Measuring Outcomes to Evaluate Dementia Programs and Interventions

Strategies, Challenges, and Benefits

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National Alzheimer’s and Dementia Resource Center
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Overview of Learning Objectives

• Identify multiple methods for collecting outcome data

• Describe risks of using outcome data collected from proxies instead of from people with dementia

• Describe the benefits of using validated outcome measures

• Provide resources for identifying validated measures

• Describe considerations in selecting a measure(s)
What are Measurable Outcomes?

- A “measurable outcome” is an observable end-result that describes how a particular intervention benefits consumers
  - It may demonstrate functional status, mental well-being, knowledge, skill, attitude, awareness or behavior

- Outcomes from projects targeting individuals living with dementia and their caregivers include, but are not limited to:
  - change in quality of life of the person living with dementia
  - change in unmet needs
  - change in stress and/or burden
  - change in caregiver self-efficacy
  - change in the responsiveness or cost-effectiveness of a service delivery system

- A measurable outcome is different than a measurable “output”, such as: the number of clients served; the number of training sessions held; or the number of service units provided.
Why Measure Outcomes

- Outcome measurement results can be used to:
  - Decide if you should continue doing what you are doing
  - Decide whether and how to change what you are doing
  - Encourage participation and support from others, including program participants and funders
## Sample Outcome Measure

<table>
<thead>
<tr>
<th>Target population</th>
<th>Intervention</th>
<th>Output Goal</th>
<th>Outcome Goal</th>
<th>Outcome Measure</th>
<th>Outcome Measurement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Persons with dementia who live alone</td>
<td>Care of People with Dementia in their Environments (COPE)</td>
<td>COPE provided to 100 persons with dementia who live alone</td>
<td>Improve quality of life of persons with dementia who live alone</td>
<td>Quality of Life in Alzheimer’s Disease (QOL-AD)</td>
<td>Implement QOL-AD pre-COPE and 30-day post-COPE</td>
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</table>
- **Surveys/Questionnaires**: Ask participants questions and record their answers
  - Questions may be open- or closed-ended
    - Closed-ended questions (e.g., yes/no) provide quantitative data
    - Open-ended questions usually generate qualitative data, but answers can be coded to yield quantitative data

- **Observation**: Directly observe operations and activities
  - Useful when the required information can be obtained by watching and listening
  - Can answer questions about whether a program is being delivered and operated as planned and can better understand both the situation and context

- **Interviews**: Conversation between interviewer and person who can provide input on issue being evaluated
  - Follow a script or guide, which may include probing questions
  - Questions are usually open-ended and data are usually qualitative, but quantitative data may be collected
Focus groups: Small-group discussions
- Moderator uses a question guide to introduce topics of interest and probe for discussion
- Data are usually qualitative but a short quantitative survey can be conducted as part of the focus group to obtain quantitative information

Secondary data: Use existing data sources (e.g., medical records)
- Abstract outcome data from secondary data sources
- Data are usually quantitative and standardized but not tailored to the evaluation
Some people with dementia, such as those in early to moderate stages of Alzheimer’s disease, have capacity to participate in data collection (Karlawish, 2008)

However, dementia is progressive, so capacity of people with dementia to participate declines over time (Moye, Karel, Gurrera, & Azar, 2006)

- Whether an individual is capable of decision making depends on whether he or she can communicate relatively consistently, understand basic information about choices, evaluate the implications of different choices, and rationally comprehend the risks and benefits associated with different options (Karel et al., 2010; Woods & Pratt, 2005).

- Because these capacities fluctuate over time and different decisions require different levels of capacity, a diagnosis of dementia—or even a specific score on a cognitive test—may not be the only criterion for determining decision-making capacity (Woods & Pratt, 2005).
There is no “gold standard” for determining capacity (Mitty, 2012).

Several decisional capacity assessment tools exist that can aid researchers in determining capacity among people with dementia (Cacchione, 2011).

