Jim Jackson Essay Prize

Experiencing Dementia:

Observations on a Short-Stay Dementia Ward

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Word Count (not including title page, footnotes, quotations or references): **6,317**

###### Preface

I

t was proving a fruitful afternoon on urology. I had come to work: taking histories; examining patients.

*After about an hour I noticed an elderly gentleman pacing up and down the corridor. He was smartly dressed in a crisp white shirt, dark green tie and tweed blazer. As he walked he periodically stopped and looked lost before journeying on. Was he alright? Did he need help?*

I approached him. Up close he was neatly kempt with thin wisps of white hair combed into a side parting. He smiled and nodded when I offered to accompany him. Polite conversation ensued. We talked of his service in France and Italy in the Second World War and the successes of his three children. He spoke with charm and intelligence, however I quickly realised something was slightly off. Occasionally he would utter nonsensical snippets, for example how the floors we walked on used to belong to an army barracks in which he was stationed after the War. When asked where he thought he was he made vague references to being in a hotel, pointing out the other patients as guests and me as a member of staff. He also made frequent reference to his wife who was coming to pick him up in an hour’s time.

*After a few laps of the corridor I felt an urge to get back to work. Although this man was pleasant I felt he was keeping me from more effable learning opportunities. I steered him towards his bed, ushered him into his armchair and drew conversation to a close.*

*Before returning to the office I flicked through the gentleman’s notes: Alzheimer’s Disease. I felt a twinge of sadness as I read that his wife had passed away two years previously. However, overall I felt I had “done well”; demonstrating appropriate and sensitive engagement with a person with dementia. On arrival at the office I caught up with the Junior Doctor and returned to work.*

*It was not long before the gentleman appeared at the office doorway. He tried to gain my attention, to which I politely refused:*

‘I’m sorry, Sir, but I have work to be getting on with. I will come and see you in a while.’

*However this failed to placate. Lingering turned into pestering and polite refusal turned into ignoring. He made his way into the office and tapped me on the shoulder. Feeling a boundary had been crossed I got up and ushered him out of the room. He stopped me in the corridor and grabbed my forearm.*

*He was angry. He explained that for the past two hours I had been keeping him waiting on a promise that I would fetch the hotel manager for him. Flummoxed, I tried to explain my side of the story (‘But Sir I was with you only five minutes ago...’) alas our realities were not reconcilable. Hostility ensued. Whilst he insisted that I account for my actions I reinforced I had done no wrong. Patience was quickly replaced by irritation. I no longer liked this man and I wanted him to go away. So I played my last card, apologetically informing him that, far from being a guest at a hotel, he was in hospital with “memory problems”. He looked pained and replied with indignation:*

*‘Do you expect me to believe that? I’m an intelligent man!’*

*I instantly felt guilty for saying something so cruel. I also felt helpless and spent of strategy. I announced my resignation:*

‘I’m sorry, Sir, but I don’t what else to say to you.’

*On cue a nurse came to my rescue. She was breezy and pacifying, taking the man by his arm and persuading him to sit down so she could get him a cup of tea. I watched as the anguish melted off his face. As she led him back to his chair she turned round and mouthed a supportive “Don’t worry”.*

*I returned back to the Doctor’s office. My overriding feelings were of uselessness and embarrassment. Uselessness because I had just experienced a communicational dead end. Far from the awkwardness of clunky dinner party conversation I had encountered a situation in which I was not experiencing the same reality as another person. I was abased, failing to find the tools necessary to engage with this man’s reality. And I felt embarrassment at how quickly I had come to resent this man. Earlier feelings of pride at a successful interaction were replaced by scorn. In the moment I hated him. A charismatic chap who delighted in telling me of his service during the war had become an angry customer deliberately antagonising me and distracting me from my work.*

*What had just happened? Why had my gentle enquiry and supportive listening failed to appease? And why was I left without any tools to reconcile our realities?*

*I took a few minutes to cool off. Then back to work.*

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***Introduction***

There can be no knowledge without emotion.

* Arnold Bennett, 1867-1931

Sometimes I find dementia difficult. Experience has seen me engage with patients with whom communication has proved a real challenge. The preface tells the story of one of these challenges. Associated with these challenges is the cooking up of powerful emotions, ranging from sadness and anxiety to resentment and even fear. Sometimes I find these emotions difficult to deal with and I am unsure how to process them. This essay represents my desire to better understand this emotional soup.

As a medical student there is seldom space for emotion ventilation. An important backdrop to this feeling is the culture of alexithymia pervasive in the medical community. In particular Johanna Shapiro’s work resonated with me.[[1]](#footnote-1) Shapiro suggests that doctors are subscribed to a profession that extols virtues of openness whilst tacitly encouraging an ethic of detachment and objectivity. [[2]](#footnote-2) This process begins right at the start of training via exposure to the “hidden curriculum”[[3]](#footnote-3). Therefore I write as a student stranded in something of an emotional hinterland; although theoretically aware of the important role emotion can play in the doctor-patient relationship I am sometimes unsure of its validity.[[4]](#footnote-4)

With this in mind I wished to undertake a series of observations in a personally provocative area – dementia care - with the goal to reflect and gain insight into thoughts and feelings aroused in a bid to better manage the emotional soup. Dementia can be a challenging illness which presents caregivers with considerable emotional distress. This research allowed me to experience the illness from the perspective of both patient and healthcare worker and to discuss the theoretical underpinnings of the associated feeling states.

