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"QUALITY OF END-OF-LIFE CARE IN CANCER PATIENTS: AN EVALUATION FROM THE CAREGIVER'S PERSPECTIVE."

Oncology

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ABSTRACT

Introduction: A common business truism is that "you can't improve what you don't measure." Yet, despite extensive work to measure the quality of curative treatments within and across countries, few efforts have focused on systematically measuring how well health systems deliver end-of-life (EOL) care. **Aims:** Health systems should aim to deliver on what matters most to patients. Concerning end of life (EOL) care, knowledge of patient preferences for care is currently lacking. **Objectives:** To quantify preference weights for key EOL care indicators. **Methods:** It was a prospective, observational, hospital-based study conducted in the Palliative Department of Mahatma Gandhi Medical College and Hospital, Jaipur, Rajasthan. The study included all the patients in end-of-life care stage, wherein their relatives have given consent/signed for Do Not Intubate, Do Not Resuscitate Policy and also had signed for End of Life Care. The survey also included those patients who had died in the past three months. **Results:** 86.5% strongly agreed that the pain and symptom management was up to the desired level. 85% strongly believed that the facilities were clean, safe, and comfortable. 75% appreciated the kind and sympathetic attitude of healthcare providers, and providers' support for nonmedical concerns had the lowest preference weight. **Conclusion:** Results reveal that not all aspects of EOL care are equally valued. Not accounting for these differences would lead to inappropriate conclusions on how best to improve EOL care.

KEYWORDS

End Of Life, Good Death, Terminal Illness, Palliative Care, Resuscitation Orders.

INTRODUCTION

The quality of death in India is an important topic that encompasses many aspects of end-of-life care, including access to palliative care, pain management, emotional support for patients and their families, and the overall experience of dying. In recent years, there has been a growing recognition of the need to improve end-of-life care in India, with efforts to expand access to palliative care services and advance discussions around death and dying. However, there are still significant challenges, including disparities in access to care based on socioeconomic status and geographic location. Efforts to improve the quality of death in India involve addressing these challenges and providing comprehensive support for patients and their families during this sensitive time.

Consider the following question: Is the Quality of Death as Important as the Quality of Life? It is crucial to pay attention to ensuring a good Quality of Death, which is on par with what doctors are traditionally trained to prioritize—the quality of life. Until around six decades ago, death was generally viewed as a specific point in time, namely, the moment at which life comes to an end.

After all, saving lives is the raison d'etre for our existence. How frequently do we ponder, "but at what cost?" Given the constraint of time, were we able to effectively allocate quality time with the caregivers of an individual whose impending passing was imminent? Were end-of-life scenarios thoroughly discussed? Our preoccupation with delivering intensive critical care, adjusting ventilator settings, correcting electrolyte imbalances, repeating imaging studies, and seeking multiple second opinions may have hindered our contemplation of the quality of death. Recognizing the psychological, social, and spiritual needs at this juncture is as crucial as honing skills in grief counseling.

Wanting to die peacefully is a natural desire for many individuals, influenced by personal values, beliefs, and experiences. Here are several reasons why someone might wish for a peaceful death:

1. Comfort and Dignity: A peaceful death allows for minimal physical discomfort and preserves the individual's dignity. It involves effective pain management and symptom control, ensuring that the person is as comfortable as possible during their final moments.

2. Sense of Closure: Dying peacefully provides an opportunity for closure and acceptance. It allows individuals to reflect on their life, reconcile relationships, and address unresolved issues, leading to emotional peace and fulfillment.

3. Quality of Life: Choosing a peaceful death prioritizes quality of life over prolonging suffering. It respects the individual's wishes and preferences for how they want to experience their end-of-life journey.

4. Minimal Burden on Loved Ones: Opting for a peaceful death can alleviate emotional and practical burdens on family members and caregivers. It may involve making decisions about end-of-life care in advance, ensuring that loved ones are prepared and supported.

5. Spiritual and Emotional Well-being: Dying peacefully often aligns with spiritual or religious beliefs, providing comfort and solace through rituals, prayers, or spiritual practices. It addresses existential concerns and fosters a sense of inner peace and spiritual fulfillment.

6. Control and Autonomy: Wanting to die peacefully reflects a desire for control and autonomy over one's own life and death decisions. It involves making informed choices about end-of-life care, including preferences for treatment, place of death, and support from healthcare providers.

