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# Retrospective analysis of ethics consultations at the Boston Medical Center

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BOSTON UNIVERSITY  
SCHOOL OF MEDICINE

Thesis

**RETROSPECTIVE ANALYSIS OF  
ETHICS CONSULTATIONS AT THE BOSTON MEDICAL CENTER**

By

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B.A., Johns Hopkins University, 2012

Submitted in partial fulfillment of the  
requirements for the degree of  
Master of Science

2015



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**RETROSPECTIVE ANALYSIS OF ETHICS CONSULTATIONS  
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**TATSUHIKO NAITO**

**ABSTRACT**

Objective: The vast majority of physicians frequently faces ethical dilemmas and feels overwhelmed as a result. Those at Boston Medical Center are no exception. Various studies show more adept handling of ethical issues can improve the quality of care and patient safety by reducing moral distress of physicians and fostering better patient-physician relationship. The method of Preventive Ethics, which actively identifies recurrent themes and underlying systematic issues among ethics consultations, is more effective than the traditional, case-by-case approach in reducing the number of ethical conflicts. The purpose of this study is to identify common themes prompting ethics consultations and any hotspots among recurrent ethical dilemmas at Boston Medical Center by using the Armstrong Clinical Ethics Coding System.

Methods: A total of 32 ethics consultations handled by the BMC Ethics Committee between October 2010 and April 2013 were reviewed. Each consultation was coded using the Armstrong Clinical Ethics Coding System. The data was analyzed to identify the types of ethical dilemma that are most prevalent at BMC. The consultations involving the most frequently occurring issues were evaluated further to expose common themes among these cases and potential underlying systematic failures.

Result: “Clinical Candidacy or Risk / Benefit Analysis” (6.25%), “Concern About Decision Maker Choices” (14.6%) and “Futility / Inappropriate or Nonbeneficial

Treatment” (13.5%) were the most prevalent types of ethical issues at BMC. Not only are these three frequently occurring, they also have a very high tendency to occur simultaneously. Further analysis of consultations involving these three issues revealed that at BMC, there are frequent instances of conflict, in which family members serving as healthcare proxies disagreed with physicians in deciding the best interest of patients with severe ailments, ultimately precipitating ethics consultations.

Discussion: Comparison with similar retrospective studies previously carried out at other institutions suggests that consultation involving the issue of futility may be more frequently occurring at BMC, which might be coming from unique systematic problems. Several interventions such as improved policies or educational training in physician-family communication should be considered.

Conclusion: According to the principles of Preventive Ethics, the issue of physician-healthcare proxy conflict regarding patient futility should be issue to be addressed at BMC. The Armstrong Clinical Ethics Coding System can serve as a much needed standard documentation format for ethics consultations, which would open up the possibility of more detailed future studies.

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## **LIST OF ABBREVIATIONS**

ASBH	American Society for Bioethics and Humanities
ACECS	Armstrong Clinical Ethics Coding System
BMC	Boston Medical Center
CEC	Clinical Ethics Consultation
CC HCEC	Core Competency for Health Care Ethics
ECEN	European Clinical Ethics Network
HCEC	Health Care Ethics Consultation
LST	Life sustaining treatment

## INTRODUCTION

Hospital ethical dilemmas are often a culmination of a number of unresolved issues that may relate, but are not limited to, patient or surrogate satisfaction with management of care; provider satisfaction with appropriate approach and level of care. Biotechnological advances in healthcare, a broader informed public and increasing economic constraints by healthcare providers may lead to increases in healthcare related ethical dilemmas. A means of accessing and employing empiric knowledge gained from such ethical dilemmas, which generally reflect the uniqueness of each hospital system, is critical to improving patient and provider experience as well as reducing healthcare costs.

Not only does more adept handling of ethical issues have intrinsic moral value, it can also improve quality of care and patient safety by reducing moral distress of physicians and fostering better patient-physician trust. This has become especially challenging in today's age where patients' trust in doctors has diminished.

This project sought to employ a validated ethics consultation coding system (the Armstrong Clinical Ethics Coding System) and to identify hotspots of ethical dilemmas at Boston Medical Center (BMC). This study retrospectively reviews all ethics consultations filed at BMC from October 2010 to April 2013, examines and identifies common themes arising among these consultants, and compares results to similar retrospective studies from other hospitals. By identifying these hotspots, BMC may be able to prevent recurrence of similar types of ethical issues, based on the concept of preventive ethics.

## **SPECIFIC AIMS**

**Aim 1.** Code and create a database of BMC ethics consultations for the period of October 2010 to April 2013 using the Armstrong Clinical Ethics Coding System

**Aim 2.** Identify common themes prompting ethics consultations and any hotspots among recurrent ethical dilemmas at BMC

**Aim 3.** Compare the result with those from similar previous studies to identify clinically significant differences.

## **BACKGROUND AND SIGNIFICANCE**

### *Physicians and ethical dilemmas*

With daily discoveries of new knowledge and technologies, quality in health care has evolved dramatically over the past several decades. Physicians now can prolong life of patients in ways that were not possible as recently as ten years ago. Innovative drugs that can treat formerly “untreatable” disease have become available. Despite such medical advancements the value of these interventions may at times be called into question when the gained survival time is spent hospitalized or living in a state of otherwise unacceptable to the patient.

In addition, dynamics around physicians – laws, relationships with pharmaceutical companies / grant providers, hospital policies –, have vastly changed and became increasingly complex. These changes substantially increased the chances that physicians encounter questions that cannot be answered by clinical expertise alone but rather involve consideration of what is morally right or wrong to do. These ethical dilemmas are not ephemeral but rather something that can haunt physicians for years (Lo, 2012, p.11).

Physicians and other health care professionals often feel overwhelmed by the need to balance the rights, demands and needs of all the involved stake holders including patients, families, insurance companies and other healthcare providers (Jeong, Armstrong, Kolton, Parker, & Wohlgemuth, 2013). In the first national survey about the frequency of ethical dilemmas encountered by physicians, nearly 90% of physicians had recently

encountered an ethical dilemma (DuVal, Clarridge, Gensler, & Danis, 2004). In a survey conducted in 2011 by the BMC Ethics Committee, 946 staff members were asked, “How often do ethical issues arise in your practice?”, 62% of the respondents answered “often / sometimes” to the question, indicating healthcare providers encounter moral dilemmas much more frequently than people might imagine. Despite the frequency of ethical dilemmas, doctors are generally reluctant to request formal ethics consultation by their hospital’s Ethics Committee. Some deem ethics consultations as an indication of an error or the lack of ability that they perceive may lead to compromising patient trusts and confidence of their patients (Orlowski, 2006). In the aforementioned survey at BMC, while 82% of respondents knew about the Ethics Committee, only 20% of them had ever requested a consult. According to a qualitative research study done by Hurst and colleagues, in the U.S., when physicians face ethical difficulties, they tend to seek assistance, avoid conflict, and try to protect the integrity of their conscience and reputation (Hurst 2005). While this may seem to contradict the BMC survey results, the authors argue that their findings actually explain why many doctors are reluctant to ask for an ethics consultation even when they face a dilemma. They hypothesize that physicians often deem ethics consultants as “outsiders.” Further, seeking help can lead to conflicts by involving more people into the equation and may undermine their integrity or reputation by tacitly admitting they cannot solve the problem themselves. Even when physicians tend to seek assistance, they may not deem ethics consultant as capable of providing effective help. The authors conclude that ethics consultation may be perceived

not as a primary source of help but more as a last resort when physicians encounter ethical dilemma (Hurst 2005).

A contributing factor to increasingly frequent ethical dilemmas may be the erosion of the patient-physician relationship in recent years. Many patients complain doctors do not spend enough time with them. In a national survey conducted by the federal government in 2008, many hospital patients expressed dissatisfaction with their care (Pear 2008). Growing number of reports indicate that patients do not trust doctors to the same extent as in the past. According to data from a study conducted by Johns Hopkins University, roughly one in four patients feel “their physicians sometimes expose them to unnecessary risk” (Parker-Pope 2008). Many factors contributed to distrust. A lot has to do with the media and the way in which even minor perceived infractions by physicians are considered highly newsworthy, are often presented in an inflammatory, exaggerated fashion, and spread instantly via the internet.

*Adverse consequences of unresolved moral dilemmas and deteriorating physician – patient relationship*

Due to the high frequency of ethical dilemmas and their inability to use ethics consults effectively, physicians can face various adverse consequences, including moral distress and burnout, if they do not handle these issues adeptly.

Physicians feel moral distress when they know what is ethically right but cannot act accordingly due to constraints or obstacles. A study done by Houston and her

colleagues showed the issue of moral distress is prevalent throughout multiple healthcare disciplines including physicians and nurses. Physicians feel the greatest moral distress when there is a rift between the wishes of a patient's family (when acting in the role of surrogate decision-makers) and what the physician himself or herself thinks should be done (Houston et al., 2013). Moral distress can itself be a problem, but it can also start the chain of negative effects. Professional burnout is "a syndrome characterized by a loss of enthusiasm for work...feeling of cynicism...and a low sense of personal accomplishment" (Shanafelt et al., 2012). One study showed physicians experience more burnout than other U.S. workers. In this particular study, which consisted of almost 7000 physicians, almost half have experienced symptoms of burnout (Shanafelt et al., 2012). Prior to this study, it was well known that medical students and doctors in training are susceptible to burnout. What is notable about this study is that even fully trained and experienced doctors are susceptible to the syndrome as well. Although Shanafelt never explicitly identified moral distress as a contributing factor to burnout there are many potential contributing factors, one of which may be moral distress. The problem of the professional can influence quality of care; physicians suffering from burnout are more susceptible to errors. A study conducted by Dr. West and his team showed higher levels of fatigue and distress leads to higher frequency of self- perceived errors among doctors (West, Tan, Habermann, Sloan, & Shanafelt, 2009).

Not only does erosion of the patient-physician relationship contribute to ethical conflicts, but physician-patient relationship is also paramount for effective treatment. It has been hypothesized that greater patient trust leads to more efficient care in several

ways such as better treatment adherence (Thom, Hall, & Pawlson, 2004). At worst a strained physician-patient relationship can result in a lawsuit which may come with significant financial cost to the medical center. Roughly 55 million or 2.4 % of national health spending was the estimated total cost of malpractice in 2008 (Reinhardt 2008).

In sum, given the impact the moral climate may have on providers, their relationship with the patient or family, and optimum use of clinical resources it would be expected that an environment fostering adept handling of ethical dilemmas would lead to better quality of care and patient safety.

#### *Ethical Consultation and its efficacy*

Medical institutions can promote such an environment by employing out ethics consultations effectively. Health care ethics consultation (HCEC) is defined as a “set of services provided by an individual or group in response to questions from patients, families, surrogates, health care providers, or other involved parties who seek to resolve uncertainty or conduct regarding value-laden concerns that emerge in health care. The general goal of ethics consultation is to improve the quality of health care through the identification, analysis, and resolution of ethical questions or concerns” (Tarzian & ASBH Core Competencies Update Task, 2013). A national survey done by Fox and her colleagues revealed 95% of all general hospitals in the U.S. either had some form of ethics consultations services or were in the process of creating one. For those with more than 400 beds, the prevalence reached 100% (Fox, Myers, & Pearlman, 2007). The same study also revealed that “within more than 6,000 general hospitals in this country,

approximately 29,000 individuals devote more than 314,000 hours to ethics consultations each year” (Fox, Myers, & Pearlman, 2007). High prevalence of ethics consultation services and large investment likely reflect its efficacy and importance in improving quality of care and the medical staff’s mental state.

According to the study done by Kalager, clinicians who requested HCEC deemed ethics consultations as useful and stated that HCEC leads to practical consequences (Kalager, Førde, & Pedersen, 2011) such as termination of ongoing treatment and greater attention paid to ethics considerations. Other studies have reported a positive impact on quality and resource utilization. For example, study reported that HCEC resulted in both shorter ICU stay and hospital stay as compared to similar patients who did not receive HCEC (Chen et al., 2014). Similar studies have been done and proactive ethics consultations also showed benefits such more documented communication or frequent decisions to forgo life sustaining therapy (Nilson, Acres, Tamerin, & Fins, 2008).