The following report will lay out the findings of this project like so. Firstly, the methodology of data capture will be briefly explained. Then I will present the results. Using specific examples from my observational diary I will draw a distinction between two major feeling states experienced: unwantedness and connection. The feeling of connection arose through interaction with healthcare workers and the feeling of unwantedness came about when health workers appeared task-orientated. will then use the discussion to unpick unwantedness as a mirror emotion to the feelings I experienced as a caregiver in a bid to understand why a nurse might be depriving patients of connection. Reasons cited are *shortage of time* and reluctance to summon the *effort* required to give face time to persons with communication difficulties. Other reasons explored in greater depth included a *social defence mechanism* posited by Isabel Menzies Lyth and Steven Sabat’s theory of *malignant positioning*. Menzies Lyth’s defence mechanism sheds light on nurse predilection for task-orientation as an effort to lessen anxiety experienced by confrontation with suffering. Sabat’s theory is used to argue that staff distanced patients by way of malignant positioning and therefore nullified opportunities for interaction. I will then offer a tentative conclusion that the power of subconscious mechanisms on the behaviour of caregivers working in an arena as emotionally charged as dementia care might be more than previously realised. Finally, taking on board lessons learned I will revisit my initial experience on the urology ward and reflect on this project’s significance for future practice.

For the sake of clarity it is worth acknowledging that I did not embark on this study with a versed understanding of psychodynamic theory. Therefore instead of shallowly employing the language of transference-countertransference I use the word “emotion” synonymously with “feeling”, and both to mean the ‘affective state of consciousness’[[5]](#footnote-5).

Methods

I spent a total of six hours directly observing care of patients with dementia on a short-stay dementia ward at a psychiatric hospital in Edinburgh. This took the form of five 1-1.5 hour long observations over the course of four consecutive weekdays.

The ward consultants were included in the organisation of the project. Additionally the lead nurse for the ward was granted responsibility for disseminating information about the observations to the nursing team. The lead nurse also introduced me to all the patients on the ward before the first observation.

The observations were loosely based on the five step psychodynamic method outlined by Davenhill et al.[[6]](#footnote-6) During the observations I dressed professionally and wore an identity badge and positioned myself in an armchair against the back wall of the ward communal lounge area. I had a diary with me to record soundbites when appropriate, however left the bulk of the write up until after each observation. I tried to remain as unobtrusive as possible and limited interaction with patients. When interaction was unavoidable it was kept to a minimum and remained neutral. I did interact with patients when deemed professionally necessary: for example assisting with controlled falls, attending to direct requests for help or informing staff of health and safety issues.

Time not formally observing was spent helping with nursing tasks; principally feeding patients at dinner time. On the last day I also joined in with an Occupational Therapy craft session. Although this time was not strictly “observation” I still recorded my thoughts and feelings when appropriate.

Consent was gained directly from patients via introduction from the lead nurse before the first observation. Prior to this, agreement was gained from next of kin via telephone and followed up by a project proposal letter. Out of the 20 patients on the ward 18 patients’ relatives agreed to the observations on the phone and were sent a follow-up project proposal letter. Two patients’ relatives were left a voicemail message and phoned a further two times to no reply. Both were sent a project proposal letter. (Coincidentally these patients were not directly observed at any point)

Although I undertook the observations primed with relevant theory[[7]](#footnote-7) I was not looking for particular themes to accord with his experience. I was also not seeking to directly answer questions set by my experience on the urology ward. In this sense the observations were “qualitative” in that they did not serve to test any particular hypotheses. Instead it was more important for me to simply “be” and reflect upon what I experienced at the time.

Results

I experienced two main feeling states during the observations. The first was a feeling of *unwantedness*. This was experienced when healthcare staff[[8]](#footnote-8) were performing tasks and not spending time with patients. The second feeling was one of *connectedness* experienced when nursing staff were with patients and free from task. These states will be illustrated using examples from my observational diary.

Key to understanding these feeling states was a contrast in perspective gained through formal observation (enjoying a patient’s perspective) and when engaged in other activity on the ward (enjoying a nurse’s perspective). These two perspectives will be referred to as “patient” and “nurse”.

#### Feeling unwanted: nurses performing tasks

A significant extent of observation saw nurses undertaking jobs or tasks.[[9]](#footnote-9) This was experienced as a patient:

“Medication round. It is apparent this is another “job” for nurses. Meds (sic) are dished out like military roll call…”

and its preponderance discussed with nursing staff:

“Stresses and strains of bureaucracy and paperwork. Not being able to spend enough time just “with” patients and feeling rushed to do other things when they are.”

It was noticed that a substitute for quality time spent with patients took the form of snippets of interaction with patients whilst moving in between jobs:

“I notice that staff walk briskly across the lounge to the staffroom. Most will engage with patients en route, bits of banter, lots of “are you alright?” It almost feels like addressing someone you meet in the street but don’t want to stop to talk to.”

