

2008

Advance care plan : end of life issues

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Capstone Proposal:

ADVANCE CARE PLAN
END OF LIFE ISSUES

Sean Becker

10/12/07

CHHS 400B

Adrienne Saxton

Keywords: End of life, Advance Care Plan, Advance Directive, Death, Five Wishes

Abstract: To educate the importance of people quality of death needs and what can happen if they are not met. I conducted an informative workshop with stories of why advance care plans are important, how they can meet someone's end-of-life needs, and what steps to take to fill out an advance care plan.

Executive Summary

Multiple Sclerosis Quality Life Project (MSQLP) is a non-profit agency that serves people with chronic illness. The agencies case manager wanted to educate the community about the importance of filing out an Advance Care Plan (ACP). End-of-life issues concern everyone.

People of every age, health, race, and religion are concerned with end-of-life issues. The little empirical evidence proves people do not like talking about end-of-life issues; on the other hand, studies show that the older people become the more concerned they are with end-of-life needs and do not recitation orders (DNR). I discovered some tragic case studies about end-of-life issues that demonstrate a need to educate community about end-of-life needs. In the case studies, no body knew what the dying person wants because it was never documented.

For my project, I conducted a pre and post-test with 16 clients chosen by my internship mentor. From the pre-test, I created a workshop at MSQLP's support groups. After the informative workshop about advance care planning and its importance, I asked each participant to fill out a performance evaluation and created a website using the workshop as an outline.

A month after the workshop ended, I conducted my post test and analyzed the performance evaluations. From the evaluations, I discovered everyone found the workshop useful and would recommend to a friend. The post test analysis found that five more people were filling out an ACP and discussion end-of-life wishes.

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My recommendation is that everyone should fill out an ACP like Five Wishes. Five Wishes is a legally binding, customizable, free, and easy to understand. You can always change your ACP to guarantee your end-of-life needs.

Internship

The Multiple Sclerosis Quality Life Project (MSQLP) is a small, private, non-profit agency that serves the Multiple Sclerosis (MS) community in Monterey, Santa Cruz and San Benito counties. MSQLP has an office located in downtown Monterey. Agency offers free case management, MS education, referrals, support groups, family and caregiver support, water aerobic exercise class and much more.

“MSQLP founded in 2000 through the efforts of clinical psychologist Lotte Marcus, PhD, and neurologist Gerard Lehrer, MD, who shared a long interest in MS.” (MSQLP 2007) Doctors and Community members notice a lot of neglect; suffer in their patients, and lack of services for their clients and patients. MSQLP then started collaborating with people with MS and their family members to form the agency.

“In 2002, MSQLP conducted a needs assessment based on extensive interviews with 85 persons with MS and 25 caregivers to determine the most critical needs of the local MS population. (MSQLP, 2007) The needs assessment demonstrated that people suffering from MS require a social worker to practice in-depth case work. The social worker would need to work with clients medical and social service needs in the tri-county area.

Issue Problem

Within the last 30 years, dying has become more complicated. People often make plans for births, yet few seem to make plans for death. When one reaches the end

of life, one may want to decide on medical treatment, funeral arrangements, and legal and financial issues but they may not be able to speak. (CHOMP) If they cannot, others will make these decisions for them. I believe a related problem is that people may not be treated or allowed to die in the way that pleases them; for instance, one may want to be treated by a specific doctor or medical team and one may also wish not to have any life support or advance resuscitation when the time comes. I conclude; the big problem is people do not think they need to create a plan for their end of life and that death, will somehow, take care of it.

Discussions about death appear to be a taboo subject. People fear discussions about death. Families and individuals are afraid to talk about death with each other. (Larson), People believe talking about death will upset family members so discussions about death often only happen when people are about to die.

When the time comes to discuss issues related to death and end of life, people are unprepared and feel powerless. (CHOMP) I think Patient needs may not be considered; doctors and nurses are often more concerned about keeping them alive. (Larson) There may be no communication about one's quality of death. Patients and families are than either furious at the system or over-stricken with creating end of life plans in a very short time while they grieve. (CHOMP)

MSQLP knows this is a problem. Their case managers have dealt with clients who from their perspective have had "bad deaths." They have seen that having an end of life plan would greatly benefit their clients. While the agency has not gathered empirical evidence about this problem, MSQLP has much anecdotal evidence from notes about their clients' deaths.

