Shared Decision Making: Views of Primary Care Clinicians in Four Oregon Rural Practice Sites

Executive Summary

Many medical decisions are unambiguous; the "right" course of action can be determined by implementing clear, evidence-based guidelines. The path is sometimes not so obvious. The ideal is a choice that aligns with the values and preferences of the patient, and a choice which assures the clinician they have offered accurate and comprehensive information needed for this decision. If uncertainty is an inherent part of many clinical decisions, is there anything that can help patients and providers clarify and identify the best medical choice? Many professionals believe that shared decision making and the use of evidence-based decision aids provides the greatest opportunity for patients to choose options that fit their value and preference framework.

Shared decision making is defined as decisions that are shared by doctors and patients, informed by the best evidence available and weighted according to specific characteristics and values of the patient. A decision making aid (DA) is an evidence-based tool developed to assist providers in facilitating SDM in their clinical setting.

This project used information from four rural primary care practices in Oregon to discover clinician understanding of the shared decision making process. It revealed their perceptions of the barriers and facilitators for a successful adoption of SDM and the use of decision aids in their clinics. Qualitative data analysis was used to gain insight into the clinician's perceptions, opinions, and attitudes about the shared decision making process, and the factors that either supported or impeded SDM use in a rural practice setting. Data collected from nine pre- and post-implementation focus group interviews with clinician participants was analyzed and the results showed a wide range of opinions and understanding of the shared

medical decision process. The primary attitude of the clinicians was that SDM is something that they already do, just not in any formal manner. The barriers to implementation of SDM in the rural setting were clearly stated by the clinicians. These clinicians articulated precise actions needed to facilitate rural based SDM; i.e. broad-based clinician training, financial incentives/reimbursement, ability to embed DAs into EHR systems.

Shared medical decision making is an important new paradigm in clinical health care and how this process and related tools can successfully translate to rural primary care is not yet fully understood. This project added rural primary care data to the larger body of SDM research to help the shared decision making process find a place in routine rural primary care.

Shared Decision Making Process in Primary Care: Qualitative Analysis of Clinician Interviews from Four Rural Practice Sites in Oregon

Myra L. Thompson R.N. MS FNP

Oregon Health & Science University

Clinical Inquiry Project for the Doctor of Nursing Practice

School of Nursing

Deborah Messecar PhD, MPH, R.N. GCNS-BC   Advisor

Lyle J. Fagnan M.D.   Clinical Mentor

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> ***"Coming together is a beginning. Keeping together is progress.***
> ***Working together is success."*** **Henry Ford**

In an ideal world, medical decisions would optimally match the patient's choice and preference. Many factors contribute to America's less than ideal health care system. The recent vigorous national debate over health care reform repeatedly reveals the high cost yet underperformance of nearly all areas of our beleaguered health care system (Davis, Schoen, & Stremikis, 2010) (OCED, 2010). It is difficult and discouraging for the lone health care clinician to feel they have any influence to improve the health care system when the overall structure is so complex and dysfunctional. The shared decision making process is one way that a clinician can insert a modicum of control and good sense into their daily practice. The above Henry Ford sentiment sums up the ethos of savvy medical practitioners who incorporate the shared decision making process in their practice. They recognize the importance of collaborative medical decisions, respecting the values and viewpoints of their patients and families without losing their own ethical bearings. Patient decision aids are available that present evidence-based value-neutral medical options that facilitate the shared decision making process. This project will evaluate the perception of clinicians from four primary care clinics located in rural Oregon regarding the shared decision making process and their use of decision aids.

The Clinical Problem

Medicine is not a consumer-driven model of care. Clinicians are not selling a retail "product" just as the consumer is not out to get a health "product" at the cheapest price possible. The provider/patient relationship is built on trust. It holds as important the belief that the provider will put the patient's interests ahead of his/her own and that the patient will trust their providers knowledge and professionalism. Noted health care economist, Victor Fuchs, describes the patient-physician relationship as very different from the one that we accept in commercial marketplaces because it requires patients and health professionals to work cooperatively (Fuchs, 1998). Most people consult some expert guide when contemplating a major retail purchase yet when a "purchase" may have life or death consequence they discover that there is no "consumers report" for health care. While it is true that patients can locate data about providers and health care facilities on the internet or by word of mouth, the average consumer is incapable of understanding the important associations and variables necessary to assemble a sound decision. A recent study was conducted to evaluate patient knowledge of basic medical conditions and treatments and it was determined that "patient knowledge of key facts relevant to recently made medical decisions is often poor and varies systematically by decision type and patient characteristics" (Fagerlin et al., 2010, p. 35). The problem is that medical science is not transparent; there is a great deal of inherent uncertainty. *Crossing the Quality Chasm*, the Institute of Medicine's seminal report outlining the goals for a new health system for the 21st century declares the need for transparency in medicine. "Make all information flow freely so that anyone involved in the system, including patients and families, can make the most informed choices and know at any time whatever facts may be relevant to a patient's decision making" (Institute of Medicine, 2001, p. 79). Atul Gawande (2002) describes this medical ambiguity as a central dilemma in health care. “The core predicament of medicine, its uncertainty, is the thing that makes being a patient so wrenching, being a doctor so difficult, and being part of the society that pays the bills so vexing” (Gawande, p. 23, 2002).

A great many medical decisions are unambiguous and the “right” course of action can be determined by implementing clear evidenced-based guidelines, some are not. If uncertainty then is an inherent part of many clinical decisions, is there anything that can help patients and providers clarify and identify the one best medical choice that aligns with their values and preferences? Many professionals believe that the shared decision making process and the use of evidenced-based decision aids provide the greatest opportunity for patients to choose options that fit their value and preference framework (Edwards & Elwyn, 2009; Legare, Ratte, Gravel, & Graham, 2008; O’Connor et al., 1999).

Description of the Problem and Relevant Stakeholders

Many hospitals around the country, with Dartmouth-Hitchcock in New Hampshire leading the way, have developed a formal process of shared decision making. These centers are located in large urban locales and may not reflect the needs or strengths of rural primary care; therefore, practice interventions from a metropolitan center may not translate well to the rural setting. This project will use information from four rural primary care practices in Oregon to discover clinician understanding of the shared decision making process and their perceptions of the barriers and facilitators for a successful adoption of this process with the use of decision aids in their clinics.

Shared decision making process. The shared decision making process (SDM) can be described as a decision jointly shared by patients, families, and their health care clinician that is used to settle on a treatment option for which there may be two or more evidenced-based medical choices. O'Connor, Llewelyn-Thomas & Flood (2004) describe shared decision making as the process of interacting with patients in arriving at informed values-based choices when options have features that patients value differently" (O'Connor, Llewelyn-Thomas, & Flood, 2004, VAR-63).

Many health treatment and screening options have no single 'best' choice. One current example is the present uncertainty about prostatic cancer screening. The majority of American men over age 50 years have been screened for prostate cancer with the blood test, prostate-specific antigen (PSA). Recent large studies have shown that the absolute benefit of this screening is negligible and concludes that this common screening practice is controversial (US Preventative services task force: Screening for prostate cancer: US Preventive services task force recommendation statement, 2008). As medical science and research advances, treatment guidelines change as well. Examples of this include hormone replacement therapy (Hersh, Stefanick, & Stafford, 2004: Rossouw et al., 2002) and vaginal delivery following caesarian section (v-back's) recommendations which have changed in just the last decade (Landon et al., 2004). Shared decision making can assist the patient, family and provider choose medical options appropriate when medical science does not provide a definitive course of treatment.

Decisions of this nature are called *preference sensitive* in the shared medical decision making process. These *preference sensitive* decisions occur when there is no scientific consensus as to the best treatment or decision; thus the patient should participate and help make the decision that fits them best. Shared medical decisions can help align management decisions with patient preferences. According to O'Connor et al "decision aids improve people's knowledge of the options, create accurate risk perceptions of their benefits and harms, reduce difficulty with decision making and increase participation in the process" (O'Connor et al., 2009, p. 2).

Some mistakenly view the shared decision making process as just another new way to reduce health care costs or provide health education. The aim is to get the right care to the right patient at the right time; to avoid both under-treatment and over-treatment and support the patient's preference (Barry, 2002). While quality patient and family education is essential to good health care, the SDM process is more than just giving the patient a booklet to read. Shared decision making and the use of decision aids prepare the patient to discuss ambiguous medical treatments with their clinicians. Use of decision aids help patients and families weigh the benefits and harms of various medical options while showing them the scientific uncertainty of their problem. According to the International Patient Decision Aids Standards Collaboration (Elwyn et al., 2006), decision aids differ from usual health education because of their specific and personalized information that focus on options and outcomes designed to prepare people for a decision. Multiple evidenced-based health decision aids/products are available to facilitate the shared medical decision making experience.

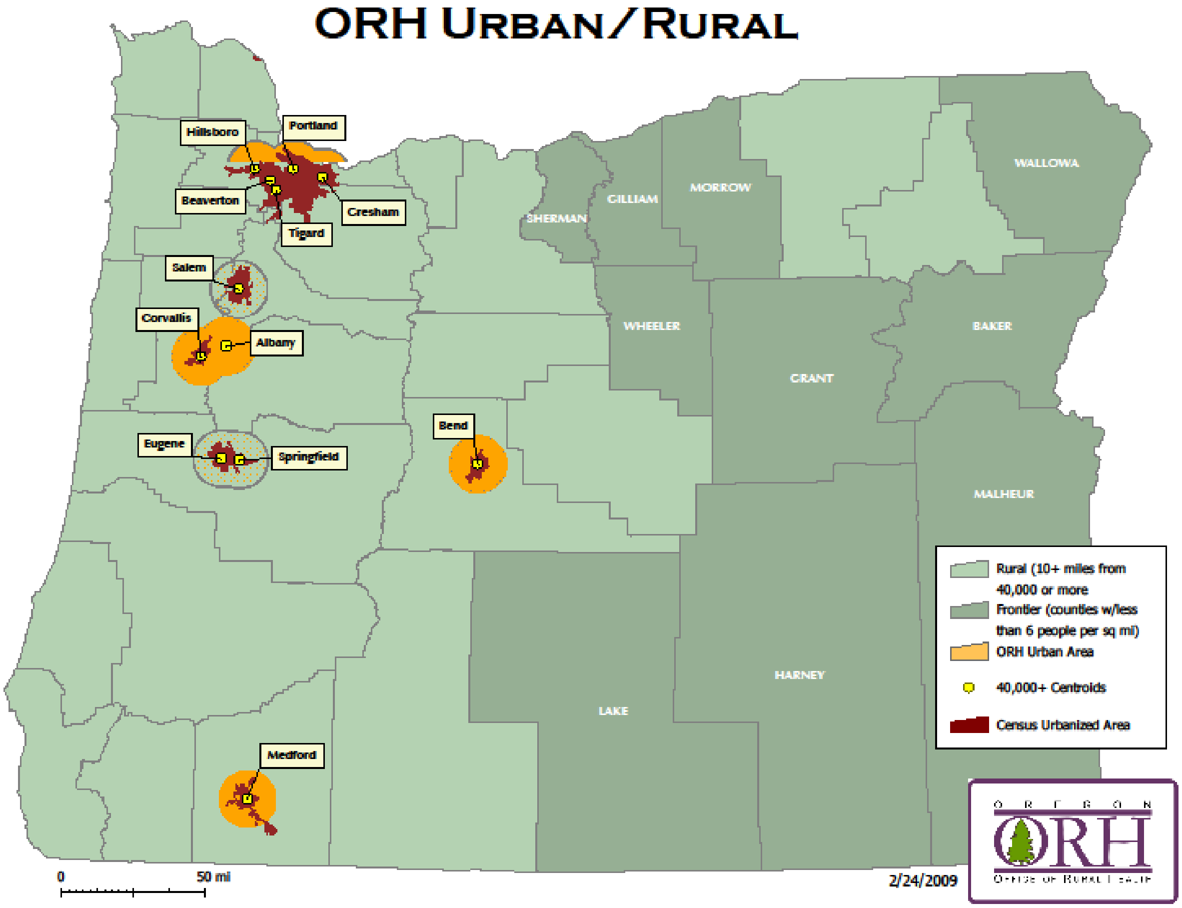
Decision aids. A decision aid (DA) is an evidenced-based tool developed to assist providers in facilitating SDM in their clinical setting. They are not simply educational but designed as an intervention to help people make specific and deliberate value choices among various acceptable options. Preference sensitive decision aids improve decision outcomes and may prevent overuse of options that an informed patient does not value. According to O'Connor, there are three key elements common to a well designed decision aid. First they much provide high-quality and up-to-date education, they must assist the patient to better judge the value of available options and also provide guidance or coaching through the SDM process (O’Connor, 2004).

This process invites patients to participate in medical decisions when there is more than one reasonable option and SDM has been identified as an important approach to effectively implement and support evidenced-based medical practice

The Foundation for Informed Medical Decision Making. The Foundation for Informed Medical Decision Making (FIMDM) is a not-for-profit (501c3) private foundation with the mission to inform and amplify the patient’s voice in health care decisions (www.fimdm.org). FIMDM has an arrangement with Health Dialog, a for-profit company, to co-produce evidenced based decision aids. The programs are used as part of the decision support and disease management services Health Dialog provides to consumers through health care organizations and employers. In 2009 FIMDM began a three year national study looking at the effectiveness of decision aids in a variety of practice settings. This three year study, *Using Decision Aids to Facilitate Shared Medical Decision Making in Primary Care Practice Study* is a multi-site implementation research project. FIMDM selected 11 primary care implementation sites representing urban, suburban, and rural practice settings as well as hospital based and independent systems. Sites include Dartmouth-Hitchcock, Palo Alto Medical Foundation, Stillwater, Minnesota, rural sites in Oregon, and others which show the range of data being collected. The Oregon Rural Practice-Based Research Network (ORPRN) is working with four member clinics on the FIMDM DA/SDM study.

Oregon Rural Practice-Based Research Network (ORPRN). ORPRN, located at Oregon Health & Science University, is a statewide network of primary care clinicians, community partners, and academicians dedicated to studying the delivery of health care to rural residents and research to reduce rural health disparities. Network members include 171 clinicians and 50 primary care practices, located in 39 rural Oregon communities which serve approximately 240,000 patients. ORPRN's research portfolio covers a wide range of health topics, including care management, shared decision making, evidenced-based prescribing, and access to cancer screening, medication safety, child health, dementia, and clinician workforce issues.

Rural Oregon Population Characteristics. Like most western states, Oregon is diverse with large open areas, dense urban areas, isolated farms and settlements.



www.ohsu.edu/ohsuedu/outreach/oregonruralhealth/data/definitions/index.cfm

Figure 1 Map of Oregon showing major metropolitan centers

Multiple federal and state agencies provide definitions for “rural” but the Oregon Office of Rural Health uses a definition based on distance from a metropolitan (centroid) setting. “All geographic areas ten or more miles from the centroid of a population center of 40,000 or more” are defined as rural. (http://www.ohsu.edu/xd/outreach/oregon-rural-health/data/rural-definitions/).

Most rural health care is provided through small physician-owned practices, generally in groups of five or few providers

When compared to urban settings, people living in rural communities are more often self employed resulting in a lack of health care insurance or problems with being under insured (Ziller, Coburn, & Yousefian, 2006) (Goetz, 2008). In a 2008 report, the numbers of rural non-elderly residents covered by public health insurance programs showed an increase of nearly 122 percent from 1987; nearly a third more rural people being covered by public plans when compared to urban residents (National Advisory Committee on Rural Health and Human Services, 2008).

The following data from the Oregon Office or Rural Health shows the number and type of health care providers in rural Oregon according to the full time equivalents (FTE) that have been noted on their 2010 licensure renewal.

Table: 1 Oregon provider FTE’s practicing in rural settings for 2010

Setting	DO FTE	MD FTE	Physician Assistants	Nurse Practitioners
Rural	206	1777	205	408

This clinical inquiry project (CIP) will use information from the data collected by ORPRN from their participation with the FIMDM national study. As part of the introduction and the implementation of the use of the shared decision making aids, ORPRN research staff conducted focus group interviews with providers at all four clinical sites. Two focus group interviews were done at each site, one before implementation of the decision aids, and then after the decision aids had been in use for approximately one year. These focus group provider interviews have not previously been transcribed. This project will analyze these data to better understand various rural provider perceptions of the SDM process.

Importance to Advanced Practice Nursing (APN) and the Doctor of Nursing Practice (DNP)

In 2010, Congress passed and the President signed into law comprehensive health care legislation. As the largest segment of health care providers, nursing has vast potential to effect wide spread changes to many aspects of the health care system. The recent Institute of Medicine report, *The Future of Nursing: Leading Change, Advancing Health*, strongly recommends that advanced practice nurses partner with physician professionals to redesign health care in the United States and that they be allowed to practice to the full extent of their education (IOM, 2010). The APN/DNP is needed to provide care to the high number of U.S. citizens who will soon be eligible for primary and preventatives services. The DNP by virtue of training and experience is able to translate the SDM research into their day to day clinical practice thus using this promising research to improve community and patient health. The DNP closes the research gap and improves quality by using point-of care decision tools to strengthen the patient-clinician relationship. Noted nurse researcher Mary Naylor R.N. PhD recognizes and champions the role of the APN to be involved in patient and family health care decisions (Naylor & Kurtzman, 2010). Doctoral prepared advanced practice nurses will translate evidenced based research into practice at the rural community level.

According to McGlynn, Asch, and Adams (2003) American patients receive only half of the recommended screening services (McGlynn, Asch, & Adams, 2003). The U.S. Preventive Services Task Force recognizes the importance of nurse providers and has developed an evidenced-based prevention resource for the APN/DNP to guide their screening, counseling, and prevention medication decisions (Trinite, Loveland-Cherry, & Marion, 2009). The APN/DNP applies scientific principles and novel innovations to prevent disease and disability for the patients they serve and the U.S. Prevention Services Task Force encourages the contribution of the APN/DNP to the promotion of effective screening services (Agency for Healthcare Research and Quality, 2009). Advanced practice nurses value health promotion and disease prevention and understand that both behavioral modification and therapeutic intervention is generally needed. Many of these decisions are best made with the SDM process. “Holistic concepts of health care along with integration of medical care with preventive and health promotional efforts, need to be adopted to significantly improve the health of Americans” (Shi & Singh, p. 124, 2009). Mundinger, Kane, Lenz, Totten, Tsai, and Cleary, et al. (2000) have shown that the APN can deliver quality care similar to that provided by primary care physicians. Horrocks, Anderson, and Salisbury (2002) found similar results when comparing British APN’s to primary care physicians in England. The APN/DNP is well suited to engage in effective translation of this knowledge to direct and advance an integrated shared decision making program for primary care.

Desired Outcome

The intended outcome of this work is to investigate the perceptions of the shared decision making process and use of DA’s of clinician working in four rural clinics in Oregon. Their opinions, attitudes, perceived barriers and facilitators to the use of SDM in their settings will be evaluated. This data will help to develop a framework that uses a "best practice" model to assist in rural primary care application of shared decision making and utilization of decision aids.

Purpose

This clinical inquiry project (CIP) will evaluate information collected by ORPRN from focus group interviews conducted pre and post decision aid implementation with rural providers at four Oregon practice sites. In the ORPRN study, researchers took extensive notes during focus group sessions and used this information in their evaluation of the implementation process. However, due to cost and time limitations they were not able to do further analytic work with the interview data. The purpose of this project will be to explore in depth each provider's perceptions of the shared decision making process and the use of decision aids in their clinical settings.

Clinical Inquiry Questions

The following clinical inquiry questions will be addressed through a qualitative analysis of rural clinician interviews from the four practice sites in the ORPRN study:

- What are their perceptions, opinions, and attitudes of shared decision making and the use of decision aids?
- What do they see as recognizable barriers to implementation of decision aids in their practice?
- What factors would facilitate implementation of shared decision making in rural clinics in Oregon?

Synthesis of Evidence

High Cost and Poor Performance of the U.S. Health Care System

The United States spends much more per capita on health care than any other country and has one of the fastest growth rates in health spending among developed countries. America spent $7,538 per person on health in 2008, more than twice the $3,000 average of all OECD countries (Organization for Economic Co-Operation and Development, 2010). Despite this higher level of spending, the United States does not achieve better outcomes on many important health measures such as quality, access, efficiency, equity and health lives (Kaiser Family Foundation, 2007). Since 2004, the Commonwealth Fund has regularly evaluated the performance of the U.S. Health care system as compared to six other developed countries. This report shows that "the U.S. health system is the most expensive in the world, but comparative analyses consistently show the United States underperforms relative to other countries on most dimensions of performance" (The Commonwealth Fund, p.v, 2010). These rankings are unsustainable given that by the year 2040 29% of the US gross domestic product (GDP) is expected to be spent on health care in America (Healthcare Economist website, October 8, 2008). The emphasis in the US health care system is on acute emergent care and not on screening and prevention services.

Yet government recommendations found in *Healthy People* (2010), outline extensive screening and prevention goals that seem out of reach with our present health care system. Donald Berwick M.D., distinguished health policy analyst, describes how cost, quality and access must align before America can claim success with health reform (Berwick, 2008). Bodenheimer and Pham (2010) recognize that primary care providers see this high cost/poor performance conundrum daily. The provider on the "front line" sees good patient care and helpful "best practice" models buried by bloated health care spending aggressively driven by a litigious society and a medical-industrial complex that is focused on rescuing people through expensive treatment instead of engaging in a patient centered medicine. Brook and Young (2010) describe the tension this creates for primary care physicians. Our health care system operates under the fallacy that “if it can be done we should do it”. Shared decision making and the use of DA’s, stop this “knee jerk” response to health treatments by matching management decisions to patient preferences. This process invites patients to participate in medical decisions when there is more than one reasonable option. Cost saving often occurs and continues to show that low cost can go hand in hand with high quality (O’Connor et al., 2007). Though providers in independent practices who are not in closed systems may not see any cost savings from fewer invasive surgeries or other treatments, they may still see the value of this approach because of the patient centered focus and because of its consistency with their values for providing high quality care.

The Dartmouth Atlas.

Rising healthcare costs remain a major challenge to the American economy. The Dartmouth Institute for Health Policy and Clinical Practice developed the Dartmouth Atlas which reports on geographic differences in health care delivery and spending (Wennberg, Brownlee, Fisher, Skinner, & Weinstein, 2008). For example, patients who live in Southern California are six times more likely to have surgery for herniated disks than patients living in New York State (Wennberg, Brownlee, Fisher, Skinner, & Weinstein, 2008). Atul Gawande (2009) brings this data down to a more personal level. He identified McAllen Texas as one of the most expensive yet least healthy place to live in America (Gawande, 2009). More spending and more utilization of services do not routinely translate into improved life expectancy for those with chronic illness (Fisher et al., 2003). This data points to an opportunity to achieve significant savings in health care costs without compromising health care quality and outcomes.

International Perception of Shared Decision Making and use of Decision Aids

Shared decision making is not a new concept. The international medical community has identified, implemented and extensively researched this subject for decades. The Cochrane Collaboration has systematically reviewed more than fifty randomized trials of decision aids from multiple countries dating from 1980 (O'Connor et al., 2009). Canada has been at the forefront of the shared decision making model and use of DA's. France Legare M.D. PhD (2008) extensively evaluated multiple research studies and determined that in spite of the vast array of studies "there is a need for well-conducted randomized controlled studies to help us identify the effective components of implementation strategies" (Legare, 2008, p. 430).

There is a significant gap between what is known in this research and what is actually practiced. The 2009 Cochrane review of 55 RCT's, provides evidence suggesting that shared medical decision making and decision aids benefit the patient by providing knowledge, lowering decisional conflict and, clarifies personal values resulting in greater agreement between value and choice for the patient (O'Connor et al., 2009). However, actual use and implementation of this process into the "real world" setting is under explored. Specifically, there has been little research or program development for shared decision making and use of DA's specific to rural primary care practice. Evidenced based shared decision making processes and decision aids that successfully translate to the rural setting with consideration of limited rural health resources is needed. This project adds important rural primary care data to the larger body of shared decision making research and DA use.

Health Care in Oregon

Development of the Oregon Health Plan. In the late 1980's the state of Oregon found that 18% of all of its citizens had no health insurance and that 20% of this uninsured number were children. Then state governor, Neil Goldschmidt, appointed an 11 member non-paid commission to examine this problem. Two thirds of the commission was health providers and the commission had broad representation from a number of stake holders. They traveled to many parts of the state gathering data from the general population and this community based approach gave credibility to their conclusions. The commission workgroup reached the following consensus:

- All citizens should have universal access to basic care
- Society is responsible to pay for poor people
- Process to define "basic" care needed
- This process must be transparent, public debate, consensus of social values was needed
- Encourage treatment that is effective
- Balance health care funding with other programs that affect health
- Funding to be explicit, sustainable and accountable

In 1988, then senate president, John Kizhaber M.D. initiated the Oregon Medicaid Priority Setting Project and the Oregon Health Services Commission (HSC) was created to rank medical services from most to least important. Oregon developed a unique system that provided a comprehensive complement of medical care for all the poor but limited the care to conditions and procedures on a prioritized list. A national furor was ignited about "rationing of care" touching off the original "death panel" debate and delaying government (HCFA) approval till

1993. The Oregon Health Plan began in 1994 with funds to cover 606 of the 743 listed diagnoses (Glass, 1998) (Bodenheimer, 1997).

Current Oregon Health Plan Status. Eighteen months ago, Senate Bill 2009 passed Oregon Legislature with the intent to improve the quality and consistency of health care, provide greater accountability to the public for resources spent in the health care system, and to seriously transform Oregon's health care system. The Oregon Health Authority (formerly the Oregon Health Plan) was created as a new agency to oversee health reform in Oregon, eliminating two boards and consolidating all state health care functions and is governed by the Health Authority Board. The recent election of John Kitzhaber M.D. to an unprecedented third term as governor ensures that Oregon will continue to aggressively tackle the problems of health care in this state. Governor Kitzhaber addressed the Oregon Health Policy board on January 18, 2011 to describe the current state budget crises driving some of these changes.

> We can deliver health care in America a lot more cheaply, a lot more effectively and get better outcomes but it will require a different delivery system. The opportunity for us, instead of just doing less of the same, in hopes that when the economy comes back we can do more of the same, is to actually to do things differently (Kitzhaber, 2011).

National and State Legislation on Shared Decision Making

The shared decision making process is not just a clinical or care model innovation that stands apart from health policy. There is movement in state and national legislation to mandate use of the better informed consent with the shared decision making process. Washington became the first state to endorse SDM when Governor Gregoire signed ESSB 5930 into law in May, 2007. The goal is to recognize that medical outcomes can be improved by patient-practitioner communication enhanced by high-quality decision aids. In Oregon the Health Authority Board has indicated that the state health care delivery system is moving towards a patient centered medical home model. The three core tenets of this care model are a move from individual patient care to population-based, a change from physician to team based care, and use of the SDM concept to create an informed activated patient.

Informed consent and SDM

Health care research over the last several decades suggests that an overhaul of our legal standard of informed consent is overdue. King and Moulton (2006) eloquently argue for redefining the present informed consent procedure to make systemic adjustments to allow for a solid use of SDM as a reliable informed consent practice (King & Moulton, 2006)**.** A shift to legislate SDM for Oregon practitioners may follow. It remains uncertain how the standard of shared decision making versus the standard informed consent will evolve.

Methods

This clinical inquiry project will use focus group interview data collected by ORPRN as part of their implementation research participation in the FIMDM three year multi-site study of use of decision aides to facilitate shared medical decision making in primary care. There are four rural primary care clinical sites that ORPRN is collecting data from as part of their participation in this national study. ORPRN have used their initial notes from these focus groups as part of their implementation evaluation plan. This clinical inquiry project will build upon this analysis by transcribing the interviews and analyzing the data in more detail. The following is a description of the how the data from the focus groups was collected in the ORPRN study, and how that data will be analyzed to meet the aims of the clinical inquiry project.

Focus Group Data Collection in the ORPRN Study

Focus groups were conducted with clinicians and staff at the four ORPRN sites prior to the DA intervention (October, 2009 – December 2009 see Appendix A) and approximately one year into the intervention (January, 2010 see Appendix B) by ORPRN researchers. The researchers conducted focus groups using a semi structured interview guide at a time convenient to practices (e.g., prior to clinic, over lunch, or after clinic hours). One researcher facilitated the focus groups and a second took field notes and audio recorded each session. Pre-assessment interview questions explored questions like “what does shared decision making mean to you?”, “what makes shared decision making hard to do in this practice?” The Post-assessment sessions explored questions like “Has your understanding of shared decision making changed?” “Describe your experience using shared decision aids?” See Appendices A and B for a copy of the pre- and post-assessment semi-structured interview guides and demographic note sheets. Interviews lasted approximately one hour in duration. Pre-intervention interviews were conducted separately with clinicians and staff at all sites to facilitate open sharing. Post-intervention interviews were conducted with both clinicians and staff at two practice sites due to scheduling challenges and clinic preferences.

Sample

ORPRN researchers invited all clinicians and staff from the four participating clinics to participate in the focus groups. Thirteen clinicians total participated in the focus group interviews. The clinician participation by ORPRN site is described in Table 1. Most of the participants were MDs (10) and were male (77%). Of the Nurse Practitioners and Physician Assistants all were female.

Participant description

Table 1 Clinician Participation in Focus Group Interviews by ORPRN Site

Clinician	Bayshore	LCMC	Winding Waters	Pioneer Memorial	Totals
MD/DO	2	2	3	3	10
NP	1	0	0	0	1
PA	0	0	1	1	2
Totals	3	2	4	4	13

Clinic Description

Table 2 presents data about each clinic site that participated in the focus group interview data collection.

Table 2 Clinic Description

Clinic Characteristics	Bayshore	LCMC	Winding Waters	Pioneer Memorial
Location				
Year started				
How rural?				
Population served				
Independent or part of system				
DAs used at site				
Has an EHR?				
Fully Paperless?				
Receives hospital reports via HL7				
Average number of annual visits				

Analysis

A thematic analysis approach described by Braun and Clarke (2006) will be used to analyze the focus group data (Braun & Clarke, 2006). Thematic analysis is a flexible data analysis approach that is easily described and less prone to data analytic error than some of the other approaches to qualitative analysis such as grounded theory that require intensive training in the method to be valid. It is a method of data analysis that relies on identifying, analyzing and reporting on patterns and themes in data.

There are six steps involved in doing a thematic analysis. First is familiarization with the data which can be accomplished during the process of preparing and or reviewing data transcripts. The second step is to develop beginning codes or generally referred to by qualitative researchers as open coding. The third step is to look for themes by collapsing some of the open codes into categories. A preliminary definition of these broader categories will be developed to facilitate the fourth step of the analysis which is to review the themes that have been generated. In this stage, some of the quotes from the interviews that illustrate these themes will be selected and included in the memos that describe the themes. In the fifth step, the memos with the definitions of the themes and associated quotes will be further refined after re-reading all memos and data excerpts. The final sixth step will involve summarizing the themes across all interviews in the form of a report of the findings. The following narrative describes in detail how the thematic analysis will be conducted.

Phase I

Data collected from the focus groups with clinician participants will be analyzed for this clinical inquiry project. Audio recordings of the focus groups will be transcribed verbatim, and clinician names will be removed. The completed transcripts will be reviewed while listening to the audio tapes to verify content and to make any notes or corrections that seem necessary.

Phase 2

Open coding will be initially performed using the techniques and strategies outlined in Braun and Clarke (2006). This initial analysis will involve detailed, reflective exploration of the transcribed interviews – basically doing line-by-line coding, reading between the lines, identifying concepts and thinking about the possible meanings of all text segments which will then be recorded in the margins of the transcribed interviews. For example, open codes might include examples of all of the barriers to SDM such as not enough time, patient literacy, or decisions being too complex. These will be highlighted in the manuscript with notes in the margins about these open codes.

Phase 3

In this part of the analysis, preliminary themes will be developed from the open coding analysis done in phase 2. Memos regarding some of the preliminary themes derived from the open coding process will be created along with preliminary definitions of the themes. The codes will be read and reread to make sure that all possible themes are captured in memo descriptions. For example, on the barriers theme, a definition might be: includes all of the factors that make asking patients to participate in decision making hard, such as, patient literacy, short clinic appointments, etc. Some factors may be clinician and setting driven, while others are about the patient and their receptivity to participating in shared decision making.

Phase 4

In Phase 4, some quotes from the interviews will be included in the memos to further illustrate the theme that the memo is trying to describe. By retrieving quotes from the interviews to best illustrate a theme, refinements in the definitions of each theme will be made. For example, when reviewing codes and memos on barriers, it may be that some attitudes about decision making on the providers part that were not initially noted in open coding become more apparent and warrant a new theme along with description and illustrative quotes.

Phases 5 and 6

In the final phase of analysis, the writing of the results is paramount and it is through the reshaping of drafts of the results that the analysis can be further refined.

Qualitative research will be used to gain insight into clinician's attitudes, behaviors, value systems, concerns, motivations, aspirations, and culture. The interviews will be audio-taped, transcribed, and made anonymous. Data analysis will examine the respondent's views of the key interview areas of shared decision making and use of decision aids..

Protection of Human Subjects

This is secondary data analysis from an ongoing study. IRB approval has been obtained for the overall ORPRN study and this project does not involve any new contact with subjects or any substantive deviation from the original aims of the FIMDM study. The principal investigator is part of the committee that will review the analysis of this data and all considerations about human subject's protection have been addressed.

References

Barry, M. J. (2002, Jan.15). Health decision aids to facilitate shared decision making in office practice. *Ann Intern Med*, *136(2*), 127-35.

Berwick, D. M., Nolan, T. W., & Whittington, J. (2008). The triple aim: care, health, and cost. *Health Affairs*, 27(3):759-769.

Bodenheimer, T. (1997, September 4). The Oregon Health Plan lesson for the nation. *NEJM*, 720-723.

Bodenheimer, T., & Pham, H. H. (2010). Primary care: Current problems and proposed solutions. *Health Affairs*, *29(5*):, 799-805.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77-101.

Brook, R. H., & Young, R. T. (2010). The primary care physician and health care reform. *JAMA*, 303(15), 1535-36.

Davis, K.Schoen, C., & Stremikis, K. (2010, June). *Mirror, Mirror on the wall: How the performance of the U.S. health care system compares internationally* (White Paper Commonwealth Fund 1400). Washington D.C.: The Commonwealth Fund.

Edwards, A.& Elwyn, G. (2009). Shared decision-making in health care: Achieving evidence-based patient choice. In *Shared Decision Making in Health Care* (pp. 3-10). Ontario: Oxford University Press Canada.

Elwyn, G., O'Connor, A., Stacey, D., Volk, R., Edwards, A., & Coulter, A. (2006). Developing a quality criteria framework for patient decision aids: online international Delphi concensus process. *BMJ, 333(7565*), 417-419.

Fagerlin, A., Sepucha, K. R., Couper, M. P., Levin, C. A., Singer, E., & Zikmund-Fisher, B. J. (2010, Sep-Oct). Patients' knowledge about 9 common health conditions: The DECISIONS survey. *Medical Decision Making*, 35-52. doi: 10.1177/0272989X10378700

Fisher, E. S., Wennberg, D. E., Stukel, T. A., Gottlieb, D. J., Lucas, F. L., & Pinder, E. L. (2003). The implications of regional variations in Medicare spending, part 2: Health outcomes and satisfaction with care. *Ann Intern Med, 138(4*), 288-298.

Fuchs, V. R. (1998). *Who shall live? Health economics and social choice*. Singapore: World Scientific Publishing Co. Pte. Ltd.

Gawande, A. (2002). *Complications A surgeon's notes on an imperfect science*. New York: Metropolitan Books, Henry Holt and Company.

Gawande, A. (2009). The cost conundrum, what a Texas town can teach us about health care. *The New Yorker*. Retrieved from http://www.newyorker.com/reporting/2009/06/01/090601fa_fact_gawande

Glass, A. (1998, May 15). The Oregon Health Plan: Development and implementation of an innovative method of delivery of health care services to the medically indigent. *Cancer (Supplement*), *82*(10), 1995-1999.

Goetz, S. J. (2008). *Self-employment in rural America: The new economic reality* (White Paper). Retrieved from Penn. State University website: http://www.aers.psu.edu/DidUNoDocs/IntFacMore_archive.cfm

Healthcare Economist website. (October 8, 2008). http://healthcare-economist.com/2008/10/29/health-care-expenditures-in-2040/

Healthy People 2010. (n.d.). *Healthy People 2010* (Office of disease prevention and health promotion US Dept. of Health and Human Services). Washington, D.C.

Hersh, A. L., Stefanick, M. L., & Stafford, R. S. (2004, January 7). National use of postmenopausal hormone therapy: Annual trends and response to recent evidence. *JAMA, 291(1*), 47-53.

Horrocks, S., Anderson, E., & Salisbury, C. (2002). Systematic review of whether nurse practitioners working in primary care can provide equivalent care to doctors.. *BMJ*, *324*(6), 819-823.

Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington D.C.: National Academy Press.

Institute of Medicine. (2010). *The future of nursing: Leading change, advancing health*. Washington, DC: U.S. Government Printing Office

King, J. S., & Moulton, B. (2006). Rethinking informed consent: The case for shared medical decision-making. *American Journal of Law and Medicine*, *32*, 429-501.

Kitzhaber, J. (2011). *Governor John Kitzhaber remarks to the Oregon Health Policy Board meeting, January 18,2011*. Unpublished manuscript.

Landon, M. B., Hauth, J. C., Leveno, K. J., Spong, C. Y., Leindecker, S., Varner, M. W., ... Wapner, R. J. (2004, December 16). Maternal and perinatal outcomes associated with a trial of labor after prior ceserean delivery. *NEJM, 351(25*), 2581-2589.

Legare, F. (2008). Establishing patient decision aids in primary care: Update on the knowledge base.. *Z. Evid.Fortbild.Qual.Gesundh (ZEFQ*), *102*, 427-430.

Legare, F., Ratte, S., Gravel, K., & Graham, I. (2008). Barriers and facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals' perceptions. *Patient Education and Counseling*, *73*, 526-535.

McGlynn, E. A., Asch, S. M., & Adams, J. (2003). The quality of health care delivered to adults in the United States. *New England Journal of Medicine, 348*, 2635-2645.

Mundinger, M. O., Kane, R. L., Lenz, E. R., Totten, A. M., Tsai, W. Y., & Cleary, P. D. (2000). Primary care outcomes in patients treated by nurse practitioners or physicians. *JAMA*, (1), 59-68. doi: Retrieved from

National Advisory Committee on Rural Health and Human Services. (2008). *The 2008 Report to the Secretary: Rural Health and Human Services Issues* (Annual Report). : .

Naylor, M. D., & Kurtzman, E. T. (2010). The role of nurse practitioners in reinventing primary care. *Health Affairs*, 29(5):893-899.

Organization for Economic Co-Operation and Development (2010). *OECD Health Data 2010*. Retrieved from OECD: http://www.oecd.org/statisticsdata/0,3381,en_2649_34631_1_119656_1_1_37407,00.html

O’Connor, A. M., Bennett, C. L., Stacey, D., Barry, M., Eden, K. B., Entwistle, V. A., .. Rovner, D. (2009,). *Decision aids for people facing health treatment or screening decisions (Review)* (White paper). Retrieved from : San Fransisco: Wiley.

O’Connor, A. M., Bennett, C. L., Stacey, D., Barry, M., Eden, K. B., Entwistle, V. A., ... Rovner, D. (2009). Decision aids for people facing health treatment or screening decisions (review). *The Cochrane Collaboration*, *Issue 3*, 1-113.

O’Connor, A. M., Llewelyn-Thomas, H. A., & Flood, A. B. (2004). Modifying unwarranted variations in health care: Shared decision making using patient decision aids. A review of the evidence base for shared decision making. *Health Affairs*. doi: 10:1377

O'Connor, A. M., Rostom, A., Fiset, V., Tetroe, J., Entwistle, V., Llewellyn-Thomas, H., ... Jones, J. (1999, September 18). Decision aids for patients facing health treatment of screening decisions: systematic review. *British Medical Journal*, *319*, 731-734.

O'Connor, A. M., Wennberg, J. E., Legare, F., Llewellyn-Thomas, H. A., Moulton, B. W., Sepucha, K. R., ... King, J. S. (2007, May/June). Toward the 'Tipping Point': Decision aids and informed patient choice. *Health Affairs*, *26(3*), 716-725.

Rossouw, J. E., Anderson, G. L., Prentice, R. L., LaCroix, A. Z., Kooperberg, C., Stefanick, M. L., ... Kotchen, J. M. (2002). Writing group for the Women's Health Initiative investigators. Risks and benefits of estrogen plus progestin in healthy prostmenopausal women: Principle results from the Women's Health Initiative randomized controlled trial. *JAMA*, *288(3)*, 321-333.

Shi, L., & Singh, D. (2009). Beliefs, Values, and Health. In A. M. Barker (Ed.), *Advanced practice nursing; Essential knowledge for the profession* (pp. 93-128). Sudbury, Massachusetts: Jones and Bartlett.

The Commonwealth Fund. (2010). *Mirror, Mirror on the wall: How the performance of the U.S. health care system compares internationally, 2010 Update* (Commonwealth Fund pub. no. 1400). Retrieved from The Commonwealth Fund: http://www.commonwealthfund.org/~/media/Files/Publications/Fund%20Report/2010/Jun/1400_Davis_Mirror_Mirror_on_the_wall_2010.pdf

Trinite, T., Loveland-Cherry, C., & Marion, L. (2009). U.S. Preventative Services Task Force: An evidenced-based prevention resource for nurse practitioners. *Journal of the American Academy of Nurse Practitioners*, 21, 301-306.

US Preventative services task force: Screening for prostate cancer: US Preventive services task force recommendation statement. (2008). *Ann Intern. Med*., *149(3*), 185-191.

Wennberg, J. E., Brownlee, S., Fisher, E. S., Skinner, J. S., & Weinstein, J. N. (2008). *An agenda for change, improving quality and curbing health care spending: Opportunities for the Congress and the Obama administration. A White Paper*. Retrieved from www.dartmouthatlas.org: www.dartmouthatlas.org/downloads/press/exp_coverage_121708.pdf

Wennberg, J., Brownlee, S., Fisher, E., Skinner, J., & Weinstein, J. (2008, December). *An agenda for change: Improving quality and curbing health care spending: Opportunities for the Congress and the Obama administration* (White Paper). Lebanon, NH: The Dartmouth Institute.

Ziller, E. C., Coburn, A. F., & Yousefian, A. E. (2006). Out-of-pockiet health spending and the rural underinsured. *Health Affairs*, *25(6*), 1688-1699.

Appendix A

Shared Decision Making Study Pre-Assessment--Semi-Structured Interview/Focus Group (Revised 10/15/09)

Interview Date: __________________________
Clinic: _______________________________________
_____CLINICIANS
_____NURSES & OFFICE STAFF
Facilitator: ______________________________
Note Taker: ______________________________
Recording Information/Record: ______________

Thank you for taking the time to meet with me today. Your participation will help us to understand the issues that influence the use of shared decision making and decision aids in primary care. We plan to use this information to help us work with you to implement decision aids in your practice. The information that you provide will be kept strictly confidential as will the identity of every clinic staff member we interview for this study. Our findings will only be reported for the clinic as a whole, and not for individuals.

With your permission we would like to record this interview, is that okay? [turn on recording devise if approval is received]

We anticipate this [interview/focus group] will take 1 hour. We want this to be an opportunity for everyone to share their opinion, while staying on time. Therefore if we cut you off it is because these are the goals in mind. Do you have any questions before we begin?

1) First, I’d like to have us go around the circle with introductions. Could you tell me who you are and what you do?

   Prompt as needed for clinicians:
   - Do you have a special focus/interest in your practice?

   Prompt as needed for nurses/staff:
   - Years in practice & years in community
   - Do you work with all the doctors or one in particular?
   - Full time or part time?

Today we are focusing on three issues: your perceptions about shared decision making in primary care, your ideas about implementing decision aids into practice, and your clinic’s experiences with practice change.

2) To get started, what does shared decision making mean to you?

[if needed] Many medical decisions are in a “gray” area because there is not enough scientific evidence that the benefits of a treatment or a test outweigh the possible harms. In these cases, reasonable people might make different choices based on their own situations and values. These conditions include choices for colorectal cancer screening (colonoscopy versus stool testing), treatment of early stage breast cancer (lumpectomy with or without chemotherapy), completing an Advance Directive (Living Will) form, weight loss surgery and many others such as osteoarthritis. For example, some people with severe osteoarthritis of the knee will want to manage their pain medically with pills and others will want to have a joint replacement. In these types of cases shared decision making, a joint process between the patient and clinician, can be useful. This process engages the patient in decision-making, helps provide the patient with information about alternative treatments, and

incorporates the patient's preferences and values into the medical plan. Our next set of questions explore how you think about shared decision making in this practice.

3) <u>When you look at your entire practice, is this a practice that uses shared decision making on a routine basis?</u>

4) <u>If you can, give us an example of your best experience with a patient and shared decision making. What was it like?</u>
   Prompt as needed:
   - What condition was the patient facing?
   - Who initiated the discussion (for example: Patient? Patient's family member/friend? You? Another clinician/staff member in your practice? Someone outside your practice?)?
   - Who was involved in the decision?
   - What did you discuss with the patient/their family or friends?
   - How were the possible benefits/risks of the various treatments communicated to the patient? Did you use any brochures, tapes, or electronic resources?
   - What was the outcome of this conversation?
   - What do you think helped this interaction go well?

5) <u>What about the opposite – give us an example of a time when shared decision making didn't go well, or when it was not used but maybe should have been.</u>
   Prompt as needed:
   - What condition was the patient facing?

   If they did not use SDM, prompt as needed:
   - Why didn't a shared decision making process seem appropriate at the time?
   - Looking back, would you have used the shared decision making approach or some other way to help this patient?

   If they used SDM, but it went poorly, prompt as needed:
   - What happened that this conversation seemed so difficult?
   - Was there another approach that should have been used – i.e. should shared decision making have occurred?

6) <u>You've just told us about a time when shared decision making didn't go so well in your practice. Can you tell us what in general makes SDM hard to do in this practice – or what makes it possible?</u>
   Prompt as needed:

- [Resources] Are there resources to help with patient education? (For example having a care manager on staff, using medical assistants or care coordinators to provide information, or linking patients with printed resources)
- [Processes] Do staff or other clinic structures facilitate shared decision making? When you have an important decision to make with a patient, what do you do? For example do you schedule longer appointments, make these decisions at the end of the day, have the doctors make a home visit, or get other members of the clinic (like a social worker) involved? [Patient factors] Is there anything about patients that come to this practice that can make it easier or more difficult to engage in shared decision making?
- [Clinician factors – including attitude] Clinicians have different styles and approaches, how does this play a role in the shared decision making process? Is there anything about the way clinicians think about these issues that make it harder or easier for shared decision making to occur in your clinic?

