

Personalized Goal Setting in the Primary Care of Persons with Cognitive Impairment: Measuring what matters most

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- No conflicts of interest

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Goal-Directed Care: A new paradigm in patient-care Shifting from...

The diagram illustrates a transition from a disease-focused approach to a patient goal-directed approach. On the left, under the heading "Disease-focused", there is a small image of a heart with a callout pointing to a detailed view of a coronary artery. Below this is a bulleted list: "– Identification and treatment of specific diseases". An arrow points to the right, leading to the heading "Patient goal-directed". To the right of the arrow is a photograph of a healthcare professional and a patient at a table, engaged in a conversation.

Disease-focused

- Identification and treatment of specific diseases

Patient goal-directed

- Care focused on achieving patient-determined outcomes

*Reuben DB, Tinetti ME. NEJM 2012;366(9):777-779.; Tinetti ME, et al. JAMA Cardiology 2016;1(1):9-10.
Reuben DB, Jennings LA. J Amer Geriatric Soc 2019, epub*

Photo source: www.UpToDate.com; Oklahoma Healthy Aging Initiative www.ohai.org

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National attention on goal-directed care

A collage of several publications and initiatives related to goal-directed care:

- New England Journal of Medicine Perspective**: "Moving From Disease-Centered to Patient Goals-Directed Care for Patients With Multiple Chronic Conditions" by Reuben DB, Tinetti ME, et al. (NEJM 2012;366(9):777-779.)
- Clinics in Geriatric Medicine**: "Patient Priority-Directed Decision Making and Care for Older Adults with Multiple Chronic Conditions" by Gary L. Fralick MD, FRCGP, Jessica Eremia MPH, & Bruce Ferrell MD, FRCGP (Clin Geriatr Med 2016;32(1):23-39)
- Journal of the American Geriatrics Society**: "Putting Goal-Oriented Patient Care Into Practice" by David B. Reuben MD, Lee A. Jennings MD, MSHS (J Am Geriatr Soc 2019)
- CMS.gov**: "Meaningful Measures Framework" and "Goals to Care" (How to keep the person in "person-centered")
- Institute for Healthcare Improvement**: "What Matters" to Older Adults: A Guide to Health Systems to Design Better Care with Older Adults
- Age-Friendly Health Systems**: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5900033/>
- NCQA**: National Committee for Quality Assurance

<https://patientprioritiescare.org>
<https://www.ncqa.org/hedis/reports-and-research/>
<http://www.hi.org/Engage/Initiatives/Age-Friendly-Health-Systems/Pages/default.aspx>
https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Downloads/CMS-Meaningful-Measures_Overview-Fact-Sheet_508_2018-02-28.pdf

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Why Focus on Patient Goals?

Disease-based Outcomes

- Address one condition
- Medical outcomes
- Population health goals
 - Universally applied
- Works for single disease; longer life expectancy
- May not capture what is most important to the patient

*Mold JV, Hamm R, Scheid D. Family Medicine 2003;35:360-4.
Reuben DB, Tinetti ME. NEJM 2012;366(9):777-779.
Tinetti ME, et al. JAMA Cardiology 2016;1(1):9-10.
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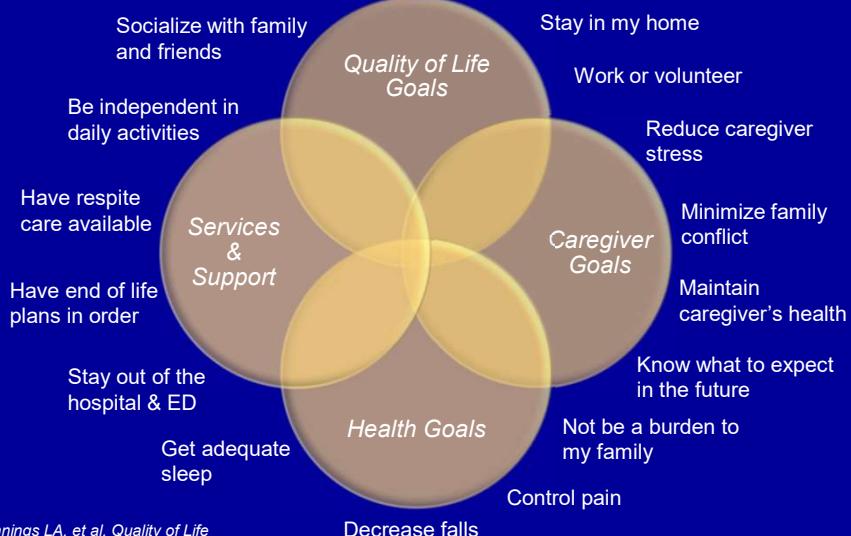
Patient-defined Outcomes

