FAMILY CASE REPORT

Optimizing Family Psychodynamics in the Exit Plan for a Good Death*

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Introduction

As primary care physicians, we diagnose and give the appropriate cure for every disease; but as family medicine specialists, we are best at doing more. We treat not only the disease but also identify the biopsychosocial needs of the patients and their families, highlighting family functions and psychodynamics through the course of an illness.

One of the challenging aspects is providing care for a terminally ill elderly patient. We cannot avoid the initial experience of equating cancer with death, evoking anxiety and depression to the patient and the family. In these circumstances, our specialty plays a greater role in providing understanding, guidance and support in the multidimensional realms of end-of-life. It is through physical, psychosocial and spiritual preparedness that one is able to respond and accept death as a reality.

This family case management report aims to present the biomedical and psychosocial care to a dying patient and her family. Specifically, it aims to: a) determine the needs of the cancer patient using the biopsychosocial model, b) analyze the family psychodynamics, impact of illness, and their functional adaptation to unexpected changes using the S-T-F-R-E-D system, c) discuss the terminal phase and quality of death of the patient using the hospice care approach and d) define, review, and present bereavement and bereavement care rendered to the family.

The Case

MEA is a 72 year old female, Roman Catholic, former housekeeper from Manila. She consulted at the Gynecology department due to post-menopausal bleeding that started in November 2015. Her family also noticed undocumented weight loss with decreased appetite, easy fatigability, non-rotatory dizziness and pallor. She consulted and eventually underwent dilatation and curettage in a private hospital. Histopathology showed endometrial endometrioid carcinoma stage 1B. Patient was advised to undergo total abdominal hysterectomy but she refused and was lost to follow-up.

It was only in March that her daughter was able to convince her to consult in the guise of a general check-up.

Upon consult, she had occasional vaginal spotting and easy fatigability. She was noted to be weak-looking with assisted ambulation. Vital signs were normal. She was obese with a BMI of 34 kg/m^2. Generalized skin pallor with pale palpebral conjunctiva was noted.

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Abdominal examination showed a globular abdomen, normoactive bowel sounds, and a 24cm x 26cm firm, fixed, non-tender pelvo-abdominal mass, 5 cm above the umbilicus and 6cm below the xiphoid. Percussion elicited dullness over the area of the mass, otherwise tympanitic over the rest of the abdomen.

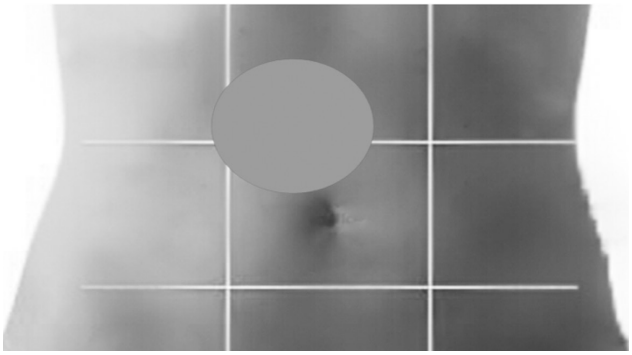


Figure 1. Representative illustration of the location of the mass

Upon internal examination, a 6cm x 4cm polypoid mass protruding from the os was seen. The uterus was normal-sized, firm, pushed anteriorly by the pelvo-abdominal mass. Both adnexae cannot be assessed. The rest of the examination is unremarkable.

A complete blood count showed low hemoglobin level at 72 mg/dl. Admitting diagnoses were endometrial endometroid carcinoma with possible cervical malignancy and anemia, severe.

On admission, she was conscious, coherent, and in distress with a BP of 160/110 HR – 118 bpm RR – 26 cpm T – 36.9C. She was transfused with 2 units of pRBC. With an elevated creatinine of 4.87mg/dl and a decreasing urine output, Nephrology service managed her as a case of chronic kidney disease probably secondary to 1) hypertensive nephrosclerosis, 2) obstructive uropathy. Whole abdominal ultrasound revealed a large pelvoabdominal cystic mass with solid components closely related to the fundus of uterus, consider ovarian new growth; contrast enhanced CT scan was suggested for further evaluation but was not done.