Some organizations have developed things called decision aids to help with the process of shared decision making. Decision aids are meant to be standardized tools that are based on the best scientific evidence available and are designed to inform patients and help them clarify their values. Decision aids can help to guide patients through the decision process with their clinicians so that they arrive at an informed choice that best fits their own values and situation. These tools can come in the format of brochures, videos, etc. Our next set of questions explore how you think about using decision aids in this practice.

7) <u>Tell me about your experience using decision aids in this practice?</u>
   Prompt:
   - Are you currently using any decision aids? How do you use them with your patients?
   - Where do you get your decision aids from? How do you update them?
   - How to you decide to share a decision aid tool with a patient?
   - Are there conditions for which decision aids would be helpful? What are they?
   - Do you think your patients are or would be receptive to using decision aids?

A key goal of this research project is to work with you, your colleagues, and your staff to incorporate decision aids into patient care.

8) <u>When you make a practice change, like increasing shared decision making by using decision aids, how would that decision be made?</u>
   Prompt if needed:
   - Who actually makes that decision?
   - When do these decision occur?
   - How do staff/others learn about these decisions/practice changes?

9) <u>I want you to imagine that your clinic was going to adopt a new set of decision aids in your practice. What do you think would help most to help make sure these decision aids were used successfully?</u>
   Prompt as needed:

- [People] Is it important to have a clinic champion or clinic leaders to coordinate efforts?
- [Format/content] Is the format of the decision aids important – for example as a hand out or as a video? Is the content/topic of the decision aid important?
- [Structure] Would it be important to have specific protocols or changes in your office work process?

10) In this study we're using a collaborative research approach to implement decision aids developed by the Foundation for Informed Medical Decision Making into real world clinic settings. If you were to participate in a project such as this, what would you consider success?
Prompt as needed:
    - So what would success look like?
    - How would you be involved in making this project successful?

Thank you for your time and for helping us to better understand this complex issue. We are:

- Working with 4 clinics and communities in rural Oregon to implement decision aids developed by the Foundation for Informed Medical Decision Making.
- Here is a list of available Decision Aids available from the Foundation. Our next step is work with your clinic to select 2-3 DAs relevant to your practice population for use in this implementation study.
- We will use feedback from these interviews as the foundation on which these collaborative efforts will be framed.

Do you have any final comments or questions?

PRE-ASSESSMENT WORK SHEET

Focus Group Participant Demographic Tracking. To be completed at time of focus group for basic tracking of **pre-assessment** participants.

	Name	Role in Clinic	Gender
1			
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Role in Clinic Options:

- Provider - Physician (MD or DO), Physician Assistant, Nurse Practitioner
- Management (practice manager, office manager, nurse manager)
- Administrative or clerical staff (billing, front desk, scheduling, medical records, etc.)
- Nurse (RN), Licensed Vocational Nurse (LVN), Licensed Practical Nurse (LPN)
- Other clinical staff or clinical support staff (medical assistant, nursing aid, technician)

Appendix B

Shared Decision Making Study 1 Year Post-Assessment
Semi-Structured Interview/Focus Group

Interview Date: ____________________________
Clinic: ____
_____CLINICIANS
_____NURSES & OFFICE STAFF
Facilitator: ______________________________________
Note Taker: ______________________________________
Recording Information/Record: _______________

Thank you for taking the time to meet with us. You probably know that about a year ago your clinic started a project to enhance shared decision making by finding ways to use decision aids in routine practice. We're here today to learn what you think about shared decision making, your views about the process of using decision aids in practice, and your thoughts about what support your clinic might need for continued success with this project. We know that you have had different levels of participation in the project - and that's fine. We think each of you have important insights to offer.

We plan to use the information from this meeting to improve our work at your clinic and with other clinics as they begin using decision aids. We will also use your comments, along with those from the other practices, to help develop guidelines that other primary care practices can refer to when they begin using shared decision making tools with their patients. We will not share your identity or the identity of any clinic staff member we interview for this study. Our findings will only be reported for the clinic as a whole, and comments will not be linked to specific individuals.

We expect this [interview/focus group] will take 1 hour. We want this to be an opportunity for everyone to share their opinion, while respecting your time. Therefore if we interrupt your or cut you off it is because these are the goals in mind. We may also ask for further clarification if the comments you make are not entirely clear. With your permission we would like to record this interview, is that okay? [turn on recording devise if approval is received] Do you have any questions before we begin?

As I mentioned, we'd like to focus on three issues: your perceptions about shared decision making in primary care, your views regarding the process of using decision aids in practice, and your thoughts about what support your clinic might need for continued success with this project.

11) First, I'd like to have us go around the circle with introductions. Could you tell me who you are and what you do at the clinic?

12) Recognizing that each of you might have a different level of engagement with the project, how would you describe your involvement in the Shared Decision Making/Decision Aid Project over the past year? (i.e., very engaged, aware of the work, just learned about it today)!

13) A key goal of this research project has been to work with the clinicians and staff in this practice to enhance shared decision making by incorporating decision aids into routine patient care. After a year of activity, what does shared decision making mean to you?

Prompt as needed:

- By participating in this project, has your understanding of shared decision making changed?

[if needed] Many medical decisions are in a "gray" area because there is not enough scientific evidence that the benefits of a treatment or a test outweigh the possible harms. In these cases, reasonable people might make different choices based on their own situations and values. These conditions include choices for colorectal cancer screening (colonoscopy versus stool testing), treatment of early stage breast cancer (lumpectomy with or without chemotherapy), completing an Advance Directive (Living Will) form, weight loss surgery and many others such as osteoarthritis. For example, some people with severe osteoarthritis of the knee will want to manage their pain medically with pills and others will want to have a joint replacement. In these types of cases shared decision making, a joint process between the patient and clinician, can be

useful. This process engages the patient in decision-making, helps provide the patient with information about alternative treatments, and incorporates the patient's preferences and values into the medical plan. Our next set of questions explore how you think about shared decision making in this practice.

14) <u>When you look at your entire practice, what does shared decision making look like here?</u>

Prompt as needed:

- Is this a practice that uses shared decision making on a routine basis?
- Has participating in this project changed the way you interact with patients?

[If needed] Decision aids are meant to facilitate the process of shared decision making. They are standardized tools that are based on the best scientific evidence available and are designed to inform patients and help them clarify their values. Decision aids can help to guide patients through the decision process with their clinicians so that they arrive at an informed choice that best fits their own values and situation. These tools can come in the format of brochures, videos, etc. Our project has used DVD decision aids developed by the Foundation for Informed Medical Decision Making.

15) <u>Tell me about your experience using decision aids in this practice?</u>

Prompt as needed:

- Are you currently using any decision aids? Why/Why not?
- How are DAs currently used with your patients?
- How have your patients responded to the using decision aids [Receptive? Reticent? Thankful?]?
- How does the clinic "market" the DA to patients – i.e., how does the clinic handle the DA "referral"?
- Are clinicians/staff more interested and aware of shared decision making since you now have these tools?
- How has incorporating influenced patient workflow? Has it led to any anticipated or unanticipated changes?

16) <u>How did your clinic approach the process of integrating decision aids into routine care?</u>

Prompt as needed:

- Who was involved?
- How were decisions about the decision aids made?
- How did staff/others learn about these decisions/practice changes?
- How has the DA implementation strategy changed over time?
- What worked well and what was difficult?

17) <u>When we initiated this project clinicians and staff mentioned facilitators/challenges to engaging in shared decision making and utilizing DAs in routine care. These included topics such as resource availability, clinical processes, patient factors, and clinician factors. Given what you know now, what are the factors that make SDM/DAs **hard** to do in this practice?</u>

Prompt as needed:

- [Resources] Are there resources to help with patient education? (For example having a care manager on staff, using medical assistants or care coordinators to provide information, or linking patients with printed resources)
- [Processes] Do staff or other clinic structures facilitate shared decision making? When you have an important decision to make with a patient, what do you do? For example do you schedule longer appointments, make these decisions at the end of the day, have the doctors make a home visit, or get other members of the clinic (like a social worker) involved? Did you change office work processes to support integration of DAs?

- [Patient factors] Is there anything about patients that come to this practice that can make it easier or more difficult to engage in shared decision making?
- [Clinician factors – including attitude] Clinicians have different styles and approaches, how does this play a role in the shared decision making process? Is there anything about the way clinicians think about these issues that make it harder or easier for shared decision making to occur in your clinic?
- [External support] How have the efforts of the ORPRN practice facilitator influenced your work?

18) <u>Given what you know now, what are the factors that make SDM/DAs **possible** to do?</u>

Prompt as needed:

- [Resources] Are there resources to help with patient education? (For example having a care manager on staff, using medical assistants or care coordinators to provide information, or linking patients with printed resources)
- [Processes] Do staff or other clinic structures facilitate shared decision making? When you have an important decision to make with a patient, what do you do? For example do you schedule longer appointments, make these decisions at the end of the day, have the doctors make a home visit, or get other members of the clinic (like a social worker) involved? Did you change office work processes to support integration of DAs?
- [Patient factors] Is there anything about patients that come to this practice that can make it easier or more difficult to engage in shared decision making?
- [Clinician factors – including attitude] Clinicians have different styles and approaches, how does this play a role in the shared decision making process? Is there anything about the way clinicians think about these issues that make it harder or easier for shared decision making to occur in your clinic?
- [External support] How have the efforts of the ORPRN practice facilitator influenced your work?

19) <u>In your opinion, what has been the most helpful in incorporating decision aids into practice? What has been the biggest barrier?</u>

20) <u>Making a practice changes, like increasing shared decision making by using decision aids, can require considerable effort by the practice. In your opinion has your clinic been successful in incorporating decision aids into regular patient care?</u>

Prompt as needed:

- How have your views of success changed since the pre-assessment/start of the project?

21) <u>If you were to start over on this project – what would you do differently?</u>

Prompt as needed:

- As the research team, what should we do differently?
- What has gone well?

22) <u>Given our discussion so far, as we move forward can you think of any support that your clinic needs to be/continue to be successful integrating decision aids into practice?</u>

Prompt as needed:

- How might the ORPRN continue to support your efforts to integrate DAs?
- What role should the ORPRN PERC play to support continued success?

23) Our approach in this study has been to use a collaborative research approach to implement decision aids into real world clinic settings. We plan to use what we've learned working with your clinic to develop a toolkit that other practices can use when integrating decision aids into primary care. With this in mind – what information do you think would be helpful to other clinics who decide to integrate DAs into routine patient care?

Prompt as needed:

- Strategies for patient identification?
- Strategies for decision aid tracking?
- Scripts for distributing decision aids?

Thank you for your time and for helping us to better understand this complex issue. In our second year of the project we plan to:

- Continue working with our 4 year 1 practices
- Recruit 2 new clinics to implement decision aids developed by the Foundation for Informed Medical Decision Making.
- Use feedback from these interviews to inform our implementation process and help in the development of a primary care decision aid implementation guide.

Do you have any final comments or questions?

POST-ASSESSMENT WORK SHEET

Focus Group Participant Demographic Tracking. To be completed at time of focus group for basic tracking of **post assessment** participants.

	Name	Role in Clinic	Gender
1			
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12			

Role in Clinic Options:

- Provider - Physician (MD or DO), Physician Assistant, Nurse Practitioner
- Management (practice manager, office manager, nurse manager)
- Administrative or clerical staff (billing, front desk, scheduling, medical records, etc.)
- Nurse (RN), Licensed Vocational Nurse (LVN), Licensed Practical Nurse (LPN)
- Other clinical staff or clinical support staff (medical assistant, nursing aid, technician)

Appendix C

Foundation for Informed Medical Decision-Making (FIMDM) Decision Aids

Title	Preference Sensitive?*
Early Breast Cancer: *Hormone Therapy and Chemotherapy - Are They Right for You?*	No
Living with Metastatic Breast Cancer: *Making the Journey Your Own*	No
Early Stage Breast Cancer: *Choosing Your Surgery*	Yes
DCIS: Choosing Your Treatment (Breast Cancer)	Yes
Breast Reconstruction: *Is It Right for You?*	Yes
Treatment Choices for Benign Prostatic Hyperplasia	Yes
Is a PSA Test Right for You?	No
Treatment Choices for Prostate Cancer	Yes
Prostate Cancer - Hormone Therapy	No
Treatment Choices for Abnormal Uterine Bleeding	Yes
Treatment Choices for Uterine Fibroids	Yes
Managing Menopause: *Choosing Treatments for Menopause Symptoms*	Yes
Ovarian Cancer: Reducing Your Risks ***Available in Booklet Only***	No
Treatment Choices for Coronary Artery Disease	Yes
Living with Coronary Heart Disease	No
Living with Heart Failure: Helping Your Heart Day-to Day	No
Living better with Chronic Pain	No
Living with Diabetes: Making Lifestyle Changes to Last a Lifetime	No
Colon Cancer Screening: *Deciding What's Right for You*	No
Coping with Symptoms of Depression	No
Chronic Low Back Pain: *Managing Your Pain and Your Life*	No
Spinal Stenosis: *Treating Low Back and Leg Symptoms*	Yes
Herniated Disc: Choosing the Right Treatment for You	Yes
Treatment Choices for Hip Osteoarthritis	Yes
Treatment Choices for Knee Osteoarthritis	Yes
Acute Low Back Pain: *Managing Your Pain through Self-Care*	Yes
Getting the Healthcare That's Right for You	No
Looking Ahead: Choices for Medical Care When You're Seriously Ill	No
Peace of Mind: *Personal Stories about Advance Directives*	No
Weight Loss Surgery: Is It Right for You?	Yes

* A DA is designated as a Preference Sensitive Condition when surgery is a possible treatment choice.

Shared Decision Making: Views of Primary Care Clinicians in Four Oregon Rural Practice Sites

Myra Ladd Thompson R.N. MS FNP

Oregon Health & Science University; School of Nursing

Clinical Inquiry Project

Candidate, Doctor of Nursing Practice

Deborah Messecar PhD, MPH, R.N., GCNS-BC   Advisor

Lyle J. Fagnan M.D.   Clinical Mentor

Shared Decision Making: Views of Primary Care Clinicians in Four Oregon Rural Practice Sites

In an ideal world, medical decisions would optimally match the patient's choice and preference. Many factors contribute to America's less than ideal health care system. The recent national debate over health care reform reveals the high cost yet underperformance in nearly all areas of our health care system (Davis, Schoen, & Stremikis, 2010; OCED, 2010).

It is difficult and discouraging for primary care clinicians to feel they have any influence to improve the health care system when the overall structure is complex and dysfunctional. The shared decision making process allows a clinician to insert a modicum of control and good sense into their daily practice. Shared decision making (SDM) describes a process where medical care decisions are jointly shared by patients, families, and their health care clinician. The process is used to settle on treatment and diagnostic options for which there may be two or more evidence-based medical choices. O'Connor, Llewelyn-Thomas & Flood (2004) describe shared decision making as the process of interacting with patients in arriving at informed, values-based choices when options have features that patients value differently" (O'Connor, Llewelyn-Thomas, & Flood, 2004, VAR,63).

Clinicians using SDM in routine care recognize the importance of collaborative medical decisions. They respect the values and viewpoints of their patients and families without losing their own ethical bearings. Patient decision aids are available that present evidence-based value-neutral medical options to facilitate the shared decision making process. The subject of this clinical inquiry project is shared decision making as understood and implemented by clinicians working in four rural primary practices in Oregon.

The Clinical Problem

Many medical decisions are unambiguous; the “right” course of action can be determined by implementing clear, evidence-based guidelines. T~~However, t~~he path is sometimes not ~~always~~ so obvious. The ideal is a choice that aligns with the values and preferences of the patient, and a choice which assures the clinician they have offered accurate and comprehensive information needed for this decision. If uncertainty is an inherent part of many clinical decisions, is there anything that can help patients and providers clarify and identify the best medical choice? ~~The ideal is a choice that aligns with the values and preferences of the patient, and a choice which assures the clinician they have offered accurate and comprehensive information needed for this decision.~~ Many professionals believe that shared decision making and the use of evidence-based decision aids provides the greatest opportunity for patients to choose options that fit their value and preference framework (Edwards & Elwyn, 2009; Legare, Ratte, Gravel, & Graham, 2008; O’Connor et al., 1999).

Medical science is not transparent; there is a great deal of inherent uncertainty. *Crossing the Quality Chasm*, the Institute of Medicine’s seminal report outlined the goals for a new health care system for the 21st century. It declares the need for transparency in medicine. “Make all information flow freely so that anyone involved in the system, including patients and families, can make the most informed choices and know at any time whatever facts may be relevant to a patient’s decision making” (Institute of Medicine, 2001, p. 79). Atul Gawande (2002) describes this medical ambiguity as a central dilemma in health care. “The core predicament of medicine, its’ uncertainty, is the thing that makes being a patient so wrenching, being a doctor so difficult, and being part of the society that pays the bills so vexing” (Gawande, p. 23, 2002).

Medicine is not a consumer-driven model of care. Clinicians are not selling a retail "product" nor are consumers out to get health care "goods" at the cheapest price possible. The clinician/patient relationship is built on trust. It holds as important the belief that the provider will put the patient's interests ahead of his/her own, and that the patient will trust their provider's knowledge and professionalism. Noted health care economist, Victor Fuchs, describes the patient-physician relationship as very different from the one that we accept in commercial marketplaces, because it requires that patients and health professionals work cooperatively (Fuchs, 1998). This explains why some people consult an expert guide when contemplating a major retail purchase, but when a "purchase" may have life or death consequences they discover there is no "consumer report" for health care. While it is true that patients can locate data about clinicians and health care facilities on the Internet or by word of mouth, the average consumer has difficulty understanding the important associations and variables necessary to assemble a sound decision.

The ethical concept of beneficence illuminates the difficulty of finding a balance between patient autonomy and clinician role. "While beneficence obligates physicians to act for the benefit of their patients, respect for autonomy requires them to ensure that patients have enough information to make a reasoned and autonomous medical decision" (Moulton & King, 2010, p. 85). This often produces a clinically difficult tension. It is not always so easy to align patient autonomy and clinician opinion. Noted biomedical ethicists, Beauchamp & Childress (2009) state,

> Traditionally, physicians relied almost exclusively on their own judgments about their patients' needs for information and treatment. However, over the last few decades,

> medicine has increasingly confronted assertions of patients' rights to make independent judgments. (Beauchamp & Childress, 2009, p. 207)

With the increasing emphasis on patient participation in medical decision making, clinicians are experiencing a wide spread cultural shift from a paternalistic model to one that supports patients in making their own health decisions.

A number of health systems around the country, including Dartmouth-Hitchcock in New Hampshire and Group Health in the Puget Sound area, have developed a formal process of shared decision making. These centers are in academic and/or large urban locales and may not reflect the needs or strengths of rural primary care; therefore, practice interventions from a metropolitan center may not translate well to the rural setting.

This project used information from four rural primary care practices in Oregon to discover clinician understanding of the shared decision making process. It revealed their perceptions of the barriers and facilitators for a successful adoption of SDM and the use of decision aids in their clinics.

Shared Decision Making

The following is a review of the basic principles and components of the shared decision making (SDM) process.

Shared Decision Making Definition

Shared decision making is defined as decisions that are shared by doctors and patients, informed by the best evidence available and weighted according to specific characteristics and values of the patient.

Decision Making Aids

A decision making aid (DA) is an evidence-based tool developed to assist providers in facilitating SDM in their clinical setting. They are not simply educational but are designed as an intervention to help people make specific and deliberate value choices among various acceptable options. Decision aids improve patient outcomes and may prevent overuse of options that an informed patient does not value. According to O'Connor, there are three key elements common to a well designed decision aid. They must provide high-quality and up-to-date education, they must assist the patient to better judge the value of available options, and they must provide guidance or coaching through the SDM process (O'Connor, 2004). The International Patient Decision Aids Standards (IPDAS) Collaboration developed a consensus based framework of quality criteria for patient decision aids (Elwyn, O'Connor, et al., 2006). This process invites patients to participate in medical decisions when there is more than one reasonable option and SDM has been identified as an important approach to effectively implement and support evidence-based medical practice.

Preference Sensitive Decision Aids

Many health care treatment and screening options have no single 'best' choice. One example is the present uncertainty about prostatic cancer screening. The majority of American men over age 50 years have been screened for prostate cancer with the blood test, prostate-specific antigen (PSA). Recent large studies have shown that the absolute benefit of this screening is negligible, and conclude that this common screening practice is controversial (U.S. Preventive Services Task Force: Screening for prostate cancer: U.S. Preventive Services Task Force recommendation statement, 2008).

As medical science and research advances, treatment guidelines change as well. Examples of these changes include hormone replacement therapy (Hersh, Stefanick, & Stafford, 2004: Rossouw et al., 2002) and vaginal birth after caesarian section (VBAC). Guidelines for these two medical options have changed in just the last decade (Landon et al., 2004).

Decisions such as the treatment of knee osteoarthritis, menopause, and prostate cancer are called *preference sensitive* in the shared medical decision making process. These *preference sensitive* decisions occur when there is no scientific consensus as to the best treatment or decision; thus the patient should participate and help make the decision that fits them best. Shared medical decisions can help align care management decisions with patient preferences and values. According to O'Connor et al., "decision aids improve people's knowledge of the options, create accurate risk perceptions of their benefits and harms, reduce difficulty with decision making and increase participation in the process" (O'Connor et al., 2009, p. 2).

Shared Decision Making Desired Outcomes

Some mistakenly view the shared decision making process as only a new way to reduce health care costs or provide health education. The aim is to get the right care to the right patient at the right time; to avoid both under-treatment and over-treatment, and support the patient's preference (Barry, 2002). While quality patient and family education is essential to good health care, the SDM process is more than just giving the patient a booklet to read. Shared decision making and the use of decision aids prepare the patient to discuss ambiguous medical treatments with their clinicians. Use of decision aids help patients and families weigh the benefits and harms of various medical options, while showing them the scientific uncertainty of their problem. According to the IPDAS collaboration (Elwyn et al., 2006), decision aids differ from usual health education because of their specific and personalized information that focus on options and outcomes designed to prepare people for a decision. A recent study, conducted to evaluate patient knowledge of basic medical conditions and treatments, determined that "patient knowledge of key facts relevant to recently made medical decisions is often poor and varies systematically by decision type and patient characteristics" (Fagerlin et al., 2010, p. 35). The results of a national study determined that recommendations and information from primary care providers strongly influenced testing decisions. The *DECISIONS* study found that ". . . although respondents generally endorsed shared decision-making process and felt informed, only 69.9% actually discussed screening before making a testing decision" (Hoffman et al., 2009, p. 1617).

Decision Aid Sources

Multiple evidence-based health decision aids/products are available to facilitate the shared medical decision making experience. A partial list includes: Healthwise, Health Dialog, Mayo Clinic and the Agency for Healthcare Research and Quality and the National Cancer Institute.

Context

The Dartmouth Atlas research has shown geographically distinct health care spending markets in the U.S. This research has shown that more spending and more utilization do not translate into improved life expectancy for those with chronic illness. This data has been one impetus to spreading information on SDM to clinicians and patients.

The Dartmouth Atlas

Rising health care costs remain a major challenge to the American economy. The Dartmouth Institute for Health Policy and Clinical Practice developed the Dartmouth Atlas, which reports on geographic differences in health care delivery and spending (Wennberg, Brownlee, Fisher, Skinner, & Weinstein, 2008). Using over a decade of Medicare data, the Dartmouth Atlas Project has described how medical resources are spread and used in the United States

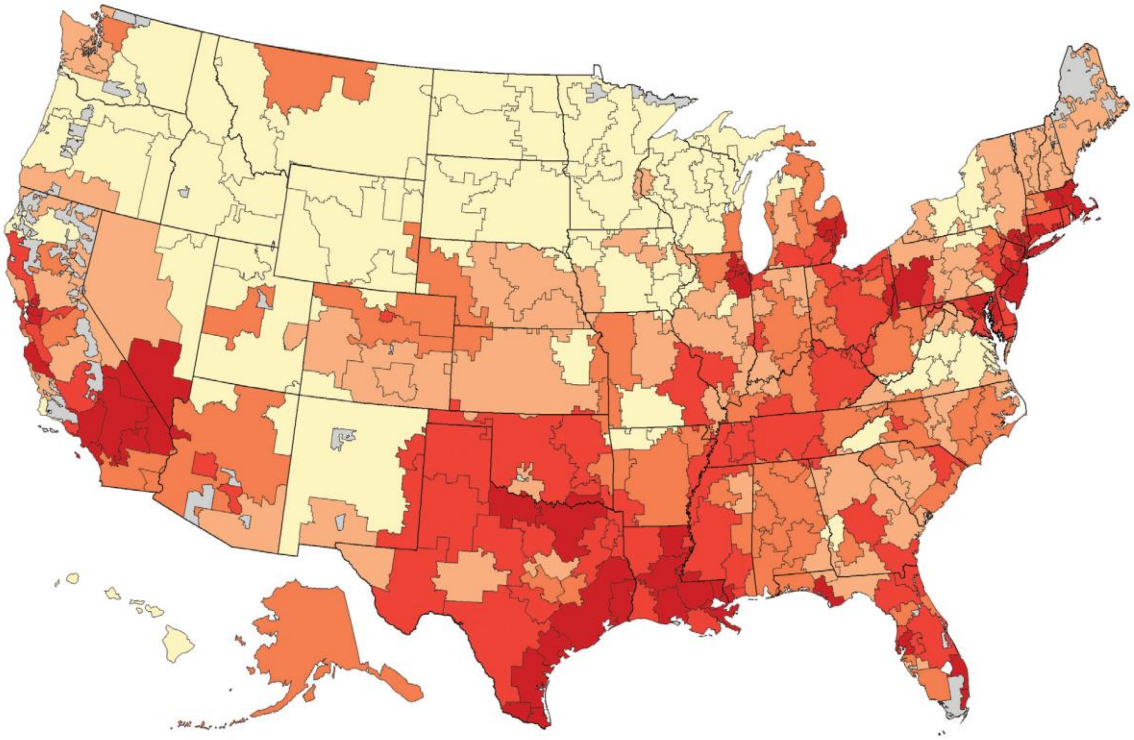

Figure 1 Medicare Spending per Beneficiary in 2005. **Darkest red equals greatest dollars spent.** (Dartmouth Institute for Health Care Policy and Clinical Practice, 2008)

It has demonstrated conspicuous variations in how health care is provided, and has shown no consistent association between the mean per capita expenditure in a geographic area and the perceptions of the quality of medical care by the people who live in those areas and their health outcomes (Fowler, Gallagher, Anthony, & Skinner, 2008).

The prevalence of invasive procedures is highly variable; for example, patients who live in Southern California are six times more likely to have surgery for herniated disks than patients living in New York State. Atul Gawande (2009) brings this data down to the community level. He identified McAllen Texas as one of the most expensive yet least healthy place to live in America (Gawande, 2009).

Higher spending and more utilization of services do not routinely translate into improved life expectancy for those with chronic illness (Fisher et al., 2003). This data points to an opportunity to achieve significant savings in health care costs without compromising health care quality.

Background

There are multiple factors that influence the success of shared decision making in Oregon. A brief review of health care policy in Oregon, past innovations, supportive organizations, and future directions and legislative influence will show the barriers and facilitators for the SDM process in our state.

Health Care in Oregon

Health policy initiatives from the State of Oregon have been followed globally for many years. When Oregon was facing escalating and unsustainable health care costs in the 1980's, the state government created an innovative yet controversial plan to ensure that health care would still be available for its citizens.

Development of the Oregon Health Plan. In the late 1980's Oregon found that 18% of all of its citizens had no health insurance, and that 20% of this uninsured number was children. Then state governor, Neil Goldschmidt, appointed an 11 member commission to examine this problem. Two-thirds of the commission consisted of health care providers. The commission had broad representation from a number of stake holders. They traveled to many parts of the state to gather data from the general population; this community based approach gave credibility to their conclusions. The commission workgroup reached the following consensus:

- All citizens should have universal access to basic care
- Society is responsible to pay for poor people

- Process to define “basic” care needed
- Process must be transparent, public debate, consensus of social values needed
- Encourage treatment that is effective
- Balance health care funding with other programs that affect health
- Funding to be explicit, sustainable, and accountable

In 1988, then senate president, John Kitzhaber, M.D., initiated the Oregon Medicaid Priority Setting Project. Out of this project the Oregon Health Services Commission was created to rank medical services from most to least important. Oregon developed a unique system that provided a comprehensive medical plan for all the poor, but limited the care to conditions and procedures on a prioritized list. A national furor was ignited about “rationing of care” which touched off the original “death panel” debates and delayed government (HCFA) approval till 1993. The Oregon Health Plan began in 1994 with funds to cover 606 of the 743 listed diagnoses (Bodenheimer, 1997a, 1997b; Glass, 1998).

Future Directions. In June 2009, House Bill 2009 passed the Oregon Legislature with the intent to improve the quality and consistency of health care, provide greater accountability to the public for resources spent in the health care system, and to seriously transform Oregon’s health care system. The Oregon Health Authority (formerly the Oregon Health Plan) was created as a new agency to oversee health care reform in Oregon, eliminating two boards and consolidating all state health care functions under the Health Authority Board.

The recent election of John Kitzhaber, M.D., to an unprecedented third term as governor ensures that Oregon will continue to aggressively tackle the problems of health care in this state. Governor Kitzhaber addressed the Oregon Health Policy Board on January 18, 2011 to describe the current state budget crises driving some of these changes:

> We can deliver health care in America a lot more cheaply, a lot more effectively and get better outcomes but it will require a different delivery system. The opportunity for us, instead of just doing less of the same, in hopes that when the economy comes back we can do more of the same, is to actually to do things differently. (Kitzhaber, 2011)

The shared decision making process is not a clinical or care model innovation that stands apart from health care policy. The SDM process may become integral to primary care delivery in our state as the Oregon Health Authority has been asked by the legislature to:

- Promote the provision of services through an integrated health home model that reduces unnecessary hospitalizations and emergency department visits.
- Require little or no cost sharing for evidence-based preventive care and services, such as care and services that have been shown to prevent acute exacerbations of disease symptoms in individuals with chronic illnesses.
- Create incentives for individuals to actively participate in their own health care and to maintain or improve their health status (S. Res. HB 2009, 2009, p. 9).

Primary care re-designs efforts. Primary care clinicians are under increasing pressure to provide a full spectrum of patient care – acute, chronic and preventative care. Some question whether they will be able to survive these demands (Bodenheimer, 2006). There are at least two models of primary care delivery under review for rural primary care in Oregon.

Patient centered medical home. In Oregon, the Health Authority Board has indicated that the state health care delivery system is moving towards a patient centered medical home model. The three core tenets of this care model are a shift from individual patient care to population-based care, a change from physician to team based care, and use of the SDM concept to create an informed and activated patient.

Care management models. Nearly one half of a primary care physician's workday is spent on activities outside the examination room. These activities focus on needed follow-up, documentation of care, and other patient related work not associated with the patient in the exam room (Gottschalk & Flocke, 2005). Other models of care delivery are being examined that may utilize the clinicians time in a more efficient manner. A recent study evaluated use of a well trained registered nurse (nurse care manager) to supervise and coordinate patients with chronic diseases (Fagnan et al., 2011). These models have potential but needs additional research to determine ways to successfully implement into rural primary care practice.

Revised informed consent. Health care research over the last several decades suggests that an overhaul of our legal standard of informed consent is overdue. King and Moulton (2006) eloquently argue for redefining the present informed consent procedure to make systemic adjustments which allow for a solid use of SDM as a reliable informed consent practice (King & Moulton, 2006**).** There is movement in state and national governments to mandate use of the shared decision making process to create a better informed consent product. Washington became the first state to endorse SDM when Governor Christine Gregoire signed ESSB 5930 into law in May 2007. The goal is to recognize that medical outcomes can be improved by patient-practitioner communication and enhanced by high-quality decision aids. A shift to legislate SDM for Oregon practitioners may follow. It remains uncertain how the standard of shared decision making versus the current informed consent process will evolve.

Research and Academic Rural Support

Oregon Rural Practice-Based Research Network (ORPRN), located at Oregon Health & Science University, is a statewide network of primary care clinicians, community partners, and academicians dedicated to studying the delivery of health care to rural residents, and conducting research to reduce rural health care disparities. Network members include 171 clinicians, 50 primary care practices located in 39 rural Oregon communities which serve approximately 240,000 patients. ORPRN's research portfolio covers a wide range of health topics, including care management, shared decision making, evidence-based prescribing, and access to cancer screening, medication safety, child health, dementia, and clinician workforce issues. Translational research aimed at enhancing the adoption of best practices in Oregon's rural primary care setting is a priority of this organization and others like it across the nation (Fagnan, Handley, Rollins, & Mold, 2010).

Oregon Rural Population and Health Care

Like most western states, Oregon is diverse with large open areas, dense urban areas, isolated farms and settlements. Oregon is the ninth largest state with 98,400 square miles. The eastern two-thirds of the state are predominantly rural; most of the state's population resides along the narrow interstate five (I-5) corridor.

A national survey from 2000 reveals that approximately two-thirds of rural health care is provided through small physician-owned practices, generally in groups of five or fewer providers (Knott & Moscovice, 2000).

Compared to urban settings, people living in rural communities are more often self-employed, which generally results in populations without health care insurance or who are underinsured (Goetz, 2008; Ziller, Coburn, & Yousefian, 2006). In a 2008 report, the numbers of rural non-elderly residents covered by public health insurance programs showed an increase of 122 percent from 1987; nearly a third more rural people were covered by public plans when compared to urban residents (National Advisory Committee on Rural Health and Human Services, 2008).

Fewer Health Care Clinicians in Rural Oregon

There is a national shortage of primary care providers and this is especially acute for many rural locations in this state. The Oregon Office of Rural Health gathers data on the number and type of full time equivalent (FTE) health care providers in rural Oregon. Practice numbers for physician assistants and advanced nurse practitioners working in urban Oregon clinical sites is not calculated as this information is not needed for the purposes of the Office of Rural Health. As seen in Table 1, only 20% of all FTE doctors of medicine and osteopathy in Oregon work in rural locations.

Table 1 Oregon provider full time equivalents (FTE) practicing in rural settings for 2010

Setting	DO FTE	MD FTE	Physician Assistants	Nurse Practitioners
Rural	206	1777	205	408
Urban	407	7509	Not Calculated	Not Calculated

Synthesis of Evidence

There are many barriers to implementation of “best-practice” models for the delivery of primary care. High health care costs, poorly distributed health care dollars and treatments, and inadequately followed evidence-base guidelines have all been shown to produce poor patient outcomes. There is considerable research evaluating the understanding, barriers, and factors facilitating the shared medical decision process.

High Cost and Poor Performance of the U.S. Health Care System

The United States spends much more per capita on health care than any other country and has one of the fastest growth rates in health care spending among developed countries. America spent $7,538 per person on health in 2008, more than twice the $3,000 average of all OECD countries (Organization for Economic Co-Operation and Development, 2010). Despite this higher level of spending, the United States does not achieve better outcomes on many important health care measures such as quality, access, efficiency, equity and healthy lives (Kaiser Family Foundation, 2007). Since 2004, the Commonwealth Fund has regularly evaluated the performance of the U.S. Health care system as compared to six other developed countries. This report shows that "the U.S. health care system is the most expensive in the world, but comparative analyses consistently show the United States underperforms relative to other countries on most dimensions of performance" (The Commonwealth Fund, p.v, 2010). These rankings are unsustainable given that by the year 2040 twenty nine percent of the US gross domestic product (GDP) is expected to be spent on health care in America (Healthcare Economist website, October 8, 2008). The emphasis in the US health care system is on acute emergent care, not on screening and prevention services. Yet government recommendations found in *Healthy People* (2010) outline extensive screening and prevention goals that seem out of reach with our present health care system. Donald Berwick, M.D., distinguished health policy analyst, describes how cost, quality and access must align before America can claim success with health care reform (Berwick, 2008). Bodenheimer and Pham (2010) recognize that primary care providers see this high cost/poor performance conundrum daily. The primary care clinician on the "front line" sees good patient care and helpful "best practice" models buried by bloated health care spending, which is aggressively driven by a litigious society and a medical-industrial complex focused on rescuing people through expensive treatment instead of engaging in patient centered medicine. Brook and Young (2010) describe the tension this creates for primary care physicians. Our health care system operates under the fallacy that "if it can be done we should do it." Shared decision making and the use of decision aids stop this "knee jerk" response to health treatments by matching management decisions to patient preferences. This process invites patients to participate in medical decisions when there is more than one reasonable option. Cost savings often occur and continue to show that low costs can go hand in hand with high quality (O’Connor et al., 2007). Though independent clinicians who are not in closed systems may not see any cost savings from fewer invasive surgeries or other treatments, they may still see the value of this approach because of its patient centered focus and its consistency with their values for providing high quality care.

International SDM Research

Shared decision making is not a new concept to our international colleagues. Medical and nursing communities across the globe have identified, implemented and extensively researched this subject for decades. Canada has been at the forefront of the SDM model and use of DAs. Annette O’Connor RN, PhD, is a nursing leader who has been instrumental in evaluating and implementing SDM around the world. Dr. O’Connor leads the International Cochrane Collaboration team that summarizes trials of patient decision aids (now over 62) and works to update a global inventory of evaluated patient decisions aids (now over 500). Dr. O’Connor also co-leads a 14-country international consensus process on standards for developing and evaluating patient decision aids (IPDAS).

France Legare, M.D., PhD (2008) has extensively evaluated multiple research studies and determined that in spite of the vast array of studies, “there is a need for well-conducted, randomized, controlled studies to help us identify the effective components of implementation strategies” (Legare, 2008, p. 430).

There is a significant gap between what is known in this research and what is actually practiced. The 2009 Cochrane review of 55 randomized controlled trials (RCT) provides evidence which suggests that shared decision making and decision aids benefit the patient by providing knowledge, lowering decisional conflict, and clarifying personal values which results in greater agreement between value and choice for the patient (O’Connor et al., 2009). However, actual use and implementation of this process into “real world” settings is under explored. This is especially true for the rural primary care site.

SDM Barriers

There are several well researched barriers both from the clinician and the patient perspective, to successful implementation of the SDM process in rural America.

Physician understanding of SDM in the U.S. There is research that has evaluated the perception and understanding of SDM from a broader perspective. In 2009, FIMDM commissioned a national survey of primary care physicians on the topic of SDM and DAs (Foundation for Informed Decision Making, 2009). The intent of this study was to understand the perceptions, experiences, as well as benefits and barriers to SDM. The top two key findings of this qualitative research showed that inadequate reimbursement rates, and limited time spent with patients were the main concerns for many of the physicians interviewed. “Two-thirds of physicians (67%) said they were very concerned about inadequate reimbursements, which topped a list of issues physicians might face in their practices. Another study found that “one in two physicians (51%) said they were very concerned about not having enough time with patients” (Foundation for Informed Decision Making, 2009, p. 2).

Even though there are decades of SDM research which have resulted in a multitude of published articles and randomized controlled trials, implementation of SDM into the everyday practice of U.S. physicians has yet to take place. Braddock, Edwards, Hasenberg, Laidley, and Levinson (1999) found that only nine percent of surgical consultations exhibited a good level of SDM. There appears to be a gap between theory and practice, since research is showing that quality SDM is occurring in only a small portion of patient visits.

Medical training for physicians in the U.S. has been slow to introduce SDM. Fifteen years ago, in 1996, a study found that ninety percent of respondents believed that physicians should have greater input in decisions than patients. Female respondents advocated for greater patient input than male respondents (Beisecker, Murden, Moore, Graham, & Nelmig, 1996). Recent research is showing improvement in training of physicians on how to use the SDM process for common family medicine problems (Legare et al.). A more recent systematic review of the barriers and facilitators to implementation of shared medical decisions showed that time constraints continued to impede successful use of the SDM process for most physicians (Gravel, Legare, & Graham, 2006). Medical education has endorsed models of clinical decision-making that range from the paternalistic to the autonomous informed patient model. Shared decision making seeks to bridge these two models of consultation.

Patient acceptance of SDM. In the current realm of patient centered medicine, patients are encouraged to take an active part in their health care choices. Previous studies however, have not shown patients are anxious to take on this role. A 1996 survey of 300 patients showed that patients would like to be informed, but not take control of their health care choices (Deber, Kraetschmer, & Irvine, 1996). These norms are changing. A 2002 survey found that two-thirds of Canadians believed that both **they** and their **provider** were responsible for health care decisions. Sixty percent of these people felt that they were personally responsible to prevent illness (Martin, 2002). A recent study showed that the U.S. patient would like to be involved with SDM at least as it pertained to preventative services (Wunderlich et al.).

Patient gender and age. A central question is whether patients want to participate in SDM. Research results have been mixed as to any gender or age differences for patients choosing to engage in the SDM process. Ende, Kazis, Ash, & Moskowitz (1989) asked 312 patients in an outpatient setting their interest in shared decision making. They found consistent findings from other studies showing that younger patients had a greater desire to participate in treatment decision making than older patients (Ende, Kazis, Ash, & Moskowitz, 1989). Societal norms may be changing as a more recent study indicated that contrary to previous understanding, older patients are interested in SDM: “Participants indicated that they would use a shared decision-making instrument in their clinical encounters” (Naik, Schulman-Green, McCorkle, Bradley, & Bogardus, 2005, p. 643). Other studies show that women wanted more health care information than men. “Although both men and woman wanted information about these topics, it was clear that women wanted more information overall” (Stewart, Abbey, Shnek, Irvine, & Grace, 2004, p. 46).

SDM Facilitators

Several prominent agencies are in favor of wide-spread utilization of SDM. Well funded research is on-going to determine the best format and sequence for using decision aids to reach a treatment choice.

The Foundation for Informed Medical Decision Making. The Foundation for Informed Medical Decision Making (FIMDM) is a not-for-profit (501c3) private foundation with the mission to inform and amplify the patient’s voice in health care decisions (www.fimdm.org). FIMDM has an arrangement with Health Dialog, a for-profit company, to co-produce evidence-based DAs. The DAs are used for decision support and disease management services. Health Dialog provides the DAs to consumers through health care organizations and employers.

In 2009 FIMDM began a three year national study to look at the effectiveness of decision aids in a variety of practice settings. This three year study, *Using Decision Aids to Facilitate Shared Medical Decision Making in Primary Care Practice,* is a multi-site implementation research project. FIMDM selected 11 primary care implementation sites representing urban, suburban, and rural practice settings which include hospital based and independent systems. Sites such as, Dartmouth-Hitchcock, Palo Alto Medical Foundation, Stillwater, Minnesota, rural sites in Oregon, and others which show the range of data being collected. The Oregon Rural Practice-Based Research Network (ORPRN) is working with four member clinics to provide rural primary care data for this demonstration study.

Importance to Advanced Practice Nursing and the Doctor of Nursing Practice

In 2010 Congress passed and the President signed into law comprehensive health care legislation. As the largest segment of health care providers, nursing has vast potential to effect broad change to many aspects of the health care system. The recent Institute of Medicine report, *The Future of Nursing: Leading Change, Advancing Health* strongly recommends that advanced practice nurses (ANP) partner with physician professionals to redesign health care in the United States, and that they be allowed to practice to the full extent of their education (IOM, 2010).

The Doctor of Nursing Practice (DNP) is the terminal degree for nurse practitioners. These clinicians practice independently by assessing, diagnosing, treating, and managing complex patients, and assume full accountability for their actions as licensed independent practitioners. As such, they assume leadership roles, foster inter-professional collaboration, and exhibit analytic skills for evaluating and providing evidence-based patient care.

The APN/DNP is needed to provide care to the high number of U.S. citizens who may soon be eligible for primary and preventative health care services. The DNP, by virtue of training and experience, is able to translate SDM research into their day to day clinical practice -- thus using this promising research to improve community and patient health. The DNP closes the research gap and improves quality by using point-of-care decision tools to strengthen the patient-clinician relationship. Noted nurse researcher Mary Naylor R.N., PhD, recognizes and champions the role of the APN to be involved in patient and family health care decisions (Naylor & Kurtzman, 2010). Doctoral level advanced practice nurses are prepared to translate evidence-based research into practice at the rural community level.

According to McGlynn, Asch, and Adams (2003), American patients receive only half of the recommended screening services (McGlynn, Asch, & Adams, 2003). The U.S. Preventive Services Task Force recognizes the importance of nurse clinicians to fill this gap, and has developed an evidence-based prevention resource for the APN/DNP to guide their screening, counseling, and preventative medication decisions (Trinite, Loveland-Cherry, & Marion, 2009). The APN/DNP applies scientific principles and novel innovations to prevent disease and disability for the patients they serve. The U.S. Prevention Services Task Force encourages the contribution of the APN/DNP to the promotion of effective screening services (Agency for Healthcare Research and Quality, 2009).

Advanced practice nurses value health care promotion and disease prevention, and understand that both behavioral modification and therapeutic intervention is generally needed. Many of these decisions are best made with the SDM process. “Holistic concepts of health care, along with integration of medical care with preventive and health promotional efforts, need to be adopted to significantly improve the health of Americans” (Shi & Singh, p. 124, 2009).

Mundinger, Kane, Lenz, Totten, Tsai, and Cleary, et al. (2000) have shown that the APN can deliver quality care similar to that provided by primary care physicians. Horrocks, Anderson, and Salisbury (2002) found related results when comparing British APNs to primary care physicians in England. The APN/DNP has the knowledge, skills, and business leadership expertise to translate this knowledge to the patient-centered primary care practice.

Desired Outcome of this Study

This clinical inquiry project used data collected by ORPRN from their participation with the FIMDM national study. As part of the introduction and the implementation of the use of shared decision making aids, ORPRN research staff conducted focus group interviews with providers at four clinical sites. Two focus group interviews were done at each site, one before implementation of the decision aids, and another after the decision aids had been in use for approximately one year. These focus group clinician interviews had not previously been transcribed. This project analyzed the data to better understand various rural provider perceptions of the SDM process.

Desired Outcome

The intended outcome of this work is to investigate the perceptions of the shared decision making process and use of decision aids by clinicians working in four rural clinics in Oregon. Their opinions, attitudes, perceived barriers and facilitators to the use of SDM in their settings were evaluated. This data may help to develop a framework that uses a “best practice” model to assist in rural primary care application of shared decision making and utilization of decision aids.

