# OCCUPATIONAL THERAPY FOR STROKE SURVIVORS IN UK CARE HOMES

Joanna C Fletcher-Smith

BSc (honours), MPhil

Thesis submitted to the University of Nottingham

For the Degree of Doctor of Philosophy

June 2015

#### Abstract

Stroke is a major contributor to the global burden of disease. It is the third main cause of death and the largest cause of adult disability in the UK. Stroke is reported to be the second most common cause of disability after dementia in the UK care home population with an estimated 25% of residents living with the consequences of stroke.

The aim of this PhD programme of research was to explore the current research evidence for the provision of occupational therapy to stroke survivors living in care homes; investigate current routine occupational therapy practice for this specific stroke population in UK care homes; and to contribute original new knowledge on the health outcomes of sub groups of the care home population with stroke.

This study was divided into four distinct projects that were completed alongside a National Institute for Health Research funded phase III multi-centre cluster randomised controlled trial of occupational therapy for care home residents with stroke known as the 'OTCH study'. The OTCH study evaluated the efficacy of delivering occupational therapy interventions targeted towards increasing and maintaining independent performance of personal self-care activities of daily living and mobility. The PhD student was a member of the OTCH study team with responsibility for delivering the intervention at the Nottingham site. A PhD studentship from the University of

i

Nottingham enabled the development of this complimentary and integrated programme of research.

Stage one (reported in chapter two) involved the completion of a Cochrane systematic review and meta-analysis as a means of systematically appraising published randomised controlled trials of occupational therapy interventions for care home residents with stroke to the highest gold standard. Systematic searching identified 1,436 unduplicated records however only 1 study met the inclusion criteria, with another trial ongoing. There was insufficient evidence from the reviewed randomised controlled trial to determine that occupational therapy improves outcomes for care home residents with stroke and therefore further high quality research in this area is needed.

Stage two (reported in chapter three) involved a national online survey study to provide contextual demographic data, along with data on the aims, content, funding and provision of occupational therapy services currently being delivered to stroke survivors residing in UK care homes. Out of a total of 138 completed questionnaires, data were analysed from 114 respondents who met the eligibility criteria of providing assessment and treatment to residents in a care home setting. The survey findings confirmed that occupational therapy is being delivered in some care homes; however, interventions for

ii

residents with stroke are not routinely delivered by stroke specialist occupational therapists and are not routinely delivered using a systematic, evidence-based approach.

Stage three (reported in chapter four) utilised the raw data from the 1,042 participants recruited to the OTCH study to perform subgroup analysis and predictive modelling (including regression modelling and generalised estimating equation (GEE) modelling) with the aim of further investigating the effect of occupational therapy on various subgroups of the participant sample. Subgroup analysis determined that age, time since stroke onset, cognitive status, mood and pain made no difference to the effect of a three month occupational therapy intervention aimed at improving or maintaining independence in basic ADLs (as measured by the Barthel Index (BI)). Predictive modelling found type of care home (residential or nursing) and cognitive status (dementia or normal cognition) to be a far greater predictor of ADL performance and mobility outcome than whether or not the resident had received the occupational therapy intervention.

Stage four (reported in chapter five) involved analysis of the content of occupational therapy intervention delivered to the OTCH study participants and their performance in self-care ADLs to account for possible reasons why the trial produced neutral results by (1) exploring the content of the treatment that the intervention arm

iii

participants received from the study occupational therapists; and (2) investigating the performance of those participants who had received the allocated occupational therapy intervention, whilst accounting for possible predictor covariates. Binary logistic regression was used to model the relationship between the dependent outcome variable and the explanatory predictor variables. Results of the analyses demonstrated that the therapists did not allocate their time according to those with greater levels of disability and higher levels of need. Residents with dementia received less therapy input than those with mild cognitive impairment or normal cognition. Cognitive status was the strongest predictor of functional outcome.

The thesis concludes by highlighting the implications of this new body of research evidence for occupational therapy clinical practice, policy, and future research.

#### Acknowledgements

Firstly I would like to thank my primary supervisor and inspirational academic role model, Professor Marion Walker for her unwavering support and encouragement throughout my research career to-date, and for her guidance throughout the PhD process. Marion, I am eternally grateful for the opportunities and mentorship you have given me.

I would like to acknowledge how generous my second supervisor Professor Catherine Sackley has been in allowing me access to the OTCH study raw data and trusting me to build my own programme of PhD research that would complement this important multi-centre cluster randomised controlled trial. Cath, it has been a privilege and a pleasure to work with you over the last four years.

I am grateful to the School of Medicine for funding my PhD studentship at the University of Nottingham.

I owe special thanks to a number of colleagues: my additional Cochrane review collaborators Dr Esther Steultjens and Miss Christine Cobley for their assistance during the systematic review and Cochrane publication process; Professor Avril Drummond, for her supervision and guidance during the completion of the national survey study, and for her critique and advice during the publication

V

process of this study; Amy Moody for providing an additional data entry error check of the survey study data prior to my analysis; Adrian Byrne for his Irish humour and patience when providing me with the statistical analysis training to enable me to complete chapters four and five; Jane Horne and Phillip Whitehead for their friendship and emotional support whilst sharing an office with me, not to mention the many cups of tea they have supplied me with! I am fortunate to work and study at the Division of Rehabilitation and Ageing with such an impressive group of talented, professional and successful individuals who continually motivate and inspire me.

I want to thank my best friends Iasamin Zakipour, Mojgan Mehran, Karen Romand, Mariam Donovan, Kuldip Newbold, Kiren Grewal, and Kate Scott-Nelson. Special thanks to Sally Birtwhistle for kindly proof reading this thesis. I am extremely lucky to have the most supportive, generous, funny, kind, beautiful and amazing friends! You lovely ladies have provided the fun and laughter throughout the challenging journey of completing my PhD. I hope you know how much you all mean to me. Thanks for your love, support, encouragement and friendship.

I wish to dedicate this thesis to my wonderful family – 'Team F-S'! I have much to thank my parents Jane and Peter Fletcher for. They gave me all the things money can't buy, taught me to work hard and

vi

never give up, and they always encouraged me to think positively and believe I could succeed. Mum and Dad thank you both for your love, support and many prayers. Also, for proof reading my work several times over and for all the additional babysitting! I thank my brother Phil for being my lifelong companion and confidant. My children, Jordan, Heidi, and Leila have been patient and understanding and provided me with their unconditional love even when writing this thesis took over my life and at times I couldn't spend as much time with them as I should. I promise to make it up to you all. Last but not least, I want to thank my husband Andy, for his endless love, patience and understanding, and for taking on more than his fair share of the household chores over the last four years! He is my rock. When I thought I couldn't get through it, he always reminded me that I could! Andy, have I told you lately.....?!

'Team F-S' I love you and this is for you!

# **Publications**

<u>Fletcher-Smith J</u>, Sackley CM, Walker MF, Burton C, Watkins C, Mant J, Roalfe AK, Wheatley K, Sheehan B, Sharp L, Stant K, Steel K, Peryer G, Irvine L and Wilde K (2015) A cluster randomised controlled trial of an occupational therapy intervention for residents with stroke living in UK care homes (OTCH). Proceedings of SRR conference. **Clinical Rehabilitation.** 29(4): 394-5.

<u>Fletcher-Smith J</u>, Drummond A, Sackley C, Moody A and Walker M (2014) Occupational therapy for care home residents with stroke: what is routine national practice? **British Journal of Occupational Therapy**. 77(5): 265-73.

<u>Fletcher-Smith JC</u>, Walker MF, Cobley CS, Steultjens EMJ and Sackley CM (2014) A Cochrane systematic review of occupational therapy for care home residents with stroke. Proceedings of SRR conference. **Clinical Rehabilitation**. 28(4): 405.

<u>Fletcher-Smith JC</u>, Walker MF, Drummond A and Sackley C (2014) A national survey of occupational therapy provision for care home residents with stroke: what is routine practice? Proceedings of SRR. **Clinical Rehabilitation**. 28(4): 410. <u>Fletcher-Smith JC</u>, Walker MF, Cobley CS, Steultjens EMJ and Sackley CM (2013) Occupational therapy for care home residents with stroke: **Cochrane Database of Systematic Reviews**. Issue 6. Art. No. CD010116.

Sackley CM, Walker MF, Burton CR, Watkins CL, Mant J, Roalfe AK, Wheatley K, Sheehan B, Sharp LJ, Stant KE, <u>Fletcher-Smith J</u>, Steel K, Wilde K, Irvine L, Peryer G, on behalf of the OTCH trial investigators (2015) A cluster randomised controlled trial of an occupational therapy intervention for residents with stroke-related disabilities living in UK care homes (OTCH). **British Medical Journal**. 350 (h468):1-11.

Sands G, Kelly D, <u>Fletcher-Smith J</u>, Birt L, and Sackley CM (2015) An occupational therapy intervention for residents with stroke living in care homes in the United Kingdom: A content analysis of occupational therapy records from the OTCH trial. **British Journal of Occupational Therapy**. 78(7): 422-30.

Contents	
----------	--

Acknowledgementsv			
Publications viii			
Figures xxi			
Tablesxxiii			
CHAPTER 11			
Introduction1			
Chapter Overview1			
1.1 Stroke1			
1.2 UK care homes4			
1.3 UK care home provision and funding5			
1.4 UK care home legislation and governance9			
1.5 The care home population12			
1.6 Care home residents with stroke14			
1.7 Occupational therapy in stroke rehabilitation17			
1.8 Occupational therapy in care homes for residents with stroke19			
1.9 Introduction to the research programme			
1.9.1 Justification for the PhD research programme25			
1.9.2 Direction of the PhD research programme			
CHAPTER 2			
A Cochrane systematic review of occupational therapy for care home			
residents with stroke			

Chapter Overview	
2.1 Introduction	
2.2 Aim	
2.3 Method	
2.3.1 Criteria for	considering studies for this review
2.3.2 Search met	hods for identification of studies
2.3.3 Data collect	tion and analysis42
2.4 Results	
2.4.1 Results of t	he search52
2.4.2 Included st	udies53
2.4.3 Excluded st	udies56
2.4.4 Risk of bias	in included studies56
2.4.5 Effects of ir	iterventions60
2.5 Discussion	65
2.5.1 Summary c	f main results66
2.5.2 Quality of t	he evidence67
2.5.3 Potential bi	as in the review process68
2.5.4 Agreement	s and disagreements with other studies or reviews.68
2.6 Conclusion	
2.6.1 Implication	s for clinical practice69
2.6.2 Implication	s for research69
CHAPTER 3	

A n	ational	survey of occupational therapy for care home residents with
stro	oke	
Cha	apter Ov	verview71
3.1	Intro	duction72
3.2	Aim .	
3.3	Meth	od74
	3.3.1	Study design74
	3.3.2	Survey type
	3.3.3	Defining the sample population and determining sample size 78
	3.3.4	Questionnaire development82
	3.3.5	Domains assessed in the questionnaire83
	3.3.6	Content and structure of the questionnaire83
	3.3.7	Introduction to the survey86
	3.3.8	Demographic data86
	3.3.9	Main questionnaire questions
	3.3.10	Piloting
	3.3.11	Ethical considerations91
	3.3.12	Survey administration91
	3.3.13	Data analysis91
3.4	Resu	lts93
	3.4.1	Sample93
	3.4.2	Respondent demographics

	3.4.3	Occupational therapy funding94
	3.4.4	Job titles95
	3.4.5	Involvement in care homes due to research studies
	3.4.6	Occupational Therapy Specialism97
	3.4.7	Referral route
	3.4.8	Referral time99
	3.4.9	Quantity of referrals 100
	3.4.10	Access to confirmation of medical diagnosis 101
	3.4.11	Prevalence of respondents who had worked with care home
	resider	ts with stroke in the last year 101
	3.4.12	Stroke specific care home information 102
	3.4.13	Stroke training 102
	3.4.14	Assessment in care homes104
	3.4.15	Occupational therapy interventions in care homes 107
	3.4.16	Treatment approaches used in care homes 108
	3.4.17	Aims of occupational therapy with care home residents with
	stroke	109
	3.4.18	Equipment provision in care homes110
	3.4.19	Funding of equipment provision in care homes 112
	3.4.20	Limitations on the occupational therapy interventions that can
	be deli	vered within a care home setting 116
	3.4.21	Additional information gathered from the survey 119
3.5	Discu	ission

	3.5.1	Availability, funding and expertise of occupational therapists
	workin	g in care homes123
	3.5.2	Care home resident referrals to occupational therapy 126
	3.5.3	Stroke specific occupational therapy provision
	3.5.4	Content of occupational therapy assessment and intervention
	3.5.5	Equipment provision
	3.5.6	Aims of occupational therapy for care home residents with
	stroke	
	3.5.7	Challenges and limitations of the practice of occupational
	therapy	y within care homes for residents with stroke
	3.5.8	Limitations of the study141
3.6	Conc	lusion
CH	APTER 4	144
Sub	group	analysis and predictive modelling using data from a multi-centre
clus	ster ran	domised controlled trial of occupational therapy for care home
res	idents v	vith stroke (the OTCH study)144
Cha	apter Ov	verview
4.1	Intro	duction
	4.1.1	OTCH study trial design and procedures146
	4.1.2	The unique contribution of the PhD student and the OTCH
	collabo	rators' roles
	4.1.3	OTCH study main summary of results

4.2	Aim	
4.3	Meth	nod
	4.3.1	PhD analysis database creation155
	4.3.2	Dealing with missing data156
	4.3.3	Selecting the outcome measures of interest from the main OTCH
	data fo	or inclusion in this PhD analysis157
	4.3.4	Statistical analysis – descriptive statistics
	4.3.5	Statistical analysis – OT versus control by sub groups 161
	4.3.6	Exploration of the degree of association between covariates prior
	to mod	delling analysis
	4.3.7	Statistical analysis –Generalized Linear Modelling 163
	4.3.8	Statistical analysis – Generalized estimating equation (GEE)
	modell	ling
4.4	Resu	ılts
	4.4.1	Participant flow through the trial from recruitment to completion
	of 3 m	onth outcome measures166
	4.4.2	Participant age and 'time since stroke' demographics by
	interve	ention arm
	4.4.3	Cognitive status and language ability at baseline
	4.4.4	Outcome measure completion rates
	4.4.5	Baseline outcome measure scores
	4.4.6	Outcome of 3 month follow-up assessments

	4.4.7	Sub group analysis comparing Barthel Index change scores by
	baselin	e characteristics180
	4.4.8	Pre-modelling stage: Variable transformations and descriptive
	statisti	cs
	4.4.9	Exploration of the degree of association between covariates . 191
	4.4.10	Generalized Linear Modelling - Logistic regression
	4.4.11	Generalized Estimating Equation (GEE) Modelling
4.5	Discu	ission
	4.5.1	Summary of the characteristics of the OTCH study sample
	populat	tion
	4.5.2	Summary of the main findings 209
	4.5.3	Summary of the sub group analysis findings 210
	4.5.4	Summary of findings from the modelling analysis 212
	4.5.5	Limitations of the study213
4.6	Conc	lusion
CHA	APTER 5	5
Ana	lysis of	the content of occupational therapy intervention delivered to the
ото	CH stud	y participants and their performance in self-care activities of daily
livir	ng	
Cha	ipter Ov	verview
5.1	Intro	duction
5.2	Aim .	
5.3	Meth	od

	5.3.1	Descriptive statistics
	5.3.2	Selection of the method of regression
5.4	Resu	ılts
	5.4.1	Performance over time on sub scores of the Barthel Index 225
	5.4.2	Content and duration of occupational therapy intervention
	sessio	ns
	5.4.3	Strength of association between binary BI sub score items and
	time s	pent in different types of OT intervention (binary)
	5.4.4	The association between the intervention delivered by the
	occupa	ational therapists and the primary outcome measure score at
	baselir	ne
	5.4.5	The association between the primary outcome measure score at
	3 mon	ths and the intervention delivered by the occupational therapists
		234
5.5	Disc	ussion
	5.5.1	Performance in activities of daily living (ADL) over time 236
	5.5.2	Frequency and intensity of the occupational therapy intervention
	delive	red to residents on the OTCH trial
	5.5.3	Content of the occupational therapy intervention delivered on
	the O1	<sup>-</sup> CH trial
	5.5.4	Targeting of intervention according to activity limitation at
	baselir	ne
	5.5.5	The association between the intervention received and the
	chang	e in functional outcome

	5.5.6 I	Limitations of the study242	
5.6	Conclu	usion	
CHA	APTER 6		
Ove	erall Sum	1 mary	
Ove	erview		
6.1	Summ	nary of key findings244	
6.2	Streng	gths of the PhD programme of research	
6.3	Limita	tions of the PhD programme of research	
6.4	Clinica	al Implications for occupational therapy250	
6.5	Policy	Implications252	
6.6	Implic	ations for future research	
6.7	Overa	Il conclusion	
Ref	erences.		
Арр	endix 1	- Cochrane Central Register of Controlled Trials (CENTRAL)	
sea	rch strat	egy:	
Арр	endix 2	- MEDLINE search strategy 273	
Арр	endix 3	- EMBASE search strategy	
Appendix 4 - Cumulative Index to Nursing and Allied Health Literature			
(CII	NAHL) se	earch strategy	
Арр	endix 5	- Allied and Complementary Medicine Database (AMED) search	
stra	itegy		
Арр	endix 6	- Occupational therapy database of systematic reviews and	
ran	domised	controlled trials (OT seeker) search strategy	

Appendix 7 - PsycINFO search strategy
Appendix 8 - Physiotherapy Evidence Database (PEDro) search strategy 284
Appendix 9 - Applied Social Index and Abstracts (ASSIA) search strategy
Appendix 10 - NHS Economic Evaluation Database (NHS EED) search
strategy
Appendix 11 - Education Resources Information Center (ERIC) search
strategy
Appendix 12 - Center for International Rehabilitation Research Information
and Exchange (CIRRIE) search strategy
Appendix 13 - Web of Science search strategy
Appendix 14 – Data extraction form 292
Appendix 15 – Survey questionnaire 293
Appendix 16 – Letter of ethical approval 303
Appendix 17 – Invitation to participate in the survey study
Appendix 18 – Participant information sheet
Appendix 19 – Table of the outcome measures used in the OTCH study308
Appendix 20 - Table showing the distribution of care home cluster size309
Appendix 21 - Table of the distribution of participants across care home
type 310
Appendix 22 - Table showing the characteristics of participants by
randomisation arm 311
Appendix 23 – Histograms and box-whisker plots of baseline MMSE scores
by randomisation arm

Appendix 24 - Histograms and box-whisker plots of baseline SST scores by
randomisation 313
Appendix 25 - Histograms and box-whisker plots of baseline RMI scores by
randomisation arm
Appendix 26 – Histograms and box-whisker plots of baseline GDS scores by
randomisation arm315
Appendix 27 – Histograms and box-whisker plots for 3 month health
outcome scores by randomisation arm
Appendix 28 – Degree of association between the binary covariates 319
Appendix 29 – Logistic regression model for health outcomes at 3 months
with baseline scores included 321
Appendix 30 – GEE models for health outcome measures with time included
as a predictor variable 322
Appendix 31 – OTCH occupational therapy intervention log
Appendix 32 – Frequency distribution graphs
Appendix 33 – Table of association between the BI sub score covariates and
the OT treatment covariates

# **Figures**

Figure 1: Study flow diagram53
Figure 2: Forest plot of comparison 1 Occupational therapy versus
standard care, outcome 1.1 Function in ADL at the end of scheduled
follow-up (Barthel ADL Index score)62
Figure 3: Forest plot of comparison 1 Occupational therapy versus
standard care, outcome 1.2 Global poor outcome (death or a drop in
ADL score) at the end of scheduled follow-up (6 months)63
Figure 4: Forest plot of comparison 1 Occupational therapy versus
standard care, outcome 1.3 Function in ADL at the end of intervention
(Barthel ADL Index score)63
Figure 5: Forest plot of comparison 1 Occupational therapy versus
standard care, outcome 1.4 Death at the end of scheduled follow-up
64
Figure 6: Forest plot of comparison 1 Occupational therapy versus
standard care, outcome 1.5 Mobility (Rivermead Mobility Index score)
at the end of scheduled follow-up65
Figure 7: Risk of bias summary: review authors' judgements about
each risk of bias item for each included study67
Figure 8: Geographical distribution of survey respondents working in
care homes94
Figure 9: Bar chart to show specialism of the survey respondents97

Figure 10:	Bar chart showing the frequency of the use of non-
standardise	ed assessments105
Figure 11:	Standardised assessments used and frequency of use.106
Figure 12:	Frequency of provision of occupational therapy
interventio	n107
Figure 13:	Treatment approaches used with care home residents
with stroke	
Figure 14:	Frequency of the provision of aids, equipment and
adaptations	5111
Figure 15:	A graph to show the responsibility for funding equipment
provided to	nursing home residents113
Figure 16:	A graph to show the responsibility for funding equipment
provided to	residential home residents114
Figure 17:	CONSORT diagram167
Figure 18:	Histograms showing frequency distribution of baseline BI
scores by r	andomisation arm175
Figure 19:	Box-whisker diagram of baseline Barthel Index scores 176

# **Tables**

Table 1:	Characteristics of included studies	54
Table 2:	Characteristics of ongoing studies	55
Table 3:	Characteristics of excluded studies	56
Table 4:	Risk of bias	58
Table 5:	Funding of occupational therapy provision in care homes	95
Table 6:	Job titles of the occupational therapists working within c	are
homes		96
Table 7:	Referral routes to occupational therapy	98
Table 8:	Stroke specific training received by the respondents	104
Table 9:	Types and frequency of non-standardised assessments u	ised
		105
Table 10	): Most common treatment aims that occupational therap	У
therapist	ts hope to achieve in their interventions with care home	
residents	s with stroke	110
Table 11		
	: 'Other' equipment that is recommended	112
	<ul><li>1: 'Other' equipment that is recommended</li><li>2: Limitations on occupational therapy practice within a car</li></ul>	
Table 12		are
Table 12 home se	2: Limitations on occupational therapy practice within a ca	are 119
Table 12 home se Table 13	2: Limitations on occupational therapy practice within a ca	are 119 are
Table 12 home se Table 13 homes fo	<ul> <li>2: Limitations on occupational therapy practice within a capture</li> <li>2: Limitations on occupational therapy practice within capture</li> <li>3: Comments about occupational therapy practice within capture</li> </ul>	are 119 are 120
Table 12 home se Table 13 homes fo Table 14	<ul> <li>2: Limitations on occupational therapy practice within a category</li> <li>2: Comments about occupational therapy practice within category</li> <li>3: Comments with stroke</li> </ul>	are 119 are 120 168

Table 16: Completion rates for the MMSE and SST assessments 169
Table 17: Baseline MMSE scores by randomisation arm170
Table 18: Baseline Sheffield Screening Test scores by randomisation
arm171
Table 19: Completion rates for all measures    173
Table 20: Participant status at each follow-up time point
Table 21: Baseline Barthel Index scores by randomisation arm 174
Table 22: Baseline Rivermead Mobility Index scores by
randomisation arm177
Table 23: Baseline Geriatric Depression Scale (GDS) scores by
randomisation arm178
Table 24: Baseline EQ5D pain and discomfort sub scores by
randomisation arm179
Table 25: Barthel Index scores at 3 months by randomisation arm
Table 26: Distribution of age by sub group (<84 yrs versus $\geq$ 84 yrs)
according to intervention arm180
Table 27: Distribution of time since stroke by sub group (<1 yr
versus $\geq$ 1 yrs) according to intervention arm
Table 28: Distribution of level of disability at baseline by sub group
(BI score 0-14 versus BI score 15-20) according to intervention arm

Table 29: Distribution of level of mobility at baseline by sub group (RMI score <7 versus RMI score >7) according to intervention arm Table 30: Distribution of cognition status at baseline by MMSE sub groups according to intervention arm ......183 Table 31: Distribution of language ability at baseline by sub group (SST score <15 versus SST score  $\geq$ 15) according to intervention arm Table 32: Distribution of mood status at baseline by GDS sub groups Table 33: Distribution of participants by pain and discomfort sub Table 34: Cut off scores for the binary form of the health outcome Table 35: Cut off scores for the binary form of the covariates ..... 189 Table 36: Frequencies and proportions of the distribution of the binary health outcomes ......189 Table 37: Frequencies and proportions of the distribution of binary health outcomes by randomisation arm ......190 Table 38: Strength of association of MMSE and SST with the Table 39: Logistic regression model for Binary Barthel Index at 3 

Table 40: Logistic regression model for BI at 3 months with BI at baseline removed......194 Table 41: Logistic regression model for RMI at 3 months with RMI at baseline removed......196 Table 42: Logistic regression model for GDS at 3 months with GDS at baseline removed......196 Table 43: Logistic regression model for EQ5D Pain & Discomfort at 3 months with EQ5D Pain & Discomfort at baseline removed ......197 Table 44: Bivariate associations between occupational therapy Table 45: GEE model for Barthel Index with time (0m & 3m outcome) Table 46: GEE model for RMI with time (0m & 3m) included as a within subject repeated variable ......200 Table 47: GEE model for GDS with time (0m & 3m) included as a Table 48: GEE model for EQ5D pain/discomfort with time (0m & 3m) Table 49: GEE model for BI outcome with time (0m & 3m) included Table 50: GEE model for BI outcome for the occupational therapy arm of the trial......203 Table 51: GEE model for the BI outcome for the control arm of the trial......204

Table 52: GEE model for RMI outcome for the occupational therapy
arm of the trial204
Table 53: GEE model for the RMI outcome for the control arm of the
trial205
Table 54: GEE model for GDS outcome for the occupational therapy
arm of the trial205
Table 55: GEE model for the GDS outcome for the control arm of the
trial205
Table 56: GEE model for the EQ5D pain/discomfort outcome for the
occupational therapy arm of the trial206
Table 57: GEE model for the EQ5D pain/discomfort outcome for the
control arm of the trial207
Table 58: Change in Barthel Index sub scores for the OT intervention
group226
Table 59: Reasons for participants not receiving the allocated
occupational therapy intervention227
Table 60: Occupational therapy intervention received         228
Table 61: Content of occupational therapy intervention
Table 62: Frequencies and proportions of the distribution of binary
covariates
Table 63: Frequencies and proportions of the distribution of the
binary BI sub scores at baseline231
Table 64: Frequencies and proportions of the distribution of the
binary health outcomes at 3 month follow-up231

Table 65: Significant associations between the BI sub score
covariates and the OT treatment covariates232
Table 66: Logistic regression model for total treatment time versus
total BI at baseline controlling for the participant characteristic
covariates
Table 67: Logistic regression model for total number of treatment
sessions versus total BI at baseline controlling for the participant
characteristic covariates
characteristic covariates234
characteristic covariates234 Table 68: Logistic regression model for total BI score at 3 months
characteristic covariates
characteristic covariates

# **CHAPTER 1**

## Introduction

## **Chapter Overview**

The central theme of this thesis is the provision of occupational therapy for stroke survivors residing in care homes in the United Kingdom (UK). This introductory chapter will provide essential background information, placing the subsequent chapters in context. The chapter will begin by describing stroke, its causes and effects. The thesis will specifically address those individuals who have survived a stroke and are permanently residing within a care home setting. A description of care homes will be given, starting with a brief history of their establishment in the UK and progressing on to describe the modern day care home population. The chapter will conclude with an overview of occupational therapy and its application to care home settings and residents with stroke.

### **1.1 Stroke**

Stroke is a major health problem in the United Kingdom. It is the third main cause of death and the largest cause of adult disability (National Audit Office, 2010). Every year in England alone, approximately 110,000 people have a stroke (National Audit Office,

University of Nottingham

Chapter 1

2010). Globally, there are an estimated 30 million people living with the consequences of stroke, most of whom have residual disabilities (World Stroke Organization, 2011). This makes stroke a leading cause of adult disability worldwide (World Stroke Organization, 2011) and a major contributor to the global burden of disease (Warlow et al., 2008).

"A stroke [is] defined as rapidly developing clinical signs of focal (and at times global) disturbance of cerebral function, lasting more than 24 hours or leading to death with no apparent cause other than that of vascular origin" (Hatano, 1976).

In layman's terms; a stroke is caused by an interruption of the blood supply to the brain, as a result of either a cerebral infarction (blockage caused by a clot) or a cerebral haemorrhage (bleed from a burst blood vessel). Blood is supplied to the brain by a complicated network of blood vessels. This disruption of blood flow within the vessels starves the brain of oxygen and nutrients, causing damage to the brain tissue. The nature of the stroke's neurological symptoms will depend on the anatomical location of the damage within the brain and the extent of the damaged area. In the most severe cases, stroke can lead to death. In the majority of cases, stroke leads to varying degrees of impairment and disability.

Around 20% to 30% of people who have a stroke die within a month (National Audit Office, 2005). Prognostic indicators for long term outcome in acute stroke include consciousness, gaze paresis, dysphagia, cognitive impairment, and urinary incontinence (Lawrence et al., 2001). Most people who survive a stroke will have some degree of post-stroke disability; for half of all stroke survivors this disability is long-term (Stroke Association, 2012). In excess of 900,000 people in England are living with the effects of stroke, with half dependent on others to participate in everyday activities, and around a third living with moderate to severe disability (National Audit Office, 2010).

The main encumbrance of stroke is survival with disability, dementia, depression, epilepsy, falls, and other stroke related complications (Rothwell, 2005). Stroke related disability can be caused by both physical and cognitive impairments. Motor impairment is the most common, affecting around 80% of individuals (Wade and Hewer, 1987) and inevitably leading to a high prevalence of residual mobility problems (Jorgensen et al., 1995) and loss of capability in activities of daily living (ADL). Frequently this restricts an individual's ability to resume their pre-stroke lifestyle.

For some stroke survivors it is possible to return home from hospital with informal support from family or organised care from health and

Chapter 1

social services. However, in the UK approximately 10% of individuals who survive a stroke are admitted directly from a hospital acute stroke ward into a care home setting (National Audit Office, 2010). There are also a number of risk factors that commonly lead to discharge to a care home, including older age, neurological deficit of the lower extremity, aphasia (communication impairment), rightsided weakness and longer length of hospital stay (Lai et al., 1998).

### **1.2 UK care homes**

Different definitions of the term 'care home' are used internationally. Even across the devolved nations of the UK, discrepancy exists in the terms used to define the different types of long-term residential care facilities in existence. In Ireland the terms 'nursing homes' and 'residential homes' are used (Regulation and Quality Improvement Authority, 2012). Scotland and Wales use the term 'care home' to include those with and without nursing care (British Geriatrics Society Scotland and Royal College of General Practitioners Scotland, 2009). In England, the Care Quality Commission refers to care homes as 'care homes with nursing services' or 'care homes without nursing' (Care Quality Commission, 2010). Under the Care Standards Act (2000) the terms 'nursing homes' and 'residential homes' were replaced by 'care homes' for institutions which provide accommodation together with nursing (for those people who need regular or constant nursing care) or personal care (for those requiring

Chapter 1

assistance with personal activities of daily living only). Thus care homes are categorised by the type of care they provide and also by ownership (Froggatt, 2004);(The National Care Homes Research and Development Forum, 2007). In this PhD thesis, the broad term 'care home' will be used to refer to residential institutions where older people (aged 65 years and over) permanently reside with personal and/or domestic care support. Care homes will include residential homes with nursing care and those without.

#### **1.3 UK care home provision and funding**

Institutional care for older people has existed in the UK for several centuries and was first nurtured through The Poor Law Amendment Act (1834). This new law ensured that the poor, including the elderly, were housed in Victorian workhouses, clothed and fed in return for hard work, frequently with harsh working conditions. Prior to this Act, the cost of caring for the poor was met by the middle and upper classes through local taxes. The inception of the new institutions known as 'work houses' accommodated those who were poor, orphans, mentally ill, disabled, or elderly; and were designed to reduce the costs of caring for such people. In the early twentieth century old and infirm people began to receive what could be described as institutional 'care' designed to meet their needs (The National Care Homes Research and Development Forum, 2007). By the mid twentieth century, the 1945 labour government had

developed a vision of providing 'hotel-like' accommodation for the working classes who required residential care. At this time, a distinction was made between services that were classified as being 'health care' services for the 'sick or infirm' (defined under the National Health Service Act 1946) and long-term social care services for the 'frail and old' (as defined by the National Assistance Act 1948). The National Health Service Act made healthcare freely available to all 'from cradle to the grave'. However under the National Assistance Act, payment was required for social care services.

The pre-1980 history of private sector residential care provision for older people has been described as 'an elusive and poorly charted topic' (Johnson et al, 2010). In contrast, in the early twenty-first century, there has been a drastic fall in the number of care homes funded by local authorities and an increase in privately funded homes. This in part was due to a need for local authorities to make financial savings. Additional factors that led to the closure of a number of local authority owned homes were the introduction of the national minimum wage alongside new 'National Minimum Standards' legislation which meant that many care homes were too expensive to provide adequate staffing levels and to adapt the environment (such as the provision of lifts and en-suite facilities to replace shared bedrooms). The closure of smaller family owned or local authority

Chapter 1

owned care homes led to a trend towards private corporate groups building larger care homes. By 2005, 30% of care home places were in homes owned by private organisations running 11 or more care homes (Lievesley et al., 2011). UK care homes for older people are now provided primarily by the private sector (Office of Fair Trading, 2005, National Care Standards Commission, 2004). The most significant change in terms of provision of long-term residential care occurred between 1980 and 2001, when the proportion of long-term places in the private sector rose from 18% to 85% (Victor, 2005). By 2005, this figure had risen to 90% of all residential care home places (Means, 2008). In 2015, the ownership of care homes is either by the independent sector or by local authority. Local authority publicly funded homes are largely in the residential care sector, but independent sector homes can be privately owned or owned by charities and religious or voluntary organisations. The reason for the boom in private care home places can be traced back to events that followed the UK general elections in 1979 and 1997, when a change of governing party resulted in political and economic consequences that affected the care of frail older people. By 1983 the Conservative Government had led a shift towards long-term care being provided primarily by the independent sector ensuring that those who required residential care were able to access board and lodging payments from the Department of Social Security. The Conservative Government later implemented the NHS and Community Care Act 1990

(Department of Health, 1990) which ended the availability of central government administered social assistance payments and transferred the financial responsibility back to the local authorities. The implementation of this Act resulted in a 60% reduction in the number of NHS overnight hospital beds for both geriatric and mental illness care (Lievesley et al., 2011). This coincided with a shift away from residential care towards an emphasis on 'care in the community' rather than hospital care. The NHS and Community Care Act 1990 changes also brought about a change to the funding of care. Between 1983 and 1993 private residential and nursing care could be funded through uncapped 'supplementary benefit' payments from the Department of Health and Social Security (DHSS). By the DHSS providing payment for care home places this acted as an incentive for older people to be cared for in private care homes rather than at home. However, currently around 30% to 33% of residents have to pay for their care home placement as 'self-funders' (Lievesley et al., 2011). Financial support from social services is means-tested and only 10% of care home residents receive a contribution from the NHS towards their care home fees (Gordon et al., 2013b). There is evidence that care homes charge different rates for similar rooms and similar care according to the resident's source of funding, with approximately one in five care homes charging 'self-funders' more than those residents funded by the local authority (Lievesley et al., 2011).

#### **1.4 UK care home legislation and governance**

In 2003 a statement of national minimum standards entitled the 'National Minimum Standards for care homes for older people' was published by the Secretary of State for Health under section 23(1) of the Care Standards Act 2000 (Department of Health, 2003). The national minimum standards set out in this document formed the core standards which applied to all care homes providing accommodation and nursing or personal care for older people. These standards formed the basis on which the National Care Standards Commission could determine whether care homes met the needs, and secured the welfare and social inclusion, of the people who lived there. The National Minimum Standards for Care Homes for Older People were drafted with an underpinning focus on five themes that were intended to provide a tool for judging the quality of life of service users (Department of Health, 2003). The standards were not stroke specific; however the general themes if adhered to should have ensured that residents with specialist needs related to stroke were accommodated fully. For example, in stating that the homes should be 'fit for purpose' the home should be fit for the purpose of providing appropriate living facilities for those with stroke-related problems such as immobility, by providing appropriate mobility equipment, ensuring rooms and doorways can accommodate wheelchairs, and that specialist transfer equipment is in place, and staff are trained in manual handling techniques for residents with hemiparesis.

The problem perhaps was not in the lack of stroke specific detail contained in the Standards but in the individuals who assessed the care homes. The care home regulators and lay assessors were unlikely to possess expert knowledge in stroke care and would not necessarily be able to identify such issues as whether people were being positioned correctly, or referred on to the appropriate services for management of stroke related complications such as spasticity, contractures and swallowing problems. Unfortunately, whilst there are national clinical guidelines (Intercollegiate Stroke Working Party, 2012) to guide stroke clinicians during the acute hospital phase of stroke care through to discharge back into the community, there are still no such stroke specific guidelines for staff within care homes. In November 2007 the Health and Social Care Bill containing measures to modernise and integrate health and social care was introduced in Parliament. One of the four key policy areas of the Health and Social Care Bill was the creation of the Care Quality Commission (CQC), a new integrated regulator for health and adult social care that brought together the three previous existing health and social care regulators into one regulatory body. The Health and Social Care Act 2008 (Department of Health, 2008) received Royal assent in July 2008 and the CQC began operating in April 2009 as the independent regulator of health and adult social care in England. In 2010, for the first time there was one single set of standards, 'The Essential Standards of Quality and Safety' that applied to all

University of Nottingham

Chapter 1

registered health care and adult social care providers. Since October 2010 all care homes have been required to register and be licensed with the COC in order to show that they are meeting these essential standards of quality and safety. The standards include: 'treating people with dignity and respect'; 'making sure food and drink meets people's needs'; 'making sure that the environment is clean and safe'; and 'managing and staffing services' (Care Quality Commission, 2009). Having one clear set of standards that apply to all registered care providers including care homes simplified the system of licensing and regulation. The CQC make unannounced inspections of services on a regular basis and at any time in response to concerns raised by the public or a health and social care professional. The Health and Social Care Act 2008 (Department of Health, 2008) gives the CQC a variety of powers to intervene and take action where the requirements of the Act are not being met. However, the COC has primarily focused on the quality of social care provision rather than health and medical care (Care Quality Commission, 2011a). Whilst the NHS has the Quality Outcomes Framework (QOF) to ensure that primary care services are systematic and evidence-based, the QOF does not address the needs of care home residents (Shah et al., 2011). As Robbins et al (2013) reported in their gualitative study, this means that existing mechanisms for quality assurance of healthcare may be failing to meet the needs of care home residents.

#### **1.5** The care home population

Whilst an appreciation of the organisation, funding and governance of care homes is useful, it is also important to have an understanding of the population who reside within such institutions. Around 423,000 older people reside in private and voluntary sector care homes in England and Wales (Laing and Buisson, 2009). In the UK, over half of all people with dementia reside in care homes (Lievesley et al., 2011). Care home residents typically have complex healthcare needs, reflecting multiple long-term conditions, significant disability and frailty; and are likely to be more dependent than older people living in their own homes (British Geriatrics Society, 2011), (Quilliam and Lapane, 2001). Overall 75% of care home residents are classified as being severely disabled (Office of Fair Trading, 2005, Bajekal, 2002). Assistance is required with at least one self-care task (such as washing or dressing) in 57% of women and 48% of men in UK care homes (Office of Fair Trading, 2005). Approximately 75% of care home residents have cognitive impairment and two thirds have behavioural disturbance (Gordon et al., 2013b). Robbins et al (2013) describe the healthcare of care home residents as 'difficult' because 'their needs are complex and unpredictable'.

Despite evidence in support of the benefits of purposeful and meaningful activity (Ballard et al., 2001), (Baum, 1995) (Kiely and Flacker, 2003), historically the level of physical activity and positive

stimulation in care home residents has been low (College of Occupational Therapists, 2007), (Challis, 2000) (Help the Aged, 2006). Recent studies (Huijben-Schoenmakers et al., 2009, Sackley et al., 2006, Cohen-Mansfield et al., 1992) report that care home residents spend as much as 63% of their day in non-therapeutic activities, such as sitting passively, unoccupied, and not interacting with others. In one pilot observational study involving residents from an 18-bed local authority residential home in England, Sackley et al (2006) describe the residents observed, as 'busy doing nothing', with residents sitting (either with their eyes open or closed) for 97% of observations. Although this was just one care home, anecdotal reports confirm that a large majority of residents are engaged in little purposeful activity during the day and have an inactive lifestyle within the care home. It is known that inactivity and immobility is associated with further deterioration of function (Sackley et al., 2008a). Due to the high levels of dependency in care home residents, they are largely reliant on the knowledge, motivation and expectations of the care staff to encourage mobility and activity. Often care home staff, who are responsible for the day to day care and companionship of residents, have limited training and little if any specialist expertise (Robbins et al., 2013). Apart from disclosure barring service (DBS) checks there are no legal requirements of qualification or training for those working in care homes. However, under government plans, announced by the Health Minister Norman

Lamb, care home workers may in the future be required to complete a basic training course covering basic nutrition and hydration, medications and promoting dignity, and moving and handling procedures (Ross, 2013).

#### **1.6 Care home residents with stroke**

It is estimated that around 20% to 25% of all care home residents in the USA (Quilliam and Lapane, 2001) and UK (National Audit Office, 2005) have had a stroke, and stroke is reported to be the second most common cause of disability after dementia in a UK nursing home population (Martin et al., 1998). Care home residents living with the adverse consequences of stroke, will most likely experience dependency in self-care, falls, pain, pressure ulcers and emotional distress as seen in other post-stroke populations (Sackley and Dewey, 2002, Langhorne et al., 2000). The care home population with stroke have a high prevalence of immobility, incontinence, and confusion (Gladman et al., 1991), (Bowman et al., 2004). Stroke survivors living in care homes (with and without nursing care) are likely to also have co-morbidities such as dementia (38% of residents), arthritis, cardiovascular disease, respiratory disease, deafness, depression, fractures and blindness (Bebbington et al., 2001). In comparison to stroke survivors who are able to remain living in their own home, evidence suggests that stroke survivors in care homes are more likely to have low mood, cognitive impairment and reduced health-related

quality of life (Leeds et al., 2004). The stroke population in care homes is likely to have co-morbidities and higher levels of impairment and disability, making them a different and possibly more complex population to stroke survivors in the community.

In addition to disability levels, stroke survivors living in care homes differ from those able to remain in their own homes in that they have very small personal living space (as little as 10 square metres in area) (Hanson et al., 2003), and much of their day is likely to be spent in homogenous facilities including, shared toilets and bathrooms and shared living areas such as a communal lounge and dining area (Help the Aged, 2007). Equipment required to complete daily activities is also likely to be shared with other residents rather than being specific to each resident's needs. Care home residents are required to live as part of a small community usually with shared daily routines such as meal times and timetabled activities. In contrast, those with stroke living in their own homes are likely to have more freedom and choice over their daily routine. Evidently, the care home population with stroke differs to the stroke population living in their own homes in many ways. The available evidence suggests that care home residents with stroke are likely to be amongst the most dependent and disabled of the general stroke population (Sackley et al., 2015).

Regardless of stroke severity, the National Stroke Strategy (Department of Health, 2007) states that people affected by stroke 'should receive care from staff with appropriate skills, competence and leadership' and that 'specialised rehabilitation needs to continue across the transition to home or care home'. Unfortunately, this ongoing longer term specialised stroke rehabilitation is not always available to stroke survivors residing in care homes (Sackley et al., 2001). As with other aspects of the National Health Service and third sector services, there are national variations in service provision and finances available to cover such longer term care (Care Quality Commission, 2011b). Commissioners of services may also be unaware of the possible benefits and the need for such on-going stroke care. The National Stroke Strategy (Department of Health, 2007) highlighted the need to provide stroke training to staff within organisations (such as care homes) that come into contact with stroke survivors. Yet, in the UK there is currently no requirement for care home staff to have stroke specific training. A recent review by the Care Quality Commission (Care Quality Commission, 2011b) (the independent regulator of health care and adult social care services in England) reported concerns around the levels of staff knowledge and skill in stroke care. The review reported that whilst local stroke pathways (policies setting out how care should be delivered) are in place across England, only 32% of the stroke pathways specifically covered people who had stroke and were residing in care homes

(Care Quality Commission, 2011b). The fourth edition of the National Clinical Guideline for Stroke (Intercollegiate Stroke Working Party, 2012) recommended that care home residents with stroke should receive assessment and treatment from stroke rehabilitation services in the same way as people with stroke living in their own homes. The guidelines also recommended that care home staff be adequately trained in the physical, psychological and social effects of stroke and the optimal management of residents with stroke. However, the recommendations in this guidance document are not legally enforceable and as a result a 'postcode lottery' exists as to how much longer term stroke support and rehabilitation is available to those with stroke residing in care homes.

## **1.7** Occupational therapy in stroke rehabilitation

Chapter three of the National Stroke Strategy (Department of Health, 2007), 'life after stroke', describes the stroke-specialised rehabilitation, care and support needed after stroke and acknowledges that a range of services need to be available locally to support the long-term needs of people who have had a stroke. The rehabilitation interventions provided by an occupational therapist are part of such services required to deliver stroke-specialised rehabilitation from the acute phase of recovery through to longer term care.

Occupational therapy aims to help people reach their maximum level of function and independence in all aspects of daily living (Legg et al., 2007a). Occupational therapists achieve this outcome by enabling people to do activities that will enhance their ability to participate, or by modifying the environment to better support participation in daily life (World Federation of Occupational Therapists, 2010). Occupational therapists define 'occupation' as much more than a chosen career. Occupation refers to every activity that people carry out during the course of everyday life (Canadian Association of Occupational Therapists, 2013). These activities of daily living (ADLs) include personal care activities such as washing, dressing, grooming, toileting and feeding and 'extended' ADL leisure activities such as gardening, crafts, reading, and other purposeful and productive activities that people choose to participate in.

Occupational therapy may specifically target the consequences of stroke by aiming to improve independence in ADLs and improving the ergonomics of the environment (World Federation of Occupational Therapists, 2010). A Cochrane systematic review and meta-analysis (Legg et al., 2006a) of nine trials (n=1,258) of occupational therapy provision to stroke patients in the community specifically focusing on personal ADLs only, showed increased performance and a reduced risk of poor outcomes such as death, deterioration or dependency in personal activities of daily living. For every 100 people who received

occupational therapy intervention, 11 (95% confidence interval 7-30) were spared a poor outcome. The review did not exclude studies with participants who were care home residents. However, one third of the trials included in the review and meta-analysis did exclude patients who were resident in, or were to be discharged to a care home (Legg et al., 2006a). Only one of the nine trials included in the review and meta-analysis (Sackley et al., 2003) involved delivering an occupational therapy intervention specifically to care home residents with stroke within a care home setting. Moreover, an individual patient data meta-analysis of randomized controlled trials of community occupational therapy for stroke patients (Walker et al., 2004) found that community occupational therapy significantly improved personal and extended ADLs and leisure activity in patients with stroke but no care home residents were included in this metaanalysis.

# **1.8 Occupational therapy in care homes for residents** with stroke

This chapter has already described how stroke survivors residing in care homes receive variable long term support. Despite evidence of the efficacy of occupational therapy in improving independence in personal ADLs and preventing deterioration in the community dwelling population with stroke (Legg et al., 2007a, Walker et al., 2004), as few as 3% of care home residents in the UK had access to occupational therapy provision in 2000 (Barodawala et al., 2001)

compared with 93% in the Netherlands (Sprangers et al., 2000). However it should be noted that the care home model within the Netherlands more closely resembles what the UK would refer to as intermediate care facilities than care homes. In the UK, intermediate care facilities (i.e. facilities where healthcare occurs somewhere between a traditional primary (community) and secondary (hospital) care setting) were proposed as an alternative to standard acute hospital care for selected patient groups requiring further long-term rehabilitation (Woodford and George, 2010). Intermediate care settings were introduced as a means to relocating 'bed blockers' and freeing up acute hospital beds whilst still providing ongoing slow stream rehabilitation to the frail elderly with some potential for improvement but unable to return straight home to independent living (Woodford and George, 2010). UK care homes on the whole offer a place of permanent residence with personal care and/or domestic assistance and little if any rehabilitation. The Netherlands has a specialty of care home medicine and more registered care home medics than community geriatricians (Hoek et al., 2003). Over a decade ago, Berg (1997) and colleagues investigated the prevalence of therapy (occupational and physical) in care homes with nursing input across the world and reported the prevalence of residents receiving therapy was 11% in the USA, 14% in Italy, 23% in Denmark, 30% in Japan, and rising to 31% in Iceland. One plausible reason for this variation in therapy provision may be due to

variations in the size, facilities and philosophy of care homes between the different countries. For example, the average care home in the UK has around 30 beds (Office of Fair Trading, 2005), compared with an average of over 160 beds in the Netherlands (Ribbe et al., 1997, Hoek et al., 2003). The question of whether or not we are comparing similar phenomena is critical for international comparisons (US Department of Health and Human Services, 1993). If care homes in the Netherlands more closely resemble intermediate care, respiteoriented facilities or rehabilitation wards than typical UK care homes, it would be unfair to draw such comparisons on occupational therapy provision between the two nations. Thus an appreciation that there are different care home models in different countries is important when drawing international comparisons. The United States Department of Health and Human Services published a report on 'nursing home care in five nations' that was part of a multi-country initiative to exchange experiences and share ideas to improve nursing home care (Van Nostrand et al., 1993).

This report compared long term care, in particular care homes, across Australia, Canada, the Netherlands, Norway and the USA. The report highlighted that whilst "nursing homes" could be compared between these nations; care homes without nursing services, sometimes referred to as "residential homes" (among other terms) were more dissimilar and therefore difficult to compare because there were so

many graduations of services and different arrangements for their provision (Van Nostrand et al., 1993). Van Nostrand et al (1993) also recognised that even within countries, care homes could differ in the type of services and intensity of care provided.

More than a decade after Berg (1997) and colleagues investigated therapy input in care homes across the world, the prevalence of qualified occupational therapists working within care home settings in the UK is still not known. These data are not recorded by the Health and Care Professions Council (HCPC) (the governing body for Allied Health Professionals) or the College of Occupational Therapists (the professional body for occupational therapists). It is possible for occupational therapists working within care homes to be employed by social services, health (NHS), directly by the care homes, or to be self-employed independent practitioners. Results of a recent survey of the availability and use of allied health care services in the Midlands suggest that 'the source of funding for therapy provision is complex and variable, with fifteen different sources or combinations of sources reported' (Sackley et al., 2009a). The most common source of funding for occupational therapy provision in care homes was private funding from the care home itself (37%) or NHS funding (30%) (Sackley et al., 2009a).

The interventions provided by an occupational therapist in a care home setting may vary but the focus of the intended outcome is likely to increase, restore or maintain independence in performing ADLs (including self-care tasks and recreational and leisure activities), increase comfort and safety, and prevent stroke related complications. The goals of occupational therapy in a care home setting are to improve, maintain, or limit the decline in functional capacity, especially in the physical, daily living, mental, and psychosocial domains; to teach adaptive strategies and techniques to foster compensatory functional abilities; to prevent costly complications; and to promote quality of life (Przybylski et al., 1996). Possible occupational therapy interventions were defined by Steultjens et al (2003) in a systematic review of occupational therapy for stroke patients, and may include: the provision of equipment and adaptations to the environment and instruction in the use of assistive devices (Barrett et al., 2001); individual resident training of daily living skills such as washing and dressing (Walker et al., 1996); individual resident training of sensory-motor functions such as grasp and release (Feys et al., 1998, Kwakkel et al., 1999); individual resident training of cognitive functions such as memory and visual scanning (Carter et al., 1983); provision of splints to achieve increased range of movement and reduce contractures in the hand (Langlois et al., 1991); education and training of primary caregivers

(care home staff) and family in such areas as correct moving and handling procedures.

Przybylski et al (1996) cited several papers (Meier, 1988, Caplan et al., 1987, Osberg et al., 1987) that considered functional capacity to be an important predictor of both life satisfaction and quality of life. The 'My Home Life' document produced just over a decade later by Help the Aged (2007) stated that occupational therapy can improve older people's everyday functioning and their quality of life (Sackley et al., 2001), (Sackley et al., 2004) and that the consequences of a lack of occupational therapy input in care homes can lead to unnecessary dependency and high rates of immobility-related complications (Sackley et al., 2004).

#### **1.9 Introduction to the research programme**

This chapter has thus far provided an introductory background to the significance and consequences of stroke and has described the population of stroke survivors who reside within UK care homes. It has also outlined the possible benefits of providing occupational therapy interventions to care home residents with stroke. This PhD research programme will build upon existing knowledge and aims to make a significant contribution to the body of evidence on occupational therapy for care home residents living with the effects of stroke.

#### **1.9.1** Justification for the PhD research programme

This chapter has established that stroke is a significant health and social care problem, with wide ranging consequences ranging from death or severe disability and dependency, to mild or moderate impairment. Chapter one highlighted the significant population of stroke survivors who reside within a care home setting and described their stroke related characteristics. In addition it described the inequity in the level of post-stroke care and rehabilitation available to this group of individuals. The chapter cited the key literature that has emphasised a need for stroke survivors to receive on-going specialist stroke care in the longer term, regardless of their place of residence. The potential of occupational therapy for improving independence in ADLs for care home residents with stroke has been introduced.

A number of key themes have thus far emerged from the introductory chapter:

(1) Certain risk factors or 'prognostic indicators' have been documented for both the outcome of acute stroke and for the likelihood of discharge to a care home. However, the long term outcomes for stroke patients discharged to care homes have been poorly documented in the literature (Leeds et al., 2004).

(2) A second theme that emerged from published survey reports that national variations exist in therapy service provision available to

stroke survivors after discharge from hospital (Care Quality Commission, 2011b), in particular to those living in care homes. The question of whether care home residents could benefit from the provision of therapy services is yet to be answered. The available literature suggests that care home residents typically have complex healthcare needs, reflecting multiple long-term conditions, significant disability and frailty; and are likely to be more dependent than older people living in their own homes (British Geriatrics Society, 2011, Quilliam and Lapane, 2001). It could be argued that their level of post stroke disability and dependency justifies the investment of therapy provision for care home residents who have had a stroke.

Occupational therapy was introduced in chapter one as a therapy service commonly available to individuals in the early rehabilitation stage post stroke. The evidence for the efficacy of occupational therapy in improving independence in personal ADLs and preventing deterioration in community dwelling stroke survivors (Legg et al., 2006a) was acknowledged. However, whilst targeted interventions aimed at increasing independence in ADL may be beneficial to care home residents with stroke (Sackley et al 2003, (Sackley et al., 2004), it was also acknowledged that the stroke population in care homes are a different population to stroke survivors residing in their own homes in the community. This leads on to the third key theme identified in the introductory chapter. Whilst there may be the

University of Nottingham

potential for occupational therapy to be delivered within care home settings to those residents with a history of stroke, it is not known whether OT is as effective in this setting with this population. It is not known whether occupational therapy is only effective for certain individuals within this complex stroke population. There may be certain post-stroke complications or prognostic indicators common to stroke survivors within care homes that affect the efficacy of occupational therapy interventions.

The PhD programme of research was designed to explore occupational therapy within care home settings for residents who have had a stroke. In particular, three gaps in the evidence have been identified requiring further exploration:

- There is evidence of the benefits of delivering occupational therapy interventions targeted towards self-care ADL in the stroke population living in their own home. Published reports indicate that some care home residents with stroke receive therapy input. A systematic evaluation of the evidence from sufficiently powered studies of the benefit or otherwise of providing an occupational therapy service for people with stroke residing in care homes has not previously been undertaken.
- Published reports suggest that access to occupational therapy may be 'patchy' for care home residents with stroke but some occupational therapists do work in care home settings. Evidence is

lacking on the demographic profile of occupational therapists working with this specific stoke population and the content of the occupational therapy that is delivered. Current routine practice needs to be explored to investigate whether it coincides with the evidence for what has been proven to be most effective in home dwelling adults.

3. As with the delivery of all evidenced based practice there is a finite level of resources available. It is therefore important to establish which groups of individuals are likely to benefit most from an intervention. The characteristics of the stroke population in care homes therefore need to be assessed in terms of whether certain factors prevent such individuals from making any functional gains through the use of targeted occupational therapy interventions. Prognosis is central to medicine and all diagnostic and therapeutic actions aim to improve an individual's prognosis (Steyerberg et al., 2010). It may be possible to determine the prognostic indicators for those care home residents most likely to benefit from the provision of occupational therapy.

## **1.9.2** Direction of the PhD research programme

This thesis aims to address three gaps in the evidence related to occupational therapy within care home settings for residents who have had a stroke.

- A Cochrane review and meta-analysis will systematically critique and synthesize the literature in order to evaluate occupational therapy interventions directed at reducing dependency in activities of daily living (ADL) for people with stroke residing in care homes.
- 2. The Cochrane systematic review and meta-analysis will provide a balanced overview of the efficacy of delivering occupational therapy to this specific group of stroke survivors. However, it will not describe what actually happens in current routine practice across the UK. A national survey will serve the purpose of exploring current UK occupational therapy practice within care homes for people with stroke.
- 3. Subgroup analyses involving data from the OTCH study, the largest trial of occupational therapy in care homes to date will be performed to determine the factors with the greatest positive impact on successful OT intervention (as measured using the Barthel ADL Index).

# **CHAPTER 2**

# A Cochrane systematic review of occupational therapy for care home residents with stroke

# **Chapter Overview**

This chapter will present the aims, methods and results of a Cochrane systematic review and meta-analysis that was undertaken to evaluate occupational therapy interventions directed at reducing dependency in activities of daily living (ADL) for people with stroke residing in care homes.

## **2.1 Introduction**

Three-quarters of strokes occur in people over the age of 65 (National Audit Office, 2010), and an increase in stroke in members of this age group of the population is predicted over the coming decade, inevitably leading to a rise in demand for care home placements. Current trends predict that the number of strokes in the EU will rise from 1.1 million per year in 2000 to 1.5 million per year by 2025 (Truelsen et al., 2006). As stated in chapter one, residents of care homes have been reported to have complex healthcare needs, reflecting multiple long-term conditions with significant disability and frailty (British Geriatrics Society, 2011). Adverse consequences of

stroke may include high dependency in self-care tasks, falls, pain, pressure ulcers and emotional distress (Kelly-Hayes et al., 2003), (Langhorne et al., 2000, Sackley and Dewey, 2002). Stroke survivors residing in care homes are likely to be amongst the most disabled, dependent and vulnerable of stroke survivors.

