Learning in the Context of Illness

BC Nephrology Days

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What We Know from the Research

- Health Care Interactions/Communications Research

- Patient-focused research

Health Communications Research

- time constraints,
- expectations,
- power imbalances,
- an over-emphasis on information-giving,
- and varying perceptions of roles and scope of practice take their toll on effective communication

- (Bartz, 1999; Bakker et. al, 2001; Bensing, Verhaak, van Dulmen & Visser, 2000; Kettunen et.al, 2000; Kruijver et.al, 2000) .

Health Care Communications Research

- communication difficulties can be described as:
- problems of diagnosis,
- a lack of patient involvement in the discussion
- inadequate provision of information to the patient.

- Studies have shown that 50% of psychosocial problems are missed, that [hcp's] interrupt an average of 18 seconds into the patient's description of the problem, that 54% of patient problems are neither elicited by the [hcp] nor disclosed by the patient, and that patients are dissatisfied with the information provided to them by [hcp's]. (Stewart,1995, p. 1424).

Health Care Communications Research

- Positive experiences of communication arose when physicians took a leadership role in opening conversations up to patients. Not appearing rushed and taking time to explain matters was important, as was maintaining hope

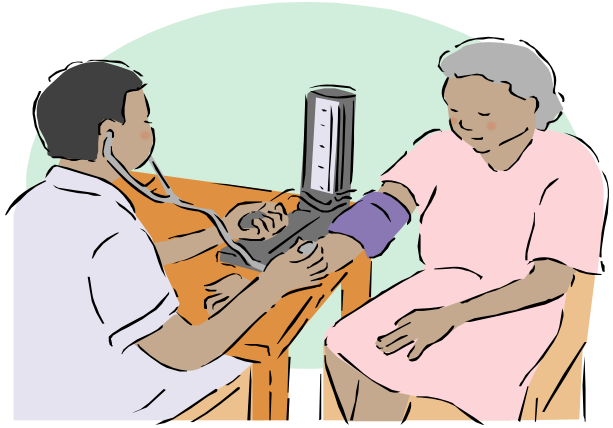
(McWilliam et.al 2000).

Health Care Interactions

- Fragmented care
- Information not retained (illness-related)
- Health care culture is not explained
- Mistakes occur
- Mistrust develops
- Vigilance about future care and taking on the role of case managing for oneself

Patient-Focused Research

The patients' perceptions of health care interactions have been poorly studied



Effects of Illness on Learning:

"I think in the beginning stages I was just so ill that it was hard for me to remember or take in a lot. I just felt so horrible…in a lot of pain, and nauseated and vomiting and just so tired and my head felt funny. I couldn't take in information. People would say something like "walking your dog, and I would say "I don't understand". Somehow my brain wasn't functioning."

Fragmented Care:

"I went to my nephrologist, said "tell me when I get a 2nd transplant what the protocol is." So he told me, I got called and I said "I'm going to be on this protocol". He (resident) said "no, no, no. Your first rejection was a technical error". I said "it was not, it was an acute cellular rejection." He said "no, I was told it was…"Anyway, it went back and forth and I said "look, I talked to my nephrologist, and I know I'm to get [medication] before I even start." And the resident agreed, "obviously you know what you're talking about…I can't find anyone else, so I'll assume you're right". So because I had that information before, and again, maybe it saved my kidney."

The Need for Support:

"I expect you as a nurse, not to just be able to put me on and take me off and do my blood pressure. I expect you to relate to me as a human being. And that's often lacking, and I understand some of the concerns about burn out. But on the other hand, maybe its sort of the divine, that you can be good at your tasks, but the real healing potential is about who you are, what you bring to that person, how you relate to that person. And that's what I need to see. And anyone that I trust has got to have that."

"Some of the people made such a difference. Even total strangers could make your day by just saying something very comforting that you weren't expecting. And that was a real surprise for me, to learn about human compassion"

Patient Focused Research: What is valued?

- The key ingredient seemed to be the relationships that developed between providers and patients/families
- Also important was a willingness, on the part of providers, to explore individual ways to manage an illness

“But I’m Not Sick” CKD Focus Group

Jan 05

Modality	Number of Patients	Gender
CKD	5	male
PD	2 (CKD until 4 mos ago)	female
Hemodialysis	4 (no CKD care, or MD only)	male
Transplant	1	female
Family Members	4	3 female, 1 male

“But I’m Not Sick” Conclusions:

- Participants indicated a need for time to adjust to the diagnosis when possible. Therefore, initial encounters with CKD staff ought to be supportive rather than educative, unless the patient indicates a desire for information.

