



Decision-Making: Considerations in MS Care

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Why consider decision-making?

- ❖ Burden of self-care management rests on those with a chronic illness
- ❖ Chronically ill face daily decisions and options on a wide range of issues
- ❖ Effective decision-making reduces the burden of illness and the strain on the health care system

(Thorne, Paterson & Russell, 2003)



Decision-Making

- ❖ Much of the research on chronic illness has focused on compliance
- ❖ Less understood is the daily requirement to make decisions and choices about wide-ranging issues
- ❖ Need to understand the expertise required, how it is learned, and how we can best support it



Kinds of Decisions

- ❖ Medication, diet, rest, activity
- ❖ Symptom monitoring and management
- ❖ Treatment initiation and adherence
- ❖ Deciding when and how to seek help and support



Decision-Making is Complex

- ❖ Often consider decision-making in discrete contexts
- ❖ Many decisions somewhat uncertain, not always guided by definite symptoms
- ❖ Need to consider context, available resources, individual perceptions, diverse lifestyles (Hollen, 1994)



Review of the literature

- ❖ Generally accepted that patients should be involved in decisions regarding their care (Thorne et al, 2003; Gotler & Flocke, 2000)
- ❖ Active participation in health care may result in better health outcomes (Bodenheimer et al, 2002; Glasgow, 2002)
- ❖ Clinician have a role in supporting patients as self-care managers (Hibbard, 2004; Thorne et al, 2003)
- ❖ Need to ensure patients have the skills, tools and knowledge to make informed decisions



Decision-Making Models

- ❖ Paternalistic model - passive role for the patient
- ❖ Informed model - characterized by information sharing
- ❖ Shared model - consensus building about preferred treatment



Lessons from the Cancer Wars

- ❖ Largely based on the work of Lesley Degner and others
- ❖ Studied men, women, parents of children with cancer
- ❖ Early studies suggested many with newly diagnosed cancer wanted the clinician to make treatment decisions (age, gender, education dependent)
- ❖ Later studies suggested both men (prostate cancer) and women (breast cancer) prefer to be more involved in medical decision-making



Commonalities and Differences Between Diseases

- ❖ Timeliness
- ❖ Interaction within a social context
- ❖ Interpretation of biomarkers
- ❖ Constructions of healthy practices
- ❖ Availability of relevant information



Decision-Making

- ❖ Approaches to patient education and care management may differ between diseases
- ❖ Need to consider meaning of the self-care decision
- ❖ Decision may be shaped by patient's expectations for the future.



Issues in MS Care

- ❖ MS lends itself to a shared decision-making model
- ❖ Shared Decision-making and Informed Choice preferred (Heeson et al, 2004)
- ❖ Patients want to have an active role



Issues in MS Care

- ❖ Many self-care decisions in MS made on a day-to-day basis.
- ❖ Immediate decisions made based on fatigue (biomarker)
- ❖ Healthy practices incorporated as part of lifestyle
(Paterson et al, 2002)



Issues in MS Care

- ❖ Newly diagnosed patients often faced with decisions about therapy initiation
- ❖ Other decisions along the illness trajectory relate to disclosure of diagnosis, whether to have children, balancing activity and energy conservation, using a mobility device



Issues in MS Care

- ❖ Need to consider...
 - ❖ Relationship to risk
 - ❖ Previous experience with health care system
 - ❖ Ethnic / cultural background
 - ❖ Not every patient wants to assume control



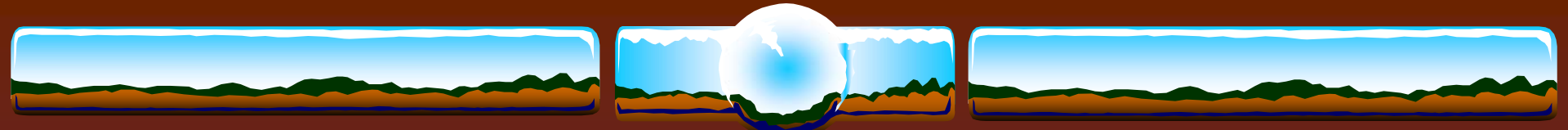
Role of the Patient

- ❖ Sift through copious quantities of educational material
- ❖ Critically evaluate information they receive
- ❖ Balance needs, preferences and desires against disease demands
- ❖ Develop knowledge and skill founded on personal experience with disease and their unique context
- ❖ Assume control, carry out treatment plans, often in the absence of clear biomarkers of success



Role of the Nurse

- ❖ Have long-term, trusting relationship with patients
- ❖ Collaboration with respect for patient's beliefs, wishes, goals, values
- ❖ Need to determine desired degree of participation
- ❖ Facilitate decision-making process
- ❖ Don't necessarily need to "agree"



Determining Degree of Decision-Making Control

- ❖ Explore what is important to the patient
- ❖ How they see themselves participating
- ❖ Be aware of the context and meaning
- ❖ Identify barriers to decision-making



Conclusions

- ❖ Common and disease specific issues related to self-care decision-making
- ❖ Decision-making is more complex than learning and complying with therapeutic recommendations
- ❖ Individuals become expert self-care decision-makers based on their unique experience with the disease



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