It is not known whether the same benefits of occupational therapy found amongst community-dwelling stroke survivors (Walker et al., 2004, Legg et al., 2006b, Legg et al., 2006a) would be seen in the care home population with stroke who have a high prevalence of immobility, incontinence, and confusion (Bowman et al., 2004). Stroke survivors living in care homes (with and without nursing care) are more likely to also have co-morbidities such as dementia (38% of residents), arthritis, cardiovascular disease, respiratory disease, deafness, depression, fractures and blindness (Bebbington et al., 2001). Overall, 75% of care home residents are classified as being severely disabled (Office of Fair Trading, 2005).

A Cochrane systematic review of rehabilitation for older people in long-term care concluded that the provision of physical rehabilitation interventions to long-term care residents is worthwhile and safe, reducing disability with few adverse events (Forster et al., 2009b). This was a narrative review as a meta-analysis could not be performed because of the heterogeneity of outcome measures used

University of Nottingham

in the included studies. This review examined physical rehabilitation defined as 'all interventions which primarily aim to maintain or improve physical function, rather than those relating to personal care or nursing needs'. The authors also excluded interventions that addressed cognitive deficits or mood disorders unless they also aimed to improve the physical state (Forster et al., 2009b). No review has examined the efficacy of occupational therapy interventions targeted specifically at improving and maintaining independence in ADL after stroke for those residing in care homes.

Chapter 2

It could be argued that the care home population has the greatest need for on-going therapy and rehabilitation post-stroke because they have such high levels of dependency and co-morbidities and low levels of activity, yet an inequitable level of therapy is currently provided compared with therapy provided to those living in their own home. Commissioners require evidence to support the effectiveness of longer-term rehabilitation therapies if they are to commission the provision of such stroke services and, at present, this evidence is lacking. The purpose of this review was to examine available evidence specifically showing the benefits of occupational therapy interventions aimed towards increasing independence in ADL (including both personal and extended ADL) for people with stroke who were residing in care homes.

# **2.2 Aim**

This systematic review aimed to measure the effects of occupational therapy interventions (provided directly by an occupational therapist or under the supervision of an occupational therapist) targeted at improving, restoring and maintaining independence in ADL (including both self-care and leisure activities) among stroke survivors residing in long-term institutional care termed collectively as 'care homes' (care homes, residential homes, nursing homes, aged-care facilities, long-term care institutions, and older people's homes). A secondary objective was to evaluate occupational therapy interventions provided to reduce complications such as depression and low mood.

# 2.3 Method

A systematic review is a method of identifying, selecting, synthesizing and appraising all high quality primary research evidence relevant to a question in order to answer it (Cochrane Collaboration, 2012). Systematic reviews aim to minimise bias by using explicit, systematic methods that are clearly documented and easily replicable. Cochrane systematic reviews are internationally recognised as the highest standard in evidence-based health care (Cochrane Collaboration 2012). They investigate the effects of interventions for prevention, treatment and rehabilitation. Due to the nature of the research question and the desire to produce 'gold standard' research evidence, a Cochrane systematic review was embarked upon.

# 2.3.1 Criteria for considering studies for this review

Studies were included if they were randomised controlled trials (RCTs) or cluster-RCTs that evaluated occupational therapy interventions with the specific aim of facilitating, restoring or maintaining independent function in any ADL (or that aimed to reduce complications) for stroke survivors (or that included a defined subgroup of stroke survivors) who were permanently residing in a care home with or without nursing care.

Studies were included that compared interventions provided by a qualified occupational therapist or by an occupational therapy assistant under the direction of a qualified occupational therapist versus standard care (i.e. routine care usually received by residents or no intervention).

Studies were also included that compared occupational therapy interventions targeting ADL with usual care interventions, and studies that compared different types of occupational therapy interventions with each other.

Quasi-randomised trials that used, for example, alternate days of the week as the method of randomisation were excluded to eliminate the possibility of systematic bias affecting outcomes (Creswell, 2009). When trials were described in a way that implied that they were

randomised, and when the demographic details of participants in each group were similar, the trial was included and sensitivity analysis was carried out in the presence or absence of these data.

Cross-over studies were included, but only data from the first phase of cross-over studies were to be included in the meta-analysis.

#### **2.3.1.1** Types of participants

In order to be as inclusive as possible the review included studies that recruited people with a clinical diagnosis of stroke regardless of their age, sex, gender, time since stroke onset or ethnic group, and those with multiple diagnoses, as long as they permanently resided in a care home. We excluded trials of mixed causes in which the percentage of participants with stroke was less than 50%.

Stroke was defined as a focal neurological deficit caused by cerebrovascular disease (confirmation of the clinical diagnosis using imaging was not compulsory).

Within the European Union, different definitions of long-term care coexist (European Commission, 2008). Definitions used by the member states vary in identifying the care recipient and in defining the services provided (European Commission, 2008). In this review the term 'care home' was used to include various public and private institutions caring for the dependent elderly, such as 'residential

homes', 'nursing homes', 'rest homes', 'old people's homes', and 'long-term care institutions'. A 'care home' was defined using the definition used in two previous Cochrane reviews (Forster et al., 2009a, Ward et al., 2008) as providing:

- communal living facilities for long-term care;
- overnight accommodation;
- nursing or personal care;
- for people with illness, disability or dependence.

Care homes from all funding models (private, charitable, not-forprofit and government owned) were included.

## 2.3.1.2 Types of interventions

The review included all occupational therapy and therapy-based interventions (delivered at either an individual or group basis) provided directly by a qualified occupational therapist, or by an occupational therapy assistant under the direction of a qualified occupational therapist, that aimed to increase or maintain occupational performance and independence, and to improve function in ADL ('personal' ADL or 'extended' ADL, or both).

Standard care was defined as the routine care that residents usually received whilst residing in a care home.

Trials that included occupational therapy as part of a multidisciplinary team intervention were only included when the occupational therapy component of the intervention could be clearly identified and extracted from the results.

## **2.3.1.3** Types of outcome measures

The systematic review process aimed to record the outcomes that were likely to reflect the domains targeted by occupational therapy intervention. The primary outcomes were:

- Performance in ADL at the end of scheduled follow-up (e.g. Barthel ADL Index score (Mahoney and Barthel, 1965), Nottingham extended ADL Index score (Nouri and Lincoln, 1987), Edmans ADL Index score (Edmans and Webster, 1997)). When both personal ADL outcomes and extended ADL outcomes were available, we used personal ADL outcome data.
- Death or a poor outcome. We defined poor outcome as deterioration in ability to perform ADL (a drop in ADL score).

The secondary outcomes were:

- Performance in ADL at the end of intervention (e.g. Barthel ADL Index score, Nottingham extended ADL Index score, Edmans ADL Index score). When both personal ADL outcomes and extended ADL outcomes were available, we used personal ADL outcome data).
- 2. Death (the number of deaths from any cause).
- Global quality of life (e.g. EuroQol EQ-5D score (EuroQol Group, 1990)).

- Mobility (e.g. Rivermead Mobility Index score (Collen et al., 1991)).
- Mood (e.g. Geriatric Depression scale score (Yesavage et al., 1982)).
- Global cognition (e.g. attention, memory, perceptual skills, problem-solving) (Mini Mental Status Examination (MMSE) score (Folstein et al., 1975)).
- 7. Admission to hospital or other higher dependency institution.
- Adverse events (e.g. falls, new pressure sores, new contractures).
- Satisfaction with care (Satisfaction with stroke Care questionnaire SASC-19 (Boter et al., 2003)).
- 10.Health economic outcomes (e.g. EuroQol EQ-5D (EuroQol Group, 1990)).

# **2.3.2** Search methods for identification of studies

Both electronic searches and hand searches were performed. The review included trials in all languages and where possible arranged translation of articles published in languages other than English. If translation was not feasible, the review included possibly relevant trials in the 'Characteristics of studies awaiting classification' table. The primary search resource was the Cochrane Stroke Group Trials Register, which was searched in August 2012. In addition, the following bibliographic databases were searched:

- Cochrane Central Register of Controlled Trials (CENTRAL) (The Cochrane Library, September 2012) (Appendix 1);
- MEDLINE (1948 to September 2012) (Appendix 2);
- EMBASE (1980 to September 2012) (Appendix 3);
- Cumulative Index to Nursing and Allied Health Literature (CINAHL) (1982 to September 2012) (Appendix 4);
- Allied and Complementary Medicine Database (AMED) (1985 to September 2012) (Appendix 5);
- Occupational therapy database of systematic reviews and randomised controlled trials (OT Seeker) (1980 to September 2012) (Appendix 6);
- PsycINFO (1967 to September 2012) (Appendix 7);
- Physiotherapy Evidence Database (PEDro) (1952 to September 2012) (Appendix 8);
- Applied Social Index and Abstracts (ASSIA) (1987 to September 2012) (Appendix 9);
- NHS Economic Evaluation Database (NHS EED) (1991 to September 2012) (Appendix 10);
- Education Resources Information Center (ERIC) (1966 to September 2012) (Appendix 11);

- Center for International Rehabilitation Research Information and Exchange (CIRRIE) (1990 to September 2012) (Appendix 12);
- Web of Science (All years searched up to September 2012) (Appendix 13);
- ProQuest Dissertations & Theses A&I

(http://search.proquest.com)

The following registers of on-going and completed trials were also searched (September 2012):

- Current Controlled Trials (www.controlled-trials.com).
- Clinical Trials (www.ClinicalTrials.gov).
- EU Clinical Trials Register (www.clinicaltrialsregister.eu).
- Stroke Trials Registry (www.strokecenter.org/trials/).
- WHO International Clinical Trials Registry Platform (www.who.int/ictrp/en/).
- Australian New Zealand Clinical Trials Registry (www.anzctr.org.au/).

The MEDLINE search strategy was developed with the help of the Cochrane Stroke Group Trials Search Co-ordinator and adapted for the other databases.

In an effort to identify additional published, unpublished and on-going trials, the following additional searches were performed:

• Reference searching

The Science Citation Index Cited Reference Search was used for forward tracking of important papers. The reference lists were searched of the identified articles that the full text was obtained for in order to look for evidence of additional studies.

• Personal contact

Authors of relevant studies were contacted to enquire about other sources of relevant information.

Hand searches

The following journals were hand searched where they were not already included in the hand searching carried out by The Cochrane Collaboration and were not included in the Cochrane Central Register of Controlled Trials (CENTRAL):

- American Journal of Occupational Therapy (1997 to November 2012).
- Australian Journal of Occupational Therapy (1980 to November 2012).
- British Journal of Occupational Therapy (1980 to November 2012).
- Canadian Journal of Occupational Therapy (1996 to November 2012).
- Clinical Rehabilitation (January 2012 to November 2012).

- Occupational Therapy International (2009 to November 2012).
- Scandinavian Journal of Occupational Therapy (1997 to November 2012).

## **2.3.3 Data collection and analysis**

#### 2.3.3.1 Selection of studies

Two review authors (JFS, CC) independently assessed all titles and abstracts of the records identified by the searches of the electronic databases and excluded all studies that clearly did not refer to an RCT or a cluster-RCT of an occupational therapy intervention for care home residents. The full-text of all remaining potentially relevant studies were obtained and the same two review authors (JFS, CC) independently assessed each study to determine whether it met the pre-defined review selection criteria. Any disagreements between the two review authors were resolved by discussion, and if necessary in consultation with a third review author (MW) until a consensus was reached. The review authors were not blinded to the names of the study authors, institutions or journal of publication. Excluded studies and the reasons for exclusion were reported in a 'Characteristics of excluded studies' table.

#### 2.3.3.2 Data extraction and management

Two review authors (JFS, CC) independently extracted data from all included published sources to ensure reliability. Where necessary,

study authors were contacted to request missing information or for clarification. The two reviewers discussed any disagreements with the third reviewer and documented the decisions. The reviewers extracted data presented only in graphs and figures whenever possible.

Review Manager 5.1 (Revman, 2011) was used to prepare and maintain the review, to perform meta-analysis of the data and to present the results graphically. The extracted data were independently entered using the Review Manager software and included full citation details of the study, numbers and characteristics of participants (inclusion and exclusion criteria), descriptions of intervention, outcome measures, intention-to-treat analysis, withdrawals and loss to follow up.

All data was extracted onto standard simple forms (appendix 14) that assisted in examining the methodological quality of identified studies. Continuous data from rating scales was included only if the measuring instrument was either (1) a self-report, or (2) completed by an independent rater or relative (not the therapist). We primarily used endpoint data and only used change data if the former was not available. Continuous data on clinical and social outcomes are often not normally distributed. To avoid applying parametric tests to non-

parametric data, the following standards were applied to all data before inclusion:

- Standard deviations and means were reported in the article or could be obtained from the authors.
- 2. When a scale started from the finite number zero, the standard deviation, when multiplied by two, was less than the mean (as otherwise the mean was unlikely to be an appropriate measure of the centre of the distribution) (Altman and Bland, 1996).

Endpoint scores on scales often have a finite start and end point and these rules can be applied. When continuous data are presented on a scale that includes a possibility of negative values (such as change data), it is difficult to tell whether or not data are skewed. Skewed data pose less of a problem in looking at means if the sample size is large.

To facilitate comparison between trials, variables that could be reported in different metrics, such as days in hospital (mean days per year, per week or per month) were converted to a common metric (e.g. mean days per month).

Where possible, outcome measures were converted to dichotomous data. This is possible by identifying cut-off points on rating scales

and dividing participants accordingly into 'clinically improved' or 'not clinically improved'.

With regards to the direction of graphs, when possible, data was entered in such a way that the area to the left of the line of no effect indicated a favourable outcome for occupational therapy intervention.

The following outcomes were included in a 'Summary of findings' table:

- Function (also referred to as 'occupational performance') in ADL (personal ADL and/or extended ADL). (When both personal ADL and extended ADL outcomes data were available, personal ADL outcome data were used.);
- Global poor outcome;
- Death;
- Quality of life;
- Mobility;
- Mood;
- Global cognition;
- Adverse events;
- Satisfaction with care;
- Health economic outcomes.

#### 2.3.3.3 Assessment of risk of bias in included studies

JFS and CC worked independently to assess risk of bias in accordance with the Cochrane Collaboration's tool for assessing quality and risk of bias (Higgins and Green, 2011). This tool addresses the evaluation of the following specific components for each trial: the method of generation of the randomisation sequence; the method of treatment allocation concealment (it was considered adequate if the assignment could not be foreseen); blinding of outcomes assessors, participants and clinicians; completeness of outcome data (including attrition and exclusions from analysis); presence of an 'intention-to-treat' analysis; selective reporting; other biases (concerns about other bias not addressed in the other domains of the tool).

The trials were then categorized as:

- low risk of bias
- high risk of bias
- unclear uncertain risk of bias

Trials with a high risk of bias, (defined as at least three out of five components categorised as 'HIGH RISK') were not included in the meta-analysis. If the two reviewers (JFS, CC) disagreed, the final decision was made by consensus with the involvement of a third review author (MW). When inadequate details of the trial were provided, we contacted the study authors to request further information.

#### 2.3.3.4 Measures of treatment effect

For dichotomous outcomes (i.e. death, deterioration in Barthel ADL Index score), the plan was to express the intervention effect as an odds ratio (OR) with 95% confidence interval (CI). For continuous outcomes (i.e. physical ADL (PADL) score, Quality of Life (QoL), depression score), the intention was to present the mean difference (MD) with corresponding 95% CI.

When studies assessed the same outcome but measured it in different ways (e.g. different questionnaires used to measure performance in PADL), we presented the data as standardised mean difference (SMD) with corresponding 95% CI.

#### 2.3.3.5 Unit of analysis issues

Analysis and pooling of clustered data can pose problems, as authors often fail to account for intra-class correlation in clustered studies, leading to a 'unit of analysis' error (Divine et al., 1992), whereby P values are low, CIs unduly narrow and statistical significance overestimated. When clustering was not accounted for in primary studies, we planned to present data in a table, in which a (\*) symbol would be used to indicate the presence of a probable unit of analysis error. When clustering had been incorporated into the analysis of primary studies, we planned to present the data as if from a noncluster randomised study, while adjusting for the clustering effect.

University of Nottingham

We had planned to follow the statistical recommendation used in a previous Cochrane review (Xia et al., 2002): binary data presented in a report should be divided by a 'design effect'. This is calculated using the mean number of participants per cluster (m) and the intraclass correlation coefficient (ICC) [Design effect = 1 + (m - 1) \*ICC] (Donner and Klar, 2002). If the ICC was not reported, it was assumed to be 0.1 (OC et al., 1999, Ukoumunne et al., 1999).

If cluster studies have been appropriately analysed with ICCs and relevant data documented in the report taken into account, synthesis with other studies is possible using the generic inverse variance technique.

When including cross-over trials the possibility of carry-over effect is a cause for concern. This occurs if an effect of the treatment in the first phase is carried over to the second phase. As a consequence, on entry into the second phase, participants can differ systematically from their initial state. Also, cross-over trials are not considered appropriate if the condition of interest is unstable (Elbourne et al., 2002). These effects are likely in stroke; therefore we intended to use only data from the first phase of cross-over studies.

Where a study involved more than two treatment groups, if relevant, we planned to present the additional treatment group in comparisons.

Where the additional treatment groups were not relevant, we did not reproduce the data.

#### 2.3.3.6 Dealing with missing data

We planned to obtain relevant missing data from the primary investigators. We evaluated important numerical data such as numbers of people screened, numbers of participants randomly assigned, losses to follow-up, and withdrawals. For any outcome, when more than 50% of the data was unaccounted for, we did not reproduce the data or use it within the analyses. If more than 50% of participants in one treatment group of a study were lost, but the total loss was less than 50%, we marked such data with (\*) to indicate that the result may be prone to bias. We also investigated attrition rates. When attrition for a binary outcome was between 0 and 50% and data had not been clearly described, we presented the data on a 'once-randomised-always-analyse' basis (intention-to-treat analysis). We assumed that participants leaving a study early had the same rates of negative outcome as those who completed the study, with the exception of the outcome of death. We planned to undertake a sensitivity analysis to test how prone the primary outcomes were to change when 'completed' data were compared with the intention-to-treat analysis. When attrition for a continuous outcome was between 0 and 50% and completer-only data were reported, we reproduced these.

#### 2.3.3.7 Assessment of heterogeneity

We planned to judge clinical heterogeneity by considering all included studies (without seeing comparison data). We planned to look for clearly outlying situations or participant groups not predicted to arise. If such outlying situations or participant groups arose, all review authors would discuss these.

In order to judge methodological heterogeneity, we planned to initially consider all included studies without seeing comparison data. All studies would be inspected for clearly outlying methods not predicted to arise. Where such methodological outliers arose, all review authors would fully discuss these until consensus was reached.

We planned to visually inspect the graphs to investigate the possibility of statistical heterogeneity. We planned to investigate heterogeneity between studies by considering the I<sup>2</sup> method alongside the X<sup>2</sup> P value. We identified an I<sup>2</sup> estimate greater than or equal to 50% accompanied by a statistically significant X<sup>2</sup> statistic as evidence of substantial levels of heterogeneity (Higgins and Green, 2011). If substantial levels of heterogeneity were found in the primary outcome, we intended to explore reasons for heterogeneity (subgroup analysis and investigation of heterogeneity). Where funnel plots were appropriate and possible we tested for funnel plot asymmetry to assess reporting bias.

#### 2.3.3.8 Data synthesis

The random-effects method incorporates an assumption that the different studies are estimating different, yet related, intervention effects. The random-effects model takes into account differences between studies even if there is no statistically significant heterogeneity. However, a disadvantage of the random-effects model is that it puts added weight onto small studies, which often are the most biased. Depending on the direction of effect, these studies can inflate or deflate the effect size. Therefore, we planned to use a fixed-effect model and to carry out sensitivity analysis to determine whether there were differences when a random-effects model was employed.

## 2.3.3.9 Subgroup analysis and investigation of heterogeneity

If data were available, we had planned a subgroup analyses for: type of intervention, intensity (dose) and duration of treatment intervention, as well as timing of occupational therapy after stroke (acute: less than six weeks; subacute: six weeks to six months; and chronic: more than six months). We anticipated carrying out standard tests of statistical heterogeneity and exploring sources of heterogeneity.

#### 2.3.3.10 Sensitivity analysis

We also planned to carry out sensitivity analyses to determine the effects of omitting trials with a high risk of bias. We intended to base

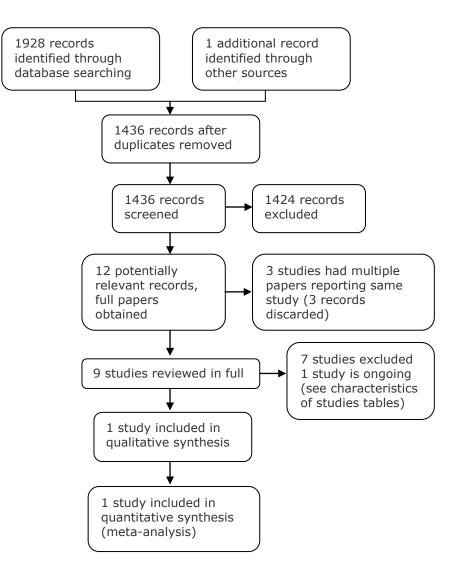
the sensitivity analyses on the method of randomisation, presence of an intention-to-treat analysis and blinding of final assessment.

## **2.4 Results**

#### 2.4.1 Results of the search

The search strategies identified a total of 1,929 results. Duplicates were removed, resulting in 1,436 records for initial screening. Two reviewers (JFS and CC) independently screened all 1,436 titles and abstracts for potentially relevant studies. A third reviewer (MW) screened 14 for which a discrepancy was noted. We obtained copies of 12 articles in full. Among these 12 articles, three studies had produced multiple articles; therefore three articles were discarded to an 'additional study information' pile. The remaining nine articles represented potential trials for inclusion in the review (Sackley et al., 2006, Braun, 2002, Braun et al., 2012, Brittle et al., 2009, Corr and Bayer, 1995, Egan et al., 2007, Sackley et al., 2007, Sackley et al., 2009a, Tsaih et al., 2012, Frandin et al., 2009, Sackley et al., 2012), of which one was included (Sackley et al., 2006) and one was an ongoing trial (Sackley et al., 2012). See Figure 1 for the study flow diagram. All included, ongoing and excluded trials were published in English; therefore no translation was required. However, we requested and obtained further details from two study authors to aid our judgement on eligibility for inclusion in the review.

#### Figure 1: Study flow diagram



## 2.4.2 Included studies

The one included trial (Sackley et al., 2006) was conducted in 2001 and included 118 participants from 12 care homes in Oxfordshire, UK. This pilot study was a cluster-randomised controlled trial with care home as the unit of randomisation (to avoid the chance of contamination that would be likely to occur if residents were randomly assigned individually). The purpose of the study was to evaluate an occupational therapy intervention to improve self-care independence for residents with stroke-related disability. Further

details of the study can be found in the characteristics of included

studies table (Table 1).

Methods	Allocation: cluster randomised control trial with random allocation at the level of care home using computer generated random numbers Blindness: allocation concealed from assessors Duration: intervention delivered over a 3-month period (duration of intervention dependent upon therapist and resident's agreed goals) Setting: 12 care homes (nursing and residential) in Oxfordshire, UK
Participants	Diagnosis: stroke N=118 Age: average age of intervention group ~ 89 years (SD~6.5); average age of control group ~ 86 (SD~9) Gender: male (n=21) and female (n=97) History: residents had moderate to severe stroke-related disability (defined by a Barthel ADL Index score of 4-15) Inclusion: residents with moderate to severe stroke related disability (defined by a Barthel ADL Index score of 4-15) Exclusion: residents with acute illness, residents receiving end-of- life care
Interventions	1. Occupational therapy targeted towards improving independence in personal ADLs, such as feeding, dressing, toileting, bathing, transferring, and mobilizing. Techniques used by the occupational therapist to improve performance in ADL included (1) task-specific practice; (2) reducing the complexity or demands of the task by changing the tools required to perform the task or by altering the environment through the provision of aids and adaptations, or by simplifying the task; and (3) specific therapeutic interventions (eg stretching to relieve tissue shortening in a hand and providing a splint). The occupational therapy intervention also included an element of education of care home staff and carers. The frequency and duration of occupational therapy intervention was dependent on the resident and therapist's agreed goals, and it took place over the 3-month period that the therapist was attached to the care home. N=63. 2. Usual care (no occupational therapist and no identified person with specific responsibility for ADL training or the provision of adaptive equipment. N=55.
Outcomes	Primary outcome: Independence in self-care ADL (Barthel ADL Index) Secondary outcomes: "poor global outcome" (defined as a deterioration in Barthel ADL Index score or death) Functional mobility (Rivermead Mobility Index) Cognitive impairment was assessed at baseline only (short Orientation-Memory-Concentration Test) - it was not an exclusion criterion.
Notes	Follow up period: 3 months and 6 months

A further on-going study (Sackley et al., 2012) appeared to meet the inclusion criteria. However, as no data was yet available for this trial,

it could not be included in a meta-analysis and will be re-considered

in future updates of this review. Further details of this study can be

found in the characteristics of on-going studies table (Table 2).

Table 2:	Characteristics	of	ongoing	studies	

Study name	A cluster randomised controlled trial of an occupational therapy intervention for residents with stroke living in UK care homes (OTCH)
Methods	Allocation: cluster randomised control trial with random allocation at the level of care home using computer generated random numbers Blindness: randomisation will be conducted by the Clinical Trials Unit and only revealed to the treating occupational therapist. Allocation will be concealed from assessors Duration: intervention delivered over a 3-month period (duration of intervention dependent upon therapist and resident's agreed goals) Setting: care homes within the UK
Participants	Diagnosis: stroke or transient ischaemic attack (TIA) Target N = 900 (from 90 care homes) Age: adults Gender: males and females Inclusion: adult men and women living in a care home with a history of stroke or transient ischaemic attack (TIA) Exclusion: active end of life care plan
Interventions	<ol> <li>Targeted course of occupational therapy (targeted repetitive training of activities of daily living, provision of adaptive equipment and minor environmental adaptations and staff training) aimed towards improving independence in personal ADL and mobility. The intervention will be delivered to both the individual resident and the care home staff by an occupational therapist over a period of 3 months.</li> <li>Standard care (which does not routinely include provision of occupational therapy)</li> </ol>
Outcomes	Primary outcome: Independence in ADL (Barthel ADL Index) Secondary outcomes: Functional mobility (Rivermead Mobility Index) Mood (15-item Geriatric Depression Scale (GDS15), and informant version) Adverse events Staff attitude Quality of life and Health utility (using the Euroqol EQ-5D) All primary and secondary outcome measures will be assessed at baseline (0 months), after the intervention (3 months) and at follow-up (6 and 12 months) In addition, the Mini-Mental State Examination (MMSE) will be used at baseline to determine the participant's cognitive impairment, not as an exclusion criterion.
Starting date	January 2010
Notes	The study is being funded by the NIHR Health Technology Assessment Programme - HTA (UK) and aims to be completed in 2013. Trial registration: ISRCTN00757750

## 2.4.3 Excluded studies

Seven studies were excluded following consideration of the full papers. We excluded studies in which participants had a mixed cause for residence in a care home and in which stroke accounted for fewer than 50% of participants; and those in which the participants were not care home residents. We also excluded studies if the intervention was not delivered by an occupational therapist. We excluded those that included occupational therapy as part of a multidisciplinary team intervention but where the occupational therapy component of the intervention could not be clearly identified and extracted from the results. The excluded studies are listed in the characteristics of excluded studies table (Table 3).

Study ID	Reason for exclusion
Braun 2012	Intervention was delivered by occupational therapists and physiotherapists. The OT component of the intervention could not be clearly identified.
Brittle 2009	Participants had mixed aetiology, less than 50% of participants had a diagnosis of stroke (23%) Intervention was delivered by physiotherapists not occupational therapists, not an occupational therapy intervention
Corr 1995	Participants were not care home residents
Egan 2007	Participants were not care home residents
Frandin 2009	Participants had mixed aetiology, less than 50% of participants had a diagnosis of stroke (confirmed by Trialists)
Sackley 2009 (Rich-T)	Participants had mixed aetiology, less than 50% of participants had a diagnosis of stroke (22%)
Tsaih 2012	Participants had mixed aetiology, less than 50% of participants had a diagnosis of stroke (Trialists confirmed 27% had a confirmed diagnosis of stroke); Intervention was not delivered by an occupational therapist, a physiotherapist delivered the therapy-based intervention

#### Table 3: Characteristics of excluded studies

## **2.4.4** Risk of bias in included studies

Two reviewers (JFS and CC) rated the methodological quality of the study independently using the bias criteria in the risk of bias table

(table 4). The reviewers' judgements about each risk of bias item for the included study are presented in table 4.

#### Table 4: Risk of bias

Bias	Reviewers' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	"Randomization was carried out independently by a statistician with random allocation at the level of care home". Method used to generate the randomisation sequence was "computer generated random numbers".
Allocation concealment (selection bias)	Low risk	"Allocation was revealed only to the occupational therapist, not to the assessors". Allocation was revealed only to the treating therapist therefore.
Blinding of participants and personnel (performance bias)	Unclear risk	Participants, care home staff and treating therapist could not be blinded as to treatment group allocation.
Blinding of outcome assessment (detection bias)	Low risk	"Assessments were completed by research staff masked to the trial allocation". Assessor was blinded as to treatment allocation.
	Low risk	"Although the analysis was by intention to treat, this was modified in the case of BI and RMI scores because of the many deaths occurring before follow-up". Data was treated on an 'intention to treat' basis and study attrition was clearly reported. At 3 month outcome 9 were missing from the control group, 4 were missing from the intervention group. At 6 month outcome 11 were missing (20 in total over 6 months) from the control group, 6 were missing (10 in total over 6 months) from the intervention group. All 'missing' data was due to the participants having died during the course of the study. This is to be expected in a frail elderly care home population.
Selective reporting (reporting bias)	Low risk	
Other bias	Unclear risk	Bias can arise from cluster designs because only 1 resident needs to reveal the group to unblind the assessor to the whole home. However this design was justified by the authors because "the chance of contamination if residents were randomized individually was very high, outweighing the disadvantages of this design".

#### 2.4.4.1 Allocation (selection bias)

With regard to allocation bias, the participants in the Sackley et al (2006) study used a clearly concealed randomisation procedure, allocating participants by care home (cluster randomised) to receive or not receive an occupational therapy intervention. Randomisation was carried out independently by a statistician with care homes grouped into three strata: type of home (residential, nursing, or both), funding source (private or local authority) and setting (urban or rural). Computer-generated random numbers were used to randomly allocate care homes to one of the two groups (occupational therapy intervention or standard care control group). Group allocation was revealed only to the treating therapist and not the outcome assessor.

#### **2.4.4.2** Blinding (performance bias and detection bias)

The outcome assessor was blinded as to the group assignment of participants. Because of the nature of the intervention, allocation concealment from participants, treating therapist or care home staff involved in the study was not possible.

#### **2.4.4.3** Incomplete outcome data (attrition bias)

The data in the included Sackley (2006) study was reported to be treated on an 'intention to treat' basis. All 'missing' data during the course of the study were related to death of participants, which is to be expected in a frail elderly population.

#### 2.4.4.4 Selective reporting (reporting bias)

The risk of selective reporting bias is unclear. The Sackley (2006) study team could not supply the reviewers with a copy of the original study protocol. The article reported all outcomes that it stated would be provided. However, it was not possible to ensure that the original intention had been to report on these specific outcomes and no additional outcomes.

#### 2.4.4.5 Other potential sources of bias

Risk of bias is possible when a cluster design is used. However, the Sackley et al (2006) study justified the use of a cluster-randomised trial because of the possibility of contamination if individual participants within each care home were randomly assigned. In a care home setting equipment is often shared and staff work with a number of residents. Therefore, the intervention provided by the occupational therapist could have easily affected the control participants unwittingly had a cluster-randomised design not been used.

## 2.4.5 Effects of interventions

Only one study was included in this review; therefore a meta-analysis was not possible. Data were available for the outcomes: function (occupational performance) in ADL at the end of scheduled follow-up, global poor outcome (death or a drop in ADL score) at the end of scheduled follow-up, function in ADL at the end of intervention, and

mobility. The data for outcomes related to function in ADL and mobility were reported in the study article as mean (SD) values, and data related to global poor outcome (death or a drop in ADL score) were reported as total N and number of participants who had clinically deteriorated in each treatment group.

#### 2.4.5.1 Primary outcomes

#### Performance (function) in ADL at the end of scheduled followup

The one included trial (Sackley et al., 2006) recorded the Barthel ADL Index score; this was used in the analysis as the measure of performance in ADL at the end of scheduled follow-up. As the included trial was a cluster-randomised trial, to take account of the design effect we used an intra-cluster correlation coefficient of 0.1 to calculate average cluster size. The average cluster size in the trial was calculated by dividing the total number of participants by the total number of care home clusters, (63+55)/(6+6)=9.83. The design effect for the trial as a whole is therefore 1 = (m-1)\*ICC = $1+(9.83-1)\times0.1=1.883$ . This results in an effective sample size in the occupational therapy intervention group of 63/1.883=33 and an effective sample size in the control group of 55/1.883=29. The design effect was applied to the outcomes data for performance (function) in ADL at the end of scheduled follow-up. The standard mean difference using a fixed-effect model was 0.39 (95% CI -0.11 to 0.90; P = 0.13).

Trials were insufficient to allow firm conclusions to be drawn.

**Figure 2:** Forest plot of comparison 1 Occupational therapy versus standard care, outcome 1.1 Function in ADL at the end of scheduled follow-up (Barthel ADL Index score)

Study or subgroup	OT interventio N	n group Mean(SD)	Standard ca N	re group Mean(SD)			an Differe ed,95% Cl	nce	Weight	Std. Mean Difference IV,Fixed,95% Cl
Sackley 2006b	33	10.2 (5.9)	29	8.1 (4.5)			•		100.0%	0.39[-0.11, 0.90]
<b>Total (95% Cl)</b> Heterogeneity: not app Test for overall effect: <i>I</i> Test for subgroup diffe	Z = 1.52 (P = 0.13		29						100.0 %	0.39 [ -0.11, 0.90 ]
			OT in	itervention group	-100	-50	0 Standar	50 rd care grou	100 p	

## Death or a poor outcome (drop in ADL score) at the end of scheduled follow-up

At six months, Sackley et al (2006) reported a reduction in the number of care home residents who died or deteriorated in their ability to perform ADL among participants who received occupational therapy intervention (32/63 51%) compared with the control group, which received standard care (42/55 76%) (OR 0.32, 95% CI 0.14 to 0.71; P = 0.005).

However, applying the design effect (1+(9.83-1)0.1=1.883) to the number of residents (participants) who died or deteriorated in their ability to perform ADL (global poor outcome) produces the following results: 17/33 (51%) in the intervention group compared with 22/29 (76%) in the control group (OR 0.34, 95% CI 0.11 to 1.01; P = 0.05). Trials were insufficient to allow firm conclusions to be drawn.

## Figure 3: Forest plot of comparison 1 Occupational therapy versus standard care, outcome 1.2 Global poor outcome (death or a drop in ADL score) at the end of scheduled follow-up (6 months)

Study or subgroup	OT intervention grouβptan n/N	ndard care group n/N		dds Ratio ixed,95% Cl		Weight	Odds Ratio M - H, Fixed, 95% Cl
Sackley 2006b	17/33	22/29				100.0 %	0.34 [0.11, 1.01]
Heterogeneity: not app Test for overall effect: 3		<b>29</b> dard care group)	•	-		100.0 %	0.34 [ 0.11, 1.01 ]
	OT inte	0.01 ervention group	0.1	1 Standard	10 I care group	100	

## 2.4.5.2 Secondary outcomes

## Performance (function) in ADL at the end of intervention)

Sackley et al (2006) reported performance in ADL at the end of the 3 month intervention period. When the design effects were applied to the published outcome data, the SMD using a fixed-effect model was 0.48 (95% CI -0.03 to 0.99; P = 0.06).

There were insufficient trials to draw firm conclusions.

Figure 4: Forest plot of comparison 1 Occupational therapy versus standard care, outcome 1.3 Function in ADL at the end of intervention (Barthel ADL Index score)

Study or subgroup	OT interventio N	n group Mean(SD)	Standard cai N	re group Mean(SD)			an Differen d,95% Cl	ce	Weight	Std. Mean Difference IV,Fixed,95% CI
Sackley 2006b	33	10.8 (5.5)	29	8.2 (5.2)					100.0%	0.48 [ -0.03, 0.99 ]
Total (95% CI) Heterogeneity: not appl Test for overall effect: Z Test for subgroup diffe	<pre>l = 1.85 (P = 0.06</pre>		29						100.0 %	0.48 [ -0.03, 0.99 ]
			OT in	tervention grou	-100 p	-50	0 Standard	50 I care group	100	

## Death at the end of scheduled follow-up

Data were available from Sackley et al (2006) for the outcome of death at end of scheduled follow-up (six months). Applying the design effect (1.883) to the reported number of deaths in the intervention group (10/63, 16%) compared with the control group

(20/55, 36%) at six months produces the following adjusted results:

5/33 (15%) in the intervention group compared with 11/29 (38%) in

the control group (OR 0.29, 95% CI 0.09 to 0.98; P = 0.05).

Trials were insufficient to allow firm conclusions to be drawn.

Figure 5: Forest plot of comparison 1 Occupational therapy versus standard care, outcome 1.4 Death at the end of scheduled follow-up

Study or subgroup	OT intervention gro.6pt: n/N	andard care group n/N		)dds Ratio Fixed,95% Cl	Weight	Odds Ratio M - H, Fixed, 95% Cl
Sackley 2006b	5/33	11/29			100.0%	0.29 [ 0.09, 0.98 ]
Heterogeneity: not app Test for overall effect:		<b>29</b> dard care group)	-	-	100.0 %	0.29 [ 0.09, 0.98 ]
		0.01	0.1	1	10 100	
	OT in	tervention group		Standard	care group	

## Global quality of life

No data were available for this outcome.

## Mobility

Sackley et al (2006) reported mobility at the end of scheduled follow-

up using the Rivermead Mobility Index score. The design effect was

applied to the reported data, resulting in a SMD (using a fixed-effect

model) of 0.14 (95% CI -0.36 to 0.64; P = 0.58).

There were insufficient trials to draw firm conclusions.

# Figure 6: Forest plot of comparison 1 Occupational therapy versus standard care, outcome 1.5 Mobility (Rivermead Mobility Index score) at the end of scheduled follow-up

Study or subgroup	OT intervention N	group S Mean(SD)	itandard ca N	re group Mean(SD)	Std. Mean Differen IV,Fixed,95% Cl	e Weight	Std. Mean Difference IV,Fixed,95% Cl
Sackley 2006b	33	5 (3.7)	29	4.5 (3.3)		100.0%	0.14 [-0.36, 0.64
<b>Total (95% Cl)</b> Heterogeneity: not appl Test for overall effect: Z Test for subgroup diffe	2 = 0.55 (P = 0.58)	abla	29			100.0 %	0.14 [ -0.36, 0.64
	nences. Not appres		OT in	-100 itervention group		50 100 care group	

#### **Other outcomes**

No data was available for the outcomes: quality of life, global cognition, adverse events, satisfaction with care, or health economic outcomes.

## 2.5 Discussion

The aim of this systematic review was to measure the effects of occupational therapy interventions (provided directly by an occupational therapist or under the supervision of an occupational therapist) targeted at improving, restoring and maintaining independence in ADL (to include both self-care and leisure activities) among stroke survivors residing in long-term institutional care termed collectively as 'care homes' (care homes, residential homes, nursing homes, aged-care facilities, long-term care institutions, and older people's homes). A secondary aim was to evaluate occupational therapy interventions aimed at reducing complications such as depression and low mood. Only one trial (Sackley et al., 2006) met the criteria for inclusion in the review and therefore data could not be pooled for further analysis and interpretation. The Sackley et

al (2006) study was a pilot study and the same study team are currently running a larger phase III multi-centre cluster randomised controlled trial (the OTCH study) (Sackley et al., 2012) which was identified during the searches and is listed in the Characteristics of on-going studies table (table 2). It is hoped that the data from the OTCH study will be available and eligible for inclusion in a metaanalysis in future updates of this review. Both the included study and the on-going study share the same objective of evaluating occupational therapy intervention delivered within care home settings to residents with stroke and their Carers, targeted at improving independence in personal activities of daily living.

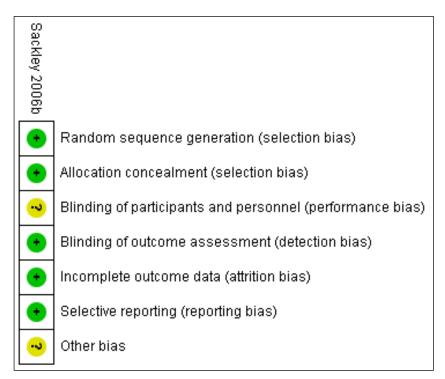
### 2.5.1 Summary of main results

One study, involving 118 participants met the inclusion criteria and was included in the review. We found one on-going study that also met the inclusion criteria for the review but the data was not yet available to include in the meta-analysis. There was insufficient data to determine whether occupational therapy interventions can improve, restore and maintain independence in activities of daily living for care home residents with stroke. There was a lack of evidence available to evaluate occupational therapy interventions aimed at reducing complications such as depression and low mood and those aimed at improving quality of life.

## 2.5.2 Quality of the evidence

The studies identified were insufficient to address all of the objectives of this review. The body of evidence identified did not allow a robust conclusion regarding the objectives of this review. Evidence could only be included from 118 participants from one study which had methodological limitations. The included study was a small pilot study and was a cluster randomised trial. We therefore had to take into account this design effect in the analysis of the results. The risk of bias in the included review has been summarised in figure 7 below.

Figure 7: Risk of bias summary: review authors' judgements about each risk of bias item for each included study



### **2.5.3 Potential bias in the review process**

We are confident that through a rigorous searching process, including comprehensive database searching and hand searching of relevant journals, we should have identified all relevant published studies. However, there is always the possibility when conducting the systematic review process that some additional studies (published and unpublished) may have been missed. If this was the case, this could have potentially introduced bias into the review.

One of the reviewers (CS) was the lead author on three of the study papers (Sackley et al., 2006, Sackley et al., 2007, Sackley et al., 2012) and a co-author on another (Brittle et al., 2009) paper that were considered for inclusion in this review. However to minimise the risk of bias, this reviewer was not included in the actual screening of papers, review and data extraction process, or decisions regarding suitability of papers for inclusion in the review.

## 2.5.4 Agreements and disagreements with other studies or reviews

To our knowledge, the effects of occupational therapy interventions targeted at improving, restoring and maintaining independence in ADL among stroke survivors residing in care homes have not been systematically reviewed before.

## **2.6 Conclusion**

## 2.6.1 Implications for clinical practice

The effectiveness of occupational therapy for care home residents with stroke remains unclear. The potential benefits of delivering occupational therapy interventions targeted at improving, restoring, and maintaining independence in ADL among stroke survivors residing in care homes can be supported by the limited evidence from the reviewed RCT. However, there is insufficient evidence in this review to conclude that occupational therapy improves outcomes for care home residents with stroke.

## **2.6.2** Implications for research

The lack of randomised controlled trials evaluating the efficacy of occupational therapy interventions for care home residents with stroke, suggests that more high quality research in this area is needed. The OT in Care Homes (OTCH) study (Sackley et al., 2012) a large multi-centre cluster randomised controlled trial (aiming to recruit 900 participants) evaluating the effects of a targeted course of occupational therapy intervention for care home residents with stroke, was currently on-going with results not available at the time of the review. Further high quality research involving care home residents with stroke is justified to investigate the effects of activities of occupational therapy intervention upon performance of activities of daily living, mobility and quality of life, and also the effects upon

complications such as depression and low mood in this population and setting.

## **CHAPTER 3**

## A national survey of occupational therapy for care home residents with stroke

## **Chapter Overview**

The previous chapter reported the findings of a Cochrane systematic review and meta-analysis of occupational therapy interventions for people with stroke living in care homes. Although the intention had been to perform a meta-analysis, this was not possible due to a lack of high quality randomised controlled trials of occupational therapy interventions for care home residents with stroke. The systematic review concluded that there was insufficient evidence (published data from only one small pilot RCT) to conclude that occupational therapy improves outcomes for care home residents with stroke. Uncertainty exists as to which specific components of occupational therapy, if any, are beneficial to stroke survivors in care homes. The focus of this chapter is to explore what current occupational therapy practice is with this specific population of stroke survivors. A national survey study was designed and carried out for this purpose.

## **3.1 Introduction**

The Cochrane systematic review of occupational therapy for care home residents with stroke, described in chapter two, evaluated the available evidence for the efficacy of delivering occupational therapy interventions to people with stroke residing in care homes. The Cochrane review provided a global perspective of the available evidence from studies that had taken place throughout the world. However, it did not provide data on what is current occupational therapy clinical practice with stroke survivors residing in care home settings. The research paper included in the aforementioned Cochrane review described the content of occupational therapy interventions that were delivered as part of a randomised controlled trial. This may not necessarily be the same as routine clinical occupational therapy delivered in this type of setting. There have been no published studies to date describing the level and content of occupational therapy provision within UK care homes for residents who have had a stroke. The College of Occupational Therapists have produced a fact sheet entitled 'occupational therapists work with people living in care homes'. However it provides only vague detail, in the form of six bullet points, on ways an occupational therapist may provide intervention to a general care home population. These bullet points include: delivering falls prevention programmes; maximising residents' potential to engage in activity and promoting social inclusion; advising on leisure activities that provide intellectual

and social stimulation to protect against dementia (Fratiglioni et al., 2007); improving the environmental design of the care home to compensate for impaired memory, learning and reasoning skills, and reduce the levels of stress experienced by people with dementia; advising carers how to support people with dementia; and training carers to enable residents' continued participation in activities. As previously highlighted in the introductory chapter of this thesis, at the turn of the century, as few as 3% of care home residents in the UK had access to therapy provision (Barodawala et al., 2001). A decade later, the prevalence of qualified occupational therapists working within care home settings is unknown. The results of a recent survey of the availability and use of allied health care services in the Midlands (Sackley et al., 2009a) indicated that the funding of therapy provision within care homes is complex and variable. It was unclear whether there were regional variations in the funding and access to occupational therapy services for care home residents with stroke. In addition, little is known about the content of occupational therapy assessment and intervention (if any) that is being delivered to stroke survivors in care homes.

### **3.2 Aim**

Thus, the aim of this study was to identify current occupational therapy practice trends of the population of occupational therapists

working with stroke survivors who reside in UK care homes and the neighbouring British Channel Islands.

This was an exploratory study with the objective of collecting demographic data along with data on the funding, content and provision of occupational therapy services within care homes. In particular, the study aimed to capture information about therapy provision for residents with a confirmed or suspected stroke.

### **3.3 Method**

This study adopted a quantitative strategy as the purpose of the study was to collect a numeric description of the current trends within the care home population. The strategy of scientific enquiry chosen as the method of data collection was that of survey research because it was considered an efficient method for systematically collecting data from a broad spectrum of occupational therapists working in care home settings with stroke survivors. Survey research is versatile, efficient and generalizable (Schutt, 2012) and therefore fits the purpose of this research programme.

## 3.3.1 Study design

A questionnaire design was chosen in preference to an interview study due to the nature of the research question and the research sample to be targeted (Creswell, 2009). The research question involved a broad area of research exploration and therefore a

questionnaire based survey would allow a larger amount of quantitative data to be captured. A questionnaire survey study would also provide a numerical description of trends of this specific population of occupational therapists working within care home settings. Whilst in-depth interviews would provide detailed views and opinions from a small sample of the care home population, interviews would not elicit quantitative data that could be generalised from the sample to the population (Babbie, 1990).

For pragmatic reasons (such as cost, ease of dissemination, and to cater for those without computer access or IT skills), a mixed mode of survey administration was used for the study; a web survey combined with a conventional paper version of the self-administered questionnaire (appendix 15).

### **3.3.2** Survey type

An internet survey was selected as the primary method of survey data collection, with a paper postal version printed as a secondary version of the questionnaire. Internet (web/online) surveys enable faster and cheaper data collection compared with paper postal questionnaires. Previous literature has suggested that having a web survey can increase response rates compared with having a postal questionnaire only (Yun and Trumbo, 2000). Web surveys can be used to study large groups of online users (Sheehan and Hoy, 1999)

and have fewer cost implications than postal questionnaires or face to face interviews. This type of electronic survey is advisable when resources are limited and the electronic version meets the needs of the target population (Yun and Trumbo, 2000). A self-completion questionnaire was developed by the author using 'Survey Monkey' (surveymonkey.com), a commercial survey design website. Survey Monkey is the 'world's leading provider of web-based survey solutions' (Survey Monkey Inc, 2014). It provides 24 hour technical support and offers the security of SSL encryption and multi-machine backup to keep data secure and was thought to meet the needs of the study. The online questionnaire was designed by the author (see sub chapter 3.3.4 'Questionnaire development' for details of the development process) and when finalised potential respondents could be directed to the website to answer the questionnaire online. A web survey was chosen in preference to an email survey (a survey in which a questionnaire is included as an attachment to an email or embedded within an email) because web surveys allow greater freedom in the use of embellishments to improve appearance and add greater appeal to the respondent; and can also be designed to include 'filter' questions to automatically skip to the next appropriate question based on the responses given (Bryman, 2008). The ability to include filter questions which enable respondents to bypass the questions that are not applicable to them is a major benefit of web surveys. Filter questions may reduce the number of respondents who

fail to complete the survey after becoming frustrated at the number of questions that are not applicable to their personal experience or situation.

The use of a web survey also meant that 'paging survey design' could be used so that each 'page' of the online version of the guestionnaire mirrored a page in the paper version of the questionnaire. In paging survey design, rather than the entire survey being presented as one continuous page in a single HTML format (as in 'scrolling survey design'), each question or group of related questions can be presented on a separate HTML form. There are certain advantages and disadvantages of using a paging survey design as opposed to a scrolling survey design. Firstly, minimal scrolling is required so that each page of the questionnaire can be viewed as a whole on the screen. Also any data from partially completed surveys are retained. It is also possible to add automated skips and routing so that the respondent is directed automatically to the next applicable question. Possible disadvantages include respondents having less control over the order in which they choose to complete items and also if a respondent chooses to opt out of the remaining questions and abandon the survey part-way through, the answers already provided will have been captured by the system. With regards to the former possible disadvantage, the questionnaire was designed with the

intention that questions should be answered in sequence, so in this case paging design was beneficial in ensuring this occurred.

To compensate for less confident computer users and those with limited internet access, a paper version of the questionnaire was made available to those who preferred this medium of data collection. Where paper postal versions of the survey questionnaire were requested, they were sent out along with a stamped addressed envelope to encourage return of the completed questionnaire.

## **3.3.3 Defining the sample population and determining sample size**

The target sample population comprised of UK qualified occupational therapists working within care home settings with people who have stroke. It was recognised that working with residents with stroke was not limited to stroke specialist occupational therapists. Potentially, all occupational therapists who treat people within a care home setting could work with residents who have a history of stroke, even if the therapy referral was related to difficulties from another diagnosis such as arthritis or dementia. The survey was therefore targeted at all occupational therapists with experience of working with people within a care home setting. The purpose of the study was to explore the practice of qualified occupational therapists who delivered their interventions within a care home setting. Therefore, those therapists who treated care home residents as outpatients

within a clinic or hospital setting were not included within the scope of the survey. However, the prevalence of qualified occupational therapists working within care home settings is something of a conundrum as little data exists on the provision of occupational therapy to the general care home population. It was therefore not possible to accurately determine the sample size required for this survey. The difficulty in targeting all occupational therapists who could potentially work with stroke survivors within a care home setting is that currently there is no reliable way to access these individuals. This is partly due to the numerous potential modes of employment in this sector (privately funded, self-employed, NHS, social services, or charity funded). On contacting the College of Occupational Therapists (the profession specific body for occupational therapists in the UK) it became apparent that there was no known database in existence containing the details and work addresses of all occupational therapists that provide assessment and/or intervention within care homes.

In order to practice as an occupational therapist in the UK, therapists must be registered with the Health and Care Professions Council (HCPC). However, the HCPC does not collect specific data on the variety of settings therapists work in and has a policy of withholding contact details of registered therapists in line with UK data protection and confidentiality legislation.

Many occupational therapists within the UK can choose to become a member of the profession's governing body, the British Association of Occupational Therapists (BAOT). BAOT has over 22,863 professional members. The College of Occupational Therapists (COT) is a registered charity and subsidiary of BAOT which acts on behalf of all members of the Association. COT supports a number of Specialist Sections which are groups of occupational therapists in related fields who work to promote their area of common clinical interest. The Specialist Sections are part of COT and work in partnership with each other to promote the development of occupational therapy knowledge and skills. Every member of BAOT has the opportunity to join a specialist section and BAOT membership is a pre-requisite of membership to a COT Specialist Section. Each specialist section promotes research within its specialist areas and disseminates information to members through a variety of media including regular email correspondence. Members of the College of Occupational Therapists Specialist Section Neurological Practice (COTSS-NP), Specialist Section Older People (COTSS-OP), and Specialist Section Independent Practice (COTSS-IP) were identified as potentially working within a care home setting with people who have had a stroke. COTSS-NP is the most likely specialist Section for therapists working with people with stroke as COTSS-NP has a stroke clinical forum group. COTSS-OP has a care home forum, and COTSS-IP may have members who are self-employed and work in care homes or

members who are employed privately by care homes. The email networks of these three Specialist Sections therefore provided an avenue to approach potential research participants. COT does not have a Specialist Section specifically for therapists working in social services and it was considered important to try and recruit as representative a sample as possible, including occupational therapists from all sectors. Therefore to ensure the request for participants reached all potential respondents, snowball sampling using social networking sites (Twitter and Facebook) and flyers at conferences were also used to advertise the survey and invite occupational therapists to participate. Occupational therapists who received the invitation to participate in the survey were encouraged to further share the web-survey link with their occupational therapy colleagues.

It is not known how many of the Specialist Section members met the inclusion criteria (e.g. had experienced working as an occupational therapist within a care home setting). On the date the email containing the request for participants was first distributed to the Specialist Sections, COTSS-NP had 866 members, COTSS-OP had 379 members and COTSS-IP had 377 members. Those with experience of working in care homes were invited to respond to the request to participate in the online survey. The final section of the survey included questions for those who had worked specifically with care home residents with a history of stroke.

#### 3.3.4 Questionnaire development

Before the questionnaire was developed, the areas of occupational therapy practice within a care home setting that required exploration were listed. These included background demographic information on the UK country and area of the country in which the therapists worked, funding of therapy provision and job title, along with more care home specific data such as the number of referrals from care homes and the referral waiting times. Questions related specifically to care home residents with stroke were listed to explore the therapists' stroke specific training, expertise and the actual content of occupational therapy assessment and intervention with such residents.

A questionnaire was then developed based on the structure of previous similar survey studies of stroke rehabilitation (Drummond et al., 2012, Walker et al., 2000, Sackley and Lincoln, 1996). These previous surveys had been successful in collating data on occupational therapists working with stroke patients and had used Likert-type scaled responses (Likert, 1932) and open ended questions to elicit both quantitative and qualitative data on the assessment and intervention provided by occupational therapists. There was also a professional working relationship already in existence between Fletcher-Smith (the PhD student) and Drummond, Walker and Sackley. This therefore provided an opportunity for open discussion

between the authors as to how the structure and content of their published surveys might have been improved upon. Initial feedback on the content, structure and wording of the questionnaire was sought from four local occupational therapy researchers. Comments from this initial consultation process were used to revise the instrument further.

### 3.3.5 Domains assessed in the questionnaire

The questionnaire comprised of three parts (appendix 15). Part one collected background demographic data from the occupational therapists (respondents), such as the country and specific work location, employer, job title, and specialism; part two collected general care home information, such as referrals, access to residents' medical information, and recent provision of occupational therapy to residents with stroke; and part three collected stroke specific data. This final part of the questionnaire aimed to capture responses only from occupational therapists who had worked with residents with stroke.

### **3.3.6 Content and structure of the questionnaire**

The questionnaire was a web based survey with prospective participants invited to visit a website where the self-completion questionnaire could be found. 'Radio buttons' were used to enable the respondents to choose between lists of possible answers to the closed questions. For open questions, respondents were invited to

University of Nottingham

Chapter 3

type their response directly into a boxed area. A number of questions contained Likert-type scale (Likert, 1932) response options of "very often", "often", "rarely", or "never". This type of scaled response allows respondents to give either a positive or negative response along a scale. The Likert scale is one of the most common techniques for conducting investigations into attitudes and opinions (Bryman, 2008) and enables the measurement of agreement (for example, 'strongly disagree' through to 'strongly agree'), frequency (for example, 'never' through to 'always') or evaluation (for example, 'very poor' through to 'very good'). As an alternative to completing the web-based survey, participants were able to request a postal paper version of the questionnaire if they were unable to access the internet website.

A hard copy of the questionnaire was developed initially using Microsoft Word for Windows 2007 (appendix 15). This paper version was used for the consultation piloting stage. Once the final question format and wording was established it was submitted to the Ethics Committee. It then provided the template for the creation of an online web-based survey. The questions were worded in the same format and order in both the online and paper version of the questionnaire survey. The only difference between the two versions was a box on the front page of the paper version, containing instructions on completing and returning the questionnaire by post.

University of Nottingham

Chapter 3

The web survey did not require these return postal instructions but did contain instructions for a request to post any relevant additional information such as a local protocol or information leaflets about the respondents' occupational therapy service for care home residents. Such additional information would provide more contextual data and maximise information gathering.

