not receiving treatment. The large volume of fluid contained within the abdominal cavity may be a concern for some patients. Without the direct supervision of staff, patients receiving peritoneal dialysis need to make day-to-day decisions about the management of their illness, and set and maintain their own dialysis schedules. This can be frightening and depressing for some patients (Luk 2002).

If the patient has the ability to control his or her own treatment and is willing to follow the treatment regularly, this should have a positive effect on his or her psychological adjustment to the illness while saving medical resources. If the patient views the responsibility for such crucial treatment as a burden and cannot cope with it, he or she will return and require more expensive treatment in hospital (Luk 2002).

The successful transfer of patients to receive dialysis at home demands that they have sufficient knowledge, skill and ability to carry out their treatment regimen. To ensure that this is the case, a rehabilitation programme is an essential aspect of health care. Klang et al (1998) assessed the physical capacity, nutritional status and psychosocial needs of dialysis patients after they had undergone a rehabilitation programme. Patients who had participated in the programme had fewer disabilities in function and mobility, were happier and experienced less loneliness and lower levels of anxiety than the control group. A better psychological status empowered patients to participate in their healthcare decisions and enabled them to better understand and control disease-specific symptoms.

Aim

The study aimed to examine whether rehabilitation services are provided to patients undergoing peritoneal dialysis in Hong Kong, and the effect such services may be having on patients’ lives.

Ethical approval

The ethics committee of Hong Kong Polytechnic University granted ethical approval for the research. Before the recorded interviews, all of the participants were informed of the purpose of the study, and of the way the data would be collected and transcribed. Confidentiality and the right to withdraw from the study were guaranteed.

Method

The Hong Kong Hospital Authority provides dialysis services in ten hospitals. Each hospital...
has a renal club, which is run voluntarily by dialysis patients who are treated in that hospital. Members of each club are the patients receiving peritoneal dialysis and haemodialysis at that hospital. Together, these ten renal clubs form the Alliance for Renal Patients Mutual Help Association.

Since each club represents patients of a regional public hospital, to enhance the representativeness of the study, members of each club were invited to participate in the study, using a convenience sampling method.

The selection criteria were that all participants should be Chinese adults with the cognitive ability to read and understand Chinese. They must currently be receiving peritoneal dialysis and have been doing so for at least one month. Those who met the eligibility criteria were first approached by the administrator of the association, and received an information sheet about the project. The administrator approached 40 patients and 33 (about three from each club) agreed to participate in the study.

The researcher then telephoned these 33 patients and provided a second detailed explanation of the purpose and nature of the study. A total of 30 patients (75 per cent) gave their consent for the study, while three refused to participate because of fatigue.

For the sake of convenience, most patients preferred to be interviewed by telephone. Data obtained from telephone interviews have been deemed to be as reliable as data obtained from face-to-face interviews (Samarel et al 1998). Open-ended questions were used, for example, do you have any rehabilitative support, who provides this support and what do you think about your psychological status in relation to the support you are receiving. To put participants at ease, the researcher developed rapport by speaking in a natural, conversational tone. To prompt reflection or expansion, probing techniques for clarification were used.

The goals of rehabilitation are to promote independence and self-care, and to maximise feelings of self-determination in patients. Rehabilitation involves the management of disability and restoration of roles from a physical, psychosocial and vocational perspective (Pryor and Smith 2002). Thus, participants were invited to explore and elicit information about their life experiences in these areas. They were also asked to report on what kind of rehabilitative support they were receiving, and who was providing that support.

The participants were free to discuss other issues related to the research topic. A pilot study was first conducted with two patients. Closed questions were used to gather demographic information. The questions were on gender, age, marital status, educational level, length of time on dialysis, income level and health status.

Data collection and analysis were simultaneous and continuous. As the number of participants interviewed increased and the data were concurrently analysed, subsequent questions were derived from the emerging responses to further explore the participants’ unique experiences (Tilden et al 2001), for example, whether economic status affected participation in exercise. The interviews progressed until no new insights emerged, indicating that the point of saturation had been reached.

To obtain meaning and understanding, thematic content analysis was applied to the narrative text (Burnard 1991). Thematic content analysis is an interpretative process whereby the researcher identifies, codes and categorises the descriptive data (Graneheim et al 2001).

Guided by the aim of the study units of meaning, a word, sentence or paragraph that reflected meaningful aspects of the experiences, were coded. Most of the categories were identified from the first 21 interviews after multiple analyses of the transcripts, but questioning continued throughout the process in order to saturate the categories (Glaser and Strauss 1979).