Figure 2. Ultrasound showing the anteverted uterus with thickened endometrium. There is a 14.85x11.43x16.95cm Pelvoabdominal cystic mass (M) with solid components closely related to the urinary bladder (UB) fundus of uterus.

Also noted were: a normal sized liver with diffuse parenchymal changes, cholelithiasis, normal sized kidneys with diffuse parenchymal changes, grade 3-4 hydronephrosis with hydroureter, partially distended urinary bladder with moderate thickening of wall, anteverted uterus with thickened endometrium, and minimal peritoneal fluid on the right.

Referral to Urology service suggested cystoscopy, retrograde pyelography, CT stent insertion, and possible bilateral percutaneous nephrostomy.

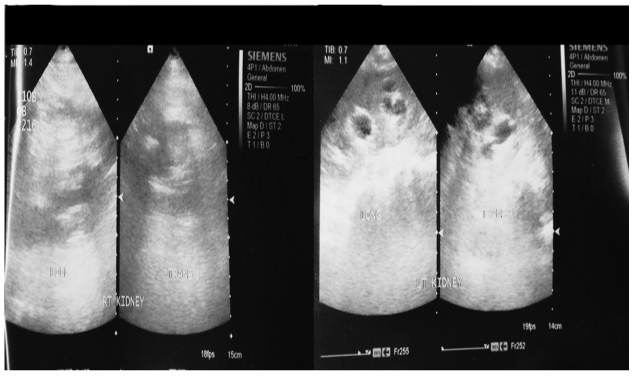


Figure 3. Ultrasound of the right and left kidneys with diffuse parenchymal changes and Grade 3-4 hydronephrosis.

The mentioned procedures overwhelmed the patient. She suddenly became irritable and uncooperative. She refused the interventions from all services including a repeat cervical and endometrial biopsy; hence the family contemplated to take the patient home against medical advice. Prior to discharge, she was referred to Family Medicine for palliative care.

Biopsychosocial Evaluation

To facilitate palliative care, we utilized the biopsychosocial model in providing a holistic care to this cancer patient who was against medico-surgical advice. The Family Health Care Program (FHCP) team reviewed the patient's history, utilized evidence-based medicine to determine prognosis and outcomes, conducted a comprehensive geriatric assessment (CGA), and recommended biomedical, psychosocial and wellness plans for this patient.

Endometrial Endometrioid Carcinoma: Epidemiology, Risk Factors and Prognosis

Worldwide, endometrial cancer is the sixth most common neoplasm in women. It is often identified at an early, localized, and treatable stage. The median age at diagnosis is 62 years. The most common sign or symptom is post-menopausal bleeding similar to our patient.

Based on our research, the exact etiology for most cases of endometrial cancer still remains to be explained, with sporadic mutations appear to cause the majority. Known risk factors include: Increased estrogen levels (as occurs in those who are obese and/or have abdominal fat, diabetes, and/or high-fat diets), use of tamoxifen therapy or hormone replacement therapy (HRT), early age at menarche (<12 years), late age at menopause, nulliparity, history of polycystic ovarian syndrome (PCOS), personal and/or family history of Lynch syndrome/hereditary non-polyposis colorectal cancer (HNPCC); breast, ovarian, and/or colorectal cancer; and/or endometrial hyperplasia, older age (≥55 years).1 For MEA, obesity causing increase in estrogen levels and old age (72) are the risk factors for her acquiring the disease.

The most common endometrial cancer cell type is endometrioid adenocarcinoma, similar to this case. The two main clinicopathological and molecular types are 1) type I - endometrioid adenocarcinoma (80%–90%), and 2) type II - non-endometrioid subtypes serous, clear-cell and undifferentiated carcinomas, as well as carcinosarcoma/malignant-mixed Müllerian tumor (10%–20%).