Purpose

This clinical inquiry project (CIP) evaluated information collected by ORPRN from clinician focus group interviews conducted before and after decision aid implementation at four rural Oregon practices. In the ORPRN study, researchers took extensive notes during focus group sessions and used this information in their evaluation of the implementation process. However, due to cost and time limitations, they were not able to do further analytic work with the interview data. This project explored, in depth, rural clinician perceptions, barriers and facilitators for shared decision making and the use of decision aids in their clinical settings.

Clinical Inquiry Questions

The following clinical inquiry questions were addressed through a qualitative analysis of rural clinician interviews from the four practice sites in the ORPRN study:

- What were their perceptions, opinions, and attitudes of shared decision making and the use of decision aids?
- What did they see as recognizable barriers to implementation of decision aids in their practice?
- What factors would facilitate implementation of shared decision making in rural clinics in Oregon?

Methods

This clinical inquiry project used focus group interview data collected by ORPRN as part of their implementation research participation in the FIMDM three year, multi-site study of shared medical decision making and decision aid use in primary care. ORPRN collected data from four rural primary care clinical sites as part of their participation in this national study. ORPRN used their initial notes from these focus groups as part of their implementation and evaluation plan. This clinical inquiry project built upon ORPRN's research by transcribing the interviews and analyzing the data in more detail. The following is a description of how the data from the focus groups was collected in the ORPRN study, and how that data was analyzed to meet the aims of the clinical inquiry project.

Focus Group Data Collection in the ORPRN Study

Focus groups were conducted with clinicians and staff at the four ORPRN sites prior to implementation of the SDM process and DAs between October 2009, and December 2009

(Appendix A). Approximately one year into the study, in January 2010, clinician post-implementation interviews were conducted by ORPRN researchers (Appendix B). Researchers conducted the focus groups using a semi-structured interview guide, and scheduled times convenient to each practice (e.g., prior to clinic, over lunch, or after clinic hours). One researcher facilitated the focus groups while a second took field notes and audio recorded each session.

Pre-implementation interviews explored questions like "What does shared decision making mean to you?" "What makes shared decision making hard to do in your practice" The post-implementation sessions explored questions like, "Has your understanding of shared decision making changed?" "Describe your experience using shared decision aids?" See Appendices A and B for a copy of the pre- and post-implementation semi-structured interview guides and demographic note sheets.

Interviews were approximately one hour in duration. Pre-implementation interviews were conducted separately with clinicians and staff at all sites to facilitate open sharing. Post-implementation interviews were conducted with both clinicians and staff at two practice sites due to scheduling challenges and clinic preferences. Appendix C shows a list of Health Dialog's DAs from which the rural clinics could choose for the study. The DAs had two learning formats per subject; a booklet aimed at about the eighth grade reading level, and an instructional DVD.

Sample

ORPRN researchers invited all clinicians and staff from the four clinics to take part in both sets of focus groups. A total of 18 clinicians participated in the pre and post implementation focus group interviews. The clinician participation from each of the ORPRN de-identified rural sites is described in Table 1. Most of the participants were males (13) and MDs (61.5%); of the four advanced nurse practitioners and physician assistants all were female.

Table 2 Clinician Participation in Focus Group Interviews by ORPRN Site

Clinic	A	B	C	D	Totals
MD	3	3	5	2	13
DO	0	0	1	0	1
APN	0	2	0	1	3
PA	1	0	0	0	1
Totals	4	5	6	3	18

Most of the clinicians interviewed had well established practices, with the mean years in practice at each rural clinic ranging from nearly 10 years to 25 years. Table 3 shows that the combined number of years these clinicians had devoted to rural primary care was at least 338 years. It may be more as work locations prior to their practice at these clinics was not known.

Table 3 Clinician Years in Practice and at Rural Clinic

	Clinic A		Clinic B		Clinic C		Clinic D	
	Years in Practice	@ Site	Years in Practice	@ Site	Years in Practice	@ Site	Years in Practice	@ Site
MD	10	3	5	5	31	31	29	29
	36	22	30	30	28	28	22	18
	11	3	12	7	27	27		
					25	16		
					24	10		
DO					38	38		
NP			13	13				
			29	29			18	18
PA	13	11						
TOTAL	**70**	**39**	**89**	**84**	**173**	**150**	**69**	**65**
Mean in years at site		**9.75**		**16.8**		**25**		**21.6**

Clinic Description

Determination of the health care needs of communities in the United States is rigorously reviewed by U.S. Department of Health and Human Services. This agency looks at three separate but related measures or indicators of medical necessity. They indicate the extent of provider need in a given location. These governmental indicators of health care needs are communicated as:

- Federally-designated Health Professional Shortage Areas (HPSA) which describe communities short on medical primary care, mental health or dental care providers. This data comes from both state and government data. Communities or locations are ranked on a scale of 0-25 with the higher numbers denoting greater service needs.
- Medically Underserved Areas (MUAs) which may include a whole county or a group of contiguous counties or a group of urban census tracts in which residents have a shortage of personal health services.
- Medically Underserved Populations (MUPs) include groups of persons who face economic, cultural or linguistic barriers to health care

The Oregon Rural Practice-based Research Network defines a rural practice if it meets at least one of two definitions. The first definition of rural is from the Oregon Office of Rural Health which defines a practice as rural if it is located greater than 10 miles from the centroid of a population center of 40,000 or more. The second definition of rural used by ORPRN is the Rural-Urban Commuting Areas (RUCAs) which was developed by the WWAMI Rural Health Research Center (RHRC) at the University of Washington. The RUCA system defines 10 major categories of rural according to size and commuting patterns (Hart, Larson, & Lishner, 2005).

Frontier settings are defined as residing in a county with a population less than or equal to 6 persons per square mile.

This information is useful in understanding how great the need for primary care providers is in a given location. A review of the scope of services offered, the HPSA, MUP, and MUA assessment, clinic ownership, and the extent of computer infrastructure and connectivity for the four clinics is noted in Table 4. All four clinics were located in rural counties and two of the four were in both rural and frontier settings.

Table 4 Clinic Description

Clinic Characteristics	Clinic A	Clinic B	Clinic C	Clinic D
Established	Early 1970's	1976	1967	1980
Rural status	Rural and frontier	Rural and frontier	Rural	Rural
Average number patients seen/yr	1300	2500	3200	3000
HPSA Score	9	0	18	19
MUA	No	No	No	Yes
MUP	No	Yes	Yes	Yes
Ownership Structure	Health District	Private	Private	Private
EHR	No	No	Yes	Yes
Meaningful Use Certified	n/a	No	No	No
Receives reports via HL7	No	No	Yes	Yes
Provides OB Care	No	Yes	Yes	Yes

Analysis

A thematic analysis approach as described by Braun and Clarke (2006) was used to analyze the focus group data (Braun & Clarke, 2006). Thematic analysis is a flexible data analysis approach that is easily described and less prone to data analytic error than some of the other approaches to qualitative analysis, such as grounded theory that requires intensive training in the method to be valid. It is a method of data analysis that relies on identifying, analyzing, and reporting on patterns and themes in data.

There are six steps involved in doing a thematic analysis. First is familiarization with the data, which can be accomplished during the process of preparing and or reviewing the data. The second step is to develop beginning codes, generally referred to by qualitative researchers as open coding. The third step is to look for themes by collapsing some of the open codes into categories. A preliminary definition of these broader categories is developed to facilitate the fourth step of the analysis, which is to review the themes that have been generated. In this stage, some of the quotes from the interviews that illustrated these themes are selected and included in the memos that describe the themes. In step five the memos with the definitions of the themes and associated quotes are further refined after re-reading all memos and data excerpts. The final step summarizes the themes across all interviews in the form of a narrative report of the findings. The following account describes in detail how thematic analysis was conducted for this study.

Phase One

Data collected from nine pre- and post-implementation focus group interviews with clinician participants was analyzed for this clinical inquiry project. Audio recordings of the focus groups were transcribed verbatim. Data from the over 69,000 words in the nine completed transcripts was used in a detailed analysis of the three clinical questions. Prior to beginning the open coding process, each transcript was reviewed while listening to the audio tapes to verify content and to make any notes or corrections that seemed necessary. Clinic and provider names were de-identified as a part of the review process.

Phase Two

Open coding was initially performed using the techniques and strategies outlined in Braun and Clarke (2006). This initial analysis involved detailed, reflective exploration of the transcribed interviews; basically doing line-by-line coding, reading between the lines, identifying concepts and thinking about the possible meanings of all text segments which were recorded in the margins of the transcribed interviews. For example, open codes included examples of the barriers to SDM such as not enough time, patient type, and interest in SDM. These were highlighted in the manuscript with notes in the margins about these open codes.

Phase Three

In this part of the analysis preliminary themes were developed from the open coding analysis completed in phase two. Memos regarding some of the preliminary themes, derived from the open coding process, were created along with preliminary definitions of the themes. The codes were read and reread to make sure that all possible themes were captured in memo descriptions. For example, on the clinician barriers theme a description included how preconceived ideas impacted the time and energy to conduct SDM. Some factors may have been clinician and setting driven, while others were about the patient and their receptivity to participating in shared decision making.

Phase Four

In Phase four, one or more quotes from the interviews were included in the memos to illustrate the themes that the memos were trying to describe. Refinements in the definitions of each theme were made by including quotes from the interviews that best illustrated these themes. For example, when reviewing codes and memos on barriers, some attitudes about shared decision making on the providers’ part were not initially noted in open coding, but they became more apparent as analysis progressed. This warranted a new theme or clarification of the theme with more description and illustrative quotes.

The work from this phase produced a separate document that showed the identified codes for all three of the clinical questions. This separate document also included one or more substantiating quotes, with the line numbers where the quote could be found. Data was collated and identified to facilitate further exploration of the interviews. Notes from this process were used to facilitate review and validation of these preliminary findings.

After this work was completed, another document was created without the quotes, which showed just lines of codes. The three research questions in the four coded pre-implementation interview transcripts were collated and merged into one document; data from the post-implementation interviews was managed in the same manner.

The single line coded process was used to develop a more precise and accurate list of all themes. This new document showed each of the three clinical questions by de-identified clinic acrostic (for example pre-implementation interview data for clinic A = A1) and by the clinical question. The single line code process helped to validate and clarify the clinical questions. It also enhanced the process of looking for overlapping themes, as well as the strengths of these themes. Throughout the process the codes were continually refined to ensure they accurately reflected the intent of each interviewee’s comments. This involved frequently going back to the original transcript to confirm the accuracy of the information.

Phases Five and Six

In the final phases of analysis, the writing of the results helped to reshape and clarify the multiple drafts of the interpretation of the focus group interview data. The narrative presents the major themes, with validating quotes.

In summary, qualitative data analysis was used to gain insight into the clinician's perceptions, opinions, and attitudes about the shared decision making process, and the factors that either supported or impeded SDM use in a rural practice setting. The interviews were audio-taped and transcribed. All identifying information was masked. Data analysis examined the respondent's views on the clinical questions related to the process of shared decision making and decision aids in their rural practice.

Protection of Human Subjects

This project was secondary data analysis of focus groups from an ongoing implementation study of use of decision aids to facilitate use of shared decision making in rural primary care practice. IRB approval has been obtained for the overall ORPRN study and this project does not involve any new contact with subjects or any substantive deviation from the original aims of the FIMDM study. The principal investigator is part of the committee that will review the analysis of this data. All considerations about human subjects' protection have been addressed.

Results

A total of 48 persons were interviewed in nine pre-implementation, and one year post-implementation interviews. At the time of the pre-implementation interviews all four clinics had at least one clinician who was somewhat familiar with SDM and DAs from initial discussions with ORPRN. Most of the remaining clinicians had not seen the DAs nor were they familiar with the SDM process. Each interview lasted about one hour and was conducted in the clinic, at the provider's convenience. The de-identified clinics are listed as A, B, C or D. The pre-implementation interviews are noted as A1 through D1; the post-implementation interviews identified as A2 through D2, with an additional post-implementation interview for clinic B as one physician was not able to meet with the others. These additional post-implementation interviews are labeled as B2a and B2b.

The three clinical inquiry questions for this project provided the guide and framework for the open-coding process. Once codes were assigned to each of the nine transcribed interviews, the codes were divided into pre-implementation interview codes (A1, B1, C1, and D1) and post-implementation interview codes (A2, B2a, B2b, C2, D2). The four clinic pre-implementation interviews were reviewed as a combined group. The post-implementation interview codes were also reviewed as a combined group. Quotes were used verbatim. The line notations and de-identified clinic acrostic were provided with each quote to allow other researchers on the FIMDM and ORPRN study to provide feedback on the analysis. Using the de-identified clinic acrostic with each quote helped illustrate areas of contrast and similarity among the rural clinics.

The transcripts were reviewed and coded to identify the rural clinician perceptions, opinions, attitudes, barriers to implementation, and facilitators of SDM in their rural setting. These clinical inquiry questions were coded as question one (Q1): perceptions, opinions and attitudes of SDM and DAs; question two (Q2): barriers to implementation of DAs; and question three (Q3): factors to facilitate implementation of SDM. The results of this coding process and subsequent categorization into themes were further organized into pre-implementation interview and post-implementation interview themes.

Pre-implementation Interview SDM Themes

The thematic analysis of the pre-implementation interviews highlighted how the views of rural clinicians shaped their understanding of the SDM process, as well as possible barriers and facilitators to using DAs in their practice. Table 5 presents the summary table for the themes that were identified in the pre-implementations interviews. In the presentation of findings, representative quote(s) about each clinical inquiry question were provided from all four sites if they were available.

Table 5 Pre-implementation Themes by Question

Question 1: What were their perceptions, opinions, and attitudes of shared decision making and the use of decision aids?
Clinician Familiarity with SDM
Importance of Patient education
Patient motivation to participate in SDM
Intra-clinic differing views
Question 2: What did they see as recognizable barriers to implementation of decision aids in their practice?
Patient age differences effecting interest in SDM
Patient preferences for SDM
Impact of Internet on patient knowledge
Patient and family literacy
Patient disinterest in SDM
Question 3: What factors would facilitate implementation of shared decision making in rural clinics in Oregon?
Rural culture and long-term patient clinician relationships
Effective and effective evidence-based decision aids
Team approach
Best format for decision aids
Need for follow up on outcomes

Perceptions, opinions and attitudes (Question one). The clinicians made many cogent observations about SDM in the decision aid pre-implementation focus group interviews; there were a range of responses. For example, familiarity with the term SDM spanned from no prior knowledge of the term to having had specific training in medical school to incorporate SDM into practice. For some of the comments there was a lot of agreement. All agreed that education of the patient would be a prerequisite for any good SDM process. For some, the perceptions of how well SDM might work were based upon clinical experiences where patients had declined to participate in SDM. On the question of whether or not clinicians should share their preferences of what would be the best decision, some thought they should, others did not.

Clinician familiarity with SDM. Some interviewees had never heard of shared medical decision making. Others had only a vague understanding of the concept, but reported they believed they did this every day with patients, albeit, not in any formal manner. Out of the 18 clinicians interviewed, only one clinician had received formal training in the SDM process.

One physician, who had never heard of the term, shared decision making, said:

> *I don't think I've ever used that term until this came up, but you know, I try personally to utilize that form of medicine that, you know, when I have thoughts on something and my patient needs to be doing this to get their input and make sure they understand why they need to do that* A1 L144-152

Two other physicians echoed a sentiment that engaging with patients about the decisions pertinent is not new to their care:

> *Well, I'm really not that familiar with what the term implies, but if you're speaking about negotiating or bargaining or dialoguing with a patient on their healthcare, I've done that personally for a quite a while* A1 L165-167

> *Since I started medicine, I believe that I help the patient make decisions about their health. I don't make them for them. That the patient ... it's the patient's life, it's the patient's health… I try to make them proactive in taking care of themselves and then… also making their own decisions, SDM would be a natural part of that* D1 L116-118

Some indicated that the level of patient participation implied by the term shared decision making process might be higher than what had traditionally been thought of:

> *I guess I think it means involving the patient in a… perhaps a higher level of decision making than traditionally has been the case. So getting the patient's input all along the way* C1 L26-28

> *If there are a couple of right answers and you're trying to help which right answer is right for this patient, that's something you do together. I mean they've all involved education, but they're… you know, one is they're not accepting our advice even though it's really good. And the other is, there are a couple of different options out there and, you know, let me, with my expertise, help you figure out which one of the options is best for you.* B1 L189-194

As indicated, one physician had been trained on the SDM process. One nurse practitioner believed patient education was a core component to her education, albeit not necessarily in the defined SDM process:

> *I think it takes some training… I've been trained in shared decision making as a way of providing care…* B1 L131-133

> *And nurse practitioners are trained in teaching. I mean that's a big part of our training, is teaching.* B1 L195

Clinicians reported a range of prior experience with the term SDM. Although some had not heard of the precise term before, many reported that they felt they used this process as part of their routine approach to care. Some acknowledged that the level of patient participation implied by the term SDM might be higher than what occurred with routine care. Some had actually received formal training in this process as part of their basic medical training. One nurse practitioner felt that patient teaching was a core element of her APN education.

Importance of patient education. Patient education was consistently mentioned as an important component of any SDM process:

> *You can't have shared decision making without health education though. How else can they make a decision?* B1 L183-184

> *I think you have to have education to have effective shared decision making.* B1 L199

Most of the clinicians commented on the importance of educating patients, and believed that SDM was more than just providing information:

> *I perceive it as educating the patient about all potential decisions that could be made and allowing them to make their own choices* C1 L 30-31

> *...not just giving the information and letting the patient decide something. Shared decision making is working with them to make them understand.* A1 L273-275

Others compared SDM to the informed consent process, where patients need to be fully educated; for example, about the risks of certain treatments or therapies:

> *…it's kind of like an informed consent almost for the patients to make sure that they really know what it is you're doing with the risks of a statin (drug).* A1 L156-158

SDM was described as a collaborative educational process that provided a good way to tell patients and families about interventions the medical community could offer them:

> *…it is a collaborative effort between physician and patient and the family in making decisions about… It seems to be particularly helpful in terms of interventions that the medical community has to offer for patients.* D1 L123-124

Overall, there seemed to be a consistent theme that patient education would be a necessary component in any application of SDM in clinical practice.

Patient motivation to participate in SDM. Some clinicians believed that their patients were not interested in participating in SDM, based on the comments patients made when they tried to engage them in making decisions. Others reported they had been deeply frustrated that patients would not engage in the SDM process when given the opportunity:

> *Most of my patients don't do shared decision making. Most of my patients are 80 or older, and if I approach it that way, they always say, "I didn't go to medical school. I want to know what you think I should do." And they want me to pretty much direct their medical care* B1 L110-114

> *So I actually pretty much wanted him to watch the PSA thing, and I kind of offered it to him, 'cause we had it. But he didn't want it. So that… that made me sad and frustrated, but we'll see. He'll do it again in three months, and then we'll have this discussion again* B1 L104-109

These perceptions of patient willingness to engage in SDM, shaped by the clinical experience, were a concern for the clinicians as they prepared to implement use of the decision aids.

Intra-clinic differing views. Rural clinician partners who had worked side by side for years expressed differing views of the SDM process. One clinician believed that it was important to communicate their biases:

> *Well, it… I try to go through… try to list the arguments for and against PSAs, and I give them my biases* C1 L74-75

Another clinician felt that the biases of the provider should not be shared:

> *I try not to…well, I try to tell them the facts first and then if they want some leaning, if they don't really care, then they'll ask me what I think, and I tell them I think that it is as often fraught with difficulties as it is help. So, yeah, I…but I tell them that's only my bias, and they…if they want to see a urologist, they can get quite the other bias.* C1 L85-89

Yet another asserted that the patient's decision needed to be respected, even when the clinician didn't agree with the outcome:

> *Shared decision making means you need to respect the decision that's made by the person who is making that decision, even if it's not what you think is the right decision.* C1 L460-462

In summary, the clinicians identified several important perceptions, opinions, and attitudes that shaped their view of SDM and its probability of success. Several clinicians, in a variety of clinics, made observations about prior familiarity with SDM, formal training in its use, patient education, patient preferences for participating in SDM, and clinician preferences for sharing their own biases about which decisions should be made. Next, pre-implementation views expressed about barriers to SDM will be reported.

Barriers to SDM (Question two). All of the rural clinics identified one or more barriers to successful use of the SDM process and DAs in their practice.

Patient age differences effecting interest in SDM. Several clinicians believed that age made a difference in using SDM; meaning that their older patients did not/would not want SDM. In one case the physician just told the patient what they should do:

> *Most of my patients are 80 or older, and if I approach it that way, they always say "I didn't go to medical school. I want to know what you think I should do." And they want me to pretty much direct their medical care. Maybe that's an age-related perception or a different perception. I have nothing opposed to shared decision making and nor do I take offense if people don't take my recommendations. But I always give them my recommendations and tell them what I think they should do* B1 L112-116
>
> *But giving them options. I think there's a generational uncomfortableness…I'm not sure that is grammatically correct, with having options about your healthcare*
> B1 L131-133

> *... maybe it's particularly in some of my older patients, they don't really want to talk about it, that's not going well. I mean I did want to tell them about various options and choices and they… I mean I have a couple of patients who tell me "well, whatever you tell me to do, that's what I'll do."* D1 L251-254

Other clinicians caring for elderly patients saw a different picture. They found their older patients were more computer and Internet savvy, as well as more interested in participating in their health care decisions than they had been in the past:

> *Not near as much as it used to be here. I think the elderly are sometimes very, very much as streamed as young people…although I suppose that there's still a generational difference, the elderly are a little more used to the old way where the doctor decides. I've got a lot of elderly patients who really want to make their own decision.* C1 L157-161

> *Depending on elderly, I have a lot of patients that are in that 60-80 active functional range who are becoming very directive and very demanding of information. They're really learning to advocate.* C1 L162-164

> *I think the elderly are sometimes very, very much as streamed as young people. Now they … although I suppose that there's still a generation difference, the elderly are a little more used to the old way where the doctor decides. I've got a lot of elderly patients who really want to make their own decision* C1 L157-161

Patient preferences for SDM. Interviewees made several comments regarding the different personalities of patients they saw, and how various patients might relate to the SDM process. Some patients and families wanted as much information as they could get; others would rather be told what to do. In the interviews, some made the observation that there were other clinicians who clearly preferred to tell their patients what to do:

> *There are some clinicians who are the doctor, and they make the decision.* C1 L145-146

> *… some of them have… you know, gravitated to those physicians.* C1 L149

> *Some patients want to be told what to do, and they will find a doctor who is directive. Other patients want to be directive, and they seek a doctor that will listen.* C1 L153-154

Patients and clinicians with this similar mind-set seemed to gravitate towards one another:

> *They want me to decide for them. That's why they come to see me.* B1 L226

Some rural clinicians believed that their patients might be more receptive to SDM than previously due to changing society norms and opinions of health care providers in general. However, there were still many patients for whom this would not be the case:

> *You can't do it with every patient, because a lot of patients will say "well, you just tell me what to do… And some of that depends on the demographic of the patient you're working with.* A1 L167-169
>
> *I think a whole lot more than they used to be. Yeah… our parent's generation, at least, was very passive, and you know, "just tell me what to do, doctor." And the doctor was the "great, great white doctor whatever you say, and we'll do it," kind of thing. You know, physicians aren't held in quite that esteem anymore.* D1 L540-545
>
> *They still put medical people on that little pedestal. And no matter how much you try to make them realize that, you know, you're just a human being that has this particular knowledge they will do anything you tell them… And that always frightens me. That is… those patients scare me, because they just put too much faith, and they don't think the process through themselves.* A1 L345-354

One rural clinician reported they could see how the SDM process would help bring their patients out of this paternalistic mindset and assist them to "buy in" to their health care decisions:

> *But I can see where we could utilize this a lot better and get the patients to buy in better as to why they're doing things and not just say "well, you're the doc. You make the decisions."* A1 L152-154

Impact of Internet on patient knowledge. The interviewees commented in several places on the impact the Internet has had on information in their practice, both in a positive and a negative manner. Some viewed the Internet as a credible source of information, quick to access, and easy to use for both the provider and patient:

> *Well, I think the Internet has been a boon to it, because you can extract reasonably credible information and give it to the patient at the time of the discussion, that will give him or her a balanced review of what you're discussing…* A1 L394-396
>
> *We have so many tools at our disposal now with the Internet, and TV* B1 L228

Many more clinicians were concerned about the misinformation patients brought into the exam room to discuss and the time and energy it took to redirect their thinking:

> *I think they're hearing that and reading that and being told that. It would be good to have some good, unbiased information. I like to spend time teaching my patients, but I don't like to argue with them if they come in with something that they've read. That's not productive.* C1 L166-169

> *I'd have people come, you know, with some printouts from their computer searches and telling me what they want to do.* A1 L204-205

> *Patients come in with an idea of what they think they want and what they think they need, and many patients come in with information based on what they've read online that is not necessarily a good medical information site, or people that they've talked to who had a great surgical outcome, and they don't understand that everybody is not the same.* C1 L133-136

> *Time is complicated by the preconceived impressions that patients come in with that need even more time to correct*. C1 L130

> *I mean hormone replacement therapy is another perfect example of that. That you can give the patient all the alternatives, and some patients, because somebody told them 30 years ago that they would be on estrogen replacement therapy the rest of their life, and if they didn't, blah blah blah, and now they've got breast cancer, and you're trying to convince them that this is estrogen receptive breast cancer. You cannot take the estrogen, and they look at you like you're crazy, because that somebody 30 years ago told them. So then it's, you know, trying to get them to understand without totally deflating their balloon.* A1 L283-290

> *The biggest impediment, I suppose… is time to get the information better to the patient in a meaningful way.* D1 L170-173

Patient and family literacy. Patient and family literacy issues were identified as potential problems to full comprehension of DAs, which would hamper successful SDM. Additional barriers such as a lack of motivation to get better, and educational levels (presumed to be related to ability to read), were described by the clinicians:

> *I know some people don't read well* B1 L269

> *And I have one guy whose parents in my practice who can't read. And so that always gives me pause, 'cause, you know, you think, "oh, how many are out there that can't read and they're just not telling you."* B1 L271-272

> *Yeah, that's right, education level of the patient* B1 L321

> *… factors including motivation, comfort, age, literacy, reading level.* B1 L322

> *The patient has to have a desire to get well and improve.* B1 L327

Patient disinterest in SDM. Clinicians observed a fundamental barrier to the incorporation of SDM when the patient had no desire to participate in the process and/or had cultural barriers that diminished clinician and patient communication:

> *Well, the trouble with shared decision making is it involves sharing something, which means the patient has to bite into it, which is what I think what we're all talking about, If they don't bite into it, if they don't… Then how can you share that?* B1 L323-326

> *I guess if you're not… in their culture… you're not able to communicate with certain people. You just don't have a good open communicate with, then they're obviously … you know, I mean you start to… and then you see their face cloud over. It's like, "I don't hear what you're saying. You know, I've already made up my mind."* A1 L459-465

Overall, there were several patient characteristics and influences that effected patient ability to engage in SDM and were identified as barriers to implementation of SDM. Things like generational differences in views of who should be making the decision, patient and family literacy, the impact of the Internet, and cultural and communication barriers prevented full patient participation in SDM.

Factors to facilitate implementation of SDM (Question three). Given that the study was just beginning, the clinicians who participated in the pre-implementation interviews had a surprising number of suggestions for using SDM in the rural setting. Each clinic had at least one provider with an idea or concept they felt would help to promote SDM at their site. These comments focused on the possible benefits of a structured DA, the best format for DAs, and the setting and environment that would support the success of this approach. These reflections were presented below.

Rural culture and long term patient clinician relationships. Clinicians noted that in most rural settings, the patient populations were fairly homogenous. They shared a similar culture with the clinician living in that same environment. As a result, the clinicians had long term patient relationships. These reasons were identified as supportive of rural SDM implementation.

> *It's a pretty homogeneous population. And so… and you kind of… when we live here, you kind of are in the culture, and everyone is sort of pointing kind of in the same direction, mostly. They identify you, I mean initially as a provider. But then after awhile, as an acquaintance or a friend.* A1 L421-424

Efficient and effective evidence based decision aids. Most rural clinicians reported they felt as if their work days were full to overflowing; the repetition of patient education would be burdensome. While use of quality DAs could reduce clinician fatigue, they needed something quick, easy, unbiased, and simple to use. Clinicians felt routine health maintenance and life style education would take time, and believed a streamlined SDM program would help:

> *It seems like the same problem comes in all the time, and you'll be saying the same little Vitamin D speech to like four people that day or the same lipid speech to four people that day. It just seems to me like I see those kinds of trends.* D1 L203-206
>
> *In general, I think I have the biggest conversations with probably has to do with health and particularly in people who are getting up into their 70s and 80s and maybe what you don't want to do. You know, like in the… starting the 40s or 50s, we've been having them do all these tests for all these years, and then as they get older, there's some things that maybe we don't need to do anymore.* D1 L235-239
>
> *. . . unbiased patient information would be really helpful and especially something where I could leave the room so that I'm not involved and say"we show this to everybody,it's the same one" That keeps me neutral so they are making their own decision.* C1L169-173
>
> *And so it would be good to have something that everybody perceived as unbiased.*
> C1 L201-202

Present health care payment structures favor interventions and procedures over education and time with patients. The system does not encourage the rural primary care clinician to take the extra time patients may need to promote health care education or explain complex medical issues. With this fee structure reality, rural clinicians are under pressure to see more patients.

Education in the exam room takes time that may decrease the number of patients seen in a day:

> *Time is a big challenge, the time to spend with patients about all the various details.* D1 L367
>
> *Medicine prizes efficiency and… yeah, efficiency* over… the *time consuming process of evaluating social context and so forth. And I think if we had more time with patients and were paid to do that, you know, it's like the stupid death panels. We talk to patients about end-of-life decisions all the time – like POLST forms. And, you know, we just have to slip it into their office visits.* D1 L347-351
>
> *…of course they like to be listened to, first of all, but I've had a number of patients tell me,"oh, you're the first doctor whose ever explained something to me." And as time pressured as we are, there's probably places that are worse than we are and don't explain anything to patients. I think the majority of patients appreciate having a discussion.* D1 L547-550

Team approach. Making SDM a clinic wide effort was seen as a priority to ensure success of the process. Having a clinic "champion" or expert would help keep the momentum for change active. In particular, having the medical assistants trained and excited about the program would be a necessity:

> *And, you know, if we had someone in the clinic that was sort of ... would take the lead in of ... implementing it and really knowing what to do and how to do it, because probably from week to week, when I come back, I've forgotten the procedure. These guys at least are here most every day, and so but I think that would help me personally.* A1 L601-606
>
> *I think the biggest challenge is getting the staff to buy in… behind it and… don't … and something that's not just on the providers, 'cause there's some stuff that we have to and remember anyway. And if you can get the medical assistants in particular to but into it and take some of the ownership in it…* D1 L602-605

Best format for decision aids. Two of the rural clinics felt space in the office for viewing DAs was important, but they did not have the needed extra room. Some also felt that an in-office DVD player was vital; even better would be to have the DAs loaded on a central server for easy access to the patient and clinician. One provider disagreed, believing that the printed handout and booklet was superior to video education. Others felt that DVDs were boring and would not be used. There was a wide range of opinions on this subject:

> *I think the video format might work* C1 L323
>
> *I agree. I would prefer… much prefer to use the video format.* C1 333
>
> *I think the patients don't want to sit down sometime and watch a DVD. You know, they just don't want* to… *I think they are cumbersome and not workable for me* B1 L229-231
>
> *…the DVDs, I think, are cumbersome and not workable for me. But what I sometimes do is I'll go print out something on this disease from the computer, like some patient information from something, and I'll say "Here. Read this. This is all about Grave's Disease." You could have radioactive iodine, you could have surgery, you could have medications, and I'd give them like 22 pages and say "this is your homework. You can go read it." To me that's much more workable than giving them a DVD or something like that.* B1 L232-237

Need for follow up on outcome. Finally, having a stable and reliable process of getting the DAs back into the clinic, and a way for the clinician to know that the patient saw the material was needed:

> *I think follow-up… maybe we need to have more intense or… a better understanding whether the decisions that you came up with at the office visit actually were implemented.* D1 L330-332
>
> *… knowing whether your shared decision making attempt, you know, actually works, you don't know a lot of time.* D1 L326-328
>
> *But they have to report back, either verbally or in some sort of standardized questionnaire or whatever to my staff, so I have something to write on that they saw it, what they thought of it, they're going to make an appointment to discuss it*. D1 L662-605

Most of the hypotheses for facilitating the use of DAs focused on qualities the DAs needed to possess to be truly useful, and the characteristics of the clinic environment that would support their use. The clinic environment characteristics included a team approach to using SDM DAs and the identification of the clinic as their medical home. System issues included the way health care is paid for with the emphasis on quantity rather than quality in a fee for service environment. Another key point clinicians raised was that with the use of DAs, follow up on the results of that process would be critical.

The pre-implementation analysis showed patterns and themes, often across all four sites, which provided meaningful information about the suitability and use of shared decision making in the rural clinical setting in Oregon.

Post-Implementation Interview SDM Themes

Approximately one year after the start of the FIMDM/ORPRN study, each clinic was re-interviewed. The following data has been obtained from these five post-interview transcribed sessions as it related to the clinical inquiry questions. Table 6 presents a summary of the themes by question for the post implementation interview analysis.

Table 6 Post-implementation Themes by Question

Question 1: What were their perceptions, opinions, and attitudes of shared decision making and the use of decision aids?
SDM concept not new, but needs to be more efficient and meaningful
SDM benefits to their clinic
High quality of DAs
Patient characteristics influence success of SDM
Should decision aids present a preferred decision?
Question 2: What did they see as recognizable barriers to implementation of decision aids in their practice?
Clinic workflow structure and scheduling
Cost and time constraints
Question 3: What factors would facilitate implementation of shared decision making in rural clinics in Oregon?
Implementation should be clinic wide
Embed DAs with the EHR
Rethink clinic workflow
Raising awareness

Perceptions, opinions and attitudes (Question one). These focus group discussions were generally more animated and lasted slightly longer than the pre-implementation interview sessions. Clinicians had a lot to say about shared medical decisions even if they were not actively involved with the study. Clinic wide observations of the process were apparent; these perceptions did not always exhibit internal agreement among clinicians in any one clinic.

SDM not new, but needs to be more efficient and meaningful. One physician who reflected on the SDM process believed that this was something he had valued and used for years. He succinctly outlined his opinion:

> *I'm finding that a lot of things that we have tried to do, tried to incorporate into our practice for a long time are becoming buzz words on the larger scheme of things, this being one of them. You know, we've always had, you know, patient information available and tried to be open to our patients in terms of making decisions. And I guess this kind of formalizes it to a certain extent with a catch word, and it's sort of redefining what we've always been trying to do… It's a matter of getting quality information to our patients in a timely way. So in some respects the concept is anything but new, but the question is how to make it work in a fashion that's efficient and meaningful and useful.* D2 L41-57

SDM benefits to their clinic. Clinicians expressed specific attitudes and understanding of the SDM process and what it could do for clinics and patients. One clinician saw improved patient communication and involvement with their health care decisions by observing:

> *… clear communication with the patients and the doctors and patients are making… to make decisions on their healthcare* B2b L28-29

Another believed that it helped patients sort through complex medical decisions:

> *I think it's important and it really helps, you know, them understand why we make recommendations and… you know, that some recommendations are complicated, that they're not just simple yes or no answers.* B2a L102-104

None of these four clinics had an electronic health record (EHR) that met requirements for "meaningful use" of the ARRA/HITECH Act of 2009. Consequently none of the clinics or providers knew, with certainty, basic and essential patient panel demographics. Without access to this information, one physician was astounded by how many patients were seen at the clinic for diseases such as diabetes and coronary heart disease:

> *I had no idea how much… how prevalent it was here. I had no idea. Well, and the coronary artery disease, too. The pain management, I knew kind of. I mean that's kind of a "gimme," but the diabetes for sure, I had no idea we had that many patients in XXX County.* A2 L110-113

One physician believed that the use of the SDM process and the DAs was helping patients make educated health care choices. By contrast, a long time partner saw benefit when his patients complied more readily with his recommendations:

> *Shared decision making is teaching on the part of the provider to get patients information so they can make an educated guess or choice.* C2 L241-241

> *It was very helpful. It really is. People need to know more about their disease processes and what the alternatives are, and, you know, they've become a more compliant… in my opinion a more compliant person. C2 L51-53*

High quality of DAs. Following a year of use, the quality of the DAs was lauded and seemed to correspond to clinician expectations:

> *Well, the information was pretty close to what I would be telling them* C2 L60

> *I've seen some of the instruments that you've used, and I've been very impressed. It's really… I think it's a very helpful process.* C2 L30

Patient characteristics influence success of SDM. One clinic expressed the perception that a patient's age and gender might make a difference in SDM participation; meaning that older patients and males would engage in this process less often than younger or female patients:

> *I think age has a lot to do with it. The older a person is, they're not going to want to do it. You know, they want… as Dr. XXX said, they want you to tell them what they need to do, and that's all they require. The younger person wants to know more about what's going on. So, it just really depends on the age of the person.* B2b L76-80

> *I think it depends on gender. Men tend to want less information and just give me to me better. And women seem to want more information.* B2b L81-82

One physician from this clinic felt that SDM was dependent on patient "type," or presumably personality, independent of age or gender:

> *And I think shared decision making means different things with different patients... I think it depends on the person… some patients want to take part in shared decision making… and they want as much information as you can get them. So it changes quite a bit depending upon the patient… some just want to be told, you know, what to do. And whether that's because they don't really understand or because they just feel like there's too many components to kind of come together and make a decision.* B2b L54-62

***Should decision aids present a preferred decision*?** Clinicians from another site expressed differing opinions regarding the importance of balanced, un-biased patient education. One physician believed that education should be without personal opinion or bias, yet her physician colleague was not concerned about "steering" or "framing" education in certain ways. These comments might be recognition of the reality of human nature or might indicate deeply held attitudes regarding the physician/patient relationship:

> *I'm happy to offer my two-bits worth. I'm as opinionated as any other physician, but I don't like to make the decision for someone else.* C2 L752-753
>
> *I really like to think of myself as the counselor, rather than the decision maker… the educator. That doesn't mean you can't frame the thing or steer it a certain way a little bit, because you all have your biases, and you probably have an opinion.* C2 L733-736
>
> *By and large, it's fairly good information, but I think it's a little bit unhelpful as it didn't always share my biases*. C2 L72-73

In summary, the post-implementation opinions recognized that SDM and DAs were of high quality, but the process needed to be more efficient and meaningful. There was strong consensus that SDM would be more efficient if the DAs were embedded in a comprehensive EHR. It is important to note that SDM might not be accepted by all patients and all providers.

Barriers to SDM (Question two). Many of the perceived barriers to a successful implementation of SDM and use of DAs in a rural clinic involved the clinic structure and flow of patients. Another substantial set of barriers were related to the cost in terms of actual outlay to purchase and maintain a decision aid library, and the significant investment of time that would be required by all clinic staff to properly use the decision aids.

***Clinic workflow, structure, and scheduling*.** Clinics expressed problems with the provider remembering to hand out the DAs, or the medical assistant over worked with managing the DAs in addition to their present work load:

> *My hardest part has been to give it to them, you talked about it and then you never go over it again*. A2 L137-138

> *What ended up happening to us is we got so busy with my M.A., trying to do everything, that things tapered off.* D2 L28

> *Feeling that I'm asking my staff to do extra work, too, even though XXX is all behind it. It is still something she has to monitor and so forth* D2 L197-198

> *… and by the time I got down the hall, I completely forgot about it. I did. I just completely forgot… by the time I would have got back in here, I would have completely forgot until I went to the next patient. "Oh, I was gonna give him that decision making.* A2 L326-335

In some clinics the physical plant made the SDM process more difficult, either by a lack of space to show the DAs or a lack of storage space in the exam room to store DAs. Returning to the exam room after the visit to hand out a DA often gave the patient more time to "remember" a new problem they needed to discuss. This was very stressful to the busy clinician who at that point, had mentally moved on to the next patient:

> *… we had no place in the clinic to show patients so they went home. C2 L74-75*

> *I mean… if we had rooms that were big enough, you know, with enough, you know, space… filing space or something that just… be sitting there talking about it, grab it and hand it out.* A2 L280-282

> *But sometimes you just know if you leave the room, and you go down the hall, and you pick that up, and you come back, and the patient has already thought of three more things they wanted to talk to you about, you know. And so sometimes you just don't want to do that.* A2 L282-285

The clinics expressed a great deal of concern about a lack of follow up for patients who had received a DA. Did the patient actually watch the DA? Did they have questions? "Closing the loop" was discussed extensively; better processes to ensure this happened were needed. Significant barriers exist for successful SDM unless this is resolved:

> (Moderator: so closing the loop, you hand it out, but you have no idea what happened*)*
> *Exactly, they'll bring it back, and just drop it off at the front, and then I thought they were supposed to make a follow-up*. A2 L144-147

> *Now patients when they do it… they see it as, you know, as part of their doctor/patient dialogue, which indeed it should be. But they expect you to know the results. So getting the results back is important.* B2b L332-335

> *So how do we know that there's been follow-up on this? I mean, say we give the information out, the patient has looked at it, and they maybe even pulled the thing out, the envelope is sitting there on their desk and just hasn't gotten mailed. How is it they get followed up on?* D2 L260-263

An interesting observation was noted by the staff at clinic A. Patients resisted making another co-pay to review the DA information with the clinician:

> *They won't. At the very beginning, there was a couple that would, but a lot of it was the co-pay. They didn't want to pay another co-pay.* A2 L148-149

> *I can see that if they wouldn't want to pay another co-pay for a visit to discuss that for sure.* A2 L153-154

Cost and time constraints. Three of the four clinics studied were privately owned. In the privately owned clinics there was concern about the financial impact of SDM implementation -- in terms of staff salaries, DA purchase, and replacement costs. One physician owner felt that financial incentives needed to be available before they could invest in such a program; the physician owner stated:

> *If you're aware of the attendant cost with this kind of a system, and you're personally accountable for it, it's never gonna work. So you need some reimbursement for this kind of additional information. There's extra time spent.* C2 L456-460

Three different clinic physicians, at this point in the interview, added:

Physician time	C2 L466
Referral time	C2 L468
Time to talk to people	C2 L469

The time associated with the SDM and DA process was not limited to increased patient/clinician time concerns. There continued to be unease about the time needed for the clinician to look at all of the DAs before distributing them to patients. One physician felt it was essential for the provider to see what was being given to the patient, to identify gaps in knowledge or areas of controversy:

> *…the main thing that I would require is that I know everything that's in it before. And so spending the time and learning all 50 DAs…it would take a lot of time.* B2a L168-169
> *Yeah, I think the decision aid was really quite good, but it took me about a half-hour to watch. It was 45 minutes.* C2 L424-425
>
> *Cause I want to know what you're saying to them. 'Cause then I've got to be able to answer it, number one, and number two, I've got to make sure I agree with what's being said, you know. If I feel like there's spots that are missing or, you know, are controversial.* B2a L169-172

One clinician had a particular concern about the inability of SDM to ensure or cement patient health care decisions when a patient's health declined or if family had a different perspective on the decision to be made:

> *...because the decisions that have been previously made seem to all go out the window. . . very few of them that continue on.* C2 L98-99
>
> *… they come and make some decisions, but they're not very fixed in stone at all. They're very wishy washy and whatever is convenient.* C2 L110-112
>
> *The number one reason is somebody in the family is looking for an easier way out.* C2 L144

In summary, after implementation a number of issues were uncovered that should be further addressed to ensure more wide spread acceptance and use of the SDM process and DAs. Most of these focused on how to revamp workflow to accommodate the aids, and thoughts about how to cover the increased cost in operations decision aids would entail.

Factors to facilitate implementation of SDM (Question three). Following a year long experience with the process of SDM and use of DAs, each clinic had suggestions for improvement.

Implementation should be clinic wide. An overriding theme was that it should be a clinic wide process, with buy-in by all staff and clinicians. Several clinics found that when a single provider in the clinic (i.e. the one working with the study) was using DAs, other patients began asking the remaining providers for "their DAs, too." It helped that the patients seemed to like them; very few patients refused to take them when asked by the clinician:

> *Well, I think it has to be a joint effort from one person to another giving out the information.* B2b L184
>
> *… which means your front desk needs to be on board, because they need to be getting a rough idea why people are coming in.* C2 L450-451
>
> *They like them. I think the diabetic ones they like*. A1 L174
>
> *… if you're going to get other people involved, it's by educating the patients so that they're asking more of the staff, and the staff can kind of run them through the system.* B2b L295-297
>
> *I will sometimes get calls or visits from other family members who have seen it even more than I had expected. But for things like making decisions about surgical intervention and a lot of those are older people. They'll look at it certainly with their spouse and often with the kids.* C2 L308-311

Embed DAs with EHR. Three out of the four clinics studied used electronic health records (EHR). Two were in the process of implementing "meaningful use" EHRs in their clinics. There were many suggestions on how to embed a SDM process, with DAs, into an office EHR. A flurry of ideas were discussed by several clinicians in one EHR-literate clinic on how they could use the patient problem list to set alerts for the staff and provider, as well as Internet-based and/or EHR patient portal suggestions:

> *I think… let me just pick up on a thread there. I think that as you move forward, especially as you contemplate moving to a new EHR and especially with a patient portal like EPIC supports, I think that we as a practice will have an increased emphasis on electronic connections. I mean patients are already doing it in an informal way. If we can systematize that and point them in a direction that we feel confident in, I think that will be much better.* D2 L92-97
>
> *… for instance, it could be set up so they go to chart. Their diagnoses are there… and demographic information. And you could have a program that automatically pulled the relevant decision-making tools for that patient. For a male, there's a PSA one. If it is a woman over 35… or 45, there's the menopause one. Then a diabetes diagnosis is*

> *there, so the diabetes one is pulled. And you can tell your patient "go read your decision making tools that are on your electronic chart.* D2 L351-362

> *Even just using a web site where patients can be directed would be helpful. "Take a book, or a DVD or I have a page that could send you to a Website. What would you like?" And maybe that would be useful. If a person says "Oh, I love using my computer. I'll go. Well here's the page, you know.* B2a L213-217

Rethink clinic workflow. They found a need to change the flow and activity in the clinic to promote the SDM process. Providers recognized that in their busy schedule it was all too easy to pass on this process, but establishing habits and routines was important:

> *It's a habit… and it's just getting into a habit of doing that. And if you don't do it religiously for a little while, then the habit…you're out of the habit.* A2 L264-266

> *Change something so it's just not that piece of paper again that we look at and go "okay, thanks, bye."* A2 L276-277

Keeping a supply of DAs in the exam room was very helpful for two of the four clinics over the study year:

> *I really think… having as many available as points of contact would be the most important, even to the point of having a file cabinet in the room with all 50 of them available with an envelope. I just found that so much easier.* B2a L192-194

> *But being able to pull it out and while they're still talking to me start writing on it and it to them and, that was… (*moderator; That was good*) Yeah* B2a L201-203

Raising awareness. Finally, some simple, but effective marketing tools were suggested as ways both the clinician (seeing the poster in the exam room), and the patient (seeing poster in waiting room and around town) might work to promulgate the clinic's SDM efforts:

> *I'm trying to get an article in the paper and raise awareness* A2 L356-357

> *I have a whole list of topics that we can put in there* (hospital newsletter) *so I'll put it on my list.* A2 L371

> *Put these up in the post office… grocery store. And that's it... I mean there's several places in the community, and have a couple down at the library and… the senior center. In the churches.* A2 L377-381

Both clinicians and staff presented ideas they believed would facilitate SDM in their setting; some ideas as sophisticated as alerts on the EHR that automatically told the clinician when the patient needed a DA, and recorded the distribution, as well as arranged for follow-up. Marketing of the SDM process, both in the clinic and around the community, was more basic, but generally thought to be very effective.

