KEHPCA
partnering
educating
advocating
palliative care
for all
Kenya Hospices and Palliative Care Association

A TOOLKIT FOR THE INTEGRATION OF SEXUAL REPRODUCTIVE HEALTH INTO PALLIATIVE CARE SERVICES

ACCESSIBLE EQUITABLE SEXUAL REPRODUCTIVE HEALTH, WHENEVER, WHEREVER PROJECT

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Abbreviations

ANC – Antenatal Care

EHR – Electronic Health Records

EMTCT – Elimination of Mother-to-Child Transmission

FGM – Female Genital Mutilation

GBV – Gender-Based Violence

HIV – Human Immunodeficiency Virus

ICPD – International Conference on Population and Development

KHIS – Kenya Health Information System

LGBTQ+ – Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, and others

M&E – Monitoring and Evaluation

PAC – Post-Abortion Care

PC – Palliative Care

PLWPCN- Person Living with Palliative Care Needs

SRH – Sexual and Reproductive Health

STI – Sexually Transmitted Infection

SDGs – Sustainable Development Goals

KEHPCA - Kenya Hospices and Palliative Care Association (KEHPCA)

Operational Definitions

- **Adolescents and Young Adults** – Individuals, typically between the ages of 10 and 24, who may have unique SRH and palliative care needs.
- **Doula** – A non-medical professional who provides emotional, physical, and informational support to individuals during childbirth, miscarriage, palliative care, or end-of-life situations.
- **Early Sexual Debutante** – The experience of engaging in sexual activity at a younger age than what is considered typical or ideal within a cultural or societal context.
- **Family Planning** – The practice of enabling individuals and couples to anticipate and attain their desired number of children and the spacing and timing of their births through contraceptive methods.
- **Female Genital Mutilation (FGM)** – The practice of altering or injuring the female genitalia for non-medical reasons, often leading to severe health complications.
- **Holistic Care** – A comprehensive approach to healthcare that considers physical, emotional, social, and spiritual well-being.
- **Infertility** – The inability to conceive after one year of unprotected intercourse or the inability to carry a pregnancy to term.
- **Palliative Care** – Specialized, patient-centered healthcare aimed at relieving severe physical, psychological, social, or spiritual suffering caused by serious illnesses, ensuring quality of life and dignity at any stage of care.
- **Palliative Reflection** – A guided process where individuals reflect on their life, relationships, and legacy, often used in palliative care settings to enhance peace and acceptance.
- **Post-Abortion Care (PAC)** – A comprehensive approach to managing physical recovery and emotional well-being after an abortion, including counseling, contraceptive advice, and infection prevention.
- **Reproductive Health Rights** – The rights of individuals to make decisions governing their bodies and access services that support their sexual and reproductive health without discrimination, coercion, or violence.
- **Safe Abortion** – A medical or surgical procedure carried out to terminate a pregnancy in a manner that ensures the safety and well-being of the patient.
- **Sexual and Reproductive Health (SRH)** – A state of physical, emotional, mental, and social well-being in relation to all aspects of sexuality and reproduction, not merely the absence of disease, dysfunction, or infirmity.
- **Sexual Health** – Issues related to sexual desire, arousal, function, and the impact of treatments or symptoms.
- **STIs (Sexually Transmitted Infections)** – Infections that are spread through sexual contact, including HIV, syphilis, gonorrhea, and chlamydia.
- **Trauma-Informed Care** – A healthcare approach that acknowledges and addresses the impact of trauma on an individual's health and well-being.
- **Women in Low-Resource Settings** – Refers to women in areas with limited access to basic SRH services, such as family planning, safe abortion, or STI treatment.

Executive Summary

Recognizing the need for tailored Sexual Reproductive Health (SRH) services for individuals with life-limiting conditions and integrating them into palliative care is an intricate blend of science and art that exemplifies a **comprehensive healthcare approach**, ensuring that patients receive the necessary support in every aspect of their health journey.

Although research consistently highlights the significant benefits of incorporating tailored Sexual Reproductive Health services into palliative care, the integration context remains a critical gap. Sexual Reproductive Health in Palliative Care is an area of health care that can improve the quality of life of both patients and their families.

As Dr. Fred Bukachi, Chairman of Nairobi Hospice, aptly states, *"Not addressing the SRH needs of patients with palliative care needs is what makes them die before they die. The sexuality and reproductive concerns of the patients, whether spoken or implied, are central to humanity and thus have a great bearing on the quality of life they lead.*"

Life threatening conditions often affect people's sexuality either directly by impairing their sexual organs or indirectly through a disease progression that interferes with an individual's sexual functioning. Additionally, these conditions may manifest psychological effects to an individual compromising their gender and sexual roles including the reproduction role and ultimately the quality of life. Incorporating Sexual and Reproductive Health services into palliative care not only addresses critical health needs but also affirms the dignity and rights of individuals with life-limiting illnesses.

This toolkit provides an essential guidance for healthcare providers seeking to implement these important services effectively within their practice, ultimately aiming for improved patient outcomes across Kenya.

Audience

This communication toolkit for integrating Sexual Reproductive Health and Rights into palliative care was developed for members of Kenya Hospices and Palliative Care Association (KEHPCA) and other players in health. It can also be used by anyone wishing to broaden their understanding of sexual reproductive health aspects in palliative care settings and improve their response to care. KEHPCA has a national footprint of over 100 facilities supporting about 50,000 people with palliative care needs annually.

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The Goal and objectives

The "Accessible Equitable Sexual Reproductive Health Whenever, wherever" project was implemented in the counties of in Laikipia, Coast, Nairobi, Siaya, and Kisii. This initiative focuses on the recognition of the need for and integration of tailored Sexual Reproductive Health services for people with lifelong or life-threatening conditions.

Key Components:

1. **Introduction to SRH and Palliative Care:** Definitions, policies, and the importance of a rights-based approach.
2. **SRH in Palliative Context:** The necessity of integrating SRH into palliative care to improve patient

dignity, autonomy, and quality of life.

3. **Special Populations:** Tailored approaches for adolescents, LGBTQ+ individuals, persons with disabilities, GBV survivors, substance users, and people living with HIV/AIDS.
4. **Comprehensive Screening Tools:** Standardized assessment frameworks for healthcare providers and doula to evaluate SRH concerns holistically.
5. **Service Delivery Models:** Integration of SRH in family planning, antenatal and maternal care, labor and delivery, post-natal care, and post-abortion care within palliative settings.
6. **Referral Pathways:** Structured models to ensure seamless access to specialized SRH services while maintaining continuity of care.
7. **Monitoring & Evaluation (M&E):** Key indicators, data collection strategies, and performance metrics to assess service effectiveness and patient outcomes.

Purpose of the toolkit

This toolkit empowers health care providers to deliver SRH services with respect, sensitivity, and adherence to legal and ethical standards, improving patient dignity and quality of life. It serves as a resource for healthcare professionals, policymakers, and advocates to integrate SRH into palliative care, contributing to a more inclusive, patient-centered healthcare system.

Chapter 1: Introduction: Sexual Reproductive Health and Palliative Care

1.1. What is Palliative Care?

The World Health Organization (WHO) definition of palliative care:

"An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psycho-social and spiritual."

Palliative care focuses on quality of life; control of pain and other distressing symptoms; attention to the psycho-social, emotional and spiritual needs of the patient. Palliative care has globally been growing in importance in recent years.

1.2. What is Sexual Reproductive Health?

According to the World Health Organization (WHO):

Sexual and Reproductive Health is a state of physical, emotional, mental and social well-being in relation to all aspects of sexuality and reproduction, not merely the absence of disease, dysfunction or infirmity.

1.3. A historical perspective of Sexual Reproductive Health

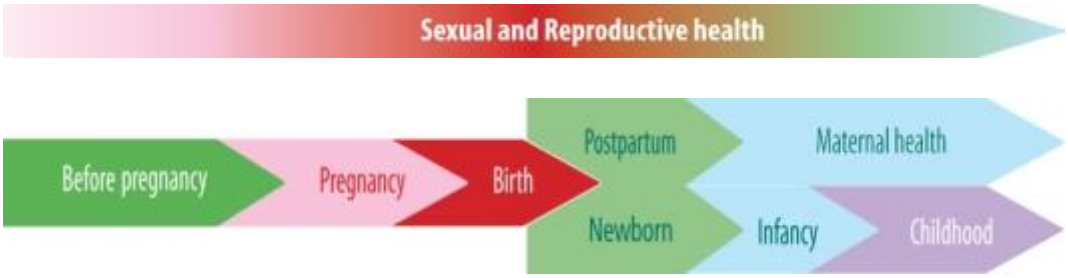
The International Conference on Population and Development (ICPD) was held from September 5 to 13, 1994, in Cairo, Egypt1. This landmark conference set a comprehensive agenda for population and development, emphasizing the importance of human rights, gender equality, and reproductive health. The ICPD emphasizes that these services should be universally accessible, free from discrimination, coercion, or violence, and are integral to reproductive rights1.

1.4. Element of Sexual Reproductive Health care

According to the ICPD Program of Action, SRH includes:

1. Family Planning: Access to contraceptive methods and education to help individuals plan their families.
2. Maternity Care: Services to ensure safe pregnancy and childbirth.
3. Prevention and Treatment of Infertility: Addressing issues related to infertility.
4. Abortion-Related Care: Providing safe and legal abortion services where permitted, and post-abortion care.
5. Prevention, Detection, and Treatment of STIs: Services to manage sexually transmitted infections

The figure below shows the full life cycle of reproductive health for program and project managers. It presents the Packages of intervention to address Sexual Reproductive Health – WHO 2010 - WHO/FCH/10.06



In management of a sexual reproductive project or program the drive is ensure that patients have access over their lifetime to the information, resources, services and support necessary to achieve a life free from discrimination, coercion, exploitation and violence.

