Arizona Reynolds Program of Applied Geriatrics: The Role of the Informationist

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The University of Arizona Health Sciences Center is one of ten academic centers chosen by the Donald W. Reynolds Foundation in 2006 to be the recipient of an almost 2 million dollar grant in the third phase of the Reynolds' *Aging and Quality of Life Program*. This initiative was created in 1996 to revolutionize geriatric training within our medical centers in order to meet the complex needs of the ever-expanding population of elders in the United States.

The Reynolds Aging and Quality of Life Program

So far, three cohorts (2002, 2003 and 2006), of ten medical centers each have been awarded 4-year, approximately 2 million dollar grants. Each center has, or is in the process of, developing a unique approach to integrating geriatric awareness and expertise at every level of medical training and practice. The grantee institutions convene at an annual meeting to network and exchange resources, ideas, and educational products that they have developed. Examples of the innovative ideas that have thus far emerged include:

- The creation and maintenance of a *Geriatric Quick Consult Web* site for students and clinicians at Virginia Commonwealth University (first cohort)
- A Chief Resident Immersion Training Program developed at Boston University (second cohort)
- The development of a "Curriculum for the Hospitalized Aging Medical Patient" (CHAMP) at the University of Chicago—which already specializes in training hospitalists (second cohort)
- A focus on the training of primary care physicians spearheaded by the University of Utah (third cohort)

The Arizona Reynolds Program of Applied Geriatrics

The Arizona Reynolds Program of Applied Geriatrics (ARPAG) at the University of Arizona has a multifaceted approach to improving the care of seniors in this, the fastest growing state in the nation. Arizona not only mirrors the proportionate growth in the number of elderly seen by the rest of the country as a result of longer life spans and the graying of the Baby Boomer generation, but is also a retirement destination for many older workers throughout the country. To meet this imminent demographic deluge, it is imperative for us to develop new health care paradigms.

In addition to incorporating geriatrics into every level of medical education within the new medical school curriculum in Tucson and the new Phoenix Campus, ARPAG views its faculty development program as the “Key Driver”. Known as the Reynolds Scholars in Aging (RSIA) Program, it is anchored in the belief that by intensively training non-geriatrician physician leaders within both primary and specialty fields in the principles of geriatric care, these leader/scholars will be transformed into true “agents of change,” in turn helping to effect a shift within the broader medical infrastructure.

The Informationist

The Arizona Reynolds Program is unique in that it has partnered with the Arizona Health Sciences Library to fund an informationist to collaborate in every aspect of the program. This collaboration is particularly crucial within the Reynolds Scholar in Aging Program portion of the grant. Davidoff and Florance (2000) in their groundbreaking editorial in the *Annals of Internal Medicine,* “The Informationist: A New Health Profession?” note that “…the medical profession falls far short in its efforts to make the critical link between the huge body of information hidden away in the medical literature and the information needed at the point of care” (p. 996). They propose a new profession, that of the informationist who would “have a clear and solid understanding of both information science and the essentials of clinical work” (p.997). Davidoff and Florance outline a four-pronged design that would guide the development of an informationist program-- models for which have now been established at institutions such as Vanderbilt University. As it happens, however, the Arizona Reynolds informationist (CH) is also a recently retired geriatrician with an even more recent library and information science degree. This fortuitous combination has allowed for a fun, productive and evolving partnership between the library and the Program on Aging. SK, Assistant Director for Services at the Arizona Health Sciences Library also provides invaluable knowledge, support, and back up from her long experience as a librarian in the medical, academic and corporate worlds.

Informationist as Team Member

As of this writing, we are approximately six months into the Reynolds Grant at the University of Arizona. Although the role of the informationist has thus far been largely focused on the Reynolds Scholar in Aging Program, we are also able to offer support to residents and fellows doing research and to faculty members conducting educational activities such as Journal Clubs or preparing for lectures.