Overall, in post-implementation the clinicians had many suggestions for ways the SDM process and the use of DAs could be facilitated, such as rethinking workflow, embedding the DAs into the EHR, and promoting the use of DAs.

Discussion

This project revealed several important findings and results. Some conclusions may be unique to Oregon but most of the results were in alignment with previous national research.

Interpretation

The clinicians at the four rural primary care clinics made many cogent observations that provided insight into what they anticipated were the challenges to implementing a SDM process in their settings. Among these concerns were pre-implementation clinician familiarities with the SDM process, the feeling that patient education and motivation would be critical for success and that within practices – the views of clinicians about use of SDM could vary widely. The reported potential barriers to use of SDM pre-implementation included age of the patient, patient preferences for SDM, the impact of the Internet on patient knowledge. There was concern that patient and family literacy and patient disinterest in participating SDM were significant barriers to the SDM process. Prior to using the DAs, the factors that clinicians thought would facilitate the SDM process included sharing a rural culture and having a long term relationship with the patients, the use of effective, evidence based decision aids, along with a team approach to using the aids. Concerns were expressed about which format would be best for the DAs. All agreed that follow up on the use of the DAs would be key to creating a system that would be effective long term.

The post-implementation interviews, following use of the structured DA tools to facilitate SDM, were revealing. Several clinicians remarked that they felt the SDM process was not a new concept. They believe that to ensure a successful implementation with efficient consistency of patient care, structural supports like the DAs would provide a more meaningful approach to the whole SDM process. Many observed that the DAs used in the SDM implementation project were high quality and most felt that quality was critical to their use of any form of DAs. Also many noted that there are several patient characteristics that influenced whether or not SDM could be successful. Several presented an interesting question in terms of whether or not the clinician should share their preferences for the patients' decision. In contrast to the pre-implementation interviews, the main barriers identified post implementation were the logistics involved with adopting the structured SDM process rather than the characteristics of the patients. In other words, after experience using the DAs most of the clinicians recognized that a significant potential barrier to their use long term was the set up of their clinic work flows and the time constraints involved in primary care practice. Facilitators identified included rethinking clinic workflow, implementing the use of the DAs clinic wide, instead of by only certain providers and staff, and embedding the DAs into the EHR. .

Context and Key Important Findings

There were multiple factors that the rural clinicians believed effected implementation of SDM for their setting.

Inconsistent understanding of SDM. An important finding of this project was that prior to the implementation study, there was not a consistent understanding and utilization of SDM in day-to-day clinical practice in any of the four clinics. In the pre interviews, the clinicians compared and contrasted what their understanding of what SDM was compared with how it was being defined nationally. They also commented about their own experiences clinically using SDM, and their prior training in this process. Among the interviewees, there were a range of responses in terms of past training in how to do SDM and their own personal experiences in involving patients clinically in decision making. Prior research confirms that evidence of high quality SDM for key issues like deciding to have surgery is sometimes lacking (Braddock et al. 1999). Only one of the 18 interviewed clinicians had received formal training for SDM. During the review of literature there was no source found that outlined SDM curricula for U.S. medical or nursing training. There were a range of responses in terms of past training in how to do SDM and their own personal experiences in involving patients clinically in decision making. As medical and nursing schools graduate more clinicians trained in SDM, this will influence the ability to implement SDM more broadly. Hence implementation of a more systematic approach to *SDM will probably require the support of a well crafted SDM program that can even out the variations in practice of SDM.*

Importance of patient education for a successful SDM process. Through all of the interviews there was a strong indication that patient education was important. The clinician interviews compared favorably with what is known about the perceptions of SDM nationally. This was mentioned far more as a key concern in the pre-implementation interviews than during the post-implementation interviews. Although it was noted in the post-implementation interviews that the quality of the DAs was remarkable and they helped to facilitate the SDM process. It may be that the quality of the aids used in the implementation process greatly diminished the concerns about lack of good patient education being a barrier to the implementation of SDM.

Patient differences in acceptance of SDM. Prior research had confirmed that there were a number of patients who would like to be informed about the choices they can make, but prefer not to take control of their health care choices (Deber et al, 1996). In the pre-implementation interviews, many clinicians reported that this was indeed the case for many of their patients. The clinicians worried that patients would not be interested in using the SDM process. Following implementation, however, most of the concerns about barriers to SDM switched from a focus on patient characteristics that would not support SDM to issues of clinic logistics. It isn't clear if this change in focus means that this barrier to SDM is not as important as it was initially thought.

Patient differences (gender and age) for choosing SDM. There was discussion about the patient "type" or characteristics regarding which patient would be interested in participating in SDM. There seems to be gender and age influences that impact the use of SDM; meaning that older patients may not want to participate in SDM and women tend to seek more information. These findings from the four rural clinics were consistent with what has been found in national studies.

Clinician interjecting personal biases. An interesting finding was how clinicians differed on whether or not they thought they should influence the decisions of patients to the options that <u>they</u> would choose, were it their choice. There was division among the clinicians regarding the acceptability of inserting personal bias into the SDM process; thereby unduly influencing the ultimate outcome.

Time and financial constraints. Three of the four sites stated that the time needed to accomplish SDM was a significant barrier. The one rural site without this complaint was a health district clinic where the providers are on salary and time constraints were not an issue.

> *We are blessed here with time to talk with our patients. We have a very generous schedule, and I feel like . . . I mean, you know, back where I was before, it was, you know, rush, rush, you cram in three more patients before you go home and you stay and dictate 'till 8 o'clock at night. And we don't get that here. So we do have . . . we are blessed with the time to talk to our patients.*A1 L459-465

Multiple recent studies support the concern of primary care providers that time restrictions and lack of reimbursement are at the forefront of the barriers to successful SDM implementation. The Fee-For-Service (FFS) environment is a barrier to effective use of SDM DAs where "time is money" from the practice perspective and from the patient perspective they do not want to have another co-pay to follow up with the clinician regarding the DA and their medical decision. They would like to get it done in one visit.

Limitations

This study was limited by the lack of reliability checks commonly found in qualitative research. Even though the data was reviewed multiple times by the student investigator, there was not a double check with a team of researchers to validate the findings. The following strategies were used to compensate for this concern. First, only verbatim accounts of what people said that were mechanically recorded were used for data analysis. Second, all data analysis was subjected to peer examination with the CIP project faculty committee members. Third, the themes identified in the project analysis were verified against the collected data (that is by examining and re-examining the selected quotes for each theme) and via the expert peer review mentioned above. However, the lack of external collaboration in development of the themes and the analysis may have weakened the overall impact of the findings.

Another limitation could be the relatively small sample size of the clinicians interviewed. Because this was a qualitative study using purposeful sampling, the concerns about the adequacy of the sample relate more to whether or not the participants who did participate were able to provide sufficient data to allow the researcher to achieve intimate familiarity with the setting or topic being investigated (Charmaz, 2006). Are the data sufficient to merit the claims made in the findings? Are there a sufficient range, number, and depth of observations contained in the data to establish credibility? Based on the experience of the ORPRN researchers, the clinicians interviewed as part of the larger implementation study are typical of the small rural practices in the state of Oregon. The focus group interviewer was a skilled researcher who expertly conducted the interviews. The data obtained from the transcribed interviews was rich and detailed. So while the small sample size could be a concern, the quality of the data collected and analyzed compensates somewhat for this limitation.

Limitations of SDM in the Rural Setting

There is very little information found in the general SDM literature regarding the use of SDM and decision aids in the rural setting. This data cannot be translated to rural settings with accuracy. More research is needed on how to adapt and/or implement SDM to the rural setting. These studies should be conducted in a way that allows results from SDM to be quantified independently. Issues that may be addressed in pilot studies may include; how to reliably identify and engage patients in SDM; development of best practice models for different kinds of health decisions (e.g., preventive services, acute care, and chronic care); and how to compensate providers for these SDM services. ORPRN is developing a framework or guide that may assist other rural clinics to implement SDM into their practice.

Conclusions

There was considerable consistency of themes from the providers in the four clinics and it may be likely that these themes represent the opinions and values of other rural clinicians. It is clear, however, that additional research regarding the use of SDM in the rural setting is needed.

The barriers to implementation of SDM in the rural setting were clearly stated by the clinicians. These clinicians articulated precise actions needed to facilitate rural based SDM; i.e. broad-based clinician training, financial incentives/reimbursement, ability to embed DAs into EHR systems. There has been little research or program development for shared decision making and use of decision aids specific to rural primary care practice in the United States. Canada, under the direction of Dr. O'Connor, has developed a system where DAs are being made available at no cost to patients over the Internet and used in conjunction with counsel from their clinician, or combined with decision support delivered via call centers with qualified nurses (www.ohri.ca/decisionaid). This Canadian model may be effective in providing evidence-based shared decision making and decision aids to the many financially strapped and underserved rural primary care clinics in America.

Supporting patients to make the best decisions should be a core component of the health care professionals' philosophy. Shared medical decision making is an important new paradigm in clinical health care and how this process and related tools can successfully translate to rural primary care is not yet fully understood. This project added rural primary care data to the larger body of SDM research to help the shared decision making process find a place in routine rural primary care.

References

Barry, M. J. (2002, Jan.15). Health decision aids to facilitate shared decision making in office practice. *Ann Intern Med*, *136(2*), 127-35.

Beauchamp, T. L., & Childress, J. F. (2009). *Principles of Biomedical Ethics* (6th ed.). New York: Oxford University Press.

Beisecker, A., Murden, R. A., Moore, W. P., Graham, D., & Nelmig, L. (1996, February). Attitudes of medical students and primary care physicians regarding input of older and younger patients in medical decisions. *Medical Care, 34*, 126-137.

Berwick, D. M., Nolan, T. W., & Whittington, J. (2008). The triple aim: care, health, and cost. *Health Affairs*, 27(3):759-769.

Bodenheimer, T. (1997a, August 28). The Oregon Health Plan-lessons for the Nation, first of two parts. *NEJM*, *337*, 651-656.

Bodenheimer, T. (1997b, Sept. 4). The Oregon Health Plan - lessons for the Nation, second of two parts. *NEJM*, *337*, 720-724.

Bodenheimer, T. (2006, August 31). Primary care - will it survive. *New Engl J Med*, *355(9*), 861-864.

Bodenheimer, T., & Pham, H. H. (2010). Primary care: Current problems and proposed solutions. *Health Affairs*. Retrieved from www.healthaffairs.org

Braddock, C. H., Edwards, K. A., Hasenberg, N. M., Laidley, T. L., & Levinson, W. (1999). Informed decision making in outpatient practice: Time to get back to basics. *Journal of the American Medical Association, 282,* 2313-20.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3,* 77-101.

Brook, R. H., & Young, R. T. (2010). The primary care physician and health care reform. *JAMA*, 303(15), 1535-36.

Charmaz, K. (2006). *Constructing grounded theory; A practical guide through qualitative analysis*. London: Sage.

Dartmouth Institute for Health Care Policy and Clinical Practice. (2008). *An Agenda for Change Improving Quality and Curbing Health Care Spending: Opportunities for the Congress and the Obama Administration* (White Paper). Retrieved from : Lebanon, New Hampshire: The Dartmouth Institute.

Davis, K.Schoen, C., & Stremikis, K. (2010, June). *Mirror, Mirror on the wall: How the performance of the U.S. health care system compares internationally* (White Paper Commonwealth Fund 1400). Washington D.C.: The Commonwealth Fund.

Deber, R. B., Kraetschmer, N., & Irvine, J. (1996, July 8). What role do patients wish to play in treatment decision making?. *Archives of Internal Medicine*, *156(13*), 1414-1420.

Edwards, A.& Elwyn, G. (2009). Shared decision-making in health care: Achieving evidence-based patient choice. In *Shared Decision Making in Health Care* (pp. 3-10). Ontario: Oxford University Press Canada.

Elwyn, G., O'Connor, A., Stacey, D., Volk, R., Edwards, A., & Coulter, A. (2006). Developing a quality criteria framework for patient decision aids: online international Delphi concensus process. *BMJ, 333(7565*), 417-419.

Ende, J., Kazis, L., Ash, A., & Moskowitz, M. A. (1989). Measuring patients' desire for autonomy: decision-making and information-seeking preferences among medical patients.. *J. Gen. Intern. Med.*, *4*, 23-30.

Fagerlin, A., Sepucha, K. R., Couper, M. P., Levin, C. A., Singer, E., & Zikmund-Fisher, B. J. (2010, Sept-Oct). Patients' knowledge about 9 common health conditions: The DECISIONS survey. *Medical Decision Making*, p. 35-52. doi: 10.1177/0272989X10378700

Fagnan, L. J., Dorr, D., Davis, M., McGinnis, P., Mahler, J., King, M. M., & Michaels, L. (2011). Turning on the care coordination switch in rural primary care. *J Ambulatory Care Manage*, *34(3*), 1-15.

Fagnan, L. J., Handley, M. A., Rollins, N., & Mold, J. (2010, July-August). Voices from left of the dial: Reflections of practice-based researchers. *JABFM*, *23 (4*), 442-451.

Fisher, E. S., Wennberg, D. E., Stukel, T. A., Gottlieb, D. J., Lucas, F. L., & Pinder, E. L. (2003). The implications of regional variations in Medicare spending, part 2: Health outcomes and satisfaction with care. *Ann Intern Med*, *138(4*), 288-298.

Foundation for Informed Decision Making. (2009, February). *Informing and involving patients in medical decisions:The primary care physicians' perspective* (Gray Literature with Corporate Author). Retrieved from www.informedmedicaldecisions.org: http://www.allhealth.org/briefingmaterials/PhysicianPerspective-1942.pdf

Foundation for informed medical decision making. (2009, Feb.). *Informing and involving patients in medical decisions: The primary care physicians' perspective Findings from a national survey of physicians* (White Paper). Retrieved from www.allhealth.org: http://www.allhealth.org/briefingmaterials/PhysicianPerspective-1942.pdf

Fowler, F. J., Gallagher, P. M., Anthony, D. L., & Skinner, J. S. (2008). Relationship between regional per capita Medicare expenditures and patient perceptions of quality of care. *JAMA*, *299(20*), 2406-2412.

Fuchs, V. R. (1998). *Who shall live? Health economics and social choice*. Singapore: World Scientific Publishing Co. Pte. Ltd.

Gawande, A. (2002). *Complications A surgeon's notes on an imperfect science*. New York: Metropolitan Books, Henry Holt and Company.

Gawande, A. (2009). The cost conundrum, what a Texas town can teach us about health care. *The New Yorker*. Retrieved from http://www.newyorker.com/reporting/2009/06/01/090601fa_fact_gawande

Glass, A. (1998, May 15). The Oregon Health Plan: Development and implementation of an innovative method of delivery of health care services to the medically indigent. *Cancer (Supplement*), *82*(10), 1995-1999.

Goetz, S. J. (2008). *Self-employment in rural America: The new economic reality* (White Paper). Retrieved from Penn. State University website: http://www.aers.psu.edu/DidUNoDocs/IntFacMore_archive.cfm

Gottschalk, A., & Flocke, S. A. (2005,). Time spent in face-to-face patient care and work outside the examination room. *Annals of Family Medicine, 3,* 488-493. doi: 10.1370/afm.404

Gravel, K., Legare, F., & Graham, I. D. (2006). Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. *Implementation Science,* . doi: 1:16 doi:10.1186/1748-5908-1-16

Hart, L. G., Larson, E. H., & Lishner, D. M. (2005, July). Rural definitions for health policy and research. *Am J Public Health, 95(7*), 1149-1155. doi: 10.2105/AJPH.2004.042432

Healthcare Economist website. (October 8, 2008). http://healthcare-economist.com/2008/10/29/health-care-expenditures-in-2040/

Healthy People 2010. (n.d.). *Healthy People 2010* (Office of disease prevention and health promotion US Dept. of Health and Human Services). Washington, D.C.

Hersh, A. L., Stefanick, M. L., & Stafford, R. S. (2004, January 7). National use of postmenopausal hormone therapy: Annual trends and response to recent evidence. *JAMA, 291(1*), 47-53.

Hoffman, R. M., Couper, M. P., Zikmund-Fisher, B. J., Levin, C. A., McNaughton-Collins, M., Helitzer, D. L., ... Barry, M. J. (2009, September, 28). Prostate cancer screening decisions: Results from the national survey of medical decisions (DECISIONS study). , *169*(17), 1611-1618.

Horrocks, S., Anderson, E., & Salisbury, C. (2002). Systematic review of whether nurse practitioners working in primary care can provide equivalent care to doctors. *BMJ*, *324*(6), 819-823.

Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington D.C.: National Academy Press.

Institute of Medicine. (2010). *The future of nursing: Leading change, advancing health*. Washington, DC: U.S. Government Printing Office

Kaiser Family Foundation. (2009). *Healthcare costs in U.S.* (Fact Sheet). Retrieved from Kaiser education: http://www.kaiseredu.org/topics_im.asp?inID=1&parentID=61&id=358

King, J. S., & Moulton, B. (2006). Rethinking informed consent: The case for shared medical decision-making. *American Journal of Law and Medicine*, *32*, 429-501.

Kitzhaber, J. (2011). *Governor John Kitzhaber remarks to the Oregon Health Policy Board meeting, January 18,2011*. Unpublished manuscript.

Knott, A., & Moscovice, I. (2000). *The practice of rural primary care - A National survey* (White Paper). Retrieved from Academy for Health Services Research and Health Policy, Meeting: http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=102272787.html

Landon, M. B., Hauth, J. C., Leveno, K. J., Spong, C. Y., Leindecker, S., Varner, M. W., ... Wapner, R. J. (2004, December 16). Maternal and perinatal outcomes associated with a trial of labor after prior cesarean delivery. *NEJM*, *351(25*), 2581-2589.

Legare, F. (2008). Establishing patient decision aids in primary care: Update on the knowledge base.. *Z. Evid.Fortbild.Qual.Gesundh (ZEFQ*), *102*, 427-430.

Legare, F., Labrecque, M., Godin, G., LeBlanc, A., Laurier, C., Grimshaw, J., ... Rheaume, C. (2011,). Training family physicians and residents in family medicine in shared decision making to improve clinical decisions regarding the use of antibiotics for acute respiratory infections: Protocol for a clustered randomized controlled trial. *BMC Family Practice*, *12*. doi: 10.1186/1471-2296-12-3.

Legare, F., Ratte, S., Gravel, K., & Graham, I. (2008). Barriers and facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals' perceptions. *Patient Education and Counseling*, *73*, 526-535.

Martin, S. (2002). "Shared responsibility" becoming the new medical buzz phrase. *Canadian Medical Association*. Retrieved from www.cmaj.ca

McGlynn, E. A., Asch, S. M., & Adams, J. (2003). The quality of health care delivered to adults in the United States. *New England Journal of Medicine, 348*, 2635-2645.

Moulton, B., & King, J. (2010, Spring). Aligning ethics with medical decision-making: The quest for informed patient choice. *Journal of Law, Medicine & Ethics*, *8*(1), 85-97.

Mundinger, M. O., Kane, R. L., Lenz, E. R., Totten, A. M., Tsai, W. Y., & Cleary, P. D. (2000). Primary care outcomes in patients treated by nurse practitioners or physicians. *JAMA, 283(1)*, 59-68.

Naik, A. D., Schulman-Green, D., McCorkle, R., Bradley, E. H., & Bogardus, S. T. (2005,). July. *General Internal Medicine*, *20(7*), 640-643.

National Advisory Committee on Rural Health and Human Services. (2008). *The 2008 Report to the Secretary: Rural Health and Human Services Issues* (Annual Report).

Naylor, M. D., & Kurtzman, E. T. (2010). The role of nurse practitioners in reinventing primary care. *Health Affairs*, 29(5):893-899.

Oregon House Bill 2009, S. Res. HB 2009, 75th Oregon Legislative Assembly - 2009 regular session Cong., http://www.leg.state.or.us/09reg/measpdf/hb2000.dir/hb2009.en.pdf 1-536 (2009) (enacted).

Organization for Economic Co-Operation and Development (2010). *OECD Health Data 2010*. Retrieved from OECD: http://www.oecd.org/statisticsdata/0,3381,en_2649_34631_1_119656_1_1_37407,00.html

O’Connor, A. M., Bennett, C. L., Stacey, D., Barry, M., Eden, K. B., Entwistle, V. A., ... Rovner, D. (2009). *Decision aids for people facing health treatment or screening decisions (Review)* (White paper). San Francisco: Wiley.

O’Connor, A. M., Bennett, C. L., Stacey, D., Barry, M., Eden, K. B., Entwistle, V. A., ... Rovner, D. (2009). Decision aids for people facing health treatment or screening decisions (review). *The Cochrane Collaboration, Issue 3*, 1-113.

O’Connor, A. M., Llewelyn-Thomas, H. A., & Flood, A. B. (2004). Modifying unwarranted variations in health care: Shared decision making using patient decision aids. A review of the evidence base for shared decision making. *Health Affairs*. VAR 63-72, doi: 10:1377

O’Connor, A. M., Rostom, A., Fiset, V., Tetroe, J., Entwistle, V., Llewellyn-Thomas, H., ... Jones, J. (1999, September 18). Decision aids for patients facing health treatment of screening decisions: systematic review. *British Medical Journal*, *319*, 731-734.

O’Connor, A. M., Wennberg, J. E., Legare, F., Llewellyn-Thomas, H. A., Moulton, B. W., Sepucha, K. R., ... King, J. S. (2007, May/June). Toward the ’Tipping Point’: Decision aids and informed patient choice. *Health Affairs*, *26(3*), 716-725.

Rossouw, J. E., Anderson, G. L., Prentice, R. L., LaCroix, A. Z., Kooperberg, C., Stefanick, M. L., ... Kotchen, J. M. (2002). Writing group for the Women’s Health Initiative investigators. Risks and benefits of estrogen plus progestin in healthy postmenopausal women: Principle results from the Women’s Health Initiative randomized controlled trial. *JAMA, 288(3*)(), 321-333. doi: Retrieved from

Shi, L., & Singh, D. (2009). Beliefs, Values, and Health. In A. M. Barker (Ed.), *Advanced practice nursing; Essential knowledge for the profession* (pp. 93-128). Sudbury, Massachusetts: Jones and Bartlett.

Stewart, D., Abbey, S., Shnek, Z., Irvine, J., & Grace, S. (2004). Gender differences in health information needs and decisional preferences in patients recovering from an acute ischemic coronary event. *Psychosomatic Medicine, 66,* 42-48.

The Commonwealth Fund. (2010). *Mirror, Mirror on the wall: How the performance of the U.S. health care system compares internationally, 2010 Update* (Commonwealth Fund pub.

no. 1400). Retrieved from The Commonwealth Fund: http://www.commonwealthfund.org/~/media/Files/Publications/Fund%20Report/2010/Jun/1400_Davis_Mirror_Mirror_on_the_wall_2010.pdf

Trinite, T., Loveland-Cherry, C., & Marion, L. (2009). U.S. Preventative Services Task Force: An evidence-based prevention resource for nurse practitioners. *Journal of the American Academy of Nurse Practitioners*, 21, 301-306.

US Preventative services task force: Screening for prostate cancer: US Preventive services task force recommendation statement. (2008). *Ann Intern. Med*., *149(3*), 185-191.

Wennberg, J. E., Brownlee, S., Fisher, E. S., Skinner, J. S., & Weinstein, J. N. (2008). *An agenda for change, improving quality and curbing health care spending: Opportunities for the Congress and the Obama administration. A White Paper*. Retrieved from www.dartmouthatlas.org: www.dartmouthatlas.org/downloads/press/exp_coverage_121708.pdf

Wennberg, J., Brownlee, S., Fisher, E., Skinner, J., & Weinstein, J. (2008, December). *An agenda for change: Improving quality and curbing health care spending: Opportunities for the Congress and the Obama administration* (White Paper). Lebanon, NH: The Dartmouth Institute.

Wunderlich, T., Cooper, G., Divine, G., Flocke, S., Oia-Tebbe, N., Stange, K., & Lafata, J. E. (2010, September). Inconsistencies in patient perceptions and observer ratings:the case for colon-rectal cancer screening. *Patient Educ Couns*, *3*, 358-363.

Ziller, E. C., Coburn, A. F., & Yousefian, A. E. (2006). Out-of-pocket health spending and the rural underinsured. *Health Affairs*, *25(6*), 1688-1699.

Appendix A

Shared Decision Making Study Pre-Assessment--Semi-Structured Interview/Focus Group (Revised 10/15/09)

Interview Date: ____________________________
Clinic: ____
_____CLINICIANS
_____NURSES & OFFICE STAFF
Facilitator: _____________________________
Note Taker: ______________________________
Recording Information/Record: ______________

Thank you for taking the time to meet with me today. Your participation will help us to understand the issues that influence the use of shared decision making and decision aids in primary care. We plan to use this information to help us work with you to implement decision aids in your practice. The information that you provide will be kept strictly confidential as will the identity of every clinic staff member we interview for this study. Our findings will only be reported for the clinic as a whole, and not for individuals.

With your permission we would like to record this interview, is that okay? [turn on recording devise if approval is received]

We anticipate this [interview/focus group] will take 1 hour. We want this to be an opportunity for everyone to share their opinion, while staying on time. Therefore if we cut you off it is because these are the goals in mind. Do you have any questions before we begin?

1) First, I'd like to have us go around the circle with introductions. Could you tell me who you are and what you do?

Prompt as needed for clinicians:

- Do you have a special focus/interest in your practice?

Prompt as needed for nurses/staff:

- Years in practice & years in community
- Do you work with all the doctors or one in particular?
- Full time or part time?

Today we are focusing on three issues: your perceptions about shared decision making in primary care, your ideas about implementing decision aids into practice, and your clinic's experiences with practice change.

2) To get started, what does shared decision making mean to you?

[if needed] Many medical decisions are in a "gray" area because there is not enough scientific evidence that the benefits of a treatment or a test outweigh the possible harms. In these cases, reasonable people might make different choices based on their own situations and values. These conditions include choices for colorectal cancer screening (colonoscopy versus stool testing), treatment of early stage breast cancer (lumpectomy with or without chemotherapy), completing an Advance Directive (Living Will) form, weight loss surgery and many others such as osteoarthritis. For example, some people with severe osteoarthritis of the knee will want to manage their pain medically with pills and others will want to have a joint replacement. In these types of cases shared decision making, a joint process between the patient and clinician, can be useful. This process engages the patient in decision-making, helps provide the patient with information about alternative treatments, and

incorporates the patient's preferences and values into the medical plan. Our next set of questions explore how you think about shared decision making in this practice.

3) When you look at your entire practice, is this a practice that uses shared decision making on a routine basis?

4) If you can, give us an example of your best experience with a patient and shared decision making. What was it like?

Prompt as needed:

- What condition was the patient facing?
- Who initiated the discussion (for example: Patient? Patient's family member/friend? You? Another clinician/staff member in your practice? Someone outside your practice?)?
- Who was involved in the decision?
- What did you discuss with the patient/their family or friends?
- How were the possible benefits/risks of the various treatments communicated to the patient? Did you use any brochures, tapes, or electronic resources?
- What was the outcome of this conversation?
- What do you think helped this interaction go well?

5) What about the opposite – give us an example of a time when shared decision making didn't go well, or when it was not used but maybe should have been.

Prompt as needed:

- What condition was the patient facing?

If they did not use SDM, prompt as needed:

- Why didn't a shared decision making process seem appropriate at the time?
- Looking back, would you have used the shared decision making approach or some other way to help this patient?

If they used SDM, but it went poorly, prompt as needed:

- What happened that this conversation seemed so difficult?
- Was there another approach that should have been used – i.e. should shared decision making have occurred?

6) You've just told us about a time when shared decision making didn't go so well in your practice. Can you tell us what in general makes SDM hard to do in this practice – or what makes it possible?

Prompt as needed:

- [Resources] Are there resources to help with patient education? (For example having a care manager on staff, using medical assistants or care coordinators to provide information, or linking patients with printed resources)
- [Processes] Do staff or other clinic structures facilitate shared decision making? When you have an important decision to make with a patient, what do you do? For example do you schedule longer appointments, make these decisions at the end of the day, have the doctors make a home visit, or get other members of the clinic (like a social worker) involved? [Patient factors] Is there anything about patients that come to this practice that can make it easier or more difficult to engage in shared decision making?
- [Clinician factors – including attitude] Clinicians have different styles and approaches, how does this play a role in the shared decision making process? Is there anything about the way clinicians think about these issues that make it harder or easier for shared decision making to occur in your clinic?

Some organizations have developed things called decision aids to help with the process of shared decision making. Decision aids are meant to be standardized tools that are based on the best scientific evidence available and are designed to inform patients and help them clarify their values. Decision aids can help to guide patients through the decision process with their clinicians so that they arrive at an informed choice that best fits their own values and situation. These tools can come in the format of brochures, videos, etc. Our next set of questions explore how you think about using decision aids in this practice.

7) <u>Tell me about your experience using decision aids in this practice?</u>

Prompt:

- Are you currently using any decision aids? How do you use them with your patients?
- Where do you get your decision aids from? How do you update them?
- How to you decide to share a decision aid tool with a patient?
- Are there conditions for which decision aids would be helpful? What are they?
- Do you think your patients are or would be receptive to using decision aids?

A key goal of this research project is to work with you, your colleagues, and your staff to incorporate decision aids into patient care.

8) <u>When you make a practice change, like increasing shared decision making by using decision aids, how would that decision be made?</u>

Prompt if needed:

- Who actually makes that decision?
- When do these decision occur?
- How do staff/others learn about these decisions/practice changes?

9) <u>I want you to imagine that your clinic was going to adopt a new set of decision aids in your practice. What do you think would help most to help make sure these decision aids were used successfully?</u>

Prompt as needed:

- [People] Is it important to have a clinic champion or clinic leaders to coordinate efforts?
- [Format/content] Is the format of the decision aids important – for example as a hand out or as a video? Is the content/topic of the decision aid important?
- [Structure] Would it be important to have specific protocols or changes in your office work process?

10) In this study we're using a collaborative research approach to implement decision aids developed by the Foundation for Informed Medical Decision Making into real world clinic settings. If you were to participate in a project such as this, what would you consider success?

Prompt as needed:

- So what would success look like?
- How would you be involved in making this project successful?

Thank you for your time and for helping us to better understand this complex issue. We are:

- Working with 4 clinics and communities in rural Oregon to implement decision aids developed by the Foundation for Informed Medical Decision Making.
- Here is a list of available Decision Aids available from the Foundation. Our next step is work with your clinic to select 2-3 DAs relevant to your practice population for use in this implementation study.
- We will use feedback from these interviews as the foundation on which these collaborative efforts will be framed.

Do you have any final comments or questions?

PRE-ASSESSMENT WORK SHEET

Focus Group Participant Demographic Tracking. To be completed at time of focus group for basic tracking of **pre-assessment** participants.

	Name	Role in Clinic	Gender
1			
2			
3			
4			
5			
6			
7			
8			
9			

Role in Clinic Options:

- Provider - Physician (MD or DO), Physician Assistant, Nurse Practitioner
- Management (practice manager, office manager, nurse manager)
- Administrative or clerical staff (billing, front desk, scheduling, medical records, etc.)
- Nurse (RN), Licensed Vocational Nurse (LVN), Licensed Practical Nurse (LPN)
- Other clinical staff or clinical support staff (medical assistant, nursing aid, technician)

Appendix B

Shared Decision Making Study 1 Year Post-Assessment
Semi-Structured Interview/Focus Group

Interview Date: ____________________________
Clinic: ____
_____CLINICIANS
_____NURSES & OFFICE STAFF
Facilitator: ______________________________________
Note Taker: ______________________________________
Recording Information/Record: _______________

Thank you for taking the time to meet with us. You probably know that about a year ago your clinic started a project to enhance shared decision making by finding ways to use decision aids in routine practice. We're here today to learn what you think about shared decision making, your views about the process of using decision aids in practice, and your thoughts about what support your clinic might need for continued success with this project. We know that you have had different levels of participation in the project - and that's fine. We think each of you have important insights to offer.

We plan to use the information from this meeting to improve our work at your clinic and with other clinics as they begin using decision aids. We will also use your comments, along with those from the other practices, to help develop guidelines that other primary care practices can refer to when they begin using shared decision making tools with their patients. We will not share your identity or the identity of any clinic staff member we interview for this study. Our findings will only be reported for the clinic as a whole, and comments will not be linked to specific individuals.

We expect this [interview/focus group] will take 1 hour. We want this to be an opportunity for everyone to share their opinion, while respecting your time. Therefore if we interrupt your or cut you off it is because these are the goals in mind. We may also ask for further clarification if the comments you make are not entirely clear. With your permission we would like to record this interview, is that okay? [turn on recording devise if approval is received]

Do you have any questions before we begin?

As I mentioned, we'd like to focus on three issues: your perceptions about shared decision making in primary care, your views regarding the process of using decision aids in practice, and your thoughts about what support your clinic might need for continued success with this project.

11) <u>First, I'd like to have us go around the circle with introductions. Could you tell me who you are and what you do at the clinic?</u>

12) <u>Recognizing that each of you might have a different level of engagement with the project, how would you describe your involvement in the Shared Decision Making/Decision Aid Project over the past year? (i.e., very engaged, aware of the work, just learned about it today)!</u>

13) <u>A key goal of this research project has been to work with the clinicians and staff in this practice to enhance shared decision making by incorporating decision aids into routine patient care. After a year of activity, what does shared decision making mean to you?</u>

Prompt as needed:

- By participating in this project, has your understanding of shared decision making changed?

[if needed] Many medical decisions are in a "gray" area because there is not enough scientific evidence that the benefits of a treatment or a test outweigh the possible harms. In these cases, reasonable people might make different choices based on their own situations and values. These conditions include choices for colorectal cancer screening (colonoscopy versus stool testing), treatment of early stage breast cancer (lumpectomy with or without chemotherapy), completing an Advance Directive (Living Will) form, weight loss surgery and many others such as osteoarthritis. For example, some people with severe osteoarthritis of the knee will want to manage their pain medically with pills and others will want to have a joint replacement.

In these types of cases shared decision making, a joint process between the patient and clinician, can be useful. This process engages the patient in decision-making, helps provide the patient with information about alternative treatments, and incorporates the patient's preferences and values into the medical plan. Our next set of questions explore how you think about shared decision making in this practice.

14) When you look at your entire practice, what does shared decision making look like here?

Prompt as needed:

- Is this a practice that uses shared decision making on a routine basis?
- Has participating in this project changed the way you interact with patients?

[If needed] Decision aids are meant to facilitate the process of shared decision making. They are standardized tools that are based on the best scientific evidence available and are designed to inform patients and help them clarify their values. Decision aids can help to guide patients through the decision process with their clinicians so that they arrive at an informed choice that best fits their own values and situation. These tools can come in the format of brochures, videos, etc. Our project has used DVD decision aids developed by the Foundation for Informed Medical Decision Making.

15) Tell me about your experience using decision aids in this practice?

Prompt as needed:

- Are you currently using any decision aids? Why/Why not?
- How are DAs currently used with your patients?
- How have your patients responded to the using decision aids [Receptive? Reticent? Thankful?]?
- How does the clinic "market" the DA to patients – i.e., how does the clinic handle the DA "referral"?
- Are clinicians/staff more interested and aware of shared decision making since you now have these tools?
- How has incorporating influenced patient workflow? Has it led to any anticipated or unanticipated changes?

16) How did your clinic approach the process of integrating decision aids into routine care?

Prompt as needed:

- Who was involved?
- How were decisions about the decision aids made?
- How did staff/others learn about these decisions/practice changes?
- How has the DA implementation strategy changed over time?
- What worked well and what was difficult?

17) When we initiated this project clinicians and staff mentioned facilitators/challenges to engaging in shared decision making and utilizing DAs in routine care. These included topics such as resource availability, clinical processes, patient factors, and clinician factors. Given what you know now, what are the factors that make SDM/DAs **hard** to do in this practice?

Prompt as needed:

- [Resources] Are there resources to help with patient education? (For example having a care manager on staff, using medical assistants or care coordinators to provide information, or linking patients with printed resources)
- [Processes] Do staff or other clinic structures facilitate shared decision making? When you have an important decision to make with a patient, what do you do? For example do you schedule longer appointments, make these decisions at the end of the day, have the doctors make a home visit, or get other members of the clinic (like a social worker) involved? Did you change office work processes to support integration of DAs?

- [Patient factors] Is there anything about patients that come to this practice that can make it easier or more difficult to engage in shared decision making?
- [Clinician factors – including attitude] Clinicians have different styles and approaches, how does this play a role in the shared decision making process? Is there anything about the way clinicians think about these issues that make it harder or easier for shared decision making to occur in your clinic?
- [External support] How have the efforts of the ORPRN practice facilitator influenced your work?

18) Given what you know now, what are the factors that make SDM/DAs **possible** to do?

Prompt as needed:

- [Resources] Are there resources to help with patient education? (For example having a care manager on staff, using medical assistants or care coordinators to provide information, or linking patients with printed resources)
- [Processes] Do staff or other clinic structures facilitate shared decision making? When you have an important decision to make with a patient, what do you do? For example do you schedule longer appointments, make these decisions at the end of the day, have the doctors make a home visit, or get other members of the clinic (like a social worker) involved? Did you change office work processes to support integration of DAs?
- [Patient factors] Is there anything about patients that come to this practice that can make it easier or more difficult to engage in shared decision making?
- [Clinician factors – including attitude] Clinicians have different styles and approaches, how does this play a role in the shared decision making process? Is there anything about the way clinicians think about these issues that make it harder or easier for shared decision making to occur in your clinic?
- [External support] How have the efforts of the ORPRN practice facilitator influenced your work?

19) In your opinion, what has been the most helpful in incorporating decision aids into practice? What has been the biggest barrier?

20) Making a practice changes, like increasing shared decision making by using decision aids, can require considerable effort by the practice. In your opinion has your clinic been successful in incorporating decision aids into regular patient care?

Prompt as needed:

- How have your views of success changed since the pre-assessment/start of the project?

21) If you were to start over on this project – what would you do differently?

Prompt as needed:

- As the research team, what should we do differently?
- What has gone well?

22) Given our discussion so far, as we move forward can you think of any support that your clinic needs to be/continue to be successful integrating decision aids into practice?

Prompt as needed:

- How might the ORPRN continue to support your efforts to integrate DAs?
- What role should the ORPRN PERC play to support continued success?

23) Our approach in this study has been to use a collaborative research approach to implement decision aids into real world clinic settings. We plan to use what we’ve learned working with your clinic to develop a toolkit that other practices can use when integrating decision aids into primary care. With this in mind – what information do you think would be helpful to other clinics who decide to integrate DAs into routine patient care?

Prompt as needed:

- Strategies for patient identification?
- Strategies for decision aid tracking?
- Scripts for distributing decision aids?

Thank you for your time and for helping us to better understand this complex issue. In our second year of the project we plan to:

- Continue working with our 4 year 1 practices
- Recruit 2 new clinics to implement decision aids developed by the Foundation for Informed Medical Decision Making.
- Use feedback from these interviews to inform our implementation process and help in the development of a primary care decision aid implementation guide.

Do you have any final comments or questions?

POST-ASSESSMENT WORK SHEET

Focus Group Participant Demographic Tracking. To be completed at time of focus group for basic tracking of **post assessment** participants.

	Name	Role in Clinic	Gender
1			
2			
3			
4			
5			
6			
7			
8			

Role in Clinic Options:

- Provider - Physician (MD or DO), Physician Assistant, Nurse Practitioner
- Management (practice manager, office manager, nurse manager)
- Administrative or clerical staff (billing, front desk, scheduling, medical records, etc.)
- Nurse (RN), Licensed Vocational Nurse (LVN), Licensed Practical Nurse (LPN)
- Other clinical staff or clinical support staff (medical assistant, nursing aid, technician)

Appendix C

Foundation for Informed Medical Decision-Making (FIMDM) Decision Aids

Title	**Preference Sensitive?***
Early Breast Cancer: *Hormone Therapy and Chemotherapy - Are They Right for You?*	No
Living with Metastatic Breast Cancer: *Making the Journey Your Own*	No
Early Stage Breast Cancer: *Choosing Your Surgery*	Yes
DCIS: Choosing Your Treatment (Breast Cancer)	Yes
Breast Reconstruction: *Is It Right for You?*	Yes
Treatment Choices for Benign Prostatic Hyperplasia	Yes
Is a PSA Test Right for You?	No
Treatment Choices for Prostate Cancer	Yes
Prostate Cancer - Hormone Therapy	No
Treatment Choices for Abnormal Uterine Bleeding	Yes
Treatment Choices for Uterine Fibroids	Yes
Managing Menopause: *Choosing Treatments for Menopause Symptoms*	Yes
Ovarian Cancer: Reducing Your Risks ***Available in Booklet Only***	No
Treatment Choices for Coronary Artery Disease	Yes
Living with Coronary Heart Disease	No
Living with Heart Failure: Helping Your Heart Day-to Day	No
Living better with Chronic Pain	No
Living with Diabetes: Making Lifestyle Changes to Last a Lifetime	No
Colon Cancer Screening: *Deciding What's Right for You*	No
Coping with Symptoms of Depression	No
Chronic Low Back Pain: *Managing Your Pain and Your Life*	No
Spinal Stenosis: *Treating Low Back and Leg Symptoms*	Yes
Herniated Disc: Choosing the Right Treatment for You	Yes
Treatment Choices for Hip Osteoarthritis	Yes
Treatment Choices for Knee Osteoarthritis	Yes
Acute Low Back Pain: *Managing Your Pain through Self-Care*	Yes
Getting the Healthcare That's Right for You	No
Looking Ahead: Choices for Medical Care When You're Seriously Ill	No
Peace of Mind: *Personal Stories about Advance Directives*	No
Weight Loss Surgery: Is It Right for You?	Yes

* A DA is designated as a Preference Sensitive Condition when surgery is a possible treatment choice.

SHARED DECISION MAKING

VIEWS OF PRIMARY CARE CLINICIANS IN FOUR RURAL PRACTICE SITES IN OREGON

Presented by: Myra Ladd Thompson RN MS FNP
Date: May 25, 2011

Committee Members

Deborah Messecar PhD, MPH, GCNS-BC RN

Advisor

Associated Professor School of Nursing

Oregon Health & Science University

Lyle J. Fagnan MD

Clinical Mentor

Oregon Rural Practice-based Research Network

Director and Investigator

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Shared Decision Making (SDM)

Shared decision making is defined as decisions that are shared by doctors and patients, informed by the best evidence available and weighted according to specific characteristics and values of the patient

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Decision Aid

A decision aid (DA) is an evidence-based tool developed to assist providers in facilitating SDM in their clinical setting

- High-quality and up-to-date education
- Assist the patient to better judge the value of available options, and they
- Provide guidance or coaching through the SDM process

(O’Connor, 2004)

Preference-sensitive decisions

Invites patients to participate in medical decisions when there is more than one reasonable option

Examples include treatment options for osteoarthritis of the knees, menopause, some screening i.e. PSA's

Preference-sensitive decisions

These *preference sensitive* decisions occur when there is no scientific consensus as to the best treatment or decision; thus the patient should participate and help make the decision that fits them best

Shared decision making outcome

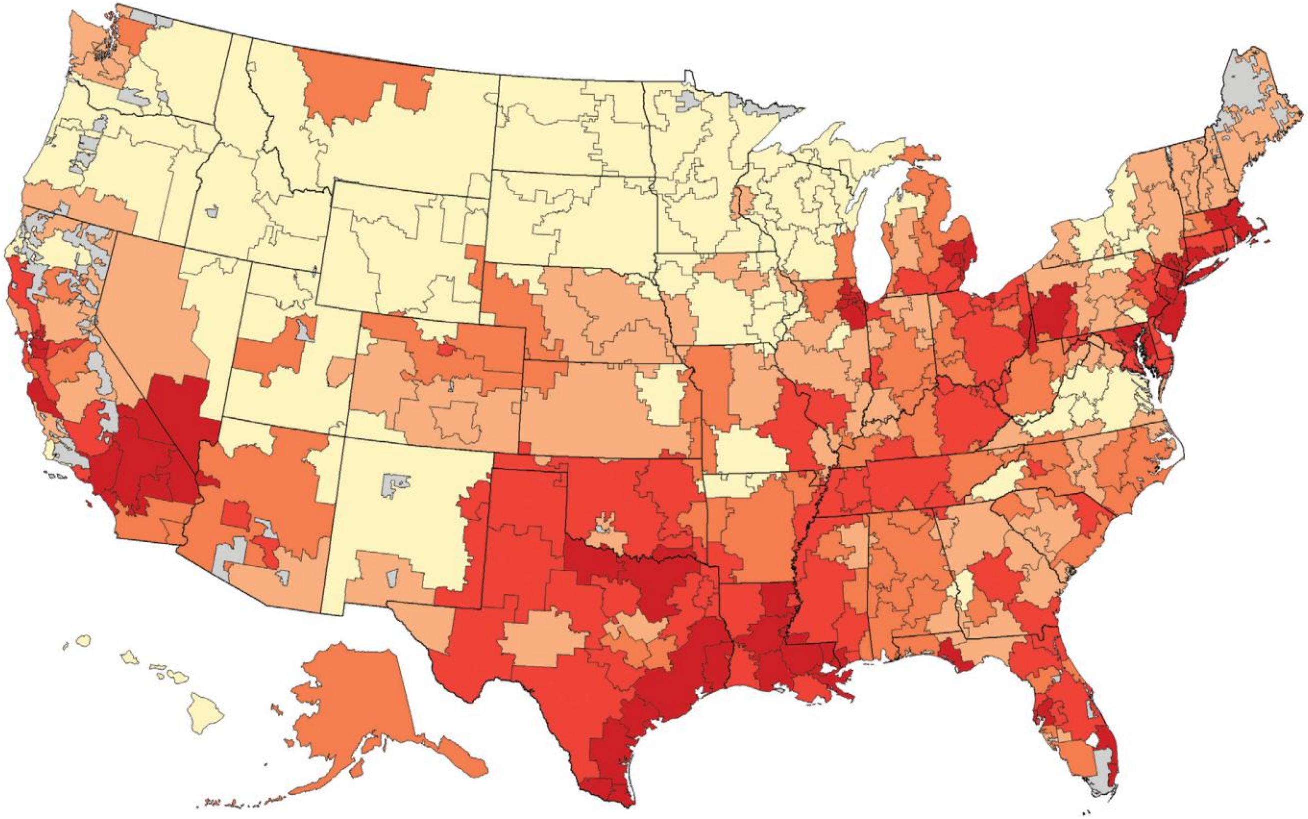
The aim is to get the right care to the right patient at the right time; to avoid both under-treatment and over-treatment, and support the patient’s preference

(Barry, 2002).

