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Compassion in healthcare – lessons from a qualitative study of the end of life care of people with dementia

Jacqueline Crowther[1], Kenneth CM Wilson[1], Siobhan Horton[2] and Mari Lloyd-Williams[1]
[1]Academic Palliative and Supportive Care Studies Group (APSCSG), Institute of Psychology, Health and Society, University of Liverpool, Liverpool L69 3GB, UK
[2]St Lukes Hospice, Winsford, Cheshire CW7 1BH, UK
Corresponding author: Mari Lloyd-Williams. Email: mlw@liv.ac.uk

Abstract

Objectives: A lack of compassion in UK healthcare settings has received much recent attention. This study explores the experiences of people with dementia in the last year of life and time surrounding death and how the presence and lack of compassion, kindness and humanity influenced the experience of care.
Design: Qualitative in-depth interviews with bereaved informal carers of people with dementia.
Setting: United Kingdom.
Participants: Forty bereaved carers – 31 women and nine men – with an age range of 18–86 years and from wide socioeconomic backgrounds participated.
Main outcome measures: Experiences of carers of care for person with dementia during last year of life.
Results: The interviews highlighted differences and challenges in care settings in providing compassionate, humanistic care and the impact of the care experienced by the person with dementia during the last year of life on informal carers during the bereavement period and beyond. Excellent examples of compassionate care were experienced alongside very poor and inhumane practices.
Conclusion: The concepts of compassion, kindness and humanity in dementia care are discussed within the paper. The ability to deliver care that is compassionate, kind and humanistic exists along a continuum across care settings – examples of excellent care sit alongside examples of very poor care and the reasons for this are explored together with discussion as to how health and social care staff can be trained and supported to deliver compassionate care.

Keywords

older people, dementia, compassion, healthcare

Introduction

The words ‘kindness’, ‘humanity’ and ‘compassion’ invoke perceptions of caring, kind-hearted, benevolent, gentle and empathic care.[1] Kindness and compassion are two core human values which are important in society and side from other moral values are the foundation of social and personal relationships. Kindness is an act or a gesture done out of goodwill towards a person or another living creature. Compassion is a deep and personal emotion and is defined as the ability to understand the emotional state of another person, i.e. ‘putting yourself in another’s shoes’. It is a much stronger feeling and urges one person to do something to alleviate or reduce the suffering of another. Having compassion leads a person to show kindness, but while all can be generous and show kindness to others not everyone can show compassion. Several reports expose what would appear to be inhumane and non-compassionate care of some of society’s most vulnerable members[2–8] which include older people and those with dementia.

These reports have lead to independent enquiries investigating concerns and complaints within both the NHS and private sectors and identify and heavily criticize the distinct lack of attention to compassion, dignity and basic care needs. Attitudes, cultures of care, organisational issues and communication skills of staff members involved in direct care and support have also been criticized and identified as priority areas for improvement.

Several actions were recommended as outcomes from the investigations including the provision of appropriate training and support for care staff. In response to some of the issues identified as problematic, a vision for nursing[3] has been published which outlines proposals for the development of a culture of compassionate care within the nursing profession and provides a framework for improving patient care building upon the *NHS Constitution*[9] and the *Caring for our Future White Paper*.[4] The nursing vision is based around the six Cs: care; compassion; competence; communication; courage; and commitment; and included in the vision is the recommendation of training in compassion. We report a recent study of 40 bereaved carers who had cared for and experienced the death of a close family member from dementia.

Methods

This national study recruited bereaved carers from Scotland, England and Wales. Purposive sampling was used, and appeals for volunteers were made via organisations (Alzheimer's Society, Age UK), the press and community networks. A total of 40 participants were recruited between February 2009 and August 2010. Interviews were conducted within participants' own homes or place of work and recorded digitally and transcribed verbatim and interviews lasted between 30 min and 80 min. One participant chose to write about their experiences due to time constraints. Field notes supplemented interpretation and analysis. Participants were encouraged to tell 'their story' with minimal interruption from the researcher which ensured events and issues important and significant to the participant were reported.

