

Report of the Ohio Compassionate Care Task Force



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Note: Appendix H contains a Glossary of terms.
The first time one of these terms is used in the report, it appears in *italics*.

March, 2004

BACKGROUND

CHRONIC PAIN

Chronic pain is among the most disabling and costly afflictions in North America. A meta-analysis of studies looking a chronic pain in the general population identified the prevalence of severe chronic pain to be 8% in children and 11% in adults (Harstall & Ospina, 2003). Chronic pain has significant socioeconomic, health, and quality of life implications. Persons afflicted with chronic pain often cannot work, participate in physical activity, or enjoy their family life or social activities. The physical and psychological consequences of inadequately managed chronic pain include decreased organ system function, impaired immune function, sleeplessness, loss of appetite, and impaired movement. Soon the person becomes the victim of a vicious cycle in which total preoccupation with pain leads to irritability and depression, putting the individual at increased risk for suicide (Fishbain, 1999).

Chronic pain is also expensive. The cost of lost productivity due to pain is estimated at \$61.2 billion annually (Stewart, et al., 2003). When medical costs are added in, the annual cost of pain is upwards of \$120 billion (Griffin, 2003).

Yet chronic pain is poorly managed, receives little attention in healthcare educational programs, and is one of the most under funded major health problems in the United States.

TERMINAL ILLNESS

“In some respects, this century’s scientific and medical advances have made living easier and dying harder” (Field & Cassel, 1997, p.14). The focus on cure too often diverts attention from the care that persons want and need (Field & Cassel, 1997). The need for expanding and responding to end-of-life care is growing rapidly. As the demographics of the aging population shift we find individuals are living longer with chronic, debilitating, and life-threatening illnesses and the rate of deaths are beginning to increase. We live in a death-denying culture that fails to promote effective planning for the end of life. Death is perceived as a failure in the medical and lay communities. Schools of medicine and nursing have little coursework in the physical and psychological needs of the dying patient. Yet, it is inevitable that we will all die; every healthcare professional will encounter death and dying in practice.

Unfortunately, most Americans today continue to die in hospitals or other health facilities, often receiving invasive, high-technology treatments that would be more appropriate for those expected to recover from their medical conditions. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment demonstrated substantial shortcomings in the care of seriously ill hospitalized adults (SUPPORT, 1995). This study revealed that patient preferences are often not known or honored, patients and family members are not accurately informed of the prognosis, pain at the end of life is often undertreated, and death too often occurs in intensive care unit settings.

Certified *hospice* programs have been delivering comprehensive, cost-effective *interdisciplinary* care to the terminally ill in this country for over 20 years. Family members of persons who died at home with hospice services are more likely to report a favorable dying experience than those whose loved one died in an institution (Teno, et al., 2004). However, many patients and families who would benefit from receiving hospice care do not receive these services. Some reasons include a reluctance of healthcare providers to discuss advance care planning, difficulties in

determining a 6-month or less prognosis, and inadequate payment for high-cost palliative interventions that are effective but cannot be paid for under hospice reimbursement systems.

Palliative care is a term used to describe comprehensive, interdisciplinary care to persons with life-threatening illnesses and their family members. It is similar to hospice care except it offers care to a broader population of patients. There is no "6-month or less" prognosis criterion for receiving palliative care services. Ideally, palliative care is initiated at the time of diagnosis with a life-threatening illness. Palliative care is both a general approach to comprehensive comfort-oriented care that is integrated with disease modifying therapies as well as a growing practice specialty for highly trained physicians, nurses, pharmacists, social workers, chaplains, and other members of the interdisciplinary team. Palliative care has been demonstrated to significantly reduce the costs of care in the final days of life (Naik, 2004).

IMPACT OF CHRONIC PAIN AND TERMINAL ILLNESS ON FAMILY CAREGIVERS

The medical progress that has brought us

increased longevity has placed unforeseen financial and emotional pressures on families. New medications and treatments allow people to leave the traditional hospital setting and return home sooner. It also thrusts family caregivers into new roles. Today, many caregivers must oversee the in-home use of sophisticated machines such as feeding tubes and respirators that were once the responsibility of only highly trained health care professionals. Often caregivers must administer multiple medications and measure daily weights, blood pressures and blood tests, reporting data to professionals so that medication dosages can be adjusted accordingly. The caregivers who provide these services frequently must also provide transportation of their loved one to and from appointments, in addition to providing nutrition, bathing and linen changes. The caregivers must become the patient's advocate, navigating a complicated health care system on behalf of their loved one. Appendix F, written by a public representative to the Task Force, illustrates some of the emotional pressures family members face.

Studies conducted by the National Alliance for Caregiving and the American Association for Retired Persons found that individuals in nearly



23 percent of American households are involved in caregiving to persons who are 50 years of age and older. Between 1987 and 1997, the number of households in the United States caring for family members or friends over age 50 tripled to over 22 million. More than 7 million older adults now have long-term care needs. This number will reach 10 million by 2020 and 14 million by 2040. (National Alliance for Caregiving/AARP, 1997)

Family caregivers are usually unpaid. They provide a vital service to the American economy, as the value of their services would exceed \$200 billion per year. They currently provide approximately 80 percent of all home care services in the country. Family caregiving may delay or avoid the need for institutionalization of their loved one (Arno, Levine & Memmott, 1999).

Family caregivers are often referred to as the "hidden patient." While caregiving can be rewarding, it is also extremely time-consuming, costly and stressful. Caregivers often put the needs of the patient ahead of their own needs. They may suffer from social isolation, sleep deprivation, and anxiety. Generally these caregivers are women. They may be elderly themselves or may be daughters or daughters-in-law who are dealing with other responsibilities such as raising their own children, attempting to main-

tain a job and have financial constraints as well. Caregivers often give up their own employment, losing personal health care benefits and payment into pension plans or into Social Security. Advocacy for family caregivers will require a collective public voice, legislative initiatives and Medicare reform. Information regarding this emerging social and public policy issue can be obtained from advocacy groups such as the National Family Caregiver Support Program, a project of the National Association of Area Agencies on Aging.

LEGISLATIVE AUTHORITY

Recognizing the importance of addressing the profound physical, psychosocial, and economic impacts of *terminal illness* and severe chronic pain, the Ohio General Assembly enacted House Bill 474 December 2002, creating the Compassionate Care Task Force. The Task Force met monthly from May 2003 through March 2004 for the purpose of studying and making recommendations concerning issues surrounding the treatment and care of persons with terminal illness or severe chronic pain. These recommendations are discussed in this report. The Task Force will continue to meet through March 2005 to address its second responsibility of monitoring and reporting on the implementation of its recommendations.

H.B. 474 delineated a variety of participants for the Compassionate Care Task Force and required the Director of Health or the Director's designee to be chairperson of the Task Force.

MEMBERSHIP

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TASK FORCE RECOMMENDATIONS

Force activities began with identification of the many barriers interfering with appropriate care of persons with chronic pain and persons with terminal illness. Following identification of barriers three subcommittees worked to (1) identify current needs and resources for pain management and palliative care in Ohio, (2) identify best practices for the care of persons with chronic pain, persons with terminal illnesses, and the family members of these two groups of patients, and (3) develop strategies to improve the pain management and palliative care practices in Ohio.

In addition to the activities of the subcommittees, a series of Town Hall Meetings were held in 9 different locations throughout the state. A total of 137 individuals attended these meetings, including patients with chronic pain, family members of persons with pain and terminal illnesses, and healthcare professionals. Their written and verbal testimonies confirmed the Task Force's perceptions about many of the barriers interfering with the care of persons with pain and those with terminal illness and reinforced some of the actions needed to begin to break down these barriers. Appendix C outlines the themes of discussion and the suggestions made by the Town Hall Meeting participants.

The reports of the Service Needs and Resources Subcommittee and the Best Practices Subcommittee are in Appendices B and C, respectively. The Practice Improvement Subcommittee used the reports from the other two subcommittees and their own group discussion to develop draft recommendations. The entire Task Force reviewed and revised these recommendations with much discussion to reach consensus.

The barriers to quality care of persons with chronic pain and persons with terminal illness serve as the framework and rationale for the recommendations.

A. Healthcare professionals receive insufficient education on the care of persons with pain and persons with terminal illnesses in their basic education programs; many practicing healthcare providers have not updated their knowledge and skills in these areas; and, there is a lack of pain and palliative care specialists throughout the state, but especially in rural areas.

1. All schools of medicine, nursing, pharmacy, and licensed allied health

professions should ensure that appropriate and sufficient curricula on pain management (acute and chronic) and palliative care are integrated into core content.

Further, these schools should:

- a. Establish and track outcomes measures for competencies for all students in caring for persons with pain and for persons with terminal illnesses.
- b. Establish an office of pain management and palliative care to be responsible for assuring the aforementioned goals are achieved.

2. Interdisciplinary pain and palliative care centers should be piloted to pursue the following objectives:

- a. Serve as model interdisciplinary pain management and palliative care clinical programs for both adult and pediatric patients and their family members.
- b. Include the use of *integrative medicine* to manage physical, emotional, social and spiritual symptoms associated with chronic pain and terminal illnesses.
- c. Train adult and pediatric pain and palliative care specialists, including medicine, nursing, pharmacy, and licensed

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allied health professions.

- d. Provide consultation and education for healthcare providers in the state including outreach to underserved areas.
- e. Lead research initiatives to improve the quality of life and quality of care for persons of all ages, and their family members, experiencing chronic pain and terminal illnesses. These research initiatives should establish evidence-based practice guidelines.

3. Entities currently responsible for education of health care professionals should develop and distribute educational programs and materials on the care of persons with pain and persons with terminal illnesses. These materials should address the needs of underserved populations, patients/families of all ages (infants through the elderly), and diverse cultural groups, and should include the following:

- a. Myths/Truths regarding the treatment of chronic pain and terminal illnesses to address the common barriers that interfere with optimal care of these populations.
- b. Medical-legal issues related to the treatment of persons with chronic pain and

those with terminal illnesses, including the appropriate treatment of pain in persons with a history of substance abuse.

- c. Cost issues related to the treatment of pain and terminal illnesses and the impact of cost on access to care and compliance with the plan of care.
- d. Importance of an interdisciplinary approach when caring for persons with chronic pain, those with terminal illnesses, and family members affected by their loved ones' illness.
- e. Significance and management of depression and other psychiatric and emotional problems in persons with chronic pain and those with terminal illnesses.
- f. Rights and responsibilities of:
 - i. Prescribers of opioids and other controlled substances.
 - ii. Pharmacists filling prescriptions for opioids and other controlled substances.
 - iii. Persons with pain and persons with terminal illnesses, including the rights of pediatric patients.
 - iv. Family members of persons with pain and those with terminal illnesses.



- g. Resource lists of evidence-based practice guidelines for palliative care, pain caused by cancer, and pain caused by other chronic conditions.
- h. Resource lists of structured training programs on the care of persons with pain and those with terminal illnesses.
- i. Resource lists of evidence-based integrative medicine interventions for the care of persons with pain and those with terminal illnesses.
- j. Summaries of recent literature related to the care of persons with pain and those with terminal illnesses.

4. All Boards licensing healthcare professionals in Ohio should discuss with their professional associations and other interested parties the feasibility of mandatory continuing education regarding pain management and palliative care. These Boards should explore requiring those parties approving or providing continuing education to annually track the number of and attendance at courses that include pain management and palliative care.

B. Patients' and their family members' misinformation and fears about pain management and palliative care interfere with appropriate care of persons with pain and

terminal illnesses; and, patients and families often find it difficult to "navigate the system" to know what to expect, find resources, and act as their own advocates.

1. The Ohio General Assembly should establish a funded Pain/Palliative Care Ombudsman program within the Department of Health whose responsibilities include:
 - a. Assisting patients/families to obtain the necessary information to be their own advocates when seeking care for pain management and palliative care from healthcare providers, including explaining patient and family rights for pain management and palliative care.
 - b. Assisting patients/families to locate resources for pain management and terminal illnesses.
 - c. Assisting patients/families to work with their insurance companies to negotiate coverage of services needed and appeal denials, when appropriate.
 - d. Developing and maintaining a web site with patient/family information on pain management and palliative care, including specialized resources and links for pediatric and adolescent patients.
 - e. Tracking and reporting to interested parties the types of barriers the public is facing in obtaining optimal pain

management and palliative care, including barriers specific to various age groups (e.g., children, adolescents, and the elderly) and diverse cultural groups.

- f. Developing and tracking the outcomes of initiatives to improve the quality of care for persons with pain and persons with terminal illnesses.

2. A pain management and palliative care service locator should be created and maintained to allow patients, their families, and providers to identify and access these services and to compare salient characteristics of available providers.

C. There is a lack of understanding of the profound impact of chronic pain and terminal illness on family systems. And, there is a lack of support to assist families to face the physical, social, emotional and financial burdens of caregiving.