1.5. Sexual Reproductive Health Rights

All individuals have a right to make decisions governing their bodies and to access services that support that right. Achievement of sexual and reproductive health relies on the realization of sexual and reproductive rights, which are based on the human rights of all individuals to:

- Have their bodily integrity, privacy and personal autonomy respected;
- Freely define their own sexuality, including sexual orientation and gender identity and expression;
- Decide whether and when to be sexually active and to Choose their sexual partners;
- Decide whether, when and who to marry;
- Decide whether, when and by what means to have a child or children, and how many children to have.

1.6. The Rationale of integrating SRH in Palliative Care:

Addressing sexual and reproductive health needs is crucial for improving the quality of life for patients with life-limiting illnesses.

People with palliative care needs have a right to accurate information and services they need to make healthy decisions about their lives in order to;

- Promote sexual health and well-being.
- Prevent disease and unintended pregnancy.
- De-risk sexual choices for themselves and their partners.
- Promote conversations that promote safer attitudes towards sexual relationships.
- Delay in sexual debut for adolescents

Health care providers need to be equipped to respond to the needs of patients and their families with correct consistent factual information, challenges myths, explores values, and develops

skills. This includes managing sexual dysfunction, providing counseling, and ensuring respectful and holistic care that is culturally appropriate in socially acceptable ways that encourages healthy SRH choices in the journey of palliative care. Telling the truth about sexuality could make it easier for people to talk with partners, care givers, community and religious leaders and other influential adults.

1.7. Integrating Palliative Care into various Sexual Reproductive Health - Services - A compendium of Care

Integrating palliative care into Sexual and Reproductive Health (SRH) services after a life-limiting diagnosis involves several key steps: These steps help ensure that patients receive compassionate and comprehensive care that addresses their unique needs and improves their quality of life as they journey through the life-limiting conditions.

1.8. Elements of a palliative care plan.

A palliative care plan is designed to fit life and needs. It may include elements such as:

a) **Symptom management.** A palliative care plan will include steps to address symptoms and improve the comfort and well-being. The care team will answer questions one may have, such as whether the pain medicines will affect treatments the one is receiving from the primary health care provider.

b) **Support and advice**. Palliative care services include support for the many difficult situations and decisions the patient and the family make when one is facing a serious illness.

c) **The family and the person** living with palliative care needs (PLWPCN) may talk with a palliative care social worker, psychologist, nurse, imam or chaplain or other team member about stress, spiritual questions, and financial concerns or how your family will cope if a loved one dies. The palliative care specialists may offer guidance or connect you with community resources.

d) **Care techniques** that improve your comfort and sense of well-being. These may include breathing techniques, healing touch, meditation, yoga, visualization or simply listening to music with headphones.

e) **Referrals.** Your palliative care specialist may refer you to other care providers, for example, specialists in psychiatry, pain medicine or internal medicine, nutritionists, integrative medicine.

f) **Advance care planning**. A palliative care team member can talk with the persons living with palliative care needs (PLWPCN) about goals and wishes for one's care.

This information could then be used to help develop an integrated SRH plan that guides their care.

Chapter 2: Policy, Legal and Communication Aspects for Advocacy

2.1 Legal and policy Framework for Sexual Reproductive Health and Palliative Care

The integration of sexual and reproductive health into palliative is guided by legal and ethical considerations surrounding SRH that ensure - patients receive appropriate care which respects their rights and autonomy.

2.2 Alignment with National Strategies**:**

- **A.** The Kenyan Constitution 2010.
- **B.** Kenya's Vision 2030
- **C.** The Health Act 2017.
- **D.** The Palliative Care Policy and National Guidelines.
- **E.** The National Sexual Reproductive Health Policies and Guidelines.
- **F.** Kenya Data Protection Act, 2019

2.3 A Comparative Look at the Policy Environment.

The Reproductive Health Policy is population-based, covering services from prenatal care to elderly needs, with a focus on women's health, pregnancy, and childbirth, while addressing SRH-related diseases, including cancer and HIV. The Palliative Care Policy emphasizes improving quality of life at the life-limiting by providing holistic care that addresses physical, emotional, psycho-social, and spiritual needs.

Aspect	Kenya Palliative Care Policy 2021-2030	Kenya National Reproductive Health Policy 2022-2032
Primary Goal	Ensure access to quality palliative care services without financial hardship.	Ensure access to high-quality reproductive health services without financial hardship.
Scope	Focuses on holistic care for life-threatening illnesses, addressing physical, psychosocial, and spiritual needs.	Focuses on reproductive health across all life stages, including maternal health, adolescents, and the elderly.
Alignment with Global Goals	Not explicitly mentioned.	Aligns with SDGs, including reducing maternal mortality and promoting gender equality.
Target Issues	Management of pain and suffering for patients with terminal illnesses.	Addresses reproductive health challenges for adolescents, adults, and the elderly.
Key Emphasis	Holistic care: physical, psychosocial, and spiritual dimensions.	Gender equality, maternal health, and addressing SRH challenges at all life stages.

2.4 A Comparative Look at the Policy Environment - alignment to the Kenya Constitution 2010

Component	Description	Kenya Constitution Alignment
National Health Policies	Align the toolkit with national health strategies prioritizing holistic patient-centered care as mentioned above	Article 43: Guarantees every person the right to accessible and adequate healthcare, including reproductive health services.
International Frameworks	Utilize international human rights frameworks (e.g., CEDAW, SDGs) to advocate for SRH needs in palliative care.	Articles 2(5) & (6): Incorporates international law, ensuring adherence to treaties promoting human rights and dignity.
Local Legislation	Examine local laws regarding palliative care provision and SRH education; advocate for changes where gaps exist hindering integration in palliative care settings.	Article 27: Ensures equality before the law and freedom from discrimination on any ground, which includes access to healthcare services.
Engaging Stakeholders	Collaborate with government agencies, NGOs, community organizations, and healthcare providers to promote policy change supporting SRH in palliative care.	Article 10: Promotes national values such as democracy and participation of all stakeholders in governance processes affecting health policies.
Raising Awareness	Conduct workshops, seminars, and media campaigns aimed at educating stakeholders about integrating SRH into palliative settings for improved patient outcomes.	Article 35: Provides the right to access information held by public bodies; crucial for raising awareness about SRH issues in palliative care contexts.
Policy Briefs & Recommendations	Develop concise briefs highlighting evidence-based recommendations for integrating SRH into existing frameworks shared with policymakers for influence on healthcare reforms.	Article 118: Advocates public participation in legislative processes; key for engaging communities in discussions around health policy reform based on their needs.
Monitoring & Evaluation Framework	Establish metrics assessing how well SRH needs are addressed within palliative care post-implementation; use findings for advocacy refinement based on identified successes or areas needing improvement.	Article 46: Protects consumer rights ensuring fair treatment; monitoring can help hold providers accountable for delivering comprehensive reproductive health services.

2.5 Recommended Action points for SRH integration Advocacy

Aspect of health policy pillars	Action points for keeping the advocacy agenda visible
1. **Advocacy and Communication**	Raising awareness and promoting reproductive health rights in PC
2. **Leadership and Governance**	Strengthening the management and coordination of reproductive health services in palliative care
3. **Service Delivery**	Ensuring the availability and accessibility of reproductive health services in pc settings
4. **Availability and Access to Essential Medicines and Commodities**	Providing necessary medical supplies and commodities in PC settings.
5. **Human Resource and Education**	Training healthcare providers and educating the public on

	reproductive health.
6. **Health Information Systems and Research**	Collecting and analyzing data to inform policy decisions.
7. **Health Care Financing**	Ensuring sustainable funding for reproductive health services.
8. Data Protection	Safeguarding personal data across all aspects of reproductive health service delivery, ensuring compliance with the Data Protection Act 2019 to protect patient confidentiality and rights.

By anchoring this toolkit within existing policies and leveraging the provisions of the Kenya Constitution that support sexual and reproductive health rights, we can effectively integrate these vital services into palliative care across Kenya. This alignment not only enhances legal backing but also promotes a more equitable approach to healthcare delivery that respects individual rights while addressing essential needs at various stages of life.

2.6 Communication about SRH in the Context of Palliative Care

Effective communication about sexuality and intimacy in palliative care requires sensitivity and awareness of cultural, religious, and personal beliefs. Healthcare providers must be trained to navigate these topics openly, ensuring alignment between verbal and nonverbal cues while promoting informed consent, autonomy, and patient-centered care.

2.7 The Doula Concept

A doula is a non-medical professional who offers emotional, physical, and informational support during significant health experiences like childbirth, miscarriage, or palliative care. The term "doula" comes from the Greek word for a supportive companion. The role grew during COVID season, as Doulas assisted individuals in navigating death. Doulas complement medical care by providing continuous support, advocacy, and comfort measures, without performing medical tasks or giving advice. Their goal is to help individuals and families find peace, live in the present, and die gracefully.

