The Pain Patient at Home – Now What Do We Do?

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Objectives

• State Resources for patients with chronic pain living at home

• Outline patient and family barriers that exist in managing pain at home
Thoughts on working with pain patients

Pain is:

• Whatever the experiencing person says it is; existing whenever the person says it does.  
  (McCaffrey 1968)

• Pain is a very personal experience for each patient & family.
What’s important?

Pain relief puts people back in control of their lives.

Relief can be concrete, or in the form of improved mood.
We meet pain patients at:

- Emergency room, inpatient hospital status or residential hospice care.
- Outpatient clinic settings.
- Own homes or residence.
- Home of family or friends as caregivers.
- Older adult residential settings, such as long term care, assisted living, group homes, independent senior apartments, etc.
Aspects of care at home

• Self-efficacy – belief you can do what’s necessary to survive.

• Achieving pain relief or control requires the belief “I can do what it takes to survive at home.”

• Pain isn’t a punishment, but can feel like it to everyone in the home.

• Pain not always recognizable. “You don’t look sick”.

• We know that medications alone are often inadequate to relieve pain or suffering.
Pain care at home

- Eventually pain patient returns to their usual setting.

- Is multidisciplinary team available to organize a discharge or continuation-of-care plan?

- Essential to determine who will assess, educate, intervene & support patient/family in residential setting.

- Patients need us to offer assistance & make a plan – clinicians practice in complex environment patients can feel insecure in.
Pain care at home

• Chronic pain affects 1 out of 3 families, or close to 30% of U.S. population. (Drum 1999)

• Providers must remember that challenge of managing chronic pain on day-to-day basis in the home, falls on patient & family.

• Self-management at home can mean patient handles much of treatment alone.

• They use whatever tools/coping techniques they’ve been educated on. What if there’s been no education?
• Physicians and/or IDT say “learn to live with this” and “you can deal with this at home”, but don’t always take time to explain to patient/family how this advice is to be followed.

• Patient/family feel unsure when care provided at home, without professional support from an IDT or physician.
Who assists pain patients at home?

- Outpatient disciplines - physicians, psychologists, nurses, social workers, PT’s, OT’s, massage therapists, etc. (episodic)
- Hospice residential care (specific diagnoses)
- Skilled home health care (short-term plan)
- Private duty home care (requires $$$)
- *Family/friends* as caregivers (not always available or willing)
Patient & family barriers

• **Values & beliefs:**
  • Pain is inevitable, necessary & builds character.
  • Pain requires a stoic response.
  • Individual wants to be a ‘good’ patient – and ‘good’ patients don’t complain.
  • Patient/family doesn’t want to bother doctor or IDT.
Patient & family barriers

• There’s lack of knowledge how to report pain or lack of improvement, to IDT.

• No expectation of effective treatment.

• Fear of ‘using up’ pain medications.

• Fears about addiction.

• Fears from caregivers about safety of giving meds at home.
• Our culture encourages pain patient to suppress their responses.

• Suppression leads to depression, tension & anxiety.

• Pain cycle is fed by these feelings.

• Becomes challenging to distract patients at home & draw attention away from pain.
Pain behaviors at home

- Crying
- Staying in bed
- Limping
- Grimacing
- Talking about pain
- Withdrawing
- Groaning
- Anger management concerns

Eventually challenging to separate patient from the pain – caregivers pay less attention; patient withdraws into themselves. Depression cycle begins.....
Pain emotions at home

- Loss of control
- Frustration
- Guilt
- Fear
- Decreased self-esteem/self-image
- Anxiety
- Irritability
- Loneliness
- Sadness/depression
- Hopelessness
- “I’m not needed”
- Apathy
What issues contribute to pain?

Home stressors can include:

- Emotional/behavioral issues
- Evolving strained family relationships
- Financial hardships (insurance payments, meds, transportation, reduced/no income, etc.)
- Employment interruptions for patient and caregivers
- Disruption of family routines & events
- Lack of education about source of pain, treatment or expectations
- Need for medication safety plan
- Lack of meaningful socialization
- Decreased contact with external family & friends
Home stressors continued:

• Impaired physical functioning – ADL’s
• Sleep disruption
• Appetite disturbances – gaining OR losing weight possible
• Not getting out of the home comfortably or easily
• Diminished ability to contribute at home
• Role changes/transitions
Who are caregivers?