- Denial is an adaptive initial response to trauma, and the denial commonly encountered in CKD ought to be recognized as an important and necessary phase

“But I’m Not Sick” Conclusions:

- Educational materials should be presented incrementally, that is, in a timely manner, guided by the patient’s current status and some relevant anticipatory information, *unless otherwise indicated by the patient*

“But I’m Not Sick” Conclusions:

- Messages of hope are as important as information about the disease and its treatment.
- Patients need to hear clearly that delaying progression is as much a focus during CKD as preparation for dialysis. For those patients referred too late for preserving kidney function, the message of hope needs to involve successful living with dialysis or other treatment

“But I’m Not Sick” Conclusions:

- CKD staff need to have (or develop) the often highly intuitive skills of assessing readiness for learning and when to suggest a need for modality decisions.
- The participants’ comments suggest that the ability to walk the tightrope of respecting denial as a coping mechanism, while recognizing when to move forward with teaching and/or preparation for dialysis if necessary, is a valuable skill.

“But I’m Not Sick” Conclusions:

- Group education sessions should include time for the participants to discuss their experiences with each other, and to hear other’s stories. If possible, dialysis patients and family members should be included.

“But I’m Not Sick” Conclusions:

- Peer support is an integral element of CKD care, and ought to be provided along the continuum of the CKD program, not just at diagnosis.

“But I’m Not Sick” Conclusions:

- Despite adequate preparation, some patients may view the need for dialysis as a defeat, and this should be recognized as a normal grieving process. This grieving should not be lost within the flurry of dialysis preparation, and additional emotional support may be necessary.

“But I’m Not Sick”

- *“I don’t think you’re teachable right away. I mean that’s the way I look at it anyway. Like when you first get it. When you’re first diagnosed with it, I don’t think you’re teachable enough when you first go in there.”*

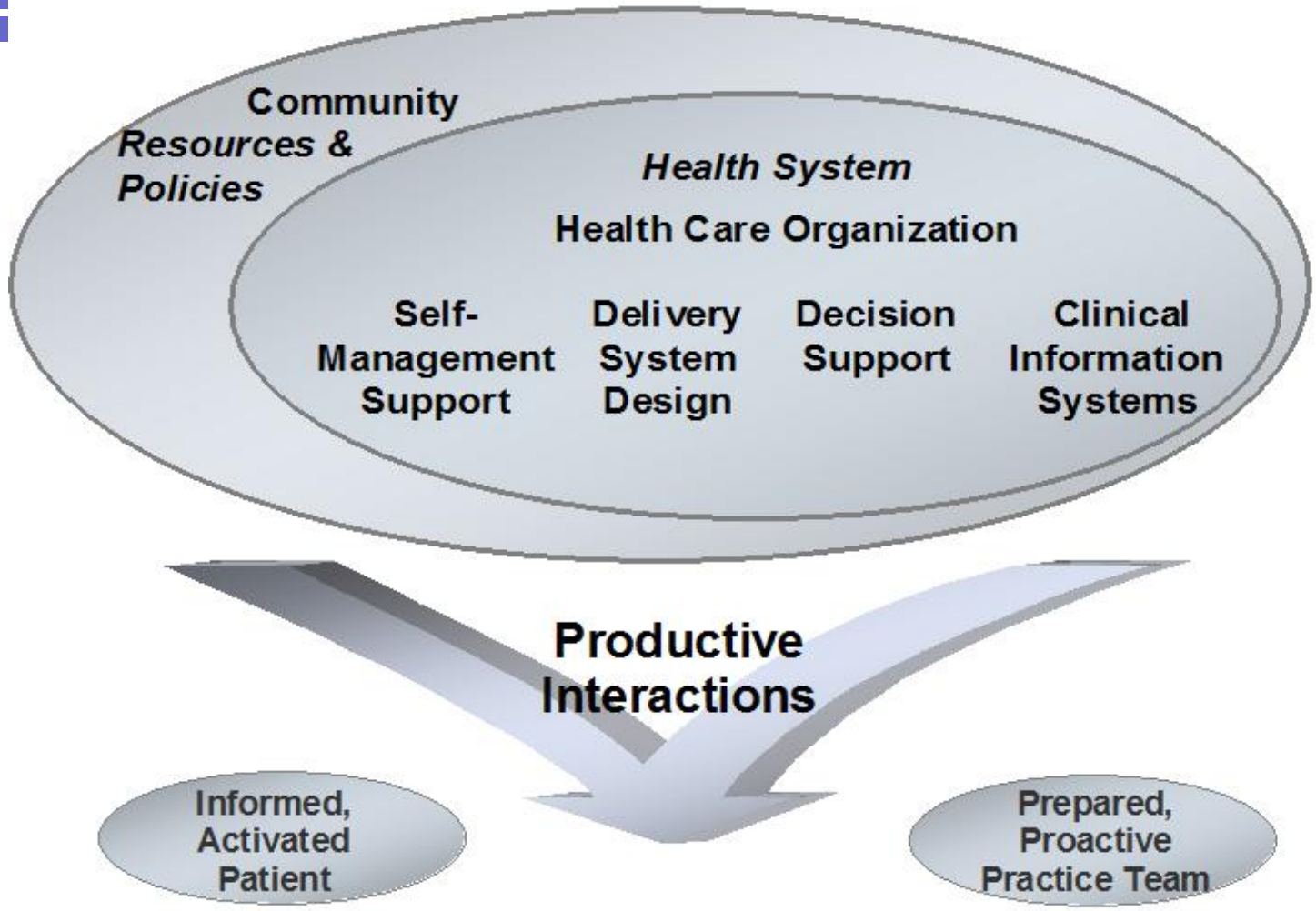
“But I’m Not Sick”