### *Preventive Ethics*

Ethics committees and their consultations in health care setting have traditionally been more reactive, addressing ethical issues after they occur, on a case-by case-basis. Simply responding to individual cases as they occur, however, may not be quite enough. It has become increasingly evident that certain ethics conflicts like those involving end-of-life issues are recurring organizational phenomena (Nelson, Gardent, Shulman, & Splaine, 2010). Thus the traditional case-by-case approach is now being criticized for not dealing with the underlying causes of these issues, which often lead to recurrence of

similar types of ethical dilemmas. Reappearance of similar problems eventually leads to avoidable moral distress and waste of resources. Nelson et al argue that while the traditional approach is not without benefit, “the process can be stressful and time-consuming for both the involved staff and the ethics committee or consultation service members” (Nelson, Gardent, Shulman, & Splaine, 2010). As mentioned earlier, such negative impact can have detrimental implications including decreased quality of care and loss of staff productivity.

In response to these shortcomings of the traditional approach, a newer approach called preventive ethics has been developed since the 1990s. Preventive ethics is defined as “activities performed by an individual or group on behalf of a health care organization to identify, prioritize and address systemic ethical issues” (Foglia, Fox, Chanko, & Bottrell, 2012). This more proactive approach is intended to identify the root cause of ethical concerns and ultimately to prevent recurrence of similar types of ethical issues. While this approach has yet to become the norm for most ethical committees, it has distinct advantages, allowing organizations to improve their ethics practices and avoid the downfalls of the traditional case-by-case approach listed above. The concept of preventive ethics, with the attendant goal of identifying hotspots of recurrent ethical dilemmas at the BMC, forms the basis for this project.

### *Ethics Committee at BMC*

Boston Medical Center (BMC), Boston, Massachusetts, USA is a private, not-for-profit, 496-bed hospital with more than 26,000 admissions and 850,000 visits in 2012 and

nearly 4,500 full-time equivalent employees including more than 1,200 physicians (Boston Medical Center, 2013). The Ethics Committee at BMC currently consists of 24 members: physicians and nurses from various different specialties and representatives from social work, legal services, pastoral care, nursing, case management, interpreter services and patient advocacy. Inclusion of individuals from various backgrounds is a common way to compose an ethics committee and is employed by institutions nationwide (Fox, Myers, & Pearlman, 2007). The BMC Ethics Committee Charter includes the following goals (Boston Medical Center, 2007):

- To maintain an easily accessible consultation service to assist in the assessment and resolution of ethical dilemmas. The consultation service shall be comprised of a team of individuals with interdisciplinary expertise.
- To develop educational programs and help to foster a culture within the BMC community that continually increases recognition of ethical dilemmas and develops improving strategies to avoid, modify, and resolve frequently occurring ethical dilemmas.
- To review, revise, propose, and develop policies related to ethical issues, and, as needed, make recommendation to the Chief Executive Office of the Boston Medical Center.
- To discuss monthly those cases that have prompted request for consultation and create a database that can serve as an educational resource.

BMC Ethics Committee employs the traditional approach to HCEC of a small multidisciplinary consult team made up of a healthcare ethicist plus members from larger committee who are experienced in ethics consultation. Consults are performed with the requesting provider teams. Recommendations and documentation of the consult are entered into the patient's chart. A more extensive form of the consult is detailed and entered into the Ethics Committee's consult database. Nearly all of the Ethics Committee members do not have significant time in their jobs during which they are dedicated specifically to the ethics consultations, and thus the consult coordinator frequently needs to spend substantial time in recruiting and establishing a consultation team. Consequently, the number of consultations that can be feasibly conducted is limited, and, in fact, the service historically convenes for approximately one consult per month, on a par with other hospitals with 400-496 beds based on the research done by Fox and her colleagues (Fox, Myers, & Pearlman, 2007). However, both the aforementioned study by Duval (DuVal, Clarridge, Gensler, & Danis, 2004), as well as the survey conducted by BMC Ethics committee suggest it is likely that the number of ethics consults is under-representing the actual incidence of ethical dilemmas at the BMC. Based on the national survey conducted by Fox, only 41% of individuals performing ethics consultations have had formal supervised training in ethics consultation (Fox, Myers, & Pearlman, 2007). The general lack of formal training in clinical ethics among staff members in ethics committee can also be applied to the BMC Ethics Committee, where generally just two members of the consult service meet the recommended American Society of Bioethics and Humanities (ASBH) skill and knowledge competencies (Jeong, Armstrong, Kolton,

Parker, & Wohlgemuth, 2013). In sum, HCEC performed at BMC appear to be on par with other comparable hospitals in the country.

### *Documentation and Evaluation of HCECs*

In the late 2000s, many bioethicists decried the lack of formal practice standards for HCECs (Fox, Myers, & Pearlman, 2007; Dubler, Webber, & Swiderski, 2009). Expanding on an initiative begun years earlier, the ASBH published the second edition of *Core Competencies for Healthcare Ethics Consultation (CC HEEC)*, which codified standards for a successful and efficient HCEC service. A key component of these standards is thorough documentation of all consultations.

Clear, organized and consistent documentation of HCEC records is crucial as it serves multiple purposes. First, it facilitates evaluation of ethics consultations and the activities of the ethics committee. This will ultimately facilitate quality improvement of the ethics consultation service by making it easier for evaluators to identify trends in consultations and potential area of systematic improvement. In fact, evaluation / quality review / improvement of the HCEC services is another proposed standard of HCEC serviced identified by the CC HEEC. Dubler argues, “[q]uality improvement is mandatory in all subspecialties of health care. As HCEC moves into the mainstream, it must be judged by mainstream standards. Clinical ethics committees and clinical ethics consultants must be subjected to the same level of transparency, account-ability, scrutiny, and oversight as other members of the staff who see patients, and, like other members of the staff, they must write notes in the chart” (Dubler, Webber, & Swiderski, 2009).

Second, related to the first purpose, properly documented ethical consultations can be utilized as a valuable educational material. Previous studies indicate that both general staff of an institution (Chen et al., 2014) and members of an ethics committee (Fox, Myers, & Pearlman, 2007) can benefit from more education on health care ethics. Third, appropriate documentation can facilitate research on clinical ethics consultations. Bramsteadt laments “[m]any facilities have performed hundreds of ethics consultations that contain valuable information that could generate research protocols, yet accessing this information can be difficult because it is not formally catalogued” (Bramstedt, Jonsen, Andereck, McGaughey, & Neidich, 2009). Last and most importantly, consistent standardized documentation facilitates discussions and exchange of understanding between different institutions by providing a common ground and structure. A lesson can be learned from the first few meetings of European Clinical Ethics Network (ECEN) meeting where participants had difficulty in sharing their experience and knowledge because they did not share the same documentation format or more specifically, technical languages (Pedersen et al., 2010). It is possible that such a standardized structure may restrain ways of presentation or discussion to some extent, but it is safe to assume potential benefits will far outweigh potential drawbacks.

Yet, despite the potential benefits, formal standards of documenting ethics consultation are yet to be established. Bramsteadt writes, “[a]n exhaustive literature review reveals no consistent description of what is recorded and how it is recorded. What few methods are published, in our view, could be improved upon. Further, no regulatory or professional body (for example, the American Society for Bioethics and Humanities)

has set standards for documentation of ethics consultation” (Bramstedt, Jonsen, Andereck, McGaughey, & Neidich, 2009). Inconsistencies in documentation can also be seen in past retrospective review of ethics consultations.

For example, a study done by Moeller had nine categories to classify central issues of ethical consultations (Moeller et al., 2012).

- Family opposed to withdrawing life sustaining treatment (LST)
- Physician does not wish to provide LST
- Patient competence or capacity in question
- Futility
- Physician opposed to withdrawing LST
- Other
- DNR
- Patient noncompliance with medical regimen
- Patient wishes are unknown

Retrospective studies done by Swetz (Swetz et al., 2007) and (Romano, Wahlander, Lang, Li, & Prager, 2009) were a little more expansive with 15 categories:

- Withdrawing or withholding treatment
- Appropriateness or treatment, goal of care, futility
- Resuscitation issues
- Legal-ethics interface
- Competency, decisional capacity
- Psychiatric issues
- Family conflict
- Staff or professional conflict
- Discharge disposition
- Allocation of resources
- Spirituality, cultural issues
- Confidentiality
- Advance directives
- Reproductive issues
- Other

Analyses using these categorization systems clearly demonstrated that one ethics consultation can involve multiple issues. Yet, these early coding systems did not establish the recommended number of categories to apply to a single consultation. In other words, one consultation might be labeled with a single category while others might be labeled with more than one. This was addressed in Nilson's study (Nilson, Acres, Tamerin, & Fins, 2008), which proposed listing of one primary issue and one secondary issue out of 22 categories:

- Advance Directive
- Brain Death
- Capacity / Informed Consent
- Confidentiality
- Discharge / Placement
- DNR
- Futility
- Isolated Incapacitated Patient
- Maternal / Fetal Conflict
- Medical Error
- Pain Management
- Refusal of Recommended Treatment
- Research Ethics
- Resource Allocation
- Surrogate Decision Making
- Transplant Issues
- Truth Telling
- Withdrawal of Ventilator
- Withdrawal of other life sustaining therapy
- Withdrawal or Withholding Artificial N&H
- Withholding of other life sustaining therapy
- Other

Such inconsistency in categorizing central issues of an ethics consultation or any other areas of documentation will make discussions and comparisons between two parties (e.g.,

individuals, teams, institutions, countries) using different format extremely difficult since they do not share the same technical language. It can also impede efficient evaluation and subsequent research. In addition, prior studies never adequately explained the definition of each category while some of them used ethics specific technical language.

Compounding the aforementioned general lack of formal training in ethics among the Committee members, this lack of standardization in documentation can contribute to miscommunication. Therefore, a standardized documentation or coding system to categorize and organize central issues in ethics consultations was much needed. The Armstrong Clinical Ethics Coding System (ACECS) was specifically designed for that purpose.

## **METHODS**

### *Study Design*

All cases from the BMC Ethics Committee Consult database from October 2010 to April 2013 (total 32 consultations) were included in the analysis. The Ethics Committee Consult service documents each consult in an established template in narrative form. Although there are no proscriptive directions, the components generally found in each consult include: patient history; description of clinical status; description of ethical dilemma as described by requesting parties and other consult participants; major issues as observed by the consult team; recommendations made; and in some instances, outcomes.

The completed consultation document for each consultation was coded using the Armstrong Clinical Ethics Coding System (ACECS) based on its central ethical conflict. After the coding was complete, the data was analyzed to identify the types of ethical dilemma that are most prevalent at the BMC.

### *Armstrong Clinical Ethics Coding System*

The Armstrong Clinical Ethics Coding System (ACECS) was developed by Dr. Kelly Armstrong at Southern Illinois University School of Medicine, a practicing clinical ethicist who has conducted over 1800 ethics consultations over the last 10 years. ACECS has been successfully adopted at various healthcare institutions including within the Boston hospital community at Boston Children's Hospital.

The ACECS uses 138 detailed descriptors of commonly experienced ethical issues in healthcare that are sorted into nine categories: 1) Treatment Decision-Making 2) Substitute Decision-Making 3) End of Life 4) Professionalism 5) Reproduction 6) Death and Post-Mortem 7) Resource Allocation 8) Research and 9) Organizational Ethics. Each subject group is then sub-divided to the more detailed descriptor classifications. For example, there are 9 codes under group 6 Death and Post-mortem (See Appendix 1 for the full list):

- 01 Brain Death
- 02 Autopsy
- 03 Visitation of location of Body After Death
- 04 Participation in Learning Exercise
- 05 Anatomical Donation
- 06 Release of Body/Disposition of Remains
- 07 Coroner/Medical Examiner/Other Government Service
- 08 Bereavement Counseling
- 09 Memorialization (hair, footprints, photo, etc.)

Each of the 138 codes in the coding system is assigned a number, the first numeral being the governing subject group category. In the above example, “Autopsy” is assigned the code 6.02. Each consultation is tagged with the three different codes that best describe the case specific ethical dilemma. Thus there are theoretically 428,536 possible ways to describe a consultation.

In addition, three modifiers are used to describe the dynamics and type of each consult: 1) Types of Ethics Intervention 2) Locus of Uncertainty or Conflict and 3) Level of Complexity (See Appendix 2 for the full list).