The title of the questionnaire was important in creating the first impression of the purpose and content of the study. The title did not mention stroke as this may have dissuaded therapists who worked in care homes but only see the occasional resident with stroke from responding and completing the survey. For this reason, 'A national survey of occupational therapy for care home residents' was chosen for the title of the survey questionnaire. The content of the questionnaire included an introduction describing the purpose of the questionnaire, instructions and contact details for completing and returning the questionnaire, and the actual questions arranged in the three domain sections. A checklist was included at the end of the questionnaire to prompt respondents to ensure they had answered each question and enclosed any additional information required. The questions were adjusted as a result of feedback from piloting the questionnaire. This is described in more detail later in subchapter 3.3.10.

# **3.3.7** Introduction to the survey

The introduction of the questionnaire served the purpose of explaining to potential respondents the focus of the survey and the purpose of collecting such data. The introduction of the survey questionnaire aimed to place the research in context and explain who should complete the questionnaire and how it should be completed. The introduction provided instructions on the completion of the survey and reassurance that confidentiality would be maintained as all responses would be anonymous. Key words were underlined to add clarity.

# 3.3.8 Demographic data

Part one of the questionnaire asked seven 'background information' questions to collect the following demographic data:

- Clarification that the respondent provided occupational therapy to care home residents (not within a clinic or hospital).
- 2. Country of work (England, Scotland, Wales, or Northern Ireland).
- 3. Specific geographical location.
- 4. Employer (e.g. NHS, Social Services, Care Home).
- 5. Job title.
- 6. Involvement in research respondents were asked whether they provided occupational therapy within care homes solely because they were involved in a research study of care home residents, rather than it being part of normal routine practice. (This was

due to the knowledge that a large national randomised controlled trial was on-going at the time of the survey and involved research occupational therapists providing interventions within care homes)

 Specialism – Respondents were asked whether they classed themselves as a 'generic OT', 'stroke specific OT', 'neurological OT', 'dementia specialist', or other specialist.

This demographic information was considered important in describing the characteristics of the occupational therapy population engaged in work within care home settings.

# 3.3.9 Main questionnaire questions

'Part two' asked five 'general care home information' questions that collated the following data:

- 1. How referrals were made to the occupational therapist.
- 2. Average length of time it takes to process referrals.
- 3. Average number of referrals received from care homes per month.
- 4. Ability to access and confirm the resident's medical diagnosis.
- 5. Whether the respondent had provided occupational therapy assessment and/or intervention to a care home resident with a suspected or confirmed diagnosis of stroke in the last 12 months.

The remaining questions related to occupational therapy provision within a care home setting to residents who had a history of stroke.

Therefore only those who answered "yes" they had worked with a resident who had had a stroke in the last 12 months were required to proceed to the final section of the questionnaire. 'Part three' of the questionnaire asked 11 'stroke specific care home intervention information' questions to collate data on the following areas:

- Stroke specific training that the respondents had received in their current post.
- The use of non-standardised assessments with care home residents with stroke.
- The standardised assessments used with care home residents with stroke.
- Occupational therapy interventions delivered to care home residents with stroke.
- 10. Treatment approaches used with this client group (e.g. Bobath, motor re-learning, compensatory).
- 11. The most common aims of treatment.
- Recommendations made regarding the provision of aids, equipment, and adaptations.
- 13. Funding arrangements for the provision of aids, equipment, and adaptations in nursing homes.
- 14. Funding arrangements for the provision of aids, equipment, and adaptations in residential homes.
- 15. Limitations on the occupational therapy interventions that can be delivered within the care home setting.

At the end of the questionnaire, additional space was provided for respondents to comment on anything else about occupational therapy for care home residents with stroke that had not been asked already but that they wanted to make known.

Lists of options and radio buttons for responses were provided for some questions. For other questions lists of options and radio buttons for Likert style responses were given or free text boxes were provided for the respondent to write in their response. Additional free text boxes for comments followed certain responses.

#### 3.3.10 Piloting

The questionnaire was initially piloted on 11 occupational therapists involved in the national multicentre 'OTCH study' cluster randomised controlled trial (http://www.controlled-trials.com/ISRCTN00757750) which, as highlighted in chapter two, was on-going at the time the survey was conducted. This was a convenience sample of occupational therapists already known to the PhD research student and currently working within care homes. The purpose of the questionnaire pilot was to test the structure and wording of the questionnaire and highlight any ambiguity in the questions. It was not piloted for the purpose of collecting data for analysis. As a result of the feedback received from the pilot process, the following minor

amendments were made to the survey tool, such as re-wording and re-ordering of questions to aid greater clarity:

- Question 4, 'Who are you employed by?' originally had four possible responses: 'Acute NHS Trust', 'PCT', 'Social Services', and 'other'. The employer options were amended to combine Acute NHS and PCT into one category called 'NHS'. Three additional response options were added: 'Private Sector', 'Selfemployed', and 'University'.
- Question 5 was originally 'What is your current pay band?' This was replaced with the question 'What is your job title?' to account for other pay structures outside of the NHS and also elicit detail on seniority/experience from the job title.
- The order of questions was altered slightly. Question 7 was initially placed as question 3. The wording of question 7 'Which of the following do you believe best applies to you?' was originally 'Do you consider yourself to be a "generic" occupational therapist or a "stroke specific" occupational therapist?' The response options were revised to include the additional options of "neurological OT", "Dementia Specialist", and "Other".

The final version of the questionnaire was then submitted to the University of Nottingham Medical School Ethics Committee for ethical approval.

#### **3.3.11 Ethical considerations**

Ethical approval for the survey study was provided by the University of Nottingham Medical School Ethics Committee in November 2011 (reference A10112011 CHS) (appendix 16).

#### 3.3.12 Survey administration

The online survey went 'live' in November 2011 and email invitations containing a web link to participate (appendix 17) and a participant information sheet (appendix 18) were sent out to 379 members of the COTSS-OP, 896 members of the COTSS-NP, and 377 members of the COTSS-IP. In addition the national survey was also advertised using the social networking sites 'Twitter' and 'Facebook', and via flyers at the UK Stroke Forum Conference 2011 which is an annual multidisciplinary meeting attended by over 1,300 delegates. Four weeks after the survey opened, a follow-up reminder email was sent out to encourage further responses. It has been reported that sending out such reminder emails can increase the response rate by 33% (Vehovar et al 2002). The survey remained open for a further 2 weeks and then closed on 30<sup>th</sup> April 2012 for data analysis.

#### **3.3.13 Data analysis**

The web survey responses from each completed questionnaire were printed and the quantitative data was manually entered into SPSS version 19 for analysis. The data were coded, entered into an SPSS spreadsheet and double entry checked. A random sample of 10%

was then checked independently by a second researcher, to highlight any possible errors before the data was analysed using descriptive statistics. The intention was to report the number of "missing data" responses. Thematic analysis was used to code the responses to the last two qualitative open-ended questions according to key words and 'themes' that emerged. Thematic analysis is a method for identifying, analysing and reporting patterns (known as 'themes') within research data (Braun and Clarke, 2006). Braun and Clarke (2006) advocated the use of thematic analysis as 'an accessible and theoretically flexible approach', which can provide a rich and detailed, yet complex, analysis of qualitative data and they described it as 'a foundational method for qualitative analysis'. For the thematic analysis of the responses to the open-ended qualitative questions, items were coded as 'themes' where the data was considered by the researcher to capture something important about the data in relation to the research question. Themes and sub-themes were organised and prevalence of the themes was noted by counting the number of survey respondents who articulated the same theme within their response. The coding approach used was data-driven in that the coding of responses into themes did not use a pre-existing coding frame to fit the responses into themes (Braun and Clarke, 2006).

#### **3.4 Results**

#### 3.4.1 Sample

A total of 138 questionnaires were completed and returned (134 respondents completed the online web survey; four respondents completed the postal version of the questionnaire). Due to the snowball sampling method employed, a response rate calculation was not possible as the number of questionnaires circulated was unknown. As stated earlier, the number of occupational therapists working within care home settings in the UK is unknown. It was also not possible to accurately predict how many potential respondents viewed the survey invitation, or would have been classed as eligible to participate (i.e. those who had actual experience of working as a qualified occupational therapist within a care home setting) from the 379 members of the COTSS-OP, 896 members of the COTSS-NP, and 377 members of the COTSS-IP who were sent the survey invitation email.

Of the 138 completed questionnaires, 114 respondents provided occupational therapy assessment and/or interventions to care home residents and were invited to proceed with the questionnaire. The remaining 24 respondents were excluded from proceeding with the survey at the first filter question because they were not qualified occupational therapists with experience of providing assessment and/or interventions within a care home setting.

# **3.4.2 Respondent demographics**

Respondents represented the four UK countries of England (n=97), Scotland (n=8), Wales (n=4) and Northern Ireland (n=1), along with the Channel Islands (n=2). This information was missing from two questionnaires. The geographical distribution of the respondents is shown in figure 8. The largest concentration of respondents came from the South East of England (n=25).

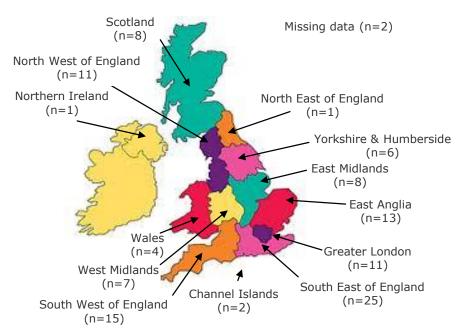


Figure 8: Geographical distribution of survey respondents working in care homes

# 3.4.3 Occupational therapy funding

The survey respondents were asked which organisation they held a contract of employment with. Table 5 shows the results of this question. The vast majority (n=82, 72%) of occupational therapists were employed by the NHS. The second most common employer (n=11, 10%) was the 'Private Sector'. Six respondents (5%) commented that they were employed by more than one employer,

however it is not known whether these therapists were working

across two different posts or in the same post but with a split budget

from two employers.

Table 5:	Funding of	occupational	therapy	provision	in care	e homes
----------	------------	--------------	---------	-----------	---------	---------

Employer	Frequency	Percentage
NHS	82	71.9
Private Sector	11	9.7
Social Services	6	5.3
Self-employed	6	5.3
Social Enterprise Company	3	2.6
Charity	2	1.7
University	1	0.9
Local Island Health Service (not NHS)	1	0.9
Missing	2	1.7
Total	114	100

# 3.4.4 Job titles

The respondents had a range of job titles, representing junior occupational therapists, through to consultant occupational therapists. Of the 112 respondents who answered this question, 107 had the profession specific terms 'occupational therapist' or 'occupational therapy' in their job title. Other words used in the respondents' job titles were those used to describe their seniority (e.g. 'consultant'); banding (e.g. 'band 6'); specialism (e.g. 'neurological'); or area of work (e.g. 'outreach'). The descriptive words used in the occupational therapists' job titles are shown in table 6.

Descriptive words used in the respondents' job title	Frequency	% of total number of responses
Occupational Therapist	53	46.4
'Band' (e.g. Band 6, Band 7)	17	14.9
Senior	13	11.4
Leader/Lead	11	9.6
Community	10	8.7
Specialist	9	7.8
Clinical	8	7.0
Neurological	7	6.1
Stroke	4	3.5
'Advanced' (e.g. Advanced OT/Practitioner)	4	3.5
Independent	2	1.8
Head (e.g. 'Head of Therapy', 'Deputy Head')	2	1.8
Consultant	1	0.9
Research	1	0.9
Missing	2	1.8

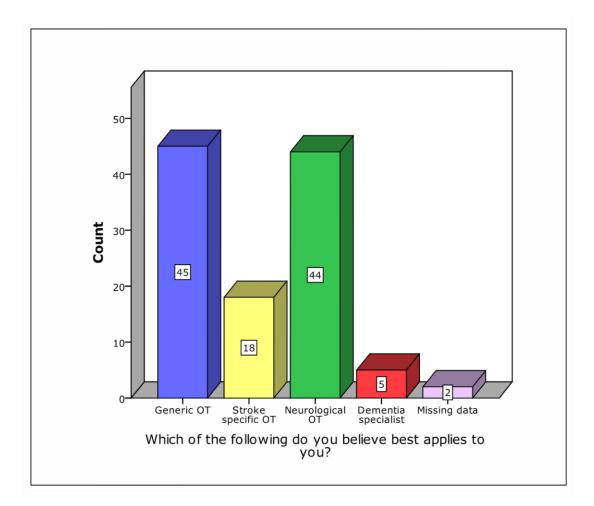
The five respondents who did not have 'OT' in their job title, had the following titles: 'Clinical Specialist in Older People', 'Posture management Clinical Advisor', 'Head of therapy', 'MDT Lead', and 'Falls Team leader'. These titles might suggest that their job roles are not profession specific and may be carried out by a physiotherapist or other allied health professional.

# 3.4.5 Involvement in care homes due to research studies

Respondents were asked if they were employed to provide occupational therapy in care homes because of a research study only. 3% of respondents replied yes, suggesting that for the majority of respondents, their intervention was being delivered within care home settings as part of normal routine clinical practice.

# 3.4.6 Occupational Therapy Specialism

The respondents were asked to select a description from a list of options that they believed best applied to them. This question was designed to elicit information about the specialism of the occupational therapists to determine how many of the respondents were stroke specialists and thus more likely to have an understanding of the complexity of stroke. Figure 9 shows the specialism of the survey respondents. The most common responses selected in reply to this question were 'Generic OT' (n=45) and 'neurological OT' (n=44). Only 18 stated that they were a stroke specialist occupational therapist.



### **3.4.7** Referral route

Part two of the survey collated general care home data that was not stroke specific including data on referrals, ease of access to confirmation of medical diagnoses, and prevalence of occupational therapists working with residents with a history of stroke. Respondents were asked how care home residents were referred to their service for OT assessment and intervention. Table 7 shows the frequency of referral routes ranked from most common to least common. It is evident that there are different referral routes, with the most common being via the resident's GP (63% of responses). Of the 69 respondents who selected the 'other' option, the most common referral route was via the resident or the resident's family direct (n=15) or via a nurse (n=10). Other referrers included social workers (n=8), other occupational therapists (n=5), solicitors involved in personal injury claims (n=2), and the Care Quality Commission (n=1). Two of the respondents stated that they were employed directly by the care home and therefore worked with residents from their employing care home.

Referrer	Frequency (Total n=114)	% of OTs who responded ``yes"
GP	72	63.2
Care home manager	66	57.9
Physiotherapist	56	49.1
Consultant	42	36.8
Speech and language therapist	37	32.5
Other	69	60.5

#### Table 7: Referral routes to occupational therapy

#### **3.4.8** Referral time

Respondents were asked how long, on average, it took from the time a referral was received to the care home resident being assessed by the occupational therapist. However, rather than specify a definite length of time in days, weeks or months, some respondents gave a range, or left a comment instead of a numerical value. This may have been a limitation of the question wording. In hindsight, the question should have been more specific and asked the respondent to state in hours or days. A numerical value was missing from nine of the responses. These respondents left comments such as 'dependent' on referral criteria', and 'variable dependent on screening and priority'. Therefore the 105 numerical responses were converted to a common unit (days) and for the responses containing a range, the median time was calculated. The average length of time from referral to assessment by the occupational therapist was then calculated by adding the total number of days and dividing by the number of responses. The average length of time from receipt of referral to the care home resident being assessed by an occupational therapist was 21 days, with responses that varied greatly and ranged from a minimum of 2 hours ("for emergency hospital admission avoidance referrals") to a maximum of 84 days. Twenty-five respondents mentioned the use of criteria to determine the priority and urgency of the referrals. These comments included criteria based on medical diagnosis e.g. '2-3 weeks if progressive neurological condition, 2-3

days if stroke within last 12 months' (R44); criteria based on whether the resident was already known to the service or not e.g. 'Within 28 days if they are not known to the service, as this is a target of the service for new clients' (R131); and criteria based on whether the medical condition is in the acute or chronic stage e.g. 'It depends how long it is post-stroke. If it is a new stroke and they are being discharged to the care home from hospital then they would be seen within 72 hours of referral. If it is an old stroke then they would wait up to 2 weeks for OT assessment' (R79).

#### **3.4.9 Quantity of referrals**

Respondents were asked how many individual care home resident referrals they (as an individual therapist) receive a month. Twelve respondents received less than 1 care home resident referral per month. A numerical value was missing from the responses of 10 respondents. One respondent gave the value of 160 residents, although this was the total number of residents living in the care home where the respondent was employed to work, rather than the likelihood that this was the number of monthly referrals. This response was therefore removed as an outlier from the calculation of the average number of referrals received per month by the respondents. Of the remaining 91 respondents who gave a numerical value of one or more per month, the average number of individual care home resident referrals received was 5 residents per month.

#### **3.4.10** Access to confirmation of medical diagnosis

As Private care homes are outside the NHS framework, care home staff (including qualified nursing staff) do not have direct access to their residents' medical records. The quality, accuracy and detail of the care home's care plans may vary from home to home. In some cases it is possible that the care plan notes will not have detailed information regarding the residents' medical history. Therefore it was considered important to investigate whether the respondents were able to access confirmation of a resident's medical diagnosis when accepting a referral. These data were missing for seven respondents. Of those who responded, all but one respondent were able to access confirmation of the resident's medical diagnosis although the ease of access varied (42% (n=44) are 'always' able to access confirmation; 49% (n=52) are 'often' able access confirmation).

# **3.4.11 Prevalence of respondents who had worked** with care home residents with stroke in the last year

Respondents were asked whether they had provided occupational therapy assessment and/or intervention to a care home resident with a suspected or confirmed diagnosis of stroke in the last 12 months. Data was missing from seven respondents. Those that answered `no' were not required to answer any further questions. The 92 respondents (81%) who answered `yes', were asked to proceed to the third and final part of the questionnaire.

#### **3.4.12** Stroke specific care home information

The third and final section of the questionnaire collated stroke specific data from the 81% of respondents who answered 'yes' they had worked with a resident with stroke in the last year. This last part of the survey explored the respondents' occupational therapy assessment and interventions with care home residents who had had a suspected or confirmed stroke.

#### 3.4.13 Stroke training

The respondents were asked if they had received any stroke specific training in their current post. Two thirds (n=62) of the respondents had received stroke specific training. They were then asked to give details of any stroke specific training they had received. The open ended responses were initially listed in full and then the key words from the comments describing the type of training were listed in an Excel spreadsheet so that themed categories could be observed. The training listed in the spreadsheet was then grouped under the themed headings of `assessment/treatment/rehabilitation'; `treatment approaches'; 'external training courses'; 'in-service training'; 'professional diploma/postgraduate modules'; 'stroke conferences'; and 'theoretical training on specific topics'. The frequency of each type of training was then calculated. The type of training and frequency mentioned by respondents is shown in table 8. The percentages are not given for the theme headings in bold because

some theme headings total more than the total number of respondents (n=62) who answered this question. This is because some respondents listed more than one sub-type of training from each themed category but the sub-types have been grouped together. The most common training theme was 'assessment, treatment & interventions', with training from this category theme being mentioned a total of 66 times. The five most common specific subjects of training experienced by the respondents were 'cognitive assessment/rehabilitation' (31%), 'Bobath' training (26%), 'splinting' (21%), 'upper limb assessment and rehab' (15%), and 'seating' (11%). Only 13% of respondents had completed postgraduate modules/professional diplomas and only 11% mentioned attendance at conferences as a means of gaining stroke related training.

Type of training/subject of training	Frequency (Total no. of training =152)	% of respondents
Assessment/treatments/interventions:	(66)	-
Cognitive assessment/rehabilitation	19	30.6
Splinting	13	20.9
Upper limb assessment and rehab	9	14.5
Seating	7	11.2
Posture management	6	9.6
Spasticity/tone management	4	6.4
Standardised & non-standardised	3	4.8
Neurological assessment & rehabilitation	1	1.6
Constraint Induced Movement Therapy	1	1.6
Gait re-education	1	1.6
FES	1	1.6
Psychological coping strategies	1	1.6
Treatment approaches:	(22)	-
Bobath	16	25.8
Normal movement	6	9.6
External training courses:	(23)	-
SOS/other SSNP training	5	8.0
Harrison training courses	4	6.4
STARS (online training)	3	4.8
Braintree training courses	3	4.8
Mary Warren training course	1	1.6
AMPS	1	1.6
Chest Heart & Stroke Assoc. training	1	1.6
NCORE training	1	1.6
Unspecified external training	4	6.4
In-service training	14	22.5
Professional postgraduate modules	8	12.9
Stroke conferences	7	11.2
Theoretical training on specific topics:	6	9.6
Vision	3	4.8
Neuroplasticity	1	1.6
Biomechanics	1	1.6
Sensation	1	1.6

#### Table 8: Stroke specific training received by the respondents

### **3.4.14** Assessment in care homes

Respondents were asked if they used non-standardised assessments

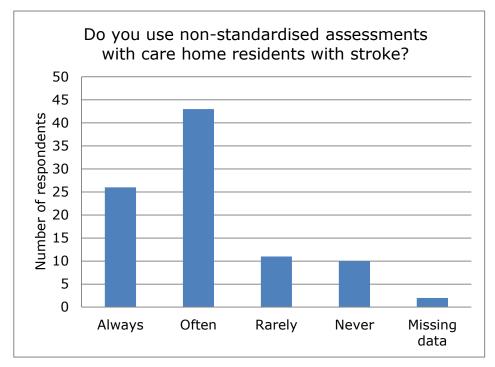
with care home residents with stroke. Of the 90 occupational

therapists who gave a response to this question, 89% used non-

standardised assessments with care home residents with stroke. The

results are shown in figure 10.





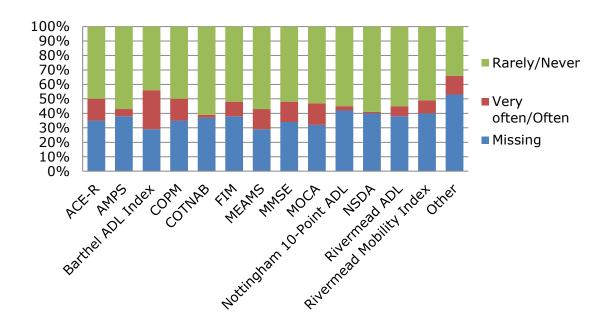
If 'non-standardised' assessment was used by the respondents, they were asked to comment. The analysis of the comments is displayed in table 9. The most frequent comment given was 'functional assessment' (46% of respondents who commented).

Type of non-standardised assessment	Number of OTs who stated they use each assessment type (N=63)	% of respondents who gave this comment out of the total number who commented		
Functional assessment	29	46%		
Seating & posture / wheelchair	7	11%		
Locally devised 'in-house'	7	11%		
Neurological screens	7	11%		
Upper limb assessment	6	10%		
Moving & handling / transfer	4	6%		
Initial interview	3	5%		

 Table 9: Types and frequency of non-standardised assessments used

Respondents were also asked to select how often ('very often', 'often', 'rarely', or 'never') they used each of the standardised assessments with the care home stroke population, from a list provided. Figure 11 shows the frequency of use of each type of standardised assessment listed.

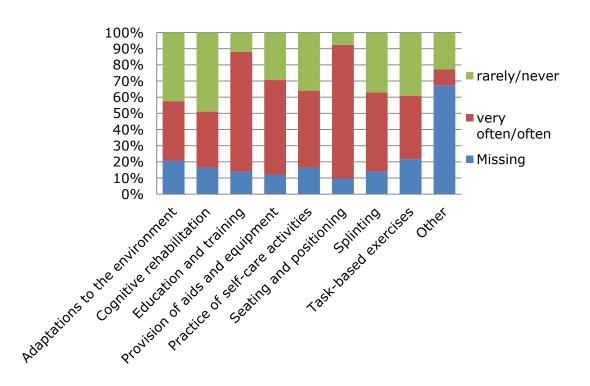




Thirty 'other' standardised assessments were used by the respondents. The most commonly mentioned 'other' standardised assessment was the Rivermead Behavioural Memory Assessment (RBMA), used by 8 of the respondents. Four of the respondents used the Rivermead Perceptual Assessment Battery (RPAB), the Cognitive Assessment of Minnesota (CAM), and the Model of Human Occupation Screening Tool (MOHOST).

# **3.4.15** Occupational therapy interventions in care homes

Respondents were asked what type of occupational therapy interventions they provided to care home residents with stroke. The responses are shown in figure 12. The most frequently provided intervention was seating / positioning and 'education / training. Cognitive rehabilitation was the occupational therapy intervention that was least frequently engaged in by occupational therapists with the care home population.





Respondents were asked to state what 'other' interventions, if any, they provided to care home residents with stroke. Five respondents stated that another intervention they provided was relocating residents back to their own home or relocating them to sheltered accommodation. Three respondents identified transfers, moving and handling advice and mobility assessment as an area of intervention they had been involved in with care home residents with stroke. Other responses included wheelchair referrals and advice, referrals to other services, multi-sensory activities, risk assessment, falls assessment and running groups. Data on the type, focus and aims of group interventions was not provided by the respondents.

### **3.4.16** Treatment approaches used in care homes

Respondents were then given a list of treatment approaches and asked to select the frequency ('very often', 'often', 'rarely', or 'never') that they were used with care home residents with stroke. Figure 13 shows the results of this question.

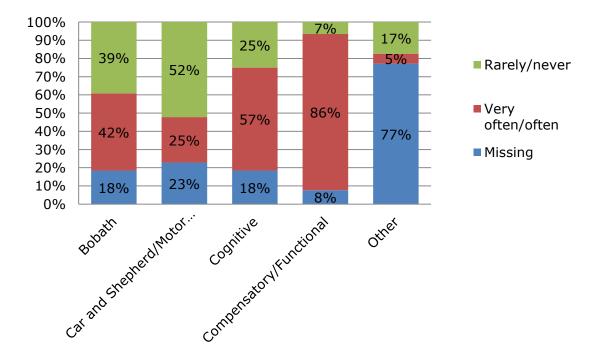


Figure 13: Treatment approaches used with care home residents with stroke

By far the most frequently used treatment approach was the 'compensatory' or 'functional' approach that was used by 86% of respondents. Two other approaches not listed as options were identified by respondents as being used with this client group. One respondent used the 'Rood approach' (a neurophysiological technique that facilitates and inhibits movement (Metcalfe and Lawes, 1998)), another used 'Myofascial release' (a soft tissue therapy for the treatment of skeletal muscle immobility and pain (DiGiovanna et al., 2005)).

# **3.4.17** Aims of occupational therapy with care home residents with stroke

Respondents were asked if they had to generalize, what would be the three most common treatment aims that they hope to achieve in their interventions with care home residents who have had a stroke. The responses were grouped into themes by sorting and matching the key words that described the treatment aims and grouping them together under a relevant theme heading. They were then ranked in order of frequency of response. Table 10 shows the results of this question.

Chapter 3

Treatment aims	Number of OTs who gave this response
Increase/maintain independence/participation in ADLS/function & mobility	58
Improve posture/seating/positioning	43
Provide advice/training/education to care home staff/family/residents	30
Improve upper limb function/manage upper limb	26
Prevention of secondary complications such as contractures, pain, pressure sores & maximise comfort	23
Improve transfers/moving and handling	19
Improve quality of life	12
Equipment/environmental adaptation recommendations	9
Increase social interaction/social activities/reduce social isolation	8
To promote safety/risk assessment	8
Resettlement in own home/reintegration back into the community	7
To assess and treat/compensate for cognitive/perceptual impairments	7
To maximise recovery	4
To ease carer strain	3
Improve emotional, social and psychological well- being	3
To promote dignity	2
Wheelchair provision	1

 Table 10: Most common treatment aims that occupational therapy therapists hope

 to achieve in their interventions with care home residents with stroke

The three most common treatment aims were: (1) to increase and/or maintain independence/participation in activities of daily living; (2)

improve posture and positioning; and (3) provide training and

education to care home staff, family and residents.

# **3.4.18 Equipment provision in care homes**

Respondents were asked to select how often they recommend the provision of aids, equipment and adaptations from a given list. The results are shown in figure 14.

Aids, Equipment & Adaptations

#### Other 79% <mark>9%</mark>12% Wheelchair 70% 24% Transfer equipment 71% 21% Specialist seating 71% 20% Stocking/tights aid 74% 14% 12% Ramps 13% 14% 73% Missing Pressure cushion 20% 730 Plate guards 13% 46% 41% Palm protectors 23% Very Mobility aids often/Often 9% 59% 33% Long-handled bath sponge 66% 14% 20% Rarely/Never Helping hand 47% 14% 39% Grab rails 48% 40% 12% Elastic shoelaces 13% 12% 75% Dycem mat 12% 51% 37% Dressing aids 64% 14% 2% Chair/bed raisers 46% 11%43% Bed lever 41% 46% 13% Adaptive cutlery 9% 60% 32% 0% 50% 100%

#### Figure 14: Frequency of the provision of aids, equipment and adaptations

Frequency provision is recommended

Transfer equipment (71%), specialist seating (71%), palm protectors (71%), and wheelchairs (70%) were the most frequently recommended items of equipment. Sixteen 'other' items were listed by respondents, of which the most frequently mentioned were splints (n=4), sleep systems (n=3) and shower chairs (n=2). The 'other' items recommended are listed in table 11 below.

#### Table 11: 'Other' equipment that is recommended

Do you recommend the provision of any 'other' aids, equipment and adaptations?	Number of OTs who gave this response		
Splints	4		
Sleep systems	3		
Shower chairs	2		
Profiling bed	1		
Tubi-grip	1		
Raised toilet seat	1		
Specialist slings	1		
Cantilever table	1		
Perching stool	1		
Orientation boards	1		

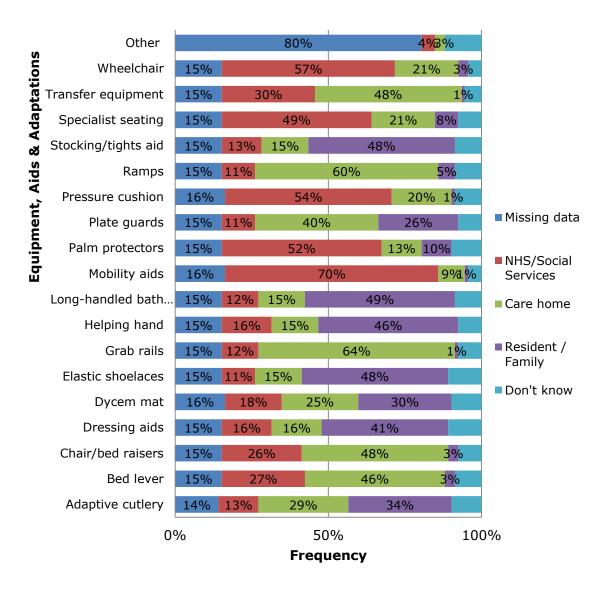
# **3.4.19** Funding of equipment provision in care homes

Having explored the frequency of recommendations by occupational therapists to provide various types of equipment, aids and adaptations to stroke survivors residing in care home settings, the respondents were then asked about the funding of such equipment for care home residents classified as 'nursing' as compared to residents classified as 'residential'. The results are displayed in figures 15 and 16.

# Figure 15: A graph to show the responsibility for funding equipment provided to nursing home residents

			. =					l
	Other		45%	)	18%	9%		
Suc	Wheelchair	10%		54%		26%	<mark>3%</mark>	
atic	Transfer equipment	11%	17%		68	3%	1%	)
lapt	Specialist seating	10%		49%		28%	9%	
& Adaptations	Stocking/tights aid	11%	15%	23%		43%		
ds 8	Ramps	11%	9%		71%		<mark>4%</mark>	
, Ai	Pressure cushion	12%		54%		309	% 1 <mark>%</mark>	Missing data
Equipment, Aids	Plate guards	11%	12%	50	%	21	%	
ipm	Palm protectors	10%		57%		18%	9%	NHS/Social Services
Equ	Mobility aids	10%		68%	)		17% 1 <mark>%</mark>	
	Long-handled bath	12%	13%	23%		45%		Care home
	Helping hand	11%	17%	22%		41%		= Decident
	Grab rails	10%	L0%		75%		1%	Resident /Family
	Elastic shoelaces	12%	12%	18%	4	-5%		■Don't know
	Dycem mat	11%	18%	35	%	27%		
	Dressing aids	11%	14%	26%		36%		
	Chair/bed raisers	10%	15%		66%	)	<mark>4%</mark>	
	Bed lever	10%	15%		70%	6	<mark>3%</mark>	
	Adaptive cutlery	11%	11%	46%	, D	25%	b	
0%		%		5	0%		10	0%
				Freq	uency	,		

# **Figure 16:** A graph to show the responsibility for funding equipment provided to residential home residents



Whilst the results displayed in the two graphs (figure 15 and figure 16) are very similar, the main differences are for the funding of transfer equipment, bed levers and chair raisers, with higher levels of NHS/Social Services funding for the residential home residents. The results show that when comparing each item of equipment or aid listed, for the residents classified as being 'nursing home' residents rather than 'residential home' residents, the frequency of equipment

being funded by the NHS/Social Services is lower. When looking at the frequency of items being funded directly by the care homes the reverse is found, with the nursing home residents' equipment having a larger percentage of funding from care homes than for the residential home residents. More generally, across both nursing and residential home residents, the items most commonly funded by the NHS and Social Services were reported to be mobility aids, palm protectors, wheelchairs, and pressure cushions. For nursing home residents the five items least likely to be funded by the NHS and Social Services were ramps (9%), grab rails (10%), adaptive cutlery (11%), plate guards (12%), and elastic shoelaces (12%). The five items least likely to be funded for residential home residents were ramps (11%), plate guards (11%), elastic shoelaces (11%), longhandled bath sponges (12%), and grab rails (12%). Across both settings, the smaller, less expensive items, such as plate guards, elastic shoe laces, and adaptive cutlery and dressing aids, were less likely to be funded by the NHS and Social Services, and more likely to be funded by the care home or the resident/resident's family. For residential home residents, the resident or their family would commonly have to buy their own adaptive cutlery and Dycem non-slip matting.

# **3.4.20** Limitations on the occupational therapy interventions that can be delivered within a care home setting

It was not known whether there would be any limitations to the types of occupational therapy interventions that could be delivered to stroke survivors residing within a care home setting. Respondents were therefore asked whether they thought there were any limitations on the occupational therapy interventions they were able to deliver within a care home setting. Responses varied in length and detail and covered a number of different issues, which were grouped into limitation 'themes'. The frequency of each theme was calculated. The following quotation mentions a number of issues, such as time restraints, rules within the care home, lack of encouragement for residents to remain independent and lack of appropriate moving and handling equipment, that limit the intervention this particular respondent felt able to deliver within a care home setting:

"Yes - most of the time input is limited in care homes as the emphasis is not on rehabilitation or promoting independence. I rarely do functional practise as the residents are not allowed to make own meals, drinks etc. If they want to work on improving independence in other tasks, it all gets done for them. They are not encouraged to remain independent. A big difficulty we have when patients are discharged from hospital to nursing home is they may require a Sam Hall turner or a rotunda [two manufacturers of turning aids for assisting in transfers]. Nursing homes near us, very rarely have

these. We recommend they buy one, but they never do and will end up hoisting the patients, so they go off their feet and then require the hoist. Therapy ends up being in vain as unless they are mobile, often hoist is the only other option. We find it so frustrating that homes won't purchase a Rotunda (as an example), they cost less than £500 and will often be able to use it with more than one resident. Our stores will not supply as it is the care home's responsibility to look after their patients needs" (R29).

The most frequently mentioned limitation theme was concerned with the compliance of the care home staff:

"It is very difficult to get carry over with staff that are constantly changing and that do not have an understanding of what you are trying to achieve. They are very risk averse, for instance hoisting is often resorted to prematurely. This makes working in care homes very frustrating" (R32).

The second most common theme was 'time limitations', as listed below by participant R138, who also went on to mention additional limitations such as the unwillingness of some other services to accept referrals for care home residents and compliance of care home staff:

"Time limitations. Difficult to refer on to other services as other services will not always accept referrals for care home residents. The

Chapter 3

success of many OT interventions is dependent on the care home staff's compliance to follow advice/instructions" (R138).

Limitations around funding was the third most common response (listed by 12 of the respondents) given and related to funding of the therapists time and also the funding of equipment:

"Only with regard to the amount of OT that I do provide and to whom I provide it as it is funding dependent rather than needs based. Rehabilitation is limited by nursing and care staff who are not rehab trained, therefore carryover can be limited" (R4).

The fourth most common theme that emerged was limitations on the aids and equipment that could be issued or obtained for care home residents:

"I cannot issue any equipment other than personal walking aids, palm protectors or splints and I can only refer to the Wheelchair Service where there is a need for specialist postural seating for the resident" (R123).

"The care homes are responsible for funding all equipment except mobility aids, wheelchairs and bespoke specialist seating. I generally find my intervention is limited by their refusal to purchase items, so make more progress with residents who have the funds to purchase these items themselves" (R27). Other less frequently mentioned limitations were also given. For

example one respondent commented that the terms of their contract

limited what they were permitted to provide within a care home

setting:

"We are not contracted to provide actual rehab programmes to

clients in residential/care home settings" (R99).

Table 12 shows the types of limitations, ranked from most frequently given response to least frequent response.

Table 12: Limitations on occupational therapy practice within a care home setting

Are there any limitations on the occupational therapy interventions you can deliver within the care home setting?	Number of OTs who gave this response
Poor carryover/compliance by care home staff	20
Time restraints	14
Funding limitations	12
Unable to provide equipment/lack of appropriate equipment	8
Lack of space & other environmental limitations	5
Unable to practice domestic/productive ADLs	3
Unable to provide splinting	3
Only allowed to provide a splinting service	3
Lack of specialist expertise	2
Care home policies	1
Unable to provide 'rehabilitation'	1
Goal limited service	1
Only receive referrals from 'poorly performing' homes	1
Only able to give advice to nursing homes not	1
intervention	
Residents ability	1
Limited awareness of the service	1

## **3.4.21** Additional information gathered from the survey

Finally, respondents were offered the opportunity to make any

additional comments about occupational therapy practice with care

home residents with stroke that hadn't been asked in the survey and

that they wanted to make known. Thirty seven respondents chose to

provide additional comments or statements. These were grouped

into themes (table 13).

 Table 13: Comments about occupational therapy practice within care homes for residents with stroke

Comment 'themes' regarding occupational therapy interventions for stroke survivors in care homes?	Number who gave this response
Referrals and resources:	17
Other professionals are also involved	1
Referrals are often in the late chronic stages of stroke / care homes don't identify problems soon enough / referrals are often made when there is a crisis	3
"Our care home support team has a 3 year development history"	1
Limited information about progress or previous interventions is passed on from the acute setting	1
Not enough OT resource (or reduced OT input) to provide adequate level of service to care home residents	3
"We would treat the same as other service users and OT will not be closed until outcomes achieved"	1
Some therapists facilitate getting people home	4
Treatment may be provided to residents outside of the care home setting in outpatient or inpatient settings	1
Therapists go in for one person but see lots of others where advice, carer training or equipment is needed.	1
Just see this as a key area for OT	1
Care home staff:	13
Care home staff often do not speak English as their first language	1
Care home staff do not always approach care with a rehab approach (i.e. they do not encourage residents to participate in daily activities) and care home variability exists in acceptance of OT interventions and implementation of recommendations	5
Care staff can have limited expertise (in understanding emotional aspects of stroke, activity limitations, communication problems, moving and handling etc) and many lack any basic stroke training	4
High staff turnover at care homes	1
Lack of communication between staff at homes	1
We have had several issues that have had to be pursued under Safeguarding adults when the home has not implemented the advice given.	1
Education and training for care home staff:	7
A large part of the OT role is providing advice, education and training for care home staff / We are encouraging stroke champions in the care homes and providing training	7
	10
Factors affecting therapy provision:	
<b>Factors affecting therapy provision:</b> Occupational therapy provision varies according to ownership of care home and employing organisation of the therapist	3

Time restraints for care home staff	1
Within the same care home setting some residents are classed as	1
"rehab clients" others are classed as long-term residential	
Activity provision should be graded and specific to each resident	1
I think that people in care homes receive less therapy in hospital	2
than people who are returning to their own homes	
Are these patients offered longer term monitoring or review?	1
Equipment provision:	з
"Generally this is a very frustrating environment to work due to	3
the lack of responsibility taken by staff and home management in	
providing equipment" / "Provision of equipment is never black and	
white and often it is a battle to get pieces of equipment provided,	
which is highly frustrating" / "Are care/residential Homes united in	
paying for items for these patients?"	
Descriptions of residents & types of problems:	8
Many residents have co-morbidities such as dementia.	2
Usually it is around management of their posture, contractures	1
and tone.	
I feel that a big issue is the number of residents sitting in	1
inappropriate armchairs.	
There is a specific care home for stroke in the area	1
Residents soon become 'passive' and this is a barrier to active	1
rehab.	
My caseload includes CVA as recent as 6 weeks prior to my	1
intervention, or can be many years post CVA so my interventions	
intervention, or can be many years post CVA so my interventions vary widely from patient to patient. There can be inappropriate discharges to a care home setting of	1
intervention, or can be many years post CVA so my interventions vary widely from patient to patient.	1
intervention, or can be many years post CVA so my interventions vary widely from patient to patient. There can be inappropriate discharges to a care home setting of	1

Some therapists felt frustrated that residents were often referred to occupational therapy in the more chronic stages of stroke, rather than early on when more progress could be made:

"Many residents in care homes are referred many months or

years after CVA. Referrals are made when there is a crisis e.g. poor

posture, contractures which require specialist equipment to help

support contracted limbs and poor posture. If referrals were made

earlier problems would not arise. Referrals need to be made earlier

for the OT to provide advice and training for care home staff for

correct management of stroke patients" (R137).

Others commented on frustrations related to the care home staff:

"OT intervention is often limited because of difficulty implementing advice and treatment. Care Home staff often do not speak English as their first language and this can affect understanding, communication, carry over and interaction with residents. Care Home staff often do not have enough time to spend with residents implementing advice/treatment" (R18).

Some therapists advocated the role of occupational therapists in educating and training care home staff:

"A large part of my role is often education & training for care home staff, especially re transfer techniques and equipment, positioning in bed, chair, wheelchair, layout of furniture, access to call bells, strategies for helping with sensory inattention etc" (R41).

The respondents also hinted at the inequitable and limited occupational therapy service received by stroke survivors residing in care homes:

"I would hope they receive the treatment they need whether in a care home or their own home. I think that people in care homes receive less therapy in hospital than people who are returning to their own homes" (R76).

"We offer a very limited service to care home residents" (R113).

In the introductory text of the questionnaire a sentence was included that invited respondents to send any additional information (such as local protocols, or information leaflets) describing the treatment provided by their occupational therapy service to care home residents. No respondents chose to send in any such additional information.

#### 3.5 Discussion

## **3.5.1** Availability, funding and expertise of occupational therapists working in care homes

This survey study sought to identify current occupational therapy practice for people with stroke living in care homes throughout the UK. It was the largest national survey of occupational therapy practice within care homes to date, with respondents representing all areas of the UK.

The main employer of occupational therapists surveyed in this sample was the NHS (72%), however a variety of funding arrangements existed including charitable, university (for research purposes), social services and private practice. Seven times as many occupational therapists worked for the NHS compared with the private sector, and only 5% were employed by Social Services. These national results differ to those found by Sackley et al (2009) in a local survey of occupational therapy provision in the Midlands where the most common employer of therapists working within care home settings

Chapter 3

was through private funding from the care homes (37%) and the second most common employer was the NHS (30%). The survey by Sackley et al (2009) was limited in that it only covered one locality. The difference in findings may be due to variations across different regions of the UK which would not have been picked up in Sackley's survey covering only the Midlands. It could be the case that health occupational therapists in the Midlands are not permitted to offer interventions to care home residents due to local policies and funding restrictions. It could also be the case that in the general occupational therapy population, of the 31,928 HPC registered occupational therapists [at the time of the survey] (Health and Care Professions Council, 2012) there are greater numbers of therapists working within the NHS as compared with Social Services. In 2008, a survey of occupational therapists working in Social Services was carried out to inform a report commissioned by the College of Occupational Therapists on behalf of the Department of Health (Riley et al., 2008). At this time there were 1,220 occupational therapists working in Adult Social Care Services in England (Riley et al., 2008). More recent data is not available as occupational therapists are not required to provide details of their current employer to the Health Professions Council upon registration and renewal. However if the figures are similar to those of 2008, then it can be deduced that the proportion of occupational therapists working in Social Services is much smaller

than the proportion of therapists working in the NHS. It is surprising that this type of data is not recorded nationally by COT or elsewhere.

Not all of the occupational therapists surveyed had profession-specific job titles. This may be reflective of generic therapy posts available within care home settings that do not require specialist occupational therapy skills. However, a job title can have a direct bearing on the perception of what the professional has to offer to care home residents. For example the title of 'Falls Specialist' suggests that the individual is only concerned with interventions to prevent falls and may not be approached for advice, assessment and interventions involving self-care activities of daily living such as feeding, washing and toileting that are considered typical occupational therapy-specific domains and skills. The interventions of these occupational therapists may be highly specialised and limited in scope and their job role may not be strictly profession specific. A Falls Specialist working in care homes may be a physiotherapist or an occupational therapist.

The largest group of occupational therapists surveyed considered themselves to be a 'Generic OT'. Only 4% classed themselves as a Dementia Specialist, which is surprising given the high prevalence of dementia within care homes with at least two thirds of all care home residents having a form of dementia (Department of Health, 2009).

Whilst the high number of neurological specialists (54%), (including stroke specific and general neurological) could be due to the fact that the Specialist Section for Neurological Practice (COTSS-NP) group's mailing list was used to disseminate the request for survey participants; the Specialist Section for Older People (COTSS-OP) would be a likely specialist section of choice for dementia specialist occupational therapists. It is possible that dementia specialists choose to join the Mental Health Specialist section (SSMH) instead of COTSS-OP and these therapists may not have been aware of the survey. Had it been possible to publish a summary of the survey study aims and invitation to participate in the study in the College of Occupational Therapists' monthly 'OT News' publication, there may have been a higher number of responses from dementia specialist occupational therapists and a higher response rate in general. However it was the policy of the editorial team at the time, not to include research study participant invitations within the publication.

### **3.5.2 Care home resident referrals to occupational therapy**

There were many referral routes to occupational therapy. Referrals were most commonly received via the resident's GP (63%). However according to the British Geriatrics Society (2012) the majority of GP's are unlikely to directly instigate a referral and are most probably requested to do so by the resident's family, care home Manager or other professionals already involved in the resident's care. The

'other' category was the second most frequently selected response to the question of referral route to OT. Of the 'other' referral routes, the most common was via the resident or resident's family (22%). Only two of the occupational therapists surveyed were directly employed by a care home to work permanently within a particular home or group of care homes under a blanket referral system. The majority of occupational therapists received referrals for a specific cause and their intervention was time limited. However, the respondents did not identify any evidence to support the decision regarding the length of time they were permitted to deliver an intervention.

The average length of time from an occupational therapist receiving the referral and going out to assess the resident was three weeks but responses varied greatly from two hours to 84 days. The Department of Health (2010) published a guide to measure referral waiting times for community-dwelling patients accessing NHS Allied Health Professionals (AHPs), including occupational therapists. An aim of the guide, entitled 'Transforming Community Services: Allied Health Professional Referral to Treatment Guide', was to reduce referral waiting times. However, the guide states that 'models of service provision vary across England' and 'it is for the NHS locally to decide' how the referral to treatment rules are applied (Department of Health, 2010). A minimum waiting time target for AHP referrals in the community was not fixed (Department of Health, 2010).

Therefore this variation in referral waiting time may be mirrored in the rest of the community dwelling population who are not residents of care homes. Little occupational therapy is likely to have been received in the acute setting by either care home residents with stroke or community dwelling stroke survivors due to the shorter length of hospitals stays in more recent years. The results of the survey suggested that for many occupational therapists working with those in care homes, the length of time from receipt of a referral to assessment varied depending on screening and priority criteria such as medical diagnosis, whether the resident was new to the service, and whether the resident's condition was in the acute or chronic stages. Whether or not a diagnosis of stroke was given a high priority was not discernible from the data.

Whilst the quantity of referrals received each month varied between occupational therapists, it was evident that referrals were being made regularly to occupational therapy services. This was a positive finding as care home residents should have equal right to access therapy services such as those offered by occupational therapy (Intercollegiate Stroke Working Party, 2012).

#### 3.5.3 Stroke specific occupational therapy provision

Of the occupational therapists surveyed, 81% had worked in a care home with residents with stroke in the last year. This proportion is

higher than the number of therapists who considered themselves to have expertise in neurological rehabilitation (of which 29% considered themselves to be a stroke specific occupational therapist). Whilst the delivery of occupational therapy assessments and interventions to individuals who had experienced a stroke was common, less than a third of the occupational therapists were stroke specialists. The National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party, 2012) state that 'all patients discharged from hospital, including those to care homes, who have residual strokerelated problems should be followed up within 72 hours by specialist stroke rehabilitation services for assessment and on-going management'. The findings from this survey imply that specialist stroke rehabilitation is not commonly available from a stroke specialist occupational therapist. The implications of this mean that therapists treating these residents may lack knowledge of the complexity of stroke. Stroke-specific, specialist care is more likely to result in positive outcomes such as survival, returning home, and independence (Stroke Unit Trialists' Collaboration, 2013).

However, more positive was the finding with regard to the training of those surveyed. Two thirds of the occupational therapists received stroke specific training. Training rarely involved completion of postgraduate modules or professional diplomas (13%), or attendance at scientific research conferences (11%). Occupational therapists

received training mainly in the use of assessments, treatments, and rehabilitation interventions for people with stroke. It is of note that 'Bobath' training and splinting were in the top three subjects of training, despite research evidence questioning the efficacy of splinting and the use of Bobath for stroke survivors (Kollen et al., 2009, Lannin and Herbert, 2003, Lannin et al., 2007). Bobath training is expensive; the cost of registration for the 'Basic Bobath' Foundation Course' at the Bobath Centre in London is £3,925 with further advanced courses costing in excess of £700 (Bobath Centre, 2013). A systematic review of 16 studies involving 813 patients with stroke concluded that there was no evidence that the Bobath approach is superior to other approaches (Kollen et al., 2009). The cost of splinting materials is also considerable, and yet despite a lack of evidence proving their effectiveness, therapists are still frequently delivering these treatments. Also of note, is the welcomed finding that some therapists are still able to access external training courses and conferences despite the current financial restraints upon the NHS training budgets. Whether this will deteriorate in the future in the current economic climate is yet to be determined.

### **3.5.4 Content of occupational therapy assessment and intervention**

Non-standardised assessments, in particular functional assessments, were frequently used to assess care home residents with stroke. It was more common for occupational therapists to use non-

standardised assessments with care home residents with stroke than to use standardised assessments. The most commonly used standardised assessment was the Barthel ADL Index (Mahoney and Barthel, 1965), which provides a global measure of dependency in ten activities of daily living (bowels, bladder, grooming, toilet use, feeding, transfers, mobility, dressing, stairs, bathing). The Barthel, although commonly used in research and clinical practice as a generic ADL checklist type assessment scale, has both a floor and ceiling effect (Quinn et al., 2011). It therefore has only limited use in a very dependent care home population due to the floor effect. The other most frequently used standardised assessments included the Canadian Occupational Performance Measure (COPM) (Law et al., 1991) and four cognitive assessments, the ACE-R (Mioshi et al., 2006); MOCA (Nasreddine et al., 2005); MEAMS (Golding, 1989); and the MMSE (Folstein et al., 1975). A total of 43 standardised assessments were used by the occupational therapists in their assessment of care home residents with stroke. These findings indicate that independence in ADLs is assessed through nonstandardised functional assessments, whilst standardised tests are used to assess cognitive decline; some of which are not actually validated for use with those over the age of 65. Functional tests are an important aspect of occupational therapy assessment but they should be used in conjunction with standardised assessments. A study of the utility of outcome measures for research in UK care

homes reported that residents' cognitive impairments and physical limitations preclude many residents from completing performancebased measures (Hoppitt et al., 2009). The study authors recognised the difficulty in selecting appropriate outcome measures for use in care home settings; due to a lack of appropriate measures available, and a lack of published studies on the validity of existing instruments for measuring specific attributes in a UK care home population (Hoppitt et al., 2009).

The four most common interventions delivered by occupational therapists to this client group were seating and positioning; education and training; provision of aids and equipment; and splinting. These were all more frequently delivered than the practice of self-care activities, task-based exercises, adaptations to the environment, and cognitive rehabilitation. Although seating and positioning was by far the most frequent intervention delivered, it is not known whether this included the actual provision of chairs and seating systems or whether the intervention was limited to assessment and advice regarding the correct positioning of residents and the most appropriate seating solutions. Evidence based practice should be the aim of all AHPs yet it is alarming that 4% of those surveyed commented that they were only permitted to provide a splinting service and no other equipment or intervention. There is no strong evidence on the efficacy of splinting the upper limb following stroke.

132

Chapter 3

Randomised controlled trials of the use of splinting to prevent spasticity and/or improve function of the hand have failed to provide sufficient evidence to support its routine use (Lannin and Herbert, 2003, Lannin et al., 2007) and therefore the current National Clinical Guidelines for Stroke do not recommend routine splinting after stroke (Intercollegiate Stroke Working Party, 2012). The Guidelines were produced by on behalf of the Royal College of Physicians by the Intercollegiate Stroke Working Party, a multidisciplinary team of experts who used extensive systematic literature searching and review using evidence-based criteria to determine the guidance. However, the Association of Chartered Physiotherapists in Neurology (ACPIN) and the College of Occupational Therapists Specialist Section for Neurological Practice (COTSS-NP) recently released a draft of their own joint splinting guidelines for adults with neurological dysfunction (College of Occupational Therapists and Chartered Society of Physiotherapists, 2014). The content of the guidelines was informed by a national online survey of occupational therapists and physiotherapists, and a systematic review. These guidelines strongly recommend that splints should be used in selected cases for the correction of range of movement, and to prevent loss in range of movement in the wrist and hand (College of Occupational Therapists and Chartered Society of Physiotherapists, 2014). The introduction of this contrasting guidance may have caused therapists confusion and uncertainty around whether or not to splint; but having been

produced, endorsed and marketed specifically by their own professional body it is likely to have provided a compelling argument to continue splinting despite the lack of evidence for effectiveness in stroke survivors, particularly those with chronic stroke in care home settings. This survey found that splinting was more common than interventions directly related to regaining or maintaining function in daily activities, such as practice of self-care ADLs, task-based exercises, adaptations to the environment and cognitive rehabilitation strategies.

Given the high emphasis on the use of standardised cognitive assessments, it is perhaps surprising that cognitive rehabilitation is the least frequently engaged in intervention. It is not clear why such importance is placed on the assessment of cognitive impairment if little importance is then placed on the actual treatment of such problems. It can be argued that there is little use in carrying out an assessment if the results are not then incorporated into a treatment plan. It is not known whether the findings from such cognitive assessments were even relayed to the care staff within the homes.

In terms of specific occupational therapy approaches, by far the most frequently adopted was the compensatory or 'functional' approach. Of those who gave a response to this question, more than half used the Bobath approach 'often' or 'very often' with care home residents

with stroke. The Bobath approach (Bobath, 1990) has been defined by the International Bobath Instructors Training Association as 'a problem-solving approach to the assessment and treatment of individuals with disturbances of function, movement, and postural control due to a lesion of the central nervous system' (Graham et al., 2009). The Bobath approach places emphasis on 'the integration of postural control and task performance, and the control of selective movement for the production of coordinated sequences of movement' . Treatment utilizes both symmetrical and asymmetrical patterns of movement with manual facilitation being used to assist the individual in problem-solving, to enable them to experience the patterns of

movement required to achieve the task . A recent systematic review by Kollen et al (2009) confirmed that overall the Bobath treatment approach was not superior to other approaches. One of the key principles of using the Bobath approach is that all carers and healthcare professionals need to use the same approach consistently in order for it to have a beneficial effect. In a care home setting it is highly unlikely that the staff, carers and families of a resident with stroke, would all be adequately Bobath-trained for this approach to be used consistently throughout the day. This could potentially render the efforts useless of these therapists who are investing their time in using a Bobath approach. A very small minority of respondents used non-evidenced based approaches such as the 'Rood approach' (Stockmeyer, 1996) and 'Myofascial release' (DiGiovanna,

2005) that may be considered 'complimentary' or 'alternative' therapy approaches rather than those core to occupational therapy.

#### 3.5.5 Equipment provision

The occupational therapists surveyed most frequently recommended the provision of pressure cushions, palm protectors, specialist seating, transfer equipment and wheelchairs to care home residents with stroke. Surprisingly, smaller less expensive items such as stocking aids, elastic shoes laces and long-handled bath sponges were rarely or never recommended. Also of note is the large number of therapists (70%) who stated that they 'often' or 'very often' recommend the provision of wheelchairs, even though this was previously mentioned as an aim of treatment by only one respondent.

Although pressure cushions were the most frequently recommended item of equipment; just over half of the therapists stated that this item would be funded by the NHS for care home residents in nursing and non-nursing homes. For all items of equipment, aids and adaptations, the care home was more likely to have to fund the equipment if it was for a resident classed as requiring nursing care rather than residential care alone. The items most likely to require self-funding from the resident or their family were the same for both nursing and residential home residents. These items were longhandled bath sponges, elastic shoe laces, stocking aids, helping

hands, dressing aids, adaptive cutlery, and Dycem mats. These items are the sorts of small daily living aids that typically cost less than £30 but can mean the difference between someone requiring assistance to feed and being able to feed themselves. The cost of providing such daily living aids is likely to be cheaper than the cost of having a carer present to assist in activities such as feeding or dressing the resident. A previous survey of equipment provision by occupational therapists in England revealed similar findings in that only a third would supply all items: most of them did not provide relatively cheap items, such as dressing aids (Lett et al., 2006).

### **3.5.6** Aims of occupational therapy for care home residents with stroke

The most common treatment aims for care home residents with stroke according to the occupational therapists surveyed, were to 'increase or maintain independence and participation in ADLs and mobility. This is interesting, given that the practice of self-care activities was only ranked the fifth most common intervention from a list of eight intervention types. Splinting, as an intervention, was more common than interventions directly related to regaining or maintaining function in daily activities. Other high ranking responses given by respondents were compatible with previous responses to related questions in the survey. For example, the second most common treatment aim of occupational therapy intervention with the care home population with stroke was to improve posture, seating

and positioning. Given that seating and positioning was the most frequently provided intervention, this response is to be expected. This aim was also reflected in the types of equipment most frequently recommended (pressure cushions, specialist seating, transfer equipment, wheelchairs and palm protectors). An important related finding from this question was that a quarter of the OTs recognised the importance of preventing secondary complications such as contractures, pain, and pressure sores. This response was ranked as the fifth most common treatment aim.