7. Respect for Personal Values: Each person's concept of a peaceful death may vary based on their values, experiences, and cultural background. Wanting to die peacefully respects these individual differences and acknowledges the uniqueness of each person's end-of-life preferences.

In essence, desiring a peaceful death is about honoring one's values, maintaining dignity, and ensuring comfort and acceptance during the dying process. It reflects a deeply personal and meaningful approach to the end of life, emphasizing quality of life and emotional well-being for both the individual and their loved ones.

The significance of the quality of death refers to the importance placed on ensuring that the end-of-life experience for individuals is as comfortable, dignified, and meaningful as possible. Here are some key aspects of its significance:

1. Dignity and Respect: Quality of death emphasizes treating dying individuals with dignity, respecting their wishes, and honoring their

autonomy. This includes considerations like pain management, emotional support, and maintaining personal preferences.

2. Comfort and Pain Management: Ensuring that physical pain and discomfort are minimized through effective pain management strategies is crucial. This can significantly improve the overall experience for the dying person and their loved ones.

3. Emotional and Spiritual Support: Addressing the emotional and spiritual needs of the dying person and their family members can help them find peace, closure, and acceptance during this challenging time.

4. Communication and Decision Making: Open and honest communication between healthcare providers, patients, and families is essential for making informed decisions about end-of-life care. This includes discussions about treatment options, prognosis, and goals of care.

5. Ethical Considerations: Quality of death raises important ethical considerations, such as respecting the patient's right to refuse treatment, ensuring cultural and religious sensitivity, and navigating complex medical and legal issues.

6. Impact on Loved Ones: A good quality of death can also positively impact the grieving process for loved ones, providing them with comfort in knowing that their loved one's wishes were respected and that they were supported throughout the dying process.

In essence, the significance of quality of death lies in promoting a compassionate and holistic approach to end-of-life care, focusing on the physical, emotional, and spiritual well-being of the dying person and their loved ones.

What is Good Death?

A "good death," also referred to as a "dignified death" or "death with dignity," encapsulates several key elements that contribute to a positive and meaningful end-of-life experience. While perceptions of what constitutes a good death can vary across cultures and individuals, there are some common elements that are often considered essential:

1. Pain Management: Effective pain and symptom management is crucial to ensuring that the dying person is as comfortable as possible. This may involve medications, therapies, and other interventions to alleviate physical suffering.

2. Clear Communication: Open and honest communication among healthcare providers, the dying person, and their loved ones helps ensure that everyone is informed about the prognosis, treatment options, and goals of care. This transparency fosters trust and allows for meaningful decision-making.

3. Respect for Wishes: Respecting the wishes and preferences of the dying person regarding their care, treatment, and end-of-life decisions is paramount. This includes honoring advance directives, such as living wills and do-not-resuscitate (DNR) orders.

4. Emotional and Spiritual Support: Providing emotional and spiritual support to the dying person and their loved ones helps them cope with the psychological and existential challenges associated with death. This support can come from healthcare professionals, counselors, clergy, and community members.

5. Maintaining Dignity: Preserving the dignity and autonomy of the dying person throughout the dying process is essential. This involves respecting their privacy, cultural beliefs, and personal values.

6. Closure and Meaning: Facilitating opportunities for the dying person and their loved ones to achieve closure, say goodbye, and find meaning in the end-of-life experience can help ease the emotional burden and promote acceptance.

7. Support for Loved Ones: Providing support and resources for family members and caregivers before, during, and after the death of a loved one is crucial. This may include bereavement counseling, practical assistance, and access to community resources.

Ultimately, a good death is about honoring the individual's dignity, preferences, and humanity throughout the dying process, while also supporting their loved ones in coping with loss. It emphasizes compassion, respect, and holistic care to ensure that the end-of-life journey is as comfortable and meaningful as possible for everyone involved.

The significance of a good death lies in several profound aspects that contribute to a dignified and meaningful end-of-life experience for individuals. Here are some key points that highlight its significance:

1. Quality of Life Until the End: A good death ensures that the dying person's quality of life is maintained or improved to the greatest extent possible until the very end. This includes effective pain and symptom management, which can alleviate suffering and enhance comfort.

