

## Vulnerable Consumers and Healthcare Experience: Patient Narratives

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There is an increasing focus on patient experience as a driver for quality healthcare services. For the most vulnerable consumers, such as people with disabilities, their experience of healthcare services is particularly important. As vulnerable consumers, people with disabilities often have complex health care needs and the greatest need for healthcare services. Yet, many suffer the lowest quality of healthcare services. For healthcare service providers, the challenge is to meet the needs of vulnerable consumers and deliver a favorable and meaningful patient experience. This paper focuses on vulnerable consumers and presents an analysis of patient narratives in terms of patient experience. More specifically, the narrative analysis considers seven dimensions of patient experience as per Hare, Law, and Brennan (2013): life experience, service design, point of delivery, accessibility, availability, specialist education and training, and consumer typology. While some of these aspects of patient experience are relevant to mainstream consumers as well as vulnerable consumers, some experiential dimensions such as accessibility are particularly important in the context of people with disabilities for example.

### Research objective

Researching patient experience for vulnerable consumers is important to understand the patients' perspective. Patient narratives offer a window to the experiential meaning of health care services and a view to the healthcare service experience for people with disabilities. Strategically, the insight offered by an analysis of patient narratives potentially translates to service design and service process improvements. As well, a more comprehensive understanding of patient experience for vulnerable consumers has practical implications for policy makers.

### Significance of the study

Patient-centered care models arrived in the 1980s, where healthcare services consider patient needs as the priority. Originally published by the Institute of Medicine (2001) and as Barry and Edgman-Levitan (2012) highlight, understanding healthcare through the patients' eyes is essential to providing patient-centered care. For vulnerable consumers, such as people with disabilities, the urgency and the importance of achieving this goal is critical to the quality of their care. This research therefore investigates the perspective of vulnerable consumers in the context of healthcare service experience for people with disabilities.

### Method

Community service organizations such as [Care Opinion](#) in the UK and [PatientsLikeMe](#) in the US, have championed the patient perspective in the quest for quality in healthcare services. Care Opinion has operated in the UK since 2005, providing an online portal for patients to share their healthcare experiences in a safe and simple manner. For this study, 200 patient stories from people with disabilities were identified via Care Opinion and the seven dimensions of patient experience from Hare et al. (2013) were applied. The seven dimensions of patient experience identified by Hare et al. (2013) are interrelated dimensions identified from a meta-analysis of literature focused on vulnerable healthcare consumers. These dimensions are life experience, service design, point of delivery, accessibility, availability, specialist education and training, and consumer typology.

### Results

The dimension of life experience encompasses stories about the struggles and stress of life for both individual consumers as well as the broader family and carers. For vulnerable consumers, engaging with healthcare services involves stress both in terms of access and service utilization. Inherent in this narrative is the need for help and support for vulnerable consumers utilizing healthcare services. For @Anon326, the birth of their premature baby and consequent hospital stay was a traumatic experience. As a non-binary person with an undisclosed disability, their story highlights the lived experience of discrimination, to the extent that the patient is potentially intimidated to surrender their child.

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The dimension of service design encompasses the complexity involved with the healthcare needs of vulnerable consumers as well as the necessary coordination of various services. For vulnerable consumers, being treated in a holistic manner is very important. That means services need to accommodate high-needs patients across multiple services. When appropriate coordination of required services is missing or inadequate, that role falls to the individual, and/or family members, and/or carers. Notably, good communication skills including, for example active listening skills, are essential for those assigned to a professional coordination role. Caring for an adult brother with multiple disabilities including, a learning disability, being hemiplegic, and epilepsy, is very challenging and especially so when they live independently but are not able to adequately care for themselves. The family had emphasized to the disability social worker for a long while prior, that the situation was highly problematic in terms of lack of self-care, lack of hygiene in the house, and even lack of a functioning toilet in the house. A local doctor flagged the possible need for the brother to be sectioned under the Mental Health Act. This possible action was supported by the family and regardless of the families' efforts to work with a multi-disciplinary team, for more than a year the brother was left with no help to wash or make meals. At the extreme, *"there were maggots coming out of the toilet, the house was so bad that they feared cross-infection for their other clients."* In contrast, the family doctor and district nurses listened. Consequently, the brother received five blood transfusions because it was discovered that he had stage 4 chronic kidney disease and was released from the hospital to a care home.