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When I started my internship, I worked with Andrea Dowdall, MSQLP's Case Manager and Program Supervisor, to examine this problem. Dowdall set up some interviews with Elle Van Tyme from the agency Transitional Hospice Care and Vikki Nelson from Compassionate Care; I also searched for empirical evidence in a review of the literature on the issue. We found that there is very little or no empirical evidence except for studies about people not wanting life support or advanced resuscitation. Most of the anecdotal evidence appeared after the events of the Terri Schiavo case. This case (Lynne, 2005) dramatically illustrated the problems related to end-of-life concerns.

Terri Schiavo, a 27-year-old Saint Petersburg Florida insurance clerk, collapsed from cardiac arrest on February 25, 1990. Her husband, Michael Schiavo, found her lying unconscious, face down in their apartment. Michael called 9-1-1 and she was rushed to Humana Northside hospital. Her doctors determined that she had suffered severe cognitive damage because of the long period of time she went without oxygen while she was unconscious. After Terri had been in a coma for 2 1/2 months, a board-certified neurologist deemed her to be in a persistent vegetative state (PVS); Terri had become unaware and unresponsive to the world around her.

At this time, the hospital released Terri into the care of her family. However, the family soon became overwhelmed trying to meet Terri's needs. The family then had Terri admitted to a rehabilitation center. Nevertheless, in 1993 Terri contracted a urinary tract infection. At this point, Michael halted further medical treatment. In 1998, Michael filed a petition to discontinue Terri's life support after talking with her doctors.

From 1998 to 2002, the Schindlers, Terri's parents, went to court challenging Michael's DNR (Do Not Resuscitate) order. The court determined that Terri would not

wish to continue life-prolonging measures. The Schindlers then opposed Michael's petition to remove her feeding tube. They asked 33 physicians (15 of them were neurologists) to view a 4-½ minute video clip edited by her parents from a 4-½ hour video recording of Terri. The physicians were asked if they thought Terri would respond to therapy. Only two of these 31 physicians had access to her medical records. The others were asked to make the determination based solely on the edited video. All of the doctors believed Terri should undergo further medical tests.

However, Judge Greer decided against the Schindlers. In 2003, the Schindlers filed an appeal of Judge Greer's ruling and sought public media attention to lobby for their case. Judge Greer once again denied their petition. At the end of 2003, officials removed Terri's feeding tube. A week later, the Florida legislature passed a law that gave their governor authority to intervene in cases that call for the removal of life support. They called it "Terri's Law". Governor Jeb Bush of Florida ordered Terri's feeding tube re-inserted and removed her from hospice care.

In 2004, Judge Baird overturned "Terri's Law" and the Florida Supreme Court declared it unconstitutional. Terri's feeding tube was then again removed (World Net Daily). Florida legislature tried to pass a law that made it illegal to cease the provision of food and water to someone with PVS. The Florida bill never passed the legislature. Meanwhile, the Schindlers kept their case alive in the media. In 2005, U.S. Senators Bill Frist and Michael Enzi called Terri to testify before the Senate. Her feeding tube was re-inserted.

Judge Greer denied Enzi and Frist's request to have Terri testify and had the feeding tube removed for the third time. The House of Representatives held an

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emergency legislative session, called the “Palm Sunday Compromise” (World Net Daily)

to determine if Terri’s case could be tried in the U.S. Supreme Court. It passed by a vote of three for, zero against, 97 not present. On March 12, 2005, Terri Schiavo’s case was re-examined by three neurologists who examined 12 of Terri’s brain scans and determined that she had no upper brain activity.

The Schindlers asked the U.S. Supreme Court to squash Judge Greer’s ruling, but the U.S. Supreme Court denied this appeal. Judge Greer issued an injunction denying the State Department of Children and Families the ability to take over Terri’s Schiavo’s case, which thus put an end to Terri Schiavo’s case. Again, with more media attention, the Circuit Court of Appeals in Atlanta agreed to consider a petition to hear the case to decide on whether or not to re-insert Terri’s feeding tube (World Net Daily). Later in the day, the court denied the Schindlers’ petition. Terri Schiavo died on March 31, 2005.

