



All in the Family: Their Role and Impact on Pain Management

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Title & Affiliation

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Disclosure

Dr. Cosio is speaking today based on his experiences as a psychologist employed by the Veterans Administration. He is not speaking as a representatives of or as an agent of the VA, and the views expressed are his own.
Nothing to disclose



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Learning Objectives

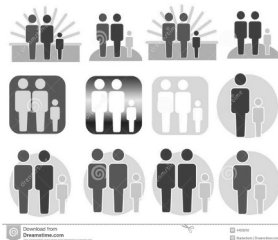
- Describe ways in which family members and caregivers can have a positive and negative effect on pain management.
- Describe the emotional needs of family members with support groups, family therapy, or individual therapy.
- Cite the ways in which family members can help their loved ones with their care plans while still maintaining the goal of autonomy.



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Definition of Family

- Family is universal institution where basic relationships exist
- Family is "first" reference group that shapes our world
- Definition:
 - a group of one or more parents and their children living together as a unit
 - consider single parent households
 - LGBTQ families
 - foster or adoptive families
 - grandparents or uncles/aunts
 - caregivers or guardians
 - 'chosen' family



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Pain is a Family Affair

- In US, approximately 100 million people suffer from chronic pain, and about 43% of households have at least one family member living with chronic pain
- Effects of chronic pain are not independent to patient, but also extend to their family and significant others
- Intractable pain can demoralize and depress both patient & their at-home caregivers, especially when there is no effective pain control or hope for relief
- Conversely, there is an equally profound effect of family responses on their loved one's pain & family dynamics may contribute to the exacerbation or recovery of pain

Dahlhamer J, Lucas J, Zeltys C, et al. Prevalence of chronic pain and high-impact chronic pain among adults—United States, 2016. *MMWR*. 2018;67(36):1001-1006.

Levanthakki W, Moore R, Draucker CD, Reiko J. Chronic pain and the family: theory-driven treatment approaches. *Issues Ment Health Nurs*. 2007;28(9):1019-1044.

Grier M. Chronic pain and the family: a new guide. 1st ed. Cambridge, MA: Harvard University Press; 2004.

Payne R, Norrhe M. Chronic pain and the family: a review. *Pain*. 1985;28(1):1-22.

Pay R. Chronic pain and family: a clinical perspective. New York, NY: Springer; 2004.



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Two Dimensions of Life with Pain

Loved one in pain:

- whose pain is invisible
- fluctuate activity levels
- have unpredictable mood swings
- show signs of depression
- lack of interest
- have doubt about reality of pain
- loss of job, friends, and productivity
- isolate themselves

Family members:

- unable to see or feel pain
- take on more responsibility
- feel stressed, powerless, guilty, and/or anxious
- withdraw plans (due to medical or disability evaluations)
- deal with emotional outbursts from patient
- feel alienated
- loss of personal support system
- loss of hopes for the future



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Two Dimensions of Life with Pain

Thus, it is important to not only consider person who is suffering in front of you, but also people directly standing behind them who may need their own support and education about pain management



Cohen P. Family manual: a manual for families of persons with pain. American Chronic Pain Association, 1998.
Kornstein D, Whitman S. Surviving a loved one's chronic pain. Pract Pain Manag. 2007;2(1):48-52.



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Spiraling Effects of Pain

- Chronic pain may negatively impact family system by intruding on every aspect of life, leading to significant consequences
 - There may be a loss of sexual expression & intimacy in couples, which may lead to separation & divorce
 - There may be social isolation which then perpetuates further attention-seeking within the health care system.
 - Family members may experience changes in their thoughts & feelings, leading to depression or anxiety
 - They may engage in ongoing unexpressed family conflict and/or bring up childhood family issues
 - Family members may begin to believe that their loved one is attention-seeking or avoiding their responsibilities, which then negatively impacts their relationships

Lewandowski W, Morris R, Draucker CB, Risko J. Chronic pain and the family: theory-driven treatment approaches. Issues Ment Health Nurs. 2007;28(9):1019-1044.



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Spiraling Effects of Pain

- Role reversals may begin to emerge between pain sufferer & other family members
 - One spouse may have led household, from cooking to yardwork. If he or she begins to suffer from pain, they may be unable to maintain those tasks, leaving partner or other family members to take them on
 - Another individual may have served as "social director" for a family, providing educational support and running errands. If this person is diagnosed with chronic pain, their responsibilities may be subsumed by another family member or duties may go unfulfilled
 - Struggle to recover lost functions & roles can be debilitating to a family, increasing stress, grief, & depression

Lewandowski W, Moris R, Draucker CB, Pisko J. Chronic pain and the family: theory-driven treatment approaches. Issues Ment Health Nurs. 2007;28(9):1019-1044.