The Dartmouth Atlas

Demonstrated conspicuous variations in how health care is provided, and has shown that patients in regions with greater levels of health expenditures and a greater use of physician visits and hospitalizations do not experience better health care outcomes or quality of care.

The Dartmouth Atlas 2005 Medicare expenditures per beneficiary



The Dartmouth Atlas findings

Patients who live in Southern California are six times more likely to have surgery for herniated disks than patients living in New York State.

Gawande, A. (2009). The cost conundrum, what a Texas town can teach us about health care. *The New Yorker*

The Foundation for Informed Medical Decision Making

In 2009 FIMDM began a three year national study to look at the effectiveness of decision aids in a variety of practice settings.

Using Decision Aids to Facilitate Shared Medical Decision Making in Primary Care Practice

Oregon Rural Practice-Based Research Network

Statewide network of primary care clinicians, community partners, and academicians dedicated to studying the delivery of health care to rural residents, and conducting research to reduce rural health care disparities

171 clinicians

50 primary care practices

39 rural Oregon communities

Serving approximately 240,000 patients

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FIMDM and ORPRN national study

Using Decision Aids to Facilitate Shared Medical Decision Making in Primary Care Practice

ORPRN providing data from 4 rural primary care practices in Oregon

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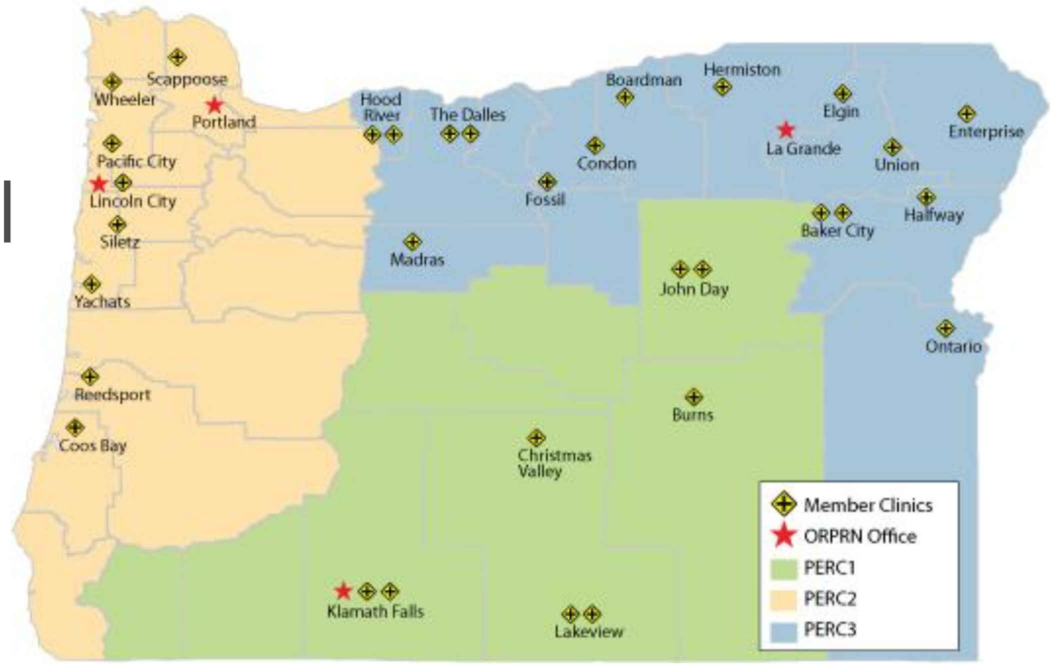
FIMDM ORPRN 3 year study

Goal

To identify best practice approaches to implementing SDM and DAs in rural practice settings

Shared decision making process: Research Sites

- Bayshore Family Medicine (North and South)
- Lincoln City Medical Center
- Pioneer Memorial
- Winding Waters



Oregon Rural Practice-Based Research Network

The mission of ORPRN is to improve the health of rural populations in Oregon through conducting and promoting health research in partnerships with the communities and practioners we serve.

PIONEER MEMORIAL CLINIC Heppner

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BAYSHORE FAMILY MEDICINE South Lincoln City

OREGON HEALTH & SCIENCE UNIVERSITY

BAYSHORE FAMILY MEDICINE NORTH Pacific City

NCE
UNIVERSITY

WINDING WATERS CLINIC

Enterprise

LINCOLN CITY MEDICAL CENTER Lincoln City

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FIMDM ORPRN study

- Pre-implementation interviews at the 4 clinics who agreed to participate

- Post-implementation interviews at these same clinics 1 year later

Clinical Inquiry Project Purpose

- This clinical inquiry project will evaluate information collected by ORPRN from focus group interviews conducted pre and post decision aid implementation with rural providers at four rural Oregon practice sites.

CLINICAL INQUIRY QUESTIONS

What were their **perceptions, opinions**, and **attitudes** of shared decision making and the use of decision aids?

What did they see as recognizable **barriers** to implementation of decision aids in their practice?

What factors would **facilitate** implementation of shared decision making in rural clinics in Oregon ?

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Research Method

- Qualitative analysis using the six-phase thematic approach described by Braun and Clarke (2006).

- Protection of human subjects was preserved as this project did not involve any new contact with subjects or substantive deviation from the original aims of the FIMDM/ORPRN study.

Research Method (continued)

- Audio tapes transcribed by qualified and OHSU certified transcriptionist(word count >69,000)
- Verified for accuracy by listening to tapes, corrections made as needed
- Themes identified by detailed review with memo notations
- Document created for each interview with corresponding supporting quote(s)

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Sample

Total of 9 interviews (each one lasting about 1 hour in length)

Pre-implementation interview: Clinicians only

Post-implementation interview: Clinicians and interested staff

The clinics were de-identified and assigned an acrostic label

No provider or staff were identified by name or by clinic

Sample

Table 2 Clinician Participation in Focus Group Interviews by ORPRN Site

Clinic	A	B	C	D	Totals
MD	3	3	5	2	13
DO	0	0	1	0	1
APN	0	2	0	1	3
PA	1	0	0	0	1
Totals	4	5	6	3	18

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Sample (continued)

Table 3 Clinician Years in Practice and at Rural Clinic

	Clinic A		Clinic B		Clinic C		Clinic D	
	Years in Practice	@ Site	Years in Practice	@ Site	Years in Practice	@ Site	Years in Practice	@ Site
MD	10	3	5	5	31	31	29	29
	36	22	30	30	28	28	22	18
	11	3	12	7	27	27		
					25	16		
					24	10		
DO					38	38		
APN			13	13				
			29	29			18	18
PA	13	11						
TOTAL	**70**	**39**	**89**	**84**	**173**	**150**	**69**	**65**
Mean in years at site		**9.75**		**16.8**		**25**		**21.6**

Sample (continued)

Table 4 Clinic Description

Clinic Characteristics	Clinic A	Clinic B	Clinic C	Clinic D
Established	Early 1970's	1976	1967	1980
Rural status	Rural and frontier	Rural and frontier	Rural	Rural
Average number patients seen/yr	1300	2500	3200	3000
HPSA Score	9	0	18	19
MUA	No	No	No	Yes
MUP	No	Yes	Yes	Yes
Ownership Structure	Health District	Private	Private	Private
EHR	No	No	Yes	Yes
Meaningful Use Certified	n/a	No	No	No
Receives reports via HL7	No	No	Yes	Yes
Provides OB Care	No	Yes	Yes	Yes

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Results The clinical inquiry questions were labeled as

Q1 = What were their **perceptions, opinions**, and **attitudes** of shared decision making and the use of decision aids?

Q2 = What did they see as recognizable **barriers** to implementation of decision aids in their practice?

Q3 = What factors would **facilitate** implementation of shared decision making in rural clinics in Oregon

Results Q1 Pre-implementation interview themes

Clinician familiarity with SDM

“I don’t think I’ve ever used that term until this came up, but you know, I try personally to utilize that form of medicine that, you know, when I have thoughts on something and my patient needs to be doing this to get their input and make sure they understand why they need to do that “ A1 L144-152

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Results Q1 Pre-implementation interview themes

Importance of Patient education

“You can’t have shared decision making without health education though. How else can they make a decision?” B1 L183-184

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Results Q1 Pre-implementation interview themes

Patient motivation to participate in SDM

“Most of my patients don’t do shared decision making. Most of my patients are 80 or older, and if I approach it that way, they always say, ‘I didn’t go to medical school. I want to know what you think I should do.’ And they want me to pretty much direct their medical care”

B1 L110-114

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Results Q1 Pre-implementation interview themes

Within practice differing clinician views

"Well, it… I try to go through… try to list the arguments for and against PSAs, and I give them my biases" C1 L74-75

"Shared decision making means you need to respect the decision that's made by the person who is making that decision, even if it's not what you think is the right decision." C1 L460-462

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Results Q2 Pre-implementation interview themes

Age and gender patient differences in interest in SDM

" ... *maybe it's particularly in some of my older patients, they don't really want to talk about it, that's not going well. I mean I did want to tell them about various options and choices and they… I mean I have a couple of patients who tell me "well, whatever you tell me to do, that's what I'll do."* D1 L251-254

Patient preferences for SDM

"Some patients want to be told what to do, and they will find a doctor who is directive. Other patients want to be directive, and they seek a doctor that will listen. " C1 L153-154

Results Q2 Pre-implementation interview themes

Impact of Internet on patient knowledge

“We have so many tools at our disposal now with the Internet, and TV” B1 L228

“I’d have people come, you know, with some printouts from their computer searches and telling me what they want to do”. A1 L204-205

Patient and family literacy

“Yeah, that’s right, education level of the patient . . . factors including motivation, comfort, age, literacy, reading level.” B1 L321-322

Results Q2 Pre-implementation interview themes

Patient disinterest in SDM

"Well, the trouble with shared decision making is it involves sharing something, which means the patient has to bite into it, which is what I think what we're all talking about, If they don't bite into it, if they don't… Then how can you share that?" B1 L323-326

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Results Q3 Pre-implementation interview themes

Rural culture and long-term patient clinician relationships

"It's a pretty homogeneous population. And so… and you kind of… when we live here, you kind of are in the culture, and everyone is sort of pointing kind of in the same direction, mostly. They identify you, I mean initially as a provider. But then after . . awhile, as an acquaintance or a friend." A1 L421-424

Effective, evidence-based decision aids

"… *unbiased patient information would be really helpful and especially something where I could leave the room so that I'm not involved and say 'we show this to everybody. It's the same one' That keeps me neutral so they are making their own decision."* C1 L169-173

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Results Q3 Pre-implementation interview themes

Team approach

"I think the biggest challenge is getting the staff to buy in… behind it and… don't … and something that's not just on the providers, 'cause there's some stuff that we have to and remember anyway. And if you can get the medical assistants in particular to but into it and take some of the ownership in it…" D1 L602-605

Best format for decision aids

"I would prefer… much prefer to use the video format." C1 333

"I think the patients don't want to sit down sometime and watch a DVD. You know, they just don't want to… *I think they are cumbersome and not workable for me"* B1 L229-231

Need for follow up on outcomes

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Results Q3 Pre-implementation interview themes

Need for follow up on outcomes

"I think follow-up… maybe we need to have more intense or… a better understanding whether the decisions that you came up with at the office visit actually were implemented." D1 L330-332

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Results Q1 Post-implementation interview themes

SDM concept not new, but needs to be more efficient and meaningful

"*I'm finding that a lot of things that we have tried to do, tried to incorporate into our practice for a long time are becoming* ***buzz words*** *on the larger scheme of things, this being one of them. You know, we've always had, you know, patient information available and tried to be open to our patients in terms of making decisions. And I guess this kind of* ***formalizes it*** *to a certain extent with a* ***catch word****, and it's sort of redefining what we've always been trying to do… It's a matter of getting quality information to our patients in a timely way. So in some respects* ***the concept is anything but new,*** *but the question is how to make it work in a fashion that's efficient and meaningful and useful."* D2 L41-57

Results Q1 Post-implementation interview themes

High quality of DAs

"I've seen some of the instruments that you've used, and I've been very impressed. It's really… I think it's a very helpful process." C2 L30

Patient characteristics influence success of SDM

*"And I think shared decision making means **different things** with **different patients**... I think it depends on the person… some patients want to take part in shared decision making… and they want **as much information as you can get them.** So it changes quite a bit depending upon the patient… some **just want to be told**, you know, **what to do**. And whether that's because they don't really understand or because they just feel like there's too many components to kind of come together and make a decision."*

B2b L54-62

Should decision aids present a preferred decision

Results Q1 Post-implementation interview themes

Should decision aids present a preferred decision

"I'm happy to offer my two-bits worth. I'm as opinionated as any other physician, but I don't like to make the decision for someone else." C2 L752-753

"By and large, it's fairly good information, but I think it's a little bit unhelpful as it didn't always share my biases." C2 L72-73

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Results Q2 Post-implementation interview themes

Clinic workflow structure and scheduling

"My hardest part has been to give it to them, you talked about it and then you never go over it again." A2 L137-138

" . . we had no place in the clinic to show patients so they went home." C2 L74-75

Cost and time constraints

"Physician time" C2 L466

"Referral time" C2 L468

"Time to talk to people" C2 L469

Results Q3 Post-implementation interview themes

Implementation should be clinic wide

"Well, I think it has to be a joint effort from one person to another giving out the information " B2b L184

Embed DAs with the EHR

… *for instance, it could be set up so they go to chart. Their diagnoses are there… and demographic information. And you could have a program that automatically pulled the relevant decision-making tools for that patient. For a male, there's a PSA one. If it is a woman over 35… or 45, there's the menopause one. Then a diabetes diagnosis is there, so the diabetes one is pulled. And you can tell your patient "go read your decision making tools that are on your electronic chart."* D2 L351-362

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Results Q3 Post-implementation interview themes

Rethink clinic workflow

“Change something so it’s just not that piece of paper again that we look at and go “okay, thanks, bye.” A2 L276-277

Raising awareness

“I’m trying to get an article in the paper and raise awareness”

A2 L356-357

“I have a whole list of topics that we can put in there (hospital newsletter) *so I’ll put it on my list*.” A2 L371

“Put these up in the post office… grocery store. And that’s it... I mean there’s several places in the community, and have a couple down at the library and… the senior center. In the churches.” A2 L377-381

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Interpretation and Discussion

Pre-implementation interview data showed rural clinicians **believing** that education for patients is important and they have been doing this – just not in any “formal” way.

Several factors may contribute to **barriers** to SDM; including both patient (age, gender, type) and clinician variables (biases).

Clinicians identified **facilitators** to SDM; they were impressed with the quality of the DAs, and feel that the long term nature of their clients will help to implement SDM in their clinics.

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Findings

- Wide variability in clinician understanding of SDM
- Patient education was consistently held as essential to primary care practice
- Multiple patient differences impact SDM
- There was considerable variability regarding clinician bias
- Time Time Time and Money

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Limitations of CIP

Less reliability checks and validations than generally seen in qualitative research

Strategies used to strengthen results

- verbatim accounts used to keep context
- data subjected to peer examination by committee members
- themes were verified through detailed review of interviews with supporting quotes

Limitations of CIP

Relatively small sample size

Strategies used to strengthen results

- use of trained researcher to facilitate interviews
- committee member with outstanding knowledge of SDM and clinics
- data obtained was rich in detail and extent

Conclusions

The SDM and DAs process is becoming widespread and more research is needed to determine how to integrate this process into the rural setting

Many patient and clinician variables exist which suggests that SDM may not be applicable for all patients and settings

Conclusions (continued)

There are significant barriers to rural use:

- lack of time to spend with patients
- lack of reimbursement for education
- expense of DAs
- limited clinic space

Running head: AMEND THE CHILD NUTRITION ACT

Amend the Child Nutrition Act

Myra L. Thompson

Oregon Health & Sciences University

Author Note

Myra L. Thompson RN MS FNP CCRN is a student in the Doctor of Nursing Practice program at Oregon Health & Sciences University, School of Nursing, Portland Oregon.

Correspondence concerning this article should be addressed to her at Bayshore Family Medicine 38505 Brooten Road, Pacific City, OR 97135. E-mail: mthompson@bfmed.net

December 10, 2009

Biosketch of Author

Myra L. Thompson RN MS FNP CCRN works as a Advanced Practice Nurse in a Rural Health Clinic on the Oregon Coast. She has been providing primary care in this location for 16 years. In addition, she continues a 26 year career as Nursing Supervisor in a rural Critical Access Hospital. This work has provided her with broad experience caring for rural patients and families. She has the distinction of being the first nurse honored with the **Oregon Rural Nurse** award in 1996.

Abstract

American children are growing up in an obeseogenic environment and will die sooner as a result. The malnutrition and chronic health problems found in overweight children create a public health concern that may be the most significant public health threat we face today in America. The United States is spending nearly $150 billion annually on obesity-related health conditions for adults and children. This places an enormous burden on our fragile health care system and the country's economic infrastructure as a whole. Reversing the trend of obesity and its associated health consequences is essential to reducing health care costs for future generations. The Child Nutrition Act (H.R. 1324) is currently under review and needs revision to mandate healthy food options. This paper proposes a policy option that would require that all federally funded school food programs offer a daily vegetarian main course food option. Children have a right to good health and they rely on us to amend legislative policies to improve their health and their future.

Key Words

Child Nutrition Act Vegetarian Obesity Hunger Cost of obesity Plant based diet

Amend the Child Nutrition Act

The United States is currently facing two distinct battles against child malnutrition. On one side is the prevalence of overweight children which has increased dramatically over the past two decades (Hedley et al., 2004). On the other hand, we find the percentage of children who are underweight is unacceptably high for such a wealthy country (Polhamus et al., 2004). Poor health in both groups stem from long term inadequate nutrition. The malnutrition and chronic health problems found in overweight and underweight children create a public health concern that may be the most significant public health threat we face today in America.

There is recent strong and growing interest among public health professionals to address these broad societal trends and evaluate policies that reduce malnutrition and obesity. The Child Nutrition Act is presently under review in congress and important policy additions and better school funding must be considered. An innovative public policy approach to help stem the rising tide of childhood obesity and poor nutrition is proposed.

Context

During the early part of the 20th century many American children were malnourished. Many different but interlocking factors are part of this problem.

Situational Factors

It became evident following the two World Wars and the great depression of the early 20th century, that America was a nutritionally poor environment for our young children. First indications of this problem became obvious when armed services administrators found many young men too ill to serve as a result of their early poor nutrition. This was also a time when dairy and livestock farmers had surplus product and needed to find other business partners.

These special interest groups were the driving force that encouraged the government to create the Child Nutrition Act.

The Child Nutrition Act

This influential act was first enacted in 1966 by President Lyndon B. Johnson. It was created after many years of successful experience with the Richard B. Russell National School Lunch Act which was signed into law by President Harry S Truman in 1946. The US government expanded this nationwide childhood food program to provide a broad array of nutritional services for young children and this in turn propped up struggling meat and dairy farms across America. This program was established then, as a way to support food prices by absorbing farm surpluses while at the same time providing subsidized food to school age children.

The Child Nutrition Act is permanently authorized but multiple other child nutrition programs such as the Special Milk Program, the Pilot Breakfast Program, the Summer Food Service Program, the Child and Adult Care Food Program, and the Special Nutrition program for Women, Infants and Children (WIC) are appropriated under the Child Nutrition Act and need reauthorization every 5 years. These authorizations expired on September 30, 2009 and are currently under legislative review for renewal and/or amendments.

The nations school based food program is administered by the Agricultural Department's Food and Nutrition Services at the federal level. This program provides low cost or free school lunch and breakfast meals to qualified students through subsidies to schools and reaches more than 39 million children nationwide at an annual cost of $18.4 billion (GAO, 2003). The food consumed at these meals makes up an important component of these children's overall nutritional intake. Free meals are supplied to about 60% of all school aged children with reduced-priced school meals available as needed. The most current (2002-03) governmental data lists the minimum federal reimbursement for each school meal at $2.14 (GAO, 2003).

Food insecurity is a major concern to many school officials and communities. In some families the only meals children eat are when they are in school. Households that are ‘food insecure’ typically do not have enough food, or not enough food that is nutritionally adequate and safe. Children who are poorly nourished are at-risk with their physical health, emotional and psychological wellbeing, intellectual achievement and social relationships with family and peers (Brown, Beardslee, & Stith, 2008). In Oregon, 12 percent of homes are determined to fall under the category of “food insecure”. This state has the third worst family hunger problem in the nation (Oregon Center for Public Policy, January 15, 2008). The societal problem of family food insecurity only makes the case for nutritionally sound school lunch menus more urgent.

During the early 20th century the family meal was generally nutritionally sound but scant in calories. By contrast, the 21st century diet is too high in calories and lacks basic nutrients. This has led some researchers to describe the problem as one of “misnourishment” where instead of getting vital healthy food children take in large amounts of cheap fats and empty calories (Bhattacharya, Currie, & Haider, 2004). Overweight children are more likely to be obese as adults and they have a higher chance of suffering from type 2 diabetes mellitus, hyperlipidemia and hypertension (Schwimmer, Burwinkle, & Varni, 2003). Food insecurity has been primarily associated with underweight individuals but it is now also linked to those who are overweight and obese.

Structural Factors

Many organizations are concerned about the need for better funding of school food programs. The Parents Advocating School Accountability based in San Francisco believe “better nourished students are better able to learn, but school districts shouldn't have to choose between subsidizing student nutrition and paying for students' other academic needs"(Woldow, 2009, p. 2).

One of the way schools have been trying to fund education and school lunch programs is by welcoming fast-food companies into their lunchrooms in exchange for donations and other incentives. Davis and Carpenter examined the relationship between proximity of fast food restaurants to schools and the rate of childhood obesity between 2002 and 2005 in California (Davis & Carpenter, 2008). This study involved more than 500,000 adolescents at middle schools and high schools in California and found that students in schools a short distance (0.5 mile or less) from a fast food outlet were more overweight or obese. The study could not determine exactly why this relationship exists but we do know that students hang out and socialize in these locations possibly making it easier to make poor food choices. The overall quality of the food supplied to our children is a concern to many. The picture found in Appendix A shows a typical grade school lunch tray. Excessive calories, high fats and limited nutrients could be the label for this picture.

In an attempt to improve the nutritional quality of school lunches The Child Nutrition Act (Public Law 108-265) that passed on June 30, 2004, included several additional provisions. Section 120/18 mandates a fresh fruit and vegetable program. "In general for the school year beginning July 2004 and each subsequent school year, the Secretary shall carry out a program to make free fresh fruits and vegetables available to the maximum extent practical"(USDA, 2004, p. 756). This law also added a local wellness policy requiring schools to establish goals for nutrition education, physical exercise, and other school based activities designed to promote student wellness.

The economic recession has financially squeezed schools creating a budgetary tension between serving good quality food and providing quality education. Most schools do not have enough funds to achieve both objectives and a misguided belief that the education is more important than nutrition generally prevails. School lunch programs often fail to provide fresh fruits, vegetables and grains as instructed by the government and instead often feed students cheaper and less nutritious canned fruits and vegetables.

Many families live in environments that perpetuate food insecurity and thus on-going obesity and there are multiple factors that contribute to this problem. Anyone who buys food regularly is aware that skyrocketing gas prices, weather-related crop failures and the diversion of our corn crop into bio-fuels and high fructose corn syrup have all led to steep food price increases. These rising food costs further disenfranchise the poor who usually can only afford cheaper high caloric and low-nutrient foods as found in fast food outlets and convenience stores. Low income neighborhoods are generally underserved by full-service markets. Even if healthy foods were readily available, many low income families cannot afford to make these foods a part of their daily diet.

The built environment and social structures in many towns reinforce the link between food insecurity and obesity. There are few opportunities for physical activity in low-income neighborhoods. They often have less safe or attractive places to play or to be physically active. Open spaces, good parks and sidewalks are rare. High rates of crime or fear of crime make parents reluctant to permit children to play outside and be physically active.

Cultural factors contribute to poor nutrition and food insecurity as well. Two examples of this is the deep fried foods that are considered staples in the south. Immigrants may have trouble finding foods from their country of origin thereby limiting the variety of food served to their family creating a nutritionally poor environment.

Our two party government system may also contribute to unequal and sporadic funding for school food programs. The general political perception is that when republicans are in office conservatives decrease welfare spending but when democrats take the lead social programs flourish. This “ying and yang” approach to program development and funding makes it difficult for schools to set long term objectives and to successful evaluate these goals.

In spite of governmental attempts to provide healthy foods for schools our children are getting heavier and sicker at a staggering rate. But just how bad is this problem?

Problem

For the first time since the Civil War, American life expectancy is projected to decrease (Olshankey et al.2005). The clear culprit is obesity with its many deadly associated diseases and to clinicians who deal with obese patients every day this comes as no surprise. Our nation must implement effective and sustainable solutions to reduce the obesity epidemic thereby lowering long term health costs to improve the health of our population and support our environment.

Policy Solution

The Child Nutrition Act (H.R. 1324) is currently under review and must be revised to require that all federally funded school food programs offer a daily vegetarian main course food option.

Evidence

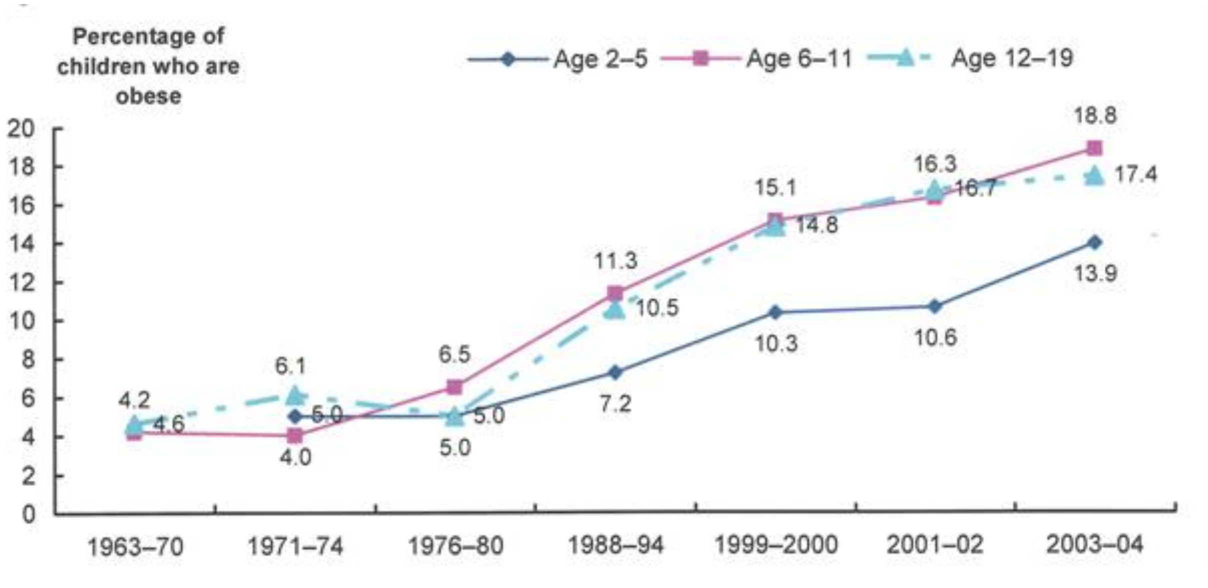
The evidence in support of this policy comes from multiple disciplines and is based on sound research providing a practicable solution to childhood obesity.

Significant rise in childhood obesity

The incidence of childhood obesity is rising rapidly in the United States and throughout the world. Today, nearly one-third of US children (more than 25 million) are obese or overweight. Increasingly, they are being diagnosed with Type 2 diabetes and hypertension, illnesses that have typically been considered “adult” diseases. Our children, now more than any other time in our history, have a greater risk of developing heart disease, stroke, cancers, and other serious ailments.

The government agency, National Health and Nutrition Examination Survey (NHANES) data from 1976–1980 and 2003–2006 show that the prevalence of obesity has increased: for children aged 2–5 years, obesity increased from 5.0% to 12.4%; for those aged 6–11 years, it has increased from 6.5% to 17.0%; and for those aged 12–19 years, prevalence increased from 5.0% to 17.6% (National Health and Nutrition Examination Survey (NHANES), n.d.).

Prevalence of obesity among children and youth, by age: 1963-2004



Source: National Center for Health Statistics (NHANES, 2006)

Healthy People 2010 identified overweight and obesity as 1 of 10 leading health indicators (a leading health indicator is a reflection of a major public health concern) in the United States and calls for a reduction in the proportion of children and adolescents who are overweight or obese yet we have made little progress toward this target goal (U.S. Dept. of Health and Human Services, Office of Disease and Health Promotion, n.d.).

Hunger and Obesity Connection

Hunger and obesity can occur within the same populations and even in the same families. These problems are generally a result of low income, lack of access to enough food, difficulty getting quality health care and increased stress (Adams, Strawn, & Chavez, 2003). Many households are struggling financially and these families often manage their limited food resources by a "feast or famine" approach. Food deprivation can cause a preoccupation with food so that when it is readily available people overeat and these foods are most often refined sugars and fats as they cost less per calorie than fresh foods. Solutions are needed that will simultaneously help people obtain food security while reducing obesity and future health problems.

Result of Obesity on Society

For all Americans, obesity is the most common, fatal, chronic and relapsing disorder of the 21st century. It is a leading cause of mortality, morbidity, disability, healthcare utilization and increased healthcare costs. Americans remain heavy and will become heavier thus straining our future healthcare system with millions of additional cases of diabetes, stroke, heart disease, degenerative joint disease and expensive disability. The United States is spending nearly $150 billion annually on obesity-related health conditions for adults and children. This places an enormous burden on our fragile health care system and the country's economic infrastructure as a whole (Wang, Beydoun, Liang, Caballero, & Kumanyika, 2008). Reversing the trend of obesity and its associated health consequences will be a major factor in reducing health care costs for future generations.

Why should we worry about this trend? Each year, obesity causes at least 112,000 excess deaths in the US (Flegel, Graubard, Williamson, & Gail, 2005). A study published in the August 24, 2006 New England Journal of Medicine showed increase risk of death among both men and women who were overweight but not obese (Adams et al., 2006). Obesity has been associated with numerous adverse health effects. They include: type 2 diabetes, high cholesterol, hypertension, gallstones, fatty liver disease, sleep apnea, gastroesophogeal reflux disease, stress incontinence, heart failure, degenerative joint disease, birth defects, miscarriages, asthma and male cancers that includes: esophageal, colorectal, liver, pancreatic, lung, prostate, kidney, non-Hodgkin’s lymphoma, multiple myeloma and leukemia, and female cancers that includes: breast, colorectal, gallbladder, pancreatic, lung, uterine, cervical, ovarian, kidney, non-Hodgkin’s lymphoma and multiple myeloma.

The cost of obesity to our healthcare system is staggering. In 1998 the medical costs are estimated to be as high as $78.5 billion, with roughly half financed by Medicare and Medicaid (Finkelstein, Fiebelkorn, & Wang, 2003). A more recent analysis of the cost of obesity found that the increased prevalence of obesity is responsible for almost $40 billion of increased medical spending through 2006, including $7 billion in Medicare prescription drug costs. It is estimated that the medical costs of obesity have risen to $147 billion per year by the end of 2008 (Finkelstein, Trogdon, Cohen, & Dietz, 2009). Obesity sickens and kills Americans at alarming rates and we are seeing a dramatic and worrisome rise in childhood obesity over the last decade.

American children are growing up in an obeseogenic environment and will die sooner as a result. Children have a right to good health and they rely on us to amend legislative policies to improve their health. Solutions are needed that will simultaneously help people obtain food security while reducing obesity and future health problems. Offering plant based menus would be an innovative policy consideration that would accomplish better long term health outcomes.

Plant Based Diet Benefits

The Centers for Disease Control and Prevention has recently completed a study of alternative medicine based on a survey of 9000 parents and it was estimated that 1:200 children in the US are forgoing meat in their diet (Barnes, Bloom, & Nahin, 2008). There is increasing cultural acceptance of the fact that a well-planned vegetarian or vegan diet is a healthy way to meet nutritional needs across the lifespan. Appendix B shows the Vegan Food Pyramid which provides a framework for food selection. Even the former high protein champions; the American Dietetic Association, have stated “a well-planned vegetarian diet, even a vegan diet, can supply all the nutrients that children require for their growth and energy needs”(American Dietetic Association, 2003 p. 1). Current research is showing the multiple health benefits of eating a primarily vegetarian or vegan diet. A meta-analysis of 27 randomized controlled and observational trials showed significant lowering of plasma cholesterol with plant based diets (Ferdowsian & Barnard, 2009). International studies have been conducted looking at the long term effects of the vegetarian diet. Research in China showed that plasma biomarkers of inflammation and antioxidant status favored a reduction in coronary heart disease risk profile for long term vegetarians (Szeto, Kwok, & Benzie, 2004). “Children raised on fruits, vegetables, whole grains, and legumes grow up to be slimmer and healthier and even live longer than their meat-eating friends”(Physicians Committee for Responsible Medicine, 2002, p. 1).

To understand the importance of this issue we need to understand the damaging effects of meat eating for our planet and see the economic and global benefits of plant based diets.

Ecological Considerations

What we choose to eat does make a difference and there are well documented wide spread environmental damage associated with using meat as a primary food source. Meat consumption is on the rise having increased by more than two and half times since 1970. The world's total meat supply was 71 million tons in 1961. In 2007, it was estimated to be 284 million tons. Per capita consumption has more than doubled over that period and world meat consumption is expected to double again by 2050 (Bittman, 2008). Mexico, a country which until recently was self sufficient in providing food for both livestock and humans now has to import grain from the US to feed its citizens and animals. Western and developing countries eat massive amounts of meat while poor countries cannot feed their starving people.

The United Nations Report *Livestock's Long Shadow – Environmental Issues and Options* published in 2006 makes a good case for reducing global consumption of meat to help the planet (Food and Agriculture Organization of the United Nations, 2006). According to this report livestock emerges as one of the top two or three most significant contributors to our serious environmental problems. The deleterious effects of livestock production are examined in greater detail in Appendix C.

The 2006 UN report *Livestock's Long Shadow* estimates that at least half of all the antibiotics produced in the United States is used on animals and that 80 percent of antibiotics used in the livestock industry is administered for disease prevention and growth promotion. Research is underway to examine the link between antibiotic resistence in humans as it relates to the massive overuse of antibiotics in the meat industry.

Ethical implications of meat eating

Americans have traditionally believed that one could never get too much protein. In the 1900’s the nutritional advice was to eat 100gms of protein a day and it is now estimated that the typical American eats about 8 oz. of meat a day, roughly twice the global average. We are 5% of the world’s population yet we eat more than 15% of the total world feed animal population. The United States livestock industry process (that is grow and kill) nearly 10 billion animals a year and it has been estimated we kill 50 million animals an hour (The Humane Society, n.d.) (Delaware Action for Animals, 2005). An average American in their lifetime will eat 12 cows, 25 hogs and 2400 chickens (United States Department of Agriculture, 2001-2002). Most of these animals come from “factory farms” which has replaced the traditional family farm food supply. It is estimated that 4 enormous factory farms are now producing the vast majority of meat consumed in America. These farms are notorious for treating animals in a manner that would jail owners of domestic animals. In other words, we are eating animals that have never seen the sun, might not have touched dirt and are subjected to mutilation techniques that is needed to sustain the crowded unhealthy conditions.

John Robbins, of Baskins & Robbins fame, clearly summarizes these problems in his seminal book, The Food Revolution (Robbins, 2001).

- 60 million people will die of starvation this year
- 60 million people could be adequately fed with grain this year if Americans reduced their intake of meat by only 10%
- 1.3 billion people could be fed with the grain and soybeans now eaten by US livestock
- 20% of the corn grown in the US is eaten by people
- 80% of the corn grown in the US is eaten by livestock

- 20,000 lbs of potatoes can be grown on one acre
- 165 lbs of beef is produced on one acre
- A child starves to death every 2 seconds

There are stark contrasts between foods eaten in the western world and food consumed in other countries. Appendix D shows pictures of a typical family from Egypt and one from America and in each picture they have displayed the foods and in what quantity they generally eat in a week. These pictures are a visual impact showing the profound contrast between the typical western diet and foods eaten in other countries. You can clearly see the difference in diets by looking at the amount and type of whole foods consumed by the family in Egypt as compared to the amount of processed and fast foods consumed by a typical American family.

A plant based diet would reduce the amount of daily protein eaten by replacing second hand protein (meat and dairy) with grains, vegetables, legumes and fruits which have more than enough protein to maintain health and control obesity. A plant based diet would reduce the health risks associated with meat and protein consumption and this should reduce our children's environmental exposure to hormones and antibiotics found in meat products. Appendix C shows the *Vegan Food Pyramid* and the wide variety of healthy foods that should be eaten.

In addition to meat, foods that are high in fat, sugar, and sodium have become a mainstay in the western diet and contribute greatly to obesity. The lack of nutritious, balanced meals coupled with children's tendency to engage in sedentary activities - watching television or video gaming - have contributed to the obesity problem.

Policy Options

One policy option is to do nothing. It is the easiest route and the surest one to succeed. The free market thrives in America and big business with large sums of money generally gets its way. It is troubling that important legislative healthcare change is often controlled by powerful lobbies and their donations no matter how urgent the health problem. Witness a recent example in congress where the government has been unable to agree and unite to halt the persistent overuse of antibiotics in healthy livestock (Harris, 2009).

Stakeholders

Multiple entities are opposed to any change in the Child Nutrition Act that would eliminate the status quo. Corporate lobbying efforts from the soft drink industry have successfully gagged the USDA from using federal funds to educate school children against soda consumption. This is in spite of recent governmental recommendations to choose and prepare foods and beverages with little added sugars.

Few lobbies are as powerful as the dairy industry which receives enormous federal subsidies. In 2000 The National Milk Producers Federation filed a complaint with the Food and Drug Administration seeking a ban on the use of the word "milk" by soybean beverage makers. They said that soy-based beverages were attempting to directly compete with dairy products and were inappropriately taking advantage of the familiarity and positive image of dairy terminology in their labeling. This lobby has the power it seems to stop any practice it disapproves of. A 2006 article from the Washington Post describes a California dairy farmer who tried to work outside the rigid system that has controlled U.S. milk production for almost 70 years and was soundly defeated by lobbyist and politicians (Morgan, Cohen, & Gaul, 2006). In 1996 Oprah devoted a program to mad cow disease. Soon thereafter, The National Cattlemen’s Beef Association sued both Oprah and her guest Howard Lyman, a rancher-turned vegetarian, for defaming beef and asked for a 11 million dollar settlement. Fortunately free speech won but not until many weeks in the courtroom and thousands of dollars were spent in defense.

Fast food companies routinely use the classroom to promote their products. Reading programs such as “Pizza’s Hut’s Book It” is one example. Under the guise of teaching, subtle and some not so subtle messages capture children’s attention and work to instill lifetime habits of rewarding themselves with unhealthy food behaviors.

It is disturbing to see previously well respected organizations become suspect when caught taking contributions from unhealthy sources. The most egregious example is the American Academy of Family Physicians recent acceptance of thousands of grant dollars from the Coco-Cola Co. The AAFP should be criticizing the soft drink companies in the strongest of language but their credibility is now squandered by the acceptance of this cash.

In the past, school lunch supervisors have been reluctant to make positive nutritional changes in their kitchens presumably as it is easier to provide a meal from a #20 can than it is to prepare meals from fresh foods. Some believe that the American diet is so ingrained that no amount of policy or taxation will reduce America’s love of meat. .

There are agencies and groups who encourage better nutrition and are vigorously working to create a better nutritional future for our children. The Institute of Medicine issued a recent report brief outlining changes needed in the school lunch requirements (Institute of Medicine, 2009). These changes include the addition of whole grains where before there were no such requirements and also a reduction in the calories and salt allowed. Diabetic organizations are encouraging more plant based diet choices. The organization, *Physician Committee for Responsible Medicine* is actively promoting a vegetarian lifestyle (PCRM, 2002). A recent study showed that a diet rich in carbohydrate and fiber (legumes, vegetables, fruits and whole cereals) is beneficial to diabetic patients due to the positive effect this diet has on cardiovascular risk factors (De Natale et al., 2009). The following programs and policies exist that work to provide healthy food to our school children.

Somerville Shape-Up Experience

The goal of this 2 year experience was to change the local school food environment to prevent excess weight gain in students attending Somerville Elementary School in Massachusetts. Food service management improved the presentation and nutrient quality of school meals and added more fresh fruits, vegetables, whole grains and low fat dairy products. Integration of food service staff, students and teachers changed attitudes, promoted nutritional education and established healthy food service menus (Goldberg et al., 2009).

Food Vouchers for Fresh Food

New Jersey has recently allowed members of the state WIC program to use their federally subsidized food checks for whole grains and fresh fruits and vegetables at farmers markets. They are at present the only state in the Northeast region to adopt this practice.

Zoning Changes

There has been long standing support for policy changes to amend zoning laws to restrict or ban the presence of fast food restaurants in certain locations (Mair, Pierce, & Teret, 2005). Zoning laws can also be used to require full service grocery stores be present in all vulnerable neighborhoods. These law changes aim to provide residents with more nutritious choices.

State Interventions to Reduce Food Insecurity

Multiple state and private agencies have been working to reduce hunger and food insecurity within states. Oregon State University has developed a free on-line educational program for health care providers and others to help clinician’s spot children who are in need of additional food support. (http://ecampus.oregonstate.edu/workforce/childhood-food-insecurity/)

A national program with activity in every state is the Feed America program which started the backpack initiative to provide food to school children and families for the days they are not in school (Feeding America, n.d.).

Outcomes and Evaluation The Sommerville experiment has demonstrated on a local level that it is possible to successfully add fresh fruits and vegetables to the school menu. This program incorporated classroom teaching to help children understand the elements of nutrition. The combination of education and food demonstration/preparation has great potential to influence students future food decisions and sway the family food choices. The New Jersey policy to allow farmers markets to participate in food vouchers benefits both the young families and the small farmer. Both of these programs are relevant to the need to create better access to healthy foods. They demonstrate a progressive approach and plan that other schools and communities can build upon. The impact of programs like these upon the overall health of the community is not known as yet.

Urban boundaries, planning and zoning have been integral to most communities for decades but this work seldom results in well balanced cities. Moving existing fast food sites and/or limiting the construction of new stores is contentious and time consuming. Even if more full service markets were made available in communities, poverty still does not allow families to purchase healthy but more costly foods.

State and national initiative such as the FeedAmerica.org foundation meet the immediate needs of students and families but omit needed efforts of long term behavior change. These policy options lack nationwide exposure and authorization and will not work quickly enough to effect change. These programs do not have longitudinal data to ensure their efficacy as the rapid rise of the obesity epidemic caught most policy makers off guard. Many communities are cobbling together ideas and programs in an attempt to quell the wave of obesity. More importantly, the U.S. has failed to deliver even half-adequate material assistance to the poor and disadvantaged which complicates efforts to promote healthy food behavior changes in our children.

Desired Policy Option

Vegetarian Menu Options in School Food Programs

This option will have the most success in refocusing childhood diets to include more plant based nutrition. American children are overweight and obese and if viable solutions to curb childhood obesity are not implemented they will live shorter lives than their parents. The Child Nutrition Act (H.R. 1324) is currently under review and a policy that requires federally funded school food programs offer a vegetarian main course option will help to reduce obesity, bring down long term health costs and ensure ecological sustainability.

This public policy revision would require a modest increase in school food subsidies. Adding a fresh plant based menu option will cost more and might take more personnel and time to prepare.

Expected Outcome of Desired Proposal

The desired policy will help children control obesity by offering healthy food choices, will teach nutritional and health principles and will help children understand the ecological and health impact of meat production and consumption. Together, these activities will produce lifelong positive health outcomes.

When ordinary citizens learn how to motivate the political system through the power of their consumer checkbook and when and how to apply legislative pressure then effective change will occur. If we know that over consumption of meat and dairy products hurt our health by contributing to obesity, morbidity and death thus increasing nationwide health costs and causing our children to die young, **and** if we understand that the livestock industry is causing wide-spread damage to our planet, **and** if we know that a cheaper, healthier more environmentally sustainable alternative is available – why wouldn’t we promote plant based menu options in our schools?

References

Adam, D. (2009). Amazon rainforests pay the price as demand for beef soars. *Guardian, UK*. Retrieved from http://www.guardian.co.uk/environment/2009/may/31/cattle-trade-brazil-greenpeace-amazon-deforestation

Adams, E. J., Strawn, L. G., & Chavez, G. (2003). Food insecurity is associated with increased risk of obesity in california women. *The American Society for Nutritional Sciences, 133*, 1070-1074.

Adams, K. F., Schatzkin, A., Harris, T. B., Kipnis, V., Mouw, T., & Barbash, R. B. et al. (2006). Overweight, obesity and mortality in a large prospective cohort of persons 50-71 years old. *NEJM, 355*, 763-778.

American Dietetic Association (2003). *A new food guide for North American vegetarians*. Retrieved December 1, 2009, from http://www.eatright.org/cps/rde/echg/hs.xsl/governance_5105_ENU_HTML.htm

Barnes, P. M., Bloom, B., & Nahin, R. L. (2008, December 10, 2008). *Complementary and alternative medicine use among adults and children: United States, 2007* (Centers for Disease Control and Prevention, National Health Statistics Reports). Hyattsville, MD: U.S. Department of Health and Human Services.