2. Dignity and Respect: It respects the dignity and autonomy of the dying person by honoring their wishes, preferences, and values. This may involve decisions about medical treatments, spiritual practices, and end-of-life rituals that are meaningful to the individual.

3. Emotional and Spiritual Well-being: Providing emotional and spiritual support helps the dying person and their loved ones navigate the psychological and existential challenges associated with death. It can promote acceptance, peace of mind, and a sense of closure.

4. Family and Social Support: A good death considers the needs of family members and caregivers, offering support and guidance throughout the dying process and during bereavement. This support helps them cope with grief and adjust to life after the loss of their loved one.

5. Ethical Considerations: Ethical considerations, such as respecting the dying person's right to autonomy and self-determination, ensuring informed consent in medical decisions, and upholding cultural and religious beliefs, are integral to achieving a good death.

6. Legacy and Meaning: A good death allows the dying person to reflect on their life, reconcile relationships, and communicate important messages to loved ones. It provides an opportunity to leave behind a meaningful legacy and impart final wisdom or guidance.

7. Community and Societal Impact: How society approaches and supports end-of-life care can influence individual experiences of dying. Promoting discussions about death and providing adequate resources for palliative and hospice care can enhance the overall quality of dying across communities.

In summary, the significance of a good death lies in promoting compassion, dignity, and holistic care for individuals facing the end of life. It emphasizes the importance of physical comfort, emotional support, respectful communication, and honoring personal values to ensure a peaceful and meaningful transition for the dying person and their loved ones.

The term "Good Death" was coined in the 1960s and unequivocally signifies that the patient's treatment, quality of life, and dignity have been meticulously adhered to, with minimal pain and suffering for the patient, family, and caregivers.[1]

The handling of the death aligns with current clinical, cultural, and ethical norms. Unnecessary or pointless treatments are not administered solely to prolong life. There is complete trust, support, and comfort between the doctor, nurse, and the patient. The patient and their loved ones have the opportunity to openly discuss their beliefs and fears and to say goodbye. If end-of-life care is unavoidable and the patient or their family agrees, aggressive therapies, medications, and interventions are discontinued, but care is never withheld.

The concept of death and the process of dying are significant in all societies and cultures. Different cultures have their own ideas about what constitutes a "good death." With advancements in medicine and technology, people are living longer, resulting in longer end-of-life periods. A "good death" is not just one specific event, but a series of social events. End-of-life support and care should be adaptable and responsive to the wishes of the dying person. Dying is a process that can be influenced, and although it is intertwined with life, there is often a reluctance to openly discuss it.

In a 2017 study, it was found that 70% of Americans expressed a preference for dying at home, a significant aspect of a dignified death. It is essential to consider the associated costs. Interventions aimed at

enhancing end-of-life care carry significant implications for both terminally ill patients and their partners/spouses. In the event of a sudden occurrence, the opportunity to engage in end-of-life discussions with family members is precluded. Conversely, individuals facing terminal illnesses have the time to address and resolve any "unfinished" psychological and practical matters. A dignified death encompasses the absence of imposing burdens on family members, the organization of personal affairs, and the attainment of a sense of fulfillment.

What is Bad Death?

A "bad death," conversely, refers to an end-of-life experience characterized by distress, suffering, lack of control, or unmet physical, emotional, and spiritual needs. Here are some aspects that contribute to the significance of a bad death:

1. Uncontrolled Pain and Symptoms: The presence of severe or untreated physical pain and symptoms can contribute significantly to a bad death. This may result from inadequate pain management or medical complications that exacerbate discomfort.

2. Loss of Dignity and Autonomy: A bad death often involves situations where the dying person feels their dignity and autonomy have been compromised. This could include invasive medical interventions against their wishes, lack of respect for cultural or religious beliefs, or feeling powerless in decision-making.

3. Emotional and Spiritual Distress: Emotional distress can arise from unresolved conflicts, unaddressed fears, or feelings of isolation. Spiritual distress may occur if the dying person's spiritual beliefs or practices are not respected or integrated into their care.

4. Communication Breakdown: Poor communication between healthcare providers, the dying person, and their family can lead to misunderstandings, uncertainty about prognosis, and unmet information needs. This can increase anxiety and distress for all involved.

5. Unresolved Issues and Regrets: A bad death may leave the dying person and their loved ones with unresolved issues or regrets, such as unexpressed feelings, strained relationships, or unfulfilled wishes.