2.8 Key Roles of Doula
Emotional Support: Offers reassurance, encouragement, and stress management techniques. **Physical Comfort:** Provides hands-on comfort measures like massage, breathing techniques, and positioning during labor. **Informational Support:** Shares evidence-based information on childbirth options and postpartum care for informed decision-making. **Advocacy:** Helps clients communicate preferences and needs to the medical team. **Continuity of Care:** Provides consistent support throughout pregnancy and postpartum.
2.9 . Impact of Doula effectiveness
• **Reduced Medical Interventions:** Lower likelihood of interventions like C-sections. • **Shorter Labor Duration:** Reduced duration of labor. • **Increased Satisfaction:** Higher satisfaction with the birthing experience. • **Improved Outcomes:** Better breastfeeding outcomes and improved maternal mental health
The 6 Guiding Principles of Doula Model of Care

- **Refrain from Medical Tasks:** Doulas should not perform clinical or medical tasks.
- **Non-judgmental Support:** Doulas should avoid imposing their values or biases on the client, supporting all choices without judgment.
- **Family-centered Approach:** The doula works with the individual and their family, without replacing partners or other care providers.
- **Holistic Care:** Doulas recognize the bio-psycho-social and spiritual aspects of the whole person, offering care accordingly.
- **Empowerment:** Doulas promote informed decision-making and encourage self-determination for the individual and family.
- **Team Members:** Doulas work as part of the healthcare team, playing a special supportive role.

2.10. Effective Communication in SRH and Palliative Care

-Why SRH in the context of Palliative care?

In Kenya, the growing triple challenge of communicable diseases, non-communicable diseases (NCDs), and pandemics, coupled with the late diagnosis of illnesses, underscores the vital role of palliative care in the healthcare system. (Ministry of Health, Kenya, 2021). Patients with palliative care needs have the right to make decisions about their bodies and access SRH services. Without palliative care, patients face unnecessary pain, suffering, and financial strain. Integrating SRH services improves well-being, prevents disease, and supports positive life experiences. Health care providers must be equipped with accurate information and skills to meet patient needs.

2.11. Communication skills: The 3 pillars of processing fears and anxieties

Effective communication in palliative care involves creating safe spaces where individuals can explore and express their fears, anxieties, and emotions. This process can be guided by three essential pillars:

1. **Mind**: Engage with thoughts and emotions through introspection, therapy, or journaling to reflect on and challenge fears.
2. **Body**: Use mindfulness, movement, and somatic exercises to reconnect with the body and release pent-up energy.
3. **Community**: Share experiences within a supportive group to foster connection, understanding, and reduce isolation. In conversations about mortality, an authentic voice helps individuals confront their truths, regrets, hidden joys, and unspoken realities, leading to resolution, understanding, and peace.

2.12 Enhancing Communication Skills

The following skills are essential:

- **Active Listening**: Training personnel to listen without judgment allows individuals to express their feelings openly and feel validated in their grief.
- **Empathy**: Recognizing and honoring the pain of others helps build trust and encourages emotional healing.

- **Clear Messaging**: During crises, one must provide clear and consistent information to reduce fear and uncertainty.
- **Cultural Sensitivity**: Acknowledging diverse ways of grieving ensures that programs and policies are inclusive and respectful of all communities.

Steps to Facilitate a Meditation session	
1. Preparation	
Setting the Space	- Choose a quiet, comfortable space free from distractions. Use calming elements like soft lighting, candles, or soothing music.
Guidance	- A facilitator or recorded script can guide participants through the meditation.
Intent	- Begin with the intention to explore mortality as a path to deeper awareness and peace.
2. Grounding	
Breathing	- Invite participants to close their eyes and take slow, deep breaths.
Awareness of the Body	- Guide them to focus on their breath, feeling the sensations of inhalation and exhalation.
Connection to the Ground	- Encourage them to become aware of their body and its connection to the ground beneath them.
3. Visualization	
Palliative Reflection	- Ask participants to imagine themselves at the end of their life, reflecting on: 1. How they lived 2. Key relationships, accomplishments, and unfulfilled desires 3. How they would want to be remembered.
Non-judgmental Observation	- Encourage participants to observe their feelings without judgment—whether fear, sadness, or gratitude.
4. Guided Questions	
Reflective Prompts	- Facilitators can use prompts to deepen reflection: - What have you cherished most in your life? - Are there relationships that need healing or closure? - What legacy do you want to leave behind? - If today were your last day, how would you spend it?
5. Letting Go	
Release of Negative Emotions	- Guide participants through the process of letting go of regrets, resentments, or attachments that no longer serve them.
Embracing Peace	- Encourage them to embrace a sense of peace and gratitude for the life they have lived.
6. Returning to the Present	
Focusing on the Breath	- Gently bring participants back to the present moment by focusing on their breath.
Carrying Insights	- Encourage them to carry the insights from the meditation into their daily lives.
1. Post-Meditation Reflection	

Journaling	- Provide participants with a journal or space to write down their thoughts and insights.
Group Discussion	- Facilitate a group discussion (if in a workshop) to share experiences and support collective learning.

Benefits of Meditation
• **Mental Clarity**: Reduces fear of the unknown and fosters acceptance. • **Emotional Healing**: Offers a safe space to process grief, loss, and unresolved emotions. • **Enhanced Relationships**: Encourages participants to express love and gratitude to those who matter most. • **Purposeful Living**: Inspires individuals to live more intentionally, focusing on what truly brings them joy and fulfillment.

Create a safe, supportive environment for participants, particularly those who may find the exercise emotionally intense. Tailor the meditation to respect cultural and spiritual beliefs, and offer follow-up support for those needing extra time to process emotions. When done with care, meditation can reduce the fear and enhance the experience of living.

Chapter 3: Comprehensive Screening Tools for SRH in Palliative Care

Screening tools are essential for assessing the Sexual and Reproductive Health (SRH) needs of palliative care patients. This chapter presents adaptable tools to guide healthcare providers in delivering ethical, confidential, and culturally sensitive care, ensuring dignity and improved quality of life. The components broadly include:

- **Physical Health and Functionality:** Assess physical aspects impacting SRH, including pain, fatigue, mobility, and body image concerns.
- **Emotional and Psychological Health:** Screen for mental health issues (depression, anxiety, self-esteem) that affect attitudes toward SRH.
- **Relationships and Intimacy:** Evaluate relationships, support systems, and intimacy concerns, including the impact of illness on these areas.
- **Sexual Health and Function:** Assess issues related to sexual desire, arousal, and function, considering the impact of treatments or symptoms.
- **Reproductive Health Needs:** Address concerns about fertility, contraception, or family planning for patients of reproductive age, in light of their palliative diagnosis.
- **Legacy Needs**: Assess for concerns related to children, childbirth, adoption, surrogacy, and test tube babies.
- **Co-morbidity**: Assess for HIV, TB, cancer, and STIs in patients of reproductive age.

1. Palliative Care Patient Assessment Tool - A Guide for Doula

The Palliative Care Patient Assessment Tool is an essential resource for Doulas, designed to guide them in providing holistic, patient-centered support. As Doulas often serve as companions and advocates for individuals receiving palliative care, this tool enables them to thoroughly evaluate and address the unique needs of their patients across multiple dimensions such as physical, emotional, social, and spiritual.

. Key Areas of assessment for Doula

1. **Physical Needs Assessment:**
   Doulasuse the tool to identify and address physical symptoms such as pain, fatigue, and mobility issues. By understanding the patient's physical state, Doulas can collaborate with healthcare providers to ensure appropriate interventions, such as pain management, comfort measures, or mobility aids.
2. **Emotional and Psychological Support:**
   The tool allows Doula to assess emotional states, including anxiety, depression, and fear, which are common in palliative care settings. By recognizing these emotional challenges, Doulas can provide compassionate presence, active listening, and emotional reassurance, fostering a sense of calm and security for the patient.
3. **Social and Relational Needs:**
   Relationships and social support play a vital role in palliative care. The tool helps Doulas evaluate the patient's key relationships, support systems, and unresolved social concerns, such as strained family ties or unmet relational goals. Doulas can facilitate meaningful conversations, mediate family dynamics, and encourage the resolution of unfinished business.
4. **Spirituality and Existential Needs:**

Spiritual well-being is a cornerstone of holistic palliative care. Doulas can use the tool to explore the patient's spiritual beliefs, existential concerns, and desired rituals or practices. By addressing these needs, Doulas help patients find meaning, peace, and closure in their final stages of life.

5. **Cultural Sensitivities and Ethical Considerations:**
   The tool underscores the importance of respecting cultural and personal values. Doula can adapt their approach to honor the patient's cultural, religious, and ethical preferences, ensuring care is both personalized and inclusive.
6. **Advance Planning and Legacy Building:**
   Doula can use the tool to assist patients in articulating their care preferences, advance directives, and legacy goals. Whether it involves documenting life stories, creating keepsakes, or planning rituals, Doula's play a pivotal role in preserving the patient's dignity and sense of purpose.

Impact of the Tool on Doula Care

This tool enhances the Doula's ability to deliver comprehensive and empathetic care. It ensures that all aspects of a patient's well-being are addressed systematically, empowering Doulasto support patients in a way that aligns with their values and wishes. Moreover, the tool fosters collaboration with healthcare providers, ensuring seamless, interdisciplinary care that meets the highest standards of palliative support.

The Palliative Care Patient Assessment Tool equips Doulaswith the insights and strategies needed to navigate the complexities of palliative care. It is an invaluable resource for ensuring that every patient receives compassionate, holistic, and dignified care tailored to their unique journey.

