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# Personalized Goal Attainment in Dementia Care: Measuring What Persons with Dementia and Their Caregivers Want

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**OBJECTIVES:** To develop a process of goal-setting and measurement of goal attainment in a dementia care management program.

**DESIGN:** Observational.

**SETTING:** Dementia care management program in an urban academic medical center.

**PARTICIPANTS:** Persons with dementia (N=101) and their caregivers; nurse practitioner dementia care managers (N=5).

**INTERVENTION:** Specification of a personalized health goal and action plan and measurement of goal attainment using goal attainment scaling in a clinical care visit.

**MEASUREMENTS:** Goal attainment at 6 and 12 months; focus groups of 5 dementia care managers.

**RESULTS:** Eighty-four percent of participant goals were nonmedical, 47% were related to quality of life, and 29% were caregiver support goals. Eighty-eight percent of participants felt that the goal they set was meaningful and 74% that the goal-setting process captured something different from usual care, and 85% found the process helpful in planning for future care. At 6 months, 74% of dyads had achieved or exceeded their expected level of goal attainment. Dementia care managers felt that the goal-setting process improved their understanding of what was most important to the patient, helped set expectations about disease progression and care needs, and provided positive reinforcement when goals were accomplished and an opportunity for revision when goals were not met.

**CONCLUSION:** Goal setting using goal attainment scaling can be incorporated into the care of persons with dementia to establish and attain person-centered goals. Research is

needed to further develop personalized goal attainment as an outcome measure for dementia care. © 2018 American Geriatrics Society and Wiley Periodicals, Inc. *J Am Geriatr Soc* 00:1–8, 2018.

**Key words:** dementia; person-centered outcomes; goal-attainment scaling

Health outcome measures for incurable chronic diseases, including Alzheimer's disease and related dementias, have focused on survival, condition-specific indicators, symptom control, and general health-related quality of life.<sup>1</sup> These outcomes are "universal" goals that most people who have a long life expectancy and are free of multiple comorbidities would want, but these goals may not be possible for or desired by persons with dementia. Thus, measures are needed to capture the success or failure in meeting an individual's health goals when traditional outcomes are not possible or may not address what is most important.

Dementia is usually a long-term disease, with median survival of 4 to 10 years.<sup>2</sup> During this time, goals and potential to achieve them may change. Early on, the goal may be to preserve function, including ability to work. As the disease progresses, goals may shift to maintaining mobility, controlling neuropsychiatric symptoms, reducing caregiver strain, and eventually ensuring a dignified death. Thus, medical care decisions should be considered within the context of the stage of the disease and the individual's goals and preferences and the trade-offs required to achieve them.

Goal attainment scaling (GAS) is one method of specifying personal health goals and measuring their attainment. Researchers have been using GAS for decades, to measure the effects of interventions primarily in mental health<sup>3</sup> and clinical rehabilitation<sup>4,5</sup> but also in comprehensive geriatric assessment<sup>6–9</sup> and Alzheimer's disease.<sup>10,11</sup> The aim of this study was to apply GAS in the clinical care of persons with dementia to elicit, specify, measure attainment of, and revise personalized goals of care. Understanding the

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feasibility of using GAS in a clinical setting is a first step in improving its application for dementia care quality improvement efforts and research.

## METHODS

### Overview

We developed and implemented a process of goal setting and measurement of goal attainment using GAS in a dementia care management program. In Phase 1, we refined the goal setting process with 32 dyads of persons with dementia and their caregivers and trained 5 nurse practitioner dementia care managers (DCMs) in GAS. In Phase 2, DCMs led 101 dyads of persons with dementia and their caregivers in goal specification using a 5-category goal attainment scale. Goal attainment was measured at 6 and 12 months. Dyads revised goals or set new goals at 6 months, if desired. Structured interviews with dyads and focus groups with DCMs were conducted to explore the process and value of goal setting and measurement using GAS in a dementia clinical care setting.

