The Everyday Challenges of Adults Living with Lupus

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MOTA Conference October 8th, 2010

St. Catherine University
The Lupus Foundation of Minnesota

Objectives

• Participant will:
  – Understand the role community based services play in delivery of client services.
  – Recognize the barriers to health care access for those living with chronic illness.
  – Identify the challenges that those living with lupus face doing everyday activities, managing physical symptoms and emotional concerns.
  – Understand the role of occupational therapy in a community setting, and how to work with community based partners to develop services.
Lupus

“I am not sure how acquainted people are to the particularities of lupus as compared to arthritis.”

Lupus Symptoms

- 4 types of lupus
  - 70% SLE
  - 10% cutaneous lupus
  - 10% drug induced
  - 10% overlap, crossover, or mixed connective tissue disorders
  - (Wallace, 2009)

- Unknown Cause
  - Socioeconomic influences

Prevalence

- Varied estimates 161,000 to 322,000 adults in U.S.
- Women
- Diverse populations
- Typical onset 15-45 years old
- Increasing incidence

(Center for Disease Control and Prevention, 2008)

Role of Community Based Services
Lupus Foundation of Minnesota

- Counseling and Therapeutic Services
- Client Outreach and Advocacy
- Case Management
- Horizon Emergency Grants (H.E.G.)
- New Client Orientation
- Community and Foundation Support Groups
- Educational and Informational Workshops and Webinars
- Education programs for professionals
Barriers to Health Care Access

Clinical Rational

• “Unfortunately patients with only general systemic manifestations are often not referred because physicians are not aware of occupational therapy measures for these symptoms. “

  Before
  After

Melvin J. L. (1989). Rheumatic Disease in the Adult and Child (pp. 93-104).
FA Davis Company, Philadelphia, Photo release obtained.
Community Based Services Role in Health Promotion

- Community Based Services
- Lupus Foundation of America
- Lupus Foundation of Minnesota
  - Cost effective
  - Efficient
  - Alternative to traditional Medical based services
  - Assessment of need

- Based Self Help programs
- Arthritis Foundation Self Help Program
- Chronic Disease Self-Management Program.

Internal Assessment Lupus Foundation of Minnesota

- Evaluation of need
  - Cheryl Como
  - SLE client
  - LFM staff
  - Board
  - Volunteers

- Location
  Lupus Foundation of Minnesota Headquarters

- Available Resources
  - Strengths
  - Weakness
  - Opportunities
  - Threats
Program Development Gantt Chart

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Year 2009 Masters Thesis Needs Assessment

Needs Assessment Purpose

- 1. Assess the everyday living challenges (needs) of adults with lupus
  - Question:
    - What are the specific everyday challenges of adults living with SLE?

- 2. Determine the participants current access to the Lupus Foundation of Minnesota (LFM) services
  - Question:
    - What is the reported access to services offered through the Lupus Foundation of Minnesota?

- 3. Explore the participants interest in attending self management programs.
  - Question:
    - Do those living with SLE express an interested in attending community based self management programs?
Methods

• Recruitment
  – Adult Male and female members of the Lupus Foundation of Minnesota
    • LFM Walk for help
    • Email
    • Website
    • Newsletter
    • Direct mailing
  – Metro area
  – Quantitative study through completion of a needs assessment survey

Tools

• The Everyday Living Needs Assessment Survey was designed in collaboration with the Lupus Foundation of Minnesota

• Survey was based on literature review:
  – Systemic Lupus Erythematosus Needs Questionnaire (SLENQ)
  – Health Assessment Questionnaire (HAQ)
  – World Health Organizations Quality of Life assessment (WHOQL)
  – Feedback from LFM on populations needs

Tool: Everyday Living Survey

- Rating scales
  - Doing Everyday Activities
  - Managing physical symptoms
  - Coping with Emotional concerns

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<th>Low Challenge</th>
<th>Moderate Challenge</th>
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- Multiple choice fill in the blank
  - Demographics
  - Health information access
  - Interest in Self Management programs

- Designed to be completed in 15 min
  - Administration in hard copy or web based format

Results

- 96 participants

- 47 Web based surveys
  - Qualtrics

- 49 Hard copy surveys
  - Coded and merged with online data utilizing Qualtrics
Doing Everyday Activities

Not Applicable  No Challenge  Low Challenge  Moderate Challenge  High Challenge

0                 1                  2       3 4

DOING EVERYDAY ACTIVITIES
Managing Physical Symptoms

MANAGING PHYSICAL SYMPTOMS
Managing Emotional Concerns

COPING WITH EMOTIONAL CONCERNS
Discussion

• Significant Challenges
• Consistent with prior studies
• LFM plays key role in delivery of services
• There is significant participant interest in self management programs that related to identified challenges.
Limitations

- Represents only the views of members of the Lupus Foundation of Minnesota
- Under representation of diverse populations
- The Everyday Living Survey is non-standardized
- No data is available on normal population

Opportunities

“If you could develop some model that would also be a model for chronic illness you could do a lot of people a lot of service.”
References