One of the strengths of the coding system is that it covers a broad range of issues that can potentially surface in daily clinical settings without resorting to lengthy description. Another strong point is that the system avoids highly technical ethics specific language, making it comprehensible not only to physicians but also to other care providers such as nurses. To further clarify and standardize, the coding system a user's guide was developed to provide a working definition and examples for each code. For example, a code "Uncooperative Behavior" is defined as (Armstrong, 2013):

Words or Actions which, through their severity or frequency, are disruptive enough to impair normal social interactions or the effective delivery of healthcare services. Generally observed as difficulty containing a strong emotional response (fear, anger, frustration, etc.) or a difficulty following the rules. This may be applied to all persons involved in care, including the patient, family and healthcare team.

Examples: Yelling, badgering, manipulating, bullying, refusal to participate in discussions or meetings, impulsive behaviors, inability or refusal to follow directions.

Commonly combined with: Decisional Capacity, Mental Illness, Substance Use, Family Issues, Concern about Decision-Maker Choices, Professionalism, Inappropriate Treatment, Maternal-Fetal Conflict, Abuse Neglect or Mandatory Reporting

Through support material like this, webinars and workshops, Dr. Armstrong has successfully trained other institutions to use the coding system. In sum, the above elements make the coding system very adoptable. This is especially important

considering staff from various backgrounds or fields comprises HCEC's and, as has been reported, many have not had a formal education in clinical ethics.

Since the ACECS can be fairly easily adopted by most Ethics Committee members it may provide a core language that is standardized and connected to the healthcare ethics literature. Its consistency and conciseness helps the members to avoid miscommunications, discuss active issues efficiently and facilitate recording that may be used for evaluation or research later. These benefits would be expected to lead to improve quality of HCEC and ultimately result in better quality of patient care and safety.

## RESULTS

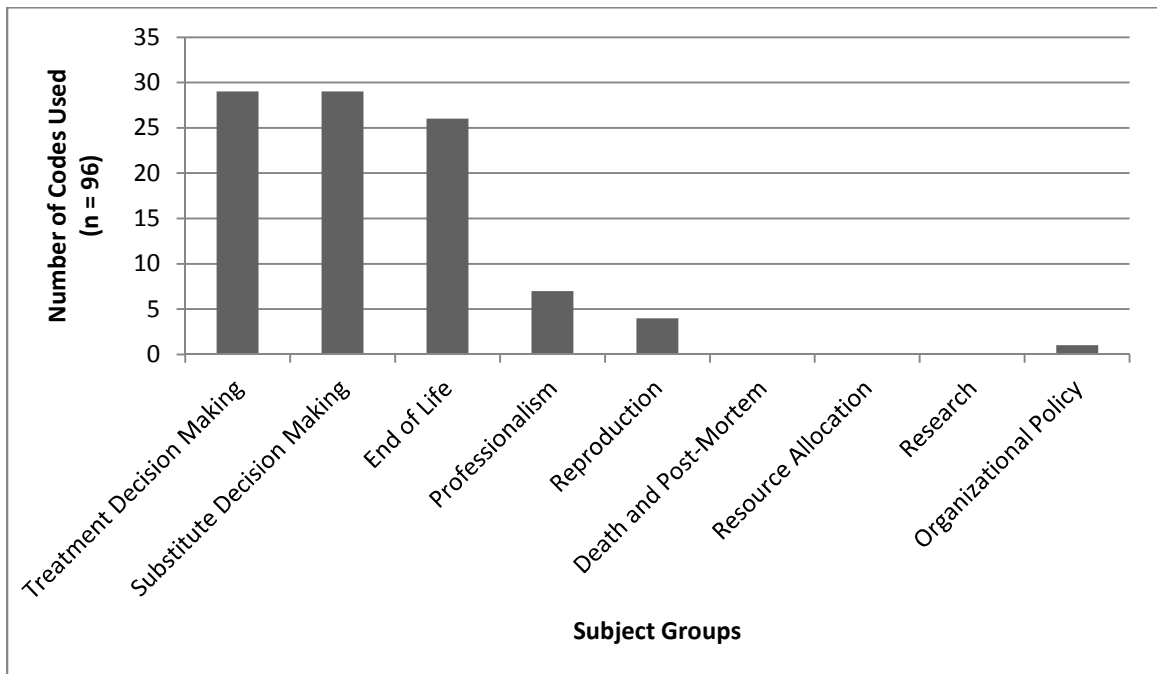
### *General Classification*

32 consultations were conducted over a period of 31 months. A single case was tagged with three different codes which each describes a very specific type of ethical dilemma or conflict (appendix 1). In other words, 96 codes were applied in this analysis. Some codes were used more often than others which reflect the types of ethical issues occurring more frequently than other types.

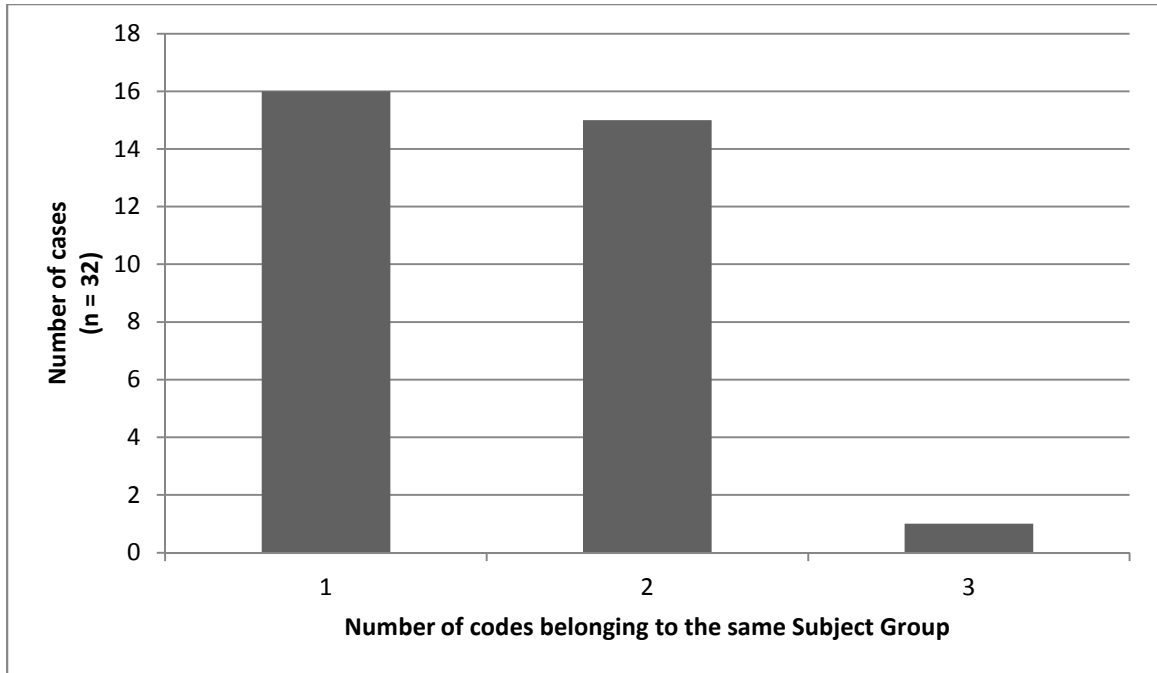
As described earlier, the specific ethical issues or their corresponding codes that share the common theme are bundled together under the same subject group and there are nine of them (Figure 1). Of the total 96 codes used, 29 (30.2%) of them were the ones that falls under the subject group “Treatment Decision Making. 29 (30.2%) of them are from “Substitute Decision Making” and 26 (27.1%) belonged to “End of Life.” Those three subject groups were the ones that are most prevalent throughout the consultations filed to the BMC during the period. There are modest frequency of issues under “Professionalism” (7 out of 96; 7.29%) and “Reproduction” (4 out of 96; 4.17%) and only a single occurrence of “Organizational Policy” (1 out of 96; 1.04%). On the other hand, there was no consultation that were linked to issues involving “Death and Post-Mortem,” “Resource Allocation” and “Research.”

The reason why the number of codes instead of the number of cases was used to measure the frequency of certain ethical issues is that some cases were tagged with more than one code from the same subject group. A single case can be tagged with up to three codes. For example, it is possible to label a consultation with codes “Resuscitation for

Full Arrest (Code # 3.01)”, “Futility / Inappropriate or Nonbeneficial Treatment (Code #3.10)” and “Concern About Decision-Maker Choices (Code #2.04).” In this case, the first two cases belong to the same subject group “End of Life.” 16 out of 32 cases (50.0%) were tagged with 2 or 3 codes from the same subject group. This creates a significant overlap when the number of cases was used to measure the frequency of issues and was thus avoided.

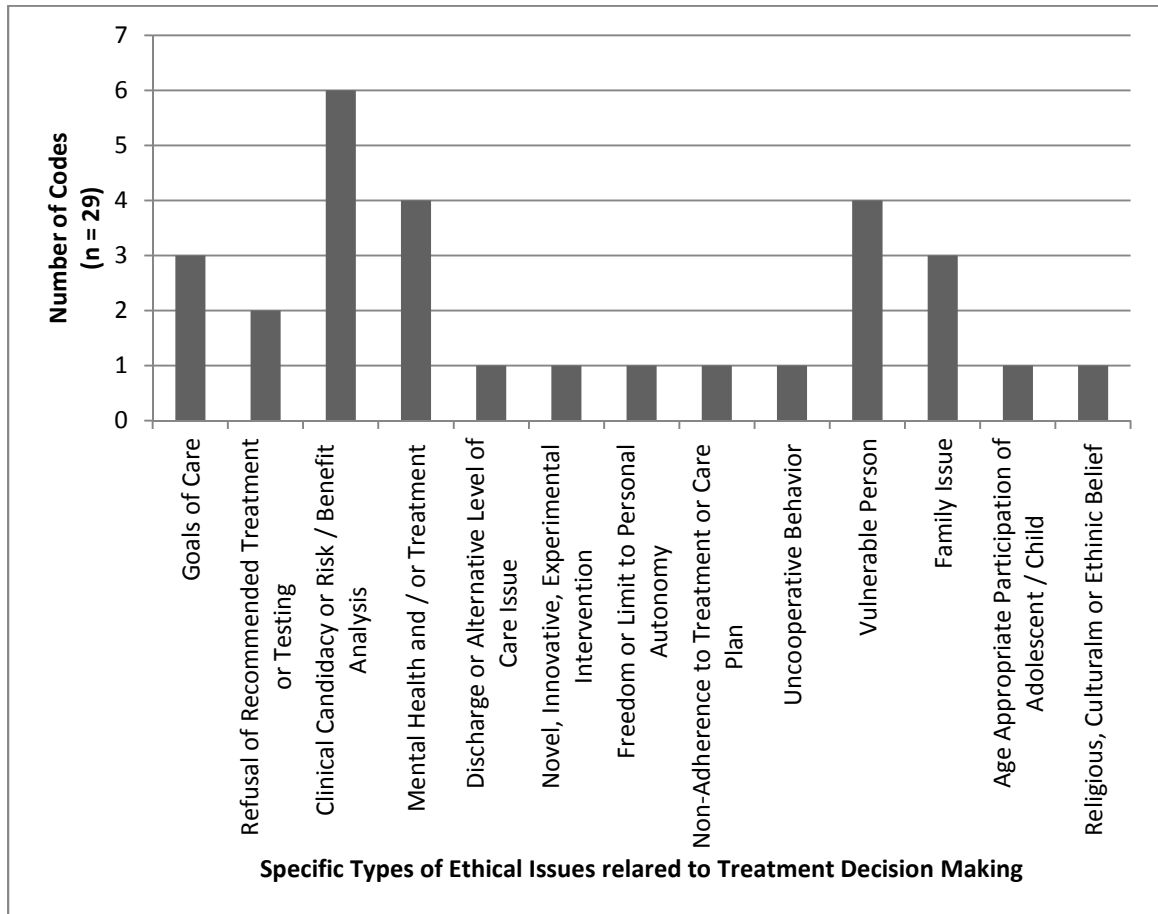


**Figure 1: Frequency of ethical issues for each Subject Groups.** The number of codes (total = 96) used from each subject group was employed as a parameter to measure the frequency of ethical issues. The distribution reveals ethical issues that fall under “Treatment Decision Making,” and/or “Substitute Decision Making” and/or “End of Life” were most prevalent.



**Figure 2: Frequency of consultations that were tagged with more than one code from the same subject group.** The number of cases (total = 32) was used as a parameter to measure the frequency. Exactly a half of total cases were labeled with 2 or 3 codes from the same subject group.

