CONCERNS IN DEMENTIA CAREGIVERS ABOUT THREATS TO THE PERSONHOOD OF PATIENTS WITH DEMENTIA: A NARRATIVE APPROACH FOR ANALYSIS

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Abstract

Objective: the aim of the current research is to capture significant areas of concern in dementia caregiving both in the community and in old-age psychiatric wards. As a reflection, the sought goal is to improve patients with dementia (PWD) personhood.

Study Design: a qualitative research approach with narrative analysis provided significant themes of concerns in the dementia caregiving. The theoretical approach is person-centred.

Material and Methods: focus groups of dementia caregivers offered the narratives for analysis. A series of probing questions were used to stimulate the discussions and the retrieval of narratives. A total of 34 caregivers participated in the study. Their professions included inpatient and community nurses, dementia doctors, social workers, community workers, clinical psychologists, support workers, and family members

Results: major themes of concern emerging were the logistic and geographical isolation of caregivers from other centres and professionals, lack of collaboration and support, absence of information sharing, shortage of staff and time resources, deficiency of support to deal with grief and burnout, shortage of specialist consultation when needed. All these aspects were felt as impacting on PWD personhood.

Conclusions: narratives emerged as a viable research instrument to record the impact of dementia caregiving on PWD personhood. Besides, by allowing caregivers in having their voice heard the research aligns with the current trends in patient-centred care which also aims to care for the carer.

Introduction

There are national and international policies in dementia care to reduce threats to the personhood of patients and enhance plans to improve quality of care. There are 800,000 people in the United Kingdom estimated as living with dementia[1,2]. According to the National Institute for Health and Care Excellence (NICE), the level of care is inconsistent[3], and some persons with dementia cannot access even basic care. The primary area of development identified for people with dementia (PWD) care in the UK includes a Patient-Centered Care (PCC) approach. This last reinforces the focus on staff competencies and seeks to reduce caregivers' concerns in the care of PWD. The overarching aim is to maintain compassion in care of PWD and reduce threats to their personhood. Compassion is a personal approach of dementia caregivers manifested as sensible humanity towards the care of PWD and characterized by deference and kindness also manifested through non-verbal gestures such as touch which brings on feelings of affection and delight[4,5]. When caregivers feel supported, the personhood of PWD also improves[6]. Instead, a 'compassion burnout' can ensue whenever caregivers experience grief and death daily[7] and no support is provided. Furthermore, the team of caregivers working with patients' needs personalized information and adequate data sharing to collaborate on patient care. Central to dementia care is the level of support available to caregivers, such as

making peer assistance and information available (also by telephone and Internet) and training of caregivers in assistive skills and crisis resolution[8]. *Fundamental Standards* of the Commission for Quality Control focuses on several points that patients should expect from their caregivers, including PCC, formality, thoughtfulness, agreement, protection, and obligation to honesty[9]. Besides, caregivers' aim is to comply with the guidelines of 'social care' intended to support PWD in their day-to-day lives, preserving their personhood, improving their public exchanges, protecting them from helpless risks, helping them in accessing supported accommodation, and making care pleasant for both patients and their carers[10,11]. Recent European and international guidelines in dementia care emphasize the importance of PCC as a pursuit for meaning and mutual respect, aiming to establish sense, direction and significance in the ordinary experiences of caregivers with patients[12]. Moreover, it is widely understood that caregivers require considerable support to achieve desired patient care outcomes. In fact, both the World Health Organization along with Alzheimer's Disease International comment that the delivery of care to PWD causes substantial stresses for caregivers on physical, emotional and financial levels[13]. Also, information relevant to patient care must be shared among primary caregivers. A study carried out in several European countries demonstrated a shortage of information on how to care for people with dementia and how to coordinate the work of those with different areas of expertise[14]. Therefore, any threat to the activity of dementia caregivers becomes a risk to the quality of care to people with dementia and their personhood. Hence, the current project aimed to capture dementia caregivers' concerns via their narratives and to propose possible solutions to their emerging problems to improve PWD personhood.