Stage	
IA	Tumor limited to endometrium
IB	Invasion to less than one-half the myometrium
IC	Invasion to more than one-half the myometrium
IIA	Endocervical glandular involvement only
IIB	Cervical stromal invasion
IIIA	Tumor invades serosa, and/or adnexa, and/or positive peritoneal cytology
IIIB	Vaginal metastases
IIIC	Metastasis to pelvic and/or periaortic lymph nodes
IVA	Tumor invasion of bladder mucosa and/or bower mucosa
IVB	Distant metastases including intra-abdominal and/or inguinal lymph nodes

Figure 4. FIGO staging of endometrial carcinoma.

A more accurate staging could be done if regional lymph nodes and distant metastasis were documented through abdominal hysterectomy. Still, the standard management of endometrial cancer is surgery, with or without radiation therapy, hormone therapy, or chemotherapy. Surgical evidence shows that total abdominal hysterectomy is still the best option for MEA.

Upon early diagnosis and treatment, endometrial endometrioid carcinoma has good prognosis. Because of the typical early clinical presentation, most cases of endometrial endometrioid cancer are treated at stage I.

If MEA was treated at diagnosis, she could have had a 95.4% 5-year relative survival rate according to evidence.[1] This could have been the case if she agreed to undergo surgery as soon as she was diagnosed. However, other psychosocial issues during that time were not addressed; hence, the refusal to management plan.

In her current state, a possible metastasis cannot be ruled out. Thus, the prognosis may be poorer than expected.

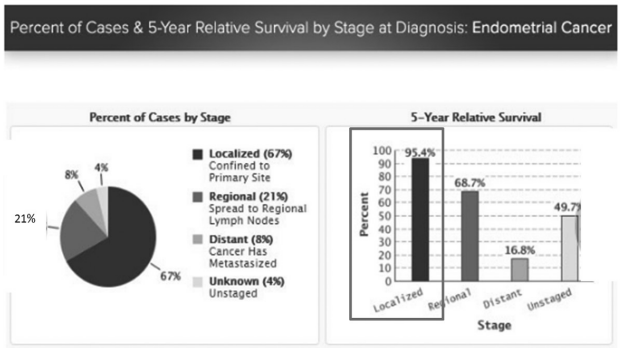


Figure 5. Relative survival rate by stage at diagnosis of endometrial cancer.

Comprehensive Geriatric Assessment

The FHCP team conducted a comprehensive geriatric assessment (CGA) to assess the cognitive, psychological, functional, nutritional and social status of our index patient. Relevant findings are summarized in the table below.

Counseling: Patient's Insights Against Surgical Procedures

On counseling, she was found to be a woman of many fears. She was against the surgical procedures suggested by other services because of her fear of pain. She also worried that undergoing surgery would mean a longer hospital stay, additional financial burden and caregiving strain to her family.

On further probing, an emotionally critical misperception on the death of her husband in 2014 was identified. Her husband died from complications of a

Table 1. Comprehensive geriatric assessment for MEA.

Domain	Assessment Tool/s	Remarks
Cognitive	Mini- Mental Status Exam	Score: 18/30 Mild Cognitive Impairment
Psychological	Geriatric Depression Scale	Score: 0/15 Not depressed
Functional	Katz Index Activities of Daily Living	Score: F Independent in all but bathing, dressing, transferring, and one additional function
	Lawton Instrumental Activities of Daily Living	Score: 3 Higher Level of Dependence
	Get Up and Go Test	Not done
Nutritional	Mini-Nutritional Assessment	Score: <17 Malnourished
Social		Identified primary caregiver and decision-maker: MAdL (daughter) *Modified Caregiver Strain Index Score: 17 (Not Strained) Secondary caregiver: AO (daughter) Breadwinner: MAA (daughter)
Environmental		No identified environmental hazard/s

cataract surgery. Since then, MEA equated surgery to death.

Upon comprehensive assessment of the family, we were able to identify a strong support group behind her. Finances were well-provided by the children since two of them work abroad. Her daughter and primary caregiver, MAdL, has many friends who also provide moral and financial support. Although we attempted to address her fears and gave constant reassurance, she still opted to forego the surgical procedures, a personal decision respected by the family and the entire medical team.