### Setting and Participants

Participants were recruited from the University of California, Los Angeles, Alzheimer's and Dementia Care program,<sup>12</sup> a dementia care management program based in an urban academic health system. The program uses nurse practitioners partnered with primary care providers and community-based organizations to address the comprehensive care needs of persons with dementia and their caregivers. Study participants were required to have a diagnosis of dementia and to have a family or friend caregiver who was willing to participate in the study and enroll as a dyad. There were no other inclusion criteria.

### Phase 1

#### *Goal Inventory Field Testing*

We administered a 41-item goal inventory<sup>13</sup> to 32 dyads to assess feasibility of use and refine the inventory. In 6 dyads, the person with dementia had early-stage disease (MMSE score  $\geq 23$ ). Dyads were asked to rate the importance of each goal over the next 6 months using a 4-category response scale (not at all important to extremely important) and to rank order the 3 goals most important to them. Dyads were asked to consider the person with dementia's and the caregiver's preferences when rating and ranking goals together. If important goals were not included on the inventory, they were asked to write them in.

#### **GAS Instrument and Training Dementia Care Managers**

Eleven dyads in Phase I completed GAS with their DCM for the 1 goal they identified as most important to attain over the next 6 months. Study investigators (LJ, DR, NW, RH) reviewed the goal scaling using the SMART goal criteria (specific, measurable, attainable, relevant, time-bound).<sup>14</sup> Investigators also examined whether the goal scaling represented clinically meaningful change across levels if scaling was precisely described at each level and if a baseline performance

level was identified.<sup>15</sup> Baseline performance level was defined as the less than expected (−1) outcome for participants who identified a goal to improve the current state (e.g., reduce falls) and was defined as the expected (0) outcome for participants who identified a goal to maintain the current state (e.g., continue to exercise daily). Defining the baseline performance level in this way allowed the scaling to accommodate persons who wished to set goals to improve a current health state and those who wanted to maintain a current state. DCMs participated in two 1-hour training sessions at which they received instruction in using GAS from study investigators (LJ, NW, DR) and role-played GAS with clinical scenarios.

### Phase 2

#### *Data collection and study visit procedures*

In Phase 2, DCMs assisted 101 dyads in goal specification using GAS, and goal attainment at 6 and 12 months was measured. The primary outcome was goal attainment at 6 months. Baseline study visits occurred in person as part of an annual Alzheimer's and Dementia Care program visit, and a research assistant made 6- and 12-month telephone follow-ups. Follow-up visits were completed within a 1-month window around the 6- or 12-month date.

During the baseline study visit, DCMs reviewed the top 3 goals that each dyad identified using the goal inventory and completed GAS for the 1 goal that the dyad identified as most important to attain over the next 6 months. After completing GAS, DCMs were encouraged to add an action plan to assist participants in articulating the steps needed to achieve the goal. The scaled goal and action plan were provided to participants at the conclusion of the visit.

DCMs also rated their perceptions of how difficult the goal would be to attain using a 4-category response scale (not at all difficult to extremely difficult). Structured interview questions about the goal setting process were asked of dyads at 6- and 12-month follow-up visits.

Four study investigators (LJ, DR, RH, NW) independently coded 11 new goals that participants proposed during both phases, grouped them into goal domains, and added them to the inventory (Supplementary Appendix S1). Study investigators discussed disagreements in coding and settled them according to consensus.

#### **Assessment of Goal Attainment**

At 6- and 12-month follow-up visits, participants reviewed the goal identified as most important at the baseline visit and discussed progress toward meeting the goal over the prior 6 months. Dyads were shown their personalized GAS and asked to rate their goal attainment using the 5-category response scale (much less than expected (−2), less than expected (−1), expected level of goal attainment (0), better than expected (+1), much better than expected (+2)).

At 6 months, dyads chose whether they wanted to continue to work on the same goal, revise the scaling of their goal, or choose a different goal to work on for the next 6 months. For dyads who wanted to revise their goal at 6 months, a second telephone visit with their DCM was scheduled to do so.

