# An exploratory study of quality of life, identity and engagement in patients with renal disease participating in a resistance exercise intervention during treatment

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By

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## Declaration

I confirm that this thesis is my original work, except where otherwise stated with reference to the original author(s). It has been submitted in partial fulfilment of the degree of Doctorate in Clinical Psychology and no part of it has been submitted for any other degree or academic qualification.

#### **Thesis Abstract**

*Title:* An exploratory study of quality of life, identity and engagement in patients with renal disease participating in a resistance exercise intervention.

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A narrative review of quantitative studies was conducted to critically appraise and synthesise the current evidence for resistance exercise as a way to improve the psychosocial well-being of older adults. Fifteen articles, which met the inclusion criteria, were retrieved. The data were synthesized and critiqued according to methodological features. The results suggest that resistance exercise can significantly improve the psychosocial well-being of older adults and may be particularly effective for clinically unwell older adults. However, a cautious interpretation should be made when analysing the results, due to the diversity of resistance exercise used. Suggestions for future research were considered.

A mixed-method approach combing both quantitative and qualitative methods was adopted for the empirical paper. Twenty-three participants were recruited through a larger study, a randomised controlled eight-week trial comparing resistance training with a treatment-as-usual group. Questionnaires were used to analyse the effect of exercise on quality of life and mental health of older adults. Results showed no significant differences between the groups. Interviews were conducted post intervention with nine participants who had been allocated to the resistance exercise group. Interview transcripts were analysed using thematic analysis. Six main themes were describe the participants' experience: *adjustment* created to to illness: capabilities/limitations of body/ability; maintaining life's qualities; impact of exercise; undertaking a research programme and being a helper. The analysis suggests that resistance exercise can improve mood, bodily confidence, social contact with others and generate routine and purpose. The findings also suggest that those who are not effectively supported may not continue with their exercise routine.

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Section A

Critical Literature Review

# A Systematic Review of the Psycho-Social Impact of Resistance Training in Older

# Adults

Prepared for Psychology of Sport and Exercise (Appendix A)

# Literature Review Abstract

## Background

Older adults constitute a key and growing population in the United Kingdom. Such growth will increasingly place a financial and social burden and is likely to strain provision of pensions and health and social care. One way to mitigate this burden may be to encourage older adults to engage in physical activity. Research indicates that resistance exercise has many health benefits for older people, including improved fitness, strength, flexibility and balance, enhanced mood and improvement in perceived quality of life.

## Objective

The current review aimed to critically appraise and synthesise the evidence for resistance exercise as a way to improve the psychosocial well-being of older adults.

## Method

A systematic search was conducted using bibliographic databases in August 2012 (updated Feb 2013). Only studies that utilised resistance exercise as an independent intervention and assessed psychosocial well-being as an outcome using standardised or validated self-report measures of quality of life and psychological functioning were included.

# Results

A total of 15 papers were identified and included in the current review. Each was examined for methodological quality, significant findings and conclusions. The results of the current review suggested that resistance exercise can significantly improve the psychosocial well-being of older adults. The evidence suggests that resistance training may be particularly effective for clinically unwell older adults, who may find aerobic exercise difficult to engage with. However, a cautious interpretation should be made when analysing the results, due to the small number of studies involved and the diversity of resistance exercise used.

# Conclusion

Resistance training can improve the psychosocial well-being of older adults and has been shown to be particularly effective for older adults with additional health conditions. However, further research is needed to determine the effectiveness of resistance exercise for both older adults with and without health problems and to provide further consensus on the optimal training programme.

Keywords: Older adult; quality of life; resistance training; systematic review

#### **1. Introduction**

Ageing population demographics worldwide reflect economic development. improvements in education and health care and an increase in life expectancy (Windle et al., 2008). Older adults constitute a key and growing population in the United Kingdom (Hendry & McVittie, 2004) and although there is no definitive consensus on the age at which a person becomes old (WHO), a common categorisation emerges from entitlement to receive state pension benefits, usually between the ages of 60-65 years (Office for National Statistics). By 2050, the British Government estimates that the number of people aged over 65 years will have reached 19 million, nearly double the number recorded in 2010. Such growth is increasingly placing a financial and social burden in developed countries and will strain provision of pensions and health and social care (Office for National Statistics, 2011): in 2007/08 the average value of NHS services for retired households was nearly double that for non-retired households. The Department of Health estimates that the average cost of providing hospital and community health services for a person aged 85 years or more is around three times greater than for a person aged 65 to 74 years (UK Parliament, 2010). While ageing challenges society, it also creates opportunities. Older people also make important contributions as family members, volunteers and active participants in the workforce. They are a significant social and economic resource, and longer life expectancy means a greater opportunity to contribute to society (WHO, 2012).

One way to manage the balance between these challenges and opportunities may be to encourage older adults to be physically active. Physical activity guidelines for older adults (65+ years) published by the Department of Health (2011) suggest that physical activity may maintain physical and cognitive function, reduce cardiovascular risk, maintain ability to carry out daily activities, improve mood and self-esteem, and reduce

the risk of falls. They advise that some physical activity is better than none, and more physical activity provides greater health benefits. Yet activity levels generally decline throughout life, and an increasing number of older adults have low levels of daily physical activity, which leads to loss of function and an increased risk of multiple serious diseases, including coronary artery disease, stroke, hypertension, colon cancer, type 2 diabetes and osteoporosis (Sallis, 2003; Sari, 2011).

Research indicates that habitual exercise has many health benefits for older people: improving fitness, strength, flexibility and balance, enhancing mood and perceived quality of life (Biddle & Mutrie, 2001; Dionigi, 2007; Taylor *et al.*, 2004). Metaanalytic and experimental studies consistently show a large antidepressant effect for exercise in older adults with clinical depression (Biddle & Faulkner, 2002). Physical activity has been shown to have a significant effect on self-efficacy, view of self, and global well-being by providing a mastery experience (Netz *et al.*, 2005). For older adults, whose self-efficacy may be diminishing along with their functional ability, physical activity may improve functional fitness (ability to independently navigate and successfully engage in their environment) promoting self-efficacy, that in turn leads to improved psychological well-being (Elavsky *et al.*, 2005; McAuley *et al.*, 2005).

In order to maintain cognitive function, reduce cardiovascular risk, maintain independence, improve mood and reduce the risk of falls, strength training (using body weight or working against a resistance), balance training (improve balance or co-ordination e.g. tai chi or yoga) and cardiovascular activities are particularly recommended as high priorities for older adults (Department of Health, 2011).

Ageing is particularly associated with progressive muscle loss (sarcopenia), which can lead to a decline in physical function and reduced mobility, decreasing the ability to perform daily living tasks, via loss in muscle strength. Sarcopenia seems to accelerate beyond the age of 50 and advanced sarcopenia leads to functional decline and increases the risk for dependence, disability, hospitalisation and mortality (Fried *et al.*, 2001). Resistance training has been suggested as the most effective strategy for delaying and treating the negative consequences associated with sarcopenia in older adults (Rolland *et al.*, 2008) and when comparing exercise training groups with control groups, it has the largest effect size (0.80) for improving mood in older adults (Arent *et al.*, 2000).

#### 1.1 Resistance Exercise

Resistance exercise is a specific form of strength training in which each effort is performed against a specific opposing force generated by resistance. As yet there is no consensus about what constitutes optimal training. A Cochrane review of the biomedical effects of such exercise, on healthy and clinically unwell older adults, revealed that resistance training is an effective intervention for improving physical functioning, strength and the performance of daily tasks (Liu & Latham, 2009). Resistance training also enhances energy expenditure, and promotes spontaneous participation in physical activity beyond its use (Hunter et al., 2004). Other less comprehensive analyses (Engels et al., 1998; Geirsdottir et al., 2012; Jette et al., 1996; Schilke et al., 1996) have shown that short-term resistance exercise interventions (8-15 weeks) improve strength, physical function, and health-related quality of life and reduce pain and stiffness in older healthy adults. Such exploration has been extended to clinically unwell older population, with Castaneda et al. (1998) concluding that physical activity may improve nutritional status, subjective wellbeing, enthusiasm and reduce risk factors for cardiovascular disease for those with renal disease. Dionigi (2007) found that participants experienced gains in competency, a sense of satisfaction and felt "good" both physically and mentally as a result of their exercise achievements and experiences. Furthermore, the participants perceived bodily sensations associated with exercise, such as arousal and tiredness, as positive signs of increased strength and health. Older adults may be motivated to maintain or increase resistance training if the connection is made between strength gains and their ability to remain independent (Whaley & Schrider 2005).

In a review commissioned by NICE examining the effectiveness and cost-effectiveness of public health interventions to promote the mental well-being in people aged 65 and over (Windle *et al.*, 2008), mixed exercise and resistance training has been shown to have small-to-moderate effects on the mental well-being of older people and aerobic exercise was shown to have a significant impact upon happiness and satisfaction in American sedentary older adults. The relationship between exercise and psychological wellbeing is widely recognised, with significant Government investment spent on encouraging an active lifestyle in order to foster good health in older age and maintain the independence and productivity of older people.

#### 1.2 Resistance Training and Quality of Life

In addition to biomedical outcome evaluations of exercise efficacy for older adults, studies have also explored impacts on quality of life. This has ensured not only that a key indicator of health is addressed, but also acknowledges the interplay between quality of life, morbidity and mortality. This is advisable for older adults, given that psychosocial and functional factors are important predictors of survival (Jofre *et al.*, 2000). A full explanation of quality of life, acknowledging psychosocial determinants, may promote the examination of the potential mechanisms that underlie the relationship between physical activity and enhanced quality of life in older adults; this will have

implications for the design, implementation, and promotion of physical activity programs (Rejeski & Mihalko, 2001).

Studies in which quality of life has been measured have often applied the construct partially and inconsistently. Quality of life in the current review adheres to WHOQOL definition (four domains: physical health, psychological well-being, social relationships and environments (WHOQOL Group, 1999)). Research to date has privileged health-related quality of life (HRQL) in examining well-being associated with medical diseases and conditions that impair function or cause symptoms. Geirsdottir *et al.* (2012) demonstrated that HRQL improved after 12 weeks of resistance exercise in a healthy older adult population with further analysis revealing improvement in physical function that predicted the improvement in HRQL. In a study focusing on the subjective experience of engaging in resistance training, Dionigi (2007) revealed that self-efficacy and social interaction were the key mechanisms underlying the link between resistance training and psychological well-being for healthy older adults.

Resistance training effects on quality of life has also been explored in those suffering from chronic health conditions, with significant benefits to functional capacity as well as quality of life (Castaneda *et al.*, 1998). Patients with heart failure have reported significant enhancement of quality of life via such exercise (including physical, psychological, social and environmental domains) (Bocalini *et al.*, 2008). Courtney *et al.* (2009) too found that a group of older adults at risk of hospital readmission, showed significantly better health-related quality of life than a control group, following a combined exercise and follow-up intervention. Such studies recommend exercise be incorporated into treatment plans, arguing that improving physical fitness, functional capacity and the ability to carry out tasks of daily living will result in increased independence and psychosocial wellbeing of older adults. With the increase in longevity

and growth of population over 65 years worldwide, means to prolong independence and later-life wellbeing are essential for both individuals and health care systems (Henwood *et al.*, 2011). Incorporating resistance training into the weekly routines of older adults, particularly those where effective aerobic exercise is precluded, may be one way to do this.

#### 1.3 Rationale and Aims of the Present Review

Previous reviews of resistance training (Castaneda et al., 1998; Hiewe & Jacobson, 2011; Hunter et al., 2004; Liu & Latham, 2009; Sari, 2011) have focused primarily on the physical benefits of exercise in the older adult population and their impact on healthcare utilization. The current review has assessed the evidence for the psychosocial effect of such exercise on older adults, a significant omission in previous reviews. The current review specifically focused on resistance exercise programmes, given extensive evidence to show that this type of intervention can have a significant impact on muscle strength and growth, which is particularly important to older adults. The link between muscle strength, functionality and quality of life, as previously discussed, suggests that resistance training will have a positive impact upon the psychosocial well-being of older adults. The current paper sought to review the recent literature in order to appraise the evidence for the impact of resistance exercise training on the quality of life (WHOQOL Group definition) of older adults. In order to be able provide robust evidence for the approach, a quantitative method was adopted for the current paper. Studies which utilised a controlled before and after design were included in order to examine the effectiveness of resistance exercise on improving the quality of life of older adults.

#### 2. Method

#### 2.1 Search Strategy for the Identification of Studies

Searches of the following electronic databases were performed to identify randomised controlled trials (RCTs) and quasi-RCTs: Cochrane Library (CENTRAL), MEDLINE, EMBASE, PsycInfo, Science Citation Index (accessed through Web of Knowledge), Science Direct and Web of Science.

In each database the following search terms were used to retrieve relevant studies; *strength* OR *resistance training* AND *older adult* AND *quality of life* OR *depression* OR *anxiety*. No other additional filters were applied. Searches were carried out between 2<sup>nd</sup> and 17<sup>th</sup> August 2012 (updated 23<sup>rd</sup> February 2013) with no time restrictions placed on publication date. All titles and abstracts were screened with articles clearly not pertinent to the review removed. The remaining papers were then scrutinised more thoroughly and the inclusion criteria then applied. The references of relevant studies were searched to identify additional trials and where appropriate, authors of relevant research were contacted.

#### 2.2 Study Selection

Studies were included in the current review if they comprised RCTs or quasi-RCTs (i.e. quasi-randomised approaches where participants' characteristics were matched when allocated to groups) comparing resistance exercise with any other exercise, drug treatment or no treatment. Resistance exercise was defined (in keeping with research definition) as a form of strength training in which each effort was performed against a specific opposing force generated by resistance. Included trials needed to report on resistance exercise interventions of at least eight weeks duration (although there is no defined optimal training programme, physical benefits can be seen after eight weeks)

and to assess explicitly the psycho-social impact of the intervention using validated outcome measures (including quality of life measures, measures of mental health (depression and anxiety) and well-being), which could then be independently extracted from the results. Trials were included if participants were defined as older adults (usually 60+ years), with or without chronic health conditions.

In order to focus exclusively on the impact of resistance exercise, trials were excluded if they combined resistance exercise with any other form of exercise. Trials were also excluded if they used weightlifting, powerlifting or bodybuilding interventions as these are competitive sports, involving different types of strength training with non-elastic forces, rather than an immovable resistance. Uncontrolled before and after studies, were also excluded, given the results would not be able to infer causality. Details of the inclusion and exclusion of studies are shown in Figure 1.

#### 2.3 Assessment of Study Quality

The reviewer independently assessed the methodological quality of the studies. The scoring system was taken from the Methodology Checklist for Controlled Trials (SIGN; 2004), a set of ten criteria for the assessment of RCTs (Appendix B). The list of criteria was adapted for the current review with items concerning blinding of investigators and participants removed, since researchers would be unlikely to be able to conduct exercise intervention trials where the investigators and participants are blinded. However the blinding of outcome assessors was included to show minimisation of bias when handling data. Each criterion was scored as either positive or negative. If the papers did not provide sufficient information (in order to be able to make a clear decision), or were unclear, then this was marked as negative. The total score was the sum of the positive criteria. No studies were excluded due to the rating of the quality of the paper, as the

quality assessment provided a framework for highlighting strengths and weaknesses of the studies and were taken into account when making conclusions about the results.

### 2.4 Analysis

For each study, the following data was extracted by the reviewer using a standard extraction form (Appendix C); data concerning type of publication, participant characteristics, study design, number of participants, recruitment procedures, nature and length of the intervention, type of control group, outcome assessments, intervention adherence, potential sources of bias, statistical techniques and major findings.

Due to the diversity of the outcome measures and designs of the included studies, a meta-analysis of the results was not suitable; therefore a narrative synthesis of the papers was conducted.

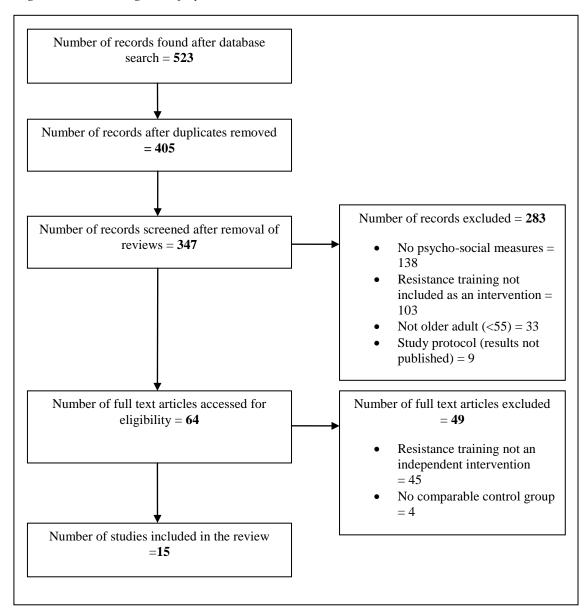


Figure 1. Flow diagram of systematic review

### 3. Results

#### 3.1 Characteristics of Included Studies

After reviewing the full articles, 64 reports were identified as potentially suitable for inclusion; of these 15 were included in the current review. The 15 studies included in the current review were published between 1997 and 2012, 14 reported RCTs and one used matched groups. Studies were conducted in Australia (n=5), Canada (n=1), Japan (n=2), The Netherlands (n=1), New Zealand (n=1), UK (n=1) and USA (n=5).

Five studies used more than one intervention, a glossary of the additional interventions can be found in Appendix D. Control groups included non-exercise adopters (Baker et al., 2011), a non-specific exercise program (Barrett & Smerdely, 2002.), educational groups (Chin A Paw et al., 2004; Kimura et al., 2010; Singh et al., 1997), wait-list controls (Damush & Damush, 1999; Katula et al., 2008; Zanuso et al., 2012), attention controls (Dibble et al., 2009; Latham et al., 2003; Lincoln et al., 2011; Miller et al., 2006; Sato et al., 2007), a 'sham' exercise program (Liu-Ambrose et al., 2005) and standard care (Singh et al., 2005). Interventions ranged in length from eight to 24 weeks and frequency ranged from one hour a week to three days a week. Eight studies used the SF-36 as a primary outcome measure (Baker et al., 2011; Barrett & Smerdely, 2002; Kimura et al., 2010; Latham et al., 2003; Lincoln et al., 2011 Sato et al., 2007; Singh et al., 1997; Singh et al., 2005), four studies used the Geriatric Depression Scale (Chin A Paw et al., 2004; Lincoln et al., 2011; Singh et al., 1997; Singh et al., 2005) and two studies used the Hamilton Rating of Depression (Singh et al., 1997; Singh et al., 2005). Other measures included Core Self Evaluation Scale (Baker et al., 2011), Dementia Quality of Life Instrument and The Vitality Plus Scale (Chin A Paw et al., 2004), Health Related Quality of Life (Damush & Damush, 1999), Parkinson's Disease Questionnaire (Dibble et al., 2009), Self-Efficacy for Strength, Satisfaction with Physical Function and Satisfaction with Life Scale (Katula et al., 2008), Quality of Life Questionnaire of the European Foundation for Osteoporosis (QUALEFFO) (Liu-Ambrose et al., 2005), Short Form 12 (Miller et al., 2006), the Beck Depression Inventory (BDI) and the Philadelphia Geriatric Morale Scale (Singh et al., 1997), Self-Efficacy of Sherer Scale and Multidimensional Health Locus of Control (Singh et al., 2005) and Trait Anxiety Inventory, Profile of Mood States and Positive Affect Negative Affect Schedule (PANAS) (Zanuso et al., 2012).

