Family Assessment - Lorenzo's Oil

CPT Jeffry Thomas Negard

Uniformed Services University of the Health Sciences

#### Family Assessment - Lorenzo's Oil

The definition of family has come under an increasing amount of attack over the past few years as people around the world seek to redefine it. With the ever changing dynamics of relationships and the changing of the definition of marriage allowing unions between people of the same sex, the definition of family according to Bomar (2009) is two or more person who are linked together by intimate association, resources, and values and consider themselves to be a family. In short, the family should be defined as whoever they say they are (Bomar, 2009).

No matter what the world determines the final definition of family to be to be, it is the job of the Family Nurse Practitioner (FNP) to take care of individuals and families throughout the lifespan. This paper is a presentation of a family assessment applied to a family in crisis and offers insight of how an FNP might go about resolving the issues that are faced, using the characters of the movie *Lorenzo's Oil* as the subjects.

#### **Family Structure**

### **Roles and Composition**

The main members of the Odone family are the father, the mother, and their small son, and they live in Washington D.C. The father, Augusto, works for the World Bank and his job moves him and his family around the world. He is the sole-provider. His wife, Michaela, is the primary caretaker and stay-at-home mom. Finally, their six-year-old son Lorenzo is the only child they have together and he eventually takes on the sick role (refer to the Appendix for the family genogram).

#### Values

The family is the primary value for the Odones as they are a tight-knit nuclear family.

Family gatherings are large and include extended members such as cousins and grandparents, as

seen at Lorenzo's birthday parties and at Christmas. When Lorenzo falls ill, everyone expresses intense concern and even Michaela's sister comes to stay for many months to assist in caring for Lorenzo.

Religion apparently played a large role in the family's life at one point and the family is Roman Catholic. But, once Lorenzo becomes ill, the mother completely gives-up her outside life to dedicate herself to caring for Lorenzo, and church no longer becomes a priority for her. Selflessness is also evident in the lives of both Augusto and Michaela as they give-up every part of themselves, including time, sleep, intimacy, and money, to dedicate themselves to researching Lorenzo's illness and finding a cure.

#### **Communication and Power**

Communication is extremely important to the Odones. Augusto buries himself in research every free hour of his day and each evening relays to Michaela what he has learned. Their living room becomes a library and classroom where they take turns educating each other on their new found knowledge and they go to great lengths to speak to other families and doctors across the Eastern Seaboard in the hopes of finding the answers they are looking for. The ability the Odones have to effectively communicate with each other is one of the many aspects that strengthen the family.

Shared power is evident in the marriage as they discuss everything, and all decisions are jointly made. They both are intelligent and strong-willed, but they have mutual respect for each other. They interact with Lorenzo's doctors together and share knowledge openly, never using it as a bargaining piece against each other or taking a superior stance.

### **Family Function**

#### Affective and Socialization

Augusto's career with the World Bank provides a unique opportunity for the family for both socialization and affective functioning. The film begins with the family living in the Comoros Islands and Lorenzo is integrated into the school system there. He is fluent in English and Italian and is learning the native language alongside the other children. The entire family is accepted as members of that society and Lorenzo find a unique friendship in an older local boy named Omouri. Lorenzo's interaction with his parents and with the native children lends evidence that he was taught honor, respect, and manners, as he is polite and caring.

All members of the Odone family are confident and independent in their own ways, but they share those gifts with each other to continually build and strengthen their relationships and resiliency. They are resourceful and rebound quickly from a crisis. In fact, a crisis or a major stressor is seen more as a challenge rather than a barrier.

## **Analysis of the Odone Family**

#### Theme of the Movie

The primary theme of *Lorenzo's Oil* is the family's fight against the medical/scientific communities' slow pace in finding a cure for Lorenzo's orphan disease, adrenoleukodystrophy (ALD), and the pushback they receive when they begin to do their own research. Because their entire world revolves around Lorenzo, Augusto and Michaela are willing to go to great lengths to find a cure. They sacrifice every part of themselves in doing so and create significant strains on their finances, intimate relationship, and family ties. But, it is their love of family and the desire to never give up, no matter what happens, that keeps them together and driving forward for many years.

The Odone family is best analyzed using the Family Systems Theory. Kaakinen, Gedaly-Duff, Coehlo and Hanson (2010) describe it as an approach that allows nurses to understand and assess families as an organized whole and/or as individuals within family units who form an interactive and interdependent system. As stressors are introduced or increase, the family increases their ability to adapt and to change (Kaakinen et al., 2010). However, with time, the stressors may become too great and ineffective coping takes place.