When I was a nurse I felt these snippets were helpful, striking a balance between task and patient. However receiving these snippets as a patient I felt unattended to:

“The insight into “how patients are doing” is very different when one is sat in a goldfish bowl (the duty office) surrounded by notes and a ringing telephone. I had such a positive impression of the livelihood of the patients when I was a nurse. Walking from the kitchen to the office and saying “hi!” to a friendly patient before locking myself away for an hour creates an impression of “all is well”. When I am a patient I experience the slow burn of tedium. When a member of staff walks by I feel like a dog waiting outside the supermarket for its owner: the expectation, elation felt when the doors slide open followed immediately by the disappointment when they walk past.”

However, the snippets did provide a momentary surge in activity in an otherwise unstimulating environment:

“There is no stimulation, no life, no excitement. Literally nothing is happening…The tiniest of moments cause excitement and become a spectacle: a door opening, a patient adjusting in his seat.

For example, with regards to the medication round:

However these snippets ultimately left me feeling unwanted, especially as they nearly always coincided with the symbolic exit of a staff member leaving the communal area through a security door:

“…for half an hour this is an interaction and spectacle – watching the medication round is something to do.”

“The moment they get out their keys to unlock the door is a powerful moment. The keys are sturdy and the locks heavy duty so the sound of unlocking is powerful and cuts through the room. It serves as a physical signal that the interaction is coming to an end.”

Therefore as a patient there was a palpable sense that one was secondary to task.

Feeling connected: nurses being “with” patients

Although less frequently observed there were instances when I felt the warmth of connection with a member of the healthcare team. This mainly coincided when nurses spent time just being “with” patients seemingly free from task. For example:

in response to moments of aggression or distress:

“Afterwards patient taken and sat down. (Occupational Therapist) crouches down on floor and holds patient’s hands. Lovely image seen through the doorframe. Like a crystallised scene in a stained glass window.”

when providing company to patients:

“D is being led round by a young nurse. He is zombie-like, jaw agape; vacant gaze…Nurse looks at him lovingly, almost longingly: “What’s the matter, D?” She understands his world. They look as though they are dancing together, like a couple in the corner at party. She hugs him. “Is that what you were wanting?”…They are intimately close; it almost looks as though she is going to kiss him. She looks into his eyes and then away as they continue to dance.”

whilst completing tasks involving patient contact. I experienced this myself when I fed dinner to a particular patient every day for the four days:

“I enjoy being with him. It is peaceful and I feel there is a common understanding between us.”

and, additionally, when patients interacted with each other:

“Witness a tender moment between two patients – can’t hear what they say but one pats the other on the back in a “you’re alright, pal, don’t worry” kind of way.”

Therefore I experienced two feelings states. The more common feeling was of unwantedness. This was felt when not in the company of healthcare staff and was experienced as being secondary to a task. The second feeling was of connectedness when interacting with a nurse that did not appear task-orientated.

The discussion will see me unpick the feeling of unwantedness. This is because it serves as a mirror emotion to the feelings aroused as a caregiver, both on the urology ward and when taking on the role of nurse in the observations. Using insight gained from both sides of the caring relationship I can speculate as to why nurses seemed so preoccupied with task. Unfortunately this will preclude a discussion of the feeling of connectedness; however there is much to be applauded in what I perceived as excellent nursing care.[[10]](#footnote-10) Therefore the following will explore the feeling of unwantedness in effort to understand why nursing staff appeared preoccupied with tasks instead of spending time with patients.

Discussion

There are likely many reasons why staff was perceived to dedicate so much time to tasks in favour of spending time with patients. Some of these are explored below. An important driver of this discussion was the contrast in feelings of “all is well” when in the role of nurse compared to the unmet need I experienced as a patient. Therefore in addition to considering two pragmatic reasons I will introduce two subconscious mechanisms as explanation for my disparity in insight. The two pragmatic reasons are a *lack of time* and the fact that engagement with some patients with dementia can be *effortful*. The first subconscious mechanism draws upon the work of Isabel Menzies Lyth in suggesting that nurses used task-orientation as a *social defence mechanism* to avoid anxieties stirred up by interaction with the infirmed. The second is Steven Sabat’s positioning theory, which suggests that staff *malignantly positioned* patients, thereby nullifying opportunities for communication.

Lack of time

A theme emerged that nurses simply did not have the time to complete all the tasks. As a result time to just be with patients became a scare resource.

Gemma Jones’ study of dementia care workers broached this issue and revealed that a shortage of time pressurised staff to "become task-orientated rather than communication-orientated”. [[11]](#footnote-11) The deleterious effects of this time pressure are particularly profound when one considers the amount of time a patient with dementia might need to communicate effectively.

As a compromise for quality interaction I experienced bitty communication from staff which, if anything, compounded feelings of unwantedness. Malcolm Goldsmith agrees with this notion, arguing that this compromise can be “counter-productive” and leave patients “psychologically damaged”.[[12]](#footnote-12) Additionally he points out that staff too can be left “feeling frustrated” [[13]](#footnote-13) as a result of half-baked interaction.

So why was the nursing team so pushed for time? Two reasons were obvious. The first was an under-resourced working force. At the time of the observation there were a high number of staff absences due to illness.