- Span conditions
- Medical & non-medical outcomes
- Personal health goals
 - Individualized
- Works for all patients; multiple chronic conditions; limited life expectancy
- Always patient-centered

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What matters most?

Findings from Focus Groups with Persons with Dementia and their Caregivers



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Jennings LA, et al. Quality of Life Research. 2017;26(3):685-93.

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One Approach to Goal-Directed Care: Goal Attainment Scaling

- Way to make a personalized health goal S.M.A.R.T.
 - Specific, Measurable, Attainable, Relevant, Time-bound
- Framework for care planning
 - Action Plan
- Measure goal achievement
 - Goal is individualized, measurement is standardized

Goal	Much less than expected (-2)	Less than expected (-1)	Expected goal attainment (0)	More than expected (+1)	Much more than expected (+2)	Action Plan
7 Interact more with grandkids	No contact with grandkids	Contacts grandkids every 2 months (current state)	Contact with grandkids monthly	Contact with grandkids bi-weekly	Contact with grandkids weekly	Make call schedule for each grandkid. Set reminder on phone.

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Can this work in primary care?

- PCORI methodology study
 - Goal setting feasible in dementia care management clinic
- NCQA demonstration project
 - Goal setting feasible with nurse and social work care managers
- Can goal setting be translated to *primary care*?
 - Nearly all persons with dementia receive care in primary care not in specialty care.

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Jennings LA, et al. JAGS 2018;66(11):2120-2127
<https://www.ncqa.org/hedis/reports-and-research/>

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Study Objectives

- Determine the feasibility and acceptability of using goal-attainment scaling to 1) set health goals and 2) measure goal achievement with persons with cognitive impairment and their family caregivers in primary care.

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Methods: Participants and Setting

- Piloted goal setting with 36 patient-caregiver dyads
- Inclusion criteria:
 - Cognitive impairment (any stage); community dwelling
 - Family caregivers
- 12 clinicians
 - 4 MDs, 3 NPs, 2 PAs, 1 RN, 2 SWs
- 5 primary care clinics
 - 2 urban academic, 2 suburban, 1 rural

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Methods: Goal Setting Intervention



- Complete goal setting during primary care visit
- One-month phone call with research assistant
- Three-month follow-up visit with clinician

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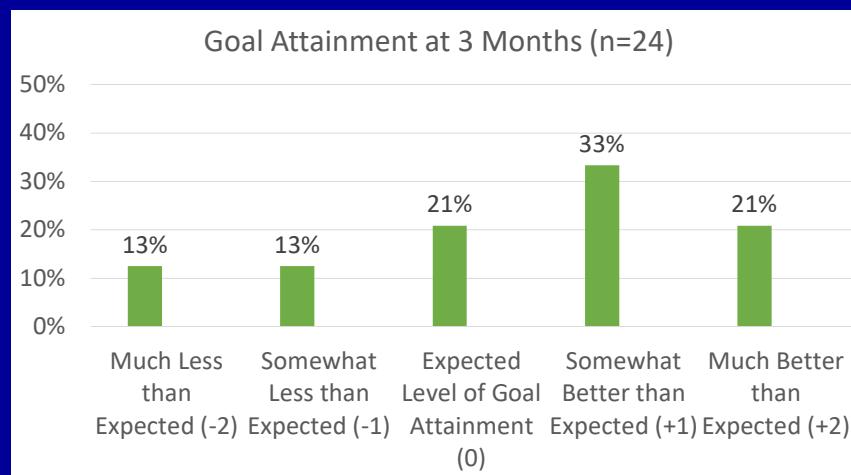
Methods: 3-Month Outcomes

- Goal attainment using 5-category scale
- Patient quality of life (QoL-AD), neuropsychiatric symptoms (NPI-Q)
- Caregiver burden (Zarit-12), quality of life (PROMIS)
- Interviews with patients, caregivers & clinicians
 - Value added to clinical care
 - Barriers to implementation in primary care

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Results: Goal Attainment at 3M



13 75% met or exceeded expected goal attainment at 3 months.

