Developing a modern focus on dementia care; an empathetic perspective on the life of the older adult

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Our role is to breathe, take perspective of the human being standing in front of us – and reassure them; why they are here, what is happening and that everything will be okay.

> With all my thoughts and maybes,
> perhaps it will be you
> who reaches my thoughts,
> understands my fears,
> and will make me feel safe.
>
> Maybe it will be you
> who I need to thank.
>
> If only I knew how.
>
> *From "Wander with me" by Norman MacNamara*[1]

INTRODUCTION

Since I was in school, I've worked in healthcare – from home care to nursing homes and then hospitals. I began working in mental health nursing around 2019, fell in love with it and four years later I've not looked back. I later decided to apply to medical school (a decision which I sometimes now look back on with as much grief as I do fondness). However, my interest and passion for mental health has not yet waivered.

Through working on a nursing team and then studying medicine, I have seen things from many different perspectives. I now work in a specialist inpatient "dementia intensive care unit" – taking admissions of patients with a confirmed diagnosis of dementia who are experiencing severe behavioural and psychological symptoms which cannot be managed in the community or on an open ward.

In this essay I aim to explore how these different perspectives have contributed to my understanding of dementia, how dementia effects the elderly patient and what we can do moving forward to provide the most effective and holistic care to these vulnerable patients.

PERCEPTIONS OF DEMENTIA; WHAT HAS A MULTIDISCIPLINARY PERSPECTIVE TAUGHT ME?

My experience of the behavioural and psychosocial symptoms of dementia, coupled with the awareness of the pathological background of these challenging presentations has opened me up to a level of compassion, care and sympathy I did not first possess.

As a naïve teenager beginning work on a complex dementia ward, it was all too easy to simply see employment as a source of income, rather than a place of responsibility. However, the incredible role models which I met on these wards very quickly changed my views and whipped me into shape. I remember thinking to myself in the early days, before I fully understood the condition:

> "Can they not just sit down in one place?"
>
> "Why do they keep hitting out at me – they're doing that on purpose!"
>
> "Why won't she just tell me what she wants?"
>
> "Can she please stop shouting and be quiet, this is definitely behavioural!"

Despite these thoughts I always had brilliant guidance and was taught how to effectively care for these individuals. However, it took much longer for me to fully understand their plight.

When we think of a difficult patient; the "demented patient" can come to mind, along with their associated challenging behaviours. We have all let out that irate sigh when a patient has been pulling out peripheral lines, wandering the wards or insisting that they need to get home. On a busy day in a hectic hospital; we can often feel the pressure added by these confused patients. However, they are not simply the "demented patient", they are an individual *living with dementia* – who has had a full life, left behind a loving family and influenced the lives of others beyond our comprehension. They are suffering, grieving and lost. Our role is to guide them, support them and care for them… breathe, take perspective of the human being standing in front of us – and reassure them; why they are here, what is happening and that everything will be okay.

INDIVIDUATION AND THE ELDERLY PATIENT; HOW CAN WE HELP OUR PATIENTS REANIMATE THEIR LIVED LIVES?

Understanding that "JP Bed 4" on the handover sheet is not only a patient, but also a person is integral to the development of us as both individuals and healthcare students.

When on clinical placement as a medical student we spend a lot of time in pursuit of the coveted "good patient historian". When we approach ward-based staff and ask for some direction we are often told to "avoid bed X, Y and Z" – and an often criterion for this directional aversion is a diagnosis of dementia. Individuals with dementia may not be the best historian, but I personally feel we can learn much more from ten minutes with them than any other patient presentation.

A much-quoted statement by Ignatieff (1993) observed:

> I learned as much from my mother when she couldn't speak to me, when she couldn't communicate, when she simply stared and received our kisses on the cheek, as I learned when she was joking and laughing.
>
> *From "Scar Tissue" by M Ignatieff*[2]

This clinical ostracisation of the dementia patient isolates not only the patient from meaningful interaction but isolates students from meaningful experience. The communication skills which can be gained from interaction with these patients are applicable to all medical specialities, all locations, and all occupations.

Jungian psychology[3] speaks of the concept of individuation. This is the way in which we are all differentiated from each other through our own distinct psychological makeup and how we become distinct from the general collective psychology of all. This individuation which makes each of us unique, is challenged at its heart by the concept of depersonalisation – in which we are seen as one of a collective and our unique individual characteristics are not recognised.

Depersonalisation of the elderly is the antithesis of providing safe, holistic and adequate care to our patients.