“*I was parachuted in so darn sick with my disease, that I was kind of overwhelmed and within a whole week I went through four hours of instructions and videos and textbooks and talking and when I got out of that room, I was totally confused. I had no idea what they were telling me and I didn’t have a clue. I went home and started reading the books and started to learn as I read the books and I think they should take a lot more time at the beginning stages to teach you things, you know. One guy at a time, one, one situation at a time, one subject at a time, get that over with, come in again, do another one*.”

“But I’m Not Sick”

“What happens is I get out of the denial, and I go more into the saying, -“ Ok how can I make this work?” I mean I could see my numbers going up and down and doing whatever they’re doing and I started to question those things. “But how could I make sure that I make that run out as long as I possibly can?” So you get into this, - “Let’s make the thing work.” …rather than, - “ How can I fix it?” …because it’s not fixable. It’s like having something that’s never going to run correctly. So you just say, -“ Let’s just do it and make it last as long as you can and do the things you want to do and as [names] said about that too, you won’t die from this, you’ll be in dialysis.”

The Care Model



Improved Outcomes

Your Work:

- empowering and preparing patients to manage their health and health care;
- delivering efficient clinical care and self-management support;
- promoting clinical care that is consistent with scientific evidence and patient preferences;
- tracking data to facilitate efficient and effective care
- creating a culture, organization and mechanisms that promote safe, high quality care;
- mobilizing resources to meet needs of patients

In Essence…

making sure a patient has enough clinical care and information to understand his/her present condition and, ideally, through treatment and education, make enough change in his or her lifestyle that the condition will at least be stable longer or more often - if not improve.

….perform miracles
every day
with scarce time and resources

That’s a daunting task!

challenging stressful time consuming

exhausting heart-breaking crazy-making

You'd think if people know they have a very bad condition or disease

and if they know they should change their lifestyle, they would….

…. but they don't.

So, the work is essentially all about motivating people to become informed about their health and to change habits that are not healthy, right?

It is not as easy as it sounds!

Wouldn’t conventional wisdom say that a personal health crisis is a powerful motivator for change?

It’s not. The odds are nine to one against significant change, even when change really matters.

In fact, discoveries from emerging fields such as cognitive science, linguistics and neuroscience are busting myths about what motivates change in behaviour.

The Myths

- Crisis is a powerful motivator for change.

  Reality: ninety percent of patients who have had coronary bypasses don’t sustain changes in unhealthy lifestyles that worsen their severe heart disease and greatly threaten their lives.

The Myths

- Change is motivated by fear.

  Reality: It’s too easy for people to go into denial about the bad things that could happen to them. Compelling, positive visions of the future are a much stronger inspiration for change.

The Myths

- Knowledge empowers people to change.

  Reality: Our thinking is guided by narratives or “frames of reference” far more than facts.

  When a fact doesn’t fit our conceptual

  “frame” - how we make sense of the world - we reject it.

  Change is inspired more by emotional appeal than factual statements.

The Myths

- Gradual change is easier to make and sustain.

  Reality: Radical, sweeping change is often easier because it yields benefits more quickly.

The Myths

- We can’t change because we get “set in our ways” as adults.

  Reality: We are amazingly flexible and resilient and we can continue to learn complex new things throughout our lives - if we are actively engaged in learning and the learning impacts our frame of reference.

In highly successful change efforts,

be they in medicine, business, public service or community, people find ways to help others see the problems or solutions in ways that influence emotions, not just thought.

(Of course, in our society, appealing to the pocket book sometimes helps, too.)

The research about what motivates change is also contributing to the field of education.

