



Reflection: Neglecting Patient's Rights

Noor-E-Marfa Amin Shivji*

College of Nursing, Ziauddin University, Pakistan

*Corresponding Author: Noor-E-Marfa Amin Shivji, College of Nursing, Ziauddin University, Pakistan.

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A 70 year old female patient electively admitted in oncology ward with diagnosis of ca bladder. She came in daycare unit for intravesical chemotherapy and was accompanied by her 2 daughters. The procedure for intra-vasical chemotherapy is to insert the foleys' catheter bag before chemo, the bladder is emptied via three way foleys, and finally the chemo is administered. After injecting chemo, the patient has to change position in lateral, supine and prone position. She was well explained about the procedure and treatment but she was constantly refusing for Foleys insertion and treatment. She was also feeling shy for touching her body. However, her daughters and staff were insisting her for the procedure. And finally, she received chemo against her will.

As this was the case of life threatening issue and saving her life was more important than anything else, so I was quiet at that time. Despite the fact, that families offer their best intentions, yet there was still question mark in my mind that whether these types of patients should receive treatment or not? Can we address this issue or not? Should we listen to the patient or follow principle of autonomy and patients rights? Or we should allow family to take this major decision of fully conscious patient?

Whole day, I kept thinking on this issue, I analyzed the risk benefit ration of patient; I recalled the principles of ethics and reviewing the legal and ethical theories of cancer patients. I even asked from her consultant that she is refusing for treatment, the consultant replied as this is her 2nd cycle so she must receive it, why didn't she refused on first cycle, I said she had the same response on 1st cycle but she was coercively received treatment. Then I asked again the consultant about the patient rights she was not sure and said "I don't know". During literature diving, I was rationale for refusing cancer treatment, there are several reasons, i.e. fear of side effects of chemo therapy, non conformity about effectiveness of treatment, hopelessness, helplessness, denial (about their illness), psychiatric disorders, dysfunction in the health care system, and the phenomenon that was even more worse, as nurse called her as a difficult patient [1]. When I analyzed the factors, more or less they all were matching with that patient except psychiatric disorder.

Although families are well wisher of patient, there are situations in which family members become unduly persuasive, manipulative, or coercive [2]. However, the refusal of cancer treatment is a serious concern and has been shown to reduce the effectiveness of treatment and decrease survival duration after diagnosis [3]. Patients often weigh the evidence of risk v/s benefit and their decisions imitate their values and beliefs rather than rely on medical evidence or advices. Nonetheless, these patients keep their medical appointments and seek reassurance for which they are not restricted; and do avail palliative care services without suffering in pain, but with dignity and have some control over the end of their life. In the meantime, they focused on living in the present, keeping to their usual schedules and routines, working, presiding over family gatherings, and seeking support and affirmation from close family and friends [1].

It is also seen in our society that Physician responses are also not supportive for the favor of patient despite of knowing patients legal rights. Thus patients who refuse conventional treatment are thought as "difficult patients" or "noncompliant".

Current evidence suggests that health care professionals often feel uncomfortable, troubled, and even distressed when dealing with patients who make decisions that go against medical advice. In such situations, communication between patients and the health care team plays a key role in developing client therapeutic relationship, gathering information, addressing patient emotions, and assisting patients in decisions about care [1]. The quality of communication in cancer care has been shown to affect patient satisfaction, decision making, patient distress and wellbeing, and compliance with treatment. It seems with the current trend of "patient-centered care" that there is a need to get a better insight into the role that the patients 'view of life, their values, and personal judgments play in the decision making process. After reviewing literature, I committed myself to be advocate of these kinds of patients.

Treatment and decision making is an ongoing process; thus, patients who initially refuse treatment may later choose to undergo conventional cancer treatment if given the adequate support, information, and time necessary to make the decision. Even if patients have declined oncologic care, they may continue to see their primary care providers and family physicians. Patients need to feel that they have not been permanently excluded from the health care system even if they make choices that are contrary to the recommendations of their medical team [4].

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