However, despite discharge against medico-surgical advice, the family was open to home visits by the FHCP team. We planned continuing medical and psychosocial care to MEA and her family. A consent form for home care was obtained.

Family Interventions

The Biopsychosocial Model in the analysis of MEA's illness is summarized in figure 6.

Recommendations were made to promote functional adaptation and avoid psychosocial decline. We discussed the illness, its course, and the best palliative approach. We mobilized the family members in providing support and comfort to the patient. Other recommendations are shown in table 2.

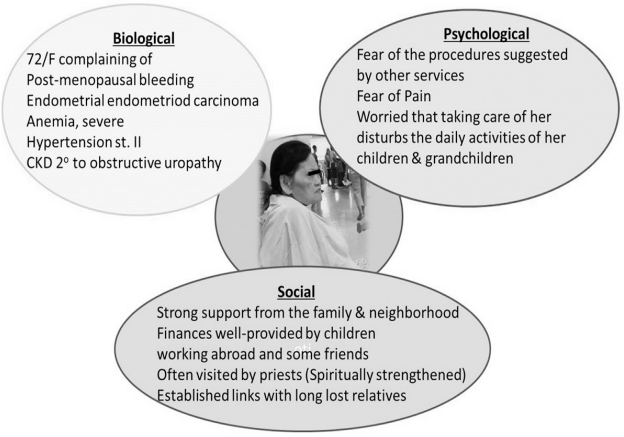


Figure 6. Biopsychosocial model of MEA's illness.

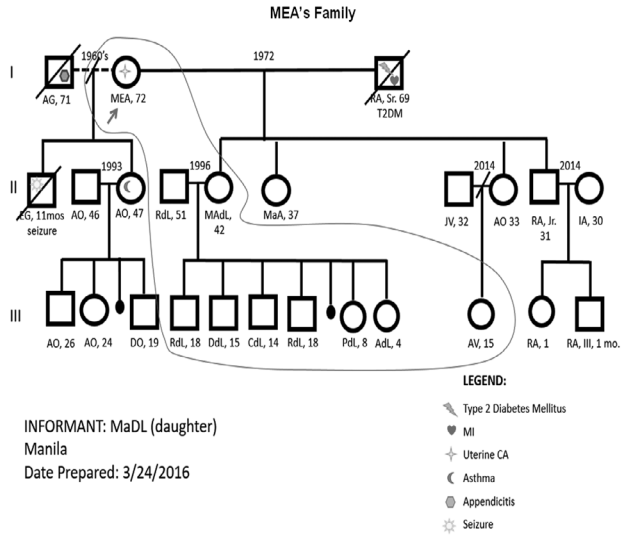
The family is a natural social system that occurs in a diversity of forms today and represents a diversity of cultural heritages. The way it functions has numerous effects on the development and well-being of its members.

In this case report, we applied the Family Systems Theory in the comprehensive analysis of the family psychodynamics, the impact of illness, and the family's functional adaptation to developmental changes using the S-T-F-R-E-D approach.

Table 2. Health recommendations for MEA, 72, index patient.

Type of Care	Problem	Recommendations
Medical	Endometrial endometriod carcinoma Anemia, resolved Hypertension stage 2 CKD secondary to obstructive uropathy	• Advise compliance with medications and medical management • Provide proper nutrition as advised • Aspiration, Bed sore precautions (egg crate matress use), and Fall precautions
Psychosocial	Adjustment from usual activities	• Continue communication • Assist the transition from hospital to home
Spiritual	Cannot attend mass or go to church because of current status	• Continue religious practices
Economic	Financial difficulties	• Proper allocation of funds • Maximize family's resources
Wellness	No vaccinations	• Update immunizations

Structure



MEA was in a unilaterally extended family. She lived with her daughter MAdL, son-in-law RdL and seven grandchildren. As a grandmother, MEA interacted well with her grandchildren, heightening her sensitivity and awareness of the need for caring. Since her diagnosis, she was able to maintain adequate support systems and was able to reconcile with relatives she had lost communication with through social media.