Bhattacharya, J., Currie, J., & Haider, S. (2004). Poverty, food insecurity and nutritional outcomes in children and adults. *Journal of Health Economics*, *23*, 839-862.

Bittman, M. (2008, January 27, 2008). Rethinking the meat-guzzler. The New York Times

Brown, J. L., Beardslee, W. H., & Stith, D. P. (2008, November 17, 2008). *Impact of school breakfast on children's health and learning* (Sodexo Foundation). : Sodexo Foundation.

CDC FastStats (2009). *National Vital Statistics Reports - Deaths, Final data for 2006*. Retrieved November 24, 2009, from http://www.cdc.gov/nchs/data/nvsr/nvsr57/nvsr57_14.pdf

Davis, B., & Carpenter, C. (2008). Proximity of fast-food restaurants to schools and adolescent obesity. *American Journal of Public Health, 99*, 505-510.

De Natale, C., Annuzzi, G., Bozzetto, L., Mazzarella, R., Costabile, G., & Ciano, O. et al. (2009). Effects of a plant-based high carbohydrate/high fiber diet versus high monounsaturated fat/low carbohydrate diet on postprandial lipids in type 2 diabetic patients. *Diabetes Care*, *32*(12), 2168-2173.

Delaware Action for Animals (2005). *Animals killed for food*. Retrieved December 1, 2009, from http://www.da4a.org/cows.htm

Feeding America (n.d.). *Backpack Program*. Retrieved December 1, 2009, from http://feddingamerica.org/our-network/network-programs/backpack-program.apx

Ferdowsian, H. R., & Barnard, N. D. (2009). Effects of plant-based diets on plasma lipids. *American Journal of Cardiology, 104*(7), 947-56.

Finkelstein, E. A., Fiebelkorn, I. C., & Wang, G. (2003). National medical spending attributable to overweight and obesity: How much, and who's paying?. *Health Affairs*, , W3-219-226.

Finkelstgein, E. A., Trogdon, J. G., Cohen, J. W., & Dietz, W. (2009). *Annual medical spending attributable to obesity: payer-and-service specific estimates*. Retrieved November 24, 2009, from http://content.healthaffairs.org/cgi/content/short/hlthaff.28.5.w822

Flegel, K. M., Graubard, B. I., Williamson, D. F., & Gail, M. H. (2005). Excess deaths associated with underweight, overweight and obesity. *JAMA*, 293, 1861-1867.

Food and Agriculture Organization of the United Nations (2006). *Livestock's Long Shadow - Environmental Issues and Options* (United Nations). Rome: FAO Corporate Document Repository.

Goldberg, J. P., Collins, J. J., Folta, S. C., McLarney, M. J., Kozower, C., & Kuder, J. et al. (2009). Retooling food service for early elementary school students in Somerville, Massachusetts: The shape up Somerville experience. *Preventing Chronic Disease, 6*, .

Harris, G. (2009, July 14, 2009). Administration seeks to restrict antibiotics in livestock. *The New York Times*, p. .

Hedley, A. A., Ogden, C. L., Johnson, C. L., Carroll, M. D., Curtain, L. R., & Flegal, K. M. (2004). Prevalence of overweight and obesity amoung US children, adolescents, and adults, 1999-2002. *JAMA*, *291*, 2847-2850.

Institute of Medicine. (2009, October). *School meals: Building blocks for healthy children* (Institute of Medicine of the National Academies). Washington D.C.: National Academies Press.

Keller, K. (2009, October 8, 2009). New Jersey expands food voucher program to encourage purchase of low fat, fresh foods. *New Jersey Real Time News*. Retrieved from http://www.nj.com/news/index.ssf/2009/10/new_jersey_expands_food_vouche.html

Mair, J. S., Pierce, M. W., & Teret, S. P. (2005, October, 2005). *The use of zoning to restrict fast food outlets: A potential strategy to combat obesity* (The Center for Public Health Law). John's Hopkins and Georgetown Universities: .

McDougall , J. (2006). *An inconvenient truth: We are eating our plant to death, Choosing a plant-food based diet is a moral issue*. Retrieved November 24, 2009, from http://www.drmcdougall.com/misc/2006nl/dec/pdftruth.pdf

Morgan, D., Cohen, S., & Gaul, G. M. (2006, December 10, 2006). Dairy industry crushed innovator who bested price-control system. *The Washington Post*, p. .

National Health and Nutrition Examination Survery (NHANES) (n.d.). *NHANES Surveys (1976–1980 and 2003–2006*). Retrieved November 23, 2009, from http://www.cdc.gov/obesity/childhood/prevalence.html

Olshansky, S. J., Passaro, D. J., Hershow, R. C., Layden, J., Carnes, B. A., & Brody, J. et al. (2005). A potential decline in life expectancy in the united states in the 21st century. *New England Journal of Medicine*, *352*(11), 1138-1145.

Oregon Center for Public Policy (January 15, 2008). *Food insecurity and hunger statistics by state*. Retrieved November 29, 2009, from http://www.ocpp.org/cgi-bin/display.cgi?page=iss080116hunger

Physicians Committee for Responsible Medicine (2002, October 7, 2002). *Vegetarian diets for children: right from the start* (Physicians Committee for Responsible Medicine). Washington, D.C.: PCRM@PCRM.org.

Polhamus, B., Dalenius, K., Thompson, D., Scanlon, K., Borland, E., & Smith, B. et al. (2004). *Pediatric nutrition surveillance 2003 report* (Centers for Disease Control and Prevention). Atlanta, GA: U.S. Department of Health and Human Services.

Robbins, J. (2001). *The food revolution:How your doiet can save your life and our world*. Berkeley, CA: Conari Press.

Schwimmer, J. B., Burwinkle, T. M., & Varni, J. W. (2003). Health-related quality of life in severely obese children and adolescents. *JAMA*, *289*, 1813-1819.

Szeto, Y. T., Kwok, T. C., & Benzie, I. F. (2004). Effects of a long-term vegetarian diet on biomarkers of antioxidant status and cardiovascular disease risk. *Nutrition*, *10*, 863-866.

The Humane Society (n.d.). *Humane eating and the three R's*. Retrieved December 1, 2009, from http://www.hsus.org/farm/humaneeating/

U.S. Dept. of Health and Human Services, Office of Disease and Health Promotion (n.d.). *Healthy People 2010*. Retrieved November 23, 2009, from http://www.healthypeople.gov/

USDA. (2004, June 30). *Child Nutrition and WIC reauthorization Act of 2004. Public Law 108-265 108th Congress* (108-265 118 STAT). Washington, DC: U.S. Government Printing Office.

United States Department of Agriculture (2001-2002). *Agrilculture fact book 2001-2001 Profiling food cunsumption in America, Chapter 2* (United States Department of Agriculture). Hyattsville, MD: Government Printing Office.

Wang, Y., Beydoun, M. A., Liang, L., Caballero, B., & Kumanyika, S. K. (2008). Will all americans become overweight or obese? Estimating the progression and cost of the US obesity epidemic. *Obesity*, *16*(10), 2323-2330.

Woldow, D. (2009). *Speak up for better school food* [Fact sheet]. Retrieved from http://www.pasaf.org/cna/index.html

Appendix A

Appendix B

The world wide effects of livestock

Atmospheric Damage: Animal agriculture is responsible for 18 percent of the world's greenhouse gas emissions. These environmentally toxic gases include: carbon dioxide, nitrous oxide, methane and ammonia. The report believes the impact is so severe that it needs to be addressed with urgency. "There is an urgent need to develop suitable institutional and policy frameworks at local, national and international levels" (Food and Agriculture Organization of the United Nations, 2006, p. 26).

Land Damage: A three-year survey by Greenpeace shows that western demand for beef and leather and an increase in cattle ranching is leading to intensified deforestation in the Amazon (Adam, 2009). Brazil surpassed Australia and the United States to become the world's biggest beef exporter in 2004, and has more than 200 million head of cattle. The Brazilian government is starting to take notice of the illegal deforestation of their rainforests for cattle grazing and officials recently removed 3,100 head of cattle that were being raised on an ecological reserve.

Water Damage: The livestock business is one of the most serious consumers of water on the planet. Livestock-rearing can use up to 200 times more water a kilogram of meat compared to a kilo of grain. Researchers have evaluated multiple levels of water usage: grain planting and irrigation, watering of livestock and management of the slaughter and packaging of meats. Estimates of daily water usage for meat and vegetarian diets have been quantified taking into

Appendix B cont.

account the amount of water used to raise, butcher and package meat for average daily meat consumption as compared to the amount of water needed to provide a plant based daily diet. A meat eating person uses about 4000 gallons of water a day. The Lacto-Ova vegetarian consumes about 1000 gallons and the person eating a diet of plant based foods only uses about 300 gallons.

To put it simply, to produce 1 lb. of feedlot beef requires 7 lbs. of feed grain which takes 7,000 lbs. of water to grow. Passing up on one hamburger will save as much water as taking 40 showers with a low flow nozzle. Water is rapidly becoming one of the world's greatest threatened resources this will only become more significant as global warming continues with expected weather changes.

Not only do livestock use enormous amounts of water they foul the waterways with feces fertilizers and other water polluting agents. "In the United Sates livestock is responsible for 55 percent of the erosion and sediment, 37 percent of the pesticide use, 50 percent of the antibiotic use, and a third of the load of nitrogen and phosphorus put into freshwater sources" (McDougall , 2006, p. 3). Drug residues, especially antibiotics and hormones found in manure and farm wastewater contaminate fresh water supplies.

Appendix C

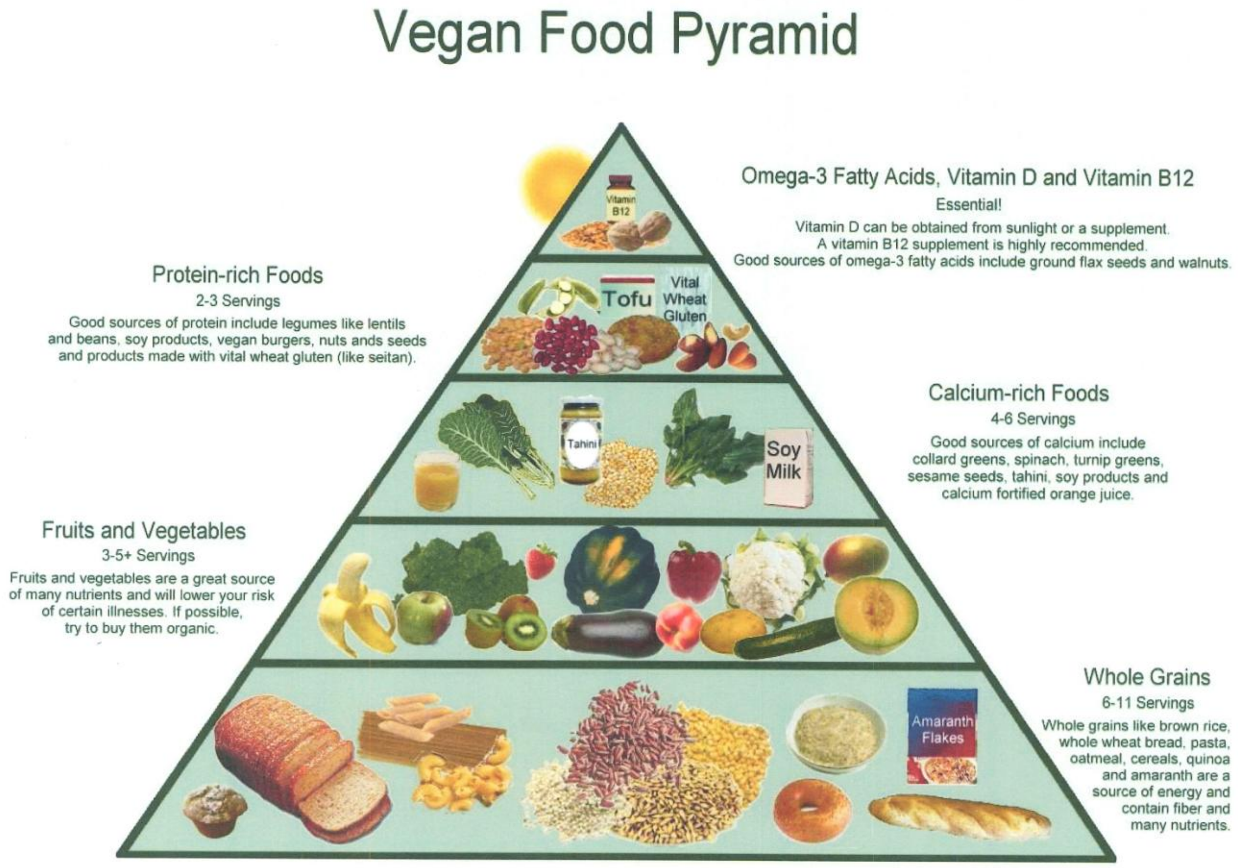
Examples showing weekly foods eaten in Egyptian and American families.

This picture is of a family in Egypt showing the type and amount of foods eaten weekly.

This picture of a family in America showing the type and amount of foods eaten weekly.

Appendix D

The variety of healthy foods available for complete nutrition without meat products.



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Running head: GOLDBERG LEADING HEALTH CARE IN OREGON

Goldberg leading health care in Oregon

Critical Analysis of a Social Change Agent

Myra L. Thompson

OHSU School of Nursing

Health Systems Organizations and Change

NURS 733

Michael Bleich PhD, RN FAAN

March 01, 2010

Goldberg leading health care in Oregon

"Not by design" is the response Dr. Goldberg gives to the question of how he came to Oregon. Who is this man, why should we care that he lives here, and why is it important to know him? The simple answer is that he may be the most powerful and influential health care change agent working within our state today. This was not his plan, however. Dr. Goldberg attended medical school intending to become a solo family practice doctor in northern Maine. During medical school he became interested in community oriented primary care and population based medicine. Following school Dr. Goldberg worked with the Indian Health Service in New Mexico for 6 years. While working with the Zuni Indians he found a work place with a "wonderful blend" of patient care, population medicine, and health administration. He found that he could help patients in the exam room and was also able to aid larger groups of populations through policy and other means. A new career direction was subtly emerging. He came to Oregon in 1991 to work in the Family Practice department at Oregon Health & Science University (OHSU). There he continued to work with disadvantaged persons, collaborating with OHSU Family Nurse Practitioner faculty caring for migrant and seasonal farm workers. He worked on the early implementation of the Oregon Health Plan and was the Medical Director of Care Oregon. An "unexpected and unanticipated" call from the newly elected Governor Ted Kulongoski in 2003 decidedly launched his new career in full time health policy. He accepted the position of Director of the Oregon Health Policy and Research Board for the state. Dr. Goldberg once again advanced his position of influence in Oregon when he accepted the position of Director of the Oregon Department of Human Services in November 2005. In the wake of the major health care problems in Oregon, in July of 2009 Governor Kulongoski appointed Dr. Goldberg to an even more critical policy position as head of the new agency, the Oregon Health Authority (OHA). This agency is taking on the responsibility of leading state-wide health care reform. It plans to deliver to the Governor a final and comprehensive plan for health care reform in Oregon by December 31, 2010.

With the generous assistance of Dr. Goldberg's secretary, he graciously agreed to meet with this doctoral student on February 9, 2009 following the monthly meeting of the OHA in Portland. I had the privilege of observing the OHA's activity and agenda and in particular, studied Dr. Goldberg's leadership style and influence as the director of this group. A letter detailing my objectives for this interview (appendix A) had been sent to Dr. Goldberg and we spent nearly an hour discussing Oregon's health problems, future health initiatives and the one health issue he believed could have been managed better.

The Problem: HB 2116

Dr. Goldberg described how vulnerable he felt when he first took over the Department of Human Services (DHS). "The day I started as the DHS director, we were way under water and I did not think the department would survive". Oregon Medicaid was in serious financial trouble and it was only going to get worse as many federal dollars were slated to be eliminated from the budget by 2007. In our interview Dr. Goldberg was asked, "What is one problem you encountered you wished that you had handled differently", he quickly replied, "How we managed the Provider tax initiative". To understand HB 2116, also known as the Provider tax, it is essential to understand the context in which it was conceived.

Context

In June 2007, Oregon embarked on an intense 2 year project conducted by the Oregon Health Fund Board (OHFB) that culminated in the passage of several important health care initiatives. The OHFB, a seven-member citizen board established in June 2007 by the passage of the Healthy Oregon Act, was chartered with the goal of developing a comprehensive plan to ensure access to health care for all Oregonians. This Board aimed to guide legislation to contain health care costs, and address issues of quality in health care and was supported in its efforts by hundreds of volunteers from many parts of the state. In November 2008, the Board submitted a comprehensive action plan, "Aim High: Building a Healthy Oregon," to Governor Kulongoski and the Oregon Legislature, providing a blueprint for reforming Oregon's health care system (State of Oregon, November 2008). One part of this comprehensive plan was the implementation of HB 2116, a tax on managed care organizations and hospitals in Oregon (State of Oregon, June 1, 2009). This essential piece of legislation was needed to continue and expand health care coverage for disadvantaged Oregonians, especially children. HB 2116 contained both a hospital tax and a health insurance premium tax. The entire cost of the premium tax would be picked up by employers who were already paying for commercial health insurance for their employees. The hospital tax could be fully recoverable through federal matching funds to avoid cost shifting this expense back to insurances or the individual. Rural hospitals were exempt.

House Bill 2116 would leverage nearly $2 billion over four years to help the state provide health insurance for 200,000 Oregonians through the Oregon Health Plan (OHP) and a new shared-cost insurance product called “Kids Connect.” 80,000 of those newly insured would be children under the age of 19 and the remaining would include an expansion of 35,000 low income adults to the OHP Standard program.

Stakeholders

As one can easily imagine, there was vigorous debate in many sectors both for and against HB 2116.

Against: It is not surprising that Oregon's hospital systems and insurance companies, as well as many in the business community, were decidedly against this proposal. They believed that taxing a narrow group of businesses for a broad-based health care expansion was not equitable or sustainable in the long term (Associated Oregon Industries, April 20, 2009). The business community believed that the assumption that premiums would remain steady and that a new tax would not substantially increase premiums was wrong. Business groups feared that fewer employers would pay for employee insurance; therefore fewer taxes would be collected leading to less money for the Oregon Health Plan. Ultimately they viewed it as a "lose-lose" situation where fewer people would have health insurance and what they had would cost even more. Oregon hospitals also reacted negatively to this proposal. They were seeing a dramatic 3-fold increase in uncompensated care during the years 2003-2004 (K. John McConnell , n.d.). They did not see how much more they could contribute to the state's health agenda and still keep their doors open. Andy Davidson, president & CEO of the Oregon Assoc. of Hospitals and Health Systems stated, "We struggle to understand the rationale and wisdom of financing the lion's share of this critical increase to the Oregon Health Plan through a 4% hospital tax on Oregon's community hospitals" (Oregon Business Report, December 3, 2008, p. 1).

For: It is obvious who was for this new tax. Primarily it was health care recipients and administrators of OHP who knew that over 600,000 Oregonians were without health insurance. Over 116,000 of these uninsured persons were children. The picture of a third of our state population without health coverage was a very powerful argument for legislative change and a revived provider tax.

Other players: The media played a significant role in this campaign by publishing multiple editorials and interviews of organizations and individuals both for and against this tax. It was interesting that the general public took little interest in this process as presumably they did not see this tax as directly affecting them.

Outcome: Passage of HB 2116

On August 4, 2009, Governor Kulongoski signed this law and it went into effect on September 28, 2009. This bill added an additional 35,000 uninsured adults to the OHP but more importantly it extended health insurance to nearly all of Oregon's uninsured children. The health care package was the signature achievement of the 2009 legislative session. The *Healthy Kids* component of HB 2116 added 80,000 uninsured children to the OHP which placed Oregon among only 12 states with universal coverage for kids (The Oregonian Editorial Board, September 29, 2009).

Dr. Goldberg described the passage of HB 216 as an "inelegant process". Too much work was done behind "closed doors" and not enough work was done to challenge the stakeholders to step into leadership roles to develop proposals for funding rather than just leaving it to the Legislature to solve.

The Critique

With the advantage of hind-sight, it is easier to identify problems and point out areas where a new approaches might have helped. The interview with Dr. Goldberg, an extensive research of recent Oregon health care reform initiatives and information gleaned from many hours of reading/lectures for NURS 733 revealed the following problems.

a) Poor communication: From the beginning, the major uproar might have been prevented if the stakeholders understood that this was not really a new tax. The 2003 Oregon Legislature passed HB 2747 which created industry-supported “provider” taxes. The hospital provider tax and the Medicaid managed care (MCO) tax generated revenue to pay for costs associated with the Oregon Health Plan (OHP) Standard program, which receives no general fund support. These Medicaid /MCO taxes generated about $180 million per year with a federal match. Both taxes were set to “sunset” October 1, 2009 and Oregon would have lost millions of federal subsidies without a new tax law.

Improvement: Early and effective consensus building would have helped to mediate the affected constituents and their possible conflicts of interest. This was a very complex problem that involved many powerful parties. Without a plan to orchestrate inevitable conflict, turmoil was sure to erupt, and that is, in fact, what happened. The Department of Human Services (DHS) had not looked far enough ahead to prepare a plan to fill the budget hole that expiration of HB 2747 was leaving. The DHS did not start discussions with the various factions involved and no common ground was established. If the DHS had communicated with the MCO's and hospitals *prior* to the construction of this bill much unrest might have been avoided. The DSH could have made a first attempt to communicate thereby gaining the "upper hand". Reaching out with early communication generally give that individual/organization an unofficial informal "authority" that help to leverage change in their favor. If this had occurred, the DHS could have set the ground rules and agenda and framed the conflict in terms of the states values and priorities.

Assumptions were made by the DHS during the early development of HB 2116 that ultimately constrained the effectiveness of this endeavor. They limited the tax to hospitals and MCO's without consideration of other revenue sources. They missed an opportunity to steer away from the middle and engage in an adaptive challenge. They acted from a state of emergency to create a solution instead of taking the time to collect meaningful data and develop structures to frame the initiative as an experimental challenge. "An experimental mind-set will mean taking greater risks than you are used to taking, you can exercise leadership in situations where you would have been held back in the past"(Heifetz, Grashow, & Linsky, 2009, p. 281). Oregon missed a golden opportunity to engage the state in their vision for health care reform.

b) Improper understanding of political relationships: Either through hubris or inattention, the DHS failed to understand the essential political relationships in Oregon working for or against real health care reform. They failed to understand that organizations may have expectations not in alignment with their core values and goals. Competing interests among for-profit and not-for-profit agencies can de-rail even the most well intended and essential programs. The DHS and the state government also allowed their agenda for health care reform to be co-opted by these competing interests. The government did not adequately control the reform agenda thus allowing the opposition to control the media and therefore public reality.

Improvement: A careful and detailed analysis of all of the stakeholders in this reform was needed to uncover relationships and values driving opposition behavior. “When you want to drive adaptive change in your organization, and others are getting in your way, it is natural to view in less-than-charitable ways those who are impeding progress, as you understand it”(Heifetz et al., 2009, p. 91). Dr. Goldberg admitted that being impatient is a leadership quality he needs to improve. In the rush to meet the “sunset” deadline, the DHS made assumptions that may have hindered the passage of what could have been a universally applauded and supported health reform action. They did not anticipate a push back to HB 2116. Change is difficult but there are several models that are useful to facilitate the transformation of ideals and goals into workable solutions. The Appreciative Inquiry theory and its step-wise process might have helped the DHS navigate the political landscape to better understand **if** the state of Oregon was ready for change. First, they should have anticipated that change was coming. Then they could have developed “advisory teams” to understand the problem, to draft a solution and then to build organization-wide awareness of the problem with potential solutions (Whitney & Bloom, 2003).

Appreciating and including grassroots organizations who are working for health care reform in Oregon would have helped. One such example is The Archimedes Movement which started in 2006 with the goal of making a difference in our personal and collective health as a state and a nation (The Archimedes Movement, n.d.). Health care rhetoric alone will not effect change, it must eventually be drawn from the individuals within our state. As Dwyer notes, "Public language is frequently used in organizations to express the concept of organizational problems or shared problems: there are no such things because problems belong to *individuals"* (C. Dwyer, Handout from Leadership intensive, Feb. 5, 2010).

Effective and lasting change may come from unlikely sources. Christensen, in The Innovator's Prescription, eloquently outlines 3 concepts that when working in concert can make for substantive change (Christensen, Grossman, & Hwang, 2009). The three elements of a disruptive solution, technological enabler, business model innovation, and value network will eventually coincide in a product or process that results in true health care reform. The transformational forces that brought change to other industries must occur in health care and what every change agent needs to realize is that no one has the power to coerce cooperation with change. Real change will occur **only** when individuals see a process or plan so compelling, desirable or meaningful that they naturally choose to participate.

In the case of HB 2116, the organizations were eventually able to agree on basic values and goals so this bill could move forward. This represents a piecemeal approach however, and it is not likely to produce radical transformation needed for health care reform in Oregon.

Summary: Health care reform is an untidy if not down-right vicious process. The national news exposes political intrigue and Machiavellian behavior that ultimately hurts the American people. Since the development of the Oregon Health Plan 20 years ago, this state has had the reputation of being a leader in health care reform. We have influenced end-of-life care with the *Death with Dignity* act and with *POLST* (physician orders for life sustaining treatment) orders and registry. Our state is slowly moving toward a public attitude that embraces the notion that life, liberty and the pursuit of happiness is fundamentally tied to the opportunity for a healthy life. Oregon is beginning to realize that the consequences of maintaining the status quo at the local, state and national level will ultimately destroy us as a nation. The real health care challenge is to create a **powerful vision**, a **common purpose** and a creative **innovation** to transition our nation to a better health care reality.

References

Associated Oregon Industries (April 20, 2009). *Public Policy and Health Care*. Retrieved March 2, 2010, from http://www.aoieap.com/_search/index.cfm?fid=1304

Christensen, C., Grossman, J., & Hwang, J. (2009). *The Innovator's Prescription: A disruptive solution for health care*. New York: MGraw Hill.

Heifetz, R., Grashow, A., & Linsky, M. (2009). *The Practice of Adaptive Leadership*. Boston, Mass.: Harvard Business Press.

K. John McConnell (n.d.). *Oregon's Cost-Shift: The Effect of Public Insurance Coverage on Uncompensated Care Report to the Oregon Office for Health Policy and Research*. Retrieved March 3, 2010, from http://www.oregon.gov/OHPPR/docs/OR_Uncom_Care-McConnell.pdf

Oregon Business Report (December 3, 2008). *Hospitals react to Governor's 4% hospital tax*. Retrieved March 3, 2010, from http://oregonbusinessreport.com/2008/12/hospitals-react-to-governors-4-hospital-tax/

State of Oregon (June 1, 2009). *HB 2116*. Retrieved March 2, 2010, from http://www.oregon.gov/OHPPR/HFB/docs/2009_Legislature_Presentations/Bills/hb2116.c.pdf

State of Oregon (November 2008). *Oregon Health Board Aim High: Building a Healthy Oregon*. Retrieved March 2, 2010, from http://www.oregon.gov/OHPPR/HFB/docs/Final_Report_12_2008.pdf

The Archimedes Movement (n.d.). *The Archimedes Movement: We can do better*. Retrieved March 2, 2010, from http://archimedesmovement.org/

The Oregonian Editorial Board (September 29, 2009). *Editorial: A banner day for Oregon kids, roads*.. Retrieved March 3, 2010, from http://www.oregonsenatedemocrats.com/tag/hb-2116

Whitney, D., & Bloom, A. T. (2003). *The Power of Appreciative Inquiry*. San Francisco: Berrett-Koehler Publishers, Inc..

Running head: SOCIAL ISOLATION AND DEATH BY SUICIDE

Social Isolation and Death by Suicide

Myra L. Thompson

Oregon Health & Sciences University

School of Nursing

Author Note

Myra L. Thompson RN MS FNP CCRN is a student in the Doctor of Nursing Practice program at Oregon Health & Sciences University, School of Nursing, Portland, Oregon. Correspondence concerning this article should be addressed to her at Bayshore Family Medicine, 38505 Brooten Road, Pacific City. OR 97135.

E-mail: mthompson@bfmed.net

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Biosketch of Author

Myra L. Thompson RN MS FNP CCRN works as an Advanced Practice Nurse in a Rural Health Clinic on the Oregon coast. She has been providing primary care in this location for 16 years. In addition, she continues a 26 year career as Nursing Supervisor in a rural Critical Care Access hospital. This work has provided her with broad experience caring for rural patients and families. She has the distinction of being the first nurse honored with the **Oregon Rural Nurse Award** in 1990.

Abstract

Americans are far more socially isolated today. This article reviews the factors of social isolation that may lead to suicide. The Advanced Practice Nurse (APN) with Doctorate preparation (DNP) can evaluate and favorably impact patients with social isolation to reduce suicide. They are well positioned to participate in community and political processes to create socially just health policies.

Key Words

Social isolation Suicide Advanced Practice Nurse Homelessness Social Capital

Social Cohesion Social Determinants of Health Social Justice

Social Isolation and Death by Suicide

"I'm tired of being sorry, of hurting people. I am tired of hurting period . . . "

These words are an excerpt from a recent two page suicide note which reveals the anguish that some people feel when they choose to end their life.

Everyone wants health – to feel good and enjoy life. Many forces other than disease determine life or death and our ability to enjoy life. While we have enjoyed fantastic advances in medical science, saving many lives, these innovations have not wholly addressed the fundamental causes of mortality and morbidity. Health must be defined and evaluated by conditions of the social setting (social determinants) by environmental and genetic factors (genomics) and by other dynamics not as yet understood but needing discovery. The World Health Organization (WHO) states, "Health policy was once thought to be about little more than the provision and funding of medical care: the social determinants of health were discussed only among academics. This is now changing. While medical care can prolong survival and improve prognosis after some serious diseases, more important for the health of the population as a whole are the social and economic conditions that make people ill and in need of medical care in the first place" (WHO, 2003 p. 7). Bell and Standish also note that "health status is largely a function of factors beyond the bounds of the health care system including income, race, behavior, genetics, and environmental conditions" (Bell & Standish, 2005, p. 339). This article takes the reader from the "broad strokes" of social determinates of health through the interconnectedness of social isolation and homelessness that may result in suicide. The

Advanced Practice Nurse (APN) with Doctorate preparation (DNP) is well positioned to evaluate and favorably impact social isolation thereby reducing the risk of suicide.

Social Determinants of Health

Nancy Krieger defines social determinants of health as “specific features of and pathways by which societal conditions affect health and that can potentially be altered by informed action” (Krieger, 2001, p. 696). Examples of these social determinants are income, education, occupation, family structure, sanitation, social support, racial discrimination, and many others. Sociologists have carefully labeled and measured these determinants since professor, Émile Durkheim defined “social facts” over a century ago (Durkheim, 1893). The field of social epidemiology seeks to identify the collective characteristics of communities that determine population wide health status. A plethora of research has been conducted that outlines specific and measurable social determinants of health. A seminal report from Canada in 1974 introduced how factors other than health care delivery are important to individual health status. The Lalonde report is considered the first modern Western government document to acknowledge that the emphasis upon a biomedical healthcare system is wrong, and that we need to look beyond the traditional health care (sick care) system if improving the health of the public is the goal (Glouberman & Millar, 2003). Many sound and well funded research projects link social determinants to health outcomes and clearly identify specific health disparities and the populations most often affected (Alvarado, Zunzunegui, Beland, & Bamvita, 2008), (Walker, Holben, & Kropf, 2006). Social conditions therefore, are major determinants of health as these determinants act collectively to shape individual biology, risk, environmental exposures, and access to resources all impacting health.

Social determinants of health **do** matter and poor social circumstances **do** affect health throughout a lifetime. Social determinants such as poverty, stress, unemployment, poor education, addiction, homelessness, hunger, and isolation can all lead to serious illness and premature death (WHO, 2003).

Social Capital and Social Cohesion

There are multiple definitions of social capital and generally include such features as: interpersonal trust, mutual aid which acts as resources for individuals and activities and/or behaviors that facilitate cooperation for mutual benefit. Social capital is external to ones's self and is primarily focused on the public good – the creation of a "civil society" with sound democracy. Relationships are formed and maintained when social capital is present. Simply put, social capital is the goodwill that is engendered by social relationships and the force these relationships have to mobilize resources and protect the individual. Social cohesion is a natural byproduct of social capital and is directly dependent on the components of the collective social capital of the citizens. Communities which have strong mutual support, less wealth inequity and effective and inclusive political institutions have healthier citizens. Places that "throw the person under the bus" are less prosperous, less satisfied, and more unhealthy. "A cohesive society is also one that is richly endowed with stocks of social capital" (Kawachi & Berkman, 2000, p.175).

While most people have dense and long term personal and social interconnectedness, others do not. It is widely recognized that social relationships and affiliations powerfully effect physical and mental health. Strong social networks involving family, friends, and meaningful community integration promote the health of individuals and their community. Social scientists now recognize that society is not just the sum of it's individuals. It is much more than this and infinitely more complex.

Social Isolation

Americans are far more socially isolated today than they were even two decades ago. During the early and mid 20th century families ate meals together, neighbors visited from their porches and communities actively engaged in civil and religious institutions. We now see these intimate and community social ties shrinking and become nonexistent. Theories abound to explain this sharp decline ranging from mothers leaving the home for work to technological transformations starting with television in the 1950's to today's high speed internet**.** Robert Putnum, a Harvard Sociologist wrote a noteworthy but somewhat controversial essay describing this phenomenon (Putnam, 1995). His article, *Bowling Alone,* stirred vigorous academic discussion by describing "civil disengagement" (social isolation) as a significant health threat. Many technological advances made since the mid 1950's have had the unintended but real result of progressively and profoundly isolating people from each other and the community. Gone are the neighborhood block parties and family picnics. E-mail has replaced going to the post office, the answering machine keep people from talking on the phone, and Facebook means you never have to actually talk with your friends you can just read about them.

A comprehensive study conducted in 2006 confirms this notion of increasing social isolation for the American public. In 1985, the General Social Survey (GSS) collected the first nationally representative data looking at whom Americans consider their confidents when important matters need to be discussed. In the 2004 GSS the authors replicated those questions to assess for changes in these social and network structures. The results show that discussion networks are smaller in 2004 than in 1985 and the number of people saying there is no one with whom they discuss important matters nearly tripled (McPherson, Lovin, & Brashears, 2006). We are finding less of a safety net of close friends and confidents and more illness and destructive behaviors. In bad times, more people now suffer alone. This was vividly portrayed in pictures following Hurricane Katrina which showed people stranded on their roofs because, as we now know, they did not know someone with a car.

Many studies show that people of color are more likely than whites to face barriers to accessing care and as a result receive a lower quality of care (U.S. Department of Health and Human Services, 2008). Demographic changes are transforming the American family. Since the 1960's, society has seen more divorce, less marriage and more teenage and unwed pregnancies. Families are more mobile, and this tends to disrupt networks and reduce neighborhood stability. One of the most significant changes to the backdrop of the American community is the influx of immigrants, both legal and illegal. This has led to a significant increase in homeless persons.

Homelessness

It is difficult to calculate the extent of the homeless plight in America. The transient nature of this problem and the reluctance of communities to acknowledge its existence make for inaccurate assessments. "Despite the development of sophisticated methodologies, difficulties inherent in homeless enumeration render nearly all counts open to criticism. National estimates of the number of homeless have generally been extrapolated from urban data to the nation as a whole (Link et al., 1996 p. 143). In January 2005 an estimate of 744,313 people were homeless in America (Cunningham & Henry, 2007). "The major reason for the growing number of homeless men, women, and children is the diminished availability of affordable housing for people who are poor or at risk due to other limitations in physical, psychological, or social functioning, such as mental illness, substance abuse , or family violence" (Aday, 2001, p. 111). Temporary homelessness has increased from a decade ago and threatens individuals and families further up the income distribution.

Of all the social determinants of health that impact homeless persons, social isolation may be the most profound. This is especially true in the depressed economic environment we now experience. The national rate of unemployment is hovering at 10% but Oregon ranks 5th in the nation at 11.3% (Bureau of Labor Statistics, 2009). Review of historical data for unemployment numbers in Oregon show a shocking rise from 5.3% in January 2008 to a high of 12.0 % in June of 2009. In terms of human cost, that figured to 133,226 **more** people living in Oregon without a paycheck. Where do people go when they can no longer afford to stay in their homes? It appears that one consequence of homelessness may be social isolation and feelings of despair which can lead to death by suicide.

Suicide

September 10 was declared as this year's World Wide Suicide Prevention Day. It has been an annual event since 2003 when the World Health Organization (WHO) declared the need to focus attention on the problem of suicide and to call for global action (International Association for Suicide Prevention, 2009). "Suicide is a huge but largely preventable public health problem, causing almost half of all violent deaths and resulting in almost one million fatalities every year, as well as economic costs in the billions of dollars" (World Health Organization, 2009). Oregon ranks at 8th in the nation in term of its suicide rate losing 579 citizens in 2005 to death by intentional acts of violence (American Foundation for Suicide Prevention, 2006).

Suicidal behavior has many complex and underlying causes. Poverty, unemployment, a family history of suicide, alcohol and drug abuse and many other problems alone or in concert can create a sense of hopelessness where people feel that suicide is their only option. One clear and consistent predisposition to suicide is a profound sense of social isolation; a lack of “connectedness” to others. The quality or type of this connectedness is not exactly clear and needs more study.

Robert Putnam’s book defines social capital as the norms of exchange and social trust that arise from interactions with others. He describes two basic forms of social capital, bonding and bridging. Bonding social capital are ties between socially similar individuals or groups. These links engender empathy and support within the network. Bridging social capital, on the other hand, represent associations between dissimilar individuals and groups. Such ties help people get ahead because they unlock assets in the networks that would have been unavailable to them without the connection (Putnam, 2000).

Together, homelessness and suicide create a major public health concern. Sociologists from the University of Alabama recently conducted a survey of 161 homeless persons to try to understand the role of social capital in mediating problems for disadvantaged persons and its impact on suicide ideation. The results were surprising. It was clear that life circumstances and depression may increase the odds that a homeless person will consider suicide, but social capital as the root cause, showed mixed effects. Their results indicate that bonding capital does not lower the odds of suicide ideation, but bridging social capital significantly lowers the odds of suicide ideation among the homeless (Irwin, Fitzpatrick, LeGory, & Ritchey, 2006).

Vulnerability of Rural Location

Is it possible that just by the fact of where you live you could be more vulnerable to taking your own life? Studies show that living in rural areas increases your risk for suicide. The precise cause was not clear but was presumed to be an outcome of fewer health providers for rural populations (Fiske, Gatz, & Hannell, 2005).

Alcohol and Suicide

Taking this thesis further, researchers discovered that in rural areas there is a strong correlation between drinking (alcohol) and taking one's own life. Research looked at the number of bars per population then matched this data to suicides both attempted and completed in 581 defined California zip codes over a 6 year period. Bar densities in particular appeared related to the incidence of suicide. Suicides occurred at greater rates in rural communities with greater bar densities (Johnson, Gruenewold, & Remer, 2009).

Familial Predisposition

We know that suicidal behaviors are closely linked to social determinants affecting a person's well-being and health. Are there other factors that contribute to the problem of suicide? Data from a longitudinal Danish survey show that a family history of completed suicide and psychiatric illness significantly and independently increase the suicide risk for members within the affected family (Qin, Agerbo, & Mortensen, 2002). Familial clusters of suicide point to genetic factors that may be working to favor suicidal ideation and death.

Environmental factors

The environment is also participating in this assembly of suicide risk factors. China has an incredibly high suicide rate with over 44% of the world's suicides occurring, for the most part, in China's rural areas. Many factors must contribute to this problem but one frightening environmental link has been discovered. The WHO published a bulletin in July 2009 describing an association between pesticide exposure and suicidal ideation. At first read, it would seem that it is the physical contact with organophosphates that is the culprit, as these pesticides have been banned in Western countries for years due to their lethal chemistry. Researchers from Tongde Hospital Zhejiang Province and King's College London studied over 10,000 residents of central and coastal China and found the first epidemiological evidence to suggest possible effects of pesticide storage on suicidal ideation. "Our research findings suggest that higher exposure to these chemicals might actually increase the risk of suicidal thoughts" (Zhang, Stewart, Phillips, Shi, & Prince, 2009, p. 3). Are there other environmental triggers operating undiscovered that are subtly altering our lives?

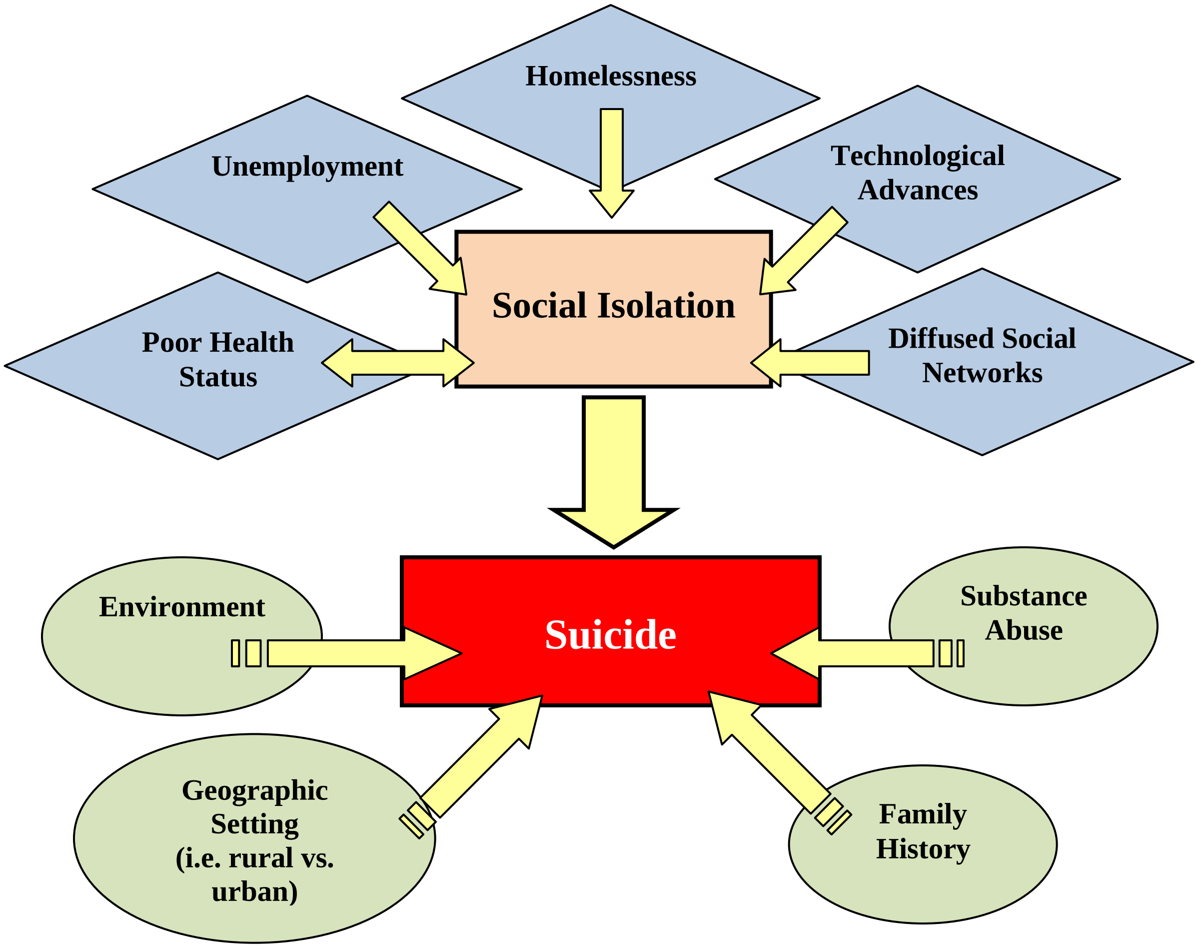
In summary, social determinants of health such as social capital and social cohesion can be absent or insufficient to protect people from social isolation. Social isolation, compounded by homelessness (and a host of other compounding factors), intertwine to create critical health disparities which can lead some people to their death.

Ethical Considerations

Health equity is not the same as equality of health. The sociological concept of health equity focuses on the distribution of resources in such a way as to systematically exclude certain members of society which, in turn causes health inequities for that affected population. True equality of health is not achievable. There will always be some population, location, individual or family that has an advantage and there will always be groups who are disenfranchised with respect to their health. The ethical framework and values of social justice (distributive justice) as applied to public health policies, work to diminish the disparity between the "haves" and "have nots". Professors Braveman and Gurslin masterfully explain the relationship of health equity and social justice. "Equity in health means equal opportunity to be healthy, for all population groups. Equity in health thus implies that resources are distributed and processes are designed in ways most likely to move toward equalizing the health outcomes of disadvantaged social groups with the outcome of their more advantaged counterparts" (Braveman & Gruskin, 2003, p. 257). This is certainly a lofty and worthy goal, but it is not an easy one to accomplish in our culture.

Social isolation is a serious problem in our society and it can be debilitating and deadly. Proactive measures have been instituted or proposed that help to reduce health disparities for isolated and homeless individuals.

Figure 1. Causal Relationships Between Social Isolation and Suicide



Advanced Nurse Practitioner Solutions

The American Nurses Association (ANA) house of delegates, approved nine provisions to the *Code of Ethics for Nurses* in 2001. The first statement with interpretation reads:

> *The nurse, in all professional relationships, practices with compassion and respect for the inherent dignity, worth and uniqueness of every individual, unrestricted by considerations of social or economic status, personal attributes, or the nature of health problems* (ANA 2001).

Advanced practice nurses have a profound responsibility to uphold this core statement for all of their patients. They are in a unique position to assess, recognize and intervene for patients who are isolated or at risk for social isolation. ANPs operate in several areas where they can successfully press for moral (social justice) policies to improve health care equity for patients in their communities.

In the exam room

The ANP should obtain or develop evidenced based screening tools for their patients. Regular evaluation of patients looking for physical signs associated with social isolation such as weight loss, skin changes and insomnia is important. They must look for mental and mood changes associated with depression such as flat affect, mood swings, poor hygiene and personal upkeep. A complete comprehensive family and social history to question housing status, employment, persons living in or leaving the home, brushes with the law, what they do “for fun” and are they having fun, do they go to church or get out shopping, are all factors the ANP needs to know about the patient. This information is important and should be part of the health record and updated annually or as needed. It is vital that the ANP also ask the patient to supply the office a name and number of a relatives or friend with permission to contact these people should the need arise. The ANP must always look for ways to build family and friend networks to augment social capital resources which will reduce feelings of isolation for at risk patients. In conducting these assessments it is important to remember that, like pain, social isolation is what the patient says it is. The patient's perception is key to identifying these problems.