Material and methods

The current research aligns with the feminist research paradigm that maintains that all facts are linked to a specific period, setting, national, collective, historical or political framework[15]. The project also included ethnographic research methods based on the systematic and recurrent observation of individuals and circumstances to answer presumed questions about the basis of the behavior of various people or communities[16]. Apart from the authors' direct observations, dementia caregivers expressed to the authors their experiences in focus groups and at department meetings, also communicating the prevailing themes of their concerns, their perceptions of system resources and their hopes for the future development of services. In fact, interview transcripts disclose individuals' perceptions of core facts in their experience and the national and social frameworks in which they exist[17]. Besides, values, standards and organizations shape the experiences of individuals[18]. Hence, a grounded theory method seemed appropriate to find recurring themes in the narratives emerging from focus groups[19]. From the narratives collected during caregivers' focus groups, six significant themes of concern and points of strength were identified. Thirty-four caregivers participating in the study were asked to identify areas requiring further support as well as their real resources available to their interprofessional team[20]. They were actively involved in inpatient and community dementia care. Their professions included nurses, doctors, social workers, community workers, support workers, and family members. A series of probing questions were used to stimulate discussion on specific topics in dementia caregivers making the basis for the narratives. To comply with confidentiality requirements, the authors did not disclose the name of any informants or patients, the locations of service provisions or the designations of hospitals or teams or of any other detail that might breach confidentiality regulations.

Results and conclusions

The following major themes emerged from the narratives and focus groups:

•*Social, logistic and geographical isolation*: 'In the place where I work, I feel isolated from the rest of the world. We are far from hospitals, medics, and other professionals to work in a partnership in the case of patients with dementia'. The probing questions were, 'Have you ever felt that your ward and the community where you work were isolated from your team or other key professionals? Have you ever worked in prohibitive conditions coping with environmental hazards, vulnerable neighboring, isolated communities, and adverse weather conditions without the help of others?' In conclusion, dementia caregivers should overcome physical and social isolation caused by the absence of support from colleagues and lacking backup in moments of need. The consequences of isolation are missed care and actions in patient care. In fact, these conditions in caregivers can cause anxiety in dealing with patients without support, while they would feel more supported when their team is complete and available.

•*Lack of collaboration and support*: 'I often feel that I need more staff and the support of my team when I am alone dealing with a patient. However, I can help others if they need me.' Probing questions were, 'Have you ever felt

lonely or abandoned in your duties? Have you ever felt that you could not get the collaboration that you needed for proper patient care?' A familiar feeling is a disappointment when the hospital or team is not hearing caregivers' voice or concerns about patient care. Instead, after proper support is provided, caregivers feel more proactive in providing patient care and less isolated.

•*Lack of information sharing*: 'I often need more information on how to deal with patients' crises, but nobody is there. I feel they are not training us enough to deal with patients with dementia'. Probing questions were, 'Have you ever felt you were missing vital information on how to deal with physical and emotional crises in patients? Have you ever felt that you need collateral history and information from colleagues to know your patients more?' In conclusion, lack of information on how to deal with physical and emotional crises in PWD can jeopardize their care or life. Instead, collateral history and information from colleagues would be helpful, making patient data available whenever and wherever needed. Also, targeted training of agency and locum personnel can reduce areas of indeterminacy of PWD care.

•*Shortage of staff and time resources*: 'There is always a shortage of staff and little time to do everything. We need more people to provide care to our patients with dementia.' Probing questions were: 'Have you ever felt the burden to work in a team or ward with a shortage of staff and a lack of time for doing all your duties?', 'Have you ever felt you wanted to spend more quality time with your patient but unable to do so because of the shortage of staff and time?' In conclusion, the shortage of time and staff resources for patient care reduce the likelihood of caregivers' empathy and compassion. Instead, a more relaxed team also requires an acceptable number of people to carry on daily duties and time to do what is needed for patient care.

•*Lack of support to deal with grief and burnout*: 'Working with terminal patients with dementia requires a lot of psychological strength. When a patient dies there is little psychological support to deal with grief'. The probing questions were, 'Have you ever felt you wanted some emotional support to deal with your grief and mourning? Have you ever felt that your level of empathy and compassion were jeopardized because of frequent losses in your work and because of the emotional impact of dementia care?' In conclusion, lack of emotional support to deal with grief and mourning leads to empathy and compassion burnout in caregivers. Instead, caregivers' emotional strength improves with psychological support to deal with the impact and grief in dementia care.

•*Lack of specialist consultation when needed*: 'Our patients are always unwell. Often, we need the guidance of a specialist, doctor or general practitioner. However, they have always little time to deal with our request, and we are left without clear plans for patient care.' Probing questions were, 'Have you ever felt that your consultant, doctor, nurse or any other person in the staff was not there when you needed them most? Have you ever felt frustrated because you needed some support in patient care while the key persons to make a decision or give information were not there?' In conclusion, dealing with significant crises in PWD care when a specialist consultation is missing reduces the quality of care. Caregivers feel frustrated when the intervention of some key person is required, but that person cannot be reached. It is not infrequent that a dementia team has no clear guidelines on how to deal with minor or significant crises in PWD care. These events leave caregivers discouraged.