Tool 1: Palliative Care Patient Assessment Tool – A Guide for Doulas

1. Patient Information

- Name:
- Age:
- Primary Diagnosis:
- Stage of Illness:
- Primary Care Provider:
- Emergency Contact:

2. Physical Assessment

- **Pain Level (0-10)**:
- **Symptoms** (e.g., nausea, fatigue, breathlessness):
- **Mobility Status**:
  - Fully mobile☐
  - Requires assistance ☐
  - Bedridden ☐
- **Sleep Quality**:
  - Good ☐
  - Interrupted ☐
  - Poor ☐
- **Appetite**:
  - Normal ☐
  - Reduced ☐
  - None ☐

3. Emotional and Psychological Needs

- **Current Emotional State**:
  - Calm ☐
  - Anxious ☐
  - Depressed ☐
  - Angry ☐
- **Primary Concerns**:
  - Fear of pain ☐
  - Fear of dying ☐
  - Family concerns ☐
  - Other:
- **Support Network**:
  - Strong ☐
  - Moderate ☐
  - Limited ☐
- **Coping Mechanisms**:
  - Journaling ☐
  - Meditation/Prayer ☐
  - Counseling ☐
  - Other:

4. Social and Relational Needs

- **Key Relationships** (Family/Friends):
    - Strong ☐
    - Strained ☐
    - None ☐
- **Unfinished Business**:
    - Relationships to mend:
    - Conversations to have:
- **Support System Availability**:
    - Caregivers: Yes ☐ No ☐
    - Community/Groups: Yes ☐ No ☐

5. Spiritual and Existential Needs

- **Spiritual Beliefs/Practices**:
    - Prayer ☐
    - Meditation ☐
    - Other:
- **Existential Concerns**:
    - Meaning and purpose ☐
    - Legacy ☐
    - Other:
- **Desired Rituals or Practices**:

6. Advance Planning and Preferences

- **Knowledge of Prognosis**: Yes ☐ No ☐
- **Advance Directives in Place**: Yes ☐ No ☐
- **Preferred Place of Care**:
    - Home ☐
    - Hospice ☐
    - Hospital ☐
- **Palliative Wishes**:
    - Desired rituals:
    - Specific care preferences:

7. Patient Goals

- **Immediate Goals**:
- **Long-Term Goals**:
- **What Does Success Look Like?**

8. Doula Notes and Plan

- **Actions for Immediate Support**:……
  ……
  ……
- **Collaborations Needed**:
    - Healthcare Providers ☐
    - Family Members ☐
    - Community Resources ☐
- **Follow-Up Plan**:……
  ……

Tool 2: Standardized Screening Tool for Sexual and Reproductive Health (SRH) in Palliative Care Patients

The Standardized Screening Tool for SRH in Palliative Care Patients is designed to assist healthcare providers in addressing the often-overlooked Sexual and Reproductive Health (SRH) needs of patients receiving palliative care. It provides a comprehensive, structured approach to assess, identify, and manage SRH concerns, ensuring that patients receive holistic and dignified care.

The Standardized Screening Tool for SRH in Palliative Care Patients is a vital resource for healthcare providers, ensuring that SRH is integrated into the broader spectrum of palliative care. It promotes patient-centered, ethical, and culturally sensitive practices, ultimately enhancing the well-being and dignity of patients in their care.

Key Features of the Tool

1. **Comprehensive Assessment Framework:**
   The tool enables healthcare providers to evaluate SRH needs across multiple domains, including medical history, reproductive health, sexual function, psycho-social factors, and cultural or religious considerations. This ensures a full understanding of the patient's SRH concerns and how they intersect with their palliative care needs.
2. **Integration into Palliative Care:**
   SRH issues are often neglected in palliative care, yet they are critical to a patient's overall well-being. This tool bridges the gap, allowing healthcare providers to address concerns such as fertility, family planning, sexual function, and intimacy, even in the context of life-threatening conditions.
3. **Patient-Centered and Culturally Sensitive:**
   By promoting open, respectful communication, the tool helps healthcare providers navigate sensitive topics like sexual health and reproductive concerns. It encourages culturally appropriate care that respects the patient's values, beliefs, and preferences.
4. **Ethical and Confidential Care:**
   The tool underscores the importance of maintaining confidentiality and ethical standards, ensuring that patients feel safe and supported when discussing sensitive aspects of their health.
5. **Adaptability for Diverse Settings:**
   The screening tool can be modified to fit various healthcare settings and patient populations, making it a versatile resource for addressing SRH needs in palliative care.

Components of the Screening Tool

1. **Patient Demographics and Medical History:** collecting detailed information about the patient's age, gender, marital status, medical history, and current diagnosis to establish a baseline for SRH assessments.
2. **Reproductive Health Assessment:** Evaluating fertility, contraceptive use, pregnancy history, and any family planning needs, especially for patients of reproductive age.
3. **Sexual Health Evaluation:** Identifying issues related to sexual desire, arousal, function, and the impact of illness or treatment on sexual activity and intimacy.
4. **Psychosocial and Emotional Factors:** Assessing emotional well-being, mental health status, relationship dynamics, and social support systems that influence SRH.
5. **Focused Physical Examination:**

Conducting physical exams to identify signs of reproductive health issues, such as sexually transmitted infections (STIs), cancers, or other concerns.

6. **Education and Counseling:**
   Providing information on SRH topics, including contraception, fertility preservation, and sexual function, while addressing myths or misconceptions.
7. **Ongoing Monitoring and Follow-Up:**
   Establishing regular follow-up appointments to reassess SRH needs, monitor symptoms, and adjust care plans as necessary.

Importance of the Tool in Palliative Care

This tool equips healthcare providers with the ability to address a critical yet often neglected component of holistic care. By incorporating SRH assessments into palliative care, providers can:

- Enhance the quality of life for patients by addressing unmet SRH needs.
- Foster open communication, allowing patients to discuss sensitive concerns without fear of judgment.
- Support patients in maintaining relationships, intimacy, and personal dignity despite the challenges of their illness.

Tool 2:**Tool for Health Care Providers: Standardized Screening Tool for Sexual and Reproductive Health (SRH) in Palliative Care Patients**

Tool 2: Tool for Health Care Providers: Standardized Screening Tool for Sexual and Reproductive Health (SRH) in Palliative Care Patients

1. Patient Demographics and Background Profile

- **Full Name:** _____
- **Age:** _____
- **Sex:** _____
- **Marital Status:** _____
- **Contact Information:** _____
- **Emergency Contact:** _____
- **Place of Residence:**
  - County: _____
  - Town: _____
  - Estate/Village: _____

2. Medical History

- **Diagnosis and Stage of Illness:** _____
- **Duration of Illness:** _____
- **Current Treatment and Medications:** _____
- **Past Medical and Surgical History:** _____
- **Family Medical History:**
  - Parents' Medical History (e.g., chronic illness, cancer): _____
  - Grandparents' Medical History (e.g., chronic illness, cancer): _____
- **Genetic History (if applicable):** _____

3. Vitals

- **Height:** _____ cm
- **Weight:** _____ kg
- **Blood Pressure:** _____
- **Temperature:** _____ °C

- **Respiration Rate:** _____

4. Physical Examination

- **Observation (Head-to-Toe):** Jaundice, swelling, anemia, other abnormalities (describe) _____
- **Pain Assessment:**
  - Pain Scale (0-10): _____ (10 = excruciating pain)
  - Pain Location: _____ (Use pictorial aids or ask the patient to point)
  - Visual Pain Description: Smiley faces, contorted faces, or other images

5. Sexual and Reproductive Health History

- Menstrual History (for Female Patients): _____
- Sexual Activity and Orientation: (e.g., LGBTQ, number of partners, polygamous unions) _____
- Contraceptive Use and Family Planning Needs: _____
- History of STIs
- HIV status: _____
- Reproductive History (e.g., pregnancies, childbirth, miscarriages): _____
- EMTCT (Elimination of Mother-To-Child Transmission): _____
- Erectile Dysfunction (for Male Patients): _____
- _____Premature Ejaculation:
- _____Painful ejaculation:
- _____ Painful sex:
- _____Concerns regarding fertility:
- _____Vaginal dryness:

6. Current SRH Concerns

- Pain or Discomfort During Sexual Activity: _____
- Changes in Sexual Desire or Function: _____
- Concerns About Fertility and Family Planning: _____
- Symptoms of STIs or Other Reproductive Health Issues: _____
- Fecundity (Reproductive Potential): _____
- Considerations for Spermatozoa/Ovary Harvesting (if desired): _____

7. Psycho-social Assessment

- Emotional and Mental Health Status: _____
- Relationship Dynamics and Support Systems: _____
- Cultural Factors Impacting SRH: _____
- Religious Beliefs Impacting SRH: _____
- Myths and Misconceptions (identified during the conversation): _____

8. Focused Physical Examination

- General Physical Examination: _____
- Focused Reproductive Organ Examination (if indicated): _____

9. Patient Education and Counseling

- Relevant SRH Information (e.g., family planning, childbirth): _____
- Available SRH Services and Support: _____

10. Ongoing Evaluations and Follow-Ups

- **Regular Follow-Ups:**
  - Next Appointment Date: _____
  - SRH Updates (if any): _____
- **Monitoring and Managing Symptoms:**
  - New or Worsening SRH Symptoms: _____
  - Adjustments to Treatment Plans: _____

- **Emotional and Psycho-social Support:**
    - Ongoing Counseling for Emotional/Mental Health: _____
    - Support Groups or Peer Support (if available): _____

11. Patient and Family Education

- Education Provided to Patient/Family on SRH Topics: _____
- Referral to Specialized SRH Services (if needed): _____

12. Documentation and Data Management

- **Record-Keeping:**
    - Detailed and Confidential Notes: _____
    - Data Protection Measures: _____
- **Data Access:** Ensuring that only authorized healthcare providers have access to updated patient information.