6. Impact on Family and Caregivers: The experience of a bad death can have a lasting impact on family members and caregivers, leading to prolonged grief, guilt, or trauma. Inadequate support during the dying process can leave caregivers feeling overwhelmed and unsupported.

7. Ethical Concerns: Issues related to ethical decision-making, such as conflicts over treatment options, lack of transparency in medical decisions, or disregard for the dying person's wishes, can contribute to a perception of a bad death.

8. Societal and Cultural Factors: Societal attitudes and cultural norms around death and dying can influence the quality of the dying experience. Stigma, fear of death, and inadequate access to palliative care services may contribute to a negative end-of-life experience.

In conclusion, the significance of a bad death underscores the importance of addressing physical comfort, emotional well-being, and spiritual needs in end-of-life care. It highlights the need for respectful communication, compassionate decision-making, and support for both the dying person and their loved ones to ensure a dignified and peaceful transition at the end of life.

"A bad death is one in which there is violence, pain, torture, dying alone, being kept alive against one's wishes, loss of dignity, and inability to communicate one's wishes. Proper communication makes a difference between a good and a bad death. Excessive use of technology, with patient and family wishes ignored, contributes to a bad death.

A common business truism is that “you can't improve what you don't measure.” Yet, despite extensive work to measure the quality of curative treatments within and across countries, few efforts have focused on systematically measuring how well health systems deliver end-of-life (EOL) care." [2]

An approach to produce a Quality of Death index [3,4] relied on various inputs, including whether or not a country had a national strategy for palliative care, availability of opioids and psychological supports, and many indicators on staffing ratios, clinical training opportunities, and other dimensions of access and quality of care, such as the presence of Do Not Resuscitate policies and patient satisfaction surveysThe metrics for evaluating end-of-life care do not always reflect the quality of care that matters most to patients and their family caregivers. Family caregivers often make decisions on behalf of the patient, so it's important to consider their perspectives. Previous attempts to assess the quality of end-of-life care have overlooked patient and caregiver preferences. Efficient health systems should prioritize what is most important to patients, which requires understanding their preferences. When it comes to curative treatment, the most crucial indicators of health system performance are minimizing disability and premature mortality, followed by cost and fairness considerations. For dying patients and their family caregivers, there are numerous other factors to take into account.[5] For example, studies have shown that dying at a place of one's choice or having access to friends and family are more important than minor increases in life extension or even pain management. Many quality indicators and patient-reported outcome instruments have been developed to assess different aspects of end-of-life care. However, only a few have tried to measure the relative importance that patients assign to these different aspects. [7,8]

Aims And Objectives

This study provides information on what family caregivers of terminally-ill patients see as most important for delivering high quality EOL care.

Provides a framework for future efforts that aim to take a preference-based approach to quantify health system performance.

MATERIAL AND METHODS

Inclusion Criteria

Terminally ill Patients, whose Caregiver's have signed for End-of-life Care.

Caregivers should not be a minor.

Exclusion Criterion

Who refused to take part in the study.

Method

A Prospective, Observational, Hospital based study conducted in the Palliative Department of Mahatma Gandhi Medical College and Hospital, Jaipur after approval by Institutional Ethical Committee.

Please keep the following information in mind:

Participants in the study fell into two categories:

A) Patients in end-of-life care who had given consent for end-of-life care, DNR/DNI were included in the study. The attendants or caregivers of these patients were counseled and informed about the study, its effects, and consent was obtained. All these patients were under palliative care.

B) Patients who had passed away in the last three months and were under palliative care were also included in the study. Family members or caregivers were counseled, and the aim of the study was explained, and consent obtained. The criteria for caregivers who could participate in this study were:

1) At least 21 years of age.
2) Capable of understanding the language.
3) Involved in discussions with healthcare professionals regarding the patient's treatment choices, assisting the patient in receiving medical care, or caring for the patient's daily well-being.
4) Privacy and confidentiality of records were assured to all the participants.

In this study, 50 patients who were under palliative care and 50 who had passed away in the last three months were included. A total of 100 participants were surveyed, and 20 did not complete the survey. The study was completed by 80 patients, of which 42 were hospital-based patients and 38 were patients who had passed away in the past three months.

