

Experiences of formal and informal care in older old age

Dr Jackie Buck
Lecturer in Adult Nursing
University of East Anglia



Social care

- Social care system offers help, care and support in people's own homes, residential and nursing homes
- Largely 'means tested'

Definition of *formal* care

- **Services provided by trained, licensed and qualified professionals**
- Services are controlled by the state or other types of organisation
- Caregivers have contracts specifying care responsibilities
- Caregivers are paid and entitled to social rights and working regulations
- Care tasks are specified according to professional qualification
- Care workers have a time schedule and go 'off duty'

Definition of *informal* care

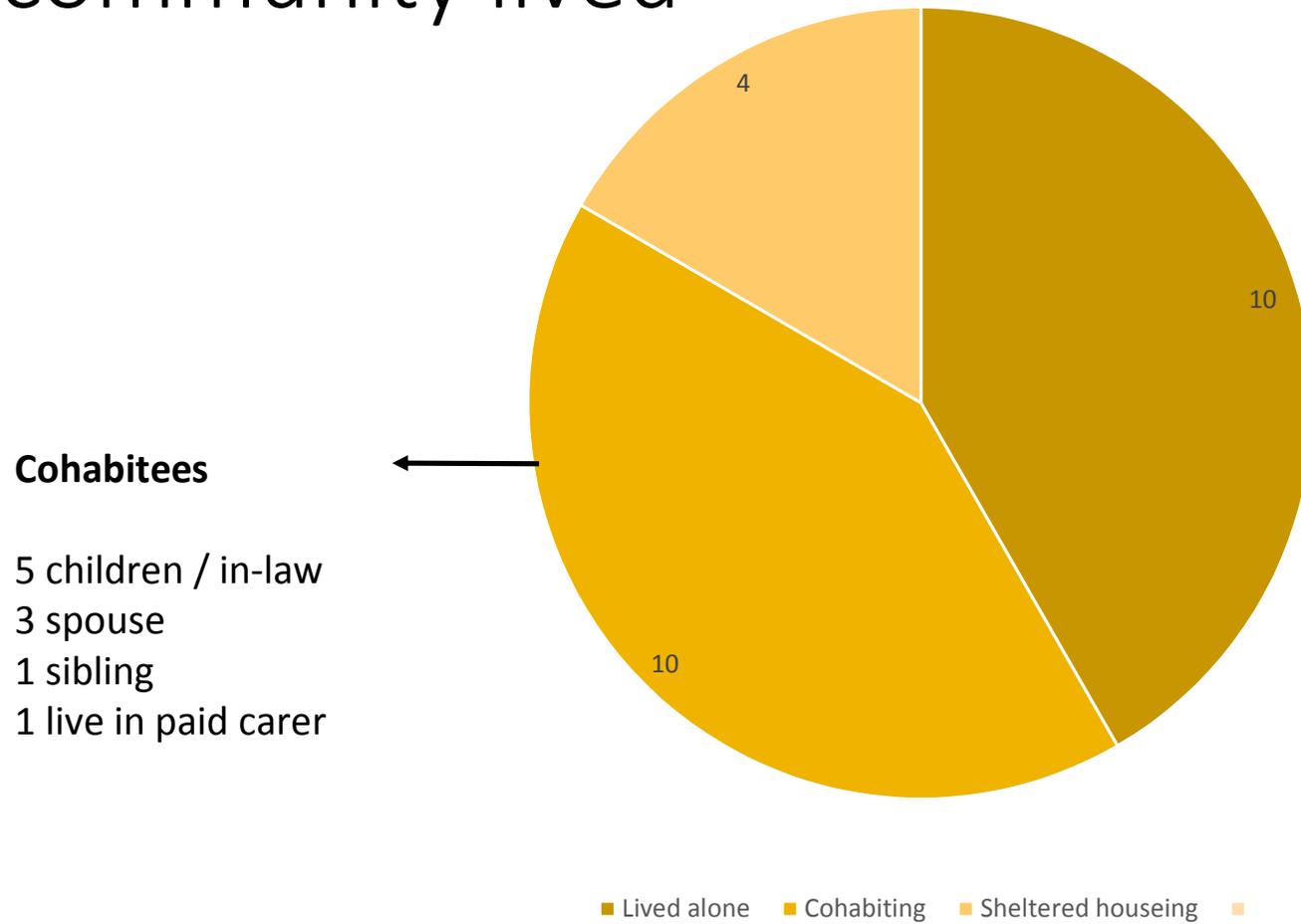
- **Care mainly provided by family, close relatives, friends or neighbours**
- Carers are non-professionals and not trained to provide care; but in some cases they may benefit from special training
- Carers are not paid although they may obtain financial contributions
- Carers perform a wide range of tasks (also performed by formal carers) including emotional support and assistance
- No limits to time spent on care – never/rarely officially ‘off duty’