1. Psychological and emotional assessment and intervention for family caregivers should be included in the interdisciplinary plan of care for patients with chronic pain and those with terminal illnesses. Particular attention should be paid to the unique needs of families caring for dying children and adolescents.

2. The General Assembly should enact legislation allowing persons receiving services through the Community Based Services Waiver programs to receive hospice services concurrently if they meet the eligibility criteria in the Medicare/Medicaid Hospice Benefit.

3. Initiatives should be investigated to evaluate the benefits and costs of programs that pay or offer supportive services to family members as caregivers for persons with chronic pain and terminal illnesses. Special efforts should be made to enable parents to be paid as caregivers for children and adolescents with terminal illness. Programs currently offering these types of benefits include the Cash and Counseling demonstration project, the PASSPORT "Choices" program, and the Ohio Department of Mental Retardation and Developmental Disabilities (MRDD) "Level 1 Waiver Handbook".

D. There are no uniformly accepted standards for palliative care or pain management programs nor uniformly accepted guidelines for care of persons with chronic pain or terminal illnesses, leading to inconsistencies and inadequacies in care provided to patients and families throughout the state. Such inadequacies

are intensified in special needs populations for whom evidence-based practice is often nonexistent.

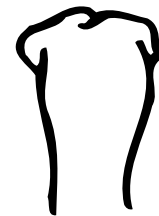
1. In order to identify themselves as providers of pain management and palliative care services, providers and agencies should adopt program standards, such as, but not limited to:

- a. Pain management program standards:
 - i. "Desirable Characteristics for Pain Treatment Facilities" from the International Association for the Study of Pain (IASP, 1990)
 - ii. "Clinical Practice Guidelines for Chronic Non-Malignant Pain Syndrome Patients" (Sanders, et. al., 1999).
- b. Palliative care program standards:
 - i. "Core Clinical Components of a Palliative Care Program" from the Center to Advance Palliative Care (CAPC, 2004).
 - ii. "Precepts for Palliative Care" from Last Acts (Last Acts, 1997).

2. Patient-driven, outcome-based guidelines should be used in providing pain management and palliative care, such as, but not limited to:

- a. Chronic pain: the VA/DoD Clinical Practice Guidelines for the Management of

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Opioid Therapy for Chronic Pain.
(Department of Veterans Affairs, 2003).

b. Palliative care: the National Comprehensive Cancer Network Palliative Care Clinical Practice Guidelines.
(National Comprehensive Cancer Network, 2003).

3. Particular attention should be paid to establishing treatment guidelines for children and adolescents, the elderly, and other special needs populations for whom current therapies are often not appropriate or proven safe and effective.

4. State agencies and institutions proposing practice standards and guidelines that impact the care of persons with chronic pain or persons with terminal illnesses should provide copies of these proposed standards and guidelines to the Ohio Pain and Palliative Care Advisory Committee (see recommendation H) for comment prior to their adoption.

E. Fear and misunderstanding of the existing statutes and rules regarding prescribing of opioid medications interfere with appropriate pain and symptom management.

1. The Ohio Pain and Palliative Care Advisory Committee (see

Recommendation H) should evaluate the report from the Legislative Services Commission, when issued, on the impact of changing the term “dangerous drugs” to “prescription medications” in all statutes and rules in the state and make recommendations regarding this change to interested parties for further discussion.

2. The State Medical Board of Ohio, Ohio State Board of Pharmacy, and State of Ohio Board of Nursing should continue and strengthen educational programs to promote proper pain management. The Ohio Legislature should support funding for these educational efforts.

3. The above Boards should work with the Pain and Palliative Care Advisory Committee (see Recommendation H) to review governing statutes and rules for relevance and consistency with current standards of care for pain management and palliative care. For example, the second opinion requirement for the diagnosis and treatment of intractable pain should be reviewed.

4. The General Assembly should appropriate funds for the State of Ohio Board of Pharmacy to establish and maintain a statewide, computerized prescription monitoring

program (PMP) for use by healthcare professionals to minimize inappropriate conduct by patients and to promote continuity and quality of care.

a. The rules generated for the PMP should provide assurances that legitimate prescribing and dispensing is protected;

b. Individual healthcare professionals should have access to PMP data concerning their individual patients for purposes of evaluating those patients’ use of controlled substances;

c. Law enforcement agencies should have access to PMP data only when reasonable cause justifies such access in the course of investigating possible abuse or diversion. There should be strong language offering protections to prescribers that the PMP is used for the primary purpose of monitoring patients and not monitoring prescribers.

d. Funded educational programs should be provided when the PMP is unveiled that include, but are not limited to, information on the rationale for the development of the PMP and how and when to use the system.

5. The current Revised Code language restricting the prescribing of Schedule II medications by advanced practice nurses

should be reviewed by the State of Ohio Board of Nursing and other interested parties to consider language changes to permit greater latitude for the treatment of pain to promote continuity and quality of care.

F. Fear of regulatory scrutiny and litigation interfere with providing appropriate care.

1. Law enforcement personnel should continue to be educated regarding the legitimate use of opioids in the care of persons with chronic pain and persons with terminal illnesses.
2. Healthcare providers should be educated regarding the actual fact patterns that lead to criminal convictions or administrative sanctions against healthcare providers.
3. The General Assembly should investigate tort reform to alleviate the malpractice crisis.

G. Inadequate payment for interdisciplinary care and for medications and interventions required for appropriate care of persons with chronic pain and persons with terminal illnesses creates barriers to access. Two important barriers interfering with access to hospice services are (1) the required estimation by the primary physician of a 6-month-or-less life

expectancy, and (2) the inability of the hospice per diem payment system to pay for beneficial, but much more expensive palliative treatments.

1. Ohio Medicaid and 3rd party payors should investigate the expansion of life expectancy eligibility for hospice services from the current 6 months to 12 months as is currently being done in many other states.
2. Ohio Medicaid and 3rd party payors should evaluate carving out certain palliative interventions such as radiation therapy, chemotherapy and transfusions from the hospice per diem as is currently being trialed in the national pediatric demonstration project.
3. As interdisciplinary team care is the standard for patients with chronic pain and those with terminal illnesses, Ohio Medicaid and 3rd party payors should establish payment schedules that appropriately pay the interdisciplinary team members involved in the care of individuals and their family members. These payment schedules must include:
 - a. Fair payment for the time spent with patients and families;
 - b. Ongoing payment for the prolonged bereavement services required for families

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of children and adolescents who have died.

c. Psychosocial interventions for persons undergoing therapy for chronic pain.

4. The Ohio General Assembly should memorialize Congress to address the above issues for Medicare.

5. Ohio Pain and Palliative Care Advisory Committee (see Recommendation H) members representing adult pain management, pediatric pain management, adult palliative care, and pediatric palliative care should be on the advisory boards of Ohio Medicaid and 3rd party payors to provide input on issues such as formulary development and pharmacy benefits management to assure adopted rules and practices promote good pain management and palliative care practices.

H. The number of individuals, groups, agencies, and organizations involved in the care of persons with chronic pain and persons with terminal illnesses can be overwhelming to investigate and can cause fragmentation in care.

1. To facilitate advocacy and decrease fragmentation of care, the Ohio Pain Advisory Committee should be renamed the Ohio Pain

and Palliative Care Advisory Committee (OPPAC) and should be funded for activities within the budget of the Pain and Palliative Care Ombudsman program.

2. The membership of OPPAC should reflect the interdisciplinary team caring for persons with pain and persons with terminal illnesses and should include consumer and family representation.

3. The OPPAC's responsibilities should include, but not be limited to:

- a. Recommending changes in laws, statutes, and rules interfering with optimal pain management and palliative care.
- b. Participating on Medicaid and 3rd Party Payor Advisory Boards.
- c. Reviewing reports from the Pain/Palliative Care Ombudsman program.
- d. Reviewing and making recommendations for content in the pain and palliative care services locator system.
- e. Reviewing and making recommendations to state agencies and institutions on proposed standards or guidelines impacting the care of persons with chronic pain or persons with terminal illnesses.

APPENDIX A - SERVICE NEEDS AND RESOURCES SUBCOMMITTEE REPORT

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PAIN MANAGEMENT AND PALLIATIVE CARE NEEDS

Persons With Terminal Illness

Statistics from the American Cancer Society website (ACS, 2004) show estimates of new cancer patients per year and cancer deaths per year; this data can be used to estimate the current number of cancer patients in the state of Ohio. The number of new cancer cases in Ohio is estimated to be 59,410 for 2004 (ACS, 2004) and 24,480 deaths from cancer are expected. As a conservative estimate, the number of new cases was multiplied by 3-1/2 to 4 times to assess the number of cancer patients at any given time in the state of Ohio. This equates to 207,935 to 237,640 cancer patients. Persons living with cancer could benefit from palliative care and those dying with cancer could benefit from hospice care.

It is important to note that cancer is certainly not the only terminal illness requiring palliative hospice care. The preliminary estimate of total deaths in Ohio for 2002 is 109,547 (Kochanek & Smith, 2004). Of these, approximately 43% are

due to chronic, life-threatening non-malignant diseases, such as cardiovascular, cerebrovascular, chronic respiratory, Alzheimer's, and chronic liver diseases. These 47,105 (43% of 109,547) persons would likely be candidates for and benefit from hospice care. Estimates of persons living with these chronic, life-threatening diseases who would benefit from palliative care are more difficult to extrapolate. Many of these conditions have life-expectancies measured in years, so the prevalence rate is significantly higher than the death rate.

Persons With Severe Chronic Pain

As discussed in the Introduction, approximately 11% of the adult and 8% of the pediatric population have severe chronic pain (Harstall & Ospina, 2003). Using 8.46 million and 2.9 million as the population of adults and children, respectively, in Ohio, there are approximately 931,000 adults and 231,000 children with severe chronic pain in Ohio. These 1,162,000 persons represent both cancer-related and non-malignant severe chronic pain.



CURRENT SERVICES AVAILABLE IN OHIO

Appendix D lists physician specialists and other health care providers by county in Ohio. Medical specialties are identified when physicians in Ohio renew their medical licenses. Each physician may list up to three specialties from a selection of approximately 60 possible choices, including medical oncology, hematology/oncology, palliative medicine, pain medicine, anesthesia pain management and psychiatry. Since there are 3 possible choices for each physician, some physicians are listed in multiple settings. As examples, palliative medicine specialists may also list themselves as pain medicine specialists and anesthesia pain management specialists may list both pain medicine and anesthesia pain management. Therefore, estimates of specialists available to care for persons with terminal illnesses and those with severe chronic pain may be overstated in this report.

Current Services Available in Ohio for Persons with Terminal Illness

Other than primary care physicians, several specialists have been identified as possible sources for taking care of patients with terminal illness. Physicians specializing in oncology or hematology/oncology are likely to care for persons with terminal illnesses, although a number of studies

have demonstrated that the focus of oncology is more on treatment of the disease than on palliation or pain management. The specialties of palliative medicine, pain medicine, and anesthesia pain management also provide care for persons with terminal illnesses. The total number of practitioners in these 3 specialties is at best 596. Given the estimate of 231,400 persons who are palliative care candidates, there are obviously not enough specialists to care for these patients and their families.

Appendix E shows Programs and Services by county. There are 89 programs providing hospice services to Ohioans. These programs serve approximately 40,000 to 45,000 patients a year, leaving 27,848 to 31,848 patients to receiving end-of-life care outside of a hospice setting despite the fact that these patients are likely hospice-appropriate. Some of these patients may receive care in one of the palliative care programs in the state. Many agencies have established or beginning palliative care services. However, there is currently no registry of these programs for Ohio.

The maps on pages 41 and 43, show the population per Hospice Service Provider and per Pediatric Palliative Care/Hospice Service Provider by county. These maps illustrate that there are many underserved areas of the state.

Although palliative medicine is a somewhat new sub-specialty, it is alarming that there are only 48 physicians who consider themselves palliative medicine specialists in Ohio. This leaves many of the 237,640 cancer patients plus the many thousands of non-cancer patients hoping that non-palliative specialists can and will fill their needs through difficult times.

Current Services in Ohio for Severe Chronic Pain

The specialties of anesthesia pain management and pain medicine are the two most likely groups involved in the care of persons with severe chronic pain. Physical medicine and rehabilitation (i.e., PM&R) specialists often deal with chronic pain, although pain management is not necessarily their area of interest. Psychiatry and psychology may also be included in caring for persons with severe chronic pain, but it should be noted that specialties in pain management under psychiatry and psychology are not that common and are needed for interdisciplinary centers and management of more difficult cases or patients.

Not only are there not enough psychiatrists and psychologists overall, there are many areas of the state that are severely underserved, as illustrated by the map on page 35 showing the population

per Bureau of Workers Compensation Certified Psychologist in the state.