Discussion

Significant concerns among dementia caregivers include the challenges of working in community or isolated wards, threats to patients' personhood due to caregivers' and patients' distance from the support of other professionals, the shortage of time or staff resources to perform patient care, a lack of professional backup to solve patients' physical and mental problems, a deficit of user-friendly technology to access patient information and learning support, and a shortage of emotional resources to deal with grief and the burden of care. The current project takes a person-centered approach[21] making the personhood of patients highly dependent on the effectiveness of caregiving. Kitwood defined personhood as a status or condition that is conferred to one person by other persons in the setting of interpersonal relationships and societal life; it infers acknowledgement, deference, and reliance[22]. The personhood of patients is reinforced by an integrated care paradigm and interprofessional teamwork based on shared esteem with paired and even interactions with synchronized, unified, uninterrupted care towards patients[23,24]. Whenever the support team for PWD is in crisis, the personhood of patients is also jeopardized. Buron has identified three levels of personhood: i) 'biological personhood' where PWD are entitled to receive support for their basic biological needs, ii) 'individual personhood' maintained through constant and empathic communication with PWD even at advanced stages of dementia and constantly ensuring their dignity and personhood, iii) 'sociologic personhood' promoted by

the integration of patients as participant members of an extended social network, which reduces the isolation caused by physical and cognitive decline[25]. Problematic dementia caregiving can trigger threats to PWD personhood. The absence of support from colleagues due to a shortage of staff and backup, or reduced supervision will trigger Kitwood's threat to personhood called 'invalidation' when staff does not acknowledge patients' feelings and requests, as well as 'banishment' by ignoring patients and by dismissing their requests[22]. Logistic and geographical isolation of caregivers or wards might be conducive to Kitwood's concepts of 'banishment' and 'intimidation', this last observed where staff provokes anxiety in a patient using psychological pressure or physical force[22]. Insufficient information and training on how to deal with patient minor physical or emotional problems invoke Kitwood's concept of 'labelling' where the diagnosis of dementia is used to justify any behaviour[22]. Shortages of time and human resources can lead to what Kitwood labels 'intimidation' and 'treachery', a trick aiming to confuse or control a person or force a patient into obedience[22]. A lack of training in dealing with patients' minor physical symptoms will lead to Kitwood's 'labelling', and 'outpacing' where the staff provides excessive information so that patients are pushed beyond their limits, and 'infantilization' where the staff tends to patronize the patients[22]. Insufficient sharing of information about patients within multidisciplinary teams leads to Kitwood's 'labelling' and 'outpacing'[22]. Meanwhile, the lack of support for coping with grief and bereavement can lead to what Kitwood called 'invalidation', and 'stigmatization', treating patients as ill entities[22]. Dealing with problematic hospital admissions and discharges leads to what Kitwood's termed 'disempowerment', discouraging patient's present skills[22]. Lack of training and supervision, as well as empathy burnout, will lead to Kitwood's 'objectification' where PWD are treated and moved as objects without feelings[22].Caregivers of PWD interviewed in the current research reported several concerns that are not easily solvable. However, when their concerns were addressed, there was an improvement in the quality of care and patients' personhood. For instance, when caregivers and dementia wards surmounted the hazards emerging from logistics and physical and geographical isolation by deploying interprofessional collaboration, patient care was less fragmented. When information about mutual patients was shared and easily accessible, their care advanced. Also, dedicating sufficient human resources and time to PWD care improved their care. Moreover, caregivers' empathy and compassion increased when their daily concerns and needs for grief and mourning were recognized and addressed. Furthermore, whenever appropriate specialist consultations, also over distance, were able to solve physical, behavioral, and emotional crises in patients, the personhood of PWD improved. Furthermore, the constant assistance of caregivers in assessing patients' physical symptoms improved patients' biological personhood. Moreover, the personalized assistance of caregivers in addressing patients' concerns might reduce threats to their personhood while discouraging empathy burnout among caregivers. Lastly, by providing wards and community with more staff also the quality of care of PWD is less fragmented while ensuring that crises in patient care can be overcome in a timely fashion without delays which can jeopardize PWD physical and mental health.

Conflict of interest

The authors of the current research express no conflict of interest in the present study. Events and focus groups were held in different health care structures while the narratives do not represent the point of any specific and identifiable health care system and organization. Instead, the research was a global analysis and the merging of different focus groups which took place in different communities, hospitals, and countries

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