All too often time is not taken to sit with the elderly patient, discuss their interests and explore the idiosyncrasies of their personas. Hudson[4] claims the concept of depersonalisation is facilitated through inadvertent use of personal detractors, such as labelling someone "aggressive" or talking over the top of their heads. Hudson goes on to explain that although these "should not be seen as deliberate acts of malice" they do ultimately have a "cumulative effect", leading to a patient becoming withdrawn, agitated, distressed and frustrated.

However, often the "repersonalisation" of the patient occurs only when they have passed. The poem "A Crabbit Old Woman" was reported to be uncovered after the death of a lady named Kate who wrote this poem down in her last days in care.

> So open your eyes, nurses, open and see,
> Not a crabbit old woman. Look closer, – see me!
>
> *From "A Crabbit Old Woman" by Phyllis McCormack*[5]

This last verse of the poem illustrates Kate's plea to be viewed as a person who has lived a full life and is struggling and suffering in her last moments. This verse is reminiscent of how healthcare workers can see others outside of their own life's context. Patients and caring are often viewed as simply an occupational task – which leads to this depersonalisation. The fact that this poem was said to only be uncovered in Kate's belongings following her death reminds us of how we are often too late to realise the individuality and importance of our patients. Although Kate's authorship of this poem was proven as urban legend, and the attribution returned to its real creator; a nurse named Phyllis McCormack, the message still holds immense meaning and lesson.

Erik Erikson's Eight Stages of Ageing[6] describes the final stage of ageing as maturity which involves "balancing despair of the end with assurance of loving life over again". In this last stage of development, which Erikson defines as over 65, he poses the existential question "Is it okay to have been me?". To allow our patients to balance these two aspects of despair and loving life, we must firstly support them in the emotional burden of mortality and facilitate them to revisit, reminisce and reanimate their lived life. This can be achieved through the use of reminiscence and occupational therapy models. A poem written by John Clare in 1997 explores the importance of facilitating and aiding the rediscovery of self in our patients:

> I am – yet what I am, none cares or knows,
> My friends forsake me like a memory lost,
> I am the self-consumer of my woes,
> They rise and vanish in oblivion's host.
>
> *From "I am!" by John Clare*[7]

UNDERSTANDING DEMENTIA; THE PSYCHOLOGY

Unravelling the label of "dementia" from a psychological standpoint reveals many complex questions which have been explored for centuries previous. We continually refer to "the older person" but who does this encompass, and how do we qualify it? How can we combat the effects of the dreaded process of "ageing" which many fear looming over them? How do we care for ourselves whilst mourning loved ones, even as they continue to walk among us?

Who is "the older person"?

When considering the "older person", how can we qualify this? There is more beyond biological years when defining the age and hence maturity of an individual. Health status, personal characteristics (e.g., attitudes toward life and self), social and work roles and personal appearance all contribute to how someone may act and how we may interpret their age or maturity. Jung suggested that "individuals develop an interest in their inner experience with advancing maturity".[8] Integral to supporting these individuals in aged life is to facilitate this interest in inner experience, the reminiscence of lived experience and the creation of new memories and comforts.

How can we combat the psychological effects of ageing?

Kernberg showed the importance of self-esteem in this development of resilience in ageing.[9] They found that those with fewer skills and low confidence tend to resist change and feel overwhelmed when reviewing life. Fear of traumatic dependency has been shown to result in restrictive lifestyles and refusal of help in older age.[10] This poses a massive barrier to providing holistic care to those in need. As the elderly loose independence due to many different factors – from confusion to decreased mobility and incontinence – this resistance to placing dependency on others can become a barrier to care. Facilitating the development of these adaptive coping skills is an important area of focus for combating the effects of ageing. Allowing our patients to feel supported and safe as they experience the progressive effects of older life allows for a more fluid adjustment into living with a diagnosis of dementia.

Mourning our loved ones while they still walk among us?

Bereavement can be viewed as much more than simply death of a loved one, it can include miscarriage, broken relationships or even loss of employment. Any form of unexpected loss can be interpreted as a bereavement. In 1994, Denning defined bereavement as "being robbed of anything we value".[11]

Bereavement has a massive impact for all those who experience it. Rees and Lutkins et al. found a seven-fold increase in mortality of bereaved spouses within one year.[12] Morin et al. reviewed this same question and found that bereaved spouses had a 1.66 times higher risk of mortality than a control group of married couples.[13] They went on to conclude that there was indeed a causal relationship here and this persists in the six-month period following bereavement. To combat this, it is imperative that we provide prompt and comprehensive bereavement counselling services to the spouses and families of our patients after they pass in our care.

