

## Zabbaleen Women's Perspectives on Suffering

Andrea Knopp, PhD, MSN, MPH, FNP-BC

Nurse Practitioner Program Coordinator, Associate Professor  
School of Nursing, James Madison University, Harrisonburg, VA  
*knoppaf@jmu.edu*

### Abstract

**Aims and Objectives:** To identify the cultural understanding of suffering and the effects on the healthcare of Coptic Zabbaleen women in Cairo, Egypt.

**Background:** Gender roles, cultural norms and beliefs of the Middle East place women in a vulnerable position resulting in isolation or disconnection from society and resources within the society resulting in inequality and disadvantages in healthcare. The women of the Zabbaleen community are a unique population of women in Cairo, Egypt who have multiple factors known to contribute to inequities in healthcare.

**Design:** Qualitative inquiry using constructivist methodology with semi-structured interviews were conducted in the area of Mokattem in Cairo, Egypt with women of the Zabbaleen community.

**Methods:** A convenience sample of women who were Copts from the Zabbaleen community between the ages of 19 and 45, married or unmarried participated in interviews at home and in the community.

**Results:** Three aspects of suffering that characterize this population are: suffering is an expected part of life, suffering is a spiritual experience and this spiritual experience identifies them with God.

**Conclusions:** These findings provide insight into cultural perspectives on suffering from a subpopulation in the Middle East/North Africa region. Zabbaleen women offer a truly distinctive perspective on health through their experiences as a disadvantaged population of a Middle Eastern country. Understanding their experiences increases knowledge of women in vulnerable populations and provides insight into issues related to health and illness in another culture.

**Relevance to clinical practice:** Nursing practice continues to provide care to diverse populations domestically and abroad: therefore, awareness of cultural themes such as suffering that impact healthcare need to be explored. Caring for a patient from a Middle Eastern community requires sensitivity and understanding of how their beliefs and backgrounds impact their ability to receive care.

**Keywords:** suffering, women's health, Middle East, vulnerable population, Coptic

### INTRODUCTION

Everyone suffers. However, the interpretation and expectation of suffering is shaped by many factors. In the last decade, social scientists have focused on social-cultural aspects of suffering and have found that religious and personal beliefs change the perception of suffering and therefore the interpretation of suffering (Fulford, 2017; Tzounis, Kerenidi, Daniil, Hatzoglou, Kotrotsiou & Gourgoulanis, 2016; Kéri, 2015; Koenig, 2012; Balboni, Vanderwerker, Block, Paulk, Lathan, Peteet & Prigerson, 2007; Tarakeshwar, Vanderwerker, Paulk, Pearce, Kasl & Prigerson, 2006; Wilkinson, 2001; Williams, Jerome, White & Fisher, 2006; Gordon, Feldman, Crose, Schoen, Griffing & Shankar, 2002). The purpose of this paper is to examine the influence of religion and culture on the meaning of suffering in Zabbaleen women of Cairo, Egypt from a healthcare perspective in the context of having Hepatitis C. This community lives in a society that incorporates traditional Egyptian beliefs and strong Christian religion in a larger society of Islam.

## Zabbaleen Women's Perspectives on Suffering

---

High rates of Hepatitis C are found in many low to middle-income countries such as Egypt, which has the highest prevalence of Hepatitis C at approximately 4.4%, with a single dominant genotype (WHO Egypt Hepatitis, 2017). The annual infection rate in Egypt is approximately 70,000 new cases, half of which will result in chronic HCV and liver cancer. Additionally, HCV mortality in Egypt is expected to double in the next 20 years (Elgharably, Gomaa, Crossey, Norsworthy, Waked & Taylor-Robinson, 2017). These elevated rates of HCV are attributed in part to a national campaign to treat schistosomiasis, or bilharzia, a helminthic infection transmitted from snails that flourish in the canals and tributaries of the Nile in the Delta regions (Rao et al., 2002). The campaign, called Parenteral Antischistosomal Therapy (PAT), lasted 15 years, from 1965 to 1980, and focused on the rural Delta regions and southern regions in Egypt where bilharzia was most prevalent and where a large portion of Copts lived (Roberts & Levitt, 2000; Hymas, Mansour, Maasoud & Dunn, 1987). Studies indicate that contaminated reusable needles and syringes used in this government campaign resulted in transmission of both Hepatitis B and C (MacKeen, 2003; Rao et al., 2002; Knopp, 2015). Sixty-eight percent of patients with Hepatitis C received schistosomiasis treatment during the PAT campaign (Rao et al., 2002). Women were not given the treatment as often as men in this program, thus the prevalence of HCV among Egyptian women is estimated between 7 to 25.3% (Mohlman et al., 2015).

The blending of the Egyptian and Christian socio-cultural traditions of the Zabbaleen women provide perspectives on suffering which differ from Western understanding of suffering. With the limited amount of literature and exposure to this population, the research increases knowledge of women who have not been explored previously. The author addresses the question: What are the healthcare experiences of the Zabbaleen Women in Cairo, Egypt? This qualitative study offers insight into how this Egyptian subculture manages health in a Middle Eastern country.

## LITERATURE REVIEW

Victor Frankl, along with C. S. Lewis, brought suffering to the forefront of psychology and religion with their respective books *Man's Search for Meaning* (2006) and *The Problem with Pain* (2009). Both work on the premise that suffering is evitable in the human existence but can be tempered with meaning found in the suffering. Though they faced radically different life experiences, Frankl as a Nazi prisoner and Lewis who became a mourning widow, the two converged on the idea that suffering understood results in a connection with self, others and possibly an existential being, which Lewis identified as his God. These views on suffering are often caged within the Western philosophy of life, death and a greater being, with an emphasis placed on maintaining composure rather than grieving our losses and therefore accepting realities of life (Fulford, 2017). Researchers in the healthcare and social sciences join psychologists in positing that suffering is lessened depending on the understanding or meaning one attaches to their agony (Fulford, 2017; Tzounis, Kerenidi, Daniil, Hatzoglou, Kotrotsiou & Gourgoulialis, 2016; Kéri, 2015; Koenig, 2012; Balboni, Vanderwerker, Block, Paulk, Lathan, Peteet & Prigerson, 2007; Tarakeshwar, Vanderwerker, Paulk, Pearce, Kasl & Prigerson, 2006; Copp 1974; Kahn and Steeves, 1995; Cassell, 1982; Parameshwar, 2006; Råholm, 2008). A review of literature focused on healthcare based research of meaning in suffering will be discussed followed by a review of Coptic history and the Coptic view of suffering.

