Independence
care system

Goals of Care in People Living with Advanced MS

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Independence Care System
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Background

For those living with Multiple Sclerosis (MS), goals of care can vary, especially for those with advanced disease.

Goals of care can be utilized by clinicians to develop a plan of care and improve QOL.

Hopes and goals may change as MS progresses.

Few studies have described the patient-stated goals of care for those with advanced MS.

Background

Independence Care System (ICS), a long-term care community based Medicaid program in NYC, cares for approximately 300 people living with advanced MS.

To be enrolled in ICS a person must be nursing home eligible and require assistance in completing their activities of daily living.

Clinical Data is captured using the interRAI Home Care Assessment System.

The population of ICS Multiple Sclerosis patients affords a unique opportunity to assess hopes and goals of care in advanced disease.

Project Objectives

- Phase 1: A study was conducted to determine what patients living with MS expressed as a goal they had for themselves. Stated goals were then grouped by theme.
- Phase 2: Pertinent outcome measures regarding improved function were then further evaluated to define plans of care.

Phase 1 Methods

Study population drawn from ICS MS patients who:

  - Meet the requirements of nursing home eligibility.
  - 98% of those remain in their home with assistance.
  - On average receive 11 hours a day of home care.
  - Mean age is 55, with a range of 29-92
  - 74% are female

- We conducted a survey of 302 patients with advanced MS.

Phase 1 Methods

- Reviewed patients most recent assessment in 2016; dates ranged from 7/9/16 to 12/29/16.
- Utilized a nursing assessment that is completed every six months and after a significant change in condition.
- The person's stated goal was captured verbatim electronically in an open text field.

Phase 1 Results: Assessment of Stated Goals

302 people were included in the study

- 37 people were unable to respond/report a goal
  - Mainly due to advanced cognitive dysfunction, aphasia, or nonverbal status
- 265 patients' goals were analyzed
  - A total of <u>336 goals</u> were reported
    - 201 members reported one goal
    - 64 members identified *more than* one goal they wanted to achieve
      - » 57 had two goals
      - » 7 had three goals

Phase 1 Results: Assessment of Stated Goals

A summary of the of the 336 stated goals revealed:

- 131 members wanted to improve their function.
  - This goal was further broken out and analyzed in Phase 2
- 104 members wanted to improve their health.
- 72 members wanted to remain in the community
  - Included social participation or home care.
- 29 goals were miscellaneous/uncategorizable
  - Custody battles, new laptop, find Jesus, etc.

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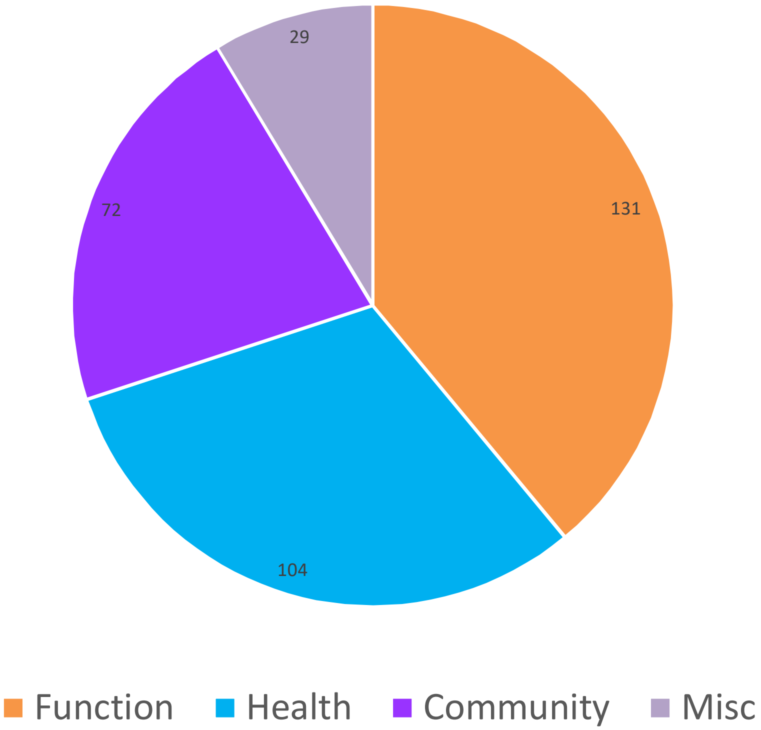
Goal Categorization



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Phase 1 Results: Improving Function

Of the 131 goals that were related to wanting to improve function:

- 61 were general statements e.g. "I want to get stronger".
- 44 were specifically related to walking/ambulation.
  - e.g. "I want to walk and greet you at the door"
- 13 were related to equipment.
- 13 were related to decreasing or preventing falls.

**Some members reported more than one type of function goal*

Phase 1 Results: Evaluating Ambulatory Function

- We identified current methods of ambulation for the 44 members who expressed that as a goal:
  - 27 members were <u>ambulatory</u>
    - 1 member was ambulating independently
    - 18 needed an assistive device to ambulate
    - 8 had some ability to walk but relied on a scooter/wheelchair to get around in their home.
  - 17 members were <u>not ambulatory</u>
    - 14 relied on a wheelchair or scooter for mobility
    - 3 were unable to get out of bed

Phase 2 Objective & Methods

- We sought further insight into the specific stated goal of improving ambulatory function.
- We contacted 25 patients with these stated goals and administered a custom-designed structured interview assessment tool.
- Using this structured interview we captured:
  - Current ambulatory status and assistive devices used
  - Specific goals for ambulatory function
  - Specific interventions desired to achieve ambulatory goals

Phase 2 Results: Two Cohorts

Ambulatory members (n=13)

- Could identify the specific challenges to walking (e.g. steps, curbs).
- Had competing priorities in their life that made focusing on improving their walking difficult (e.g. raising children, going to school).

Non-ambulatory members (n=12)

- Had not been ambulatory for *at least* two years.
- Had difficulty expressing what they or their health care team could do to support them in reaching their goal.
- Referenced needing a “cure.”

Phase 2: Ambulatory Goals in Both Cohorts

- In both ambulatory and non-ambulatory patients:
  - Physical therapy was the most frequently identified intervention that people believed could assist them in reaching their goal.
  - If walking was improved, it was believed that it would result in increased independence and ability to participate in social activities.
  - The outcome of achieving the goal often included walking – “I would like to walk to my mother’s house”.
- Non-ambulatory patients expressed a desire to walk without specific gait-related interventions.

Conclusions & Next Steps

- Expressed goals of patients with advanced MS were often discordant with degree of ambulatory function.
- A shared understanding of goals of care for people with advanced MS is necessary for patients and clinicians.
- It is necessary for clinicians to have difficult conversations:
  - Motivational interviewing techniques
  - Framing and supporting how mobility devices can increase independence
- Developing a collaborative approach to care:
  - Setting incremental goals based on achievable outcomes e.g. “what would you like to do next month that would help you reach your goal”.

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