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The Overlooked Voice: Advocating for ~~Patient~~ Client Agency in Medical Practice

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Abstract

This paper presents narratives where doctors overlooked the importance of listening, resulting in human, funny, tragic, and sometimes deadly experiences, and outcomes. It argues for enhancing client agency in medical interactions, emphasising the transformative impact of valuing clients' perspectives. I draw on experiences highlighting the consequences of dismissing voices in the hope of acting as a springboard need for a person-centred approach in healthcare. While miscommunication or a lack of effective communication between doctors and clients can contribute to errors, I acknowledge that the causes of medical mistakes are multifaceted, and I, from the outset, declare that I have great respect for doctors, also as a doctor's daughter. This chapter, begs all professionals to listen to and consider information, even if it does not make sense to them, and always to treat patients as clients. The paper considers the philosophical and practical implications of the words patient and client and then leaves the narratives to dominate.

Keywords: miscommunication, narratives, patient, client, healthcare

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This paper presents narratives where medics overlooked the importance of listening, resulting in human, funny, tragic, and sometimes deadly situations, experiences, and outcomes. It argues for enhancing client agency in medical interactions, emphasising the transformative impact of valuing ~~patients'~~ clients' perspectives. I draw on experiences highlighting the consequences of dismissing voices in the hope of acting as a springboard for the urgent need of a person-centred approach in healthcare.

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~~Patient~~ Client Agency: What's in a Name?

The terminology used in healthcare can vary and different terms may be used in different contexts or regions. Traditionally, patient has been widely used to refer to individuals receiving medical care. Client is more commonly associated with business or professional services (Dupuis et al., 2012; Falkenstein et al., 2016). More recently, the literature presents a shift in some sectors of society towards using terms like Clients, Service Users, or Consumers in healthcare to emphasise a more person-centred and collaborative approach. This change reflects a move towards viewing healthcare as a service industry where patients have more agency and are actively involved in their care decisions (Costa et al., 2019; Farid et al., 2023; Freshwater, 2015). The Content Authority Website (2023) explains that:

> When it comes to the healthcare industry, there is often confusion over whether to use the word "client" or "patient". The truth is, both terms can be used interchangeably, but there are subtle differences between the two. In general, "client" is more commonly used in the context of healthcare services provided by private practices or clinics, while "patient" is more commonly used in healthcare services that hospitals or other medical facilities provide. (para.1)

This website argues that client and patient hold distinct meanings in healthcare contexts. Clients typically seek services from healthcare providers, viewing them as service providers and themselves as consumers; whilst patients receive medical care from a healthcare provider seen as a caregiver, emphasising the need for care. The website argues that while the distinction may seem subtle, it significantly influences interactions between healthcare professionals and those seeking care. They detail that, for instance, therapists perceiving clients as customers might adopt a business-like approach, focusing on satisfaction and retention; whilst doctors may view patients as individuals in need of care may prioritise compassion and empathy, emphasising overall wellbeing and recovery.

Common usage errors involve incorrectly using client in healthcare instead of the more appropriate term patient and vice versa in non-healthcare settings, where choosing between client and patient depends on various factors, such as service settings, the nature of the professional relationship, and the interaction goals. Legal documents often use patients, reflecting an association with medical treatment; psychological treatment uses clients, implying a collaborative relationship and aligning with the collaborative nature of therapy; whilst in alternative medicine, practitioners may prefer client due to its holistic connotations (Dupuis et al., 2012; Tran et al., 2018).

Whilst I can perhaps accept that, in a person's best interest, in legal terms, one may accept the use of the word patient, I am afraid I have to disagree with the arguments above regarding when and when not to use client or patient. These arguments seem to imply that difference would need to be made if the persons' issue were mental or physical and if one were paying directly or using state-funded facilities. In my view, using the word client instead of patient, is "Respectful language, a cornerstone of reducing harm and suffering" (Tran et al., 2018, p. 4).

Ultimately, the choice of terminology depends on beliefs, culture, and philosophy: The philosophy of a nation, healthcare organisations, cultural and linguistic contexts, or specific efforts to promote patient empowerment. Regardless of terminology, the key focus should be fostering open communication, mutual respect, and a collaborative approach between healthcare providers and those seeking care. However,

language mirrors one's beliefs and attitudes more glaringly than one would perhaps want; and therefore, I believe that the vocabulary one uses reveals one's conscious and unconscious beliefs and attitudes (Deber et al., 2005; Flores-Sandoval, 2021; Gazzola et al., 2023; Lloyd et al., 2001). Grasser et al., (2023) added that, in relation to mental health:

> Identifying preferred terminology is important because language, including terminology surrounding medical conditions and the people who have them, is a conduit for propagating stigma (p. 654).