### Statistical analyses

Frequencies or means and standard deviations were used to summarize participant demographic characteristics. The Mini-Mental State Examination (MMSE),<sup>16</sup> an inventory of basic activities of daily living (ADLs),<sup>17</sup> the Neuropsychiatric Inventory Questionnaire (NPI-Q),<sup>18</sup> and the Modified Caregiver Strain Index (MCSI)<sup>19</sup> were also completed with each dyad as part of a routine Alzheimer's and Dementia Care visit.

Goal attainment at 6 months was first examined as a 5-category ordinal scale and then dichotomized (yes/no), defined as a score of 0, +1, or +2 (yes) versus a score of -1 or -2 (no).

Bivariate statistics (2-sample t-test, chi-square test, Fisher exact test) were used to examine whether goal attainment at 6 months differed according to DCM, goal difficulty rating, goal type (caregiver support goals vs goals in other categories), dementia stage (defined according to baseline MMSE score), baseline ADL score, baseline NPI-Q symptom severity score, baseline MCSI score, caregiver relationship, and whether the caregiver lived with the person with dementia. We used the Benjamini-Hochberg procedure<sup>20</sup> for multiple comparisons with a false discovery rate of 0.10. Given the small sample sizes, subgroup analyses were not powered for hypothesis testing and thus were considered exploratory.

### Qualitative analyses of structured interviews and focus groups

Responses from structured interview questions about the goal-setting process completed with dyads at 6- and 12-month follow-up visits were classified as yes/no or into categories. Study investigators (LJ, DR, RH, NW) reviewed any qualitative comments that participants provided during interviews, supplemented by audio-recordings if clarification was needed. Responses to interview questions are shown in Table 3.

We conducted 2 focus groups with 5 DCMs to understand the process and clinical value of using GAS to set goals and measure their attainment in a dementia care clinical setting. The first focus group guide was developed from DCM experiences in Phase 1. After completing analyses from the first focus group (conducted at the mid-point of Phase 2), the guide for the second focus group (conducted at study end) was created to allow exploration of emerging themes. (See Supplementary Appendix S2 for focus group guides.) Focus groups were approximately 60 minutes and were audio-recorded and transcribed verbatim. Two study investigators (LAJ, DBR) independently coded transcripts line by line using deductive (a priori) and inductive (emerging from the data) coding approaches<sup>21-23</sup> to develop a coding scheme. The full study team discussed emerging themes and exemplary texts, and any differences in coding were settled according to group consensus.

The institutional review board at the University of California, Los Angeles, approved this study (IRB#14-001228).

## RESULTS

One hundred thirty-three individuals with dementia were included in the study (Phase 1, n=32 and Phase 2, n=101) (age range 51–100, 65% female, 30% racial or ethnic minorities, mean MMSE score  $15.8 \pm 7.8$ ). Thirty-two percent of caregivers were spouses, and 57% were children; 70% lived with

**Table 1. Participant Characteristics (N=133)**

Characteristic	Value
<b>Person with dementia</b>	
Age, mean±SD (range 51–100)	83.4 ± 9.2
Female, n (%)	86 (65)
Race and ethnicity, n (%) (N=101)	
Hispanic	15 (15)
Non-Hispanic black	19 (19)
Non-Hispanic white	61 (60)
Asian	3 (3)
Other	3 (3)
Primary language not English, n (%)	20 (15)
Marital status, n (%) (N=112)	
Married, living with partner	43 (38)
Widowed	51 (46)
Divorced, separated, single	18 (16)
Education, n (%) (N=112)	
≤Some high school	25 (22)
High school graduate	20 (18)
Some college or college graduate	44 (39)
Graduate school	23 (21)
MMSE score, mean±SD (range 0–30) (N=112)	15.8 ± 7.8
Number of activities of daily living performed independently, median (interquartile range) (range 0–6) (N=86)	4 (2–6)
NPI-Q symptom severity score, mean±SD (range 0–36) (N=99)	10.1 ± 6.4
<b>Caregiver</b>	
Relationship, n (%)	
Spouse	43 (32)
Child	76 (57)
Other	14 (11)
Lives with patient, n (%) (N=107)	75 (70)
Age, mean±SD (range 37–99) (N=88)	62.3 ± 13.5
Female, n (%)	98 (74)
NPI-Q caregiver distress score, mean±SD (range 0–60) (N=98)	11.8 ± 9.4
Modified Caregiver Strain Index score, mean±SD (range 0–26) (N=91)	10.2 ± 6.0