## **Stressors and Coping**

Stressors are introduced into the Odone's life slowly, but over time, they have a cumulative and sometimes detrimental effect. As Lorenzo's disability progressed the family had to make small changes to accommodate his needs. However, once he became incapacitated, both Michaela and Augusto had to make great sacrifices in order to care for him. A hospital bed was set-up in the living room and Michaela spent all day by Lorenzo's bedside, tending to his every need, as they are unwilling to have him permanently hospitalized. It is Michaela's belief that no one can take better care of Lorenzo than she can. Once the strain became too great, Michael's sister came to live with them, and they also hired (and fired) many nurses to assist with Lorenzo's care during the course of his disease.

Lorenzo's illness puts strain on family finances as Augusto begins taking more and more time off from work to research ALD. There is never any mention if his career is in jeopardy, but there is evidence his colleagues support him as they take up a collection at one point to help him with finances. He eventually takes a second mortgage on the home and the home begins to show neglect and disrepair as time progresses, but none of this affects his search for a cure.

The limited knowledge of Lorenzo's disease by the medical community is another significant stressor for the Odone's. Enraged by worldwide disinterest in finding a cure, they delve into research themselves. Augusto educates himself about the disease process and subjects such as biochemistry and neuroscience in the hopes that he can discover a cure on his own. The

family reaches out to support groups and biomedical research laboratories across the U.S. and Europe hoping someone will hear their plea and assist them in finding a cure. Quitting and accepting fate are not a part of the Odone's belief system.

Evidence of ineffective coping is seen in Augusto's chain-smoking and Michaela's withdrawal from church, eating, and her siblings and parents. Augusto and Michaela become so hyper-focused on caring for Lorenzo that they neglect themselves. Michaela is in such deep denial regarding Lorenzo's disease that it is many years before she finally breaks down and admits that he may never get better. It was at this point that she began to allow outsiders assist her in Lorenzo's care and even invites his old friend Omouri to come from Comoros and stay with them in the hopes that his mere presence may have a positive effect on his health.

## The Family Nurse Practitioner Approach

The primary goal of the Family Nurse Practitioner for the Odone family is to assist in intervening and relieving them of their major stressors. There are numerous individual and family assessment instruments to aid in helping identify stressors, and once those are identified, the FNP can create an action plan. Because a pediatrician provides Lorenzo's care, the FNP's role would be to care for the physical and mental health of Augusto and Michaela while acting as a family advocate, counselor, and case manager to help them locate the resources they need.

For Michaela, although she was able to provide excellent care for Lorenzo, she had cut herself off from her friends, church, and eventually her family to do so. The FNP can assist by helping to locate part-time or even full-time home-health professionals so Michaela could reenter the society she left behind. By supporting her ability to take breaks from the home environment, the FNP is helping Michaela's mental and physical health and therefore reducing her role strain. A mental health referral would be beneficial for both Augusto and Michaela.

7

Late in the film, it is evident there had not been any form of intimacy between Augusto and Michaela in years, and so a home health-nurse might also be able to provide them with the ability to leave the house together on date nights or short vacations to help them rekindle their marriage. Marriage counseling is another service they would benefit from as their stress is causing resentment, anger, and arguing between them due to their ineffective coping mechanisms. At the present time, the only times they leave the house together are to attend support groups or visit with medical professionals.

To assist the family in seeking meaningful solutions to their healthcare needs, the FNP can also intervene in Augusto and Michaela's personal health. Augusto is in need of smoking cessation classes and medications, and Michaela needs nutritional counseling as she has neglected her diet to spend as much time with Lorenzo as possible. Michaela may also benefit from a weekly exercise class to help with her overall mental and physical well being as this will allow her time away from the house. By setting realistic expectations regarding Lorenzo's outcome, and addressing one issue at a time instead of attempting to make major changes, the FNP can assist the Odone's in restoring normalcy to their lives over time.

## References

- Bomar, P.J. (2009). Promoting health in families (3rd edition). Philadelphia, PA: Saunders.
- Kaakinen, J. R., Gedaly-Duff, V., Coehlo, D. P., & Hanson, S. H. (2010). Family health care nursing (4th ed.). Philadelphia, PA: F. A. Davis Company.
- Mitchell, D., & Miller, G. (Producers), & Miller, G. (Director). (1992). *Lorenzo's Oil* [Motion Picture]. USA: Universal Pictures.

# Appendix

## Genogram of the Odone Family