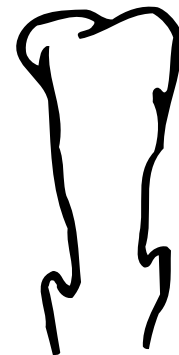
The Needs and Services subcommittee felt that a listing of pain “centers” was not quantifiable or qualifiable for the state of Ohio. A number of very difficult issues in determining available services and disciplines were identified, including the lack of accepted criteria to use to identify a program as a pain center. The Bureau of Workers Compensation does have designated Chronic Pain Program Providers that must meet standard criteria. Appendix E lists the counties with these programs and the map on page 45 shows the population per BWC Chronic Pain Program Provider.

Addiction medicine and addiction psychiatry are sub-specialty listings that are included in this data. Although their services would potentially apply to terminal illness, it is felt that their care is more germane to chronic pain. Statistics indicate that somewhere between 10% to 15% of the population has a lifetime predisposition to develop the disease of addiction. The concern of some clinicians who treat chronic pain is that some people who abuse or are addicted to opioid drugs feign or exaggerate their pain symptoms to obtain drugs. The Substance Abuse and Mental Health Services Administration (2003) reports that 8.3% of Americans were using illicit

drugs in 2002, including marijuana, cocaine, hallucinogens, psychotherapeutics, pain relievers, tranquilizers, and stimulants. Applying even this conservative statistic to the number of persons in Ohio with severe chronic pain, it is likely that at least 96,500 persons in Ohio use drugs illicitly in addition to having chronic pain. Managing pain in this population is extremely complex and necessitates the expertise of addiction specialists. There are 98 addiction medicine specialists and 58 addiction psychiatry specialists in the state of Ohio, a ratio of 1 specialist for every 619 persons with these complex problems. The map on page 39 highlights the paucity of addiction medicine physicians in the state.

The total number of pain medicine specialists and anesthesia pain management specialists (those most likely involved in the care of severe chronic pain) is 465 – if neither of these two pain specialties cross-matched. Thus, at the maximum there are 465 pain specialists for 1 million patients with severe chronic pain in Ohio, or 2150 patients per physician (not counting persons with terminal illnesses). Pain specialists are often located in areas of high population only, as illustrated in the map on page 37, making access to these services extremely difficult for persons in rural areas of the state.

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APPENDIX B - BEST PRACTICES SUBCOMMITTEE REPORT

After reviewing many different pain management and palliative care practice guidelines, the Best Practices Subcommittee members concluded there are many good, evidence-based guidelines for the treatment of various types of acute and chronic pain and for the treatment of persons experiencing physical, psychosocial, emotional, and spiritual symptoms of terminal illnesses. As new guidelines are constantly being developed and published, a process of approving or endorsing guidelines would be overwhelming to begin and likely never kept up-to-date. The key features of best practice guidelines are that they are evidence-based, linked to positive patient outcomes, and address the multidimensional nature of pain and the symptoms of terminal illnesses by using an interdisciplinary approach to care. Persons looking to adopt specific guidelines for practice need to look for these three features.

Despite the breadth and depth of guidelines available to practitioners, there are too many patients whose pain and other symptoms are not being addressed. It appears the problem is not identifying best practice models, but getting these best practices put into practice.

Education of Health Care Professionals

One of the most significant barriers to implementing good pain management and palliative care practices is a lack of knowledge. While all healthcare providers will encounter persons with pain and persons with terminal illnesses in practice, they receive very little education on these topics in their basic education programs. According to Ira Byock, MD from the Promoting Excellence in End of Life Care project, funded by Robert Wood Johnson Foundation, "medical education provides 300 hours of obstetrics to every student when few will ever deliver babies, but offers maybe 40 hours of training in pain management and care of the dying for the majority of physicians who will care for the population that is 100% at risk of need of that care." In a 1996 survey of internal medicine house officers at a teaching hospital, most house officers reported 1-5 hours of prior formal training in palliative care, 1-5 hours in pain management, and 6-10 hours in ethics (Clark, et al., 2003).

It is the belief of the Best Practices Subcommittee that one effective strategy to integrate best practices for pain management and palliative care is to begin to integrate these best practices into the

curricula of all schools of medical, nursing, pharmacy, and licensed allied health professions. Pain management and care of persons with advanced diseases can and should be integrated through each area of disease state management, eliminating a need for additional courses per se. Ury, et al. (2002) demonstrated that teaching a pain and palliative curriculum is associated with sustained improvement in medical residents' prescribing practices. With a coordinated effort to integrate pain and palliative care into all areas of study, the impact on practice could be profound.

Best Practice Centers

In addition, the Best Practices Subcommittee believes that using medical schools in Ohio as centers for pain control and palliative care would produce multiple benefits. These centers would serve as model programs in providing *culturally competent* pain management and palliative care for all age groups, including the use of integrative medicine to manage physical, emotional, social and spiritual symptoms associated with chronic pain and terminal illnesses; serve as training centers for the needed adult and pediatric pain and palliative care specialists, including medicine, nursing, pharmacy, and licensed

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allied health professions; provide a continuous source of consultation and education for health-care providers in the state, including outreach to underserved areas; and lead research initiatives to improve the quality of life and quality of care for persons of all ages, and their family members, experiencing chronic pain and terminal illnesses. Ideally, mobile health care teams from these centers would go out into the community to provide hands-on mentoring and consistent training in the interdisciplinary team model for addressing the complexities of caring for persons with chronic pain and terminal illnesses. To demonstrate the effectiveness of medical school-based pain and palliative care centers, at least one pilot study should be funded and outcomes measures for care and education evaluated.

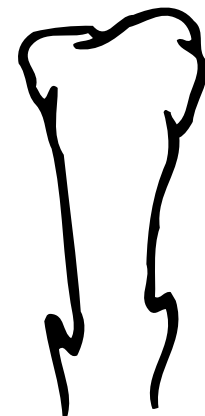
Education of Practicing Clinicians

Professionals who have completed their basic education programs need to integrate best practices for pain management and palliative care into practice as well. Ideally, professionals in practice identify their own learning needs and seek out appropriate continuing education programs. This approach does not work well when people “don’t know what they don’t know”. In

California, legal cases and patient complaints of under-managed pain were used to demonstrate the need for education in medical schools and for continuing education. In 2002 their general assembly passed legislation requiring 12 hours of mandatory continuing education (CE) in pain management and palliative care. Although there continues to be debate on the impact of CE on practice, California participants in the Education for Physicians in End of Life Care program co-sponsored by the Southern California Cancer Pain Initiative and other hosts report positive feedback from participants, including from those who were initially reluctant and displeased with having to fulfill this requirement (Hastie, Kovner, Ferrell, & Grant, 2003).

Prescription Monitoring

The concern held by some clinicians that some people who abuse or are addicted to opioid drugs feign or exaggerate their pain symptoms to obtain drugs interferes with the management of pain for the vast majority of chronic pain patients who are seeking relief from their suffering. Prescription monitoring programs (PMP) may be used by clinicians to check a patient’s prescription drug history to determine if the individual is



“doctor shopping” (Crosse, 2004). When properly designed PMPs assist in identifying individuals who are potentially misusing their prescription medications from those who have legitimate needs. One potential unintended effect of PMPs can be a continuation of undertreatment of pain due to clinician fear that the PMP is being used to monitor the prescriber. An effective PMP must include safeguards so that patients in pain are not denied treatment (AACPI, 2002).

Education of Public, Patients, and Family Members

While there are multiple sources of information on pain management and care of the terminally ill in brochures from organizations, web sites, and the popular press, it is difficult and overwhelming for individuals who are in pain or are stressed to evaluate the quality and manage the quantity of information. Individuals would benefit from a program that could answer questions, link them to community resources, and assist them to be advocates for quality of care. The Nursing Home Ombudsman was established under the Older Americans Act of 1979. This independent program works with the Department of Aging and the Area Agencies on Aging to provide information and advocacy for persons in nursing homes serves. This program can be viewed as a model for an ombudsman program

for pain and palliative care.

The Oregon Department of Human Services web site on Pain Management (ODHS, 2004) serves as a model for education of patient, family, and professional education via the internet. The site is easy to navigate and provides links to appropriate resources. (See Appendix G for a consumer’s point of view on this type of information service.)

APPENDIX C - TOWN HALL MEETINGS

INTRODUCTION

Town Hall Meetings provided a forum to get input from persons dealing with terminal illness or severe chronic pain, family members of persons with terminal illness or severe chronic pain, and healthcare professionals caring for persons with terminal illness or severe chronic pain.

Local offices of the American Cancer Society identified locations and assisted in advertising these meetings. In addition, press releases were sent to newspapers in all locations. These meetings were moderated by Virginia Haller, MD, Chairperson of the Task Force and Debra Heidrich, MSN, RN, Executive Director of the Task Force.

DATES AND LOCATIONS

Town Hall meetings were held in the following locations. Late morning and early evening 1-and-1/2-hour sessions were held in each location, except Dayton where one 3-hour session was held from late morning to early afternoon.

- October 29, 2003 - Marietta
- October 31 - Dayton
- November 4 - North Canton
- November 6 - Toledo
- November 7 - Cleveland
- November 11 - Columbus
- November 18 - Cincinnati
- November 19 - Akron
- December 9 - Athens/Albany

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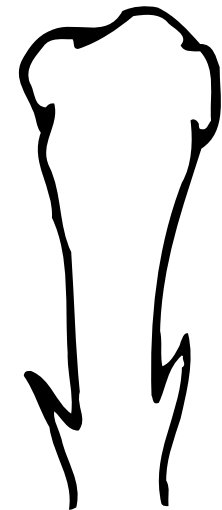


Themes	Marietta	Dayton	North Canton	Toledo	Cleveland	Columbus	Cincinnati	Akron	Athens/Albany
Professionals issues leading to undertreatment of pain.									
Lack of basic education on pain management	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️
Many not keeping up-to-date with current pain management practices	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️
Misunderstandings or fears of regulatory scrutiny	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️
Fear that pain management at end of life hastens death; fear that pain control at end of life will appear to be assisted suicide	☹️		☹️	☹️					☹️
Real or perceived fear of patients becoming addicted or diverting medications	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️
Lack of understanding of pain in the elderly; more complicated if dementia is present	☹️	☹️			☹️		☹️	☹️	☹️

THEMES OF DISCUSSIONS

This table highlights the types of issues addressed in each session and the suggestions made to improve the care of persons with terminal illnesses and those with severe chronic pain.

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Themes	Marietta	Dayton	North Canton	Toledo	Cleveland	Columbus	Cincinnati	Akron	Athens/Albany
Patient factors interfering with receiving adequate pain management.									
Fear of becoming or being perceived as addicted	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️
Belief that nothing can be done about their pain (sometimes reinforced by their healthcare professional)	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️
Not enough pain management specialists	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️
Cost of medications is sometimes prohibitive	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️
Professional factors interfering with appropriate care of the terminally ill.									
Professionals are uncomfortable discussing end of life care issues because it is not addressed in basic education programs	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️
Some professional view a referral to hospice as "giving up"; most do not know difference between hospice and palliative care	☹️		☹️	☹️	☹️		☹️	☹️	☹️

THEMES OF DISCUSSIONS

(CONTINUED)

This table highlights the types of issues addressed in each session and the suggestions made to improve the care of persons with terminal illnesses and those with severe chronic pain.

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Themes	Marietta	Dayton	North Canton	Toledo	Cleveland	Columbus	Cincinnati	Akron	Athens/Albany
Patient factors interfering with receiving adequate pain management.									
Pediatric patients need to have the option to receive potentially curative interventions along with hospice care							☹	☹	
All patients need better attention to symptom control throughout course of terminal illness	☹	☹	☹	☹	☹	☹	☹	☹	☹
System issues interfering with pain management and palliative care.									
Reimbursement system is centered around rehabilitation which does not fit the needs of persons with advanced, progressive diseases		☹	☹				☹		
The certification of a 6-month or less prognosis is difficult in non-cancer diagnoses, yet these patients and families need the full range of hospice/palliative care services		☹	☹		☹		☹	☹	☹
The inability to receive PASSPORT services and hospice concurrently prevents many needed hospice referrals			☹		☹		☹	☹	☹

THEMES OF DISCUSSIONS

(CONTINUED)

This table highlights the types of issues addressed in each session and the suggestions made to improve the care of persons with terminal illnesses and those with severe chronic pain.

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Themes	Marietta	Dayton	North Canton	Toledo	Cleveland	Columbus	Cincinnati	Akron	Athens/Albany
System issues - continued.									
Qualified personal caregivers are scarce and expensive (often not covered by insurance)					☹		☹	☹	☹
Referrals to pain management specialist require extensive documentation	☹	☹							
There are long waits due to a scarcity of specialists	☹	☹			☹	☹		☹	☹
The scarcity of resources is complicated by some physicians no longer accepting Workers Compensation or Medicaid patients due to inadequate payment		☹	☹			☹	☹	☹	
Many pain specialists do not offer interdisciplinary care because the payment is not adequate		☹		☹		☹		☹	☹
The impact of pain on quality of living is often not addressed, sometimes leading to depression and thoughts of suicide		☹			☹	☹	☹		☹

THEMES OF DISCUSSIONS

(CONTINUED)

This table highlights the types of issues addressed in each session and the suggestions made to improve the care of persons with terminal illnesses and those with severe chronic pain.