Stott and Finley described the best practice for bereavement was for the healthcare professional to "understand and be available" for the bereaved.[14] Subjectively, the emotional support indicated by Scott and Finley is more feasible in an inpatient setting due to the relationship developed with family members, compared to an acute death. However, we must separate informal support from that which is provided in the form of official organised bereavement counselling. The famed mother of nursing, Florence Nightingale, wrote that "apprehension, uncertainty, waiting, expectation, fear of surprise, do a patient more harm than any exertion".[15] This statement emphasises the importance of us providing this emotional support to our patients to understand what is happening to them and what the future may hold – this can allow them to develop the personal adaptivity to cope with a symptomatically progressive condition.

Within his work *Mourning and Melancholia* Freud proposed that grief is a normal reaction to loss but should be limited to within a two-year period.[16] He theorised that the pain which is often associated with grief was due to *decathexis* – the withdrawal of ties from the deceased. This can initially be difficult to connect with a dementia diagnosis; however, although we have not lost a loved one, we have lost many of the ties which once brought us together. This can cause a feeling of loss and of dis-investment with the individual which triggers the emotional aspects of decathexis and hence the grief process.

A PALLIATIVE PERSPECTIVE OF DEMENTIA

Dementia care can also be viewed from a palliative standpoint. Hudson states that "rather than fatalism born of despair, palliative care focuses on the person who is living until death occurs … healing can occur even when cure is not possible".[4] This takes a much more optimistic view of palliative care and ties in with the concept of revisiting, reminiscing, and reanimating lived life which I mentioned previously.

The connotations attached to palliative care can aid carers attitudes in caring for those with dementia – as it places focus on the value of a mutual relationship between patient and staff. This concept forms the basis of person-centred care which is the aim of all therapeutic relationships developed between us and our patients. Hudson goes on to state that through these values "life is sustained, and hope is nurtured through honest and trusting relationships developed and refined over time".[4]

Sampson et al. completed a systematic review of palliative care efficacy in dementia care. They reported "equivocal results" and state limitations surrounding a lack of formal evidence base on which to plan a palliative approach.[17] Additionally, ethical issues, prognostic uncertainty and lack of robust outcome measures made results difficult to quantify. However, despite a lack of evidence-based efficacy, the principles of palliative care stated in Hudson's writings do prevail in providing effective and holistic care to the dementia patient as they approach their end of life.

MOVING FORWARD; HOW DO WE EFFECTIVELY TREAT DEMENTIA?

So now we have evaluated these perspectives – how do we move forward? Hudson posits that we should "focus upon the person with dementia rather than upon the person with dementia".[4] For me, this makes me think of how, although dementia has a common presentation, each person who experiences it reacts and copes differently. Therefore, the care and therapeutic engagement required for each person will be unique.

The works of Martin Buber are seen as the foundation upon which "person-centred care" is built. In his book "I and Thou" he discusses the difference between types of relationships.[18] He describes an "I-It" relationship which develops when the "other" is viewed as an object; causing the meeting to remain distant and uncreative. Conversely, if the "other" is accepted genuinely as a sentient then the possibility of dialogue develops which leads to change and an "I-Thou" relationship. These concepts are pivotal in us counteracting the culture of depersonalisation which we explored earlier.

Our relationship with our patients as professionals is vitally important in their care, coping and recovery. Hudson provides an interesting take on resuscitation – while we are all very familiar with the concept and act of cardiopulmonary resuscitation, we can also apply this word to a psychosocial view. Hudson states "rather than think in terms of reviving people from apparent death, nurses should think in terms of restoring people to the wholeness of life".[4] There is a collective understanding of the need to provide physical resuscitation, but a similar value needs to be placed onto psychological resuscitation in order to facilitate and maintain the quality of life which our patients deserve.

CONCLUSION

Ultimately, care for our patients with dementia will always be individualistic, as no one case is the same. Killick and Allan said "nurses who use imagination, ingenuity, intuition and creative responses should be rewarded and supported – for people dying with dementia fit no conventional model".[19] Review data for therapies used in dementia show inconclusive results because no single treatment fits a disease with such a variable presentation. Dementia can vary from person to person and day to day for the individual, so we need to be ready to adapt our care and be creative with our interventions to suit that.

Maintaining the dignity, joy and individuality of our patients should always remain central to our care. The individuals we care for have lived full and loving lives before they have made the journey to join us on the ward. We need to help them relive and celebrate these journeys. Likewise, adverse experiences in life can often haunt our patients and it is our role to provide a safe and protective environment for them through development of a therapeutic and trusting rapport.

I am forever grateful for the plentiful experiences I've had with the individuals in my care. I've had enlightening conversations, rewarding moments and hilarious encounters. Conversely, I've had incredibly difficult and frustrating experiences. I've left work and cried; I've gone home and swore I'd never go back to work again. However, I know that I have developed as a medical student and a person because of these experiences, that the work we do is important, and that every day and every experience is a privilege for me to live through.

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REFERENCES

(a full list available on request)