## SUFFERING IN HEALTHCARE

The importance of meaning in suffering is not necessarily a new theory for nursing. In the mid-seventies when nurse researcher Copp (1974) found two factors which influenced the experience of suffering: belief systems and coping mechanisms. Fear of the unknown and imaginings of what could happen increased the sense of suffering, while positive effects of beliefs and coping on suffering mitigated fear and provided a foundation for establishing meaning.

Over the following decades, researchers argued that meaning in suffering reduced the perceived threat to self or the future, or the fear factor (Cassell, 1982; Steeves and Kahn, 1987; Steeves, Kahn and Benoliel, 1990). Later

## **Zabbaleen Women's Perspectives on Suffering**

---

research by Kahn and Steeves (1995) with oncology patients' narratives of suffering led to the development of principles of suffering. First, suffering is uniquely experienced by the individual and involves threats to self, similar to the aforementioned ideas of Copp(1974). Secondly, suffering "is a fundamental experience involved with a person's sense of body, social world and time" (pg. 13). Lastly, implied suffering was changeable for the individual based on social-cultural aspects as well as the element of time, including the social context of time and perception of time in suffering.

Janet Younger (1995) also explored the experience of suffering, focusing on community and connectedness of the individual who is in anguish. She describes the ongoing development of isolation that begins with separation and moves through shame and stigma to alienation (pg 59-50). This experience of alienation becomes "otherness" when significant others pull away in fear that the suffering could occur to them, leaving pain unrelieved and the sufferer to self-identify as a reluctant stranger. The sufferer seeks a voice to express the misery, mute or expressive, in order to process and begin to find meaning in the painful experience. She then brings into the discussion the role of caring in sharing the shadow side of suffering through which the patient feels validated and eventually liberated, allowing them to continue toward wholeness and able to restore connectedness.

Råholm (2008) explored the transformation of suffering by the value placed on the telling of suffering by the sufferer. She describes meaning in terms of processing and adaption through narrative. A critical part of understanding meaning in suffering is in the story told by the sufferer; the patient can label and massage the experience to place the suffering in a context that is more acceptable based on historical, emotional, religious and cultural lens. Råholm (2008) concluded that when suffering is processed in this manner, more meaning is attached to the experience, along with greater understanding.

Not only is it critical for those suffering to tell their story, Ferrell, like Younger, highlighted the importance of being present with individuals who suffer (Ferrell, 1995; Ferrell, 2008; Younger, 1995). Caregivers who attempt to alleviate suffering can give the sufferer some control that reduces the threat to self while providing succor by aiding the individuals as they place suffering in context (Ferrell, 2008). Examples are seen in cancer survivors who tell their narratives in social media providing a means to understanding their suffering on a larger scale (Keim-Malpass, Adelstein & Kavalieratos, 2015). Fulford describes this role of the health care professional as an "enlightened witness," providing a safe place for the patient to share, grieve, and be vulnerable (2017). Ferrell and other researchers (Ferrell, 2008; Fulford, 2017; Musa & Hamid, 2008; Selby et al., 2009; Hearn & Deeny, 2007) also noted that for those who work in situations that involve anguish, the distress of others could be taken on and become personalized, as it becomes personalized for the witness, creating both a conflict in understanding and a conflict to self by not being able to alleviate the angst of the sufferer. Thus, it is necessary to find meaning in suffering whether experienced by self or by others and to practice self-care and reflection to prevent compassion fatigue and burnout (Fulford, 2017).

## **RELIGIOUS/SPIRITUAL COPING**

Just as mental perceptions of one's tribulations play important roles in the patient's overall health, religiosity and spirituality have been investigated to determine whether this influences healing. A recent study of 75 COPD patients in Greece of various religious and non-religious views discovered that only one participant reported religiosity and spirituality were not an important factor in life (Tzounis, Kerenidi, Daniil, Hatzoglou, Kotrotsiou & Gourgoulis, 2016). There were no indications from participants that their illness was seen as a punishment from a higher power.

Research has demonstrated an association between religiosity and spirituality, improved coping, and an increased quality of life (QOL) with positive religiosity and spirituality emotions, including wellbeing, happiness, hope, optimism, purpose and meaning, increased self-esteem, feelings of communion with a higher power, and a sense of control over one's life, while negative religious coping such as perceiving one's illness as a divine punishment, is associated with distress and decrements of QOL (Koenig, 2012; Balboni, Vanderwerker, Block, Paulk, Lathan,

## Zabbaleen Women's Perspectives on Suffering

---

Peteet&Prigerson, 2007; Tarakeshwar, Vanderwerker, Paulk, Pearce, Kasl&Prigerson, 2006). A review of 444 studies conducted since the 1960's examining the correlation between religiosity/spirituality and depression found that 61% of participants reported a significant inverse relationship with religiosity and spirituality and depression and 7% positively related with depression (Koenig, 2012). Moreover, those who are more religious/spiritual were found to have better health and adapt more quickly to health challenges compared to those who are less spiritual/religious, showing a link between physiological consequences to mental health and well being (Koenig, 2012). Additionally, Balboni et al. discovered an association between religiousness/spirituality and desires to undergo aggressive, possible life-extending treatment (Balboni, Vanderwerker, Block, Paulk, Lathan, Peteet&Prigerson, 2007). This may be in part due to the belief of a partnership with a higher power, allowing the patient some control over the disease (Tzounis, Kerenidi, Daniil, Hatzoglou, Kotrotsiou & Gourgoulisanis, 2016).

In both religiosity/spirituality and non-religious/spiritual patients, (positive) spirituality is seen as an important dimension of one's life where in the patient seeks control of his disease through partnership with a higher power, perhaps through seeking support from the healing power of icons, and finding the place of worship to be a place in which to escape their problems and ultimately find deeper meaning and connection (Fulford, 2017; Tzounis, Kerenidi, Daniil, Hatzoglou, Kotrotsiou & Gourgoulisanis, 2016; Balboni, Vanderwerker, Block, Paulk, Lathan, Peteet&Prigerson, 2007; Tarakeshwar, Vanderwerker, Paulk, Pearce, Kasl&Prigerson, 2006).