Each indicator has five levels ranging from strongly disagree to strongly agree (Table 2). Questions evaluated key aspects of the patient's experience during the last six weeks of life. Participants or

caregivers were asked to empathize with the patient's experiences and answer the questions accordingly.

RESULTS

In this study, the mean age of caregivers was 52.9 years (SD = 15.3 years), with 44% being female. The majority of caregivers were married or in a civil partnership (71.25%), and nearly half (48.15%) had a bachelor's degree or higher. The relationship to the patient varied, with most being friends (13.75%), colleagues (12.75%), or other relatives (18.75%). A significant proportion of caregivers (95%) were involved in helping the patient get medical care and looking after their daily needs.

The patients in the study had a mean age of 55.5 years (SD = 20.9 years) at the time of death, and 68.75% were married or in a civil partnership. Most patients (68.75%) had a bachelor's degree or higher. The majority of patients (73.75%) rated the care they received during their last six weeks of life as very good or good. The most common professional services received were in-patient medical care (61.25%) and at-home medical care (55%). A significant proportion of patients (58.75%) had difficulty communicating due to their condition or treatments.

The assessment of patient's end-of-life (EOL) experiences using 13 indicators revealed high levels of satisfaction with several aspects of care. The most positively rated indicators were:

- Managed pain and discomfort (86.25% strongly agreed)
- Clean and safe space (85% strongly agreed)
- Preferred place of death (77.50% strongly agreed)
- Care was well coordinated (75% strongly agreed)

The least positively rated indicators were:

- Spiritual needs (6.25% strongly agreed)
- Cope emotionally (6.25% strongly agreed)
- Costs were not a barrier (12.50% strongly agreed)

Statistical analysis, using chi-square tests or independent t-tests where appropriate, could be conducted to determine if there are significant differences in EOL experiences based on patient and caregiver characteristics (e.g., age, gender, education, relationship). However, the data provided in this study is not sufficient to conduct these tests. The sample size for some categories is too small (e.g., only 1 caregiver was a child of the patient), and the data for some variables are not presented in a way that allows for statistical comparison (e.g., the time since the patient died is presented in ranges rather than specific values).

Table 1 consists of two parts (a) shows the characteristics of Caregiver and (b) show characteristics of the Patient. Age group of the patients studied was between 40-75 years of which female were approximately 44 percent. A set of 13 indicators (9) were used to develop a series of questions that captured quality of care delivery across relevant domains.

Indicators

Numbers	Indicators of Patients' EOL Experience Over Last 6 weeks of life
1	Clear and timely information
	Health care providers gave patients clear and timely information so patient could make informed decisions.
2	Treated kindly
	Health care providers treated patients kindly and sympathetically.
3	Spiritual needs
	Health care providers supported patients' spiritual, religious, and/or cultural needs
4	Contact with family
	Health care providers allowed patients to contact their friends and Family
5	Asked enough questions
	Health care providers asked enough questions to understand patients' needs
6	Quality of life extending treatments
	Health care providers provided appropriate level &quality of life-extending treatments
7	Managed pain and discomfort
	Health care providers controlled pain and discomfort as well as the patients wanted.
8	Cope emotionally
	Health care providers gave patients support to help them cope emotionally.
9	Clean and safe space
	The Centre was clean, safe, and comfortable.
10	Care was well coordinated
	Health care providers provided care that was well coordinated.
`11	Nonmedical concerns
	Health care providers helped with patients' nonmedical concerns.
12	Preferred place of death
	Health care providers made sure that patients were cared for and dies at their place of Choice.
13	Costs were not a barrier.
	Costs were not a barrier to getting appropriate care.