#### 3.2 Methodological Quality of Included Studies

The assessment of the quality of the studies is shown in Table 1. The majority of studies (n=9) were rated as moderate quality. Four studies were rated as high quality (Barrett & Smerdely, 2002; Chin A Paw *et al.*, 2004; Latham *et al.*, 2003; Miller *et al.*, 2006) and two studies were rated as low in quality (Baker *et al.*, 2011; Dibble *et al.*, 2009). The majority of studies provided clear descriptions of the recruitment procedure, details of the characteristics of participants (demographic variables) and the statistical methods used. Eight of the studies reported prospective power calculations and two of the studies (Damush & Damush, 1999; Katula *et al.*, 2008) reported how a lack of power may have influenced their results, and therefore may have been a limitation of the studies reporting adequate concealment methods. The majority of studies (n=10) reported on the validity and reliability of the outcome measures used, however, five studies did not. As there were a number of different outcome measures used, it would have been useful to discuss the reliability and validity of the measures, to understand the rationale for their selection.

	Baker	Barrett	Chin A Paw	Damush	Dibble	Katula	Kimura	Latham	Lincoln	Liu-Ambrose	Miller	Sato	Singh (USA)	(Australia)	Singh	Zanuso
Addresses an appropriate and clearly focused question	~	~	~	~	~	~	~	~	✓	✓	√	~	√	✓		~
Randomised assignment to treatment groups	-	✓	✓	✓	X	✓	✓	~	~	√	✓	✓	~	~		~
Adequate concealment method used	х	√	✓	Х	Х	Х	Х	✓	Х	√	✓	Х	Х	~		Х
Outcome assessor blinded	X	√	✓	X	X	X	Х	✓	-	~	~	-	✓	~		X
Treatment and control groups similar at start of trial	~	~	✓	~	~	~	~	~	~	✓	~	~	✓	~		✓
Only difference between groups is the treatment under investigation	~	✓	✓	✓	✓	✓	~	~	~	✓	✓	✓	✓	~		✓
All relevant outcomes are measured in a standard, valid and reliable way	X	√	✓	✓	✓	√	-	~	~	~	✓	~	✓	~		~
Percentage of dropouts from each treatment arm		RT 4.5%, CON 4.5%	ST 28%, FT20%, COM22%, CON31%	RT 17%, CON 6%	RT 0%, CON 13%	ST 27%, PT 20%, CON 13%	RT 16%, CON 23%	RT 7%, CON 11%	RT 0%, CON 0%	RT 6%, AT 5%, CON 6%	NS 8%, RT 8%, NS&RT 8%, CON 4%	OG 0%, TG 8%, CON 0%	RT 0%, CON 0%		HI 10%, LI 15%, CON 5%	RT 0%, CON 0%
Intention to treat analysis	Х	✓	✓	Х	Х	Х	Х	✓	-	Х	✓	-	Х	X		Х
Overall quality assessment of the study	Low	High	High	Moderate	Low	Moderate	Moderate	High	Moderate	Moderate	High	Moderate	Moderate		Moderate	Moderate

Table 1. Assessment of methodological quality of included studies

The results that emerged were categorised on the basis of application of resistance exercise to healthy and unwell populations.

#### 3.3.1 Healthy population studies

Of the 15 studies included in the current review, seven used participants from a non-clinical population. Six of these studies examined the psychosocial impact of resistance training and one of the studies (Baker *et al.*, 2011) examined the predictive power of core self evaluation on exercise adoption. The length of the resistance training programs ranged from eight weeks to six months, and the frequency of the sessions was either twice weekly or three times a week. Characteristics of the included studies can be found in Table 2.

Two studies found that resistance exercise was shown to have a significant positive impact on psychosocial well-being (Katula *et al.*, 2008; Kimura *et al.*, 2010) and a further study (Zanuso *et al.*, 2012) reported modest positive effects. All three studies were rated as moderate-quality. Katula *et al.* (2008) found that both power training and strength training showed significant positive changes in self-efficacy, when compared to the control group, yet, only power training showed significant changes in satisfaction with life and physical function, when compared to the control group. Kimura *et al.* (2010) found progressive resistance training had a positive, but modest effect on mental health, according to SF-36 outcomes, when compared to a health education group. However, both these studies report limitations of small sample sizes, indicating lack of statistical power (Katula *et al.*, 2008) and possible ceiling effects of an already healthy group of participants (Kimura *et al.*, 2010). Zaunso *et al.* (2012) reported mixed findings, showing that both the resistance exercise group and the control group had

significantly reduced levels of anxiety after 12 weeks. Positive affect (measured by the PANAS) was unaffected, however analysis of interaction effects showed negative affect significantly declined in the exercise group. Positive aspects of mood states (measured by the POMS) were maintained by the exercise group and significantly deteriorated in the control group, suggesting that resistance training is capable of maintaining positive aspects of mood in older participants and can promote a modest improvement in psychological functioning. Furthermore, the results may have been restricted, as both groups showed very positive psychological profiles compared to relevant age-related norms. However, generalisability of the results may be limited due to the small sample size involved (n=20).

In a fourth study, core self-evaluation (CSE (a construct that is theoretically antecedent to four personality traits: locus of control, self-esteem, emotional stability and generalised self-efficacy)) was shown to be a significant predictor of resistance exercise adoption in healthy older adults living in Australia (Baker *et al.*, 2011). Regression analysis showed that CSE was the strongest independent predictor of resistance training adoption, accounting for an additional 10% of the variance, beyond that accounted for by demographic and health status variables. Therefore, this suggested that it may be important to consider CSE as a construct when targeting older individuals to engage and maintain involvement in resistance exercise programs. However, the study was rated as low-quality and the small sample size may limit the robustness of these findings, as well as the homogeneity of the participants involved.

Two high-quality (Chin A Paw *et al.*, 2004; Barrett & Smerdely, 2002) and one moderate-quality (Damush & Damush, 1999) studies found no significant impact of resistance training on the psychosocial well-being of older adults. Chin A Paw *et al.* (2004) found minimal, non-significant differences between groups on quality of life,

vitality and depression scales and interestingly, the combined exercise group showed a slight decline on the scales when compared to the control group. However, the control group's potentially socially facilitative education program may have influenced the impact of the exercise intervention and average scores at baseline may have left little room for improvement (ceiling effect). Using the SF-36, Barrett and Smerdely (2002) found that neither the resistance exercise group nor the control group improved significantly from baseline in any subscale on the SF-36 at the p>0.003 level. However, post hoc power was  $\beta$ =0.9, suggesting a type II error was possible. Lastly, Damush and Damush (1999) found that resistance exercisers' change in mental and physical health functioning did not differ significantly from a social waiting list control group after an eight week intervention, although the mean differences between groups were in the predicted direction (improvement) for anxiety, depression and self-reported physical health functioning. The results of this study may be limited by low power, as a result of a small sample size and the lack of an additional no contact control group, which would account for the social exposure to both the exercise and wait list control groups.

The results provide mixed support for the psychosocial benefit of resistance exercise training with a healthy older adult population. However, interestingly, none of the studies reported negative consequences of healthy older adults taking part in such a programme.

	Study design and location	Inclusion criteria	Ν	Recruitment procedures	Intervention and duration	Control or comparison group	Outcome and assessments	Intervention adherence or attendance
	Baker <i>et al.</i> , RCT, Australia	Resident in one of two retirement villages. Medically eligible	N=118 (n=38 in exercise group)	Intensive promotional campaign, using flyers and local media.	10-week resistance training program for 3 days per week	Non-exercise adopters	CSE scale SF-36. Core self evaluation was predictive of progressive resistance training adoption.	10.6% of participants adopted exercise intervention
Healthy Population	Barrett & Smerdely, RCT, Australia	>60 years No contra-indications of participation in exercise group	N= 44	Advertisement in local paper, flyers distributed to recreational clubs and community groups.	Progressive resistance exercise training, one hour class, twice a week for 10 weeks.	Non-specific exercise program with a focus on flexibility.	SF-36 Neither group improved significantly from baseline. Possible type ii error made.	40 participants completed intervention.
Healthy	Chin A Paw <i>et al.</i> , RCT, The Netherlands	>65 years Living in a nursing or residential care facility, able to walk 6 metres or more, able to comprehend study procedures, no medical contraindication, no rapidly progressive medical illness, not moving away from the home within 6 months.	N=244	Informative meetings at care home	Strength training programme twice a week for 6 months	All round functional training, Combination training, and control group – educational group	Dementia Quality of Life Instrument, The Vitality Plus Scale, Geriatric Depression Scale. Exercise does not affect quality of life, vitality or depression of older adults.	Drop-outs 28% strength training, 20% functional training, 22% combined training and 31% control group
	Damush & Damush, RCT, USA	>55 years	N=71	'no obligation' seminars	8 week twice weekly strength training intervention	Wait list control	Health Related Quality of Life No significant difference between groups	Exercise – 17% drop out Control – 6% drop out

# Table 2. Characteristics of Healthy Population Studies

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	Katula <i>et al.</i> , RCT, USA	Self-reported difficulty with carrying out daily physical tasks. Aged 65 years or older, community dwelling and capable of walking unassisted or with a cane.	N=45	Flyers distributed to retirement communities, searching clinical trials register, and advertisements in local newspaper.	Power training – 3 times a week for 12 weeks Strength training – 3 times a week for 12 weeks	Wait list control – contacted every month to see if changes in their lifestyle.	Self-efficacy for Strength (SE), Satisfaction with Physical Function (SPF), Satisfaction with Life Scale (SWLS). PT – significant increases in SE, SPF and SWLS compared to Control. ST significant increases in SE only.	PT – 2 lost to follow- up. ST – 4 lost to follow- up. Control – 3 lost to follow-up.
-	Kimura <i>et al.</i> , RCT, Japan	Community dwelling; aged 65 or older; ambulatory with or without assistance; and no physical health conditions which would prevent inclusion.	N=171	Advertisements in publications on the local community and through clubs for the elderly.	3-month facility based program using progressive resistance training and balance training.	Health Education Program – 1.5 hours of lectures on health promotion, twice a month for 3 months.	SF-36. Significant improvement on Mental Health component of SF-36 between groups.	<ul> <li>137 Completed.</li> <li>Exercise group – 14 drop-outs</li> <li>Control – 20 drop- outs.</li> <li>119 attended all assessments.</li> </ul>
	Zanuso et al., RCT, UK	Aged 65 or older; not involved in an exercise program in the last five years, healthy.	N=20	Recruited within local civic centre.	12 week progressive isotonic resistance exercise program, 3 times per week, 12 weeks.	Wait list control.	Trait Anxiety Inventory, Profile of Mood States, Positive Affect Negative Affect Scale. Both gps significantly reduced trait anxiety, negative affect declined in exercise gp, positive mood state maintained in exercise gp.	Exercise attendance - 90.7%

Healthy Population

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#### 3.3.2 Studies of unwell populations

Eight studies reported data on participants from a clinical population. Two studies examined the impact of resistance training on frail older people (Latham *et al.*, 2003; Sato *et al.*, 2007), one study used nutritionally at-risk older adults, who had been hospitalised following a fall-related lower limb fracture (Miller *et al.*, 2006), one study used adults diagnosed with Parkinson's disease (Dibble *et al.*, 2009), one study used adults diagnosed with type 2 diabetes (Lincoln *et al.*, 2011), one study used older women suffering with osteopenia or osteoporosis (Liu-Ambrose *et al.*, 2005) and two studies used older adults diagnosed with either major or minor depression (Singh *et al.*, 1997; Singh *et al.*, 2005). Characteristics of included studies can be found in Table 3.

Six studies reported a positive effect of resistance training on clinically unwell older adults, although the magnitude of the reported effect varied between them. The resistance exercise programs ranged from eight to 25 weeks and the frequency ranged from once weekly to three times a week.

Lincoln *et al.* (2011), rated as moderate-quality, reported that a 16 week resistance exercise program significantly improved depression scores on the GDS  $(3.1 \pm 3.5 \text{ vs.} 12.4 \pm 8)$  and the mental component of the SF-36 (54.4 ± 6.9 vs. 44.5 ± 10.1) in Puerto Rican older adults diagnosed with type 2 diabetes, when compared to an attention control group.

When comparing resistance training with agility training, and a stretching control group, with older adults suffering with osteoporosis, Liu-Ambrose *et al.* (2005) reported that there were no significant differences between groups among changes observed on scores of quality of life. However, there were significant improvements on quality of life within the resistance group (10%) and the agility group (13%). Resistance training

showed significant improvement on domains of pain (p=0.03, by 33%) and leisure and social activities (p=0.03, by 20%). The results provide moderate-quality evidence which suggests that agility training most likely improved the quality of life of participants through interpersonal interaction, whereas, resistance training most likely improved quality of life by significantly reducing the experience of back pain and increasing participants' self-efficacy, by providing constant feedback on their improvement i.e. lifting heavier weights.

Sato *et al.* (2007) compared a once-weekly and twice-weekly water-based resistance exercise program in older frail adults with an attention control group. Scores on the SF-36 showed significant improvement in both groups, compared to the control group. The physical and mental component scores of the SF-36 were significantly higher in the twice-weekly group at three months compared to the 'once' and control group and at six months, scores were similar to the 'once' group. The results provide moderate-quality evidence suggesting that increasing the frequency of resistance exercise elicits rapid improvement in the quality of life of frail older adults, before reaching a plateau. However, additional factors, which may be salient to this population, such as body function, body structure and social relationships were not included as outcome measures, but may have contributed to changes in quality of life.

Two studies rated as moderate-quality (by the same lead author) investigated the effect of resistance training on depression. Singh *et al.* (1997) reported significant improvement in both self and therapist-rated scores of depression in the resistance exercise group, compared to the control group. Furthermore, improvements were of two to three times the magnitude of the control group, with 59% of the resistance group responding to treatment compared to 26% of the usual care group. At baseline, quality of life scores were below that for the age-matched population for both groups. Four subscales of the SF-36 significantly improved in the resistance exercise group and all subscales approximated or exceeded age-matched normal scores, whereas the control group scored below normal reference ranges on most subscales.

Singh *et al.* (2005) reported a significant improvement over time across all groups for self-rated and therapist scores of depression. However, improvement in scores was significantly higher in the high intensity resistance group (ES = 1.84, 1.37 and 0.75 for GDS and ES = 1.85, 1.21 and 0.70 for HRDS in high, low and standard care groups respectively) and the high intensity resistance intervention was shown to be twice as effective (61% with clinical response) as the low intensity resistance exercise (29% clinical response) and GP standard care (21% clinical response). Quality of life scores improved significantly across all groups; with significantly greater effect of the high intensity resistance training had similar efficacy to standard antidepressant medication, with a clinically meaningful response in 60% of participants. This lends support to a dose-response effect for progressive resistance training. However, both studies should be viewed in relation to their small sample sizes and constrained statistical power.

In a preliminary study using participants living with mild to moderate Parkinson's disease, Dibble *et al.* (2009) found a significant time by group interaction effect for the single index score of the PDQ-39. Calculation of within group effect sizes demonstrated improvements in quality of life in the resistance exercise group (ES = 0.45), which exceeded those demonstrated by the control group (ES = 0.08). However, the results should be interpreted with caution due to the low-quality reporting of the study. In addition, the improvement in quality of life scores occurred in the absence of significant changes in severity of motor deficits.

By contrast two studies rated as high-quality revealed that resistance training did not have a positive effect on the psychosocial well-being of clinically unwell older adults. Latham *et al.* (2003) found that the quality of life (as indicated on the SF-36) of frail older adults did not significantly improve, when compared to an attention control group. Furthermore, the results showed that the resistance exercise group showed a significant increase in self-reported fatigue (p=0.002) and lower scores on the vitality domain of the SF-36, when compared to the control group. The resistance exercise group also presented with increased risk of musculoskeletal injury requiring medical attention or incurring functional limitation for two days or more. A cautious approach to highintensity resistance exercise for frail older people is thus warranted. Although, given the exercise program was home-based, with circumscribed therapist visits, risk of injury may have been heightened, by lack of supervision. Participants so recently hospitalised may not have been most appropriate to engage in a home-based exercise program

Miller *et al.* (2006) also examined participants who had been recently hospitalised with a lower limb fracture and who were nutritionally at risk. Those in the resistance group commenced training seven days after injury. There were no significant differences in quality of life scores between groups. However, the results suggested that the participants remained in (nutritional) negative energy until at least 12 weeks post injury, therefore limiting the possible effectiveness of the intervention.

	Study design and location	Inclusion criteria	Ν	Recruitment procedures	Intervention and duration	Control or comparison group	Outcome and assessments	Intervention adherence or attendance
	Dibble <i>et al.</i> , Matched Groups, USA	Mild to moderate PD, aged between 40-85 years.	N=29	Unknown	45-60 min, 3 days/week, 12 week rehabilitation programme	'active' controls	Parkinson's Disease Questionnaire (PDQ-39). No significant difference between groups, however exercise group showed greater improvement.	Exercise – no drop outs Control – one drop out
llation	Latham <i>et al.</i> , RCT, New Zealand and Australia	65 years or older; considered frail, no clear indication or contraindication to study treatments.	N=243	Screening of medical records of all patients admitted to hospital wards.	Resistance exercise, 3 times a week for 10 weeks.	Control group – frequency matched telephone calls and home visits from research physical therapist.	Physical Component Score of SF-36. No significant effect of resistance exercise on HRQoL	Outcome measures - 222 patients (91%). Exercise gp adhered to 82% of sessions.
Unwell Population	Lincoln <i>et al.</i> , RCT, USA	Puerto Rican men and women; older than 60 years; type 2 diabetes.	N=58	Unknown	Resistance exercise – 3 times a week for 16 weeks. Each session 45 mins.	Control group – received phone calls every other week.	Geriatric Depression Scale (GDS) and SF-36. Significant improvement on GDS and SF-36 scores for exercise group.	No drop-outs.
	Liu-Ambrose <i>et al.</i> , RCT, Canada.	Women aged between 75 to 85 years; resident of greater Vancouver; osteoporosis or osteopenia diagnosed between 1996 and 2002.	N=104	Newspaper, radio advertisements and posters. Screening of computer database.	Resistance exercise – 50 min group session, twice a week, 25 weeks. Agility exercise – as above	Stretching (sham exercise) – frequency as intervention groups.	QUALEFFO (quality of life questionnaire of the European Foundation for Osteoporosis). No significant differences between groups. Resistance and Agility showed significant improvement within groups	Resistance exercise – 85% compliance Agility exercise – 87% compliance Control – 79% compliance.