Transactional Patterns

MEA's family typically display stable, collaborative, purposeful interactions. However, an onset of illness may disrupt the interactive sequences and cause changes needed in order to reaffirm their unity in dealing with a life transition.

A closer look into the family's transactional patterns show that MEA used to be the primary decision maker and breadwinner of the family; however after her diagnosis of cancer, there was a shift of role noted. The task of decision making and caregiving was assigned to her daughters MAdL and OA, and the breadwinner role was handled by her daughter MaA who was then working abroad. The role shifts allowed the family to maintain stability and purpose. The grandchildren, knowing their grandmother's condition, also helped in the task of caregiving whenever able.

In assessing the family's transactional patterns, it is important to establish rapport with family members especially with the primary caregiver and breadwinner in order to assess them from time to time.

We explored the sentiments of the patient with her family. As the primary care physician we asked, "What can I help you with?" We addressed their fears, pains, and other possible functional and psychosocial problems. Awareness of the strength and identifying the needs of the family through an analysis of their recurring patterns of interactive sequences help in creating an appropriate action plan.

Flexibility/Adaptability

As families face challenges, their ability to adapt varies. Cancer being a chronic illness may lead to either a deteriorated condition making the family support weak, or it can be viewed as a life challenge presenting an opportunity for growth and bringing the family closer together. A family as a whole, or one or more of its members, may manifest dysfunctional behavior during periods of persistent stress, but family processes may mediate the patient's recovery, allowing the family system to rally, buffer stress, reduce the chances of dysfunction, and support optimal adaptation.

In the illness trajectory, the family is in the adjustment to outcome. Being in this stage, they adapted well with the impact of illness, adjusted resources well and managed finances accordingly. They also developed caregiving strategies, including delegation of tasks and time allocation, as to avoid caregiver strain.

The Family APGAR

Their Family APGAR, answered by MEA and the two caregivers were congruent and interpreted as highly functional (score 9-10).

Table 3. Family APGAR.

APGAR	MEA	MA dL	AO
Affection	2	2	2
Partnership	2	2	2
Growth	2	1	1
Adaptation	2	2	2
Resolve	2	2	2
TOTAL	10	9	9

SCREEM

Based on the SCREEM assessment, there were more strengths than weaknesses making them able to cope with crisis.

Resonance

Resonance measures the sensitivity of family members toward one another focusing on boundaries and emotional distance between family members. In MEA's family, enmeshment of the siblings to their sick mother was noted especially in providing care, finances, and time. MaA lived far in terms of distance from MEA but still was able to provide enough finances and showed concern and care. MAdL and AO spent an abundant amount of time taking care of their mother, assisting her physically, emotionally, and spiritually. At the same time, other members of the household, including the felt need for them to have roles in taking care of the patient.

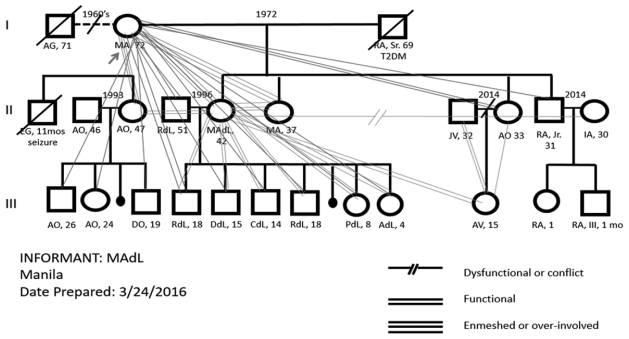


Figure 8. Family dynamics

Table 4. Family SCREEM.