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Themes	Marietta	Dayton	North Canton	Toledo	Cleveland	Columbus	Cincinnati	Akron	Athens/Albany
System issues - continued.									
Restrictions on prescriptive authority for controlled medications of advance practice nurses interferes with access to and continuity of care				☹️	☹️			☹️	
Limits on the number of pills that can be dispensed to Medicaid patients interferes with good treatment					☹️	☹️			
There is little to no payment for effective complementary therapies and support services	☹️				☹️			☹️	☹️
Resources, information and guidelines for care of pediatric patients with chronic pain and terminal illness are lacking							☹️	☹️	☹️
Hopeful trends.									
Palliative care programs are in place or being developed	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️
There are many motivated professionals who have pursued continuing education on own	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️	☹️

THEMES OF DISCUSSIONS

(CONTINUED)

This table highlights the types of issues addressed in each session and the suggestions made to improve the care of persons with terminal illnesses and those with severe chronic pain.

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Themes	Marietta	Dayton	North Canton	Toledo	Cleveland	Columbus	Cincinnati	Akron	Athens/Albany
Suggestions for improvement.									
Curricula on pain management and palliative care should be included in basic education for healthcare professionals	☺	☺	☺	☺	☺	☺	☺	☺	☺
Mandatory continuing education in pain management and palliative care should be required for physicians, nurses, and pharmacists	☺	☺	☺	☺	☺	☺	☺	☺	☺
There should be a centralized place for patients, family members and professionals to get quick information and access to resources	☺	☺		☺		☺	☺	☺	☺
Protocols should be developed to trigger automatic referrals to palliative care teams for patients with advanced diseases	☺		☺	☺	☺		☺		
More support for the family members of persons with chronic pain and persons with terminal illness is needed, including respite care	☺	☺	☺	☺	☺	☺	☺	☺	☺
The cost of caring for a loved one at home (including lost wages) should be recognized and reimbursed through being paid as caregivers							☺	☺	☺

THEMES OF DISCUSSIONS

(CONTINUED)

This table highlights the types of issues addressed in each session and the suggestions made to improve the care of persons with terminal illnesses and those with severe chronic pain.

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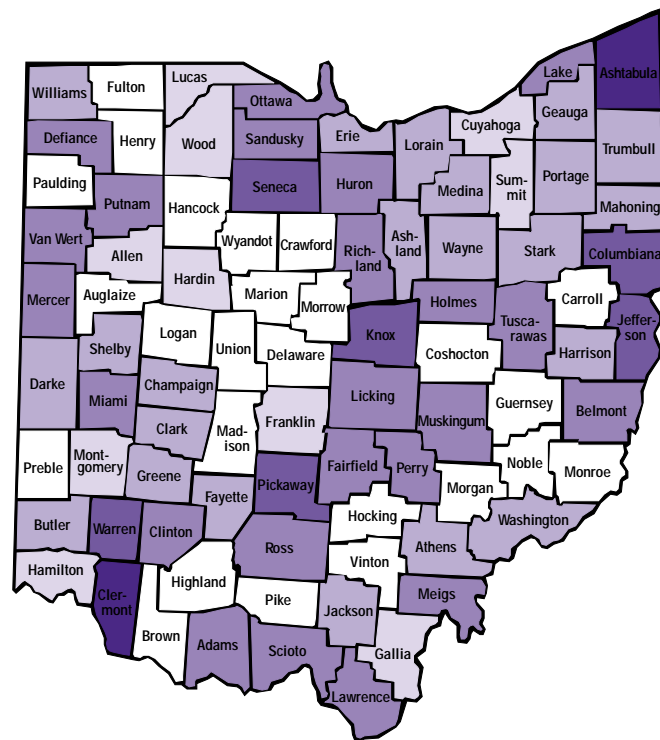


County Name	County Population Per 2000 Census	DO's	MD's	Social Workers	Acupuncturists	Massage Therapists	PT's	OT's	Psychologists	BWC Certified Psychologists
None		9	142	0	10	20	0	0	3,684	0
Adams	27,330	1	23	26	0	10	5	2		1
Allen	108,473	26	258	175	0	76	37	26		12
Ashland	52,523	8	61	59	0	41	13	6		3
Ashtabula	102,728	30	91	119	0	26	28	12		1
Athens	62,223	80	43	108	0	36	49	8		6
Auglaize	46,611	11	35	49	0	37	22	7		0
Belmont	70,226	17	91	61	0	13	31	14		2
Brown	42,285	3	41	46	0	23	5	3		0
Butler	332,807	26	407	363	0	148	154	92		18
Carroll	28,836	5	19	26	0	20	5	3		0
Champaign	38,890	1	13	43	0	27	8	5		3
Clark	144,742	22	213	194	1	89	46	25		8
Clermont	177,977	8	101	173	0	84	80	52		1
Clinton	40,543	4	76	43	0	23	15	1		1
Columbiana	112,075	38	111	94	0	53	39	15		2
Coshocton	36,655	7	27	45	0	14	7	2		0
Crawford	46,966	14	46	59	0	22	10	11		0
Cuyahoga	1,393,978	352	5626	3667	13	670	791	531		203
Drake	53,309	6	42	49	0	31	17	5		3
Defiance	39,500	4	58	57	0	18	6	8		1
Delaware	109,989	24	151	236	0	66	91	50		0
Erie	79,551	54	122	99	0	49	30	21		5
Fairfield	122,759	28	187	200	0	42	62	34		5
Fayette	28,433	2	27	18	0	5	9	1		2
Franklin	1,068,978	473	3280	2966	13	757	657	476		160
Fulton	42,084	2	31	54	0	16	19	6		0
Gallia	31,069	15	65	60	0	8	12	4		4
Geauga	90,895	25	121	125	0	75	44	30		8
Greene	147,886	50	261	246	0	114	69	45		9
Guernsey	40,792	11	62	85	0	5	11	6		0

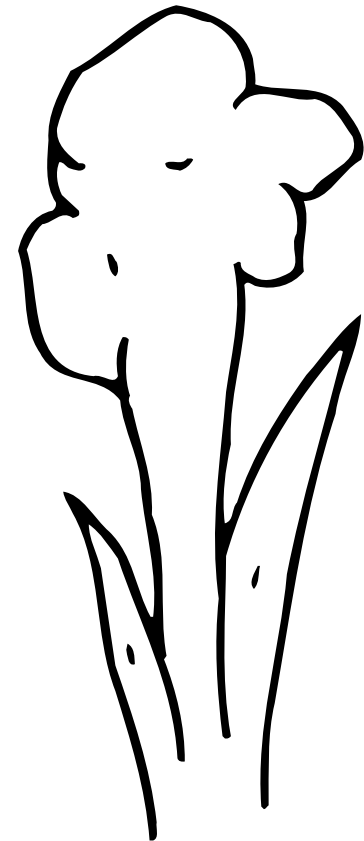
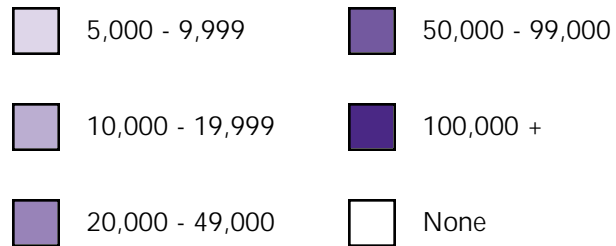
APPENDIX D - HEALTHCARE PROFESSIONALS BY COUNTY

Date Sources for Appendix D & E: State of Ohio Medical Board; Ohio Data Network; Ohio State Board of Psychology; Ohio Board of Nursing; Bureau of Workers Compensation; Ohio Hospice and Palliative Care Organization; US Chiropractors

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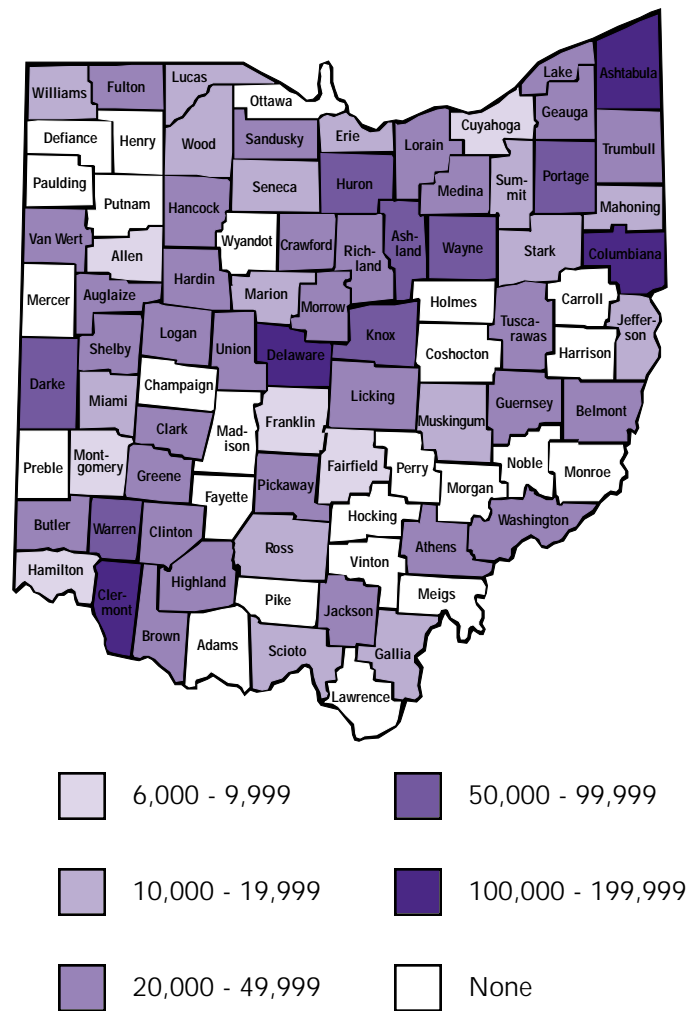
Population per
BWC Certified Psychologists
(Information based on data from Appendix D)



County Name	County Population Per 2000 Census	DO's	MD's	Social Workers	Acupuncturists	Massage Therapists	PT's	OT's	Psychologists	BWC Certified Psychologists
Hamilton	845,303	85	3489	2144	4	691	516	307		123
Hancock	71,295	19	137	108	0	41	37	19		0
Hardin	31,945	3	12	17	0	8	8	2		4
Harrison	15,856	1	9	13	0	2	5	2		1
Henry	29,210	0	17	42	0	10	18	5		0
Highland	40,875	7	43	31	0	18	13	7		0
Hocking	28,241	3	20	24	0	12	7	3		0
Holmes	38,943	0	32	29	0	15	6	3		1
Huron	59,487	24	62	61	0	40	23	15		2
Jackson	32,641	17	18	36	0	13	8	3		3
Jefferson	73,894	16	115	60	0	10	19	1		1
Knox	54,500	9	61	97	0	47	13	8		1
Lake	227,511	43	343	382	1	152	120	80		8
Lawrence	62,319	13	45	60	0	6	12	7		2
Licking	145,491	36	132	201	0	54	41	30		7
Logan	46,005	21	41	62	0	28	15	8		0
Lorain	284,664	43	385	379	0	122	116	69		16
Lucas	455,054	131	1454	862	2	210	239	125		80
Madison	40,213	12	26	41	0	8	16	7		0
Mahoning	257,555	136	540	460	0	239	131	50		20
Marion	66,217	7	115	66	0	16	9	8		0
Medina	151,095	16	206	239	1	98	107	68		15
Meigs	23,072	1	5	22	0	6	9	3		1
Mercer	40,924	10	39	41	0	29	14	8		1
Miami	98,868	24	102	108	0	71	45	22		3
Monroe	15,180	1	4	13	0	2	2	2		0
Montgomery	559,062	256	1533	1022	1	383	277	178		68
Morgan	14,897	0	4	12	0	6	1	0		0
Morrow	31,628	4	14	36	0	14	10	3		0
Muskingum	84,585	19	159	94	0	24	35	20		4
Noble	14,058	4	3	10	0	1	2	0		0