Accordingly, much of the research and theory points to the critical aspect of meaning in suffering. Even though many of these authors are based in Western culture, recurrent themes may be seen across cultural lines uniting the human spirit. In summation, suffering is personal, threatening to self and influenced by multiple factors; however, travail is changed by assigning meaning to it through the process of telling about the torment (Fulford, 2017). Suffering and its meaning are complex and oriented on the individual's life experiences. Unfortunately, research on this topic has been biased toward the Western beliefs with little information on understanding of suffering from a non-western perspective. Exploring suffering in other cultures allows a greater overall understanding from a global perspective, providing insight into approaches to relieve suffering that could be more sensitive. One such example of a culture vastly different from popular Western culture is the Coptic culture of the Zabbaleen in Cairo, Egypt and thus there is value in its investigation.

## COPTS

Coptic Zabbaleen in Egypt are a population that blends several socio-economic systems, religions and cultural histories. Copts are Egyptians who believe they descended from the Egyptian Pharaohs prior to the Arabic influx in the 6<sup>th</sup> century, converted to Christianity by the Apostle Mark (Cannuyer, 2001; Kamil, 1987; Shenouda, 1995). The Council of Nicaea recognized the Coptic Church in 325 AD as a religion separate and distinct from other Christian denominations of the time, based primarily on differing views of Christ and the powers of the pope.

To understand the influence the Coptic Church has on the community of the Zabbaleen, it is critical to note the strong sense of history found in the teachings of the church. The incredible beauty of the church structure and art at the Mokattam Mountain in southeastern Cairo stands as a testimony to the faith of the Copts, dating back to the conversion of the people of Egypt to Christianity by the Apostle Mark in the first century (Samaan & Sukkary, 1978; Meinardus, 1970; Kamil, 1987). The Copts claim to be direct descendants of the Pharaohs prior to the Arab invasion in the 6<sup>th</sup> century when Arabs brought the teachings of Mohammed to the area along with other societal changes. By the 12<sup>th</sup> century Egypt was a prominently Muslim country while Copts, a once proud and dominant population, found themselves a tolerated minority.

Modern Copts continue to practice their faith in ways very similar to the early traditions of the church. For instance, a tattoo of a cross on the left hand between the thumb and forefinger or on the underside of the wrist

## **Zabbaleen Women's Perspectives on Suffering**

---

identifies them as Copts, with the remembrance of what Christ suffered for them on the cross, begun early in the 5<sup>th</sup> century (Meinardus, 1970). Remaining close to their original practices, the orthodox Coptic faith has survived for many centuries in an Islamic country.

### **ZABBALEEN COPTS**

The Zabbaleen are a subset of the population of Copts who live in an area of southeast Cairo known as Mokattem or Nashir Minyet. The Copts who live in Mokattem and collect garbage for their source of income are known as the Zabbaleen or the “garbage people” of Cairo. Garbage kept in their homes is sorted to supply income in recyclables and fodder for farm animals housed on the roofs of their multiple family buildings. Poor economic conditions, prejudice, and social restrictions for this population have resulted in crowded living conditions and limited sanitation (Knopp, 2015). There are also high rates of Hepatitis C in this population and across Egypt due to a government program that used unclean needles in a program to prevent schistosomiasis from 1965 to 1980 (WHO Egypt Hepatitis, 2017; Deuffic-Burban, Mohamed, Larouze, Carrat & Valleron, 2006). The community is isolated within walls surrounding an old part of Cairo. The Zabbaleen mingle within their own community, dreading religious and cultural persecution, with marriages usually confined to friends and extended families. A recent example of their fears realized occurred during a religious holiday celebration when two attacks focused on Copts resulted in multiple deaths (Samaan & Walsh, 2017). For the Copts, this is a regular occurrence.

### **COPTS AND SUFFERING**

The history of the Coptic Church is filled with references to persecution and the “suffering church” (Cannuyer, 2001; Assad, 1987). Coptic writings as early as the second and third centuries focused on believers suffering as Christ suffered bodily and spiritually (Davis, 2008). Coptic teachings continue to reinforce this idea in sermons and written commentaries, spurring believers to remember “He (Christ) was not relieved of his suffering in this life and his followers are encouraged to persevere in their suffering” (Shenouda, 1999).

The church teachings clearly state the expectation of suffering, whether it is emotional, spiritual or physical. Suffering is often mentioned in the Liturgy of the Coptic Church, performed on a regular basis to educate and inform parishioners on the stance of the church on suffering (Shenouda, 1999). However, much of the local church work focuses on alleviation of suffering in the physical sense through donations of food, clothing and reduced fee medical care. The writings of the church urge believers to care for the sick and help the poor as their founder the Apostle Mark did so by assisting others in their suffering; focus is taken away from one's own suffering resulting in a modeling of Christ's behavior of service and humility (Shenouda, 1999; Williams, Jerome, White & Fisher, 2006).

For the Zabbaleen women in Cairo, socio-cultural, political, religious, and health factors form meaning of woe. Beliefs about suffering shaped by teachings from the church have affected the women's views of these phenomena while other parts of the society have influenced methods of coping. Copts interpret suffering based on a history filled with the suffering of martyrs and the church; past and current events have also shaped their understanding on individual and community levels.

### **METHODS**

A qualitative design was used for this study, as there is limited information about the Zabbaleen sub-culture in Egypt. Constructivism methodology uses hermeneutical and dialectical processes to uncover meanings, or the essence, to reach an interpretation of an experience (Lincoln & Guba, 2005; Cohen, Kahn & Steeves, 2000). This type of ethnography focuses on the voice of the participants and shares control of the research process between the researcher and the participants (Denzin & Lincoln, 2017; Al-Saggaf & Williamson, 2006; Williamson, 2006). With that in mind, an ethnographic approach with constructivist methodology was the most appropriate design to describe and interpret the healthcare experiences of the Zabbaleen women from the context of their culture.

## **Zabbaleen Women's Perspectives on Suffering**

---

Ethical review and approval was obtained prior to initiation of the study from the University of Virginia IRB. Informed consent was obtained prior to each interview by written or verbal consent depending on the participants' literacy level.