"The more that is discovered about how the brain works and the various motives which drive human behaviour, the more we are convinced that education has to be about much more than exposing people to information."

21st Century Learning Initiative

New understandings are re-shaping perceptions of the learning process and how educators can promote it.

We now know:

1. The behaviourist model of learning is incomplete: learning is *not* all about teaching - we cannot teach everyone in the same way and expect that each person will learn to potential.

2. Education must address individual learners *in situ.*

Teaching needs to take into account a person's frame of reference, his/her readiness to learn, his/her learning style preferences, and cultural background.

3. The brain is a pattern-seeking organ constantly searching for order in chaos. The order we create for ourselves becomes our frame of reference for future learning.

4. Learning is not linear - it requires learners to connect new learning with what they already know and have experienced. These connections happen more like the formation of a web than they do a light bulb turning on.

5. In optimal learning, teaching and the learner's readiness to learn are integrated rather than separate processes. The learner is given opportunities to be mindful of his/her own learning process - he/she becomes aware of the experience of the learning.

There Are Multiple Intelligences

Howard Gardner (Harvard) uses his theory of multiple intelligences to show that we have multiple survival strategies that include an ability to look at any situation and think about it from a number of different perspectives.

Different forms of intelligence enable each of us "to make sense of our environments in very different ways."

These "different ways" are critical to our survival. The balance between emotion and logic, the role of intuition, and the relationship between intrinsic and extrinsic motivation are all part of the "complex adaptive system" that best describes the brain's ability to deal with the messiness of both ordinary everyday life situations *and* the crisis of life-threatening situations.

We know now more than ever

(and good teachers have always known this)

- There is no one best way to teach. In fact, there are always multiple ways to teach and they vary in effectiveness depending upon the context, the learner and the educator.

- An effective educator takes this into account and actually sets up the learning situation so that there are diverse ways in which an individual can learn.

- There *are* patterns, principles and practices which are commonly accepted to be effective and there are others which have been seen to be less effective or discredited entirely.

Key Concepts

- Learner centred
- Experiential
- Reflective
- Authentic
- Holistic
- Social
- Collaborative
- Democratic
- Cognitive
- Developmental
- Constructivist
- Interesting and Challenging

Principles of Learning

Three Principles of Learning represent a consensus and provide a succinct and useful summary of fundamental understanding against which all teaching practice can be measured.

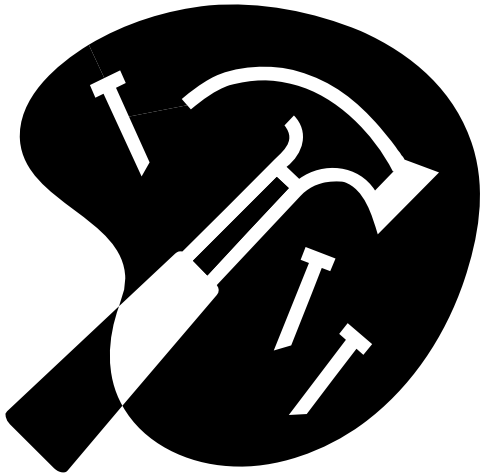
Principles of Learning

Applied to patient education:

1. Learning requires the active participation of the patient-learner and family.
2. People learn in a variety of ways and at different rates.
3. Learning is both an individual and a group process.

Apply these principles to:

- Climate and Environment
- Planning
- Teaching
- Closure



Climate and Environment

- Learner (patient/family) and educator work collaboratively to create learning routines
- The place where learners gather to learn offers comfort and inspiration as well as knowledge

Climate and Environment

- There is a sense of cohort (team), patience and compassion for each other
- There is understanding that each individual in the cohort will learn and progress in a different way and with different timing

Readiness, Positive Attitudes and Perceptions About Learning

- Readiness, attitudes and perceptions affect a person's ability to learn.
- If a person is not ready to learn or does not see the value of learning, most of the information shared just won't sink in - even if one's very life depends on it.
- Without positive attitudes and perceptions, people do not learn well.

Checklist:

- Establish a relationship with each person in the group.
- Monitor and attend to your own attitudes.
- Engage in equitable and positive behavior.
- Recognize and provide for participants' individual differences.
- Respond positively to participants' incorrect responses or lack of response.

- Vary the positive reinforcement offered when participants give the correct response.
- Structure opportunities for participants to work with each other.
- Provide opportunities for participants to get to know and accept each other.
- Help participants develop their ability to use their own strategies for gaining acceptance from their instructor and peers.