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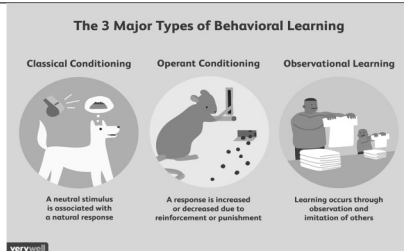
Roles That May Be Altered

- | | |
|---------------------------|--------------------------------|
| ▪ Supportive husband/wife | ▪ Homework supervisor |
| ▪ Mother/father | ▪ Social director |
| ▪ Breadwinner | ▪ Disciplinarian |
| ▪ Community volunteer | ▪ Confidant |
| ▪ Cook | ▪ Bill payer |
| ▪ Gardener | ▪ Financial planner |
| ▪ Chauffeur | ▪ Active neighbor/friend |
| ▪ Errand runner | ▪ Vacation planner/participant |



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Learned Behaviors



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When Caregivers Reinforce Pain Behaviors

- Chronic pain can also impact family system with significant positive outcomes, although this is less common
 - If a spouse was controlling before they developed a chronic pain condition, then other family members may now have more freedom
 - Family members may feel good about helping a loved one if they have a strong need to help others
 - A decrease in intimacy may feel positive to person who experiences intimacy, or even sex, with their loved one as unwanted
 - Some members of household may get additional support or sympathy from other family members
 - These positive outcomes can lead to family members unintentionally trying to get patient to maintain sick role
 - Case example of old couple

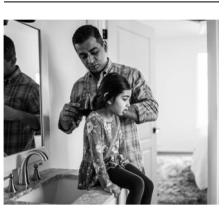


Coppen D. Family manual: a manual for families of persons with pain. American Chronic Pain Association, 2016.



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When Caregivers Reinforce Pain Behaviors



- Presence of a familial caregiver may contribute to enhanced cohesion & resilience as everyone works together to adapt to demands of chronic pain
- Family may also be responsible, in part, for maintaining & perpetuating pain behaviors
- Those who are nearest to person manifesting pain behavior will almost always respond to them
 - their mere presence may come to serve as a cue for increased reports of pain
- Reinforcements of maladaptive behavior may occur when family members unintentionally provide attention or react too caringly to pain complaints
- This is best seen in situations where person in pain has an overprotective partner or spouse
- While attention is certainly a form of love expression, it may also be a negative reinforcement if abused
- Case example of dependent couple

Lewandowski W, Morin P, Cropper CE, Belsz J. Chronic pain and the family: theory-driven treatment approaches. *Health Horizons*. 2016; 10(6):10-14.
Roy R. Chronic pain and family: a critical perspective. New York, NY: Springer; 2006.
Block AJ, Kanner EF, Singer B. Behavioral treatment of chronic pain: the spouse as a discriminative cue for pain behavior. *Pain*. 1983;5(2):143-152.
Kramer CF, Koch A, Taylor MB. Behavioral approaches to treatment of chronic pain: the inaccuracy of patient self-report measures. *Arch Phys Med Rehabil*. 1981;62(1):138-143.



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When Caregivers Reinforce Pain Behaviors

- Family caregivers may also:
 - promote fear of harm; despite meaning well
 - they may begin taking over tasks
 - even speaking for their loved one who is suffering from pain
 - any effort to terminate stressful impact of their pain complaints
- This approach may actually detract from their loved one's independence & self-efficacy
- It is important for person suffering from pain to maintain their independence & that family members support them in this regard

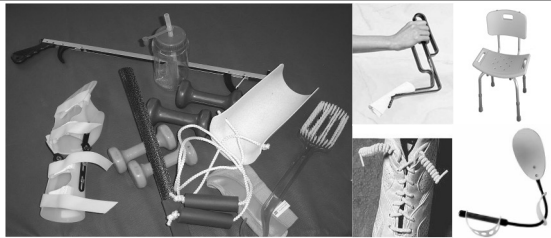


Neckers PM. Psychiatric: V. Models of family functioning and their contribution to patient outcomes in chronic pain. *Medis Econ*. 1993;17(3):285-318.



