ARTHРИTIS COMMUNITY RESEARCH & EVALUATION UNIT (ACREU)

The Wellesley Hospital Research Institute

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SUPPLEMENT TO WORKING PAPER 94-2

CENTRAL EAST ONTARIO

DELIVERY OF COMMUNITY-BASED SERVICES FOR PEOPLE WITH ARTHRITIS

A Survey of Disability and Mobility among Consultation and Therapy Service Clients seen in May 1993
May 1994

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EXECUTIVE SUMMARY

With current emphasis on efficient health service delivery in Ontario, it has become important to investigate methods of defining the optimal balance between home-based versus group and ambulatory care services for people with arthritis. With this in mind, a survey of all adult clients seen by The Arthritis Society’s Consultation and Therapy Service (CTS) was conducted in May, 1993. Since April 1, 1994, the CTS has been divided up according to District Health Council Regions. This report is for clients living in the Central East Region.

The survey used a self-administered questionnaire to gather data on disability, pain, and mobility in the community. A total of 240 questionnaires were returned in the Central East Region, from 221 clients. Most questionnaires (95%) were from home therapy services. A greater proportion of clients were seen by occupational therapy, and a smaller proportion of clients were seen in ambulatory care settings in this region during the month of May, as compared to the province. The findings from this survey are broadly applicable to all clients seen in this region annually.

The average age of clients seen in the Central East Region was 57 years and 81% were female. The most frequently reported diagnoses was rheumatoid arthritis (49%), followed by osteoarthritis (30%) and fibromyalgia (30%). A greater proportion of clients in the Central East Region reported a diagnosis of fibromyalgia, and the mean duration of musculoskeletal diagnoses was 8.5 years. Thirty-four percent of clients surveyed in this region indicated at least one other non-musculoskeletal comorbid condition.

The average disability score of clients in the Central East Region indicated greater disability than in all other regions except the North East Region. A larger proportion of clients reported having much difficulty or being unable to walk in the Central East Region as compared to the province overall (54% versus 47%). The majority of clients had much difficulty or were unable to do errands/chores and gripping/opening. Assistive devices were most commonly used for hygiene activities. The single most commonly used assistive devices were canes and jar openers.

Almost one quarter of clients reported some restriction in independent mobility, with 20% being unable to leave the immediate surroundings of their homes independently.

Most CTS clients in the Central East Region reported going out of their homes more than once a week (74%). A greater proportion of clients reported only getting out of the house once monthly or less (11%), than in the province (6%). Clients in this region also reported less access to a car in their households (74%).
• Despite clients being generally more disabled and less mobile in this region, the proportion of clients who were deemed suitable by their therapists for participation in therapy in ambulatory settings in the Central East Region (61%) was similar to that of the province (60%).

• It is estimated that 20%-39% of clients need to be seen at home, based on the proportion of clients with reduced mobility and the therapists' assessment. Home therapy services will continue to be a necessity for those clients too disabled or otherwise unable to attend services in a group setting. Clients who could receive the bulk of their care in ambulatory settings may also require at least one visit for assessment of the home environment.

• The results of this survey provide some preliminary information that could be used to develop guidelines to facilitate decision-making with regard to type of service delivery for clients with arthritis, with the goal of providing more efficient services.
I. INTRODUCTION:

The Arthritis Society, Ontario, together with the Arthritis Community Research and Evaluation Unit (ACREU) conducted a survey of the Consultation and Therapy Service (CTS) clients seen over one month, to gather information regarding disability and mobility status of this client group. Data collected during this survey were analyzed provincially, and by Arthritis Society regions in the original report (see client survey-provincial report, for more details). Since April 1, 1994, the CTS has been divided up according to District Health Council Regions (DHC). Five additional DHC regional reports have been prepared. The following report is for the Central East Region.

The goal of the survey was to provide information about the disability and mobility status of CTS clients to enhance service planning and development.

Specific objectives of the survey included:

1. To provide descriptive information for CTS clients overall, for the three therapy home services (physiotherapy, occupational therapy, and social work), for the ambulatory services (hydrotherapy, groups, clinics), and for the DHC Regions;

2. To provide information regarding disability in CTS clients;

3. To provide descriptive information regarding pain reported by CTS clients;

4. To provide descriptive information regarding mobility in the community for CTS clients;

5. To investigate how the characteristics of clients might provide information to help determine the balance between home and ambulatory care services.

II. METHODS:

1. Procedure

Therapists were requested to give questionnaires to all CTS clients ages 18 and over seen in the month of May, 1993. Clients who were seen in more than one service completed a questionnaire for each service.