A survey in an Australian regional mental health service concluded that:

> Client was identified as the preferred term followed by consumer, patient, and other terms. The results indicated that the treatment setting influences the way people prefer to be addressed. In the hospital setting, people preferred to be known as patients, whereas in community settings, they preferred client and consumer. (Lloyd et al., 2001, p. 324)

A Historical Guide?

Harper (2001) explained that both words have their origins in Latin: Client comes from cliens, which referred to a dependent or follower and patient from patiens, which means suffering or enduring.

In ancient Rome, a cliens was a person under the protection of a patron, typically a more powerful or influential individual. Over time, the meaning evolved, and in medieval and later usage, came to denote someone who seeks professional services or advice, often in legal financial contexts (Olivetti, 2003-2027). In the modern context, especially in healthcare, the term emphasises a more collaborative and equal relationship between those seeking services and service providers, reflecting a shift towards autonomy and shared decision-making.

The original usage of patiens was more closely tied to the idea of enduring or suffering through an illness. In medieval and early modern English, the term became associated with someone undergoing medical treatment or care, emphasising the passive role of those receiving care. Whilst the historical roots suggest a more passive stance, in contemporary healthcare, efforts have been made to move away from the notion of passivity, recognising patients' active role in managing their health, particularly when consumer-mentality started to increase (Bloch, 2003; McLaughlin, 2009; Sluzki, 2000).

Both client and patient have undergone semantic shifts, reflecting changes in societal attitudes towards relationships, autonomy, and the nature of receiving services. However, differences remain. While client continues to emphasise collaboration and partnership, patient retains its historical ties to enduring or suffering, though its modern usage acknowledges the active involvement of individuals in their own healthcare. As discussed above, the choice between these terms often reflects broader shifts in societal values and approaches to healthcare. Thus, confusion and disagreement over the correct terminology prevail (de Haan, 2010; Deber et al., 2005; Ratnapalan, 2009).

When Fiction Mirrors Reality

Experiences of miscommunications have been documented for centuries, even in the literature. In Gustave Flaubert's (2013) 1856 novel, protagonist Emma Bovary struggles with dissatisfaction in her marriage, seeks solace in romantic fantasies, and starts experiencing health issues. She consults various doctors, who all dismiss her complaints. The failure of these physicians to understand her emotional distress and provide meaningful support directly contributes to Madam Bovary's downward spiral, ultimately leading to her tragic end. Edna Pontellier (Chopin, 1981) grapples with societal expectations and her own desires. When Edna seeks medical advice regarding her emotional struggles, she is prescribed rest and isolation. The doctors failed to comprehend Edna's internal turmoil and provide appropriate support, again contributing to the novel's tragic ending.

In Tolstoy's 1878 classic novel, Anna Karenina (Tolstoy, 1995) suffers from postpartum depression and seeks medical help. Unfortunately, her doctor, more concerned with societal norms than Anna's wellbeing, prescribes rest and isolation. The lack of empathetic listening and understanding contributes to Anna's deteriorating mental health, ultimately leading to tragic consequences. Charlotte Perkins Gilman's (1981) short story The Yellow Paper deals with another woman suffering from postpartum depression and being confined to a room by her physician husband. The doctor dismisses her concerns and refuses to acknowledge her deteriorating mental state, leading to a tragic outcome.

As depicted in literature and historical accounts, these narratives of miscommunication with doctors resonate across centuries and persist in contemporary society, reflecting enduring challenges. The theme of misunderstood symptoms, dismissive attitudes, and inadequate communication between ~~patients~~ clients and healthcare providers transcends temporal boundaries. Narratives illustrate instances of dire consequences due to misinterpretation or cultural misunderstandings. The continuity of these narratives highlights the persistent need for effective communication in healthcare, emphasising the enduring importance of fostering understanding, empathy, and collaboration between medical professionals and ~~patients~~ clients across different eras and cultural contexts.

The Narrative

Whilst the above literature examples deal with women and mental health, this paper's narratives include physical issues. Narratives have been fictionalised so that all examples can be regarded as anonymous. These stories may have happened to me, my relatives, friends, and acquaintances, even if presented using the first-person writing style. The only two exceptions are my son's thumb incident and my car accident, which I also wrote in the first person. I have only retained the individual's gender if and when it pertained to the narrative. I have otherwise used general-neutral names. All names start with a C to present my standpoint that the word client should replace patient in medical and mental health jargon.