Some Alzheimer's and Dementia Care programmatic data are incomplete because some forms were not completed during the clinical visit. If the Mini-Mental State Examination (MMSE) score was missing (N=29), the prior year's score was used. SD=standard deviation; NPI-Q=Neuropsychiatric Inventory—Questionnaire.

the person with dementia. Mean MCSI score was  $10.2 \pm 6.0$  (range 0–26), indicating moderate strain on average (Table 1).

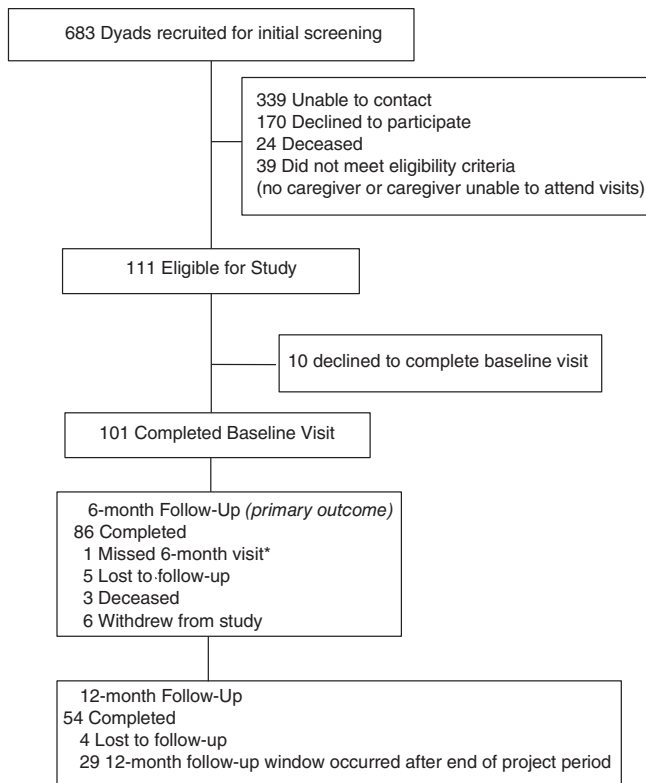
One hundred twelve (84%) goals were nonmedical. Goals related to improving the quality of life of the person with dementia were most commonly selected (n=62, 47%), followed by caregiver support goals (n=39, 29%). Commonly chosen goals relating to the person with dementia included physical safety (n=20), continuing to live at home (n=11), receiving medical care related to dementia (n=8), avoiding hospitalization (n=7), mental stimulation (n=6), and physical activity (n=6). Commonly chosen caregiver goals included maintaining the caregiver's own health (n=15), managing stress (n=7), and minimizing family conflict related to dementia caregiving (n=5). There was great diversity of goals, with 34 different goals chosen from the inventory. There was no clear pattern to goal selection according to cognitive status as assessed using the MMSE.

Examples of goals and how participants scaled them in Phase 2 (n=101) are presented in Table 2. Eighty-six