*Specific Issues under Treatment Decision Making*



**Figure 3: Frequency of specific types of ethical issues under Treatment Decision Making.** The number of times a particular code was used was employed as a parameter to measure the frequency of ethical issues. The codes from this particular subject group were used total 29 times. Out of 26 different specific codes, only 13 of them were actually used. Code #1.05, which denotes “Clinical Candidacy or Risk / Benefit Analysis” was used most frequently. “Goals of Care,” “Mental Health and / or Treatment,” “Vulnerable Person,” and “Family Issue” also had relatively higher frequency.

Of the 22 cases that had codes belonging to the subject group Treatment Decision Making, 16 of them had only one code from the subject group. Six of them had two codes while one had its all three codes from the subject group. This means a total of 29 codes (out of 96; 30.2%) that belong to the subject group were assigned to the consultations.

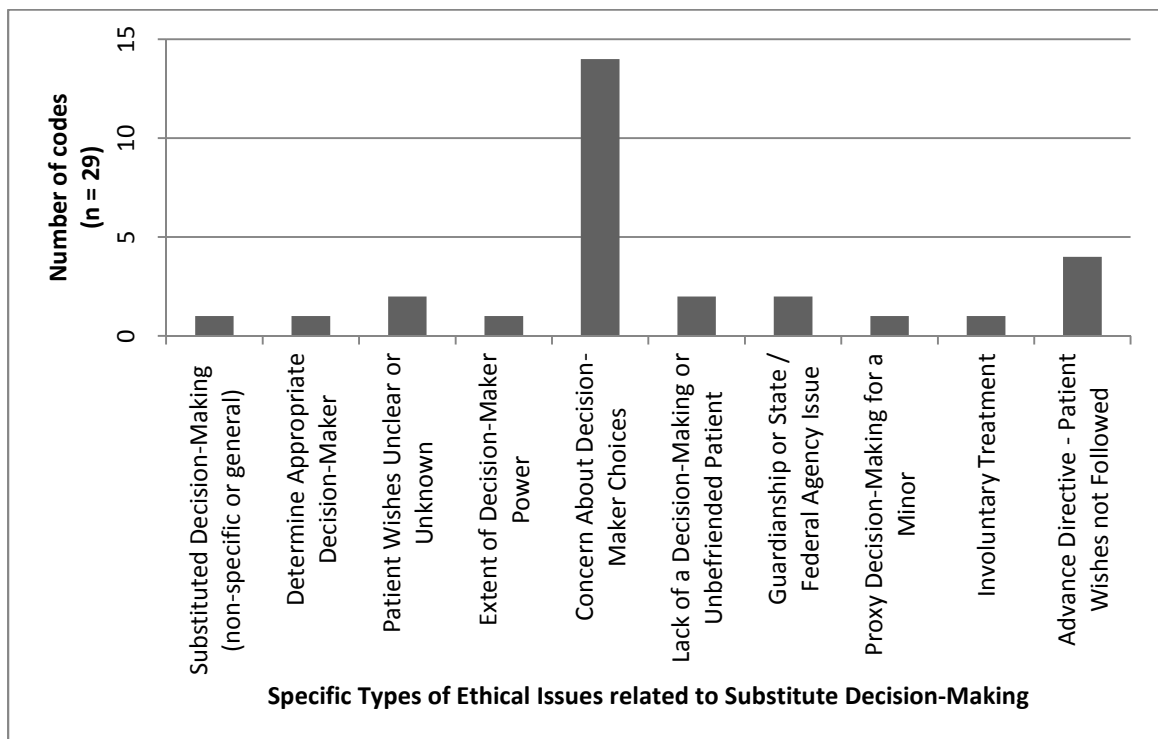
Within the subject group, there are 26 specific codes or subcategories that each pertains

to more specific ethical issues of the topic (Appendix 1). Each specific code can be used only once per case. For example, you cannot use the code “Mental Health and /or Treatment (Code # 1.07)” twice on one case; thus there’s no chance of overlap. In other words, if the code was used three times, there were three different cases that were labeled with that code. The frequency of issues that belong to each subcategory was measured (Figure 3). Of the 26 specific types of issues within the subject group, only 13 of were actually observed (and 7 of them were used only once). The most prevalent issue under this particular category was ones related to “clinical candidacy or risk / benefit analysis (Code # 1.05).” Of the total 96 codes from the entire sample (29 codes from this subject group), six of them were this particular code. (Since there’s no overlap, this also means that, of the total 32 cases, six of them were tagged with this code). This marks the frequency of 6.25% (6 out of 96). Issues about “Mental Health and /or Treatment,” “Vulnerable Person,” (both 4.17%; 4 out of 96) “Goals of Care,” and “Family Issues” (both 3.13%; 3 out of 96) were also relatively prevalent as well.

#### *Specific Issues under Substitute Decision Making*

25 consultations had codes from the subject group “Substituted Decision Making.” 21 of them had only one code from the subject group while four had two codes. Therefore, total 29 codes (out of 96; 30.2%) that belong to the subject group were assigned among 32 consultations. Within this particular subject group, there are 16 specific codes or subcategories (Appendix 1). Of the 16 specific types of issues within the family, 10 of were actually observed (and 5 of them were used only once). The issue

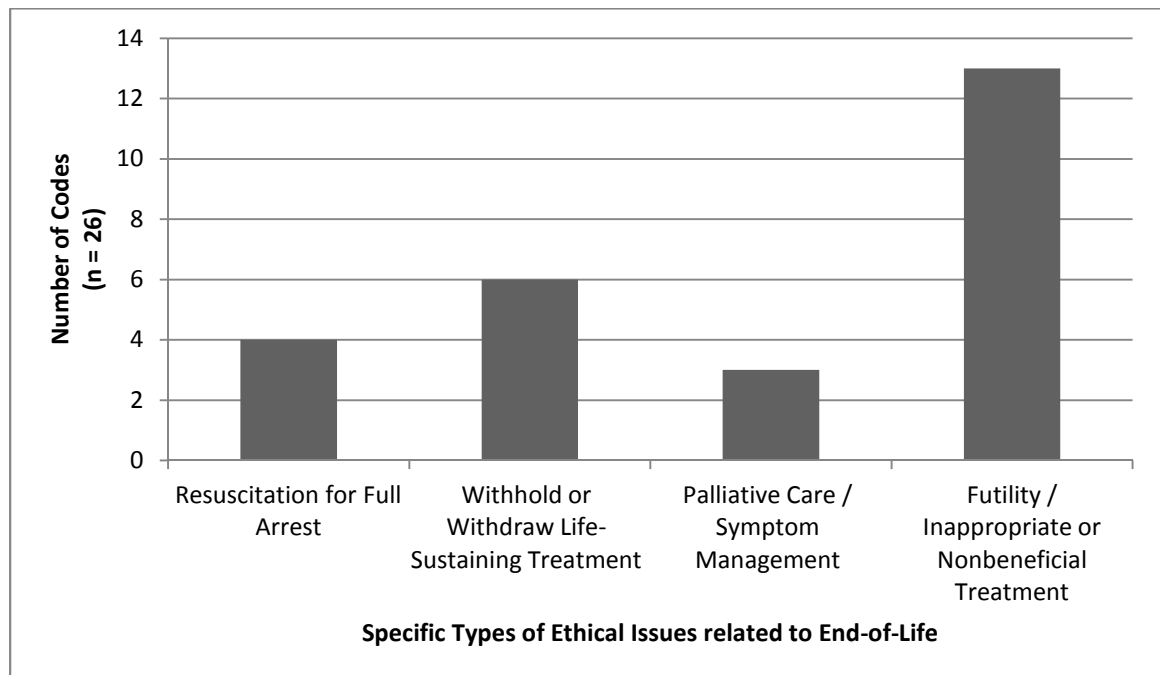
of “Concern About Decision-Maker Choices (Code #2.04)” was dominantly prevalent within this subject group (Figure 4). Of the total 96 codes from the entire sample (29 codes from this subject group), 14 of them were this particular code. Not only does this make the frequency 14.6% (14 out of 96), it almost makes up the half of all codes from this particular subject group. Issues related to “Advanced Directive – Patient Wishes Not Followed (Code #2.14)” had moderate frequency of 4.17% (4 out of 96).



**Figure 4: Frequency of specific types of ethical issues under Substitute Decision Making.** The number of times a particular code was used was employed as a parameter to measure the frequency of ethical issues. The codes from this particular subject group were used total 29 times. Out of 16 different specific codes, 10 of them were actually used. Code #2.04, which denotes “Concern About Decision Maker Choices” was used predominantly. Use of Code #2.14, “Advanced Directive Patient Wished not Followed,” had relatively higher frequency.

### *Specific Issues under End of Life*

There were 21 cases that were labeled with at least one code from this particular subject group “End of Life.” 16 of them just had one code while 5 of them had two. Thus, a total of 26 codes (out of 96, 27.1%) were used among 32 cases. Within this particular subject group, while there are 11 subcategories (Appendix 1), only four of them were actually used. Among the four, the issue of “Futility / Inappropriate or Nonbeneficial Treatment (Code # 3.10)” was most prevalent by a large margin (13.5%; 13 out of 96). It makes exactly the half of all codes from this particular subject group. While not as explicit, the remaining three still had moderately high frequency as well: “Resuscitation of Full Arrest (4.17%; 4 out of 96),” “Withhold / Withdraw Life-Sustaining Treatment (6.25%; 6 out of 96)” and “Palliative Care / Symptom Management (3.13%; 3 out of 96).”

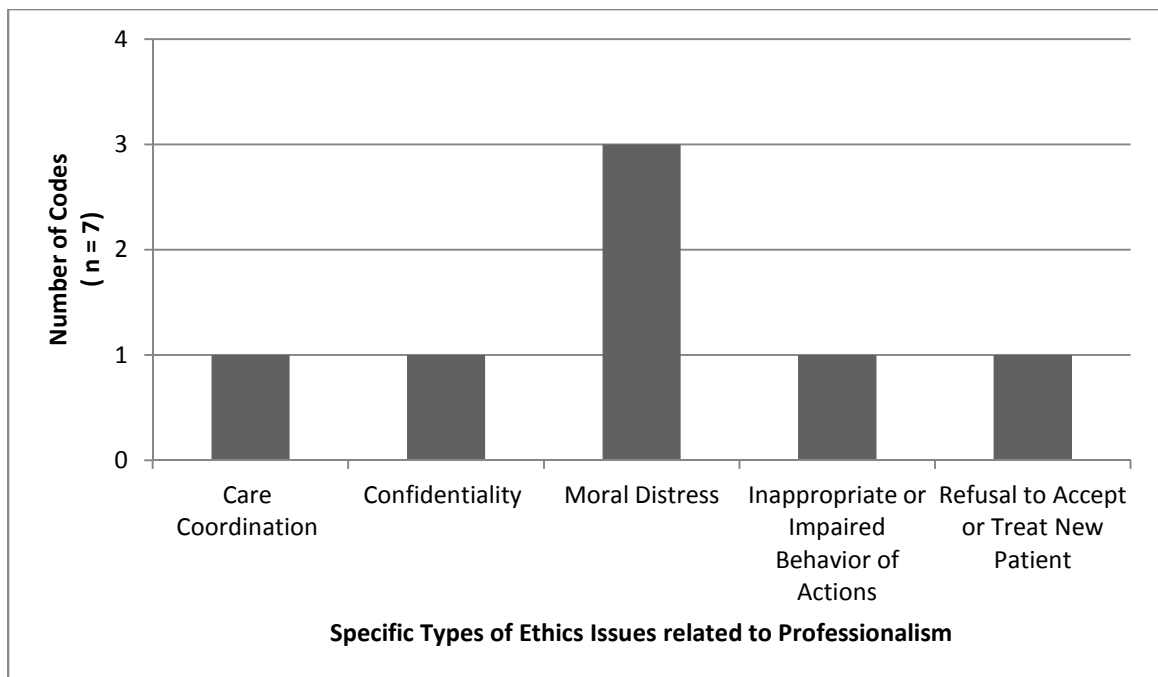


**Figure 5: Frequency of specific types of ethical issues under End-Of-Life.** The number of times a particular code was used was employed as a parameter to measure the frequency of ethical issues. The codes from this particular subject group were used a total

of 26 times. Out of 11 different specific codes, only 4 of them were actually observed. Code #3.10 for “Futility / Inappropriate or Nonbeneficial Treatment” was used predominantly.

