"Expecting"
A Family Case Discussion*

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INTRODUCTION

The practice of family medicine extends from womb to tomb and provides opportunities to care for not just one but all members of the family. Regardless of the complaint that brings a patient to the clinic, a family physician's role is to provide comprehensive care for the patient, the family, to go beyond the biomedical approach, not just to treat the disease but also to address the impact of the illness, and to have a continuing plan for promoting the family's wellness.

Families are greatly affected by the presence of chronic illnesses in any of its members. How then does a family physician address the potential problems of a chronic disease in the family especially if the sick member is one of the parents, with an unborn child? This paper aims to discuss the circumstances and situational relationships of a family with pregnant mother with a newly diagnosed kidney disease that would require hemodialysis.

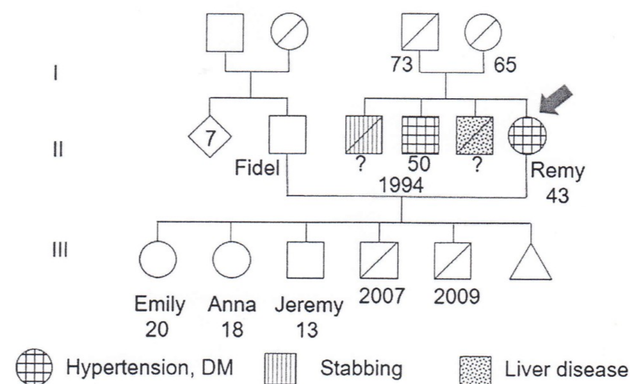
INDEX PATIENT

Remy, 43, is the mother of a family of five in Caloocan City. She is a known hypertensive and diabetic. Remy and her husband, Fidel, learned of the present pregnancy at two months age of gestation. She had four prenatal checkups since then. Despite having minimal bipedal edema, Remy had good baseline functional capacity and was independent in activities of daily living. She was admitted on August 15, 2015 at the OB Admitting Section of Philippine General Hospital for the complaint of dyspnea.

Two weeks prior to admission, the patient started to experience increasing shortness of breath related to exertion. This was associated with generalized weakness, anorexia, nausea, occasional vomiting, and orthopnea. She was also noted to be pale and had frothy urine. Progression of the symptoms prompted the patient and her husband to seek consult at a local clinic. Initial laboratory findings revealed a high serum creatinine and she was referred to a government tertiary hospital for hemodialysis.

The patient was maintained on metoprolol and metformin, both taken with poor compliance. Highest blood pressure was at 160/90 mmHg, with a usual range of 110-120/70-80 mmHg. The medications were discontinued at two months age of gestation upon knowledge of the pregnancy. The patient was hospitalized for excision of a pancreatic cyst in the past

A review of the family history reveals that hypertension and diabetes ran in Remy's family. One brother died from complications of an unspecified liver disease. There was no PTB, bronchial asthma, cardiac, renal, or thyroid disease in the family.



Remy had four pregnancies prior to the present one. She delivered her firstborn when she was 23 years old. Their fourth child died three days after birth while the fifth died in utero. No symptoms of hypertension or other similar illnesses were noted during the previous pregnancies. Remy's LMP was on March 12, 2015. The couple had been practicing withdrawal method as contraception for the past few years.

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The patient is a non-smoker but has had previous exposure of secondhand smoke from her husband. She had occasional alcohol intake but she denies any illicit drug use. There was no history of domestic abuse.

Remy was received tachypneic and with an elevated BP of 140/90 mmHg. Remy had grade II bipedal edema. The rest of the systemic physical examination was normal. Fundic height was 20 cm, with fetal weight estimated to be less than 500 g and fetal heart tones at 145 bpm. Pelvic exam revealed a closed cervix, parous vagina, no adnexal masses/ tenderness, and an enlarged uterus. The capillary blood glucose on admission was 253 mg/dL.

The admitting impression at the time was: (1) pregnancy uterine, 22 2/7 weeks AOG by LMP, G6P5 (5003), (2) pregestational diabetes mellitus, type 2, uncontrolled, (3) chronic hypertension, and (4) s/p excision of pancreatic cyst (2000, PGH).