**Table 2. Examples of Scaled Goals**

Goal Category	Goal Description	Attainment Levels					Action Plan
		Much Less Than Expected	Somewhat Less Than Expected	Expected	Somewhat Better Than Expected	Much Better Than Expected	
Medical care	Less burdensome medical care; fewer healthcare visits; pain better controlled	Hospital admission	7 healthcare visits per month; no change in pain level (current state)	4–5 healthcare visits per month; no change in pain	Reduction in pain; 4–5 healthcare visits per month	Pain free; 4–5 healthcare visits per month	Discuss pain management with PCP; refer to pain clinic; telephone visits with DCM
Physical quality of life	Improve safety by reducing falls	>4 falls in 6 months; fall with injury	4 falls in last 6 months; no injuries (current state)	2–3 falls in next 6 months; no injuries	1 fall in next 6 months; no injuries	No falls, no injuries in next 6 months	Physical therapy, walker, nightlight, evening caregiver.
Social–emotional quality of life	Keep Mom’s mind stimulated	Not participating in any activities; stops watching movies	Watches television and movies at home; does not get out (current state)	1 activity outside home once per week; more in-home activities with caregiver	Activities outside home > 1 d/wk; more in-home activities with caregiver	Activities outside home daily; more in-home activities with caregiver	Hire caregiver more knowledgeable about dementia who can take Mom to outside activities
Accessing services	Legal and financial affairs in order	Legal or financial problem occurs	No DPOA established. (current state)	Establish DPOA for finances	Establish DPOA for finances; have understanding of accounts, taxes, and mortgage	No legal concerns about finances	Patient and son will attend legal clinic; DCM provided elder law attorney information
Caregiver support	Maintain caregiver’s own health	Unable to maintain daily exercise; cooking at home less (diet worse)	Unable to maintain daily exercise	Walk 1.5 miles daily (current state)	Add floor exercises to routine; diet changes	Walk daily; floor exercises; change diet; follow-up with own doctor	Daughter will explore resources that DCM provides to expand hired caregiver hours to use during exercise

PCP=primary care provider; DCM=dementia care manager; DPOA=durable power of attorney.



**Figure 1.** Flow of participants (Phase 2). One participant did not complete a 6-month follow-up visit but completed a 12-month follow-up visit.

participants (85%) completed a 6-month follow-up visit and 54 (53%) a 12-month follow-up visit (Figure 1).

Seventy-four percent of participants achieved or exceeded their expected level of goal attainment (n=64 at 6 months; n=40 at 12 months) (Figure 2). Dyads rated almost all goals selected as extremely (83%) or very important (13%), and DCMs rated most goals as a little (43%) or moderately difficult (32%). Only 11 participants (13%) revised the scaling of their goal or chose a new goal at 6 months.

Baseline median ADL score was higher (more independent; 4.0, interquartile range (IQR) 2–6) in those who attained goals at 6 months than in those who did not (2.5, IQR 1–4) (Wilcoxon rank-sum,  $z=-2.33$ ,  $p=.02$ ), although this was not significant after correction for multiple comparisons. Goal attainment did not differ according to other participant characteristics, DCM, or goal difficulty or category.

Table 3 shows the perceptions of persons with dementia and their caregivers of the goal-setting process using GAS. At 6 months, 40% of respondents indicated that it was difficult to rate and rank the importance of goals; at 12 months, 28% reported difficulty. At 6 months, most rated the goal-setting process as valuable; 85% reported that it was helpful for planning for future care, 74% felt that the process got at something different from usual medical care, and 88% regarded the goals they set as meaningful. Forty-eight percent would have preferred to work on more than 1 goal. Ninety-five percent of participants felt that the DCM was the right person with whom to discuss goals, and 79% felt that a timeframe of 6 months to obtain their goals was about right. At 12 months, 57% had

discussed their goals with another healthcare provider, and 70% had discussed goals with family members. Eighty-three percent planned to continue to work on their goal.

In focus groups, DCMs expressed that the goal-setting process improved their understanding of what was most important to their patients and identified goals they might have otherwise missed.

*“The times that it was most helpful for me was when I was surprised by their goal. When it was something I didn’t find out in an annual visit.”*

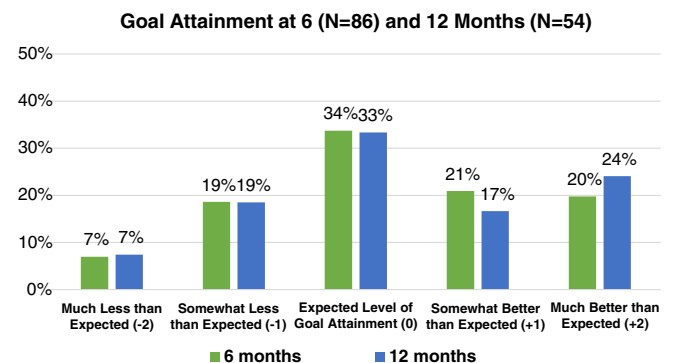
*“It was valuable for me because it told me what my patient’s goal was, and it might have been different from mine. If it [the goal] was in a different direction, maybe I should be looking at their direction more than mine.”*

They identified situations when persons with dementia or caregivers chose goals they felt were clinically unrealistic (e.g., drive a car again) or very difficult to achieve (e.g., live at home without caregivers) as challenging. They also reported that the GAS process helped set expectations about disease progression and care needs for persons with dementia and caregivers.