Sample

- 18 lived in long term care

- 24 lived in the community

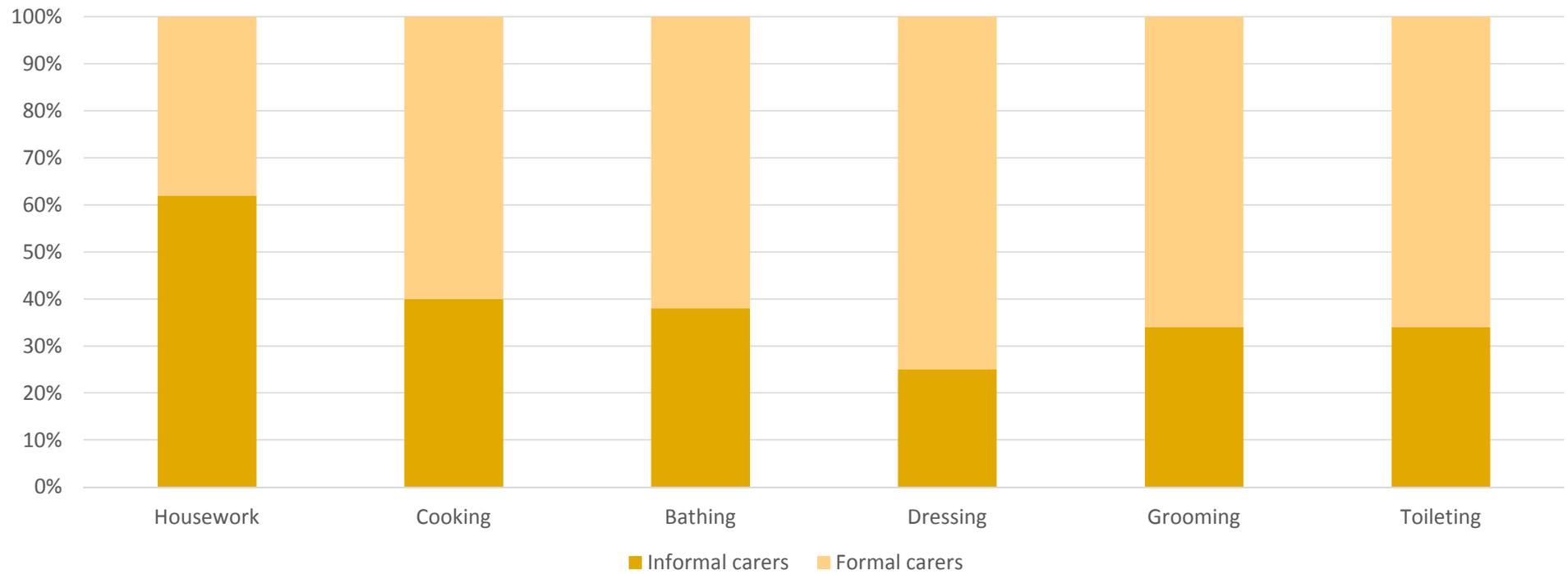
Where and with who people in the community lived



Formal care services in the community

| Total community dwelling | | |
|--------------------------|----|----|
| N=24 | | |
| | n | % |
| No formal services | 8 | 33 |
| Care assistants | 10 | 42 |
| Private domestic | 7 | 29 |
| Community nurse | 6 | 26 |
| Meal delivery | 6 | 26 |
| Home help | 2 | 9 |
| Day centre | 2 | 9 |

Proportion of care provided by informal and formal carers (community dwellers)