### **SAMPLE**

A convenience sample of Coptic women, between the ages of 19 and 45+, married or unmarried, living in either of the Zabbaleen communities of Cairo were participants for this ethnography. Some of the older women were unsure of their birthday since they were born in rural areas by birth attendants, and based their age on their Egyptian ID card. Twelve women were interviewed individually and in small groups that formed when a relative, friend or male family member joined, often while the interview was in progress. Otherwise, eight of the interviews were done in the privacy of the women's homes while the additional four interviews were done more casually as the women were working or outside. Two women were interviewed twice. The average age of the participants was 36. Two interviewees were single, three were widowed, and the other seven were married. Younger women were more difficult to access for interviewing and were more reluctant to talk, as they were being protected by their families or too busy to talk while working. The women were referred to as "Lady" as a traditional form of respect.

### **DATA COLLECTION**

Data were collected over three months in the Zabbaleen communities of Mokattem and Tora in Cairo by the first author. The data consisted of semi-structured interviews and informal interviews that occurred in private homes, at storefronts, in informal group conversations in the church courtyard and on street sides. Data also included field notes made while observing the community and talking to leaders in the church before, during and after interviews with the women. Field notes were recorded while walking in the streets of Mokattem and Tora. Observations were made in the church courtyard and family gathering area outside the church after morning and evening services. The first author also made field notes while observing her contact person, a church worker, provide services to the community, such as distributing clothing and food. The notes also included conversation and observations of non-Copts while traveling and interacting in the larger community of Cairo.

A female contact person provided by the church leader, Father Samaan, introduced the women to the researcher and participated as a guide and as one of two interpreters/translators used for data collection. The other translator was a female native English speaker who had lived and worked in the area for 10 years. Consecutive real-time, in person translation allowed more in depth exploration and clarification of topics. Interviews were recorded digitally in Arabic and transcribed into written Arabic. Within two weeks, the written Arabic data were translated into written English, then cross-checked and translated back into Arabic by bilingual translators and transcribers in Egypt for validation.

### **DATA ANALYSIS**

Data analysis followed standard ethnographic methods and began while in the field (Denzin & Lincoln, 2017). Schemas were organized into broader categories that were grouped into overarching themes that represented the experiences of the Zabbaleen women's culture. Immersion in the field, comparative analysis of data while in the field, and multiple readings aided in maintaining rigor in coding the data into meaningful segments to develop the themes (Cohen, Kahn & Steeves, 2000; Creswell, 2012).

The ethnographic methods provided rich descriptions of a unique population of women not previously explored from the standpoint of suffering. The interviews included in this article were with women who themselves had Hepatitis C (HCV) or were caring for a family member with HCV, with the high prevalence of HCV in Egypt caused by a vaccination program that used contaminated needles (Knopp, 2015).

### RESULTS

The findings present a complex picture of suffering as these disadvantaged women experienced and tried to make meaning of it. In interviews with women, the conversation often contained references to proverbs from Egyptian culture and quotes from the Bible. One mother of four children who was diagnosed with Hepatitis C (HCV) two years earlier sat on a hard plank bed with a brightly patterned cover. In her second story apartment, the only window was open to let in fresh air, and pictures of Jesus and Coptic popes decorated the walls. The woman, Lady H, described what Hepatitis C (HCV) had done to her family. At one point she quoted an Egyptian Proverb, "much sorrow teaches how to cry".

Lady H said she had been wandering around Egypt with her four children trying to find treatment for them. She also said suffering from HCV is part of life. Suffering educated about sadness, but there was nothing else to be gained from the suffering. Her anguish resulted in an action, roaming around Egypt seeking assistance and non-Western medicines or cures for her family, which produced only the result of grief. This was a restless search for an elusive answer, rather than a doctor visit that would cost money the family did not have. Moreover, she was afraid the doctor would find several additional ailments.

Lady N, who was approximately 40 years old, was under treatment for HCV along with her husband and three of her five children. Most of the family had been diagnosed a year prior to the interview. Her other two children were positive for HCV but were too young to be enrolled in the treatment program available in Mokattem. She knew her neighbors were aware of her diagnosis; since Mokattem was such a close-knit community, it was difficult to keep information private. Lack of money and resources for treatment limited the possibility of receiving care in another location that would allow more discretion.

Lady N: Believe me; all what my friends tell me is hurting... they say you are afflicted. People are afflicted by one adversity but you have four. When I go with my husband and children to take the treatment, when our friends go with us, those who take it say you are afflicted. People are normally afflicted by one adversity but you have four. People say things that hurt.

This woman expressed the idea of suffering as affliction. Other women who had the disease were telling this woman she was afflicted since this happened to her and many of her family. The other women made a statement that, while true, was still hurtful. The pain came from her friends reminding her of how poorly off she and her family were; no consolation and no meaning were offered. Lady N appeared passive in telling the story, providing no explanation or mitigation for the hurtfulness of her friends' comments. Her affliction drained her financial, emotional, physical and social resources.

The greater the suffering, the more identity with Christ could be achieved. Yet the social aspects beat the women down, particularly the women who had several members with HCV. The perception seems to be, "my suffering may be difficult, but yours is worse," creating a hierarchy of suffering so to speak. It brings to mind that if one type of suffering was taken away, another suffering would take its place. The fear factor of the unknown suffering was greater than the fear of the known suffering. The women expected to suffer, but would rather have the known suffering or a newer suffering could be worse, "like hers".

In contrast, Lady D's home was boisterous. Her adolescent daughter came in during the interview with her cousin excitedly discussing her impending marriage. The daughter was too busy to interview, but her mother was more than willing to discuss difficulties related to HCV in their daily life. Even though the mother was positive for HCV, other members of the family felt the impact.

Lady D: We trust God... We suffered. We were suffering and having lots of expenses since five months. We cannot buy the trousseau of her sister. Yesterday we were about to sell her gold... if God wills, she will get married before getting her final grades.