- Evaluation to Sign Consent (Resnick et al., 2007)
- Hopemont Capacity Assessment Interview (Edelstein, 1999)
- Capacity to Consent to Treatment Interview (Marson, Ingram, Cody, & Harrell, 1995)

Limited decisional capacity among individuals with dementia also may be indicated by difficulties with naming and delayed memory (Moye et al., 2006).
Engaging proxies, such as caregivers or family members, is a valuable option for data collection when the person with dementia does not have capacity to participate or provide informed consent.

- However, proxy decision-makers commonly make research enrollment decisions based on what they think will maximize the well-being of the person with dementia, not a substituted judgment of what the person with dementia would decide (Karlawish et al., 2008).

- Data provided by proxies commonly differ from data provided by people with dementia (Clarke & Keady, 2002; Sands, Ferreira, Stewart, Brod, & Yaffe, 2004).

- People with dementia have been found to have higher hopes for their quality of life than their caregivers do for them (Thorgrimsen et al., 2003).
Selecting an Appropriate Outcome Measure

- Does it measure the right outcome(s)?
- Is it reliable?
- Is it valid?
- What are data collection considerations?
Measuring the Intended Outcomes

Develop a clear logic model
- Stakeholder agreement

Get specific
- Choose one or more outcome(s)
- Subtle variations

Confirm the outcome(s) is realistic
- Intensity of intervention
- Timing of data collection
Reliable and Valid Measures

- Reliability – “The extent to which a measure produces the same results when used repeatedly to measure the same thing.”

- Validity – “The extent to which a measure actually measures what it is intended to measure.”

From *Evaluation: A Systematic Approach* by Rossi, Lipsey and Freeman
Benefits of Using Existing Validated Measures

✔ Measures the intended outcome

✔ Saves time

✔ Adds credibility to results

✔ May allow some comparability
Obtaining Validated Measures

- National Alzheimer’s and Dementia Resource Center
  - Evaluating Dementia Services and Supports: Instrument Resource List
    - [https://nadrc.acl.gov/node/70](https://nadrc.acl.gov/node/70)
  - 73 instruments
  - 25 domains – e.g. burden, formal supports, cognitive functioning, risk assessment, unmet needs, behavioral symptoms, quality of life
  - Easy to access
  - Scoring, administration
  - Permissions
Considerations in Selecting a Measure

- Who is collecting the data?
  - What level of expertise is needed?
  - What training is needed?

- Who is responding?
  - Person with dementia, caregiver, professional
  - Cognitive capacity

- Other considerations
  - Mode – Phone, in person, electronic, paper
  - Burden – Number of questions, amount of time required
  - Flow – When and how it will fit into the intervention process
# Frequency of Data Collection

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Typical Use</th>
<th>Pros</th>
<th>Cons</th>
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<tbody>
<tr>
<td>One time</td>
<td>Very brief interventions</td>
<td>Least resource intensive</td>
<td>Respondent self-reporting introduces bias</td>
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<tr>
<td></td>
<td></td>
<td>Little respondent time required</td>
<td></td>
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<tr>
<td>Pre/post</td>
<td>Training sessions, measuring knowledge change</td>
<td>Allows measure of change</td>
<td>Only measures immediate impact</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Relatively little time required</td>
<td></td>
</tr>
<tr>
<td>Pre/post with follow-up</td>
<td>More intensive interventions that impact well-being over time or involve practice change</td>
<td>Allows measure of impact over time</td>
<td>Resource-intensive</td>
</tr>
</tbody>
</table>


More information

- Michael Lepore, mlepore@rti.org

- Stephanie Hughes, shughes@rti.org

- National Alzheimer’s and Dementia Resource Center, nadrc.acl.gov
  - Evaluating Dementia Services and Supports: Instrument Resource List
    https://nadrc.acl.gov/node/70
Measuring Outcomes to Evaluate Dementia Programs and Interventions: Strategies, Challenges, and Benefits

Elizabeth Blount
January 30, 2019
BRI CARE CONSULTATION: PROGRAM OVERVIEW

• Evidence-based information, coaching and support program for adults with chronic health conditions and their caregivers

• Telephonic/e-mail delivery method

• Personalized and tailored coaching

• Provides: ongoing support, help finding practical solutions to present concerns, future planning/prevention, and adjusts to changes in care