*Specific Issues under Professionalism*

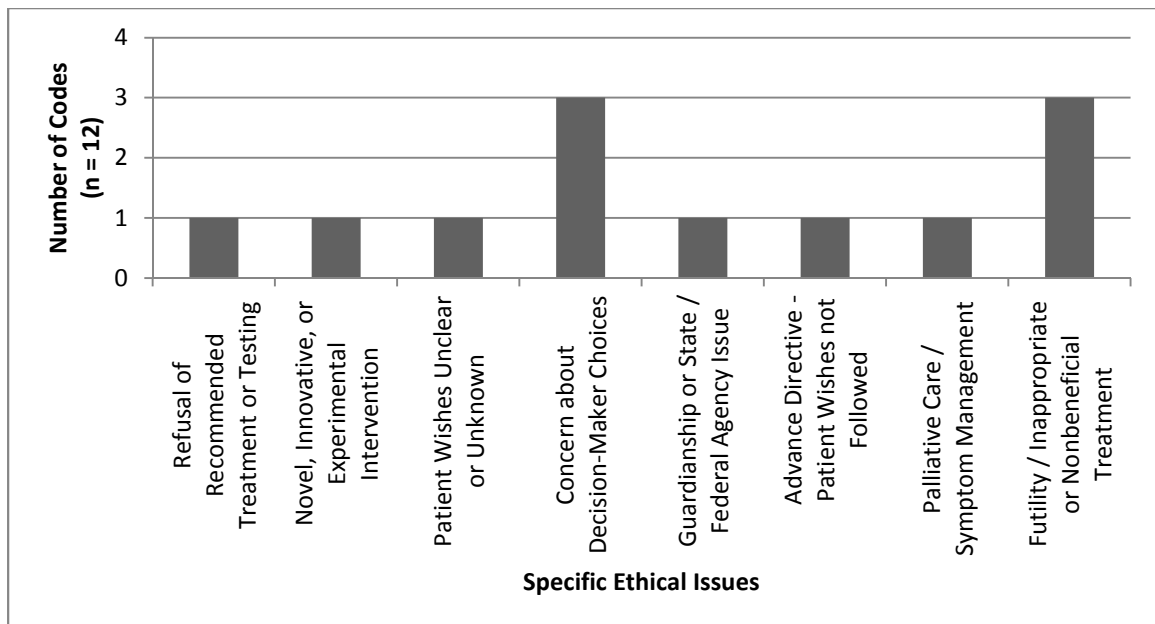
The subject group “Professionalism” had seven codes (out of 96; 7.29%) from six cases with in the sample (fives cases with one code while one case with two). Within this particular subject group, there are 19 subcategories (Appendix 1). Yet, only five of them were actually observed. Among the five, the subcategory “Moral Distress (Code #4.05)” was most frequently used (3 out of 96; 3.12%). The other four were all used only once.



**Figure 6: Frequency of specific types of ethical issues under Professionalism:** The number of times a particular code was used was employed as a parameter to measure the frequency of ethical issues. The codes from this particular subject group were used a total of seven times. Out of 19 different specific codes, only 4 of them were actually observed. Code #4.05 for “Moral Distress” was used most frequently.

*Issues that coincide with Clinical Candidacy or Risk / Benefit Analysis*

As stated above, there were six cases that involved the issues that can be classified as “Clinical Candidacy or Risk / Benefit Analysis.” (i.e.: the code for “Clinical Candidacy or Risk / Benefit Analysis,” Code #1.05, was used six times while cataloguing the 32 consultations). This was the most prevalent type of ethical issues under the Treatment Decision Making subject group. Because each consultation is labeled with three different codes, among these six cases that share Code #1.05, there are a total of 12 additional codes. In fact, there were eight different subcategories that occurred simultaneously with Code #1.05. Examining the distribution of these codes reveals the trend of ethical issue subcategories that coincide with “Clinical Candidacy or Risk / Benefit Analysis” (Figure 7). Among the 12 codes from the six cases, three of them were Code #2.04 (Concern About Decision-Maker Choices) and another three were Code #3.10 (Futility / Inappropriate or Nonbeneficial Treatment). This means there were three consultations that were tagged with both Code #1.05 and Code #2.04. Similarly, This means there were three consultations that were tagged with both Code #1.05 and Code #3.10. It is noteworthy that these two combinations are not mutually exclusive. In fact, there was one consultation that had all Code #1.05, #2.04 and #3.10.

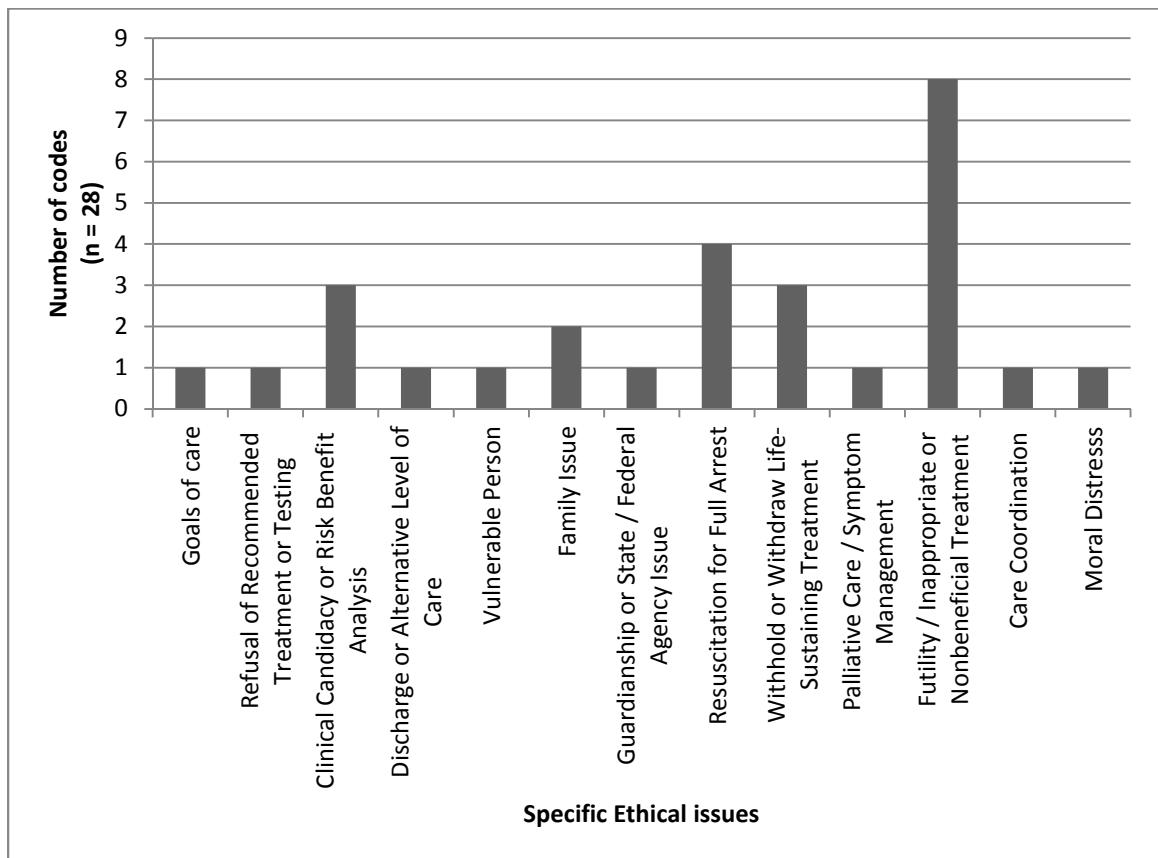


**Figure 7: Ethical Issues that co-occurred with Clinical Candidacy or Risk / Benefit Analysis.** The number of times a particular code was used was employed as a parameter to measure the frequency of ethical issues matching the criterion. “Concern About Decision-Maker Choices” and “Futility / Inappropriate or Nonbeneficial Treatment” showed stronger tendency to coincide with “Clinical Candidacy or Risk / Benefit Analysis.”

*Issues that coincide with Concern About Decision-Maker Choices*

Aforementioned 14 cases that demonstrated Concern About Decision-Maker Choices (Code #2.04) made it most predominant subcategory of ethical issues under the subject group “Substituted Decision Making.” Among these 14 cases, there were total 28 additional codes that demonstrate types of issues that co-occurred with Concern About Decision-Maker Choices (Figure 8). 13 different types of ethical issues fit the criteria. Futility / Inappropriate or Nonbeneficial Treatment once again was very prevalent among the cases of interest (There were seven consultations that could be described as both “Concern About Decision-Maker Choices” and “Futility / Inappropriate or Nonbeneficial Treatment.” However, under this particular condition, the subcategory was single-

handedly dominant. There were several subcategories that had relatively higher co-occurrence rate than other: “Clinical Candidacy or Risk Benefit Analysis”, “Resuscitation of Full Arrest” and “Withhold or withdraw Life Sustaining Treatment.”

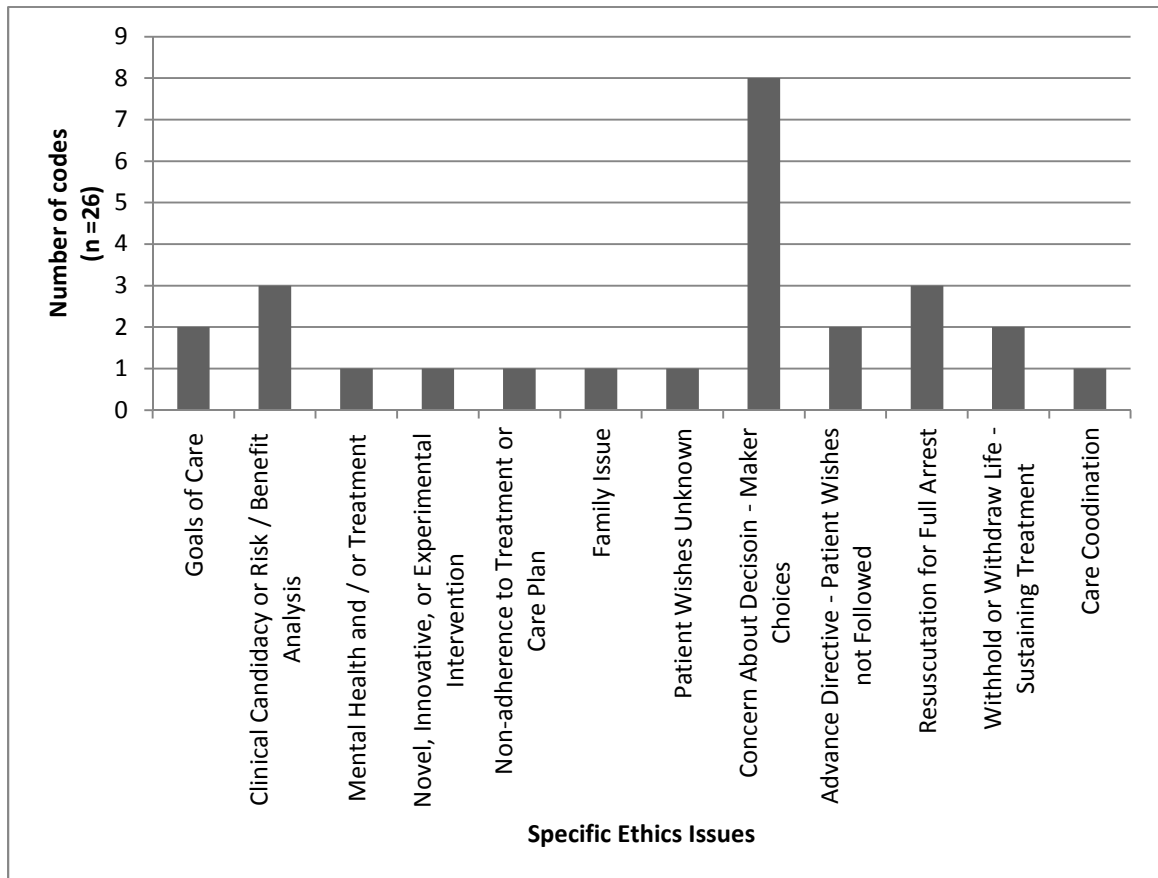


**Figure 8: Ethical Issues that co-occurred with Concern About Decision-Maker Choices.** The number of times a particular code was used was employed as a parameter to measure the frequency of ethical issues matching the criterion. “Futility / Inappropriate or Nonbeneficial Treatment” showed very strong tendency to coincide with “Concern About Decision Maker.”

