

How does the delivery of paid homecare compare to the agreed care plan for clients living with dementia?



Care Plan

GENERAL CAREGIVING	M	T	W	T	F	S	S
Dressing							
Eating							
Hydrating							
Administering medications							
Toileting							

HYGIENE	M	T	W	T	F	S	S
Daily personal hygiene							

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Overview

- Background
- Aims and objectives of the study
- Methods
- Findings
- Strengths & Limitations
- Discussion and conclusions
- Acknowledgements



Background

Over 50 million people living with dementia (PLWD) worldwide, Over 850K in UK (Livingston et al.,2020).

Across Europe & US approx. 2/3 of (PLWD) live in their own home (Willink et al., 2020) supported by homecare workers (HCW) Supports independence

HCW's Supports > 350, 000 older people in England (60% HCW work with PLWD) – Inconsistent provision

HCW - well- placed to provide '*Person –Centred Care*' in dementia (Cooper et al.,2017)



Rationale and Research Question

- **Care plans** communicate information about the PLWD, directs care and support. Digital versions are developing (**Guisado-Fernandez et al., 2019**) but underused
- Previous research on care plan use for PLWD has focussed on NHS settings (**Drummond & Simpson, 2017**) and found barriers to using care plans effectively.
- No research to date that looks at Care plans in *Homecare* settings with PLWD- my study addresses this gap in knowledge.

‘How does the delivery of paid homecare compare to the agreed care plan for clients living with dementia? ‘

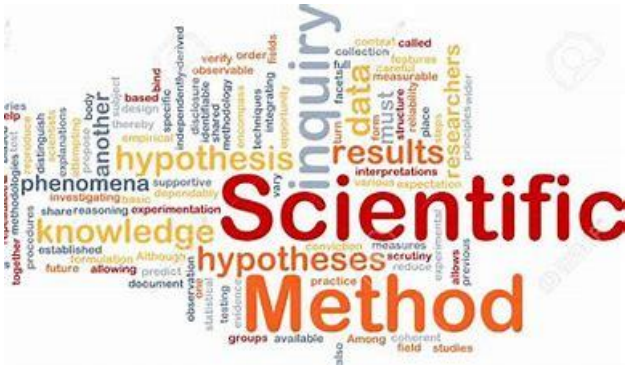
The study: Aims and Objectives

Aims -

- To elicit comparisons between the care that is delivered by HCW to PLWD and the information contained within the client care plan.

Objectives –

- Conduct a **Secondary Thematic Analysis** using data (Notes and records) of observations between HCW and their clients who are living with dementia. (16 HCW & 17 PLWD)



Methods

Study Design- *Qualitative secondary analysis*

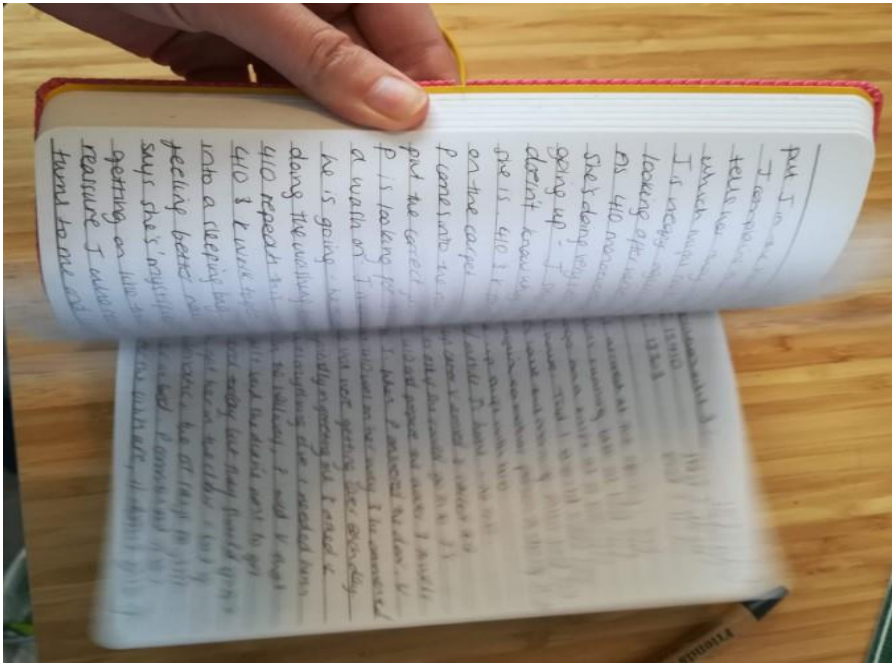
Setting and sample from the primary study - *Participant observations*

Data analysis - *Analytic approach*

Findings- *Demographic Characteristics*

Study Design

- I undertook a **secondary qualitative analysis** of **primary ethnographic** data (comparing client's **care plans** with **field notes** from observed care)
- Full details of the recruitment process and procedures are reported elsewhere (Leverton, Burton, Beresford-Dent, Rapaport, Manthorpe, Azocar, et al., 2021; Leverton, Burton, Beresford-Dent, Rapaport, Manthorpe, Mansour, et al., 2021) .
- Three researchers,(psychology and sociology backgrounds) collected the primary data using an **ethnographic approach**
- Multi-site observations of Home care workers (HCW) and people living with dementia (PLWD), between September 2018 and March 2019.