Another reason was administration bookending normal nursing activities with unwanted paperwork. This was articulated by a member of the team:

Delving into the muddy waters underlying the reasons for this administration is beyond the scope of this paper. However it is worth citing Kontos, who theorises that one of the side effects of striving for top-down efficiency in healthcare is creating a system wherein “the measure of care lies with the physical task rather than the quality of human interaction.”[[14]](#footnote-14) Such an idea accords with my perception of nurses reluctantly completing paper exercises which demand the benchmarking of ineffable processes of care against abstract numerical criteria.

“Feels like for everything you do you have to record it three times in three separate places.”

Kontos’ point resonates with my experience as a medical student in two ways. The first is with regard to the modus operandi of the medical student. I do not write immune to the pressures of a seemingly infinite curriculum and expected competence at long list of practical procedures. As a result one becomes inculcated into the belief that spending unstructured time with patients can be secondary to gaining harder (more examinable) skills. With this in mind I am aware of the language I employed at the start of the urology vignette. I was there to “do work” and became restless when I sensed time with a patient was stealing from more “effable learning opportunities”. This hierarchy of learning goes some way to explain how quality time with patients can become secondary to task completion. The second problem is closely related. As a result of medical student preference for concrete learning opportunities the patient can be used as a means to achieve learning ends. An example of this is my inability to resist undertaking a mini mental state exam[[15]](#footnote-15) on the patient on the urology ward, thereby turning an organic conversation into an information seeking exercise. Therefore not only may time be stolen from patients in favour of task completion but time spent with patients could be stripped of quality due to medical students perceiving patients as means to achieve ends.

Therefore the unwantedness I experienced can be straightforwardly explained by staff lacking time to spend with patients. This problem was articulated by hurried nurses and experienced by the observer as a pressured working environment. Although this problem is by no means unique to dementia services it is pertinent when considering the extra amount of time patients with dementia might need to communicate adequately. Two reasons for this lack of time were offered: an undersupplied working force and an abundance of paperwork that steals away time that could be spent with patients. I offer credence to this latter point in my experience as a medical student and my desire for effable learning opportunities. Sometimes the pressure to learn hard skills supersedes spending time with patients free from agenda and time spent with patients may lack in richness when one uses persons to tick off learning objectives.

### Effort-laden

Another consideration is that spending time with patients with dementia can be effort-laden and as such nurses might shy away from opportunities to communicate. This idea is echoed by Goldsmith, who acknowledges that a caregiver must make a decision to provide “extra energy and input into the communication if it is to be a meaningful one.”[[16]](#footnote-16) This also marries with the experiences of the researcher, who recalls a patient with whom communication required extra effort:

“Stilted conversation. Extreme word-finding difficulties.”

It saddening to learn how patients who are self-aware of the extra effort required to communicate might experience this as burdensome, as one contributor to Goldsmith’s Consultation Document shared: “People haven’t got the time to talk to me now because it takes a such a long time.” It is not hard to imagine how such a feeling might compound any pre-existing experience of isolation or unwantedness.

Additionally not only can such encounters be physically tiring they are also arguably abasing. Goldsmith comments on the “humbling” effects of interaction with some persons with dementia by drawing us “into a world in which we recognise the limitations of our own power.”[[17]](#footnote-17) I share this sentiment, recalling the awkwardness and embarrassment felt when aware that I lacked the tools required to reconcile another person’s reality:

“Took a seat next to a coffee table and a patient in a wheelchair wearing a flat cap who makes ‘blahblahblah noises’. Unsure whether it is meaningful.”

I make reference to similar feelings in my urological vignette. Announcing my communicational resignation was associated with feelings of uselessness and embarrassment. Understandably these are feeling states one would seek to avoid.

A sensible counter argument to this would be that the training and expertise of the nursing staff equips them with the tools necessary to enjoy spending time with patients with communication difficulties. However, observation of nurses spending time in the staffroom or leaving the hospital when on break goes some way to demonstrate that time spent with patients is in some way more effortful or unenjoyable than with the company of themselves or other nurses.

Therefore another simple explanation for nurses spending time away from patients is that time with patients can be unenjoyably effortful and therefore occupation is preferred with other activities. This resonates with me as a caregiver, reflecting on feelings of irritation and resentment felt towards patients with whom communication proved challenging.

Social defence mechanism

A third explanation for the inordinate amount of time nurses appeared occupied with tasks is offered by Isabel Menzies Lyth.[[18]](#footnote-18) Menzies Lyth conducted an empirical study of the nursing service of a large general hospital.[[19]](#footnote-19) She noted that the nursing role demanded repeated exposure to “people who are physically ill or injured” which lead to “high levels of tension, distress and anxiety”[[20]](#footnote-20). She posits that in response to these anxieties unconscious defences are created to shield staff from emotional trauma. Some of these defence mechanisms are initiated by the individual[[21]](#footnote-21) whereas others were initiated by the social system[[22]](#footnote-22).

One of these social defence mechanisms includes “the attempt to eliminate decisions by ritual task-performance”. Menzies Lyth observed student nurses engaging in task performance with almost ritual commitment despite it not being “objectively necessary”.[[23]](#footnote-23) She theorised that deference to task lessened anxiety by removing the number and variety of decisions affecting patient welfare outwith the sphere of individual responsibility.