Additionally, we provide an always-available conduit to needed information. The informationist attends the weekly Reynolds leadership meeting and is thus tapped into day-to-day information needs. Reynolds’ faculty also freely e-mail requests as they arise. Frequently particular documents are needed which may be difficult for the non-librarian to find (e.g. an entire issue of an *Archives of Internal Medicine* supplement on quality indicators in the care of frail elderly or an online document such as “An Evaluation of Provider Educational Needs in Geriatric Care.”) Occasionally a quick bibliography is needed—in answer, for example to the question: are there available textbooks in the field of Geriatric Oncology? These are services that we are able to provide quickly and efficiently. We can also occasionally step in and write, for example a consumer-based article on falls in the elderly intended for a newsletter to be distributed in the Indian Health Service (IHS) clinics. We can assist with collaborative efforts such as the creation of customized forms—for example a needed Transition of Care template for hospitalized IHS elders.

In the future we hope to be able to expand our role, for example attending rounds to help provide "point-of-service" information at the bedside. We also anticipate joining the teams that travel to rural or tribal facilities to provide individualized education and support for clinicians who are practicing in remote settings.

Reynolds Scholars in Aging Program: The Scholars

As noted, the informationist's most pivotal role is within the subset of the grant devoted to faculty development, the Reynolds Scholar in Aging Program (RSIA). A total of 17 scholars (8 in the first cohort appointed for 15 months and 9 in the second cohort appointed for 18 months) have been chosen from the College of Medicine and the Southern Arizona Veterans Administration Health Care System (SAVAHCS). The Scholars include:

- Dr. C.C.: Associate Professor of Surgery/Urology; Chief of the Section of Urology; Residency Director.
- Dr. H.V., Professor of Surgery and Interim Head of the Department of Surgery-
- Dr. W.G., Professor of Orthopedics and Head of Department of Orthopedics
- Dr. S.B., Professor of Anesthesiology and Head, Department of Anesthesiology
- Dr. G.W.: Associate Professor of Clinical Medicine-- actively involved in developing the new curriculum.
- Dr. H.M. Professor of Emergency Medicine; Department Head for Emergency Medicine; Director of the Arizona Emergency Medicine Research Center.
- Dr. J.W.: Associate Professor, Department of Surgery; Residency Director.
- Dr. P. L.: Associate Professor, Clinical Family & Community Medicine; Program Director for the Family Medicine Residency--also completed a fellowship in Integrative Medicine in 2005.
- Dr. R.M.: Associate Professor, Clinical Medicine; Program Director for the Internal Medicine Residency Program; Section Head for the Medical Education Office; chair of the Graduate Medical Education Committee.
- Dr. S.C. Professor in the Department of Gynecology and Medicine who is also the Director of the Office of Women's Cancers; Associate Head for Academic Affairs with the Department of Obstetrics and Gynecology.
- Dr. J.U.: Hospitalist and Division Chair, Department of Medicine at the Southern Arizona Veterans Administration Health Care System

In addition to the university- based Scholars in Aging, two physicians in each cohort have also been chosen from different Indian Health Service (IHS) and tribal medical facilities throughout the state. Currently there is one Scholar from the Whiteriver Apache reservation and a second from Hopi Health Center.

In becoming thoroughly versed in the principles of geriatric care, it is anticipated that these scholars will seamlessly integrate these principles not only into their own practices and specialties but also into the curricula and into their mentoring at every level –from junior faculty and fellows, to residents and medical students.

Reynolds Scholars in Aging: The Program

The Reynolds Scholar in Aging Program consists of five activities:

1. Intensive Training: in the "core principles of geriatric care and geriatric aspects of their field of specialty." (*Program Summary*, p.17). This is accomplished through a combination of sessions with the mentor (see #2), informationist, and additional web based and individual learning modules customized to the scholars' specialties.
2. Structured Mentoring and Support: Each scholar is paired with a mentor who specializes in geriatric medicine. The scholar/mentor pairs then work closely with the informationist. (A more detailed description of this collaboration is included below.)
3. Reynolds Care in Aging (CAPstone) Project: The scholars "develop, implement and evaluate a 'Reynolds Care in Aging Project' (CAPstone project)." This project is intended to solve "real world clinical problems…[which will] result in improved care for frail elders" (p.17). As an example, one scholar is implementing a method by which clinicians can readily access a patient's advance directives within the electronic medical record (EMR)—or be prompted with a reminder if advance directives are not yet in place.
4. Integration of Geriatric Curricula: The scholars participate in Reynolds Seminars and also "champion the integration of geriatric curricula for medical students, residents, faculty and practicing physicians through Grand Rounds, and local/national conferences" (p.17).
5. Scholarly Activity: The scholars are expected to produce lectures, publications, and abstracts in an aging-related aspect of their field.