Accepting help in the community

- Largely accepting of need for assistance from formal carers

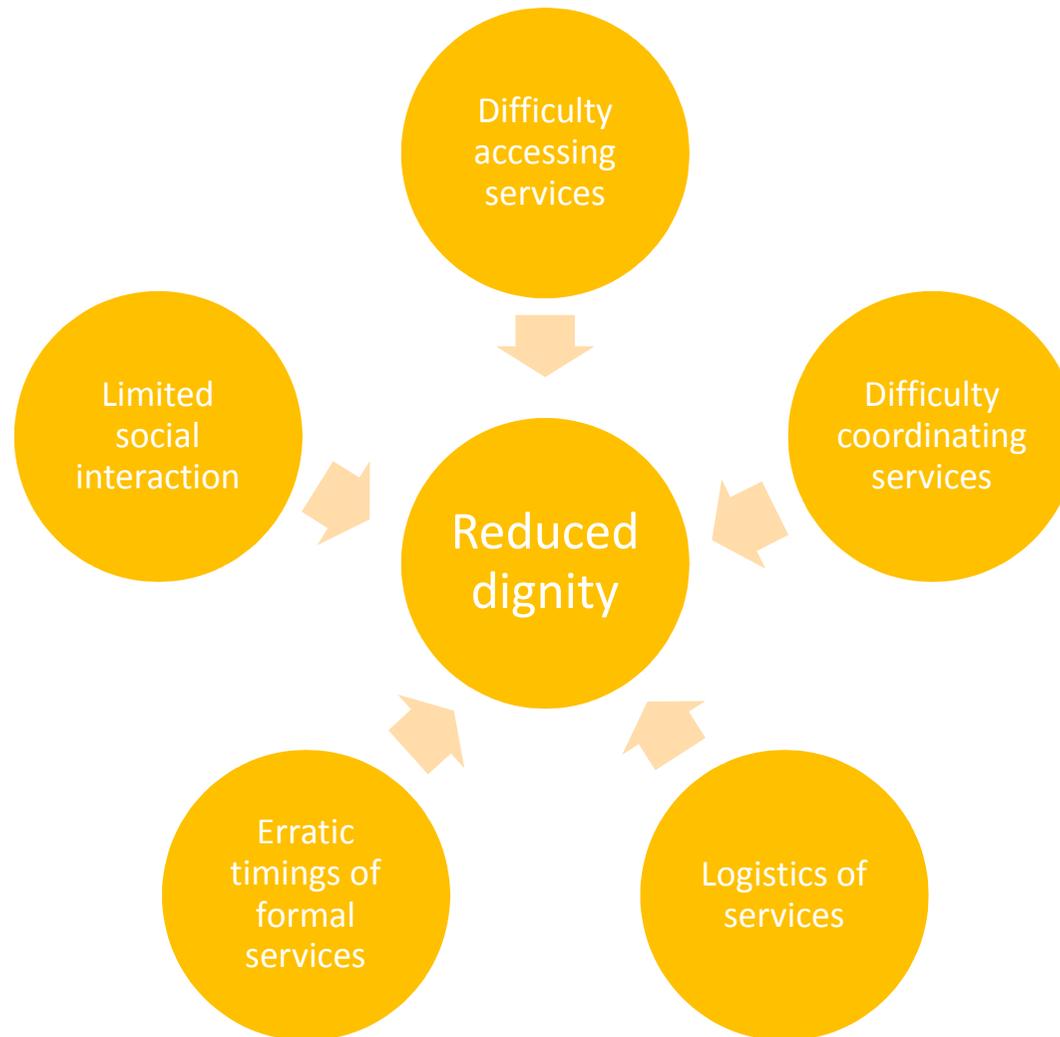
Accepting help in the community

- Often (not always) people in the community more resistive to increasing or prolonged levels of care from their relatives than from formal carers