The interview process was informed by narrative interviewing which unlike a traditional structured interview that has a detailed series of questions to be answered; the unstructured narrative interview is designed to provide an opportunity for the participant to give a detailed account of a particular experience, event or point in time. The aim of the interview was to elicit narratives which focused on a particular point in time, experiences within this time frame and an event, which in this case was death. To use a prestructured interview design would have only allowed participants to select isolated parts from their own story and in effect filling in or completing pre-existing narratives by the researcher.

This study utilized qualitative methodology informed by Grounded Theory[10,11] and phenomenology.[12] Full ethical approval (RETH/000206) was obtained. Analysis commenced from the outset of data collection. Once transcribed, transcripts were returned to participants for verification. All transcripts were read by all authors and re-read by the researcher. Line by line coding of transcripts, memo writing, development of categories and emergence of themes followed and emerging themes were compared, discussed and agreed. Data saturation, participants reporting the same or similar issues began to occur when recruitment reached 35 participants and a further five participants were recruited to ensure saturation had been fully been achieved. Field notes and notes on non-verbal communications relating to statements made by participants were referred to during analysis for clarification of setting and contexts.

Results

Participants were recruited from the North West of England ($n = 21$), North East of England ($n = 4$), Wales ($n = 9$), Scotland ($n = 6$) and all lived in urban, rural and semi-rural areas. Participants were 31 female and nine male carers with an age range of 18–86 years and included wide socioeconomic backgrounds.

Within the study, 22 people with dementia had died in a District General Hospital, 14 within care homes and four within a family home. The majority had experienced care in several different care settings prior to death (Table 1).

Grounded Theory was not applied in its true sense to this study. The aim was to invite carers to inform us what were the problems and therefore the work and data were grounded in their experiences as we wanted their personal perspectives on the topic. This work was clinically embedded and was not so much about generating new theory as about illuminating the deeply personal experiences of caring for a person with dementia in the last year of life and for these cumulative experiences to inform future research as well as service development.

Table 1. Characteristics of participating bereaved carers.

Bereaved carers, *n*	40
Place of death	
District general hospital	22 (55%)
Care homes	14 (35%)
Family homes	4 (10%)
Gender	
Male	10 (25%)
Female	30 (75%)
Relationship to person with dementia	
Husband	7 (17.5%)
Wife	17 (42.5%)
Son	3 (7.5%)
Daughter	10 (25%)
Other family	2 (5%)
Friend/neighbour	1 (2.5%)
Age range	18–86 years
Range of time caring	18 months–20 years
Average time	5.1 years
Range of time since death	3 months–5 years
Average time	1.75 years

Compassion, kindness and humanity in formal/professional care

The words compassion, kindness and humane were frequently words used by participants to describe the care given and this included compassion, kindness and humanity in formal care and the compassion, kindness and the humanity of 'strangers'.

Compassion, kindness and humanity in formal care applied not only to direct care givers but also to ancillary staff:

> Another act of kindness was when he was in hospital the secretary of the vicar in charge of the hospital, I went down enquiring about services, Muslim services, she said "I believe your husband likes nice coffee, he can have a nice cup of coffee with me" so she brought special cups in, biscuits and special coffee for him. (wife P32**)**

Dawson-Goodey[13] highlighted the importance of 'small things' making the difference. As the quote below indicates, it is the small things and little acts of kindness that are most meaningful to people.

> Another little act of kindness, I bought my husband new jogging bottoms and a top ...... nurse didn't put it on until just before he was going to see the oncologist ... so he wouldn't make a mess of it ... I just thought ... they are so busy there ... little acts of kindness like that are very important aren't they? (wife P32)

The ability of formal carers to put themselves in the informal carer's position was valued – this ability to provide compassionate care surpassed age and gender as the quote below reveals.

> Care given by staff was truly excellent I can only praise them ... certain older members of staff who were absolutely great with him ... when I would thank them they would say "well, we would do this for our own mum or our own dad you know"... also what I found was the young carers who were there they too were excellent, they were very patient. (daughter P39)

There were also acts of unkindness and a lack of compassion witnessed across care settings.