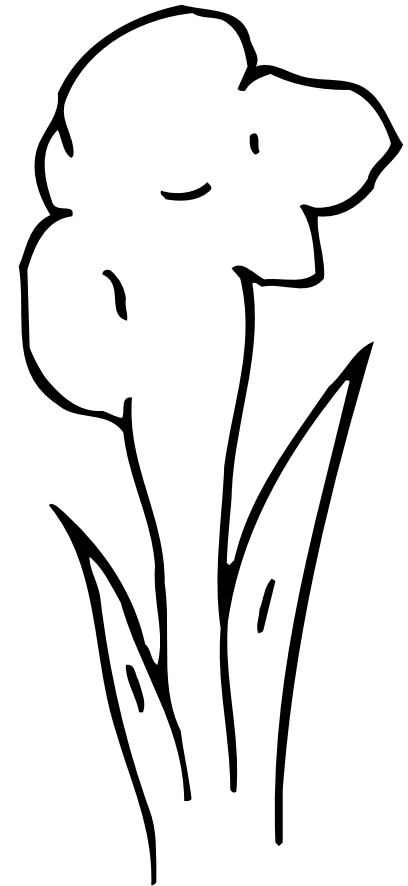
APPENDIX D - (CONTINUED)

Date Sources for Appendix D & E: State of Ohio Medical Board; Ohio Data Network; Ohio State Board of Psychology; Ohio Board of Nursing; Bureau of Workers Compensation; Ohio Hospice and Palliative Care Organization; US Chiropractors



**Population per
Pain Medicine Physician**
(Information based on data from Appendix D)

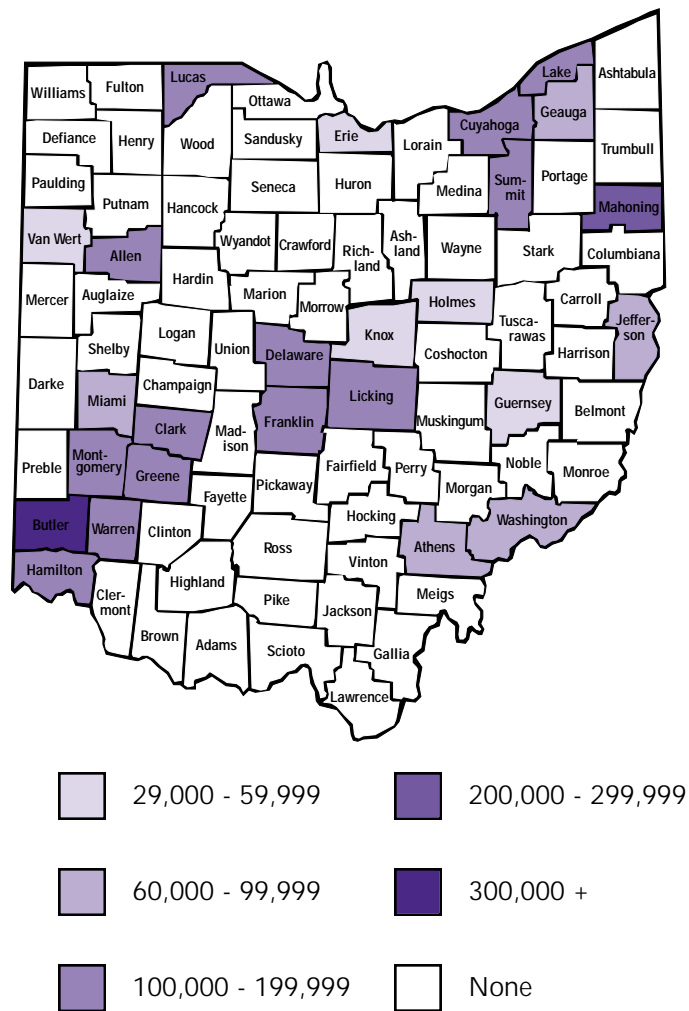
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County Name	County Population Per 2000 Census	DO's	MD's	Social Workers	Acupuncturists	Massage Therapists	PT's	OT's	Psychologists	BWC Certified Psychologists
Ottawa	40,985	7	39	49	0	21	22	8		1
Paulding	20,293	5	8	13	0	6	8	1		0
Perry	34,078	9	6	14	0	4	8	4		1
Pickaway	52,727	11	37	51	0	15	13	10		1
Pike	27,695	2	28	16	0	6	3	2		0
Portage	152,031	31	127	161	10	120	62	29		12
Preble	42,337	8	9	26	0	15	3	5		0
Putman	34,726	3	19	49	0	45	27	15		1
Richland	128,852	31	226	182	0	76	41	44		3
Ross	73,345	28	129	79	1	15	25	12		3
Sandusky	61,792	26	72	52	0	35	12	7		2
Scioto	79,195	31	123	91	0	13	21	28		3
Seneca	58,683	3	56	52	0	49	34	12		1
Shelby	47,910	9	44	49	0	20	18	9		3
Stark	378,098	158	742	588	1	305	193	98		30
Summit	542,899	251	1270	1044	1	354	256	113		95
Trumbull	225,116	87	265	255	1	119	96	51		18
Tuscarawas	90,914	16	104	90	0	52	22	8		4
Union	40,909	15	52	59	0	11	19	9		0
VanWert	29,659	3	26	40	0	16	6	4		1
Vinton	12,806	1	1	11	0	4	1	1		0
Warren	158,383	38	163	211	1	126	118	67		2
Washington	63,251	34	82	41	0	18	20	12		5
Wayne	111,564	23	129	238	0	65	31	16		7
Williams	39,188	1	48	34	0	17	14	8		2
Wood	121,065	20	146	196	1	67	66	42		18
Wyandot	22,908	3	18	14	0	9	7	1		0
Out of State		1193	8680	0	6	605	749	357		201
Bad Data Entry		0	0	3279	0	0	0	0		0
TOTALS	11,353,140	4,364	33,675	23,301	59	7,202	6,141	3,537	3,684	1,233

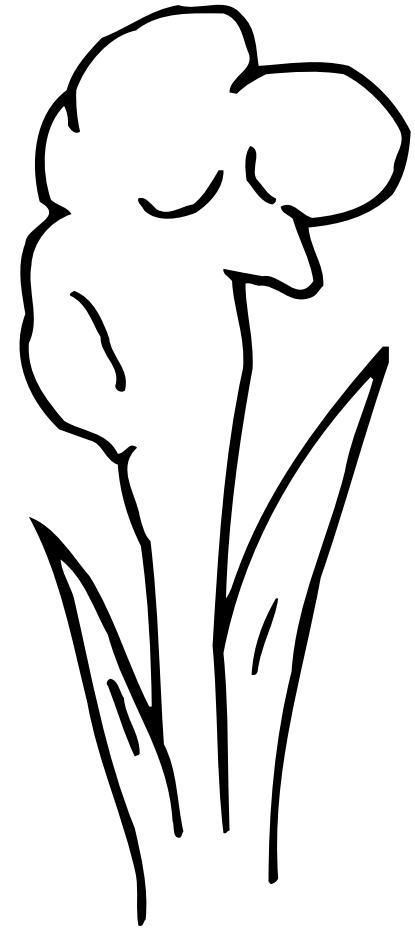
APPENDIX D - (CONTINUED)

Date Sources for Appendix D & E: State of Ohio Medical Board; Ohio Data Network; Ohio State Board of Psychology; Ohio Board of Nursing; Bureau of Workers Compensation; Ohio Hospice and Palliative Care Organization; US Chiropractors



**Population per
Addiction Medicine Physician**
(Information based on data from Appendix D)

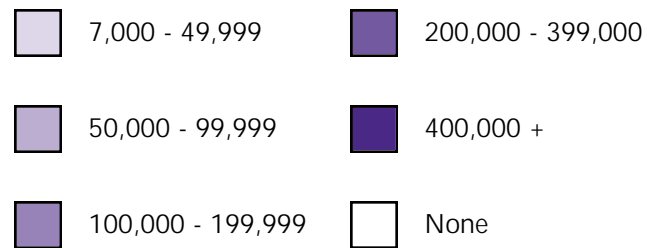
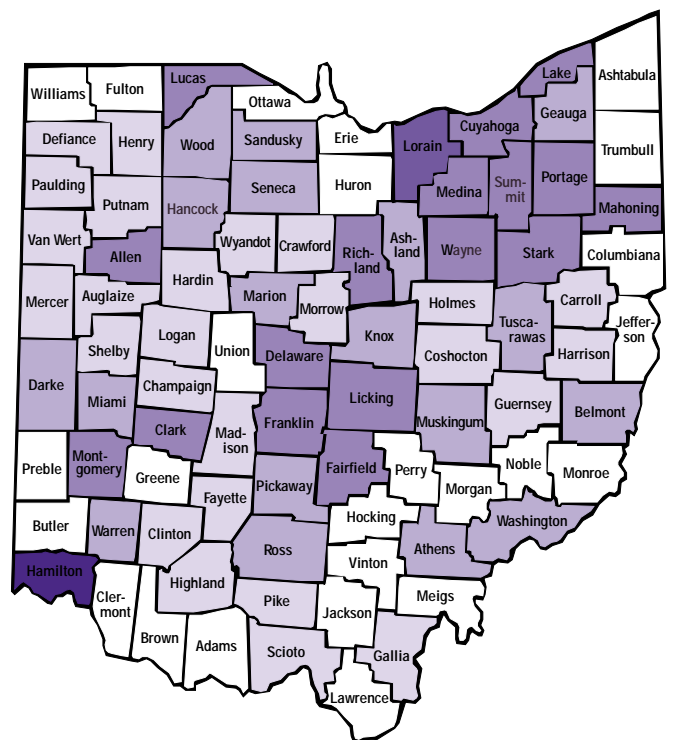
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County Name	County Population Per 2000 Census	Anesth Pain	Pain Medicine	Palliative Medicine	PM&R	Medical Oncology	Hematology Oncology	Addiction Medicine	Addiction Psychology	Psychology CNS/NPs
None		0	0	0	0	0	0	0	0	0
Adams	27,330	0	0	0	0	0	0	0	0	1
Allen	108,473	2	1	0	6	2	2	1	1	1
Ashland	52,523	0	0	0	1	0	0	0	0	0
Ashtabula	102,728	0	0	1	0	0	0	0	0	0
Athens	62,223	0	0	0	0	2	0	1	0	2
Auglaize	46,611	0	1	0	0	0	1	0	0	0
Belmont	70,226	1	1	0	1	0	0	0	0	0
Brown	42,285	0	0	0	0	1	0	0	0	1
Butler	332,807	2	0	1	1	6	0	1	0	8
Carroll	28,836	0	0	0	0	0	0	0	0	0
Champaign	38,890	0	0	0	0	0	0	0	0	0
Clark	144,742	4	0	0	1	2	0	1	0	1
Clermont	177,977	1	0	0	0	0	0	0	0	6
Clinton	40,543	0	0	0	1	0	0	0	0	0
Columbiana	112,075	0	0	0	0	1	0	0	0	1
Coshocton	36,655	0	0	0	0	0	0	0	0	0
Crawford	46,966	0	0	0	1	0	0	0	0	0
Cuyahoga	1,393,978	38	11	11	52	71	23	8	11	47
Drake	53,309	0	0	0	0	0	1	0	0	0
Defiance	39,500	0	0	0	0	0	0	0	0	0
Delaware	109,989	1	0	0	0	0	0	1	0	2
Erie	79,551	2	0	0	2	3	0	2	0	1
Fairfield	122,759	4	1	0	7	1	1	0	0	0
Fayette	28,433	0	0	0	0	0	0	0	0	0
Franklin	1,068,978	19	11	7	52	35	20	6	4	26
Fulton	42,084	0	0	0	0	0	1	0	0	1
Gallia	31,069	0	0	0	1	1	0	0	0	1
Geauga	90,895	1	0	0	1	0	1	1	0	4
Greene	147,886	1	1	1	1	1	1	1	1	0
Guernsey	40,792	1	0	0	0	1	0	1	1	0

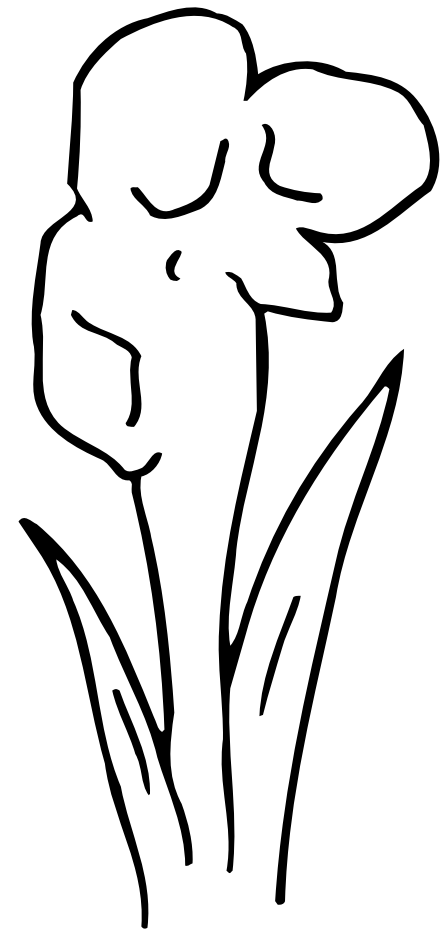
APPENDIX D - (CONTINUED)