In enlightening the root of these anxieties driving these defence mechanisms Menzies Lyth tips her hat to Freud and the psychodynamic tensions between life-giving and death-giving phantasies experienced as an infant.[[24]](#footnote-24) At its core this idea alludes to how management of suffering serves up humans with a painful reminder of their own mortality. As such we devise social strategies to deny or avoid these feelings.

Although the fine detail of such a theory is a touch esoteric the more general idea of caregivers establishing defence mechanisms in response to emotional trauma is a popular one.[[25]](#footnote-25) Indeed one contributor to Goldsmith bats off previously explored excuses of lack of time as a “greatly over-used excuse” by some nurses who “appear to feel safer if not involved with the feelings and needs of the client with dementia”.[[26]](#footnote-26) Dunham et al also heeds this idea, reminding us that “caregivers do not intend to be malicious” however “adopt these strategies because they are often overwhelmed by the demands of the disease.”[[27]](#footnote-27)

### An example of this was my experience of a nurse thoughtlessly squirting foul-tasting medication into a patient’s mouth:

“Nurse comes in to squirt medicine into F’s mouth in the middle of his dinner. “Open up F!” Horrible. Feel embarrassed, ashamed.”

### Such cold and detached efficiency could be painted by Menzies Lyth as a picture of a nurse so allegiant to task that the patient is morphed into a means to an end with which to complete it.[[28]](#footnote-28)

Lyth’s argument complements my experience as a patient. Staff seemed committed to task completion and a convincing motivation for this might lie in subconscious defence mechanisms obviating the anxiety associated with exposure to the infirmed. In line with this I recall earlier discussion of medical student time preferentially spent “doing work” and see how this could be a mechanism employed to obviate distress. However, I write aware that feelings aroused in me when spending time with patients with dementia could be colouring my insight into the motivations of potentially less psychologically vulnerable others. However, as Menzies Lyth’s study looked at over 500 nurses, 150 of whom were speciality trained, it is prudent to note that even the most experienced healthcare worker is not immune to these powerful libidinal impulses. I also cannot speculate on whether it was staff down on the ground or higher forces that expressed preference for task - it may well be that nursing staff deferred to task against their will. With this in mind it is worth considering one final argument that attempts to explain excess time away from patients as a result of neither preference for nor compulsion to task completion but instead due to depersonalisation of patients and subsequent lack of interest in interaction

### Malignant positioning

The final explanation draws insight from Steven Sabat’s theory of malignant positioning.[[29]](#footnote-29) This explains the distancing of patients by associating the “primary social personae” of persons with dementia as one of “patient”[[30]](#footnote-30). As a result persons are positioned as inferior and their ability to meaningfully communicate diminished. Key to this process is negative stigmata of dementia and a subsequent diminishment of the value of interaction. Therefore opportunities for connection with patients are overlooked. In this way Sabat describes how the diagnosis of dementia “sets the stage”[[31]](#footnote-31) with potentially meaningful behaviour disregarded when viewed through the lens of illness.

I realised I was guilty of this process overtly:

“One patient paces up and down the ward every 15 minutes or so... He’s done this every day since I have been here. I’ve lumped this (behaviour) into the “crazy” category – this is some repetitive action explained by dementia. I ask the nurse why he does that. “To keep fit…he used to be a physiotherapist.”

and implicitly:

*“On the way from the lounge to the staffroom to write up my notes a softly spoken man asks me for the time. He apologies for his “short term memory problems.” “How is your observation going?” he asks. This pleasantly surprises me. I should have more faith.”*

Following on from this Sabat argues that malignant positioning opens up the door for malignant social psychology to ensue. Penned by Tom Kitwood, malignant social psychology describes social processes that compound the symptoms of dementia by encouraging the creation of narratives that confirm the initial positioning.[[32]](#footnote-32) An example is the objectification[[33]](#footnote-33) of the person, which was witnessed when the care of someone was discussed in close proximity to another patient:

“A relative goes up to one of the nurses to share his concern about why his relative is sleeping so much. They discuss him and the other patients almost directly over B, who is slumped in chair in between them.”

Other examples included infantilisation:

and ignoring:

Nurse: (Tea round) “Do you want a plain or a chocolate one?

Patient: “Chocolate one.”

Nurse: “Chocolate one? I’ll give you one of each, ey?”

“Patients come and tap on the window. Doors shut in their face. Avoid eye contact.”

(I also recount deliberately ignoring the gentleman on the urology ward)

Additionally I noticed staff’s preoccupation with quelling “challenging behaviours” (for example aggression, shouting, swearing, violence, stubbornness and wandering)[[34]](#footnote-34). Staff made a case for these behaviours presenting a threat to the wellbeing of the person with dementia and other patients on the ward. In many ways this is fair; for example the wandering of an elderly person with dementia forces one to consider associated falls risk.