> Seemed to be no compassion on the ward it was ... it was horrible the way me dad died, absolutely horrible ... well I felt it was dreadful ... I just felt there was no ... there was no caring if he'd have been in a side room ... had a little bit of dignity where he could have been quiet ... where you'd got a lot of so poorly people ... you go over what he must have gone through. (daughter P09)

As this participant's father approached death, there was no privacy and he died on an open ward. It was common place for people with dementia to die on an open busy ward with the promise of transfer to a side room not materializing.

A participants' description of care within a specialist dementia care home reveals what can happen when compassion is not present. The behaviour of formal carers towards the father was interpreted by family as unkind and de-humanising.

> He was really getting to be unhappy, we knew he was unhappy, a woman (member of staff) stood outside the door in the corridor outside his room, she couldn't see me, she didn't know I was there, she said "I'm absolutely fed up with him" at the top of her voice, so me dad would've heard it without a shadow of a doubt, "if he doesn't wanna be here, we certainly don't want him here, I don't know why they don't just come and get him and take him", Why the unkindness? ... I never expected that, I never expected the disrespect, the unkindness. (daughter P11)

In the quote below, nine years since the death of her father, we can see evidence of the negative impact and lasting effects upon a carer when poor communications and target driven care from professionals are perceived to have occurred.

> The memory clinic showed no interest whatsoever in the carer, I think that's what struck me more than anything, they just wanted to know really whether dad could tick the right boxes to merit he could stay on Aricept. (daughter P03)

Compassion, kindness and humanity from strangers

There were many acts of what participants perceived as compassionate, kind and humane care from groups of people who were not known, i.e. were 'strangers' but who appeared willing to help in times of need. This ranged from people in local communities such as postmen and barbers to those in the wider communities: taxi drivers, police and funeral directors.

> Dad took him in the barbers once, barber was really, really good with him, he sort of understood the situation, he used to like going to the barbers, he would

> let the barber shave him properly, he would let the barber cut his hair, wouldn't let anyone else do it. (granddaughter P05)

The description of the barber being 'really, really good' reveals how appreciative carers were and the impact for the person with dementia who despite his illness also clearly understood that he was being treated with kindness and respect. The barber appeared to 'understand the situation' without any apparent prior training, knowledge or experience of people with dementia.

> I would definitely say kindness of strangers was something that really became apparent you can be so reliant on strangers . . . we had a couple of taxi drivers who gave him free lifts back when he was found wandering, that type of thing. (granddaughter P07)

There were examples of strangers 'coming to the rescue' of people with dementia. Carer (P07) was a full-time postgraduate student whose seniors had little understanding of the caring role and responsibilities.

Compassion also remained important and meaningful after death. Funeral directors appeared to be a significant group of people who demonstrated acts of compassion and kindness at a difficult and emotional time.

> The funeral director, he was so polite, so nice they rang me everyday before K's funeral to ask if I was alright. (wife P19)

> They were a good help really, the funeral directors, we knew nothing, there was no help at the hospital whatsoever . . . he got taken to the C funeral service . . . where we saw him again . . . he looked beautiful there . . . I mean he looked thin but immaculate absolutely immaculate. (wife P09)

Discussion

This study revealed many important aspects of compassionate care for people with dementia. The importance of compassionate care is relevant to all health and social care sectors. Kitwood[14] described the person-centred model of dementia care and argued that cultural values, the social and emotional history of people with dementia and daily practices of caring for patients could exacerbate the disease process and that dementia was socially constructed and believed acquiring knowledge about the person with dementia was the key to delivering good, individualised person-centred care until the end of life. There was evidence in the study of the person-centred model of care being applied.

It was also apparent that formal carers and others did not require an in-depth knowledge of a disease and its trajectory to incorporate acts of kindness into caring and to deliver care in a humane, compassionate manner. The barber, hospital ancillary staff and funeral director would have little if any prior knowledge of the disease and the person with dementia but were perceived as kind, compassionate and 'person-centred' in their approaches and interactions.