13. Coordination/Referral

- **Internal Coordination:** _____
- External coordination
    - Coordinating with Other Providers (e.g., gynecologists, urologists) _____

14. Feedback and Continuous Improvement

- Patient/Family Feedback on SRH Services Provided: _____
- Service Improvement Plan Based on Feedback: _____

End of Screening Tool

Chapter 4: Referral Pathways for SRH Services in Palliative Care

4.1. Developing Referral Pathways

Developing efficient referral pathways for Sexual and Reproductive Health (SRH) services in palliative care is a trans-formative approach to achieving comprehensive, integrated care. These pathways are essential for bridging the gap between palliative care and specialized SRH services, ensuring patients receive seamless, interdisciplinary care tailored to their unique needs. An effective referral pathway begins with a clear understanding of the patient's SRH and palliative care requirements, followed by well-defined processes for connecting patients to appropriate specialists or services.

Multidisciplinary collaboration between SRH specialists (gynecologists, urologists, mental health professionals, and relationship counselors) and palliative care providers ensures a smooth referral process. Clear protocols should be established, outlining when and why referrals are made, the criteria for referral, and the type of SRH services required. Standardized referral forms are essential for effectively communicating the patient's medical history, SRH concerns, and relevant palliative care details.

Referral Form for SRH in Palliative Care

Essential Patient Information

- **Full Name**: _____
- **Date of Birth**: _____
- **Gender**: _____
- **Contact Information**:
  - Phone: _____
  - Email: _____
- **Address**: _____

Referring Healthcare Provider

- **Name**: _____
- **Job Title**: _____
- **Contact Information**:
  - Phone: _____
  - Email: _____
- **Referring Organization**: _____

Reason for Referral

- **Primary Diagnosis**: _____
- **Current Treatments**: _____
- **SRH Concerns** (check all that apply):
  - ☐ Contraception and Family Planning
  - ☐ Sexual Dysfunction
  - ☐ Menstrual disorder
  - ☐ STIs
  - ☐ Fertility Concerns
  - ☐ Other (please specify): _____

SRH History

- **Menstrual History (for female patients): _____**
- **Sexual Activity and Orientation: _____**
- **Contraceptive Use: _____**
- **History of STIs: _____**
- **Reproductive History (pregnancies, childbirth, miscarriages, etc.):**
  _____

Current SRH Symptoms

- **Pain or Discomfort: _____**

- **Changes in Sexual Desire or Function: _____**
- **Other Symptoms: _____**

Psychosocial Assessment

- **Emotional and Mental Health Status: _____**
- **Relationship Dynamics and Support Systems: _____**
- **Cultural and Religious Beliefs Impacting SRH: _____**

Consent and Confidentiality

- **Has the patient consented to this referral?**
  - ☐ Yes
  - ☐ No (please explain): _____
- **If the patient lacked capacity to consent, who consented?**
  - ☐ Legal Representative
  - ☐ Best Interest Decision
  - ☐ Other (please specify): _____

Referral Details

- **Referred to**: _____
- **Specialist Contact Information**:
  - Phone: _____
  - Email: _____
- **Date of Referral**: _____

Additional Information

- **Relevant Medical History: _____**
- **Current Medications: _____**
- **Any Other Relevant Information: _____**

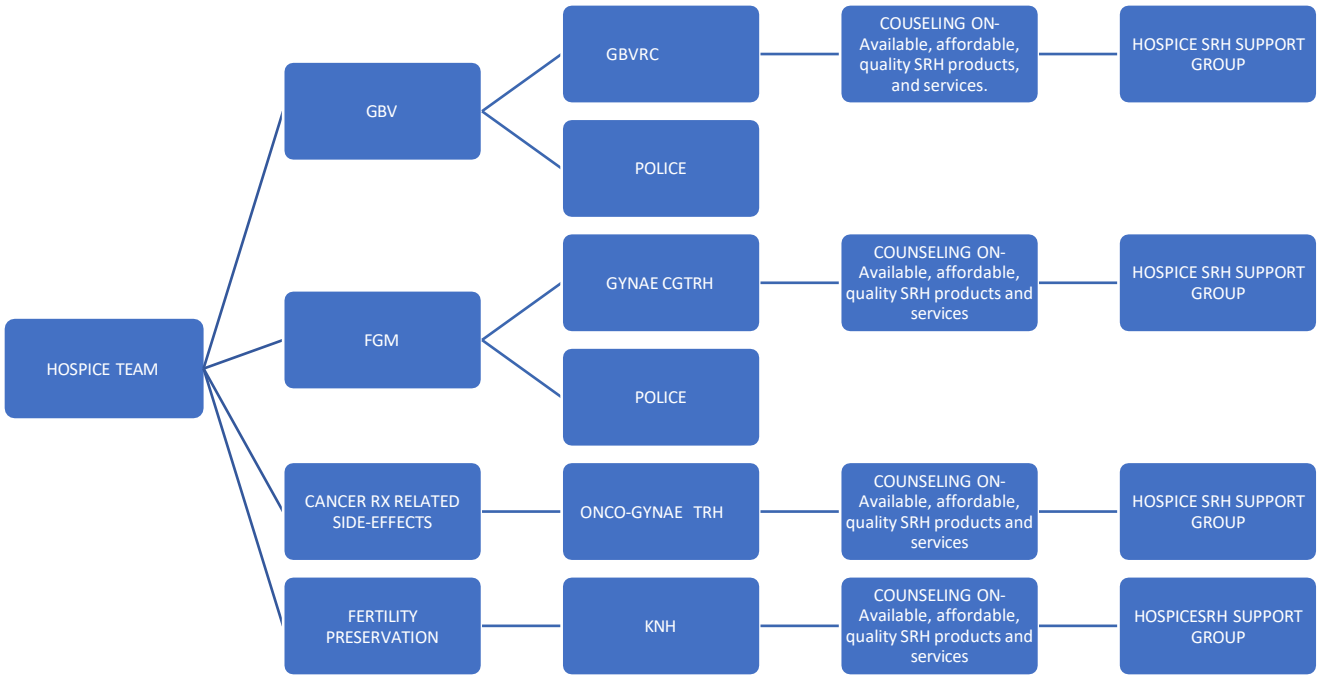
Follow-Up

- **Next Appointment Date: _____**
- **Feedback from Specialist: _____**

By implementing a standardized screening tool, establishing effective communication strategies, and creating structured referral pathways, healthcare providers can ensure that patients with palliative care needs receive holistic, compassionate, and patient-centered support for their sexual and reproductive health (SRH).

This framework not only improves the quality of life for patients but also empowers healthcare providers to address the complex and unique SRH needs within palliative care in a professional and empathetic manner

Referral Pathways are a flexible format which may include urologists, gynecologists, breast surgeons, sexologists, massage experts and other intimacy management teams in the area.



At KNH for instance referral for breast cancer or cancers of the reproductive tract (such as ovarian, cervical, uterine, or vaginal cancer), you should consider the following options:

1. **Primary Care Physician (PCP) or Gynecologist** – Your first step should be consulting your PCP or gynecologist. They can perform initial screenings and refer you to a specialist
2. **Diagnostic experts** will include a radiologist or pathologist, whose findings will have one referred to an oncologist.
3. **Oncologist (Cancer Specialist)** – Depending on your diagnosis, you may need to see a **medical oncologist** (for chemotherapy and targeted treatments), a **surgical oncologist** (for tumor removal), or a **radiation oncologist** (for radiation therapy).

Breast Cancer & Gynecologic Cancer Centers – Many hospitals have specialized cancer centers focused on breast cancer and reproductive cancers. **Specialist Referrals** – If you need an expert in gynecologic oncology, a **gynecologic oncologist** is a doctor specializing in cancers of the reproductive organs

Chapter 5: A compendium of Care for Integrating Palliative Care into various SRH Care Services

Integrating palliative care into Sexual and Reproductive Health (SRH) services after a life-limiting diagnosis involves several key steps: These steps help ensure that patients receive compassionate and comprehensive care that addresses their unique needs and improves their quality of life. The integration of palliative care into SRH services has evolved to address the holistic needs of patients with life-limiting illnesses.

5.1. Family Planning Care Setting

Family planning in this context extends beyond conventional reproductive health services to include tailored support for managing pain, physical discomfort, emotional distress, and the psychological complexities arising from life-limiting illnesses. This integration is essential to uphold patients' dignity, autonomy, and quality of life.

Category	**Details**
Safe and Appropriate Contraceptive Options	
Personalized Contraceptive Counseling	● assess medical condition, illness stage, and treatments ● recommend safer methods that will minimize health risks ● decide if to make temporary of permanent solutions. ● discussed all these based on patient preferences and prognosis.
Counseling for Family Planning in Palliative Contexts	
Balancing Family Planning and Palliative Care Goals	- Counseling helps patients understand how their health condition impacts family planning options (e.g., avoiding pregnancy strain for life-limiting ill patients).
Supporting Emotional and Psychological Needs	- Counseling provides support for emotional conflict about fertility, sexuality, and children, offering a safe space to explore feelings.
Promoting Informed Decision-Making	- Patients and partners receive accurate, evidence-based information about family planning options to make informed choices aligned with their values and health priorities.
Addressing Cultural and Social Beliefs	- Family planning discussions respect cultural, religious, and social contexts, promoting health and safety while considering personal beliefs.
Prevention and Management of STIs/RTIs	
Risk Assessment Treatment Integration	- Regular screening for and treatment of STIs/RTIs is important for palliative care patients who may still be sexually active. Risk factors include reduced immunity and opportunistic infections.
Partner Management	- Partner involvement is essential in preventing reinfection. Counseling and treatment options are provided for partners as part of integrated care.