The Scholars and the Informationist

The informationist is available to assist the scholars at any of the above junctures. In addition to performing searches as needed, we offer one-on-one educational sessions to each of the scholars on searching PubMed and other databases, as well as a more general introduction to the multiple resources available through the Arizona Health Sciences Library.

We anticipate playing an integral collaborative role as the scholars develop their CAPstone projects (see # 3 above) and pursue their geriatrics related educational (#4) and scholarly (#5) activities.

Question of the Month

Perhaps the most unique feature of the informationist's role in the Scholar in Aging Program, however, is the "Clinical Question of the Month." In collaboration with their mentors, scholars compose queries based on issues that have arisen in the context of their practices. These questions run the full range from very clinically specific to very broad, "fuzzier" topics relating to ethics and cultural context.

Examples of specific questions are: 1) *In PICO format: in older adults who have been vaccinated for zoster, compared with similar adults who have not been so vaccinated, what is the event rate of herpes zoster?* 2) *What are causes of persistently elevated d dimers in older patients with recurring clots (PE/DVT etc)?*

An example of a broader question is: *What is known about creating an effective ED Emergency Department] care environment for elder care (from first responders, through discharge)-- in terms of obtaining adequate data, maximizing communication, supporting sensory deficits, configuring the physical environment to optimize functioning, incorporating safety features, enabling efficient care for providers, and providing transitional data to discharge environment?* Or, *How does treatment of ovarian cancer differ between younger and older women?*

Often case scenarios are presented with the clinical question embedded within them. For example: *Older male from NH [nursing home] with advanced dementia admitted to hospital as full code. No MPOA, [medical power of attorney] no relatives, no guardian per records from NH. His wishes are unobtainable given current dementia or perhaps co-existing delirium due to acute illness – i.e., he is oriented only to self. He has progressive respiratory failure and team forced to make decision to intubate/send to ICU or no. Given current legal climate in US, team decides to send to ICU, is intubated, and eventually dies while in ICU. [Physician] wonders if there is any literature to support not sending him to the ICU - could he have decided on hospice or similar using ethics committee - or any recommendations on this topic in the geriatric literature?*

Scholars also ask for culturally specific information such as: *Are there references for discussing or implementing code status (do not resuscitate/allow natural death) in Navajo or Hopi communities?* (See appendix) Or: *What is known about depression among American Indian (e.g. Apache and/or Navajo) or other tribes? In terms of epidemiology and risk factors, clinical presentation, effects of treatments?*

After receiving a question, the informationist conducts a search in *PubMed* and many of the evidence-based databases such as the *Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effectiveness (DARE), ACP Journal Club,* and—most recently *Up to Date,* and chooses the most relevant resources. She then summarizes and synthesizes a response, whose lengths have ranged anywhere from one to ten (single spaced) pages. An annotated bibliography with links to the full text (wherever available) of all resources used is appended to the response and submitted to the mentor/scholar team. They are invited to submit further clarifying questions and also to evaluate the usefulness of the response to their knowledge base and clinical practice. In this manner we hope to achieve the goal, articulated in the "*Program Summary*" of providing

> ….evidence-based material in response to clinical questions. This inquiry process is important because it: a) Provides a real 'needs assessment' from which we can modify the curriculum; b) Builds an evidence-based library within each specialty and; c) Can be the basis for extension of academic activities, such as lectures, web-based training, case-based training or journal articles. (p.17)

The responses will form the basis of a regular feature in the *Arizona Geriatric Society Journal* and will also be featured, on a rotating basis, on the Web site (under construction) of the Arizona Program of Applied Geriatrics. As an example, the question about end of life discussions within American Indian communities is included in the appendix to this article.

Both the Arizona Reynolds Program of Applied Geriatrics and the Arizona Health Sciences Library are enthusiastic about our partnership. One insight that has emerged is that clinicians' knowledge gaps are not always attributable to their lack of time or expertise in accessing the information—the sheer volume of which seems overwhelmingly vast. Equally vast, particularly in the field of geriatrics are conclusive evidence-based answers to many of the questions that clinicians are asking. Ultimately, perhaps we will be able to positively influence not only the thought and practice patterns of physicians caring for older individuals, but the nature and structure of the research and clinical studies upon which those thought and practice patterns ultimately depend.