There are countless number of validated tools to assess depression, anxiety, cognition, mood disorder, substance abuse and many other problems. It is not possible to utilize them all. The ANP should match valid well researched tools to the characteristics of their patient population and use these tools consistently.

Referrals

The ANP must have well established lines of consultations with mental health professionals and a thorough knowledge of community resources such as women and family shelters, food banks, and various support groups. This information needs to be available and routinely updated so staff and clinicians can make timely interventions. The ANP can intervene early by setting up a plan of care that includes these community resources.

Political change

Advanced practice nurses and especially the Doctorate of Nursing Practice prepared ANP must participate in the political process to effect positive patient care outcomes. Catherine J. Dood, in the book <u>Advanced Practice Nursing</u> (2009) lists ten specific strategies that the ANP can utilize to gain political expertise (Dodd, 2009). These are practical and applicable to the working nurse and can be viewed in Appendix A. They should strengthen partnerships with local, state and federal policy makers and with agencies in housing, transportation, education and economic development.

Future Research

The inequities in the health status of most Americans are a persistent and ever increasing problem and investigations continue. Furthermore, research that explores the relationship between social isolation and suicide is limited. The connection is intuitive but actual data demonstrating the causal relationship is insufficient and more research is needed.

Summary

The Advanced Practice Nurse (APN) with Doctorate preparation (DNP) is well suited to champion socially responsible and moral (social justice) measures to support health equity across all sectors of their community. This can be accomplished by the professional examples they display, the societal norms they embrace (tolerance and justice) and the laws they help craft and support. Differences in health will always exist but equal opportunity to be healthy is a basic human right and should be protected for all.

Appendix A

Ten universal commandments of politics and reasons to obey them.

1. The personal is political. Each of us is just one personal or social injustice away from being involved in politics. Every vote counts.
2. Friends come and go but enemies accumulate
3. Politics is the art of the possible. Count votes in advance. The majority rules.
4. Be polite, be persistent, be persuasive, and send thank-you notes. Write, write, write, ghost write and write.
5. Ignore your mother's rule. Talk to strangers or network. Carry business cards, flaunt your professional credentials proudly.
6. Money is the mother's milk of politics. Give it early and if you don't have it, raise it . . . even if you do have it, raise it!
7. Negotiate visibility. Take credit, Take control
8. Politics has a chit economy, so keep track. Seniority counts
9. Reputations are permanent
10. Don't' let 'em get to ya

Dodd, C. J. (2009). Making the political process work. In A. M. Barker (Ed.), *Advanced practice nursing: Essential knowledge for the profession* (pp. 305-315). Sudbury, MA: Jones and Bartlett Publishers.

References

Aday, L. A. (2001). *At risk in America* (2nd ed.). San Francisco, CA: Jossey-Bass.

Alvarado, B., Zunzunegui, M. V., Beland, F., & Bamvita, J. M. (2008). Life course social and health conditions linked to frailty in Latin American older men and women.. *The Gerontological Society of America, 63*, 1399-1406.

American Foundation for Suicide Prevention (2006). *Facts and figures: State statistics* [White paper]. Retrieved from American Foundation for Suicide Prevention: http://www.afsp.org/index.cfm?fuseaction=home.viewpage&page_id=05114FBE-E445-7831-F0C1494E2FADB8EA

American Nurses Association. (2001, July, 2001). *Code of ethics for nurses with intrepretive statements* (ANA). Silver Spring, MD: ANA.

Bell, J., & Standish, M. (2005). Perspective communities and health policy: A pathway for change. *Health Affairs, 24,* 339-342.

Braveman, P., & Gruskin, S. (2003). Defining equity in health. *Journal of Epidemiology and Community Health, 57*, 254-258.

Bureau of Labor Statistics (2009, November 20, 2009). *Unemployment rates for states* [White paper]. Retrieved from United States Department of Labor: http://www.bls.gov/web/laumstrk.htm

Compton, M. T., Thompson, N. J., & Kaslow, N. J. (2005). Social environmental factors associated with suicide attempt among low-income African Americans. *Social Psychiatry + Psychiatric Epidemiology, 40*(), 175-185.

Cunningham, M., & Henry, M. (2007, January, 2007). *Homelessness counts* (National Alliance to end Homelessness). Washington D.C.: .

Dodd, C. J. (2009). Making the political process work. In A. M. Barker (Ed.), *Advanced practice nursing: Essential knowledge for the profession* (pp. 305-315). Sudbury, MA: Jones and Bartlett Publishers.

Durkheim, D. E. (1893). In *Rock, Paul (2002) Sociological theories of crime*. Oxford, England: Oxford University Press.

Fiske, A., Gatz, M., & Hannell, E. (2005). Rural suicide rates and availability of health care providers. *Journal of Community Psychology*, *33*, 537-543.

Glouberman, S., & Millar, J. (2003). Evolution of the determinants of health, health policy, and health information systems in Canada. *American Journal of Public Health*, *93*, 388-392.

International Association for Suicide Prevention (Producer). (2009). *Suicide prevention in different cultures* [Video file]. Retrieved from http://www.iasp.info/wspd/pdf/2009_wspd_announcement.pdf

Irwin, J., Fitzpatrick, K., LeGory, M., & Ritchey, F. (2006, August 11). *Social capital and suicide ideation among the homeless*. Paper presented at the American Sociological Association, Montreal, Quebec.

Johnson, F. W., Gruenewold, P. J., & Remer, L. G. (2009). Suicide and alcohol: Do outlet’s play a role?. *Alcohol: Clinical and Experimental Research*, *33*(12), 2124-2133.

Kawachi, I., & Berkman, L. (2000). Social cohesion, social capital and health. In *Social epidemiology* (pp. 174-191-191). New York: Oxford University Press.

Krieger, N. (2001). A glossary for social epidemiology. *Journal of Epidemiological Community Health*, *55*, 693-700.

Link, B., Phelan, J., Stueve, A., Moore, R., Breshnahan, M., & Struening, E. (1996). Public attitudes and beliefs about homeless people. In J. Baumohl (Ed.), *Homelessness in america* (pp. 143-149). Phoenix: The Oryx Press.

McPherson, M., Lovin, L. S., & Brashears, M. E. (2006). Social isolation in america: changes in core discussion networks over two decades. *American Sociological Review, 71*, 353-375.

Putnam, R. (2000). *Bowling alone: The collapse and revival of american community*. New York: Simon & Schuster.

Putnam, R. D. (1995). Bowling alone: America’s declining social capital. *Journal of Democracy, 6*(1), 65-78.

Qin, P., Agerbo, E., & Mortensen, P. B. (2002). Suicidal risk in relation to family history of completed suicides and psychiatric disorders: A nested case-controlled study based on longitudinal registers. *Lancet, 360*, 1126-1130.

U.S. Department of Health and Human Services. (2008, February, 2008). *National Healthcare Disparities Report 2007* (Agency for Healthcare Research and Quality). Washington, D.C.: AHRQ Publication No. 08-0041.

Walker, J., Holben, D., & Kropf, M. (2006). Food insecurity is associated with poor social capital and poor health in females from households receiving WIC along and WIC plus farmers’ market nutrition program. *Journal of the American Dietetic Association*, *106,* A69-A70.

World Health Organization (2003). *Social determinants of health: The solid facts, 2nd ed.* (World Health Organization). R. Wilkinson & M. Marmot eds. Copenhagen, Denmark

World Health Organization (Producer). (2009). *World Suicide Prevention Day* [Video file]. Retrieved from http://www.who.int/mediacentre/news/releases/2004/pr61/en/print.html

Zhang, J., Stewart, R., Phillips, M., Shi, Q., & Prince, M. (2009, July 28,2009). *Pesticide exposure and suicidal ideation in rural communities in Zhejiang province, China* [White paper]. Retrieved from Bulletin of the World Health Organization: http://www.who.int/bulletin/volumes/87/10/08-054122/en/print.html

Shared Medical Appointments: The Future for Cost Effective Comprehensive Patient Care Delivery by the Advanced Practice Nurse

Myra L. Thompson R.N. M.S. FNP
Bayshore Family Medicine
38505 Brooten Road
Pacific City, OR 97315
503-965-6555
Fax: 503-965-6800
Email: mthompson@bfmed.net
Oregon Health & Sciences University
School of Nursing

Case Study Submission - Publishable manuscript

Doctor of Nursing Practice degree

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Abstract

The dwindling supply of primary care providers just when they are critically needed is a challenge that can be partially met by the counterintuitive shared medical appointment model. This innovation has been around for several years and is a cost effective and rewarding approach to the delivery of value added primary care. 10-15 patients are sequentially interviewed, examined, and treated in a group setting very much like they would be in a typical individual appointment. The process is protected by confidentiality agreements that are signed at the beginning of each session. A team of four individuals including the provider, a behaviorist, a documenter, and a medical assistant are required to run each session which is highly organized and closely run to meet a 90 minute window of group time. While emphasis is placed on the delivery of medical care, there are expanded opportunities for patient education, counseling, group support, and health maintenance. Provider benefits include enhanced satisfaction with the quality and amount of care delivered and increased efficiency leveraging the benefits of group activities while meeting all criteria for appropriate coding and billing. Additional benefits accrued to patients include enhanced access, more time with their provider, opportunity for sharing health concerns in a group setting which has been found to be helpful on many levels.

Shared Medical Appointments: The Future for Cost Effective Comprehensive Patient Care Delivery by the Advanced Practice Nurse

Future Major Newspaper Headline
March 2014

"Advanced Nurse Practitioners have been successful in closing the patient/practitioner gap through the use of an innovative care delivery model giving many Americans now with medical insurance access to high quality and cost effective health care."

This is a fictional future newspaper quote but it is also a prediction from the Institutes of Medicine (IOM) report *The Future of Nursing: Leading Change, Advancing Health.* "Nurses have the opportunity to play a central role in transforming the health care system to create a more accessible, high-quality, and value-driven environment for patients" (Institute of Medicine, 2010, p. 3-1). By the year 2014 health care reform will allow an estimated 32 million to 38 million new patients to buy into health care coverage. This change is occurring while a *perfect storm* brews within our country's health care industry. There is already a shortage of primary care providers many of whom will be retiring and they are not being sufficiently replaced (Brook & Young, 2010) (Bodenheimer & Pham, 2010). This is all happening as the baby boomer generation requires mounting medical attention for escalating and largely preventable chronic diseases. As the need for primary care rapidly accelerates, the unanswered and critical question is, how will these already overworked practitioners manage to care for even more and, most likely sicker, patients?

Background of the Problem

Everyone in health care is frustrated. The metaphorical three legged health care stool of access, quality and cost control, is constantly tipping one way or another (Berwick, Nolan, & Whittington, 2008). Health care providers generally cannot deliver the personalized high quality patient care they would like. Patients often cannot get appointments when needed and when they do the typical 10-15 min office visit leaves them discouraged and feeling as if they have not really been treated at all. The following is a brief summary of a few of these problems from both the provider and the patient perspective.

Provider Concerns

In recent years there has been an ever increasing accumulation of challenges for primary care providers. The rising cost of health care is taking a correspondingly larger proportion of personal income rendering more and more individuals and families unable to afford health care. There is increasing demands of third party payers with aggressive denial for preexisting conditions, burgeoning prior authorizations required for an ever mounting number of procedures and consultations, restrictive drug formularies and, more time spent in the office by the provider to complete documentation for what in the past could simply be ordered or dispensed. This all leads to increasing pressure to spend less time with patients so that more patients can be seen to offset the escalating overhead from a multitude of competing arenas. There is a growing volume of telephone calls as the primary care providers' patient panel grows. The presence of registered nurses in the office is rare as most clinics hire less trained and qualified staff to help offset the high cost of personnel. The evolving critical decisions regarding electronic health records and the intrusive nature of the computer in the exam room are all perpetual challenges to providers.

Patient Concerns

From the perspective of the patient there are multiple frustrations that stem from an increasing sense of alienation from their provider because of the pressure of time. Patients are also faced with a bewildering maze of hoops and chutes that must be negotiated due to the requirements of third party payers. These difficulties perpetuate the ongoing challenge of gaining access to high quality health care when needed. The result is that a perpetual array of physical and psychosocial needs go unmet in the current brief individual office visit setting.

In the face of these problems, the practice of individualized office visits may become economically unsustainable and the use of innovative and disruptive models for patient care delivery will be essential. Harvard business school Professor Clayton Christensen defines a disruptive innovation as one that allows for greater access and convenience to the public use of a service with lower cost and acceptable quality outcomes (Christensen, Grossman, & Hwang, 2009). The advanced practice nurse (ANP) must look toward novel patient care delivery models to be a success in this rapidly changing environment. Dr. Mary Naylor and others believes that the increasing volume of advanced nurse practitioners strategically positions the ANP to positively change the course of primary care in America (Naylor & Kurtzman, 2010).

The Shared Medical Appointment model is a practical and tested solution that meets the demands of high patient volumes and cost effective high quality patient care while also producing a positive experience for both the practitioner and the patient.

What is a Shared Medical Appointment?

It is not easy to describe the Shared Medical Appointment (SMA) process. Intuitively it seems an inappropriate setting for the intimate processes that take place behind the exam room door. Who would want to discuss in a public setting their personal health issues? While there are, of course, some health care problems best left behind the door as individual appointments, these are fewer than expected.

This health care delivery model was developed and refined over the past 12 years by Edward B. Noffsinger, PhD, a practicing Clinical Psychologist. The SMA originated from his own experience as a patient and from his frustration with the health care system when dealing with his chronic and potentially life threatening medical condition. He has outlined two separate but related SMA models that are useful in a variety of patient care settings. Dr. Noffsinger has developed and refined these models from experience with 20,000 patient visits and over 400 different providers and presents these findings in a comprehensive text (Noffsinger, 2010).

Use of an electronic health record (EHR) is not absolutely essential but without one, concurrent documentation is nearly impossible. There are four essential people needed to conduct an SMA: the provider, documenter, behaviorist and the medical assistant or nurse. Cost savings occur when medical assistants are trained to document the visit, often from a standard template. The behaviorist position can be filled by any number of trained individuals from nutritionists to registered nurses. Ideally, to maintain the cost savings attributed to this model, persons who can charge for patient care delivery should do just that – see patients.

There are two versions for what is referred to in generic form as a Shared Medical Appointment, the drop in group and the physical shared medical appointments.

Definition of a Drop In Group Medical Appointment

The Drop In Group Medical Appointment, or DIGMA as it is often referred to, reduces the time patients have to wait for return follow-up visits and is helpful to get new patients into the clinic.

There are three types of DIGMAs, heterogeneous, homogeneous, and mixed, based upon the diagnoses or problems. Experience from hundreds of DIGMAs in a multitude of settings clearly supports the counterintuitive concept that the heterogeneous type is the most common and clearly the most beneficial. There are a number of reasons why this turns out to be the case but in general the reasons are patient, not provider driven. Newly minted providers frequently wish to limit the DIGMA to a specific diagnosis or related diagnoses, such as diabetes or cardiac patients, but experience has shown that over time group forces and practical issues push the DIGMA toward a heterogeneous format where a wide variety of problems including chronic diseases and acute illnesses are dealt with simultaneously. While the bulk of the patients for any given DIGMA session will be prescheduled, there is opportunity to "drop in" although notification at least a day ahead is encouraged. Same day appointments and walk-ins are a bit more challenging. DIGMAs are scheduled on a regular basis and can be monthly, biweekly, weekly, daily, and even more than once a day depending on the skill level and experience of the staff available to the provider and the size of the provider's panel of patients. Each DIGMA is an isolated event and has no continuity to previous DIGMAs. The patient/provider association remains unbroken just as it would for individual office visits.

A description of the flow of a single DIGMA session is the best jumping off point to understand how this model works and how it can create a more accessible, high-quality, and value-driven environment for patients and providers.

Pre-visit work.

- Several days prior to the session a medical assistant or nurse will call all patients scheduled to attend. The ideal size has been shown to be 10-16 patients with one support person allowed per patient. Providers must be willing to invite their patients and promote the program for it to be successful.
- All laboratory and diagnostic studies are obtained prior to the DIGMA and results are made available before the session.
- The provider may review the patient's chart prior to the DIGMA session.
- The group room and all IT infrastructures are assessed and deemed ready. Healthy refreshments have been purchased and are ready.

15-30 minutes prior to the start of session.

- The nurse or medical assistant writes down pre-visit laboratory results on a whiteboard next to the patient name, circling or writing all abnormal values in red.
- Early arrivals check in and receive a patient information packet, name tag and a confidentiality form to read and sign.
- Patients are taken to a separate room for vital signs and a review of current medications and allergies. Health maintenance information is reviewed and updated in the EHR. This intake activity continues until all patients have been processed or until the beginning of the session.
- The behaviorist arrives about 15 minutes ahead of the scheduled session to welcome patients and make them comfortable. Each patient is asked what their primary concerns are for that day and these are written on a separate board next to the patient's name. Patients are invited to enjoy healthy refreshments at any time during the session.

The 90 minute session begins.

- The behaviorist begins with a three-five minute introduction reviewing the nature of the SMA visit and what to expect. Privacy expectations are stressed and confidentiality forms are signed and returned at each session. Patients are invited to share the general health information they learn with family members and others but they must not discuss individual patients by name. The behaviorist also finds out if anyone needs to leave early.
- The provider arrives after most of the preliminary activity has been completed and greets the group. There is no set order for seeing patients but often it is a "first come first served" process. The behaviorist generally alerts the provider as to which patients need to

leave early and may help direct the order in which patients need to be seen. One vital role of the behaviorist is to subtly serve as a timekeeper for the provider. From this point on, the group dynamic is rather fluid as patients may be quietly led out of the room for the taking of vital signs and other intake activity. It is surprising how unobtrusive and effortless this in and out flow of patients can occur. The provider may or may not use a computer to view the patient's EHR, but if used, it is quickly accessed and the computer does not get between the patient and the provider. The remainder of the time is spent giving one on one medical care with the taking of pertinent history, review of systems, physical exam, counseling, medical decision-making, and a treatment plan just like what occurs in an individual appointment except that it is witnessed/shared by all in the group. Issues of a very personal or private nature are not generally discussed. The provider completes an appropriate exam unless disrobing is required. Private time with the provider will occur only if needed toward the end of the session and usually is not needed for more than two -three patients if any at all. Providers must resist the temptation to turn this into a private appointment.

- There is a dedicated documenter who, while listening to the provider, notes the history of the presenting illness (HPI) and review of systems, updates the history, documents the exam as verbalized, records the plan of care and creates a patient instruction sheet within the electronic medical record. When the provider has completed the face to face time, attention is turned to the record which is reviewed, edited and completed, all of which generally takes less than a minute or two. While this is occurring, the behaviorist takes over the group and continues to keep the focus on the current patient and related issues. Once the provider is finished with the medical record they immediately proceed to the next patient, continuing the same process. During the exam there may be active participation by group members who offer personal comments or suggestions to the patient being examined.

- During the time spent with each patient there will be opportunities for education just as in an individual appointment, but extensive formal patient education is not done by the provider during the DIGMA because the time is truly dedicated to the delivery of medical care. This is what allows the provider to be 200-300% more productive during this time. The provider and behaviorist must monitor the duration of each encounter so as to not exceed the time limit. Stopping on time is just as important as starting on time.
- At the close of the session, the provider leaves the group area promptly but the behaviorist and medical assistant stays by for 10-15 minutes to dismiss the patients. They are encouraged to make their next appointment for a DIGMA and staff is available for scheduling. Patients often make return DIGMA appointments just as they did for individual office visits.

Definition of a Physicals Shared Medical Appointment

The Physicals Shared Medical Appointment, or PSMA as it is commonly referred to, shares many of the major elements of a DIGMA. They are often used for heterogeneous diagnoses such as well adult exams or sub-specialty diagnoses. The sessions flow a little differently. When patients arrive intake (vital signs, history, medication review, allergies and health maintenance) is completed and they are placed in an exam room. Ideally at least four exam rooms are available in close proximity to the group session room. The behaviorist works in the group room while the provider quickly moves through the exam rooms completing the individual physical exams generally in about seven-eight minutes per patient **without** much education or treatment plan development unless a major physical finding is discovered and then the patient is treated as if it is an individual exam. The first one half of the 90 minute session is spent with patients flowing in and out of exam rooms with the behaviorist working in the group room and the provider conducting the physical exams. Once all the exams are completed the group stays together for the remainder of the shared group experience. The provider then addresses each patient individually to complete their treatment plan, answer any questions and to provide needed patient education which is often applicable to the whole group.

Benefits of SMA’s

From the provider’s standpoint costs are controlled by creating a “one-stop healthcare shopping experience.” There is an increase in efficiency, productivity, and access with better opportunity for increased patient education, health maintenance, and chronic disease management. The psychosocial needs of the patients can be met through interaction with team members and other attendees. There is a return to a high level of personal and professional satisfaction with improved job performance on the part of the provider. The patient care team experiences enhanced cohesion and participation with an increase in job satisfaction. This care model can renew the doctor-patient relationship that has been so seriously eroded in recent decades.

Patients gain greater access to their provider during the 90 minutes. They experience a high level of nuanced care that is comprehensive and individualized despite the fact that it is provided in a group setting. Patients have increased and prompt access to care due to the “drop-in” nature of group appointments. They experience empathy, support, and understanding from other group attendees and are often motivated and encouraged by the experience and contributions of other attendees. The concept of empathetic listening may be a positive force during these visits. Dr. Eric Cassel, noted physician and medical bioethicist explains how one person can lend strength to another which allows for the creation of personal meaning (Cassel, 1982). The opportunity to tell their story and to hear other patient's stories may be key to the comforting and meaningful experience patients generally gain from the SMA. They also receive broad patient education in areas where they might not have thought to ask questions. The SMA team often hears from patients, "I never thought to ask that question".

The financial benefits become readily apparent when comparing the income that is typical from seeing five to six patients during 90 minutes to the 10-15 patients that can easily be seen in an equivalent time via the SMA model.   The intensity of service for SMA patients are usually a level three and often reach a level four depending on the number and complexity of the problems addressed, the documented exam, and the accompanying treatment plan. For many practitioners it is a "priceless" event to leave the office with all their patient charts well documented and closed.

All of these benefits lead to less provider and staff burn out thus increasing the primary care delivery capacities for our communities.

Potential Adverse Outcomes of SMA's

One adverse outcome of this model may be that patients feel like their care is being diluted and they cannot see a personal benefit in this model. They may see this as a "money making scheme" instead of a value added encounter. Clinic staff must understand that the SMA model is not a substitute care system but just another choice for patients who may find the proactive healthcare experience beneficial.

Summary

It is hard to argue against a program that creates an accessible, high-quality, and value-driven environment for patients and for providers. Dr. Neuwirth, Chief of Clinical Effectiveness and Innovation at Harvard Vanguard Medical Associates/Atrius Health states that “the SMA represents a more organized way to deliver high-quality ambulatory medical care . . . it creates a community of caring within each patient visit and changes the story of the patient from one of isolation frustration and fear to hope, dignity, community, and empowerment” (Neuwirth, 2010, p. xvii). While the effect of the SMA creates a healing setting for patients it also has a secondary healing effect for the practitioner.

As one of those aging and tired front line primary care providers it would be a relief to see the actual headlines proclaiming how the advanced practice nurse has helped to close the enormous patient/practitioner gap through the use of the Shared Medical Appointment care delivery model.

Author's Note

I would like to gratefully acknowledge the Shared Medical Appointments team members at Harvard Vanguard Medical Associates/Atrius Health, Boston, MA. They generously shared all aspects of their knowledge of the SMA process over 4 long days and made me feel welcome every second of the time. Special thanks to Deb Prescott, Program Manager, Shared Medical Appointments, who graciously took my late night call and set up this experience and answered all my questions and the many I did not know to ask.

References

Berwick, D. M., Nolan, T. W., & Whittington, J. (2008). The triple aim: care, health, and cost. *Health Affairs*, 27(3):759-769.

Bodenheimer, T., & Pham, H. H. (2010). Primary care: Current problems and proposed solutions. *Health Affairs*, *29(5*):, 799-805.

Brook, R. H., & Young, R. T. (2010). The primary care physician and health care reform. *JAMA*, 303(15), 1535-36.

Cassel, E. J. (1982). The nature of suffering and the goals of medicine. *New England Journal of Medicine*, 306(11): 639-645.

Christensen, C. M., Grossman, J. H., & Hwang, J. (2009). *The innovator's prescription: A disruptive solution for health care*. New York: McGraw Hill.

Institute of Medicine. (2010). *The future of nursing: Leading change, advancing health*. Washington, DC: U.S. Government Printing Office

Naylor, M. D., & Kurtzman, E. T. (2010). The role of nurse practitioners in reinventing primary care. *Health Affairs*, 29(5):893-899.

Neuwirth, Z. E. (2010). Noffsinger, E.B. author. Foreword:. *Running group visits in your practice* (pp. vii-xix). New York: Springer.

Noffsinger, E. B. (2010). *Running group visits in your practice*. New York: Springer.

Acute Decompensating Aortic Stenosis in the Rural Clinic: How Consistently Applied Office Policies Protect Both the Patient and Provider

Myra L. Thompson R.N. MS FNP

Oregon Health & Sciences University

School of Nursing

Case Study Submission for the Doctor of Nursing Practice degree

Advisor: Deborah Messecar PhD, MPH, R.N., GCNS-BC

Clinical Mentor: Lyle J. Fagnan M.D.

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Acute Decompensating Aortic Stenosis in the Rural Clinic: How Consistently Applied Office Policies Protect Both the Patient and Provider

Acute decompensating aortic stenosis is not commonly diagnosed in the rural primary care clinic. Generally these patients present to the emergency room with acute symptoms or die suddenly outside of health care settings. This case study describes a patient with severe life threatening decompensating aortic stenosis diagnosed by the advanced practice nurse (APN) in a rural health clinic and reviews the essential office policies that may have saved his life.

Clinical Background

Aortic Valve Physiology

The aortic valve is situated between the left ventricle and the aorta and is normally composed of three leaflets. Blood flows through the heart by pressure changes from one area to another. The pressure gradient is an expression of the pressure (mmHg) that is necessary for movement of blood through a vessel or across a valve. At any given pressure gradient, the actual flow rate is determined by the resistance to that flow. The factors determining the resistance are described by the *Poiseuille relationship*. The three factors described in this law affecting blood flow are: vessel length, vessel diameter or radius, and blood viscosity. Of these three factors the most important physiologically is vessel diameter. The pressure gradient across a physiologically normal aortic valve during ejection is minimal; however the presence of aortic stenosis greatly increases the pressure gradient to restriction of blood flow by the diseased valve.

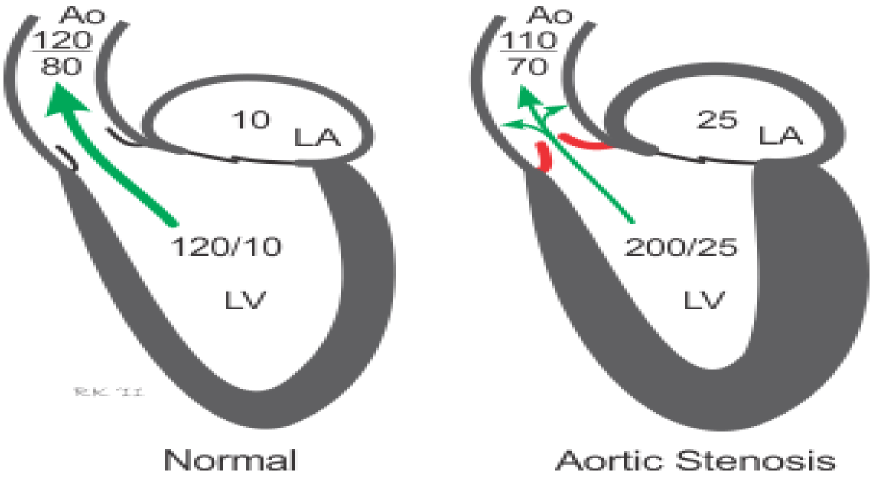

Figure 1 Diagram of intra-cardiac pressures with normal physiology and with aortic stenosis (http://www.cvphysiology.com/Heart%20Disease/HD004.htm)

Aortic Valvular Disease

Any one of the four cardiac valves can become diseased from either a congenital abnormality or during a person's lifetime. The aortic valve can become restrictive to flow and is referred to as stenotic. When the valve leaks it is termed insufficient, regurgitating or incompetent. The causes for these valve diseases are by and large well understood but in some cases the etiology is never discovered.

Congenital aortic valve disease. Congenital heart valve disease more commonly affects the pulmonary and aortic valves when they improperly develop into the wrong size, configuration, or do not attach properly. In the case of the aortic valve, the most common congenital valve abnormality is the bicuspid valve.

***Bicuspid aortic valve* (*BAV*).** This is a defect of the aortic valve that results in the formation of two leaflets or cusps instead of the normal three. This aortic valve congenital abnormality occurs in approximately one percent of the general population (Jashari, Van Hoeck, Goffin, & Vanderkelen, 2009).

Acquired valvular disease. This refers to other, generally infective disorders, which damage formerly normal valves. Rheumatic fever, once a significant contributor to aortic valve disease, has been dramatically reduced by better diagnosis of group A beta-hemolytic streptococcal infections and the use of antibiotics (Lee & Wessels, 2006) (Gerber et al., 2009). Bacterial endocarditis can damage the aortic valve causing scarring and holes which cause either regurgitation or stenosis. Acute cardiac events such as papillary muscle rupture from a myocardial infarction can cause life-threatening cardiac valve regurgitation with loss of cardiac output and death.

Risk factors for acquired valvular disease. They are very similar to the risk factors associated with heart disease in general. They are age, unhealthy blood cholesterol levels, high blood pressure, smoking, insulin resistance, diabetes, overweight and obesity, lack of physical activity, and a family history of early heart disease. Otto (1997) et al has shown that "risk factor studies suggest that progression of degenerative valvular aortic stenosis may be related to clinical factors such as serum lipid levels or smoking" (Otto et al., 1997, p.2269). Exceptions are the risk factors for endocarditis such as intravenous drug use and/or hospital nosocomial infections resulting in bacterial sepsis.

Clinical Problem

Mr. DH* is a 57 year old Caucasian male who called the rural clinic on March 3, 2011, requesting antibiotics for his "cold". This was denied and the patient was offered a same day appointment which he declined. On March 4, he called again now asking to be seen.

*all identifying features have been removed, including the actual dates of service. To better illustrate the progression of this clinical problem alternate dates have been inserted

His usual physician was not in the clinic that day, and he was seen by the APN. He was accompanied to the office visit by his wife.

Past Medical History

This patient has had a long history of anxiety, hyperlipidemia, and was rarely symptomatic with chronic obstructive pulmonary disease. He recalled being told he had a murmur when he about 30 years old. He denied problems with hypertension and had no history of rheumatic fever. The presence of his murmur was noted in the clinic notes, but because of his insurance situation this has never been worked up at the patient's request.

Surgical History

Mr.DH had a tonsillectomy as a child and a lumbar laminectomy in 1985.

Medications

He takes simvastatin daily and alprazolam twice daily. He uses albuterol inhalers for occasional shortness of breath and oxycodone on rare occasions for musculoskeletal pain.

Family History

His father is alive at age 84 with a history of coronary artery disease and acute myocardial infarction at age 82. His mother died at age 72 with Alzheimer's; his three siblings are alive and in good health.

Habits

Mr. DH admitted to a 44 year history of smoking one pack of cigarettes a day. He had been counseled regarding the importance of quitting but had not done so. He also admitted to drinking two to four beers a day but denied use of hard liquor. There was no current or past use of illicit drugs, specifically no intravenous drug use.

Social

The patient is married and works full time as a painting contractor. He does not have medical insurance and this has contributed to his medical noncompliance in the past.

History of Present Illness

His chief complaint was a two day history of upper chest and neck fullness and upper respiratory congestion and shortness of breath. He denied fever, sweats, chills and pain with breathing. There was no facial pain, nasal discharge and he denied swelling of his feet or ankles. No gastroenterology symptoms such as difficulty swallowing, heart burn, nausea, diarrhea or changes in bowels were found. There were no recent falls or other trauma. He stated he was sleeping well. He used Tums and aspirin for two days without relief of symptoms. He denied syncope but did admit to occasional dizziness over the preceding two days, “Sometimes I feel like I am going to pass out”.

Objective findings

The following office note details the physical findings.

BMI: 30.9. BP: 100/60. H: 69.5 in. W: 213.0 lbs. P: 90 and irregular RR:18 Sa02 97% room air.

GEN: 57 year old white male in no acute distress. He drove himself to the clinic and is here today with wife. Ambulates into room without problems and not obviously short of breath. Able to converse without difficulty.

HEENT :
* TMs and canals are clear.
* Pharynx is not injected and there are no oral lesions.
* Nasal passages are clear. Facial swelling is not noted.
No pain to palpation over sinuses bilaterally
NECK :
* There is no cervical lymph node enlargement, masses, or tenderness. There is a slight fullness over the left anterior left neck from above the clavicle to mid neck. Significant left carotid bruit or transmitted murmur heard.
* There is no noted thyroid enlargement.
LUNGS :
* Breath sounds are clear and equal bilaterally with good exchange.
* Respiratory effort is normal.
CARDIOVASCULAR :
* Rate and rhythm is irregular with rates between 80-100 Significant holo-systolic murmur grade 5/6 No thrill noted.

* Extremities show no clubbing cyanosis or edema. (unable to obtain an EKG: at this time)
ABDOMEN :
* Palpation shows no significant tenderness or masses. Bowel sounds are normal.
* There is no hepatosplenomegaly.
20min discussion re: the need for immediate follow-up re: this significant murmur. Both the patient and wife are reluctant to go to the hospital as they do not have insurance. I advised the wife she should drive and take him directly to the emergency room. They have agreed to this plan. After the patient left the clinic, Dr. XX in the emergency room was called and given a report of these findings. Call also placed to resp. therapy to seek an urgent ECHO while the patient is in the emergency room. Echo tech states he will follow up and work with the ER staff to get this exam done.

Clinical Course and Outcome

Mr. DH was seen and evaluated in the local hospital emergency room where the electrocardiogram and the cardiac echocardiogram revealed severe decompensating aortic stenosis and the presence of a severely thickened bicuspid aortic valve. He was transferred urgently to tertiary care for specialty cardiac and surgical services not available in the rural community.

Mr. DH underwent aortic valve replacement with a #25 Carpentier-Edwards pericardial bioprosthesis on March 5, 2011. He remained hospitalized for 12 days and was treated for complications of pneumothorax and third degree heart block requiring a permanent pacemaker. Presently, his primary care physician reports he is doing well, that he has stopped smoking, and is expected to return to full function when recover is complete.

Clinical Significance

Several important lessons crucial to high quality rural primary care delivery are highlighted in this case study. First and foremost is the policy of not prescribing medications for patients who have not been seen by a provider. While at times a good case can be made for “bending the rules”, for example, the patient was just seen for the problem and is well known by the provider, it is not uncommon that either the provider or the patient pays a stiff price for such deviations. In this case study, if the office had granted Mr. DH’s request for antibiotics his condition would have likely worsened and he could have died suddenly at home or in the local emergency room. Establishing intra-clinic policies that discourage treating patients over the phone are important for a well run and safe organization. The rural clinic in this case study adopted this policy many years ago and every new patient is given a 19 page printed office brochure outlining office policies. In the chapter titled, *After hours, Emergency and Hospital Care,* patients find,

> The telephone is a great help in your care, but it can also be a challenge. At times, what seems to be a simple problem cannot be properly managed without being seen. Things are not always as they appear and quality care cannot be provided by telephone alone. We do not prescribe antibiotics or order x-rays without an appointment (Thompson, 2004, p.13).

Another important lesson is that the excellent primary care provider must develop consistent patterns of behavior and decision making that always put the safety of the patient first despite countless demands that intrude on these judgments. One way providers can be lured into poor decisions is to overly sympathize with the patients' financial concerns and create diagnostic or treatment "short-cuts", exposing them and their patients to potentially disastrous outcomes. Stories abound in health care circles of missed meningitis, fractures or other serious problems all for a lack of critical review and judgment on the part of the provider. Primary care providers are constantly faced with the tension of treating either the no insurance and/or the under-insured patients who needs our attention, treatments and drugs. Health care is enormously expensive and it is very important that providers make every health care dollar count. Needless tests and treatments contribute to increased health care costs and miss an opportunity to educate the patient in what is appropriate, however, missing the **one** test or exam that will clinch the diagnosis can end in tragedy. Balancing the issues of cost and critically important tests and interventions is a daily challenge. In the case of Mr. DH, he was fortunate to have gotten the necessary treatment at the time of his most critical need. In retrospect, this would have been difficult to accomplish under ordinary circumstances without the added urgency of a life threatening situation. No provider or health care organization willfully withholds lifesaving treatment, but for many other less urgent conditions, patients, and occasionally providers are culpable for rising health care costs due to poor outcomes when early warning signs are ignored.

The rapidly rising cost of health care is particularly destructive to middle class America. The Harvard School of Business has been studying the frequency of medical bankruptcies for over a decade. In 2001 they found that 46% of all bankruptcies in the five states studied were a result of excessive medical expenses. In 2007, they found that medical bankruptcy rose to 62% of all bankruptcies and 3/4th of these bankruptcies occurred in middle class medically insured households (Himmelstein, Thorne, Warren, & Woolhandler, 2009). This form of impoverishment is becoming exceedingly common for the middle class and it is especially severe in rural America where there are larger numbers of older, uninsured, or under-insured citizens (Ziller, Coburn, & Yousefian, 2006).

The rural primary provider faces multiple challenges from all directions in our health environment. Beauchamp and Childress (2009) believe that some forms of beneficence are essential to ethical patient care. They state that “morality requires not only that we treat persons autonomously and refrain from harming them, but also that we contribute to their welfare” (Beauchamp & Childress, 2009, p. 197). Every provider has the authority and social obligation to make patient centered decisions within their own practice setting. As in any relationship, the only power we really hold is the power to be in charge of our own decisions and actions.

References

Beauchamp, T. L., & Childress, J. F. (2009). *Principles of biomedical ethics* (6th ed.). New York: Oxford University Press.

Gerber, M. A., Baltimore, R. S., Eaton, C. B., Gewitz, M., Rowley, A. H., Shulman, S. T., & Taubert, K. A. (2009). Prevention of rheumatic fever and diagnosis and treatment of acute streptococcal pharyngitis. *Circulation*, *119*, 1541-1551.

Himmelstein, D., Thorne, D., Warren, E., & Woolhandler, S. (2009, August). Medical bankruptcy in the United States, 2007: Results of a national study. *The American Journal of Medicine*, *122(8*), 741-746.

Jashari, R., Van Hoeck, B., Goffin, Y., & Vanderkelen, A. (2009, May). The incidence of congenital bicuspid or bileaflet and quadricuspid or quadrileaflet arterial valves in 3,861 donor hearts in the European Homograft Bank. *J Heart Valve Dis*, *18(3*), 337-344.

Lee, G. M., & Wessels, M. R. (2006). Changing epidemiology of acutge rheumatic fever in the United States. *Clin Infect Dis, 42*, 448-450.

Otto, C. A., Burwash, I. G., Legget, M. E., Munt, B. I., Fujioka, M., Healy, N. L., ... Schwaegler, R. G. (1997). Prospective study of asymptomatic valvular aortic stenosis: Clinical echocardiogram and exercise predictors of outcome. *Circulation, 95*, 2262-2270.

Thompson, A. P. (2004). *Bayshore Family Medicine New Patient Brochure*. Unpublished manuscript.

Ziller, E. C., Coburn, A. F., & Yousefian, A. E. (2006). Health spending and the rural underinsured. *Health Affairs, 25(6*), 1688-1699.

Chronic Lyme Disease: Sorting Fact from Fiction from the Front Line

Myra L. Thompson R.N. M.S. FNP

Oregon Health & Science University

School of Nursing

Case Study Submission for the Doctor of Nursing Practice degree

Advisor: Deborah Messecar PhD, MPH, R.N., GCNS-BC

Chronic Lyme Disease: Sorting Fact from Fiction from the Front Line

Lyme disease is the most common vector-borne disease in the United States. This disease has significant physical manifestations, yet for most patients its' emotional toil may be just as debilitating as the disease itself. This case study reviews a patient with Lyme disease and her rural advanced nurse practitioner, describing their journey through a confusing labyrinth of medical specialists and treatments. The lessons learned from this case study may help other practitioners who are faced with a sick patient, no clear diagnosis, and a maze of conflicting information that pits evidenced based medical science against well structured and passionate citizens and fringe medical organizations.

Lyme Update

Lyme disease was named in 1977 following an unusual outbreak of arthritis in New Lyme, Connecticut when physicians reported a cluster of 39 patients with mysterious arthritic symptoms (Steere, et al., 1977). This prompted a serious investigation and the spirochete, *Borrelia burgdorferi*, was discovered in 1984 by Dr. Willi Burgdorfer to be the causal organism. A tiny deer tick no larger than a poppy seed transmits the spirochete to humans through a bite.

Acute Lyme Disease

Acute Lyme disease, also known as early localized Lyme disease, occurs within the first month after infection. Erythema migrans, known as the "bull's-eye-rash" is taught to providers as the hallmark diagnostic sign. Unfortunately, this rash is not evident in about 50% of patients bitten by the infected tick (Lautin, McNeil, Liegner, Stricker, & Sigal, 2002). This missed diagnostic clue means that many patients do not receive urgent first line antibiotic treatments. The Infectious Diseases Society of America (IDSA) developed guidelines that are generally adopted by mainstream infectious disease practitioners (Wormser et al., 2006). These guidelines outline in detail early management of Lyme disease but pointedly dismiss the existence of chronic Lyme disease. Many patients believe that delays in treatment, or under treatment, have left them with what they believe is chronic Lyme disease.

Chronic Lyme Disease

Chronic disseminated Lyme disease, or as named by the IDSA, presumed post-Lyme disease, is characterized by such wide-spread and diverse symptoms as headache, myalgia, joint pain, low-grade fever, and neurological symptoms including cognitive impairment, The existence of chronic Lyme disease is sharply debated. The chronic manifestation of Lyme disease is not recognized by the IDSA or by many conventional medical practitioners. The vague nature of these on-going symptoms without objective physical or laboratory findings closes the door in their opinion to accepting this as a “real” disorder. Johnson & Feder (2010) recently surveyed 285 primary care physicians in Connecticut to determine regional treatment patterns for their patients with chronic Lyme disease (Johnson & Feder, 2010). They found that only 2.1% of these physicians diagnose or treat patients for presumed chronic Lyme disease. Dr’s Johnson and Feder’s research concluded that in Connecticut, a state that is highly literate about Lyme disease, 49.8% of all primary care physicians do not believe in the existence of chronic Lyme disease. Dr. Savely, (2008) a chronic Lyme disease advocate and clinician states “the philosophy of the Infections Diseases Society of America (ISDA) is that Lyme disease is rare, difficult to contract, and straightforward to cure” (Savely, 2008, p. 236). This captures the essence of the current medical melee and the increasingly fierce and political debate over chronic Lyme disease.

Incidence of Lyme Disease in the United States and Oregon

The Centers for Disease Control (CDC) reports the incidence of Lyme disease as this is a reportable disease in all 50 states. It is clear by the following figure that the eastern seaboard has far more diagnoses than the mid and western states.

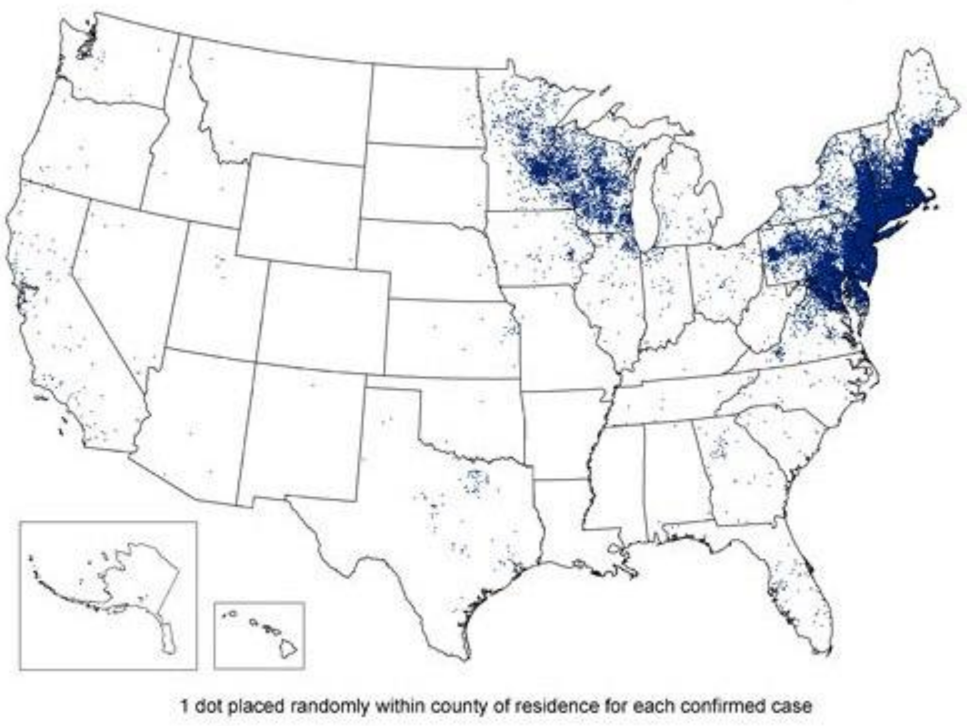

***Figure* 1. State by state reporting of incidence of Lyme disease from the CDC 2009**

Retrieved from: http://www.cdc.gov/ncidod/dvbid/lyme/ld_Incidence.htm

In the USA, endemic foci exist along the Atlantic coast concentrated from Massachusetts to Maryland, in the upper Midwest in an expanding focus moving toward the West to California, Oregon and Washington. Data from 2008 show that the average reported annual incidence of Lyme disease per 100,000 population during 2003 to 2005 in 10 northeastern and upper Midwest reference states was 29.2 (Centers for Disease Prevention and Control, 2007). Contrast this 29.2

per 100,000 population data with Oregon’s same three year average of 0.84 per 100,000 populations and it appears that Oregon is relatively free of Lyme disease (Doggett et al., 2008).