Parameter	Resource	Pathology
Social	Open intrafamilial lines of communication Supportive intrafamilial relationships Healthy/supportive exrafamilial relationships	Sometimes, presence of animosity/rivalry
Cultural	Absence of or very few beliefs/practices that are unacceptable to our culture or negatively affect way of living	Previously believed in herbal medicines for treatment hence delay of proper medical management
Religious	Spirituality is positively influencing way of life Practicing one's faith, enduring because of his faith Some priests were able to visit upon request	Cannot attend mass regularly because of responsibilities at home & caregiving duties for MAdL
Economic	Ability to allocate funds properly Ability to make ends meet most of the time	Sometimes financial needs are not met if funds from abroad did not come on time
Educational	Level of education is not a hindrance to achievement, livelihood, success	Level of education hinders comprehension of some challenging circumstances
Medical	Other family members are healthy	Poor compliance w/ medical management Inappropriate medical consultation

Even after MEA was diagnosed with endometrial cancer, the relationship of the family did not change. On the contrary, even stronger links among family members were established.

According to Sulmasy (2002), the healing professions should serve the needs of patients as whole persons. Patients are considered beings-in-relationship, and illness can be considered a disruption in biological relationships that in turn affect all the other relational aspects of a person.[2]

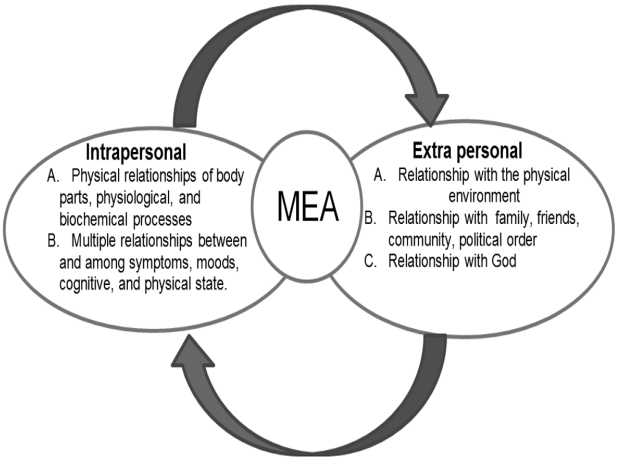


Figure 9. Illness and the manifold of relationships of the patient as a human person

Ecology

The Ecomap of MEA showed that she and her family received a strong support from the community, mostly positive and provides energy for MEA. Whenever problems arose financially, they were successfully able to make ends met despite the odds. Perhaps it was not only the family who was working hard together but also the community that was mobilized. This included the moral and financial support from friends and the government, the extended family, and the family healthcare program team. All of these added up to the strong support from her family and her firm belief in GOD.

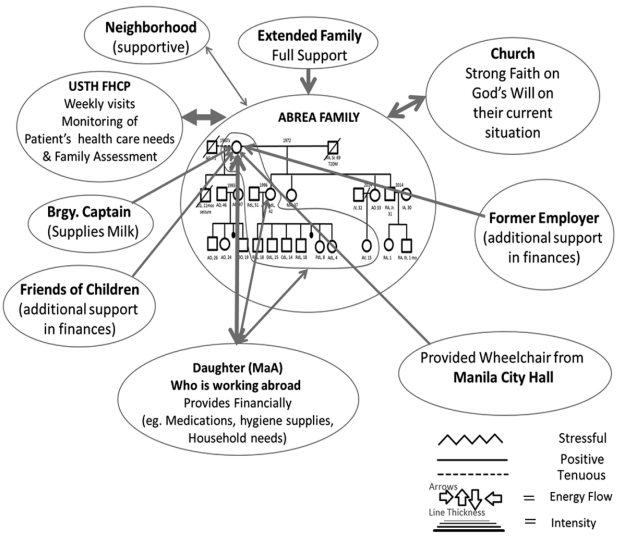


Figure 10. Family ECOMAP

Developmental Milestone

Developmental frameworks for studying families were done by family sociologists in an effort to account for regularities in family life over time. In 1980, Carter and McGoldrick broadened the life cycle concept to include a multidimensional multicultural, multigenerational perspective.[3]

Family Life Cycle

The key principle in the Family in Later Life is accepting the shifting of generational goals. Since the beginning of MEA's illness, her daughters became decision makers and care givers which initially was her own role when she was well. They all had to adjust, especially in their caregiving strategies and living arrangements so as to avoid conflicts. Although she was at her later years, she still had to maintain contact with younger generations and deal with them. Fortunately, her grandchildren were very cooperative in the role of caregiving.

