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Physicians' and Nurses' perspectives on the importance of advance directives in tertiary care hospitals

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Author's Contribution

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A B S T R A C T

Objective: This study aimed to explore and identify the nurses' and physicians' views about Advance Directives and identified their perspectives on its importance, in the context of Pakistan.

Methodology: Using a purposive sample, six physicians and seven nurses from two tertiary care hospitals in Karachi participated in the study. Data was collected using semi structured interviews that were transcribed verbatim. The interviews were coded and categorized manually. Analysis of the data drew four categories: roles of physicians and nurses in the End of life care, challenges they faced while taking end of life care decisions; their perspectives about Advance Directives, and the scope of acceptability of Advance Directives in the context of a Pakistani society.

Results: This study revealed that patients' families and physicians usually take decisions for patients' End of Life care. Although majority of participants acknowledged the usefulness of Advance Directives, they explicated several issues that may be encountered in implementing it. The issues included non-disclosure of diagnosis to the patient in Pakistani culture, the tedious legalization process involved, and the potential problem of forged documents.

Conclusion: Participants recommended establishment of Palliative Care services before execution of Advance Directives. This study indicated viability of Advance Directives; however, a wider exploration would be required in terms of study population. Reforms to support this concept would be required in systems, structure, legal policy, and training of Health care professionals. Besides these transformations, promotion of public education about the advantages of Advance Directives could enhance their acceptability among the general population.

Keywords: End of life care, Pakistani, advance directives, perspectives

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Introduction

Worldwide, advancements in health care technology have been directed towards elaborative and futile treatments instead of PC for the terminally ill. Futile treatments refer to the provision of continuous medical or surgical treatment to the patient that may defuse the symptoms of the disease without curing it. They may lead to overtreatment and cause misery to the patient, and thus burden the family and society [1]. Because of these aggressive treatments, nearly two million people in

America are restricted to nursing homes and nearly 30,000 patients are surviving in comatose or permanently vegetative states [2, 3]. In Pakistan, families may exhaust their financial resources for the treatment of their loved ones, without considerable results.

The issue of futile treatment can be curtailed through ADs. ADs refer to the individual's expression of wishes about the type of treatment that they wish to receive when they become incompetent to make decisions [4]. ADs

have legal standing and it could be exercised in the form of a living will, health care proxy, or a durable power of Attorney. The living will is a directive in which individuals leave instructions about the extent of their treatment. Power of Attorneys and health care proxies, authorize a surrogate decision maker to take decisions on their behalf should they become incompetent to do so themselves [4].

In the absence of ADs, health care providers, especially physicians and nurses, face difficulties when confronted with the patients' EOLC decisions as they may be compelled to prolong the patient's life, but without quality [5]. Worldwide, especially in the western countries, ADs are currently used for the medical treatment of patients. As early as 1991, 93% of the outpatients in the US desired ADs [6]. Although the concept of ADs originated from USA, the need for ADs has been realized worldwide [7]. Research in the Asian countries, such as Thailand, Japan, and Malaysia suggests that ADs could be a useful strategy to overcome issues related to futile treatments, but according to a number of researchers certain modifications would be required to make it culturally relevant [8, 9, 10]. However, to the best of researcher's knowledge, the concept of ADs remained unexplored in Pakistan. Therefore, this study was designed to explore physicians' and nurses' perspectives about the importance of ADs, as they are the key stakeholders in the healthcare system.

As a healthcare professional working for a tertiary care hospital in Pakistan for fifteen years, the principal investigator had the experience of observing the plight of patients, and relatives in ICU, where use of gadgets like ventilators, Bipaps, etc., has led to delayed and miserable deaths, instead of making it a peaceful, natural process. The incumbent financial burden was also substantial causing families to lose most of their savings for the treatment of their loved ones who, in most cases, remained in a vegetative state before death.

The aim of this study was to explore the physicians' and nurses' views about ADs and to identify their perspectives on the importance of ADs in the context of Pakistan. It specifically aimed to answer the following questions:

1. What roles do the physicians and nurses play in the EOLC?

2. What challenges are faced by physicians and nurses related to the EOLC decisions in tertiary care hospitals?

3. What are the views of physicians and nurses about the importance of ADs?

Methodology

An exploratory descriptive design was used to seek a comprehensive understanding and deep insights of a phenomenon [11]. A purposive sample of thirteen participants including physicians and nurses with a minimum experience of two years in critical care areas were recruited from two tertiary care hospitals in Karachi. One of them was private and the other was a charitable hospital. A diverse group of subjects was recruited to ensure variation in demographics of the study participants. This sampling strategy was used to obtain cases deemed information rich for the study purpose [10].