(Actual Field note book)

Setting and sample from the primary study –

(The data I then used for my study)

Participant observations

- In the **Primary Study, (Leverton et al., 2021)** 6 Home care Agencies consented to take part in ethnographic participant observations of home care visits of PLWD
- **For the current study (my sample)** - observation field notes of **16** HCW , providing care to **17** PLWD at home. (**100** hrs of obs. reviewed and **103** field notes compared to redacted care plans)
- I included **care plans** of the 17 PLWD (collected in the primary study)
- Client anonymity was ensured in the collected data through use of a pseudonym name, starting with: Letter “**A**”- for HCW, e.g., “**Alison**”, letter “**B**”- for the PLWD, e.g., “**Brenda**”, and “**C**”- denoting the family carer’s name, e.g., “**Cameron**”.

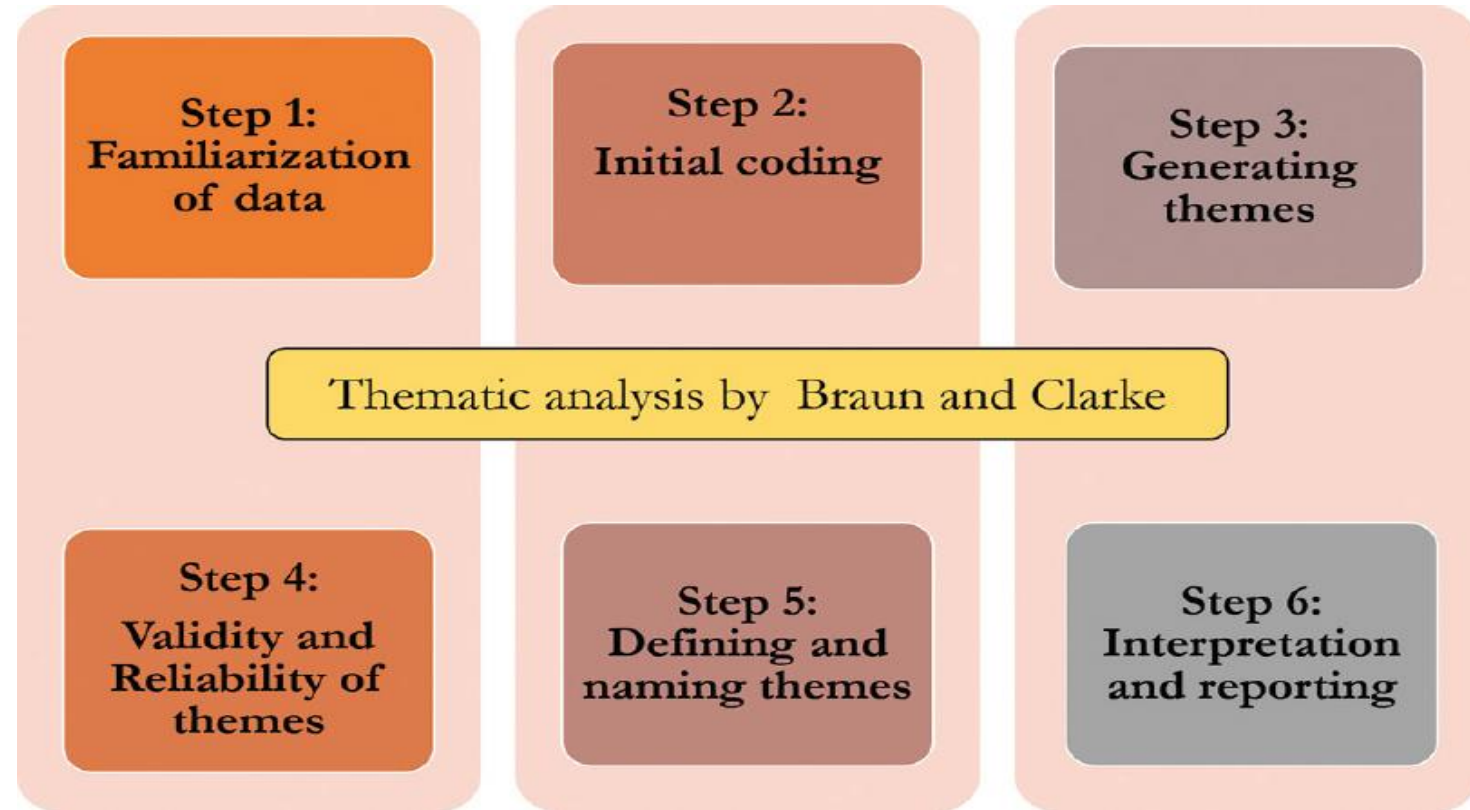
Data analysis - *Analytic approach*

- Braun and Clarke's framework for **Reflexive Thematic Analysis** (Braun & Clarke, 2006, 2019, 2021)
- Flexible to interpret the data - not tied to any particular epistemological or theoretical perspective
- **Constructivist** perspective, (dynamic between the homecare workers and the PLWD in homecare context)

Analytic Process

I compared care plans with observation field notes.

** **Reflexivity** was key!



Findings

Demographic Characteristics

- I reviewed observation fieldnotes of **17** PLWD and **16** HCW, together with the respective care plan.
- HCW were all female, with a mean age of **48.9** years; PLWD comprised 3 males between **61- 84** years and **14** females between **77** and **96** years. Participant characteristics are detailed in **Table 1**.



Table 1. Client name & age	Homecare worker and organisation (1,2,3 etc.)	Private or Local Authority agency funded care	Care Plan Up to date? (Y/N/review date not reported [NR])	Scheduled visit duration, (Per visit)	Client Needs (As stated within the care plan) * SEE KEY	Living situation
