



Putting Compassion Back into Care

Focus on Minority Ethnic Families Experiencing Dementia

Abstract

Public services are stressed by soaring demand, inadequate capacity, staff burnout and low morale with strikes reflecting profound unhappiness. With so many difficulties, the fundamental need for compassion in public services has been eroded, with adverse consequences for patients and their families or carers. The need for compassion is not only an individual's humanitarian and professional responsibility but one that should be given high priority by organisations, educational institutions, and professional bodies.

The care of patients with dementia and support for families or carers provides a perfect example of such disparities and their devastating impact. The implications for families affected by dementia in minority ethnic or marginalised communities are considered alongside the need for a 'paradigm shift' to patient-centred, 'needs-based' services to improve outcomes. This article explores and attempts to extrapolate the relevance of personal experience to those in minority ethnic or marginalised communities on whom there is limited information and those who have little voice or advocacy.¹ There is a distinct role for charitable and third-sector organisations with a deeper understanding of the cultural context to demonstrate leadership in moving policy and resources to address such societal and service disparities.

Keywords

Compassionate care, marginalised communities, minority ethnic, dementia, health disparities

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What Is Compassion?

'Putting yourself in the shoes of others and doing something about it!' ²

Compassion is described in the context of health care as being comprised of virtues (honesty, kindness, helpful, non-judgment) and actions (smile, touch, care, support, flexibility) aimed at relieving the suffering of patients. ³ This is different to empathy (putting yourself in the shoes of others), sympathy (feelings of pity for someone else's misfortune), love (feelings of affection for someone) and kindness (being helpful and caring about others). These five key virtues (ESCL&K) need to be the basic principles of behaviour in public services led by a focus on compassion. Compassion is not necessarily a simple process; indeed, many compassionate acts require knowing what the other values, connecting with them, and responding in a way that is meaningful for that person. It is not about what we choose to do for other people, but what we choose to do together with them. Sharing personal information with patients and admitting mistakes are key methods for identifying common ground. ⁴ It thus implies a level of reciprocity and interdependence, and compassionate care can, therefore, be defined as a relational activity. ⁵

Providing compassionate care is a key constitutional value of the UK National Health Service (NHS) and there has been an increased commitment to ensure this is delivered in patient interactions. However, there is a lack of a consistent definition and understanding among professionals. Current conceptualisations of compassion do not privilege the voice of service users, despite them being key stakeholders within the NHS. Additionally, the literature lacks ethnically diverse perspectives, although ethnically minoritised individuals experience more negative outcomes within the health system. ⁶ In addition to lower socioeconomic status, factors, including bias, stereotyping, racism, gender, limited prevailing language proficiency and immigration status are crucial

determinants of care and impact on compassion. ⁷ There are deficiencies in access to the whole spectrum of care from primary to hospital-based healthcare and social services experienced by minoritised populations ⁸ and greater efforts are needed to improve professionals' skills regarding minority populations. ⁹

There is a need for in-depth cross-cultural and psychosocial literacy on the part of healthcare providers. Trust, mutual respect, and understanding on the part of the caregiver and patient are crucial to optimising therapeutic outcomes. Compassionate care can only be fostered and supported in a dynamic, well-resourced, and nurturing environment. This involves organisations or services recognising and respecting the individuality of service users and providing care according to their needs. Removing "power imbalances" in the way services use judgements, control and language is essential.

Case history

Having seen the realities of the patient's experience in the health and care systems (as my wife of 57 years succumbed over three years from vascular dementia in a memory care home). During this time, she developed kidney cancer requiring surgery; I was told that despite her complete dependency on me as her registered carer with Lasting Power of Attorney, I would not be allowed to be with her in the hospital during her admission. I had to leave her at the door unsupported despite self-isolating for two weeks and being shown to be Covid test negative. Eventually, I was allowed to prove that by being a carer (not a visitor), I added value to the team looking after her.

I asked the nursing staff, especially the most junior and the nursing assistants what they felt about the restriction of access. It was apparent from their observations shared confidentially with me that managerial compliance had overridden basic humanity.

My wife deteriorated quickly, being forced to admit her to a memory care home at the point of care 'burnout'.¹⁰ We found a rare care home with an owner determined to build homes to the standard his own mother would require, were she to need residential care. After nine months of loving care, she fell fracturing her hip. I was instructed by medical staff to admit her to the hospital forthwith for her hip to be pinned under surgery. We experienced the inevitable wait in an overburdened emergency department that has become the norm now. Should she have been considered fit enough for surgery, she would have needed a high-dependency bed, (at a time when all such facilities were saturated with patients with COVID-19) before a difficult rehabilitation back to a life of severe dementia.