Cal's Story

Medical professionals consistently dismissed Cal's persistent complaints of unexplained pain. Despite repeated attempts to convey the severity of their symptoms, their concerns were trivialised and attributed to stress. Unfortunately, a later diagnosis revealed a life-threatening condition that could have been addressed earlier if the medical team had taken their complaints seriously. Cal did not die, but an earlier diagnosis would have spared them two surgeries followed by radiotherapy. It is incredible that Cal is not bitter about the experience and always refers to the Maltese proverb that when someone thinks you are dead when you are still alive, seven years are added to your life.

Cai's Story

Cai was not Maltese, and their cultural background and communication style – verbal and non-verbal - differed from the doctors and nurses attending to them. Their expressions of discomfort and subtle cues were not adequately understood, leading to a misdiagnosis and a prolonged period of suffering. With a more culturally sensitive and person-centred approach, the medical team could have accurately deciphered Cai's concerns, preventing unnecessary anguish.

The Broken? Thumb

I was waiting for my children to finish their afterschool activity. My children's gym teacher called me in. An aluminium door had squashed my son's thumb. Off we drove to the nearest Primary Health Centre (at the time known as Polyclinic) with his thumb in the air and the white towel wrapped around his hand slowly turning red. Five of us, my son, my daughter, and two classmates I was taking home, entered and my son was given priority. The doctor prodded and checked the thumb. My six-year-old kept repeating that the doctor was hurting him and that he was sure the thumb was broken. The doctor kept assuring him that it was not and that "you are just being a baby fusspot," a phrase which remains etched in my brain. This did not go down well with a child who was trying to be assertive and share the pain that he was feeling.

The doctor insisted that there was no need for an X-ray. I was losing my temper, let alone what my child was feeling. Therefore, I told the doctor that I would be asking for an X-ray, and he either wrote us the necessary prescription to go to the main hospital (there was no service of X-ray in polyclinics back then) or we would go to the emergency ward without his prescription. The doctor begrudgingly wrote this prescription, and off we drove to the main state hospital, the then St Luke's Hospital, where the results showed that the thumb was indeed broken, apart from being lacerated. My son asked for a copy of his X-ray. Relieved that we could go home, we walked to the car (I thought!).

As you can imagine, after driving around the island with four young children who were by now flustered, hungry, and annoyed, I was looking forward to getting the children home. I switched on the car and my son asked where we were going. "Home, after dropping off your classmates," I replied. "No. We are not", he piped indignantly. He insisted that we go back

to the Polyclinic so that he could show “That Doctor” his X-ray and that “I was not just being a baby fusspot”.

The group of five again entered the Polyclinic, and my son asked for the “That Doctor”. The nurse remembered us. With a smirk, she asked us to wait and accompanied my son to the doctor’s office. What happened inside that office I do not know as only the nurse went in with my son. However, my son came out smiling and the nurse was trying to contain her laughter.

My December 1998 Car Traffic Accident

In December 1998, I was hit by a car. Below is a series of events that are as comical as tragic. On the day of the accident, I had spent a whole day with students and colleagues eating nibbles and drinking cheap wine. I was then hit by a car in the evening whilst shopping in Sliema. I have no memories of the accident, but the post-accident first memory in the emergency room has stuck.

The Emergency Ward

The ambulance screeched to a halt. I was urgently wheeled into St Luke’s Hospital. I started coming in and going out of consciousness, starting from the bright hospital light as I was being wheeled in, with no recollection of being hit, put on a stretcher, and ambulance-driven to the hospital, a 45-minute-window memory I have been told will never come back

A medical team, at least six nurses and a doctor were tearing off my trousers to assess the damage, and I kept telling them that I needed to vomit. They assured me this was only a “feeling” since I had hit my head. I kept asking and pleading to “please bring me a bucket”, and their response was the same assurance. Suddenly, a volcano erupted. All the cheap wine and nibbles projectiled on at least three people … Then they brought me a kidney bowl.

The Post-Operative Hospital Experience

After four years on first crutches and then wearing a brace, in June 2003, I was finally assigned a posterior-cruciate knee surgery. As I gradually regained consciousness in the post-surgery recovery room, I felt a throbbing pain in my non-operated leg, a sensation that seemed more intense than expected. At the time, I did not even realise which leg it was. Disoriented and still groggy from the anaesthesia, I tried to communicate my discomfort to the attending nurses. "Excuse me, my leg hurts," I managed to mumble. The nurses, engrossed in their routines, briefly glanced my way with a casual reassurance. "It’s normal to experience some pain after surgery. You will be fine," one of them replied, her tone carrying an air of routine comfort.