1. Barbara (80)	Avery -4	Local Authority	N	30 – 45 minutes	A, B, C, D, E,F,G	Lives with son
2. Brenda (93)	Alison -2	Local Authority	Y	30 minutes	A, B, D, F, G, L	Lives alone
3. Betty (Data missing)	Angela - 1	Private	Y	3 hours	B, F, G, H	Lives alone
4. Bridget (94)	Alison -2	Local Authority	Y	30 minutes	A, B, F, G, K, H, L	Lives alone.
5. Benji (84)	Alison -2	Local Authority	Y	30 minutes	A, E, J,	Lives with wife
6. Bernice (89)	Alison -2	Local Authority	NR	15 minutes	B, G, F, H, L	Lives alone
7. Beth (85)	Alison, Amy, Alice & April -2	Local Authority	Y	15-30 minutes + 4-hour respite visits twice a week	A, B, C, D, J	Lives with husband
8. Bea (89)	Aysha (6)	Local Authority	Y	30 minutes	A, B, D, F, G, H, L	Lives alone
9. Bara (98)	Alexa & Aida (5)	Private	Y	1- hour	A, B, C, D, E, F, G, H, I	Lives alone
10. Beatrice (96)	Anna & Audrey -2	Local Authority	N	24-hour care package	A, B, C, D, E, F, K, L	Lives alone
11. Belinda (82)	Anya (4)	Local Authority	N	30 minutes	A, B, D, F, G	Lives alone
12. Benita (88)	Annie (5)	Private	Y	1- 5 hours	F, H.	Lives alone
13. Beverly (77)	Ashley, Abby & Alina (3)	Private	Y	1 hour	A, D, K, L	Lives with husband
14. Bonnie (84)	Ashley (3)	Private	Y	1.5 – 3 hours	A, B, E, F, G, H, L	Lives alone
15. Boris (77)	Alexa (5)	Private	Y	2 hours	A, C, D, G, H, J,	Lives with wife
16. Brian (61)	April - 2	Local Authority	Y	3 hours (sitting service)	A, D, E, J	Lives with wife
17. Bryony (99)	Amanda (6)	Local Authority	N	30 minutes	A, B, D, E, F, G, H, L	Lives alone

KEY TO NEEDS:

A. Personal Care. B. Nutrition/Hydration C. Mobility support. D. Contingence needs E. Social Support F. Medication. G. Meal Preparation H. Support I. Shopping J. Sitting Service/Respite K. Get client up and/ or put client to bed. L. Household chores, (hoovering, washing – up etc.)

Qualitative Analysis Findings

(One overarching theme & two sub-themes)

‘Care Plans as a starting point’.

*a. Person-centred care planning
b. Filling in the gaps.*

‘Care Plans as a starting point’.