2. The Questionnaire

The self-administered questionnaire was designed to measure clients’ perceptions of their disability and mobility status. The questionnaire consisted of three sections (see Appendix A). The first section contained some basic questions relating to client characteristics, such as date of birth, diagnosis, and whether the client was a new referral and/or a consultation only. A consultation is defined by the CTS, as a limited intervention for a client of three visits or less. Additional
demographic information was retrieved from client case data forms at The Arthritis Society (see provincial report for details).

The second section consisted of the disability and the pain subscales of the Health Assessment Questionnaire (HAQ)\(^1\). The HAQ is a standardized validated questionnaire designed to measure disability in clients with arthritis. A disability index is calculated ranging from 0 to 3, with the level of disability increasing with the score (see provincial report for more details). The amount of pain experienced due to arthritis in the past week was measured on a scale of 1 to 7, with 1 labelled as "none", 4 labelled as "moderate", and 7 labelled as "extreme" pain.

The third section of the questionnaire was composed of several questions related to the client's level of mobility in their environment (mobility handicap). The mobility questions were originally developed in the context of an earlier population survey.\(^2\) Clients were asked about their ability to move around in their home, and to leave their home and its immediate surroundings taking into account the assistive devices/equipment that they normally used.

3. Analysis

Analyses by service was not done in this regional report, as the majority of the clients surveyed were home therapy clients, most of whom were seen by physiotherapy. Therefore, analysis was generally conducted by individual. The first completed questionnaire by each client was used for the analysis.

Analysis by service (and by ambulatory versus home care clients) is reported in the provincial report.

In the presentation of results, percentages have been calculated excluding missing data. The proportion with missing data from the client completed questionnaire is generally low.

III. RESULTS:

1. Characteristics of CTS Clients

   a. Services received

A total of 240 questionnaires were returned from the Central East Region from 221 individual clients. Most of the questionnaires were completed by home therapy clients (35%), with physiotherapy clients completing 59% of all surveys (Figure 1.1). A greater proportion of clients were seen by occupational therapy (26%), and a smaller proportion of clients were seen in ambulatory care settings (5%) in this region during the month of May, as compared to the province (occupational therapy - 12%, ambulatory - 16%). The majority of clients were continuing clients, with 34% of those who responded identified as new referrals. Of new referrals, 24% were identified as consults only.
b. Demographic characteristics

TABLE 2.1: Demographic Characteristics of Clients (N = 221).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Category</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>Mean (s.d.)</td>
<td>56.6 (17.5)</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>Female</td>
<td>179 (81%)</td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
<td>Married/Common law</td>
<td>119 (58.3%)</td>
<td></td>
</tr>
<tr>
<td>Primary Language</td>
<td>English</td>
<td>177 (83.5%)</td>
<td></td>
</tr>
<tr>
<td>Household Size</td>
<td>Lives Alone</td>
<td>46 (21.8%)</td>
<td></td>
</tr>
<tr>
<td>Total Years of Education</td>
<td>Mean (s.d.)</td>
<td>11.7 (3.9)</td>
<td></td>
</tr>
<tr>
<td>Employment Status</td>
<td>Employed:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Full-time</td>
<td>29 (13.1%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Part-time</td>
<td>10 (4.5%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Self-employed</td>
<td>3 (1.4%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not Employed:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Retired/Voluntarily</td>
<td>67 (30.3%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not Working</td>
<td>35 (15.8%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Homemaking</td>
<td>33 (14.9%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>LTD</td>
<td>47 (21.2%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other*</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Other category includes: student, unemployed/looking for work, volunteer, maternity leave, temporarily laid off, sick leave, short-term disability.
The average age of clients seen in the month of May was 57 years (Table 2.1). Most clients were women (81%) who were married or living common law (58%). Eighty-four percent of clients who responded reported English as their first language. The majority of clients were not working for pay, and were either retired or voluntarily not working, homemakers, or on long-term disability.

c. **Diagnosis**

![Figure 1.2: Most Frequently Reported Diagnoses](image)

**FIGURE 1.2**
**MOST FREQUENTLY REPORTED DIAGNOSES**

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Percent of Clients Reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rheumatoid Arthritis</td>
<td></td>
</tr>
<tr>
<td>Osteoarthritis</td>
<td></td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td></td>
</tr>
<tr>
<td>Low Back Pain</td>
<td></td>
</tr>
<tr>
<td>Osteoporosis</td>
<td></td>
</tr>
</tbody>
</table>

As the clients could report more than one diagnosis, Figure 1.2 depicts the proportion who checked off one diagnosis as well as in combinations with other musculoskeletal diagnoses.