- 44 M (21%) of adult populations provide unpaid care to person age 18 or older.

- 61% of caregivers are middle-aged women.

- 13% of caregivers age 65 or older.

- 59% have external employment in addition to caregiving duties.

- 50% of employed female caregivers have made changes at work - going in late, leaving early, working less, etc.

(www.womenshealth.gov)

- The patient’s situation is typically assessed; who pays attention to the family’s needs at home?
Experiences of family & caregivers

• Professionals benefit from making assessment of pain patient & family in their home - why?

• What does family think about the patient’s pain?

• How do they react to demonstrations of pain behaviors or emotions?

• What distresses the family most about the patient’s pain?
**Family feelings**

- Family members don’t always recognize they may have become part of the ‘pain game’.
- Caregivers have good intentions but can overprotect patient – impede self-management or independence.
- They may experience:
  - Controlling behaviors.
  - Desire for sympathy from the patient.
  - Bottled-up feelings causing lashing out verbally, etc.
  - Feelings of sadness or grief.
  - Feelings of helplessness.
  - Anger/guilt reactions – disruption to their own life & routine.
• Families may experience fear about determining whether patient’s pain is mild, moderate or severe – and medicating appropriately.

• May have fear about patient over-or-under-medicating himself.

• Lack of understanding/education about need for medication safety plans.
Steps to help the patient at home

• Education from the IDT – reduces unreasonable expectations.

• Maintain good communication with IDT & family about treatment plans, medication needs, etc.

• Support from skilled home health care to learn home management, if appropriate.

• Assistance from private duty home care (if $$$ allows) or volunteer caregivers until patient independent.

• Determine who can provide respite care for family when/if necessary.
• Exercise – be as active as possible. *Fear of pain* will lead to giving up enjoyable things.

• Distraction – diverts attention away from pain. Pleasant experiences help cope with pain.

• Identify capabilities, not just limitations. Improves mood!

• Follow medication regimen carefully to avoid overuse, & side effects such as constipation, drowsiness, cognitive impairment, poor nutrition, etc.
• Individual, family and/or group counseling to sort through, assess and treat emotional & behavioral issues.

• Learn stress reduction or relaxation techniques.

• Don’t allow conversations to always turn to pain as topic.

• Develop accommodations at home that allow patient to complete simple tasks...

  vs.

  “this is the way we’ve always done this.”
Steps to help family at home

• Individual, family or group support & counseling.

• Education from the IDT to prevent unreasonable expectations.

• No hovering - overly attentive behavior interferes with self-management.

• Don’t give up activities family enjoys for sake of pain patient.

• Discuss roles reversals, financial issues, behavioral changes, etc. together - professional facilitation may be needed.
• Be prepared to ask for and **accept** help from others.

• Identify what can, and cannot, be changed. Example: can’t change patient’s behavior, but can change way it’s reacted to.

• Establish a daily routine for family & patient – prioritize.

• Reduce isolation – arrange for meaningful social interactions.

• Find a distraction – diverts attention away from the ‘sick role’.
• Two ways we try to cope:
  • Annoyed – “Not this again”.
  • Sad or worried – “Let me do that”.

Neither choice helps create or maintain good relationship with the patient or promotes survival. Patient may think they’re not needed.
Developing home medication safety plan

• Needed when patient becomes reliant on meds or develops preoccupation with taking them.

• Realization patient taking more meds than prescribed.

• Patient using more than one physician or pharmacy for meds.

• Patient has used someone else’s meds.

• Frequent ER visits outside of physician appointments.

• Family should know medication names, dosage, schedule, for safety.
What SW brings to pain care

• Function of SW’s includes: clinician, advocate, case manager, educator, etc.
• SW brings expertise in assessment of patient in environment.
• SW brings commitment to ease suffering from pain & maximizing quality of life.
• Medical SW understands physical & mental health issues.
• SW’s have skills in problem-solving, & providing patients/families with resources.
• SW’s exceptional at providing collaboration, dignity, autonomy, and understanding to pain patient.
Thank you for your attention!
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