# Table 3. Characteristics of Unwell Population Studies

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	Miller <i>et al.</i> , RCT, Australia.	Aged 70 years or over; admitted to hospital with fall-related lower limb fracture between September 2000 and October 2002; resident of South Adelaide.	N=100	Recruited from orthopaedic wards.	Resistance training – 3 times per week for 12 weeks. 20-30 minutes per session. Nutritional supplement – Fortisip	Attention control – tri-weekly visits in weeks 1-6 and weekly visits in weeks 7-12.	Short Form 12. No significant differences in QoL.	93% completed study.
-	Sato <i>et al.</i> , RCT, Japan.	Help with daily living necessary; aged 65 or older; no cognitive impairment; no regular exercise outside study	N=30	Informational talks.	Once group – 1 hour of exercise in water once a week. Twice group – 1 hour of exercise in water twice weekly.	Control group – attention and social interaction at day centre.	SF-36. Significant increases in PCS and MCS at 3 and 6 months compared to pre, in the once and twice groups.	One non-completer in Twice group. Exercise adherence Once group – 95% Twice group – 95.3%
	Singh et al., RCT, USA	Aged 60 or over; fulfilled the DSM-IV criteria for either unipolar major or minor depression or dysthymia.	N=32	Mailing lists and local advertising.	Resistance training 3 days per week for 10 weeks.	Control group – interactive health education program 2 days a week for one hour.	BDI; GDS; Hamilton Rating of Depression; Philadelphia Geriatric Morale Scale, SF-36. BDI, GDS, HRSD & SF-36 – significant improvement in exercise group compared to control. No significant difference on GMS for either group.	Compliance in exercise group – 93% Control group – 95%.
-	Singh <i>et al.</i> , RCT, Australia	Aged over 60; fulfilled DSM-IV criteria for major depression, minor depression or dysthymia; GDS score of 14 or more.	N=60	Recruited through GPs.	High Resistance exercise gp – large muscle groups, 3 days per week, 8 weeks. Low Resistance exercise gp – low intensity resistance exercise, 3 days/week, 8 weeks.	Standard care from GP.	Hamilton Rating Scale of Depression, Geriatric Depression Scale, Self-Efficacy Scale of Sherer, SF-36, Multidimensional Health Locus of Control. Significant improvements over time for exercise HRSD & GDS. 6/8 domains of SF-36 improved significantly across all groups. Greatest improvements in HIGH group.	6 dropouts. Compliance with exercise sessions – 95-100% in HIGH 99-100% in LOW

#### 4. Discussion

#### 4.1 Summary and discussion of key findings

Four high-quality, nine moderate-quality and two low-quality studies, which compared resistance training with either additional training groups or control groups, were included in the current review.

Four high-quality studies (Barrett *et al.*, 2002; Chin A Paw *et al.*, 2004; Latham *et al.*, 2003; Miller *et al.*, 2006) and one moderate-quality study (Damush *et al.*, 1999) found no significant difference between participants allocated to resistance exercise and those allocated to combined training or control groups. However, although rated as high-quality, these studies were not without limitations. The study by Barrett and Smerdely (2002) contained fewer than 50 participants, increasing the likelihood of a Type II error. Both Chin A Paw *et al.* (2004) and Damush and Damush (1999) utilised social groups as their controls, which may have negated the impact of the exercise group. Furthermore, participants in these studies were scoring average or above average on quality of life measures at baseline, limiting scope for marked improvement. Interestingly, neither of the studies using clinically healthy participants (Barrett & Smerdely, 2002; Chin A Paw *et al.*, 2004) reported negative consequences of undertaking a resistance exercise programme. So whilst the improvement of psychosocial well-being may be limited in this group, it is possible that resistance training is capable of maintaining positive aspects of quality of life in older adults.

Participants in both Latham *et al.* (2003) and Miller *et al.* (2006) studies had recently been discharged from hospital and were either frail or nutritionally at risk, therefore may have benefited from physical rehabilitation before commencing resistance training.

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Eight moderate-quality (Katula *et al.*, 2008; Kimura *et al.*, 2010; Lincoln *et al.*, 2011; Liu-Ambrose *et al.*, 2005; Sato *et al.*, 2007; Singh *et al.*, 1997; Singh *et al.*, 2005) and two low-quality (Baker *et al.*, 2011; Dibble *et al.*, 2009) studies found resistance exercise to have a significant positive effect on the quality of life of older adults. Participants both with and without overt disease appeared to benefit from undertaking a resistance exercise programme when compared to an additional intervention or a control group. Additionally, the majority of studies reported associated significant increases in the strength, muscle mass and power of the participants, echoing Hunter *et al.* (2004) and Geirsdottir *et al.* (2012) findings that increased physical ability may ease the difficulty of performing activities of daily living and lead to an increase in functional ability. This is likely to be important in maintaining the independence of older adults, and the increase in physical activity may prolong healthy ageing.

With regards to depression, resistance exercise was found to significantly improve scores on condition-specific measures. Furthermore, the improvement was shown to be three times that of the control group, and high intensity resistance exercise was shown to have a similar clinically meaningful response to antidepressant medication. The results support the growing evidence base for the positive impact of exercise on mental health (Arent *et al.*, 2000; Biddle & Mutrie, 2001). However, Daley and Jolly (2012) presented more equivocal evidence for the impact of physical activity on depression and suggested that depressed patients should not be routinely advised to exercise, as they may not be able to comply with the recommendations. Therefore, motivation appears to be key, with those who are motivated to exercise more likely to achieve behavioural change, and should be considered as a construct when selecting participants for future studies.

Resistance training may be more appropriate for the unwell population group who may have multiple co-morbidities, which may limit effective participation in aerobic exercise. Frail older people, in particular, may be dissuaded from aerobic exercise due to the fear of falling. Gillespie and Freidman (2007) found that 76% of older adults who reported fear of falling modified their activity level secondary to this fear. The results for the impact of resistance training on the psychosocial well-being of frail older people were equivocal. However, the use of water, instead of resistance machines or bands, may mitigate any negative effects found in this population group. Water is a supportive exercise environment and may provide additional benefits by reducing the risk of falls and other injuries that occur whilst performing exercise (Takeshima *et al.*, 2001). Resistance training was also found to have a positive effect on the psychosocial wellbeing of older adults diagnosed with Parkinson's disease, type 2 diabetes and osteopenia or osteoporosis.

## 4.2 Older Adult Rehabilitation

The current review supported the effect of resistance training on enhanced self-efficacy, view of self, mood, global well-being, as well as improved daily functioning. It is clear from the review that maintaining and improving the quality of life of both healthy and unwell older adults should be considered as important when designing exercise and rehabilitation programs for this group. Lee *et al.* (2008) suggested that the attitudes and beliefs that older adults possess about the costs and benefits of exercise in later life can influence their activity level. Many older adults do not consider themselves to be candidates for exercise programs because they associate exercise with extreme physical exertion. Barriers may also be present (exercise equipment, transport systems, hospital staff unable to engage in exercise promotion) which may prevent them from engaging (Kontos *et al.*, 2007). Therefore, providing exercise programs that emphasize

educational and patient monitoring methods to promote self-efficacy for independent exercise are warranted (Izawa *et al.*, 2004; Tsay *et al.*, 2005). Carlson *et al.* (2001) found that patients with coronary heart disease who participated in modified cardiac rehabilitation, which provided strategies for transition to independent exercise, had higher levels of exercise self-efficacy and adherence than those who participated in traditional cardiac rehabilitation.

Whilst the studies in the current review add to the research, which suggests that resistance exercise can benefit older adults, there appears to be little agreement on how best to implement resistance exercise programs. Bates *et al.* (2009) argued that onceweekly community-based strength programs may be more accessible for, and acceptable to, older adults than similar programs which require more frequent attendance or are fitness or medical centre-based. Foley *et al.* (2011) recommended that after rehabilitation, older adults should be encouraged to continue a progressive, high-intensity, supervised, centre-based exercise program at a minimum frequency of once a week. Whereas Moullec and Ninot (2010) suggested that an integrated programme (comprising physical activity, education and psychosocial support) can significantly improve functional and emotional dimensions of quality of life.

## 4.3 Measuring the quality of life of older adults

The studies in the current review considered the levels of psychosocial well-being of older adults undertaking a resistance exercise program using a variety of generic and specific measurement tools. This is not unexpected, as quality life is a broad concept which includes elements of physical, psychological, social, cognitive, spiritual and environmental functioning (Kelley-Gillespie, 2012). The measures included in the current review varied in concept, construction, design and content but do not appear to

have been particularly patient centred. The SF-36 (primary outcome measure in eight of the included studies) is a generic measure and includes questions on domains which have been found to be important to most adults when assessing quality of life. However it does not include questions on sleep, relationships, sexual functioning, dependence/independence, self-perception or perception of the future, which may be particularly relevant to patients and older adults. Additionally, some of the factors included in the questionnaire may be irrelevant or redundant to some individuals (Carr & Higginson, 2001).

Measuring quality of life from only a physiological perspective (e.g. Parkinson's Disease Questionnaire; Self-Efficacy for Strength; Satisfaction with Physical Function) is limiting in that it focuses only on the physical condition and the needs that condition provokes. Looking only at a psychological perspective (e.g. BDI; Trait Anxiety Inventory; Profile of Mood States; PANAS; Hamilton Rating of Depression; Geriatric Depression Inventory) may ignore the external economic, political and social realities that affect older people (Bond, 1999). Quality of life measures that incorporate both medical and social indicators of quality of life with inter-psychic well-being may be the most accurate and thorough (Kelley-Gillespie, 2009).

### 4.4 Limitations of the current review

A number of limitations should be taken into account when interpreting these findings. Firstly, the included papers varied in quality, with the majority of papers rated as 'moderate' quality. Studies may have been classified as having lower quality than they actually had as data and/or information were missing from some of the reports. Only four of the included studies utilised an intention-to-treat analysis. The remaining 11 studies varied in rates of attrition from 0% to 27% in the resistance exercise groups, 5% to 8% in the additional intervention groups and 0% to 23% in the control groups. The use of 'completed case' analysis may have led to a reduction of statistical power, due to a decrease in sample size, therefore the robustness of the findings should be questioned. Two studies (Damush & Damush, 1999; Katula *et al.*, 2008) attempted to address this by utilising power calculations retrospectively.

Secondly, the included studies themselves had their limitations, such as the variety of instruments used to measure quality of life, lack of details about exercise protocols (Baker *et* al. 2011; Dibble *et al.* 2009; Lincoln *et al.* 2011) and variability of exercise duration.

Thirdly, with regard to the review itself, although a systematic approach was followed, the search method employed focused solely on RCTs. Whilst this increased the ability to make causal inferences about the effect of resistance training on the quality of life of older adults, it has meant that the external validity (generalisability) of the results is restricted. It is possible that participants taking part in a RCT may be more motivated to exercise and to comply with exercise programs and may therefore not be representative of all older adults who might benefit from resistance exercise. The question the current review sought to answer lent itself to quantitative enquiry, therefore discounting potentially relevant qualitative material regarding the subjective experience of engaging in resistance exercise and individual beliefs regarding its impact on psycho-social well-being.

## 4.5 Clinical Implications

The results of the current review suggest that resistance exercise training can have a positive impact upon the psychosocial well-being of older adults. However, a cautious interpretation should be made when analysing the results, due to the small number of

studies involved. Given study diversity, as well as the diversity of exercise programmes and absence of focus on core components, these results cannot be considered authoritative or provide a consensus for the optimal training programme and how such a training programme should be implemented. Further research is needed to determine the effectiveness of resistance exercise for both older adults with and without clinical diagnoses and more rigour should be encouraged when selecting prospective participants, particularly with regard to potential contraindications for resistance training. Encouraging older adults to initiate and maintain physical activity needs to be addressed and may be facilitated by focusing on factors that influence adherence, thereby aiding the design of more effective (increase in participation and change in physical activity levels) exercise programmes (King et al., 1998). Furthermore, as quality of life and psychosocial well-being continue to be broad undefined concepts, the use of qualitative methodology may be useful to investigate the individualised effects of resistance exercise on this population group and may also permit refinement of target measures of psychosocial and psychological outcomes in order to help develop research.

### 4.6 Conclusion

The tendency of older people to be sedentary puts them at risk for serious health problems. The current review has demonstrated that resistance exercise training can provide significant improvement in functional and emotional well-being in clinically unwell older adults and maintain functional and emotional well-being in clinically healthy older adults. However, enduring lifestyle change is unlikely be achieved by short, temporary interventions. Future research should consider interventions that promote exercise self-efficacy, increase confidence and exercise behaviour, independent of structured rehabilitation programmes, and overcome barriers to achieving relevant fitness outcomes.

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Section B

**Empirical Paper** 

An exploratory study of quality of life, identity and engagement in patients with renal disease participating in a resistance exercise intervention during treatment

# **Empirical Paper Abstract**

# Background

A prominent but often under-researched chronic condition is that of chronic kidney disease (CKD). The quality of life of those diagnosed with CKD is frequently reported as poor. Resistance exercise is known to increase muscular strength and mass, desirable for this patient group, as well as having the effect of improving functional ability. However, older adults' participation in exercise and evaluation of its effects is equivocal.

# Method

A multi-method approach was adopted. Twenty-three participants were recruited through a larger study, a randomised controlled 8-week trial comparing the effects of resistance training with a treatment-as-usual control group. Questionnaires were used to generate pilot data to analyse the effect of exercise on quality of life/mental health on older adults. Qualitative data were collected through semi-structured interviews conducted post-intervention with nine participants who had been allocated to the resistance exercise group and analysed using thematic analysis.

# Results

There were no significant differences between the resistance exercise and control group on any of the quality of life measures. Improvement within groups was found on the HADS anxiety, SF-36 general and perception of illness in the exercise group, and HADS, SF-36 role emotional, perception of illness and physical self-efficacy in the control group.

Analysis of the interview data showed that six themes emerged across all of the dataset: adjustment to illness; capabilities/limitations of body/ability; maintaining life's qualities; impact of exercise; undertaking a research programme and being a helper.

# Conclusion

Thematic analysis revealed that participants in the current study found engaging with resistance exercise to be a positive experience by developing not only functional strength, but also improvements in mood, bodily confidence and social contact with others. In addition, committing to the sessions generated routine and purpose. However, the findings also suggest that those who are not effectively supported may not continue with their exercise routine, despite being aware of the health benefits.

### **1. Introduction**

#### 1.1 Background

With an aging population demographic has come a dramatic shift in the causes of death, from acute illness at the beginning of the 20<sup>th</sup> century to chronic illness at its end (Aldwin *et al.*, 2007). One prominent but often under-researched chronic condition is that of chronic kidney disease (CKD), a widespread medical condition in which the ability of the kidneys to carry out their function (help to maintain blood pressure, maintain levels of chemicals in the blood, produce vitamin D and erythropoietin) is reduced (NICE, 2008). In the UK, it is estimated that about one in five men and one in four women aged between 65 and 74 have some degree of CKD. This trend is expected to continue to rise at an annual rate of 5-8% (NHS, 2012; El Nahas & Bello, 2005).

Whilst UK data were less evident, numerous cohort studies in the USA and Japan have identified hypertension, diabetes, hyperlipidaemia (elevated levels of lipids and/or lipoproteins in the blood), obesity, and smoking as risk factors or markers in the general population for the development of CKD (El Nahas & Bello, 2005). The condition itself is divided into five stages defined by evidence of kidney damage and level of renal function (NCC-CC, 2008). As renal function declines, the disease ultimately reaches the life threatening end stage (Chang *et al.*, 2010). There is no cure for kidney disease, however treatment (lifestyle advice, blood pressure control, antihypertensive medication, statins and antiplatelet drugs) can slow or halt the progression of the disease (NICE, 2008). In the event of kidney failure, patients' survival requires dialysis or kidney transplantation (Davison, 2007).

Quality of life of those diagnosed with CKD is frequently reported as poor, with fatigue and dietary restrictions, loss of autonomy, changes in self-image and family dynamics

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reported as prominent as well as increased psychological morbidity (Casteneda *et al.*, 1998). Both physical integrity and social relationships are adversely affected as many life-sustaining practices cease. Eating, drinking, urinating and sleeping are no longer habitual responses to daily living (Kierans & Maynooth, 2001). Reduced physical fitness and physical functioning, resulting from feeling unwell, low morale, excessive fatigue and progressive deconditioning, impinges on the ability and capacity to perform activities in everyday life and leads to an increasingly sedentary lifestyle (Heiwe & Jacobson, 2011). Loss of appetite and resultant malnutrition also contribute to muscle loss in a significant number of patients, with many forty year old patients who have had years of renal failure and dialysis suffering from weakness equivalent to that of much older healthy populations (Smith *et al.*, 2012).

## 1.2 Body Renewal

Arguably, the way a person experiences their body is central to how they see themselves (Phoenix *et al.*, 2007). Prior to diagnosis of disease or in the absences of overt, known pathology, the body can be construed as a connected whole. However, the onset of chronic disease, and its treatment, involves major changes in body image (Helman, 1995). Kierans and Maynooth (2001) suggested that diagnosis creates a radical shift in locus of control from the inside to the outside. The self becomes defined exclusively in terms of one's disease, its treatment and related experience (Devins *et al.*, 1997) and the body is seen as fragile and deteriorating. Encouraging those with chronic conditions, not least those with CKD, to re-connect with their bodies and to view themselves as resilient may give them the determination to face the future (Caress *et al.*, 2001). This may be achieved by engaging in exercise during treatment, focusing attention on what the body is able to do, whilst improving the physical condition of the body. However,

well studied, with research to date predominantly focusing on individuals diagnosed with cancer.

Participants diagnosed with cancer, receiving chemotherapy, have revealed the importance of physical fitness and appearance for psychological and social well-being. Deterioration in muscle function caused by the treatment has been reported as particularly distressing, independent of age or gender. However participation in a six-week exercise programme enabled the participants to regain a sense of control of their bodies by revitalising some of their own physical resources (Adamsen *et* al., 2009).

### 1.3 Exercise

The relationship between exercise and psychological wellbeing is widely recognised, with significant Government investment spent on encouraging an active lifestyle. There has been a wealth of literature investigating the apparent benefits of exercise in nonclinical populations (Pinto *et al.*, 2003). However, there is also evidence to suggest that physical activity may not only improve the psychosocial aspects of surviving illness, but may improve tolerance for treatment and reduce risks for secondary illnesses (Schwartz, 2004). In a review looking at the potential benefits of exercise training in patients diagnosed with renal disease, Castaneda *et al.* (1998) found that physical activity may improve nutritional status, subjective wellbeing, enthusiasm and reduce risk factors for cardiovascular disease. They also reported that exercise treatments can be started early on in the course of the disease and can be continued while patients receive medical treatment and await renal transplant.

Additionally, exercise participation can be a highly valued and meaningful activity for those with a chronic physical health condition (Graham *et al.*, 2008). This research revealed exercise as a means to manage mood and pain, allow continued investment in

the self and preserve or enhance self-image. They also pointed to the role of exercise in furthering a sense of familiarity and connectedness with one's body and others experiencing similar difficulties.