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Results: Patients and Caregivers

- High care satisfaction after goal-setting
 - 100% felt goal setting was helpful in planning for future
 - 96% felt process was different from usual care
 - 92% planned to continue to work on goals after study
- Mean caregiver burden lower at 3 months
 - 14.7 (SD 9.9) vs. 11.7 (SD 10.0), p=0.098
- No difference in patient or caregiver quality of life
- Goal setting discussions ranged 8 to 45 minutes
(Mean 24 minutes, SD 10)

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Patient and Caregiver Perspectives about Goal Setting

Themes	Example Quotes
Covered care domains beyond medical needs	<i>"My goal was more personalized than strictly medical; I did some soul searching." (person with cognitive impairment)</i>
Gave clinician a better sense of patient's needs	<i>"We discussed some personal issues with a professional that we wouldn't otherwise have had the opportunity to address." (person with cognitive impairment)</i>
Helped set expectations	<i>"Helped me to realize limitations and what was possible to accomplish." (child caregiver)</i>
Empowered caregivers; encouraged caregiver self-care	<i>"Allowed me to finally attend a support group by making it an actual goal, rather than something I just think I need to do, but never do." (spouse caregiver)</i>

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Themes	Example Quotes
Improved understanding of what was important to patients	<i>"It does help you to pay more attention to the individual instead of focusing on just the medical side." (NP)</i>
Aligned treatment recommendations with goals	<i>"It clearly defines where we're headed, and it allows you to target care towards what's important to the patient." (RN)</i>
Longer visit length was a barrier to use	<i>"It's an extra step in our work-up that often is not done because of time constraints." (MD)</i> <i>"...if you have too much else going on in the visit, it's difficult." (MD)</i>
Goal attainment scaling takes practice	<i>"The first one or two was daunting in that I hadn't done it before..." (PA)</i>

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Goal Attainment Scaling: Advantages vs. Challenges

Advantages	Challenges
Goals are specific, measurable	Clinician time constraints
Goals are personalized; meaningful to patients	Scaling takes training and practice
Goals can be revised	Culture of disease-based care
Facilitates care planning	Unrealistic goals
Patients/families like it	Goals of and for others (e.g., family, clinician)

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Summary

- Goal-oriented approach to care
 - Helps patients achieve what is most important to them
- Goal attainment scaling
 - Feasible for persons with cognitive impairment in primary care
 - Adds value and time to clinical care
- Ongoing study to refine approach and facilitate wider use

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Questions?

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Results: Participant Characteristics

Person with cognitive impairment		M (SD) or N (%)
Age		78.8 (11.9)
Female		23 (64%)
White, Non-Hispanic		30 (83%)
Montreal Cognitive Assessment, range 0-27 (lower score=greater impairment)		13.8 (9.2)
Bristol Activities of Daily Living, range 0-44 (higher score=greater impairment)		15.7 (13.9)
Number of medications taken daily, range 0-26		9.2 (6.4)
Caregiver		
Female		27 (75%)
Spouse of patient		17 (47%)
Child of patient		14 (39%)
Lives with patient		24 (67%)
College educated		24 (67%)

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Example Goals and Scaling

Goal	Much less than expected (-2)	Less than expected (-1)	Expected goal attainment (0)	More than expected (+1)	Much more than expected (+2)	Action Plan
Get out of the house more often	Doesn't get out of the house, stays home most days. (current state)	Go with daughter to pick up grandson once a week	Go with daughter to pick up grandson 2X/week. Stay out 30 min.	Go with daughter to pick up grandson and go get a coke 2X/week. Stay out 45 min.	Go with daughter to pick up grandson and go get a coke 3X/week. Stay out 60 min.	Daughter will facilitate getting patient out of house more often. Encouraged to call provider if difficulty.
Get adequate sleep	Less than 4 hours of sleep at night	Gets 4 - 5 hours of sleep (current state)	Get 6 hours of sleep	Get 7 hours of sleep	Get 8 hours of sleep	Change bath to evening. Start melatonin. Neurology referral for nighttime hallucinations

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