“I stayed over with her one night just to see exactly what happened in the mornings. When she woke up I helped her on the commode but after that she didn’t want me to help her get dressed or anything. She said “you’ve all done enough now. I’m getting help now to let’s just wait for them to come”. So she stayed in bed and, you know, they didn’t come until a quarter to eleven” (Proxy of No. 3211, daughter, 97, lived alone)

| Activity of daily living | ADL disability | | Missing disability response | | Person identified as main helper | | | | | | |
|--------------------------|----------------|----|-----------------------------|----|----------------------------------|----------|-----|----------------|--------------------|---------------------------|-----------|
| | n | % | n | % | Spouse | Daughter | Son | Other relative | Friend / neighbour | Formal community services | LTC staff |
| Shopping | 38 | 95 | 2 | 5 | | 11 | 3 | 10 | 3 | 2 | 9 |
| Managing finances | 29 | 76 | 4 | 10 | 1 | 10 | 7 | 8 | 1 | 1 | 1 |
| Cooking | 32 | 76 | - | - | 1 | 1 | 2 | 2 | | 9 | 17 |
| Housework | 34 | 83 | 1 | 2 | 1 | 1 | 2 | 4 | 2 | 6 | 18 |
| Laundry | 35 | 88 | 2 | 5 | 1 | 6 | 2 | 5 | | 4 | 17 |
| Bathing | 29 | 71 | 1 | 2 | 1 | | 1 | 2 | | 7 | 18 |
| Grooming | 16 | 39 | 1 | 2 | 1 | | 1 | | | 4 | 10 |
| Dressing | 26 | 63 | 1 | 2 | 1 | | 1 | 1 | | 9 | 14 |
| Toileting | 19 | 46 | 1 | 2 | 1 | | 1 | | 1 | 6 | 8 |
| Eating | 11 | 27 | 1 | 2 | | | 1 | 1 | | 4 | 5 |
| Taking medication | 27 | 66 | 2 | 5 | 1 | | 3 | 2 | | 8 | 13 |

People living in the community
were being enabled to live *where*
they want, but not necessarily
how they want



Timing of services

- Biggest issue identified was the reliability in timing and scheduling of personal care assistants in the community
- Helplessness and lack of control over fundamental areas of their lives, such as sleep/wake times, meal times and bathroom use
 - Failure to maintain dignity
 - Affected health, well being and quality of life

- No. 2952 - reported being incredibly hungry and “busting” to go to the toilet upon the arrival of carers in the morning (99)
- No. 2705 - having had breakfast at 11 o’ clock, not hungry for lunch an hour later (97)
- No. 3211 - developed a sore, aching spine and joints from having to lie in bed for almost **16** hours from 6pm until 10am. She became clinically dehydrated from deliberately restricting her fluid intake to avoid going to the toilet during the time bed (97)

“One time she just couldn’t hold on and it was very upsetting, she never used to have accidents, she was always so clean, and she was apologising and apologising to the girl who came. She felt so ashamed but of course it shouldn’t have happened” (Proxy of No. 3211, daughter, 97, lived alone)

“Well they, stop here, the carers, they say ‘Do you want to go back to bed?’ And they see me to my bed, pull my covers up and then they go off. So, I’m alone...That’s the only time in the day I don’t like it at all...Not always but sometimes when you get to bed first of all you do feel lonely” (No. 2888, 100, lived alone)

Care coordination/lack of care coordination

- Lot of time spent on coordinating care
- Frustrating as often problems with 'the system' which seemed insurmountable
- Inefficiencies

“Yes, I mean, I can’t...tell you how many forms I’ve filled in, how many phone calls, how many visits, how many letters I had to write, rushing”
(Proxy of No. 0330, daughter, 96, Sheltered Housing)

“I saw the social worker once, she was absolutely useless. Absolutely useless. In fact she turned to me and said “you ought to be a social worker”. ‘Cos I did it all” (Proxy of No. 3154, great niece, 95, lived alone)

Limited time allocation

- The care staff did not arrive until 08:40 hrs. The lady that arrived...asked Nannie to sign her time sheet and on inspecting this to my dismay it showed the time of visit was 07:30. I asked her to change the time and she refused. She did not offer breakfast, a wash or anything. She emptied the commode, made a drink and left after approximately 5 minutes. (Proxy of No. 2705, daughter, 97, alone private house)