*“Sometimes their goal was way off base in regards to what we can do, and that was helpful to know...her goal was to go to Paris next year and see the Eiffel Tower with her father, but he’s in a nursing home...It was helpful for me to see how much I needed to manage their expectations. It was helpful to have an organized way to get that information.”*

DCMs also expressed value in revising goals with persons with dementia and caregivers when a goal was not attained.

*“If they didn’t quite get what they wanted after 6 months, they were better prepared to have that [goal-setting] conversation at 6 months because they realized that it was a lot harder to make it to support groups or to go to the gym or to hire that caregiver than they thought it was going to be. Then their expectations changed, not only of themselves, but also of the situation. I looked at it as valuable instead of looking at it as a*



**Figure 2.** Goal attainment at 6 and 12 months.



**Table 3. Dyad Perceptions of Goal-Setting Process**

Perception	6 months, N=86	12 months, N=54
	<b>n (%)</b>	
	<b>yes</b>	
Was it difficult for you to rate and rank the importance of goals?	34 (40)	15 (28)
Was thinking about goals helpful to you in planning for future care?	73 (85)	45 (83)
Did the goal-setting process get at something that is different from usual medical care?	64 (74)	41 (76)
Do you feel that the goal you set is meaningful?	76 (88)	50 (93)
Would have preferred to work on more than one goal?	41 (48)	26 (48)
Was your DCM the right person to discuss your goals with?	82 (95)	45 (83)
	<b>About right</b>	
Was the time you spent talking about your goal with your DCM too short, too long, or about right? <sup>1</sup>	73 (85)	48 (89)
Was the timeframe of 6 months to attain your goal too long, too short, or about right? <sup>2</sup>	68 (79)	39 (72)
	<b>yes</b>	
Since enrolling in study, have you discussed your goal with another health care provider?		31 (57)
Since enrolling in study, have you discussed your goal with your family or friends?		38 (70)
Will you continue to work on your goal after the study?		45 (83)

Item-level response rates at 6 months ranged from 93–100% (n=80–86 for each item). Item level response rates at 12 months ranged from 91–100% (n=49–54 for each item).

<sup>1</sup>Few respondents indicated that time spent talking about their goal with their dementia care manager (DCM) was too short (6 months: n=7 (8%); 12 months: n=2 (4%). No respondents indicated that time spent talking about their goal with their DCM was too long at either time point.

<sup>2</sup>Few respondents felt 6 months was too short a time to attain their goal (6 months: n=4 (5%); 12 months: n=8 (15%)). Similarly, few respondents felt 6 months was too long a time to attain their goal (6 months: n=8 (9%); 12 months: n=2 (4%)).

*failure—for us to see why this didn't work and then figure out how we can make it more appropriate."*

DCMs thought the GAS process empowered caregivers who did not feel confident in their decision-making and provided positive reinforcement to caregivers and persons with dementia who were able to accomplish part or all of their goals.

*"Caregivers have a lot to say and a lot of concerns, and the typical provider is not going to [ask]... 'what do you want?' So they appreciated that... adding goals could be a way to let them know they are being heard."*

*"Working through the goal gave the patient or caregiver some feeling of accomplishment and power."*

Some persons with dementia and caregivers had difficulty completing the extremes of the 5-point GAS scale (much worse (−2) or much better (+2) than expected), and DCMs suggested a 3-point scale as an alternative for some people.<sup>24</sup> DCMs reported that the GAS process added about 15 to 20 minutes to their clinic visit, on average.