However, data reporting older adults' participation in exercise and evaluation of its effects is equivocal. A review of older adults' participation in falls-prevention interventions (Bunn *et al.*, 2008) identified both facilitators and barriers to participation, the latter including: an absence previous exercise, physical discomfort, underlying beliefs about being 'too lazy', perception of being 'too old to exercise', poor knowledge of suitable exercise and poor access to exercise facilities. Facilitators were not simply the obverse of barriers (previous exercise and habit), but included social dimensions such as fun and enjoyment. Notably many of these themes identified older adults' self-perception and beliefs about how they were viewed by others, suggesting that physical activity interventions aimed at improving the self-perception of exercise self-efficacy can have positive effects on confidence and ability to initiate and maintain physical activity behaviour (Lee *et al.*, 2008).

#### 1.3.1 Resistance Exercise

Resistance exercise is a specific form of strength training in which each effort is performed against a specific opposing force generated by resistance. Healthy participants have reported gains in competency, a sense of satisfaction and felt "good" both physically and mentally as a result of their exercise achievements and experiences (Dionigi, 2007). Furthermore, participants' perceived bodily sensations associated with exercise, such as arousal and tiredness, were reported as positive signs of increased strength and health. Whaley and Schrider (2005) suggested that an older person may be motivated to maintain or increase resistance training if a connection is made between strength gains and their ability to remain independent.

Resistance exercise is known to increase muscular strength and mass, desirable for an older patient group who are more vulnerable to falls, as well as having the effect of improving skeletal muscle function, functional ability and ultimately quality of life. In a study of low-intensity strength training in adult haemodialysis patients, Chen *et al.* (2010) found improvement in physical performance, nutritional status and physical activity sustained beyond the study parameters. They suggested that low-intensity resistance exercise was promising as an adjunct to the routine care of patients with kidney failure treated by haemodialysis. Additionally, in a systematic review of exercise in haemodialysis patients, Sengura-Ortí (2010) identified resistance exercise as having a large positive effect on health-related quality of life, and positive effects on functional tests, quadriceps and overall lower limb strength. These results should be treated cautiously due to the small number of studies involved, however further investigations into resistance exercise appear warranted, given potential to mitigate the significant loss of muscle mass that occurs in haemodialysis patients (Sengura-Ortí, 2010).

# 1.4 The Present Study

The present study forms part of a larger, physiologically-orientated study examining the effect of a traditional high-load resistance training programme on skeletal muscle, functional ability and quality of life of chronic kidney disease patients. The larger study aims to establish the practicality of a resistance exercise programme in the chronic kidney disease population, and will provide preliminary data about the effect of the resistance exercise programme on physical functioning, fatigue level, quality of life, appetite and nutrition, muscle size and strength, risk factors for cardiovascular disease

and the cellular, biochemical and molecular mechanisms involved in the above effects. The current subordinate study focused on the participants' experience of having undergone a resistance exercise programme, the effect it had on their quality of life and their perceptions of their illness and body, both before and after participation.

# 1.5 Research Questions

- What is the participant's experience of having undergone resistance exercise training?
- What is the impact of participation in a resistance exercise programme on the perceived quality of life of those diagnosed with renal disease?
- How does participation in a resistance exercise programme allow participants to relate to their illness and a sense of identity?

# 1.6 Aims and Objectives

The main aims of the proposed study were:

- To examine the effect of a traditional high-load resistance training programme on the quality of life of renal disease patients.
- To explore the beliefs of participants about their physical ability and bodily competence and if this changes after participation in the programme.
- To explore the meaning of exercise in relation to illness and autonomy.

The objectives of the proposed study were:

- To broaden the existing literature on patients diagnosed with chronic renal disease by exploring the usefulness of exercise as a rehabilitation programme and generate understanding of the individual experiences of patients.
- To inform the design of future rehabilitation programmes for this patient group, including potential structure and benefits.

## 2. Method

#### 2.1 Study Design

Due to the dearth of literature on physical activity participation among people with chronic kidney disease, a multi-method approach, integrating both quantitative and qualitative methods was adopted. The current study was able to amend the protocol of the larger study to include additional quality of life questionnaires, deemed suitable for this patient group, and accessed the participants to invite them for interview for qualitative data collection.

Participants were recruited through the larger study (Appendix E), a randomised controlled eight-week trial comparing the effects of resistance training with a treatmentas-usual control group. The larger study commenced participant recruitment in the Spring of 2011. As the current study was a small scale pilot, all participants recruited from September 2011 were asked to participate. Quantitative assessments using questionnaires were used to generate pilot data to analyse the effect of exercise on quality of life/mental health of older adults. The questionnaires were administered at baseline and again at the end of the intervention. Qualitative data for the current study was collected through semi-structured interviews conducted post-intervention with participants who had been allocated to the resistance exercise group. Interviews and analysis of data were informed and achieved via use of thematic analysis. The approach permitted elucidation of in-depth information and enabled exploration of experience and meaning.

### 2.2 Thematic Analysis

Thematic analysis has been described as a method for identifying, analysing, reporting and interpreting patterns within data (Boyatzis, 1998; Braun & Clarke, 2006). It is suggested that thematic analysis is not wedded to any pre-existing theoretical perspective and therefore can be used within different theoretical frameworks (Braun & Clarke, 2006). The current study proposed an essentialist or realist framework and therefore the analysis sought to report experience, meaning and the reality of participants (Appendix F).

The interaction between, and experience of, renal disease and exercise appeared to be an under-researched area, therefore the aim of the analysis was to provide a rich thematic description of the entire data set, rather than to focus on a detailed account of one particular theme within the data set. This meant that the data was subjected to an inductive analysis (Frith & Gleeson, 2004) and themes were identified at a semantic level (Boyatzis, 1998). The selection of thematic analysis as opposed to other approaches is considered in the critical reflection section.

### 2.3 Ethical Approval

Ethical approval was sought and granted through the NHS Local Ethics Committee (Appendix G).

Given the current study formed part of a larger study, the inclusion and exclusion criteria for the total pool of potential participants were set from the larger study (Appendix E).

Twenty-three participants diagnosed with moderately severe kidney disease (Stages 3b-4), aged between 40 and 85 years were identified for eligibility from renal clinics at their local hospital by staff involved in their routine clinical care. Younger participants were excluded from the current study, as their muscle quality was likely to be significantly different to that of older patients. Therefore older adults in the current study were defined as CKD patients who had decreased muscle quality, normally those aged 40 and over. The participants were randomised to either the resistance exercise group or the control group. One participant from the exercise group and three participants from the control group withdrew from the study. One participant died during participation of the study. Therefore the results reflect 18 remaining participants. Demographic information from the participants who completed the questionnaires is presented in Table 1.

Variable		Experimental Group (n=11)	Control Group (n=7)
Age (mean years (SD))		59.4 (9.18)	64.6 (12.54)
Gender	Male	5	6
	Female	6	1
Ethnicity	White	10	6
	South Asian	1	1

Table 1. Demographic characteristics of participants who completed questionnaires

The eleven participants allocated to the resistance exercise group were then invited to attend a one-to-one interview. Two participants declined to attend; therefore the results reflect nine participants. Demographic information is presented in Table 2.

Participant	Age	Gender	Ethnicity	Time lapse between last exercise 'class' and interview
Tom	58	Male	White British	seven months
Susan	65	Female	White British	three months
Rachel	49	Female	White British	four months
Andrew	56	Male	White British	eight months
Tony	67	Male	White British	eleven months
Linda	57	Female	White British	three months
June	63	Female	White British	three months
Robert	80	Male	White British	two months
Joanna	45	Female	White British	two months
	I		I	

Table 2. Demographic characteristics of interview participants.

### 2.5 Measures

The Hospital Anxiety and Depression Scale and the 36-item Short-Form Health Survey were measures collected as part of the larger study. The Physical Self-Efficacy Scale and Brief Illness Perception Questionnaire were additional measures added by the current study to provide information about self-efficacy and illness perception, which were estimated to have important effects on cognitive, affective and behavioural patterns. 2.5.1 Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith,1983, as cited in Crawford et al., 2001)

The HADS is a brief (14 item), self-report measure of anxiety and depression. Developed for use in general medical out-patient clinics it is now widely used in clinical practice and research. The HADS comprises two subscales, Anxiety and Depression (seven items each); questions are rated on a Likert scale from 0 to 3. Scores for each subscale are summed with a maximum of 21. Higher subscales indicate elevated levels of morbidity and the authors recommend a cut-off score of 8 to indicate clinical levels of anxiety or depression. The HADS has satisfactory internal consistency, test-retest reliability, face, concurrent and construct validity (Snaith & Zigmond, 1994).

#### 2.5.2 36-item Short-Form Health Survey (SF-36) (Ware & Sherbourne, 1992)

The SF-36 is a multi-purpose short-form health survey. It yields an 8-scale profile of functional health and well-being scores as well as psychometrically based physical and mental health summary measures. It is a generic measure, as opposed to one that targets a specific age, disease or treatment group. The reliability of the eight scales and two summary measures have exceeded the minimum standard of 0.70 recommended for measures used in group comparisons (Tsai *et al.*, 1997) and it has satisfactory content, construct and predictive validity.

2.5.3 Physical Self-Efficacy Scale (PSE) (Ryckman et al., 1982, as cited in Fischer & Corcoran, 2007)

The PSE is a 22-item questionnaire, and is based on the assumption that people's expectations about their own efficacy have important effects on cognitive, affective and behavioural patterns. The PSE is designed to measure individual differences in perceived physical competence and feelings of confidence in displaying physical skills to others. The PSE has good internal consistency with an overall alpha of 0.81 and six-week test-retest correlations of 0.80. The PSE has good concurrent and predictive validity, correlating significantly with a number of other measures.

2.5.4 The Brief Illness Perception Questionnaire (Brief IPQ) (Broadbent *et al.*,2006)

The Brief IPQ uses a single-item scale approach to assess the cognitive and emotional representations of illness on a continuous linear scale. The shorter version of the IPQ was developed to use when a long questionnaire is prohibitive, such as with very ill participants or when there is limited time available for assessment. The Brief IPQ has shown good test-retest reliability, predictive, discriminant and concurrent validity (Broadbent *et al.*, 2006).

### 2.5.5 Semi-Structured Interview Schedule

A semi-structured interview schedule was constructed for the purposes of the current study (Appendix H). The schedule was flexible and was adapted and evolved as information was generated from early interviews. Topics for discussion and sample questions were listed in advance, but the exact wording and ordering of questions was developed in the course of the interview, depending upon what issues were raised by the participant. Audio-recording equipment was required in order to record the interviews, with the informed consent of the participants. Eight of the interviews were transcribed by a professional transcriber who was an academic administrator who had experience of handling sensitive information and was required to sign a confidentiality agreement (Appendix I).

#### 2.6 Procedure

Both the larger study and the current study were discussed and explained to potential participants at a routine clinic visit by the nursing staff. Patients who expressed an interest in the study were provided with an Information Sheet (Appendix J), with a reply slip allowing the subject to indicate their willingness to participate or to request further information. Written consent was then obtained.

Each participant was randomly assigned, by researchers in the larger study, to either take part in the resistance training intervention (N=12) or to the non-training control group (N=11). Randomisation was performed using the block method by Altman and Bland (1999).

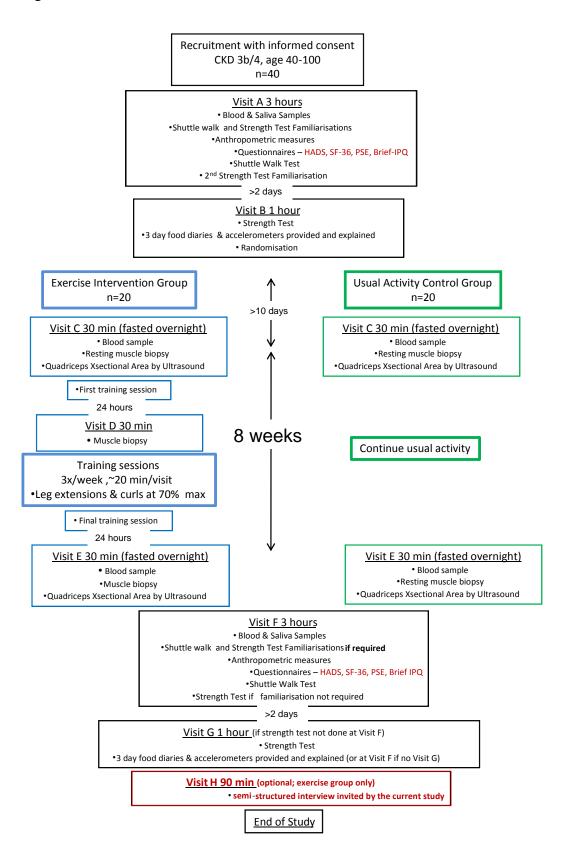
Participants followed the procedure of the larger study (Figure 1). The control group were asked to continue with their normal daily activities and routine clinical care. The intervention group were also asked to continue with their routine clinical care but in addition, were asked to attend training sessions three times a week for eight weeks at the local hospital. The training sessions themselves involved only the participant and an associate researcher; however, there was opportunity for participants to meet others at the start/end of the sessions.

The resistance exercise comprised leg extensions performed on a fixed resistance machine at 70% of maximum strength (as measured in the baseline assessments). The training was individualised and typically consisted of three sets of 12-15 repetitions. The weight was increased through the eight weeks as the participant became stronger. Each training session lasted twenty minutes, with the participant first warming up with 5-10 minutes of light aerobic exercise, followed by the resistance training as described above. The session ended with another five minutes of gentle aerobic exercise and some

stretches to cool down. Participants were asked to attend all training sessions (N=24), however a few missed sessions were tolerated. In line with the larger study, participants were excluded from the analysis if they failed to attend at least 18 sessions (75%) or if they missed more than three consecutive training sessions.

After eight weeks, all participants were asked to attend two final visits where baseline assessments were repeated. The participants in the resistance exercise group were then invited, by researchers in the larger study, to attend a one-to-one interview in a building on the hospital site, but separate from where the resistance exercise or kidney clinics took place. The participants were then contacted directly by the researcher in the current study to arrange a convenient date and time. Consent to take part was obtained at the beginning of each interview by the researcher in the current study (Appendix K), and the participants were reminded of their right to withdraw at any time. The interviews followed the semi-structured interview schedule, but the researcher in the current study maintained a flexible approach and the participants were encouraged to raise issues they felt pertinent to the study. The interviews were audio recorded and lasted between 45-80 minutes, with the recorded sections lasting between 25-65 minutes.

### Figure 1. Procedure Flow Chart



#### 2.7 Analysis

### 2.7.1 Statistical Analysis

The data were presented as mean  $\pm$  standard deviation (SD) and analysed using computer software (IBM SPSS statistics version 20). The differences between the pre and post scores for all subscales were calculated and entered as a separate variable. Data were tested for normality using the Shapiro-Wilks test. Pearson correlations were conducted to determine the strength of the relationship of the subscales within two of the measures (HADS & SF-36). Significant weak/moderate correlations were found between the anxiety and depression subscales of the HADS and between several of the subscales of the SF-36. No correlation was found to be above r=0.6, therefore each subscale was treated as a separate variable

For parametric data, an independent measures t-test was used to analyse the difference between the pre and post scores between groups and non-parametric data were analysed using Mann-Whitney U test.

Post hoc power analysis was calculated using G\*Power software (Faul et al., 2007).

## 2.7.2 Qualitative Analysis

Data from the interviews were transcribed verbatim and were initially analysed using line by line coding, applying descriptive labels to each line of the transcript. This enabled the researcher to become immersed in the data set and the analysis firmly grounded in the data. These codes were then sorted into potential themes, by grouping all the relevant data extracts into groups. The name of each code (and a brief description) was written on separate pieces of paper and organised into theme-piles (Braun & Clarke, 2006). As the initial themes emerged, the coded extracts for each theme were collated and examined to see if they formed a coherent pattern. The researcher then read and re-read the transcripts looking for further examples, as well as disconfirming data. This also helped to code any data that had been missed in earlier stages of coding. The themes and sub-themes were clustered and arranged into a thematic explanatory map (Appendix L), which was then compared against the data to see if it provided an explanatory framework for each case. This was refined until a model of 'best-fit' was developed.

## 2.8 Quality Checks on Interview Data

The reliability of the current study was enhanced by being transparent and explicit about methodological procedure to enable replication. To improve validity of thematic analysis, sections of transcripts were independently coded by the research supervisor. The current study then employed the quality checks for thematic analysis proposed by Braun and Clarke (2006) using a 15-point checklist to judge that the theory and method had been rigorously applied.

### 3. Results

#### 3.1 Statistical Analysis

Differences within and between groups in scores of quality of life are shown in Table 3. There were no significant differences between the resistance exercise and control group on any of the quality of life measures. However, post hoc power analysis was found to be 0.36 (Appendix M). Improvement between baseline and post scores were found on the HADS anxiety, SF-36 general and perception of illness (Brief IPQ) in the resistance exercise group and HADS (anxiety and depression), SF-36 role emotional, perception of illness and physical self-efficacy in the control group. The differences between pre and post scores did not reach statistical significance.

### 3.1.1 Questionnaire data for interview participants

The results from the questionnaires for each individual who participated in the interviews are presented in graphical form. The results reflect eight participants, as the questionnaires were not obtainable for one of the participants. Four participants reported reduced levels of anxiety post-intervention, two reported no change, and two reported increased levels of anxiety (Figure 2). The results for the SF-36 general subscale show four participants reported improvement in their general functioning post-intervention, one reported no change, and three reported reduction in their general functioning (Figure 3). The results from the PSE and the Brief IPQ reflect seven participants, as completed questionnaires were not obtainable for a further participant. Three participants reported improvement in their perceived self-efficacy, whilst four reported reduction in their perceived self-efficacy post-intervention (Figure 4). Five participants reported deterioration in their perception of CKD, one reported no change and one reported improvement in their perception post-intervention (Figure 5).