## Zabbaleen Women's Perspectives on Suffering

---

In this community, a young woman marries a family rather than an individual, and the trousseau, which often consists of gold jewelry, is reflective of the family's wealth and standing. Not being able to provide a trousseau or worse, having to sell gold, is a great shame. Additionally, having to sell the gold because of an illness compounds shame brought upon the family; the shame of suffering from HCV is thus intensified by financial shame, which can lead to more cultural distress, particularly when a family cannot marry off a daughter. When one daughter is unacceptable to marry, that affects the other daughters' ability to marry. Having daughters remain at home, unwed, in turn increases the economic burden of the family. Lady D explains, "The older must marry first to avoid shame. If one is shamed it will carry to all other (daughters)".

Suffering for Lady D involved spiritual ambivalence in addition to the emotional, financial, and cultural distress. Her first sentence was a statement of her trust in God but it is followed by a litany of the suffering her situation has caused her and her family. She clearly labeled her circumstances as suffering, but did not express the idea that God will solve her problems. As she continued talking in her interview about the trials of trying to get her daughter married, she kept returning to the idea of suffering using a phrase repeated frequently in every conversation in this community, "If God wills" or "Inshallah". This phrase indicates the blending of the cultures of Coptic and Islam, wanting to end the pain but not wanting to overstep the bounds of God's will. The resolution of her suffering was dependent upon the power and intervention of God rather than being in her control.

In another interview, Lady O expressed the view that God is the authority over suffering and disease. He determines who will suffer and how, while women passively accepted God's decisions for their lives. Lady O kept three of her young grandchildren at her upper apartment since she could not work an outside job because of her HCV. She also had arthritis in her knees and did not move without pain. Her husband had died years ago after suffering from what she described as a terrible mental illness. When she talked about her health experiences, she summed up her ideas on suffering in this quote:

Lady O: We are poor Lord, whatever you do; we are in your hands Lord. We don't complain about anything... We have no one but God. We don't depend on anyone, only God.

She accepted what had happened in her life as God's will to do what He wanted and she had no way to change her situation. She referred to her poverty, "We are poor, Lord" but did not indicate whether she was talking about poverty in a spiritual or financial sense. Whether it was a lack of income or humility, she felt she could not change her circumstance by petition or complaint. The idea of petitioning the government or the church hierarchy or even her neighbors was not even a consideration.

Lady S who acted as a guide in the community but also had family members with HCV explained, "We know where HCV comes from but we don't know why we have too much. It is one more thing added to our burden." Lady S also seemed to be more of a leader in the community and a church worker but she also used words such as such as "punishment", and a situation to escape." She even planned to have her children marry outside the community to "get away" from the "troubles" of having HCV.

When Lady H was asked where HCV comes from, she said, "I don't know." Lady S interrupted because she did not like the answer and said, "Everyone is a special case for God and He permits this." Lady S thus tried to encourage as well as chastise Lady H by bringing God into the conversation, saying God is aware of this disease and allows it to continue. If the disease is permitted, then God has purposefully allowed the disease rather than healing the disease. The statement that everyone is special and known to God was meant to be a reassurance that God is not unaware of Lady H's circumstance. Like shepherding a lost sheep back to the fold, this reminder was to reinforce faith as much as to offer assurance.

Lady H also told of an incident when she was healed of an inflammation of the gall bladder while on an X-ray table prior to having an operation. After telling the story of her healing, she said, "Every time God performs a miracle, I rejoice more and say that God is really at work." It was clear to her that God intervened to heal her gall bladder disease, but why a benevolent God would choose to heal one disease and not another seemed to blur the clarity of her faith.



## Zabbaleen Women's Perspectives on Suffering

---

These women believed their lives were determined by something other than themselves. Chronic suffering forced them to consider what was controlling their lives and how much they could alter it. Meaning was difficult for them to discern. Because of their lifestyle and religious beliefs, the women saw God as a determiner of their suffering, much as other cultures would blame politicians, global economics, greedy business people and care-providers as the cause or in yet other cultures spirit forces, fate or random chance as the seed of suffering. In the interviews with Zabbaleen women, the search for meaning in suffering was bound by their history, the beliefs that God decided their suffering, and their ability to accept suffering as outside their control.

### DISCUSSION

In the view of these women, suffering does not serve a purpose. As these women noted, suffering only produced tears. The idea of finding meaning in suffering was not a conscious endeavor. Another Egyptian proverb says, *"When the sad woman started to be happy, she could not find a place for her."* Suffering is so much a part of their lives, without it they did not know what to do. Many of the Egyptian proverbs the women quoted dated back to before the Arabic invasions and Christianization and were remnants of early beliefs. These proverbs reinforced the expectation of suffering which were ingrained through repetition of traditional beliefs and sayings; the women were actually attaching meaning to the suffering based on their historical and cultural lens.

In addition, the Zabbaleen viewed their history going back to ancient times of the Pharaohs. Their sense of time magnified the sense of loss. Their culture had attained its height prior to the birth of Christ, and now a portion of the society lived at the lowest level of income and standing. Individual and community suffering were magnified by the passage of time. The length of their suffering seemed protracted. Kahn and Steeves' (1995) notion of the suffering of body, time and social world are clearly seen in the Zabbaleen's descriptions. Retelling of history infuses the suffering with a broader understanding and in itself changes the meaning retrospectively in time. The mother's suffering emotionally or physically was passed on generationally to the daughters. Therefore, the time and social context was ever present, in the past as the mother's experience and in the future as passed on to the daughters.

The Zabbaleen women believed that to suffer was to identify with Christ. In this there was some benefit in having suffered. In suffering, a believer became more mature, moving closer to God. God was aware of suffering and allowed circumstances to happen. This can be viewed as a "calling" or mission to suffer that is directly related to the teachings of the church and writings of the leaders of the church. Similar to the idea of identifying with Christ in suffering was the idea that misery made the individual special in the eyes of God. To suffer was to be like the suffering Christ, becoming more spiritually advanced.

Conversely, if suffering were to be alleviated, the specialness of suffering was taken away. God might not be as close when suffering was removed. This is admittedly complex, but viewed in the light of the teachings on Christ, suffering was conceivable. Samaan, a saint in the Coptic church, suffered affliction when he blinded himself after experiencing lust. Of course it is a stretch for the women who through no fault of their own had Hepatitis C to compare themselves to St. Samaan; however, suffering is suffering and as a devout man, he participated in miracles and was revered as special in the eyes of God. If Samaan had not suffered, he might not have been involved in the miracles. The women do not expect sainthood for their suffering but feel choosing not to suffer denies the will of God, alienates God, and negates potential benefits of suffering.