## DISCUSSION

This study is proof of concept that GAS can be used in the clinical care of persons with dementia to elicit, specify, measure attainment of, and revise personalized goals of care. We used GAS to facilitate the process of making a personalized goal SMART,<sup>14</sup> and as a measurement tool, allowing the standardized assessment of goal attainment across the study cohort at 6 and 12 months. Most goals that persons with dementia and their caregivers identified were not related to medical care; instead, they focused on broader aspects of quality of life or caregiver support. Although

most people had attained their goals at follow-up, approximately one-fourth did not, demonstrating that this approach can capture failure as well as success in meeting outcomes. Approximately 10% of participants wanted to revise their goals at follow-up, which is particularly important in dementia because goals may evolve as the disease progresses. Most participants and dementia care managers found the goal-setting process to be valuable and felt it captured something different from usual medical care.

Our findings have important implications for the clinical care of persons with dementia and may be applicable to persons with other advanced illnesses and multiple morbidities. By focusing on goals that are important to patients, the success or failure of healthcare interventions can be explicitly evaluated. Personalized goal attainment might be used to measure the quality of care provided or to evaluate models of dementia care management or care management for other conditions,<sup>25</sup> but to do so requires specification of goals and how they can be met.

Many of the goals identified (e.g., low caregiver strain, ensuring safety, living at home) are generally applicable for persons with dementia and their caregivers, but what it meant to achieve these "universal" outcomes<sup>1</sup> was often very individualized. For example, one caregiver defined safety as avoiding falls, whereas another defined it as preventing wandering. GAS can accommodate such diverse preferences within the context of achieving an overall goal (e.g., patient safety). Moreover, there were trade-offs even among these commonly desired health outcomes (e.g., a child accepting a more intensive caregiving role to avoid long-term nursing home placement of a parent). Although some of the goals identified were similar to existing self-reported outcome measures (e.g., functional status), other goals were more idiosyncratic and not well captured in existing measures (e.g., attending a family reunion). GAS allows these person-specific goals to be measured as important outcomes.

The goals identified in this study and compiled in the final inventory confirm and extend prior work examining care preferences of persons with dementia and their caregivers.<sup>26–30</sup> The similarity of values articulated across studies underscores the need to measure person-centered outcomes within these domains.

Although this study was successful at showing proof of concept, there are practical barriers to the wider use of GAS in clinical settings. Provider and health system barriers include visit time constraints, a culture of disease-specific outcomes and cure, and a workforce unprepared to use GAS. If the GAS discussion required 20 minutes, based on the national median nurse practitioner salary (\$104,000)<sup>31</sup> plus 40% benefits, the intervention would cost approximately \$25 per participant. There are also persons with dementia and caregiver barriers to implementation, including unrealistic goals (e.g., reverse cognitive impairment), and situations in which the goals of the person with dementia and caregiver do not align (e.g., autonomy vs safety). This study begins to address some of these limitations by showing that it is feasible to use GAS in an outpatient dementia care setting. We also used a goal-setting process that involved a dyad (person with dementia and caregiver), because achieving the person with dementia's goal often depends upon caregiver support. The process of goal-setting as a dyad also facilitated discussion between persons with dementia and their caregivers about the person's values and care preferences, which could be used to guide the caregiver in future decision-making.

Although GAS has been widely used in clinical rehabilitation studies,<sup>4,5</sup> there has been less research using GAS in persons with cognitive impairment.<sup>10,11</sup> To further develop goal attainment as a rigorous outcome measure in dementia research,<sup>15</sup> future work should compare goal attainment with other self-reported outcome measures, where available, to examine the construct validity of goal attainment as an outcome. For example, the attainment of a personalized goal to reduce caregiver stress might correspond to a decrease in an index of caregiver burden. The small sample size in this study limited comparisons with self-reported outcome measures. Future research should also examine whether the process of goal-setting changes care delivery and whether care received is aligned with the articulated goals of the person with dementia.