The family was very reassuring, even contemplated on exploring options to help their current situation like

mobilizing extended family resources and receiving support from the community, i.e. milk supply from the barangay chairman and wheelchair from the city hall. This is a prime time where the family needs to be supported not just medically but most of all psychologically, socially, and spiritually.

Family Timeline

Important life events in MEA's family are depicted in figure 11.

Figure 11. Family timeline

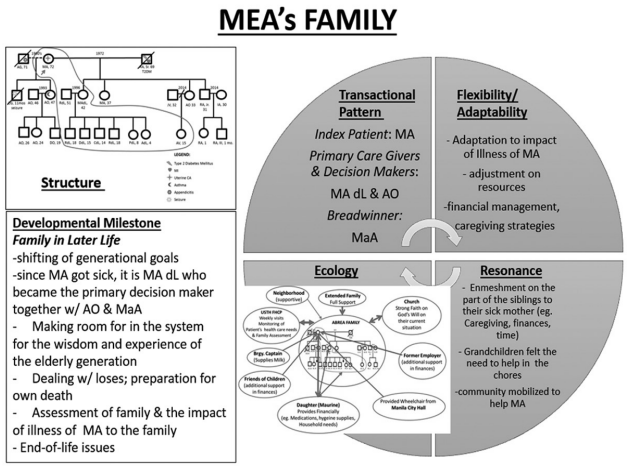


Figure 12. MEA's family system

Follow-up Interventions and Outcomes

Regular home visits started a week from MEA's discharge from the hospital. On first home care, she was found to be awake, comfortable, conversant, and bed- bound but sits with assistance. She also complained of occasional left leg pain. She had good appetite but preferred soft diet. Her family was advised regarding aspiration and bed sore precautions, and proper nutrition. She was also reminded to follow-up with gynecology and family medicine at the outpatient department.

In the family meeting, the patient and her three daughters who were the primary caregivers and breadwinner were present. Family CEA was employed. They knew and accepted that the patient has cancer, however they could not fully decide as a family what to do next because of lack of medical information. The gaps in these aspects of prognosis and future plans were supplied. After weeks of indecisiveness and confusion, they were empowered as a family to reach a consensus for non-aggressive treatment and palliative care.

Wellness recommendations for other family members were also formulated.

The Exit Plan: The Terminal Phase of Illness

On the succeeding visits, terminal symptoms were observed such as delirium, restlessness, and anxiety. Hospice care plans were formulated. Hospice care is comfort care without curative intent. It is a specific type of palliative care for people who likely have ≤ 6 months to live. Hospice care is always palliative, but not all palliative care is hospice.

Our goals were to assist the patient and the family deal with death and prepare a realistic exit plan. The FHCP team ensured the acceptance and healthy response of the family to the illness and impending death. Other danger stressors such as caregiver burden, pain, anxiety, depression, functional decline, and other psychosocial issues were tackled immediately so there was no interruption in providing the best possible care for the patient.

How do we address end-of life issues? This is where the physician-patient-family relationship comes in as part of the therapeutic triad, with everyone listening, sympathizing, assisting, and reassuring each other.[4]

Advanced Directives

The family agreed on hydration by IV route, nursing care, and laboratory tests should they be needed during the course of her care. They declined administration of resuscitation, defibrillation, and breathing assistance, dialysis, blood products and organ donation.

End-of-life means differently from the understanding of the patient, family, and the medical provider.[4] The patient perceived this as a peaceful transition from life to death without suffering. For her family, it is the time of reflection, sadness and grief; for some members, it may also be a time of regret and guilt.