Social interaction

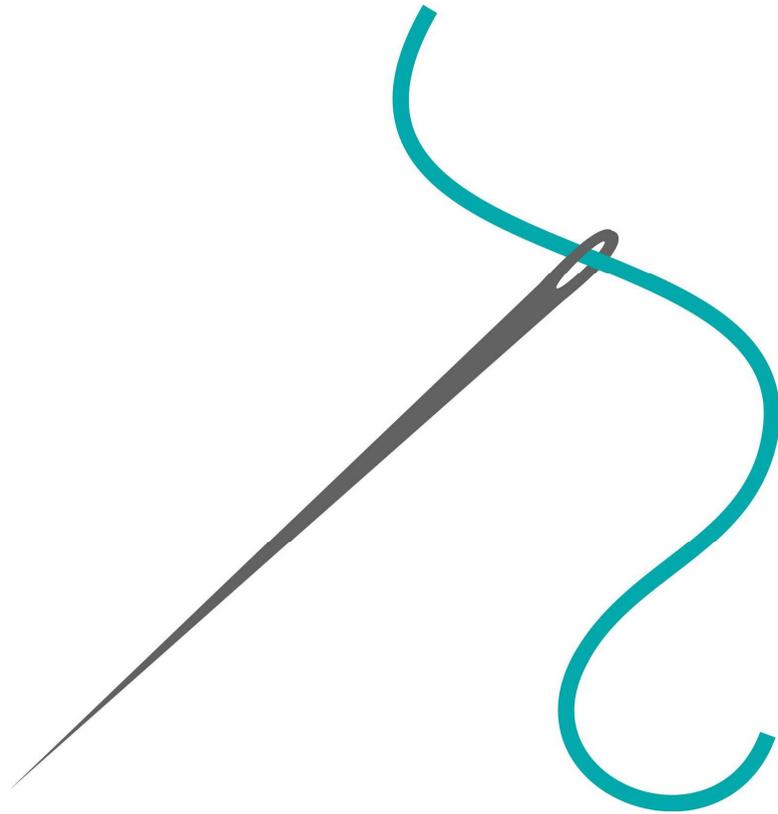
- Many people felt care assistants in the community simply didn't have time to provide real social company or engagement for the older person, which would have been appreciated
- Similar findings in care homes, where staff were often perceived to be consumed by paperwork to the detriment of the older people
- Unsettled by language differences with some staff

Continence

- Great reluctance to use commodes, especially in the presence of carers, preferred to walk, unsteadily, to use bathrooms
- Continence aids
 - Pads problematic – one size fits all policy
 - Ill-fitting pads causing discomfort, unnecessary distress
 - Long term care and in the community

- Respondent: “Well, you can’t go to the toilet when you want unless you do it in your pants”
- Interviewer: *“Because you have to wait for carers?”*
- Respondent: “Yes, or you can’t do it when they come. You want to, but you’d break your neck before they get here”
- Interviewer: *“That must be extremely difficult”*
- Respondent: “It is”

(No. 2952, 99, lived alone)



Vulnerability

“Being nice to your carers” key component of maintaining independence at home, to avoid a bad reputation that would compromise quality of care (No. 2888, 100, lived alone)

“Well as far as I could see he cooked for him (the paid carer). He had the telephone upstairs in his bedroom and he spent all the time on the phone, and it was a huge phone bill (laughs). I mean, he’d served the purpose that he was in the house” (Proxy of No. 2930, daughter, 97, lived with paid carer)

Carers arriving at person’s house even though she had cancelled the service, she was worried they could use the key in the ‘key-box’ to enter her unoccupied house

- Older people having to open their doors to unexpected strangers at unpredictable times

“No, no you never know who is coming. That’s another thing which I think, for older people, is very baffling. But on the hand, its better than no-one...well we do get the same ones but you never know which. And *(lowering her voice)* some are much better than others” (Proxy of No 3185, wife, 101, lived together)

Summary

- Biggest issue identified in the study was the reliability in timing and scheduling of care assistants in the formal care system.
 - Violation of service user autonomy, leading to helplessness and lack of control over fundamental areas such as sleep/wake times, meal times and bathroom use
 - Failure to maintain dignity
 - Increasing vulnerability
- What is a difficult time already confounded by great difficulty accessing and co-ordinating services

“Well, I’m gonna stay here as long as possible. I hope I can stay here for the rest of my days. That’s what I’m hoping for. I know there are facilities if you can’t, but there’s no place like home” (No. 1370, lived alone)