However there is much to be said for challenging behaviour representing a “valid response to the way that the world perceived by the individual”[[35]](#footnote-35) and thus being worthy of elucidation. For example, research by Hussain revealed that 93% of all wandering journeys seemingly lead to a logical destination.[[36]](#footnote-36) This interpretation understands challenging behaviour as something *we* (healthcare workers, relatives etc.) are challenged by and not as something that is inherently challenging. This is particularly relevant for aggressive behaviours, which staff may find difficult to cope with and leave them feeling emotionally hurt. Positioning strategies are therefore employed in effort to deal with these difficult emotions. As a result patients “attract labels like *difficult* or *noncompliant* (original emphasis)” that rationalise the “hidden bias of their helpers”.[[37]](#footnote-37) This serves to reward patients who are “happy and quiet” with benign paternalism from staff whereas those presenting “challenging behaviours” are deemed “naughty or “doing it on purpose”.[[38]](#footnote-38)

In light of this I noticed how nurse preference for passivity could be seen as serving to stabilise the emotional wellbeing of *staff*, not patients. This was noticed in the plying of patients with hot drinks:

“Siting down, drowning patients in tea, coffee, biscuits.”

and the insistence on sitting:

Patient: “When is my daughter getting here?”

Nurse: “Around quarter past one.”

Patient: “Am I just supposed to sit here?”

Nurse: “Yes, you sit there.”

This idea is echoed by Tom Main[[39]](#footnote-39), who recalls the use of sedatives in hospital “only at the moment when [the nurse] had reached the limit of her human resources and was no longer able to stand the patient’s problems without anxiety, impatience, guilt, anger, or despair.”[[40]](#footnote-40) His quip that “it was always the patient and never the nurse who took the sedative”[[41]](#footnote-41) resonates with the reader, who reflects on an almost prescription-like administration of hot drinks and biscuits at times of turbulence or distress.[[42]](#footnote-42)

Therefore an alternative (or likely co-existing) phenomenon explaining why nurses spent so much time away from patients can be explained by a disregarding of the need for interaction secondary to malignant positioning. Important to this understanding is the guilt associated with my own positioning of patients that began almost immediately upon arrival on the ward. As a result of this positioning examples of malignant social psychology were observed. Of particular note was staff’s prescription of pseudo-sedative measures in effort to tolerate the emotional anxiety provoked by challenging behaviours.

Conclusions

The aim of this project was for me to gain deeper insight into the emotions at play when interacting with patients with dementia. A challenging experience with a patient and suspicion towards the validity of emotions aroused pushed me to investigate their origins in a bid to improve my relationship with patients.

This study saw me undertake a short series of observations in a dementia ward. The result was an experience of two major feeling states: unwantedness and connection. The feeling of connection came about through interaction with healthcare workers. Conversely a feeling of unwantedness arose when health workers appeared task-orientated. This feeling of unwantedness was unpicked in effort to understand why a nurse might be depriving patients of connection. Reasons cited were shortage of time and reluctance to summon the effort required to give face time to persons with communication difficulties. Other reasons explored in greater depth included a social defence mechanism and a psychological positioning strategy. The social defence mechanism shed light on nurse predilection for task-orientation as an effort to lessen anxiety experienced by confrontation with suffering. Alternatively it was argued that staff distanced patients by way of malignant positioning and therefore nullified opportunities for interaction.

By way of conclusion I will try and answer the question the project ended up posing: why might a health professional choose to spend time away from patients in favour of completing tasks? Here I consciously bring back the use of “health professional” instead of “nurse”. This is because I see tremendous parity between the actions and perceived motivations of the nurses on the dementia ward and the medical student writing about his experience on the urology attachment. A difficult interaction with a patient provoked feelings of resentment which lead to embarrassment and abasement. Intrinsic to the arousal of these feelings was my preference to engage in tasks on the ward and limit time spent with patients, with subsequent irritation experienced when the reality of this balance was tipped the other way.

My initial experience on urology and the observations I later undertook allowed me to enjoy the view of both patient and healthcare provider. Bringing these viewpoints together I can now share the insight gained, contrasting feelings of unwantedness experienced as a patient and the counterpart feelings driving preference for task in a healthcare professional. Taking advantage of these different viewpoints has allowed me to speculate on why caregivers ostensibly preferred task completion to patient contact. I offered two groups of reasons as to why this may be: pragmatic and subconscious.

It is undeniable that pragmatic issues of poverty of time and communication difficulties provide roadblocks to quality contact. Not only were these issues observed on the dementia ward but I realised them when writing the urology vignette. However, I am reluctant to accord them much significance. Instead, I suspect there is something deeper going on. This is because as a patient I experienced unwantedness yet as a healthcare provider I was ignorant to this unmet need. Therefore despite me *knowing* that patients might be yearning for connection I was disinclined to offer it. Such a decision explained purely by pragmatics is unlikely – tasks need to be done but hardly in favour of placating human suffering. Instead I believe efforts to obviate emotional grief manifested as preoccupation with task. The source of this grief is likely attributable to Freudian impulses as exampled by Menzies Lyth, however as I was also consciously guilty of employing distancing strategies and witnessed explicit examples of malignant social psychology I suspect psychological strategies as articulated by Sabat were also at play. Therefore, especially given the limited outlet for emotional ventilation experienced as a medical student, I am inclined to conclude that untapped emotional grief suffered as a result of repeated exposure to the infirmed dictates my behaviour as a healthcare worker far more than previously realised.