Date Sources for Appendix D & E: State of Ohio Medical Board; Ohio Data Network; Ohio State Board of Psychology; Ohio Board of Nursing; Bureau of Workers Compensation; Ohio Hospice and Palliative Care Organization; US Chiropractors



Population per Hospice Service
(Information based on data from Appendix D)

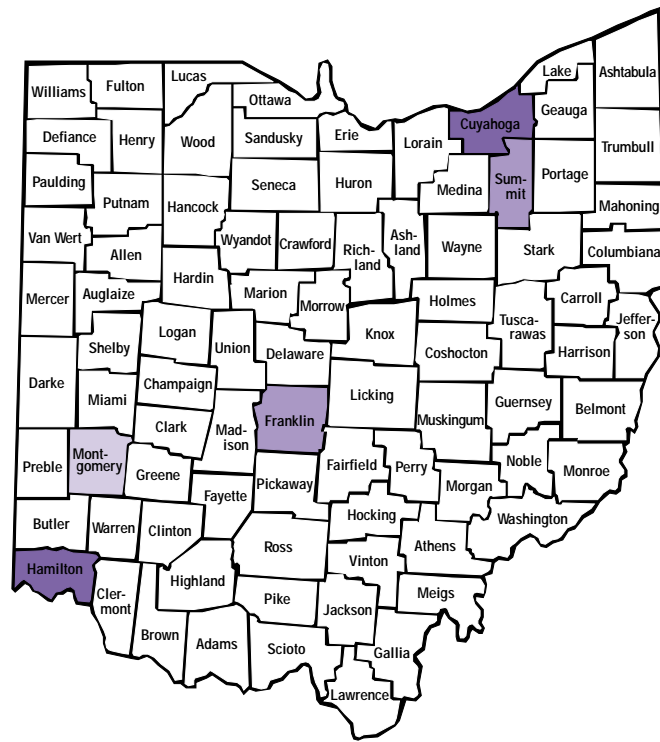
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County Name	County Population Per 2000 Census	Anesth Pain	Pain Medicine	Palliative Medicine	PM&R	Medical Oncology	Hematology Oncology	Addiction Medicine	Addiction Psychology	Psychology CNS/NPs
Hamilton	845,303	25	9	0	45	27	16	5	8	33
Hancock	71,295	0	0	0	1	2	0	0	0	1
Hardin	31,945	0	0	0	0	0	1	0	0	0
Harrison	15,856	0	0	0	0	0	0	0	0	0
Henry	29,210	0	0	0	0	0	0	0	1	1
Highland	40,875	0	0	0	0	0	1	0	0	0
Hocking	28,241	0	0	0	0	0	0	0	0	0
Holmes	38,943	0	0	0	0	0	0	1	0	0
Huron	59,487	0	1	0	0	0	0	0	0	0
Jackson	32,641	0	0	0	0	1	0	0	0	0
Jefferson	73,894	1	0	0	1	1	3	1	0	1
Knox	54,500	0	0	0	1	0	0	1	0	0
Lake	227,511	0	2	0	2	1	3	2	0	6
Lawrence	62,319	0	0	0	0	0	0	0	0	1
Licking	145,491	1	0	1	2	1	0	1	0	2
Logan	46,005	0	1	0	1	0	0	0	0	0
Lorain	284,664	6	2	1	1	2	1	0	0	4
Lucas	455,054	13	5	0	15	9	3	4	2	5
Madison	40,213	0	0	0	0	0	0	0	0	0
Mahoning	257,555	7	1	1	5	3	3	1	0	6
Marion	66,217	3	1	0	0	1	1	0	0	0
Medina	151,095	2	1	1	1	1	0	0	0	4
Meigs	23,072	0	0	0	0	0	0	0	0	0
Mercer	40,924	0	0	0	0	0	0	0	0	0
Miami	98,868	1	0	1	2	1	0	1	0	0
Monroe	15,180	0	0	0	0	0	0	0	0	0
Montgomery	559,062	11	5	3	21	11	6	4	4	11
Morgan	14,897	0	0	0	0	0	0	0	0	0
Morrow	31,628	0	0	1	0	0	0	0	0	0
Muskingum	84,585	2	0	0	1	1	1	0	0	0
Noble	14,058	0	0	0	0	0	0	0	0	0

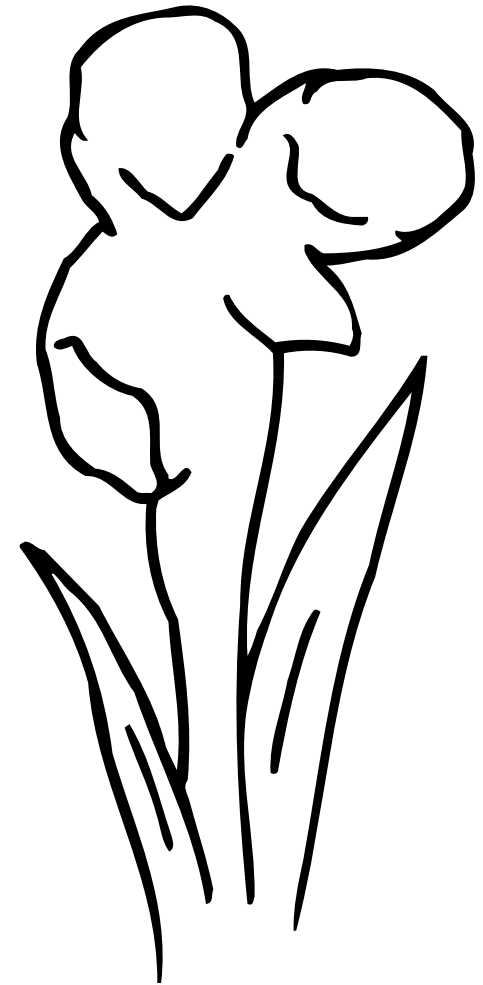
APPENDIX D - (CONTINUED)

Date Sources for Appendix D & E: State of Ohio Medical Board; Ohio Data Network; Ohio State Board of Psychology; Ohio Board of Nursing; Bureau of Workers Compensation; Ohio Hospice and Palliative Care Organization; US Chiropractors



**Population per
Pediatric Palliative Care/Hospice
Service Provider**
(Information based on data from Appendix D)

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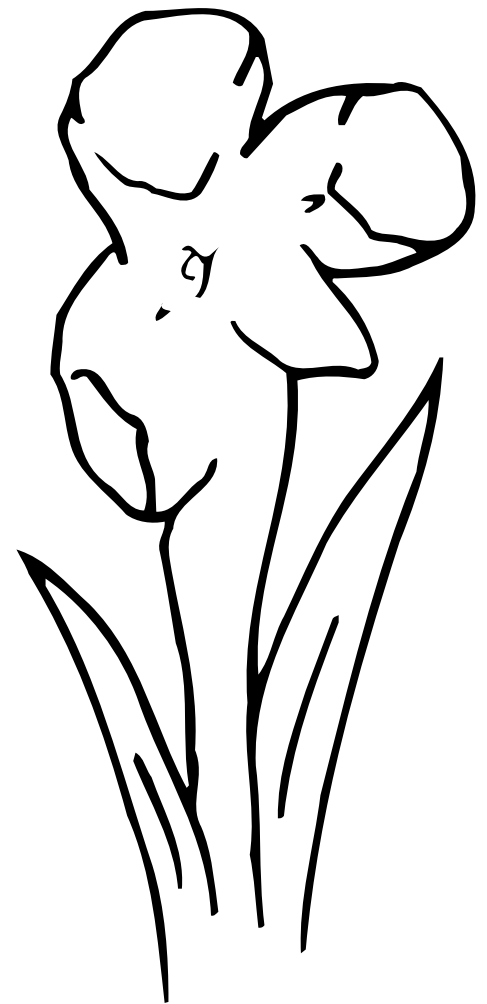
County Name	County Population Per 2000 Census	Anesth Pain	Pain Medicine	Palliative Medicine	PM&R	Medical Oncology	Hematology Oncology	Addiction Medicine	Addiction Psychology	Psychology CNS/NPs
Ottawa	40,985	0	0	0	0	0	0	0	0	0
Paulding	20,293	0	0	0	0	0	0	0	0	0
Perry	34,078	0	0	0	0	0	0	0	0	0
Pickaway	52,727	1	0	0	1	0	0	0	0	0
Pike	27,695	0	0	0	0	0	0	0	0	0
Portage	152,031	2	0	0	1	0	0	0	0	3
Preble	42,337	0	0	0	0	0	0	0	0	0
Putman	34,726	0	0	0	0	0	0	0	0	0
Richland	128,852	0	1	0	2	2	1	0	1	1
Ross	73,345	1	1	0	3	0	0	0	0	1
Sandusky	61,792	0	0	0	1	1	0	0	0	2
Scioto	79,195	0	1	0	2	1	0	0	0	0
Seneca	58,683	1	0	0	0	2	0	0	0	0
Shelby	47,910	1	1	0	0	0	0	0	0	0
Stark	378,098	4	4	0	9	6	5	0	1	10
Summit	542,899	8	6	0	6	10	4	3	2	24
Trumbull	225,116	1	1	4	3	0	0	0	0	1
Tuscarawas	90,914	1	0	0	0	1	0	0	0	0
Union	40,909	0	0	0	1	0	0	0	0	0
VanWert	29,659	0	0	0	1	0	0	1	0	0
Vinton	12,806	0	0	0	0	0	0	0	0	0
Warren	158,383	1	1	0	1	0	0	1	0	1
Washington	63,251	1	0	0	1	0	0	1	0	0
Wayne	111,564	0	0	0	0	1	1	0	1	0
Williams	39,188	0	0	0	1	1	0	0	0	0
Wood	121,065	2	1	1	2	1	0	0	0	1
Wyandot	22,908	0	0	0	0	0	0	0	0	0
Out of State		0	0	0	0	0	0	0	0	0
Bad Data Entry		0	0	0	0	0	0	0	0	0
TOTALS	11,353,140	173	72	35	262	215	101	51	38	222

APPENDIX D - (CONTINUED)

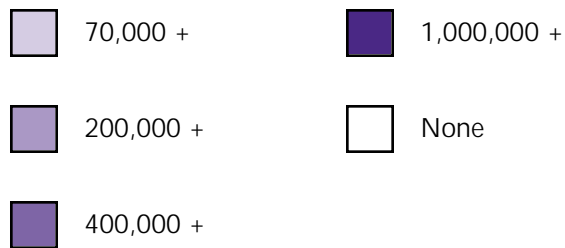
Date Sources for Appendix D & E: State of Ohio Medical Board; Ohio Data Network; Ohio State Board of Psychology; Ohio Board of Nursing; Bureau of Workers Compensation; Ohio Hospice and Palliative Care Organization; US Chiropractors



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**Population per
BWC Certified Chronic
Pain Program Provider**
(Information based on data from Appendix D)



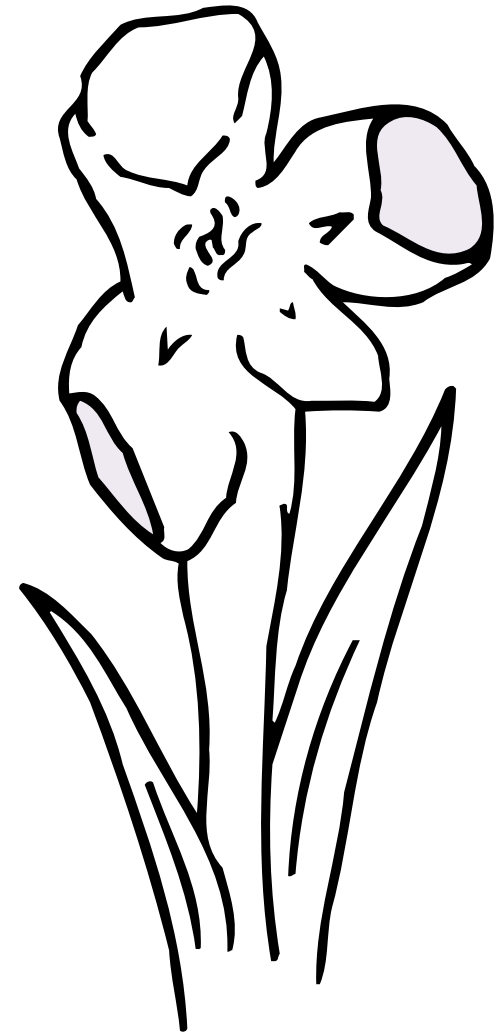
County Name	County Population Per 2000 Census	Hospice Services	Pediatric Chronic Pain Services	Pediatric Palliative Care/Hospice Services	BWC Certified Chronic Pain Programs	Chiropractic Practices
Adams	27,330					2
Allen	108,473	1				12
Ashland	52,523	1				4
Ashtabula	102,728					8
Athens	62,223	1				6
Auglaize	46,611	1				3
Belmont	70,226	1			1	2
Brown	42,285					1
Butler	332,807					30
Carroll	28,836	1				2
Champaign	38,890					2
Clark	144,742	1				10
Clermont	177,977					11
Clinton	40,543	1				3
Columbiana	112,075					12
Coshocton	36,655	1				3
Crawford	46,966	1				5
Cuyahoga	1,393,978	8	1	3		40
Drake	53,309	1				4
Defiance	39,500	1				6
Delaware	109,989	1				6
Erie	79,551	0				10
Fairfield	122,759	1				9
Fayette	28,433	1				
Franklin	1,068,978	6		2	1	55
Fulton	42,084	0				9
Gallia	31,069	1				3
Geauga	90,895	1				6
Greene	147,886					6
Guernsey	40,792	1				3
Hamilton	845,303	2	1	2	2	31