Laboratory workup was done which revealed anemia with a hemoglobin of 60 mg/dL, elevated BUN and creatinine, with an eGFR of 3.2 mL/ min/1.73 m^2, and glucosuria (+2), albuminuria (+2) and negative ketones on urinalysis. Arterial blood gas showed metabolic acidosis. Biometry showed a single live intrauterine pregnancy with good cardiac and somatic activities, 17 2/7 weeks AOG by composite aging, with an estimated fetal weight of 179 grams.

Working impression was then revised to: (1) chronic kidney disease, stage V, in uremia, secondary to hypertensive/diabetic kidney disease, with secondary anemia, (2) pregestational diabetes mellitus, type 2, (3) chronic hypertension, stage II, (4) pregnancy uterine, 22 2/7 weeks AOG by LMP, (5) s/p excision of pancreatic cyst.

Remy's biomedical problems were identified as follows: (1) newly diagnosed deteriorating renal function from hypertension and diabetes, two chronic conditions complicating her current pregnancy: (2) pregestational diabetes and (3) chronic hypertension, and lastly, (4) her current pregnancy. Goals for Remy were (1) renal replacement therapy, (2) blood sugar control, (3) blood pressure control, (4) maintenance of the pregnancy, and lastly, (5) to manage new problems as they arise. During the course of her admission, Remy was also seen and co-managed by the following services: Renal, Endocrinology, Perinatology, Ophthalmology, Cardiology, and Dietary.

There were 12 sessions of hemodialysis during the admission, with a decreasing creatinine trend from 1,101 pmol/L on admission to 385 pmol/ L. Remy received blood transfusions with three units packed RBC and was prescribed with sodium bicarbonate, ferrous sulfate and folic acid, calcium carbonate and vitamin D, furosemide, and erythropoetin.

Insulin was started, blood sugar levels were monitoring regularly, and doses of insulin titrated. Metformin could have been continued during the pregnancy until insulin was started, as hyperglycemia is a potential teratogen. However, clinical trials are still needed before this can become a formal recommendation (Feig & Moses, 2011).

Hypertension was treated with methyldopa and nifedipine, with regular monitoring of Remy's blood pressure. Blood pressure spikes were addressed with nicardipine and titration of doses of anti-hypertensive medications. For pregnant hypertensive patients with chronic kidney disease, target BP is from 120/80 mmHg to less than 140/90 mmHg (Task Force on Hypertension in Pregnancy, 2013). The use of most beta-blockers, ACE-inhibitors, angiotensin receptor blockers and diuretics are recommended against in pregnancy (Kjeldsen et al., 2014).

Progress of the pregnancy was monitored through fetal movement and biometry. A congenital anomaly screening was planned and medications known to be safe during pregnancy were given. Remy was prescribed a diet tailored for a pregnant patient with diabetes ongoing dialysis. Intensive hemodialysis, feto-maternal monitoring, avoiding protein restriction and ensuring that the mother reaches target weight gain have been shown to improve pregnancy outcomes, (Hladunewich et al., 2014; Manisco et al., 2015).

Risks of future pregnancies were discussed with Remy and Fidel. The couple planned for Remy to undergo ligation after the current pregnancy. The option of vasectomy was also offered to Fidel.

New problems such as recurrence of dyspnea and the onset of cough and dysuria were investigated and managed. A hospital-acquired pneumonia was ruled out and Remy was started treatment for heart failure from hypertensive heart disease. Appropriate antibiotics were also started for a urinary tract infection.

Remy went home on methyldopa, nifedipine, insulin and prenatal supplements, with blood pressure and blood sugar monitoring, and with plans of continued outpatient dialysis.

After her discharge, Remy was refused dialysis by the outpatient centers they went to since the centers are ill-equipped to handle a pregnant patient. Thus, she again became weak and dyspneic.

Eventually, Remy was readmitted and was able to undergo three sessions of hemodialysis. With improving symptoms, plans were made for Remy's discharge. The plan was to continue hemodialysis in PGFI on an outpatient basis due to the special circumstances during the remaining weeks of the pregnancy.