**Findings**

Of the 30 participants, 13 were male and 17 were female. The participants ranged in age from 29 to 70 years, with a mean age of 49.6 years. Three were widowed, 22 were married and the remainder were either divorced or had never married. Nineteen had completed a secondary level of education, while the others were educated to primary level. All of the participants either did not have a job or had retired. The mean number of years during which the participants had undergone dialysis was 8.3, with a range of 1 to 14. Eight commented that their health status was worsening, 14 said that it was static, and eight felt that it was fluctuating.

The interviews lasted between 45 and 80 minutes, but most were about 60 minutes. Table 1 lists the categories derived from the interviews. The underlying dimensions that emerged from the interview texts are described below.

**Rehabilitation support received** The participants recalled that before they were discharged for home peritoneal dialysis, the hospitals arranged a training programme lasting between five to 14 days. The main purpose of the training programme was to equip them and/or their caregivers with the skills to perform dialysis. Follow-up home visits were only arranged for those with problems related to performing the dialysis, for example, those with
a high recurrence of peritonitis. All of the participants commented that apart from the training programme, little support was provided by the hospital. Health institutions seldom organised health talks. All of the participants said that if they had problems, they could make enquiries at the ward. The participants commented that the staff were helpful and informative. References to staff characteristics included: ‘The staff were knowledgeable and enthusiastic’ (Participants 2, 4, 8, 10, 13, 14, 17, 20, 22, 26 and 28).

However, all of the participants said that they usually sought answers from other patients. The tendency for them to first seek help from their peers rather than from staff was because their peers could give them more practical information to deal with issues of daily life, since ‘...they are in the same boat’ (Participants 4, 6, 7 and 10). **Support for informational needs** All participants said that they usually sought answers from other patients. For example, on the day of follow-up they sought the advice of their peers at the service counter organised by the renal club to which they belonged and which was run by patient volunteers, or they spoke to other patients when queuing for the follow-up consultation.

All of the participants said that health talks were occasionally organised by the renal clubs. Comments indicated that they were satisfied with the talks, for example: ‘I had a chance to learn’ (Participant 1), and ‘The session was very informative’ (Participants 3, 8, 10 and 14). However, on questions related to diet, all of the participants preferred to seek advice from their peers rather than from a dietician or nurse. Their comments included: ‘If I followed their advice, I would have nothing to eat’ (Participants 3, 4, 7, 10, 11, 13, 17, 20 and 21).

**Support during psychological crises** The participants said that the renal clubs regularly arranged activities such as visits to wards and social meetings to provide psychological support for new patients. During the activities, patients volunteered to share their experiences with new patients. Sometimes, ad hoc support was provided to worried patients referred by staff or social workers.

Twenty-three participants recalled the counselling support as being helpful: ‘I can discuss the problem more with people with similar health problems, since they have been there too’ (Participant 3). Nevertheless, these activities were not always well accepted. Three participants said: ‘I do not share with others, nobody can help’ (Participants 4, 7 and 9). Two reported that: ‘It is not so easy to talk with strangers; one cannot be too open’ (Participants 4 and 7). Formal counselling was suggested by three participants: ‘I would like to seek support from a well-trained professional, like a clinical psychologist’ (Participants 9, 11 and 14).

**Support for physical and social integration** Although general fatigue was reported by all participants, to improve their social integration, the majority tried to participate in activities that were occasionally arranged by the renal clubs or by the patients themselves, such as spring festival party, annual celebration, autumn outing, annual dinner, day camp, night camp, group dinner, sports meeting, charity walk and cuttle fishing.

Twenty participants described themselves as physically active. They performed exercises and/or participated in recreational activities at least twice a week, for example, swimming, strolling, jogging, ping pong, dancing, t’ai chi or qi gong, lawn bowling, bush walking and calisthenics. Of these, five reported engaging in exercise three or more times per week, for 30 minutes to three hours each time. The habit of exercise was begun one to six years ago.

**Impact of rehabilitation support on patients’ lives** Psychological status To pass the time,

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majority of participants were involved in voluntary work to offer support to other patients in need. Five participants were peer counsellors. Fifteen ran the non-profit counter, which sold accessories to patients receiving dialysis, for two hours per week on the follow-up day. Seven helped with shopping for patients who were very ill. Home visits to other patients were seldom undertaken. The reason was that ‘not so many people like to be visited at home’ (Participants 2 and 7).