Data was collected through semi structured, in-depth interviews with probes to elicit the participants' verbal responses and non-verbal cues. Semi structured interviews permit flexibility to express ideas and thoughts liberally and help the researcher obtain enough data on preferred themes. The participants expressed their views either in English, Urdu, or bilingually. The interviews were transcribed verbatim by professional transcribers. Approval was obtained from the Ethical Review committee of both the hospitals before data collection.

Concurrent with the qualitative research approach, data analysis was done simultaneously with the data collection [12]. This strategy helped in identification of data gaps in the responses of the participants. Transcripts were verified with the recordings to acquire an in-depth understanding before synthesizing the data. Responses of participants to each question were collated. Relevant words, phrases and sentences were highlighted for coding both latent and manifest ideas and similar codes were grouped for sub categories and categories. The analysis process was overseen by the research supervisors.

Results

There were nearly equal number of participants in terms of profession and their work experience ranged

from three to thirty years and only three participants had formally learnt about ADs.

The analysis obtained from the interviews was organized into categories and subcategories as are explained below with excerpts from the participants' interviews.

Table 1: Categories and Sub-categories of the findings.

Categories	Sub-categories
Roles in the EOLC	Care provider
	Counselor
	Decision Maker
Challenges in the EOLC Decisions	Disagreements in decision making
	Financial Issues
	Distributive justice
	Communication issues
	Quality of Life (QOL)
	Dealing with family care givers
Perspectives about ADs	Awareness about ADs
	Advantages of ADs
	Potential implications of ADs
Potential scope of acceptability of ADs in Pakistan	By self
	By loved ones
	By society

Roles in the End of Life Care:

Three roles were quite apparent for nurses and physicians such as that of a care provider, counselor, and decision maker. Analysis revealed that the most common role adopted was of a decision maker. Majority of the participants shared scenarios about decision making where the family was involved in decision making for the terminally ill patients. Physicians in the non-paying hospital viewed themselves as independent decision makers and usually informed the family about the decision.

“End of life care decisions in the ICU are not patient-family decisions. If the families have specific concerns, we take them into consideration but these patients are in critical conditions and decisions should be taken by the health care teams.”

This quote reflects that the family is not always considered capable of decision making and it is the physicians' prerogative to decide.

Most nurses felt that decisions were mainly made by doctors, in consultation with the family, and these views came from the non-paying hospital.

“We are not directly involved in the care decisions; it is the family and the doctors who decide.”

However, the ICU nurses of the paying hospital facilitated decision making related to the continuity of care, but it was dependent on their individual knowledge and experience.

“Fifty percent role is played by the nurses in the EOLC decisions. When the consultant takes his decision in the ICU setting, the nurses' input is valued considerably because they are the primary care givers.”

Challenges in End of Life care decisions:

Several challenges in the EOLC decisions were identified by the participants, such as disagreements in decision making, financial issues, distributive justice, communication issues, patient's QOL, and dealing with family care givers.

The participants identified that multiple stakeholders are involved in the decision making, whose interests, responsibilities, and perspectives vary to a significant extent, which, in turn, complicates the decision-making process, as one participant explained,

“The patient's son in Karachi had already signed for DNR with pharmacological support. So, the patient was put on T piece. After 7-9 hours in this state, the other son arrived from Dubai...., he created a chaos, and said that the code status be changed to full code. So, this was a challenge; the decision taken in the presence of one son was changed by the other son, who was more powerful and, thus, demanded to revert the decision”

All the participants referred to financial burdens faced by the family. A physician explains,

“A woman had cancer and they kept treating her and eventually she died. Her husband had to sell his house and everything. If, at the end, the yield is so small and the economic devastation is great, we need to discuss finances, looking at the extreme expenditure of the patients”.

Some participants highlighted the issue of limited resources and its implications on distributive justice. In their view, due to lack of resources, decision to continue treatment for one patient would mean denial of care for the others.

A scenario when the code status was undecided,

“The ventilator was occupied for three days on a terminally ill patient, and she finally expired in the ED...someone else could have benefitted from it and survived, but that family was not convinced”

Most participants identified ineffective communication as a challenge and were concerned that information given to the patients and families was inadequate, inappropriate and delayed. A nurse said,

“Counseling should start with the diagnosis of a terminal illness, but it doesn’t happen. When things start getting worse, and then the counseling starts. At that time the patients’ and the families’ become resistant.”