The point of delivery dimension is about staff attitude and communication. Understandably, communication is recognized as key to a quality patient experience. Having an established relationship with service providers is very important for vulnerable consumers given their often, complex healthcare needs. Conversely, poor interaction experiences do not reflect well on front-line personnel. More specifically, effective communication and a respectful attitude is closely linked to patient empowerment. A patient story that demonstrates the importance of timely and clear communication is provided by service user @JTWPatient. Suffering with a rheumatic and neurological condition that requires regular blood and lungs monitoring, this patient presented with breathing problems and was referred by his usual physician for an urgent x-ray. The patient had recently moved residences and so intently checked this new address was accurately noted in their health records, so the appointment letter was mailed to the correct address. An updated address at the doctor's office however, does not ensure this address is communicated and updated throughout the NHS system. Consequently, the patient's written advisement for the 'urgent' x-ray appointment never arrived. *"Unfortunately the appointment never arrived, resulting in me missing the appointment and my [doctor] being informed that I did not attend."* The patient was advised by their doctor's office to *"personally call all the services I had regular contact with individually to provide them with my new address, including Clinical Imaging."* In this effort, the patient *"bounced between various departments...explaining... and reexplaining."* When they finally got through to the right clinical imaging office, the patient was informed the original advice he had received was incorrect.

This story from @JTWPatient is a story about poor communication by front-line personnel but also the potentially very serious implications of inaccurate system records for vulnerable consumers. Again, communication skills of the healthcare professionals and personnel are critical to the service process and patient experience. As well as poor communication, this patient story demonstrates how accessibility to healthcare services for vulnerable consumers should be considered more broadly than physical access. While the dimension of accessibility may begin with physical access, accessibility is also considered in terms of the service process and especially the decision-making process. Yet, as evident from @JTWPatient's story vulnerable consumers may willingly participate in the service process and suffer a negative patient experience, to the extent of inaccessibility, regardless.

The dimension of availability is about constraints on patient choice. Vulnerable consumers experience constraints with regards choice of service provider for example. The following comments were made by someone with disabilities who lived in the central London (UK) for 30 years, then moved to North West England. In London, this participant *"...was always able to see a Doctor."* Yet, in the North West calling for an appointment *"...is quite impossible."* This participant summarizes their negative experience by highlighting a lack of continuity in their medical care that results in an unnecessary level of suffering. The dimension of specialist education and training for health professionals and case coordinators for example is an issue that needs attention, from the consumer perspective. Practitioners and other front-line service providers are reported to generally lack knowledge about disability conditions. While detailed knowledge about any and all conditions is impractical, consumers' perceive a general lack of awareness about disabilities as well as specific knowledge on handling people with disabilities. Addressing the issue

involves training for professionals to consider the consumer perspective as well as training for consumers regarding assertiveness for example. The patient story offered by @ChruchSt demonstrates a basic service process recommendation that involves zero cost to achieve an improved consumer experience. This person has Asperger Syndrome, does not like to be called without warning, has repeatedly requested a text message prior to any call as a note of fore warning. The lack of a simple text prior to any call causes this individual day-long stressful anxiety. Understanding why such a simple service process adjustment is necessary and important is better appreciated by someone with the same condition or at least potentially appreciated with more diverse and informed front-line personnel.

The dimension of consumer empowerment emerges when considering the doctor-patient, consumer-service provider, relationship. While some patients are proactive in managing their health and interacting with medical and health professionals, others take on a more passive role. People with disabilities and/or their respective carers, are sometimes forced to take a proactive and assertive stance is getting the care they need. A relevant story comes from @Shepparton, who is someone with a disability, and a patient of the surgery they are commenting on for the past three years. Given their disabilities, sometimes this individual needs to see a doctor on short notice but describes the surgery as becoming "...almost inaccessible" and the need to "...jump through hoops to see a Dr." In a proactive manner, this person calls on the support of their consultant. This person also recognizes that that doctor's who are not "present" during a patient consultation are also not going to provide the necessary care and guidance. This patient story is about someone needing reassurance and support in their proactive health management efforts and yet their experience is a story of a vulnerable consumer being dismissed.

In contrast to the story from @Shepparton about a vulnerable consumer who is not adequately or appropriately attended to, listened to, or supported in the health management, another story is offered by @Sunnyside, who is a carer reporting a very positive patient experience. Their short story highlights the proactive efforts of the front-line personnel, and their respectful, friendly, and professional attitudes. Essentially, this story is a reminder that health care services are a caring profession, where ideally those consuming such services are indeed empowered.

### Conclusion

This investigation of the patient experience for vulnerable consumers, focusing on people with disabilities, demonstrates the insight that can be achieved by considering a consumer perspective through an analysis of patient narratives.

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