I saw this protocolised decision to be cruel and demanded palliative care to allow her to die in dignity, according to her previously expressed wish- never to be admitted to the hospital again. I was told nobody had ever refused this surgery but a compassionate GP overseeing the home agreed and triggered our community nurses to set up a diamorphine drip to relieve her pain and distress. She died quietly three days later. Care home staff sat with us, they held our hands and wept as she died. They came to her funeral to celebrate what she had meant to them through her contented demeanour.

Compassionate Care

In family conferences organised by Congenital Hyperinsulinism International (CHI), I asked the >200 families of babies born with this devastating illness whether they had received compassionate care in the children's hospitals to which they had been admitted.¹¹ Individual doctors and nurses were remembered for their care, but not one family felt that compassion was embedded in the institution as a fundamental principle. In recent years, there has been a growing recognition in the UK of the importance of compassion in healthcare, both for patients and for staff. Compassionate care leads to better patient outcomes, increased patient satisfaction, and improved staff morale. Despite this, my experiences show that there is a mismatch between theory and rhetoric and the realities of frontline service delivery, this

issue is compounded for those who are marginalised by society. Hence, I decided to investigate the experience of patients and families of those with dementia from minority backgrounds.

Patient care is an extremely difficult and challenging activity. Institutions need to recognise how compassion is informed by the availability of adequate resources and the robustness of organisational structures and processes. Why even under the best of circumstances, there will be some challenging interactions or mismatch of expectations and agendas with patients or their distressed families. In such fractious interactions, healthcare professionals must not neglect their own physical and emotional health as they assiduously address the formidable challenges of providing equitable health care. Caregivers should be encouraged to seek help and support from family, friends, and professional colleagues without hesitation.⁷ The impact of COVID-19, staff shortages and lack of time is undoubtedly true, but in my view should not be excuses for poor behaviour or inadequate institutional resources.

Ethnic disparities in access to end-of-life care reflect disparities in access to many kinds of care. Barriers to optimum end-of-life care for minority patients include insensitivity to cultural differences in attitudes toward death and end-of-life care and understandable mistrust of the healthcare system due to the history of bias in medicine.¹² In addition to individual and relationship factors that impact on compassionate care practice, there are organisational factors that impact on the clinical environment and team; and leadership factors that hinder or enable a compassionate care culture. There are several enabling factors that enhance a culture conducive to providing compassionate care. These include leaders who act as positive role models, good relationships between team members and a focus on staff wellbeing.¹³

We need a cultural transformation with a cascade of actions:

- **Humanity - Humanise your patient.** Every care organisation should promote patient-centred care and seek their active participation in the design, development, and delivery of care services.
- **Central Operating Principle - Compassion** should be the central operating principle in NHS and care settings and must determine the allocation of resources. We should consider not only the compassionate qualities of individual practitioners but also the overall design of healthcare systems.¹⁴
- **Accountability - Hold one's institutions** accountable for providing culturally and linguistically competent care. Accountability against defined metrics should be led by the CEO in institutions and inspected by the Care Quality Commission and regulatory bodies.
- **Educational Interventions - The earlier and better focus** is required on compassion for recruitment and teaching programmes for all grades of professionals and healthcare staff.
- **Levelling up - Substantial changes** are needed in health education policy and funding to ensure caregivers from marginalised communities are encouraged to join the workforce, so organisations can continue to have access to a diverse, high-quality health professional workforce which is necessary to maintain the health of an increasingly diverse nation.¹⁵
- **Co-development & Partnership - The views** of patients and families should be sought regularly.
- **Raising Concerns - A willingness** to encourage staff at all levels to expose poor practices alongside celebrating excellent care. Maintaining systems for confidential reporting, protection for whistle-blowers and psychological safety.
- **Tackling Bias - Counteracting** unconscious bias requires awareness, introspection, authenticity, humility, compassion, communication, and a

willingness to act. Tools such as the Implicit Association Test should be essential for all staff training. Advocate that the affiliated institution's analyses of patient satisfaction and outcome include cultural group data and that the results lead to concrete action.

Young-onset dementia

During my wife's stay in her memory care home, I saw a much younger woman on her floor being visited by her children. In view of my background as an advocate for children and young people, I started to research the evidence of the impact of young-onset dementia on families. I exposed the fact that they were largely invisible in policy and practice, being Britain's 'Hidden Young Mourners'. On further enquiry, I heard harrowing accounts of the consequences. Accordingly, I published my findings on the impact of young-onset dementia on families affected.¹⁶ I have been unable to find any references to the needs of children and young people so affected in families in minority or marginalised communities in the UK, nor any reference to the realities of the challenges in their lives.