References

Arizona Reynolds Program of Applied Geriatrics: Program Summary (2006) (internal document)

Davidoff, F. & Florance, V. (2000). The Informationist: A New Health Profession? *Annals of Internal Medicine 132*(12) 996-998.

Appendix

Sample Scholar Question with Response and Annotated Bibliography:

Are there references for discussing or implementing code status (do not resuscitate/allow natural death) in Navajo or Hopi communities?

There is little written on code status and palliative care in American Indian communities as a whole, significantly less which focuses specifically on the Navajo and nothing that I could find which specifically addresses Hopi concerns.

Hepburn and Reed (1995) note that [at the time of their writing, 1995,] "the literature is practically mute on end-of life decision making" (p.98). Their article, "Ethical and Clinical Issues with Native-American Elders: End-of Life Decision Making" is divided into a review of the literature followed by a report of their own qualitative research in which they conducted "a dozen interviews with health-care workers involved with a number of different groups (including Navaho [sic], Mountain and Southern Ute, Chippewa, Pueblos, and Apache)" (p.105). In these interviews they focused on "four key concepts related to end-of-life decision-making: autonomy, advance directives, competence, and surrogate decision-making" (p. 104). They conclude with some basic guidelines for clinicians.

Throughout the article, the authors stress the tremendous diversity that exists between tribes and that although some common themes may emerge when cultural values are compared to the dominant culture—great care must be made not to generalize. Specifically, they discuss the fact that there is, among Native Americans, a "perception that time is circular, rather than linear," and that

> a cycle of birth, life, and death is fundamental in nature and requires no manipulation or anticipation. With some exceptions, this sense of the circularity of time makes talking about death relatively easy; however, among some groups (such as the Navaho [sic]), belief is strong that talking about death may precipitate it and therefore should be avoided (p.100).

This last point emerges in every article that touches even tangentially on issues of death and dying within Navajo communities. It is mentioned by Melvina McCabe in her article, "Patient Self-Determination Act: A Native American (Navajo) Perspective," and forms the crux of Taylor's 2004 article in the Journal of Social Philosophy, "Autonomy and Informed Consent on the Navajo Reservation." In this article he discusses, at great length the Catch-22 that

> the traditional Navajo ask that their healthcare providers "*Doo'ajiniadah*" (approximately, "don't talk negatively!"). However, if a healthcare provider honors her Navajo patients' *Doo'ajiniadah* request, these patients will be unable to give their informed consent to their treatment, for they will not receive the information that they need to make informed decisions. The traditional Navajo also refuse to participate in the discussions concerning advance directives that are mandated by the PSDA, for they believe that talking about the possibility that they will become terminally ill and/or in a persistent unconscious state will either cause them to suffer this fate or else make it more likely that they will (p508).

Taylor presents Ruth Macklin's solution to this dilemma primarily for the purpose of disputing it. Macklin, whose extensive writings I did not read, apparently suggests that:

> rather than disclosing the risks of their prospective treatments to those Navajo patients who hold the traditional beliefs concerning causation, this information would be withheld from them, on the grounds that, given their belief system, a 'lower' standard of informed

> consent should apply to them. Macklin argues that both concern for the autonomy of the Navajo patient and concern for his well-being support this approach to the problem. ... (p.509).

Taylor offers the alternative philosophical argument that "a Navajo might *not* decide to go untreated if he is *also* 'thinking negatively' about remaining untreated" (p.511). He offers the following alternative solution:

> The traditional Navajo patient should be asked if he wishes his healthcare provider to withhold information from him about the risks of his treatment options. This will enable him autonomously to decide if he wishes to avoid the 'negative thinking' that he might otherwise engage in, and which might lead both to the diminution of his mental well being as well as his physical well being (if he thereby refuses treatment that he would be better off pursuing) [pp. 513-4].

Taylor concludes by arguing that this surrender of some degree of autonomy, an ethical principle which is held in very high regard by Navajos, can be justified if one views autonomy as *instrumentally* valuable rather than *intrinsically* valuable. The convolutions of this philosophical article reflect the conceptual and cultural complexities involved in approaching the subject death and dying from a medical model in American Indian communities.