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Maintaining Independence



PainWeek

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When Caregivers Reinforce Pain Behaviors



- Some families also deal with emotional problems at a somatic level
 - they exhibit their emotional problems with physical complaints
- Opposite may also be true
 - Those who suffer from pain may live alone
 - May have no family nearby
 - Lack of a support system in place
 - They oftentimes feel ignored or express frustration because they do not have anyone to talk to about their problems

Hughes MC, Zivin R. Children with psychogenic abdominal pain and their families: management during hospitalization. Clin Pediatr. 1978;17(7):569-573.

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How to Assess Family Functioning

- If family is involved in maintaining patient's pain, then they should also be included in assessment & treatment of pain
- Several self-report instruments have been developed to measure family functioning, which may be used with families of patients who suffer from chronic pain, including:
 - Family Adaptability and Cohesion Evaluation Scales (FACES II)
 - Family Environment Scale (FES)
 - McMaster Family Assessment Device (FAD)

Flor H, Turk DC, Rudy TE. Pain and families. II. Assessment and treatment. Pain. 1987;30(1):29-45.
Olson DH, Russell CS, Sprenkle DH. Circumplex model of marital and family systems: VI. Theoretical update. Fam Process. 1983;22(1):69-83.
Moos RH, Meeus RS. Family environment scale manual. Palo Alto, CA: Consulting Psychologists' Press; 1981.
Epstein NB, Baldwin LM, Bishop DS. The McMaster family assessment device. J Marital Fam Ther. 1983;9(2):171-180.

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How to Assess Family Functioning

- There are also observational measures that may be used to assess family interactions, including:
 - Revealed Differences technique
 - all members answer controversial questionnaire & then share differences between family
 - asked to talk over things as family as watch through two-way mirror
 - Simulated Family Activity Measurement (SIMFAM) technique
 - hypothetical family situations are enacted to see how they relate to each other
 - Manual Interaction Coding System (MICS)
 - baseline assessment of behaviors occurring in family interaction
- These assessments have not been established specifically for chronic pain



Shostrom FL. Husband-wife interaction over revealed differences. Am Sociol Rev. 1951;16(4):488-473.
 Green M, Tennen C. SIMFAM: a technique for observational measurement and experimental analysis in families. In: Alford L, Cooper H, Hill R, Orvaschel H, Tennen C, eds. Family: a symposium on theoretical, methodological, and clinical issues. New York: Springer, 1977. pp. 107-124.
 Green M, Tennen C. The Manual Interaction Coding System. Eugene, OR: University of Oregon; 1971.



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How to Assess Family Functioning

- During interview, the practitioner should obtain a family history of pain, ideally at a first visit
- Information about familial interactions preceding exacerbations & meaning or attributions ascribed to pain are important to decipher
- Self-report measures such as those listed below may be used to gather some of this information:
 - Spouse's Perception of Disease (SPOD) questionnaire
 - West Haven Yale Multidimensional Pain Inventory (WHYMPI)
 - diary to relate pain to a spouse's behaviors, indicating:
 - when they saw their partners in pain
 - how they recognized that they were in pain
 - what they did to relieve their partners' pain
 - how they felt, if what they did was useful
 - classified into punishing-passive, solicitous, and distracting behaviors
- Family members should be made to feel comfortable when asking for family or couples counseling if needed

Baron R, Turk DC, Clark TE. Pain and families: II. Assessment and treatment. Pain. 1997;68(1):55-65.
 Green M, Tennen C. The Manual Interaction Coding System. Eugene, OR: University of Oregon; 1971. pp. 107-124.
 Green M, Turk DC, Clark TE. The West Haven Yale Multidimensional Pain Inventory. (WHYMPI). Pain. 1988;33(1):245-256.



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When to Refer Family & Couples Counseling

- Refer a family or couple to counseling when there is evidence of stress, grief, anger or conflict in the relationship and can be helpful to address specific issues
- Family or couple may pursue family therapy along with other types of mental health or addiction treatments
- Counseling can be helpful to patient & their family members to understand one another better and learn coping skills to bring them closer together
- Clinicians can also educate patients & their families about benefits of counseling



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When to Refer Family & Couples Counseling



- Addressing emotions with support groups or therapy can help to strengthen family & reduce suffering of all involved
- Research has shown that discussion groups for patients with chronic pain and their family helps to improve:
 - Communication
 - support mutual relationships
 - provide better coping strategies

Lemmers G, Ederl J, Heinen M, Van Rossum-Boshuizen B, Sabbe B. Family discussion groups for patients with chronic pain: a pilot study. *Pain & Ther*. 2005;2(1):21-32.