The women also did not have an expectation of the suffering to end, at least not on this physical plane. It was tied to the corporal world, to be relieved on the spiritual plane. The greater the suffering, the more identity with Christ. Yet the social aspects overtook the women, particularly the women who had several members with HCV. The idea that, "My suffering may be difficult, but yours is worse," creates a hierarchy of agony. It brings to mind that if one type of suffering was taken away, another form would take its place. The fear of unknown suffering was greater than the fear of known suffering. The women expected to suffer but would rather have the known, or it could be worse "like her".

## Zabbaleen Women's Perspectives on Suffering

---

Let us look back at Frankl's and Lewis' interpretation of suffering. A just position occurs between the women's beliefs influenced by Islam and the surrounding culture and their own Christian beliefs. The teaching on Islamic thought is noted in the women's narratives of suffering. The idea that a greater being would cause suffering ties into the principle of judgment, versus the Judeo-Christian idea of a loving Supreme being. It also contrasts with the beliefs of mortality in the afterlife. Mortality is believed to be a paradise based on rewards in Islam and based on forgiveness in Christian teachings, each with an overlay of suffering endured either by one or many. This is admittedly an oversimplification for this paper, but the hybrid of these seemingly contrasted beliefs is the ethos that suffering will occur.

When analyzing the women's beliefs about suffering, there appears to be some continuity with the writings of Western researchers such as Younger (1995). Younger discusses steps by which a sufferer becomes isolated and loses their place in the community. The Zabbaleen women clearly express this when discussing the stigma related to their HCV diagnosis. The "alienation" as Younger (1995) calls it also spreads to the family as seen in the women who state the diagnosis affected her daughter's ability to marry. The isolation mentioned by the women in this study is magnified by the time and effort it takes to receive treatment and healthcare in their location. Locating medicine and providers also causes them to pull away from activities in the community, compounding the effects of alienation by the illness. Separation, shame and stigma are encompassed in Younger's theory of suffering, seen in the common theme of marginalization for the Zabbaleen women due to their culture, socioeconomic status, and poor health due to HCV.

Frankl's (2006) Western thoughts attest suffering happens to us but does not define us, that we (the sufferers) define the meaning; for him, that is the ultimate human achievement. C.S. Lewis (2015) follows more closely with the women's description that suffering brings about the result of being closer to God and more like Christ. Both of these writers' thoughts parallel the Coptic church assumptions about suffering that were iterated by the women and by Lady S in particular during the conversation with Lady H.

Both positive and negative religious/spiritual coping mechanisms were observed in the Zabbaleen community, though there was a significant emphasis on destructive beliefs (such as not having control over one's health or life) rather than constructive ones (wellbeing, hope, optimism, self-esteem). Along with beliefs and practices, this community seeks support from what Tzounis et al. (2016) referred to as the healing power of icons, such as the prevalent cross tattoo. Often these women feel alienated, unaccepted, and unable to express themselves without deferring to their religious and cultural beliefs. Yet it is through positive traits like wisdom, care, involvement, commitment, and creating a common bond that feelings of connectedness are restored (Younger, 1995).

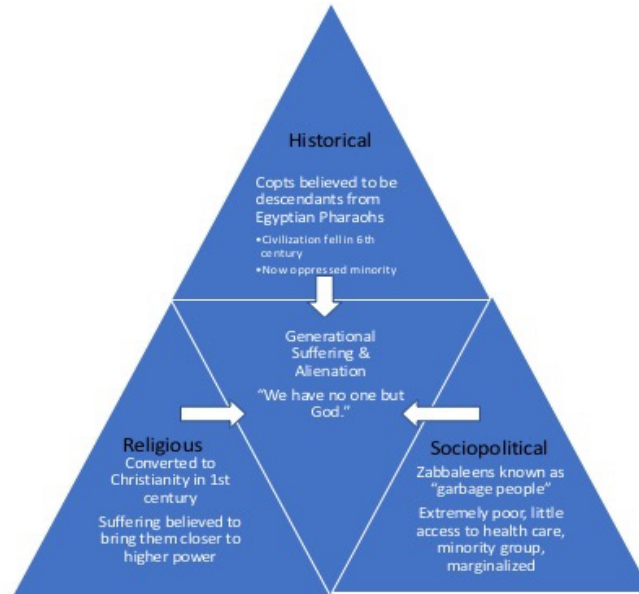
It is difficult to "compare" suffering in Middle Eastern women and the known understanding of suffering within the Western culture, particularly as the Zabbaleen women are uniquely blended in Islamic and Christian culture. What is almost unsurmountable to this culture, and emphasizes the isolation, is the lack of resources and infrastructure the Egyptian community has when compared to Western countries. By acting as "enlightened witness" (Fulford, 2017) healthcare workers can provide these women with a healthy space in which to process and grow. Indeed, the human experience is what draws these two worlds together by building a bridge of understanding.

## CONCLUSION

This paper discusses twists and turns to the understanding of suffering presented in Western research. Meaning is important in regard to suffering, no matter where you are, but the type of meaning differs. While the Zabbaleen women attach the meaning from a historical and spiritual sense, it is not with the purpose to relieve the suffering; rather it is more to increase their spirituality by becoming more Christ like. The more the women could identify with Christ, more meaning was attached to their suffering. The meaning to become more like Christ made the suffering tolerable or as Younger (1995), Fulford (2017), Lewis (2015) and Frankl (2006)

## Zabbaleen Women's Perspectives on Suffering

state, lessened the suffering. While in Western contexts, we tend to want to relieve all suffering as much as possible. Westerners expect to *not* suffer, and will go to great lengths to prevent, ignore, and remove suffering. The Zabbaleen women, in contrast, are born into political, religious, and social suffering, which continues throughout their lives as shown in Figure 1. That is the greatest divergence seen in this study.



**Fig1.** Themes of Zabbaleen Women's Suffering. This figure illustrates the external historical, sociopolitical and religious forces on the internal understanding of suffering and alienation of the Zabbaleen women.