The Terri Schiavo case exposed the world to the complications in the end of life. Furthermore, Terri Schiavo advertised the importance and the controversy with end of life issues. Terri died at age 41, so her age demonstrates the complications with end of life affects everyone. The Terri Schiavo case became a good crutch for MSQLP staff to examine their client’s deaths.

MSQLP has also offered many stories of “bad deaths” or case studies MS deaths. Once story is a client who lived with a lot of pain had become increasingly disabled. She became hospitalized and went from the hospital to a nursing home. She has been very unhappy with her situation for years. She was unhappy at home and now she was unhappy at the nursing home. In the middle of the night, the nursing home staff finds her unconscious and rushes her to the hospital. At the time, her primary care doctor was out

of town and her medical power of attorney did not know she wanted to refuse medical treatment. When she started recovering, this client was furious that she was not allowed die. The client's primary care doctor knew that she only wanted comfort care and not medical treatment.

Another story is a client who recently died never made any funeral plans. Her children and mother did not know what kind of funeral arrangements to make. The client's children said she would want a memorial service but her mother disagreed. However, they agreed to cremate the client's body.

The cases demonstrate the major problems when one reaches the end of life. In each case, clients does not receive there needs; since it was not documented and friends and family were left in conflict with one another to decide what each believes their loved one wanted. Terri Schiavo's case shows that end of life is the concern of the young and the old; not to mention, her story has conflicting thoughts about what was best for her. Terri's husband and parents seemed to greatly disagree about removing her feeding tube. Because of the conflict, Terri became an instrument of pro-life lobbyism and no one stopped to think about her needs and health condition.

With end of life issues, everyone is affected. The issue here is that not one person is unaffected; everyone will die. Death does not just come to the elderly. Young and middle-aged people can suddenly face the end of their life, much like Terri Schiavo. All social classes, races, ages, and ethnicity will face the end of their life; and as such, are subject to the problems associated in medical treatment, funeral arrangements, communication of life support wishes, and appointing people to advocate when one can no longer speak for themselves.

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Death is unpredictable. At anytime, one might face an incident or surprising health illness that can end ones life. It is important to have some kind of plan or something to insure one can receive their end of life needs.

Literature Review

Empirical

Kelly Barnes's exploratory research examined a sample of 37 patients who took part in focus groups. The participants were patients and their relatives randomly sampled among oncology dialysis that were seeking palliative care to alleviate pain. Barnes objective was "to explore the acceptability of an interview schedule, designed to encourage conversations regarding future care" (Barnes, 2007).

Of the 37 patients approached to take part, 22 agreed to participate in the research but the 22 participates withdrew saying, "they were not interested." Results of the focus group analysis showed that 12% considered talking about end of life care with their family. An important note is that the Barnes research focused on dialysis and palliative treatment and not end-of-life care.

Dr. Russ Kolarik did a study on advance directives (AD) in 2003. His research looked at treatment and values in academic medical settings (Kolarik, 2002). Kolarik examined AD at two University medical centers and conducted phone interviews with selected patients. The study enrolled 278 randomly selected patients. The results from the study: 69% refused to take part in the study, 25% already had an AD, and 1% was too mental ill to answer the question.

Kolarik's results found that patients are unlikely to discuss advance directives with physicians and leave end of life decision to family members. From his study, I feel that it

is safe to assume his subjects had no ACP created. This study reinforces my belief that people are afraid to talk about death. Although Kolairk study is more about AD, the content of discussion about ACP is similar.

The last empirical research examined comes from the United States Health and Human Services. B. Kass-Barteleme conducted a series of research projects in 2003 that looked at ACP instead of AD (also called living wills). Kass-Barteleme's research on the opinions of senior citizens, and at what point they would refuse CPR or life sustaining measures is most valuable. (Kass-Barteleme, 2003) Kass-Barteleme's research is valuable because it empirically demonstrates the importance of living wills or DNR (Do Not Resuscitate) orders from those who feel closest to death. From the research, I found that people are more likely to want a DNR or file an AD the older they get.