5.2 Antenatal and Maternal Care Setting

Integrating palliative care into antenatal and maternal care provides a holistic framework to support pregnant individuals with life-limiting conditions. This integration ensures that physical, emotional, and psychological needs are addressed, alongside routine maternal health services, to improve quality of life and promote dignity for both the mother and the unborn child.

Key Components of Palliative care integration in Antenatal and Maternal Care	
1. Comprehensive Assessment of Maternal and Palliative Needs	
Dual Health Focus	- An assessment of both antenatal requirements (such as fetal development and maternal well-being) and comprehensive palliative care considerations (including pain management and symptom alleviation). - Review of medical, obstetric, and gynecological histories to understand progression of the patient's life-limiting illness.
Holistic Approach	- Palliative assessments consider physical symptoms (pain, fatigue), emotional stressors (anxiety), and spiritual needs during pregnancy.
2. Pain and Symptom Management	
Pain Relief	- Pain management strategies tailored to minimize risks to both mother and fetus (e.g., massage, relaxation techniques). - Medications chosen carefully to avoid adverse effects on fetal development while ensuring maternal comfort.
Management of Pregnancy-Related Symptoms	- Common pregnancy symptoms (nausea, back pain, fatigue) are managed alongside palliative symptoms to improve overall well-being.
3. Emotional and Psychological Support	
Addressing Emotional Distress	- Provides counselling and emotional support to help patients process complex emotions like fear, grief, and guilt related to pregnancy and life-limiting illness.
Building Trust and Rapport	- Focus on fostering trust and open communication, ensuring patients feel supported in discussing their needs and concerns.
Support for Decision-Making	- Guidance on critical decisions (e.g., care preferences, birth plans, long-term planning for the child).
4. Adaptation of Routine Antenatal Services	
Tetanus Toxoid Vaccination	- Administered with careful consideration of the patient's immune status and overall health.
Malaria Prophylaxis (IPT)	- Safe preventive measures, including medication and insecticide-treated nets, with close monitoring for adverse effects.
Nutritional Support	- Collaboration with dietitians to design nutritional plans that accommodate pregnancy's metabolic demands and the patient's physical limitations.
5. STI/RTI Screening and Treatment	
Routine Screening	- Regular screening for STIs/RTIs to protect maternal and fetal health.

Integrated Treatment Plans	- Treatment protocols for STIs/RTIs aligned with palliative care needs, ensuring no conflicts with existing treatments or worsening of symptoms.
6. Multidisciplinary Care Approach	
Collaboration Between Specialists	- A multidisciplinary team, including obstetricians, palliative care providers, social workers, and spiritual counselors, ensures comprehensive care.
Individualized Care Plans	- Care plans are personalized to address both maternal health and palliative care needs, avoiding conflicts between treatments.
7. Post-Delivery Care and Planning	
Support for Newborn Care	- Postnatal care plans include guidance on infant care, considering the mother's physical and emotional limitations.
Family Engagement	- Family members are engaged to provide support and ensure continuity of care for both mother and child.
Advance Care Planning	- Support for planning the baby's future, including guardianship arrangements if necessary.

Integrating palliative care into antenatal and maternal care provides holistic support for pregnant individuals with life-limiting conditions, addressing pain, emotional well-being, and complications. It promotes dignity, autonomy, and quality of life for both mother and child, relying on multidisciplinary collaboration and cultural sensitivity.

5.3 Labor and Delivery

Integrating palliative care into labor and delivery addresses the unique needs of patients with life-limiting conditions, focusing on pain management, emotional support, and dignity. This approach enhances the childbirth experience, creating a compassionate environment for the mother and family, improving quality of life.

Key Components of Palliative Care Integration in Labor and Delivery

Category	Details
1. Preparing for Labor with a Palliative Care Approach	
Comprehensive History Taking	- A detailed review of the patient's obstetric, medical, and palliative condition ensures that all aspects of care are aligned. - Providers assess the stage of the patient's illness, existing symptoms, and potential complications during labor.
Individualized Birth Plan	- A collaborative birth plan is developed, incorporating the patient's preferences, comfort measures, and medical needs. - Decisions on pain management options, delivery methods (vaginal or cesarean), and neonatal care are made in consultation with the patient and family.
2. Pain and Symptom Management During Labor	
Safe and Effective Pain Relief	- Pain management strategies, including epidurals, analgesics, or non-pharmacological techniques, are adapted to the patient's palliative condition and stage of illness. - Palliative care ensures that any medication used does not interfere with the

	patient's existing treatments or exacerbate symptoms.
Addressing Fatigue and Weakness	- Interventions such as assisted pushing or cesarean delivery may be considered for patients with limited physical strength due to their condition.
Non-Pharmacological Support	- Techniques like guided breathing, relaxation exercises, and emotional reassurance are provided to enhance comfort during labor
3. Emotional and Psychological Support	
Building Confidence and Reducing Fear	- Labor can be particularly stressful for patients with life-limiting conditions. Continuous emotional support is provided to alleviate fear and anxiety. - Care teams focus on maintaining a calm, reassuring environment to reduce emotional distress.
Partner and Family Involvement	- Family members are engaged in the labor process to provide emotional support and share in the experience, enhancing the patient's sense of connection and support.
Grief Counseling	- For patients facing a poor prognosis, counselors and social workers offer guidance and psychological support to navigate complex emotions during labor.
4. Coordinated Delivery with a Multidisciplinary Team	
Collaborative Care Approach	- Labor and delivery involve close coordination between obstetricians, palliative care specialists, anesthetists, and nurses to ensure comprehensive care. - Teams are prepared to manage complications related to the patient's underlying condition, such as respiratory distress or cardiovascular instability.
Flexibility in Delivery Methods	- Decisions on vaginal or cesarean delivery are made based on the patient's health, fetal status, and palliative care goals. - Emergency interventions are planned with the patient's overall prognosis and comfort in mind.
5. Post-Delivery Palliative Support	
Pain and Symptom Monitoring	- Post-delivery, patients are closely monitored for pain, fatigue, and other symptoms, ensuring timely interventions for comfort.
Emotional and Psychological Care	- Counseling continues to support the patient and family in adapting to the postpartum period, addressing any grief, joy, or mixed emotions.
Family-Centered Support	- Care plans include guidance for newborn care, recognizing the patient's physical limitations and need for ongoing support.

The recognition of palliative care in labor and delivery ensures that the unique needs of patients with life-limiting conditions are met with compassion, expertise, and dignity. Pain management, emotional support, and multidisciplinary collaboration creates a safe and supportive environment that prioritizes the well-being of both the mother and baby.

5.4. Post-Natal Care

Post-natal care with an integrated palliative care approach focuses on providing holistic support to mothers recovering from childbirth, particularly those with life-limiting conditions. This integration ensures that physical recovery, emotional well-being, and family dynamics are addressed comprehensively, enabling mothers to care for their newborns while managing their health

challenges with dignity and autonomy.

Key Components of Palliative Care Integration in Post-Natal Care

Category	Details
1. Physical and Emotional Assessments	
Physical Recovery	- Post-natal care includes monitoring for postpartum complications such as infections, hemorrhage, or delayed healing, with adjustments made for patients with chronic or life-limiting conditions. - Symptom management (e.g., pain, fatigue, or nausea) is tailored to enhance the patient's comfort during recovery.
Emotional and Psychological Needs	- The emotional challenges of postpartum recovery are compounded by the presence of a life-limiting illness. Counseling helps address anxiety, depression, or feelings of guilt or inadequacy. - Emotional support extends to grief counseling for mothers who may have concerns about their prognosis and the future of their child.
Parenting Support	- Assistance is provided to help mothers navigate the emotional complexities of parenting while managing their own health.
2. Family and Self-Care Guidance	
Infant Care Education	- Guidance on breastfeeding, nutrition, and general infant care is provided, adapting recommendations to the mother's physical capabilities and energy levels. - Alternative care options, such as formula feeding, are discussed if breastfeeding is not viable due to the mother's condition or treatments.
Support for Self-Care	- Patients are educated on self-care practices that align with their palliative needs, including managing symptoms, adhering to medications, and balancing rest with care-giving responsibilities.
Family Engagement	- Family members are encouraged to participate in care-giving, ensuring the mother has adequate support in caring for her newborn and managing her health. - Discussions may include planning for long-term family support, particularly in cases where the mother's prognosis limits her active parenting role.
Promoting Autonomy	- Care plans emphasize strategies that empower the mother to remain actively involved in family life and decision-making, fostering a sense of control and fulfillment.
3. Follow-Up and Support	
Routine Monitoring	- Follow-up appointments are essential to monitor the mother's recovery, manage ongoing symptoms, and address any emerging complications. - Health assessments include screening for postpartum depression, nutritional status, and physical strength.
Access to SRH Services	- Mothers are provided with family planning counseling to prevent unintended pregnancies, ensuring safe contraceptive methods are chosen based on their health status. - STI prevention and treatment services are integrated into follow-up care to address any risks that may arise post-delivery.