# Table 3. Quality of life outcomes

Variable		Resistance Exercise (n=11)			Control Group (n=7)			Effect size
		Pre	Post	Change (pre-post)	Pre	Post	Change (pre-post)	(exercise vs. control)
HADS	anxiety	6.3 (2.26)*	6.1 (6.15)	-0.22 (2.86)	5.67 (6.12)	4.8 (6.14)	-0.83 (0.75)	0.21
	depression	4.9 (3.25)	4.9 (3.47)	0.0 (1.41)	4.33 (2.94)	4.0 (4.52)	-0.03 (2.42)	0.23
SF-36	General	50.38 (26.62)	51.38 (21.88)	+1.00 (14.61)	40.67 (24.96)	35.17 (17.65)	-5.56 (8.22)	0.82
	Physical	55.0 (32.4)	53.75 (37.30)	-1.25 (21.67)	71.67 (30.93)	63.33 (31.73)	-8.33 (9.31)	-0.28
	Role Physical	43.06 (43.81)	34.38 (44.19)	-9.37 (35.2)	54.17 (51.03)	50.0 (47.43)	-4.17 (55.72)	-0.34
	Role Emotional	87.5 (33.36)	58.31 (42.72)	-29.19 (37.54)	72.22 (44.31)	77.77 (34.44)	+5.55 (44.32)	-0.50
	Social	81.25 (17.68)	73.44 (27.9)	-1.56 (14.07)	77.08 (33.93)	77.08 (38.26)	0.00 (15.81)	-0.11
	Pain	66.5 (24.06)	65.5 (27.41)	-1.00 (16.66)	72.83 (34.1)	69.0 (35.38)	-3.83 (28.95)	-0.11
	Mental	79.0 (9.97)	65.5 (27.41)	-7.00 (13.65)	76.0 (20.71)	67.33 (21.23)	-8.67 (8.55)	0.24
	Vitality	48.75 (22.48)	48.13 (24.92)	-0.63 (9.04)	48.33 (26.58)	46.67 (22.06)	-1.67 (9.31)	0.06
IPQ		47.2 (10.96)	44.6 (10.55)	-3.00 (8.50)	53.86 (9.04)	47.14 (16.18)	-6.71 (14.40)	-0.19
PSE		80.78 (14.22)	78.56 (13.22)	-2.00 (12.13)	78.83 (14.16)	84.83 (13.78)	+6.0 (7.29)	-0.46

\*Data presented as mean (SD)

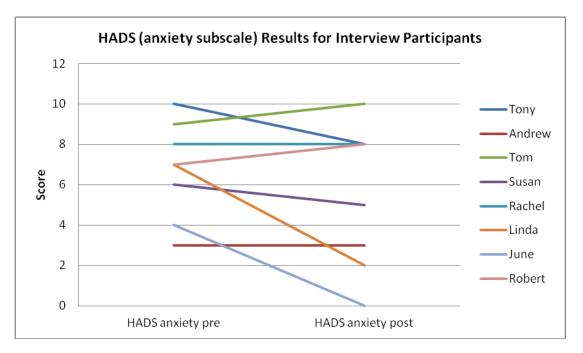
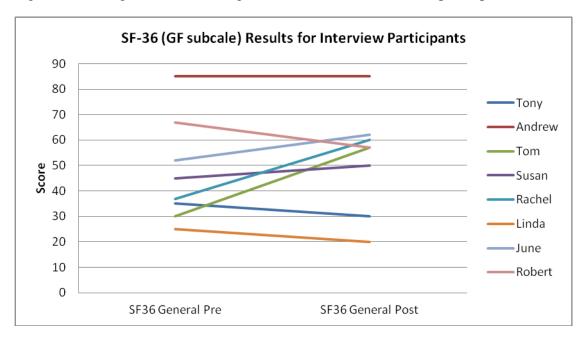
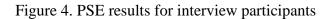


Figure 2. HADS anxiety subscale results for interview participants

Figure 3. SF-36 general functioning subscale results for interview participants





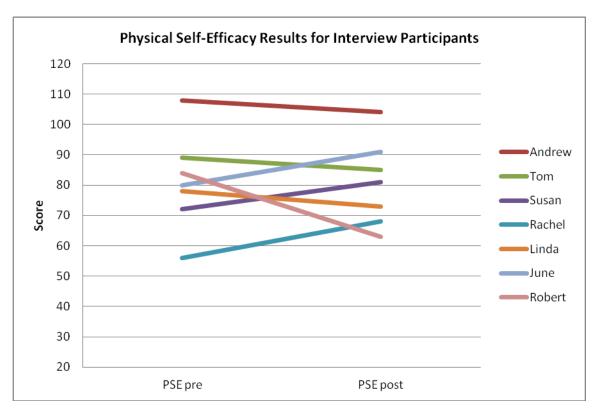
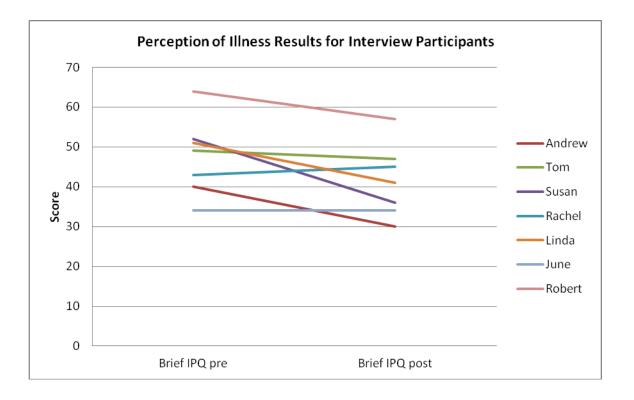


Figure 5. Brief-IPQ result for interview participants



## 3.2 Thematic Analysis

Interviews were conducted with nine participants (five women and four men) who had been allocated to, and participated in the resistance exercise group. Participants ranged in age from 45 to 80 years (mean age 60). Although there were considerable differences in the lived experiences of the participants, there were six themes that emerged across the complete dataset: *adjustment to illness; capabilities/limitations of body/ability; maintaining life's qualities; impact of exercise; undertaking a research programme* and *being a helper* (Appendix L). Some of themes were more prominent in some of the accounts than in others.

## 3.2.1 Adjustment to Illness

An emphasis on adjustment to illness was the main overarching theme that emerged from the data. Adjustment appeared to reflect participants coming to terms with a significant life limiting diagnosis, learning to live with kidney disease and encompasses the impact on both the participants (self-identity) and their families, the participants' uncertainty about illness progression and their future, having to incorporate a medication regime into their lives and engagement with, and reliance on the hospital.

Participants spoke of the shock of being diagnosed with kidney disease and the impact that it had on them.

Normally I was a bit more happy go lucky and take things on the chin, but err......Yes I think it, being struck down with this illness, it's sort of a, well it's a life changer, a heck of a shock... and I think that's taken its toll, you know, that we're not indestructible and you never know what the future holds, you know, next week is another week. **Tom from line 110** 

It took me a long time to come to terms with my illness....um, I suppose it's the same as anybody when something goes wrong you wonder why it happens to you, when you can't.....see any reason that you have done anything wrong for this to happen. So that took a lot of adjusting to...and I had moments and certainly got very depressed at times.

## Tony from line 20

Participants described feeling a lack of personal agency and of being unable to do anything to improve their health, or facilitate recovery. Some of the participants spoke of fear of physical health deterioration and the possibility of requiring dialysis and therefore implied reliance on machinery to sustain life.

So at the back of my mind there is always that thought (getting worse). The absolute dread for me would be going on dialysis, you know, where you're not in control of what's happening to your body at all. Linda from line 157

There are a few measures you can take to help yourself but it's not like other illnesses, where you know, making lifestyle changes has a significant impact on how the disease is, and how it affects your well-being. So I think that, you experience, a feeling of a lack of control over what it happening to you. **June from line 30** 

Some of the participants discussed the adverse effects of required medication to maintain their health and resultant side effects. In particular, the male participants seemed to struggle to come to terms with the visible side effects of taking steroids and changes in their body shape and muscle tone.

Loss of muscle tone yes, but the other side of the coin is that you get bloated with these steroids, so I did put on weight, um, which I wasn't particularly happy about it but it goes with the territory doesn't it, you do what you have to do. Um, fortunately I'm off the steroids at present and my (coughs) my weight's reduced, partially to do with that I should think. Tony from line 123

But err I think they affect me as well, the steroids I think, you know, if I'm being honest I think the steroids make me feel a bit shaky and.....I don't know about the (other medication) but err I think steroids have made me erm a bit hamsterish and a bit pot bellied and my muscles aren't as good as they used to be, in my arms especially I noticed that, I get tired in my arms. **Tom from line 67** 

Finding a medication regime without significant adverse consequences appeared to be both stressful and anxiety provoking. The participants acknowledged that they needed their medication to maintain the function of their kidneys, but had not anticipated the negative physical and psychological consequences (lethargy, low mood, increased appetite, swollen ankles, aching muscles, loss of muscle tone, weight gain). Finding a medication regime which suited them could be protracted, but had a significant positive effect on their capacity to cope with daily life.

I am currently on a form of medication which, my medication has had to be changed several times because it hasn't suited me, erm and I have found that quite, quite.....depressing really. Erm having got on to an erm, a medication regime that appears to suit me, I am feeling a lot more laid back about the whole thing, I was a lot more anxious, I am a lot less anxious about it (illness) now. June from line 61

All participants appeared very mindful of liaison with their medical team, either to be monitored or to clarify what was happening to them. Some participants described clinic attendance as anxiety provoking, fearing that doctors would confirm deterioration in kidney function. However, positive results (maintenance of kidney function) provided reassurance, direction and some agency, as well as enabling participants to feel upbeat about the future.

It's always at the back of your mind that next time you go to see Doctor (name), he may say 'oh it's gone down that bit further'. Linda from line 146

Um things are ticking over quite nicely, I see the consultant on a regular basis, three monthly, and depending on what he says, as to whether anything needs changing or not, I do accordingly. And if the results are positive then I have a better outlook obviously to know that what I Am doing is the right thing. **Tony from line 25** 

Two participants reported experiencing no symptoms and appeared to resist identifying themselves as a patient. They actively reflected on their health status only at routine appointments and when in contact with their doctor.

I didn't really know it was an illness, you know. I mean I've never been told sort of anything. So I sort of didn't know I was ill, you know. So erm (long pause) I don't know, I don't know as I'm ill or not, you know. **Rachel from line 394** 

There's no um, I didn't know I'd got a kidney problem.....and there's still no um, no um (pause) no manifestations of it physically. Andrew from line 141

3.2.2 Capabilities/Limitations of Body/Ability

The theme of capabilities and limitations of body and ability encompassed participants discussing adapting to bodily changes. This appeared to be related to either functional changes associated with ageing and limitations in the body's capacity to engage in routine daily activities or functional changes associated with living with kidney disease. *Obviously I can't do things because of my age, even if there wasn't a problem with my kidneys....'* **Tony from line 62** 

erm you can't substitute wanting to do more in the garden because physically I'm not able to do it, but you know, you've got to live with that sort of thing. Robert from line 102

Whereas functional changes associated with ageing were somewhat anticipated, and tolerated as inevitable, the impact of kidney disease on the body's ability seemed much harder to accept and for some, it appeared to create resentment towards the disease.

And I do get shaky, I'm not as strong as I was, I've not got the, I've not got the strength or stamina, So that's the toughest bit, you know, stuff I used to take for granted I've got to think twice about, yes. **Tom from line 247** 

It's the muscle wasting that's so horrible I think because your mind's not ready for your body to start acting like that, you know, your mind's still young but your body's acting like a 60 or 70 year old and it's not right, it's just not a natural thing, you know. If I was like in my 70s, yes, I'd expect to be a bit slower, but certainly not in my 40s and 50s, you know. **Linda from line 533** 

Some of the participants also spoke of the difficulties in maintaining their bodies and improving their general health and fitness. Although they were aware of the necessity to be healthier, they still faced challenges in sustaining a healthy diet and lifestyle.

And I keep saying to myself, Rachel you've got to try and lose some (weight) but I mean, erm this healthy eating thing, I don't know how it's going to go, how long it's going to go on for. I mean we're all getting a bit hungry at times...... **Rachel from line 501** 

## 3.2.3 Maintaining Life's Qualities

This theme appeared to encompass respondents' attempts to maintain resilience and independence. The majority of participants reflected on life quality in positive terms and viewed taking steps to preserve and improve their quality of life as life enhancement. For some this was facilitated by retirement and the availability of time.

Yeah and another thing about quality of life is time as well, you know time was at a premium before, umm and it's not any longer. If I want to spend several hours doing something, I can do it. If I want to spend several hours actually doing nothing I can do it as well, you know. Andrew from line 114

For other participants being diagnosed with kidney disease had changed the way they viewed their quality of life, and prompted them to re-evaluate what was important to them.

I'll tell you what I do every day, it doesn't matter whether it's hail or rain or shine, I say thank you for another one, whereas before I didn't bother, you know. I cherish every day whereas before we just, I think I took things for granted more. So that's been a change. **Tom from line 113** 

The majority of participants emphasised control over their quality of life as highly significant. Control appeared to be explicitly associated with developing resilience and appeared to have a positive impact on them.

Yes because I think I have a reasonably good.....reasonably good control over those aspects of my life, yeah. So I am able to tune in to those little things that are, I.....am going to be able to deal with things that I don't particularly enjoy or whatever, but I am able to access the, you know, the things that are important to me as well. June from line 84

I think you know, you think you are doing something and therefore psychologically it makes you feel as though you are trying to get over or to improve, yeah. So I think that way it (exercise) does definitely. **Susan from line 359** 

For others whilst there was acknowledgement that life quality was important, there seemed to be resignation to a reality of limits to what they could do personally to improve their circumstances.

Well a great deal really, erm but I do see it's out of our hands to be frank. Erm but while you can maintain it (quality of life) as long as you can err, and that's, that's it, that, it means a lot, full stop. **Robert from line 112** 

3.2.4 Impact of Exercise

The theme of impact of exercise encapsulated the participants' history of exercise behaviour, current exercise behaviour and their appraisals of the effects of undertaking a resistance exercise programme. For the majority (five) of the participants the programme had enabled them to develop a routine and had encouraged them to carry on exercising. For others, they had found it hard to maintain exercise by themselves.

Only three of the participants had attended a gym before starting the study, yet most of the participants described themselves as being active when younger, either through playing sports, or leading active and busy lives.

And err, as I say, erm although I've never been a member of a gym, I've always said I don't need a gym, I've got a garden, you know, I'm always doing something. You know, I've not got muscles out here but I was always very active and I err kept active. Tom from line 365

I used to run for miles a few years ago, you are talking 15-20 years ago, a long time. But yeah I was always exercising, swimming, running, always ran, I couldn't do it now (laughs). But you see, in your body, you kind of think I want to do that again, but I can't do that, erm...yeah it (exercise) was always huge, but I don't know where it went. Joanna from line 105

All participants disclosed feeling better, both physically and mentally, after an exercise session. Some noted a 'buzz' or feeling full of vigour for the first time. Others spoke of having more confidence in their bodies, seeing their legs improving in muscle strength.

But I really enjoyed that (exercise) that was the first time, the first and only time that I've ever felt that burning in your legs. And I was listening to one of these Olympic fellas on the telly going on about the lactic acid in his legs and that burning, and I thought I know what he means now, you know. I thought that was really good. Linda from line 246

I must say I did feel better while I was doing it, you know, I said to the researcher 'I can't believe my legs feel great', you know. Susan from line 119

Diagnosis of a chronic condition had contributed to a loss of daily routine for five participants. From being occupied and work-orientated, participants reported becoming focused on recuperating and staying at home. Committing to the exercise sessions helped foster routine and gave purpose to get out of the house.

I think if I haven't had had that programme I might have gone round the bend, you know. It gave me something to get in the car for and go and do, whereas I'd been used to having a very active life, a very full on job, and err the programme really I suppose err filled part of that, that I hadn't got anymore, you know, because I was away from my workplace. Yes, so mentally it kept me positive. **Tom from line 532** 

I like to be as active as I can, um, this study helped me to get back into a, a kind of routine which had been lacking before. But of course the illness does that sort of thing anyway so it was a kick up the backside if you like, um, to help me get back into some form of exercise, regular, you know. **Tony from line 6** 

Some of the participants noted how engaging in the resistance exercise had encouraged them to continue with exercise outside of the study, and develop their own exercise routine.

.....I would say it gave me food for thought and made me think yes this is ok, because previous to this I thought how do I fit it in, I can't fit it in I am too busy.....but fitting that in it kind of had to three times a week, so I think you can.....so I have been out and bought walking trainers, so yes. It's more wellbeing I think, more positivity mentally. Joanna from line 53

The suggestion made to me was pilates. So I have joined a pilates class and I am actually enjoying that, erm. Something new that I am doing, I am enjoying doing and that I feel is probably having some benefit physically. June from line 50

However, others reported ongoing struggle to exercise, despite understanding its benefits for them. Some expressed a lack of confidence in knowing which exercise was best, which they suggested underscored their inability to continue. For others, without the regular support and encouragement from the researcher, self-motivation diminished and they found it increasingly difficult to continue with exercising. I'd like to but I just don't know where to go. I know because I've got COPD I'm allowed to use erm, I think I could get something from the hospital, a letter or something where you could go to a gym and you, at certain times of the day and get reduced prices to go in, but at the same time I'd want to know that I had somebody who knew, like, you know, like a physiotherapist who would be able to set me something that I knew I could, you know certain targets that I'd get to go for. I have no idea what is the best exercise for what. Linda from line 553

Some days I wish I could get out more and walk more and others days I think 'oh I can't be bothered'. **Rachel from line 92** 

3.2.5 Undertaking a Research Programme

This theme encapsulated both the positives and negatives of participation, and suggestions for the future. Participants spoke of the social support and encouragement they received from interacting with the research team, which seemed to be something that they hadn't necessarily expected from taking part in physical health research. For the majority of participants (eight) this incidental social contact meant that the experience of taking part was an enjoyable one.

But I have to say that I enjoyed the atmosphere of it and the camaraderie of it and the people I was working with.....as much as the exercise itself. **Tony from line 162** 

They're all really nice, you know, you just felt like you were part of the family, which made a big difference, you know. It felt like they were there for you, you know, even though, you know, you're only part of it but you're important. Linda from line 403

Participants spoke of having confidence in the research team (the team's understanding of their disease, competence in delivering the resistance training and awareness of the

boundaries of increasing resistance) and the belief that they were in safe hands. For some of the participants, this motivated them to think about how to incorporate exercise into their routine, for others, it made them wary of trying to exercise by themselves and reinforced the desire of having others around them when exercising.

I think it's like having a personal trainer and it's um, it's, it's not only someone taking you through the mechanics of it, it's someone trying to push you to your limit, but knowing what that limit is and not allowing you to hurt yourself. **Andrew from line 405** 

And they understood how far they could push you, you know. It scares me that you could be pushed to the limit and go and break something, whereas a proper, somebody who's trained knows how far you can go without damaging anything. Linda from line 271

For some of the participants, having someone waiting for them provided extra incentive to go. Expectation of attendance meant that participants entered into a social contract with the researcher and therefore felt obliged to go, so as not to let them down. Without this, participants commented on the difficulties of maintaining an exercise routine.

And another thing I think because you have arranged to go there I would never dream of letting them (researcher) down.....so you are like forced to go whether you feel like it or not and you do it. Whereas right now no. I don't feel like doing much today, so I try to do the exercises they showed me, but I don't always try. **Susan from line 121** 

So you are going to somebody and it wasn't like a machine will miss me, I if didn't go the machine didn't care, but you are kind of letting somebody down if you don't go, so you felt you had to, you had made a promise so you have got to do it. Whereas if you are left to your own devices sometimes you falter off don't you. **Joanna from line 14**  Participants spoke about some of the difficulties associated with participating in the research. For some, it was the burden of frequency, of attending the sessions three times a week, and the impact that this had on their normal routine.

It did kind of interfere a bit with my children, I did feel a bit of a.....poor wreck.....So I did feel that pull, I felt a bit stretched erm and I said I would do one again but......I don't know if I would. I would really like to but probably when things are calmer. Joanna from line 243

For others, it was the circumscribed nature of the exercise programme, focused only on strengthening the legs, whereas strengthening other parts of the body (arms, torso) was considered to be equally important and valuable for the participants. Some participants described wanting a more general programme with additional follow-up, to increase their motivation to carry on with the exercises and to reassure them that they would continue to be supported.