APPENDIX E - PROGRAMS & SERVICES BY COUNTY

Date Sources for Appendix D & E: State of Ohio Medical Board; Ohio Data Network; Ohio State Board of Psychology; Ohio Board of Nursing; Bureau of Workers Compensation; Ohio Hospice and Palliative Care Organization; US Chiropractors

County Name	County Population Per 2000 Census	Hospice Services	Pediatric Chronic Pain Services	Pediatric Palliative Care/Hospice Services	BWC Certified Chronic Pain Programs	Chiropractic Practices
Hancock	71,295	1				13
Hardin	31,945	1				3
Harrison	15,856	2				2
Henry	29,210	1				
Highland	40,875	1				2
Hocking	28,241	0				
Holmes	38,943	1				1
Huron	59,487	0				2
Jackson	32,641	0				2
Jefferson	73,894	0				6
Knox	54,500	1				1
Lake	227,511	2				13
Lawrence	62,319	0				2
Licking	145,491	1				11
Logan	46,005	1				6
Lorain	284,664	1			1	20
Lucas	455,054	3			1	39
Madison	40,213	1				3
Mahoning	257,555	2				34
Marion	66,217	1				5
Medina	151,095	1				7
Meigs	23,072	0				
Mercer	40,924	1				3
Miami	98,868	1				9
Monroe	15,180					
Montgomery	559,062	3		2		33
Morgan	14,897					
Morrow	31,628	1				
Muskingum	84,585	1				8
Noble	14,058					
Ottawa	40,985					3

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APPENDIX E - (CONTINUED)

Date Sources for Appendix D & E: State of Ohio Medical Board; Ohio Data Network; Ohio State Board of Psychology; Ohio Board of Nursing; Bureau of Workers Compensation; Ohio Hospice and Palliative Care Organization; US Chiropractors

County Name	County Population Per 2000 Census	Hospice Services	Pediatric Chronic Pain Services	Pediatric Palliative Care/Hospice Services	BWC Certified Chronic Pain Programs	Chiropractic Practices
Paulding	20,293	1				
Perry	34,078					2
Pickaway	52,727	1				4
Pike	27,695	1				3
Portage	152,031	1				6
Preble	42,337					2
Putman	34,726	1				2
Richland	128,852	1				13
Ross	73,345	1			1	8
Sandusky	61,792	1				5
Scioto	79,195	2				5
Seneca	58,683	1				10
Shelby	47,910	1				4
Stark	378,098	3				50
Summit	542,899	3	1	1		18
Trumbull	225,116					10
Tuscarawas	90,914	1				9
Union	40,909					17
VanWert	29,659	1				3
Vinton	12,806					
Warren	158,383	2				7
Washington	63,251	1				1
Wayne	111,564	1				8
Williams	39,188					4
Wood	121,065	2				5
Wyandot	22,908	1				2
Out of State						
Bad Data Entry						
TOTALS	11,353,140	89	3	10	7	730

APPENDIX F - A CAREGIVERS POINT OF VIEW

Anita Jackson, Public/Family Representative

Marriage and parenthood are two titles that evoke certain images of responsibility when spoken. Pictures of quiet dinners, relaxing evenings at home and romantic dinners often come to mind when one thinks of marriage. From the other perspective one may think of play dates, school plays, and trips to the park as the fun side of parenting. However, when marriage or parenting, in my case both, involves a loved one living with chronic pain or terminal illness, those images disappear.

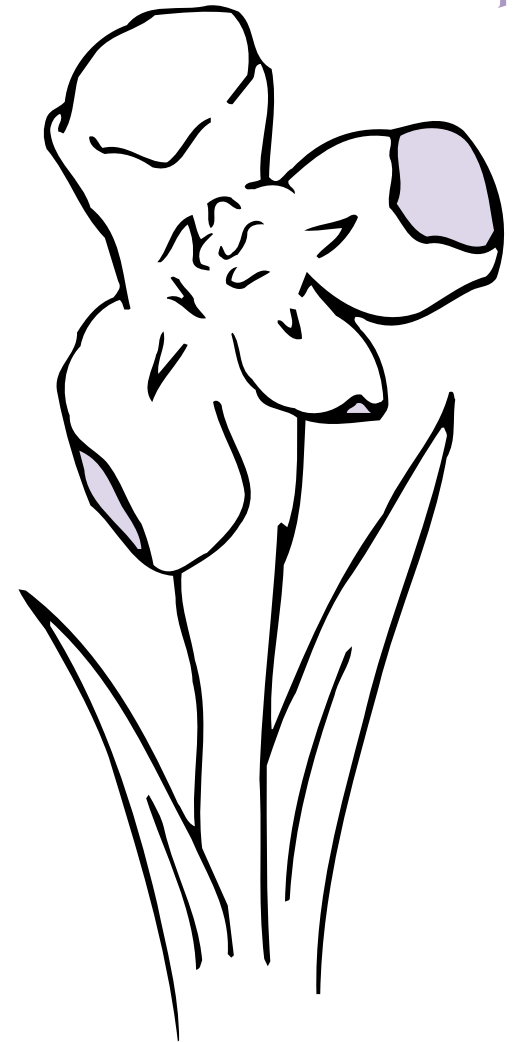
It is imperative that the effect a person's pain has on loved ones be considered when providing care. Pain can reverberate at such a level that no one can avoid its touch. The effect touches family, friends, co-workers, and those in the community. Not only does the pain itself have an effect but the depression and anxiety that often accompany pain can, and does, prevent one from participating emotionally with the ones around them. It is this obstacle that can damage relationships, especially with spouses and children. Unfortunately, the patient may not 'see' the damage because their main focus is on relieving their own pain. Only by including the family in the treatment process can the treating physician fully evaluate the impact of a person's pain.

Treating the pain of an adult can be difficult enough but what if that patient is a child? Children living with pain are all too often not managed adequately for fear of over-prescribing, or perhaps ignorance that children do not really experience pain. Children do experience pain and no parent wants to watch their child suffer, no matter how minor the cause may seem. To watch a child living with a terminal illness experience pain is even more wrenching. Parents are faced with not only trying to comfort their child in pain but, at the same time, cope with their own emotional and psychological pain.

The role of advocate becomes a primary focus as parents try to become their child's voice by interpreting words, actions, and emotions into a pain scale. Once that task is achieved parents are often scrutinized for being emotional and are summarily dismissed.

Patients, families, and parents are too often considered emotional, unreasonable, or unrealistic. Quality of care is and should be an important goal in treating a person with pain but not if it becomes an obstacle. Maybe the first question to ask is "What quality of life is this patient, family, or parent looking to achieve?"

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APPENDIX G - IDEAS TO HELP PATIENTS AND THEIR CAREGIVERS

Randall Hertzner, Patient Representative

A RECIPE FOR FRUSTRATION

The most challenging aspect of chronic pain management for a patient is finding information about physicians and possible treatments.

- There are no central registries of physicians and their specialties as related to chronic pain (i.e., lower back, headache, joints, etc.)
- There is no central clearinghouse where patients can get informational materials about the different types of pain (i.e., cancer, arthritis, fibromyalgia, Lupus, etc.)
- There is no place for patients to gather or meet to exchange information and ideas about physicians, therapies, or complementary activities that might bring relief.

Ironically, the one thing that many patients probably do have - especially if their pain has caused them to become disabled - is time to think about their problems.

Combine these factors with the fact that chronic pain patients are extremely motivated people, constantly seeking information and resources to help alleviate their suffering, and you have a recipe for extreme frustration.

BUT WHAT ABOUT THE INTERNET?

People assume because we live in a wonderful age of information with easy access via the Internet, that finding any of the previously mentioned people or resources should not be an issue. However, this ignores the fact that too much information, scattered among too many resources, is just as much of a dead-end as finding nothing.

People who have no pain issues would find it difficult to spend hours in front of a computer trying to sort through hundreds of thousands of pages devoted to pain management, all the while facing the additional challenge of learning a new language (medical terminology) while seeking help for themselves.

This is not to say that good websites aren't out there - they are. However, finding them, and locating those with the specific information a patient might be seeking is still a difficult task.

POINTS OF CONTACT

The key to helping provide information to people with chronic pain is finding points of contact and making use of those points.

Points of contact would include (in no order): physician offices, hospitals, support groups, pharmacies, physical therapy centers, senior citizen centers, government offices (i.e., VA, Worker's Compensation), women's health centers, and complementary care facilities (massage centers, health spas, etc.)

All of these areas (and any other where people with chronic pain might congregate) should be used to at least offer a starting point for those who are interested in seeking more information.

A STATEWIDE OFFICE AND A MODEL

To provide informational materials for these points of contact, Ohio should consider creating a statewide office devoted to chronic pain issues. Whether this office exists as part of a board, commission, agency, or independently, it would give a focal point for the challenge of educating the general public about issues related to chronic pain.

The only such office that now exists in the U.S. is in Oregon, and is part of that state's Department of Human Services. The director of the office, Carol Misrack, is a Registered Nurse, and is also a chronic pain patient.

A key aspect of the office responsibilities is to provide information to patients and the general public, as well as educating medical professionals.

Such an ombudsman type position would allow those interested in chronic pain issues to be channeled into a central area. It would also provide a central location for medical professionals, patients, caregivers, policymakers and the general public to contact.

Having one office coordinate chronic pain management issues for Ohio would provide a strong foundation for anyone who has an interest in the topic - whether they are located in the state or elsewhere.

One of the services that could be provided is allowing people to become part of a central database that would include any individuals or organizations with an interest in chronic pain. This will be of vital help should the state want to address related issues of education for medical professionals, revise medical designations, or simply reach out to those with an interest in the topic.

AN OHIO WEBSITE ABOUT PAIN ISSUES

The Internet is going to be the primary source of information for most people in the next decade (if not sooner) and already serves that purpose for many, if not most Ohioans. An Ohio-based Web page on chronic pain would certainly provide a much-needed starting point for those who live with chronic pain.

Such a site should include (but not be limited to) the following:

- A glossary (medical and other pain-related terminology)
- Bulletin board access to exchange information with others on physicians, physical therapy facilities, medications and complementary treatments (i.e., massage, meditation, bio-feedback)
- Links to other sites determined to be helpful for chronic pain patients, professionals, and caregivers
- General information on chronic pain
- Information about pain and the link to depression and anxiety
- Information specifically for healthcare professionals
- Information specific to pain and certain

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diseases (i.e., cancer)

- Background on the Compassionate Care Task Force/recommendations

The site should have a name that includes the words "pain" or "chronic pain" so that anyone doing a Web search would be more likely to come across the homepage with little trouble.

The site should also be listed as part of the federal government's portal to all other state and associated Web listing. This is located at www.firstgov.gov.

Under ideal circumstances (with a supporting budget), there would be someone (perhaps the ombudsman or a staff person) to write regular feature stories or tips about chronic pain that could be included on the site.

If the site were located with a state commission or agency, technical support could be provided by that entity's staff. To help Ohio defray some startup costs, Carol Misrack of Oregon has offered Ohio the use of any information now used on her state's site, such as the glossary, and would be willing to provide guidance in setting up the site.

EDUCATION BENEFITS

An Ohio Website could also provide benefits for physicians, therapists and others involved in the care of people with chronic pain.

The site could be used to provide information to health professionals on training needed to meet criteria for state licensing. There could be links set up to work with Ohio's medical schools and other institutions that provide healthcare courses.

RECOMMENDED LISTS

The Internet is a fluid resource that is constantly evolving, however an on-going review of websites that feature information about chronic pain has led to a recommendation that any Ohio site should include (but not be limited to) links to the following:

- American Academy of Pain Management
- American Academy of Pain Medicine
- The American Chronic Pain Association
- American Pain Foundation
- American Pain Society
- Mayo Clinic Pain Management Center
- Partners Against Pain
- Oregon Department of Human Services
- American Society of Pain Management Nurses
- Cancer Pain Education for Patients and Families

- Chronic Pain Forum
- National Chronic Pain Outreach Association
- National Foundation for the Treatment of Pain

SUMMARY

Ohio has an opportunity to become only the second state to create an office or commission that deals exclusively with issues related to chronic pain. Oregon is the only other state to have such an office, and that office is located within the Oregon Department of Human Services.