Emphasis on Long-Term Support	- Patients are connected with community resources, support groups, or home care services to ensure continuity of care after the immediate postpartum period.
Advance Care Planning	- For mothers with life-limiting illnesses, follow-up care includes discussions about advance directives, guardianship planning for the child, and emotional preparation for the family.

Integrating palliative care into post-natal care offers a compassionate, patient-centered approach for mothers with life-limiting illnesses. It combines physical recovery, emotional support, and family-focused strategies, allowing mothers to engage in their child's life while managing their health with dignity. Ongoing follow-ups and long-term support ensure comprehensive care for both mother and family.

5.5 Post-Abortion Care

Post-abortion care, combined with palliative care, provides a holistic approach to supporting patients recovering from abortion, particularly those facing life-limiting conditions. This integration ensures that physical recovery, emotional well-being, and psychological needs are comprehensively addressed, enabling patients to navigate post-abortion recovery with dignity, comfort, and autonomy.

Key Components of Palliative Care Integration in Post-Abortion Care	
1. Physical and Emotional Needs Assessment	
Conduct a comprehensive physical assessment.	- Evaluate the patient's physical recovery, focusing on pain, signs of infection, and the healing process. - Monitor for complications such as excessive bleeding, uterine perforation, or retained tissue. - Tailor care to the patient's palliative condition, ensuring that existing symptoms like fatigue, nausea, or weakness are considered in the recovery process.
Emotional Health Assessment	- Address the psychological and emotional impact of abortion, which may be compounded by the stress of living with a life-limiting illness. - Provide counseling to help patients process emotions such as grief, guilt, or relief in a supportive, non-judgmental environment.
2. Symptom Management and Palliative Care Integration	
Pain Management	- Develop a pain management plan that aligns with the patient's overall palliative needs, considering both pharmacological and non-pharmacological interventions. - Medications used should be safe and not interfere with palliative care treatments or exacerbate other symptoms.
Infection Prevention and Treatment	- Prevent infections by ensuring proper uterine evacuation, administering antibiotics if needed, and providing hygiene education. - Proactively treat any detected infections with medications that are compatible with the patient's condition and palliative care regimen.
Nutritional Support	- Provide dietary guidance to support physical recovery and manage energy

	levels, tailored to any dietary restrictions from the patient's illness or treatments.
3. Counseling and Emotional Support	
Post-Abortion Counseling	- Offer counseling to address emotional responses to abortion, focusing on providing a safe space for the patient to express concerns or feelings. - Discuss how their life-limiting condition may affect future reproductive decisions.
Family and Partner Involvement	- Encourage open communication with partners or family members, helping them understand and support the patient's recovery journey.
Grief and Loss Support	- Provide psychological care for patients grieving the loss of a pregnancy, particularly if the abortion decision was influenced by medical risks to the patient or fetus.
4. Education on Sexual and Reproductive Health (SRH)	
Contraceptive Counseling	- Offer advice on family planning to prevent unintended pregnancies, ensuring that the chosen methods are compatible with the patient's health. - Discuss long-term contraceptive options, such as IUDs or implants, if appropriate for the patient's condition.
STI Prevention	- Provide education on safe sexual practices, including consistent condom use, to reduce the risk of sexually transmitted infections (STIs). - Offer STI testing and treatment for both the patient and their partner, if necessary.
5. Follow-Up Care and Support	
Routine Monitoring	- Schedule follow-ups to assess physical recovery, monitor for complications, and ensure emotional well-being. - Reevaluate the patient's palliative care plan to incorporate any changes in their health status post-abortion.
Advance Care Planning	- For patients with life-limiting conditions, follow-up care may include discussions on reproductive health goals, advance directives, and palliative planning.

Integrating palliative care into post-abortion care provides a compassionate, patient-centered approach to recovery. By providing comprehensive care that addresses physical, emotional, and reproductive health needs, patients can receive tailored support. Multidisciplinary teams, culturally sensitive counseling, and ongoing follow-up care are crucial for improving patient outcomes and quality of life during this challenging period.

Chapter 6: Addressing SRH and Palliative Care Needs of Special Populations

6.1. Who is the right patient to target?

The right patients to target are those in transition moving from health to illness, curative care to comfort care, and from life to death. We bear witness to this sacred time by offering neutral support, comfort, and collaborating with medical teams and family members.

SRH and Palliative Care Needs of Special Populations	
Adolescents and Young Adults	
Unique Needs	- Adolescents with life-limiting conditions may experience disrupted sexual development and struggle with identity, intimacy, and fertility concerns. - They require support to navigate body image issues, future family planning, and emotional challenges associated with life-threatening conditions. - Adolescents have a dire need for confidentiality.
SRH Integration	- **Education:** Provide age-appropriate, culturally sensitive SRH education on topics like contraception, STI prevention, and safe sexual practices. - **Fertility Preservation:** Discuss options for preserving fertility (e.g., sperm or egg freezing) when treatment risks impacting reproductive potential. - **Psychological Support:** Offer counselling to address self-esteem, social relationships, and future aspirations. • Menstrual health management • Vaginal and cervical hygiene HPV vaccination should be administered according to national guidelines, targeting individuals aged 10 to 14 years. • Early sexual debute. This refers to the experience of an individual engaging in sexual activity at a younger age than what is considered typical or ideal within a specific cultural, societal, or developmental context.
Best Practices	- Involve youth-friendly services that ensure confidentiality and foster trust. - Engage family members while respecting the adolescent's autonomy.
LGBTQ+ Individuals	
Unique Needs	LGBTQIA2S+ individuals often face stigma, discrimination and barriers to accessing SRH and palliative care. - Their needs may include managing gender dysphoria, navigating relationships, and addressing reproductive options in the context of a life-limiting illness.
SRH Integration	- **Inclusive Care**: Create an affirming environment that respects diverse sexual orientations, gender identities, and expressions. - **Relationship Support**: Provide counselling for partners, ensuring they are included in care planning when desired. - **Reproductive Health**: Address unique SRH needs, such as hormone therapy continuity, safe contraception, and fertility options
Best Practices	- Train healthcare providers on LGBTQ+ health issues to ensure competent and non-discriminatory care.

	- Incorporate inclusive language and policies in palliative care settings.
People with Disabilities	
Unique Needs	- People with physical, intellectual, or developmental disabilities may face assumptions that they are asexual, leading to unmet SRH needs. - They require accessible, tailored support for addressing intimacy, family planning, and emotional well-being.
SRH Integration	- **Accessible Services**: Ensure facilities and educational materials are adapted for individuals with disabilities. - **Empowerment**: Encourage open discussions about sexuality, intimacy, and reproductive rights. - **Care Coordination**: Collaborate with caregivers while prioritizing the individual's autonomy and preferences.
Women in Low-Resource Settings including refugees	
Unique Needs	- Women in low-resource settings may lack access to basic SRH services, such as family planning, safe abortion, or STI treatment. - They may face cultural or economic barriers to seeking care, exacerbating the burden of life-limiting illnesses.
SRH Integration	- **Community Engagement**: Work with local leaders to promote awareness and reduce stigma around SRH in palliative care. - **Mobile Clinics**: Offer SRH and palliative care services through outreach programs to improve access. - **Economic Support**: Address financial barriers by providing free or subsidized services and essential supplies.
Best Practices	- Incorporate culturally sensitive approaches to care delivery. - Leverage technology (e.g., telehealth) to provide remote support where in-person services are unavailable.
Individuals Living with HIV/AIDS	
Unique Needs	- HIV-positive individuals may face overlapping palliative and SRH needs, including managing opportunistic infections, fertility issues, and stigma. - Sexual health concerns, such as the risk of STI co-infections, are particularly relevant.
SRH Integration	- Contraceptive Counseling: Offer options that are safe with antiretroviral therapy. - HIV and STI Screening and Treatment: Provide routine STI checks and treatment. - Psychological Support: Address mental health challenges stemming from stigma and the dual burden of HIV and life-limiting illness.
Best Practices	- Foster a non-judgmental environment to encourage open discussion about SRH. - Provide family-centered care that includes partner testing and counseling.
- GBV survivors	
Unique Needs	- **Physical trauma**: Survivors may experience physical injuries or chronic pain resulting from GBV. - **Psychological trauma**: Survivors may have mental health challenges, including PTSD, depression, and anxiety.