# **3.5.7 Challenges and limitations of the practice of occupational therapy within care homes for residents with stroke**

There were a number of perceived limitations to the occupational therapy interventions that could be delivered within a care home setting to people with stroke. Limitations included time restraints, care home rules, lack of encouragement for residents to remain independent (due to the ethos/culture of the home), and lack of appropriate equipment. The most frequently mentioned limitation theme was lack of compliance of the care home staff. Compliance was perceived to be dependent upon the knowledge and understanding of the care home staff and was affected by the high turnover of staff and large numbers of staff working different shifts and not communicating the therapist's recommendations to one another at staff handover. Also there was a fear for the safety of the

residents within their care, making them risk averse, and therefore things like the practise of hoisting residents was often resorted to prematurely. Clearly there is a need for care home staff to receive training on the effects of stroke and the potential of rehabilitation to promote independence. Occupational therapists may be well equipped to deliver such training and according to the responses received in the survey, many are already doing so.

Predictably, time was the second most common theme to emerge, and funding was the third most common limitation mentioned. This related to the funding of therapists' time and also the funding of equipment. Some occupational therapists mentioned the care home manager's unwillingness to purchase necessary equipment such as 'Rotunda' transfer equipment or appropriate seating. For stroke survivors residing in care homes their access to adaptive equipment is dependent upon the nature of the funding of their placement. Where they are funded on a residential (but not nursing care) basis they should have access to equipment via health and social services funding in the same way as somebody with stroke living in their own home. However, for those residents that come under nursing care funding, they often face more difficulty in obtaining equipment because the purchasing of such aids and equipment is the responsibility of the care home if it is something usually required by a resident (Kent et al., 2003). As care homes are largely run as

139

Chapter 3

Chapter 3

private businesses, anecdotal reports hint that some owners try to limit the amount of equipment purchased by the home. In theory, the higher rate of fees paid to the care home to cover nursing care should cover the cost of necessary equipment (Department for Communities and Local Government, 2014), but the reality is that equipment provision funded by care homes is inconsistent and inequitable; as is the provision of adaptive equipment through local authority occupational therapy teams (Sackley et al., 2009b, Fletcher-Smith et al., 2014).

The information gained from the free text statements at the end of the questionnaire provided additional insight into the provision of occupational therapy for care home residents with stroke. For example, it further highlighted that referrals to assess care home residents with stroke were often received months, or years after the stroke had occurred. Residents were commonly in the chronic stages of stroke and referred to occupational therapy once the resident had already reached a crisis point. A more seamless transition for residents with stroke from the acute hospital to the care home with continuation of rehabilitation services such as those provided by an occupational therapist, might prevent some of the post-stroke complications such as contractures and pressure sores from occurring. If such a model of transitional care were to exist it would enable the therapist to work more closely with staff within the care

home environment in order to advise on appropriate seating and positioning for example, thus preventing some of the problems seen in the chronic stroke population within care homes (Sackley et al., 2008a).

Another situation highlighted by these comments was the high number of care home staff for whom English was not their first language. These staff often did not have adequate comprehension of the language to be able to fully understand the resident or the therapist, and were unable to communicate effectively and interact on anything more than a superficial level. That does not necessarily imply that such staff were providing inferior care to residents but it did cause difficulties in communication.

The care home environment was described as 'frustrating', and delivering standard routine occupational therapy interventions such as the provision of equipment was described as 'a battle'.

#### 3.5.8 Limitations of the study

As is common with descriptive research, this study depended on human responses, making it possible that distortion of the data could have occurred. There are certain limitations in using self-completion questionnaires to survey a population. It was possible that biased questions may have been included in the questionnaire, although this

should have been minimised by the piloting phase of the questionnaire development. Although the researcher aimed to keep the questions as simple and straight forward as possible, the researcher had no control over how the respondents interpreted the questions. Unlike interviews, there was no way of probing beyond the responses given in the completed questionnaires. It was also not possible to work out a response rate and therefore the bias of the final sample cannot be checked.

This survey served the purpose of identifying current occupational therapy practice for people with stroke residing in UK care homes. It provided an overview of national practice for a sample of the UK population of occupational therapists working in care home settings with residents who have had a stroke. A further qualitative study using in-depth interviews with such occupational therapists would provide richer contextual data to support and explain these survey findings further.

#### 3.6 Conclusion

This survey gathered data from occupational therapists across the United Kingdom in order to explore current routine occupational therapy practice within care homes for residents living with effects of a stroke. The survey findings confirm that occupational therapy is being delivered in some care homes; however, interventions for

142

Chapter 3

residents with stroke are not routinely delivered by stroke specialist occupational therapists and the expertise and training of therapists varies.

There is inconsistency in the type of occupational therapy service provided across the UK. Once a referral to occupational therapy has been made, residents with stroke can expect to wait an average of 3 weeks to be assessed by a therapist. The occupational therapists are mainly 'generic' without specialist stroke expertise and their access to stroke specific training opportunities vary. Although the latest version of the National Clinical Guidelines for Stroke acknowledges that care home residents rarely receive any treatment from rehabilitation services, the guidelines recommend that all care home residents with stroke 'should receive assessment and treatment from stroke rehabilitation services in the same way as patients living in their own homes' (Intercollegiate Stroke Working Party, 2012). These survey findings suggest that at present this is not happening consistently across the UK.

Whilst it is a positive finding that some stroke survivors within care homes are receiving occupational therapy, the interventions provided are not delivered using a systematic approach and are not routinely evidence based.

#### **CHAPTER 4**

Sub group analysis and predictive modelling using data from a multi-centre cluster randomised controlled trial of occupational therapy for care home residents with stroke (the OTCH study).

#### **Chapter Overview**

This chapter will build upon the previous chapters by introducing the occupational therapy for care home residents with stroke (OTCH) study; the largest occupational therapy stroke rehabilitation trial to date. The main analysis and results of the OTCH study will be summarised in order to place this independent but nested PhD study in context. The PhD study involved independent detailed analysis using the OTCH trial data to explore sub groups within the trial population followed by the application of regression modelling techniques to determine whether predictors of a successful occupational therapy outcome could be identified for the trial population.

#### 4.1 Introduction

The Cochrane systematic review concluded that there was insufficient evidence to support or refute the benefits of occupational therapy for

care home residents with stroke and that more randomised controlled trials were warranted. Whilst evidence from clinical trials is sparse, the national survey reported in the previous chapter provided evidence that some care home residents with stroke are receiving occupational therapy support and interventions. This PhD programme of research has been completed alongside a National Institute for Health Research (NIHR) Health Technology Assessment (HTA) grant funded phase III multi-centre study. This cluster randomised controlled trial of an occupational therapy intervention for residents with stroke living in UK <u>care homes</u>, is known by the acronym 'OTCH'. The OTCH study was identified in the Cochrane Review as an on-going study and characteristics of the trial were listed in the 'characteristics of on-going studies' table on page 48. The primary outcome of interest in the OTCH study was independence in self-care activities of daily living (also commonly referred to as personal ADLs) as measured by the Barthel Index (BI) (Mahoney and Barthel, 1965). The primary analysis was the response in BI score in the intervention group at three month follow-up (immediately after the intervention) compared with the BI score in the control group at three months post randomisation. This chapter reports on methods of analysis used on the OTCH trial data that complimented the work undertaken by the OTCH trial statistician reported in the main study paper.

Before describing the aims and methods of the PhD student's analyses, this work first needs to be placed in context in relation to the main OTCH trial. The purpose of the OTCH study was to investigate the effects of a targeted course of occupational therapy for people with stroke living in a UK care home setting. The primary hypothesis was that care home residents with stroke would increase or maintain their independence in performing basic ADLs and level of mobility when given a three month targeted course of occupational therapy. The secondary hypothesis was that a targeted course of occupational therapy would have a positive impact on functional health outcomes such as mobility, mood, and quality of life.

#### 4.1.1 OTCH study trial design and procedures

The OTCH study was a pragmatic phase III, single-blind cluster randomised controlled trial with health economic evaluation. Alongside the main OTCH trial and this PhD programme of research, a process evaluation was also carried out by a PhD student at Bangor University to investigate the barriers and facilitators to the delivery of the OTCH interventions within care home settings (Masterson-Algar et al., 2014). Eleven trial administrative study centre sites covering several regions of the UK, participated in the OTCH trial. Collaborating centres included: Birmingham South and Birmingham Central (2 sites), Bangor, Bournemouth, Coventry, Lancashire, Norwich, Nottingham, Plymouth, Solent, Staffordshire, Taunton, and Wolverhampton.

Each study site used the UK CQC website to identify care homes in their region with more than 10 beds including all funding models (private, charitable, not for profit and local authority). Care homes were invited to participate and consenting care home managers were asked to identify those residents who had a confirmed or suspected diagnoses of stroke or transient ischaemic attack (TIA). All residents with a history of stroke or TIA were eligible to participate in the trial, unless they were actively receiving end-of-life care with a life expectancy of less than six months. None of the identified care homes were actively delivering occupational therapy to their residents.

Research Assistants collected baseline demographic data for each participant including their date of birth, date of stroke, side of stroke, date of care home admission, co-morbidities and prescribed medications. The baseline assessments with the primary and secondary outcome measures were carried out either directly with the participant or by proxy with a carer (either a relative or member of care home staff). At baseline only, participants were assessed on the following two measures: the Sheffield Screening Test of Acquired Language Disorders (SST) (Syder, 1993), an assessment of receptive

and expressive aphasia; and the Mini Mental Status Examination (MMSE) (Folstein et al., 1975), an assessment of cognition. At baseline, three, six and twelve month follow-up participants were assessed using the primary outcome measures the modified BI (Mahoney and Barthel, 1965); and the following secondary outcomes: the Rivermead Mobility Index (RMI) (Collen et al., 1991), the Geriatric Depression Scale (GDS) (Yesavage et al., 1982), and the EuroQol-5D (EQ-5D) (EuroQol Group, 1990). A table of the outcome measures used in the OTCH trial, their measurement purpose, time of administration and type of data is included in appendix 19.

Care homes were cluster randomised by an independent statistician at the Birmingham University Clinical Trials Unit, allocated on a 50:50 basis to either the intervention or control arm, and stratified according to: type of care provided (nursing or residential) and trial site location. The independent assessors were blinded to group allocation.

The participants in care home clusters randomised to receive occupational therapy intervention received an individualised occupational therapy treatment programme for a period of up to three months from a qualified HCPC registered occupational therapist. The occupational therapy interventions were targeted towards improving independence in personal activities of daily living such as

Chapter 4

feeding, dressing and toileting and improving mobility and transfers. The intervention was provided to the individual residents and involved the care home staff employing a 'client centred approach' (Paterson et al., 2005) and a 'task specific training approach' (Duncan, 1997). Adaptive equipment was provided as part of the study intervention, as were adaptations to the care home environment such as chair raises, bed levers, raised toilet seats and grab rails. In addition, the care home staff received individual training and group workshop sessions on facilitating independence and safe mobility.

The participants in the control homes received standard care only. Findings from a national survey (Fletcher-Smith et al., 2014) reported in chapter 3 and a local survey (Sackley et al., 2001) established that occupational therapy provision in care homes is ad-hoc and rarely routinely available. Barodawala et al (2001) estimated that 3% of residents have access to on-going therapy, and no other profession takes responsibility for the provision of adaptive equipment or the task-related practice of self-care ADLs.

### 4.1.2 The unique contribution of the PhD student and the OTCH collaborators' roles

The PhD student was a collaborator on the main OTCH study as the treating occupational therapist for the Nottingham site; and devised the care home staff training package that was delivered across all sites. The PhD student was responsible for obtaining endorsement from the UK Forum for Stroke

Training for the OTCH care home staff training workshop that she devised and developed with the research occupational therapist from the Birmingham study site. The PhD student was employed to work part-time (50% WTE) as the research occupational therapist for the Nottingham OTCH trial site to deliver the therapy intervention to care home residents in the experimental arm of the trial. For the remaining days of the week she completed her own programme of post-graduate research in fulfilment of her PhD studentship on a part-time basis.

The PhD student completed the Cochrane systematic review (chapter 2) and national survey study (chapter 3) and was then granted access to the OTCH trial raw data to perform her own detailed subgroup analysis of outcomes for the two intervention groups (occupational therapy versus control). In addition to the subgroup analysis, the PhD student also undertook predictive modelling of the data including logistic regression analysis and generalised estimating equation (GEE) modelling for the purpose of examining how well certain participant characteristics or 'predictor variables' could explain the outcomes of the study.

The Chief Investigator (Professor Catherine Sackley) was based at the central study site in Birmingham (and later relocated to Norwich). The CI had overall responsibility for the conduct and management of the OTCH study, was lead author of the main paper and acted as second supervisor to the PhD student.

The OTCH trial statistician carried out the analysis required for the main OTCH trial paper and provided the PhD student with the raw data files but did not provide any statistical advice or training to the PhD student. The PhD student accessed appropriate training in statistical analysis from the University of Nottingham. Further details of the independent analysis undertaken by the PhD student are given later in this and the subsequent chapter.

Another student at Bangor University (Patricia Masterson-Algar) carried out a Process Evaluation of the OTCH study as part of her PhD programme of research under the supervision of Professor Christopher Burton, the PI based at the Bangor study site.

Both PhD projects were separate independent studies that complimented the research being undertaken in the main OTCH multi-centre cluster RCT.

#### 4.1.3 OTCH study main summary of results

#### 4.1.3.1 Participant recruitment

Recruitment and randomisation of participating care homes occurred between May 2010 and March 2012 and exceeded the pre-planned target of 840 residents, with N=1,042 participants, from 228 care homes (114 homes in each arm). More care homes were recruited than originally planned because the average cluster size was smaller than predicted (appendix 20) with a median cluster size of 4 (IQR 2 to 6). Cluster size ranged from one participant (in 29 care homes) to 23 participants (in one care home).

The 114 care homes randomised to the occupational therapy intervention arm contained 568 participants; the 114 care homes randomised to the control arm contained slightly fewer eligible residents with 474 participants.

The majority of participants resided in care homes with nursing care (64%) and this was well balanced between the two intervention arms. A summary table of the distribution of randomised care homes and participants is given in appendix 21.

### 4.1.3.2 Participant characteristics

The characteristics of the participants were equally balanced between the two intervention arms and similar for all demographic descriptors (a table showing the characteristics of participants by randomisation arm is given in appendix 22). Participants were 64% female, and ranged in age from 43 to 102 years with a mean age of 82.9 years (SD 9.2). The majority of participants were white British (n=926, 88.9%) and co-morbidities such as neurological disease (n=666, 63.9%), cardiovascular disease (n=619, 59.4%), muscular disease (n=414, 39.7%), and falls (n=403, 38.7%) were common across both intervention groups.

# 4.1.3.3 **Primary outcome**

The adjusted mean difference in Barthel Index score between groups at three months was 0.19 points higher in the intervention arm (95% CI -0.33 to 0.70, p=0.48). This difference did not reach statistical significance at the 0.05 level, nor did it represent a significant clinical impact (Hsieh et al., 2007).

# 4.1.3.4 Secondary outcomes

Similarly, at three and six month follow-up, the Barthel Index data showed no significant differences between groups. At six months the adjusted mean difference in Barthel Index score was 0.00 points (95% CI -0.52 to 0.53, p=0.99), and 0.16 (95% CI -0.40 to 0.72, p=0.58) at twelve months. In addition, the results for mobility, mood, and health related quality of life showed no statistically significant or clinically important differences between groups, at each follow-up time-point.

# 4.2 Aim

The purpose of this PhD analysis, using the OTCH study data, was two-fold:

 to further investigate the effects of a targeted course of occupational therapy by comparing different sub groups of the OTCH study care home population with stroke; and (2) to investigate whether a difference could be detected between the two intervention arms of the trial when logistic regression and GEE modelling were applied to the data.

In part one of the analyses, the following hypotheses were tested:

- Age will affect how much improvement can be gained in selfcare ADL independence;
- (2) Length of time since stroke will affect how much improvement can be gained in self-care ADL independence;
- (3) Those with higher levels of independence at baseline will show greater improvement in ADL ability as a result of occupational therapy intervention than those with high levels of dependency at baseline;
- (4) Those with higher levels of mobility will show greater improvement in ADL independence as a result of occupational therapy intervention than those with immobility;
- (5) Those with normal cognition will show greater improvement in ADL independence following occupational therapy intervention;
- (6) Those with normal language ability will show greater improvement in ability to perform personal ADLs following occupational therapy intervention than those with aphasia;

- (7) Those with normal mood will make greater improvements in ability to perform personal ADLs following occupational therapy intervention than those with low mood;
- (8) Those with pain and discomfort will be less independent in personal ADLs;

In part two of the analyses, logistic regression and generalised estimating equation (GEE) modelling were applied to the OTCH data to compare the two intervention arms of the trial.

# 4.3 Method

# 4.3.1 PhD analysis database creation

Ethical approval for this independent study to be carried out by the PhD student in Nottingham in conjunction with the main trial analysis was obtained in October 2009 from the Coventry Research Ethics Committee (Reference: 09/H1210/88).

The data for each outcome measure was exported in separate Excel files; two files for each outcome measure, one containing the sub scores, and one containing the total scores. Separate Excel files containing the treatment log data and the participant demographic data were also created. These separate Excel files were password protected and sent to the Nottingham site for use in this PhD programme of work. In order to undertake the data analysis, the

separate files first needed to be merged into one full dataset. The pairs of Excel files (e.g. 'statBarthel.xls' and 'statBarthelscore.xls') for each outcome measure were merged into one excel file containing both the assessment sub scores and the total scores. Once the full Excel files had been created for each outcome measure they then needed to be converted from long format to wide format (with one row of data representing a participant, and all their associated data at each follow-up time point). This enabled the files to be merged into one large dataset for the analysis to be carried out using the IBM SPSS Statistics programme (IBM Corp, 2010). The data editor window was used to define and code each variable in the full SPSS data set. When the full and clean data matrix was complete it was then necessary to transform, recode and create some additional new variables from the data, in order to carry out the required statistical analysis techniques.

### 4.3.2 Dealing with missing data

The pre-analysis stage involved checking the full data set for missing data. 'Missing' data was coded as 888 and 'not applicable' data was coded as 999. The amount of missing data was explored both list-wise (the number of missing values for each variable listed) and pairwise (the number of missing values for each participant). Where a participant had missing sub scores for a particular outcome measure, the total score was entered as 888 ('missing') rather than adding the

remaining sub scores and omitting the missing data, as this would have given an inaccurate total score.

The OTCH trial Manager had contacted all trial sites with a list of missing data to request they check paper copies of the assessments and study forms and provide any omitted detail where possible. Therefore the 'missing' data in the Excel files that were obtained from the Central study site for this PhD study were deemed to be unobtainable and due to the actual data not being recorded by the researchers at the study sites, possibly due to lack of recorded data within the care homes' own records.

The SPSS default settings were used to decide whether listwise or pairwise deletion of records was performed. Thus listwise deletion was used in the majority of the analysis (as it drops variables rather than dropping participants) and pairwise deletion was used only for descriptive statistics and correlations.

# 4.3.3 Selecting the outcome measures of interest from the main OTCH data for inclusion in this PhD analysis

Baseline assessments were completed before randomisation at 0 months and follow-up, primary and secondary outcome assessments were completed at 3 months after randomisation (after the 3 month intervention phase), and were repeated at 6 months and 12 months

post randomisation. For the purpose of this PhD programme of research only baseline and 3 month outcome data were analysed as this PhD study aimed to analyse in detail the immediate effects of the intervention on as large a sample size as possible.

The primary outcome in the OTCH study was independence in selfcare activities of daily living (ADL). This was measured using the modified Barthel ADL Index (BI) (Mahoney and Barthel, 1965), a commonly used measure of self-care independence in both clinical practice and research that is widely regarded as the gold standard for assessing functional independence (Wright et al., 1998, Royal College of Physicians, 1998, National Institute for Health and Care Excellence, 2013). It contains 10 items of basic ADLs such as feeding, grooming washing, transferring from bed to chair, toileting and walking indoors. Each item is scored on an ordinal scale, depending on the individual's ability to perform the activity. A total score of 20 would represent independence in all 10 ADLs. The BI is the most widely used measure of ADL in stroke trials as it specifically assesses function in basic daily activities (Sulter et al., 1999, Kasner, 2006). Furthermore, the BI was used in previous studies investigating the efficacy of occupational therapy for increasing functional performance in care home residents (Legg et al., 2007b, Sackley et al., 2006, Sackley et al., 2008b). A 2 point change in score is widely accepted as being clinically significant as it equates to a change that is

perceived as a step change in function (Hsieh et al., 2007). A 2 point increase in score would equate to being unable to feed without physical help, to being able to manage feeding independently.

The secondary outcome measures included:

- The Rivermead Mobility Index (RMI) (Collen et al., 1991), a 15 item measure of functional mobility (scored from 0 to 15, with 15 representing someone who is fully mobile). The assessment scores the individual's ability to roll in bed, sit up, transfer, walk with help, walk outside and pick something up from the floor.
- The Geriatric Depression Scale-15 (GDS-15) (Yesavage et al., 1982, Sheikh and Yesavage, 1986), a 15 item measure that can be interpreted as an indication of the presence or absence of depressive mood.
- 3. The EuroQoI-5D (EQ-5D) (EuroQol Group, 1990), a wellestablished quality of life measure was used together with a specially designed resource usage questionnaire to provide data for cost-effectiveness analysis for the main OTCH trial analysis. This PhD programme of research did not include any health economic analysis as this analysis was performed by the OTCH trial health economist. The PhD analysis did however include data from the pain and discomfort question from the EQ-5D. Underwood et al (2013) established that this sub question of

the EQ-5D could be used in isolation to ascertain the presence or absence of pain and also the level of pain experienced.

Descriptive statistics were presented for all primary and secondary outcome measures to place the characteristics of the OTCH study sample in context. For the subgroup analysis the total scores on the Barthel Index were included as the primary measure of independence in ADLs. Total RMI score was used as a measure of mobility; GDS total score was included as a measure of mood; the only individual EQ-5D sub score deemed to provide information not already covered by the other outcome measures was the pain and discomfort sub score. The remaining EQ-5D sub scores were not included in the main subgroup analysis.

All outcome measures used in the subgroup analysis were included in the logistic regression analysis. For the GEE modelling the primary outcome measure was used.

### 4.3.4 Statistical analysis – descriptive statistics

The first stage of data analysis began following the creation of the complete data set, after the data had been checked for any potential errors. The first stage involved the use of descriptive statistics to explore and describe the sample of participants and their characteristics and assessment scores at each phase of the trial.

Descriptive statistics were used to create a CONSORT (Rennie, 2001, Moher, 1998) diagram and to produce tables of data by intervention arm (occupational therapy treatment versus control) for all demographic data and all outcome measure data at each follow-up assessment phase.

Histograms were created for all outcome measure variables to check the distribution of scores across the sample. When data is normally distributed, the mean and standard deviation can be relied upon as a true representation of the sample's scores. However when the data is skewed it is more appropriate to report the median and interquartile range. Box plots were used to show a visual comparison between the two intervention arms of the group mean, median and range of scores.

# 4.3.5 Statistical analysis – OT versus control by sub groups

Following descriptive statistical analysis, inferential statistical analysis using the Mann-Whitney test (Mann and Whitney, 1947) was used to compare the distributions of descriptive data scores between the two intervention arms according to the sub groups.

# 4.3.6 Exploration of the degree of association between covariates prior to modelling analysis

Before modelling could be performed, the relationship between the covariates first had to be explored using correlation analysis.

Correlation analysis is a procedure for quantifying (known as the correlation coefficient) the relationship between two or more variables. It provides a measure of the strength and direction of the relationship. Kendall's Tau and the Contingency Coefficient are two examples of the types of correlation that can be used for measuring relationships between variables. Kendall's Tau is a nonparametric measure that was developed as an alternative procedure for the Spearman correlation and can be used when measuring the relationship between ordinal variables (Plichta and Kelvin, 2013). Tau was appropriate for testing the association between the ordinal versus ordinal covariates. The Contingency Coefficient is a nonparametric technique that can be used to measure the relationship between two nominal variables, that need not be dichotomous in nature (Plichta and Kelvin, 2013). This test was used to test the association between the nominal versus ordinal covariates and the nominal versus nominal covariates.

Where covariates were found to be highly associated they were investigated further to improve the accuracy of model robustness and were removed from the final model. Where strong association between covariates was found the two variables were tested separately against the BI and other health outcomes at both time points. The variable with the strongest association with the BI was kept for the final model and that with the weakest association was

discarded. The analysis was conducted in a bivariate manner (i.e. two variables at a time). Correlation coefficients can range from -1 to +1, where 0 equals no relationship. When examining the correlation coefficient output data for the correlation analysis including covariates and health outcome variables, the interpretation used by several statistics authors (Plichta and Kelvin, 2013, Cohen, 1988, Gliner et al., 2002, Kraemer et al., 2003) was adopted so that a value of  $\pm$ .10 was regarded as weak to non-existent,  $\pm$ .30 was regarded as moderate, and  $\pm$ .50 was regarded as substantial. Once a strong association was found between two or more covariates then the ones with the strongest association with the health outcome variables was selected for modelling. The covariate mix was also investigated for multicollinearity using standard multiple linear regression modelling.

# 4.3.7 Statistical analysis –Generalized Linear Modelling

Depending on the nature of the variables generalized linear modelling was applied to analyse OT versus control at baseline and 3 months, controlling for the covariates (predictor variables).

Regression can be used to examine how much a particular set of independent variables can explain sufficiently the outcome. Regression models provide a way of predicting an outcome from one predictor variable (simple regression) or several predictor variables

(multiple regression) (Field, 2009). For example, stroke severity (as measured using the National Institute for Health Stroke Scale (NIH-SS) (Brott et al., 1989) is a well-established predictor of stroke outcome at one month and one year after stroke (Andersen et al., 2011). Multivariable regression analysis (also known as multivariate analysis) is a tool for determining the relative contributions of different causes to a single event (Katz, 2006).

(Plichta and Kelvin, 2012) presented the following general procedure for performing a regression analysis for almost any multivariate analysis:

Step 1: Define the specific hypothesis that is being tested.

Step 2: Run univariate frequencies and obtain the appropriate descriptive statistics.

Step 3: Run the bivariate analyses.

Step 4: Choose the initial variables for the multivariate analysis.

Step 5: Run the full model.

Step 6: Re-run the model, or compare blocks to obtain the best possible model.

This general procedure was followed in order to perform multiple regression analysis.

# 4.3.8 Statistical analysis – Generalized estimating equation (GEE) modelling

Given the study population of frail elderly stroke survivors, the data was unlikely to be normally distributed and therefore non parametric tests were considered the most suitable. Statistical analysis techniques involving modelling help to determine the factors that contribute to the intervention being most effective. Moreover, in the absence of the intervention being found to be effective; modelling accounts for factors that may have affected the outcome. Whereas a t-test would not consider the effects of other underlying characteristics that might affect outcome; modelling allows control over such confounding factors. Before modelling analysis could be performed, an appropriate model needed to be selected that would account for the type of data, distributions of data, time, and cluster effects. Random effects models (also known as mixed models) use maximum likelihood estimation and regression approaches (Hubbard et al., 2010). However, in cluster trials (such as the OTCH trial) the covariates and health outcome variables of participants within clusters is often correlated (Ghisletta and Spini, 2004) thus violating independence assumptions made by traditional regression procedures (Hubbard et al 2010). The aim of the GEE is to estimate the average response over the population (known as "population-averaged" effects) rather than the regression parameters that would enable prediction of the effect of changing one or more covariates on a given

individual. GEE thereby provides an unbiased estimation of population-averaged regression coefficients (Ghisletta and Spini, 2004).

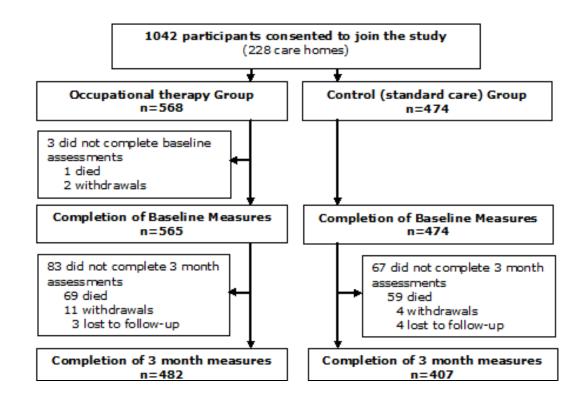
In order to perform GEE modelling, it was necessary to first explore the data for any simple correlations that existed between the variables of interest to account for other characteristics (confounders) besides the effect of the assigned treatment intervention. The distribution of the OTCH trial data was expected to be 'non-normal' in its' distribution due to the participant population. After confirming the distribution of the data, to address the non-normally distributed state of the variable data, the approach taken was to categorise the variables into binary form. The categorisation of the variables into binary form is explained in sub chapter 4.4.8 'Pre-modelling stage: variable transformations and descriptive statistics'. The categorised data was analysed using logistic regression and then GEE modelling was performed.

### 4.4 Results

# 4.4.1 Participant flow through the trial from recruitment to completion of 3 month outcome measures

The CONSORT diagram in figure 17 shows the progress of participants throughout the duration of the trial. Of the 568 participants randomised to receive the intervention, three did not

complete baseline assessments as one died and two withdrew from the trial. This resulted in 565 participants in the intervention arm completing the baseline assessments and 474 participants in the control arm completing the measures. By the three month outcome assessment, 482 participants in the intervention arm completed the outcome assessments compared with 407 participants in the control arm.



#### Figure 17: CONSORT diagram

# 4.4.2 Participant age and 'time since stroke' demographics by intervention arm

The full age distribution by randomisation arm is shown in table 14.

Age group	Total	Randomis	ation arm
	participants (N=1,042)	OT (N=568)	Control (N=474)
	n (%)	n (%)	n (%)
Under 49	3 (0.29)	1 (0.2)	2 (0.4)
50-59	19 (1.82)	12 (2.1)	7 (1.5)
60-69	67 (6.43)	37 (6.5)	30 (6.3)
70-79	228 (21.88)	111 (19.5)	117 (24.7)
80-89	475 (45.59)	283 (49.8)	192 (40.5)
90-99	239 (22.94)	119 (21.0)	120 (25.3)
100+	7 (0.67)	3 (0.5)	4 (0.8)
Unknown	4 (0.38)	2 (0.4)	2 (0.4)

#### Table 14: Age distribution according to randomisation arm

Just under a quarter (n=246, 23.6%) of participants were aged over 90 and seven of these were 100 years old or more. The median age was 84 years (IQR 78 – 89). The time since stroke onset from the date of recruitment to the trial was explored between groups according to their assigned randomisation arm (table 15).

Time since stroke o	Time since stroke onset (at		sation arm	
recruitment)	recruitment)		Control	
		(N=568)	(N=474)	
Valid stroke	n (%)	241 (42.4)	264 (55.7)	
No stroke date	n (%)	327 (57.6)	210 (44.3)	
Weeks since stroke a	t recruitment:			
	median (IQR)	160.3 (66.4 – 362.7)	146.3 (53.8 - 303.2)	
	mode	15*	3*	
Ra	ange (min – max)	0 - 1,527	1 - 2,293	
Years since stroke at	recruitment:			
	median (IQR)	3.1 (1.3 – 7.0)	2.8 (1.0 - 5.8)	
	mode	1	1	
Range (min – max)		0 – 29	0 - 44	
Was the participant's stroke more		n (%)	n (%)	
than 6 months ago?				
	Yes	218 (90.5)	240 (90.9)	
	No	23 (9.5%)	24 (9.1)	

Table 15:	Time since stroke	onset at recruitment	by randomisation arm
-----------	-------------------	----------------------	----------------------

 $\ast \overline{\text{multiple}}$  modes exist, therefore the smallest value is given

This analysis was only possible for those participants who had 'date of stroke' data. Of the 1,042 participants, 48.5% (n=505) had a date of stroke onset. This data was recorded for 55.7% of control arm

participants compared with 42.4% of those in the intervention arm. Across both arms of the trial, time since stroke ranged from 0 weeks to 2,293 weeks (44 years). The median number of years since stroke was comparable across both groups: 3.1 years (IQR 1.3 to 7.0) in the occupational therapy group and 2.8 years (IQR 1.0 to 5.8) in the control group. Participants were categorised according to whether their stroke was more of less than six months ago at time of recruitment. Both randomisation arms were similar with 90.5% (n=218) of participants in the intervention arm having had their stroke more than 6 months ago and 90.9% (n=240) of the control arm being more than 6 months post-stroke.

# 4.4.3 Cognitive status and language ability at baseline

Mini Mental Status Examination (MMSE) scores were collated at baseline to provide an indication of the participants' cognitive status upon entering the trial. The Sheffield Screening Test of Acquired Language Disorder (SST) was administered at baseline to provide an indication of language ability. The completion rates for the MMSE and SST assessments at baseline are given below in table 16.

Table 16:	Completion	rates fo	or the	MMSE	and	SST	assessments	
-----------	------------	----------	--------	------	-----	-----	-------------	--

	-	nal Therapy 568	Control N=474		
Baseline	Assessments	Partially	Assessment	Partially	
Assessment	fully	completed	fully	completed	
	completed	assessments	completed	assessments	
	n (%)	n (%)	n (%)	n (%)	
MMSE	398 (70.1)	50 (8.8)	362 (76.4)	4 (0.8)	
SST	424 (74.6)	33 (5.8)	374 (78.9)	25 (5.3)	

From the 1,042 randomised participants, a total of 760 (72.9%) fully completed each question on the MMSE assessment. For the baseline assessment of language ability, 798 participants fully completed the SST.

The MMSE is scored out of a total of 30 with a score less than 27 indicative of cognitive impairment. Level of cognitive impairment is scored under four ordinal categories as listed in table 17. The two intervention arms were evenly matched for all categories of cognitive impairment.

		Randomisa	ation arm
	Total participants (N=1,042)	Occupational therapy (N=568)	Control (N=474)
MMSE [0-30]:	N (%)	n (%)	n (%)
Severe cognitive impairment [0-10]	292 (38.4)	148 (37.2)	144 (39.8)
Moderate cognitive impairment [11-20]	250 (32.9)	131 (32.9)	119 (32.9)
Mild cognitive impairment [21-26]	170 (22.4)	91 (22.9)	79 (21.8)
Normal cognitive function [27-30]	48 (6.3)	28 (7.0)	20 (5.5)
	N (%)	n (%)	n (%)
MMSE assessments completed	760 (72.9)	398 (70.1)	362 (76.4)
Missing MMSE total score	282 (27.1)	170 (29.9)	112 (23.6)
	Mean (sd)	Mean (sd)	Mean (sd)
Total MMSE score	13.41 (9.3)	13.58 (9.5)	13.24 (9.0)

 Table 17: Baseline MMSE scores by randomisation arm

The overall majority of participants (71.3%, n=542) scored between 0 and 20, meaning that most residents had moderate to severe cognitive impairment. Less than a quarter (22.4%, n=170) of participants had mild cognitive impairment and only 6.3% (n=48) had normal cognitive function. The mean scores were matched between groups with a mean of 13.58 (SD 9.5) in the occupational therapy intervention arm and 13.24 (SD 9.0) in the control arm.

The frequency distribution of baseline MMSE scores was plotted on a histogram for each randomisation arm of the trial (appendix 23). The histograms revealed a high level of positive skew and lack of symmetry in the distribution of total MMSE scores across both arms of the trial. Positive kurtosis showed that the most frequent scores were clustered around 0. The median score for the occupational therapy intervention group was 14.5 (IQR 4 to 22), the median for the control was 14.0 (IQR 5.75 to 21). The MMSE scores in both groups ranged from 0 to 30. Participants were closely matched for cognition across intervention arms of the trial.

The level of language impairment (if any) was assessed at baseline using the Sheffield Screening Test for Acquired Language Disorder (SST) (Syder, 1993). The SST is scored out of 20 with scores less than 15 indicating the presence of language impairment (table 18). Of the 798 participants who completed the assessment, 57.4% (n=458) had language impairment.

		Randomisation arm		
	Total participants (N=1,042)	OT (N=568)	Control (N=474)	
SST score [0-20]	N (%)	n (%)	n (%)	
Language impairment [<15]	458 (57.4)	245 (57.8)	213 (57.0)	
SST assessment completed	798 (76.6)	424 (74.6)	374 (78.9)	
Missing SST total score	244 (23.4)	144 (25.4)	100 (21.1)	
	Mean (SD)	Mean (SD)	Mean (SD)	
Total SST score	10.93 (7.1)	10.86 (7.2)	11.00 (7.0)	

Table 18:	Baseline	Sheffield	Screening	Test score	es by	randomisation arm
-----------	----------	-----------	-----------	------------	-------	-------------------

The frequency distribution of baseline SST scores was plotted on a histogram for each randomisation arm of the trial (appendix 24). Unlike the positively skewed scores in the other baseline assessments, for the SST scores the mode was 0 but the remaining data was negatively skewed in the opposite direction towards the higher scores. The two intervention arms of the trial were equally matched, each had a median score of 13; although the IQR differed slightly with an IQR of 3 to 17 in the occupational therapy intervention group compared with an IQR of 5 to 17 in the control group. Both intervention arms of the trial were therefore well matched at baseline for communication ability.

### 4.4.4 **Outcome measure completion rates**

The completion rates were equally matched between groups for all outcome measures across both time points (table 19). However at each assessment phase, the completion rate between the different outcome measures varied. For example, at baseline the BI was fully completed (either fully or partially) by 1,039 participants, however the RMI was completed by 1,038 participants, and the GDS by only 984 participants. This disparity in completion of the separate outcome measures occurred across both time points. At no assessment phase, was a single outcome measure completed by all participants.

Chapter 4

		Occupational Therapy N=568			ntrol 474
Outcome	Assessment	Assessments	Partially	Assessment	Partially
	time point	fully	completed	fully	completed
		completed	assessments	completed	assessments
		n (%)	n (%)	n (%)	n (%)
BI	Baseline	562 (98.9)	3 (0.5)	467 (98.5)	7 (1.5)
	3 months	479 (84.3)	3 (0.5)	391 (82.5)	12 (2.5)
RMI	Baseline	556 (97.9)	9 (1.6)	456 (96.2)	17 (3.6)
	3 months	472 (83.1)	8 (1.4)	398 (84.0)	4 (0.8)
GDS	Baseline	330 (58.1)	204 (35.9)	261 (55.1)	189 (39.9)
	3 months	265 (46.7)	191 (33.6)	223 (47.0)	147 (31.0)
EQ5D	Baseline	506 (89.1)	38 (6.7)	424 (89.5)	38 (8.0)
	3 months	433 (76.2)	32 (5.6)	366 (77.2)	22 (4.6)

Table 19:	Completion	rates for	all	measures
-----------	------------	-----------	-----	----------

The status of participants were analysed at both outcome assessment phases of the trial (table 20) to account for the outcome measure completion rates throughout the duration of the trial. At baseline, three participants from the occupational therapy intervention group were unable to complete outcome measures because they had either died (n=1) or withdrawn from the trial (n=2). By the three month follow-up assessment, 85.3% of participants (n=889) remained alive and part of the trial, with 129 participants having died, 12 withdrawn, and 7 lost to follow-up.

Trial phase	Status	Total	Randomisation arm	
		participants (N=1,042)	OT (N=568)	Control (N=474)
		n (%)	n (%)	n (%)
Baseline	Alive	1,039 (99.7)	565 (99.4)	474 (100)
	Dead	1 (0.1)	1 (0.2)	-
	Withdrawn	2 (0.2)	2 (0.4)	-
	Lost to follow-up	-	-	-
3 month	Alive	889 (85.3)	482 (84.9)	407 (85.9)
follow-up	Dead	129 (12.4)	70 (12.3)	59 (12.5)
	Withdrawn	17 (1.6)	13 (2.3)	4 (0.8)
	Lost to follow-up	7 (0.7)	3 (0.5)	4 (0.8)

 Table 20: Participant status at each follow-up time point

# 4.4.5 **Baseline outcome measure scores**

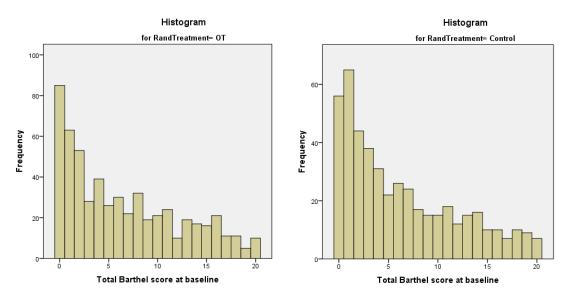
1,039 participants (99.7%) of the 1,042 who entered the trial and were randomised still remained part of the trial at baseline assessment. Not all participants fully completed every question of the BI assessment and therefore a total score was missing for some individuals who only partially completed the assessment. 1,029 participants (98.8% of the original sample) had a total BI score at baseline. The scores are displayed in table 21 according to BI score category and randomisation arm.

		Randomisation arm		
	Total participants (N=1,042)	Occupational therapy (N=568)	Control (N=474)	
<b>Barthel Index category:</b>	N (%)	n (%)	n (%)	
Very severe [0-4]	502 (48.8)	268 (47.7)	234 (50.1)	
Severe [5-9]	233 (22.6)	129 (22.9)	104 (22.3)	
Moderate [10-14]	167 (16.3)	91 (16.2)	76 (16.3)	
Mild [15-19]	110 (10.6)	64 (11.4)	46 (9.8)	
Independent [20]	17 (1.7)	10 (1.8)	7 (1.5)	
	N (%)	n (%)	n (%)	
BI assessments fully completed	1,029 (98.8)	562 (98.9)	467 (98.5)	
Missing total score	13 (1.2)	6 (1.1)	7 (1.5)	
	Mean (sd)	Mean (sd)	Mean (sd)	
Total BI score	6.38 (5.7)	6.47 (5.8)	6.27 (5.7)	

Table 21: Baseli	ne Barthel	Index scores	by randomisation arm

Almost half (48.8%) of all participants scored between 0 and 4 on BI at baseline; placing them in the 'very severe' category of disability. The majority of participants (87.7%) were classed as 'moderately' to 'very severely' disabled and were dependent on assistance for basic ADLs. The frequency distribution of baseline BI scores was plotted on a

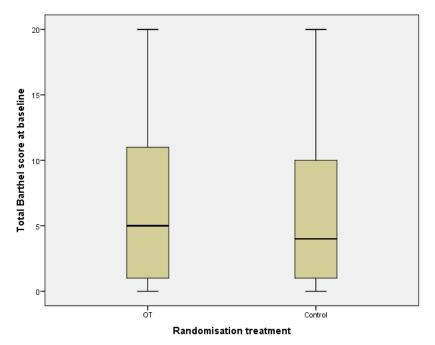
histogram for each randomisation arm of the trial (figure 18).



**Figure 18: Histograms showing frequency distribution of baseline BI scores by** randomisation arm

Both graphs in figure 18 showed positively skewed scores with the frequent scores clustered at the lower end and the tail towards the higher or more positive scores. The mean baseline BI score for the occupational therapy intervention arm was 6.47 (SD 5.8) and for the control arm the mean score was 6.27 (SD 5.7). The box-whisker diagram below (figure 19) displays the data on total BI scores by intervention arm.





The median BI score at baseline for the intervention group was 5 with an inter-quartile range (IQR) of 1 to 11. The median BI score at baseline for the control group was 4 (IQR 1 to 10). The box-whisker diagram (figure 19) clearly illustrates that the range of BI scores and the median and IQR are equally matched between groups.

At baseline assessment 1,012 participants (97.1% of the 1,042 who entered the trial and were randomised) completed all sub scores on the RMI giving them a baseline total RMI score. The RMI is scored from 0 to 15 with 15 being more mobile. The mean score for the entire study population and the two intervention arms are given in table 22.

		Randomisation arm		
	Total participants (N=1,042)	OT (N=568)	Control (N=474)	
Rivermead Mobility Index [0-15]:	N (%)	n (%)	n (%)	
Completed RMI assessments	1,012 (97.1)	556 (97.9)	456 (96.2)	
Missing RMI total score	30 (2.9)	12 (2.1)	18 (3.8)	
	Mean (SD)	Mean (SD)	Mean (SD)	
Total RMI score	3 (3.8)	3.12 (3.8)	2.85 (3.7)	

Table 22:	Baseline	Rivermead	Mobility	Index	scores b	bv	randomisation arm
	Dubernie	I.I.I.C.IIIICaa		AIIGOA	500105 1	~ 7	ranaonnoación ann

The frequency distribution of baseline RMI scores was plotted on a histogram for each randomisation arm of the trial and also a boxwhisker diagram (appendix 25). The histogram revealed positively skewed data with frequent low scores (mode of 0 for both randomisation arms); this is highly indicative of a largely immobile sample population. It was evident from the box-whisker diagram that the median and IQR were comparable between the two intervention arms. However the range of scores was wider in the occupational therapy intervention group than the control. The control group also contained 10 outliers who had particularly high scores outside of the normal range of the rest of the group. The top whisker was much longer than the bottom whisker in each case and this reflected the asymmetrical data or 'skew' that was illustrated in the histograms of the same data. The median score was 1 (IQR 0 to 6) for the occupational therapy arm and 1 (IQR 0 to 5) for the control arm.

Participants' mood was assessed at baseline using the 15 question version of the GDS. Scores according to category of mood are given in table 23. A total GDS score at baseline was missing from 43.3% (n=451) of randomised participants. There were very slightly more depressed participants in the control group (56.3%) compared with the intervention group (52.7%).

 Table 23: Baseline Geriatric Depression Scale (GDS) scores by randomisation arm

		Randomis	ation arm
Geriatric Depression Scale [0-15]	Total participants (N=1,042)	OT (N=568)	Control (N=474)
	N (%)	n (%)	n (%)
Normal [0-5]	270 (45.7)	156 (47.3)	114 (43.7)
Suggests depression [>5]	196 (33.1)	98 (29.7)	98 (37.5)
Depression [>10]	125 (21.2)	76 (23.0)	49 (18.8)
	N (%)	n (%)	n (%)
Completed GDS assessments	591 (56.7)	330 (58.1)	261 (55.1)
Missing GDS total score	451 (43.3)	238 (41.9)	213 (44.9)
	Mean (sd)	Mean (sd)	Mean (sd)
Total GDS score	6.26 (3.61)	6.23 (3.7)	6.30 (3.5)

When considering the study population as a whole, there were more participants with scores suggesting depression (54.3%, n=321) than those within normal range (45.7%, n=270). A histogram and boxwhisker plot (appendix 26) revealed GDS baseline scores that were not normally distributed in either intervention arm of the trial. The median score for the occupational therapy intervention arm was 6.0 (IQR 3 to 9), and the median score for the control arm was 6.0 (IQR 4 to 9). The range of scores was the same across both groups. The pain and discomfort sub scores for the EQ5D at baseline by

randomisation arm are displayed in table 24. At baseline more than

49% in each trial arm reported pain or discomfort.

Table 24: Bas	eline EQ5D pain and	discomfort sub scores	by randomisation arm
---------------	---------------------	-----------------------	----------------------

		Randomisation arm			
	Total participants (N=1,042)	OT (N=568)	Control (N=474)		
EQ5D	N (%)	n (%)	n (%)		
Pain / Discomfort					
No pain or discomfort	463 (47.0)	236 (44.4)	227 (50.1)		
Moderate pain or discomfort	450 (45.7)	246 (46.2)	204 (45.0)		
Extreme pain or discomfort	72 (7.3)	50 (9.4)	22 (4.9)		
Completed pain/discomfort score	985 (94.5)	532 (93.7)	453 (95.6)		
Missing EQ5D pain/discomfort	57 (5.5)	36 (6.3)	21 (4.4)		
score					

# 4.4.6 Outcome of 3 month follow-up assessments

889 of the 1,042 randomised participants remained in the trial at 3 month follow-up. Of those, remaining at 3 month follow-up, 870 participants fully completed the BI assessment, giving them a BI total score. Table 25 shows the BI scores at 3 months by category of BI score and randomisation arm.

		Randomisation arm		
	Total participants (N=1,042)	Occupational therapy (N=568)	Control (N=474)	
Barthel Index category:	N (%)	n (%)	n (%)	
Very severe [0-4]	462 (53.1)	242 (50.5)	220 (56.3)	
Severe [5-9]	184 (21.2)	107 (22.4)	77 (19.7)	
Moderate [10-14]	120 (13.7)	64 (13.3)	56 (14.3)	
Mild [15-19]	96 (11.1)	61 (12.8)	35 (8.9)	
Independent [20]	8 (0.9)	5 (1.0)	3 (0.8)	
	N (%)	n (%)	n (%)	
BI assessments completed	870	479 (84.3)	391 (82.5)	
Missing total score	172	89 (15.7)	83 (17.5)	
	Mean (SD)	Mean (SD)	Mean (SD)	
Total BI score	5.89 (5.6)	6.11 (5.7)	5.62 (5.5)	

At 3 month follow-up more than half (53.1%) of all participants scored between 0 and 4 on the BI; placing them in the 'very severe' category of disability. The number of 'independent' participants had halved since baseline assessment from 17 participants to 8. Histograms (appendix 27) revealed positively skewed data. The median BI score at 3 month follow-up for the occupational therapy intervention group was 4 (IQR 1 to 10) and the median score for the control group was 3 (IQR 1 to 9).

# 4.4.7 Sub group analysis comparing Barthel Index change scores by baseline characteristics

# 4.4.7.1 Improvement in BI by age at baseline

The participants were split into subgroups by age using the median

age as the cut off. The median age of participants was 84 years.

Thus participants were grouped according to whether they were aged

less than 84 years or 84 years and above (table 26).

Table 26: Distribution of age by sub group (<84 yrs versus  $\geq$ 84 yrs) according to intervention arm

	Randomisation arm		
Age sub group:	ОТ	Control	
<84 yrs n (%)	258 (45.6%)	219 (46.4%)	
<u>&gt;</u> 84 yrs n (%)	308 (54.4%)	253 (53.6%)	

Their BI change scores were then compared for the occupational therapy intervention arm and the control arm by age subgroups (<84 yrs versus  $\geq$ 84 yrs) using the Mann-Whitney U test. The distribution of change in BI score between baseline and 3 month follow-up was no

different between age subgroups for the OT group (p=.416) and the control (p=.123).

### 4.4.7.2 Improvement in BI by length of time since stroke

Participants were split into subgroups by length of time post-stroke according to whether they were 1 year or less since stroke onset or more than 1 year post-stroke (table 27).

Table 27: Distribution of time since stroke by sub group (<1 yr versus  $\geq$ 1 yrs) according to intervention arm

		Randomisation arm			
Time since stroke:		ОТ	Control		
<u>&lt;</u> 1 yr	n (%)	54 (22.4%)	67 (25.4%)		
>1 yr	n (%)	187 (77.6%)	197 (74.6%)		

BI change scores were then compared for the occupational therapy intervention arm and the control arm by time since stroke subgroups ( $\leq 1$  yr versus >1 yrs) using the Mann-Whitney U test. The distribution of change in BI score between baseline and 3 month follow-up was no different between time since stroke subgroups for the OT group (p=.767) and the control (p=.416).

### 4.4.7.3 Improvement in BI by level of disability at baseline

Participants were split into subgroups by level of disability at baseline

according to whether they were independent/had mild disability [15-

20] or had moderate/severe/very severe disability[0-14] (table 28).

Table 28: Distribution of level of disability at baseline by sub group (BI score 0-14versus BI score 15-20) according to intervention arm

		Randomisation arm		
Level of disability at baseline accor	ОТ	Control		
BI score [0-20]:				
0-14 (mod. to very severe disability)	n (%)	54 (22.4%)	67 (25.4%)	
15-20 (mild disability/independent)	n (%)	187 (77.6%)	197 (74.6%)	

Their BI change scores were then compared for the occupational therapy intervention arm and the control arm by level of disability at baseline subgroups (BI score 0-14 versus BI score 15-20) using the Mann-Whitney U test. The distribution of change in BI score between baseline and 3 month follow-up was no different between baseline disability level subgroups for the control group (p=.234). However there was a statistically significant difference in change scores across baseline BI categories for the active occupational therapy intervention group (p=.026).

## 4.4.7.4 Improvement in BI by level of mobility at baseline

Participants were split into subgroups by level of mobility at baseline according to whether they had an RMI score of <7 or an RMI score of 7+, representing immobility versus mobility (table 29).

Table 29: Distribution of level of mobility at baseline by sub group (RMI score <7 versus RMI score  $\geq$ 7) according to intervention arm

		Randomisa	ation arm
Level of mobility at baseline according to RMI score:		ОТ	Control
<7 (Immobile/poor mobility)	n (%)	434 (78.1%)	374 (82.0%)
(Better mobility/mobile)	n(%)	122 (21.9%)	82 (18.0%)

The BI change scores were then compared for the occupational therapy intervention arm and the control arm by level of baseline mobility subgroups (RMI score <7 versus RMI score  $\geq$ 7) using the Mann-Whitney U test. The distribution of change in BI score between baseline and 3 month follow-up was no different between baseline mobility subgroups for the control group (p=.247). However there

was a statistically significant difference in change scores across baseline RMI categories for the active occupational therapy intervention group (p=.006).

## 4.4.7.5 Improvement in BI by cognitive status at baseline

Participants were sub grouped according to their cognitive status at baseline as defined by their MMSE score (table 30). Those with a score of 0-10 are classed as having severe cognitive impairment, a score of 11-20 indicates moderate cognitive impairment, 21-26 suggests only mild cognitive impairment, and a score of 27-30 indicates normal cognitive function (no dementia).

 Table 30: Distribution of cognition status at baseline by MMSE sub groups

 according to intervention arm

		Randomisation arm	
Cognitive status subgroup		ОТ	Control
according to MMSE score:			
Severe cognitive impairment	n (%)	148 (37.2%)	144 (39.8%)
Moderate cognitive impairment	n (%)	131 (32.9%)	119 (32.9%)
Mild cognitive impairment	n (%)	91 (22.9%)	79 (21.8%)
Normal cognition	n (%)	28 (7.0%)	20 (5.5%)

The Kruskal-Wallis statistic was used to test for statistically significant differences between these subgroups. Across cognition subgroups in the occupational therapy intervention arm of the trial there was no statistically significant difference in the distribution of change in BI score (p=.328). There was also no statistically significant difference across the cognition subgroups in the control arm (p=.484).

# 4.4.7.6 Improvement in BI by language ability at baseline

Participants were then grouped into subgroups according to whether

or not their SST score at baseline was indicative of language

impairment [SST<15] or not [15-20] (table 31).

Table 31: Distribution of language ability at baseline by sub group (SST score <15</th>versus SST score  $\geq$ 15) according to intervention arm

		Randomisation arm	
Language ability at baseline according to SST score:		ОТ	Control
<15 (Language impairment)	n (%)	245 (57.8%)	213 (57.0%)
≥15 (Normal language)	n (%)	179 (42.2%)	161 (43.0%)

For those participants in the control group there was no statistically significant difference (p=.868) in the distribution of BI change scores across subgroups of language impaired versus normal language ability. However, for those participants in the occupational therapy arm of the trial, there was a statistically significant difference (p=.019) in change scores between those who had language impairment and those who did not.

# 4.4.7.7 Improvement in BI by category of mood at baseline

Participants were grouped according to their baseline GDS score into three sub groups: normal mood [GDS 0-5], possible depression [GDS >5], and depressed [>10] (table 32).

		Randomisation arm	
Mood status subgroup according to GDS score [0-15]:		ОТ	Control
Depression [>10]	n (%)	76 (23.0%)	49 (18.8%)
Suggests depression [6-9]	n (%)	98 (29.7%)	98 (37.5%)
Normal mood [0-5]	n (%)	156 (47.3%)	114 (43.7%)

Table 32: Distribution of mood sta	tus at baseline by GDS	sub groups according to
intervention arm		

The Kruskal-Wallis statistic was used to test for statistically significant

difference in BI change scores between baseline and 3 month follow-

up. The distribution of change scores was the same across sub

groups of GDS for the occupational therapy intervention group

(p=.525) and the control arm of the trial (p=.265).

# 4.4.7.8 Improvement in BI by category of pain and discomfort at baseline

Participants were grouped according to whether they had any pain or

discomfort at baseline or not according to the EQ-5D pain and

discomfort sub score (table 33).

Table 33: Distribution of participants by pain and discomfort sub groups accordingto intervention arm

		Randomisation arm	
Pain and discomfort status at		ОТ	Control
baseline according to EQ5	):		
Pain and/or discomfort	n (%)	332 (58.5%)	247 (52.1%)
No pain and/or discomfort	n (%)	236 (41.5%)	227 (47.9%)

The Mann-Whitney U test found no statistically significant difference in the distribution of change in BI between baseline and 3 month follow-up across the pain and discomfort subgroups in both the occupational therapy arm of the trial (p=.212) and the control arm of the trial (p=.182).

# 4.4.8 Pre-modelling stage: Variable transformations and descriptive statistics

Both the health outcome measure variables and the participant characteristic covariates were categorised into binary form in preparation for the modelling analysis. For the variables to be converted to binary format, the cut off scores needed to be determined. For the health outcome data (BI, RMI, GDS, and EQ5D Pain and Discomfort outcome measures) the cut off score for the preferred positive outcome was used versus the negative dependent outcome range of scores. The cut off scores for the binary form of the health outcome variables are given in table 34.

Table 34: Cut off scores for the bi	nary form of the health	outcome variables
-------------------------------------	-------------------------	-------------------

Outcome measure	Original scoring cut offs	Binary cut off scores
Barthel ADL Index	20 = Independent	$1 = \ge 15$
	15 - 19 = Mild dependency 10 - 14 = Moderate dependency	0 = <15
	5 - 9 = Severely dependent	
	0 - 4 = Very severely dependent	
Rivermead Mobility	Scored 0-15	1 = 7+
Index	7+ = Able to walk/better mobility	0 = <7
	<7 = No walking/poor mobility	
Geriatric Depression	10 - 15 = Depression	1 = <u>&lt;</u> 5
Scale	>5 = Suggests depression	0 = >5
	0 - 5 = Normal	
EQ5D Pain and	3 = Extreme pain/discomfort	1 = 1
Discomfort score	2 = Moderate pain/discomfort	0 = 2/3
	1 = No pain or discomfort	

For the Barthel Index a cut off score of 15 was chosen for the categorisation of binary scores. Thus the binary score 0 was assigned to the original BI scores of 0 to 14 and represented participants who were moderately dependent to very severely dependent. The binary score 1 was assigned to those who had originally scored between 15 and 20 on the BI and were independent or only mildly dependent.