Table -1

A	Caregiver characteristics	N=80	
		N	%
	Age in years (Mean [SD])	52.9	SD- 15.3 years
	Female	35	44%
	Marital status		
	Single / never married	22	27.50%
	Married / living as a couple / civil partnership	57	71.25
	Other	1	1.25
	Bachelor's degree or higher level of education	39	48.15
	Relationship to the patient		
	Spouse or partner	4	5%
	Parent	10	12.50%
	Grandparent	14	17.75%
	Sibling	5	6.25%
	Child	1	1.25%
	Close friend	11	13.75%
	Colleague/co-worker	10	12.75%
	Other (Aunt/Uncle/Other)	15	18.75%
	Caregiver was at least somewhat involved in...		
	Talking with doctors about treatment decisions?	4	5%
	Helping patient get medical care, such as going with them to doctors visit.	76	95%
	Looking after patient's day-to-day needs?	76	95%
	Time since caregiver first learned of patient's Terminal Condition before patients' death.	47	59%
	Between 6 months and 1 yrs.	18	22.50%
	Between 1 and 3 yrs.	15	18.75%
	Locus of control for health and healthcare use (% who strongly agree/agree with statements)		
	I prefer to leave all health care decisions to the Doctor.	57	71.25%
	I am able to help doctors understand what is important to me about my health care.	72	90%
	My health depends mostly on luck.	65	81.25%
	I can do things to improve my health other than what doctors tell me to do.	64	80%
	I want as much information as possible to make decisions about my health care.	72	90%
B	SECTION	N= 80	%
	Patient characteristics Overall		
	Patients age at death (Mean, SD)	55.5	SD-20.9
	Marital status	13	16.25%
	Single / never married	55	68.75%
	Married / living as a couple	12	15%
	Other		
	Bachelor's degree or higher level of education	55	68.75%
	Time since patient died		
	< 6 months	34	42.50%
	Between 6 months and 1 yr	29	36.25%
	Between 1 and 2 yrs	17	21.25%
	Care provided to patient during the last 6 weeks of life was mostly ….		

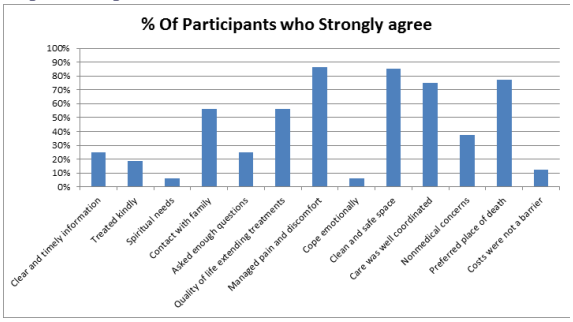
	Very good or good	59	73.75%
	Neither good nor poor	12	15%
	Poor or very poor	8	10%
	Don't know/not sure	2	2.50%
	Professional services received by patient		
	Nonmedical support	24	30%
	At-home medical care	44	55%
	In-patient medical care	49	61.25%
	Outpatient medical care	38	47.50%
	Palliative/hospice care	20	25%
	Traditional or herbal medicine	15	18.75%
	Other	0	0.00%
	Patient's ability to communicate during last 6 weeks of life		
	Had a condition or treatments that made it difficult for them to communicate	47	58.75%
	Had trouble getting what they needed because they did not speak the same language as their Doctors or Nurses	32	40%
	Main reason for patient's death		
	Cancer	58	72.50%
	Heart problems	8	10%
	Kidney diseases	5	6.25%
	Stroke	5	6.25%
	Others	4	5%

Table -2

Numbers	Attribute /Indicators	Levels.					
		1(Strongly Disagree)	2(Disagree)	3(Uncertain)	4 (Agree)	5 (Strongly Agree)	% Of Participants who Strongly agree
1	Clear and timely information	5	6	9	40	20	25%
2	Treated kindly	4	4	15	42	15	18.75%
3	Spiritual needs	15	15	25	20	5	6.25%
4	Contact with family	0	0	15	20	45	56.25%
5	Asked enough questions	5	5	30	25	20	25%
6	Quality of life extending treatments	7	7	11	10	45	56.25%
7	Managed pain and discomfort	0	0	4	7	69	86.25%
8	Cope emotionally	20	25	15	15	5	6.25%
9	Clean and safe space	0	0	2	10	68	85%
10	Care was well coordinated	0	0	2	18	60	75%
11	Non-medical concerns	1	7	16	26	30	37.50%
12	Preferred place of death	0	0	3	15	62	77.50%
13	Costs were not a barrier	25	15	15	15	10	12.50%

Relative Indicators compared in percentage with responses who strongly agreed.

Graphical Representation.



DISCUSSION

A good death is often considered to be peaceful, dignified, and without suffering. It involves being able to say goodbye and make peace with loved ones, as well as having the chance to settle any unfinished business. A good death also includes having the opportunity to express one's wishes regarding end-of-life care and receiving the necessary support to ensure physical comfort and emotional well-being during the dying process.