And I would think that a programme for patients like myself, as a matter of course following being discharged from hospital, should be put in place for all sorts of muscle areas. I mean my legs I feel are alright because I'm walking around and doing things but I think my arms and upper, I get tired in my arms and I think a set course of, I don't know, physio or physical activity or whatever, properly monitored, it will give people like myself a lot of err confidence. **Tom from line 168** 

You know, I just wish it, you know, was available, erm not just to a few but, you know, probably twice a year to catch up and do it again so that you know in the meantime you can try to keep your levels up because you're going to be doing it again sometime rather than just a one-off, you know. Linda from line 463

3.2.6 Being a Helper

The final theme of being a helper encapsulated the participants' feelings about being able to reciprocate, and contribute to the renal unit and the staff who had supported them. Most of the participants expressed gratitude for the care they had received from the medical team, and saw participating in research as a way to meaningfully give back.

Erm I just felt pleased about it and positive that I was contributing to, you know, a bit of payback really because as I said earlier I've been looked after very well. Tom from line 578

I just thought, I was just approached err, while I was in the clinic one day and I thought well, anything you can do, if I can help out then fine because you are always helping me (laughs) it's nice to be able to give something. Joanna from line 125

I think, I think the main objective was to help, yeah, I think from my point of view erm they were trying to do something worthwhile and therefore if you could help you ought to try to help. June from line 233

Some participants also spoke about trying to help future patients by contributing to research, which seemed as important than any personal gains acquired by completing the programme.

I didn't know what it was going to achieve but I thought well anything that helps other people in the future. I mean other things can't come out unless somebody tries these things out, you know, so somebody's got to do it and, you know, I thought well why not. Linda from line 495 If I gain some benefit that's a bonus, if it helps those down the line I will be very happy, we will be very happy, not I, somebody else will get the benefit if you don't. So that's the whole thing encapsulated really. **Robert from line 408** 

I was glad to take part in the programme because any involvement in something which is about generally improving the health for a group of people who um, who it might benefit, just seemed to be a good thing to do really. **Andrew from line 329** 

## 4. Discussion

## 4.1 Discussion of the Results

Chronic kidney disease (CKD) is a chronic condition which, via debilitating symptoms, reduces daily activity and increases muscle loss, leading to an impaired quality of life. Resistance exercise, with its potential to effectively increase muscle mass, is an appropriate rehabilitative strategy for both mitigation and prevention of gradual physical deconditioning, however resistance exercise training for the CKD population has not been well studied.

The current study was designed to examine the effect of resistance exercise on the quality of life of those diagnosed with CKD, using both quantitative measures to generate pilot data, and semi-structured interviews to elucidate participants' experience of completing the programme. There were no significant differences found between the resistance exercise group and the control group on the subscales of the Hospital Anxiety and Depression Scale (HADS) and 36-item Short-Form Health Survey (SF-36) or the Brief Illness Perception Questionnaire (Brief IPQ) and the Physical Self-Efficacy Scale (PSE). However, the overall sample showed very low levels of anxiety and depression prior to participating in the current study.

The mean differences within the resistance exercise group were in the predicted direction for reduced anxiety, improved general functioning and perception of illness. It is possible that changes in mental health functioning and perceived improvements in quality of life develop over a longer duration of resistance training, rather than eight weeks. CKD haemodialysis patients undertaking high intensity resistance exercise have shown improvements in self-reported physical functioning and vitality (as measured by SF-36) following three months (Cheema *et al.*, 2007; Johansen *et al.*, 2006) and six

months (Chen *et al.*, 2010) of training. The measures used in the current study were generic measures and not designed specifically for the CKD population. Therefore they did not include questions on areas such as relationships, sexual functioning, dependence/independence, self-perception or perception of the future, which may be particularly relevant to this patient group due to the progressive deconditioning nature of this illness, and therefore the potential life-limiting effects. Additionally, some of the factors included in the questionnaires may have been irrelevant or redundant (Carr & Higginson, 2001), therefore insufficiently measuring change in participants' quality of life. However, the current study suffered from low statistical power, therefore increasing the likelihood that a statistically significant result would not have been found, even if present.

# 4.1.1 Interpretation of Qualitative Data

Thematic analysis was used to provide more detailed understanding of participants' experience of engaging in an eight-week resistance exercise programme and the impact of this type of exercise on living with CKD. The final thematic map (Appendix L) revealing six themes found in the data was developed from the ground up, using an inductive approach.

Adjustment to illness, as a theme, referred to the coping strategies employed by the participants to manage their reality as a CKD patient. Participants discussed their frustration and fears at being diagnosed and the altering effect diagnosis had on their daily lives. Devins *et al.* (1997) suggested that the day-to-day experience of chronic illness exerts powerful influences on self-concept, leading individuals to define themselves in terms of the condition and its treatment. In addition, CKD offers limited opportunities for personal control, thereby creating reliance on medication and hospital

staff. Medication was often experienced by the participants as intrusive, creating adverse side-effects. Adjustment was improved when a stable medication regime was introduced. Contact with health professionals was viewed as ambivalent, with participants both apprehensive (due to uncertainty of health status) and reassured (if health status was maintained). Therefore, engagement with the resistance exercise programme could be viewed as enabling the participants to receive regular health checks, due to proximity with health professionals, and this therefore informed and reassured participants of their health status.

All participants discussed changes in body function and ability, attributable either to ageing or as a result of CKD. Whilst changes associated with ageing appeared to be expected, physical changes due to CKD appeared less tolerable. This was hardly surprising, as evidence suggests that CKD is associated with the development of impaired physical function in previously well-functioning older people (Fried *et al.*, 2006). In particular, two of the male participants reported struggling with the resultant muscle loss associated with CKD and prescribed medication. Research suggests that it may be more acceptable to men for changes in physical function to be a result of the natural ageing process (and therefore inevitable), rather than resulting from 'ill-health', which may suggest bodily weakness and reduced masculinity, hindering the capacity for demonstrating socially desirable characteristics of strength and stamina (Chapple & Ziebland, 2002; Clarke *et al.*, 2008; Robertson *et al.*, 2010; White, 2002). From this view, resistance exercise may enable men to regain their masculinity by differentiating themselves from 'ostensibly thin and fragile women' through the development of lean muscle mass (Mills & D'Alfonso, 2007).

The importance of trying to maintain physical functioning was acknowledged by all the participants, but some faced challenges in sustaining a healthy lifestyle. Aldwin *et al.* 

(2007) suggested that a capacity to sustain positive emotions is an important factor in promoting optimal functioning and high quality of life among older adults. This seems increasingly essential for those living with a chronic health condition. In a longitudinal study of older Australian adults, Sargent-Cox *et al.* (2012) found that whilst it may not be possible to change an older adult's health status, promoting or improving control beliefs and self-esteem may assist older adults to generate more adaptive behaviours and health strategies that result in more positive perceptions of ageing. Psychological resources of expectancy of control are an important protective mechanism for older adults coping with health stressors and age-related change (Gerstorf *et al.*, 2011; Lachman, 2006). Strategies to improve resilience and positivity may therefore be significant for this patient group. Better physical functioning makes daily life easier and allows the individual to participate in activities that are meaningful to them with fewer restrictions (Smith & Burton, 2012), thereby maintaining quality of life, which was identified by all participants as important.

Resistance training has been shown to increase functional capacity and lower limb strength (Heiwe & Jacobson, 2011; Liu & Latham, 2009; Sengura-Orti, 2010). Whilst it was expected that the participants in the current study would report physical improvement, additionally, they reported increased confidence in their bodies, improved mental well-being and enjoyment from taking part in the sessions. This supports previous research (Aarts *et al.*, 1997; Faulkner & Taylor, 2005; Klusmann *et al.*, 2012) which suggested that exercise can have an immediate and long lasting impact on wellbeing, contribute to an enhancement in health and positively influence ageing dissatisfaction. Furthermore, the eight-week training programme enabled the participants to develop a routine, which for some had been missing since becoming unwell. Several of the participants spoke of the programme giving them the impetus to develop their own exercise routine, supporting findings from Tulle and Dorrer (2012) which showed it is possible for people who have had little history of sustained exercise to internalise the disposition to become physically active, and to work towards improvements in physical competence. Sniehotta *et al.* (2005) proposed that once individuals gain experience with exercise, utilising barrier-focused self-regulation strategies (coping planning) emerged as the greatest predictor of sustained behavioural change.

However, other participants found the maintenance of exercise more difficult and reported obstacles to continued exercise behaviour. These included lack of facilities and uncertainty about which type of exercise promotes health. Similar to results from Newson and Kemps' (2007) study, the female participants in the current study were more likely than the male participants to indicate obstacles that prevented them from exercising. Lack of social support and encouragement was also given as an obstacle to exercising. Participants spoke of struggling with self-motivation and/or being intimidated by entering the gym environment alone. Previous research on the Health Action Process Approach (Biddle & Fuchs, 2009; Schwarzer, 2008) has suggested that individuals with strong self-doubts are more likely to anticipate failure and are more inclined to worry about possible performance deficiencies, therefore aborting their attempts to exercise prematurely.

Previous research has suggestd that adults gravitate towards the exercise behaviours of those around them (Daley & Huffen, 2005; Faulkner *et al.*, 2008; Luszczyska *et al.*, 2004; Plante *et al.*, 2010). The majority of participants in the current study who continued to exercise, consciously chose to exercise with others (personal trainer, exercise classes, gym partner) and reported benefits of exercising with people whom they perceived to be high-fit or had confidence in their exercise-specific knowledge.

Such reports appear to suggest that if the experience is found to be satisfactory; an enhanced tendency to repeat the action emerges and eventually an exercise habit forms that no longer needs to be guided by reasoned considerations. For those participants who struggled to maintain exercise, they may benefit from being encouraged to choose an exercise behaviour that leads to immediate satisfactory experiences and can be executed within the boundaries of their personal capabilities (Aarts *et al.*, 1997).

Engaging in the research process was reported to be a positive experience for all the participants who were interviewed. However, most respondents expressed regret that the exercise programme had concluded, and was particularly emphasised by those for whom exercise maintenance had been a struggle and who believed that the physical gains achieved during the eight-week intervention had since been lost. This is supported by Taylor *et al.* (2004) who concluded that aerobic exercise is not effective in preventing the loss of muscle strength with ageing, and 75% of the benefits of strength training are lost within three months of ending sessions. Therefore for those who had not continued with exercise, or who were concentrating solely on aerobic exercise, any benefits to muscle strength they had accumulated through participating in the programme had been significantly reduced. It therefore seems important to support this patient group to regularly access resistance exercise sessions, particularly as most daily activities, such as the displacement of body weight during walking or rising from a chair, require the generation of power rather than strength alone (Skelton *et al.*, 1994; Taylor *et al.*, 2004).

The final theme of 'being a helper' suggests that the participants were able to find meaning in their disease by being able to give something back to the medical team who had supported them. The desire to reciprocate may therefore be an important motivating factor for older adults. Reciprocity was found to be a major theme that facilitated participation in exercise in older women post hip fracture (Resnick *et al.*, 2005). From this perspective, participants were no longer solely defined by their disease or seen only as patients, but were able to meaningfully contribute towards the future care of others. In a qualitative study examining the effect of exercise on those with chronic conditions, Graham *et al.* (2008) suggested that the self-selection of participants reflects an underlying decisional process to pursue a proactive, effortful behaviour and may be reflected in the current study as the participants desiring to assist the medical team, and therefore gaining a degree of personal control.

# 4.2 Clinical Implications

The current study indicated a number of lines of potential action. Participants reported benefits to physical strength, bodily confidence, mood and daily functioning whilst engaging in a resistance exercise programme. This suggests that resistance exercise may be a viable adjunctive treatment for this patient group, particularly for those who live an increasingly sedentary lifestyle; it can be incorporated early on in the course of the disease.

Most of the participants were encouraged by exercising in a non-threatening environment (hospital gym) whilst monitored by trained instructors. This seemed to be more accessible, particularly for those who had previously avoided going to a gym due to anxieties about exercising alongside younger and fitter gym-users. Therefore, when considering implementing future resistance exercise programmes, practitioners need to develop ways of breaking down barriers to provide an inclusive gym environment, whereby older adults, particularly those with chronic conditions, can feel confident in accessing the gym equipment and confident in the advice given to them by the gym instructors. Research on older adults' beliefs about resistance training suggests that ongoing one-to-one demonstration, guidance, feedback and encouragement has the potential to instill self-efficacy in older people and therefore increase the likelihood that they will continue with resistance training on a long-term basis. Furthermore, providing opportunities for social interaction may maintain interest and enjoyment whilst exercising (Dionigi, 2007).

As benefits achieved through resistance exercise appear to dissipate by three months after cessation, greater consideration of sustaining older adult exercise behaviour is required. Given participants felt discontinuing exercise at the programme conclusion was related to a lack of confidence in both their exercise-specific expertise and ability to exercise safely, future resistance exercise programmes should consider ways to improve self-efficacy and physical activity intentions. Stewart et al. (2001) incorporated individually tailored exercise programmes with social cognitive theory and principles of self-efficacy enhancement, readiness to change and motivational techniques for physically underactive older adults. Results revealed a significant increase in physical activity. This view was supported by Sniehotta et al. (2003) who suggested that treatments that aim to facilitate change in habitual behaviours should address planning as a powerful self-regulatory tool, which can help to translate goals into behaviour. Differentiating between action planning (when, where, how) and coping planning (link between anticipated risk situations and suitable coping responses) not only provides a clearer understanding of self-regulation strategies, but also aids to design cost-effective psychological interventions.

Patients may also benefit from personalised planners, whereby after completion of the resistance exercise programme, they are set exercise targets (proximal goals) and encouraged to attend review sessions. This thereby provides information about the types of exercise behaviours which will have clear advantages for them, can be executed

within their personal capabilities, and focuses attention on proximal outcomes which is more effective than directing attention to distal ones (Aarts *et al.*, (1997).

# 4.3 Limitations of the Research

Several limitations in this study need to be acknowledged. Firstly, the number of participants for the statistical analysis was small. The consequence of obtaining a small sample size was low power, therefore heightening the risk of a Type II error being made.

Secondly, the quantification of psychological wellbeing and quality of life is difficult. There are many instruments that measure different aspects of wellbeing and the measures used were chosen to reflect generalisable concepts of quality of life. It is therefore possible that the questionnaires used in this study were not specific enough for the CKD population and may not have included questions that were particularly relevant to patients and older adults.

Thirdly, the majority of participants who completed questionnaires and all of the participants who attended an interview were white British. It therefore needs to be taken into consideration that the results that emerged from the current study may not be generalisable beyond this specific population. In addition, the individuals who volunteered for the study (particularly the interview) may have had considerably different experiences from those who chose not to participate.

Fourthly, due to the large amount of qualitative data collected, several decisions were made on how to present the data and what to include and what to leave out. This means that there has unavoidably been an influence of the researcher's position and knowledge base on what has been presented. However, the transparency of the research process together with the systematic application of method as suggested by Braun and Clarke (2006) has tried to justify these decisions.

# 4.4 Future Research

In light of the restricted generalisability of the results, but also important potential clinical implications, further research is undoubtedly warranted.

Replication of the study with a larger sample would provide greater statistical power for quantitative measurement of changes in quality of life. It would also be helpful to see if the emergent themes in this study would be duplicated, therefore allowing for greater generalisability. Efforts should be made to recruit participants from an ethnic and cultural mix that is representative of the British CKD population. This will aid in ensuring that the findings from studies, and interventions proposed from the research base, are suitable and relevant to the whole of the CKD population.

Including quality of life indicators in patient monitoring is important due to the close relationship between quality of life, morbidity and mortality (Jofre *et al.*, 2000). Development of condition specific measures, which include questions pertinent to this patient group, and are sensitive enough to elicit changes in patients' functioning (as evidenced by the participants' interviews in the current study) will uphold quality of life as an important outcome indicator.

Future research may benefit from evaluating whole body resistance training. Whilst improving the function of the leg muscles is vitally important to maintain independence of daily functioning, participants in this study also commented on the impact of poor arm muscles, and reduction in whole body strength. Longer-term interventions designed

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to ameliorate this may provide greater insight in to the effect of resistance exercise on the quality of life of this patient group.

## 4.5 Conclusion

Historically, there has been little research that has addressed the effect of resistance exercise on the quality of life of those diagnosed with chronic kidney disease (CKD). Up until now, the majority of research has focused on the functional benefits this form of exercise can provide.

The current study aimed to examine the participants' experience of taking part in an eight-week resistance exercise programme, their perception of the impact of resistance exercise on their quality of life, and their beliefs about their physical ability and bodily competence, both before and after participation. The participants in the current study described undertaking a resistance exercise programme as a positive experience, feeling better both physically and mentally after completing each session. The majority of participants also expressed greater confidence in their bodies after completing the eightweek programme, which enabled them to feel positive about their body's ability when engaging in daily activities. Committing to the sessions fostered the development of an exercise routine and for some participants, was acknowledged to provide a sense of purpose, which had been missing since the onset of their illness. This appeared to be linked to their improved perception of their quality of life.

Resistance training has the potential to be an effective rehabilitation programme for this patient group by developing, not only functional strength, but also improvements in mood, bodily confidence, social contact with others and generating routine and purpose. The findings also suggested that those who are not effectively supported may not continue with their exercise routine, despite being aware of the health benefits.

This research adds to the literature exploring the importance of developing exercise self-efficacy and reducing barriers to enable older adults diagnosed with chronic disease to continue to exercise. It is hoped that the findings from the current study will add weight to Smith and Burton's (2012) findings which suggest that encouragement to exercise can be presented in a positive light, with physical and mental improvements attainable, even if CKD has negative impacts on other aspects of life.

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Section C

**Critical Appraisal** 

#### **Critical Appraisal**

This section provides a critical evaluation of the research process and is a combination of my thoughts having reached the end of the project, as well as issues raised and challenges faced during the completion of the research. A table of the research process can be found in Appendix N.

#### 1. Project selection

Other than my undergraduate dissertation I had not been involved in research, therefore when I started the course I was uncertain about the whole research process and what I wanted my project to focus on. The research fair was helpful in identifying a project that would be relevant to clinical practice and my attention was caught by a project which built on my interests from my undergraduate degree. Body image and quality of life were areas of interest to me already and I was intrigued by the impact of a chronic illness on a person's identity and functional ability, and the use of exercise to mitigate negative appraisals. Meeting with potential academic and field supervisors furthered my interest and as I became more familiar with the literature surrounding chronic kidney disease (CKD), the more I understood about the debilitating effects it can have and how much of an under researched area it was.

A search of the literature regarding the impact of resistance exercise on the quality of life of those with CKD identified no studies in this area. Research seemed to focus on the changes in functional ability and muscle strength achieved by resistance exercise, or where quality of life was considered, it seemed to be with the addition of non-specific quality of life questionnaires.

The larger study was already in the recruitment phase by the time of the research fair. However, after discussions with my field supervisor we agreed that adding more specific measures regarding illness and physical self-efficacy (Brief IPQ, PSE) would be useful to generate pilot data with this patient group. My field supervisor also welcomed the addition of a qualitative element to the study, as this would be able to inform the design of any future exercise programmes for the CKD population.