Why do some formal carers appear not to be able to provide compassionate care. Chambliss[15] suggested routinisation and traumatic events appear normal to staff employed within hospitals – the more experienced nurse has to deal with all manner of things including naked bodies, bodily waste and dying patients. An increase in exposure to traumatic events may result in the absence of certain behaviours in order to maintain self-preservation and protection. The caring domain is from birth to death, from 'womb to tomb' – the humanism of medicine, in contrast to the purely 'scientific and heroic fighting' of saving life.[16]

In today's society of targets and health outcomes, minimal attention has been paid to the potential health consequences for nurses and others providing care and caring within the healthcare system. Compassion fatigue (or secondary traumatic stress) has emerged as a natural consequence of caring.[17]

An individual's death is marked by the ritual of a funeral[18] and in this study, undertakers were particularly noted for their kind and compassionate approach. In the funeral industry, personal values underpinning awareness would be essential to a successful business. Hyland and Morse[19] reported research in the United States has shown that the role has evolved over the last 50 years from preparing and burying the dead to that of: co-ordinator and planner, confidant, counsellor, salesman, manager and comforter of family and friends of the deceased. As people become more distant from their communities and from religious leaders, the funeral director may be the only 'official visitor' (or indeed in some cases the only visitor) for the bereaved and their compassionate approach is embedded within the very practical aspects of their work.

Dementia is a public health issue requiring a public health approach and involvement of all aspects of society and local communities. The development of compassionate communities[20] and dementia-friendly communities[6,21] will depend upon the goodwill and interest of those groups described as 'strangers' within this study – e.g. the barber, funeral director and ancillary staff, if communities are to become truly compassionate and dementia-friendly. Meeting the challenges and standards set out in the Dementia Strategy[5] and the Dementia Challenge[6] and providing dementia friendly[6] and compassionate communities across the disease trajectory, including end of life care and at the point of death will be a major challenge for society.

What this study adds

Recently, the Francis Report[8] has highlighted what can happen if as a society we are unable to support our clinical staff in delivering care to patients that is kind and compassionate? Target-driven care may be a necessity in healthcare but it must not be at the expense of compassion. The work of Gilbert[22] has demonstrated the need to be compassionate with ourselves in order to be compassionate with others. Care home staff are generally poorly paid and undervalued and the 'hard work of caring' is rarely acknowledged. This study has revealed that knowledge and information about individuals alone does not necessarily lead to compassionate care, strangers (with no knowledge or information) were in some instances better at taking care of the person with dementia and their families. Compassion burnout should be identified and addressed in healthcare, and more attention and support offered to those who experience death regularly, e.g. in care of the elderly settings. As authors we also believe that the most important teachers are the bereaved carers – we need to listen and give more opportunities for bereaved carers to share their experiences (both good and bad) and to be more involved with both undergraduate and postgraduate education.

Study limitations

We acknowledge that we were not able to interview a sequential sample of carers of people dying with dementia and that participants self-selected into the study and were in that case a biased sample and that most carers were female. In addition, the average time since death was 1.75 years (range 3 months to 5 years) and only four people with dementia had died at home therefore the carers experiences were predominantly within hospitals and care homes. We however recruited throughout the UK including areas of high and low social deprivation and a wide age range of carers were recruited. Although, in some cases, considerable time had elapsed since the death, the participants' recall of the last year of life was remarkably good with great clarity surrounding care in the last year of life and at the time of death.

Conclusions

A large number of people with dementia end their lives in 24-hour care environments either in hospital or a care home as occurred with 90% of the relatives of carers interviewed in this study. The Department of Health[9] report on the National Health Service states in providing compassionate care:

> ...we respond with humanity and kindness to each person's pain, distress, anxiety or need. We search for the things we can do, however small, to give comfort and relieve suffering. We find time for those we serve and work alongside. We do not wait to be asked, because we care...

Is it possible to achieve a universal standard of compassionate care for patients dying with dementia? While there are excellent examples, much work is still required to ensure our health and social care workforce are able to respond with kindness, humanity and compassion to each person's pain, anxiety or distress.

Declarations

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Guarantor: ML-W

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