The research findings indicate that when it comes to end-of-life care, not all aspects receive equal emphasis. The study revealed that pain management and discomfort were effectively addressed, highlighting improved access to medication. Additionally, the provision of clean and comfortable surroundings, as well as supportive services, along with facilitating contact with close friends and family, were rated as significant priorities for individuals in end-of-life care. The study also found that prolonging life moderately was not the primary focus of end-of-life care. Furthermore, the support provided by healthcare providers for spiritual, psychosocial, and non-medical concerns was deemed to be relatively less important. It is possible that respondents perceived these issues as falling outside the traditional scope of healthcare providers. The research also noted that individuals with recent experiences with end-of-life care exhibited different preferences, possibly due to recall effects or as a reflection of the evolving nature of bereavement. [9,10]

Analyzing 13 indicators

The survey revealed the following results: 86.5% of respondents strongly agreed that pain and symptom management met their expectations. 85% strongly believed that care was provided in a clean and safe environment. 75% agreed that care was well coordinated. 77.5% indicated that their preferences regarding the place of death were strongly respected. Non-medical issues, spiritual needs, contact with family, coping with emotions, and answering raised questions were given a 37.5% weightage. Many respondents strongly believed that the treatment to improve the quality of life in the last days of life was worth accomplishing, while 40-45% of respondents did not fully understand the concept of quality of life in a dying patient.

Being heard at the end of life care is of utmost importance for several reasons:

1. Respect for Autonomy: Allowing the dying person to express their wishes, concerns, and preferences ensures that their autonomy and dignity are respected. This includes decisions about medical treatments, pain management, and spiritual and emotional support.

2. Quality of Care: Effective communication between healthcare providers, patients, and families enhances the quality of care provided. Understanding the patient's values, goals, and priorities enables healthcare teams to tailor care plans that align with the patient's wishes and preferences.

3. Reducing Anxiety and Uncertainty: Expressing fears, concerns, and emotions can help alleviate anxiety and uncertainty for the dying person. Being heard provides an opportunity for them to address unresolved issues, communicate important messages to loved ones, and find emotional closure.

4. Empowerment and Control: Being able to participate in decision-making and having their voices heard empowers the dying person, giving them a sense of control over their own end-of-life experience. This can contribute to a greater sense of peace and acceptance.

5. Improving Family and Caregiver Understanding: Effective communication also benefits family members and caregivers by helping them understand the patient's wishes and providing guidance on how to support their loved one during the dying process. This fosters a more supportive and informed caregiving environment.

6. Enhancing Bereavement Process: For loved ones left behind, knowing that their family member's wishes were heard and respected can facilitate the bereavement process. It can reduce feelings of guilt or uncertainty about whether they made the right decisions on behalf of the dying person.

In essence, being heard at the end of life care is crucial for promoting patient-centered care, respecting individual autonomy, and enhancing overall quality of life during the dying process. It supports emotional

well-being, facilitates meaningful communication, and ensures that the dying person's wishes are honored, which is essential for a dignified and compassionate end-of-life experience.

Timely information about a life-limiting illness is crucial for several reasons, both for the patient and their loved ones:

1. Empowerment and Informed Decision Making: When patients receive timely information about their diagnosis and prognosis, they are empowered to make informed decisions about their treatment options, end-of-life care preferences, and advance care planning. This helps them maintain a sense of control over their own healthcare journey.

2. Quality of Life: Understanding the nature and progression of their illness allows patients to prioritize their goals and preferences for care. They can focus on treatments that align with their values and may choose to pursue interventions that improve their quality of life and manage symptoms effectively.

3. Preparation and Planning: Timely information gives patients and their families the opportunity to plan for the future. This includes making arrangements for caregiving, financial planning, legal matters (such as creating a will or advance directives), and addressing practical concerns related to their illness.

4. Emotional and Psychological Preparation: Knowledge about a life-limiting illness allows individuals and their families to emotionally prepare for the challenges ahead. It provides an opportunity to process feelings of shock, grief, and uncertainty, and to seek appropriate support from healthcare professionals, counselors, and support groups.

5. Facilitating Communication: Open and honest communication between patients, families, and healthcare providers is essential for establishing trust and ensuring that everyone involved understands the prognosis and treatment goals. It encourages meaningful discussions about hopes, fears, and end-of-life preferences.