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Therapeutic Relationship

- Therapeutic relationship (also therapeutic alliance, helping alliance, or working alliance) refers to relationship between a healthcare professional & a patient
- It has been found to predict treatment adherence, agreement, & outcome across a range of patient diagnoses & treatment settings
- Research on statistical power of therapeutic relationship now reflects more than 1,000 findings
- In humanistic approach in psychology, Carl Rogers identified a number necessary and sufficient conditions that are required for therapeutic change to take place.
- These include:
 - authentic /genuineness
 - unconditional positive regard
 - empathy



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Family-Oriented Psychotherapies

- RCT have indicated that family-oriented psychotherapies used to treat chronic illnesses generally have small effects; more research is required
 - There are several treatment approaches involving family members that have been developed
1. Operant-behavioral treatment
 - based on operant conditioning model of chronic pain, which proposes that pain behaviors are influenced by social responses of family members
 - over time, family responses may become rooted patterns which leads to increased dependency and disability
 - family members are taught to validate their loved one's pain but also disregard maladaptive behaviors and reinforce wellness behaviors
 - these interventions have been shown to be effective when combined with family support and education about coping skills

Martin LM, Schulz R. Involving family in professional interventions for chronic illness. *Curr Opin Psychol*. 2007;1(2):98-94.
Kane RD, Orr JD, Wax EA. Treating families of chronic pain patients: application of a cognitive-behavioral transactional model. In: Turk DC, Gatchel RJ, eds. *Psychological approaches to pain management: a transdisciplinary handbook*. New York, NY: Guilford Press; 2002:258-272.
Rennett JM, Gidycz RA. Assessment of couples and families with chronic pain. In: Turk DC, Mersback R, eds. *Handbook of pain assessment*. New York, NY: Guilford Press; 2001:246-261.
Rosenau JM, Jensen MP, Turner JB, Gidycz RA, Hays RD. Chronic pain patient-partner interactions: Further support for a behavioral model of chronic pain. *Behav Ther*. 2000;31(1):15-40.
Sole-Solters AB, Vrijman JB, Coenen ME, et al. Chronic low-back pain: what does cognitive coping skills training add to operant behavioral treatment? Results of a randomized clinical trial. *J Consult Clin Psychol*. 1997;65(1):61-64.
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Reinforcement of Pain

Positively reinforce well-behaviors, which decreases perception of helplessness!



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Family-Oriented Psychotherapies

2. Cognitive-behavioral treatment (CBT)

- based on cognitive-behavioral transactional model
- proposes that family develops a relatively stable set of beliefs about illness, pain, disability, & coping over time
- focus is to direct family toward developing an adaptive problem-solving approach to pain management
- involves increasing effective use of available family resources (time, energy, knowledge, skills and abilities)
- teaches family members new adaptive coping skills
- helps them draw upon available external resources (schools, community centers, childcare programs, women's centers, and other community networks)
- there has been empirical support for effectiveness of CBT with spouses of chronic pain sufferers

Kille-DeJure AM, Vetter JM, Guzman ME, et al. Chronic low-back pain: what does cognitive coping skills training add to operant behavioral treatment? Results of a randomized clinical trial. J Consult Clin Psychol. 1994;62(2):257-264.
 Cira J, Castillo L, Kania R. The influence of family and culture on pain. In: Devlin RH, Breibart WS, eds. Psychosocial aspects of pain: A handbook for health care providers. Seattle, WA: IASP Press; 2004.
 Turk DC, Kania RD, Rosenburg R. Effects of marital interaction on chronic pain and disability: Examining the downside of social support. Rehabil Psychol. 1992;37(4):259-274.
 Savelle TJ, Chalmers DR, Raucous D, et al. Spouse-assisted coping skills training in the management of osteoarthritis knee pain. Arthritis Rheumatism. 1996;39(4):279-291.



