

The benefits and mechanisms of peer support for people who start dialysis without preparation

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Introduction

Peer support (PS) - the provision of informational and emotional support by people with experience of illness to others sharing the condition – is valued by people with kidney disease (Hughes et al 2009) and can bring about behaviour change (Perry et al 2005). Its use has not been studied among people who start dialysis without preparation. Such individuals experience greater morbidity, mortality, hospitalization, and reduced quality of life. PS might ameliorate some of these disadvantages.

This paper reports a qualitative analysis of interviews conducted as part of a pilot study exploring the feasibility and effects of giving PS to people presenting late to renal services. It was supported by a BRS/BKPA grant and received required ethical approvals.

Methods

All cognitively able individuals starting maintenance dialysis at our Trust between 28/10/17 and 27/10/18 and within 90 days of presentation to kidney services or without attending a preparatory (low-clearance) clinic were invited to participate.

Interventional participants were offered four sessions of PS in the month following dialysis start in addition to standard care. The peer supporters were volunteer patients themselves living with RRT with training in and experience of supporting other patients.

Participants' experiences of starting dialysis without preparation and receiving PS were explored through semi-structured interviews. These were transcribed verbatim. Analysis was performed inductively and guided by Braun & Clarke's six phases of thematic analysis.

Results (See Fig 1 for thematic map)

Nine of the eleven participants who received PS and completed follow-up were interviewed (one died before interview and one declined).

Starting dialysis with little preparation was a negative experience for all participants. Difficulties resulted from its adverse physical and practical impacts, together with feelings of shock and loss of control.

Inadequate delivery and comprehension of information lead to patients having little understanding of what was going on or their options.

The support participants described receiving from peers could be divided into emotional, appraisal, and informational support. For most participants the experience was entirely positive. Elements which made it particularly meaningful and valued were the authenticity of reports from those with lived experience of dialysis and the usefulness of non-verbal information (seeing their supporter looked normal, observing that dialysis wasn't painful, etc). Meeting people who had not just survived but thrived on dialysis gave hope, encouragement, and reassurance, making recipients feel immediately better and more empowered to make a successful life on dialysis for themselves.

'I do not have a life anymore. All my life is just, I feel like I am just repeating a cycle... I feel so worthless... she gave me hope, she gave me the confidence that I needed' (F, 52)

'It wasn't explained to me in layman's terms. That is the big problem... I have learnt more from the patients than I have the medical staff to be honest' (M, 69)

Conclusions

Information from peer supporters is more understandable, authentic, and meaningful than information provided by professionals. PS mitigates some of the difficulties associated with starting dialysis suddenly and should be available to all.