6. Maximizing Time for Supportive Care: Early recognition of a life-limiting illness enables healthcare teams to initiate supportive care interventions promptly. This includes palliative care services to manage symptoms, provide emotional support, and improve overall well-being.

7. Reducing Emergency Situations: Timely information helps prevent unnecessary hospitalizations and emergency room visits by enabling proactive management of symptoms and complications associated with the illness.

Overall, timely information about a life-limiting illness plays a vital role in promoting patient-centered care, respecting individual autonomy, and improving the quality of life for patients and their families during a challenging and sensitive time. It empowers individuals to make decisions that align with their values and preferences, fosters effective communication, and facilitates comprehensive support and care planning.

The importance of addressing spiritual needs at the end of life is significant for several reasons:

1. Finding Meaning and Purpose: Many individuals facing the end of life experience a heightened need to find meaning and purpose in their lives. Addressing spiritual needs allows them to reflect on their beliefs, values, and life experiences, helping them find comfort and peace amidst their circumstances.

2. Coping with Existential Distress: Approaching death can bring about existential distress, including questions about the meaning of life, suffering, and the afterlife. Spiritual care provides a framework for exploring these existential concerns and finding resolution or acceptance.

3. Enhancing Quality of Life: Meeting spiritual needs can contribute to a higher quality of life by promoting emotional and psychological well-being. It can reduce anxiety, fear, and feelings of isolation, fostering a sense of inner peace and resilience during the dying process.

4. Supporting Decision-Making and Acceptance: Spiritual beliefs often influence decision-making at the end of life, including choices about medical treatments, advance care planning, and preferences for care. Addressing spiritual needs helps individuals align their decisions with their values and beliefs, facilitating acceptance and clarity.

5. Providing Comfort and Solace: Spiritual care can offer comfort and solace to patients and their families, providing rituals, prayers, or spiritual practices that offer emotional support and a sense of connection to something larger than oneself.

6. Supporting Family and Caregivers: Spiritual care extends to the family and caregivers, helping them cope with grief, loss, and the emotional challenges of caregiving. It provides a framework for shared rituals, prayers, or spiritual support that can strengthen relationships and provide mutual comfort.

7. Respecting Diversity: Recognizing and respecting diverse spiritual and religious beliefs ensures culturally sensitive care. Healthcare providers who are attuned to spiritual needs can provide personalized care that honors and respects individual beliefs and practices.

8. Holistic Approach to Care: Addressing spiritual needs complements physical, emotional, and social aspects of care, promoting a holistic approach that supports the whole person. This comprehensive care approach can improve patient outcomes and overall satisfaction with care.

In conclusion, addressing spiritual needs at the end of life is essential for promoting holistic, patient-centered care that respects individual beliefs, values, and cultural practices. It enhances quality of life, supports emotional well-being, and provides comfort and meaning during a sensitive and profound life transition.

Quotes from patients who have experienced what could be considered a good death often reflect their sense of peace, acceptance, and readiness. Here are a few examples:

1. "I feel at peace knowing I've said everything I needed to say and that my family understands my wishes. I'm ready."
2. "Being surrounded by loved ones and feeling their love as I pass brings me great comfort."
3. "I'm grateful for the care I've received. I feel respected and in control of my journey."
4. "I've had a good life, and I'm thankful for every moment. I'm ready to rest now."
5. "I find solace in knowing that my pain is managed, and I can focus on saying goodbye."
6. "I feel a sense of closure and acceptance. I'm leaving this world with no regrets."

These quotes illustrate a sense of peace, acceptance of one's circumstances, and the importance of emotional and physical comfort in achieving a good death. They often highlight themes of love, gratitude, closure, and readiness to transition, which are essential elements in the concept of a dignified end-of-life experience.

CONCLUSION -

In conclusion, this study provides valuable insights into the EOL experiences of patients and their caregivers. While many aspects of care were rated positively, there are areas for improvement, particularly in addressing spiritual and emotional needs and managing the financial burden of care. These findings can inform the development of interventions and policies to enhance the quality of EOL care.

Ethical Consideration

The study was reviewed by Ethical Committee of Mahatma Gandhi Medical College and Hospital Jaipur, Rajasthan and approved the study vide letter No No./MGMC&H/IEC/JPR/2023/1843.

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Consent

Well Informed Consent was taken from all the respondents.

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