	- **Reproductive health risks**: GBV survivors may face unintended pregnancies, STIs, or complications related to reproductive health. - **Social stigma**: Survivors may experience discrimination or isolation from communities, complicating access to care.
SRH Integration	- **Comprehensive care**: SRH services should be incorporated into the palliative care plan, addressing reproductive health needs such as contraception, safe pregnancy, and STI prevention/treatment. - **Trauma-informed approach**: Providing care in a safe, supportive environment that acknowledges the survivor's experiences and avoids re-traumatization. - **Mental health support**: Integrating psychological counseling and mental health services into the care plan to address trauma, emotional well-being, and sexual health. **- Confidentiality and privacy:** Ensuring survivors' privacy and confidentiality, particularly regarding their sexual health needs, is crucial to establishing trust.
Best Practices	- **Patient-centered care**: Tailor the care approach to the survivor's specific emotional, psychological, and physical needs. - **Multi-disciplinary care**: Involve social workers, counselors, healthcare providers, and legal support services to offer holistic care that addresses the survivor's diverse needs. - **Training of healthcare providers**: Healthcare professionals should be trained in handling GBV survivors, providing trauma-informed care, and addressing sexual and reproductive health with sensitivity. - **Community engagement**: Involve the community to reduce stigma and improve access to care, particularly in low-resource settings. - **Advocacy for rights**: Ensure that GBV survivors are aware of their rights and that legal support is accessible if needed, especially related to issues of reproductive health, safety, and autonomy.
Substance users	
Unique Needs	- Chronic health issues (e.g., STIs, organ damage) - Mental health challenges (e.g., depression, anxiety) - Higher risk of STI transmission and unprotected sex - Stigma and impaired decision-making due to substance use
SRH Integration	- Provide contraception (e.g., LARCs) and STI prevention (e.g., condoms, PrEPS) - Integrate harm reduction strategies (e.g., needle exchange) - Address mental health as part of SRH care - Educate on safer sexual practices and reproductive health
Best Practices	- Trauma-informed, non-judgmental care - Integrated care teams (addiction, mental health, sexual health experts) - Support reproductive decision-making and recovery - Peer support and community-based services
- Mental illness	
Unique Needs	- Co-occurring physical, emotional, and cognitive challenges - Increased vulnerability to STIs, sexual abuse, and exploitation - Medication side effects impacting sexual function or libido

	- Stigma, isolation, and difficulty in making informed decisions about sexual health
SRH Integration	- Address contraception, STI prevention, and sexual health education, focusing on informed decision-making. - Consider medication side effects on sexual function and provide appropriate interventions. - Tailor support to individual mental health conditions (e.g., depression, anxiety, psychosis). - Provide accessible, non-judgmental, and confidential SRH services.
Best Practices	- Integrate mental health and SRH care in a collaborative, holistic approach - Use a trauma-informed care model and prioritize autonomy and consent - Offer individualized counseling and education, with clear communication and support to navigate sexual health decisions - Ensure staff are trained to address the intersection of mental health and sexual health without stigma
Survivors of Female Genital Mutilation (FGM)	
Unique Needs	- **Physical complications**: Chronic pain, infections, difficulties with childbirth, and urinary or menstrual issues. - **Psychological trauma**: PTSD, anxiety, depression, and feelings of shame or disempowerment. - **Sexual health concerns**: Decreased sexual pleasure, pain during intercourse, and difficulties with intimacy. - **Social stigma**: Marginalization and discrimination due to cultural beliefs or the effects of FGM.
SRH Integration	- **Comprehensive care**: Address pain management, infection prevention, and sexual health education (e.g., treatment options, alternatives to FGM). - **Trauma-informed approach**: Provide care in a sensitive and non-judgmental manner, respecting survivors' autonomy and dignity. - **Psychological support**: Offer counseling to address mental health and sexual well-being. - **Childbirth support**: Provide specialized care for safe childbirth, as FGM can complicate labor and delivery.
Best Practices	- **Multidisciplinary care**: Involve gynecologists, psychologists, and cultural mediators to provide holistic support. - **Culturally sensitive care**: Respect cultural contexts and beliefs while providing SRH education and services - **Community engagement**: Educate and engage with communities to reduce stigma, prevent FGM, and offer support to survivors. - **Empowerment and advocacy**: Advocate for survivors' rights, ensuring access to healthcare, and provide empowerment through education and support networks

Chapter 7: Monitoring and Evaluation (M&E)

Monitoring and Evaluation (M&E) of SRH integration into palliative care is essential for assessing effectiveness, efficiency, and sustainability. A strong M&E framework ensures services meet patient needs, align with quality standards, and follow policy directives, fostering continuous improvement in SRH services within palliative care.

7.1. Key Components of M&E in SRH and Palliative Care Integration

M&E efforts must be guided by specific **indicators** and their corresponding **outcomes**, which measure both quantitative and qualitative aspects of service delivery. Below are the key indicators and outcomes to monitor and evaluate the integration of SRH services into palliative care.

Section	Indicator	Outcome
1. **Family Planning**	✧ Percentage of women using modern contraceptive methods	✧ Increase in the number of women using modern family planning methods, improving reproductive health management.
	✧ Percentage of patients receiving counseling on family planning options	✧ Improved knowledge and counseling about family planning methods for palliative care patients.
	✧ Adherence to prescribed contraceptive methods	✧ Higher adherence rates to contraceptive methods, ensuring consistent family planning.
2. **Antenatal and Maternal Care**	✧ Percentage of pregnant women receiving early antenatal care (within 1st trimester)	✧ Increased early initiation of ANC services, leading to better maternal and fetal health outcomes.
	✧ Number of women attending a minimum of 4 ANC visits	✧ Improved maternal health outcomes with regular antenatal visits.
	✧ Screening and management of pregnancy-related complications (e.g., hypertension, anemia)	✧ Decreased incidence of pregnancy-related complications and improved management of identified risks in palliative care patients.
3. **Post-Natal Care**	✧ Percentage of women receiving post-natal care within the first 48 hours after delivery	✧ Increased uptake of immediate post-natal care, reducing maternal and neonatal morbidity.
	✧ Exclusive breastfeeding rates at 6 months postpartum	✧ Higher exclusive breastfeeding rates, supporting infant health and development.
4. Post-Natal Care	✧ Number of women receiving counseling on post-natal depression and mental health	✧ Enhanced mental health support for new mothers, reducing post-natal depression and related risks.
5. **Post-Abortion Care**	✧ Percentage of women receiving post-abortion counseling and care	✧ Increased support for women post-abortion, including emotional counseling and medical care to prevent complications.
	✧ Management of complications from unsafe abortions	✧ Reduction in complications and maternal morbidity due to unsafe abortions, with timely medical interventions.
6. Labor and	✧ Percentage of women with a	✧ Increased patient empowerment and informed

	Delivery	birth plan and informed consent	decision-making in the labor and delivery process.
		✧ Proportion of women who experience complications during delivery (e.g., hemorrhage, dystocia)	✧ Decrease in labor and delivery complications, improving maternal health outcomes.
		✧ Percentage of women receiving pain management during labor	✧ Enhanced pain relief and management, leading to improved delivery experiences for women.
7.	**Sexual and Reproductive Health (SRH)**	✧ Percentage of patients screened for sexually transmitted infections (STIs)	✧ Increased STI screening and treatment, improving sexual health outcomes.
		✧ Availability of SRH services to underserved populations (e.g., rural, LGBTQ+)	✧ Enhanced accessibility of SRH services to marginalized and underserved populations.
8.	**Provider Competency and Performance**	✧ Percentage of providers receiving training on SRH care in palliative settings	✧ Improved provider competency in delivering SRH care within palliative care, ensuring high-quality service.
9.	**Infection Rates**	✧ Prevalence and incidence of SRH-related infections (HIV, STIs, etc.)	✧ Reduction in the prevalence of SRH-related infections within palliative care settings.
10.	**Treatment Adherence**	✧ Percentage of patients adhering to SRH treatment plans (e.g., HIV medication, contraceptives)	✧ Improved adherence to treatment plans, ensuring better management of SRH conditions.
11.	**Quality of Life Improvements**	✧ Patient-reported outcomes on physical, emotional, and sexual health	✧ Improved overall health and well-being, with better sexual and reproductive health outcomes.
12.	**Equity in Access**	✧ Percentage of marginalized groups (women, LGBTQ+, rural) accessing SRH services	✧ Increased service accessibility for marginalized groups, ensuring inclusive care for all patient populations.

7.2. Data Collection Methods

Method	Details
Electronic Health Records (EHRs)	Track patient histories, SRH diagnoses, treatments, and outcomes. Integrate with systems like KHIS for trend analysis.
Patient and Family Surveys	Administer structured surveys to gather feedback on satisfaction, accessibility, and quality of care (digital and in-person).
Focus Groups and Interviews	Conduct qualitative interviews with patients, families, and providers for deeper insights into SRH service experiences.
Routine Facility Audits	Use checklists to evaluate service delivery, SRH resources, and clinical protocol compliance.
Community Feedback Mechanisms	Engage community health workers and peer educators for real-time feedback on patient experiences and challenges.
Patient Logs	Encourage patients/caregivers to maintain logs documenting

	symptoms, medication adherence, and side effects.

7.3. Feedback Mechanisms

Method	Details
Patient and Family Feedback Channels	Provide accessible channels (suggestion boxes, surveys, or digital apps) for patients and families to voice concerns.
Regular Stakeholder Meetings	Hold meetings with healthcare providers, policymakers, and community organizations to discuss integration progress.
Healthcare Provider Roundtables	Create spaces for providers to share experiences and solutions, promoting collaborative problem-solving.
Community Health Worker Input	Gather insights from community health workers who interact with patients outside clinical settings to identify barriers.

7.4. Challenges in M&E and Mitigation Strategies

Challenge	Details
Data Gaps	Limited access to accurate, timely data on SRH within palliative care.
Resource Constraints	Insufficient funding for implementing comprehensive M&E systems.
Cultural Barriers	Sensitivity around discussing SRH topics in some communities.
Provider Resistance	Resistance to change or additional workloads among healthcare staff.

Mitigation Strategy	Details
Capacity Building	Train staff on the importance of M&E and equip them with data collection and analysis skills.
Community Engagement	Conduct awareness campaigns to address stigma and promote understanding of SRH in palliative care.
Leveraging Technology	Use cost-effective digital tools for data collection and feedback.
Policy Advocacy	Work with policymakers to secure funding and support for M&E initiatives.

A well-designed Monitoring and Evaluation system is integral to the successful integration of Sexual and Reproductive Health into palliative care. By using the above indicators and outcomes to track progress, identify gaps, and ensure the continuous improvement of services, healthcare providers can enhance care quality, equity, and patient outcomes. Ultimately, this ensures that we track the key pillars of intervention effectively.

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