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Cognitive-Behavioral Family Therapy

- There are 4 steps to the process:
 1. Assessment
 2. Target behaviors & thoughts for change
 3. Educate
 4. Replace & retrain



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ABC Model



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Family Schemas & Core Beliefs

- Overgeneralization – Taking isolated cases & using them to make wide generalizations
- Mental filter – Focusing almost exclusively on certain, usually negative or upsetting, aspects of an event while ignoring other positive aspects
- Jumping to conclusions – Drawing conclusions (usually negative) from little (if any) evidence. Two specific subtypes are also identified:
 - Mind reading – Assuming special knowledge of intentions or thoughts of others
 - Fortune telling – Exaggerating how things will turn out before they happen
- Emotional reasoning – Making decisions & arguments based on intuitions or personal feeling rather than an objective rationale and evidence

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Family-Oriented Psychotherapies

- There are 3 other family-oriented therapies that include spouse or family, including structural, cognitive, and strategic
- These family-oriented therapies have scant research to support their effectiveness
- Structural family therapy
 - proposes that family system structures contribute to development & perpetuation of pain
 - enmeshment
 - roles and rules
 - poor communication
 - lack of conflict resolution
 - withholding feelings
 - avoiding emotionally laden topics
 - treatment concentrates on changing structure of family so that a new homeostasis may be reached without patient taking on "sick" role

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Family-Oriented Psychotherapies

- Cognitive family therapy
 - focuses on self-disclosure in marriage & a resulting uptake in couple's closeness & intimacy
 - couple is encouraged to share appraisals & thoughts about each other & openly express negative emotions
- Strategic family therapy
 - consist of interventions that are practical & problem-oriented
 - these may include a comprehensive assessment by a therapist



Flor H, Turk DC, Rudy TE. Pain and families. In: Assessment and treatment. Pain. 1997;20(1):29-45.
 Garcia RL, Dale JL. Family therapy for juvenile rheumatoid pain: Evidence for its effectiveness. Seminars
 in Pain Medicine. 2002;12(7):484.
 Wenzel SL. Mindfulness, neurobiological symptoms, and cognitive therapy. Psychosomatics.
 November 17, 2008;49(6):585-595.
 Morrison JF, Dale JL. Psychological aspects of somatization in families. 2. Intervention strategies and
 outcomes. Child Psychology Clin. 1992;33(1):95.



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Mindfulness-based Therapies

- Mindfulness is a type of meditation commonly used in pain management
- Mindfulness is an exercise in just noticing, or awareness
- Several types of interventions that include mindfulness:
 - Mindfulness-Based Stress Reduction (MBSR)
 - Acceptance & commitment therapy (ACT)
 - Dialectical behavior therapy (DBT)
 - Mindfulness-based cognitive therapy (MBCT)
- Practicing short meditation exercises is a great way to break away from pain, and it may also reduce anxiety, depression, and sleep trouble
- Evidence of improved pain associated with mindfulness interventions
- May be effective in treating at least some aspects of somatization disorders, including fibromyalgia

Schwar, C. (2011). Mindfulness meditation improves connectivity in the brain. Harvard Women's Health Watch, April 28, 2011.
 Cohen, M., 2009. E. Schirag, E. et al. (2014). Meditation Programs for Psychological Stress and Well-being: A Systematic Review and Meta-analysis. JAMA internal medicine. Jan 6 2014.
 Lohman, S. & Schirag, K. (2013). Mindfulness-based therapies in the treatment of somatization disorders: A systematic review and meta-analysis. PLoS one, 8(8), e71824.



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How to Encourage Family Self-Care

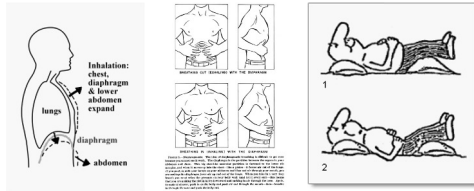
- Members of the family should be encouraged to address their own pain & stress resulting from these circumstances
- First and foremost, they should maintain a healthy lifestyle:
 - healthy diet
 - exercise
 - relaxation
 - sleep hygiene
 - personal hygiene
 - refusing bad habits
 - social support
- This will not only help family face difficult times ahead, but it may also serve as a model to their loved one suffering from chronic pain
- Familial caregivers should avoid coddling or being punitive toward their loved one suffering from pain & should ideally take on a more facilitative role

Roy R. Chronic pain and family: a clinical perspective. New York, NY: Springer; 2000.