Remy began to experience episodes of vaginal spotting and medical management for threatened abortion was started. Repeat biometry at this time showed that the baby still had not reached viable age.

Shortly prior to her planned discharge, Remy went into premature labor. She delivered a live but very small baby weighing only 360 grams. The neonate was 27 3/7 weeks AOG at this time. Remy and Felix refused aggressive neonatal resuscitation and the baby was given direct skin-to-skin contact with Remy until he died after a few hours.

Remy was discharged to continue hemodialysis with a local dialysis center. Medications were shifted to losartan, carvedilol, amlodipine, and aspirin and simvastatin were started. Follow-ups with the different services were scheduled.

On OPD follow up, Remy had decreased orthopnea, weakness, edema, improved sleep and increased urine output. She was compliant with medications, blood pressure and blood sugar monitoring, and was able to undergo outpatient hemodialysis. Remy was now independent in activities of daily living from previously needing assistance.

DESCRIPTION OF THE FAMILY

The Perez family is a family of five based in Caloocan City. Remy, the index patient, is the mother. The household is composed of the immediate family except for the middle child who already lived with her own family. The family lived in an owned house in a compound with the father's family of origin.

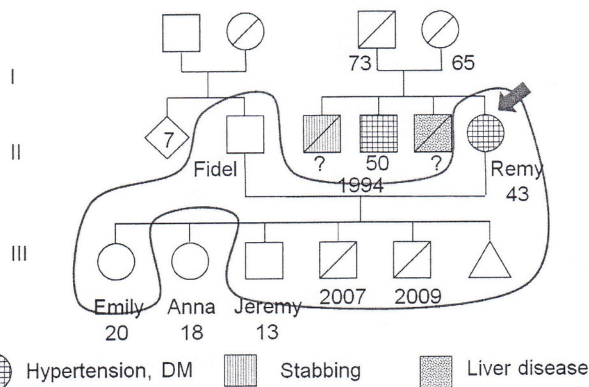

FIGURE 1. Perez Family Genogram (September 2015, Philippine General Hospital)

The family is in launching stage in the life cycle and is nuclear in structure with three children 13, 17 and 20 years of age. The key principle of this stage is accepting entries and exits into the family system (Alip, Jr., 2014). Family life cycle stages that are supposed to launch members outside the system can be a difficult time for a family to cope with, especially if there's a severe illness in the family.

Remy was a housewife while Fidel was a fisherman. Prior to the onset of symptoms, the index patient took care of most of the household tasks while the father, Fidel, and the eldest child, Emily, both worked to finance the needs of the family. Emily has been working for three years, most recently as a saleslady at a mall in Divisoria. The middle child, Anna, already lived separately with her own family. Jeremy, the youngest child, was still attending school.

CASE ANALYSIS

Having a member with chronic kidney disease has consequences on the family. Issues that arise include the inability of the sick parent to fulfill gender-specific parental roles (Smith, & Soliday, 2001). Mothers such as Remy become less able to do housework and take care of children. For parents with chronic kidney disease, the time spent together by the family becomes less because of the illness. While dialysis and hospitalization take the patient away from the family, the fatigue that is a common symptom in chronic kidney disease also prevent patients from spending as much time with the family as before (Smith, & Soliday, 2001).

Another concern of renal patients who are parents is how it causes the children to worry (Smith, & Soliday, 2001). Aside from missing having their mother at home, Remy's three children were scared by their mother's illness and worried about their future sibling's condition.

The patient's prolonged admission and subsequent readmission allow a family physician to observe and assist the Perez family in going from one stage of the illness trajectory to another. The disclosure of the diagnosis of chronic kidney disease and the knowledge of the possible consequences comprise the impact phase. It is understandable that the family's initial reaction was that of anxiety and being overwhelmed.

After all family members understood Remy's condition and the treatment plan, the next step was to guide them through major therapeutic efforts. An important part in the management of Remy's illness was the assurance that regular hemodialysis would be done. Financial difficulties is another problem identified by parents with chronic kidney disease, due to the cost of treatment (Smith, & Soliday, 2001). Early into the admission, it was evident that the financial resources of the family was limited and would not be able to sustain the cost of her treatment. The present income of the family was substantially less than what Fidel had earned before.