It is beyond question that women in disadvantaged situations such as this will suffer. What is our response to that? A misunderstanding could occur in trying to provide healthcare for these populations or develop programs that do not take into account the views of suffering as an expected spiritual experience. These women and others might see suffering as serving a higher purpose and view the alleviation of suffering as a kind of loss. Parmeshwar (2006) and Råholm (2008) have discussed the ideas of an even higher meaning for suffering. Parmeshwar (2006) in particular gives us a framework to approach this. He discussed the experience of suffering (noema) and the result of the suffering (noesis) as steps toward reaching self-awareness; suffering is of value in maturation as a believer, and the Zabbaleen women view suffering differently from many Western women. Though we should not allow suffering in this population, researchers need to approach their anguish with awareness that suffering is perceived differently based on cultural and personal experiences.

### Issues in studying non-Western experiences

A personal issue the first author experienced while in the field was mentioned in the literature review about being present with individuals who suffer. Seeing the difficulties these women faced while unable to help them created a type of suffering for me similar to what aid workers experience. Not much could be done with the present resources to ease their suffering. As a witness to their suffering, I heard their experiences and gave them my full presence in which they voiced suffering; for me, listening and being present with them personalized their torment. The women often asked about my family to try to understand who I was while I was there. This brought about more connection, as I could identify having children who were sick. While recording field notes, I attempted to give meaning to what I had seen, processing it through my Western understanding of suffering. By doing so, their experiences of misery became part of my lived experiences of suffering and changed my understanding of grief.

## Zabbaleen Women's Perspectives on Suffering

---

Younger (1995) emphasizes the role of voice in suffering. By providing an outlet for expressive suffering, the Zabbaleen women had a conduit for their "lament". Younger describes this as part of a 3-step process to distance the suffering, gain hope in affirming the suffering, and to find an interpretation or understating. She calls this step "indispensable". In recording the women's narratives, trust and connectedness are built, and in facing the "shadow side of life" together (Younger, 1995), we demonstrate the true manifestation of caring.

## RELEVANCE TO CLINICAL PRACTICE

This study provides insight into understanding suffering from the unique perspective of women in a culture that is not easily accessible, and begins to fill a gap in our understanding of non-Westerners. The findings also provide insight into possible causes of health program failures due to misunderstandings of the women's view of suffering. As nurses are called upon to provide care for diverse population domestically and internationally, the awareness of cultural interpretations of what health and suffering mean creates a better ability to affectively impact health. The area of palliative care that aims to relieve suffering is a point of intersection with this research and nursing. Better understanding when providing palliative care to women of this culture in our country would allow better interaction with the patient and family when alleviating pain. It also lends insight into the isolation and alienation shared by this population, magnified by their beliefs, their culture, their language and their search for meaning in suffering, particularly if they are living in a Western country. The knowledge of different cultural, religious and social perspectives on suffering can guide further research in suffering, health, treatment options and plans, and the human experience through a global emphasis.

## ACKNOWLEDGEMENTS

Declaration of Conflicting Interests

The author declares no conflicts of interest with respect to the authorship and/or publication of this article.

## REFERENCES

- Assad, M. (1987). Mission in the Coptic church: Perspective, doctrine and practice. *Mission Studies*, 4, (1), 21-34.
- Balboni T., Vanderwerker L., Block S., Paulk E., Lathan C., Peteet J. & Prigerson H. (2007). Religiousness and Spiritual Support Among Advanced Cancer Patients and Associations With End-of-Life Treatment Preferences and Quality of Life. *Journal of Clinical Oncology* 25:5, 555-560.
- Cannuyer, C. (2001). *Coptic Egypt: The Christians of the Nile* (Sophie Hawkes, Trans.). London: Thames & Hudson. (Original work published in 2000)
- Cassell, E. J. (1982). The nature of suffering and the goals of medicine. *New England Journal of Medicine*, 306, 639-645.
- Cohen, M.Z., Kahn, D., & Steeves, R.H. (2000). *Hermeneutic Phenomenological Research: a practical guide for nurse researchers*. California: Sage.
- Copp, L. A. (1974). The spectrum of suffering. *The American Journal of Nursing*, 74, 491-495.
- Creswell, J. E. (2012). 3<sup>rd</sup> ed. *Qualitative inquiry and research design: Choosing among five traditions*. California: Sage.
- Davis, S. J. (2008). *Coptic Christology in practice: Incarnation and divine participation in late antique and medieval Egypt*. New York: Oxford University Press.
- Denzin, N. & Lincoln, Y. (2017). 5<sup>th</sup> ed. *The Sage Handbook of Qualitative Research*. Sage: Thousand Oaks, CA
- Deuffic-Burban, S., Mohamed, M. K., Larouze, B., Carrat, F. & Valleron, A. (2006). Expected increase in Hepatitis C-related mortality in Egypt due to pre-2000 infections. *Journal of Hepatology*, 44, 455-461.