For the RMI a score of 7 was selected as the binary cut off. The sub score items within the RMI increase in difficulty from the start of the assessment to completion. A score of 7 was decided as the cut off as University of Nottingham

Chapter 4

a score of 7 would represent a reasonable level of mobility including the ability to roll in bed, sit on the edge of the bed without help, transfer from a chair to standing in less than 15 seconds, stand unsupported for 10 seconds, transfer from bed to chair independently and mobilise 10 metres (with or without a walking aid). The binary score 1 was assigned to represent the positive health outcome of a RMI score of 7 or more. The binary score 0 was assigned to original RMI scores of less than 7 to reflect poorer mobility/immobility.

On the GDS, the normal cut off score that suggests an individual possibly has depression is a score greater than 5. Thus the binary negative score 0 was assigned to the original GDS scores of >5 and a binary score of 1 reflected the positive outcome of an absence of depression (determined by an original GDS score of 5 or less).

The EQ-5D pain and discomfort scores were converted to binary format by assigning 1 to the positive outcome of 'no pain or discomfort' (original score of 1), and the negative binary score 0 was assigned to the original scores 2 and 3, representing moderate to extreme pain and discomfort.

The participant characteristic covariates were converted to binary form according to the original type of variable. The scaled variables without standard defined cut offs (age and care home cluster size)

University of Nottingham

Chapter 4

were converted to binary form by using the median score as the cut off. The scaled variables with pre-defined cut off scores (cognitive status at baseline as defined by the MMSE score and language ability at baseline as defined by the Sheffield Screening Test score) were converted to binary by splitting the variable groups into two and assigning the 0 to the negative outcome scores (i.e. MMSE score <21 = severe or moderate cognitive impairment; SST score <15 = language impairment) and the 1 to the positive outcome scores.

The binary nominal variables (gender, falls history, stroke status at baseline, intervention arm of the trial and care home type) were assigned a 0 or 1. The nominal ethnicity variable was converted to binary format by assigning white participants to 1 and all other ethnic backgrounds to 0.

The 'time since stroke' variable was converted to binary form by assigning 1 to represent one or more years and 0 to represent less than a year post-stroke. The cut off scores for the binary form of the covariates are given in table 35.

Г <u>-</u> -		· · · · · · · · · · · · · · · · · ·
Covariate	Cut off used	Binary cut off
		scores
Age	Median = 84 years	1 = <u>&gt;</u> 84 years
		0 = <84 years
Gender	Female or Male	1 = Female
		0 = Male
Ethnicity	White or other ethnicity	1 = White
		0 = Other
Falls History	1+fall or no falls	1 = Falls
		0 = No falls
Stroke status at	Confirmed stroke or	1 = Confirmed stroke
baseline	everything else	0 = Everything else
Intervention arm	OT or Control	1 = OT
		0 = Control
Cognitive status	21+ (Mild cognitive	1 = Normal cognition
at baseline (MMSE	impairment/normal cognition)	/mild impairment
score)	versus <21 (moderate/severe	0 = Severe/moderate
	cognitive impairment)	cognitive impairment
Language ability	15+ (Normal language	1 = 15 + (Normal)
(SST score)	ability) versus <15 (language	0 = <15 (Impaired)
	impairment)	
Time since stroke	More than 1 year post-stroke	1 = >1 year
	or 1 year or less post-stroke	0 = <u>&lt;</u> 1 year
Care home cluster	Median = 4	1 = <u>&gt;</u> 4
size		0 = <4
Care home status	Residential home or nursing	1 = Residential
type	home	0 = Nursing home

#### Table 35: Cut off scores for the binary form of the covariates

The frequencies and proportions of each of the new binary health

outcomes are displayed in table 36.

Table 36: Frequencies and proportions of the distribution of the bit	nary health
outcomes	

Health outcome	Dependent `0' variable n (%)	Independent `1' variable n (%)
BI at baseline	902 (87.7%)	127 (12.3%)
BI at 3 months	766 (88.1%)	104 (11.9%)
RMI at baseline	808 (79.8%)	204 (20.2%)
RMI at 3 months	720 (82.8%)	150 (17.2%)
GDS at baseline	200 (33.8%)	391 (66.2%)
GDS at 3 months	200 (41.0%)	288 (59.0%)
EQ5D (pain) at baseline	522 (53.0%)	463 (47.0%)
EQ5D (pain) at 3 months	412 (48.7%)	434 (51.3%)

Descriptive statistics were then used to describe the frequency distribution of the binary health outcome variables according to randomisation arm (OT versus control). The frequencies and

proportions are given in table 37 below.

 Table 37: Frequencies and proportions of the distribution of binary health outcomes

 by randomisation arm

	Occupational therapy arm		Conti	ol arm
Health outcome	Dependent `0' variable n (%)	Independent `1' variable n (%)	Dependent `0' variable n (%)	Independent `1' variable n (%)
BI at Om	488 (86.8%)	74 (13.2%)	414 (88.7%)	53 (11.3)
BI at 3m	413 (86.2%)	66 (13.8%)	353 (90.3%)	38 (9.7%
RMI at 0m	434 (78.1%)	122 (21.9%)	374 (82.0%)	82 (18.0%)
RMI at 3m	388 (82.2%)	84 (17.8%)	332 (83.4%)	66 (16.6%)
GDS at 0m	120 (36.4%)	210 (63.6%)	80 (30.7%)	181 (69.3%)
GDS at 3m	101 (38.1%)	164 (61.9%)	99 (44.4%)	124 (55.6%)
EQ5D (pain) at 0m	296 (55.6%)	236 (44.4%)	226 (49.9%)	227 (50.1%)
EQ5D (pain) at 3m	237 (51.7%)	221 (48.3%)	175 (45.1%)	213 (54.9%)

The pre-modelling exploratory analysis involved comparison of the occupational therapy group versus the control group for all health outcomes using the Mann Whitney test.

Using the Mann Whitney test, the binary BI scores in the intervention arm (median = 0) did not differ significantly from the control arm (median = 0) at baseline, U = 128,841, z = -0.88, p = 0.378, r = -0.03. By the 3 month follow-up assessment, the intervention arm (median = 0) still did not differ significantly from the control arm (median = 0), U = 89,842.50, z = -1.84, p = 0.066, r = -0.06.

Using the Mann Whitney test, the binary RMI scores in the intervention arm (median = 0) did not differ significantly from the control arm (median = 0) at baseline, U = 121,748, z = -1.56, p = 0.118, r = -0.05. By the 3 month follow-up assessment, the

intervention arm (median = 0) still did not differ significantly from the control arm (median = 0), U = 92,788, z = -0.47, p = 0.637, r = -0.02.

The binary GDS scores in the intervention arm (median = 1) did not differ significantly from the control arm (median = 1) at baseline, U = 40,605, z = -1.46, p = 0.145, r = -0.06. By the 3 month followup assessment, the intervention arm (median = 1) still did not differ significantly from the control arm (median = 1), U = 27,691.5, z = -1.40, p = 0.160, r = -0.06.

Using the Mann Whitney test, the binary EQ-5D pain and discomfort scores in the intervention arm (median = 0) did not differ significantly from the control arm (median = 1) at baseline, U = 113,570, z = -1.80, p = 0.072, r = -0.06. By the 3 month follow-up assessment, the intervention arm (median = 0) still did not differ significantly from the control arm (median = 1), U = 82,949,z = -1.93, p = 0.054, r = -0.07.

# 4.4.9 Exploration of the degree of association between covariates

Before progressing to run the modelling analysis, the relationship between the covariates had to be explored. The contingency coefficient was used for the nominal variables and nominal versus ordinal variables and Gamma was used for the ordinal versus ordinal variables. The strength of association is given in a table in appendix 28. The only covariates found to have a strong association were the MMSE score and SST score. Multicollinearity was not detected. Because these two covariates were found to be closely associated, they could mask the effects of one another if both were entered into the model. To prevent diluting the effects of both of these covariates, one was therefore removed from each model. Of the two covariates, the one to remain in each model was the predictor variable with the strongest relationship to the dependent variable. The MMSE was found to have a closer association with the BI, RMI, and GDS than the SST; the SST had a closer association with the EQ-5D Pain and Discomfort as shown in table 38.

Covariate (as binary total score)	Strength of association with MMSE (binary total score)		Strength o associatio SST (bina score)	n with
	Gamma	P value	Gamma	P value
Barthel Index at Baseline	.566*	< 0.001	.508	< 0.001
Barthel Index at 3 months	.609*	< 0.001	.541	< 0.001
RMI at baseline	.427*	< 0.001	.330	< 0.001
RMI at 3 months	.463*	< 0.001	.390	< 0.001
GDS at baseline	.030*	0.769	003	0.977
GDS at 3 months	.164*	0.135	006	0.955
EQ5D Pain/Discomfort at baseline	113	0.163	194*	0.007
EQ5D Pain/Discomfort at 3 months	086	0.318	125*	0.108

Table 38: Strength of association of MMSE and SST with the dependent variables

\*Indicates which of the two covariates had the strongest association with the dependent variables.

# 4.4.10 Generalized Linear Modelling - Logistic regression

Prior to running the models for the health outcomes at 3 months

logistic regression models were first tested for the baseline health

outcome measures to confirm that there was no statistically

significant difference between the occupational therapy and control arms of the trial after controlling for all the covariates at baseline. The logistic regression models for BI at baseline (OR 1.4, CI 0.7 – 2.7 p=0.3), RMI at baseline (OR 1.4, CI 0.8 – 2.4 p=0.3), GDS at baseline (OR 0.8, CI 0.5 – 1.4 p=0.4), and EQ-5D Pain/Discomfort at baseline (OR 0.8, CI 0.6 – 1.3 p=0.4) confirmed that there was no statistically significant difference between the two groups prior to the intervention phase.

The logistic regression model for BI at 3 months (independent versus dependent) was repeated twice, first with BI score at baseline included as a predictor variable (table 39) and then again without the inclusion of BI at baseline in the model (table 40).

Barthel Index at 3 months ('Independent' score of <u>&gt;</u> 15)				
Predictor variable	OR	95% CI	P value	
Barthel Index at Baseline	104.0	30.5 - 354.5	<001**	
(Independent Vs Dependent)				
Age	1.4	0.5 - 4.0	0.569	
( <u>&gt;</u> 84 yrs Vs <84 yrs)				
Gender	2.1	0.6 - 7.3	0.265	
(Female Vs Male)				
Ethnicity	0.4	0.1 - 2.3	0.271	
(White Vs Other)				
Fall history	1.3	0.4 - 3.6	0.663	
(Falls Vs No falls)				
Stroke Eligibility	3.1	0.7 - 13.1	0.129	
(Confirmed Vs Suspected/TIA)				
OT v Control	2.9	1.0 - 9.0	0.060	
MMSE at baseline	2.9	1.0 - 8.6	0.045*	
(Normal Vs impaired cognition)				
Time post stroke	0.9	0.3 – 2.9	0.816	
(>1yr Vs <u>&lt;</u> 1yr)				
Type of care home	2.9	1.0 - 8.3	0.055	
(Residential Vs Nursing)				
Care home cluster size at baseline	0.5	0.2 - 1.8	0.311	
( <u>&gt;</u> 4 Vs <4)				

Table 39: Logistic regression mode	I for Binary Barthel Index at 3 months
------------------------------------	----------------------------------------

\*Significant at the 5% level \*\*Significant at the 1% level

Barthel Index at 3 months ('Independent' score of <u>&gt;</u> 15)				
Predictor variable	OR	95% CI	P value	
Age ( <u>&gt;</u> 84 yrs Vs <84 yrs)	1.1	0.5 – 2.2	0.872	
Gender (Female Vs Male)	1.2	0.5 – 2.7	0.725	
Ethnicity (White Vs Other)	0.7	0.2 - 2.9	0.594	
Fall history (Falls Vs No falls)	1.5	0.7 - 3.1	0.276	
Stroke Eligibility (Confirmed Vs Suspected/TIA)	1.0	0.4 - 2.5	0.996	
OT v Control	2.4	1.1 - 5.0	0.022*	
MMSE at baseline (Normal Vs impaired cognition)	3.5	1.7 – 7.2	0.001**	
Time post stroke (>1yr Vs <u>&lt;</u> 1yr)	0.9	0.4 - 2.2	0.880	
Type of care home (Residential Vs Nursing)	5.7	2.6 - 12.3	<0.001**	
Care home cluster size at baseline $(\geq 4 \text{ Vs } < 4)$	0.8	0.4 - 1.9	0.619	

#### Table 40: Logistic regression model for BI at 3 months with BI at baseline removed

\*Significant at the 5% level \*\*Significant at the 1% level

The first model (table 39) demonstrated that BI at baseline (independent versus control) was the biggest predictor of successful BI outcome at 3 months (OR 1.4.0 CI 30.5 – 354.5, p<0.001). MMSE status was also significant at the 5% level. BI at baseline was removed from the model in order to investigate what other factors could predict a successful BI at 3 months (table 40).

This revised model demonstrated that those in the OT arm of the trial were 2.4 times more likely to have a successful BI (independent) at 3 months than those in the control arm of the trial (OR 2.4 CI 1.7 – 7.2, p=0.022). Other strong predictors of a successful BI at 3 months were whether the resident was a nursing or residential home

resident (OR 5.7 CI 2.6 – 12.3, p = < 0.001) and cognitive status (MMSE category) at baseline (OR 3.5 CI 1.7 – 7.2, p = 0.001).

The logistic regression models for the remaining three health outcome measures (RMI, GDS, and EQ5D pain & discomfort) were ran with their own health outcome baseline variable included as a predictor variable (appendix 29) to confirm that for each outcome, the strongest predictor is its' equivalent variable at baseline. They were then run without the baseline outcome included as a predictor.

When RMI at baseline was removed from the RMI model (table 41) the strongest predictor of independent mobility was category of care home. Those in a residential home were 4.7 times more likely to have independent mobility at 3 months than those in a nursing home (OR 4.7 CI 2.5 – 9.0, p<0.001). Intervention arm (OT versus Control) was not a statistically significant predictor (OR 1.7, CI 0.9 – 3.1 p=0.103).

Rivermead Mobility Index at 3 months (`Better' mobility score of <u>&gt;7)</u>				
Predictor variable	ÓR	95% CI	P value	
Age	0.7	0.4 - 1.4	0.311	
<u>(&gt;</u> 84 yrs Vs <84 yrs)				
Gender	1.2	0.6 - 2.4	0.649	
(Female Vs Male)				
Ethnicity	1.0	0.3 – 3.9	0.994	
(White Vs Other)				
Fall history	1.4	0.8 – 2.7	0.252	
(Falls Vs No falls)				
Stroke Eligibility	0.9	0.4 - 2.1	0.885	
(Confirmed Vs Suspected/TIA)				
OT v Control	1.7	0.9 - 3.1	0.103	
MMSE at baseline	1.8	1.0 - 3.4	0.064	
(Normal Vs impaired cognition)				
Time post stroke	1.0	0.5 – 2.0	0.899	
(>1yr Vs <u>&lt;</u> 1yr)				
Type of care home	4.7	2.5 – 9.0	<0.001**	
(Residential Vs Nursing)				
Care home cluster size at baseline	0.9	0.4 - 1.9	0.806	
<u>(&gt;</u> 4 Vs <4)				
*Significant at the 5% level **Sig	gnificant a	t the 1% level		

# Table 41: Logistic regression model for RMI at 3 months with RMI at baseline removed

A logistic regression model for mood at 3 months as measured by the

GDS was created (table 42).

# Table 42: Logistic regression model for GDS at 3 months with GDS at baselineremoved

<b>OR</b> 0.4	95% CI	P value
0.4		
	0.2 - 0.7	0.003**
1.4	0.7 – 2.9	0.342
0.7	0.2 - 2.6	0.585
1.2	0.7 - 2.4	0.511
0.5	0.2 - 1.4	0.201
0.9	0.5 - 1.7	0.763
1.5	0.8 - 3.0	0.240
1.5	0.7 - 3.0	0.263
1.5	0.7 - 3.0	0.312
2.2	1.0 - 4.7	0.049*
	0.7 1.2 0.5 0.9 1.5 1.5 1.5 2.2	0.7 $0.2 - 2.6$ $1.2$ $0.7 - 2.4$ $0.5$ $0.2 - 1.4$ $0.9$ $0.5 - 1.7$ $1.5$ $0.8 - 3.0$ $1.5$ $0.7 - 3.0$

\*Significant at the 5% level \*\*Significant at the 1% level

Intervention arm (OT versus control) was not a significant predictor of mood at 3 months. The strongest predictor of normal mood at 3 month outcome was care home cluster size (OR 2.2 CI 1.0 – 4.7, p=0.049), in favour of care homes with 4 or more residents with stroke compared with those with less than 4 residents with stroke. Age was also significant (OR 0.4 CI 0.2 – 0.7, p=0.003).

For the model for pain and discomfort at 3 months as measured by the EQ5D pain and discomfort subsection (table 43), MMSE was removed from the predictor covariate mix but SST was included as SST was found to be more closely associated in the pre-modelling analysis. Gender was the strongest statistically significant predictor of pain and discomfort at 3 months (OR 0.5 CI 0.3 – 0.8, p=0.008).

EQ5D Pain and Discomfort at 3 months			
Predictor variable	(No pain) OR	95% CI	P value
Age ( <u>&gt;</u> 84 yrs Vs <84 yrs)	1.3	0.8 - 2.0	0.297
Gender (Female Vs Male)	0.5	0.3 - 0.8	0.008**
Ethnicity (White Vs Other)	0.8	0.3 - 2.1	0.702
Fall history (Falls Vs No falls)	0.9	0.6 - 1.4	0.513
Stroke Eligibility (Confirmed Vs Suspected/TIA)	0.6	0.3 - 1.1	0.105
OT v Control	0.8	0.5 - 1.2	0.234
SST at baseline (Normal Vs Impaired language)	0.8	0.5 - 1.3	0.361
Time post stroke (>1yr Vs <u>&lt;</u> 1yr)	1.2	0.7 – 2.0	0.552
Type of care home (Residential Vs Nursing)	1.2	0.7 – 2.0	0.509
Care home cluster size at baseline $(\geq 4 \text{ Vs } < 4)$	1.2	0.7 – 2.1	0.505

Table 43: Logistic regression model for EQ5D Pain & Discomfort at 3 months with	١
EQ5D Pain & Discomfort at baseline removed	

\*Significant at the 5% level \*\*Significant at the 1% level

Table 44 summarises the bivariate associations between occupational

therapy versus control and all the health outcome variables.

 Table 44: Bivariate associations between occupational therapy versus control and the dependent health outcome variables.

Occupational Therapy versus Control			
Health outcome	OR	95% CI	P value
BI at 3 months	2.4	1.1 - 5.0	0.022*
RMI at 3 months	1.7	0.9 - 3.1	0.103
GDS at 3 months	0.9	0.5 - 1.7	0.763
EQ5D pain/discomfort at 3 months	0.8	0.5 - 1.3	0.361

\*Significant at the 5% level \*\*Significant at the 1% level

Intervention arm (Occupational Therapy versus Control) was a statistically significant predictor variable for BI binary score at 3 month follow-up, controlling for all other predictor variables in the model. Intervention arm was not a significant predictor of outcome for the remaining three measures (RMI, GDS and EQ-5D pain/discomfort) at 3 months.

## 4.4.11 Generalized Estimating Equation (GEE) Modelling

Each participant was identified by linking them to their care home and site so that the model correctly identified each participant at each time point. The within subject variation was accounted for by the time variable (which was re-coded 0m and 3m from time 1, 2). An autoregressive working correlation matrix was then selected as it best fit the nature of the data between baseline and 3 months.

A generalised estimating equation (GEE) model was created for each of the four health outcome variables (BI, RMI, GDS, and EQ-5D

pain/discomfort). Another four models were then created with the

time variable included.

The GEE model for Binary BI with the time variable included as a

within subject repeated variable is given below in table 45.

Table 45: GEE model for Barthel Index with time (0m & 3m outcome) included as a within subject repeated variable

Barthel Index				
Predictor variable	OR	95% CI	P value	
Age	0.9	0.5 - 1.6	0.705	
Gender	1.1	0.5 - 2.1	0.840	
Ethnicity	0.7	0.2 - 2.0	0.480	
Fall history	1.3	0.7 – 2.5	0.346	
Stroke Eligibility	0.6	0.3 - 1.3	0.178	
OT v Control	1.7	0.9 - 3.2	0.086	
MMSE at baseline	3.1	1.7 - 5.8	<0.001**	
Time post stroke	1.0	0.5 - 2.1	0.999	
Residential v Nursing	7.0	3.6 - 13.7	<0.001**	
Care home cluster size at baseline	1.1	0.6 - 2.3	0.726	
*Cignificant at the E0/ lovel	*****	ificant at the 1	0/ 10/01	

\*Significant at the 5% level \*\*Significant at the 1% level

The strongest predictor of BI outcome was type of care home (nursing or residential). Participants in residential homes were 7 times more likely to have a positive binary BI outcome (independence in ADLs) than those in nursing homes (OR 7.0 CI 3.6 - 13.7,  $p < 0.001^{**}$ ). Binary MMSE score at baseline (cognitive impairment versus normal cognition) was also a strongly statistically significant predictor of positive outcome of binary BI score (OR 3.1 CI 1.7 - 5.8,  $p < 0.001^{**}$ ). The GEE model for RMI with the time variable included as a within subject repeated variable is given in table 46.

RMI				
Predictor variable	OR	95% CI	P value	
Age	0.8	0.5 - 1.4	0.383	
Gender	0.9	0.5 - 1.7	0.816	
Ethnicity	0.9	0.3 - 2.8	0.827	
Fall history	1.7	1.0 - 2.8	0.056	
Stroke Eligibility	0.7	0.3 - 1.3	0.223	
OT v Control	1.5	0.9 – 2.5	0.136	
MMSE at baseline	2.3	1.3 - 3.8	0.002**	
Time post stroke	0.9	0.5 - 1.6	0.691	
Residential v Nursing	5.6	3.3 - 9.7	<0.001**	
Care home cluster size at baseline	1.1	0.6 - 1.9	0.882	

Table 46: GEE model for RMI with time (	0m & 3m) included as a within subject
repeated variable	

\*Significant at the 5% level \*\*Significant at the 1% level

Intervention arm was not a significant predictor of positive mobility outcome. Type of care home was the strongest predictor with those in a residential home 5.6 times more likely to have independent mobility (OR 5.6 CI 3.3 – 9.7, p<0.001). Cognitive status at baseline was also a strong predictor of mobility status with those who had normal cognition (as determined by a MMSE score of 21 and above) 2.3 times more likely to have independent mobility than those with cognitive impairment (OR 2.3, CI 1.3 – 3.8, p=0.002).

The GEE model for GDS (table 47) found the strongest predictors of a positive `normal' mood outcome to be age (OR 0.5 CI 0.3 – 0.8, p=0.007) and care home cluster size (OR 1.8 CI 1.0 – 3.0, p=0.043).

GDS			
Predictor variable	OR	95% CI	P value
Age	0.5	0.3 - 0.8	0.007**
Gender	0.9	0.5 - 1.5	0.634
Ethnicity	0.7	0.2 - 1.8	0.424
Fall history	1.2	0.8 - 2.0	0.391
Stroke Eligibility	0.7	0.3 - 1.4	0.259
OT v Control	0.9	0.6 - 1.4	0.543
MMSE at baseline	1.3	0.8 - 2.1	0.360
Time post stroke	1.2	0.7 – 2.0	0.514
Residential v Nursing	0.9	0.6 - 1.6	0.793
Care home cluster size at baseline	1.8	1.0 - 3.0	0.043*

# Table 47: GEE model for GDS with time (0m & 3m) included as a within subject repeated variable

\*Significant at the 5% level \*\*Significant at the 1% level

Finally a GEE model was created for EQ-5D pain and discomfort (table 48). As with the logistic regression models, MMSE was removed from the model as a predictor variable and the SST variable was included as a predictor instead. The strongest predictor of pain and discomfort was gender with men more likely to experience pain than women (OR 0.6 CI 0.4 – 0.9 p=0.008). For every 6 women that experienced pain, there were 10 men also experiencing pain.

Table 48: GEE model for EQ-5D pain/discomfort with time (0m & 3m) in	ncluded as	a
within subject repeated variable		

EQ-5D pain/discomfort			
Predictor variable	OR	95% CI	P value
Age	1.1	0.7 - 1.5	0.803
Gender	0.6	0.4 - 0.9	0.008**
Ethnicity	1.4	0.7 - 2.6	0.326
Fall history	0.9	0.7 - 1.3	0.735
Stroke Eligibility	0.6	0.4 - 1.0	0.062
OT v Control	0.8	0.6 - 1.1	0.232
SST at baseline	0.7	0.5 - 1.0	0.065
Time post stroke	1.4	0.9 - 2.0	0.105
Residential v Nursing	1.2	0.8 - 1.8	0.301
Care home cluster size at baseline	1.1	0.7 - 1.7	0.691

\*Significant at the 5% level \*\*Significant at the 1% level

The GEE models were then repeated for the four health outcome dependent variables (BI, RMI, GDS, and EQ-5D pain/discomfort) but instead of including 'time' (0 months and 3 months) as a within

subject repeated variable, time was included as a repeated measure to see how time (between baseline and 3 month follow-up) impacted upon each health outcome adjusting for the other covariates. The model for Binary BI with the time variable included as a predictor is given below in table 49.

 Table 49: GEE model for BI outcome with time (0m & 3m) included as a predictor variable

Barthel Index					
Predictor variable	OR	95% CI	P value		
Age	0.9	0.5 - 1.6	0.700		
Gender	1.1	0.5 - 2.1	0.849		
Ethnicity	0.7	0.2 - 2.0	0.487		
Fall history	1.3	0.7 – 2.5	0.346		
Stroke Eligibility	0.6	0.3 - 1.3	0.175		
OT v Control	1.7	0.9 – 3.2	0.088		
MMSE at baseline	3.1	1.6 - 5.8	<0.001**		
Time post stroke	1.0	0.5 - 2.1	0.996		
Residential v Nursing	7.0	3.6 - 13.7	<0.001**		
Care home cluster size at baseline	1.1	0.6 - 2.3	0.722		
Time	1.0	0.7 - 1.3	0.885		
*Significant at the 5% lovel **Significant at the 1% lovel					

\*Significant at the 5% level \*\*Significant at the 1% level

By including time as a predictor variable it had no statistical effect on changing the predictive strength of the other covariates included in the model. The same was found for predictor variables for the remaining three health outcome models (RMI, GDS, and EQ-5D pain & discomfort) when time was included as a predictor variable. These models are included in appendix 30.

Four separate health outcome GEE models were then created for those participants in the occupational therapy intervention arm and another four were created for those in the control arm of the trial to explore the predictors of a successful outcome for those in the OT intervention arm and how those models varied from the control

models.

The GEE model for BI outcome for the occupational therapy arm of the trial is displayed in table 50.

Table 50: GEE model for BI outcome for the occupational therapy arm of the trial

Barthel Index for the OT arm only			
Predictor variable	OR	95% CI	P value
Age	0.9	0.4 - 2.1	0.834
Gender	0.5	0.2 - 1.2	0.112
Ethnicity	0.7	0.3 - 2.0	0.523
Fall history	1.4	0.6 - 3.2	0.419
Stroke Eligibility	0.7	0.3 - 1.8	0.414
MMSE at baseline	4.5	1.9 - 10.9	0.001**
Time post stroke	1.0	0.3 - 2.8	0.953
Residential v Nursing	8.7	3.6 - 20.8	<0.001**
Care home cluster size at baseline	0.7	0.3 - 1.8	0.484
Time	1.2	0.8 - 1.7	0.360

\*Significant at the 5% level \*\*Significant at the 1% level

The strongest predictors of BI outcome were the same for the OT arm of the trial as they were for the previous models including both intervention arms of the trial. However when the GEE model for BI outcome was created for the control arm of the trial (table 51), the strongest predictors were care home type (nursing home versus residential home), but MMSE status at baseline was not significant. Instead other strong predictors were ethnicity and gender.

Barthel Index outcome for the Control arm only			
Predictor variable	OR	95% CI	P value
Age	0.6	0.2 - 1.5	0.256
Gender	3.4	1.3 - 8.9	0.012*
Ethnicity	0.2	0.1 - 0.6	0.002**
Fall history	1.1	0.5 – 2.7	0.796
Stroke Eligibility	0.4	0.1 - 1.0	0.038*
MMSE at baseline	2.2	0.9 - 5.3	0.084
Time post stroke	0.8	0.3 - 2.1	0.686
Residential v Nursing	6.1	2.3 - 16.0	<0.001**
Care home cluster size at baseline	1.6	0.7 - 3.9	0.295
Time	0.8	0.5 - 1.2	0.278

#### Table 51: GEE model for the BI outcome for the control arm of the trial

\*Significant at the 5% level \*\*Significant at the 1% level

The GEE model for RMI outcome for the occupational therapy arm of

the trial is given in table 52.

Table 52: GEE model for RMI outcome for the occupational therapy arm of the trial

Rivermead Mobility Index for the OT arm only			
Predictor variable	OR	95% CI	P value
Age	0.9	0.5 - 2.0	0.871
Gender	0.6	0.3 - 1.3	0.191
Ethnicity	1.0	0.4 - 2.7	0.949
Fall history	1.7	0.8 - 3.4	0.158
Stroke Eligibility	0.6	0.3 - 1.3	0.169
MMSE at baseline	2.8	1.3 - 5.8	0.007*
Time post stroke	1.1	0.5 – 2.7	0.781
Residential v Nursing	5.3	2.4 - 11.7	<0.001**
Care home cluster size at baseline	0.6	0.3 - 1.3	0.212
Time	1.0	0.7 - 1.4	0.868

\*Significant at the 5% level \*\*Significant at the 1% level

Care home type was the strongest predictor (OR 5.3 CI 2.4 – 11.7, p < 0.001). This was also the case for the GEE model for RMI outcome for the control arm of the trial (table 53) and the previous GEE RMI model including both intervention arms of the trial (table 46).

Rivermead Mobility Index outcome for the Control arm only			
Predictor variable	OR	95% CI	P value
Age	0.6	0.3 - 1.2	0.149
Gender	1.5	0.7 - 3.5	0.305
Ethnicity	0.4	0.1 - 1.1	0.070
Fall history	1.6	0.7 - 3.3	0.258
Stroke Eligibility	0.6	0.2 - 1.6	0.298
MMSE at baseline	2.0	0.9 - 4.2	0.082
Time post stroke	0.6	0.3 - 1.4	0.279
Residential v Nursing	6.0	2.8 - 13.0	<0.001**
Care home cluster size at baseline	1.5	0.6 - 3.4	0.384
Time	0.7	0.5 - 1.1	0.088

#### Table 53: GEE model for the RMI outcome for the control arm of the trial

\*Significant at the 5% level \*\*Significant at the 1% level

GEE models for GDS outcome were created for the occupational

therapy arm of the trial (table 54) and the control arm of the trial

(table 55). The significant predictors for each model differed.

Geriatric Depression Scale outcome for the OT arm only				
Predictor variable	OR	95% CI	P value	
Age	0.6	0.3 - 1.2	0.147	
Gender	0.8	0.4 - 1.6	0.566	
Ethnicity	0.8	0.3 - 2.1	0.607	
Fall history	1.4	0.7 - 3.0	0.349	
Stroke Eligibility	0.7	0.3 - 1.7	0.433	
MMSE at baseline	0.9	0.5 - 1.8	0.770	
Time post stroke	1.2	0.6 - 2.4	0.669	
Residential v Nursing	0.8	0.4 - 1.7	0.597	
Care home cluster size at baseline	2.5	1.2 - 5.6	0.019*	
Time	0.8	0.5 - 1.3	0.412	

\*Significant at the 5% level \*\*Significant at the 1% level

#### Table 55: GEE model for the GDS outcome for the control arm of the trial

Geriatric Depression Scale outcome for the Control arm only				
Predictor variable	OR	95% CI	P value	
Age	0.5	0.2 - 0.9	0.015*	
Gender	1.1	0.6 - 2.2	0.710	
Ethnicity	0.9	0.3 - 2.3	0.780	
Fall history	1.2	0.6 - 2.2	0.599	
Stroke Eligibility	0.7	0.3 - 1.8	0.465	
MMSE at baseline	1.8	0.9 - 3.6	0.091	
Time post stroke	1.3	0.7 - 2.4	0.488	
Residential v Nursing	1.1	0.6 - 2.2	0.736	
Care home cluster size at baseline	1.4	0.7 - 2.8	0.363	
Time	0.8	0.5 - 1.2	0.240	

\*Significant at the 5% level \*\*Significant at the 1% level

Age was found to be a significant predictor in the earlier GEE model for GDS that had included both intervention arms of the trial (table 47) and was also significant for the control model but not the OT model.

In the case of the GEE models for the EQ-5D pain and discomfort outcome, the OT model that included both arms of the trial (table 48) had found gender to be the most significant predictor of pain and discomfort, as did the model (table 56) for the occupational therapy arm of the trial.

 Table 56: GEE model for the EQ5D pain/discomfort outcome for the occupational

 therapy arm of the trial

EQ5D Pain & Discomfort outcome for the OT arm only				
Predictor variable	OR	95% CI	P value	
Age	1.1	0.6 - 1.8	0.796	
Gender	0.5	0.3 - 0.8	0.010**	
Ethnicity	1.1	0.5 - 2.2	0.846	
Fall history	1.0	0.6 - 1.8	0.876	
Stroke Eligibility	0.6	0.3 - 1.2	0.135	
SST at baseline	1.1	0.7 - 1.9	0.619	
Time post stroke	1.4	0.8 - 2.4	0.270	
Nursing v Residential	1.3	0.7 - 2.4	0.349	
Care home cluster size at baseline	1.2	0.6 - 2.1	0.644	
Time	1.2	0.9 - 1.7	0.290	
		0.9 - 1.7	0.290	

\*Significant at the 5% level \*\*Significant at the 1% level

When the model was adjusted so that the dependent outcome of interest was the EQ-5D binary score for the control arm of the trial (table 57), gender became insignificant but language ability (as determined by the binary SST score at baseline) become a strong predictor, as did ethnicity.

EQ5D pain/discomfort outcome for the Control arm only				
Predictor variable	OR	95% CI	P value	
Age	1.0	0.6 - 1.7	0.881	
Gender	0.7	0.4 - 1.1	0.149	
Ethnicity	2.5	1.3 - 5.0	0.007**	
Fall history	0.9	0.5 - 1.4	0.572	
Stroke Eligibility	0.6	0.4 - 1.1	0.106	
SST at baseline	0.5	0.3 - 0.7	0.001**	
Time post stroke	1.4	0.8 - 2.3	0.234	
Nursing v Residential	1.2	0.7 - 1.8	0.564	
Care home cluster size at baseline	1.1	0.6 - 1.8	0.824	
Time	1.2	0.9 - 1.8	0.270	

# Table 57: GEE model for the EQ5D pain/discomfort outcome for the control arm of the trial

\*Significant at the 5% level \*\*Significant at the 1% level

#### 4.5 Discussion

# 4.5.1 Summary of the characteristics of the OTCH study sample population

This analysis was conducted on the OTCH trial data from a care home population with high levels of dependency, cognitive impairment and co-morbidities and as such matched the typical care home population commonly described in the literature, as having complex healthcare needs, reflecting multiple long-term conditions, significant disability and frailty (British Geriatrics Society, 2011, Quilliam and Lapane, 2001, Goodman et al., 2014). In terms of specific demographics the OTCH population was frail, elderly (average median age of 84 years) with co-morbidities present in 89% of residents. Just over two thirds had moderate to severe cognitive impairment and more than half had language impairment. Almost half of all participants were classed as having 'very severe' disability at baseline and only 2% were independent with basic ADLs. The average RMI score represented high levels of immobility. More than half of all participants had low

mood or depression. Just over half of all participants reported experiencing moderate or severe pain and discomfort at baseline. This description of the characteristics of the OTCH study population matched that of the sample populations used in two other large scale studies also conducted in care homes during the time of the OTCH trial. Namely those of the care home outcome study (CHOS); a longitudinal cohort study carried out across 11 Nottinghamshire care homes (Gordon et al., 2013a); and the HTA funded OPERA study (Underwood et al., 2013) that aimed to evaluate the impact of a `whole-home' intervention, consisting of training for residential and nursing home staff supplemented with a twice-weekly, physiotherapist-led exercise class on depressive symptoms in care home residents.

With regard to the stroke characteristics of the OTCH study sample, although date of stroke was unknown for just over half of participants, for those with a valid date, 91% had experienced their stroke more than six months ago and the average (median) number of years post stroke was three years. The implication of this finding being that the majority of participants were in the chronic stages of the condition and were likely to already have irreversible post-stroke complications such as established contractures and incontinence (Sackley et al., 2008a). Had the participants been in the more acute phase of stroke recovery and newly admitted to the care homes it

could be argued that the intervention would have been more likely to have succeeded in increasing mobility and independence in ADLs. There is a growing body of evidence in support of early and intensive interventions after stroke being associated with improved functional outcomes (Cumming et al., 2011, Kwakkel et al., 2004, Langhorne et al., 1996, Kwakkel et al., 1997). A systematic review and metaanalysis by Kwakkel et al (2004) found clinically relevant improvements in mobility (gait speed) and ADL when therapy was provided within the first six months after stroke.

#### 4.5.2 Summary of the main findings

This was a closely matched population with that reported in the pilot cluster-randomised controlled trial of occupational therapy for care home residents with stroke (Sackley et al., 2006) which resulted in a positive outcome. The number of residents who died by the three month follow-up phase was almost identical between the phase II pilot study (Sackley et al., 2006) and the definitive phase III OTCH trial with 11% and 12% respectively. However, in the definitive OTCH trial, of those who survived less than 1% of participants were independent in ADLs. More than half of all participants were classed as having very severe disability resulting in dependency in performing daily activities. Furthermore, the main trial analysis found no statistical or clinical differences between the groups (Sackley et al., 2015). In comparison, the intervention group in the phase II pilot

University of Nottingham

Chapter 4

trial had demonstrated a tendency for improvement between baseline and three months compared with the control group who showed a trend towards deterioration. The findings of the pilot study had suggested the possibility that even a relatively small amount of occupational therapy intervention might have a significant effect on the residents of a care home (Sackley et al., 2006). The neutral results from the definitive phase III OTCH trial, suggest this isn't the case.

Other recent therapy intervention trials in care home settings have had similar neutral results (Chin A Paw et al., 2006, Underwood et al., 2013). Chin A Paw et al (2006) reported that a six month intervention of moderate intensity exercise training neither enhanced habitual physical activity nor affected complaints of constipation among older people living in long-term care facilities. The OPERA study (Underwood et al., 2013) failed to show any statistically significant difference in any of the outcome measures.

#### 4.5.3 Summary of the sub group analysis findings

Although the OTCH study and other recent intervention trials in care homes have not been effective for the general care home population, it was considered possible that such interventions may have a positive outcome for certain subgroups of the care home population. This PhD analysis investigated the effect of occupational therapy on

various subgroups of the participant sample and determined that age, time since stroke, gender, cognitive status and depression status at baseline made no difference to improving independence in performing ADLs. However, level of disability at baseline did affect change in BI scores for those residents who received the occupational therapy intervention. In addition, those in the OT group experienced statistically significant differences in change scores depending on their level of mobility at baseline. This finding echoed the results of a study by Lui and MacKenzie (1999) which found that people with a higher baseline BI on admission showed more improvement than those with lower BI scores. Cognitive status, the presence of pain or discomfort, and mood at baseline made no difference to the distribution of change in BI scores but language ability did make a statistically significant difference for those in the occupational therapy arm of the trial.

Prior to the modelling analysis, the exploratory analysis compared the two intervention arms of the trial for all health outcomes in binary form and found no difference between groups for BI, RMI, GDS, or EQ-5D pain and discomfort. This finding was consistent with those from the main trial analysis, which compared the scaled versions of the measures rather than the binary form. This highlighted that there was no difference between groups regardless of whether the standard scaled version of the assessment scores were used or

whether they were converted to binary format to represent a more crude cut off of positive outcome versus negative outcome.

When the degree of association was explored between covariates, the only covariates found to have a strong association were the MMSE score and SST score. This can be explained because individuals with dementia commonly have language impairment as a symptom of the dementia (Tang-Wai and Graham, 2008).

# 4.5.4 Summary of findings from the modelling analysis

Logistic regression modelling demonstrated that for each health outcome model, its' baseline score was the strongest predictor of a positive outcome at 3 months. For the BI and RMI models, type of care home was consistently a statistically significant predictor. Type of care home may be considered a proxy for severity of disability as those in nursing homes require increased levels of care compared with residential home residents. This finding essentially showed a relationship between severity and poor outcome. Intervention arm was only a statistically significant predictor variable for the BI model.

There was some variation in the significant variables across all three GEE model types and also some clear consistencies. For the GEE models for BI and RMI including all participants and the same models for the OT arm only, care home type and MMSE score were the

University of Nottingham

Chapter 4

strongest predictors of positive outcome. The significant predictors for the four health outcome models that included the whole care home population were the same as for the four models for the occupational therapy arm. Type of care home was a significant predictor for all types of GEE model predicting BI and RMI outcome.

Logistic regressing and GEE modelling was applied to the OTCH study data to investigate whether this alternative method of data analysis could find a statistically significant difference between the two intervention arms of the trial. Using logistic regression for the primary outcome a positive effect was found for the OT arm of the trial, however on the whole there was no difference between the intervention groups. Type of care home and cognitive status was a far greater predictor of health outcome than intervention arm.

Across the whole OTCH trial care home population sample, care home residents became less independent, less mobile and more depressed by three month follow-up. However, people had less pain and discomfort. These results were the same across both intervention groups.

#### 4.5.5 Limitations of the study

Missing data prevented analysis with a full and complete dataset. For example a 'date of stroke' was missing from just over half of the

participants involved in the study. Missing data led to analysis with a smaller sample size than that recruited to the study. Whilst missing data is not uncommon in large clinical trials, in the case of the OTCH study it was largely due to the resident records in care homes being poorly completed and maintained.

Limitations of the main OTCH study have already been discussed in the study's main trial report (Sackley et al., 2015) and include an acknowledgement that the focus was on improving independence in self-care ADLs specifically. Therefore the effects of occupational therapy interventions targeted towards increasing participation (for example in leisure activities) are unknown. Furthermore, the primary outcome measure possibly did not capture all the benefits that residents may have gained from receiving occupational therapy interventions.

This PhD analysis could have been limited in that it was utilising a dataset that had already been collected as part of the protocol for a cluster randomised controlled trial. However the OTCH trial collected a vast amount of data allowing for further detailed analysis. All trials have missing data, and OTCH was no different. Data was largely missing due to care home records being poor in the amount of the residents' history that was recorded, such as the date of stroke and date of care home admission.

## 4.6 Conclusion

Sub group analysis determined that age, time since stroke, cognitive status, mood and pain made no difference to the effect of a three month occupational therapy intervention aimed at improving or maintaining independent performance in basic ADLs (as measured by the Barthel Index). However, for those in the occupational therapy arm of the trial, baseline disability level, mobility, and language ability did have a statistically significant affect on positive outcome.

Therefore the following null hypotheses were supported by the sub group analysis:

- Age does not affect how much improvement can be gained in self-care ADL independence;
- (2) Length of time since stroke does not affect how much improvement can be gained in self-care ADL independence;
- (3) Those with normal cognition do not show greater improvement in ADL independence following occupational therapy intervention;
- (4) Those with normal mood do not make greater improvements in ability to perform personal ADLs following occupational therapy intervention than those with low mood;
- (5) Those with pain and discomfort will be more independent in personal ADLs.

The remaining hypotheses regarding subgroups were supported for the occupational therapy arm of the trial:

- (1) Those with higher levels of independence at baseline show greater improvement in ADL ability as a result of occupational therapy intervention than those with high levels of dependency at baseline;
- (2) Those with higher levels of mobility show greater improvement in ADL independence as a result of occupational therapy intervention than those with immobility;
- (3) Those with normal language ability show greater improvement in ability to perform personal ADLs following occupational therapy intervention than those with aphasia.

Logistic regression modelling found intervention arm to be a significant predictor for successful BI outcome but detected no difference between the two intervention arms for all other health outcomes. Type of care home (residential or nursing) and cognitive status (dementia or normal cognition as measured by the MMSE) was a far greater predictor of ADL performance and mobility outcome than whether or not the resident had received the occupational therapy intervention.

Ability to perform self-care ADLs was more likely to deteriorate than remain the same. Stroke survivors in care homes were likely to become more dependent in activities of daily living over a period of three months regardless of whether occupational therapy intervention was received or not.

## **CHAPTER 5**

Analysis of the content of occupational therapy intervention delivered to the OTCH study participants and their performance in self-care activities of daily living

### **Chapter Overview**

This chapter will narrow its focus to the intervention arm of the OTCH trial in order to analyse the content of the occupational therapy intervention that was delivered during the trial and suggest possible reasons why the trial intervention was not effective in improving or maintaining the participants' performance in self-care ADLs.

### **5.1 Introduction**

The survey study reported in chapter three provided data on the content of usual occupational therapy practice within care homes. The intervention planned in the OTCH study protocol was to be targeted specifically towards improving and/or maintaining performance in self-care ADLs and mobility. The previous chapter concluded that the occupational therapy intervention delivered as part of the OTCH trial did not improve or maintain residents' ability to perform basic self-care ADLs and there was no statistically significant

difference across groups for any of the other health outcomes that were measured. The purpose of the analysis in this chapter was to examine the content of the intervention that was actually delivered and to explore whether the specific interventions were targeted appropriately towards the self-care ADLs that the resident needed to improve performance in and mobility.

The care home population with stroke is diverse and complex and it was possible that the outcome of occupational therapy for participants of the OTCH trial was not the same for all residents who received the intervention. This was because the specific treatments were individualized according to the participants' goal setting needs. As described in the introductory thesis chapter, care home residents differ across a spectrum in functional ability from those who are totally dependent and nursed in bed 24 hours a day, with no ability to swallow, incontinence, and aphasia (i.e. care home residents with nursing care), to those who are independently mobile and able to manage self-care activities independently but require help with domestic tasks such as meal preparation and laundry (i.e. care home residents without nursing care). It may therefore be useful to consider the prognostic indicators that may account for those people most likely to benefit from the provision of occupational therapy. Ultimately, prognosis is central to medicine and all diagnostic and therapeutic actions aim to improve a person's prognosis (Steyerberg

et al., 2010). Whilst it will never be possible to predict the outcome for any one individual, multivariable analysis can be used to provide information on the prognosis of a group of patients with a shared set of known prognostic indicators (Katz, 2006).

## 5.2 Aim

The aim of the OTCH study analysis reported in this chapter was to account for possible reasons why the trial produced neutral results by (1) exploring the content of the treatment that the intervention arm participants received from the study occupational therapists; and (2) investigating the performance of those participants who had received the allocated occupational therapy intervention, whilst accounting for possible predictor covariates (used in the previous chapter four modeling analysis).

The research questions for this study were:

- 1. What were the sub score items on the Barthel Index that participants showed most improvement in?
- 2. How did occupational therapists spend their time during the intervention?
- 3. Did the occupational therapists target their interventions appropriately according to the participants' activity limitations at baseline?

4. Was the content and duration of the occupational therapy interventions associated with a positive change in Barthel Index score at 3 month follow-up?

#### 5.3 Method

This study adopted a quantitative approach to analysing the content of the occupational therapy intervention that was delivered to the care home residents participating in the trial. A separate gualitative process evaluation was conducted alongside this PhD programme of work by another PhD student and member of the OTCH study team (Masterson-Algar et al., 2014). The intention was that the two approaches (quantitative and qualitative) adopted in these two PhD studies would complement each other and further add to the body of evidence derived from the OTCH study. The OTCH data set that was created in SPSS for the subgroup analysis and modeling work reported in the previous chapter was used for the analysis in this thesis chapter. The data file was split by intervention arm and only data for participants in the occupational therapy arm of the trial were included in the analysis. The reason for this being that the focus was no longer on comparing the two arms of the trial but on exploring the content of the intervention that was delivered and the correlation with change scores in sub scores on the Barthel Index. Thus the variables of particular interest were those related to the primary outcome measure data pre and post intervention for those

randomized to receive the occupational therapy intervention along with the data collected in the occupational therapy intervention logs. Variables were added to the dataset from the data collected in the occupational therapists' intervention logs. A copy of the intervention log is included as appendix 31. The sub scores of the BI were included in the analysis, excluding those for questions 9 and 10 on urinary and faecal continence, as aspects of toileting, such as transferring on and off the toilet or commode and managing garments and wiping, are self-care ADLs addressed as part of occupational therapy interventions but the issue of continence is not typically treated by an occupational therapist.

#### 5.3.1 Descriptive statistics

Descriptive statistics were used to report the participants' sub score data for the BI and also the content of the treatment sessions delivered by the occupational therapists to the participants in the intervention arm of the trial. Histograms for each variable were plotted to explore the distribution of the data. It was anticipated that the data may not be normally distributed and this would lead to the need to create binary cut offs for the predictor variables and health outcome variables as was the case in chapter 4. The treatment time binary cut off scores would be 0 minutes versus 1+ minutes; and the BI sub scores were transformed into the binary form: 0 = dependent, 1 = independent.

Analysis of the content and duration of occupational therapy interventions then led to the bivariate analysis between the total amount of occupational therapy intervention time and the BI score at baseline. This was followed by bivariate analysis between the total amount of occupational therapy intervention time and BI score at 3 month follow-up. Cross tabs were used to analyse the sub level data on BI components and the component variables for treatment time and number of sessions. Logistic regression was then used to analyse the binary data.

### 5.3.2 Selection of the method of regression

Multivariable regression can be used to model the relationship between a dependent variable (Y) and one or more explanatory variables (X). This was demonstrated in the previous chapter. Multivariable regression allows the researcher to ask the general question "what is the best predictor of...".

A regression model was designed for this study using the technique of multiple logistic regression. Multivariate regression (more than one variable or 'predictor') enables the effects of several independent variables to be considered on one dependent variable of interest simultaneously. This was important because the health outcome of interest could have been affected by more than one variable (e.g. age, the presence of co-morbidities, cognition, mobility, mood, and

Chapter 5

communication). In using a multivariate regression model, it was possible to determine which factors were the most important and which variable was statistically significant and strongly associated with the outcome (Plichta and Kelvin, 2012).

The type of multivariable regression used was dictated by the nature of the outcome variable, the dependent variable and the predictor variables. The outcome variables were dichotomous variables which are the simplest kind of categorical variable, with two discrete values (categories) (Katz, 2006). In simple linear regression the outcome variable must be a continuous scale variable and one predictor variable (either continuous or dichotomous) is used to model a linear relationship (Field, 2009). Multiple linear regression is a similar regression modelling technique but there may be several predictor variables as opposed to one alone. For linear regression to be a valid model, the assumption is that the observed data contain a relationship that is linear. When the outcome variable is categorical, the assumption of a linear relationship is violated (Berry, 1993). In the case of a regression analysis involving a categorical variable, logistic regression must be used rather than linear regression (Field, 2009), p265). When predicting membership of only two categorical outcomes, the analysis is referred to as 'binary logistic regression'. When the outcome includes more than two categories, multinomial (or polychotomous) logistic regression is used (Field, 2009), p271).

Chapter 5

In logistic regression, instead of predicting the value of a variable Y from a predictor variable  $X_1$  (or several predictor variables), the probability of Y occurring given known values of  $X_1$ , is predicted. The equation for simple linear regression can be extended for multiple linear regression, so too can the equation for logistic regression. In this study the outcome is binary thereby dictating that binary logistic regression was the most suitable method of regression analysis for use in this study.

When conducting multiple bivariate comparisons some statisticians recommend adjusting for multiple comparisons using a Bonferroni correction, which effectively "charges" for the number of comparisons performed by requiring a lower p value before concluding that a comparison is statistically significant (Katz, 2011). However, Rothman (1990) argues that there are major disadvantages to adjusting for multiple comparisons and that no adjustment is required. A Bonferroni correction was therefore not applied to the *p* value.

### 5.4 Results

### 5.4.1 Performance over time on sub scores of the Barthel Index

The occupational therapy group's performance of ADLs over time (from pre intervention to post intervention) was analysed according to category of change score ('improved', 'maintained', or

'deteriorated') for each of the 10 BI sub scores (table 58). Of the 10 ADL items measured by the BI, the one that had the highest percentage of participants show improvement in their performance was bed to chair transfers. 14.3% of participants improved their ability to transfer from bed to chair following the completion of the three month occupational therapy intervention. Bathing and/or showering was the item that showed the least amount of change with 95.2% of participants retaining the same score; neither improving nor deteriorating in their ability to perform the activity of bathing and/or showering. The BI item that showed the largest proportion of participant deterioration (23.3% of participants) was bowel continence. Across all 10 ADL sub items between 62.9% and 95.2% of participants maintained the same score between baseline and 3 month follow-up.

Change in BI sub score between baseline and 3 month follow-up		OT (N=568)
Question 1: Bathing/showering		(11-508)
Valid total score at both follow-up phases	n (%)	482 (84.9)
Improved score	n (%)	8 (1.7)
Maintained same	n (%)	459 (95.2)
Score Deteriorated	n (%)	15 (3.1)
Question 2: Stairs		
Valid total score at both follow-up phases	n (%)	482
Improved score	n (%)	35 (7.3)
Maintained same score	n (%)	389 (80.7)
Score Deteriorated	n (%)	58 (12.0)
Question 3: Dressing		
Valid total score at both follow-up phases	n (%)	482
Improved score	n (%)	45 (9.4)
Maintained same score	n (%)	378 (78.4)
Score Deteriorated	n (%)	59 (12.2)
Question 4: Indoor mobility		
Valid total score at both follow-up phases	n (%)	480
Improved score	n (%)	47 (9.8)
Maintained same score	n (%)	357 (74.4)
Score Deteriorated	n (%)	76 (15.8)
Question 5: Transfer bed to chair		
Valid total score at both follow-up phases	n (%)	481

<b>Table 58: Change in Barthe</b>	Index sub scores for th	ne OT intervention group
-----------------------------------	-------------------------	--------------------------

		1
Improved score	n (%)	69 (14.3)
Maintained same score	n (%)	312 (64.9)
Score Deteriorated	n (%)	100 (20.8)
Question 6: Feeding		
Valid total score at both follow-up phases	n (%)	480
Improved score	n (%)	64 (13.3)
Maintained same score	n (%)	330 (68.8)
Score Deteriorated	n (%)	86 (17.9)
Question 7: Toileting		
Valid total score at both follow-up phases	n (%)	480
Improved score	n (%)	36 (7.5)
Maintained same score	n (%)	377 (78.5)
Score Deteriorated	n (%)	67 (14.0)
Question 8: Wash face, brush teeth & I	nair	
Valid total score at both follow-up phases	n (%)	481
Improved score	n (%)	51 (10.6)
Maintained same score	n (%)	371 (77.1)
Score Deteriorated	n (%)	59 (12.3)
Question 9: Continence (urine)		
Valid total score at both follow-up phases	n (%)	481
Improved score	n (%)	51 (10.6)
Maintained same score	n (%)	336 (69.9)
Score Deteriorated	n (%)	94 (19.5)
Question 10: Continence (bowels)		
Valid total score at both follow-up phases	n (%)	480
Improved score	n (%)	66 (13.8)
Maintained same score	n (%)	302 (62.9)
Score Deteriorated	n (%)	112 (23.3)

## 5.4.2 Content and duration of occupational therapy intervention sessions

Of the 1,042 participants recruited and randomised, 568 participants

were allocated to receive the occupational therapy intervention. Of

these, 87.7% (n=498) received the allocated intervention. Table 59

reports the reasons that 70 of the participants in the treatment arm

of the trial did not receive the allocated intervention.

 Table 59: Reasons for participants not receiving the allocated occupational therapy intervention

Participants allocated to the OT intervention arm (N=568)		
Reasons for not receiving intervention: n (%)		
Withdrew from study before intervention phase	11 (1.9)	
Died prior to intervention phase	24 (4.2)	
Died during intervention phase	15 (2.6)	
Unknown reason/missing data	20 (3.6)	
Total	70 (12.3)	

The number of occupational therapy treatment sessions received by each participant in the intervention arm (table 60) ranged from 0 to 18 sessions. The median number of intervention sessions was 4.0 (IQR 2.0 to 6.0). The total number of occupational therapy intervention sessions delivered to the intervention arm during the trial was 2,539 interventions. The total time spent in delivering occupational therapy interventions was 103,641 minutes. This equated to a median time of 142.5 minutes (2.4 hours) (IQR 85.0 to 258.8 minutes) per participant.

		OT Group (N=568)
Participants who received intervention	n n(%)	498 (87.7)
Number of OT interventions:		
	Median (IQR)	4.0 (2.0-6.0)
	Range	0-18
	Total (N)	2,539
Intervention time:		
Total time in minutes per participant	Median (IQR)	142.5 (85.0-258.8)
	Range	0-1,380
Total t	ime in minutes	103,641

 Table 60: Occupational therapy intervention received

The content of the occupational therapy interventions delivered to trial participants in the intervention arm is given in table 61.