The most prevalent diagnosis reported was rheumatoid arthritis (49%), followed by osteoarthritis (30%) and fibromyalgia (30%). A greater proportion of clients in the Central East Region reported a diagnosis of fibromyalgia in this region as compared to the province (17.1%). Rheumatoid arthritis was checked off more frequently alone than in combination with other diagnoses. Osteoarthritis was more frequently checked off in combination with other diagnoses, especially with rheumatoid arthritis. Fibromyalgia, osteoporosis and low back pain were also more frequently checked off.
with other diagnoses. Generally, 44% (123) of clients checked off more than one musculoskeletal diagnosis.

The mean duration of arthritis diagnoses was 8.5 years. Thirty-four percent of clients surveyed in this region also indicated at least one other non-musculoskeletal comorbid condition.

2. Level of Disability
The majority of clients had much difficulty or were unable to do errands/chores, grip, reach and hygiene activities (Figure 2.1). Smaller proportions of clients were unable to grip as compared to the other top categories, but experienced much difficulty in activities requiring gripping. A larger proportion of clients reported having much difficulty or being unable to walk in the Central East Region as compared to the province overall (54% versus 47%).

These findings are generally similar to those in Figure 2.2, which portrays the functional activities that clients required assistance from another person. The majority of clients required assistance with errands/chores, and grip. A large proportion of clients also required assistance reaching.

One third of clients used a cane for walking. Assistive devices were most commonly used for hygiene activities; 32% of clients used a
FIGURE 2.2
HAQ FUNCTIONAL CATEGORIES
Activities Requiring Assistance from Another Person

<table>
<thead>
<tr>
<th>Category</th>
<th>Percent of Clients Requiring Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Errands/chores</td>
<td>63.5</td>
</tr>
<tr>
<td>Gripping/opening</td>
<td>63.3</td>
</tr>
<tr>
<td>Reach</td>
<td>43.4</td>
</tr>
<tr>
<td>Dressing/Grooming</td>
<td>25.8</td>
</tr>
<tr>
<td>Hygiene</td>
<td>18.6</td>
</tr>
<tr>
<td>Walking</td>
<td>16.7</td>
</tr>
<tr>
<td>Arising</td>
<td>14.9</td>
</tr>
<tr>
<td>Eating</td>
<td>6.8</td>
</tr>
</tbody>
</table>

Clients with rheumatoid arthritis only (excluding those without osteoarthritis or fibromyalgia), had a higher average HAQ score than those with only osteoarthritis or fibromyalgia. Clients with osteoarthritis and fibromyalgia had similar HAQ scores (see provincial report for more details regarding HAQ scores).

raised toilet seat, 23% used a bathtub bar, and 20% used a bathtub seat. A large proportion of clients also used jar openers to assist them with gripping/opening (24%). Clients in the Central East Region used overall, an average of 2.3 assistive devices.

a. Disability Scores
   (Health Assessment Questionnaire)

The average HAQ score obtained by clients in the Central East Region was 1.6. This score was significantly greater (indicating greater disability) than those obtained by clients in all other regions except for the North East Region. Generally, HAQ scores increased with age, and were greater for females than for males.
3. Mobility

a. Independent mobility and confinement to home

FIGURE 3.1
MOBILITY ACTIVITIES
Restrictions in Independent Mobility

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unable to leave surroundings of home</td>
<td>19.9</td>
</tr>
<tr>
<td>Unable to go out of home</td>
<td>13.1</td>
</tr>
<tr>
<td>Unable to move between floors</td>
<td>10.4</td>
</tr>
<tr>
<td>Unable to move between rooms</td>
<td>2.7</td>
</tr>
</tbody>
</table>

*with regularly used assistive devices

Inability to leave the surroundings of their home was the most frequently reported mobility-related limitation (Figure 3.1). Of the clients surveyed in the Central East Region, 20% reported that they were unable to leave the immediate surroundings of their homes independently. Limitations were also reported in ability to go out of the home independently (13%), and to move between floors (10%). Most clients were able to move from room to room inside of the home independently. Independent mobility decreased with increasing age (see provincial report for more details).

Overall, 24% of clients seen by the CTS in the Central East Region during the month of May, reported restriction in independent mobility in at least one of the above mobility activities.

Clients with some restriction in their mobility had a significantly higher HAQ disability index than those who didn’t (2.29 vs. 1.4, p<.001).
Most CTS clients in this region go out of their homes more than once a week (Figure 3.2). Fourteen percent of clients get out once weekly or several times monthly, and 11% of clients are only able to get out once a month or less. A larger proportion of clients seen in this region got out of their homes once a month or less, compared to those in the provincial study (11% versus 6%). Frequency of outings decreased with increasing age. Seventy-four percent of clients in this region had access to a car in their households, whereas 81% of clients in the province overall, had access to a car.