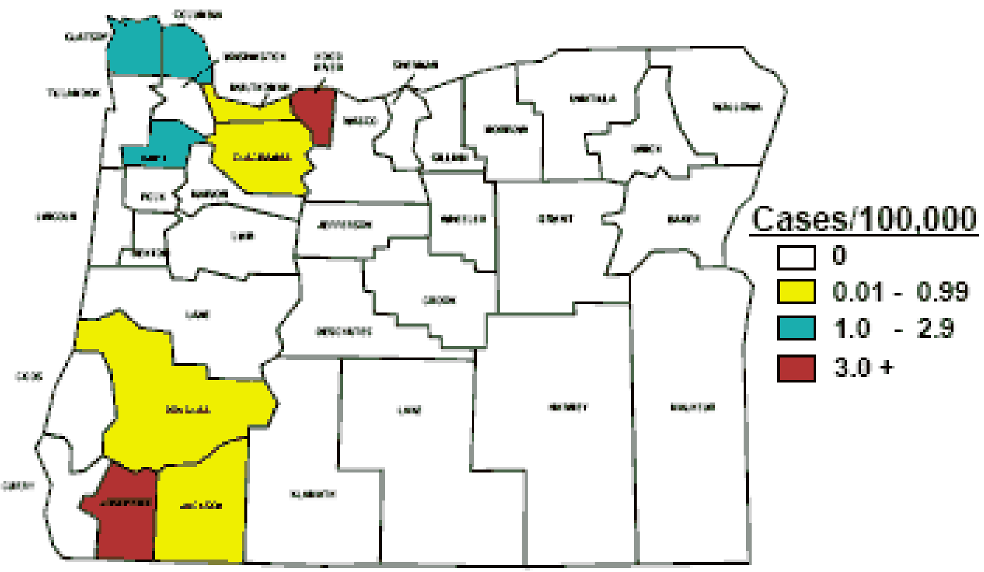

Figure 2. **Oregon State Incidence of Lyme Disease by County, 2002** (Doggett et al.,2008)

Three counties in the southwestern part of the state and those along the Columbia River have reported the majority of the cases found in Oregon (Doggett et al., 2008).

Tick-borne Co-infections

Lyme disease is a serious tick-borne infection but it is not the only deadly infection transmitted from tick bites. Scientists now recognize more than a dozen tick-borne diseases in the United States and new ones are still being discovered. Ticks usually carry more than one bacterium. This occurs as the tick feeds on wild life in their region causing multiple deadly bacteria to thrive in their gut exposing the human victim to numerous bacterial infections. Some of the more common of these co-infections are:

Babesia: Babesiosis is an infection caused by a malaria-like parasite that infects red blood cells.

Ehrlichia: Ehrlichiosis is caused by tick-borne rickettsial parasites called Ehrlichia that infect the monocytes (human monocyctic ehrlichiosis *HME)* or the granulocytes (human granulocyctic ehrlichiosis *HGE*). The later was renamed anaplasmosis in 2003.

Bartonella: Bartonella henselae causes a serious infection that has previously been thought to be is mainly carried by cats (cat-scratch fever) and which causes endocarditis, and several other serious diseases. It is now known that ticks, lice and fleas carry this bacterium.

There are many more actual and suspected tick-borne diseases. Practical and helpful information for the clinician who is trying to sort through potential co-infections from tick bites can be found at *lymedisease.org* web site (http://www.lymedisease.org/pdf/coinfections.pdf).

Chronic Lyme Disease Controversy - an Overview

The CDC's clinical criteria for Lyme disease are quite narrowly defined. This ensures a high degree of specificity in the diagnoses. The IDSA, with over 8,000 physician members, generally sets the accepted medical standards for infectious diseases in the United States. Both the CDC and the IDSA have clear guidelines for treating the acute phase of Lyme disease, which includes oral antibiotics with consideration for a short course of IV antibiotics. After these few weeks of aggressive treatment both organizations pronounce the patient as cured from Lyme disease.

There are a number of medical providers and concerned citizens who feel that in some cases the bacteria remain and produce multiple chronic ailments that can wax, wane , and linger for years. These “Lyme literate” practitioners and citizens organized in 1999 to create The International Lyme and Associated Diseases Society (ILADS). This non-profit group advocates for greater acceptance of the controversial medical diagnosis of chronic Lyme disease, and to disallow state medical board discrimination for practitioners who provide long term medication management and treatment for chronic Lyme disease patients.

These groups differ in the scope of their interpretation of chronic Lyme disease. The first group has a narrow view that require clear cut objective data while the second group believes that when resolution of symptoms occurs following antibiotic therapy absolute diagnostic criteria is unnecessary. They believe that erring on the side of treating patients with probable Lyme disease helps people who otherwise would not get treatment. ISDA members argue on the other hand, that it is dangerous to use prolonged IV antibiotic therapy. “The prospective, controlled clinical trials of extended antibiotic treatment of Lyme disease have demonstrated considerable risk of harm, including potentially life-threatening adverse events, attributable both to antibiotic treatment and to intravascular access devices” (Lantos et al., 2010, p. 3). Both sets of clinicians may be practicing medicine in a reasonable fashion based on the application of certain diagnostic principles. The therapeutic approaches differ considerably however, when viewed from a perceptive of the narrow vs. the broad criteria for diagnosis.

The internet and other sources fuel "Lyme Wars," which has ignited a debate on the true nature and threat of the country's most common insect-spread disease. Many angered and concerned patients, families and practitioners are taking this controversy straight to their government. Vitriolic debates have been heard in the Connecticut, New Hampshire, California and other state houses in an attempt to pass legislation to free providers to treat Lyme disease as they see fit (Lantos et al., 2010). One side feels like they are fighting **for** their lives, the other side believes they are fighting to **protect** life. Dr. Raphael Stricker (Stricker, Lautin, & Burrascano, 2005) a well known Lyme disease researcher outlines the salient controversial science and politics of Lyme disease, concluding that “the optimal antibiotic regimen for chronic Lyme disease remains to be determined” (Stricker et al., 2005, p. 1).

Case Presentation

Ms. NS is a middle-aged Caucasian female who lived for many years in Sonoma County, California on ten acres of wooded land with her many animals. In July, 1997 she recalls a large red round and raised rash on her right calf in mid July 1997. Believing this was spider bite she did not seek medical attention. Two weeks later she experienced intense flu like symptoms, lasting for two days with lingering malaise, muscle and joint pain. Ms. NS continued to work full time as a masters prepared marriage and family counselor, but she was finding it harder to manage her workload due to the fatigue and fleeting episodes of confusion. One evening in mid December 1998, Ms. NS noticed that her sense of smell has disappeared. By the next day her right knee became so swollen and painful that it was difficult to walk. She was seen by an advanced nurse practitioner who obtained knee synovial fluid which showed a 137,000 white blood cell count. No follow up call or appointment was made and the symptoms worsened till she presented to the local emergency department on December 31, 1998 where she was placed on antibiotics for a “badly infected knee”. At a follow-up appointment in January 1999, the patient asked her primary care provider (PCP) for blood work to rule out Lyme disease. Since her initial illness in July of 1997, she had been exhaustively trying to find a diagnosis and Lyme disease seemed to fit her symptoms. Ms. NS tested serology positive (enzyme-linked immunosorbent assay ELISA, followed up by Western Blot) for *B burgdorferi* and she was placed on three weeks of Doxycycline and pronounced “cured”. Two months later in March of 1999, without relief of symptoms and after discovering numerous patient-driven web sites and organizations describing the symptoms of chronic Lyme disease Ms. NS went back to her PCP and asked for more antibiotics. She was then sent by referral to an infectious disease specialist who told her “that’s all we can do for you”. Ms. NS’s symptoms worsened with complaints of numbness both hands and feet, persistent cognitive disturbances, blurred vision, anorexia, insomnia and tinnitus. After feeling abandoned by her PCP and mainstream medicine she sought medical care in a variety of disciplines such as, chiropractors and naturopathic physicians. She found a Chiropractor who partnered with a medical provider and she received four weeks of two grams ceftriaxone intravenously (IV) daily for four weeks in April 1999. Ms. NS’s symptoms improved following the month of IV antibiotics and she felt “almost like my old self”. Six months later her symptoms returned with such severity that she had to resign from work and live on her disability insurance income and was eventually was awarded Medicare disability in 2001.

Ms. NS and her partner moved to Oregon in 2002 and she was first seen by this rural FNP in September 2005. She had seen two local rural family medicine physicians and had been referred to and seen by an infectious disease (ID) specialist. The patient brought multiple previous medical records and laboratory findings to this first visit including the summary of her visit with the ID physician. In the conclusion of this report, the ID physician stated that he believed she had “late disseminated Lyme disease but that she had received the recommended treatment and no further treatment is recommended at this time”.

Medication list: Wellbutrin XL 300mg one by mouth daily, Vicodin 5/500mg one by mouth twice daily as needed, Tizanidine 2mg one by mouth at bedtime, Gabapentin 600mg one by mouth at bedtime. Occasional multi-vitamins, Omega 3’s and blended vegetable drinks.

Past Medical History: Seasonal allergies well controlled with over the counter medications, Moderate depression since 2005.

Family History: Father died age 73 from renal carcinoma, Mother died age 54 from acute myocardial infarction, one brother age 46 in good health.

Habits: No smoking (never) no use of alcohol, no use of illicit drugs or marijuana.

Surgical History: Tubal ligation

Social: Gravida 0 Para 0, present partner for 20 years

Chief Complaint: As taken from her medical record on her first visit dated 9/21/2005, "Still with 'brain fogginess' having a hard time completing sentences, decreased sense of smell, pain, swelling and stiffness all major joints – hips, knees and ankles. Difficulty with walking. Significant fatigue, cannot spend more than a few hours in a car without feeling ill. Feels like I 'cannot function at all and I used to work full time' Depressed but denies suicidal ideation"

Objective: Ms. NS appeared to be a good historian is pleasant and eager to find help for her complaints. She appears somewhat thin and her affect is fairly subdued. Wt: 149 BP: 108/66 P: 72 RR: 18 T: 98.2 oral. Physical exam was unremarkable.

Plan: During the 60 minute new patient appointment it was agreed that the FNP would investigate chronic Lyme disease and that Ms. NS would agree to see an infectious disease expert to collaborate with the FNP for her on-going care.

Summary: Over the next three months the rural clinic made repeated calls and faxed requests for an infectious disease consult. Two tertiary clinics refused to see the patient and finally after four months of effort the FNP was able to make an appointment for the patient at the state's leading teaching hospital. Two days before the appointment the rural clinic received a fax from the university saying "We are unable to see this patient in referral as 'Dr. X' does not believe in the existence of chronic Lyme disease". At this point, Ms. NS's symptoms had exacerbated to such a degree that she had not left her house except for medical appointments in over three months.

Over the course of the next year, the FNP and the patient worked closely to manage her symptoms and in late 2006 Ms. NS brought to the office the name and website of a Lyme disease specialist ("Lyme literate") she had found on a patient support website. The rural FNP researched the provider and communicated by email and phone with this clinician and arrangements were made to have the patient be seen in her office in San Francisco California in January 2007. At this visit, the provider tested Ms. NS for Lyme and co-infections finding that she persisted with Lyme disease and was positive for Babesia. The recommended treatment was long-term IV antibiotic therapy. After conferring by email and following receipt of the consultation note, the rural FNP felt comfortable to order a PICC line placed and daily IV ceftriaxone. Ms. NS is currently in her third year of alternating IV and oral antibiotics with regular antibiotic "holidays". She completes regular blood counts (CBC) and chemistries (CMP) every two weeks without any abnormal findings. She continues to see the Lyme specialist yearly and the rural FNP every three months.

In summary, while this patient has not improved to her pre-illness good health, the long-term antibiotic therapy has helped her become well enough to travel with her partner and to maintain most normal daily activities. More importantly, she feels like she has her "mind" back with near normal cognitive function without the severe depression her chronic illness caused.

Application to DNP practice

The rural FNP faced several significant clinical and ethical junctures during the care described in this case study. The first came at the initial office visit when she could have dismissed the patient by telling her that chronic Lyme disease was beyond the scope and expertise of her FNP practice. That would have been true, but then, that statement is likely true of every other rural medical provider in her town. A second judgment was made when she chose to embrace the broad view of chronic Lyme disease treatment. After extensive research, the FNP concluded that chronic Lyme disease was primarily a clinical diagnosis, one not solely based on empirical evidence. This was a risky decision as it placed the advanced nurse practitioner at odds with mainstream ID physicians. Not a particularly comfortable place for a rural FNP to be.

Beauchamp & Childress (2009) inscribe the Hippocratic Oath with both *nonmaleficence* (do no harm) and *beneficence* (try to help) qualities. “Morality requires not only that we treat persons autonomously and refrain from harming them, but also that we contribute to their welfare (Beauchamp & Childress, 2009, p. 197).

Sometimes the right, moral and ethical decision requires the clinician to take a chance for the welfare of their patient and manage the “fall out” should it occur.

References

Beauchamp, T. L., & Childress, J. F. (2009). *Principles of biomedical ethics* (6th ed.). New York: Oxford University Press.

Centers for Disease Prevention and Control. (2007, June). *Lyme disease - United States 2003-2005* (Fact Sheet MMWR Wkly.Rep. 56573-576). Retrieved from CDC: http://www.cdc.gov/media/mmwrnews/2007/n070614.htm

Doggett, J. S., Kohlhepp, S., Gresbrink, R., Metz, P., Gleaves, C., & Gilbert, D. (2008, June). Lyme disease in Oregon. *Journal of Clinical Microbiology*, *46(6*), 2115-2118.

Johnson, M., & Feder, H. M. (2010). Chronic Lyme disease: A survey of Connecticut primary care physicians. *The Journal of Pediatrics*, *157(6*), 1025-1029.

Lantos, P. M., Charini, W. A., Medoff, G., Moro, M. H., Mushatt, D. M., Parsonnet, J., ... Baker, C. J. (2010, July 1). Final report of the Lyme disease review panel of the infectious diseases Society of America. *Clinical Infectious Diseases*, *51*, 1-5.

Lautin, A., McNeil, E. L., Liegner, K. B., Stricker, R. B., & Sigal, L. H. (2002). Lyme disease controversy:use and misuse of language. *Annuals of Internal Medicine*, *137*, 775-777.

Savely, V. R. (2008, July/August). Update on Lyme disease: The hidden epidemic. *Journal of Infusion Nursing*, *31(4*), 236-240.

Steere, A. C., Malawista, S. E., Syndman, D. R., Shope, R. E., Andiman, W. A., & Ross, M. R. (1977). Lyme arthritis: An epidemic of oligoarticular arthritis in children and adults in three Connecticut communities. *Arthritis Rheum*, *20*, 7-17.

Stricker, R. B., Lautin, A., & Burrascano, J. J. (2005). Lyne disease: point/counterpoint. *Expert Rev. Anti Infect. Ther*., *3(2*), 1-11.

Wormser, G. P., Dattwyler, R. J., Shapiro, E. D., Steere, A. C., Klempner, M. S., Krause, P. J., ... Nadelman, R. B. (2006). The clinical assessment, treatment, and prevention of Lyme disease, Human Granulocytic Anaplasmosis, and Babesiosis: Clinical practice guidelines by the Infectious Diseases Society of America. *Clinical Infectious Diseases*, *43(9*), 1089-1134.

Allocation of Rural Health Care Resources: One Patient Case Study from a Distributive Justice Perspective

Myra L. Thompson R.N. MS FNP

Oregon Health & Sciences University

Case Study Submission for the Doctor of Nursing Practice degree

Advisor: Deborah Messecar PhD, MPH, R.N., GCNS-BC

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Allocation of Rural Health Care Resources: One Patient Case Study from a Distributive Justice Perspective

This case study will describe the impact a single patient had on the rural health care system where he lives. It describes the tension that exists between patient choice and the needs of the rural health care system and community from the perspectives of distributive justice and autonomy as described by Beauchamp and Childress (2009).

Background

Mr. Mitch A. Evans * is a 30 year old Caucasian male who lives intermittently with family members in a rural town in Oregon. Mr. Evans has multiple chronic illnesses with a medical history which includes diabetes mellitus type two, chronic balanitis, lower extremity cellulitis, hypertension, congestive heart failure, gastroparesis, obesity, alcohol, tobacco and illicit drug use. A review of the rural hospital clinic and hospital records revealed ten known encounters with medical professionals between the dates of May 28, 2009 and July 6, 2009. This 40 day summary shows five inpatient admissions, four emergency department visits and one office visit. The total cost of these ten encounters to the local rural health care system was $96,011.51. None of these visits needed intensive care services and since the patient did not have health insurance they were considered "self pay". These stays culminated in significant frustration to the staff and usually ended by his choice to leave the institution against medical advice (AMA). This resulted in unresolved health problems requiring repeat visits to the emergency room and additional inpatient re-admissions.

This case study will review the medical problems, plan of care and features of Mr. Evan's

***All identifying information have been altered to protect confidentiality* personal preferences which exacerbated the situation. It will discuss the actions and feelings of hospital staff when faced with a moral conflict. An examination of the rural hospital's "prima facie" duties both to the patient and to the community it serves will show the tension these variables bring to the health care setting. Of the four major principles of medical ethics, respect for autonomy, nonmaleficence, beneficence and justice, the dilemma presented by this case study concentrates primarily on the principles of respect for autonomy and distributive justice.

Case Presentation

Review of the Medical Problem

Mr. Evans was seen in the emergency department on the evening of May 28, 2009. He presented with complaints of pain in the scrotum and upper right thigh. His medical history includes: hypertension, congestive heart failure, diabetes mellitus, obesity, balanitis and gastroparesis. Mr. Evans told the emergency room staff that he has just gotten out of a hospital and that he was suppose to follow-up with intravenous antibiotic infusions through the Peripherally inserted central catheter (PICC) which was still present in the left upper arm. Medical follow-up had been made by the discharging hospital but he failed to keep his appointments. Medical records were obtained from the previous institution which showed a five day hospitalization with surgical, urology, gastrointestinal, and internal medicine consultations. Multiple labs, cultures and radiological studies had been performed. He had been discharged on May 26 with the diagnosis of a Methicillin-resistant Staphylococcus aureus (MRSA) infection of the upper right thigh and uncontrolled diabetes mellitus. Both conditions had been addressed by providing prescriptions for low cost medications and appointments for intravenous infusion (IV) of Vancomycin every 12 hours with appropriate physician follow-up. By the evening of May 28, Mr. Evans had missed two days of intravenous Vancomycin and was complaining that the pain in his scrotum and right upper thigh was increasing. The emergency room physician notified the on-call hospitalist and the patient was admitted for pain control, intravenous treatment of the on-going MRSA infection and to control his diabetes mellitus. A surgeon was again consulted for possible incision and drainage of the upper thigh infection. Mr. Evans was admitted to the general medical floor at 2350. A review of the inpatient records show evidence of a difficult and demanding patient with frequent verbal threats to leave the hospital with swearing and verbal abuse directed at the staff. He refused to take routine medications, refused to allow lab draws and refused to wear an oxygen saturation monitor. He made frequent requests for intravenous Dilaudid and Ativan. He became angry and yelled at the nurses when the pain and nausea medications were not administered per his request. Mr. Evans left the hospital against medical advice (AMA) on the afternoon of May 29, 2009.

Mr. Evans presented again to the emergency department two days later on June 1, 2009 at 1750. He complained of left upper arm pain around the PICC insertion site and of increasing right upper thigh pain. Mr. Evans had not been taking his insulin and his blood glucose level was 327. The emergency department physician again recommended admission and he arrived on the medical floor at 1600. Mr. Evans aggressively and loudly complained about staff and treatments throughout this stay. He refused to be seen by respiratory therapy for oxygen saturation monitoring and berated the staff verbally. This patient again left the hospital AMA at 1735 on the afternoon of June 3, stating “I’ll just get my care in eastern Oregon”. After much effort the nursing staff was able to remove the PICC without sustaining personal harm.

On the morning of June 10, 2009 the patient returned to the emergency department with complaints of right leg pain, chest pain and hematemesis. He stated that the upper right leg wound had improved but it was now open and draining. Four hours of emergency room evaluation and treatment was given before he was re-admitted to the medical floor at 1500. The admitting physician spent considerable time in counsel with Mr. Evans and writes that the patient now recognizes he “has to take more responsibility for his illness and cannot check out AMA from the hospital while he is being treated.” Mr. Evans was discharged with a plan of care on June 16, 2009.

The remaining seven health care ER/inpatient admissions were similar to the above descriptions. He continued to leave the health care setting AMA, angry and without any indication he was willing to follow the plan of care. Hospital administration and risk management were contacted by the patient with complaints about his care. Mr. Evans was last seen by the local emergency room staff at 2130 on the night of July 6, 2009.

During these 40 days Mr. Evans was offered and received multiple opportunities to improve his health. He was evaluated by many health care professionals but there seemed to be little if any patient cooperation or interest in developing a trusting and therapeutic nurse/doctor/patient relationship. He consistently made deliberate choices that damaged his health and sabotaged his plan of care. He was lucid and direct about his wishes dictating to the staff what he would and would not tolerate. In short, he plainly exercised his right to make personal health care choices. Medical ethic literature outline the concept of respect for autonomy, that being the right of the individual to direct their care and voice their values and choices. This concept is “To respect autonomous agents is to acknowledge their right to hold views, to make choices, and to take actions based on their personal values and beliefs” (Beauchamp & Childress, 2009, p. 101). By his actions it seemed that Mr. Evans needed personal autonomy and was not willing to share authority or responsibility for his health.

Background and Previous Medical Interactions

Mr. Evans has a long history of exposure to hospitals. He was diagnosed at age 14 with diabetes and developed a serious mistrust of hospitals and health care workers. He told the hospital social worker that “my parents both died in the hospital and I know they will kill me too.” Previously he worked at a deli and service station but the peripheral neuropathy from the long standing diabetes mellitus made standing and even walking difficult. He said he could not even walk to the bus stop due to the pain and was essentially house bound with a limited social life. He was living with his sister in small low income housing. The patient is obese and continues to smoke and drink alcohol.

Social History

Mr. Evans has not been able to work for several years yet has refused all help to apply for state assistance. He is eligible for tribal health care on at least two different Indian reservations. He admits to previous methamphetamine use and currently uses tobacco and alcohol. He also states that “I need to get out of here (local town) to stop drinking.” He had been given a medical marijuana card and uses this to help with painful peripheral neuropathy. He does not have a wife or children that the hospital is aware of and admits to being shuttled from brother to sister for care. His level of education or reading comprehension is unclear in the medical records. The last line from the progress note on his last hospital admission reads “that his sister cannot provide the care that he needs. He indicates that if discharged he will go to the beach presumably in a sheltered area outdoors.”

Opportunities to Improve Health

Mr. Evans has made full use of the health care resources in the rural health care system yet his chronic conditions have not been stabilized. The following additional observations and recommendations are suggested.

Establish care with a primary care clinician. Mr. Evans needed to establish a relationship with a primary care provider. The busy family physician or nurse practitioner sees these diagnoses on a daily basis. All of these chronic conditions could be well managed in the primary care arena generally eliminating in-patient and emergency room charges. Clinic visits are vastly cheaper than emergency room or in-hospital admission charges. The financial data shows a single clinic charge of $390.60. The in-patient charges range from $4,997.44 to $35,290.30 per stay. The rural health care system could have potentially saved over $90,000 if his health care had occurred in a clinic instead of in the hospital. Primary care providers are the backbone of patient care services in the rural community and there are too few practitioners. Recruitment efforts should be vigorous.

Improve communication and identification of high risk patients. High quality health care requires cooperation of both the patient and the participating health care system/practitioner. The patient must first admit he needs help then it is helpful if they approach the health care system in a respectful positive manner. The health care system/providers must learn to recognize these at risk clients and their particular needs to intervene early in their health care experience. Understanding non-compliant behaviors will help health care providers develop strategies to encourage effective treatment and avoid serious consequences (Kleinsinger, 2003). Many non-compliant patients crave autonomy. They view their behavior as self regulatory and independent (Conrad, 1987). Self neglect, as a concept of intentionally neglecting prescribed self care activities despite available resources and knowledge, is one way of understanding Mr. Evan's inability to follow-through with his plan of care (Reed & Leonard, 1989). With this information the health care provider can recognize common therapeutic goals and collaborate on mutually acceptable strategies.

Develop and implement strategies to deal with the difficult patient. Mr. Evans presented to the emergency department in June and demanded IV pain medication before a medical evaluation was even started. This rapidly lead to a verbal disagreement ending with the emergency room doctor insisting on a medical evaluation and the patient refusing thus leaving the emergency room without treatment for a blood sugar over 500. A better therapeutic approach to Mr. Evan's pain may have resulted in quicker access to care and treatment of his out of control diabetes and infection. Recognition of pain in all emergency room patients even if they are labeled as "frequent flyers" or "drug seeking" should be the standard (Millard, 2007).

Discussion

Ethical Considerations

The ethical concepts of autonomy and self determination are deeply rooted in our culture yet the economics of clinical care press for radical reform of our health care system. Should **all** of the people get **all** of the care **all** of the time? Should citizens receive health care according to their societal contributions? These questions must be addressed. The core values of fair utilization of scarce resources, personal responsibility and self determination are evident in this case. The four major ethical perspectives on distributive justice as they relate to Mr. Evans may be considered as follows:

- Mr. Evans has not contributed to society nor to the betterment of his health so he does not deserve further health care (Libertarian)

- Mr. Evans has immense individual health care needs which supersede societal needs. (Utilitarian)
- Mr. Evans has used up his share of health care and should not receive further care. (Egalitarian)
- Mr. Evans deserves whatever health care he needs at whatever the cost. (Humanitarian)

None of these statements are entirely accurate and this case exposes multiple and common moral and ethical problems in our health care delivery systems, the people served, and the professionals who work within these systems.

There is often friction between patient wishes/choices (autonomy) and the plan of care (paternalism). Historically the medical system endorses paternalism: an authority figure who knows what is best. "In ethical terms, paternalism represents the opinion that beneficience is a higher value than autonomy" (Jonsen, Siegler, & Winslade, 2006,p 54). When patients are competent to make their own health choices (decisional capacity) paternalism is considered ethically suspect. What is not as clear ethically is the appropriate moral and ethical position for the rural health care system which pays for this patient's right for health care autonomy.

Rural Patient Considerations

There are those who may believe that Mr. Evans has a moral and personal responsibility to follow a healthy lifestyle. The American culture has not, as yet, demanded this behavior but pilot programs are in place to reward responsible personal health choices (Steinbrook, 2006). Health care professionals recognize the relationship of chronic disease and substance abuse and become frustrated when they see these harmful practices continue in chronically ill patients. Medical problems caused by personal behaviors are socially less acceptable and the staff view patients like Mr. Evans as exploiting the local hospital and driving up health care costs for all. Mr. Evan's behavior may simply indicate a desire for autonomy, respect and self determination while the health care providers concentrate solely on his medical condition and ignore his need for independence. Ethical dilemmas surface within these two conflicting agendas. Obesity, alcoholism and smoking critically strain health care budgets, yet the fat, cigarette smoking, drunk pays no more than the person who chooses healthy habits. This may be changing as new laws are enacted across the nation that mandate that patients with unhealthy lifestyles pay more for their health care. The notion of a "fat tax" (Jacobson & Brownell, 2000) or a "sin tax" (Manning, Keeler, Newhouse, Sloss, & Wasserman, 1989) to help pay for the increased health care costs for persons who engage in unhealthy behaviors is not new concept. These ideas are now poised to become legislative reality. The state of Arizona is currently considering adding a fifty dollar tax to all Medicaid patients who smoke, are overweight, or have diabetes (Carlson, 2011).

Rural Health Care Professional Considerations

Hospital staff and primary care clinicians experience stress when caring for the non-compliant patient. Large numbers of practitioners claim a lack of control and a chaotic work pace as reasons for their feelings of "burnout" (Haas, Leiser, Magill, & Sanyer, 2005). Management of the difficult patient is stressful, time consuming and usually not very rewarding. These patients also create potential legal jeopardy for the treating physicians and advanced practice nurses. They often feel powerless when confronted with these patients and their problems. Moral distress occurs when staff and clinicians face external forces over which they have no control, cannot change, and view as morally corrupt (Laabs, 2007). These feelings of anger, powerlessness and frustration were clearly evident in the nurses and physicians caring for

Mr. Evans. The patient made multiple small demands, pitting one staff member against another to get what he wanted and when that stopped working he would abruptly leave AMA. A staff nurse stated when reflecting on his distress while caring for this patient, “I will never be able to go through that again.”

Utilization of rural health care resources

The excessive cost for non-urgent visits to emergency rooms (ER) is staggering. This has been a health industry concern for some time (Thompson & Glick, 1999). This practice is enormously expensive and it does not offer comprehensive quality longitudinal care. The emergency room is designed to take care of emergencies. It is for patients who can barely breathe from pneumonia not for people suffering from run-of-the-mill colds. Too often emergency departments offer an accessible and convenient alternative to primary care facilities. Patients know they will have greater access to a wider range of diagnostic procedures and they often don’t mind waiting for this comprehensive care. Just as Mr. Evan’s frequently used the emergency room to obtain intravenous pain medication so do many patients in America. (McCaffery, Grimm, Pasero, Ferrell, & Uman, 2005). Every hospital emergency room has certain obligations, including those imposed by the federal Emergency Medical Treatment and Active Labor Act (EMTALA). When dealing with the disruptive or abusive patient in the ER the hospital has to walk a fine line to provide medical screening to everyone yet keep resources available for true emergencies.

Conclusion

Strong leadership is required to transform the U.S. health care system. A key message in the recent Institute of Medicine report, The Future of Nursing, is that “nurses should be full partners, with physicians and other health professionals, in redesigning health care in the United

States (Institute of Medicine, 2010 p. 1-11). Since society and our elected officials have not been able to "get on the same page" to define a standard public value for personal health responsibility, nurses can step up to be transformational leaders to help in the redesign of our health care system.

Dr. Ed Leap, a rural emergency room physician in South Carolina humorously yet eloquently makes his case for personal health responsibility in his essay, *If Coyotes Were as Big as Minivans* (Leap, 2006). This is a thought provoking read which helps to articulate the core problem of health care disparities as basic to the moral fiber of our society. In summary, it is important for nursing and other health care professional to help clarify and articulate societal values and then finally establish measures that promote responsible health behavior while actually improving health and saving money.

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References

Alfandre, D. J. (2009). *'I'm going home": Discharges against medical advice* (Mayo Clinic Proceedings) [Abstract]. Retrieved from http://www.mayoclinicproceedings.com/content/84/3/255.abstract.

Beauchamp, T. L., & Childress, J. F. (2009). Respect for autonomy. In *Principles of Biomedical Ethics* (pp. 99-140). New York: Oxford University Press.

Carlson, M. (2011). *Arizona Medicaid considers tax on smokers and the obese*. Retrieved from http://www.huffingtonpost.com/huff-wires/20110401/us-arizona-medicaid-obesity-tax/

Conrad, P. (1987). The noncompliant patient in search of autonomy. *The Hastings Center Report*, *17*, 15-17.

Doyle, E. (2009). Is your patient leaving against medical advice? *Today's Hospitalist*, *June*, 22-24.

Haas, L. J., Leiser, J. P., Magill, M. K., & Sanyer, O. N. (2005). Management of the difficult patient. *American Family Physician*, *72*, 2063-8.

Institute of Medicine. (2010). *The future of nursing: Leading change, advancing health*. Washington, DC: U.S. Government Printing Office

Jacobson, M., & Brownell, K. (2000). Small taxes on soft drinks and snack foods to promote health. *American Journal of Public Health*, *90*, 854-857.

Jonsen, A. R., Siegler, M., & Winslade, W. J. (2006). *Cinical ethics: a practical approach to ethical decisions in clinical medicine* (6th ed.). New York: McGraw-Hill

Kleinsinger, F. (2003). Understanding noncompliant behavior: definitions and causes. *The Permanente Journal*, *7*, 18-21.

Laabs, C. A. (2007). Primary care nurse practitioners' integrity when faced with moral conflict. *Nursing Ethics*, *14*, 795-809.

Leap, E. (2006). If Coyotes were as big as minivans. *Emergency Medicine News*, *28*, 10-11.

Manning, W. G., Keeler, E. B., Newhouse, J. P., Sloss, E. M., & Wasserman, J. (1989, March). *The taxes of sin: Do smokers and drinkers pay their way?* (White Paper Rand Report N-2941-NCH-SR). Retrieved from rand.org: http://www.rand.org/pubs/notes/2009/N2941.pdf

McCaffery, M., Grimm, M. A., Pasero, C., Ferrell, B., & Uman, G. C. (2005). On the meaning of "drug seeking". *Pain Management Nursing*, *6*, 122-136.

Millard, W. B. (2007). Grounding frequent flyers, not abandoning them: drug seekers in the ED. *Annals of Emergency Medicine*, *49*, 36-45.

Reed, P. G., & Leonard, V. E. (1989). An analysis of the concept of self-neglect. *Adv Nurs Sci*., 1, 39-53.

Steinbrook, R. (2006). Imposing personal responsibility for health. *The New England Journal of Medicine*, *355*, 753-756.

Thompson, K. M., & Glick, D. F. (1999). Cost analysis of emergency room use by low-income patients. *Nursing Economics*, *44*, 128-32.

Shared Medical Decision Making – A Rural Primary Care Example of a Patient-centered Value Added Collaborative Medical Decision

Myra L. Thompson R.N., MS, FNP

Oregon Health & Science University

School of Nursing

Case Report, submitted for the Doctor of Nursing Practice degree

Advisor: Deborah Messecar PhD, MPH, R.N., GCNS-BC

Clinical Mentor: Lyle J. Fagnan M.D.

May, 2011

“To do good work, one must first have good tools”

Confucius

Medical and nursing providers are trained to evaluate evidenced based research and then provide their opinions to patients during the treatment plan process. Unfortunately, the patient-provider relationship has not always focused on patient involvement in these medical decisions. Historically this relationship was based on a paternalistic model of care. The provider evaluated the treatment options and prescribed what they thought was the best course of action. Medical and nursing professionals generally create quality treatment plans that they believe will help their patient but they often fail to ask the patient for their opinion in this process. Providers agree that it is an ethical and professional responsibility to involve patients in their medical decisions yet patients often do not see themselves as an integral part of this potentially life-altering medical decision-making process. There is on-going tension and debate to align medical ethics and medical decision-making. Moulton and King state, “Many physicians have yet to strike the ideal balance between absolute patient autonomy and beneficence” (Moulton & King, 2010, p. 2). This lack of patient involvement is problematic as advances in medical science and technology have introduced a growing number of treatment options – many with no single “best” choice. Patients now face ever-more complex medical decisions with multiple choices, each with no clear advantage and with risks and harms that patients may value differently. Who then directs and controls the patient treatment plan? Is it the provider armed with years of training and experience or is it the patient with their own life experiences, values, and beliefs? It is becoming clear that it must be an equal collaboration with a well documented and evidenced-based educational exchange. Patients must be able to actively and meaningfully participate in their health care plan.

No one debates that it is a patients fundamental right to be fully informed of all options, risks and benefits and to participate in the decisions that affect his or her health. Providers are then faced with the problem of providing up-to-date evidenced based treatment options for their patients and then work with each patient to map a personalized treatment course. This is a “tall order” for the busy rural primary care provider. Not only is it difficult to scour the medical literature on a regular basis to ensure that the treatment options offered are in fact the most current and evidenced based, but the time it would take per patient to assemble this data and explain it would add many hours to their already long work day. Unfortunately, this problem helps to perpetuate the paternalistic approach of “this is what you need to do”. It is quicker to **tell** the patient their plan of care then to **ask** them what they think the plan should be.

It is also a great challenge to provide evidenced based medical choices to the variety of patients and diagnoses seen in a busy rural primary care practice. Specialty medical practices may only need to prepare for a handful of diagnoses. One way to meet the goal of a patient centered practice in the varied primary care setting is to use evidence-based decision aids in a collaborative shared medical decision approach with patients and families.

Shared decision making (SDM) with the use of decision aids is part of a larger movement for patient-centered medical care that helps patients make decisions about their best health care options. Decision aids are standardized, evidenced–based tools intended to transmit complex clinical information and facilitate the process of arriving at an informed, value-added choice among two or more health care alternatives. Decision aids for people facing health treatment choices can help patients and families get information on the options and possible benefits and harms of available health treatments. The development of aids for shared medical decision-making is not new but it is beginning to be recognized by many groups as an important priority (Hill et al., 2009). Health Dialog is a for-profit business that has partnered with the Foundation for Informed Medical Decision Making to create evidenced based decision aids and to help implement these into clinical practice. These sites can be found at www.healthdialog.com and at www.informedmedicaldecisions.org.

The purpose of this paper is to outline the use of decision aids with the shared decision making approach as a rural patient, family and clinician grapple with a life-threatening decision.

Patient Summary

LH is a 74 year old Caucasian female who was first seen in the rural clinic, June of 2010. She was seeking a local primary care provider while undergoing chemotherapy for inflammatory breast cancer before a planned left mastectomy.

Past medical history

Her past medical history includes, Familial Adenomatous Polyposis (FAP), mild asthma and menopause.

Surgical history

Previous surgeries include a colectomy, total abdominal hysterectomy and bilateral salpingo-oophorectomy and a cholecystectomy in 1982. She did undergo a left breast mastectomy revealing a lymph node positive, stage four breast cancer, in July, 2010. A port-a-cath was placed for post-operative chemotherapy.

Family History

Ms. LH's father died age 60 from colon cancer which was subsequently presumed to be FAP. Her mother lived till age 91 and died from "old age". Her older brother died age 44 from colon cancer, a result of untreated FAP. The patients sister is alive and well at age 70 with a past history of breast cancer (type not known) which required surgical mastectomy at age 46. This sister does not have the genetic mutation for FAP.

Social History

LF is divorced with three children and no grandchildren; she worked as a secretary until retirement. Genetic testing reveals that two of her three children have inherited FAP and both have undergone prophylactic colectomies. Prior to the November 2009 inflammatory breast cancer diagnosis the patient was living independently without problems.

Summary of Familial Adenomatous Polyposis and Inflammatory Breast Cancer

Familial adenomatous polyposis (FAP) is the most common of the adenomatous polyposis syndromes. It is an autosomal dominant inherited disorder characterized by the early onset of hundreds to thousands of adenomatous polyps throughout the colon. If left untreated, it is believed that all patients with this syndrome will develop colon cancer by ages 35-55. In addition, there is an increased risk for the development of other malignancies.

Figure 1. Endoscopic view of FAP in the colon

Estimates of the frequency of the disease vary from one case in 6,850 persons to one case in 31,250 persons, and this frequency appears to be constant worldwide (http://ghr.nlm.nih.gov/condition/familial-adenomatous-polyposis, n.d.).

At present the recommended treatment continues to be the draconian act of a full colectomy. Research continues in an effort to find measures to reduce and diminish these colon polyps with the goal to offer a less drastic treatment for this uncommon but fatal disease. Non-steroidal-anti-inflammatory medications have shown to be of some benefit (Mantovani, Allavena, Sica, & Balkwill, 2008). At present, the only widely accepted option for people with FAP is a colectomy with all of the emotional and physical hardships that includes.

Inflammatory breast cancer (IBC) represents the most virulent form of breast cancer. It is characterized by involvement of the skin and rapid progression of the disease. Inflammatory breast cancer is a rare but very aggressive type of breast cancer in which the cancer cells block the lymph vessels in the skin of the breast. This type of breast cancer is called “inflammatory” because the breast often looks swollen and red, or “inflamed.” IBC accounts for one to five percent of all breast cancer cases in the United States (Woodward & Cristofanilli, 2009). The prognosis for women with IBC is poor as this type of cancer is more likely to have metastasized at the time of diagnosis than for non-IBC cases. As a result, the five-year survival rate for patients with IBC is between 25 and 50 percent, which is significantly lower than the survival rate for patients with non-IBC breast cancer (Anderson, Schairer, Chen, Hance, & Levine, 2005).

Figure 2. Right breast inflammatory cancer

Worldwide research has shown a genetic link between the mutations causing FAP and inflammatory breast cancer (Van der Auwera et al., 2008) and this association may be of biological and clinical importance.

Patient and Family Shared Decision Making Process

LH was next seen in the clinic on August 4, 2010 with complaints of a urinary tract infection. She had just been released from the hospital after her July 9 left mastectomy. A chest drain and a port-a-cath remained in place. Home health nurses and physical therapists were seeing LH several times a week under the direction of her surgeon and oncologist. The urinary tract infection was treated with the appropriate antibiotics at this office visit. She returned to the office on August 26 with complaints of continued painful urination. A review of this patients' progress showed that she had been re-hospitalized for acute renal failure and congestive heart failure. She had received multiple antibiotics for sepsis stemming from an infected chest drain and her port-a-cath had clotted and was unusable. At this visit she appeared physically more frail and ill-appearing. She had recently been discharged from a skilled care facility to the care of her daughter. The daughter was comfortable and pleased to be the primary care giver to her mother and it appeared that adequate resources were in place to create a safe and therapeutic healing home environment. The oncology and hematology notes were available for review and they revealed that LH had not completed her course of chemotherapy and had elected to forgo the recommended radiation therapy, Herceptin treatment, and other exams. When asked, LH stated that she did not wish further treatment; however, her daughter who was present at the exam expressed a desire for her mother to continue with the specialists recommendations. This was discussed at some length in the office. Seeing the differing values prompted the clinician to offer two decision aids (DA) for the patient and family to review. The DA booklets titled *Peace of Mind* and *Looking Ahead* were provided and the patient was asked to view these with her family and return within two weeks with a spokesperson family member to discuss the next step in her treatment plan. The *Peace of Mind* booklet provides personal stories about advanced directives and the steps needed to create these legal documents. The *Looking Ahead* resource helps people with serious illnesses become better prepared for what may happen to them. The concepts of palliative care and hospice are well described and it is accompanied by a 37 min DVD with information on multiple other resources.

Figure 2. Shared decision making booklets and DVD's from Health Dialog

During the first two weeks of September, LH's oncology office made several calls to the rural clinic asking the clinician and staff to work with LH to help her complete her radiation therapy, to start the Herceptin treatment, and to get other studies they felt were necessary. Gastroenterology and urology referrals were made for the patient after she reluctantly agreed to further evaluation and possible treatment. On September 20, 2010, LH and her daughter were again seen in the clinic. The patient appeared less fatigued and was more animated at this visit. In general she appeared stronger with a good appetite, stable weight, normal vital signs and no complaints. About 30 minutes was spent in the office discussing the patients' end of life values, desires and choices. The decision aids were returned and they were helpful in facilitating an in-depth discussion about her wishes and values regarding further treatment for the breast cancer. The daughter, as the designated family spokesperson, and the patient expressed full agreement that palliative care was the best choice for her at this time. Ms. LH was diagnosed as a young adult with the FAP and was witness to the death and illness of many family members. She understood and accepted that she was not likely to survive her inflammatory breast cancer. These life experiences formed end of life values that may be different from other persons who are seriously ill. Also, two of her children have lived with life-threatening illnesses and they experience life differently as a result of the FAP "cure". As a result of these personal experiences they collectively embraced the value and belief that LH should experience her remaining life without additional invasive and painful events.

When asked, the daughter stated that the other siblings also support this decision. LH expressed gratitude at being offered additional information as it gave her the tools she needed to make this decision and to clearly communicate this to her oncologist. During the course of this interaction it became clear that having the information provided by the decision aids helped the family, patient, and the clinician reach consensus. Seeing the aligned family and patient values and commitment helped the advanced practice nurse (ANP) become comfortable with this decision as well.

Summary

Too often the patient's personal values and health beliefs are underweighted in the health care decision process. Edwards and Elwyn state that "the relationship between a patient and their health professional is viewed as one of the most complex interpersonal relationships" (Edwards & Elwyn, 2009, p. 3). In the provider's attempts at beneficence, paternalistic approaches can surface. The advanced practice nurse can play a crucial role in tying health care choices to patient values and beliefs which support patient autonomy and will help to reduce paternalistic decisions.

Decision tools are designed to supplement the patient-provider interaction and they are especially useful when there are differing cultural and personal health beliefs between the patient/family and provider.

References

Anderson, W., Schairer, C., Chen, B., Hance, K., & Levine, P. (2005). Epidemiology of inflammatory breast cancer (IBC). *Breast Disease*, *22*, 9-23.

Edwards, A., & Elwyn, G. (2009). Shared decision-making in health care: Achieving evidence-based patient choice. In *Shared Decision Making in Health Care* (pp. 3-10). Ontario: Oxford University Press Canada.

Hill, L., Mueller, M., Roussos, S., Hovell, M., Fontanesi, J., Hill, J., & Salas, N. (2009). Opportunities for the use of decision aids in primary care. *Family Medicine*, *41*(5), 350-355.

Mantovani, A., Allavena, P., Sica, A., & Balkwill, F. (2008, July 24). Cancer-related inflammation. *Nature*, *454*, 436-444. doi: 10.1038/nature07205

Moulton, B., & King, J. S. (2010). Aligning ethics with medical decision-making: The quest for informed patient choice. *Journal of Law, Medicine & Ethics*, *5*, 2-14.

Van der Auwera, I., Van Laere, S. J., Van Den Bosch, S. M., Van den Eynden, G. G., Trinh, B. X., Van Dam, P. A., ... Dirix, L. Y. (2008). Aberrant methylation of the Adenomatous Polyposis Coli (APC) gene promoter is associated with the inflammatory breast cancer phenotype. *British Journal of Cancer*, *99*, 1735-1742.

Woodward, W. A., & Cristofanilli, M. (2009). Inflammatory breast cancer. *Seminars in Radiation Oncology*, *19*(4), 256-265.

http://ghr.nlm.nih.gov/condition/familial-adenomatous-polyposis. (n.d.).

OREGON HEALTH & SCIENCE UNIVERSITY
SCHOOL OF NURSING
Ashland Klamath Falls La Grande Portland

DNP Clinical Inquiry Project Report & DNP Portfolio Approval

Student Name: Myra Ladd Thompson

Degree: Doctor of Nursing Practice

Title of Study:

Shared Decision Making: Views of Primary Care Clinicians in Four Oregon Practice Sites

APPROVED:

Committee Chair: Deborah C. Messecar PhD, GCNS-BC RN Signature:
(name and credentials)

Committee Member: Lyle J. Fagnan M.D. Signature: Lyle Fagnan
(name and credentials)

Committee Member: Signature:
(name and credentials)

Michael R. Bleich, PhD, RN, MPH, FAAN
Dean, School of Nursing Signature: Michael R. Bleich

Date: 6-13-11

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