Three things were salient from reviewing the family lifeline: that previously, the family's income was sufficient to cover previous medical expenses; that the family had coped well with two previous negative pregnancy outcomes; and that this was the first pregnancy they would experience that would be complicated by diabetes, hypertension, and now, chronic kidney disease that required hemodialysis. Remy found it hard especially since she could compare this pregnancy to the relatively uneventful course of the previous ones. Like all expecting parents, the couple wanted to deliver a healthy baby once term. Flowever, the couple have been advised of the uncertainty of the outcome of the pregnancy given Remy's comorbid illnesses. Thus, the couple's anticipation has been overshadowed by other concerns--the need to control Remy's blood sugar and blood pressure, and the need to find funds so that Remy gets regular hemodialysis.

A shift in family roles is expected as a response of the family to the illness (Smith, & Soliday, 2001). With Remy in the hospital and unable to fulfill her role in taking care of the household, readjustment in roles in the family took place. Fidel and Emily needed to leave work to assume the role of watchers. Anna, although already with her own family, came home often to take care of the household while their mother was in the hospital.

When Remy began to show signs of improvement, the family began to enter the phase of early adjustments to outcomes. Continuation of the treatment plan once at home was ensured. Readjustment in roles at home continued, with all three children and Fidel pitching in with housework that Remy used to do.

Family function was assessed using APGAR which yielded a score of 10 from Remy and a score of 8 from Emily. The score may be indicative of a highly functional family, the characteristics of which enable families to cope well with illness in a family member.

The resources of the family were assessed using the SCREEM tool. Aside from showing the problem of meeting the financial demands of the current illness, it reflected the family's difficulty in accessing medical care in their community. The family was unaware of the medical resources available nearby, aside from not being able to easily afford these medical services. Although they had a relative who initially helped out with medical expenses, the family would be unable to sustain dialysis out of pocket with the family's income and lack of savings. Philhealth coverage could not be utilized during the admission due to incomplete contributions. It would have allowed Remy with 45 sessions of dialysis as an inpatient and another 45 sessions on an outpatient basis in one year.

At P4,500 per session, the family would spend P13,500 per week at the recommended frequency of dialysis while still getting their Philhealth coverage in order. The couple was promised financial assistance from the local church but also knew not to rely solely on that. They were yet to approach PCSO for assistance. The family found out that a dialysis center was planned to be built in the local area that would be able provide dialysis services at a lower cost.

When Remy's continued dialysis and improvement were unexpectedly sidetracked, it was understandable that the family, especially Emily, felt frustration and helplessness.

Pregnancy loss entails the loss of the future of the child, and may result in a loss of sense of self and a sense of inadequacy in fulfilling the role of procreation. It is considered a form of disenfranchised grief or mourning that is complicated by the lack of societal norms (Van Dinter M., & Graves L., 2012).

Guilt may be felt over what may have been done to cause or to prevent it, and symptoms of anxiety and depression may appear. Other family members may have their own reactions to the pregnancy loss. Fathers may feel self-blame, a sense loss of identity as a father, and a need to hide feelings. The children may make conclusions about the cause of the pregnancy loss, at times blaming themselves or the parents (Van Dinter M., & Graves L., 2012).

Physicians may also grieve for a patient's pregnancy loss, may question own actions or feel some responsibility for the outcome. Difficulty in providing support to the family may result (Van Dinter M., & Graves L., 2012).

The couple felt prepared for the turn of events since the prognosis of the pregnancy was already known to them. Remy and Fidel were against aggressive neonatal resuscitation to spare the baby from further suffering, knowing the small odds he had of survival. While Remy could talk about her feelings, Fidel was not ready to talk about how he felt after losing the baby.

The couple reported that faith has helped them during this difficult time. The major difficulty the family had was still in finding funds to sustain regular hemodialysis.

The changes in the family can also be viewed in a positive light since the index patient found her husband and children as a source of strength, owing to the open communication among the family members during this time and their sharing responsibility with the housework. While Emily was scared for her mother and the baby, she also became afraid for her own health, which resulted in a decision to take better care of herself.