Anecdotal Studies

One of the major cases that pushed for Advance Care Planning (ACP) and addressed end of life issues is the Terri Schiavo case. I found an article written by Diana Lynne on wnd.com (World Net Daily.com) that describes the Terri Schiavo case. Lynne's story seems somewhat biased, to me, against Michael Schiavo. I believe Lynne's article on World Net Daily is questionable, so I compared the Schiavo case article I found on Wikipedia. The Wikipedia article seems to have no alter-motive, but simply states the facts. Lynne's article appears to paint Michael, Terri's doctors, and Judge Greer as a villain and the pro-life lobbyist as heroes that were unable to succeed.

The final article I used for evidence is an editorial found on CMAJ (Canadian Medical Association Journal), I found they had interesting feelings and thoughts related to the Terri Schiavo case. The editorial article written by Joseph Erban was important from

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legal, medical, and emotional perspectives. Erban's article discussed how complicated death can be - you are grieving for your loved one and the last things you want to experience are legal or medical problems.

In conclusion, the literature review gives a good overview of how people feel about death and advance directives. Two things the articles identify are that ACP and advance directives are highly controversial (World Daily Net & CMAJ). Concluding, death is still a huge taboo in our culture; only small populations of the elderly and cancer patients appear to be willing to discuss plans for their death.

Capstone Project

For my capstone project, I hosted an educational workshop about ACP in MSQLP Oldermeyer center's and Salinas monthly support groups. Before I could host the workshop, there were two tasks to complete. First, I needed to conduct phone pre-test of clients Dowdall chose. Second, a small number of MSQLP staff, clients and volunteers needed to sign off on my proposed ACP presentation.

I created a pre-test survey to determine how to present the ACP information to MSQLP clients. The phone questionnaire was made of four simple yes or no questions:

1. Have you had any discussions with you doctor about medical treatments should your disease advance for the worse?
2. Are there any discussions you have had about how to access of advance care services available to use should your medical condition worsen?
3. Do you know the different types of resuscitation and Life support?
4. Do you know about the Five Wishes document?

Once Dowdall approved of the questions, she picked out 16 clients for me to call and ask them the questions. The 4 questions from the pre-test demonstrated that 16 of MSQLP clients have not filed an ACP, they have had no discussions about the end of their life with families or doctors, and none of them have ever heard about Five Wishes (Figure 1).

Next, I designed an outline presentation for approval by MSQLP. Two staff members, two board members, and an active client in MSQLP met with me to hear my presentation and give feedback on what worked and did not work. I met with the MSQLP group twice. Both times, they gave me lots of feedback for me to use in my workshop. Finally, before the workshops I filled out my own Five Wishes document.

Implementation of the workshop included two modules, three stories and Five Wishes ACP document. At the October support groups, I shared three stories, two were “bad death” stories and the third was the Terri Schiavo case. Then I explained how Five Wishes document using my own Five Wishes as the example.

After finishing the workshops, I created a website using the CSUMB home server. The webpage consisted of links to Aging with Dignity, the agency that created Five Wishes, CHOMP’s (Community Hospital of Monterey Peninsula) conversations with life seminar (an in-depth seminar about ACP), coalition for Compassionate Care Alliance and the stories of MSQLP “bad deaths” and Terri Schiavo. The webpage is meant to reinforce the workshops. I shared the website with MSQLP and other agencies. Website URL: <http://home.csUMB.edu/b/beckerseanp/world/>.

I evaluated the impact of the workshop with a post-test phone call and after each workshop administered performance evaluations. The performance evaluations examined whether support group members found the workshop important and useful; the results

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showed that all 15 people found the workshop useful and useful and important (Figure 3).

A month after the workshops, I asked the same 16 clients four additional yes or no

questions to determine if an impact was made. I asked:

1. Were you able to attend the Advance Care plan workshops?
2. Have you started filling out a Five Wishes?
3. Have you discussed your end of life wishes to your close family and friends?
4. Have you discussed or made plans to discuss medical treatments with your doctor should your disease advance for the worse?

My evaluations showed that 1/3 of the clients surveyed attended the workshops. Five more clients have started filling out a Five Wishes. Four more have had end-of-life discussions with their doctors and Eight more have had end-of-life discussions with their close friends & family (Figure 2).