Therefore I swing the balance in favour of subconscious processes driving healthcare professionals’ distance from patients, or at the very least conclude that these factors are owed are lot more importance than one might otherwise consider in what is likely a melting pot of reasons, conscious or otherwise, explaining healthcare deference to task. This conclusion is tentative and is primarily informed from my feelings during the observations. However it serves to highlight that, in addition to the very real pragmatic roadblocks that might prevent healthcare staff spending time with patients, it is prudent to acknowledge the powerful subconscious mechanisms that serve to protect us from emotional vulnerabilities. This is especially pertinent in the emotionally charged arena of healthcare, in which, whether known to us or not, these forces might be influencing our behaviour more than we care to realise.

Final thoughts

This project has taught me a great deal, most of which has not come in the form of tidy conclusions. It is therefore fitting to include some of what I have learned as a few final thoughts.

Firstly, a valuable lesson has been a vastly improved understanding of the experience of dementia. This has come about not only through time spent working and observing on the ward but has been gained through reading some of the truly superb literature on the philosophy and psychology of care of persons with the disease.

In particular, taking on the role of patient has taught me the value of human connection. I experienced a profound feeling state of unwantedness; a need only quenched by genuine human interaction. This can take the form of a “Good morning!” on one’s way to the staff room or through close and sensitive listening. One of the most powerful insights into the value of this connection was through regular time spent with one of the patients on the dementia ward. Unfortunately (like most of the raw data) the specifics did not find its way into the main body of the text. It is worth sharing here.

The man was an ex-factory worker in his mid-sixties. He suffered dementia as a result of both alcohol misuse and previous strokes. Therefore, aside from being wheelchair bound secondary to hemiplegia, his most immediately striking symptom was expressive dysphagia. This meant that, in spite of his best efforts, intended sentences were physically unable to be expressed. His mouth and tongue could not muster the mechanics needed to speak. Over the week I spent about an hour at lunch helping him with his dinner and discussing his life.

Initially conversation was limited to “ayes” and shakes of the head. He was frequently frustrated, quickly ending efforts to answer questions with a dejected sigh and roll of the eyes. And I was nervous, frequently stuck for conversation and finding it difficult to gauge the balance between helping and babying. However over the course of the week I became more relaxed. A bond developed. By the end of the week we were laughing over stories shared. And quite remarkably his dysphagia had dampened and his self-expression had drastically improved. Now he was able to speak short sentences and react to things happening around him (the most memorable of these being when, in the process of me displaying ineptitude at feeding him soup, he remarked: “You’re not very good at this, are you?”). He would also have occasional lucid moments. His speech became free from impediment; as if for three seconds he was dementia-free. One of these moments came through reflection on a life well lived (“I have no regrets. Absolutely none. Why regret when you can live?”). Other moments I will keep for myself.

It is reassuring to know that quality time spent with a patient - including listening, sharing, encouraging, laughing, crying, holding - can be demonstrably healing. For this man his symptoms were relieved right before my eyes. This and the lessons learned above makes me confident that future practice will see me less likely to fall back on excuses of time, instead trusting its value as a healer.

Continuing on this theme begs the implications of this research for future practice. I do not profess grand claims destined to steer the course of dementia treatment. Instead there are two personal lessons I will be taking forward.

The first of these pertains to the value of reflective practice. Perhaps one of the most valuable take-home messages is that reflecting upon and writing about my emotional insecurities does not make me immune to them. However, *acknowledgment* of these forces is a valuable step towards owning them. Taking these findings forward has seen a personal endeavour to channel future emotions into a formal conceptual process. I have started reading into emotional regulation and look forward to organising my thoughts into research investigating the utility of emotions in medicine. It is warming to realise that these aspirations were kindled by the experiences gained through this project and my subsequent interest in reflective practice.

The second lesson regards my attitudes towards dementia. I am pleased to state that dementia no longer frightens me (as much). I used to feel distance when faced with a disease I believed robbed the person of so much. Now I enjoy a calm curiosity to understand the person behind a condition that leaves far more behind than it takes away. This distance has been eased not only by gaining a more considered understanding of a commonly misunderstood and stigmatised condition but by taking steps towards embracing the powerful emotions aroused when confronted with this occasionally abasing condition.

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1. Shapiro J, “Does Medical Education Promote Professional Alexithymia? A Call for Attending to the Emotions of Patients and Self in Medical Training” *Academic Medicine* 2011; 86: 326-32 [↑](#footnote-ref-1)
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5. http://dictionary.reference.com/browse/emotion [↑](#footnote-ref-5)
6. # Davenhill R (ed). Looking Into Later Life: A Psychoanalytic Approach to Depression and Dementia In Old Age. Karnac, London (2007) p131-132. Loosely in that my exposure was far less than the twenty week recommendation and I did not engage in a supervision group to reflect on the observations.

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7. # See Bibliography. In particular Hughes JC, Louw S, and Sabat SR (eds). Dementia: Mind, Meaning and the Person. Oxford University Press, Oxford (2006) and Killick J, Allan K. Communication and the care of people with dementia. Open University Press, Buckingham (2001) are invaluable resources.