You'll know you are on the right track by looking at the relationships that are developing:

- leader to participant and participant to participant relationships are evidence of a positive learning culture
- respect and dignity is evident through learning interactions
- participants take a socially responsible role in their own learning and supporting the learning of others

Planning

- Plan ways to find out about the experience and learning styles of the participants
- Set objectives for learning that reflect various learning styles and participant needs

Planning

- Plan to maximize the use of a variety of resources to enhance instruction and meet the needs of students
- Plan for independent practice and reinforcement

Planning

- Plan to reflect knowledge, needs, skills and abilities for each student
- Plan so that the presentation and activities provide for monitoring of individual understanding and re-teaching, if necessary

Planning

- Plan to reflect learner involvement and ownership of self-assessment criteria
- Plan to address motivation and relevance to participants

Teaching

- the session links the current topic to the overall context

Teaching

- skills and information are presented efficiently, clearly, and accurately
- skills and information are presented in a way which is relevant to the participants

Teaching

- the presenter's spoken and written language is carefully matched to participants' ability and chosen to enhance learning

Teaching

- Construct a meaningful context for the information being presented

Checklist:

1 Help participants understand how to construct meaning

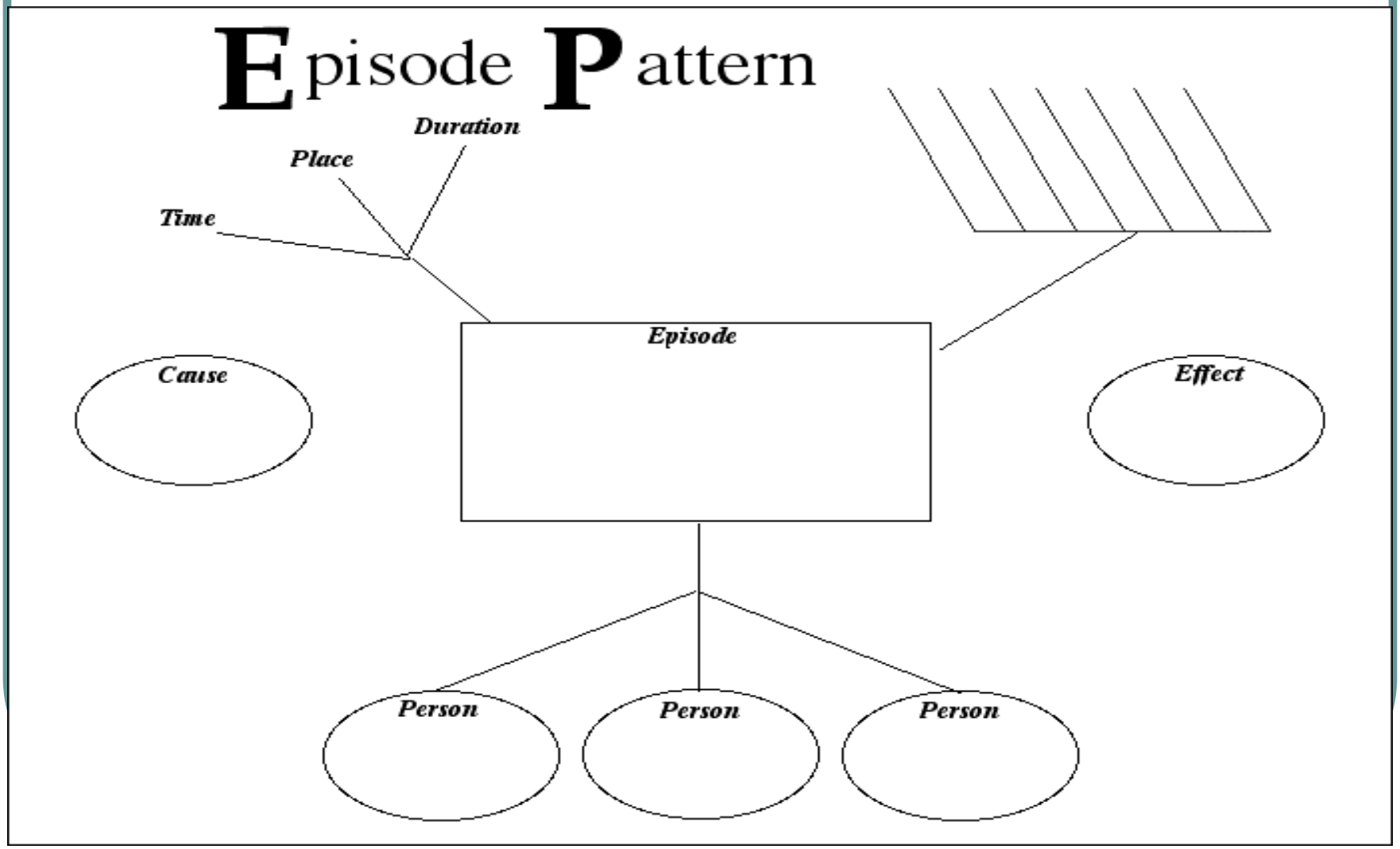
2 Help participants experience information using a variety of senses and “frameworks”