- **Care plans** were the central and initial repository of client information:
- **HCW acquired client-related knowledge from sources beyond the care plan:** other HCW, clients’ family:
‘Caroline (wife) and her son went out shortly after I arrived. I asked April* what was going on with Brian* and she told me he had a bad chest infection and had been critically unwell in hospital over Christmas. Caroline told her Brian is sleeping all the time and not eating or drinking.’*
- **HCW not observed to refer directly to the care plan *prior* to care-delivery:**
- **HCW - seemed implicitly aware of the care tasks- sometimes observed to make errors (when Care plan not consulted).**
‘Alice also corrected what Amy had written and told her to cross it out and write the correct thing – e.g., Beth didn’t give herself medication as Amy had written, it was in fact Cameron who does this.’

Person- centred Care Planning

Care plans that were *specific to the individual client*, enabled more *person-centred care*:

(Care Plan):

'Bara needs all her meals prepared for her' ... 'Bara can make decisions with support'

(Observed behaviour):

'Alexa takes the plate and asks Bara if she fancies a dessert. She offers Bara three choices from which Bara chooses trifle.'

Less specific care plans < person- centred :

(Care Plan):

'People with dementia can become apathetic and uninterested in their usual activities..... they may also lose intent in socialising'

(Observed behaviour):

'The conversation is light-hearted and covers a variety of topics and Bea includes me in their conversation about holidays that she is going on, reminiscing about the work she used to do, and how she likes singing and dancing'.



‘Filling in the gaps’.

1. HCW used **initiative** and **creativity** to support the PLWD (Beth) in the absence of clear instruction or guidance in the Care Plan; they were observed to be *‘filling in the gaps’*, first e.g. highlights how lack of info. can create issues for the client.

(Care Plan states):

‘Assist with personal care, change pad, check pressure area, reposition, apply cream if needed’.

A disorganized ‘Double- handed’ personal care task ensued... PLWD became distressed

2. By contrast

(Care Plan states):

‘Bring a dining chair into the bathroom ready for Bara to sit on for drying after her shower. Walk in with Bara to the shower leaving her trolley at the bathroom door. Help Bara to take her nightwear off. Place non-slip mat in the shower floor and run the shower to Bara’s preferred temperature. Guide her hand until she has hold of the grab rail in the shower and has lifted her feet over the step-mainly for confidence. Bara will wash the front of her body, caregivers to assist with washing back, legs and feet’.

Discussion

(Main findings)

First qualitative study to explore how care plans are used and interpreted by HCW

Compares whether the care that is provided by HCW for PLWD reflects what is written within their care plan

- *Care plans as a starting point* – Are they being used for the purpose they were designed for; do they articulate the needs?; do HCW use them to inform care?
- *Person-centred care planning* - Tailored to the client and their individual needs ? (independence, choice, communication) Facilitate PCC? to what extent? (e.g. provide healthy meals – what and how?)
- *Filling in the gaps* - Vague care plans = HCW filling in gaps (HCW intuitive/responsiveness; relationship with client ; emotional needs, risk; training, PLWD autonomy/ agency?)



Strengths and limitations

Strengths

- Novel secondary analysis – comparison between care that is delivered and the Care Plan.
- Expands & builds on previous research ([Drummond and Simpson, 2017](#)) - NHS settings only
- Diverse sample (6 diverse locations, combination of private and LA.HC agencies)
- Qual. research - rich in depth- lived exp. of PLWD & HCW & Family carers
- Early- on, suggestion to look at sub-set of FN .. I looked at entire set (103 notes)

Limitations

- Secondary Thematic Analysis – not my findings ; *Based on my interpretations of the researcher-observations*
- Qual. research - subjective ??
- I limited bias by thorough analysis of ALL FN (three different researcher perspectives and 16 HCW observed)
- Checked out –interpretations/findings regularly with supervisory team and researchers from Primary study

Practice Implications

- No standard for CP across agencies and settings- variations , particularly in private settings
- In statutory setting their use has been inconsistent (Reeves et al, 2014)
- Staff reported barriers to using CP: Previous study of CP with PLWD (Drummond and Simpson 2017)
- Relatives can be a helpful resource
- Potential for technological/digital options ??





- Lack of standardisation on Care Plans used in practice
- For dementia, flexibility is key – Care Plans not currently designed or enabled to be readily responsive and flexible.
- Vague Care plans increased the potential for HCW to ‘Think on their feet’.... Stressful for PWD and HCW
- Care Plans which were not Person- centred impacted quality of life of PWD, by contrast when Person- centred QOL improved and potentially working conditions of HCW
- Care Plans are not always the Primary source of information about the client (For HCW)

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Thank You for listening!

NEXT STEPS

More research to follow...

Started a PhD

Comparing and contrasting Admiral Nursing and other specialist Dementia Nursing models.

Settings- Mostly in the home

Impact to people living with dementia and/or their family

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