Quality of Death

The concept of good death is a primary goal in the end-of-life care. According to a study by Lanaban & Sorrosa, the perception of good death among cancer patients, caregivers/family members, and healthcare providers includes the concept of good death, manner of death, place of death, and who should be present in the time of death. The concept of good death includes physical comfort, acceptance, sense of fulfillment, preparedness, family support, resolution of conflicts, and sense of peace.[5]

MEA desired a pain-free death, without any preference to place of death, but in the presence of her family, friends, and doctors/healthcare providers at her side.

In a study by Geok Ling Lee, a good death may be understood as reconciling the biopsychosocial and spiritual aspects in the end of life. We identified five key points in providing a quality death for MEA. These were: 1) preparations for death, 2) family and social relationships, 3) moments at or near death, 4) comfort and physical care, and 5) spiritual well-being.[6]

Preparation for Death

In this stage, we assessed the family's readiness to accept the imminent death. MEA also actively participated in the preparation of her own funeral, preferring to be cremated and buried near her husband's grave in Cagayan de Oro.

It was an ideal step in patient empowerment to make personal and social arrangements to get themselves ready for death. We also saw this as a significant experience for the caregivers.

Family and Social Relationships

MEA enjoyed a positive experience of receiving support from friends and the FHCP team during the dying process. Our home care visits became more frequent, at least 3x/week.

Family relationships were strengthened by re-connecting with her long lost sister from the United States. The FHCP team aided the family members how to let go and satisfy the patient's last requests to fulfill a favorable caregiving experience.

Moments At or Near Death

Patient expressed her desire for a quick death, sparing the family of witnessing the suffering.

Comfort and Physical Care

Providing physical comfort, having the caregivers at bedside and encouraging independence in daily activities were perceived important. Having no pain and no unnecessary prolongation of life were observed to be equally essential by her daughters, MAdL and AO.

Spiritual Well-being

This crucial step highlights MEA's religious needs, having lived a meaningful life. The biological, psychological,

social, and spiritual dimensions of the person should be integrated.[2]

In home visits, we facilitated the rendering of the sacraments of anointing of the sick and reconciliation, as well as regular pastoral visits. These resulted to patient's cheerful disposition. The patient and the family were not just being prepared for death but also for the life after death.

The Death Event

MEA was rushed to the emergency room because of dyspnea. That moment, the two daughters uttered, "Mama waited for you, Doc". There I realized that she was "waiting" for the FHCP team to make her "good death" come to pass. The whole waiting time was hard but I could see sadness accompanied by peace in the faces of her daughters. I felt I, their family doctor, was part of their journey to be home with our Creator.

Bereavement Care

Bereavement is defined as 'the entire experience of family members and friends in the anticipation, death, and subsequent adjustment to living following the death of a loved one'.[7] The time of death and subsequent bereavement is one which produces a wide variety of emotional reactions in the bereaved such as sadness, anger, separation distress, denial, loss of interest in self and social functioning, constant replaying of the death and events leading up to it. To elucidate, following is a typical conversation I had with her daughter MAdL, the primary caregiver. I felt her sorrow and yearning to feel her mother's presence. She preoccupied herself with arranging her mother's burial up to the extent that she could not sleep and eat on time. As primary care physicians, we must realize that this may be a part of her bereavement but still, support and an action plan must be made. Continuity of care is warranted to ensure a healthy grieving response of the family.

The range of clinical interventions available suggests that no single approach will suit and may only be required by those people who develop 'abnormal' grief or associated anxiety, depression and post-traumatic stress disorder. Identifying and targeting these individuals may be a useful strategy.[7]

Conclusion

We presented the case of MEA, with endometrial endometrioid carcinoma probably with metastasis, who chose conservative management for her illness.

The family psychodynamics, impact of illness, and their functional adaptation to unexpected changes were evaluated by applying the Family Systems Theory. The terminal phase and quality of death of the patient using the hospice care approach was also discussed. In the end, the bereavement care rendered to the family was amply discussed.

Using the biopsychosocial model, recommendations were made to promote both quality of life and quality of death. The family was the patient's and care team's greatest ally in the implementation of the exit plan.

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