The participants concluded that the volunteer work increased their personal growth and wellbeing. Twenty participants said that by helping others to deal more effectively with problems in their lives, they also benefited: ‘One way to enhance the zest for living is to extend a helping hand to others’ (Participant 12). They increased their levels of self-confidence, enthusiasm for life, feelings of goodwill towards others and social interactions. Ten participants said: ‘I am less home-bound, watch less TV, and go out more often’ (Participants 3, 7, 9, 10, 12, 14, 15, 18, 20 and 21). Eleven reported that: ‘Having the chance to help others, I have the sense that I am making a contribution, and I feel happier’ (Participants 5, 7, 8, 11, 12, 14, 16, 17, 18, 20 and 21).

However, while the experience of being a volunteer was rich and rewarding for most, some of the encounters could have a negative effect. Four participants commented: ‘I was very down when I was dealing with the deterioration in health and finally the death of one peer patient whom I had been helping devotedly’ (Participants 4, 7, 11 and 13).

**Physical, social and financial integration** All participants viewed the maintenance of an energetic and social life as a means to ward off stress and loneliness. The participants commented that exercise was a way to stay fit as well as a way to enhance wellbeing: ‘I feel less fatigued’ (Participants 3, 9, 14, 17 and 18). They reported feeling rejuvenated and healthy after undergoing these activities: ‘I feel more relaxed, less bedridden and sick’ (Participants 3, 9, 14, 17 and 18) and ‘I walk faster’ (Participants 3, 9, 14, 17 and 18). The activities were not only helpful for their physical strength, but also for social integration: ‘Practising t’ai chi every morning in the park, I can have a regular chance to breathe fresh air. The whole team usually goes to a tea house afterwards to have dim sum. This is fun. Before, I just spent time sleeping at home’ (Participant 18).

Three of the participants had changed their exercise habits. They attributed their progressive reduction in capacity for exercise to the worsening of their health. One stopped practising t’ai chi because he was not physically strong enough to continue. Two adopted less rigorous exercises, from playing ping pong to gate ball (derived from croquet), because of progressive weakness. Three stopped exercising completely because of newly developed physiological problems: two contracted cancer and one had palpitations. Because they were repeatedly hospitalised, they exhibited less of an ability to recover after each episode of inactivity: ‘I found it very hard to rebound after being bedridden’ (Participant 27). Four had never exercised regularly before and after the dialysis became progressively trailer and eventually confined to home.

The patients’ activities were not only affected by their functional level, but also by their financial status. They had no income. All of them were unemployed, except one who was running his own business but claimed to have made no money so far. Their financial difficulty was an obstacle for them to perform physical activities in a group. For example, the t’ai chi class depended on the availability of a volunteer tutor and a subsidised venue. These factors are difficult to control. The participants also indicated that the expense of travelling to and from the venue was another concern.

**Discussion**

The Hong Kong Hospital Authority does not provide rehabilitation for patients receiving dialysis. Perhaps this is because the disabilities of these patients are relatively invisible compared with the motor deficits associated with paraplegia or stroke. Patients initiate most support services. Little has been done by hospital staff to enable patients to manage chronic diseases long term. The reported level of rehabilitation is far from acceptable.

Patients undergoing peritoneal dialysis are expected to have the discipline to pay close attention to the details required to perform dialysis at home. Such an expectation can cause patients significant stress. To enable these patients to lead reasonably productive lives, it is essential that they are encouraged from the outset to gain control of their lives and to confront and solve some of the problems associated with chronic illness. Teng et al. (2003) stated that as soon as the patient returns home, the government should provide rehabilitation services. This fulfils the aim of a ‘seamless health care system’ promoted by the hospital authority (Hong Kong Hospital Authority 2000).

Lorig et al. (2001) argued that rehabilitation programmes are beneficial for patients. The hospital authority should integrate rehabilitation into the treatment programme. To conduct a successful rehabilitation programme, healthcare
staff should recognise the problems that patients experience, understand and meet their expressed needs and respect their feelings when they are discharged to the community. The following complex concerns revealed in the present study should be considered in the planning of a rehabilitation programme.

To promote the self-care, self-determination and independence of patients, the training programme provided by hospitals should not only focus on giving patients the requisite knowledge of dialysis, but also the ability to cope with other aspects of their condition. For example, regarding dietary restrictions, Chinese people consider eating an important part of life. Many idioms reflect the importance of eating in Chinese culture, for example, the saying that eating is every person’s first priority, a Confucian saying that eating and sex are the most natural of human activities and a Cantonese saying that one works hard for good food (Luk 2001). When recommending a therapeutic diet for patients undergoing dialysis, nurses should attempt to provide advice on a diet regimen that is practical and realistic.