In and out of consciousness, as often happens after surgery, I woke up several times and, progressively less groggy, wondered why my left unoperated leg was hurting me, realising slowly that it was my non-operated leg. I was asleep when my family came to see me, so I could not share this with them. Throughout the night, I kept waking up and asking nurses to check my left leg. However, I was repeatedly told that I was imagining things and that I was a fusspot (funny how my son and I heard the same word - fusspot in English even though conversing in Maltese).

I understood that postoperative pain was a part of the process, but something about the intensity and persistence of the pain in my leg felt off. I persisted in expressing my concerns, hoping for a more thorough evaluation. As the minutes stretched into what felt like hours, the pain in my leg intensified.

Frustration and a sense of helplessness settled in as I struggled to convey the urgency of my discomfort. Then, the surgeon started his rounds. I shared my feelings, apologised for being a nuisance, and begged him to check my left leg. He lifted the bedsheet and immediately became angry, calling the nurses. He looked at my leg, which had a compression stocking, and immediately noticed that the stocking was poorly placed, causing undue pressure and constriction in certain areas of my leg. The realisation prompted a swift adjustment as the compression stocking put on to prevent thrombosis had tourniqueted my left thigh. The minute it was taken off, I first felt agony, it took two hours for the throbbing to stop, then relief from the searing pain that had plagued me since waking up from surgery … and the risk of losing my better leg.

The experience left me with a mix of emotions - relief that the source of my agony had been identified and rectified, but later frustration … and later fury … at the dismissal of my concerns. It does not stop…

Hospital Dismissal

The nurses explained that I could go home once I could use the stairs. I was informed that this exercise would start the next day. Due to

the way my cast was, I would not wear underwear, so I was only wearing a hospital gown. The next day, two nurses came and excitedly announced that I would start this stair exercise there and then … during visiting hours.

The Cholera Shot

Caz, now in her sixties, was a secondary school student in the early seventies. A possible cholera epidemic required all children to be given a cholera injection. Caz's class was taken to the nurses' room and put in two queues to enter the nurses' room two at a time, where two medical professionals were giving shots. Caz entered and suddenly started shouting, "No, Wait, Wait!" as one medical professional grabbed her left arm and the other medical professional the right arm, each holding an injection. Caz's cries were ignored, and they ended up being injected in both arms. Her "No, Wait, Wait", had probably been interpreted as fear and/or resistance.

The Newborn

When my daughter was born, different doctors, including teams with medical students, kept coming in to examine her, and there was much murmuring amongst them. She was born 15 days early, and my husband was abroad when she was born, so that was a lonely experience. I kept asking the nurses to inform me what the doctors were murmuring about but always got the reply, "You have nothing to worry about", which only increased my anxiety. On the day I was to be discharged, her file was inadvertently left in a hanging container at the end of the bed. I opened it and saw the term jaundice.

I was so angry that I was not told that I took the file home with me to photocopy. As soon as I arrived home (this was the pre-mobile life), I received a call from the hospital as a panicked nurse could not find the file and if, by chance, I had it. I must admit I white-lied and told the nurse who called to give me a minute to check. After a two-minute (timed for effect!) pause, I exclaimed, "Oh Dear! I took it by mistake; I will get it to you as soon as I can".

I am Sick, Not Senile!

Cel was diagnosed as coeliac in her early 60s. She visited a specialist who put her on a diet to repair the damage to her intestines. She was to follow the diet for six months and then return to the specialist. Six months elapsed. Upon examining her, the specialist found no improvement or weight gain and chastised her for not following the prescribed diet. Cel responded, "I may be sick, but I am certainly not senile. I followed your diet meticulously". After a couple of minutes of the specialist continuing to disbelieve her, Cel's daughter, who was present, interjected and, containing her anger and disbelief, asked the specialist if there could possibly be another unrelated reason to being coeliac.

After much hooing and haaing, the specialist referred Cel to another specialist who concluded a respiratory complication. Cel never wanted to return to the first specialist and instead continued with the second specialist, who listened to her, responded to her symptoms and comments, and supported her until her demise six years later.

Reflection

These narratives lead me to conclude that initial medical training needs to include interpersonal and helping skills. I am honoured to say that I was part of the team that designed and coordinated the first interpersonal skills course for medicine students at the University of Malta around 15 years ago. Until this paper's publication, these are still part of the medical undergraduate training, and it is hoped that similar content, which the medical programme of the University of Malta refers to as Behavioural Sciences, continues to increase. Similar courses are included in health-related professions such as nursing, but more are needed (University of Malta, n.d.a; n.d.b),

I am sure many of us have similar experiences to narrate regarding professionals at times not listening to their clients. This is more important in the medical context. An error in judgment or a simple error can affect a person. For example, I heard a story about a young woman scheduled to undergo a dilation and curettage (DNC) procedure. She just happened to want to look at her chart at the end of the bed. She saw the word hysterectomy and knew what it meant. A minor error could have lost her the opportunity to become a mother.