#### 2. Choice of research methodology

Qualitative methodology was not familiar to me, but the more familiar I became with the literature on CKD the more certain I became that I did not want to solely focus on quantitative data which would show whether resistance exercise generated significant improvement in participants' quality of life and perception of illness. I wanted to explore the meaning of their illness, the lived experience and not just if, but how resistance exercise impacted upon this patient group. Individual interviews were selected as the method of data collection for a number of reasons. Firstly, as I was interested in the effect of resistance training on the individual, focus groups did not seem appropriate. Secondly, reflections on my epistemological stance identified a position of essentialism, which meant reporting the experiences, meaning and the reality of participants living with CKD and participating in a resistance exercise programme. Conducting individual interviews meant that participants would have time to engage in this conversation, with perhaps less censorship than in a focus group with other patients or by writing their answers on open-ended questionnaires.

#### 3. Peer and ethical review

As well as informal communication with my supervisors, research team and experts in the field of CKD, I submitted my proposal to the university for peer review. This helped me to think about what my study would add to the larger study and how to make sure that my study was not simply seen as an adjunct, but as research in its own right. The peer review process also helped me to think about qualitative data analysis, which methodology was most suited to my research question, and how I could make improvements to the semi-structured interview schedule. I discussed this with my supervisors and made some minor changes in wording as a result.

In some ways I felt relieved when I learned that I would need to submit two substantial amendments, rather than make a new application to the ethics committee. In other ways I felt I had somehow missed out on the IRAS form and ethics application process and was seen as 'lucky' by my peers. However, submitting amendments brought its own challenges, as I felt that I had to 'come up to scratch' with the rest of the research team. Making changes to the existing protocol, participant information sheets, consent form, and completing the amendment form was a daunting experience and I was overwhelmed by the fear of 'getting it wrong'. As the addition of interviews was specifically for my study, I also had to write a new participation information sheet and consent form. My field supervisor was very supportive throughout this process and it was a relief to find that the amendments were accepted. This relief was short-lived when I was informed that in order to be added to the study by the R&D (research and development) department, I would have to complete the Good Clinical Practice (GCP) training and undergo a consent assessment. Again my fears about 'getting it wrong' were prominent and I probably over prepared for them, by spending a lot of time on both. This was further reinforced by my belief that research was 'hard' and something that other people did. However, I passed both and my confidence in my research abilities grew.

#### 4. Data collection

As the questionnaires were distributed at pre-planned visits (in line with the protocol of the larger study) I did not have to contact participants directly to collect the quantitative data. However, with hindsight, this may have increased the chances of participants not responding. During collection of the completed questionnaires, it was found that there were often questions unanswered, either on the pre, post, or both questionnaires, or the questionnaires had not been completed at all. Whilst data analysis allowed for some of the questionnaires to still be included, if several of the questions on individual subscales had not been answered they could not be entered into the analysis. Added to the withdrawal of several participants from the larger study, this further decreased the statistical power of my study. Therefore, whilst my attendance at every visit would not have been practical, it may have been prudent for me to attend several of the visits, to aid the research associate with the completion of the questionnaires.

My initial enthusiasm about starting recruitment for the interviews was heightened when I learned that several of the participants had expressed an interest to take part. By June 2012 I had nine participants who had agreed to take part and I was given their details for me to contact them. I had encountered some difficulty with finding a venue to conduct the interviews in. I was aware that the hospital was a central location for most of the participants, but did not want them to view either myself or the interview as part of their clinical team/care. I made enquiries into a couple of venues close to the hospital, but was unable to find rooms that were suitable. Aware of the time scale I decided to make a compromise and arranged to hold the interviews at the education centre on the hospital site. This meant that the interviews were held in a central location, easily accessible for most of the participants, but on the opposite side of the site to the renal department and hospital gym where the resistance training had taken place. Whilst it was expected that to some extent the participants would constitute a fairly homogenous group (similar age, stage of CKD, working or retired), given the diversity of the local area, it was somewhat unexpected that all interviewees were white British. Thus the homogeneity and small sample size are acknowledged as limitations of the study. However, as a qualitative piece of research, I felt that the emphasis of my study had not been on producing objective generalisable results, but was more about subjective accounts and experience, in order to help inform the design of future exercise programmes.

The morning of the first interview I felt nervous and under pressure to do things 'right'. I had practiced reading through the participant information form and taking consent, and had tried to memorise my interview schedule. The research associate accompanied me to introduce me to the participant and to observe me taking consent, to make sure that I did it correctly. To some degree I think this added to my nerves and served as a reminder that I wasn't a seasoned researcher. However, once I commenced the interview I instantly felt more at ease and believe that my clinical skills came to the fore. I enjoyed all of the interviews immensely, although some participants were more difficult to build up a rapport with than others. I believe that taking up the stance of a researcher allowed me to free up my thinking and take a step back from assessment and formulation. Whilst there were certainly times when I was intrigued by something a participant had said, and perhaps would have pursued in a clinical interview, it was interesting to have the semi-structured interview schedule to direct me back to the purpose of the interview, whilst allowing me to be flexible enough to discuss topics that were relevant but that I had not anticipated.

#### 5. Transcription

I had not transcribed interview data before and I found this task to be the most daunting. However, after speaking to my supervisor, we agreed that I should use what was left of my study budget to pay for as many interviews as needed to be transcribed professionally. I decided that I would transcribe the first interview and then pay for the remainder to be transcribed for me. Transcription is not a neutral process and both myself and the professional transcriber, would have to make numerous decisions not only *what* to transcribe (e.g. pauses, intonations) but also how to interpret what we heard on the recordings and how to represent this on paper. It was clear when looking at our transcripts, that we had reached different decisions on how to report pauses, repetitions, laughter etc. and how we decided to arrange the interviews on paper.

I found transcribing the first interview to be hugely helpful; it helped me to become familiar with the data and I found myself reading the transcript in the participant's voice, which I think helped me to remain grounded in what the participant had said rather than my interpretation of it. Although I had the other interviews professionally transcribed, I still replayed the interviews with the transcripts in front of me, so that I could make additions to the transcripts and make sure I had the detail that I needed for the analysis. Again, this process helped me to become more familiar with the data, but not as familiar as with the interview I had transcribed. Whilst transcribing might often be seen as a chore, if I were to conduct qualitative research again, I would advocate transcribing the data myself, as long as time permitted.

#### 6. Data Analysis

With regards to quantitative data analysis, I had not used SPSS with any regularity since my undergraduate degree and unfortunately that was several versions ago. The up-todate version of SPSS seemed to be more of a minefield than I remembered and it took me longer than anticipated to become familiar with it. I sought the advice of a statistician to advise me on how to input the data, so that I could carry out the tests that I wanted to. Unfortunately none of the statistical tests proved to be significant, but due to the small sample size, this was not surprising. The length of time spent scoring, inputting and analysing the quantitative data was much longer than I had predicted and it I were to replicate the study I would allocate more time for this.

## 6.1 Qualitative Data Analysis

I decided to use thematic analysis, as opposed to other methods, because I wanted to focus on *what* was said, rather than *how* it was said. Thematic analysis is a method for identifying, analysing and reporting patterns within data. Whilst other methods, such as, IPA and grounded theory also seek patterns in data, they are both theoretically bounded (Braun & Clarke, 2006) and attempt to understand the phenomenon in question or generate a plausible theory of the phenomenon respectively.

Thematic analysis in not wedded to any pre-existing theoretical framework (Braun & Clarke, 2006), however for the purposes of the current study, was used from an essentialist perspective to report the experience and reality of the participants' both before, during and after completing the resistance training programme. Inductive semantic analysis was chosen (rather than deductive latent analysis) and therefore I attempted to code the data without trying to fit it into a pre-existing theoretical frame or my own preconceptions and I did not attempt to go beyond what the participants had said. As I had not used thematic analysis before I was concerned that I would not get it 'right' or know when to stop. However, I enjoyed bringing the interviews together and was encouraged by the visual aspect of it (lots of different coloured post-its) as it

seemed to make it more tangible and helped me to become immersed in the data. Discussing the themes with my supervisor reinforced what I had found within the data and helped me to consider when to stop.

The next hurdle was on deciding what to include and what to leave out for the results and discussion sections of my empirical paper. I had not realised how difficult I would find this. I felt a keen sense of wanting to do justice to what all of the participants had said and of not wanting to miss out things that they had considered important. Therefore, whenever I made conclusions about the themes, I made sure that they were reinforced by the data set itself.

7. Overall Learning Points

The project as a whole developed my theoretical and clinical understanding, of living with chronic disease and the possible use of exercise to ameliorate its effects, from a simply 'inquisitive' position at the start, to one where I have acquired knowledge and feel more informed in this specialist area.

A key reflection of the whole research is of being 'good enough'. There is no such thing as the 'perfect' research, and whilst discussions in academic meetings can help to inform and design aims and objectives, there are always things that happen that are not expected (not finding a suitable room, incomplete questionnaires, struggling with statistical software).

As previously stated, I have limited experience in conducting research and 'real world', rather than undergraduate research, proved to be a much more active process. With the knowledge and skills gained throughout this process, I have developed confidence in my research abilities and have an increased awareness of some of the practicalities that it involves. With the encouragement of my academic supervisor, I have also developed my ability to collate and critically appraise the evidence base and apply these findings to clinical practice, which will be invaluable in my career as a clinical psychologist.

# 8. References

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative

Research in Psychology, 3 (2), 77-101.

Section D

Appendices

#### Appendix A Guidelines for Authors

### **Psychology of Sport and Exercise – Guide for Authors**

#### INTRODUCTION

*Psychology of Sport and Exercise* is an international forum for scholarly reports in the psychology of sport and exercise, broadly defined. Manuscripts that will be considered for publication will present results from high quality empirical research, comprehensive research reviews (narrative or statistical), protocol papers, and reports of professional practice (which will need to demonstrate academic rigour and go beyond mere description. The journal is open to the use of diverse methodological approaches.

#### Submission

Submission to this journal proceeds totally online and you will be guided stepwise through the creation and uploading of your files. The system automatically converts source files to a single PDF file of the article, which is used in the peer-review process. Please note that even though manuscript source files are converted to PDF files at submission for the review process, these source files are needed for further processing after acceptance. All correspondence, including notification of the Editor's decision and requests for revision, takes place by e-mail removing the need for a paper trail.

#### Additional Information

If you wish to contact one of the Editors-in-Chief for any reason, (e.g. becoming a reviewer, interest in joining editorial board, issue about journal policy) please email Nikolaos Ntoumanis at <u>n.ntoumanis@bham.ac.uk</u>.

#### PREPARATION

Manuscripts should be prepared following the general style guidelines set forth in the *Publication Manual of the American Psychological Association (6th Edition, July 2009)*. All manuscripts should be presented as concisely as possible, and our preference is to receive manuscripts that are 30 pages in length or less including references, tables and figures. For longer manuscripts, authors should contact the Editor-in-Chief prior to submission with a clear justification for the need for a longer manuscript.

The editors will also consider brief reports and research notes for publication and such submissions should be a maximum of 14 pages including abstract (150 words max for brief reports and short notes), main text, references, tables and figures

#### Language

Authors who require information about language editing and copyediting services pre- and post-submission please visit <a href="http://www.elsevier.com/languagepolishing">http://www.elsevier.com/languagepolishing</a> or contact authorsupport@elsevier.com for more information. Please note Elsevier neither endorses nor takes responsibility for any products, goods or services offered by outside vendors through our services or in any advertising. For more information please refer to our Terms & Conditions:

http://www.elsevier.com/termsandconditions.

#### Use of wordprocessing software

It is important that the file be saved in the native format of the wordprocessor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the wordprocessor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. When preparing tables, if you are using a table grid, use only one grid for each individual table and not a grid for each row. If no grid is used, use tabs, not spaces, to align columns. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier: http://www.elsevier.com/guidepublication). Note that source files of figures, tables and text graphics will be required whether or not you embed your figures in the text. See also the section on Electronic artwork.

To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your wordprocessor.

#### Article structure

#### **Subdivision**

Divide your article into clearly defined sections. Each subsection is given a brief heading as follows: Abstract, Introduction, Method, Results, and Discussion for empirical articles and Abstract, Introduction, Approach, Findings, and Discussion for theoretical/review articles. Each heading should appear on its own separate line. Subsections should be used as much as possible when crossreferencing text: refer to the subsection by heading as opposed to simply "the text".

#### Introduction

State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

#### Material and methods

Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described.

#### Theory/calculation

A Theory section should extend, not repeat, the background to the article already dealt with in the Introduction and lay the foundation for further work. In contrast, a Calculation section represents a practical development from a theoretical basis.

#### Results

Please include effect sizes and confidence intervals.

#### Discussion

This should explore the significance of the results of the work, not repeat them. A combined Results and Discussion section is often appropriate. Avoid extensive citations and discussion of published literature.

#### Conclusions

The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

#### Appendices

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

#### Essential title page information

• *Title.* Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.

• **Author names and affiliations.** Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a

lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.

• Corresponding author. Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. Ensure that phone numbers (with country and area code) are provided in addition to the e-mail address and the complete postal address. Contact details must be kept up to date by the corresponding author.

• **Present/permanent address.** If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

#### Abstract

The journal uses a structured abstract with the following subheadings: Objectives, Design, Method, Results, and Conclusions. Abstracts should not exceed 250 words (150 words for brief reports and short notes).

#### **Highlights**

Highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point). See http://www.elsevier.com/highlights for examples.

#### Keywords

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

#### **Abbreviations**

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

#### **Acknowledgements**

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

#### Footnotes

Footnotes should be used sparingly. Number them consecutively throughout the article, using superscript Arabic numbers. Many wordprocessors build footnotes into the text, and this feature may be used. Should this not be the case, indicate the position of footnotes in the text and present the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list. *Table footnotes* 

Indicate each footnote in a table with a superscript lowercase letter.

#### **Tables**

Number tables consecutively in accordance with their appearance in the text. Place footnotes to tables below the table body and indicate them with superscript lowercase letters. Avoid vertical rules. Be sparing in the use of tables and ensure that the data presented in tables do not duplicate results described elsewhere in the article.

#### References

#### Citation in text

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

#### Web references

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.),

should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

#### References in a special issue

Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue. *Reference management software* 

This journal has standard templates available in key reference management packages EndNote (http://www.endnote.com/support/enstyles.asp) and Reference Manager

(http://refman.com/support/rmstyles.asp). Using plug-ins to wordprocessing packages, authors only need to select the appropriate journal template when preparing their article and the list of references and citations to these will be formatted according to the journal style which is described below. *Reference style* 

Text: Citations in the text should follow the referencing style used by the American Psychological Association 6th Edition. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition, ISBN 978-1-4338-0561-5, copies of which may be ordered from http://books.apa.org/books.cfm?id=4200067. List: references should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.

# Appendix B Quality Assessment Checklist

si g	Methodology Checklist 2: Controlled Trials		
Study	identification (Include author, title, year of publication, journal titl	e, pages)	
Guidel	ine topic: Key	Question No:	
Befor	e completing this checklist, consider:		
1	<ul> <li>Is the paper a randomized controlled trial or a constudy design algorithm available from SIGN and make controlled clinical trial questions 1.2, 1.3, and 1.4 a rated higher than 1+</li> <li>Is the paper relevant to key question? Analyse using F Comparison Outcome). IF NO REJECT (give reason be</li> </ul>	sure you have the correct cheare not relevant, and the study ICO (Patient or Population Inte	cklist. If it is a cannot be ervention
	on for rejection: Reason for rejection: 1. Paper not relevance specify):		
Check	list completed by:		
Sectio	on 1: Internal validity		
In a w	ell conducted RCT study	In this study this criterion is:	
1.1	The study addresses an appropriate and clearly focused question.	Well covered Adequately addressed Poorly addressed	Not addressed Not reported Not applicable
1.2	The assignment of subjects to treatment groups is randomised	Well covered Adequately addressed Poorly addressed	Not addressed Not reported Not applicable
1.3			
	An adequate concealment method is used	Well covered Adequately addressed Poorly addressed	Not addressed Not reported Not applicable

1.5	The treatment and control groups are similar at the start of the trial	Well covered	Not addressed
		Adequately addressed	Not reported
		Poorly addressed	Not applicable
1.6	The only difference between groups is the treatment under investigation	Well covered	Not addressed
		Adequately addressed	Not reported
		Poorly addressed	Not applicable
1.7	All relevant outcomes are measured in a standard, valid and reliable way	Well covered	Not addressed
		Adequately addressed	Not reported
		Poorly addressed	Not applicable
1.8	What percentage of the individuals or clusters recruited into		
1.0	each treatment arm of the study dropped out before the study was completed?		
1.9	All the subjects are analysed in the groups to which they were randomly allocated (often referred to as intention to treat	Well covered	Not addressed
	analysis)	Adequately addressed	Not reported
		Poorly addressed	Not applicable
1.10	Where the study is carried out at more than one site, results are comparable for all sites	Well covered	Not addressed
		Adequately addressed	Not reported
		Poorly addressed	Not applicable
SECT	ION 2: OVERALL ASSESSMENT OF THE STUDY		
2.1	How well was the study done to minimise bias? Code ++, +, or –		
2.2	Taking into account clinical considerations, your evaluation of the methodology used, and the statistical power of the study, are you certain that the overall effect is due to the study intervention?		
2.3	Are the results of this study directly applicable to the patient group targeted by this guideline?		
2.4	<b>Notes.</b> Summarise the authors conclusions. Add any commer extent to which it answers your question.	nts on your own assessment	of the study, and the

# Appendix C Data extraction form

Record Number		Lead Author		Dat		
Record Number		Lead Author		Dat	e	
Number	]	Number		Nu	mber	
receiving		receiving usual			eiving any	
intervention		care or control			intervention	
	\$	group				
Design, study						
duration and						
follow up:						
<b>.</b>						
Exercise						
intervention(s)						
Variables						
measured						
Measurement						
tool						
1001						
Analysis						
	0 1		3.7	NT	TT 1	
Quality	Sample		Yes	No	Unclear	Not relevant
assessment						
	Adequate					
	Random					
	Representative					
	Interpreting results		Yes	No	Unclear	Not relevant
	Mostly validated measu	ires				
	Mostly appropriate timi	ng of measures			1	
	•	-				
	Measures consistent with	th aims			1	
	Conclusions consistent	with results				
	Conclusions consistent	min results				

# Appendix D Glossary of Additional Interventions Used

Study	Additional Intervention Used
Barrett et al. 2002	<b>Flexibility Control Program</b> Stretches for the major muscle groups (25 mins) as well as some light cardiovascular exercise (20 mins) and very low intensity strengthening (15 mins).
Chin A Paw et al. 2004	All-round Functional Training         5-10 minutes of warm-up activities – walking, exercise to music         30-35 minutes of skills training in game-like and co-operative activities         5-10 minutes cool down – stretching and relaxation
	<b>Combination</b> Once weekly a complete strength training session and once weekly a complete functional training session
Katula et al. 2008	<b>Power Training</b> Trained on Keiser pneumatic resistance machines. Focus on lower extremity, but several upper body strength training exercises included. Participants were told to complete the concentric phase of movement "as fast as possible", pause briefly at the midpoint of movement and complete the eccentric phase of the movement in approximately 2-3 seconds
Latham <i>et al.</i> 2003	Vitamin D supplement Single oral dose of six 1.25mg calciferol tablets.
Liu- Ambrose <i>et al.</i> 2005	Agility Training Challenged coordination, balance and psychomotor performance using ball games, relay races, dance movements and obstacle courses
Miller <i>et</i> <i>al</i> . 2006	Nutritional Supplement Fortisip (6.3KJ (1.5KCAL)/mL, 16% protein, 35% fat and 49% carbohydrate) estimated to meet 45% of individually estimated total energy requirements and ranged from 580-800mL per day

#### Appendix E Larger Study Protocol

Study title: Resistance Exercise for Older Patients with Chronic Kidney Disease Aims:

The study will establish the practicality of a resistance exercise programme in the CKD population, and will provide preliminary data about:

- The effect of the resistance exercise programme on physical functioning, fatigue level, quality of life, and appetite and nutrition.
- The effect of the resistance exercise programme on muscle size and strength.
- The effect of the resistance exercise programme on risk factors for cardiovascular disease
- The cellular, biochemical and molecular mechanisms involved in the above effects.