(1) The most basic need for Ohioans (from a consumer point of view) is a starting point.

Creating an office or commission that employs a fulltime ombudsman would be the ideal place for Ohioans who have chronic pain and their families to get help. It would also provide a central clearinghouse for professionals who treat patients (physicians, nurses, physical therapist, pharmacists, and complementary professions as well as caregivers).

As part of this office, a Website that includes very basic, easily-understood information about chronic pain would also provide a service that would be extremely helpful to patients who now have to search extensively and sift through hundreds of Websites to find what they need.

Although there are many sites now available that incorporate various aspects of chronic pain and its treatment, there is only one state-managed site, and Ohio has the opportunity to make use of this state's experience - and expand upon it.

(2) Such an office and Website would also provide a central area where Ohioans could get a listing of both physicians and facilities that specialize in the treatment of chronic pain.

There is currently no way for patients to find physicians who specialize in pain management, other than through word of mouth or a process of "hit and miss" where the patient goes to a doctor and gets a referral to another doctor who may treat that patient's particular problem.

One example of this problem is that many neurologists are competent to treat chronic pain, but often these physicians end up "specializing" in certain types of pain (i.e., headaches) but there is no way for patients to find out this information unless they happen to go to this doctor or hear about them from another patient or physician.

(3) There is no central place in Ohio that can provide the option of support and information for patients who have chronic pain.

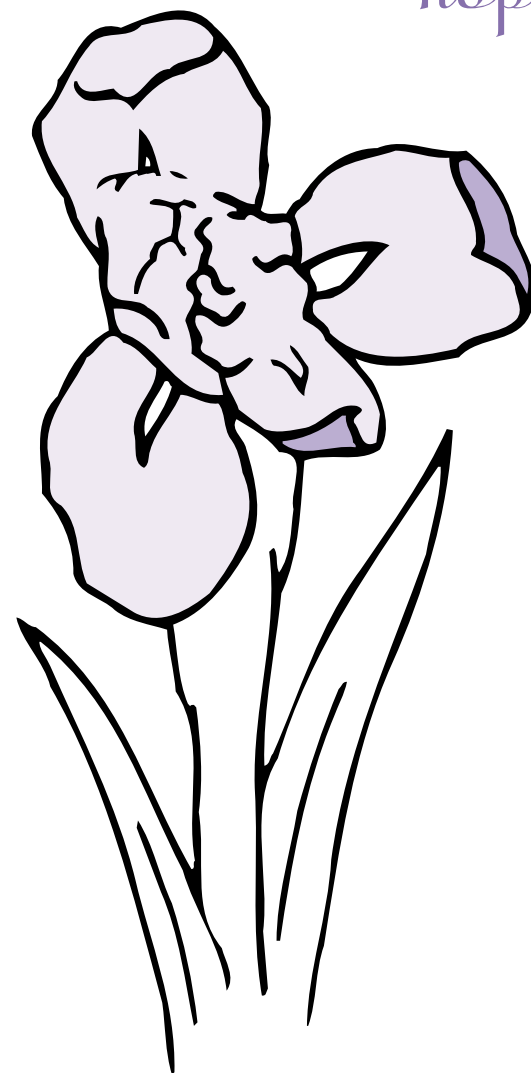
With a state-based office or commission, some

type of program could be established for patients to find support, and to exchange information about physicians, facilities, therapies or medications.

An ombudsman working in a state-based setting could provide these services by working with state legislators to lay the framework and overcome potential legal obstacles, including liability issues, in setting up such a service.

Appendix G is the work of one Ohio Compassionate Care Task Force member and does not represent the views of anyone but the author. The recommendations included are the result of months of research and contact with people who either work with those who have chronic pain, or live with chronic pain.

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APPENDIX H - GLOSSARY

Addiction: A primary, chronic, neurobiological disease, with genetic, psychosocial, and environmental factors influencing its development and manifestations. It is characterized by behaviors that include one or more of the following: impaired control over drug use, compulsive use, continued use despite harm, and craving. (AAPM/APS/ASAM, 2001).

Chronic Pain: Pain without apparent biological value that has persisted beyond the normal tissue healing time (usually taken to be 3 months) (IASP).

Complementary and Alternative Medicine: A group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine. Complementary medicine is used together with conventional medicine; alternative medicine is used in place of conventional medicine (National Center for Complementary and Alternative Medicine).

Culture: Common lifestyles, languages, behavior patterns, traditions, and beliefs that are learned and passed on from one generation to the next. Culture influences how individuals view relationships to surrounding environment, religion, time, and each other and provides individuals with specific rules for dealing with the universal events of life - birth, mating, child-rearing, illness, pain, and death.

Culturally Competent Care: Providing care that is sensitive to issues related to *culture*, race, gender, sexual orientation, social class, and economic situation.

Hospice Care: Hospice care is a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well. Hospice focuses on caring, not curing and, in most cases, care is provided in the patient's home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Due to some insurance guidelines, hospice care is often not available until the patient's physician certifies a 6-month or less prognosis. Integrative Medicine: A combination of mainstream medical therapies and Complementary and Alternative medicine therapies for which there is some high-quality scientific evidence of safety and effectiveness (National Center for Complementary and Alternative Medicine).

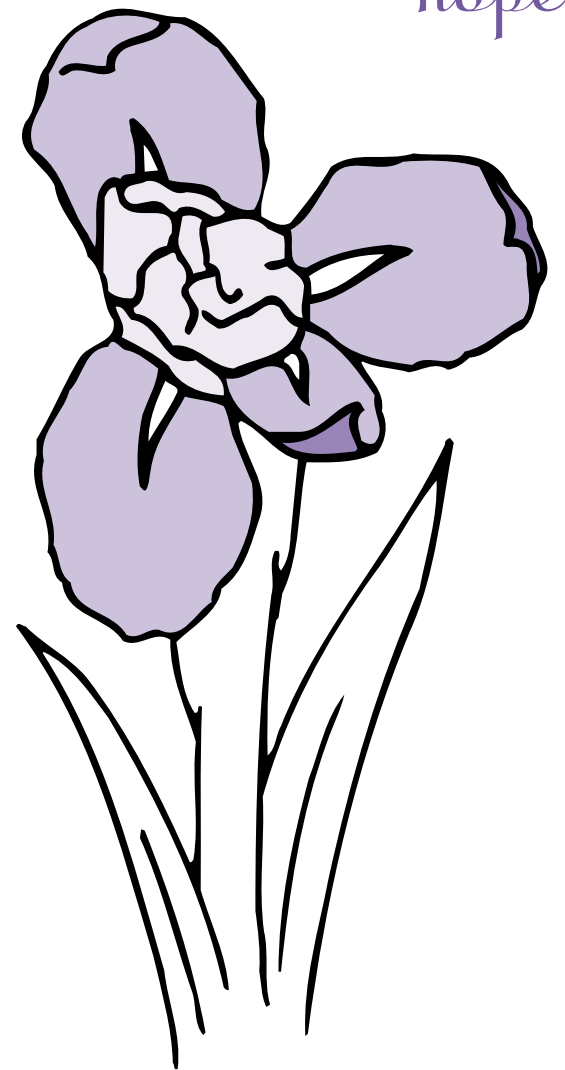
Interdisciplinary Team: A functioning unit, composed of individuals with varied and specialized training, who coordinate their activities to provide services.

Pain: An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (IASP).

Palliative Care: The active total care for persons with serious medical illness, especially chronic and progressive life-limiting conditions. Major concerns are pain and symptom management, information sharing and advance care planning, psychosocial and spiritual support, and coordination of care across settings. Palliative care begins at the time of diagnosis with the intensity and range of palliative interventions based on patient and family needs. Palliative care is interdisciplinary with the patient and family as active participants on the interdisciplinary team (adapted from: WHO, 1990; Quality of Life Workgroup, 2004).

Terminal Illness: An irreversible, incurable condition caused by disease, illness, or injury which limits the individual's life expectancy to 12 months or less (Adapted from the Ohio Revised Code in the Uniform Rights of the Terminally III Act).

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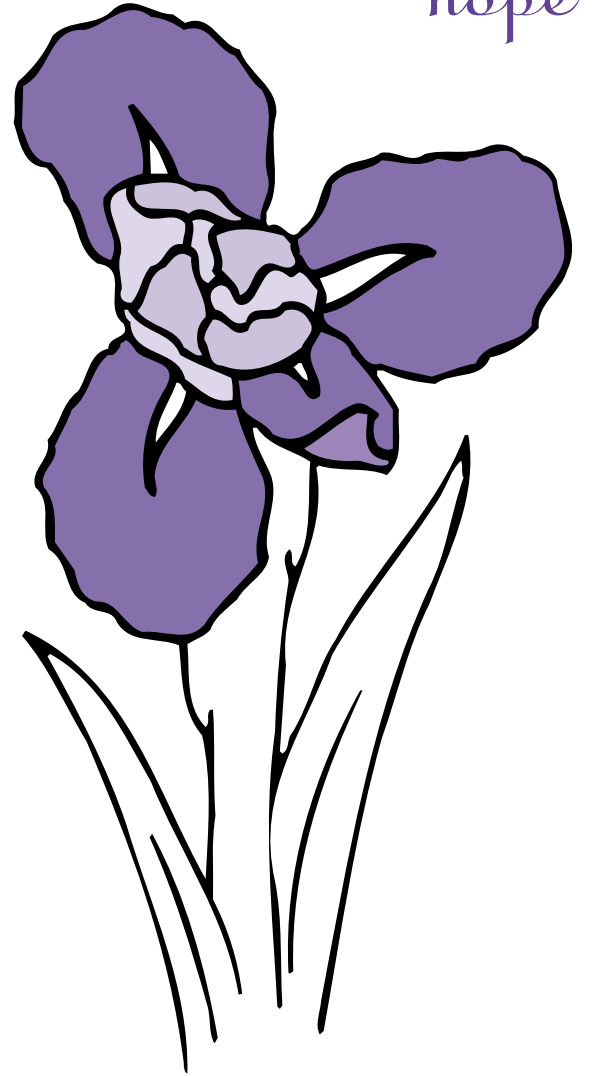
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wisdom
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The Iris that grows and blossoms throughout this report symbolizes wisdom, faith, and hope.

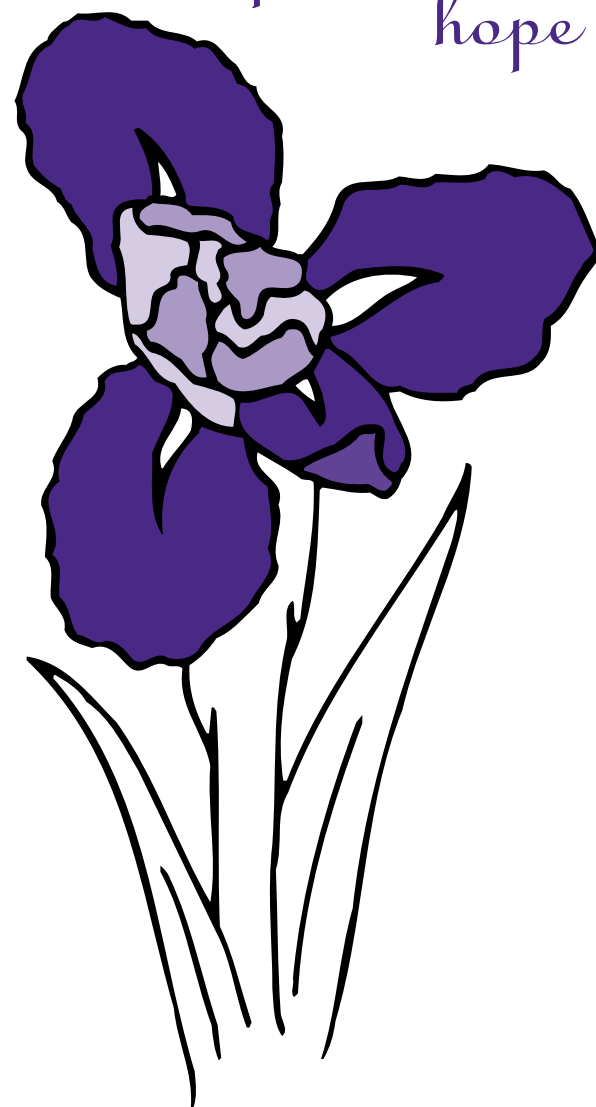
The members of the Compassionate Care Task Force believe that the recommendations in this report also symbolize wisdom, faith, and hope:

...Wisdom to seek and to provide quality care for persons with terminal illnesses and those with chronic pain through education of the public and health care professionals;

...Faith to continue working toward this goal of quality care for persons with terminal illnesses and those with chronic pain despite the many barriers; and,

...Hope that through caring, communication and collaboration this goal of quality care for persons with terminal illnesses and chronic pain will be achieved.

To see the Iris blossom, watch the right side of the booklet as you quickly flip through the pages.



wisdom

faith

hope