Content of treatment	:	OT Group (N=568)
Assessment	Median (IQR) time (mins) per resident	45.0 (30.0-60.0)
	Range	0-210
	Total time in minutes	23,733
	% of total treatment time	22.9%
Communication	Median (IQR) time (mins) per resident	65.0 (35.0-120-0)
	Range	0-935
	Total time in minutes	50,475
	% of total treatment time	48.7%
Cognition	Median (IQR) time (mins) per resident	0.0 (0.0-0.0)
_	Range	0-135
	Total time in minutes	900
	% of total treatment time	0.9%
Functional activities	Median (IQR) time (mins) per resident	0.0 (0.0-0.0)
	Range	0-275
	Total time in minutes	6,405
	% of total treatment time	6.2%
Transfers	Median (IQR) time (mins) per resident	0.0 (0.0-0.0)
	Range	0-325
	Total time in minutes	1,260
	% of total treatment time	1.2%
Mobility	Median (IQR) time (mins) per resident	0.0 (0.0-15.0)
-	Range	0-270
	Total time in minutes	7,006
	% of total treatment time	6.8%
Equipment	Median (IQR) time (mins) per resident	0.0 (0.0-20.0)
	Range	0-200
	Total time in minutes	7,666
	% of total treatment time	7.4%
Other	Median (IQR) time (mins) per resident	0.0 (0.0-0.0)
	Range	0-385
	Total time in minutes	6,196
	% of total treatment time	6.0%

#### Table 61: Content of occupational therapy intervention

The interventions delivered by the occupational therapist to each participant in the occupational therapy arm of the trial were recorded in an intervention log (appendix 31). The eight different types of interventions were listed as: assessment, communication, cognition, functional activities, transfers, mobility, equipment and 'other'. Of these types of intervention, the most time was spent in communication (with the resident, resident's carers, or family). A total of 50,475 minutes were spent in communication overall and time spent in communication per participant ranged from 0 (n=21) to

Mobility total time

'Other' total time

Equipment total time

935 minutes (n=1) with a mode time of 30 minutes of `communication' related intervention per participant. The least amount of time was spent in delivering occupational therapy interventions related to cognition. A total of 900 minutes was spent on cognition with the mode time in minutes being 0 minutes. A median time per participant of 45 minutes (IQR 30.0 to 60.0) was spent in assessment but for all the remaining types of interventions the median time per participant was 0 minutes.

Histograms for the treatment time and number of sessions variables revealed that the data was non-normally distributed (appendix 32), therefore the variables were converted to binary form for the next phase of analysis, whereby no time (0 minutes) = 0, one or more minutes = 1; and no treatment sessions = 0, one or more treatment sessions = 1 (table 62).

Covariate	1	`0' variable n (%)	`1' variable n (%)
Total treatment time (<142.	5mins v <u>&gt;</u> 142.5mins)	250 (50.0%)	250 (50.0%)
Total number of treatment sessi	ons (<4 v <u>&gt;</u> 4)	242 (42.6%)	326 (57.4%)
Assessment total time	(0 mins v >0 mins)	39 (7.8%)	459 (92.2%)
Communication total time	(0 mins v >0 mins)	21 (4.2%)	478 (95.8%)
Cognition total time	(0 mins v >0 mins)	476 (95.2%)	24 (4.8%)
Functional activities total time	(0 mins v >0 mins)	385 (77.0%)	115 (23.0%)
Transfers total time	(0 mins v >0 mins)	465 (93.0%)	35 (7.0%)

(0 mins v > 0 mins)

(0 mins v > 0 mins)

(0 mins v > 0 mins)

344 (68.8%)

301 (60.2%)

391 (78.2%)

156 (31.2%)

199 (39.8%)

109 (21.8%)

The frequency distribution of the binary BI sub scores at baseline (table 63) showed that for all items on the BI over half of all participants were in the dependent category.

Barthel Index at baseline	Dependent `0' variable n (%)	Independent `1' variable n (%)
Question 1: Bathing/showering	539 (95.4%)	26 (4.6%)
Question 2: Stairs	530 (93.8%)	35 (6.2%)
Question 3: Dressing	505 (89.4%)	60 (10.6%)
Question 4: Indoor mobility	441 (78.5%)	121 (21.5%)
Question 5: Transfer bed to chair	423 (75.0%)	141 (25.0%)
Question 6: Feeding	344 (61.0%)	220 (39.0%
Question 7: Toileting	459 (81.4%)	105 (18.6%)
Question 8: Wash face, brush teeth/hair	350 (62.1%)	214 (37.9%)

### Table 63: Frequencies and proportions of the distribution of the binary BI subscores at baseline

The analysis of the frequency distribution of binary BI sub scores at 3

month follow-up (table 64) showed that for all items on the BI, over

half of all participants were still in the dependent category.

Table 64: Frequencies and proportions of the distribution of the binary hea	alth
outcomes at 3 month follow-up	

Barthel Index at 3 months	Dependent `0' variable n (%)	Independent `1' variable n (%)
Question 1: Bathing/showering	466 (96.7%)	16 (3.3%)
Question 2: Stairs	458 (95.0%)	24 (5.0%)
Question 3: Dressing	430 (89.2%)	52 (10.8%)
Question 4: Indoor mobility	384 (79.7%)	98 (20.3%)
Question 5: Transfer bed to chair	370 (76.8%)	112 (23.2%)
Question 6: Feeding	297 (61.7%)	184 (38.3%)
Question 7: Toileting	393 (81.7%)	88 (18.3%)
Question 8: Wash face, brush teeth/hair	299 (62.0%)	183 (38.0%)

### 5.4.3 Strength of association between binary BI sub score items and time spent in different types of OT intervention (binary)

Bivariate analysis between specific BI sub scores at baseline and

three months and the treatment minutes in different occupational

therapy intervention types using Kendall's Tau B was used to assess

the significant strength of relationship between the covariates. The

full table showing all results is included in appendix 33. The results

of significance are included in table 65.

Barthel Index sub score item	Assessme nt phase	Specific OT treatment	Strength of association
	-		(Kendall's tau-b)
Q1: Bathing/Showering	Baseline	-	-
(Dependent or Independent)	3 month	Cognition	-0.044 <sup>a</sup> (p=.001)**
		Equipment	-0.087 <sup>a</sup> (p=.041)*
Q2: Stairs	Baseline	Cognition	-0.061 <sup>a</sup> (p<.001)**
(Dependent or Independent)		Equipment	-0.090 <sup>a</sup> (p=.031)*
	3 month	Functional	-0.082 <sup>a</sup> (p=.022)*
		activities	
		Equipment	-0.092 <sup>a</sup> (p=.034)*
Q3: Dressing	Baseline	Functional	-0.083 <sup>a</sup> (p=.029)*
(Dependent or Independent)		Mobility	0.127 <sup>a</sup> (p=.011)*
	3 month	Mobility	0.137 <sup>a</sup> (p=.008)*
Q4: Indoor Mobility	Baseline	Cognition	-0.070 <sup>a</sup> (p=.042)*
(Dependent or Independent)	3 month	Mobility	0.098 <sup>a</sup> (p=.046)*
Q5: Transfer bed to chair	Baseline	Functional	-0.088 <sup>a</sup> (p=.034)*
(Dependent or Independent)		activities	
	3 month	Assessment	-0.147 <sup>a</sup> (p=.012)*
		Functional	-0.087ª (p=.045)*
		activities	
		Mobility	0.116 <sup>a</sup> (p=.017)*
Q6: Feeding	Baseline	Mobility	0.095 <sup>a</sup> (p=.035)*
(Dependent or Independent)	3 month	Mobility	0.195 <sup>a</sup> (p<.001)**
Q7: Toileting	Baseline	Mobility	0.151 <sup>a</sup> (p=.002)**
(Dependent or Independent)	3 month	Mobility	0.166 <sup>a</sup> (p=.001)**
Q8: Wash face, brush	Baseline	Communicatio	0.087 <sup>a</sup> (p=.032)*
teeth/hair		n	
(Dependent or Independent)		Mobility	0.201 <sup>a</sup> (p<.001)**
		`Other `	0.091 <sup>a</sup> (p=.046)*
h h h	3 month	Mobility	0.259 <sup>a</sup> (p<.001)**

#### Table 65: Significant associations between the BI sub score covariates and the OT treatment covariates

<sup>a</sup>Weak association  $(\pm .10)$ \*Significant at the 5% level \*\*Significant at the 1% level

<sup>b</sup>Moderate association ( $\pm$ .30)

<sup>C</sup>Substantial association ( $\pm$ .50)

#### The association between the intervention 5.4.4 delivered by the occupational therapists and the primary outcome measure score at baseline

Generalised linear regression modelling using logistic regression was

used to investigate whether the amount of occupational therapy

intervention that was delivered to each participant was associated

with the score on the baseline primary outcome measures. Table 66

reports the logistic regression model for total occupational therapy

treatment (intervention) time versus baseline BI score, controlling for

the participant characteristic covariates.

Total treatment time					
Predictor variable	OR	95% CI	P value		
Total BI at baseline: 15+ (independent/mild)	0.5	0.2 - 1.3	0.139		
Age: 84 yrs and older	0.8	0.4 - 1.6	0.497		
Gender: female	1.3	0.6 - 2.7	0.501		
Ethnicity: white	1.1	0.3 - 3.7	0.927		
Fall history: 1 or more falls	1.0	0.5 – 2.1	0.914		
Stroke Eligibility: confirmed stroke	1.0	0.4 - 2.5	0.996		
MMSE score: 21+ at baseline (normal/mild)	2.1	1.0 - 4.3	0.058*		
Time post stroke: more than 1 yr	0.5	0.2 - 1.2	0.116		
Type of care home: Residential	0.8	0.4 - 1.8	0.595		
Care home cluster size: 4+	0.6	0.2 - 1.4	0.236		
Circle in the provided the second se					

Table 66: Logistic regression model for total treatment time versus total BI at
baseline controlling for the participant characteristic covariates

Significant at the 5% level \*\*Significant at the 1% level

Total BI at baseline was not a significant predictor of the total treatment time the participants received from the occupational therapists. However, cognitive status at baseline (the presence of dementia or not as determined by the MMSE) was a significant predictor of the amount of occupational therapy intervention received. Those with mild cognitive impairment or normal cognition were 2.1 times more likely to receive the median number of minutes or more in therapy time with the study occupational therapist than those participants classified as having moderate or severe cognitive impairment.

Table 67 reports the logistic regression model for total number of occupational therapy treatment (intervention) sessions versus baseline BI score, controlling for the participant characteristic covariates.

Total number of treatment sessions			
Predictor variable	OR	95% CI	P value
Total BI at baseline: 15+ (independent/mild)	0.5	0.2 - 1.2	0.122
Age: 84 yrs and older	0.7	0.3 - 1.3	0.239
Gender: female	0.6	0.3 - 1.2	0.146
Ethnicity: white	0.9	0.2 - 3.1	0.822
Fall history: 1 or more falls	1.0	0.5 - 1.9	0.889
Stroke Eligibility: confirmed stroke	2.4	1.0 - 5.8	0.046*
MMSE score: 21+ at baseline (normal/mild)	2.0	1.0 - 4.3	0.061*
Time post stroke: more than 1 yr	0.5	0.2 - 1.1	0.072
Type of care home: Residential	1.4	0.6 - 3.1	0.441
Care home cluster size: 4+	0.8	0.3 - 1.9	0.619

Table 67: Logistic regression model for total number of treatment sessions versus
total BI at baseline controlling for the participant characteristic covariates

\*Significant at the 5% level \*\*Significant at the 1% level

Total BI at baseline was not a significant predictor of the number of treatment sessions the participants received from the occupational therapists. Moreover, as with the model for treatment time, cognitive status at baseline (the presence of dementia or not as determined by the MMSE) was a significant predictor of the number of occupational therapy intervention visits received. Those with mild cognitive impairment or normal cognition were twice as likely to receive the median number of minutes or more in therapy time with the study occupational therapist than those participants classified as having moderate or severe cognitive impairment. In addition to cognitive status those who had a confirmed diagnosis of stroke were 2.4 times more likely to have four or more visits from the occupational therapist than those with a TIA or unconfirmed stroke.

# 5.4.5 The association between the primary outcome measure score at 3 months and the intervention delivered by the occupational therapists

Generalised linear regression modelling using logistic regression was used to investigate whether the three month primary outcome measure score was associated with the amount of intervention time

that had been received by each participant, controlling for the

participant characteristic covariates (table 68).

Table 68: Logistic regression model for total BI score at 3 months versus total OTintervention time controlling for the participant characteristic covariates

Total binary BI score at 3 months (independent/mild disability)			
Predictor variable	OR	95% CI	P value
Total intervention time: 142.5+ mins (>average)	0.8	0.3 - 2.1	0.637
Age: 84 yrs and older	1.1	0.4 - 3.0	0.858
Gender: female	0.7	0.2 - 1.9	0.437
Ethnicity: white	0.9	0.1 - 8.6	0.938
Fall history: 1 or more falls	1.3	0.5 - 3.4	0.612
Stroke Eligibility: confirmed stroke	0.9	0.3 – 2.9	0.840
MMSE at baseline: 21+ at baseline (normal/mild)	4.2	1.6 - 11.3	0.004**
Time post stroke: more than 1 yr	0.7	0.2 - 2.0	0.460
Type of care home: Residential	6.1	2.2 - 17.1	0.001**
Care home cluster size: 4+	0.6	0.2 - 1.7	0.301

\*Significant at the 5% level \*\*Significant at the 1% level

The amount of intervention time the therapists spent with residents was not a significant predictor of positive outcome. More therapy time did not predict improvement in binary BI score at three month follow-up. The strongest significant predictor of a positive BI score at three months was type of care home, with those in residential homes 6.1 times more likely to have a positive BI outcome than those in nursing homes. The other strongly significant predictor of a positive BI score at three months was cognitive status, with those residents with a baseline MMSE score of 21 or more being 4.2 times more likely to score 15 to 20 on the BI, than those classed as having moderate or severe cognitive impairment. A similar model was tested to investigate whether the three month

primary outcome measure score was associated with the number of

occupational therapy sessions received by each participant (table 69).

Table 69: Logistic regression model for total BI score at 3 months versus totalnumber of treatment sessions, controlling for participant characteristic covariates

Total binary BI score at 3 months (independent/mild disability)			
Predictor variable	OR	95% CI	P value
Total number of OT sessions: 4+ (>average)	0.6	0.2 - 1.6	0.264
Age: 84 yrs and older	1.2	0.5 - 3.2	0.715
Gender: female	0.6	0.2 - 1.7	0.322
Ethnicity: white	0.6	0.1 - 4.3	0.644
Fall history: 1 or more falls	1.4	0.5 - 3.8	0.480
Stroke eligibility: confirmed stroke	1.0	0.3 - 3.3	0.992
MMSE at baseline: 21+ at baseline (normal/mild)	4.7	1.8 - 12.7	0.002**
Time post stroke: more than 1 yr	0.6	0.2 - 1.9	0.402
Type of care home: Residential	6.8	2.4 - 19.0	< 0.001
			**
Care home cluster size: 4+	0.6	0.2 - 1.8	0.346
*Cignificant at the EV lovel **Cignificant at the 10/ lovel			

\*Significant at the 5% level \*\*Significant at the 1% level

Total number of intervention sessions was not a significant predictor of a positive BI outcome at three month follow-up. Type of care home and cognitive status were the only significant predictors of a positive three month outcome.

### 5.5 Discussion

### 5.5.1 Performance in activities of daily living (ADL) over time

Analysis of the Barthel Index (BI) sub scores for participants in the intervention arm of the OTCH trial revealed that of all ADL items measured by the BI, residents gained most improvement in bed to chair transfers. Participants showed most deterioration in bowel continence. Across all 10 BI items, around two thirds of participants maintained the same score between baseline and three months (neither improving nor deteriorating).

# 5.5.2 Frequency and intensity of the occupational therapy intervention delivered to residents on the OTCH trial

A randomised controlled programme evaluation conducted in Canada by Przybylski et al (1996) concluded that increasing the amount of therapy delivered can have a positive effect on the functional status and cost of care of long-term care residents. Within the intervention arm of the trial 12.3% of participants (n=70) allocated to receive occupational therapy intervention did not receive any treatment. This is in stark contrast with 4.8% (n=3) who should have received occupational therapy input but didn't in the Sackley et al (2006) pilot study. Over a three month period the maximum number of OT intervention visits received by the residents was 18, with residents on average receiving 4 visits from an occupational therapist. With the growing consensus that intensity of treatment affects outcomes (Kwakkel et al., 1997); the quantity of sessions delivered throughout the three month intervention phase was considered an important factor to explore. The results showed that on average the visits were fewer than once per week and only a little more than one per month. If increased treatment results in increased performance then amount of intervention could be a factor in the failure of the OTCH study to produce statistically significant findings. The previous Sackley et al (2006) pilot study found an improvement in the ADL performance of those residents who had received occupational therapy intervention. However, although the baseline characteristics of the participants

Chapter 5

from the previous pilot study were closely matched, the occupational therapy intervention received by the participants on the two studies was not comparative in terms of frequency and duration. Care home residents who participated in the pilot trial received on average 2.7 visits per month which equates to around 8.1 visits over the duration of the three month intervention period. This was twice the number of visits received by the participants in the definitive trial. In terms of total treatment duration over the course of the intervention period, the participants on the pilot trial received on average 13.5 hours of occupational therapy input each, compared with only 2.4 hours each for those participants on the definitive trial. This meant that the pilot trial participants had received just over five and a half times more occupational therapy input time than those on the subsequent definitive OTCH trial.

### 5.5.3 Content of the occupational therapy intervention delivered on the OTCH trial

The national survey study reported in chapter three, found the four most common occupational therapy interventions delivered in care homes to residents with stroke were related to seating and positioning; education and training; the provision of aids and equipment; and splinting. The practice of self-care activities, taskbased exercises, adaptations to the environment and cognitive rehabilitation were less common. In the OTCH study the interventions delivered by the trial occupational therapists were

Chapter 5

intended to be targeted towards the maintenance and/or improvement of independence in personal self-care activities of daily living and mobility. In the previous pilot trial, the intervention delivered by the study therapists had largely reflected this aim with 32% of their intervention time being spent on assessment and goal setting, 21% of time spent on mobility and 19% of their time focussed on functional activities including transfers. However, analysis of the intervention delivered during the definitive OTCH trial, revealed a discrepancy between the stated aim and objectives of the study and the intervention that was actually delivered. Almost half (48.7%) of the therapists' intervention time was spent in communication. These communication activities included direct communication with the resident and also discussions with the care home staff, residents' family members and other visitors and communication related to liaison and referral to other health and social care services and professionals. Besides talking with or about the resident, the occupational therapists also spent on average 45 minutes per resident engaged in the assessment of their abilities and difficulties related to functional performance. This equated to just under a guarter of the total intervention time. However, the assessment did not appear to lead to a targeted intervention as on average 0 minutes per participant were spent in any other form of treatment directly related to improving function in ADLs, mobility and transfers. The participants in the pilot study received twice as much

therapy time directed at improving performance in ADLs, mobility and transfers. This finding may account for the difference in the neutral outcome of the definitive OTCH study compared with the more positive results from the previous pilot randomised controlled trial of the same intervention.

### 5.5.4 Targeting of intervention according to activity limitation at baseline

The modelling analysis in this chapter sought to determine whether the intervention time and number of therapist visits was targeted according to the participants' functional status at baseline. This would show whether those residents with more severe levels of stroke-related disability (as determined by BI score) and therefore higher levels of dependency received more of the therapists' time than those residents who were more able. The results of the modelling analysis demonstrated that baseline BI status was not a significant predictor of the amount of occupational therapy time participants received. Although the resident's level of independence was not found to be associated with the amount of occupational therapy intervention time they received, their cognitive status (as determined by their MMSE score at baseline) was found to be a significant predictor of intervention time received. The presence of dementia was associated with less intervention time. Specifically, cognitive interventions received the least amount of time. Similarly, BI status at baseline was not a significant predictor of the number of

occupational therapy treatment sessions received; however stroke eligibility and MMSE status at baseline were statistically significant predictors.

### 5.5.5 The association between the intervention received and the change in functional outcome

Effective interventions targeted towards increasing independence in self-care ADLs should increase the chances of a positive outcome on relevant assessments of performance in ADLs. Moreover, it could be hypothesised that more intervention (frequency and duration) would lead to higher increases in performance. Logistic regression modelling investigated whether the outcome of the three month follow-up assessment was significantly associated with the amount and frequency of intervention received. Analysis revealed that the amount of occupational therapy intervention time received by the participants was not a statistically significant predictor of the BI outcome at three months. However, cognitive status (MMSE score) at baseline and type of care home were statistically significant predictors of three month BI outcome.

Moreover, the total number of intervention sessions was also not found to be a statistically significant predictor of BI score at three months but MMSE and care home type was in this model, suggesting that the focus of the occupational therapists' intervention time was strongly influenced by the residents cognitive status over and above

their level of functional performance in personal ADLs at baseline. However, it is also possible that the provision of therapy was influenced by the interests, knowledge, and skills of the therapists (Enderby, 2012).

### 5.5.6 Limitations of the study

This was a quantitative study and therefore it tells nothing of the fidelity of the occupational therapy intervention that was delivered by the different research therapists across the trial sites. Such qualitative data on the content and context of occupational therapy delivery was the focus of the PhD programme of research completed by Masterson-Algar (2014).

'Intensive therapy takes considerable commitment on the part of the therapist, patient, [care home staff] and family members and is not always achievable or acceptable' (Enderby, 2012). A limitation of this study, therefore, is that it does not explain or account for possible reasons why more intensive therapy was not achievable or acceptable to the resident. The residents may have been offered more occupational therapy input but declined participation or were too unwell to receive it. The study protocol permitted recruitment of participants by consultee in cases where individuals lacked the mental capacity to provide informed consent for themselves. These

participants may have been less accepting of the interventions that were then offered to them once they were recruited to the trial.

Ultimately, this analysis was hypothesis generating and the findings are the result of applying alternative data analysis techniques to those applied in the main OTCH study. Further research would be needed to test whether the models can be applied to other sample populations of care home survivors with stroke.

### 5.6 Conclusion

Overall, residents who received occupational therapy showed little improvement in their performance of personal ADLs. One possible explanation for this was an inadequate frequency and duration of therapy sessions. Moreover, the focus of therapy time was largely on communication and not directed at targeted interventions related to improving function in ADLs, mobility and transfers. It would appear that therapists did not allocate their time according to those with greater levels of baseline disability and higher levels of need. On the contrary, therapists' time was not directed by baseline assessment scores and those with dementia received less occupational therapy than those with mild cognitive impairment or normal cognition. Cognitive status was the strongest predictor of functional outcome.

### **CHAPTER 6**

### **Overall Summary**

### **Overview**

This chapter will summarise the key findings from this PhD programme of research, highlighting both the strengths and limitations of the work that was carried out. The implications for clinical practice, policy and future research will be discussed, prior to an overall concluding message being given on this new contribution to knowledge.

### 6.1 Summary of key findings

There is a significant volume of research evidence that demonstrates that early post-stroke rehabilitation and continuity of services post discharge maintains and improves functional outcomes and quality of life after stroke. However, less attention has been focused on research into the needs of those with stroke in care homes. This PhD programme of research focused specifically on the provision of occupational therapy for care home residents living with the consequences of stroke. The rationale for undertaking the Cochrane review (reported in chapter two), was to systematically critique and synthesize the literature in order to evaluate occupational therapy

interventions directed at reducing dependency in activities of daily living (ADL) for people with stroke residing in care homes. The intention was to provide a balanced overview of the efficacy of delivering occupational therapy to this specific group of stroke survivors. However, the search strategy resulted in too few trials for a meta-analysis to be possible. Only one small pilot randomised controlled trial met the criteria for inclusion, along with the much larger ongoing multi centre trial (the OTCH trial) that had not yet been published at the time the review was completed.

The Systematic review was therefore unable to draw a definitive conclusion as to the benefits of occupational therapy interventions for care home residents with stroke. Had it been possible to answer the question of whether occupational therapy was of benefit to this specific population, a review of randomised trials would still not have provided data on what actually happens in current routine practice across the UK. A national survey was therefore designed and implemented for this purpose.

Previous reports of those with stroke in care homes have described unmet needs, and suggested major problems in terms of provision of rehabilitation and therapist input (Cowman et al., 2010, Noone et al., 2001). The survey aimed to provide current national data on the provision of occupational therapy to care home residents across the

Chapter 6

UK. Important and insightful information was gathered through the survey from a total of 138 completed questionnaires. Of these, 114 represented data from occupational therapists who had worked within a care home setting during the past year. The survey findings confirmed the statement made in the Care Quality Commission's (2011b) report that national variations exist in the therapy service provision available to stroke survivors after discharge from hospital, in particular to those living in care homes. A key finding from the survey study was that for those stroke survivors in care homes receiving occupational therapy, the intervention is often time limited, rarely delivered by a stroke specialist and does not usually include evidence based treatments targeted towards increasing independence in personal ADLs. These survey findings echoed those reported by Cowman et al (2010) who reported that the rehabilitation and complex care needs of care home residents with stroke were not being addressed in a systematic manner.

Whilst targeted interventions aimed at increasing independence in ADL may be beneficial to some care home residents with stroke (Sackley et al., 2003, Sackley et al., 2004), the OTCH phase III cluster randomised controlled trial was unable to prove the efficacy of occupational therapy for the general care home population with stroke, as the study resulted in neutral findings (Sackley et al., 2015). Chapters four and five involved further exploration of the

OTCH trial data, including subgroup analysis, regression analysis and GEE modeling.

Sub group analysis in chapter four determined that age, time since stroke, cognitive status, mood and pain made no difference to the effect of the three month occupational therapy intervention on improving or maintaining independent performance in basic ADLs. However, for those in the occupational therapy arm of the trial, baseline disability level, mobility, and language ability *did* have a statistically significant affect on positive outcome.

Logistic regression modeling revealed that the type of care home (residential or nursing) and the resident's cognitive status (dementia or normal cognition as measured by the MMSE) was a far greater predictor of ADL performance and mobility outcome than whether or not the resident had received the occupational therapy intervention. Furthermore, regression modelling showed that this sample of stroke survivors in care homes became more dependent in ADLs over a period of three months regardless of whether or not they received the input of an occupational therapist. This finding suggests that it is more realistic to direct the focus of interventions towards maintenance of the resident's declining capabilities rather than aiming to "rehabilitate" or gain improvements in ADL performance and mobility.

Chapter 6

Chapter five analysed the content of the occupational therapy intervention that was delivered by the OTCH study therapists to the experimental arm of the trial. This data exploration revealed that the focus of therapy time was largely on communication and not directed at interventions directly related to improving function in ADLs, mobility and transfers. Therapists did not allocate their time according to those with the most need for intervention and the greatest levels of baseline disability. Participants with dementia and lower levels of cognition received less occupational therapy time than those without cognitive impairment and cognitive status was found to be the strongest predictor of functional outcome.

#### 6.2 Strengths of the PhD programme of research

A strength of this PhD programme of research is the multiple rigorous research methods that were employed to investigate the application of occupational therapy interventions for those with stroke residing in UK care homes. The Cochrane review sought to draw together relevant high quality research evidence from an international perspective that could be related to occupational therapy practice in UK care homes. This systematic review (Fletcher-Smith et al., 2013) was published by the Cochrane library which represents the gold standard in systematic reviews and meta-analysis. The review findings highlighted a clear lack of clinical trials in this area.

The survey study provided evidence for the content of current clinical practice in this setting. The sample represented occupational therapists from across the UK working with care home residents affected by stroke. It highlighted that current practice for this specific stroke population is not always systematic or evidence based. The survey study was published in the British Journal of Occupational Therapy with the intention of sparking further consideration and critical analysis of this specific area of occupational therapy practice.

Being a member of the OTCH study team allowed access to the raw data from the largest trial of occupational therapy in care homes to date and the fortunate ability to be able to probe the findings and apply different statistical techniques to generate further hypotheses. Whilst the sub group analysis and modelling work may be classed as "fishing the data", these two chapters demonstrated the application of complex statistical analysis to a large and complicated data set and provided further insights into the study sample population.

### 6.3 Limitations of the PhD programme of research

As is the case with most, if not all research studies, this PhD programme of research had a number of limitations. The generalisability of the survey study was limited to those occupational therapists that responded. As such it is not generalisable to the entire UK population of therapists working with care home residents

Chapter 6

with stroke. Probing of responses was not possible in the survey study and a follow-up in-depth interview study would be needed to add further context and clarity to the survey responses and key findings.

The OTCH analysis results presented in chapters four and five are also limited to a UK population only. The analysis was limited to the data that was generated as part of the main OTCH cluster randomised controlled trial. As such the variables under analysis were dictated by the data collected in the study protocol. This largely meant that the available dataset was related to the OTCH study's focus of occupational therapy being targeted specifically towards improving independence in self-care ADLs and mobility. However, according to the profession's guiding philosophy, holistic occupational therapy practice would also include consideration of productivity and leisure activities. This PhD programme of research did not address the possibility of targeting interventions towards increasing participation in extended ADLs such as leisure or recreational activities.

### 6.4 Clinical Implications for occupational therapy

At the time of completing and publishing the findings of the Cochrane systematic review the effectiveness of occupational therapy for care home residents with stroke remained unclear. The potential benefits

Chapter 6

of delivering occupational therapy interventions targeted at improving, restoring, and maintaining independence in ADL among stroke survivors residing in care homes was supported by the limited evidence from the reviewed single centre pilot RCT.

The findings of the national survey of current occupational therapy clinical practice in care homes revealed that the majority of occupational therapy provision is funded through the NHS. This means that occupational therapy services within care homes are largely subject to NHS commissioning decisions and are potentially at risk of being de-commissioned in areas with insufficient funding. The potential for de-commissioning is even more likely if there is insufficient evidence to support the efficacy of such an intervention for this specific population.

Whilst the national survey revealed disparity in the types of assessment and interventions delivered to care home residents with stroke, the survey confirmed the most common aim of occupational therapy was to increase or maintain the residents' participation and independence in activities of daily living. Whilst the survey suggested that on the whole occupational therapists were not using a systematic, evidenced based approach; the OTCH study analysis determined that occupational therapy targeted towards improving independence in self-care ADLS and mobility, although effective in

other own-home residing stroke populations, was not effective in the care home population with stroke.

### 6.5 Policy Implications

In light of the findings from this PhD programme of research the recommendation in the national clinical guidelines, that all care home residents with stroke 'should receive assessment and treatment from stroke rehabilitation services in the same way as patients living in their own homes' requires further consideration.

The care home population with stroke is a different more dependent population. As such, it cannot be compared with the general stroke population. This patient group presents with high levels of functional and cognitive impairment (Cowman et al., 2010). Policies should reflect the different needs of this severe stroke population. The logistic regression modelling analysis in chapter four found that ADL performance depended more on the type of care home (residential or nursing) and the cognitive status of the resident than whether or not they had received occupational therapy intervention. Ability to perform self-care ADLs was more likely to deteriorate than remain the same in this population of care home stroke survivors. The terminology used in stroke policy related to those in care homes therefore needs to take into account the low level of function and the likelihood of multiple co-morbidities including severe cognitive

Chapter 6

decline. Policy should consider 'maintenance' and prevention of deterioration alongside the realms of what 'rehabilitation' might be possible.

There is evidence that the organisation of acute and rehabilitation stroke services can have an important effect on patient outcome (Langhorne and Dennis, 1998). Attention needs to be given to the organisation and delivery of appropriate care and therapy services to those stroke survivors who are residing in care homes post stroke. Kumlien and Axelsson (2000) advise that good organisation and sufficient resources are required to improve the care provided in care homes. Care home residents with stroke have greater care and rehabilitation needs and therefore care home staff need to be equipped to care for such residents competently (Smith et al., 2008). The national survey study reported in chapter three highlighted that occupational therapy provision was often time-limited and that education and training of care home staff who provide much of the day-to-day care was an aspect of occupational therapy practice within care homes for a third of the occupational therapists surveyed. Respondents also commented that the success of certain interventions was dependent on the compliance of care home staff and that care home staff were not usually rehabilitation trained, thereby limiting the carryover of therapeutic interventions. In addition, respondents commented that care home staff do not always

Chapter 6

speak English as their first language and there was a high turnover of staff within care homes. With regards to staff training, a two year study in Glasgow that incorporated a survey of care home nurses (n=115) and senior care home assistants (n=19) from a stratified random selection of 25 care homes, found that 'care home staff need and want more stroke training' (Smith et al., 2008). The large proportion of care home residents with stroke and high dependency levels represents a considerable service and care requirement (Cowman et al., 2010). Whilst the latest edition of the Intercollegiate Stroke Working Party's (2012) National Clinical Guidelines make reference to those stroke survivors living in care homes, guidelines and standards for practice should go further by including recommendations on the stroke specialist knowledge and skills required by those working with this specific stroke population.

The Organization for Economic Co-Operation and Development (2013) reported the Worldwide problem of a lack of a regulatory body to monitor the labour supply of the care home workforce. The findings of chapter four give insights into the important skills needed by this workforce in order to care effectively for the care home population with stroke. Care home staff need the knowledge and skills to manage caring for older stroke survivors who have comorbidities, poor mobility, severe cognitive impairment,

communication difficulties, low mood and moderate to extreme pain or discomfort and who are likely to deteriorate further over time.

### 6.6 Implications for future research

Further research is needed to ascertain what, if any, targeted interventions can be of benefit to this complex care home population. Studies are needed to determine if specific populations within the general care home population with stroke may benefit from occupational therapy. The OTCH trial sample analysed in chapters four and five were on average living with the chronic stages of stroke (i.e. around two to three years post-stroke). Stroke patients discharged to care homes usually have a shorter mean length of stay (around 5.6 days) on an acute stroke unit ward before the decision to discharge is made, in comparison with those patients who go on to receive further rehabilitation (Kumlien et al., 1999). This means that the participants recruited to the OTCH trial were likely to have received little inpatient stroke unit rehabilitation prior to taking up residence in a care home. A further randomised controlled trial would be required to test whether a targeted occupational therapy intervention during the very early phase after stroke across the transition from hospital discharge to care home residence could have a positive effect.

Chapter 6

The main OTCH trial aimed to evaluate whether occupational therapy should be recommended as part of a routine package of care to all care home residents in the UK living with stroke-related disabilities (Sackley et al., 2015). Sackley et al (2015) found no evidence of benefit of a three month course of individualised occupational therapy, involving patient centred goal setting, staff education, and adaptation of the environment for care home residents with stroke. A fundamental difference between this definitive trial with neutral results and the more promising earlier pilot trial was the severity of disability at baseline. In the earlier phase II pilot trial the mean baseline BI score in the intervention arm was in the moderate range, compared with more than 70% of participants being graded as severe or very severe on the BI at baseline in the definitive OTCH trial (Sackley et al., 2015). Analysis of participant baseline characteristics in chapter four revealed that the majority of participants (>70%) had moderate to severe cognitive impairment. Such impairment may have limited the care home residents' capacity to actively engage in the occupational therapy assessment and intervention process. The results of the GEE modelling analysis in chapter five indicate that further research is needed to evaluate whether occupational therapy could be of benefit to care home residents if targeted to those in residential homes with only mild cognitive impairment. A crosssectional study, conducted annually in Austrian care homes with nursing input (Schuessler et al., 2015), has provided data from 3,577

residents to support the conclusion that residents with dementia have significantly higher degrees of care dependency than residents without dementia. Residents with dementia also have a significantly higher prevalence of urinary incontinence, faecal incontinence, double incontinence, and falls (Schuessler et al., 2015). In the Future research focussing specifically on the benefits of providing occupational therapy to those care home residents with stroke who do not have severe cognitive impairment (dementia) is therefore warranted.

The prevalence of severe stroke related disabilities and dementia in the care home population demands further attention in terms of future research into the most beneficial and cost effective interventions to manage this complex and vulnerable group of dependent and inactive elderly residents. It may be more realistic to focus future research interventions on maintenance and quality of life rather than aiming to improve independence in ADLs for this particular population of stroke survivors.

Moreover, additional research is required to evaluate the effects of targeting occupational therapy interventions towards improving participation in leisure and social activities within the care home setting for those with the potential physical and cognitive capacity to engage in such interventions.

#### 6.7 Overall conclusion

This PhD programme of research sought to evaluate and contribute to the body of evidence on occupational therapy for care home residents living with the effects of stroke. The potential of occupational therapy for improving independence in ADLs for this particular client group was explored using a range of research methods.

There have been to date, a lack of high quality RCTS outside of the OTCH research group. Further robust studies in this area are therefore warranted. Despite the lack of evidence in support of occupational therapy provision to this particular client group, some occupational therapists are delivering interventions to UK care home residents with a history of stroke. However therapy provision is neither systematic nor evidence-based.

Subgroup analysis and modelling of the data from the largest trial of occupational therapy for care home residents with stroke to date revealed that type of care home (a proxy for level of disability and dependency) and cognitive status were far greater predictors of ADL performance and mobility outcome than whether or not participants received occupational therapy intervention. Overall, residents who received occupational therapy showed little improvement in their performance of personal ADLS or mobility. Cognitive status was the strongest predictor of functional performance.

Chapter 6

This suggests a need to test whether provision of occupational therapy targeted towards improving independence in ADLs should be restricted to those care home residents with stroke related disabilities who more closely resemble the stroke survivor population living in their own homes in the community. Care home residents with stroke deteriorated in functional ability over a period of three months regardless of whether or not they received occupational therapy. For those residents with severe cognitive impairment, it may therefore be more appropriate to consider alternative aims of occupational therapy intervention, such as maintenance of current abilities and comfort, prevention of deterioration, and promoting social participation within the care home environment and quality of life. The traditional ideals of rehabilitation to promote functional improvement may be asking too much of this dependent elderly, frail, immobile population with stroke related disabilities, co-morbidities, significant cognitive impairment and low mood.

#### References

1834. The Poor Law Amendment Act. England and Wales.

Altman, D. G. & Bland, J. M. 1996. Detecting skewness from summary information. *British Medical Journal*, 313, 1200.

Andersen, K. K., Andersen, Z. J. & Olsen, T. S. 2011. Predictors of Early and Late Case-Fatality in a Nationwide Danish Study of 26,818 patients with First-Ever Ischemic Stroke. *Stroke*, 42, 2806-12.

Babbie, E. 1990. *Survey research methods,* Belmont, CA, Wadsworth Publishing Company.

Bajekal, M. 2002. Health Survey for England 2000. *Care homes and their residents.* London.

Ballard, C., O'Brien, J. & James, I. 2001. Quality of life for people with dementia living in residential and nursing home care: the impact of performance on activities of daily living, behavioral and psychological symptoms, language skills, and psychotropic drugs. *International Psychogeriatrics*, 13, 93-106.

Barodawala, S., Kesavan, S. & Young, J. 2001. A survey of physiotherapy and occupational therapy provision in UK nursing homes. *Clinical Rehabilitation*, 15, 607-10.

Barrett, J. A., Watkins, C., Plant, R., Dickinson, H., Clayton, L., Sharma, A. K. & et al 2001. The COSTAR wheelchair study: a two-centre pilot study of self-propulsion in a wheelchair in early stroke rehabilitation. *Clinical Rehabilitation*, 15, 32-41.

Baum, C. 1995. The contribution of occupation to function in persons with Alzheimer's disease. *Journal of Occupational Science: Australia*, 2, 59-67. Bebbington, A., Darton, R. & Netten, A. 2001. Care Homes for Older People: Admissions, needs and outcomes. Canterbury: PSSRU.

Berg, K., Sherwood, S., Murphy, K., Carpenter, G. I., Gilgen, R. & Phillips, C. D. 1997. Rehabilitation in nursing homes: a cross-national comparison of recipients. *Age & Ageing*, 26, 37-42.

Berry, W. D. 1993. *Understanding regression assumptions,* Newbury Park, CA, Sage.

Bobath, B. 1990. Adult Hemiplegia: Evaluation and treatment. 3rd ed. London: Heinemann Medical Books.

Bobath Centre. 2013. *Introductory Bobath Courses* [Online]. Available: <u>www.bobath.org.uk/index.php/education-and-training/introductory-</u> <u>courses/</u>.

Boter, H., de Haan, R. J. & Rinkel, G. J. 2003. Clinimetric evaluation of a Satisfaction-With-Stroke-Care questionnaire. *Neurology*, 250, 534-41. Bowman, C., Ellerby, M. & Whistler, J. 2004. A national census of care home residents. *Age and Ageing*, 33, 561-566.

Braun, J. A. 2002. Commentary on the quality improvement case study. *Journal of the American Medical Directors Association*, 3, 97-100.

Braun, S. M., Beurskens, A. J., Kleymen, M., Oudelaar, B., Schols, J. M. & Wade, D. T. 2012. A multicenter randomized controlled trial to compare subacute 'treatment as usual' with and without mental practice among persons with stroke in Dutch nursing homes. *Journal of the American Medical Directors Association*, 13, 85.

Braun, V. & Clarke, V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.

British Geriatrics Society 2011. Quest for quality *An inquiry into the quality of healthcare support for older people in care homes: a call for leadership, partnership and quality improvement.* London.

British Geriatrics Society 2012. Failing the Frail: A Chaotic Approach to Commissioning Healthcare Services for Care Homes. London.

British Geriatrics Society Scotland and Royal College of General Practitioners Scotland 2009. Frailty, Older People and Care Homes, Can we do better?: Improving what we do?

Brittle, N., Patel, S., Wright, C., Baral, S., Versfeld, P. & Sackley, C. 2009. An exploratory cluster randomized controlled trial of group exercise on mobility and depression in care home residents. *Clinical Rehabilitation*, 23, 146-54.

Brott, T., Adams Jr, H. P., Olinger, C. P., Marler, J. R., Barsan, W. G., Biller, J., Spilker, J., Holleran, R., Eberle, R. & Hertzberg, V. 1989. Measurement of acute cerebral infarction: A clinical examination scale. *Stroke*, 20, 864-70.

Bryman, A. 2008. *Social Research Methods,* Oxford, UK, Oxford University Press.

Canadian Association of Occupational Therapists. 2013. *Occupational Therapy - Definition* [Online].

http://www.caot.ca/default.asp?pageid=1344: Canadian Association of Occupational Therapists. [Accessed 31st July 2014].

Caplan, A. L., Callahan, D. & Haas, J. 1987. Ethical and policy issues in rehabilitation medicine, Hastings Center Report. Briarcliff Manor (NY): Hastings Center.

Care Quality Commission 2009. Guidance about compliance: Essential standards of quality and safety. London.

Care Quality Commission 2010. Essential standards of quality and safety. London.

Care Quality Commission. 2011a. *About us care homes* [Online]. <u>http://www.cqc.org.uk/public/about-us#carehomes</u>. [Accessed 13/06/2014.

Care Quality Commission 2011b. Supporting life after stroke: A review of services for people who have had a stroke and their carers. London.

Carter, L. T., Howard, B. E. & O'Neil, W. A. 1983. Effectiveness of cognitive skill remediation in acute stroke patients. *American Journal of Occupational Therapy*, 37, 320-6.

Challis, D. 2000. Dependency in older people recently admitted to care homes. *Age and Ageing*, 29, 255-60.

Chin A Paw, M., van Poppel, M. N. M. & van Mechelen, W. 2006. Effects of resistence and functional-skills training on habitual activity and constipation among older adults living in long-term care facilities: a randomized controlled trial. *BMC Geriatrics*, 6, 1-9.

Cochrane Collaboration. 2012. *The Cochrane Collaboration: Cochrane Reviews [online]* [Online]. Freiburg, Germany. Available:

http://www.cochrane.org/cochrane-reviews [Accessed 12/02/2013.

Cohen, J. 1988. *Statistical power analysis for the behavioural sciences,* Hillsdale, New Jersey, Erlbaum. Cohen-Mansfield, J., Marx, M. & Werner, P. 1992. Observational data on time use and behaviour problems in the nursing home. *Journal of Applied Gerontology*, 11, 111-21.

College of Occupational Therapists 2007. *Activity Provision: Benchmarking good practice in care homes,* London, College of Occupational Therapists. College of Occupational Therapists & Chartered Society of Physiotherapists 2014. Splinting for the prevention and correction of contractures in adults with neurological dysfunction: Practice guideline for occupational therapists and physiotherapists (draft). London.

Collen, F. M., Wade, D. T., Robb, G. F. & Bradshaw, C. M. 1991. The Rivermead Mobility Index: a further development of the Rivermead Motor Assessment. *International Disability Studies*, 13, 50-4.

Corr, S. & Bayer, A. 1995. Occupational therapy for stroke patients after hospital discharge: a randomized controlled trial. *Clinical Rehabilitation*, 9, 291-6.

Cowman, S., Royston, M., Hickey, A., Horgan, F., McGee, H. & O'Neill, D. 2010. Stroke and nursing home care: a national survey of nursing homes. *BMC geriatrics*, 10, 4.

Creswell, J. W. 2009. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches,* California, Sage.

Cumming, T. B., Thrift, A. G., Collier, J. M., Churilov, L., Dewey, H. M., Donnan, G. A. & Bernhardt, J. 2011. Very early mobilization after stroke fast-tracks return to walking: further results from the phase II AVERT randomized controlled trial. *Stroke*, 42, 153-8.

Department for Communities and Local Government 2014. NHS Funding in Care Homes. *Factsheet 4.* London: First Stop.

Department of Health 1990. NHS and Community Care Act 1990. *In:* Health, D. o. (ed.). London: HMSO.

Department of Health 2003. Care homes for older people: national minimum standards and the Care Homes Regulations: third edition (revised). *In:* Health, D. o. (ed.). London: The Stationery Office.

Department of Health 2007. National Stroke strategy. *In:* Health, D. o. (ed.). London: DH.

Department of Health 2008. Health and Social Care Act 2008. London: Her Majesty's Stationery Office.

Department of Health 2009. Living well with dementia: A National Dementia Strategy. *In:* Health, D. o. (ed.). London: Department of Health.

Department of Health 2010. Transforming Community Services: Allied Health Professional Referral to Treatment Guide. London: The Stationery Office.

DiGiovanna, E. 2005. Myofascial (soft tissue) Techniques. *In:* Stanley, S. & J, D. D. (eds.) *An Osteopathic Approach to Diagnosis and Treatment.* Third ed. Philadelphia, PA: Lippincott Williams & Wilkins.

DiGiovanna, E., Schiowitz, S. & Dowling, D. J. 2005. *Myofascial Techniques: An Osteopathic Approach to Diagnosis and Treatment,* Philadelphia, Lippincott Williams & Wilkins.

Divine, G. W., Brown, J. T. & Frazier, L. M. 1992. The unit of analysis error in studies about physicians' patient care behaviour. *Journal of General Internal Medicine*, 7, 623-9.

Donner, A. & Klar, N. 2002. Issues in the meta-analysis of cluster randomized trials. *Statistics in Medicine*, 21, 2971-80.

Drummond, A., Whitehead, P., Fellows, K., Edwards, C. & Sprigg, N. 2012. Occupational therapy pre discharge home visits for patients with a stroke: what is national practice? *British Journal of Occupational Therapy*, 75, 396-402.

Duncan, P. 1997. Synthesis of intervention trials to improve motor recovery following stroke. *Topics in stroke rehabilitation*, 3, 1-20.

Edmans, J. A. & Webster, J. 1997. The Edmans ADL Index: validity and reliability. *Disability Rehabilitation*, 19, 465-76.

Egan, M., Kessler, D., Laporte, L., Metcalfe, V. & Carter, M. 2007. A pilot randomized controlled trial of community-based occupational therapy in late stroke rehabilitation. *Topics in Stroke Rehabilitation*, 14, 37-45.

Elbourne, D., Altman, D. G., Higgins, J. P. T., Curtina, F., Worthington, H. V. & Vaile, A. 2002. A meta-analysis involving cross-over trials:

methodological issues. *International Journal of Epidemiology*, 31, 140-9. Enderby, P. 2012. How much therapy is enough? The impossible question! *International Journal of Speech-Language Pathology*, 14, 432-7. European Commission 2008. Long-term care in the European Union.

Luxembourg.

EuroQol Group 1990. EuroQol - a new facility for the measurement of health-related quality of life. *Health Policy*, 16, 199-208.

Feys, H. M., De Weerdt, W. J., Selz, B. E., Cox-Steck, G. A., Spichiger, R. & Vereeck, L. E. 1998. Effect of a therapeutic intervention for the hemiplegic upper limb in the acute phase of stroke. *Stroke*, 29, 785-92.

Field, A. 2009. *Discovering Statistics Using SPSS*, London, Sage.

Fletcher-Smith, J., Drummond, A., Sackley, C., Moody, A. & Walker, M. 2014. Occupational therapy for care home residents with stroke: what is routine national practice? *British Journal of Occupational Therapy*, 77, 265-73.

Fletcher-Smith, J. C., Walker, M. F., Cobley, C. S., Steultjens, E. M. J. & Sackley, C. M. 2013. Occupational therapy for care home residents with stroke. *Cochrane Database of Systematic Reviews*.

Folstein, M. F., Folstein, S. E. & McHugh, P. R. 1975. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189-98.

Forster, A., Lambley, R., Hardy, J., Young, J., Smith, J., Green, J. & Burns, E. 2009a. Rehabilitation for older people in long-term care. *Cochrane Database of Systematic Reviews*.

Forster, A., Lambley, R., Hardy, J., Young, J., Smith, J., Green, J. & Burns, E. 2009b. Rehabilitation for older people in long-term care. *Cochrane database of systematic reviews (Online)*, CD004294.

Frandin, K., Borell, L., Gronstedt, H., Bergland, A., Helbostad, J. L., Puggaard, L., Andresen, M., Granbo, R. & Hellstrom, K. 2009. A Nordic multi-center study on physical and daily activities for residents in nursing home settings: design of a randomized, controlled trial. *Aging Clinical and Experimental Research*, 21, 314-322.

Fratiglioni, L., Winblad, B. & Struass, E. 2007. Prevention of Alzheimer's disease and dementia: major findings from the Kungsholmen project. *Physiology and Behaviour*, 92, 98-104.

Froggatt, K. 2004. *Palliative Care in Care Homes for Older People,* London, The National Council for Palliative Care.

Ghisletta, P. & Spini, D. 2004. An introduction to generalized estimating equations and an application to assess selectivity effects in a longitudinal

study on very old individuals. *Journal of Educational and Behavioural Statistics*, 29, 421-37.

Gladman, J., Albazzaz, M. & Barer, D. 1991. A survey of survivors of acute stroke discharged from hospital to private nursing homes in Nottingham. *Health Trends*, 23, 158-60.

Gliner, J. A., Morgan, G. A. & Harmon, R. J. 2002. Basic associational designs: analysis and interpretation. *Journal of the American Academy of Child and Adolescent Psychiatry*, 41, 1256-8.

Golding, E. 1989. Middlesex Elderly Assessment of Mental State. Bury St Edmunds: Thames Valley Test Company.

Goodman, C., Gordon, A. L., Martin, F., Iliffe, S., Bowman, C., Schneider, J., Meyer, J., Victor, C., Gage, H., Gladman, J. R. F. & Dening, T. 2014. Effective health care for older people resident

in care homes: the optimal study protocol for

realist review. Systematic Reviews, 3, 49.

Gordon, A. L., Franklin, M., Bradshaw, L., Logan, P., Elliott, R. & Gladman, J. R. 2013a. Health status of UK care home residents: a cohort study. *Age and Ageing Advance Access*, 0, 1-6.

Gordon, A. L., Franklin, M., Bradshaw, L., Logan, p., Elliott, R. & Gladman, J. R. 2013b. Health status of UK care home residents: a cohort study. *Age and Ageing Advance Access*, 0, 1-6.

Graham, J. V., EustaCE, c., Brock, k., Swain, E. & Irwin-Carruthers, S. 2009. The Bobath concept in contemporary clinical practice. *Topics in Stroke Rehabilitation*, 16, 57-68.

Hanson, J., Kellaher, L., Rowlands, M., Percival, J., Marcoux, J. & Zako, R. 2003. Profiling the Housing Stock for Older People from Domesticity to Caring. <<u>http://www.bartlett.ucl.ac.uk/research/space/housingfutures/2-EQUAL/UCL\_EQUAL.pdf></u>.

Hatano, S. 1976. Experience from a multicentre stroke register: a preliminary report. *Bulletin of the World Health Organisation*, 54, 541-553. Health and Care Professions Council. 2012. *About Registration: Professions* [Online]. <u>http://www.hcpc-</u>

<u>uk.org.uk/aboutregistration/professions/index.asp?id=6</u>. Available: <u>http://www.hcpc-uk.org.uk/aboutregistration/professions/index.asp?id=6</u> 2012].

Help the Aged 2006. Quality of life in care homes. London.

Help the Aged 2007. My Home Life: quality of life in care homes - a review of the literature. London.

Higgins, J. P. T. & Green, S. 2011. Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0. The Cochrane Collaboration, Available from <u>www.cochrane-handbook.org</u>.

Hoek, J. F., Ribbe, M. W., Hertogh, C. M. P. M. & Vleuten, C. P. M. 2003. The role of the specialist physician in nursing homes: the Netherlands' experience. *International Journal of Geriatric Psychiatry*, 18, 244-9. Hoppitt, T., Sackley, C. & Wright, C. 2009. Finding the right outcome

measures for care home research. *Age and Ageing*, 39, 119-22.

Hsieh, Y. W., Wang, C. H., Wu, S. C., Chen, P. C., Sheu, C. F. & Hsieh, C. L. 2007. Establishing the minimal clinically important difference of the Barthel Index in stroke patients. *Neurorehabilitation Neural Repair*, 21, 233-8. Hubbard, A. E., Ahern, J., Fleischer, N. L., van der Laan, M., Lippman, S. A., Jewell, N., Bruckner, T. & Satariano, W. A. 2010. To GEE or not to GEE: comparing population average and mixed models for estimating the associations between neighbourhood risk factors and health. *Epidemiology*, 21, 467-74.

Huijben-Schoenmakers, M., Gamel, C. & Hafsteinsdottir, T. B. 2009. Filling up the hours: how do stroke patients on a rehabilitation nursing home spend the day? *Clinical Rehabilitation*, 23, 1145-1150.

IBM Corp 2010. IBM SPSS Statistics for Windows. Version 19.0 ed. Armonk, NY: IBM Corp.

Intercollegiate Stroke Working Party 2012. *National clinical guideline for stroke,* London, Royal College of Physicians.

Jorgensen, H. S., Nakayama, H., Raaschou, H. O., Vivelarsen, J., Stoier, M. & Olsen, T. S. 1995. OUTCOME AND TIME-COURSE OF RECOVERY IN STROKE .1. OUTCOME - THE COPENHAGEN STROKE STUDY. *Archives of Physical Medicine and Rehabilitation*, 76, 399-405.

Kasner, S. E. 2006. Clinical interpretation and use of stroke scales. *Lancet Neurology*, 5, 603-12.

Katz, M. H. 2006. *Multivariable analysis: A practical guide for clinicians,* Cambridge, Cambridge University Press.

Katz, M. H. 2011. *Multivariable Analysis: A practical guide for clinicians and public health researchers,* Cambridge, UK, Cambridge University Press.

Kelly-Hayes, M., Beiser, A., Kase, C. S., Scaramucci, A., D'Agostino, R. B. & Wolf, P. A. 2003. The influence of gender and age on disability following ischemic stroke: The Framingham study. *Journal of Stroke and Cerebrovascular Diseases*, 12, 119-126.

Kent, F., Keynton-Hook, P. & Rush, A. 2003. The Provision of Equipment in Care Homes. Integration of Community Equipment Services (ICES).

Kiely, D. & Flacker, J. 2003. The protective effect of social engagement on 1-year mortality in a long-stay nursing home population. *Journal of Clinical Epidemiology*, 56, 472-8.

Kollen, B. J., Lennon, S., Lyons, B., Wheatley-Smith, L., Scheper, M., Buurke, J. H., Halfens, J., Geurts, A. C. & Kwakkel, G. 2009. The effectiveness of the Bobath concept in stroke rehabilitation: what is the evidence? *Stroke*, 40, e89-97.

Kraemer, H. C., Morgan, G., Leech, N., Gliner, J. A., Vaske, J. & Harmon, R. J. 2003. Measures of clinical significance. *Journal of the American Academy of Child and Adolescent Psychiatry*, 42, 1524-9.

Kumlien, S. & Axelsson, K. 2000. The nursing care of stroke patients in nursing homes. Nurses' descriptions and experiences relating to cognition and mood. *Journal of Clinical Nursing*, 9, 489-497.

Kumlien, S., Axelsson, K., Ljunggren, G. & Winblad, B. 1999. Stroke patients ready for discharge from acute care - a multidimensional assessment of functions and further care. *Disability and Rehabilitation*, 21, 31-8.

Kwakkel, G., Eagenaar, R., Koelman, T., Lankhorst, G. & Koetsier, J. 1997. Effects of intensity of stroke rehabilitation: a research synthesis. *Stroke*, 28, 1550-6.

Kwakkel, G., Kollen, B. J. & Wagenaar, R. C. 1999. Therapy Impact on Functional Recovery in Stroke Rehabilitation: A critical review of the literature. *Physiotherapy*, 85, 377-391.

Kwakkel, G., van Peppen, R., Wagenaar, R. C., Dauphinee, S. W., Richards, C., Ashburn, A., Miller, K., Lincoln, N., Partridge, C., Wellwood, I. &

Langhorne, P. 2004. Effects of Augmented Exercise Therapy Time After Stroke. *Stroke*, 35, 2529-39.

Lai, S., Alter, M., Friday, G., Lai, S. & Sobel, E. 1998. Disposition after acute stroke: who is not sent home from hospital? *Neuroepidemiology*, 17, 21-9. Laing & Buisson 2009. Care of elderly people UK market survey. 22nd ed.: Laing and Buisson Ltd.

Langhorne, P. & Dennis, M. 1998. *Stroke Units: an evidence-based approach.*, London, BMJ Books.

Langhorne, P., Stott, D., Robertson, L., MacDonald, J., Jones, L., McAlpine, C., Dick, F., Taylor, G. & Murray, G. 2000. Medical complications after stroke: a multicenter study. *Stroke.*, 31, 1223-9.

Langhorne, P., Wagenaar, R. & Partridge, C. 1996. Physiotherapy after stroke: more is better? *Physiotherapy Research International*, 1, 75-88. Langlois, S., Pederson, L. & MacKinnon, J. R. 1991. The effects of splinting on the spastic hemiplegic hand: report of a feasibility study. *Canadian Journal of Occupational Therapy*, 58, 17-25.

Lannin, N. A. & Herbert, R. D. 2003. Is hand splinting effective for adults following stroke? A systematic review and methodological critique of published research. *Clinical Rehabilitation*, 17, 807-16.