Participants: 40 participants with moderately severe chronic kidney disease (Stages 3b-4), aged between 40 and 100 years.

## Exclusion criteria:

Participants under the age of 40 were excluded from participating in the study, as were those who were unfit for the exercise programme due to significant physical comorbidity (unstable hypertension, potentially lethal arrhythmia, myocardial infarction within the previous six months, unstable angina, active liver disease, uncontrolled diabetes mellitus, advanced cerebral or peripheral vascular disease). Patients with physical impairment sufficient to prevent undertaking of the exercise programme were also excluded. The use of walking aids did not exclude potential participants. Patients who had insufficient command of English to be able to give informed consent or comply with the training protocol were also excluded, as this was a small study designed to establish the effectiveness of the intervention.

# Appendix F Epistemological Statement

Braun and Clarke (2006) make clear the importance of clearly stating the epistemological underpinnings of any thematic analysis research endeavour. The researcher took an essentialist or realist position, therefore the analysis sought to report the experience, meaning and the reality of participants completing a resistance exercise programme. This position assumes a unidirectional relationship between meaning and experience and language, with language reflecting, and allowing articulation of, meaning and experience.

# Appendix G Ethics Committee and R&D approval

National Research Ethics Committee Reference Number: 10/H0406/50

Research and Development Approval letter:

IRECTORATE OF	RESEARCH & DEVELOPMENT	Research & D	evelopment Office
irector:			
ssistant Director:			
&D Manager:	1/2		
Direct Dial:			
25/11/2011			
Dear Dr			
Ref:	10927		
Title:	Resistance exercise for ok disease	der patients with chron	ic kidney
Project Status: End Date:	Project Approved 31/08/2015		
of Lindsey Roger	bmitting documentation for No s, for the above study.		nent – addition
I confirm that the NHS Tr effect.	amendment has the approva rust R&D Department and ma	I of the by be implemented with	immediate
The documents	eceived are as follows:		
Document Nam	e	Version Number	Date
Document Nam	CHICCP		
Lindsey Rogers			24.11.11

#### Appendix H Interview Schedule

The following questions were asked to all participants and could be adapted as the interviews progress.

- 1. How would you best describe yourself as a person?
- 2. How do you perceive your physical and mental health?
  - *i*. Has this changed since you took part in this programme?
  - *ii.* If so, in what way has this changed?
- 3. What does quality of life mean to you?
  - *i*. How do you perceive your quality of life?
  - ii. Has this changed since the onset of your illness?
- 4. Can you tell me about your past experiences with exercise?
  - *i*. Has this changed during your lifetime? (periods of increased/decreased exercise)
  - *ii.* Have you ever been involved in a (resistance) exercise programme?
- 5. How did you feel about your physical appearance before your illness started?
- 6. What feelings do you associate with your body now that you have completed the programme?

- Have you experienced any changes in your physical or mental health associated with your involvement in this programme? (probe for positive and negative changes)
  - i. How do these changes relate to your quality of life and daily living?
- 8. What did you expect from taking part in the programme?
  - i. Were their expectations met?
- 9. Would you recommend this type of exercise intervention?
  - i. Why or why not?
- 10. Do you anticipate continuing with resistance exercise training? (Ask them to expand on the reasons for continuing or not continuing)

Is there anything else that you would like me to know about your experiences with your involvement in this study?

# Appendix I Confidentiality Statement

The signed original confidentiality statement has been submitted with the interview transcripts as part of the addenda.

APPENDIX A	
	University of Leicester
	School of Psychology – Doctorate in Clinical Psychology
	<b>Confidentiality Statement for Transcribers</b>
	n Psychological Society has published a set of guidelines on ethical principles for ng research. One of these principles concerns maintaining the confidentiality of information obtained from participants during an investigation.
concordan	anscriber you have access to material obtained from research participants. In ce with the BPS ethical guidelines, the Doctorate in Clinical Psychology Resear requires that you sign this Confidentiality Statement for every project in which y act as transcriber.
General	
<ul> <li>I understand</li> </ul>	nd that the material I am transcribing is confidential
The material	al transcribed will be discussed with no-one
<ul> <li>The identity</li> </ul>	y of research participants will not be divulged
Transcript	ion Procedure
<ul> <li>Transcription</li> </ul>	on will be conducted in such a way that the confidentiality of the material is maintained
	e that audio-recordings cannot be overheard and that transcripts, or parts of transcript d by people without official right of access
<ul> <li>All material</li> </ul>	Is relating to transcription will be returned to the researcher
Signed	Date
Print Name	
Researcher	LINDSEY ROGERS
Project Title	An exploratory study of quality of life, identity
	and engagement in patients with renal disease
	participating in a resistance exercise interiention
	diving treatment.

# Appendix J Participant Information Sheet

Direct Dial:	
Direct Fax:	

# **Muscle Building Exercise for Kidney Patients**

# Participant Information Sheet for Interview

# Version 1 23<sup>rd</sup> November 2011

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

# What is the purpose of the study?

Kidney disease can cause muscle wasting which leads to weakness, fatigue and reduced daily activity. This may be a particular problem in older people with kidney disease. In healthy older people, and in other chronic diseases, we know that regular muscle-building exercise can help to build muscle size and strength, increase physical capacity and improve overall health. We are carrying out a research study to find out whether a muscle strength training programme can have similar beneficial effects in older people with kidney disease (over 40 years).

We are also interested in finding out about the experiences and opinions of the patients who have completed a muscle strength training programme, to see whether they noticed any benefits or encountered any difficulties in taking part.

To help us understand these things, we will invite patients to attend a one-on-one confidential interview with a researcher who has no involvement with the clinical team, at a location away from the hospital to discuss their opinions, feelings and ideas about having taken part in muscle strength training. The content of the interviews will then be analysed to help us understand how strength training affects the physical and mental well being of older people with kidney disease

## Why have I been chosen?

You have been chosen because you have taken part in a muscle strength training programme during the main part of the research study "Muscle Building Exercise in Kidney Patients".

We are doing this research so we can understand better how exercise helps kidney patients.

Altogether we will ask 10 kidney patients who have taken part in the exercise training research to participate in this final part of the study.

## Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

## What will happen to me if I take part?

If you decide to take part, we will arrange for you to attend a one-toone interview at a mutually agreed time, which will take place at a venue local to **sector**. The interviews will be held in a comfortable, private room and will last up to about 90 minutes.

You will only be asked to talk about you physical and mental health, and exercise, not any other subject.

We will use a tape recorder to record what people say in the interviews so that we can analyse them later. The recordings will be transcribed and all the comments analysed together to give us a full picture of peoples' experiences. The recordings will be stored safely and treated in the strictest confidence.

Nothing you say in the interviews will be reported back to those involved in your care or anyone not present at the time, except anonymously in the form of a report or publication about the study. We may use direct quotations of what you say in the interview, but this will always be anonymous and no one will be able to tell that it was you who said it.

# What do I have to do?

During the study, we ask you to continue your life in the usual way. You should follow your usual recommended diet, and take your other medicines as prescribed.

## What are the possible disadvantages and risks of taking part?

The only disadvantage of taking part is that you will need to attend an interview. This will take up some of your own time. We will reimburse any travel expenses you incur in taking part in this research study.

# What are the possible benefits of taking part?

There are no direct benefits to you of taking part in this research.

# What happens when the research study stops?

Your usual clinical care will continue unchanged.

# What if something goes wrong?

In the very unlikely event of you being harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms would be available to you.

If you wish to mal	ke a complaint a	about the	study you can c	ontact	
			by writing	to	
				,	or
telephoning	(free ph	none numb	per).		

# Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be anonymous. Your identity will not be associated with the recordings we make, and everything you say will be entirely anonymous, including any direct quotations we may use in publications.

# What will happen to the results of the research study?

We will inform you of the results of the research when they are available; we expect this will be in 2013. The results will then be published in a medical journal. All information will be anonymised so you will not be identified in any report or publication.

# Who is organising and funding the research?

The	The research is being organised by staff at the										
led	by				and	is	funded	by	а	research	award
adm	ninis	tered by	the								

# Who has reviewed the study?

All research that involves NHS patients or staff, information from NHS medical records or uses NHS premises or facilities must be approved by an NHS Research Ethics Committee before it goes ahead.

This study has been approved by an NHS Local Research Ethics Committee. Approval means that the committee is satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits and that you have been given sufficient information on which to make an informed decision.

# **Contact for Further Information**

If you want any further information about this study please contact the Chief Investigator on on on the lead scientist on on the lead.

# Thank you for reading this, and for considering taking part in this study.

You will be given a copy of this information sheet and a signed

consent form to keep.

## Appendix K Consent Form

#### **CONSENT FORM FOR INTERVIEW**

#### Title of Project: Muscle Building Exercise for Kidney Patients

Please initial box

Name of Researcher:

I confirm that I have read and understand the Interview Information Sheet version 1 dated 23 <sup>rd</sup> November 2011 for the above study and have had the
opportunity to ask questions.

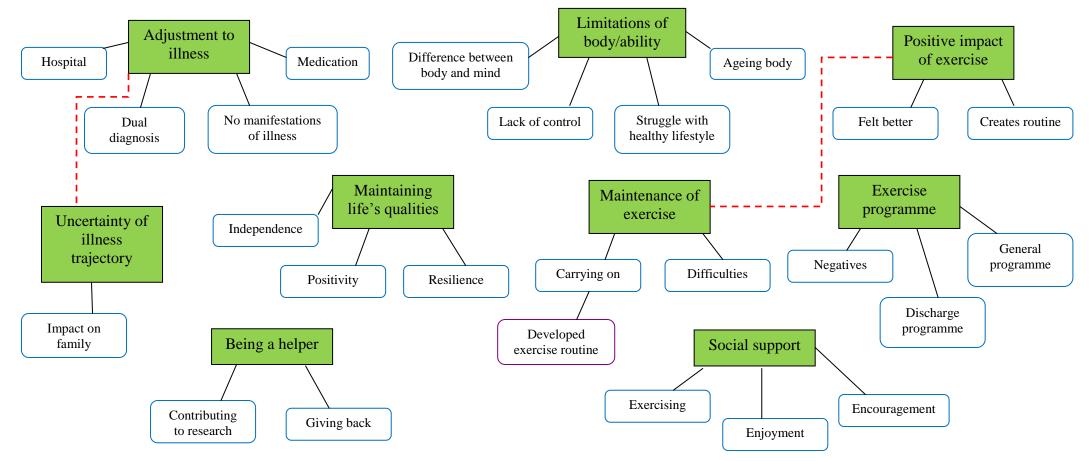
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
- 3. I agree to the interview being audio-taped and used anonymously for research purposes. I understand that the recording will be treated as confidential, stored securely and destroyed once the results of the study have been published.
- 4. I understand the researchers may use direct quotations from the interview in publications, but that these will be anonymous and it will not be possible to identify me from any quotations used.
- 5. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
- 6. I agree to take part in the above study.

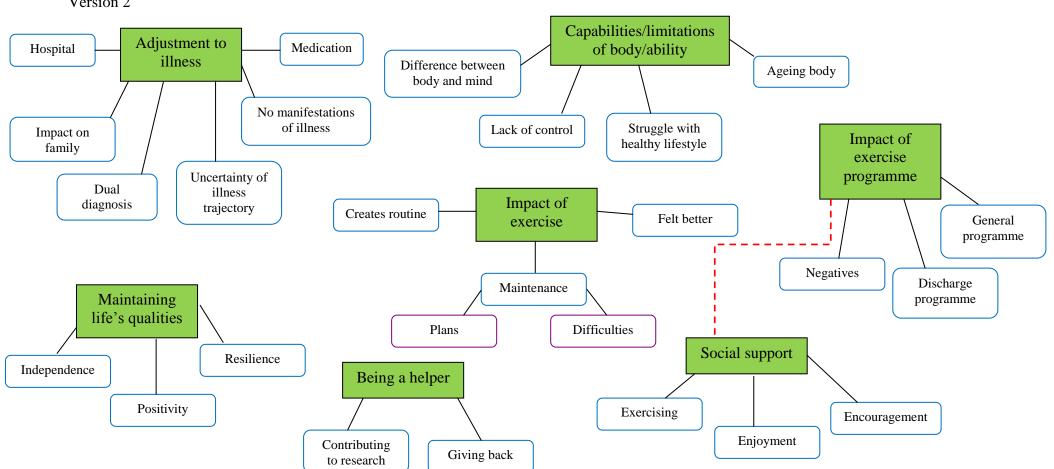
Name of Patient	Date	Signature
Name of Person taking consent	Date	Signature
Researcher	Date	Signature

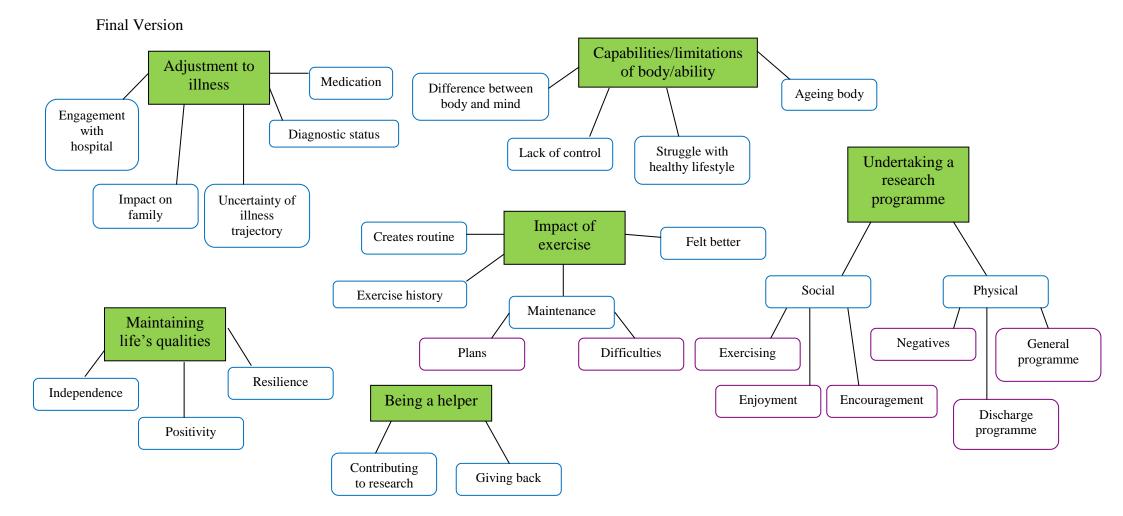
#### 1 for patient; 1 for researcher; 1 to be kept with hospital notes

## Appendix L Development of Thematic Map

Version 1







# Appendix M Statistical Results

# Independent Sample t-test Results

		Levene's Equality of	Test for Variances	t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2- tailed)	Mean Difference	Std. Error Difference	95% Confidenc Diffe	e Interval of the rence
									Lower	Upper
HADS anxiety (pre-post)	Equal variances assumed	3.509	.082	.525	14	.608	.63333	1.20660	-1.95456	3.22122
SF36 General (pre-post)	Equal variances assumed	1.664	.220	1.302	13	.216	9.38889	7.21227	-1.47033	2.73700
SF36 Social (pre-post)	Equal variances assumed	.566	.466	195	12	.849	-1.56250	8.00543	-19.00483	15.87983
SF36 Pain (pre-post)	Equal variances assumed	.372	.553	.232	12	.820	2.83333	12.20909	-23.76799	29.43466
Brief IPQ (pre-post)	Equal variances assumed	.304	.590	646	14	.529	-3.71429	5.74820	-16.04295	8.61437
PSE (pre-post)	Equal variances assumed	1.848	.197	1.440	13	.173	8.00000	5.55470	-4.00020	20.00020

# Mann-Whitney U Test Results

The difference between the pre and post scores of non-parametric data.

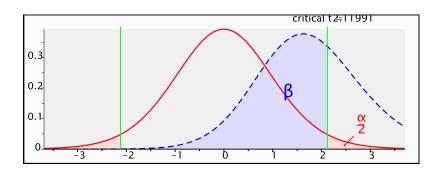
Hypothesis Test Summary					
	Null Hypothesis	Test	Sig.	Decision	
1	The distribution of HADSdeptime i the same across categories of Group.	Independent- isSamples Mann- Whitney U Test	.428 <sup>1</sup>	Retain the null hypothesis.	
2	The distribution of SF36Phystime the same across categories of Group.	Independent- isSamples Mann- Whitney U Test	.662 <sup>1</sup>	Retain the null hypothesis.	
з	The distribution of SF36RolePtime is the same across categories of Group.	Independent- eSamples Mann- Whitney U Test	.950 <sup>1</sup>	Retain the null hypothesis.	
4	The distribution of SF36RoleEtime is the same across categories of Group.	Independent- eSamples Mann- Whitney U Test	.142 <sup>1</sup>	Retain the null hypothesis.	
5	The distribution of SF36Mentaltim is the same across categories of Group.	Independent- neSamples Mann- Whitney U Test	.456 <sup>1</sup>	Retain the null hypothesis.	
6	The distribution of SF36Vitalitytim is the same across categories of Group.	Independent- Masamples Mann- Whitney U Test	.955 <sup>1</sup>	Retain the null hypothesis.	

Asymptotic significances are displayed. The significance level is .05.

<sup>1</sup>Exact significance is displayed for this test.

## Post hoc Power Analysis

Power = 0.3575758 (based on effect size calculated from SF-36 general sub-scale)



# Appendix N Research Process

<b>Research Activity</b>	Timescale	
Consult with academic supervisor and field	Jan – June 2011	
supervisor.	Jan – June 2011	
Submit initial research proposal.	May 2011	
First substantial amendment regarding addition of questionnaires submitted to ethics committee.	July 2011	
First amendment approved. Questionnaires distributed to participants.	Sept 2011	
Second substantial amendment regarding addition of interviews submitted to ethics committee.	Nov 2011	
Second amendment approved.	Jan 2012	
Interviews conducted with participants.	June – August 2012	
Questionnaire data analysed.	Dec 2012 – Jan 2013	
Interviews transcribed.	Dec 2012 – Feb 2013	
Begin writing up thesis, going back to the data accordingly.	Jan – April 2013	
Analyse interviews.	Feb 2013	
Viva preparation.	May – July 2013	
Presentation of research to renal research group.	June 2013	
Preparation for journal and poster.	July – Sept 2013	