Major Learning Outcomes Used

The major learning outcomes that will apply to my capstone project are Information management, Systems management, and Knowledge of Health and Human services.

Information Management

After the workshop, I created an informational website on ACP using CSUMB's home server. This website demonstrated my skills and knowledge in using modern technology to manage information over the net. The website has links to various websites discussing and creating ACP. Examples of links are Aging with Dignity (creators of the Five Wishes), and the transitional Hospice of Monterey.

Systems Management

I collected forms, evaluations, and papers from the various organizations involved in ACP. These collected papers are evidence that I have filtered through important parts of the systems involved. In the workshop, I explained each of the systems roles in the clients ACP. The workshops helped the client understand the legal, medical, and family systems process when filing and filling out an ACP (Five Wishes).

Knowledge of Health and Human services

The ACP workshop demonstrates knowledge about health and social concerns with DNR and life support. My creation of the ACP website and facilitation of the end-of-life workshop provided valuable information about ACP by informing the community about the importance of completing an ACP. Furthermore, I influenced the MSQLP community to advocate for their own end-of-life needs and changed their behavior accordingly.

CSUMB Vision Statement

When reflecting on CSUMB's vision statement, I think about the focus on serving diverse populations, especially the working class and uneducated. My ACP workshop objective was to educate people of its importance. Furthermore, ACP affects all living people; after all, everyone must die. The workshop empowered MSQLP's diverse clientele on the importance of ACP, and the evaluation demonstrates that many of them are taking steps to creating a plan that meets their end-of-life needs.

Conclusion & Recommendations

From the project, I have made some realizations about ACP. An ACP takes time to fill out, and before one starts to fill out their plan, they should discuss their end-of-life

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wishes with their family and friends. People also should talk with their doctor about medical treatments, so they know what treatments they want and who they want to treat them.

An ACP or end of life wishes is a very important document that should not be taken lightly or ignored. End-of-life issues affect everyone, the young, old, health, sick, disability, and others. There is little empirical evidence that demonstrate a need for ACP; however, the case studies like Terri Schiavo and MSQLP clients demonstrate a huge need.

In the end, my recommendation is that everyone should fill out an ACP. An ACP functions like an insurance policy for our end-of-life needs. One never knows when they may be hospitalized from a car accident or contracting illness, and if they are one should receive the treatment and service that one wants. ACP should be filled out when your healthy.

In conclusion, an ACP seems to be the most vital next to ones birth certificate. My evaluations show how I increased awareness about the importance about ACP. If I had more time between my implementation and evaluation, my results would show a higher number of clients filling out their Five Wishes.