The peer counselling discussed in the present study brought together new patients and those already undergoing treatment. The patients shared their emotions and supported each other, and learnt practical tips about self-care from experienced peers. A similar finding was reported in Brunier et al’s (2002) study. Brunier et al (2002) stated that renal peer support volunteers possibly improved their own wellbeing by helping others with chronic renal failure. One concern is that if peer counsellors do not receive appropriate training, they may not have the skills to deal with the tensions arising during counselling with their peers, as reported in the present study.

Poor physical status and progressively increasing frailty caused by a sedentary lifestyle are common in patients of all ages requiring dialysis (Koufaki et al 2002). Nevertheless, most participants in the present study led active lives, and their physical habits were not correlated to their level of activity before starting dialysis but were determined by their remaining functional ability. This finding differs from that reported in Allen and Gappmaier’s (1997) study, which reported that the physical activity habits of patients undergoing haemodialysis could be predicted based on activity habits before starting haemodialysis.

Regular exercise is important in enabling a patient to maintain physical health and mobility. Fitness can increase the ability of patients to take part in activities that previously brought them pleasure, thus reducing feelings of depression and improving their overall psychological functioning (Koufaki et al 2002). The prevention of frailty will also reduce the costs associated with the loss of employment, loss of independence in activities of daily living and increased risk of hospitalisation. By reducing hospital stays, the government will undoubtedly save thousands of dollars.

In the present study, poverty was a hurdle for participants who wished to continue exercising, with a reported 97 per cent unemployment rate. This rate is much higher than that reported in Luk’s (2001) study. The decline in Hong Kong’s economy in recent years has perhaps had a significant effect on this vulnerable group. It is difficult for a patient on dialysis to find a regular job since employers may be reluctant to hire a worker who needs to spend hours each day having dialysis and to take regular leave for medical follow-ups.

The positive effects of participating in an education programme prevailed during the first six months of dialysis treatment, after which they diminished (Klang et al 1998). Comprehensive and ongoing assessments that identify early warning signs of change and inform early intervention to prevent adverse situations are important (Pryor and Smith 2002). For example, staff should regularly re-examine the dialysis technique of patients. Thus, patient education should be ongoing during the predialysis stage and continued after maintenance dialysis has been established.

To ensure positive outcomes from peer counselling, nurses should provide appropriate training for peer counsellors. Thus, while the recipient can benefit from the counselling, the peer counsellor could cope with the negative psychological impact caused by counselling, if any (Pryor and Smith 2002).

Nurses should co-ordinate the input from all members of the healthcare team as well as the family. Their participation will not only provide a chance for them to exchange ideas, but also provide an opportunity for patients and their families to discuss the patient’s physical and psychological condition with health professionals, peer patients and each other (Klang et al 1998).

Working is an important aspect of life for many individuals, helping them to retain the sense of a meaningful existence. Support for retraining and employment is important. Counselling on finding a purpose in other roles is beneficial for those who cannot return to work (Luk 2001).

When earning capacity is affected, the
expenses incurred by exercise represent a tremendous burden to patients. Hospitals should initiate efforts to regularly arrange a regimen of physical activity for patients at their local hospital. It is hoped that this will alleviate the financial burden on patients from having to pay tuition and a venue-booking fee.

Study limitations

Many participants in this study had remained active. When interpreting the results, the researcher had to consider the findings in the light of the convenience sampling method adopted. Those who were willing to be interviewed were probably comparatively fit. Failure to gain access to patients who were confined to home may have excluded those who were not active. Thus, the sampling method reduces the generalisability of the study’s findings.

Conclusion

Hospitals should initiate efforts to provide rehabilitation services for patients undergoing dialysis. The findings of this study will help nurses determine how to improve existing rehabilitation services for patients undergoing continuous ambulatory peritoneal dialysis, especially as the study was the first to investigate the availability of rehabilitation services provided to this group of patients in Hong Kong.

Acknowledgement

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IMPLICATIONS FOR PRACTICE

- Nurses should direct resources to areas where improvements may be required so that patients have a greater chance of leading a life that resembles as closely as possible the one they led before undergoing dialysis.
- This study, although conducted in Hong Kong, has implications for other contexts where rehabilitation is being promoted. The data obtained can provide the basis for further research.

References

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