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Teaching Relaxation



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How to Encourage Family Self-Care

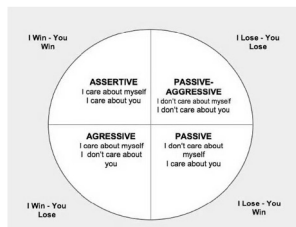
- Family/caregivers can also work to acknowledge and overcome any special obstacles that may occur when communicating with a person suffering from chronic pain
- Family members will want to learn as much as they can about their loved one's condition & about treatment options
 - keep in mind that when communicating with their loved one's doctors, they must first obtain permission & consider HIPPA regulations
 - always allow person in pain to directly speak to doctor & only provide additional information when specifically asked to do so
 - add insight into loved one's pain by sharing their perception using a pain score (0 to 10), describing it as it unfolds throughout day, & helping their loved one complete a pain log or diary
 - may also inquire further about side effects & dosages of medications and/or appropriate activity levels & limitations.

Covered in Family manual: a manual for families of persons with pain. American Chronic Pain Association. 1998.
 Overcoming Pain: Ten tips for communicating with a person suffering from chronic pain. July 2, 2019. Available at: <https://www.chronicpain.com/en/ips-for-communicating-with-a-person-suffering-from-chronic-pain/>.
 Accessed October 18, 2019.



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Assertiveness Skills



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Improving Communication

1. **Listen!**
 - Repeating and summarizing what is said is also a skill associated with good listening
2. **Don't Fake It**
 - It can be unpleasant to listen to someone talk about their pain--you don't have to have all the answers
3. **Understand that pain sufferers may be afraid to say how they are feeling**
 - Not expressing or underreporting pain are coping mechanisms which can be misleading to the unsuspecting
4. **Look for non-verbal cues**
 - Look for sweating, irritability, sleep disturbance, restlessness, difficulty concentrating, decreased activity, and suicidal thoughts
5. **Believe people when they say they are in pain**
 - Myth exists that they exaggerate their pain in order to gain sympathy or avoid responsibilities--actually rare



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Improving Communication

6. **Asking 'helpful' questions can stimulate hope**
 - Rarely chronic pain sufferers are ever asked directly how satisfied they are with their treatment, and whether they think their pain is bearable
7. **Avoid "words that maim"**
 - Lines such as "you'll just have to learn to live with it" or "you don't look sick"--such talk dissipates hope
8. **Have compassion**
 - Try and put aside your cares and preoccupations even for just a few minutes and listen with an open heart
9. **Be honest about the limitations of your own knowledge**
 - It is better to admit you 'don't know' the answer rather than to say something which may unintentionally destroy hope
10. **Remember, pain is not what you think it is**
 - Concept of pain has undergone considerable revision in recent decades. Pain is different for everybody, depending on personality & life history of person experiencing it



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How to Encourage Family Self-Care



- A good model may be to encourage family members to view situation as "our fight" and not "their fight," being careful not to take negative behaviors of loved one too personally
- Families & support systems work best when everyone is operating cohesively
- Frontline practitioners need to be aware of how chronic pain is associated with functional limitations due to positive & negative reinforcements from family dynamic in response to pain
- It is important to include family members in pain education & treatment approaches, & to encourage communication between them, which has been shown to improve outcomes
- Case example of healthy couple

©2010-2012, Trudy P. Cook, L.A. Chronic Pain Coach. Back pain: cognitive behavioral therapy with family therapy. ©2010-2012, Trudy P. Cook & Sheri D. Cook. Pain and the family: the experience of the partners of people living with chronic pain. J Clin Neurosci. 2012;25(12):3191-3192-3193.



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Pain Education for Family Members

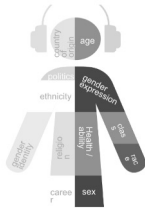
- What to expect from their loved one's first visit
- Introduce them to the staff
- What are the goals of the clinic
- What is a comprehensive pain management plan
- What are the different treatment options available
- What future appointments to expect
- How to use the "0" to "10" pain scale
- With whom else their loved one may be scheduled
- Pain management takes time



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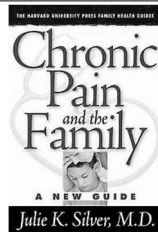
Cultural Considerations

- Culture consists of many different concepts, such as:
 - race or ethnicity
 - religion or spirituality
 - sex or gender identity
 - language or country of origin
 - socio-economic status
 - being able-bodied
 - sexual orientation
 - age or view of older members' role
- These concepts can create a barrier to adequate pain management



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Resources for Families/Caregivers



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For More Information:

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- Phone: 312-569-8703
- Facebook: DrDavidCosio