Lannin, N. A., Novak, I. & Cusick, A. 2007. A systematic review of upper extremity casting for children and adults with central nervous system motor disorders. *Clinical Rehabilitation*, 21, 963-76.

Law, M., Baptiste, S., Carswell, A., McColl, M. A., Polatajko, H. & Pollock, N. 1991. Canadian Occupational Performance Measure. Toronto, ON: CAOT Publications.

Lawrence, E. S., Coshall, C., Dundas, R., Stewart, J., Rudd, A. G., Howard, R. & Wolfe, C. D. A. 2001. Estimates of the prevalence of acute stroke impairments and disability in a multiethnic population. *Stroke*, 32, 1279-1284.

Leeds, L., Meara, J. & Hobson, P. 2004. The impact of discharge to a care home on longer term stroke outcomes. *Clinical Rehabilitation*, 18, 924-8. Legg, L., Drummond, A. & Langhorne, P. 2006a. Occupational therapy for patients with problems in activities of daily living after stroke. *Cochrane Database of Systematic Reviews*.

Legg, L., Drummond, A., Leonardi-Bee, J., Gladman, J. R. F., Corr, S., Donkervoort, M., Edmans, J., Gilbertson, L., Jongbloed, L., Logan, P., Sackley, C., Walker, M. & Langhorne, P. 2007a. Occupational therapy for patients with problems in personal activities of daily living after stroke: systematic review of randomised trials. *Bmj*, 335, 922.

Legg, L., Drummond, A., Leonardi-Bee, J., Gladman, J. R. F., Corr, S., Donkervoort, M., Edmans, J., Gilbertson, L., Jongboed, L., Logan, P., Sackley, C., Walker, M. & Langhorne, P. 2007b. Occupational therapy for patients with problems in personal activities of daily living after stroke: systematic review of randomised trials. *British Medical Journal*, 335, 922-925.

Legg, L. A., Drummond, A. E. & Langhorne, P. 2006b. Occupational therapy for patients with problems in activities of daily living after stroke *Cochrane Database of Systematic Reviews*.

Lett, K., Sackley, C. & Littlechild, R. 2006. The Use of Fair Access to Care Services' Eligibility Criteria for Equipment Provision within Local Authorities in England. *British Journal of Occupational Therapy*, 69, 420-2. Lievesley, N., Crosby, G., Bowman, C. & Midwinter, E. 2011. *The changing role of care homes,* London, Bupa and Centre for Policy on Ageing.

Likert, R. 1932. A technique for the measurement of attitudes. *Archives of Psychology*, 22, 55.

Lui, M. H. & MacKenzie, A. E. 1999. Chinese elderly patients' perceptions of their rehabilitation needs following a stroke. *Journal of Advanced Nursing*, 30, 391-400.

Mahoney, F. I. & Barthel, D. W. 1965. Functional evaluation: the Barthel Index. *Maryland State Medical Journal*, 14, 61-5.

Mann, H. & Whitney, D. 1947. On a test of whether one of two random variables is stochastically larger than the other. *Annals of Mathematical Statistics*, 18, 50-60.

Martin, J., Meltzer, H. & Elliot, D. 1998. The prevalence of disability among adults. London: HMSO.

Masterson-Algar, P., Burton, C. R., Rycroft-Malone, J. S., C.M. & Walker, M. F. 2014. Towards a programme theory for fidelity in the evaluation of complex interventions. *Journal of Evaluation in Clinical Practice*, 20, 445-52.

Meier, R. H. 1988. Recent developments in rehabilitation giving rise to important new (and old) ethical issues and concerns. *American Journal of Physical Medicine Rehabilitation*, 69, 7-10.

Metcalfe, A. B. & Lawes, N. 1998. A modern interpretation of the Rood approach. *Physical Therapy Reviews*, 3, 195-212.

Mioshi, E., Dawson, K., Mitchell, J. & Hodges, J. R. 2006. Addenbrooke's Cognitive Examination Revised (ACE-R): a brief cognitive test battery for dementia screening. *International Journal of Geriatric Psychiatry*, 21, 1078-85.

Moher, D. 1998. CONSORT: an evolving tool to help improve the quality of reports of randomized controlled trials. Consolidated Standards of Reporting Trials. *Journal of the American Medical Association*, 279, 1489-91.

Nasreddine, Z. S., Phillips, N. A., Bedirian, V., Charbonneau, S., Whitehead, V., Collin, I., Cummings, J. L. & Chertkow, H. 2005. The Montreal Cognitive Assessment (MoCA): A Brief Screening Tool for Mild Cognitive Impairment. *Journal of the American Geriatrics Society*, 53, 695-9.

National Audit Office 2005. Reducing Brain Damage: Faster access to better stroke care. *In:* NAO (ed.). London: The Stationary Office.

National Audit Office 2010. Progress in Improving Stroke Care.

National Care Standards Commission 2004. How Do We Care? The

availability of registered care homes and children's homes in England and their performance against National Minimum Standards 2002-2003. London. National Institute for Health and Care Excellence 2013. Stroke

rehabilitation: Long term rehabilitation after stroke. London: NICE. Noone, I., Fan, C. W., Tarrant, H., O'Keeffe, S., McDonnell, R. & Crow, M. 2001. What happens to stroke patients after discharge? *Irish Medical Journal*, 94, 151-2.

Nouri, F. & Lincoln, N. B. 1987. An extended activities of daily living scale for stroke patients. *Clinical Rehabilitation*, 1, 233-8.

OC, U., MC, G., S, C., JAC, S. & PGJ, B. 1999. Methods for evaluating areawide and organisation-based intervention in health and health care: a systematic review. *Health Technology Assessment*, **3**, 1-75.

Office of Fair Trading 2005. Care Homes for Older People in the UK. A market study. London: Office of Fair Trading.

Organization for Economic Co-Operation and Development 2013. *Good life in old age.,* Paris, France, OECD Publishing.

Osberg, J. G., McGuire, G. E., DeJong, G. & Seward, M. L. 1987. Life satisfaction and quality of life among disabled elderly adults. *Journal of Gerontology*, 42, 228-30.

Paterson, M., Higgs, J. & et al 2005. The artistry of judgement: a model for occupational therapy practice. *British Journal of Occupational Therapy*, 68, 409-17.

Plichta, S. B. & Kelvin, E. 2012. *Munro's Statistical Methods for Health Care Research,* Philadephia, Lippincott Williams & Wilkins.

Plichta, S. B. & Kelvin, E. A. 2013. *Munro's Statistical Methods for Health Care Research,* Philadelphia, PA, Lippincott Williams & Wilkins.

Przybylski, B. R., Dumont, D., Watkins, M. E., Warren, S. A., Beaulne, A. P. & Lier, D. A. 1996. Outcomes of Enhanced Physical and Occupational Therapy Service in a Nursing Home Setting. *Archives of Physical Medicine Rehabilitation*, 77, 554-61.

Quilliam, B. J. & Lapane, K. L. 2001. Clinical correlates and drug treatment of residents with stroke in long-term care. *Stroke*, 32, 1385-93.

Quinn, T. J., Langhorne, P. & Stott, D. J. 2011. Barthel Index for Stroke Trials: Development, Properties, and Application. *Stroke*, 42, 1146-51. Regulation and Quality Improvement Authority. 2012. *Who we regulate* [Online]. Available:

http://www.rqia.org.uk/what we do/registration inspection and reviews/ who we regulate.cfm.

Rennie, D. 2001. CONSORT revised - improving the reporting of randomised trials. *Journal of the American Medical Association*, 285, 2006-7.

Revman 2011. Review (RevMan). 5.1 ed. Copenhagen: The Nordic Cochrane Centre, The Cochrane Collaboration.

Ribbe, M. W., Ljunggren, G., Steel, K., Topinkova, E., Hawes, C. & Ikegami, N. 1997. Nursing homes in 10 nations: A coparison between countries and settings. *Age and Ageing*, 26, 3-12.

Riley, J., Whitcombe, S. & Vincent, C. 2008. Occupational therapy in adult social care in England: sustaining a high quality workforce for the future. London.

Robbins, I., Gordon, A., Dyas, J., Logan, P. & Gladman, J. 2013. Explaining the barriers to and tensions in delivering effective healthcare in UK care homes: a qualitative study. *BMJ Open*, 3.

Ross, T. 2013. Care home staff to have compulsory training under government plans to protect elderly. *The Telegraph*.

Rothman, K. J. 1990. No adjustments are needed for multiple comparisons. *Epidemiology*, 1, 43-6.

Rothwell, P. M. 2005. Lack of epidemiological data on secondary stroke prevention. *The Lancet Neurology*, 4, 518-519.

Royal College of Physicians 1998. Enhancing the health of older people in long-term care: Clinical Guidelines.

Sackley, C., Brittle, N., Smitaa, P., Ellins, J., Scott, M., Wright, C. & Devey, M. E. 2008a. The Prevalence of Joint Contractures, Pressure Sores, Painful Shoulder, Other Pain, Falls, and Depression in the Year After a Severely Disabling Stroke. *Stroke*, 39, 3329-3334.

Sackley, C. & Dewey, M. 2002. The frequency of joint contractures, pressure sores, painful shoulder, other pain and falls after severely disabling stroke. *Clinical Rehabilitation*, 16, 114-115.

Sackley, C., Hoppitt, T., Cardosa, K. & Levin, S. 2009a. The availability and use of allied health care in care homes in the Midlands, UK. *International Journal of Therapy and Rehabilitation*, 16, 218-24.

Sackley, C., Lett, K. & Littlechild, R. 2009b. Equipment provision by local authority occupational therapy teams using the Fair Access to Care Services eligibility framework: a vignette and interview study. *British Journal of Occupational Therapy*, 72, 259-65.

Sackley, C. & Lincoln, N. 1996. Physiotherapy treatment of stroke patients: a survey of current practice. *Physiotherapy Theory*, 12, 87-96.

Sackley, C., Patel, S. & Wright, C. 2007. Rehabilitation in care homes (RICH-T): a cluster-randomized controlled trial. *Physiotherapy Research International*, 12, 205.

Sackley, C., Rodriguez, N., van den Berg, M., Badger, F., Wright, C. & Besemer, J. 2008b. A phase II exploratory cluster randomized controlled trial of a group mobility training and staff education intervention to promote urinary continence in UK care homes. *Clinical Rehabilitation*, 22, 714-21. Sackley, C., Wade, D. & Mant, D. 2003. Is the intervention of an occupational therapist effective in increasing independence for residents with stroke living in a care home? *Cerebrovascular Diseases*, 16, 112 (Abst

P481).

Sackley, C., Wade, D. T., Mant, D., Atkinson, J. C., Yudkin, P., Cardoso, K., Levin, S., Lee, V. B. & Reel, K. 2006. Cluster randomized pilot controlled trial of an occupational therapy intervention for residents with stroke in UK care homes. *Stroke*, 37, 2336-41.

Sackley, C. M., Atkinson, J. C. & Walker, M. F. 2004. Occupational Therapy in Nursing and Residential Care Settings: A Description of a Randomised Controlled Trial Intervention. *The British Journal of Occupational Therapy*, 67, 104-110.

Sackley, C. M., Burton, C. R., Herron-Marx, S., Lett, K., Mant, J., Roalfe, A. K., Sharp, L. J., Sheehan, B., Stant, K. E., Walker, M. F., Watkins, C. L., Wheatley, K., Williams, J., Yao, G. L., Feltham, M. G. & study, O. 2012. A cluster randomised controlled trial of an occupational therapy intervention for residents with stroke living in UK care homes (OTCH): study protocol. *BMC Neurology*, 12, 52.

Sackley, C. M., Gatt, J. & Walker, M. F. 2001. The use of rehabilitation services by private nursing homes in Nottingham. *Age and Ageing*, 30, 532-3.

Sackley, C. M., Walker, M. F., Burton, C. R., Watkins, C., Mant, J., Roalfe, A. K., Wheatley, K., Sheehan, B., Sharp, L. J., Stant, K. E., Fletcher-Smith, J., Steel, K., Wilde, K., Peryer, G. & on behalf of the OTCH trial investigators 2015. A cluster randomised controlled trial of an occupational therapy intervention for residents with stroke living in UK care homes (OTCH). *British Medical Journal*, 350, 1-11.

Schuessler, S., Dassen, T. & Lohrmann, C. 2015. Comparison of care dependency and related nursing care problems between Austrian nursing home residents with and without dementia. *European Geriatric Medicine*, 6, 46-52.

Schutt, J. 2012. *Research Methods in Education,* Boston, SAGE Publications. Shah, S., Carey, I., Harris, T. & et al 2011. Quality of chronic disease care for older people in care homes and the community in a primary care pay for performance system: retrospective study. *British Medical Journal,* 342, 912.

Sheehan, K. B. & Hoy, M. G. 1999. Using email to survey internet users in the United States: Methodology and assessment. *Journal of Computer Mediated Communication*, 4, [Online]. Available:

http://www.ascusc.org/jcmc/vol4/issue3/sheehan.html.

Sheikh, J. & Yesavage, J. 1986. Geriatric Depression Scale (GDS): recent evidence and development of a shorter version. *Clinical Gerontology*, 5, 165-73.

Smith, L. N., Craig, L. E., Weir, C. J. & McAlpine, C. H. 2008. The evidencebase for stroke education in care homes. *Nurse Education Today.*, 28, 829-40.

Sprangers, M., de Regt, E., Andries, F., van Agt, H., Bijl, R. & de Boer, J. 2000. Which chronic conditions are associated with better or poorer quality of life? *Journal of Clinical Epidemiology*, 53, 895-907.

Steultjens, E. M. J., Dekker, J., Bouter, L. M., van de Nes, J. C. M., Cup, E. H. C. & van den Ende, C. H. M. 2003. Occupational therapy for stroke patients: A systematic review. *Stroke*, 34, 676-87.

Steyerberg, E. W., Vickers, A. J., Cook, N. R., Gerds, T., Gonen, M., Obuchowski, N., Pencina, M. J. & Kattan, M. W. 2010. Assessing the performance of prediction models a framework for traditional and novel measures. *Epidemiology*, 21, 128-38.

Stockmeyer, S. A. 1996. An interpretation of the approach of Rood to the treatment of neuromuscular dysfunction. *American Journal of Physical Medicine*, 46, 900-46.

Stroke Association 2012. Struggling to Recover: Life after stroke campaign briefing. London.

Stroke Unit Trialists' Collaboration. 2013. Organised inpatient (stroke unit) care for stroke (Review). *Cochrane Database of Systematic Reviews* [Online].

Sulter, G., Steen, C. & De Keyser, J. 1999. Use of the Barthel index and modified Rankin scale in acute stroke trials. *Stroke*, 30, 1538-41.

Survey Monkey Inc. 2014. *Survey Monkey: Everything you wanted to know, but were afraid to ask* [Online].

https://<u>www.surveymonkey.com/mp/aboutus/</u>. Available:

https://<u>www.surveymonkey.com/mp/aboutus/</u> [Accessed 15th November 2014].

Syder, D. 1993. Sheffield Screening Test for Acquired Language Disorders. Windsor: NFER-Nelson.

Tang-Wai, D. F. & Graham, N. L. 2008. Assessment of Language Function in Dementia. *Geriatrics and Aging*, 11, 103-10.

The National Care Homes Research and Development Forum 2007. My Home Life - Quality of life in care homes: A review of the literature. London: Help the Aged.

Truelsen, T., Piechowski-Jozwiak, B. & Bonita, R. 2006. Stroke incidence and prevalence in Europe: a review of available data. *European Journal of Neurology*, 13, 581-98.

Tsaih, P.-L., Shih, Y.-L. & Hu, M.-H. 2012. Low-intensity task-oriented exercise for ambulation-challenged residents in long-term care facilities. *American Journal of Physical Medicine and Rehabilitation*, 91, 616-24. Ukoumunne, O. C., Gulliford, M. C., Chinn, S., Sterne, J. A. C. & Burney, P. G. J. 1999. Methods for evaluating area-wide and organisation-based intervention in health and health care: a systematic review. *Health Technology Assessment*, 3, 1-75.

Underwood, M., Lamb, S., Eldridge, S., Sheehan, B. & Slowther, A. 2013. Exercise for depression in care home residents: a randomised controlled trial with cost-effectiveness analysis (OPERA). *Health Technology Assessment*, 17, 281.

US Department of Health and Human Services 1993. Medicaid Source Book: Background and Data Analysis. Washington DC: US Government Printing office.

Van Nostrand, J. F., Clark, R. F. & Romoren, T. I. 1993. Nursing home care in five nations. *Journal of the International Federation on Ageing*, XX, 1-5. Victor, C. 2005. *The Social Context of Ageing: A Textbook of Gerontology*, Oxfordshire, Routledge.

Wade, D. T. & Hewer, R. L. 1987. Motor loss and swallowing difficulty after stroke: frequency, recovery and prognosis. *Acta Neurol Scand.*, 76, 50–54. Walker, M., Leonardi-Bee, J., Bath, P., Langhorne, P., Dewey, M., Corr, S., Drummond, A., Gilbertson, L., Gladman, J., Jongbloed, L., Logan, P. & Parker, C. 2004. Individual patient data meta-analysis of randomized controlled trials of community occupational therapy for stroke patients. *Stroke*, 35, 2226-32.

Walker, M. F., Drummond, A. E. & Lincoln, N. B. 1996. Evaluation of dressing practice for stroke patients after discharge from hospital: a crossover design study. *Clinical Rehabilitation*, 10, 23-31.

Walker, M. F., Drummond, A. E. R., Gatt, J. & Sackley, C. M. 2000. Occupational therapy for stroke patients: a survey of current practice. *British Journal of Occupational Therapy*, 63, 367-72.

Ward, D., Drahota, A., Gal, D., Severs, M. & Dean, T. P. 2008. Care home versus hospital and own home environments for rehabilitation of older people. *Cochrane Database of Systematic Reviews.* 

Warlow, C. P., Van Gijn, J., Dennis, M. S., Wardlow, J. M., Bamford, J. M., Hankey, G. J., Sandercock, P. A. G., Rinkel, G., Langhorne, P., Sudlow, C. & Rothwell, P. 2008. *Stroke: Practical management*, Wiley-Blackwell. Woodford, H. J. & George, J. 2010. Intermediate care for older people in the

UK. Clinical Medicine, 10, 119-123.

World Federation of Occupational Therapists. 2010. WFOT Council Statement on Occupational Therapy [Online].

<u>www.wfot.org/Portals/0/PDF/Statement on Occupational Therapy.pdf</u>. [Accessed 11/07/2014 2014].

World Stroke Organization 2011. World stroke Campaign. Geneva, Switzerland: WSO.

Wright, J., Cross, J. & Lamb, S. 1998. Physiotherapy Outcome Measures for Rehabilitation of Elderly People: Responsiveness to change of the Rivermead Mobility Index and Barthel Index. *Physiotherapy*, 84, 216-21.
Xia, J., Merinder, L. B. & Belgamwar, M. R. 2002. Psychoeducation for schizophrenia. *Cochrane Database of Systematic Reviews* [Online].
Yesavage, J. A., Brink, T. L., Rose, T. L., Lum, O., Huang, V. & Adey, M. 1982. Development and validation of a geriatric depression screening scale:

a preliminary report. Journal of Psychiatric Research, 17, 37-49.

Yun, G. W. & Trumbo, C. W. 2000. Comparative response to a survey executed by post, email, and web form. *Journal of Computer-Mediated Communication*, 6.

#### **Appendix 1 - Cochrane Central Register of Controlled**

#### Trials (CENTRAL) search strategy:

1. (stroke):ti,ab,kw in Trials

2. (residential home):ti,ab,kw or (residential care):ti,ab,kw or (nursing home):ti,ab,kw or (care home):ti,ab,kw or (institution\*):ti,ab,kw in Trials 3. (long-term care):ti,ab,kw in Trials

4. (#2 OR #3) in Title, Abstract or Keywords

5. (rehabilitation):ti,ab,kw or (activities of daily living):ti,ab,kw or (art therapy):ti,ab,kw or (bibliotherapy):ti,ab,kw or (dance therapy):ti,ab,kw in Trials

6. (exercise therapy):ti,ab,kw or (music therapy):ti,ab,kw or (occupational therapy):ti,ab,kw or (recreation therapy):ti,ab,kw or (vocational rehabilitation):ti,ab,kw in Trials

7. (leisure activities):ti,ab,kw or (recreation):ti,ab,kw or (human activities):ti,ab,kw or (task performance and analysis):ti,ab,kw or (self-care):ti,ab,kw in Trials

8. (recovery of function):ti,ab,kw or (goals):ti,ab,kw or (ADL):ti,ab,kw or (occupational therap\*):ti,ab,kw or (exercise):ti,ab,kw in Trials

9. (leisure):ti,ab,kw or (recreation\*):ti,ab,kw or (selfcare):ti,ab,kw or (personal care OR self manage\* OR personal manage\*):ti,ab,kw or (function):ti,ab,kw in Trials

10. (dressing OR feeding OR eating OR toilet\* OR bathing OR washing OR grooming OR mobility):ti,ab,kw or (everyday activit\* OR everyday functioning):ti,ab,kw or (gardening OR reading OR painting OR drawing OR craft\* or dance OR dancing):ti,ab,kw in Trials

11. (#5 OR #6 OR #7 OR #8 OR #9 OR #10) in Title, Abstract or Keywords 12. (#1 AND #4 AND #11) in Title, Abstract or Keywords

13. (randomized controlled trial\* OR cross-over OR cross over OR cross over OR crossover):ti,ab,kw or (random allocation OR quasi-random\* OR quasi random\*):ti,ab,kw or (controlled clinical trial OR clinical trial OR assign\* OR allocat\*):ti,ab,kw or (control group\* OR double-blind OR single-blind OR cross-over stud\* OR masked):ti,ab,kw or (program evaluation OR comparative study OR random\* OR RCT OR control):ti,ab,kw in Trials

14. (#12 AND #13) in Title, Abstract or Keywords

#### **Appendix 2 - MEDLINE search strategy**

1. cerebrovascular disorders/ or exp basal ganglia cerebrovascular disease/ or exp brain ischemia/ or exp carotid artery diseases/ or exp intracranial arterial diseases/ or exp "intracranial embolism and thrombosis"/ or exp intracranial haemorrhages/ or stroke/ or exp brain infarction/ or stroke, lacunar/ or vertebral artery dissection/

2. (stroke or poststroke or post-stroke or cerebrovasc\$ or brain vasc\$ or cerebral vasc\$ or cva\$ or apoplex\$ or SAH).tw.

3. ((brain\$ or cerebr\$ or cerebell\$ or intracran\$ or intracerebral) adj5 (isch?emi\$ or infarct\$ or thrombo\$ or emboli\$ or occlus\$)).tw.

4. ((brain\$ or cerebr\$ or cerebell\$ or intracerebral or intracranial or subarachnoid) adj5 (haemorrhage\$ or hemorrhage\$ or haematoma\$ or hematoma\$ or bleed\$)).tw.

5. hemiplegia/ or exp paresis/

6. (hemipleg\$ or hemipar\$ or paresis or paretic).tw.

7. 1 or 2 or 3 or 4 or 5 or 6

8. residential facilities/ or group homes/ or halfway houses/ or homes for the aged/ or exp nursing homes/

9. institutionalization/ or long-term care/ or Housing for the Elderly/

10. ((care or nursing or residential or rest or old\$ people\$ or old folk\$ or group or geriatric) adj2 (home or homes)).tw.

11. ((long term or long-term or residential or institution\$) adj care).tw.

12. ((aged or elderly or geriatric or extended) adj2 care adj2 (facility or facilities)).tw.

13. ((aged or elderly) adj3 (home or homes)).tw.

14. 8 or 9 or 10 or 11 or 12 or 13

15. rehabilitation/ or "activities of daily living"/ or art therapy/ or bibliotherapy/ or dance therapy/ or exp exercise therapy/ or music therapy/ or occupational therapy/ or recreation therapy/ or rehabilitation, vocational/

16. leisure activities/ or exp recreation/ or human activities/

17. "Task Performance and Analysis"/ or self-care/ or recovery of function/ or goals/

18. ((activit\$ adj3 daily living) or ADL or ADLs).tw.

19. (occupational therap\$ or rehabilitation or exercis\$ or leisure or recreation\$ or self-care or selfcare).tw.

20. ((self or personal) adj5 (care or manage\$)).tw.

21. (recover\$ adj5 function\$).tw.

22. (dressing or feeding or eating or toilet\$ or bathing or washing or grooming or mobility).tw.

23. (everyday adj3 (activit\$ or functioning)).tw.

24. (gardening or reading or painting or drawing or craft\$ or dance or dancing).tw.

25. 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24

26. 7 and 14 and 25

27. cerebrovascular disorders/rh or exp basal ganglia cerebrovascular disease/rh or exp brain ischemia/rh or exp carotid artery diseases/rh or exp intracranial arterial diseases/rh or exp "intracranial embolism and

thrombosis"/rh or exp intracranial hemorrhages/rh or stroke/rh or exp brain infarction/rh or stroke, lacunar/rh or vertebral artery dissection/rh

- 28. 14 and 27
- 29. 26 or 28
- 30. Randomized Controlled Trials as Topic/
- 31. random allocation/
- 32. Controlled Clinical Trials as Topic/
- 33. control groups/
- 34. clinical trials as topic/
- 35. double-blind method/
- 36. single-blind method/
- 37. cross-over studies/
- 38. Therapies, Investigational/
- 39. Research Design/
- 40. Program Evaluation/
- 41. evaluation studies as topic/
- 42. randomized controlled trial.pt.
- 43. controlled clinical trial.pt.
- 44. clinical trial.pt.
- 45. (evaluation studies or comparative study).pt.
- 46. (random\$ or RCT or RCTs).tw.
- 47. (controlled adj5 (trial\$ or stud\$)).tw.
- 48. (clinical\$ adj5 trial\$).tw.

49. ((control or treatment or experiment\$ or intervention) adj5 (group\$ or subject\$ or

patient\$)).tw.

50. (quasi-random\$ or quasi random\$ or pseudo-random\$ or pseudo random\$).tw.

51. ((control or experiment\$ or conservative) adj5 (treatment or therapy or procedure or

manage\$)).tw.

52. ((singl\$ or doubl\$ or tripl\$ or trebl\$) adj5 (blind\$ or mask\$)).tw.

- 53. (cross-over or cross over or crossover).tw.
- 54. (assign\$ or allocat\$).tw.
- 55. controls.tw.
- 56. or/30-55
- 57. 29 and 56

#### **Appendix 3 - EMBASE search strategy**

1. cerebrovascular disorders/ or exp basal ganglia cerebrovascular disease/ or exp brain ischemia/ or exp carotid artery diseases/ or exp intracranial arterial diseases/ or exp "intracranial embolism and thrombosis"/ or exp intracranial haemorrhages/ or stroke/ or exp brain infarction/ or stroke, lacunar/ or vertebral artery dissection/

2. (stroke or poststroke or post-stroke or cerebrovasc\$ or brain vasc\$ or cerebral vasc\$ or cva\$ or apoplex\$ or SAH).tw.

3. ((brain\$ or cerebr\$ or cerebell\$ or intracran\$ or intracerebral) adj5 (isch?emi\$ or infarct\$ or thrombo\$ or emboli\$ or occlus\$)).tw.

4. ((brain\$ or cerebr\$ or cerebell\$ or intracerebral or intracranial or subarachnoid) adj5 (haemorrhage\$ or hemorrhage\$ or haematoma\$ or hematoma\$ or bleed\$)).tw.

5. hemiplegia/ or exp paresis/

6. (hemipleg\$ or hemipar\$ or paresis or paretic).tw.

7. 1 or 2 or 3 or 4 or 5 or 6

8. residential facilities/ or group homes/ or halfway houses/ or homes for the aged/ or exp nursing homes/

9. institutionalization/ or long-term care/ or Housing for the Elderly/ 10. ((care or nursing or residential or rest or old\$ people\$ or old folk\$ or group

or geriatric) adj2 (home or homes)).tw.

11. ((long term or long-term or residential or institution\$) adj care).tw. 12. ((aged or elderly or geriatric or extended) adj2 care adj2 (facility or facilities)).tw.

13. ((aged or elderly) adj3 (home or homes)).tw.

14. 8 or 9 or 10 or 11 or 12 or 13

15. rehabilitation/ or "activities of daily living"/ or art therapy/ or bibliotherapy/ or dance therapy/ or exp exercise therapy/ or music therapy/ or occupational therapy/ or recreation therapy/ or rehabilitation, vocational/

16. leisure activities/ or exp recreation/ or human activities/

17. "Task Performance and Analysis"/ or self-care/ or recovery of function/ or goals/

18. ((activit\$ adj3 daily living) or ADL or ADLs).tw.

19. (occupational therap\$ or rehabilitation or exercis\$ or leisure or recreation\$ or self-care or selfcare).tw.

20. ((self or personal) adj5 (care or manage\$)).tw.

21. (recover\$ adj5 function\$).tw.

22. (dressing or feeding or eating or toilet\$ or bathing or washing or grooming or mobility).tw.

23. (everyday adj3 (activit\$ or functioning)).tw.

24. (gardening or reading or painting or drawing or craft\$ or dance or dancing).tw.

25. 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24

26. 7 and 14 and 25

27. cerebrovascular disorders/rh or exp basal ganglia cerebrovascular disease/rh or exp brain ischemia/rh or exp carotid artery diseases/rh or exp intracranial arterial diseases/rh or exp "intracranial embolism and thrombosis"/rh or exp intracranial hemorrhages/rh or stroke/rh or exp brain infarction/rh or stroke, lacunar/rh or vertebral artery dissection/rh 28. 14 and 27 29. 26 or 28

30. Randomized Controlled Trials as Topic/

31. random allocation/

32. Controlled Clinical Trials as Topic/

33. control groups/

34. clinical trials as topic/

35. double-blind method/

36. single-blind method/

37. cross-over studies/

38. Therapies, Investigational/

39. Research Design/

40. Program Evaluation/

41. evaluation studies as topic/

42. randomized controlled trial.pt.

43. controlled clinical trial.pt.

44. clinical trial.pt.

45. (evaluation studies or comparative study).pt.

46. (random\$ or RCT or RCTs).tw.

47. (controlled adj5 (trial\$ or stud\$)).tw.

48. (clinical\$ adj5 trial\$).tw.

49. ((control or treatment or experiment\$ or intervention) adj5 (group\$ or subject\$ or

patient\$)).tw.

50. (quasi-random\$ or quasi random\$ or pseudo-random\$ or pseudo random\$).tw.

51. ((control or experiment\$ or conservative) adj5 (treatment or therapy or procedure or

manage\$)).tw.

52. ((singl\$ or doubl\$ or tripl\$ or trebl\$) adj5 (blind\$ or mask\$)).tw.

53. (cross-over or cross over or crossover).tw.

54. (assign\$ or allocat\$).tw.

55. controls.tw.

56. or/30-55

57. 29 and 56

#### **Appendix 4 - Cumulative Index to Nursing and Allied**

#### Health Literature (CINAHL) search strategy

1. TX cerebrovascular disorder\* or basal ganglia cerebrovascular disease or brain ischemia or carotid \* diseases or intracranial \* diseases or intracranial embolism or intracranial thrombosis or intracranial haemorrhage\* or stroke or brain infarct\* or lacunar stroke or vertebral artery dissection or poststroke or post-stroke or cerebrovasc\* or brain vasc\* or cerebral vasc\* or cva\* or apoplex\* or SAH or brain\* isch#emi\* or brain\* infarct\* or brain\* thrombo\* or brain\* emboli\* or brain\* occlus\* or cerebr\* isch#emi\* or cerebr\* infarct\* or cerebr\* thrombo\* or cerebr\* emboli\* or cerebr\* occlus\* or cerebell\* isch#emi\* or cerebell\* infarct\* or cerebell\* thrombo\* or cerebell\* emboli\* or cerebell\* occlus\* or intracran\* isch#emi\* or intracran\* infarct\* or intracran\* thrombo\* or intracran\* emboli\* or intracran\* occlus\* or intracerebral isch#emi\* or intracerebral\* infarct\* or intracerebral thrombo\* or intracerebral emboli\* or intracerebral occlus\* or brain\* haemorrhage\* or brain\* hemorrhage\* or brain\* h#ematoma\* or brain\* bleed\* or cerebr\* haemorrhage\* or cerebr\* hemorrhage\* or cerebr\* h#ematoma\* or cerebr\* bleed\* or cerebell\* haemorrhage\* or cerebell\* hemorrhage\* or cerebell\* h#ematoma\* or cerebell\* bleed\* or intracerebral haemorrhage\* or intracerebral hemorrhage\* or intracerebral h#ematoma\* or intracerebral bleed\* or intracranial haemorrhage\* or intracranial hemorrhage\* or intracranial h#ematoma\* or intracranial bleed\* or subarachnoid haemorrhage\* or subarachnoid hemorrhage\* or subarachnoid h#ematoma\* or subarachnoid bleed\* or hemipleg\* or paresis or hemipar\* or paretic

2. TX residential facilit\* or group home or halfway house\* or homes for the aged or institutionalization or long-term care or Housing for the Elderly or care home\* or nursing home\* or residential home\* or rest home\* or old \* home\* or group home\* or geriatric home\* or long term care or long-term care or residential care or institution\* care or aged care facilit\* or elderly care facilit\* or geriatric care facilit\* or extended care facilit\* or aged home\* or elderly home\*

3. TX rehabilitation or activities of daily living or art therapy or bibliotherapy or dance therapy or exercise therapy or music therapy or occupational therapy or recreation therapy or rehabilitation or vocational rehabilitation or leisure activities or recreation or human activities or task performance or task analysis or self-care or recovery \* function or goals or activit\* daily living or ADL or ADLs or occupational therap\* or exercis\* or leisure or recreation\* or selfcare or personal care or personal manage\* or self manage\* or recover\* function\* or dressing or feeding or eating or toilet\* or bathing or washing or grooming or mobility or everyday activit\* or everyday functioning or gardening or reading or painting or drawing or craft\* or dance or dancing

4. TX Randomized \* trials or random allocation or Controlled \* trials or control group\* or clinical trial\* or double-blind method or single-blind method or crossover studies or research design or program evaluation or evaluation stud\* or comparitive study or random\* trial\* or random\* stud\* or RCT or RCTs or treatment group\* or intervention group\* or control subject\* or treatment subject\* or experiment\* subject\* or intervention subject\* or control patient\* or treatment patient\* or experiment\* patient\* or intervention patient\* or quasirandom\* or quasi random\* or pseudo-random\* or pseudo random\* or control or experiment\* or conservative treatment or conservative therapy or conservative procedure or conservative manage\* or singl\* blind\* or sing\* mask\* or doubl\* blind\* or doubl\* mask\* or tripl\* blind\* or tripl\* mask\* or trebl\* blind\* or trebl\* mask\* or cross-over or cross over or crossover or assign\* or allocat\* or controls 5. 1 AND 2 AND 3 AND 4

#### **Appendix 5 - Allied and Complementary Medicine**

#### Database (AMED) search strategy

1. cerebrovascular disorders/ or exp basal ganglia cerebrovascular disease/ or exp brain ischemia/ or exp carotid artery diseases/ or exp intracranial arterial diseases/ or exp "intracranial embolism and thrombosis"/ or exp intracranial haemorrhages/ or stroke/ or exp brain infarction/ or stroke, lacunar/ or vertebral artery dissection/

2. (stroke or poststroke or post-stroke or cerebrovasc\$ or brain vasc\$ or cerebral vasc\$ or cva\$ or apoplex\$ or SAH).tw.

3. ((brain\$ or cerebr\$ or cerebell\$ or intracran\$ or intracerebral) adj5 (isch?emi\$ or infarct\$ or thrombo\$ or emboli\$ or occlus\$)).tw.

4. ((brain\$ or cerebr\$ or cerebell\$ or intracerebral or intracranial or subarachnoid) adj5 (haemorrhage\$ or hemorrhage\$ or haematoma\$ or hematoma\$ or bleed\$)).tw.

5. hemiplegia/ or exp paresis/

6. (hemipleg\$ or hemipar\$ or paresis or paretic).tw.

7. 1 or 2 or 3 or 4 or 5 or 6

8. residential facilities/ or group homes/ or halfway houses/ or homes for the aged/ or exp nursing homes/

9. institutionalization/ or long-term care/ or Housing for the Elderly/

10. ((care or nursing or residential or rest or old\$ people\$ or old folk\$ or group or geriatric) adj2 (home or homes)).tw.

11. ((long term or long-term or residential or institution\$) adj care).tw.

12. ((aged or elderly or geriatric or extended) adj2 care adj2 (facility or facilities)).tw.

13. ((aged or elderly) adj3 (home or homes)).tw.

14. 8 or 9 or 10 or 11 or 12 or 13

15. rehabilitation/ or "activities of daily living"/ or art therapy/ or bibliotherapy/ or dance therapy/ or exp exercise therapy/ or music therapy/ or occupational therapy/ or recreation therapy/ or rehabilitation, vocational/

16. leisure activities/ or exp recreation/ or human activities/

17. "Task Performance and Analysis"/ or self-care/ or recovery of function/ or goals/

18. ((activit\$ adj3 daily living) or ADL or ADLs).tw.

19. (occupational therap\$ or rehabilitation or exercis\$ or leisure or

recreation\$ or self-care or selfcare).tw.

20. ((self or personal) adj5 (care or manage\$)).tw.

21. (recover\$ adj5 function\$).tw.

22. (dressing or feeding or eating or toilet\$ or bathing or washing or grooming or mobility).tw.

23. (everyday adj3 (activit\$ or functioning)).tw.

24. (gardening or reading or painting or drawing or craft\$ or dance or dancing).tw.

25. 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24

26. 7 and 14 and 25

27. cerebrovascular disorders/rh or exp basal ganglia cerebrovascular disease/rh or exp brain ischemia/rh or exp carotid artery diseases/rh or exp

intracranial arterial diseases/rh or exp "intracranial embolism and thrombosis"/rh or exp intracranial hemorrhages/rh or stroke/rh or exp brain infarction/rh or stroke, lacunar/rh or vertebral artery dissection/rh 28. 14 and 27

- 28. 14 and 2 29. 26 or 28
- 30. Randomized Controlled Trials as Topic/
- 31. random allocation/
- 32. Controlled Clinical Trials as Topic/
- 33. control groups/
- 34. clinical trials as topic/
- 35. double-blind method/
- 36. single-blind method/
- 37. cross-over studies/
- 38. Therapies, Investigational/
- 39. Research Design/
- 40. Program Evaluation/
- 41. evaluation studies as topic/
- 42. randomized controlled trial.pt.
- 43. controlled clinical trial.pt.
- 44. clinical trial.pt.
- 45. (evaluation studies or comparative study).pt.
- 46. (random\$ or RCT or RCTs).tw.
- 47. (controlled adj5 (trial\$ or stud\$)).tw.
- 48. (clinical\$ adj5 trial\$).tw.

49. ((control or treatment or experiment\$ or intervention) adj5 (group\$ or subject\$ or

patient\$)).tw.

50. (quasi-random\$ or quasi random\$ or pseudo-random\$ or pseudo random\$).tw.

51. ((control or experiment\$ or conservative) adj5 (treatment or therapy or procedure or

manage\$)).tw.

- 52. ((singl\$ or doubl\$ or tripl\$ or trebl\$) adj5 (blind\$ or mask\$)).tw.
- 53. (cross-over or cross over or crossover).tw.
- 54. (assign\$ or allocat\$).tw.
- 55. controls.tw.
- 56. or/30-55
- 57. 29 and 56

# Appendix 6 - Occupational therapy database of systematic reviews and randomised controlled trials (OT seeker) search strategy

"stroke" AND "care home" AND "occupational therapy"

#### **Appendix 7 - PsycINFO search strategy**

1. cerebrovascular disorders/ or exp basal ganglia cerebrovascular disease/ or exp brain ischemia/ or exp carotid artery diseases/ or exp intracranial arterial diseases/ or exp "intracranial embolism and thrombosis"/ or exp intracranial haemorrhages/ or stroke/ or exp brain infarction/ or stroke, lacunar/ or vertebral artery dissection/

2. (stroke or poststroke or post-stroke or cerebrovasc\$ or brain vasc\$ or cerebral vasc\$ or cva\$ or apoplex\$ or SAH).tw.

3. ((brain\$ or cerebr\$ or cerebell\$ or intracran\$ or intracerebral) adj5 (isch?emi\$ or infarct\$ or thrombo\$ or emboli\$ or occlus\$)).tw.

4. ((brain\$ or cerebr\$ or cerebell\$ or intracerebral or intracranial or subarachnoid) adj5 (haemorrhage\$ or hemorrhage\$ or haematoma\$ or hematoma\$ or bleed\$)).tw.

5. hemiplegia/ or exp paresis/

6. (hemipleg\$ or hemipar\$ or paresis or paretic).tw.

7. 1 or 2 or 3 or 4 or 5 or 6

8. residential facilities/ or group homes/ or halfway houses/ or homes for the aged/ or exp nursing homes/

9. institutionalization/ or long-term care/ or Housing for the Elderly/

10. ((care or nursing or residential or rest or old\$ people\$ or old folk\$ or group or geriatric) adj2 (home or homes)).tw.

11. ((long term or long-term or residential or institution\$) adj care).tw.

12. ((aged or elderly or geriatric or extended) adj2 care adj2 (facility or facilities)).tw.

13. ((aged or elderly) adj3 (home or homes)).tw.

14. 8 or 9 or 10 or 11 or 12 or 13

15. rehabilitation/ or "activities of daily living"/ or art therapy/ or bibliotherapy/ or dance therapy/ or exp exercise therapy/ or music therapy/ or occupational therapy/ or recreation therapy/ or rehabilitation, vocational/

16. leisure activities/ or exp recreation/ or human activities/

17. "Task Performance and Analysis"/ or self-care/ or recovery of function/ or goals/

18. ((activit\$ adj3 daily living) or ADL or ADLs).tw.

19. (occupational therap\$ or rehabilitation or exercis\$ or leisure or recreation\$ or self-care or selfcare).tw.

20. ((self or personal) adj5 (care or manage\$)).tw.

21. (recover\$ adj5 function\$).tw.

22. (dressing or feeding or eating or toilet\$ or bathing or washing or grooming or mobility).tw.

23. (everyday adj3 (activit\$ or functioning)).tw.

24. (gardening or reading or painting or drawing or craft\$ or dance or dancing).tw.

25. 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24

26. 7 and 14 and 25

27. cerebrovascular disorders/rh or exp basal ganglia cerebrovascular disease/rh or exp brain ischemia/rh or exp carotid artery diseases/rh or exp intracranial arterial diseases/rh or exp "intracranial embolism and

thrombosis"/rh or exp intracranial hemorrhages/rh or stroke/rh or exp brain infarction/rh or stroke, lacunar/rh or vertebral artery dissection/rh

- 28. 14 and 27
- 29. 26 or 28
- 30. Randomized Controlled Trials as Topic/
- 31. random allocation/
- 32. Controlled Clinical Trials as Topic/
- 33. control groups/
- 34. clinical trials as topic/
- 35. double-blind method/
- 36. single-blind method/
- 37. cross-over studies/
- 38. Therapies, Investigational/
- 39. Research Design/
- 40. Program Evaluation/
- 41. evaluation studies as topic/
- 42. randomized controlled trial.pt.
- 43. controlled clinical trial.pt.
- 44. clinical trial.pt.
- 45. (evaluation studies or comparative study).pt.
- 46. (random\$ or RCT or RCTs).tw.
- 47. (controlled adj5 (trial\$ or stud\$)).tw.
- 48. (clinical\$ adj5 trial\$).tw.

49. ((control or treatment or experiment\$ or intervention) adj5 (group\$ or subject\$ or

patient\$)).tw.

50. (quasi-random\$ or quasi random\$ or pseudo-random\$ or pseudo random\$).tw.

51. ((control or experiment\$ or conservative) adj5 (treatment or therapy or procedure or

manage\$)).tw.

52. ((singl\$ or doubl\$ or tripl\$ or trebl\$) adj5 (blind\$ or mask\$)).tw.

- 53. (cross-over or cross over or crossover).tw.
- 54. (assign\$ or allocat\$).tw.
- 55. controls.tw.
- 56. or/30-55
- 57. 29 and 56

#### **Appendix 8 - Physiotherapy Evidence Database (PEDro)**

#### search strategy

stroke AND occupational therapy AND care home

#### **Appendix 9 - Applied Social Index and Abstracts**

#### (ASSIA) search strategy

((all("cerebrovascular disorders") OR "stroke" OR ("brain infarction" OR "brain haemorrhage") OR all("carotid artery disease\*") OR "vertebral artery dissection") AND ("residential home\*" OR "nursing home\*" OR "group homes" OR "homes for the aged" OR "long-term care" OR "long term care" OR institutionalization\* OR "institutional care")) AND (rehabilitation or "activities of daily living" or "art therapy" or bibliotherapy or "dance therapy" or "exercise therapy" or "music therapy" or "occupational therapy" or "recreation therapy" or "vocational rehabilitation" or "leisure activities" or "recreation" or "human activities" or "task performance and analysis" or "self-care" or "recovery of function" or "goals" or ADL or ADLs or "occupational therapist" or "exercise" or leisure or recreation\* or selfcare or "self care" or "self manage\*" or "personal care" or "personal manage\*" or dressing or feeding or eating or toilet\* or bathing or washing or grooming or mobility or "everday activit\*" or "everyday functioning" or gardening or reading or painting or drawing or craft\* or dance or dancing) AND ("randomized controlled trial\*" or "random allocation" or "controlled clinical trials" or "control groups" or "clinical trial\*" or "double-blind" or "single-blind" "cross-over studies" or "program evaluation" or random\* or RCT or RCTs or "controlled trial\*" or "controlled stud\*" or "control group\*" or "treatment group\*" or "experimental group\*" or "intervention group\*" or "quasi-random\*" or "quasi random\*" or "pseudo-random\*" or "pseudo random" or control or "single blind\*" or "double blind\*" or "tr\* blind\*" or cross-over or "cross over" or crossover or assign\* or allocat\* or controls)

# Appendix 10 - NHS Economic Evaluation Database (NHS EED) search strategy

"(stroke) in Title, Abstract or Keywords and (residential home) OR (residential care) OR (nursing home) OR (care home) OR (institution\*) OR (long-term care) in Title, Abstract or Keywords and (rehabilitation) OR (activities of daily living) OR (art therapy) OR (bibliotherapy) OR (dance therapy) OR (exercise therapy) or (music therapy) OR (occupational therapy) OR (recreation therapy) OR (vocational rehabilitation) OR (leisure activities) OR (recreation) OR (human activities) OR (task performance and analysis) OR (self-care) OR (recovery of function) OR (goals) OR (ADL) OR (occupational therap\*) or (exercise) OR (leisure) OR (recreation\*) OR (selfcare) OR (personal care OR self manage\* OR personal manage\*) or (function) in Title, Abstract or Keywords or (dressing or feeding oreating or toilet\* or bathing or washing or grooming or mobility) OR (everyday activit\* OR everyday functioning) OR (gardening OR reading OR painting OR drawing OR craft\* OR dance OR dancing) in Title, Abstract or Keywords and (randomized controlled trial\* OR cross-over OR cross over OR crossover) OR (random allocation OR guasi-random\* OR guasi random) OR (controlled clinical trial OR clinical trial OR assign\* OR allocat\*) OR (control group\* OR double-blind OR single-blind OR cross-over stud\* OR masked) OR (program evaluation OR comparative study OR random\* OR RCT OR control) in Title, Abstract or Keywords in NHS Economic Evaluation Database"

#### **Appendix 11 - Education Resources Information Center**

#### (ERIC) search strategy

((all("cerebrovascular disorders") OR "stroke" OR ("brain infarction" OR "brain haemorrhage") OR all("carotid artery disease\*") OR "vertebral artery dissection") AND ("residential home\*" OR "nursing home\*" OR "group homes" OR "homes for the aged" OR "long-term care" OR "long term care" OR institutionalization\* OR "institutional care")) AND (rehabilitation or "activities of daily living" or "art therapy" or bibliotherapy or "dance therapy" or "exercise therapy" or "music therapy" or "occupational therapy" or "recreation therapy" or "vocational rehabilitation" or "leisure activities" or "recreation" or "human activities" or "task performance and analysis" or "self-care" or "recovery of function" or "goals" or ADL or ADLs or "occupational therapist" or "exercise" or leisure or recreation\* or selfcare or "self care" or "self manage\*" or "personal care" or "personal manage\*" or dressing or feeding or eating or toilet\* or bathing or washing or grooming or mobility or "everday activit\*" or "everyday functioning" or gardening or reading or painting or drawing or craft\* or dance or dancing) AND ("randomized controlled trial\*" or "random allocation" or "controlled clinical trials" or "control groups" or "clinical trial\*" or "double-blind" or "single-blind" "cross-over studies" or "program evaluation" or random\* or RCT or RCTs or "controlled trial\*" or "controlled stud\*" or "control group\*" or "treatment group\*" or "experimental group\*" or "intervention group\*" or "quasi-random\*" or "quasi random\*" or "pseudo-random\*" or "pseudo random" or control or "single blind\*" or "double blind\*" or "tr\* blind\*" or cross-over or "cross over" or crossover or assign\* or allocat\* or controls)

#### **Appendix 12 - Center for International Rehabilitation**

#### **Research Information and Exchange (CIRRIE) search**

#### strategy

- 1. stroke (subject)
- 2. AND occupational therapy (subject)
- 3. AND care home (subject)
- 4. OR nursing home (subject)
- 5. OR residential home (subject)

#### **Appendix 13 - Web of Science search strategy**

1. Topic=(stroke or poststroke or "post stroke" or apoplex\* or cerebrovasc\* or brain vasc\* or cerebral vasc\* or cva or SAH or "cerebrovascular disorders" or "basal ganglia cerebrovascular disease" or "brain ischemia" or "carotid artery diseases" or "intracranial arterial diseases" or "intracranial embolism" or "intracranial thrombosis" or "intracranial haemorrhages" or "brain infarction" or "lacunar stroke" or "vertebral artery dissection") OR Topic=(brain isch\$emi\* or brain infarct or brain thrombo\* or brain emboli\* or brain occlus\* or brain h\$emorrhage\$ or hemiplegia or paresis or hemipleg\* or hemipar\* or paresis or paretic)

2. TS=("residential facilities" or "group homes" or "halfway houses" or "homes" for the aged" or "nursing homes" or "institutionalization" or "long term care" or "housing for the elderly" or "care home\*" or "nursing home\*" or "residential home\*" or "rest home\*" or "old peoples home\*" or "old folks home\*" or "geriatric home\*" or "long-term care" or "residential care" or "institutional care") 3. TS=(rehabilitation or "activities of daily living" or "art therapy" or bibliotherapy or "dance therapy" or "exercise therapy" or "music therapy" or "occupational therapy" or "recreation therapy" or "vocational rehabilitation" or "leisure activities" or recreation or "human activities" or "task performance" or "task analysis" or "self care" or "recovery of function" or goals or ADL\* or "occupational therap\*" or exercise or leisure or recreation\* or selfcare or "self manage\*" or "personal care" or "personal manage\*" or "recovery of function" or dressing or feeding or eating or toilet\* or bathing or washing or grooming or mobility or "everyday activit\*" or "everyday functioning" or gardening or reading or painting or drawing or craft\* or dance or dancing) 4. TS=("randomized controlled trial\*" or "random allocation" or "controlled clinical trial\*" or "control group\*" or "clinical trial\*" or "double blind method" or "single blind method" or "cross over studies" or "investigational therapies" or "research design" or "program evaluation" or "evaluation stud\*" or "comparative study" or random\* or RCT\* or "controlled trial\*" or "controlled stud\*" or "treatment group\*" or "experiment\* group\*" or "intervention group\*" or "quasi random\*" or "pseudo random\*" or "control treatment" or "control therapy" or "control procedure" or "experiment\* treatment" or "experiment\* therapy" or "experiment\* procedure" or "conservative treatment" or "conservative therapy" or "conservative procedure" or "conservative manage\*" or "single blind\*" or "double blind\*" or "triple blind\*" or "treble blind\*" or assign\* or allocat\* or controls)

5. #4 AND #3 AND #2 AND #1

#### DATA EXTRACTION FORM

Trial ID:
Review author ID:
Author contact details:
Action:
METHODS
Allocation:
Blindness:
Duration:
Setting:
PARTICIPANTS
Diagnosis:
N=
Age:
Gender:
History:
Included: Excluded:
INTERVENTIONS
1.
2.
OUTCOMES - able to use (list what was measured and how it was measured)
1.
2.
3.
4.
5.
6.
Outcomes unable to use – and WHY:
NOTES:

RISK OF BIAS TABLE

Component	Judgement	Description
Adequate method of	Yes / Unclear / No	
generation of the		
randomisation sequence?	(underline or highlight chosen	
	judgement)	
Allocation concealment?	Yes / Unclear / No	
Blinding?	Yes / Unclear / No	
Incomplete outcome data	Yes / Unclear / No	
addressed?		
Free of selective reporting?	Yes / Unclear / No	
Free of other bias?	Yes / Unclear / No	



#### UNIVERSITY<sup>OF</sup> BIRMINGHAM

### A NATIONAL SURVEY OF OCCUPATIONAL THERAPY FOR CARE HOME RESIDENTS

This questionnaire is part of a larger study investigating the efficacy of providing <u>o</u>ccupational <u>t</u>herapy interventions to people who have had a stroke and are residing in UK <u>care homes</u>, known as 'the OTCH study'. The purpose of this survey is to find out what current occupational therapy practice is within a care home setting.

If you are a <u>qualified occupational therapist</u> who provides or has provided occupational therapy intervention within a <u>care home setting (residential homes or nursing homes)</u>, we would very much appreciate your help in completing this questionnaire. This will enable us to find out more about the current provision of occupational therapy for people who live in care homes throughout the UK. In particular, we are interested in finding out more about therapy provision for residents with a confirmed or suspected stroke.

For each question, please choose the answer(s) that best applies and please try not to leave any questions blank.

Please feel free to enclose or email any additional information which you feel best describes the treatment you provide e.g. a local protocol, information leaflets. This information will not be stored with your answers, so we will be able to keep the information you give us absolutely <u>confidential</u>.

#### Returning the questionnaire

Please complete and return the questionnaire and any enclosures by **DATE 2011** in the envelope provided to:

Joanna Fletcher-Smith University of Nottingham Division of Rehabilitation and Ageing Room B108, Medical School Queens Medical Centre Nottingham, NG7 2UH

If you need any additional help to complete the questionnaire, or have any questions about the OTCH study, please contact Joanna Fletcher-Smith on:

(0115) 8230432 or joanna.fletcher-smith@nottingham.ac.uk

If you know other occupational therapists who may be willing to participate in this survey, you are welcome to either photocopy this questionnaire, or request further copies.

#### Online version of the questionnaire

An online version of this questionnaire is available from the following web link:

#### www.surveymonkey.com/s/OTCH

#### PART 1: BACKGROUND INFORMATION

**1.** Do you provide occupational therapy assessment and/or intervention to care home residents within their care home? (*please tick ONE box only*)

Yes

No

#### IF YOU ANSWERED 'YES', please proceed to questions 2.

**IF YOU ANSWERED 'NO'**, please **do not answer any further questions**. We only wish to survey occupational therapists who provide assessment and intervention within a care home. **Thank you for your time**.

#### 2. In which UK Country do you work? (please tick ONE box only)

England	
Wales	
Scotland	
Northern Ireland	

#### 3. In which city or town do you work? (please state)

.....

.....

#### 4. Who are you employed by? (please tick all that apply)

NHS	
Social Services	
Private sector	
Self-employed	
University	
Other	
If 'other', please state:	
5. What is your job title?	

6. Are you employed to provide occupational therapy in care homes BECAUSE of a research study only?

(plea	ise tick	ONE	box	only)
-------	----------	-----	-----	-------

Yes	
No	

#### 7. Which of the following do you believe best applies to you?

(please tick ONE box only)

Generic OT	
Stroke specific OT	
Neurological OT	
Dementia specialist	
Other	
If 'other', please state:	

#### PART 2: GENERAL CARE HOME INFORMATION

**8.** How are care home residents referred to your service for OT assessment and intervention? *(please tick all that apply)* 

Consultant referral	
Care home manager referral	
GP referral	
Physiotherapist referral	
Speech and language therapist referral	
Other	
If 'other', please state:	

### 9. How long, on average, does it take from the time a referral is received to the care home resident being assessed by an occupational therapist? (*please state*)

.....

## **10.** Approximately how many individual care home resident referrals do you (as an individual therapist) receive a month?

(please state the number of care home residents)

.....

**11.** When you receive a referral for a care home resident are you able to access confirmation of the **person's medical diagnosis?** (*please tick ONE box only*)

	Always	Often	Rarely	Never	
Please comment:					

**12.** In the last 12 months, have you provided occupational therapy assessment and/or intervention to a care home resident with a suspected or confirmed diagnosis of stroke? (*please tick ONE box only*)

Yes
-----

N	n

IF YOU ANSWERED 'YES', please proceed to the questions in part 3

**IF YOU ANSWERED 'NO'**, please **do not answer any further questions.** The remaining questions in part 3 of the survey relate only to occupational therapy provided within a care home setting to residents who have had a stroke. **Thank you for your time.** 

#### PART 3: STROKE SPECIFIC CARE HOME INFORMATION

The following questions relate specifically to your occupational therapy assessment and/or intervention with care home residents who have had a suspected or confirmed stroke.

#### 13. In your current post, have you received any stroke specific training?

(please tick ONE box only)

Yes				
No				
If yes, please give details of any stroke specific training that you have received: <i>(please state)</i>				

### **14. Do you use non-standardised assessments with care home residents with stroke?** *(please tick ONE box only)*

	Always	Often	Rarely	Never
If 'non-standardised' assess	ment is used, p	lease commer	nt:	

# **15.** Do you use any of the following standardised assessments with care home residents with stroke? *(please tick ONE option for EACH assessment)*

	Very often	Often	Rarely	Never
ACE-R				
AMPS				
Barthel ADL Index				
Behavioural Inattention Test				
СОРМ				
COTNAB				
FIM				
MEAMS				
MMSE				
MOCA				
Nottingham 10-Point ADL				
NSDA				
Rivermead ADL				
Rivermead Mobility Index				
Other				
If 'other', please state:				

.....