Many participants shared scenarios where life was prolonged, with a decline in the QOL where patients were kept alive in vegetative states. An intensivist shared,

“A 20-year-old woman devastated from a road traffic accident was paralyzed from below the neck, with severe encephalopathy. She had a bed sore which went all the way down to the sacrum... and she decompensated and yet the family said, ‘do everything.’ This patient had no life ...but the family wanted everything to be done.”

Perspectives about ADs:

Most participants had awareness regarding the concept of ADs. In line with the existing literature many participants in the current study described ADs as patient’s own wishes about the care and treatment in terminal illness. The idea that prevailed was an expression of autonomy.

All the participants had knowledge about ADs and understood that it’s a legal document, but a few perceived

ADs to be only for the terminally ill. For instance, a physician asserted that,

“ADs are legal documents and should be made for patients who are bed bound, those with terminal illnesses, and cancers”.

Some of the participants understood that there could be a surrogate decision maker. As a nurse explained,

“The patient can make another person responsible to take a decision on his behalf it can be his son or daughter”.

The participants recognized that ADs would have several benefits which would minimize the challenges at the EOLC. They expressed that with ADs decision making for the terminally ill will become easy, there would be equity in resource allocation, and would ensure QOL. Some of the participants expressed that PC services are needed in our country and they should be established before ADs. A physician stated,

“It’s going to take time; like in the western countries, they did not jump to ADs.... one can approach it from another angle; we can set up PC services and then ADs could follow”

The analyses highlighted some implications that must be considered. The participants anticipated that a thorough legal mechanism, infrastructure, and mass education would be required. There would be hindrances due to the paternalistic culture, where the disclosure of diagnosis is limited to the family. A physician articulated,

“It’s like a big elephant in a room [issue] nobody wants to talk about. Many a times, I have family members who come to my clinic even before the patient, and would say, ‘my mother should not come to know about the diagnosis.’ So, that is a major challenge in our culture, and it does not give us the opportunity to discuss ADs.”

Moreover, concern regarding the possibility of forging of documents was expressed, due to which stringent legal laws need to be in place. A physician expressed,

“A country where the judicial system is a joke and there is no legal system to tell what is right or wrong. Anybody can write, ‘this patient does not want to be resuscitated’, and get it signed and then how will I challenge that in the court of law. It can be used against me.”

Potential scope of acceptability of ADs in Pakistan:

All the participants in this study were in favor of ADs for themselves. Most of them had expressed their ADs informally to their friends or family. A nurse said,

“God forbid, if something happens to me and I am dying, then do not unnecessarily prolong my life. I have told my friends about this.”

Most of the participants were in favor of discussing with their loved ones about their decision in conditions of terminal illness. Some participants expressed that they would prefer life sustaining treatments for their loved ones only if their prognosis would be good. Talking about her mother a nurse explained,

“It will depend ... what her co-morbidities are, and whether she requires ventilation for a reversible condition, I would go for it. But, God forbid if it is an irreversible condition, then I would not opt for intubation.”

This response implied that participants had a misconception that ADs are limited for the terminally ill patients.

Nearly half the participants expressed that ADs are a positive step in healthcare, a nurse stated,

“I guess, once ADs are introduced ... people will accept them. The responses may not be good initially, but when people will realize that the patient can die peacefully by having an AD, they will accept it.”

Most participants believed that the acceptance of ADs would be proportional to the level of education. A physician stated,

“In our country, with such a low literacy rate, people will not understand the concept of ADs but among the educated families it would be accepted.”

A nurse administrator revealed that ADs are being implemented, but usually it is the family who makes the decision when the patient is terminally ill. She elaborated,

“ADs are being implemented, like people express that we don't want to go for support. It is being done for oncology patients, but there is no policy. ... So, we have started with the critical patients, but it is informal.”

Some participants were of the view that if a renowned hospital takes the lead in implementing the policy, it will be readily accepted and other hospitals would follow. A nurse said,

“If the policy of ADs could be initiated by internationally affiliated hospitals, like AKUH, whose services are availed by more educated and literate patients or consumers, the chances of its acceptability will increase.”

Discussion

The two main roles discussed by most participants were of a decision maker and a counselor. It was found that the physicians usually made the EOLC decisions in collaboration with the families, but the patients were not involved most of the time. Comparing the views on ADs from different cultures findings corroborated with our results, that in Asian cultures, end of life (EOL) decisions were made by physicians and families, whereas, in the Western culture decisions were usually made by the physicians and patients [14, 15].