*Issues that coincide with Futility / Inappropriate or Nonbeneficial Treatment*

As stated in the previous section, there were 13 consultations that were tagged with Code #3.10 Futility / Inappropriate or Nonbeneficial Treatment, most frequently

occurring type under the End of Life Subject Group. Among these 13 consultations that share the code #3.10, there total 26 additional codes, which represent types of ethical issues that tend to coincide with “Futility / Inappropriate or Nonbeneficial Treatment.” These 26 codes come from 12 different specific types (Figure 9). Concern About Decision-Maker Choices showed the highest coincidence rate, which fits perfectly with the result stated in the section right above. “Clinical Candidacy or Risk / Benefit Analysis” and “Resuscitation for Full Arrest” had relatively higher rate.



**Figure 9: Ethical Issues that co-occurred with Futility / Inappropriate or Nonbeneficial Treatment.** The number of times a particular code was used was employed as a parameter to measure the frequency of ethical issues matching the criterion. “Concern About Decision Maker” showed very strong tendency to coincide with “Futility / Inappropriate or Nonbeneficial Treatment.”

### *Modifiers*

As previously stated, there are three different layers of modifiers: 1) Types of Ethics Intervention 2) Locus of Uncertainty or Conflict and 3) Level of Complexity (Appendix 2).

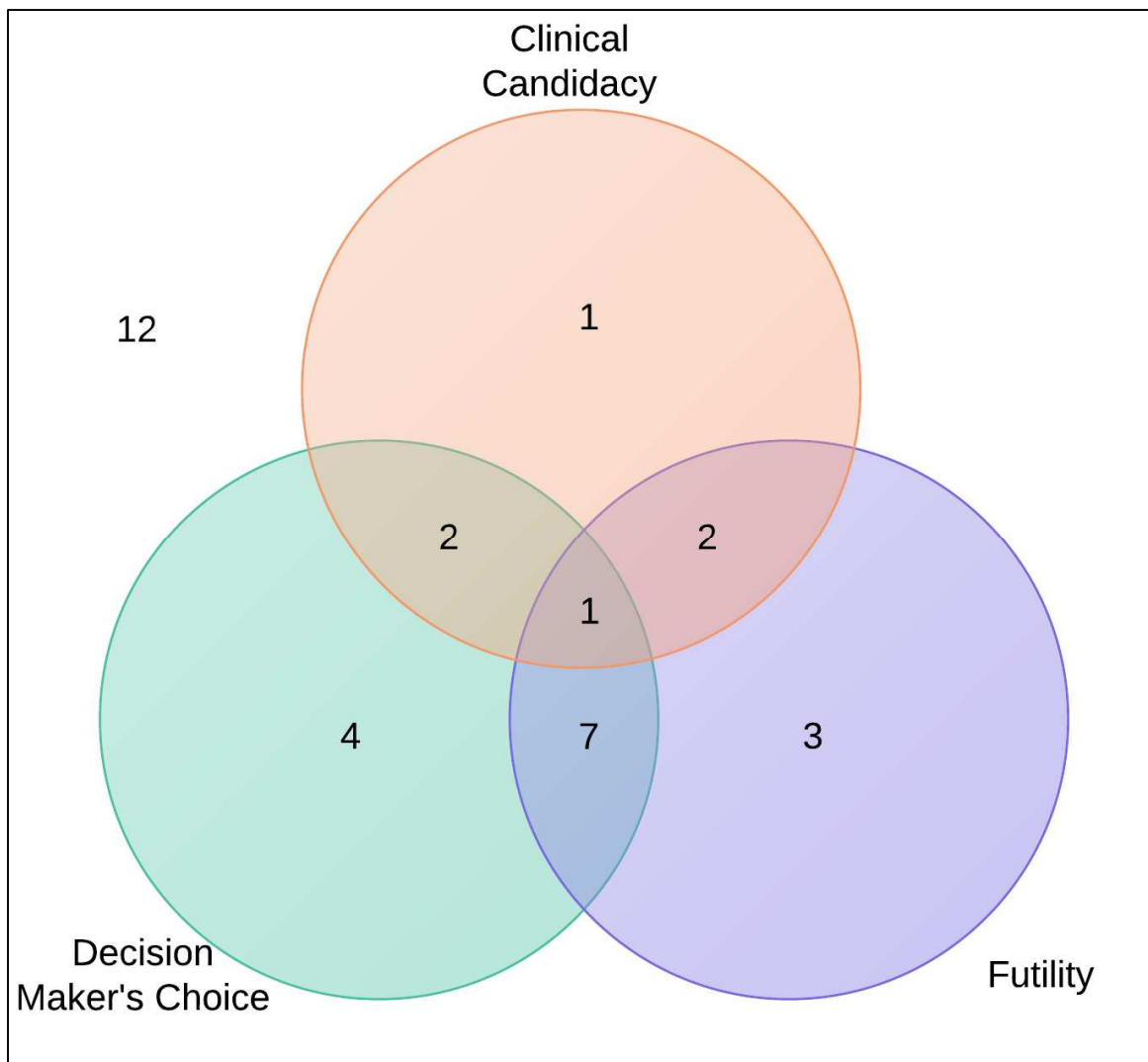
For the modifier level 1, 20 of 32 consultations were classified as “Conflict or Disagreement,” seven were “Values Clarification and Integration,” four were “Clarification / Analysis of Issues or Problem Solving” and one was “Documentation, Policy, Legal Issue.”

For the modifier level 2, in the majority of cases, uncertainty or conflict resides in either between Patient’s Family and Team (16 out of 32) or Patient and team (9 out of 32).

For the modifier level 3, all of the cases apply to either Intermediate or Advanced level of complexity.

### *Examining the Three Major Hits*

For the sake of simplicity, “Clinical Candidacy or Risk / Benefit Analysis”, “Concern About Decision Maker Choices” and “Futility / Inappropriate or Nonbeneficial Treatment” are now called “The Three Major Hits.” As the previous three sections suggested, they tend to co-occur with one another. Of the 32 consultations examined, 20 of them were classified with at least one of the three. 12 of them had more than one of the three (i.e. coincidence). There was one case that had all of the three. These overlaps are depicted in the Figure 10.



**Figure 10: Intersections of consultations involving the Three Major Hits.** Venn Diagram of consultations that were classified with at least one of the Three Major Hits (Clinical Candidacy, Concern about Decision Maker and Futility).

One of the advantages of the ACECS is that it allows one to narrow down to the themes of consultations that represent recurrent ethical dilemmas. By re-evaluating representative cases and scrutinizing what exactly elicited these consultations, one may be able to expose underlying reasons and possible systematic problems. The organization

can then work to address these underlying issues and/or systematic problems to attempt to prevent future ethical dilemmas.

There were six consultations that involved the issue of Clinical Candidacy or Risk / Benefit Analysis. The ACECS defines it as follows (Armstrong, 2013):

#### 1.05 Clinical Candidacy or Risk / Benefit Analysis

The consideration of whether a medical or surgical procedure is worth risk to the patient as compared to anticipated benefits. Intervention that can provide care for a patient's condition may provide unacceptable harm as well and prompt a care provider to determine that a patient is ineligible for clinical intervention.

Example: Surgical Procedures, chemotherapy and other pharmacotherapy, end of life care, futility, procedures / examinations performed under anesthesia, organ transplantation, clinical trial exclusion

These six consultations were identified and revisited for further evaluation. In five cases, patients' clinical candidacy was questioned because proposed treatments, including surgeries, were aggressive and were accompanied by significant risks or side effects. The remaining one case involved a novel treatment (fecal transplant) that had never been implemented at the BMC. In all six cases, patients were inflicted with severe ailments including metastatic cancers, traumatic brain injury and severe *Clostridium difficile* infection. The trend is hardly surprising since non-severe ailments usually do not require aggressive treatments that are controversial enough to elicit the issue of Clinical Candidacy due to its potential risks. In addition, the definition itself explains why this particular type of ethical issue tends to coincide with that of Futility / Nonbeneficial Treatment.

14 consultations involved the issue of Concern About the Decision Maker

Choices. It is defined as follows (Armstrong, 2013):

#### 2.04 Concern About Decision-Maker Choices

When a stake holder express concern that the designated decision-maker is not, or cannot, make decision in the best interest of the patient or in keeping with the patient's wishes, values or beliefs

They were re-examined with one focus: who were the designated decision makers (proxies) in each case? In 12 cases, it was patient's family member(s) who were in a position to make the decision on behalf of the patients. Even when multiple family members were involved in the decision making process, there was usually one single legal health care proxy. There was one case that had a protective service agency as a decision maker. The last remaining case had a court appointed guardian as a legal health care proxy.

Moreover, 13 consultations that involved the issue of Futility / Inappropriate or Nonbeneficial Treatment were revisited to chart what exactly was considered as futile in each case. The definition of Futility / Inappropriate or Nonbeneficial Treatment per the ACECS (Armstrong, 2013):

#### 3.10 Futility / Inappropriate or Nonbeneficial Treatment

Treatment provided to a patient when there is no reasonable hope for cure or benefit, or whose goal is merely prolonging the dying process.

Commonly combined with: Resource Allocation, Cost, Policy, Extent of Decision-Maker Power, Goals of Care, Family Issue, Palliative Care, Advocacy or Social Responsibility

In 10 cases, what was considered as potentially futile was initiation or continuation of aggressive and curative treatments on patients whose ailments are near the end stage (In

these cases, they are suffering from not only originally diagnosed ailments but also various complications stemming from them). In two cases, initiation or continuation of life sustaining treatment was deemed as potentially futile. In the remaining one case, keeping the patient's full code status was deemed as futile.

Following this, eight consultations that involved BOTH "Concern About the Decision Maker Choices" and "Futility / Inappropriate or Nonbeneficial Treatment" were re-examined to expose a potential common theme. As previously noted, these two "hits" showed significant overlap (Figure 8-9). In seven cases, patients' family (who participate as designated decision makers) insisted on the continuation of curative or life-sustaining treatments while the teams (physicians) believed such was not for the best interest of the patients due to their poor conditions and prognosis. In the remaining one case, a family member (proxy) was more supportive of palliative care while the patient had expressed the desire to "do everything" and the team believed there was indeed some chance of meaningful recovery.

Therefore, it can be concluded, at BMC, there are frequent instances (25%; 8 out of 32 total cases) that a discrepancy between patients' family (who is also partaking as designated proxy) and physicians' team, in terms of what is the best interest of the patient, goes unresolved and precipitates ethics consultations. Most of the times, it occurs because families are unable to give up on patients with a minimal chance of meaningful recovery. This is only bolstered by results shown by the modifiers. 62.5% (20 out of 32) of consultations were classified as "Conflict or Disagreement" and 50% (16 out of 32) of cases had uncertainty or conflict between "Patient's Family and Team." This tendency of

conflict to arise over the issue of “futility” is somewhat consistent with similar retrospective studies done in the past, (Moeller et al., 2012; Swetz et al., 2007; Romano, Wahlander, Lang, Li, & Prager, 2009; Nilson, Acres, Tamerin, & Fins, 2008) yet still could be linked to the systematic problem unique to the BMC.

## **DISCUSSION**

The study demonstrated that ethical issues related to “Treatment Decision Making,” “Substitute Decision Making,” or “End of Life” were most prevalent and more likely to elicit ethics consultations at BMC (Figure 1).

More specifically, “Clinical Candidacy or Risk / Benefit Analysis” (belonging to the Treatment Decision Making Subject Group), “Concern About Decision Maker Choices” (belonging to the Substitute Decision Making Subject Group) and “Futility / Inappropriate or Nonbeneficial Treatment” (belonging to the End of Life Group) are recurrent themes throughout the consultations examined (Figure 3-5). Not only are these “Three Major Hits” prevalent, they also have a very high tendency to occur simultaneously at BMC (Figure 10).