Figure 1

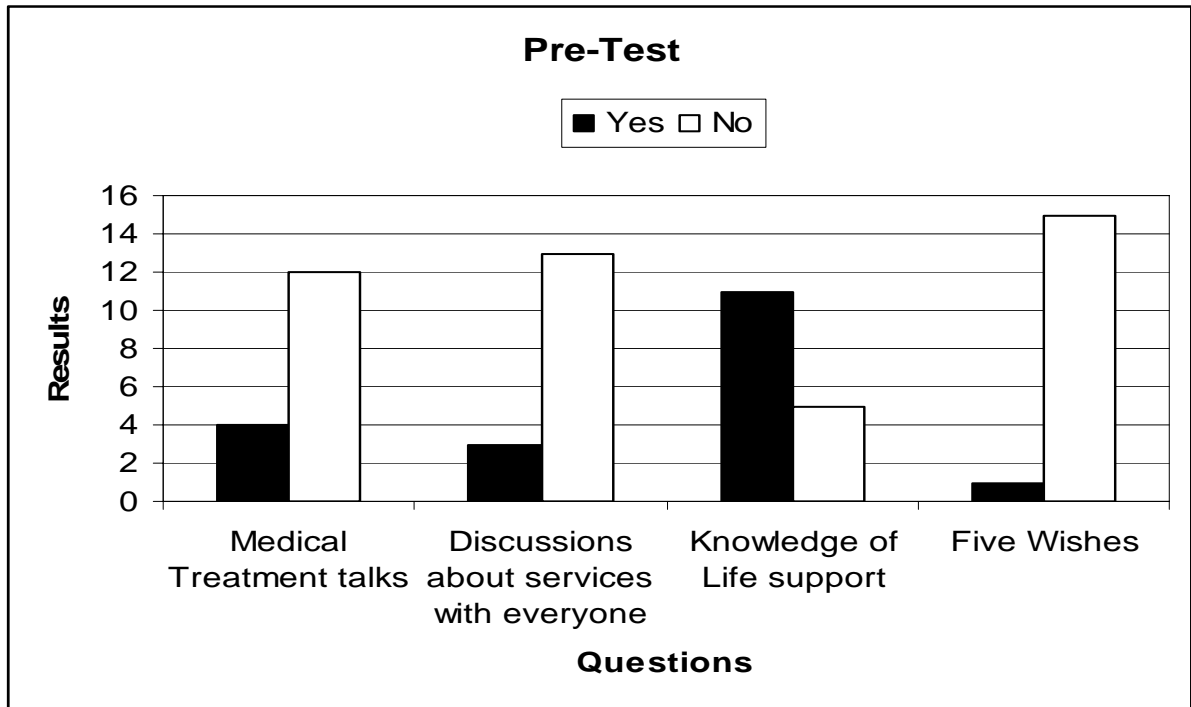


Figure 2

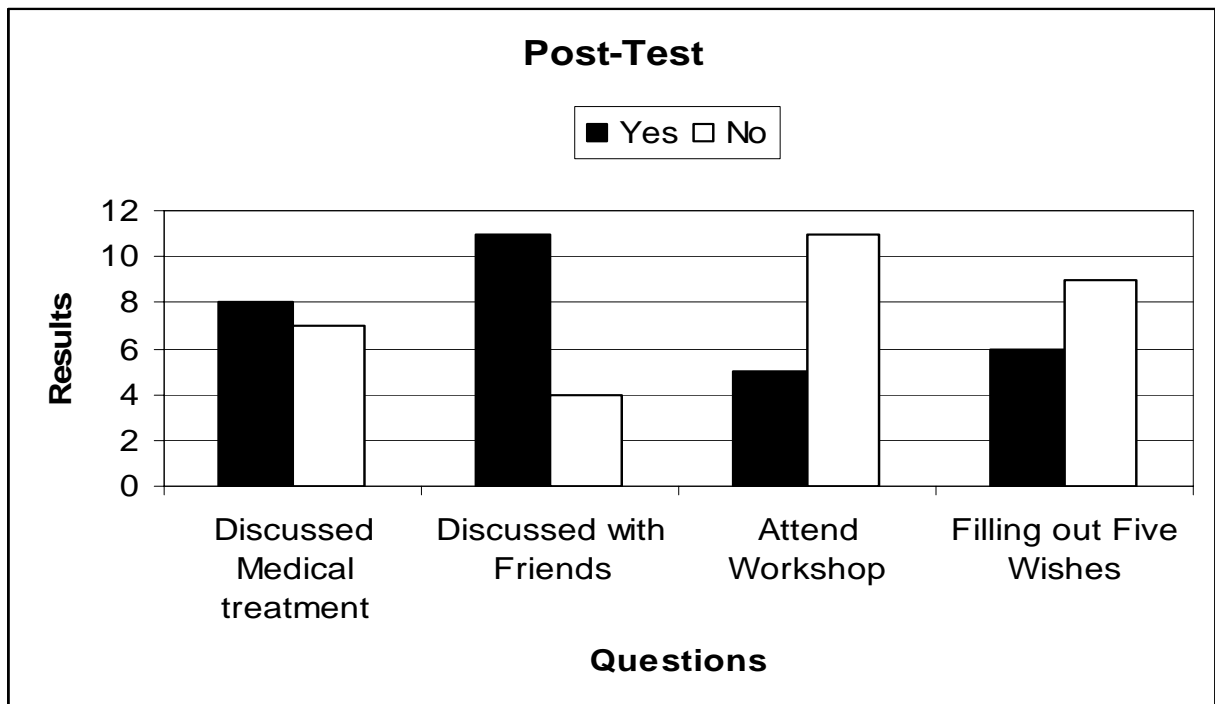
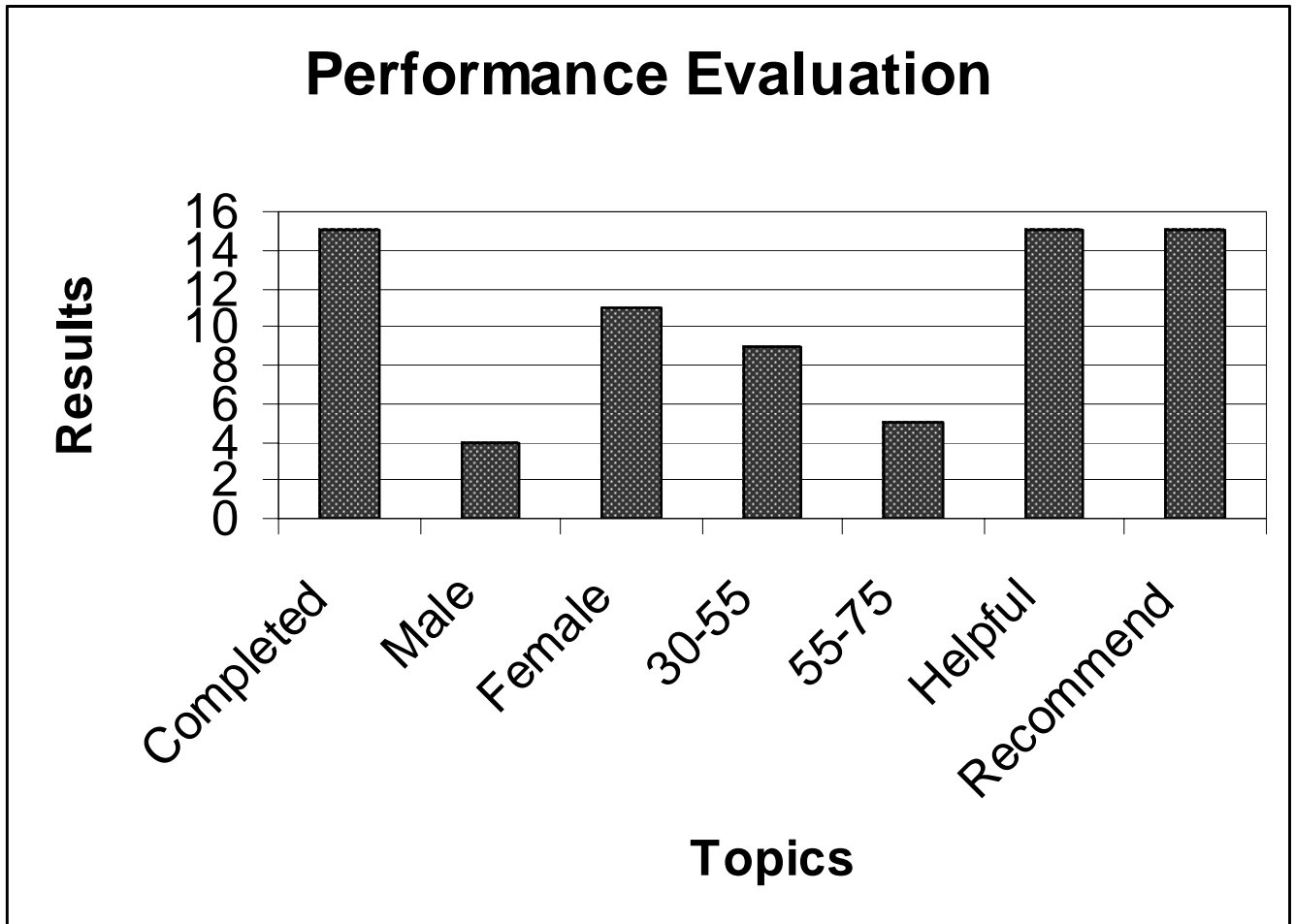


Figure 3



Comments:

- I was not aware of five Wishes could be fast and take care of important issues!
- This sums up really what a person; family can do and be ready for end of life situation.
- Honesty of what is needed from speaker.
- Not aware of Five Wishes and the details of the questions.
- Glad Sean presents this information.
- Something everyone should do, not hush-hush
- Stating the process of what I want to done and knowing my family burden.

Citation

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