In general Taylor's suggestions seem more suitable for true informed consent of elective procedures than for considerations of DNR orders or arrangements for palliative care. This may actually be useful for, as Hepburn & Reed (1995) found in their series of interviews, there was a strong "distinction between end-of-life decisions made in advance of a life-threatening situation and those made in the face of such a situation. The former presented considerable difficulty and were variably obtainable; the latter were typically accessible" (p.105). With regard to making true end of life decisions, the authors found that patients and their families "accepted their situation and impending death as something to be expected and unavoidable. Their decisions, in these circumstances, to be in harmony with the larger cycles of life were taken matter of factly and were not seen as great struggles" (p.105). Along these lines, Kitzes and Berger note:

> Many families are unaware that the prevailing Western model for end-of-life health care applies life-prolonging efforts unless specific alternate plans are made. The IHS, similar to most private health care systems and emergency medical systems in the United States, practices automatic activation of cardiopulmonary resuscitation (CPR) therapy, regardless of a patient's disease state, unless a documented advanced directive is available. Yet for many American Indian families and their clinical providers, the legal requirements for advance directives are intrusive and insensitive.

…bringing us back to our original conundrum:

> For many AI/AN individuals the premature discussion of future, untoward events is believed to lead to their occurrence. Even experienced clinicians have difficulty knowing

> when and how to approach families to discuss care beyond cure, DNR decisions, organ donations, and autopsy. Within the privacy of extended family meetings, these issues are often considered only "when the time comes."

Finally, several of the authors conclude with suggestions and guidelines, which, though vague, can be helpful. The common denominator of these suggestions is the need to be flexible. Protocols cannot be overly rigid—either in terms of who on staff actually obtains the advance directive, or which family member it is received from. "Fixed procedures (for instance, it is the role of the nurse or the social worker to get patients' advance directives) and protocols (only signed and witnessed forms can be acted on) many not be successful and may create a barrier to ascertaining the patients' true wishes" (Hepburn & Reed, 1995, p.107). "…[T]he family group will present itself in its own shape, and the clinician should not attempt to prescribe or proscribe membership" (p.109).

Occasionally communications must be indirect. Hepburn & Reed describe a situation in which a patient spoke of the care a relative received several years back and it was only after a period of time that the clinicians were able to recognize that-- in her manner of speaking about that care—the patient was signaling her own wish to be treated in a similar fashion. Communications may occur over prolonged period of time and take forms not immediately recognizable by Anglo practitioners.

> Clinicians who are not Native Americans reported leaving conversations with patients or with patients and families thinking that nothing of substance had occurred only to be told by a Native-American participant that an important decision had been reached. Aside from the issue of needing a language interpreter when the elder's language is not English or when she or he is more comfortable in a native language, clinical encounters with elders may require cultural interpreters (p. 109).

Hampton (2005) suggests: "Trained community health representatives who know the family and their culture are ideal for interpreting those end-of life issues" (p.39).

There is clearly no universal advance directives protocol that can be easily retrofitted to American Indian communities. How the need to remain extremely flexible to maintain cultural respect and sensitivity conforms to the simultaneous trends within American medicine to try to standardize care, meet accreditation needs and protect clinicians from liability is one of several larger questions which emerges.

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References

Finke, B., Bowannie, T., & Kitzes, J. (2004). Palliative care in the pueblo of Zuni. *Journal of palliative medicine, 7*(1), 135-143.

The American Indian and Alaska Native population is aging and the leading causes of death for those aged 55 and older are chronic diseases such as cancer, heart disease, and the complications of diabetes. There are limited formal palliative care services available to rural and reservation dwelling American Indians and Alaska Natives. This collaboration between a tribally operated home health care agency and a federally operated Indian Health Service hospital, with the support of a palliative care center within an academic medical center, has established a palliative care program in the Pueblo of Zuni. The program is based in the tribal home health agency. Barriers to development included the rural setting with limited professional workforce, competing demands in a small agency, the need for coordination across distinct organizations, and the need to address the dying process in a culturally proficient manner. Family-focused interviews and other techniques were used to tailor the palliative care program to the unique cultural setting. The program has sought to integrate inpatient care of terminally ill patients at the Indian Health Service (IHS) hospital with outpatient hospice care. The initial goal of obtaining certification as a Medicare Hospice provider has not been met and remains a goal. Meanwhile alternative mechanisms for funding the services have been found. The experience of this collaboration suggests that a tribally based, culturally proficient palliative care program can be developed within an American Indian/Alaska Native community and that it can drive the local health system toward improved end-of-life care.