Key facts: Young onset dementia encompasses people <65 years affecting people between 30-64 years.¹⁷

- Estimated that it occurs overall with 70,800/955,000 patients (7.5%)
- Higher prevalence in some ethnic groups although precise data are not available.
- More likely to have genetic causes.
- Average time to diagnosis = 4.4 years; after 2-5 referrals
- Estimate <100,000 children and young people overall in families, but no data on South Asian Families
- Occurs at parental peak earning capacity and role model function.
- Can have a devastating impact on the lives and the prospects of children and young people in families.

There is a research base on dementia generally in South Asian families that exposes the serious inequities and disadvantages that occur in the

different cultural backgrounds in such families. Despite this, I have not been able to find research that looks specifically at young onset dementia and its impact on children and young people in these communities, and this deficiency should be addressed as a matter of urgency. Of special concern must be the impact on girls and young women in view of their roles within families as caregivers.¹⁸

A 'needs-based approach to services

Importantly, there is a need for a *re-framing* of how we view and categorise family caregivers and understand their needs. This involves recognising that some groups of caregivers may be particularly vulnerable to caregiver burden or other negative health outcomes in addition to barriers to accessing needed support. It is important to understand the often invisible work of, and hidden burdens experienced by family caregivers. Their effort, understanding, and compassion enable so many dying individuals to live out their final days with dignity. It is thus imperative for us to recognise the extraordinary effort that is made every day by family caregivers who care for dying individuals with dedication and ensure that they are provided with all the means necessary to carry out this valuable work.¹⁹

South Asian Dementia Pathway

An example is the scale of the challenges faced by South Asian communities is spelt out in the work from Bradford University: People from South Asian communities are at greater risk of developing dementia but are less likely to access all points of the care pathway – and more likely to present in crisis and/or at a later stage. They are more likely to face barriers including a late or missed diagnosis, reduced access to treatments, and inappropriate or inadequate support coupled with problems caused by language barriers. They often rely on local, community-led organisations for support. The number of people from South Asian communities with dementia is expected to increase sevenfold by 2051, due in part to inequalities in service provision and the increased risk of other health factors

associated with dementia. For white British people, the rise is expected to be more modest – doubling over the same time. Combatting the current one-size-fits-all model, the South Asian Dementia Pathway Toolkit (ADaPT) aims to provide more accessible, tailored resources enabling services to provide more culturally appropriate care. Designed to address the uphill struggle that many people from South Asian backgrounds face, the toolkit includes short films, animations, awareness-raising materials, assessments, and post-diagnostic support – all of which have been culturally and linguistically adapted for people from South Asian communities.²⁰

A 'Paradigm shift' in the design of services

Caregivers often encounter environments and situations that utilise methods of force as a component of clinical care. These include emergency care, critical care, and psychiatry. The frequency of forced care varies by cultural context, patient demographics, and clinician.²¹ Immigrants are twice more likely to be restrained than native persons, indicating potential clinician bias or at least significant challenges in clinicians' application of alternative care practices in the care of minority patients.²² There are many commonalities in the challenges facing dementia services in the UK generally (let alone in South Asian families) with those for children's services.²³ Without considering diversity, patterns in vulnerability and inequity are overlooked, and thus continually reinforced in health policy.¹⁹

A 'paradigm shift' is needed based on understanding the **needs** of the person, the families, and the staff at each milestone in the journey from dementia to end-of-life care. Several educational interventions need to be considered including de-escalation training and crisis management skills, person-centred care approaches, and compassionate care approaches—to support development across clinical care settings. Minimisation of the need for forced care and the implementation of compassionate force in treatment requires thoughtful and comprehensive educational plans.²¹

I suggest that this 'needs-based journey' is useful in defining a more 'holistic' approach to services and further study is needed to validate this proposal, especially in the different cultural groups within marginalised communities.

Conclusions

Caring for "our fellow humans" is a wonderful and gratifying privilege. The healthcare profession enables individuals through a lifelong learning process to be competent caregivers. With this privilege comes tremendous responsibility.⁷ Compassionate care is essential for every healthcare professional and institution to embrace but this is not possible without adequate resources, training and allowing patients and their carers to have an equal voice.

Dementia care is an area where the impact of compassionate care plays out to its full potential. It is likely to become the dominating condition driving services in the immediate and long-term future.²⁴ Attention to possible bias and careful consideration of the appropriateness of power balance in interactions, especially in members of minority and marginalized groups, is essential.²¹ There is incontrovertible evidence that the experiences and outcomes for such people and families in marginalised communities are far worse than those for majority communities.

Addressing these challenges demands research, education, and political action. Clinical outcomes are correlated with the degree of patient's perception of empathy and compassion from their providers.²⁵ There is a need for compassion in services, and a new practical approach to the design of services based on assessing the needs (and not the professional bunkers) of the person, the family and of staff at each milestone in the journey through birth to the end-of-life care.

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