3 Help participants to construct meaning for vocabulary terms

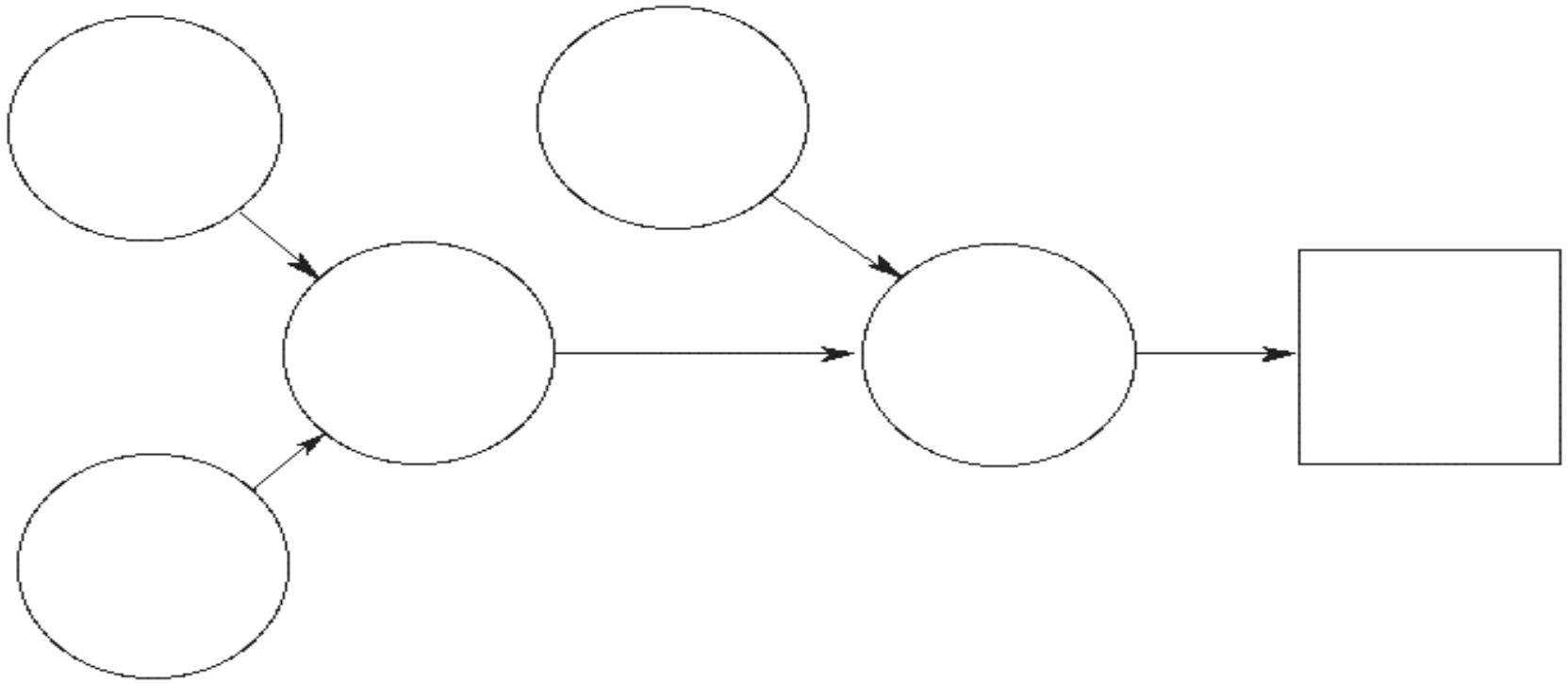
Checklist:

4 Create opportunities for participants to discover the new information for themselves. **(e.g., concept attainment)**

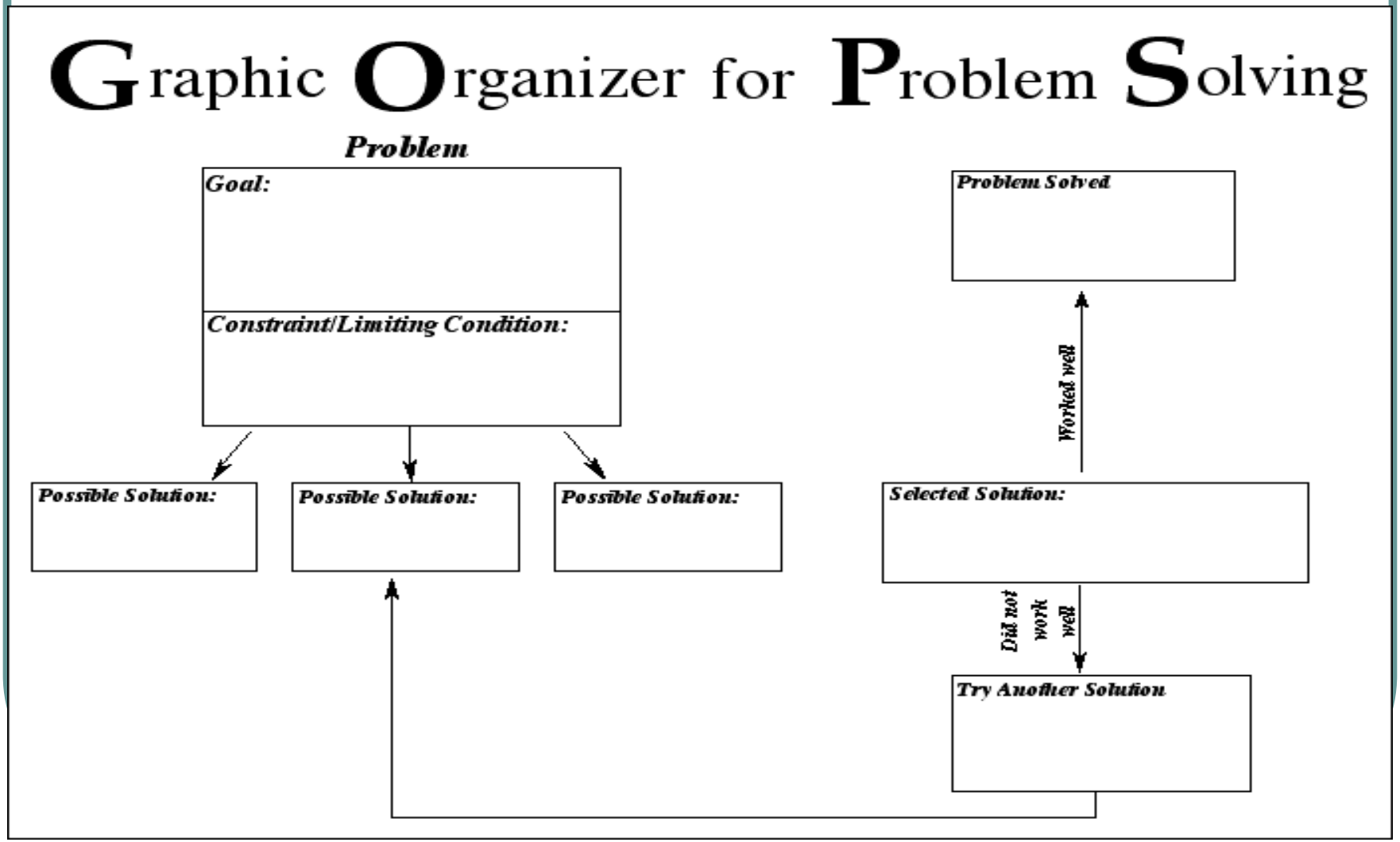
5 Use instructional techniques that provide students with strategies to use before, during, and after they receive information (ie. graphic organizers)


Episode Pattern
Duration
Place
Time
Episode
Cause
Effect
Person
Person
Person

Cause and Effect Patterns



Graphic Organizer for Problem Solving



Teaching

- Include a variety of questioning techniques, some of which promote higher level thinking skills such as application, analysis and synthesis

Checklist:

1. Encourage discussion by using open-ended questions

2. Decide on the goals or purposes of questions

3. Choose important--rather than trivial--material to emphasize participants' in-depth exploration of essential/key questions

Checklist:

4. Avoid "yes" and "no" questions

5. Use "probe" questions to encourage participants to elaborate and support assertions and claims

Checklist:

6. Ensure that participants clearly understand the questions--and avoid a "guessing game”

7. Avoid questions that "contain the answer”

8. Anticipate participants' responses to questions, yet allow for divergent thinking and original responses

Closure

- closure provides a link to the purpose of the lesson
- closure provides a link to previous and subsequent learning

You'll Know You Are on Track When Patient-Learners are:

- Being clear and seeking clarity
- Being open minded
- Restraining impulsivity
- Taking a position when the information (or lack of information) warrants it

You'll Know You Are on Track When Patient-learners are:

- Being sensitive to others' feelings and level of knowledge (this includes family)
- Engaging intensely in tasks even when answers or solutions are not immediately apparent

You'll Know You Are on Track When Patient-learners are:

- Pushing the limits of your knowledge because they are gaining so much of their own
- Generating their own standards of evaluation
- Generating new ways to view a situation outside the boundaries of standard convention
- Being aware of their own thinking

You'll Know You Are On Track When Patient-learners are:

- Planning ahead
- Being aware of necessary actions and resources
- Using your feedback effectively
- Evaluating the effectiveness of their own actions

Hey, this is a description of an informed and activated patient!