• Service delivery period determined by licensed site
Key Components of Program

• Initial Assessment: gradual identification of present or future concerns, both medical and non-medical

• Action Plan: evolving set of simple and achievable tasks to address concerns step-by-step, begins in first call

• Maintenance and Support: regularly maintained contacts to monitor care situation (more frequent as needed) and respond to any changes
BRI CARE CONSULTATION: PROGRAM OVERVIEW

Program Development History

• Nine different research demonstrations/projects over 2 decades

• Program demonstration in Georgia:
  – 2010-2013
  – Funded by Administration on Aging/Administration for Community Living
  – 3 phases:
    • Original 3 Year Grant Demonstration: 2010-2013
    • Atlanta Regional Commission (ARC) Pilot Project: 2013-2014
    • BRI Care Consultation Statewide Expansion: 2013-present
PROGRAM IMPLEMENTATION HISTORY IN GEORGIA

• Challenges identified by Georgia Division of Aging Services (GDAS) and Area Agencies on Aging (AAAs) with Georgia Alzheimer’s Disease or Related Dementias (ADRD) families:
  – Growing waiting lists
  – Underutilized formal services
  – Programs serving both caregiver and ADRD care recipient
  – Effective service abilities using face-to-face methods

• BRI Care Consultation program chosen because:
  – High efficiency level: cost effectiveness of telephonic model
  – Ability to contact care consultant
  – Care Consultation Information System (CCIS) guided program delivery
  – Effective in wide range of agencies
ORIGINAL GRANT DEMONSTRATION

• Program delivered at three AAAs:
  – Atlanta Regional Commission
  – Heart of Georgia Altamaha
  – Legacy Link

• Eligibility criteria for program participation included:
  – Care receivers with/without a formal dementia diagnosis
  – Care receiver living in the community, with a primary caregiver (living in the home or elsewhere)
  – Care receiver living in community without an identified primary caregiver
  – Ability to read and speak English
Instruments utilized to measure outcomes same as original studies that tested efficacy of program.

Measure outcomes established for project:
- Enrollment
- Attrition
- Caregiver Depression
- Caregiving Confidence or self-efficacy
- Caregiver Social Isolation
- Caregiver Health Strain

Caregiver Needs Met-including total needs met and eight categories of needs, including:
- Informal help
- Dementia diagnosis
- Daily tasks
- Respite
- Legal/financial
- Support
- Service access
- Living arrangements
Results:

- Enrollment and Attrition:
  - Enrolled: exceeded overall goal
  - Attrition: slightly higher than national average
- Depression:
  - Decrease in caregivers of persons with high behavior problems
- Caregiver Confidence or self-efficacy:
  - Increase in total sample and caregivers of persons with high behavior problems
ORIGINAL GRANT DEMONSTRATION: RESULTS

• Results:
  – Social Isolation
    • Decrease in caregivers of persons with high behavior problems and high cognitive impairment
  – Health Strain
    • Decrease in caregivers of persons with high behaviors problems
  – Needs Met
    • Increase in total sample
STATEWIDE EXPANSION: GOALS

• Goals identified for expansion:
  – Maximize the use limited resources
  – Enhance sustainability of aging network through fee-for-service options
  – Infuse evidence-based programs throughout the aging network
  – Improve coordination between formal and informal care
  – Improve the focus on prevention and person-centered care
  – Improve availability of services in rural areas
STATEWIDE EXPANSION: WHERE WE ARE NOW

- Continued scaling of the program in Georgia:
  - Implementation Sites:
    - 9 direct, 3 referring
  - Ongoing Training and Technical Assistance Provided:
    - RCI: providing additional, comprehensive, tailored
    - BRIA: overall, part of standard licensing agreement
  - Families Served:
    - No longer serving only ADRD families
  - Private Pay/Fee-for-Service Model Development
  - Data Collection:
    - Continually through Care Consultation Information System (CCIS)
REFERENCES


KEEP UP WITH US

Social media:
@rcicaregiving
@benrose1908
@georgiadepartmentofhumanservices

Website:
www.rosalynncarter.org
www.benrose.org
https://aging.georgia.gov
Thank You!
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