The most commonly discussed challenge was disagreements in decision making due to multiple stakeholders and their varying interests and accountabilities. Previous studies have also referred to these issues; such as differences in family and medical decisions, within the family, among medical teams, and between family and patient opinions [16, 14, 17, 18]. Another challenge, faced by the nurses and physicians, was financial constraints of the families of the terminally ill. This finding corresponds with the available literature [19, 20, 21, 22]. The existing literature has identified distributive justice as one of the consequences of life sustaining treatments in the terminally ill [23, 24, 25]. Similarly, it was also highlighted in the current study, as in a country like Pakistan if scarce health care resources are used on the terminally ill, salvageable patients are denied care.

In line with the existing literature, the participants in the current study described ADs as patient's own wishes about the care and treatment in terminal illness [8, 26, 27, 28, 29]. These phrases reflected the principle of autonomy. A few participants had limited understanding of ADs as they thought that ADs could only be prepared for the terminally ill and many were not aware about proxy decision making. This was due to the lack of education about ADs. This study, therefore, necessitates that continuing education workshops be conducted for raising

awareness about ADs which corresponds with the available literature [9, 7].

In the participants' view, the main advantage of ADs was that decision making could be easier, as the onus of responsibility would be on the patient, instead of family members or HCPs and same has been expressed by participants in another study [26]. Participants identified ADs to be advantageous in terms of QOL as they focused on quality, rather than longevity of life. Another acknowledgement by the participants was equity in resource allocation, which was also consistent with other studies [23, 24, 25]. Thus, the use of ADs would benefit the patients and the health care organizations.

With regard to the implications of ADs, the participants expressed concerns about law enforcement in Pakistan. The process of legalization was highlighted by the physicians, who asserted that there should be a thorough legal process. A study contradicted the findings of the study and maintained that ADs should be used as guidance for decision making in EOLC, but should not be legally binding [17]. The difference in the opinions of the studies may be explained by the fact that one study was done in Portugal, where the judicial system is stringent, whereas, the existing study was conducted in Pakistan, where the judicial system is malleable and not so rigorous. Another concern was the issue that these documents could be forged and used to suit the relatives' wishes and later be used against them (physicians). A similar finding was revealed in a German study, where participants expressed their fear that relatives could abuse such documents [31].

Corresponding to the studies in Japan, Taiwan and Thailand, the participants of the current study reported that non-disclosure of diagnosis created hurdles in exploring options for ADs with their patients [8, 30, 10]. In contrast, the studies about ADs conducted in the western cultures emphasize that diagnosis and prognosis should be discussed with the patients to make informed EOLC decisions [32]. The reason for the difference was the population, and their cultural differences.

Similar to the studies conducted in the western world the participants of the current study unanimously favored ADs for self and others in this era of technology [33, 17]. However, studies conducted in other Asian cultures did

not hold favorable response for ADs [8, 9]. Similar to the findings in a study, the participants of the current study believed that discussion with loved ones about their ADs would be helpful [34]. Contrary to the findings of studies in other eastern cultures, the acceptance of ADs among HCPs in this study appeared to be higher. With regard to implementation of ADs in Pakistan, participants verbalized that this concept will gradually gain social acceptance and popularity. Moreover, the participants reported that ADs would be readily accepted if reputable hospitals would take the lead in implementing them.

This study generated data for further research on ADs. In addition, it even provided an opportunity for the participants to read about the concept and reflect on their perspectives about the importance of the phenomenon. Although this study indicates viability of ADs in the context of Pakistan, the participants were limited to thirteen nurses and doctors from two hospitals in Karachi. To gauge the acceptability of this concept among the general public, broader surveys of the population and HCPs are needed.

On the basis of suggestions from the participants and the analysis, some recommendations have been set forth for health care organizations and HCPs. Health care organizations and the government need to realize the importance of ADs in this era of advance technology. A policy regarding ADs should be made, after legal approval, at the government and institutional levels. Furthermore, health care institutions must include the concept of ADs and PC in their curricula. As part of continuing education, sessions for physicians and nurses must be arranged on ADs, EOL communication, and PC. In order to implement ADs, PC services need to be established first. Awareness on the concept of ADs for the general population must be created in conjunction with health education for chronic and terminal illnesses.

Conclusion

Although there are difficulties and intricacies associated with the introduction and implementation of ADs, the execution of this concept in healthcare is a necessity. HCPs need to be educated and trained in relevant skills to implement this concept. This study indicated that the idea of ADs is viable in Pakistan. However, a broader exploration would be required with a

wider population. Moreover, a detailed exploration is required for the feasibility of ADs in terms of systems, structure, and legal policy needed to support this concept. Nevertheless, informal implementation of ADs to a certain extent is currently being done and public education could enhance their acceptability among the general population.

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