   [↑](#footnote-ref-7)
8. Because the vast majority of healthcare workers observed were nursing staff the term “nurse” will be used interchangeably. [↑](#footnote-ref-8)
9. From the perspective of the lounge area it was difficult to gauge exactly what some of these tasks were, however more obvious examples included spending large periods of time in the duty office (mainly appearing to be writing in patient notes but also conversing with colleagues, spending time on the computer and on the telephone), making teas and coffees, distributing lunch and dinner, and undertaking medicine rounds. [↑](#footnote-ref-9)
10. # This connectedness was associated with nurses reinforcing personhood. In particular I witnessed one nurse achieve the “poetic awareness” that Tom Kitwood alludes to: a calm and slowness of communication akin to metaphorical understanding. See Kitwood T. Dementia Reconsidered: The Person Comes First. Open University Press, Buckingham (1998)

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11. Jones G. A communication model for dementia. In *Care Giving In Dementia, Research and Application*. London, Tavistock/Toutledge (1992) p.86 [↑](#footnote-ref-11)
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    [↑](#footnote-ref-12)
13. The problem of time pulling staff away from patients is magnified when viewed against a backdrop of under-stimulation. Again such a theme is reported in the literature, with Clisset et al reporting gross lack of stimulation in acute hospital setting for patients with dementia and Nolan et al finding patients on long stay wards remained passive for 87% of the time. As an observer I also experienced this very acutely. See Clissett P, Porock D, Harwood RH, Gladman JRF “The challenges of achieving person-centred care in acute hospitals: A qualitative study of people with dementia and their families*” International Journal of Nursing Studies* 2013; 50: 1495-1503 and Nolan M, Grant G, Nolan J, “Busy doing nothing: activity and interactional levels amongst different populations of elderly patients” *Journal of Advanced Nursing* 1995; 22: 528–538. [↑](#footnote-ref-13)
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15. I write how I assessed orientation to place; a key component of the Mini Mental State Examination (MMSE). See <http://www.mountsinai.on.ca/care/psych/on-call-resources/on-call-resources/mmse.pdf> (last accessed 25.08.2015) [↑](#footnote-ref-15)
16. Goldsmith (1996). This factor is of course inextricable with feeling time is scarce as a sense of hurriedness might dissuade staff to put in extended periods with patients perceived as time-consuming. [↑](#footnote-ref-16)
17. *Ibid* p.10 [↑](#footnote-ref-17)
18. Original paper: Menzies IEP, “The functioning of social systems as a defence against anxiety: a report on a study of the nursing service of a general hospital” *Human Relations* 1959; 13: 95-121. My source was a shortened version of the original paper found at <http://www.moderntimesworkplace.com/archives/ericsess/sessvol1/Lythp439.opd.pdf> (last accessed 06.02.2015. [↑](#footnote-ref-18)
19. Although her work was not explicitly focussing on care of patients with dementia there are parallels with the high numbers of older people observed in her study and the related emotions cooked up when working in the hospital setting. [↑](#footnote-ref-19)
20. *Ibid* p.439 [↑](#footnote-ref-20)
21. Including, amongst others: dropping out of training; frequent changes of job; seeking postgraduate training; and taking short periods of sick leave. [↑](#footnote-ref-21)
22. Including, amongst others: under-employment of student nurses; excessive movement of student nurses; threat of crisis and operational breakdown. [↑](#footnote-ref-22)
23. *Ibid* p.446 [↑](#footnote-ref-23)
24. P.440: “Feeling omnipotent and attributing dynamic reality to these feelings and impulses, the infant believes that the libidinal impulses are literally life-giving and the aggressive impulses death-dealing…The atmosphere is charged with death and destruction. This gives rise to great anxiety. Infants thus fear for the effect of aggressive forces on the people they love and on themselves…They fear the demands that will be made on them for reparation and the punishment and the revenge that may result, and that libidinal impulses…cannot control the aggressive impulses sufficiently to prevent chaos and destruction.” [↑](#footnote-ref-24)
25. For example see Weil S *Waiting on God* (1951) London: Routledge and Kegan Paul Limited p.67 [↑](#footnote-ref-25)
26. Goldsmith p.80 [↑](#footnote-ref-26)
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28. This explanation is (hopefully) more likely than one that realises the nurse as a sadist or psychopath. [↑](#footnote-ref-28)
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30. *Ibid* p271 [↑](#footnote-ref-30)
31. *Ibid* p.289 [↑](#footnote-ref-31)
32. # Kitwood T. Dementia Reconsidered: The Person Comes First. Open University Press, Buckingham (1998) p.46

    [↑](#footnote-ref-32)
33. Objectification is especially pertinent to dementia sufferers, for whom a loss of memory and ability to communicate in a “hypercognitive” society frees them from expectations made of more rational person and provides incentive to lessen their status as a moral person. See Post SG “Respectare: moral respect for the lives of the deeply forgetful” in Hughes et al. p223-234 [↑](#footnote-ref-33)
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40. *Ibid* p.130 [↑](#footnote-ref-40)
41. *Ibid* [↑](#footnote-ref-41)
42. This is especially pertinent to dementia because the contract of care (that a patient “gets better” in response to treatment) is not bi-directional, promulgating feelings of uselessness and resentment from the caregiver. Main: “The sufferer who frustrates a keen therapist by failing to improve is always in danger of meeting primitive human behaviour disguised as treatment.” p.130 [↑](#footnote-ref-42)