

Renal rehabilitation services within the United Kingdom: protocol for the British Renal Society Rehabilitation Network survey of current practice and perspectives

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Rehabilitation Network (BRS-RN).

Introduction

This protocol describes a planned survey of current rehabilitation provision for renal patients across the UK. Rehabilitation, defined as ‘a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environment’ (World Health Organization, 2011), is gaining increasing recognition as a key component with the management of CKD.

Individuals with CKD often live with multi-morbidity, frailty and have high levels of healthcare utilisation (Caplin et al., 2011, Tonelli et al., 2018). Kidney disease is also associated with reduced mental wellbeing (Abdel-Kader et al., 2009), cognitive impairment (Angermann et al., 2017), bone disease (McNerny and Nickolas, 2017), and muscle wasting which contributes to reduced physical activity and function (Padilla et al., 2008) and consequently an increased risk of mortality and morbidity (MacKinnon et al., 2018). It is also well recognised that some symptoms associated with CKD, particularly fatigue, nausea, and loss of appetite, can lead to

functional deterioration and withdrawal from daily routines and occupations, significantly impacting quality of life (MacKinnon et al., 2018, Bonner et al., 2010) .

Rehabilitation is increasingly being shown to successfully address many of these issues, and yet a survey conducted on behalf of the British Renal Society Rehabilitation Network (BRS-RN) in 2014, highlighted that encouragement with exercise and physical activity for people living with CKD was limited, and access to rehabilitation programmes inconsistent across the UK (Greenwood et al., 2014). Such disparity may lead to unwarranted variation across a range of important outcomes. A wealth of recent research evidence has highlighted the efficacy of structured exercise rehabilitation across a myriad of outcomes, including exercise capacity, physical function and quality of life (Young et al., 2018, Gomes Neto et al., 2018, Barcellos, 2015). This updated evidence may have positively influenced the integration of renal rehabilitation into clinical practice. Additionally, practice may also have changed in response to numerous guidance documents which recommend that people with CKD have access to Physiotherapy, Occupational Therapy and Exercise Practitioners (which include; exercise physiologists and clinical exercise scientists) to provide a holistic approach to rehabilitation (Greenwood et al., 2014, Farrington et al., 2017, Ashby et al., 2019, BASES 2015).

Considering these advances, the 2014 survey may no longer provide a current reflection of rehabilitation practice within the UK. Additionally, the 2014 focused primarily on exercise-based rehabilitation programmes. Holistic rehabilitation, however, includes a broader range of interventions which support individuals to maintain a healthy lifestyle. Cognitive screening, symptom management strategies and relaxation techniques enable people living with CKD to

manage their condition and sustain meaningful occupation (Bennett et al., 2017, Leland et al., 2017, Kurella Tamura and Yaffe, 2011). There is also growing evidence for the benefits of engagement with creative activities. The All-Party Parliamentary Group on Arts, Health and Wellbeing found that participation in art-based activities can support people who are living with long-term conditions, by reducing loneliness, anxiety, depression and stress and boosting resilience and overall wellbeing (All-Party Parliamentary Group on Arts, 2017). These types of rehabilitation interventions were not explored in the 2014 survey, and access to such services is therefore currently unknown.

Aims

The BRS-RN was established in 2011 as a multidisciplinary group which aims to support and inform the development of renal rehabilitation in the UK. This survey, conducted by the BRS-RN aims to: (i) describe the current provision of rehabilitation (defined as access to both qualified and assistant Occupational Therapy, Physiotherapy and Exercise Practitioners) to renal patients across the UK; (ii) identify areas of regional variance in rehabilitation provision; and (iii) understand current perceptions of barriers to renal rehabilitation within the UK, and to compare this with that described previously (Greenwood et al., 2014).

This data will facilitate a better understanding of how far developments in the field of renal rehabilitation research have influenced clinical practice, will provide a baseline by which to measure future improvement and be used to underpin future guidance from the BRS-RN regarding service development and workforce planning which supports the implementation of high quality renal rehabilitation.

Methods

A bespoke online survey will be used to provide a detailed description of the current provision of rehabilitation across the CKD trajectory within the UK, and to capture perceptions of barriers to the provision of renal rehabilitation.

Participants and Settings

Attempts will be made to engage all 87 hub renal units, and 198 satellite units within the UK and Northern Ireland within the survey. Units will be identified via the Renal Association database (Renal Association, 2019).

Ethics

Ethical approval is not required as the project is a service evaluation. Completion and return of the survey will be considered indicative of willingness to participate and to imply consent.

Survey development and piloting

An online survey (Online Surveys (formally BOS), Jisc, Bristol), was developed by researchers (with experience in survey development), Physiotherapists, Occupational Therapists and Exercise Practitioners (with experience of delivering rehabilitation to people living with CKD) as there are no existing validated tools designed to capture the data required (Kelley et al., 2003). The survey comprises four core sections: general information; outpatient services

(which includes questions relating to intradialytic exercise programmes, structured renal rehabilitation programmes and therapy clinics); inpatient services; and perceptions of barriers to rehabilitation.

Each section will capture information relating to:

- the renal unit completing the survey;
- the types of rehabilitation services provided as a clinical programme available to people living with CKD, across the trajectory of stages, treatment modalities and settings;
- the professions that are providing these services, including their levels and grades and the corresponding week time equivalent (WTE);
- the availability of, and access to, Clinical Exercise Practitioners.