Further evaluation of consultations involving the Three Major Hits revealed several interesting trends at BMC. First, the clinical candidacy of patients was questioned mostly because aggressive treatments with significant risks were proposed in order to counter ailments in dire conditions. Second, when there is a concern about decision maker’s choices, it is often the patient’s family member(s) who are designated to make decision for patient’s behalf. Third, treatments considered as futile were mostly curative and aggressive treatments on patients with minimal chance of meaningful recovery. Finally, there are frequent instances that family members partaking as proxy disagree with physicians in deciding the best interest of patients with severe ailments, which eventually lead to ethics consultations. In order to have better grasp of this trend, the result of this study was compared to other studies carried out in the past.

### *Comparing with the Past Studies*

Similar retrospective studies have been done in the past. Comparing this study to them may expose issues that are unique to BMC. It must be noted, however, the classification system is vastly less expansive compared to the ACECS. It usually consisted of a mere nine to 22 specific categories contrary to the ACECS's 138. As mentioned in the introduction, such discrepancy makes a perfect comparison between different studies almost impossible.

Moeller used a nine category classification system in his retrospective study (Moeller et al., 2012). He observed a total of 195 reasons for the 100 ethics consultations he analyzed. His five most frequently reported reasons for the ethics consultations were: “(1) Family opposed to withdrawing life-sustaining treatment (LST), (2) Physician does not wish to provide LST, (3) Patient competence or capacity in question, (4) Issues of futility, and (5) Physician opposed to withdrawing LST. While the issue of futility was the fourth in the order, its raw frequency (observed in 25 cases out of 100) was not too far behind the top three (28, 27 and 27 out of 100, respectively).

Swetz retrospectively studied his 255 consultations using a classification system with 15 categories (Swetz et al., 2007). Just like Moller's study, consultations were requested for multiple reasons. The leading reason for consultations was “Competency, decisional capacity,” which applied to 82% of his consultations. It was followed by: “Staff or Professional Conflict (76%),” “Quality of Life, end-of-care (60%),” “Appropriateness of treatment, goals of care, and futility (54%)” and “Withdrawing or withholding treatment (52%).”

Romano used Swetz 's classification system to analyze his 168 consultations (Romano, Wahlander, Lang, Li, & Prager, 2009). The most common reason for ethics consultation request was "Withdrawing or withholding treatment (108 of 168; 64%), followed by Appropriateness of treatment, goals of care, and futility (14%)," "Competency, decisional capacity, (10%)," "Resuscitation Issues (8%)" and "Legal-ethics interface (7%)."

Finally, Nilson used a 22 category classification system to study 53 consultations (Nilson, Acres, Tamerin, & Fins, 2008). Common ethical dilemmas encountered were "Withdrawal of life sustaining-care (28 out of 53)," "advance directives (15)," "Withholding of life sustaining therapy / DNR (8)," "Refusal of recommended treatment (6)," "capacity/informed consent (5)", "surrogate decision making (5)", "withholding of other life-sustaining therapies (4)", "futility (4)", and "issues with isolated, incapacitated patients (4)."

These past studies show the issue of futility can be one of the most common reasons for ethics consultations (Swetz and Moeller), although not uniformly the case (Romano or Nilson). In this particular study at BMC, the issue of futility was the second leading specific reason for consultations (involved in 13 cases out of 32; 40.6%) only behind the issue of Concern about Decision maker choices (14 cases of 32; 43.8%). First, this ranking demonstrates the issue of futility is a more significant problem than at the institutions in which Romano's and Nilson's studies took place. Second, this study shows higher raw frequency (40.6%) than Moeller's (25%). Finally, Swetz's classification system does not include a specific code for the issue of clinical candidacy (the third

leading cause at the BMC with 18.8%) like the ACECS does. Also, the issue of futility is bundled together as “Appropriateness or treatment, goal of care, futility.” Once again, the ACECS has is an individual code for the issue of goals of care (Appendix 1). Therefore, it can be argued that the actual number could be lower if Swetz’s samples were tagged by the ACECS. In sum, comparison with the past studies demonstrates the frequency of ethical issues involving futility leading to ethical consultations may be higher in BMC than the norm. There are several possible explanations for this. First, it may have to do with the level of care BMC is providing. Since the institution specializes in the very advanced level of tertiary medical care, it is safe to assume that BMC deals with patients in more complex and dire condition than many other institutions. This larger denominator may lead to more cases involving the issue of futility. Another potential explanation is the diversity of patients BMC is serving, especially in terms of their ethnicity. As explained in the next section, different cultures have different perspectives, which may turn into a source of miscommunication between physicians and patients’ surrogates.

#### *Potential Intervention to address the issue of futility at the BMC*

While the issue of futility itself is universal among health institutions, its relatively higher frequency could be considered reflection of systematic problems unique to BMC. In addition, this study newly exposed intricate relationship between the issues of futility with other very common ethics problems such as substituted decision making (As past studies never analyzed the combination of reasons leading to ethics consultations or re-visited consultations for sake of more context). Therefore, it can be argued that this

particular issue or systematic flaw that's causing it is something that needs to be addressed first over other types of ethical issues at BMC.

According to Lo (Lo, 2012, p.121), one systematic way to facilitate avoiding or resolving conflicts involving the issue of futility is developing written guidelines about futile / nonbeneficial treatments. This enables physicians to demonstrate that their decisions regarding futile treatments are based on well considered standards, not on something random. Lo cites the Houston Policy as one of the models of institutional policy on futile treatment. The Houston Policy emphasizes these three points:

“[t]he first is that rather than relying on a substantive definition of futility, the policy should rely on a procedural approach that recognizes the importance of thorough institutional review of each case. The second is that the policy should be based on open and fair processes involving patients, physicians, and institutions. The third is that the policy should be clearly grounded on professional integrity and institutional integrity as a balance to patient autonomy.” (Halevy & Brody, 1996)

Joseph reviewed recently published studies and their empirical data regarding the role of hospital policy on medical futility in conflict resolutions (Joseph, 2011). He concluded that hospital policies on medical futility are effective in resolving conflicts and improving end-of-life care. Therefore, one potential intervention to be considered is to establish or review and improve their policy / guideline regarding the issue of futility / nonbeneficial treatment at BMC.

Another important aspect brought up by Lo is better communication between physicians and surrogates. While many physicians tend to avoid unpleasant discussions about futile treatments with patients / surrogates and opt to make decisions unilaterally instead, Lo argues that it is better to have more discussions than having less. Via

discussion with patients or surrogates, physicians can show their respect for them and clarify goals of care, expectations, needs and concerns (Lo, 2012, p.120). On the other hand, Lo warns unilateral decisions by physicians tend to polarize disagreements instead of resolving it. This is especially important considering that it has been empirically shown that many surrogates do not agree with physicians' judgments of prognosis. A study done by Zier demonstrated that it is very common among surrogate decision makers to doubt about physicians' ability to predict medical futility (Zier 2009). In this particular study, 64% of surrogates interviewed expressed doubts stemming from various reasons "including beliefs that individual physicians' prediction may be unreliable, and need for surrogates to see for themselves the futility of a situation before accepting physicians' prognostication, and the possibility that God will intercede to change patients' outcomes" (Zier et al., 2009). Another study showed less than 2% of surrogates formed their beliefs about the patients' prognosis based solely on prognostic information provided by physicians (Boyd et al., 2010). Boyd listed five other main factors that affect surrogates' opinion about the patients' prognosis: "1) patient's unique intrinsic qualities and will to live; 2) interpretations of the patient's physical appearance or status; 3) the patient's history of illness and / or survival; 4) surrogates' beliefs in the power of their bedside presence; and 5) optimism, intuition, and faith" (Boyd et al., 2010). These findings demonstrate that the thought process of surrogates on patient's prognostic estimates is vastly different from that of physicians. Thus physicians take this into consideration and communicate with surrogates accordingly.

One approach for physicians to understand surrogate's perspective and respond to their emotional needs is empathic comments. Lo argues:

Empathic comments, which reflect the speaker's emotions, encourage patients or surrogates to explore emotions and discuss difficult topics...Some physicians might fear that exploring emotions might arouse in the patient and family feelings of anger, hopelessness, or sadness that doctors are powerless to alleviate. Patients and families, however, will have these emotions whether or not physicians choose to probe them. After these emotions are discussed openly, the patients and family no longer must face them alone. Talking about emotional reactions to serious illness is frequently therapeutic and helps patients and families to accept a grave prognosis. Furthermore, anxiety and depression can be treated once they are identified. It is valuable for physicians to listen to patients and families. In turn, patients who feel they are understood might then be more willing to listen to the physician's perspective (Lo, 2012, p.182).

After physicians understand surrogates' perspective and expectations, it is also important for them to address surrogates' expectations when they are unrealistic. While physicians need to do so without destroying surrogates' hope, it is also harmful to focus exclusively on hope. Back claims "exclusive focus on hope constricts options for discussing how a patient, family and physician can work together with a life threatening illness" (Back, Arnold, & Quill, 2003). Instead, by employing the dual approach, "Hope for the best, and prepare for the worst," physicians can facilitate surrogates to address fears and clarify priorities without destroying their hope or limiting treatment options. This increases the chance to resolve potential issues of futility before it becomes inevitable. Another technique physicians can employ is "I wish statements." Quill argues that while expressing empathy is critical, the means to do so is equally important. It has been observed that many physicians use the phrase "I am sorry" as their empathic response.

While this is well-intentioned and far from inappropriate, it can also be misinterpreted or misdirected. Instead, Quill found saying “I wish...(things were different)” to patient and surrogates is more an effective initial response (Quill, Arnold, & Platt, 2001). The advantage of this strategy is that an “I wish” statement can both acknowledge the hope and suggest the desired outcome is unrealistic. By allowing physicians to express both their empathy and limitation to families or surrogates, this technique will facilitate averting potential conflict between physicians and families over the issue of futility.

Lastly, Lo advises physicians to be sensitive to cultural and religious issues. For example, different cultures tend to have different perspectives on sufferings, death and pain. This is especially important at BMC where patients’ ethnic background is historically diverse. In addition, aforementioned articles stated surrogates’ religious beliefs have significant influence on how surrogates interpret the prognosis (Zier et al., 2009; Boyd et al., 2010).

In sum, another systematic intervention BMC should consider is to improve education or training program on physicians’ communication skills with surrogates employing approaches or techniques listed above. In fact, the BMC medical intensive care unit has embarked on a quality improvement initiative to promote earlier communication between physicians and surrogates of critically ill patients about goals of care for patients with anticipated poor prognosis to try to prevent these types of ethical dilemmas from arising.

### *Critiquing the ACECS*

As stated in the introduction section, there is yet to be an uniformly accepted standard documentation format of HCEC records. In addition, as described in earlier part the *Comparing with the Past Studies* section of the Discussion, different classification systems employed by different retrospective studies makes meaningful comparison among them extremely difficult. This signifies the importance of a standard coding system and the ACECS could well be one. As mentioned in the Methods section, the ACECS has significant advantages over other coding system, which include (but are not limited to) much broader subcategories. However, the ACECS is not without flaws. First, it only allows three codes (i.e. specific types of issues) to describe a consultation, while some of past studies never had such limits. When there are more than three codes that are appropriate, an evaluator needs to choose the three that best entails the core issue of the consultation. This is highly interpretive and thus subjectivity of the evaluator can play a larger role than other coding systems. In addition, by limiting the number of codes applied, the ACECS risks some types of issues needing attention to go unnoticed. In addition, while more codes for more specific types of issues makes evaluation more detailed, it forces an evaluator to explore more options during the coding process. Until the evaluator is fully trained and accustomed, it may force him to spend more time to code consultations than he would with less sophisticated coding system. In the field of medicine where physicians can spare only so much time, this issue is not negligible.

## CONCLUSION

Using the ACECS, several common themes prompting ethics consultations at BMC were exposed. Specifically, the issue of futility / nonbeneficial treatment is arguably a type of issue that must be addressed first over others due to its implications and comparably higher frequency than those in past studies. This is a complex issue for which there's not a silver bullet or quick fix, yet several interventions should be considered to address the issue at the systematic level.

There are some limitations with this particular study. First, it is easy to note that the sample size (32 consultations) is not very large. Second, as stated several times, comparison of results between this study and past studies are not necessarily perfect due to the different classification / coding systems they employed. Third, each consultation was coded by a person who has never been formally trained in the ACECS or as a M.D. While the coding was reviewed by a M.D. who is a member of the BMC and has been directly trained by Dr. Armstrong on the ACECS, there's a chance that the coding would have been different if the sample was coded by a trained individual from the first place.