Narratives and Terminology?

You may wonder why I present these narratives and discuss the client/patient terminology. I see these related. The choice between using client or patient in healthcare has implications beyond semantics. The shift towards using clients should gain traction in all healthcare settings due to empowerment and agency (Table 1). Ultimately, the choice should consider the specific context, the nature of the healthcare interaction, cultural context, and

individuals' preferences. Striking a balance that respects autonomy and agency while maintaining clarity and professionalism is essential in fostering positive healthcare relationships (Ammentorp et al., 2007; de Rothewelle, 2021; Lampus & Wuisan, 2024).

Table 1

Reasons to use Client over Patient

Client	Patient
Empowerment & Agency	
Associated with more collaboration and empowerment between individuals and professionals, emphasising clients' active role in decision-making and care planning.	May carry more passive meaning, implying one-sided dynamics where individuals receive care without active involvement in informed decision-making processes.
Holistic Approaches to Health	
Sometimes favoured in settings that embrace a holistic view of health, implying a broader scope that includes treatment and promotion of wellbeing.	Seen as more traditionally aligned with the medical model, focusing primarily on diagnosing and treating rather than a comprehensive approach to health.
Stigma Reduction	
Helps reduce stigma associated with seeking mental health services and may contribute to normalising the process of seeking help for mental and emotional wellbeing.	With historical roots in healthcare and, if used appropriately, does not carry an inherent stigma; perhaps respects the expertise of healthcare professionals.
Professional and Ethical Considerations	
In specific therapeutic or counselling settings, using client is common and aligns with ethical principles of confidentiality and autonomy.	In medical settings, especially during acute care or emergency situations, patient might be preferred for clarity and to maintain focus on the immediate medical needs.
Legal and Documentation Practices	
In mental health and counselling fields, the word client reflects these interactions as relational and collaborative in nature.	In medical documentation and legal contexts, used for clarity and consistency, primarily when referring to someone under the care of a healthcare professional.

Conclusion

These narratives underscore the critical need for medical professionals to prioritise ~~patient~~ client agency in their practice and to honestly believe that they are working with clients and not for patients. Recognising ~~patients~~ clients as active partners in their healthcare allows for a more comprehensive understanding of unique needs and experiences. "The creation of communication imbued with empathetic understanding encourages [~~patient~~ client] openness. This condition can help doctors gain a deeper understanding of the patient's situation and maximize treatment" (Lampus & Wuisan, 2024, p. 156).

By fostering open communication and valuing clients' perspectives, healthcare providers can enhance the accuracy of diagnoses, improve treatment adherence, and ultimately contribute to more positive health outcomes (Bloch, 2003; McLaughlin, 2009; Raeissi et al., 2023). Lampus and Wuisan (2024) concluded that "five aspects of effective communication laws, serving as independent variables—namely respect, empathy, audible, clarity, and humble - significantly influence patient satisfaction and loyalty" (p. 156).

Implementing ~~patient~~ client agency requires a shift in the traditional power dynamics within the doctor- ~~patient~~ client relationship. Healthcare professionals should actively encourage their ~~patient~~ client to share their experiences, listen attentively to their concerns, and collaborate on treatment plans. This person-centred approach not only reduces the risk of tragic outcomes resulting from overlooked symptoms and unheard/misunderstood communication but also respects the inherent dignity and humanity of each individual under medical care (Alkhudhairi, 2019; Morgan, 2013). Salik and Ashurst (2019) cautioned that

"Miscommunication is to blame for up to 30% of malpractice awarded lawsuits, where a patient is incapacitated or killed, according to the Control Risk Insurance Company" (para. 1).

The narratives highlighted in this paper emphasise the urgent need for a paradigm shift in healthcare, where ~~patient~~ client agency takes precedence. The tragedies resulting from the dismissal of voices underscore the ethical imperative for medical professionals to actively listen, respect, and engage with their patient client. By recognising the significance of client-agency, healthcare providers can contribute to a more compassionate, effective, and humane healthcare system (Abbasinia et al., 2020; Stewart et al., 2024; Nauheim, 2024). Ratnapalan (2009) tried to pave the way forward:

Most people do not choose to get ill, and shared decision-making undoubtedly allows them to have some control in a situation that is largely beyond their control. However, does this make them clients? Isn't shared decision-making part of contemporary medicine, regardless of the names? The client versus patient debate is not black and white; there are shades of grey, and perhaps it's time to develop a new word that isn't so laden with old meanings. (para. 6)

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