## Zabbaleen Women's Perspectives on Suffering

---

- Elgharably, A., Gomaa, A., Crossey, M., Norsworthy, P., Waked, I., & Taylor-Robinson, S. (2017). Hepatitis C in Egypt-past, present and future. *International Journal of General Medicine*, 10, 1-6.
- Ferrell, B. (1995). When culture clashes with pain control. *Nursing* 95, 90.
- Ferrell, B. (2008) The nature of suffering and the goals of nursing. *Oncology Nursing Forum*, 35, 241-246.
- Frankl, V. (2006). *Man's Search for Meaning*. (5<sup>th</sup> ed.). Boston: Beacon Press.
- Fulford, W. (2017). Hidden Suffering and the Effects of Adverse Childhood Experiences. *Religions*, 8, 31, 1-33. doi:10.3390/rel8030031
- Gordon P, Feldman D., Crose R., Schoen E, Griffing G, & Shankar J. (2002) The role of religious beliefs in coping with chronic illness. *Counseling and Values*, 46, 162-174. doi: 10.1002/j.2161-007X.2002.tb00210.x
- Hearn, A., & Deeny, P. (2007). The value of support for aid workers in complex emergencies: A phenomenological study. *Disaster Management and Response*, 5(2), 28-35.
- Hymas, K.C., Mansour, M.M., Massoud, A., & Dunn M.A. (1987). Parenteral Antischistosomal Therapy: Potential risk factor for hepatitis B infection. *Journal of Medical Virology*, 23, 109-114.
- Kahn, D. & Steeves, R. (1986). The experience of suffering: Conceptual clarification and theoretical definition. *Journal of Advanced Nursing*, 11, 623-631.
- Kahn, D. & Steeves, R. (1995). The significance of suffering in cancer care. *Seminars in Oncology Nursing*, 11(1), 9-16.
- Kamil, J. (1987). *Coptic Egypt: History and guide*. Cairo: American University in Cairo Press.
- Keim-Malpass, J., Adelstein, K. & Kavalieratos, D. (2015). Legacy making through illness blogs: Online spaces for young adults approaching the end of life. *Journal of Adolescent and Young Adult Oncology*, 4 (4), 209-212.
- Keri, S. (2015). Suffering Has No Race or Nation: The Psychological Impact of the Refugee Crisis in Hungary and the Occurrence of Posttraumatic Stress Disorder *Soc. Sci.*, 4(4), 1079-1086. doi:10.3390/socsci4041079
- Knopp, A. (2015). Healthcare Experiences of Zabbaleen Women in Cairo, Egypt. *International Journal of Research Nursing*, 6(1). doi: 10.3844/ijrnsp.2015.1.9
- Koenig, H. (2012). Religion, Spirituality, and Health: The Research and Clinical Implications. *International Scholarly Research Network Psychiatry*. Volume 2012, Article ID 278730. doi:10.5402/2012/278730
- Lewis, C.S. (2015). *The Problem of Pain*. (Rev.ed). New York: HarperOne.
- MacKeen, D. (2003). *Bad Blood in Egypt*. Retrieved from [http://dir.salon.com/story/news/feature/2003//06/02/hep\\_c/](http://dir.salon.com/story/news/feature/2003//06/02/hep_c/)
- Meinardus, O. (1970). *Christian Egypt, faith and life*. Cairo: French Institute of Oriental Archeology.
- Mohlman, M.K., Saleh, D.A., Ezzat, E., Abdel-Hamid, M., Korba, B., Shetty, K., ...Loffredo, C.A. (2015). Viral transmission risk factors in an Egyptian population with high hepatitis C prevalence. *BMC Public Health*, (15). doi: 10.1186/s12889-015-2369-y
- Musa, S. & Hamid, A. (2008). Psychological problems, among aid workers operating in Darfur. *Social Behavior and Personality*, 36, 407-416.
- Parameshwar, S. (2006). Inventing higher purpose through suffering: The transformation of the transformational leader. *The Leadership Quarterly*, 17, 454-474.
- Roberts, L. & Levitt, E.B. (2000). University of Maryland School of Medicine study links hepatitis C spread in Egypt to injection campaigns. Retrieved from University of Maryland Medical Center website: <http://www.umm\egypt hepatitis\edu>

## Zabbaleen Women's Perspectives on Suffering

---

- Råholm, M. (2008). Uncovering the ethics of suffering using a narrative approach. *Nursing Ethics*, 15(1), 62-72.
- Rao, M., Naficy, A., Darwish, M.A., Darwish, N.M., Schisterman, E., Clemens, J.D., & Edelman, R. (2002). Further evidence for association of hepatitis C infection with parenteral schistosomiasis treatment in Egypt. *Biomed Central (BMC) Infectious diseases* 2, 1-17. doi: 10.1186/1471-2334-2-29
- Samaan, M. & Sukkary, S. (1978). The Copts and Muslims. In S. Joseph & B. Pillsbury (Eds.), *Muslim-Christian conflicts: Economic, political, and social origins* (pp. 129-150). Boulder, CO: Westview Press.
- Samaan, M. & Walsh, D. (2017, April 9). ISIS claims two deadly explosions at Egyptian Coptic Church on Palm Sunday. *New York Times*. Retrieved from: <https://www.nytimes.com/2017/04/09/world/middleeast/explosion-egypt-coptic-christian-church.html>
- Selby, S., Moulding, N., Clark, S., Jones, A., Braunack-Mayer, A., & Beilby, J. (2009) Back home: a qualitative study exploring re-entering cross-cultural missionary aid workers loss and grief. *Omega*, 59 (1), 19-38.
- Shenouda III, H. H. (1995). The beholder of god: Mark the evangelist, saint and martyr. 4<sup>th</sup> ed. (Samir Mikhail & Maged Mikhail, Trans.). California: St. Peter and St Paul Coptic Orthodox Church.
- Shenouda III, Pope (1999). The Divine Liturgy of Saint Gregory the theologian according to the rites of the Coptic Orthodox Church. Sydney: Coptic Orthodox Theological College.
- Steeves R., & Kahn, D. (1987). Experience of meaning in suffering. *Journal of Nursing Scholarship*, 19, 114-116.
- Steeves, R., Kahn, D., & Benoliel, J. (1990). Nurses' interpretation of the suffering of their patients. *Western Journal of Nursing Research*. 12, 715-731.
- Tarakshwar N., Vanderwerker L., Paulk E., Pearce M., Kasl S. & Prigerson H. (2006). Religious Coping is Associated with the Quality of Life of Patients with Advanced Cancer. *Journal of Palliative Medicine*. 9(3), 646-657.
- Tzounis E., Kerenid Ti, Daniil Z., Hatzoglou C., Kotrotsiou E. & Gourgoulialis K. (2016). A Qualitative Content Analysis of Spirituality and Religiosity amongst Greek COPD Patients. *Religions*. 7(3), 22. doi:10.3390/rel7030022
- WHO. Egypt Hepatitis. (2017). Retrieved June 30 2017 from <http://www.who.int/countries/egy/en/>
- Wilkinson, I. (2001). Thinking with suffering. *Cultural Values*, 5, 421-444.
- Williams, M., Jerome, A., White, K., & Fisher, A. (2006). Making sense of suffering: A preliminary study of changes in religious women adjusting to severe adversity. *Counseling and Values*, 50, 84-98.
- Younger, J.B. (1995). The alienation of the sufferer. *Advanced Nursing Science*, 17(4), 53-72.

**Citation:** Andrea Knopp, PhD, MSN, MPH, FNP-BC "Zabbaleen Women's Perspectives on Suffering". *American Research Journal of Nursing*. 2017; 3(1): 1-14.

**Copyright** © 2017 Andrea Knopp, PhD, MSN, MPH, FNP-BC, This is an open access article distributed under the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.