Within the survey, definitions of intradialytic exercise, structured outpatient programmes of renal rehabilitation and conservative care will be provided to ensure consistent responses (Greenwood et al., 2012). The questions relating to perceived barriers to the implementation of renal rehabilitation will be developed from the survey conducted by Greenwood et al. (2014). These questions will utilise a 5-point Likert scale ranging from 0 (strongly disagree) to 4 (strongly agree). The questionnaire will take approximately 15 minutes to complete.

The survey will be hosted by the University of Leicester and shared with experts in the field, identified via the BRS-RN for refinement. The revised survey will then be piloted by therapy units at the University Hospitals of Leicester NHS Trust, Leicester, King's College Hospital

London and Guys and St Thomas NHS Trust, London, to inform iterative modifications to both the survey and protocol.

Data collection

A regional model will be used to distribute surveys and gather data. The regions and constituent number of hub and satellite units are presented in Figure 1. For the purposes of the survey Wales, Scotland and Northern Ireland will not be divided into regions.

Figure 1 Map of UK regions to be surveyed, with constituent numbers of hub and satellite renal units

Representatives across the UK from all three professional groups (Physiotherapists, Occupational Therapists and Exercise Practitioners) will be identified via the BRS-RN. These regional representatives will be responsible for gathering data from the renal units within their region, and for following up non-responders by email, phone or (where possible) face to face.

To ensure consistency within the data collection methods used, the same procedures for data collection will be followed across all regions. These procedures are outlined within Figure 2.

Figure 2 Data collection flow diagram

The regional representatives will be provided with a list of the hub and satellite units within their region and asked to identify the respective Occupational therapy and Physiotherapy leads for each. These leads will be invited to complete the survey in the first instance, as previous work undertaken has highlighted this to yield the most complete dataset possible (Ancliffe, 2018). Therapy leads providing rehabilitation within each hub unit will also be asked to provide information on any rehabilitation services offered within any affiliated satellite units.

Therapy leads will be given three weeks to respond to the survey or decline to participate. After that time a follow-up email, phone call, or where possible, face to face will be made by the regional representative. After two weeks, if no response is received the regional representative will contact the Clinical Director for that renal unit and invite them to complete the survey. Clinical Directors will be identified via the Renal Association. Again, non-responders will be followed-up via email, phone or face to face after three weeks. If after two further weeks no response is received from the Clinical Director, the unit will be recorded as a non-responder. Finally, if appropriate, returned surveys which highlight that renal patients access rehabilitation services provided by Exercise Practitioners, may be followed up with a further bespoke survey to capture further information on the nature and provision of these services.

Analysis

A response rate of 65% will be considered *a priori* to provide a representative sample, as this level of response has been used previously in national surveys of rehabilitation practice

(Connolly et al., 2014). UK renal rehabilitation provision and perception of barriers will be described using descriptive statistics (mean and standard deviation, and frequency for categorical variables). The frequency of missing data will be reported. Chi-squared tests will be used to examine the associations between barriers to rehabilitation that were identified within the 2014 survey of UK renal rehabilitation (Greenwood et al., 2014). Qualitative free text comments will be subject to thematic analysis (Braun and Clarke, 2006).

Discussion and conclusions

There is a wealth of evidence recognising the myriad benefits of people living with CKD engaging in rehabilitation (Young et al., 2018, Gomes Neto et al., 2018, Greenwood et al., 2012, Barcellos, 2015) and a growing recognition of the importance of rehabilitation within clinical guidance for renal services (Farrington et al., 2017, Ashby et al., 2019). Despite this, existing evidence suggests that accessing these services can be challenging (Greenwood et al., 2014).

This survey aims to describe the current provision of renal rehabilitation across the UK and identify areas of regional inequality, as well as understand current perceptions of barriers to rehabilitation for this patient group within the UK. To the best of our knowledge, this survey is also the first to have a holistic and comprehensively multidisciplinary focus, capturing data across a range of settings, professional groups and stages of CKD, and moving beyond a focus just upon the provision of exercise and physical activity programmes.

Key points

- Rehabilitation for people living with CKD has an important impact upon a range of health and well-being outcomes
- Rehabilitation is recommended within numerous national and international guidance for renal care, and yet existing evidence highlights numerous barriers to accessing such services.
- There are also no recent data examining current practice within UK renal rehabilitation services.
- The BRS RN aim to survey Renal Units across the UK to 1) describe the current provision of rehabilitation to renal patients across the UK; 2) identify areas of regional variance in rehabilitation provision; and 3) understand current perceptions of barriers to renal rehabilitation within the UK.
- This work will provide an up to date understanding of current multidisciplinary rehabilitation provision in the UK and will support the implementation of a comprehensive specialist rehabilitation for people living with CKD by dedicated multi-professional teams.

Statement of ethics

The authors warrant that the submitted manuscript is their original work, has not been published before and is not being considered for publication by another publisher.

Conflict of Interests

The authors declare no conflicts of interest. The views expressed in this publication are those of the authors and not necessarily those of the NHS, the National Institute for Health Research or the Department of Health. The funders had no role in the study design; collection, analysis, and interpretation of the data; writing the report; and the decision to submit the report for publication.

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