In Other Words

- **Research can inform practice**
- **Brain Research is changing what we understand about how people learn**
- **It is possible to give structure to an learning process**
- **Reflection can change thinking**

In Other Words

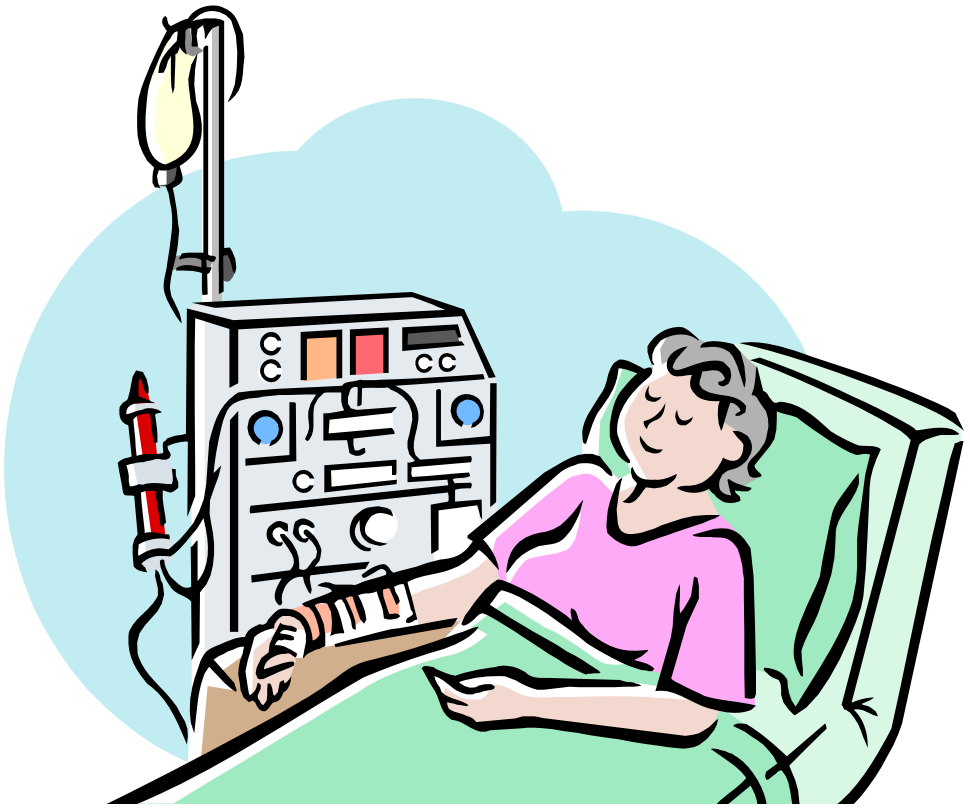
- **There is a need for ownership and buy-in of participants**
- **It is important to involve and honour all participants through dialogue**
- ***"Cause Causit"* We want to be in charge of our own destiny**

In Other Words

- **Change is an evolutionary process not a revolutionary process**
- **Work from your circle of influence**
- **We need a repertoire of processes in order to engage people**
- **We include in our structures and our dialogue emerging needs as they arise**

In Other Words

- **Decision-making can be informed by dialogue**
- **Each participant is competent**
- **We need to constantly check in with participants about how the process is going**
- **Build on prior knowledge**



Parting Thoughts For Teaching in CKD/ESRD

- Can/should we clarify our goals for different types of interactions (clinic, education, hospitalization, training, transition to a new modality)?
- Can/should we separate formal teaching from clinic type interactions?
- Are groups an effective medium for educative and social aspects of illness management?

Parting Thoughts

- How can we improve our connection and effectiveness with patients during short interactions (ie clinic settings)?
- How can we better integrate collaborative planning and assessment of readiness into our interactions with patients and families?

Parting Thoughts

" I want to be listened to…not necessarily agreed with. It's a negotiation, so I want to be not only acknowledged, but really listen to me because I do know and there are things I know more than my providers know, as well as things they know too. The way I see it, we have our own areas of expertise and so, you as a nurse, you give that to me, and I as the patient, give that and then we come up with some kind of plan."