4. Therapists' Assessment of Suitability for Groups

Therapists who saw clients at home were requested to check off which of their clients they felt would be suitable candidates to go out of their homes for group therapy in an ambulatory setting. The therapists that responded indicated that 61% of clients seen at home in this region could potentially go out to receive therapy in a group setting.
IV. DISCUSSION

The primary purpose of the Consultation and Therapy Service (CTS) client survey was to provide information regarding clients' disability and mobility status in order to enhance service planning and development. An important question underpinning the survey was what proportion of home therapy clients needed to receive their care in the home, and what proportion could participate in ambulatory care programs.

There were several major differences found among clients in the Central East Region as compared to the clients provincially. A greater proportion of clients were seen by occupational therapy, and a smaller proportion of clients were seen in ambulatory care settings in this region during the month of May, as compared to the province. A greater proportion of clients in the Central East Region reported a diagnosis of fibromyalgia. The average disability score of clients in the Central East Region indicated greater disability than in all other regions except for the North East Region. A larger proportion of clients reported having much difficulty or being unable to walk in the Central East Region as compared to the province overall (54% versus 47%). Although reported mobility restrictions were approximately the same in this region as in the province generally, clients in the Central East Region reported going out of their homes less. Clients in this region also reported less access to a car in their households.

Despite clients being generally more disabled and less mobile in this region, the proportion of clients who were deemed suitable by their therapists for participation in therapy in ambulatory settings in the Central East Region was similar to that of the province. The provincial analysis found that the clients' walking ability, frequency of outings, and access to a car were related to the therapists' assessment of suitability for participation in groups. The results of this regional analysis supports the general finding that none of these client characteristics are strongly predictive of the therapists' decision, and that therapists consider a variety of factors when determining whether clients were suitable for participation in groups (see provincial report for more details).

While all clients may benefit from home-based services, it appears that many who are currently seen at home could potentially be seen in an ambulatory setting. A limited appraisal suggests that the proportion of clients who need to be seen at home in this region ranges from 20%-39%. Conversely 61%-80% of home therapy clients could potentially participate in groups in ambulatory settings. This is based on the proportions of clients unable to leave the surroundings of their homes independently, and clients whom the therapists identified could not participate in therapy in an ambulatory setting.

An increased level of ambulatory care provision could lead to greater efficiency in the use of staff, and savings of both time and travel costs of therapist home visits. Results indicate that home therapy services will however, continue to be a necessity, not only for those clients too disabled or otherwise unable to attend services in a group setting, but also for ambulatory clients who may require important input in the home environment to facilitate their continued independence in the community.

REFERENCES


APPENDIX A:
The Arthritis Society Consultation and Therapy Service

CLIENT SURVEY

Dear Client:

We are asking all people seen by the Arthritis Society Consultation and Therapy Service to complete a Client Survey during the month of May. This information will help us identify the needs of all people with arthritis and help us plan for future services and programs. Make sure that you complete all 5 pages. All information given in this survey will be kept confidential and will not affect your current treatment. If you have any questions, please call Lyn Maguire or Linda Rothman at 416-926-5156.

CLIENT NAME __________________________ Date of Birth ___/___/____ SEX: M F
dd/ mm/ yy

First
Surname
(please print)

1. Please check (✓) the main kind(s) of arthritis that you have.

- [ ] Rheumatoid Arthritis
- [ ] Osteoarthritis/Degenerative Arthritis
- [ ] Scleroderma
- [ ] Reiter’s Syndrome
- [ ] Tendonitis/Bursitis
- [ ] Systemic Lupus Erythematosus
- [ ] Other __________________________
- [ ] Fibromyalgia
- [ ] Gout
- [ ] Psoriatic Arthritis
- [ ] Low Back Pain
- [ ] Osteoporosis
- [ ] Ankylosing Spondylitis
- [ ] Don’t Know

Therapist Only

Completed by:

[ ] Client independently Consult Only [ ] yes [ ] no

[ ] Therapist assisted New Referral [ ] yes [ ] no

[ ] Other assistance

Therapist Name

Region ______________________

Today’s Date ___/___/____

[ ] Therapist

Date of Opening ___/___/____

dd/ mm/ yy

For future programs: Suitable for clinics/groups [ ] yes [ ] no
2. Please check the **one** response which best describes your **usual** abilities OVER THE PAST WEEK:

<table>
<thead>
<tr>
<th></th>
<th>Without Any Difficulty</th>
<th>With Some Difficulty</th>
<th>With Much Difficulty</th>
<th>Unable To Do</th>
</tr>
</thead>
</table>

DRESSING AND GROOMING

Are you able to:
- Dress yourself, including tying shoelaces and doing buttons
- Shampoo your hair

ARISING

Are you able to:
- Stand up from an armless straight chair
- Get in and out of bed

EATING

Are you able to:
- Cut your meat
- Lift a full cup or glass to your mouth
- Open a new milk carton

WALKING

Are you able to:
- Walk outdoors on flat ground
- Climb up five steps

3. Please check any AIDS or DEVICES that you usually use for any of these activities:

- Cane
- Walker
- Built up or Special Utensils
- Crutches
- Special or Built Up Chair
- Wheelchair
- Devices used for dressing (button hook, zipper pull, long-handed shoe horn etc.)

Other (Please Specify) ______________________________________________________

4. Please check any categories for which you usually need HELP FROM ANOTHER PERSON:

- Eating
- Dressing and Grooming
- Arising
- Walking
5. Please check the one response which best describes your usual abilities OVER THE PAST WEEK:

<table>
<thead>
<tr>
<th></th>
<th>Without Any Difficulty</th>
<th>With Some Difficulty</th>
<th>With Much Difficulty</th>
<th>Unable To Do</th>
</tr>
</thead>
</table>

**HYGIENE**

Are you able to:
- Wash and dry your entire body
- Take a tub bath
- Get on and off the toilet

**REACH**

Are you able to:
- Reach and get down a 5 pound object (such as a bag of sugar from just above your head)
- Bend down to pick up clothing from the floor

**GRIP**

Are you able to:
- Open car doors
- Open jars which have been previously opened
- Turn faucets on and off

**ACTIVITIES**

Are you able to:
- Run errands and shop
- Get in and out of a car
- Do chores such as vacuuming or yardwork

6. Please check any AIDS or DEVICES that you usually use for any of these activities:

___ Raised Toilet Seat  ___ Bathtub Bar
___ Bathtub Seat  ___ Long-Handled Appliances for Reach
___ Jar Opener (for jars previously opened)  ___ Long-Handled Appliances in Bathroom
Other (Please Specify) ________________________________

7. Please check any categories for which you usually need HELP FROM ANOTHER PERSON:

___ Hygiene  ___ Gripping and Opening Things
___ Reach  ___ Errands and Chores
8. How much pain have you had because of your arthritis in the past week? (Please circle one number)

None  Moderate  Extreme
1  2  3  4  5  6  7

9. On your own, or using any assistive devices/equipment that you normally use, are you usually able to:

- Move from room to room  □ Yes  □ No
- Go out of your home  □ Yes  □ No
- Leave the immediate surroundings of your home (yard, sidewalk)  □ Yes  □ No
- Move to another floor in your home  □ Yes  □ No  □ Does not apply

** If you have answered "yes" (or does not apply) to all of the above, skip to question #11.

10. WITH HELP from another person, are you usually able to:

- Move from room to room  □ Yes  □ No
- Go out of your home  □ Yes  □ No
- Leave the immediate surroundings of your home (yard, sidewalk)  □ Yes  □ No
- Move to another floor in your home  □ Yes  □ No  □ Does not apply

11. Do you have access to a car in your household, as either a driver or a passenger? (excluding taxis)

□ Yes  □ No
12. Do you use:

- Taxis................................................................. □ Yes □ No
- Public Transit....................................................... □ Yes □ No
- Transportation for people with disabilities............... □ Yes □ No
- Rides from family/friends who do not live with you...... □ Yes □ No

13. Where do you usually go, when you go out? (Please check all that apply)

□ Shop/do errands □ Work outside of home □ Overnight trips
□ Visit friends/relatives □ Religious institution □ Meetings/club
□ Hairdresser/barber □ Walk the dog □ Medical appointments
□ Recreational activities (e.g. movies, sports theatre) □ Volunteer □ Take the children to school/daycare

□ Other (please specify) ________________________________

14. Generally, how often do you usually go out? (Please check only one)

□ every day □ several times a month □ a few times a year
□ several times a week □ once a month □ never
□ once a week □ less than once a month

15. Have you had any of your joints replaced in the last six months?

□ Yes □ No

If yes, please check which joint(s):

Knee: □ Right □ □ Hip: □ Right □
□ Left □ □ Left □

□ Other joint(s) (please specify) ________________________________

Thank You!