INTERVENTIONS

The family was assisted as they went through the phases from the impact phase up to early adjustment to outcome. The disease and treatment plan were explained in simple terms in an effort to dispel the anxiety that the patient and the family members felt and to avoid creating confusion. This would ensure that the family can absorb essential medical information and to establish open lines of communication between the doctors and the patient and the family. Coordination of the treatment plan with the other doctors on board was also done.

Assistance in mobilizing economic resources was done by referring the family to the Medical Social Service for access to the DOH-Medical Assistance Fund. The family was encouraged to apply for assistance from PCSO for Remy's hemodialysis. The couple was also advised by the service to complete their Philhealth contributions to be able to use the coverage during succeeding hospitalizations and/or during the birth. To help the family access medical services in the community, a list of outpatient hemodialysis centers close to their home was provided by the Renal service, to continue dialysis sessions.

Remy's status after the first hospital discharge was followed through SMS, with updates being received from the eldest daughter which revealed the problem encountered in undergoing outpatient hemodialysis. Communication with the eldest daughter and coordination with the other services resulted in eventual readmission for the hemodialysis that Remy needed.

Psychosocial support was provided to the index patient and the other family members with her in the hospital by allowing them to ventilate emotions.

A brief bereavement interview was conducted and the couple both reported feelings of hurting and sadness after losing the baby. However, the couple said they had already accepted the prognosis of the pregnancy as it was explained to them early on. There were no symptoms present that could be problematic manifestations of grief for either one of them at that time.

The following measures have been recommended when confronted with a patient dealing with pregnancy loss and applied: (1) assess the level of grief and individualize counseling accordingly, (2) acknowledge and try to dispel guilt if present, (3) acknowledge the grief, (4) include the father in the counseling, (5) provide comfort, empathy and

and support. Other measures include (6) guiding on how to share the news, (7) reassuring them about the future, and lastly, (8) anticipating grief on its anniversary (Griebel, Halvorsen, Golemon, & Day, 2005; Van Dinter M., & Graves L., 2012).

In general, while the couple was experien-cing grief in response to pregnancy loss, at this time, they were more preoccupied with Remy's illness and treatment.

Plans for Remy's case was as follow: (1) to follow up the family's Philhealth coverage, (2) to apply for assistance from PCSO, (3) to be able to have the requested labs done for follow-up check-ups, (4) to ensure continued intake of prescribed medications, (5) to continue following the prescribed diet for her conditions, (6) to follow-up as scheduled with the other clinics, (6) to follow up for AV fistula creation and tubal ligation.

Long-term plans for the family's wellness include ensuring continued open communication among family members. Second, the family needs to be ensured that the family transitions through the family life cycle changes expected during the launching family stage. Third, adjustment of the whole family to the "new normal'' needs to be ensured as Remy gets better and becomes able to assume her previous role in the household. Another goal was to make sure that Fidel would be able to return to work in the near future.

The individual wellness plans for the members of the family include exercise, dietary prescription, dental exam and annual chest x-rays, vaccinations for all members, and breast exams for Remy, Emily and Anna. Individual wellness plans specific for each family member are as follows: for Felix, maintenance of smoking cessation and abstinence from alcohol; for Jeremy, anticipatory advice on the avoidance of vices; for Anna, birth spacing.

PERSONAL INSIGHTS

The family physician has an under-appreciated role in the coordination of care of patients requiring multidisciplinary care. Knowledge in the care of a pregnant patient, beyond providing prenatal care, should also be part of the experience of a family medicine trainee.

Assessing the impact of illness and the factors that affect the ability of families to cope with illness in a family member is a skill that should be applied to patients with potentially serious or chronic conditions. Prognosticating patients to prepare families for possible bad outcomes is a skill that is necessary in family medicine

Lastly, patient care does not end upon patient's discharge or at the end of their outpatient consults until we see them again for follow-up. Certain situations call for a doctor to follow up patients through other means such SMS and phone calls, and to make arrangements for their behalf.

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