There are several things that can be done in the future studies. First, there should be a study with a larger sample size, which would not only give the identification of hotspots more validity but also would expose the characteristics of the ACECS (both pros and cons) more vividly. Another potential future study is more in-depth analysis regarding specific issues under substituted decision making. Unlike this study which used the ACECS, the vast majority of past studies never considered different specific types of issues regarding substituted decision making. As demonstrated by the examples in the

Introductions section, they usually had one big category “Substituted Decision Making,” which fails to describe the issue in more details. Using the ACECS, future studies will be able to decipher this particular subject group in more specific and detailed manner.

**ACECS - Armstrong Clinical Ethics Coding System 2013©**

<b>Treatment Decision-Making</b>	<b>3.00</b>	<b>End-of-Life</b>	<b>6.00</b>	<b>Death and Post-mortem</b>
01 Decisional Capacity	01 Resuscitation for Full Arrest	01 Resuscitation	01 Brain Death	01 Autopsy
02 Informed Consent	02 Resuscitation Pre-Arrest Emergency/for Procedure	02 Resuscitation Pre-Arrest Emergency/for Procedure	02 Violation or Location of Body After Death	02 Participation in Learning Exercise
03 Goals of Care	03 Withhold or Withdraw Life-Sustaining Treatment	03 Artificial Nutrition or Hydration	04 Anatomical Donation	04 Release of Body/Disposition of Remains
04 Refusal or Recommended Treatment or Testing	04 Palliative Care/Symptom Management	05 Hospice	05 Release of Body/Disposition of Remains	06 Bereavement Counseling
05 Clinical Candidacy or Risk/Benefit Analysis	05 Palliative Sedation	06 Palliative Sedation	06 Coroner/Medical Examiner/Other Gov't Sep	07 Memorialization (hair, footprints, photos, ei
06 Communication Issue or Barrier	06 Euthanasia	07 Euthanasia	07 Resource Allocation	08 Cost
07 Mental Health and/or Treatment	08 Assisted Suicide/Physician Aid in Dying	08 Futility/Inappropriate or Nonbeneficial Treatment	08 Availability	09 Staffing or Expertise
08 Discharge or Alternative Level of Care Issue	09 Organ and Tissue Donation or Receipt	09 Professionalism	09 Insurance	09 Eligibility or Access
09 Pain Management	10 Professionalism	01 Care Coordination	06 Emergency Privatization	06 Medical Tourism
10 Genetics and Genetic Testing	01 Confidentiality/Privacy/HIPAA	02 Confidentiality/Privacy/HIPAA	07 Bribery or Corruption	07 Human Rights
11 Preventative Intervention	03 Information Disclosure/Request Not to Disclose	03 Abuse, Neglect, or Mandatory Reporting	08 Research	01 Clinical Study Design
12 Complementary, Integrative, Alternative Medicines	04 Moral Distress	05 Consistent Objection	01 Clinical Study Conduct	02 Independent or Institutional Review
13 Body Image, Alteration, or Modification	05 Paternalism or Moral Bias	06 Conflict of Interest	03 Therapeutic Misconception	04 Biobanking or Tissue Sampling
14 Cognitive Enhancement	06 Preferential Treatment	07 Inappropriate or Impaired Behavior or Actions	05 Funding or Compensation	06 Compassionate or Emergency Use
15 Novel, Innovative, or Experimental Intervention	08 Treatment of Self or Family Members	08 Training or Education Issue	07 Device or Drug Development or Approval	08 Authorship, Presentation, or Publication Iss
16 Freedom or Limit to Personal Autonomy	09 Medical Error or Adverse Event	09 Refusal to Accept or Treat New Patient	09 Intellectual Property or Commercialization I	09 Organizational Ethics
17 Non-Adherence to Treatment or Care Plan	10 Dimiss Patient from Practice	10 Potential Harm to Others or a Party/Notification	01 Organizational Policy	01 Organizational Mission and Goals
18 Substance Use	11 Safety or Security	11 Advocacy, Social Responsibility, or Stewardship	02 Structure and Hierarchy	03 Organizational Climate
19 Uncooperative Behavior	12 Legality or Permissibility of Action	01 Sexuality or Sexual Health	04 Organizational Climate	05 Procedural Fairness or Justice Issue
20 Vulnerable Person	01 Contraception	02 Pregnancy or Prenatal Care	06 Risk Management	07 Financial Management
21 Family Issue	03 Pregnancy or Prenatal Care	03 Fetal Testing or Treatment	08 Human Resources	09 Public Relations, Marketing, or Social Medi
22 Discrimination Concern	04 Maternal-Fetal Conflict	04 Termination of Pregnancy	10 Industry or Insurance Relationships	11 Union or Labor Relationships
23 Coercion or Exploitation Concern	05 Sterilization	05 Surrogacy or Gestational Carrier Issue	12 Data Collection and Use	12 Image, Recording, or Film Management
24 Age Appropriate Participation of Adolescents/Child	06 Custody Issues	06 Genetic Donation or Retrieval	13 Image, Recording, or Film Management	14 Health Information Management (HIM)
25 Religious, Cultural, or Ethnic Belief/Tradition	07 Assisted Fertility or Reproductive Technology	07 Embryo Research, Adoption, or Destruction		
99 Other	08 PWS or Post-Mortem Pregnancy	08 Gender Issue		
<b>Substitute Decision-Making</b>	<b>4.00</b>	<b>Reproduction</b>	<b>8.00</b>	<b>Research</b>
01 Determine Appropriate Decision-Maker	01 Care Coordination	01 Sexuality or Sexual Health	01 Clinical Study Design	01 Clinical Study Conduct
02 Patient Wishes Unclear or Unknown	02 Confidentiality/Privacy/HIPAA	02 Contraception	02 Independent or Institutional Review	03 Therapeutic Misconception
03 Extent of Decision-Maker Power	03 Information Disclosure/Request Not to Disclose	03 Pregnancy or Prenatal Care	03 Biobanking or Tissue Sampling	04 Funding or Compensation
04 Concern About Decision-Maker Choices	04 Abuse, Neglect, or Mandatory Reporting	04 Fetal Testing or Treatment	04 Compassionate or Emergency Use	05 Device or Drug Development or Approval
05 Remove or Replace Decision-Maker	05 Consistent Objection	05 Maternal-Fetal Conflict	05 Authorship, Presentation, or Publication Iss	05 Intellectual Property or Commercialization I
06 Lack of a Decision-Maker or Unbefriended Patient	06 Conflict of Interest	06 Termination of Pregnancy	06 Organizational Ethics	06 Organizational Policy
07 Guardianship or State/Federal Agency Issue	07 Inappropriate or Impaired Behavior or Actions	07 Sterilization	07 Organizational Mission and Goals	07 Structure and Hierarchy
08 EMTALA, CAPTA, or Other Legally Required Care	08 Training or Education Issue	08 Surrogacy or Gestational Carrier Issue	08 Organizational Climate	08 Procedural Fairness or Justice Issue
09 Proxy Decision-Making for a Minor	09 Medical Error or Adverse Event	09 Genetic Donation or Retrieval	09 Risk Management	09 Human Resources
10 Assent of Patient	10 Dimiss Patient from Practice	10 Embryo Research, Adoption, or Destruction	10 Public Relations, Marketing, or Social Medi	10 Industry or Insurance Relationships
11 Involuntary Treatment	11 Safety or Security	11 PWS or Post-Mortem Pregnancy	11 Union or Labor Relationships	11 Data Collection and Use
12 Emergency Consent	12 Legality or Permissibility of Action		12 Image, Recording, or Film Management	12 Health Information Management (HIM)
13 Create, Change, Void Advance Directive	01 Contraception			
14 Advance Care Planning Process	02 Pregnancy or Prenatal Care			
15 Interpretation or Applicability of Advance Directive	03 Fetal Testing or Treatment			
16 Advance Directive -- Patient Wishes not Followed	04 Maternal-Fetal Conflict			

*Coding for Ethics Consultations is achieved through any combination of up to three codes. Place Modifiers at the beginning of the coding, and separate codes with commas.*

- Examples: D, F, II, 5.06, 1.17, 1.07  
 E, b, I, 2.01, 2.02, 3.03  
 C, I, III, 3.10, 6.01, 9.01  
 A, g, IV, 1.24, 1.01, 1.04P

**P Pediatric Case**

**Modifiers Level 1 – Type of Ethics Intervention**

- A. Conflict or disagreement
- B. Values Clarification and Integration
- C. Clarification/Analysis of Issues or Problem-solving
- D. Answer Questions/Provide Support
- E. Documentation, Policy, Legal Issue
- F. Develop Recommendation (New or novel issue)
- G. Review

**Modifiers Level 2 – Locus of Uncertainty or Conflict**

- a. Patient
- b. Family (or Proxy)
- c. Physician
- d. Team (Nurse, Social Worker, Physicians, etc)
- e. Patient – Family
- f. Patient – Physician
- g. Patient – Team
- h. Family – Physician
- i. Family – Team
- j. Physician – Physician
- k. Physician – Team
- l. Team – Team
- m. Patient/Family – Physician – Team
- n. Administration/Policy/System Issue
- o. External Organization

**Modifiers Level 3 – Level of Complexity**

- I. Basic
- II. Intermediate
- III. Advanced
- IV. Expert

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## Curriculum Vitae

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### Immigration Status:

International Student (Citizenship: Japan)

### Language:

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### Interests:

Psycho-oncology, Mind-Body connection, Psychosocial aspect of medicine, Bioethics, Psychiatry, Positive Psychology, Oncology, Palliative Care, Medical Sociology, Counseling, Psychology Complementary and Alternative Medicine

### Computer Skills:

Microsoft Word, PowerPoint, Excel

### Education:

Sep, 2012-  
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(Graduate  
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#### **MAMS (Masters in medical science) Program**

Boston University School of Medicine, Boston, MA

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Overall GPA (current): 3.3

*Relevant Course Work: Introduction to Human Physiology, Introduction to Histology, Biochemistry, Introduction to Medical Pharmacology, Behavioral Medicine*

May, 2012

#### **Bachelor of Arts in Biology and Psychology**

Minor in Bioethics

Pre-Medicine

Johns Hopkins University, Baltimore, MD

Overall GPA: 3.24

Recipient of Dean's List, Fall 2008

*Relevant Course Work: Biochemistry, Introduction to Organic Chemistry, Cell Biology, Genetics, Behavioral Endocrinology, Complexity of Cancer, Introduction to Abnormal Psychology, Counseling Psychology, Lab Analysis of Psychological Data, Theory and Methods for Clinical Psychology, Introduction to Physiological*

*Psychology, Positive Psychology, Introduction to Bioethics, The Ethics and History of Human Experimentation, Medical Sociology*

**Honors:**

2011 Spring  
Abroad

**DIS Intercultural Leadership Award:** Danish Institute for Study

**Research:**

2013 May – Present

Research to identify most prevalent types of ethical conflicts at Boston Medical Center using the Armstrong Clinical Ethics Coding System

Boston Medical Center, Boston, MA

- Co-Researcher: Michael Jeong, MD, Renda Wiener, MD, MPH
- Supervisor: Michael Jeong, MD

2009 Fall-2012 May

Research on predictors of readmission and future success rate of discharged somatoform disorder patients

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- Co-Researcher: Amy Chang, Johns Hopkins University Undergraduate
- Supervisor: Dr. Glenn Treisman, MD, PhD – Psychiatrist

**Extracurricular Activity:**

2011 Summer

Community Service at Project Place Baltimore, MD

- Administrative work at the office

2011 Spring

Studying Abroad in Denmark with Danish Institution for Study Abroad (DIS)

- Took classes such as Positive Psychology (core program), Complexity of Cancer, Introduction to Danish Language / Culture

Herlev Rebels American Football Club in Herlev, Denmark

- Played CB/WR/KR for 3 games, recorded 2 interceptions

Community Service at Support and Contact Centre in Copenhagen, Denmark

- Volunteered in the Social Café at the Support and Contact Center, a mental health service offered by the Copenhagen City Counsel

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Medical Shadowing Experience at Johns Hopkins Hospital,  
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- Accompanied Dr. Glenn Treisman, MD, PhD – Psychiatrist, on clinical rounds

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Japanese Student International (JSI) at Johns Hopkins University,  
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- Co-President in 2011, Organized Cultural Events and fund raisers