Clinical Research from the Patient Perspective

Susan Lowell Butler

Introduction to the Principles & Practices of Clinical Research
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Session Outline:

I. Understanding the patient
   Why people participate in clinical trials

   Impact of illness on patients
      Debility

      "Grief"

      Disorientation

      Loss of control

   Struggling with the clinical environment
      Difficulties in navigation

      Loss of personal identity

      Apprehension regarding trials

      New faces, new rules

II. Understanding family caregivers
    Life disruption

    Worry about the patient

    Inability to "fix" the problem

    Financial burdens

    Overload
Struggling to learn about the disease, consequences

Learning to be a caregiver

How caregivers can help you

What caregivers need from you

III. **Key components in patient support**

**Becoming an expert patient communicator**

1. Basic skills
   - Treating the whole person
   - Realigning allegiances
   - Understanding today’s “new” patient
   - Listening – more than a 9-letter word
   - What you do, and don’t do, matters: the basics to consider

2. Key questions make the difference

3. Privacy issues

4. Language issues

5. Being present

6. Presenting options

**Effective introduction to a clinical trial**

Institutional attitudes make all the difference

Respectful presentation

The truth about: randomization, costs, side effects, life style

**Managing bad news**

Language

Settings
Company
Timing
Ethics
Support

End of life issues: when cure isn’t possible
  Palliative care – center stage
  Understanding hospice care
  What matters to your patient?
  Advance directives

IV. Empowering your patients
Why this helps you and your patients
  Encouraging assertiveness: techniques and suggestions