Hampton, J. W. (2005). End-of-life issues for American Indians: A commentary. *Journal of cancer education : the official journal of the American Association for Cancer Education, 20*(1 Suppl), 37-40.

Hepburn, K., & Reed, R. (1995). Ethical and clinical issues with Native American elders. end-of-life decision making. *Clinics in geriatric medicine, 11*(1), 97-111.

This article offers guidance to clinicians for approaching and conducting end-of-life decision-making conversations with Native American elders. The guidelines emphasize the need for flexibility and clarity in communication, avoidance of insistence on formal structures and rigid time frames for decision-making, sensitivity to the cultural and family situation of the elder, and recognition that cultural as well as language interpretation may be necessary. Given the great diversity of the tribes and bands as well as languages among native people and the paucity of empirical work on this topic, the tentative nature of these guidelines is stressed.

Kitzes, J. (2001) Talking Circle: Palliative Care and End of Life Care for American Indian and Alaska Native Communities. [Electronic version]. *IHS Primary Care Provider 26* (5), 73-74.

Kitzes, J., & Berger, L. (2004). End-of-life issues for American Indians/Alaska Natives: Insights from one Indian health service area. *Journal of palliative medicine, 7*(6), 830-838. BACKGROUND: In the United States, the American Indian and Alaska Native (AI/AN) population is aging and the leading causes of death for those 55 and older are chronic diseases such as cancer, heart disease, and the complications of diabetes. Since 1955, the federally directed Indian Health Service, along with Tribal governments has been providing comprehensive health care to over 500 AI/AN communities. OBJECTIVE: This is the first study to examine end-of-life and palliative care issues broadly at selected Indian Health Service facilities in the Albuquerque area. DESIGN: Retrospective medical records review identified from randomized New Mexico Department of Health American Indian resident death certificates, 50 years of age and over, from 1994-1998. Interviews with hospital administrators, medical records personnel, and cultural advisors regarding end-of-life policies and procedures were conducted. RESULTS: The study documents very limited formal palliative care services available to rural and reservation-dwelling American Indians and Alaska Natives. However, new initiatives and training in palliative care are emerging. CONCLUSIONS: Recommendations for fostering expansion of end-of-life and palliative care services for AI/AN persons are discussed.

McCabe, M. (1994). Patient self-determination act: A Native American (Navajo) perspective. *Cambridge quarterly of healthcare ethics : CQ : the international journal of healthcare ethics committees, 3*(3), 419-421.

Taylor, J. S. (2004). Autonomy and informed consent on the Navajo reservation. *Journal of social philosophy, 35*(4), 506-516.

This article suggests a solution for the implementation of the Patient Self-Determination Act (PSDA) in the medical facilities that serve the Navajo. The correct solution to the difficulty of implementing on the Navajo reservation those aspects of the PSDA that are concerned with ensuring that healthcare professionals secure their patients' informed consent to their medical treatment is to provide traditional Navajo patients with the opportunity autonomously to cede a degree of their autonomy to their healthcare provider. This solution recognizes that some Navajo patients might autonomously wish to give up some of their autonomy to secure their well-being, and that respect for their autonomy requires that this wish be respected. That respect for a person's autonomy requires that he should be allowed autonomously to give up some degree of his autonomy might at first sight appear conceptually problematic. But this is so only if one holds that autonomy intrinsically valuable. If one holds autonomy to be instrumentally valuable, then the claim that respect for a person's autonomy requires that he be allowed autonomously to relinquish some degree of his autonomy is not problematic at all, if the person concerned relinquishes some of his autonomy to secure the good that he usually uses his autonomy to secure. Thus, that a traditional Navajo patient would be willing to sacrifice a degree of his autonomy to secure his well-being indicates that for him his autonomy is of primarily instrumental value.

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