## 16. Do you provide any of the following occupational therapy interventions to care home residents with stroke?

(please tick ONE option for EACH type of intervention)

	Very often	Often	Rarely	Never
Adaptations to the environment				
Cognitive rehabilitation				
Education and training				
Provision of aids and equipment				
Practice of self-care activities				
Seating & positioning				
Splinting				
Task-based exercises				
Other				
If 'other', please state:				

## **17.** Do you use any of the following treatment approaches with care home residents who have had a stroke? (*please tick ONE option for EACH type of treatment approach*)

	Very often	Often	Rarely	Never
Bobath				
Carr and Shepherd / Motor Relearning				
Cognitive				
Compensatory / Functional				
Other				
If 'other', please state:				

18. Occupational therapists treat individuals and each individual is recognised as being unique. However, if you had to generalize, what would be the three most common treatment aims that you hope to achieve in your interventions with care home residents who have had a stroke?

1	
2	
3	

**19.** Do you recommend the provision of any of the following aids, equipment and adaptations? *(please tick ONE option for EACH piece of equipment)* 

	Very often	Often	Rarely	Never
Adaptive cutlery				
Bed lever				
Chair/bed raisers				
Dressing aids				
Dycem mat				
Elastic shoelaces				
Grab rails				
Helping hand				
Long-handled bath sponge				
Mobility aids				
Palm protectors				
Plate guard				
Pressure cushion				
Ramps				
Stocking/tights aid				
Specialist seating				
Transfer equipment				
Wheelchair				
Other				

If 'other', please state: .....

# **20.** In the area of the UK that you work, who is responsible for <u>funding</u> the provision of the following aids and equipment to <u>nursing</u> home residents with stroke? (please tick ONE option for EACH aid/piece of equipment)

	NHS/Social services	Care home	Resident/family	Don't know
Adaptive cutlery				
Bed lever				
Chair/bed raisers				
Dressing aids				
Dycem mat				
Elastic shoelaces				
Grab rails				
Helping hand				
Long-handled bath sponge				
Mobility aids				
Palm protectors				
Plate guard				
Pressure cushion				
Ramps				
Stocking/tights aid				
Specialist seating				
Transfer equipment				
Wheelchair				
Other				
If 'other', please state:				

## 21. In the area of the UK that you work, who is responsible for <u>funding</u> the provision of the following aids and equipment to <u>residential</u> home residents with stroke?

(please tick ONE option for EACH aid/piece of equipment)

	NHS/Social services	Care home	Resident/family	Don't know
Adaptive cutlery				
Bed lever				
Chair/bed raisers				
Dressing aids				
Dycem mat				
Elastic shoelaces				
Grab rails				
Helping hand				
Long-handled bath sponge				
Mobility aids				
Palm protectors				
Plate guard				
Pressure cushion				
Ramps				
Stocking/tights aid				
Specialist seating				
Transfer equipment				
Wheelchair				
Other				
If 'other', please state:				

**22.** Are there any limitations on the occupational therapy interventions you can deliver within the care home setting? (*please state*)

23. Is there ANYTHING ELSE about occupational therapy for care home residents with stroke that we haven't asked and YOU THINK WE SHOULD KNOW?

(please state)

.....

## Thank you for participating in this research survey

#### Checklist:

Please check that you have answered each question correctly.

Please check that you have enclosed any additional information that you feel best describes the treatment you provide e.g. a local protocol, information leaflets. This information will not be stored with your answers, so we will be able to keep the information you give us absolutely <u>confidential</u>

Direct line/e-mail +44 (0) 115 8231063 Louise.Sabir@nottingham.ac.uk

24<sup>th</sup> November 2011

Joanna Fletcher-Smith, Research Occupational Therapist/PhD Student, Room B108 Division of Rehabilitation and Ageing School of Community Health Sciences QMC Campus Nottingham University Hospitals



Medical School Research Ethics Committee Division of Therapeutics & Molecular Medicine D Floor, South Block Queen's Medical Centre Nottingham NG7 2UH

Tel: +44 (0) 115 8231063 Fax: +44 (0) 115 8231059

Dear Joanna

#### Ethics Reference No: A10112011 CHS

Study Title: A national survey of occupational therapy for care home residents. Primary PhD Supervisor: Professor Marion Walker, Professor in Stroke Rehabilitation, Division of Rehabilitation and Ageing, School of Community Health Sciences.

**Co Supervisors:** Professor Catherine Sackley, Professor in Physiotherapy Research, Division of Primary Care Clinical Sciences, School of Health and Population Sciences, University of Birmingham, Dr Avril Drummond, Associate Professor and Reader, Division of Rehabilitation and Ageing, School of Community Health Sciences. **Student:** Joanna Fletcher-Smith, Research Occupational Therapist/PhD Student, Division of Rehabilitation and Ageing, School of Community Health Sciences **Duration of Study:** 21/11/2011 -24/02/2012 (3 months)

Thank you for your letter dated 24/11/2011 responding to the issues raised by the Committee and enclosing the following revised document as requested:

Appendix A OTCH Survey Version 9, 24/11/2011

This has been reviewed and approved.

Approval is given on the understanding that the Conditions of Approval set out below are followed.

#### Conditions of Approval

You must follow the protocol agreed and any changes to the protocol will require prior Ethics' Committee approval.

This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.

You promptly inform the Chairman of the Research Ethics Committee of

 Deviations from or changes to the protocol which are made to eliminate immediate hazards to the research subjects. Dear Occupational Therapist,

#### Invitation to participate in:

### A NATIONAL SURVEY OF OCCUPATIONAL THERAPY FOR

#### CARE HOME RESIDENTS

This questionnaire survey is part of a larger study investigating the efficacy of providing <u>occupational therapy</u> interventions to people who have had a stroke and are residing in UK <u>care homes</u>, known as 'the OTCH study'. The purpose of this survey is to find out what current occupational therapy practice is within a care home setting.

If you are a <u>qualified occupational therapist</u> who provides or has provided occupational therapy intervention within a <u>care home setting (residential homes or nursing homes)</u>, we would very much appreciate your help in completing this questionnaire. This will enable us to find out more about the current provision of occupational therapy for people who live in care homes throughout the UK. In particular, we are interested in finding out more about therapy provision for residents with a confirmed or suspected stroke.

It is estimated that around a quarter of all care home residents have had a stroke and the current national level and content of occupational therapy provision delivered to this client group is not known.

If you would like to take part in this survey, please read the participant information sheet contained in this email before proceeding to the online survey at the website address below.

www.onlinesurveywebsitelinktogohere

University of Nottingham School of Community Health Sciences Division of Rehabilitation and Ageing B Floor, Medical School Queens Medical Centre Nottingham NG7 2UH



## A NATIONAL SURVEY OF OCCUPATIONAL THERAPY

## FOR CARE HOME RESIDENTS

Joanna Fletcher-Smith, Professor Marion Walker, Professor Catherine Sackley, Dr Avril Drummond

## **Participant Information Sheet**

You have been invited to take part in a research study. Before you decide whether to take part 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 to. Ask us if there is anything that is not clear or if you would like more information. Thank you for reading this.

#### Background

Stroke is one of the top three causes of death and the largest cause of disability in the UK. It is estimated that a quarter of all care homes residents have had a stroke. Care home residents with stroke are likely to be amongst the most disabled, dependent and vulnerable stroke survivors and are more likely to have additional complications as compared with those living in their own homes. It could be argued that the care home population have the greatest need for ongoing therapy and rehabilitation post stroke. Yet few care home residents receive ongoing rehabilitation. Occupational therapy can specifically target the consequences of stroke by aiming to improve independence in self-care activities and improving the ergonomics of the environment. It is not known how many occupational therapists are currently working in care homes across the UK. This data is not recorded by the Health Professions Council or the College of Occupational Therapists.

The purpose of this research is to find out more about the current provision of occupational therapy for people who live in care homes throughout the UK. In particular, we are interested in finding out more about therapy provision for residents with a confirmed or suspected stroke.

#### What does the study involve?

If you choose to participate in this survey study you will be required to complete one online questionnaire. The questionnaire should take no longer than 15 minutes.

#### Why have you been chosen?

You have been chosen as a potential research participant because you are an occupational therapist. Occupational therapists may work with people who have had a stroke and may have experience of working within care home settings. We would like to know whether you currently work or have worked with people in care homes and we are interested in your experiences of working with this specific group of clients.

#### Do you 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 able to keep this information sheet. If you decide to take part you will need to follow the link to the survey website. In proceeding to complete the questionnaire, this will be taken to mean that you 'consent' to participate in the study. If you decide to take part you are still free to withdraw at any time and without giving a reason. You may choose to complete a paper postal version of the questionnaire if this is more convenient for you.

#### What do I have to do?

If you would like to participate in the survey please follow the web link. This will take you to the welcome page where you will be asked to give consent by selecting the option to consent and proceed to the questionnaire. You will not be required to give any identifiable data and all responses will be anonymous. The survey questions should take no more than 15 minutes. If you prefer to complete a paper version of the questionnaire, these can be requested from Joanna Fletcher-Smith by email at: joanna.fletcher-smith@nottingham.ac.uk or by telephone on (0115) 8230432.

#### Who can I complain to?

In case you have a complaint with anything to do with the study, you can initially approach the lead investigator, Joanna Fletcher-Smith. If this achieves no satisfactory outcome, you should then contact the Ethics Committee Secretary, Mrs Louise Sabir, Division of Therapeutics and Molecular Medicine, D Floor, South Block, Queen's Medical Centre, Nottingham, NG7 2UH. Telephone 0115 8231063. E-mail louise.sabir@nottingham.ac.uk.

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

Yes, all survey responses will be anonymous and your participation in the study will be kept confidential.

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

This study is being completed as part of a larger programme of research in part fulfilment of a PhD. The results will be written up in Joanna Fletcher-Smith's PhD thesis. The researcher will also aim to publish the findings of the survey in a peer reviewed journal relevant to occupational therapy clinicians and other members of the stroke rehabilitation community. When the results are published members of the three participating specialist sections will be informed via their member newsletters. An article will also be submitted to 'OT News'. An article will also be submitted to 'OT News' to inform members of the British Association of Occupational Therapists and College of Occupational Therapists of the results.

#### Who is organising and funding the research?

The University of Nottingham is sponsoring the research. This survey study is part of a PhD student research programme. This is being supervised by Professors from the University of Nottingham and the University of Birmingham.

#### Who has reviewed the study?

This study has been reviewed and approved by the University of Nottingham Medical School Ethics Committee and the Nottingham Stroke Research Consumer Group.

#### **Contact for Further Information**

Joanna Fletcher-Smith (PhD student/Research occupational therapist) <u>Joanna.fletcher-smith@nottingham.ac.uk</u> Division of Rehabilitation and Ageing, Room B108, Medical School, QMC, Nottingham, NG7 2UH (0115) 8230432

Outcome measure	Measurement purpose	Time of administration	Data type
Sheffield Screening Test for Acquired Language Disorders	Receptive and expressive communication ability	Baseline only	Ordinal scale or categorical if cut off scores are used <sup>1</sup>
Mini Mental State Examination (MMSE)	Cognitive function	Baseline only	Ordinal or categorical if the cut off scores are used <sup>2</sup>
Barthel ADL Index	Independence in self-care daily activities	Baseline, 3 months, 6 months & 12 months	Ordinal or Categorical if converted to a binary outcome (2 point increase in score = 'clinically improved', 0 increase ='no improvement')
Rivermead Mobility Index	Functional mobility	Baseline, 3 months, 6 months & 12 months	Ordinal scale. 15 items scored: yes=1, no=0.
Geriatric Depression Scale	Mood	Baseline, 3 months, 6 months & 12 months	Ordinal or categorical if the cut off scores are used <sup>3</sup>
EQ-5D	Quality of life	Baseline, 3 months, 6 months & 12 months	Ordinal

#### Table of the outcome measures used in the OTCH study

<sup>1</sup> scored from 0-20. Cut off scores are age dependent.  $\leq$ 59 = 17, 60-69 yrs = 16,  $\leq$ 70 = 15. (A score of <15 has been regarded as the optimal cut off point for the detection of language impairment after stroke with a sensitivity of 89% and specificity of 88% (Sackley et al., 2006)

<sup>2</sup>Most widely accepted & frequently used cut off score is 23. (Normal cog function = 27-30, mild cognitive impairment = 21-26, moderate cognitive impairment = 11-20, severe cognitive impairment = 0-10.)

<sup>3</sup>Original scoring for 30 item GDS: Normal = 0-9, mild depression = 10-19, severe depression = 20-30. GDS-SF (15 item) scoring: Normal = 0-5, >5 suggests depression,  $\geq$ 10 is almost always indicative of depression.

	Randomisation arm			
Care home cluster size	OT care homes	Control care homes		
	n=114	n=114		
	Number of clusters (%)	Number of clusters (%)		
1	11 (9.6)	18 (15.8)		
2	17 (14.9)	21 (18.4)		
3	13 (11.4)	15 (13.2)		
4	20 (17.5)	23 (20.2)		
5	18 (15.8)	12 (10.5)		
6	9 (7.9)	6 (5.3)		
7	5 (4.4)	5 (4.4)		
8	6 (5.3)	5 (4.4)		
9	8 (7.0)	1 (0.9)		
10	3 (2.6)	1 (0.9)		
11	0 (0)	3 (2.6)		
12	1 (0.9)	1 (0.9)		
13	0 (0)	1 (0.9)		
14	0 (0)	1 (0.9)		
15	0 (0)	1 (0.9)		
16	0 (0)	0 (0)		
17	0 (0)	0 (0)		
18	0 (0)	0 (0)		
19	1 (0.9)	0 (0)		
20	0 (0)	0 (0)		
21	1 (0.9)	0 (0)		
22	0 (0)	0 (0)		
23	1 (0.9)	0 (0)		

## Table showing the distribution of care home cluster size

	Randomisation arm		
	OT Control		
Number of care homes n (%)	114 (50)	114 (50)	
Type of care home n (%)			
Residential	53 (46.5)	54 (47.4)	
Nursing	61 (53.5)	60 (52.6)	
Centre n (%)			
University of Birmingham	37 (32.4)	36 (31.5)	
University of Nottingham	10 (8.7)	12 (10.5)	
Bangor University	8 (7.0)	9 (7.8)	
University of Central Lancashire	8 (7.0)	8 (7.0)	
Solent Healthcare PCT	13 (11.4)	13 (11.4)	
Plymouth	8 (7.0)	6 (5.2)	
Wolverhampton	8 (7.0)	8 (7.0)	
Taunton	4 (3.5)	4 (3.5)	
Stoke on Trent	4 (3.5)	6 (5.2)	
Coventry & Warwickshire	7 (6.1)	7 (6.1)	
Bournemouth & Poole	7 (6.1)	5 (4.3)	
Number of participants n (%)	568 (54.5)	474 (45.5)	
Type of care homen (%)			
Residential	207 (36.4)	166 (35.0)	
Nursing	361 (63.6)	308 (65.0)	
Centre n (%)			
University of Birmingham	189 (33.3)	133 (28.1)	
University of Nottingham	73 (12.9)	53 (11.2)	
Bangor University	59 (10.4)	45 (9.5)	
University of Central Lancashire	44 (7.7)	42 (8.9)	
Solent Healthcare PCT	56 (9.9)	52 (11.0)	
Plymouth	22 (3.9)	18 (3.8)	
Wolverhampton	31 (5.5)	27 (5.7)	
Taunton	25 (4.4)	20 (4.2)	
Stoke on Trent	11 (1.9)	38 (8.0)	
Coventry & Warwickshire	29 (5.1)	27 (5.7)	
Bournemouth & Poole	29 (5.1)	19 (4.0)	
Participants per care home			
Mean (sd)	5 (3.7)	4.2 (3.0)	
Median (IQR)	4 (3 to 6)	4 (2 to 5)	

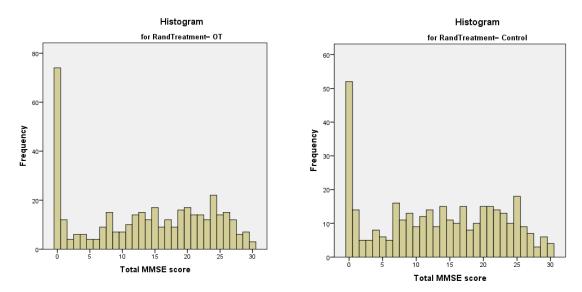
## Table of the distribution of participants across care home type

## Table showing the characteristics of participants by randomisation

#### arm

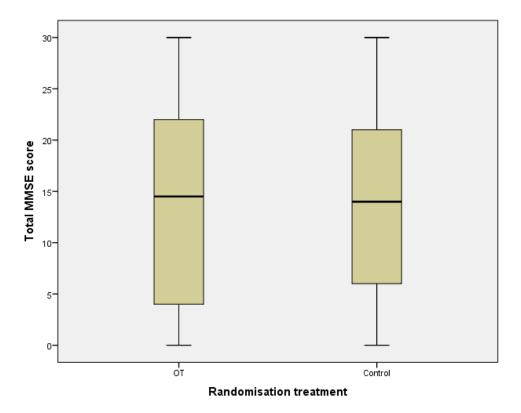
Characteristic	Characteristic Rar		
		OT Control	
		(N=568)	(N=474)
Age in years	mean (sd)	82.68 (9.08)	83.07 (9.41)
	median	84.00	85.00
	mode	89	87
Age range	(min – max)	46 - 101	43 - 102
Missing age	n (%)	2 (0.4)	2 (0.4)
Gender:	n (%)		
Male		203 (35.7)	174 (36.7)
Female		365 (64.3)	300 (63.3)
Ethnicity:	n (%)		
White British		495 (87.1)	431 (90.9)
White Irish		13 (2.3)	5 (1.1)
Other White background		9 (1.6)	9 (0.2)
White & Black Caribbea	n	2 (0.4)	2 (0.4)
Indian		9 (1.6)	5 (1.1)
Pakistani		1 (0.2)	0 (0)
Caribbean		11 (1.9)	6 (1.3)
African		2 (0.4)	1 (0.2)
Other		1 (0.2)	1 (0.2)
Unknown	(6/)	24 (4.2)	13 (2.7)
Co-morbidities:	n (%)		
Cardiovascular disease		342 (60.2)	277 (58.4)
Respiratory disease		90 (15.8)	76 (16.0)
Hepatic disease		6 (1.05)	8 (1.6)
Gastrointestinal disease		96 (16.9)	78 (16.4)
Renal disease		38 (6.6)	50 (10.5)
Urological disease		92 (16.1)	80 (16.8)
Neurological disease		371 (65.3)	295 (62.2)
Muscular disease		214 (37.6)	200 (42.1)
Dermatological disease		86 (15.1)	71 (14.9)
Fall history	n (%)	203 (35.7)	200 (42.1)
Confirmed eligibility: Confirmed stroke	11 (%)	334 (58.8)	318 (67.1)
Confirmed TIA		47 (8.3)	
Suspected stroke		180 (31.7)	28 (5.9) 123 (25.9)
No stroke or TIA		7 (1.2)	5 (1.1)
NU SLIUKE UI TIA		/ (1.2)	J (1.1)

## Histograms showing frequency distribution of baseline MMSE scores

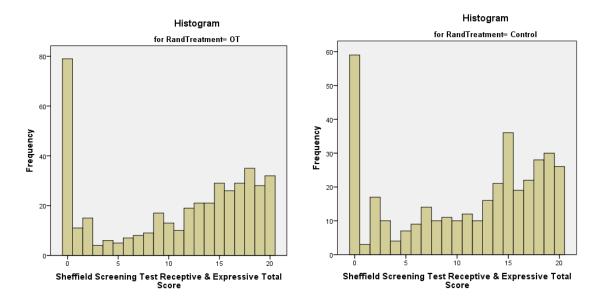


#### by randomisation arm

## Box-whisker diagram of baseline MMSE score

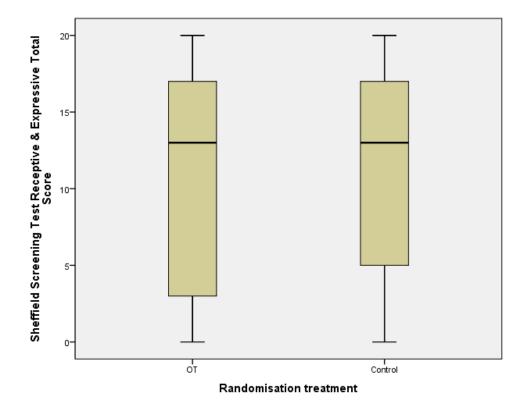


## Histograms showing frequency distribution of baseline SST scores

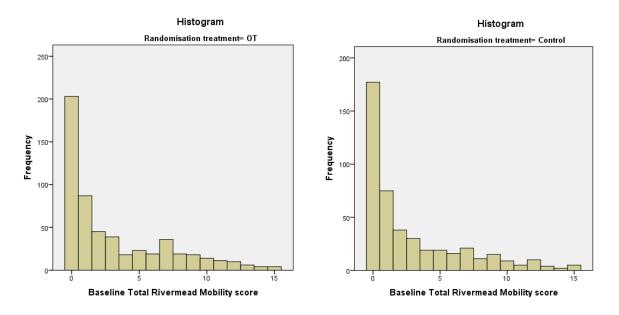


#### by randomisation arm.

## Box-whisker diagram of baseline Sheffield Screening Test scores

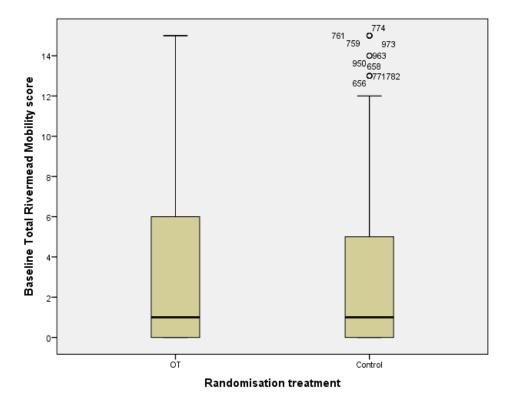


## Histograms showing frequency distribution of baseline RMI scores

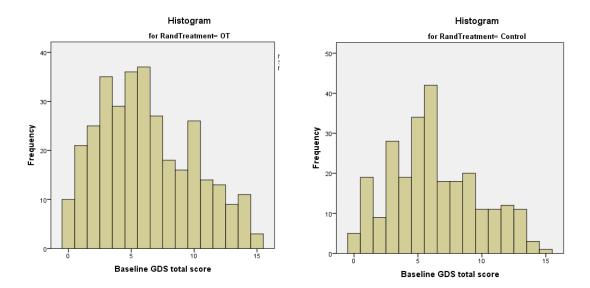


#### by randomisation arm

### Box whisker diagram of baseline Rivermead Mobility Index scores

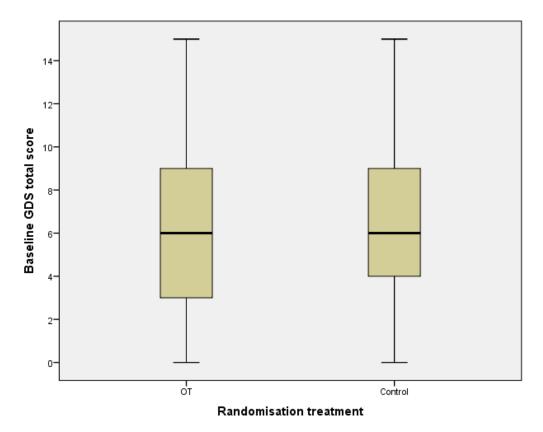


## Histograms showing frequency distribution of baseline GDS scores

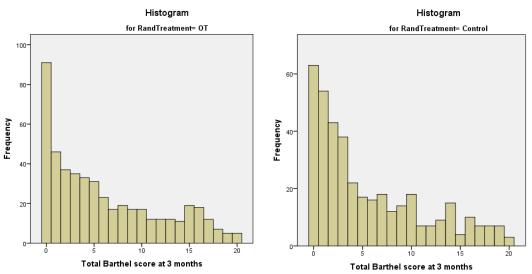


#### by randomisation arm

### Box-whisker diagram of baseline GDS scores

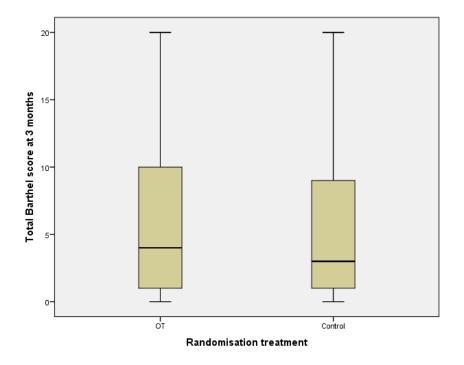


## Histograms showing frequency distribution of 3 month BI scores by

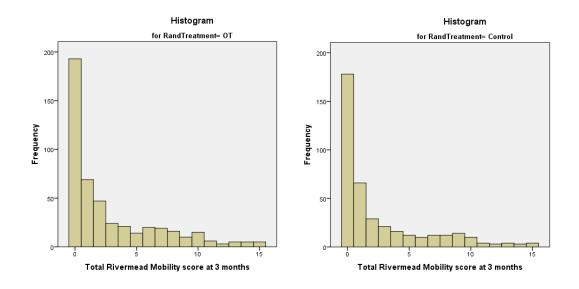


## randomisation arm

## Box-whisker diagram of 3 month Barthel Index scores

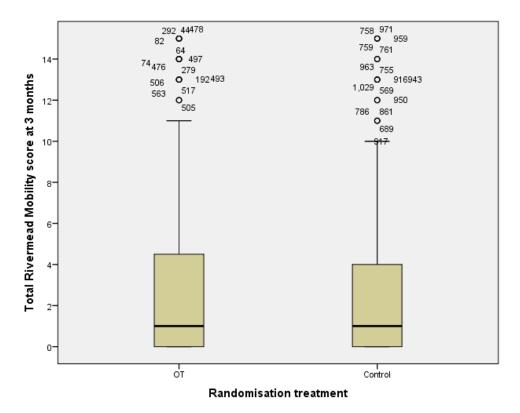


### Histograms showing frequency distribution of 3 month RMI scores

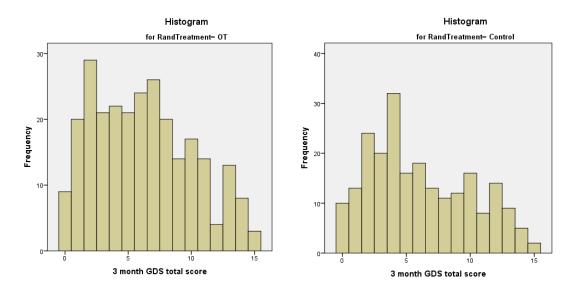


#### by randomisation arm

#### Box-whisker diagram of 3 month Rivermead Mobility Index scores

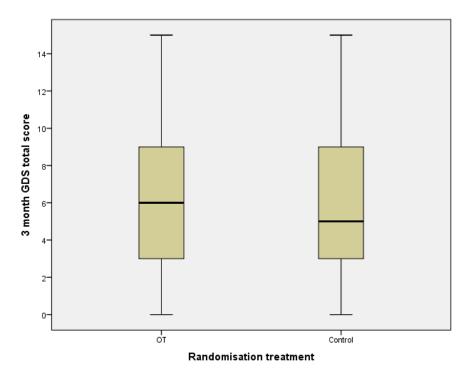


### Histograms showing frequency distribution of 3 month GDS scores



### by randomisation arm

## Box-whisker diagram of 3 month GDS scores



## Degree of association between the binary covariates

Covariate 1	Covariate 2	Strength of association as determined by:		
		Gamma	Contingency coefficient	
Age at baseline as binary (84yrs+ or <84yrs)	Gender	-	.275	
Age at baseline as binary (84yrs+ or <84yrs)	Ethnicity (white or other)	-	.089	
Age at baseline as binary (84yrs+ or <84yrs)	Falls history (0 or 1+)	.206		
Age at baseline as binary (84yrs+ or <84yrs)	Confirmed stroke or not at baseline	-	.132	
Age at baseline as binary (84yrs+ or <84yrs)	OT versus control	-	.008	
Age at baseline as binary (84yrs+ or <84yrs)	MMSE total score as binary at baseline	083		
Age at baseline as binary (84yrs+ or <84yrs)	Sheffield Screening Test score as binary at baseline	.154		
Age at baseline as binary (84yrs+ or <84yrs)	Time since stroke (>1yr v 1yr or less)	215		
Age at baseline as binary (84yrs+ or <84yrs)	Nursing v Residential Home	-	.078	
Age at baseline as binary (84yrs+ or <84yrs)	Care home cluster size (median+ or <median)< td=""><td>039</td><td>-</td></median)<>	039	-	
Gender	Ethnicity (white or other)	-	.078	
Gender	Falls history (0 or 1+)	-	.065	
Gender	Confirmed stroke or not at baseline	-	.083	
Gender	OT versus control	-	.010	
Gender	MMSE total score as binary at baseline	-	.005	
Gender	Sheffield Screening Test score as binary at baseline	-	.076	
Gender	Time since stroke (>1yr v 1yr or less)	-	.033	
Gender	Nursing v Residential Home	-	.041	
Gender	Care home cluster size (median+ or <median)< td=""><td>-</td><td>.034</td></median)<>	-	.034	
Ethnicity (white or other)	Falls history (0 or 1+)	-	.056	
Ethnicity (white or other)	Confirmed stroke or not at baseline	-	.042	
Ethnicity (white or other)	OT versus control	-	.050	
Ethnicity (white or other)	MMSE total score as binary at baseline	-	.037	
Ethnicity (white or other)	Sheffield Screening Test score as binary at baseline	-	.079	
Ethnicity (white or other)	Time since stroke (>1yr v 1yr or less)	-	.013	
Ethnicity (white or other)	Nursing v Residential Home	-	.017	
Ethnicity (white or other)	Care home cluster size (median+ or <median)< td=""><td>-</td><td>.013</td></median)<>	-	.013	
Falls history (0 or 1+)	Confirmed stroke or not at baseline	-	.135	
Falls history (0 or 1+)	OT versus control	-	.058	
Falls history (0 or 1+)	MMSE total score as binary at baseline	.095	-	
Falls history (0 or 1+)	Sheffield Screening Test score as binary at baseline	.141	-	
Falls history (0 or 1+)	Time since stroke (>1yr v	.000	-	

	1yr or less)		
Falls history (0 or 1+)	Nursing v Residential Home	-	.119
Falls history (0 or 1+)	Care home cluster size	045	
	(median+ or <median)< td=""><td></td><td></td></median)<>		
Confirmed stroke or not at	OT versus control	-	.085
baseline			
Confirmed stroke or not at	MMSE total score as binary	-	.072
baseline	at baseline		
Confirmed stroke or not at	Sheffield Screening Test	-	.043
baseline	score as binary at baseline		
Confirmed stroke or not at	Time since stroke (>1yr v	-	.083
baseline	1yr or less)		
Confirmed stroke or not at	Nursing v Residential Home	-	.137
baseline			
Confirmed stroke or not at	Care home cluster size	-	.019
baseline	(median+ or <median)< td=""><td></td><td></td></median)<>		
OT versus control	MMSE total score as binary	-	.028
	at baseline		
OT versus control	Sheffield Screening Test	-	.008
07	score as binary at baseline		0.05
OT versus control	Time since stroke (>1yr v	-	.035
	1yr or less)		015
OT versus control	Nursing v Residential Home Care home cluster size	-	.015
OT versus control		-	.095
MMSE total score as binary	(median+ or <median) Sheffield Screening Test</median) 	<mark>.911</mark>	-
at baseline	score as binary at baseline	<mark>.911</mark>	-
MMSE total score as binary	Time since stroke (>1yr v	.029	
at baseline	1yr or less)	.029	-
MMSE total score as binary	Nursing v Residential Home	-	.109
at baseline	Nurshing V Residential Home		.105
MMSE total score as binary	Care home cluster size	173	-
at baseline	(median+ or <median)< td=""><td>1170</td><td></td></median)<>	1170	
Sheffield Screening Test	Time since stroke (>1yr v	168	-
score as binary at baseline	1yr or less)		
Sheffield Screening Test	Nursing v Residential Home	-	.101
score as binary at baseline			
Sheffield Screening Test	Care home cluster size	105	-
score as binary at baseline	(median+ or <median)< td=""><td></td><td></td></median)<>		
Time since stroke (>1yr v	Nursing v Residential Home	-	.074
1yr or less)			
Time since stroke (>1yr v	Care home cluster size	.135	-
1yr or less)	(median+ or <median)< td=""><td></td><td></td></median)<>		
Nursing v Residential Home	Care home cluster size	-	.267
	(median+ or <median)< td=""><td></td><td></td></median)<>		

\*Gamma association of 0.30 = strong association between the covariates

#### Logistic regression model for RMI at 3 months with RMI at baseline included

Rivermead Mobility Index at 3 months					
Predictor variable	OR	95% CI	P value		
RMI at Baseline	44.5	17.9 - 110.4	<0.001**		
Age	0.7	0.3 - 1.5	0.328		
Gender	1.7	0.7 - 4.3	0.295		
Ethnicity	0.8	0.1 - 4.9	0.792		
Fall history	0.9	0.4 - 2.1	0.785		
Stroke Eligibility	2.1	0.7 - 6.2	0.198		
OT v Control	2.3	1.0 - 5.5	0.051		
MMSE at baseline	1.1	0.5 - 2.6	0.812		
Time post stroke	1.0	0.4 - 2.5	0.940		
Nursing v Residential	2.6	1.1 - 6.3	0.027*		
Care home cluster size at baseline	1.0	0.4 - 2.7	0.996		

\*Significant at the 5% level \*\*Significant at the 1% level

#### Logistic regression model for GDS at 3 months with GDS at baseline included

Geriatric Depression Scale at 3 months					
Predictor variable	OR	95% CI	P value		
GDS at Baseline	11.0	4.3 - 28.1	<0.001**		
Age	0.6	0.2 - 1.3	0.191		
Gender	2.5	0.9 - 6.8	0.069		
Ethnicity	1.4	0.3 - 7.0	0.675		
Fall history	1.6	0.6 - 3.9	0.343		
Stroke Eligibility	0.5	0.1 - 2.0	0.295		
OT v Control	0.9	0.4 - 2.1	0.819		
MMSE at baseline	1.5	0.6 - 3.8	0.358		
Time post stroke	3.5	1.3 - 9.2	0.012*		
Nursing v Residential	1.2	0.4 - 3.3	0.743		
Care home cluster size at baseline	1.6	0.6 - 4.5	0.393		

\*Significant at the 5% level \*\*Significant at the 1% level

## Logistic regression model for EQ5D Pain & Discomfort at 3 months with EQ5D Pain & Discomfort at baseline included

EQ5D Pain and Discomfort at 3 months					
Predictor variable	OR	95% CI	P value		
EQ5D Pain/Discomfort at Baseline	4.0	2.5 - 6.5	<0.001**		
Age	1.3	0.8 - 2.1	0.295		
Gender	0.5	0.3 - 0.9	0.017*		
Ethnicity	0.7	0.3 - 1.9	0.477		
Fall history	0.8	0.5 - 1.3	0.424		
Stroke Eligibility	0.7	0.4 - 1.4	0.346		
OT v Control	0.8	0.5 - 1.2	0.282		
SST at baseline	1.0	0.6 - 1.6	0.969		
Time post stroke	1.0	0.6 - 1.7	0.913		
Nursing v Residential	1.2	0.7 - 2.0	0.553		
Care home cluster size at baseline	1.2	0.7 - 2.2	0.505		

\*Significant at the 5% level \*\*Significant at the 1% level

#### GEE model for RMI with time (0m & 3m) included as a predictor variable

Rivermead Mobility Index					
Predictor variable OR 95% CI P v					
Age	0.8	0.5 - 1.4	0.405		
Gender	0.9	0.5 - 1.7	0.818		
Ethnicity	0.9	0.3 - 2.8	0.867		
Fall history	1.7	1.0 - 2.8	0.054		
Stroke Eligibility	0.7	0.3 - 1.3	0.210		
OT v Control	1.5	0.9 - 2.5	0.140		
MMSE at baseline	2.3	1.4 - 3.9	0.002*		
Time post stroke	0.9	0.5 - 1.6	0.705		
Nursing v Residential	5.6	3.3 - 9.7	<0.001**		
Care home cluster size at baseline	1.0	0.6 - 1.9	0.914		
Time	0.8	0.6 - 1.1	0.168		

\*Significant at the 5% level \*\*Significant at the 1% level

#### GEE model for GDS with time (0m & 3m) included as a predictor variable

Geriatric Depression Scale				
Predictor variable	OR	95% CI	P value	
Age	0.5	0.3 - 0.8	0.006*	
Gender	0.9	0.6 - 1.5	0.691	
Ethnicity	0.7	0.2 - 1.8	0.411	
Fall history	1.2	0.8 - 2.0	0.368	
Stroke Eligibility	0.7	0.3 - 1.4	0.257	
OT v Control	0.9	0.6 - 1.4	0.529	
MMSE at baseline	1.3	0.8 - 2.1	0.344	
Time post stroke	1.2	0.7 - 1.9	0.556	
Nursing v Residential	0.9	0.6 - 1.5	0.739	
Care home cluster size at baseline	1.7	1.0 - 3.0	0.049	
Time	0.8	0.6 - 1.1	0.140	

\*Significant at the 5% level \*\*Significant at the 1% level

## GEE model for EQ5D pain/discomfort with time (0m & 3m) included as a predictor variable

Geriatric Depression Scale					
Predictor variable	OR	95% CI	P value		
Age	1.1	0.7 - 1.5	0.799		
Gender	0.6	0.4 - 0.9	0.008*		
Ethnicity	1.4	0.7 – 2.6	0.315		
Fall history	0.9	0.7 - 1.3	0.713		
Stroke Eligibility	0.6	0.4 - 1.0	0.061		
OT v Control	0.8	0.6 - 1.1	0.230		
SST at baseline	0.7	0.5 - 1.0	0.065		
Time post stroke	1.4	0.9 - 2.0	0.105		
Nursing v Residential	1.2	0.8 - 1.8	0.301		
Care home cluster size at baseline	1.1	0.7 - 1.7	0.680		
Time	1.2	1.0 - 1.6	0.122		

\*Significant at the 5% level \*\*Significant at the 1% level





#### **Occupational Therapy Intervention Log**

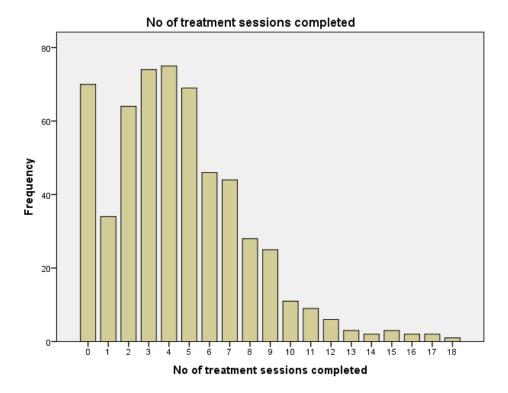
At each visit please record the approximate time in minutes spent on each of the areas below:

					(	Category	of inter	vention		_	
			Assessment and goal setting	Communication Including listening to residents' concerns or life story, information giving (to residents, staff or relatives), referrals to other agencies and ordering equipment	ADL training Transfers and mobility Including aspects of wheelchair provision if directly concerned with mobility rather than seating			Other Including treating impairments directly and the use of leisure activities	Total		
		Date			<u>Cognitive</u>	Functional	Cognitive	Functional	Including preventative interventions, such as wheelchair cushions and palm protectors		
	1										
	2										
	3										
	4										
	5										
1	6										
Visit											

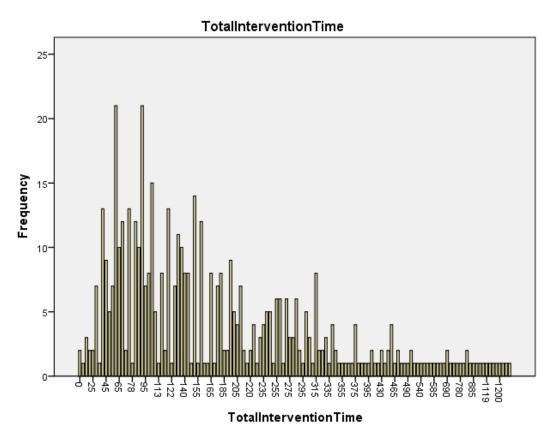
OTCH\_OT\_Intervention\_Log\_v2.0\_04Sept10.doc

Occupational Therapy Intervention Log

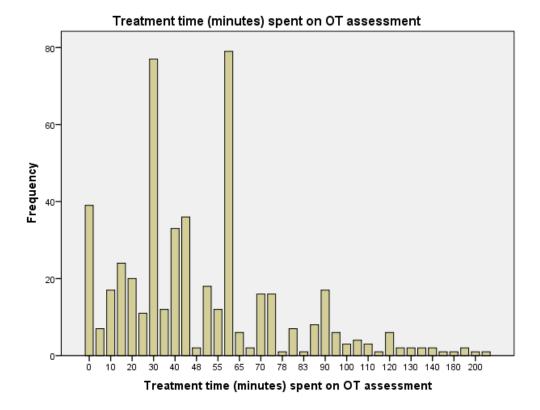
## Total number of occupational therapy intervention sessions received by participants



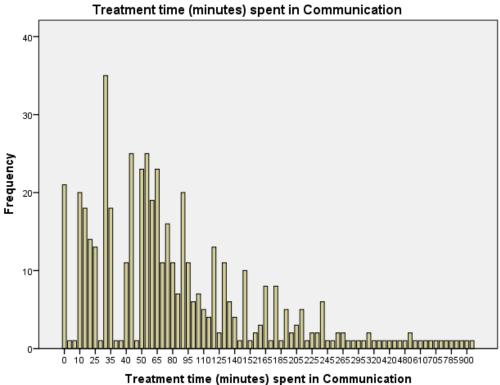
**Residents' total occupational therapy intervention time** 



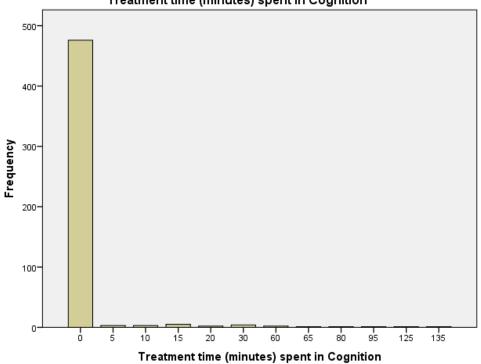
#### Residents' occupational therapy time engaged in assessment



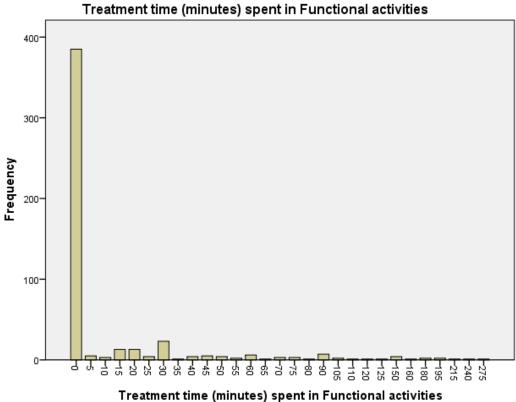
#### Residents' occupational therapy time engaged in communication



#### Residents' occupational therapy time engaged in cognitive interventions

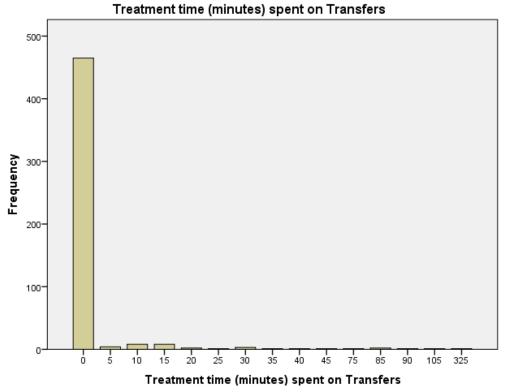


#### Residents' occupational therapy time engaged in functional activities

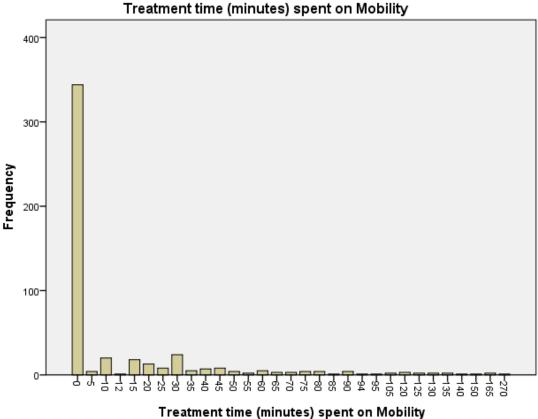


#### Treatment time (minutes) spent in Cognition

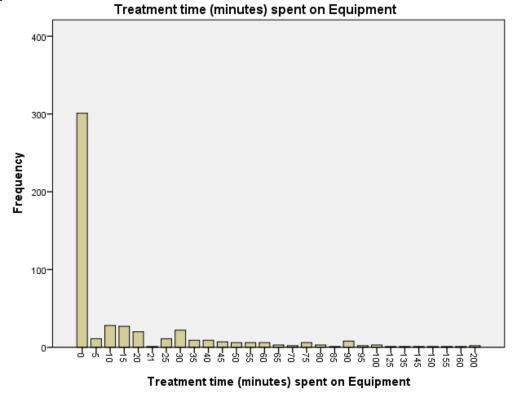






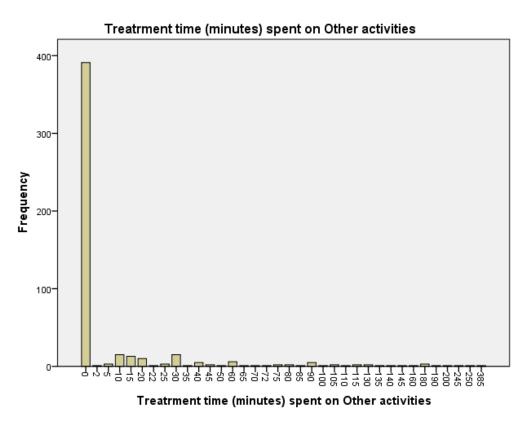


325



## Residents' occupational therapy time engaged in equipment provision

Residents' occupational therapy time engaged in 'other' activities



326

## Table of association between the BI sub score covariates and the OTtreatment covariates

Covariate 1	Covariate 2	Strength of
(Barthel Index sub score	OT treatment time	association as
item)	spent on:	determined by:
item)	spene on	Kendall's tau-b
Baseline Q1:	Assessment	-0.036
Bathing/Showering	(0  mins or  > 0  mins)	(p=.510)
(Dependent or Independent)	Communication	-0.089
	(0  mins or  > 0  mins)	(p=.223)
	Cognition	-0.009
	(0 mins or >0 mins)	(p=.835)
	Functional activities	0.027
	(0 mins or >0 mins)	(p=.569)
	Transfers	0.045
	(0 mins or >0 mins)	(p=.430)
	Mobility	0.083
	(0 mins or >0 mins)	(p=.099)
	Equipment	-0.037
	(0 mins or >0 mins)	(p=.398)
	'Other activities'	0.012
	(0 mins or >0 mins)	(p=.791)
Baseline Q2: Stairs	Assessment	-0.069
(Dependent or Independent)	(0 mins or >0 mins)	(p=.241)
	Communication	-0.062
	(0 mins or >0 mins)	(p=.322)
	Cognition	<mark>-0.061</mark>
	(0 mins or >0 mins)	(p<.001)
	Functional activities	0.003
	(0 mins or >0 mins)	(p=.940)
	Transfers	-0.012
	(0 mins or >0 mins)	(p=.776)
	Mobility	0.041
	(0 mins or >0 mins)	(p=.385)
	Equipment	-0.090
	<pre>(0 mins or &gt;0 mins) `Other activities'</pre>	(p=.031) 0.031
	(0 mins or >0 mins)	(p=.523)
Baseline Q3: Dressing	Assessment	-0.043
(Dependent or Independent)	(0 mins or >0 mins)	(p=.411)
(Dependent of Independent)	Communication	-0.023
	(0  mins or  > 0  mins)	(p=.643)
	Cognition	-0.048
	(0  mins or  > 0  mins)	(p=.123)
	Functional activities	-0.083
	(0  mins or  > 0  mins)	(p=.029)
	Transfers	0.006
	(0 mins or >0 mins)	(p=.903)
	Mobility	0.127 (Weak)
	(0  mins or  > 0  mins)	(p=.011)
	Equipment	-0.072
	(0 mins or >0 mins)	(p=.092)
	'Other activities'	0.004
	(0 mins or >0 mins)	(p=.937)
Baseline Q4: Indoor Mobility	Assessment	-0.087

		( ( ( ) )
(Dependent or Independent)	(0 mins or >0 mins)	(p=.100)
	Communication	-0.059
	(0 mins or >0 mins)	(p=.261)
	Cognition	<mark>-0.070</mark>
	(0 mins or >0 mins)	(p=.042)
	Functional activities	-0.069
	(0 mins or >0 mins)	(p=.098)
	Transfers	-0.065
	(0  mins or  >0  mins)	(p=.079)
	Mobility	0.043
	(0  mins or  >0  mins)	(p=.347)
	Equipment	-0.062
	(0  mins or  >0  mins)	(p=.158)
	'Other activities'	-0.032
	(0 mins or >0 mins)	(p=.466)
Baseline Q5: Transfer bed to	Assessment	-0.093
chair	(0 mins or >0 mins)	(p=.071)
(Dependent or Independent)	Communication	-0.062
	(0  mins or  > 0  mins)	(p=.230)
	Cognition	-0.044
	(0  mins or  > 0  mins)	(p=.263)
	Functional activities	-0.088
	(0  mins or  > 0  mins)	(p=.034)
	Transfers	0.003
	(0  mins or  > 0  mins)	(p=.948)
	Mobility	0.066
	(0  mins or  > 0  mins)	(p=.153)
	Equipment	-0.049
	(0  mins or  > 0  mins)	(p=.263)
	'Other activities'	-0.039
	(0 mins or >0 mins)	(p=.364)
Baseline Q6: Feeding	Assessment	-0.074
(Dependent or Independent)	(0  mins or  > 0  mins)	(p=.114)
(Dependent of Independent)	Communication	-0.053
	(0 mins or >0 mins)	(p=.257)
	Cognition $(0, \min c)$	-0.068
	(0 mins or >0 mins) Functional activities	(p=.103) 0.030
	(0 mins or >0 mins)	(p=.499)
	Transfers $(0, mins, or > 0, mins)$	-0.031
	(0 mins or >0 mins)	(p=.473)
	Mobility	0.095
	(0 mins or >0 mins)	(p=.035)
	Equipment	-0.045
	(0 mins or >0 mins)	(p=.315)
	'Other activities'	-0.044
	(0 mins or >0 mins)	(p=.316)
Baseline Q7: Toileting	Assessment	-0.035
(Dependent or Independent)	(0 mins or >0 mins)	(p=.471)
	Communication	-0.001
	(0 mins or >0 mins)	(p=.984)
	Cognition	-0.036
	(0 mins or >0 mins)	(p=.348)
	Functional activities	0.004
	(0 mins or >0 mins)	(p=.927)
	Transfers	-0.032

		( ( ) )
	(0 mins or >0 mins)	(p=.432)
	Mobility	0.151 (weak)
	(0 mins or >0 mins)	(p=.002)
	Equipment	-0.026
	(0 mins or >0 mins)	(p=.557)
	'Other activities'	-0.007
	(0  mins or  > 0  mins)	(p=.882)
Baseline Q8: Wash face,	Assessment	-0.016
brush teeth/hair	(0 mins or >0 mins)	(p=.729)
(Dependent or Independent)	Communication	0.087
	(0 mins or >0 mins)	(p=.032)
	Cognition	-0.008
	(0  mins or  >0  mins)	(P=.854)
	Functional activities	0.086
	(0 mins or >0 mins)	(p=.060)
	Transfers	0.036
	(0 mins or >0 mins)	(p=.431)
	Mobility	0.201 (moderate)
	(0  mins or  > 0  mins)	(p<.001)
	Equipment	0.049
	(0  mins or  > 0  mins)	(p=.276)
	'Other activities'	0.091
	(0  mins or  > 0  mins)	(p=.046)
3 months Q1:	Assessment	-0.088
Bathing/Showering	(0  mins or  > 0  mins)	(p=.234)
(Dependent or Independent)	Communication	-0.105
(Dependent of Independent)	(0  mins or  > 0  mins)	(p=.256)
	Cognition	-0.044
	(0  mins or  > 0  mins)	(p=.001)
	Functional activities	0.005
	(0  mins or  > 0  mins)	(p=.915)
	Transfers	0.037
	(0 mins or >0 mins)	(p=.530) -0.003
	Mobility	
	(0 mins or >0 mins)	(p=.940)
	Equipment	-0.087
	(0 mins or >0 mins)	(p=.041)
	'Other activities'	0.096
	(0 mins or >0 mins)	(p=.106)
3 months Q2: Stairs	Assessment	-0.016
(Dependent or Independent)	(0 mins or >0 mins)	(p=.763)
	Communication	-0.017
	(0 mins or >0 mins)	(p=.752)
	Cognition	-0.009
	(0 mins or >0 mins)	(p=.837)
	Functional activities	-0.082
	(0 mins or >0 mins)	(p=.022)
	Transfers	0.050
	(0 mins or >0 mins)	(p=.409)
	Mobility	-0.051
	(0 mins or >0 mins)	(p=.232)
	Equipment	<mark>-0.092</mark>
	(0 mins or >0 mins)	(p=.034)
	'Other activities'	0.067
	(0 mins or >0 mins)	(p=.217)
3 months Q3: Dressing	Assessment	-0.091

		( ( ))
(Dependent or Independent)	(0 mins or >0 mins)	(p=.139)
	Communication	-0.017
	(0 mins or >0 mins)	(p=.746)
	Cognition	-0.053
	(0 mins or >0 mins)	(p=.101)
	Functional activities	-0.055
	(0  mins or  > 0  mins)	(p=.197)
	Transfers	-0.022
	(0 mins or >0 mins)	(p=.604)
	Mobility	0.137 (Weak)
	(0  mins or  > 0  mins)	(p=.008)
	Equipment	-0.049
	(0 mins or >0 mins)	(p=.278)
	`Other activities'	0.037
	(0  mins or  > 0  mins)	(p=.450)
3 months Q4: Indoor	Assessment	-0.092
Mobility (Dependent or	(0  mins or  > 0  mins)	(p=.099)
Independent)	Communication	-0.003
	(0 mins or >0 mins)	(p=.943)
	Cognition	0.001
	(0  mins or  > 0  mins)	
	Functional activities	(p=.978) -0.046
	(0 mins or >0 mins)	
		(p=.300)
	Transfers	-0.041
	(0 mins or >0 mins)	(p=.324)
	Mobility	0.098
	(0 mins or >0 mins)	(p=.046)
	Equipment	0.007
	(0 mins or >0 mins)	(p=.881)
	'Other activities'	0.007
	(0 mins or >0 mins)	(p=.876)
3 months Q5: Transfer bed	Assessment	-0.147 (weak)
to chair	(0 mins or >0 mins)	(p=.012)
(Dependent or Independent)	Communication	-0.019
	(0 mins or >0 mins)	(p=.696)
	Cognition	-0.040
	(0 mins or >0 mins)	(p=.343)
	Functional activities	<mark>-0.087</mark>
	(0 mins or >0 mins)	(p=.045)
	Transfers	-0.002
	(0 mins or >0 mins)	(p=.962)
	Mobility	0.116 (Weak)
	(0 mins or >0 mins)	(p=.017)
	Equipment	-0.006
	(0  mins or  > 0  mins)	(p=.898)
	'Other activities'	-0.046
	(0  mins or  > 0  mins)	(p=.299)
3 months Q6: Feeding	Assessment	-0.026
(Dependent or Independent)	(0  mins or  > 0  mins)	(p=.582)
	Communication	0.012
	(0  mins or  > 0  mins)	(p=.795)
	Cognition	0.013
	(0  mins or  > 0  mins)	(p=.779)
	Functional activities	0.023
	(0 mins or >0 mins)	(p=.625)
	Transfers	-0.021

	(0 mins or >0 mins)	(p=.648)
	Mobility	0.195 (moderate)
	(0  mins or  > 0  mins)	(p<.001)
	Equipment	-0.003
	(0  mins or  > 0  mins)	(p=.950)
	'Other activities'	0.006
	(0  mins or  > 0  mins)	(p=.904)
3 months Q7: Toileting	Assessment	-0.086
(Dependent or Independent)	(0  mins or  > 0  mins)	(p=.128)
(Dependent of Independent)	Communication	-0.044
	(0  mins or  > 0  mins)	(p=.426)
	Cognition	-0.063
	(0  mins or  > 0  mins)	(p=.077)
	Functional activities	-0.050
	(0  mins or  > 0  mins)	(p=.263)
	Transfers	-0.030
	(0  mins or  > 0  mins)	(p=.478)
	Mobility	0.166 (Weak)
	(0  mins or  > 0  mins)	(p=.001)
	Equipment	0.044
	(0  mins or  > 0  mins)	(p=.354)
	'Other activities'	-0.009
	(0  mins or  > 0  mins)	(p=.847)
3 months Q8: Wash face,	Assessment	-0.008
brush teeth/hair	(0  mins or  > 0  mins)	(p=.866)
(Dependent or Independent)	Communication	0.012
(Dependent of Independent)	(0  mins or  > 0  mins)	(p=.787)
	Cognition	0.033
	(0  mins or  > 0  mins)	(p=.496)
	Functional activities	0.084
	(0  mins or  > 0  mins)	(p=.077)
	Transfers	0.046
	(0  mins or  > 0  mins)	(p=.335)
	Mobility	0.259 (moderate)
	(0  mins or  > 0  mins)	(p<.001)
	Equipment	0.058
	(0  mins or  > 0  mins)	(p=.215)
	'Other activities'	0.057
	(0  mins or  > 0  mins)	(p=.225)