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LIVING AT HOME WITH DEMENTIA AND INCONTINENCE: A QUALITATIVE ANALYSIS OF PATIENT, FAMILY CARER AND HEALTH CARE PROFESSIONALS' PERSPECTIVES

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Background:

People with dementia are more likely than other people of the same age to experience bladder or bowel incontinence(1). Distressing and difficult to manage for both the person with dementia and family carers, incontinence often contributes to the breakdown of care(2). We aimed to characterise incontinence problems faced by people with dementia and their carers.

Methods:

People with dementia, carers and healthcare professionals were interviewed using semi-structured topic guides. Invitations were made via WWW.joindementiaresearch.nihr.ac.uk, dementia cafes and care teams. Healthcare professionals (dementia care and continence care nurses) were invited via their employer. The interviews were transcribed and constant comparison techniques were used to interpret the data.

Results:

45 people (27 family carers, 2 people with dementia, 8 continence nurses and 8 dementia nurses) took part. Many carers found coping with incontinence to be the most upsetting and stressful part of their caring experience. They reported feeling unsupported, without information or expert advice. Continence product provision from the NHS was often inadequate in terms of number or design. Dementia nurses reported little continence care knowledge and continence nurses had not received any dementia training. Carers often relied on inconsistent continence information from peers or product manufacturers. Some viewed incontinence problems as a "red line" beyond which they could not provide care, leading to unwanted admittance to residential care. Others adapted to providing continence care, but often experienced highly distressing periods of trial and error when learning how to cope. Resulting continence management strategies were often unsuccessful.

Conclusion:

Carers of people living with dementia and incontinence are being left to struggle alone, often with devastating and costly consequences. Currently there is little support or expertise available. Two urgent priorities were identified: Better information/advice and appropriate product provision. A co-designed handbook for carers is being developed from this work for future testing.

References

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2. Schulter PJ et al (2017) Urinary incontinence, but not fecal incontinence, is a risk factor for admission to aged residential care of older persons in New Zealand. *Neurology and Urodynamics*; 36: 6, 1588-1595.