When interpreting these findings, the limitations of the study should be considered. This study used GAS in a single dementia care management program in an urban community-dwelling population. Thus, these findings may not be applicable to some other dementia care settings. Additionally, GAS was performed with nurse practitioners, and these findings may not translate to other types of care providers such as physicians or social workers. The study also included only a small number of participants with early-stage dementia (n=23, 17%); thus, the goal-attainment data largely reflect caregiver input because most participants' cognitive impairment was too advanced to participate in rating goal attainment at follow-up. Small sample sizes also limited the robustness of comparisons of goal attainment in different subgroups.

The findings of the study suggest that goal setting and GAS can be incorporated into clinical care of persons with dementia and used as an outcome measure. Further

research on the use of GAS in dementia cohorts and comparisons with other self-reported outcome measures should be performed to further develop personalized goal attainment as a useful outcome measure for clinical care and dementia research.

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**Conflict of Interest:** The authors have no conflicts of interest to report.

**Author Contributions:** Jennings: conception and design, acquisition of data, analysis and interpretation of data; drafting article; critical revision for important intellectual content; final approval. Hays, Wenger: conception and design, analysis and interpretation of data; critical revision for important intellectual content; final approval. Ramirez: acquisition of data; critical revision for important intellectual content; final approval. Reuben: conception and design; acquisition of data; analysis and interpretation of data; critical revision for important intellectual content; final approval.

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## REFERENCES

1. Working Group on Health Outcomes for Older Persons with Multiple Chronic Conditions. Universal health outcome measures for older persons with multiple chronic conditions. *J Am Geriatr Soc* 2012;60:2333–2341.
2. Xie J, Brayne C, Matthews FE. Survival times in people with dementia: analysis from population based cohort study with 14 year follow-up. *BMJ (Clin Res Ed)* 2008;336:258–262.
3. Kiresuk TJ, Sherman RE. Goal attainment scaling: A general method for evaluating comprehensive community mental health programs. *Community Ment Health J* 1968;4:443–453.



4. Turner-Stokes L. Goal attainment scaling (GAS) in rehabilitation: A practical guide. *Clin Rehabil* 2009;23:362–370.
5. Hurn J, Kneebone I, Cropley M. Goal setting as an outcome measure: A systematic review. *Clin Rehabil* 2006;20:756–772.
6. Moorhouse P, Theou O, Fay S et al. Treatment in a geriatric day hospital improve individualized outcome measures using goal attainment scaling. *BMC Geriatr* 2017;17:9.
7. Rockwood K, Howlett S, Stadnyk K et al. Responsiveness of goal attainment scaling in a randomized controlled trial of comprehensive geriatric assessment. *J Clin Epidemiol* 2003;56:736–743.
8. Rockwood K, Stolee P, Fox RA. Use of goal attainment scaling in measuring clinically important change in the frail elderly. *J Clin Epidemiol* 1993;46:1113–1118.
9. Yip AM, Gorman MC, Stadnyk K et al. A standardized menu for goal attainment scaling in the care of frail elders. *Gerontologist* 1998;38:735–742.
10. Rockwood K, Fay S, Song X et al. Attainment of treatment goals by people with Alzheimer's disease receiving galantamine: A randomized controlled trial. *Can Med Assoc J* 2006;174:1099–1105.
11. Rockwood K, Howlett SE, Hoffman D et al. Clinical meaningfulness of Alzheimer's Disease Assessment Scale-Cognitive subscale change in relation to goal attainment in patients on cholinesterase inhibitors. *Alzheimers Dement* 2017;13:1098–1106.
12. Reuben DB, Everson LC, Wenger NS et al. The University of California at Los Angeles Alzheimer's and Dementia Care program for comprehensive, coordinated, patient-centered care: Preliminary data. *J Am Geriatr Soc* 2013;61:2214–2218.
13. Jennings LA, Palamaru A, Corona MG et al. Patient and caregiver goals for dementia care. *Qual Life Res* 2017;26:685–693.
14. Meyer PJ. *What Would You Do If You Knew You Couldn't Fail? Creating S.M.A.R.T. Goals. Attitude Is Everything: If You Want to Succeed Above and Beyond.* Waco, Texas: The Meyer Resource Group, Inc.; 2003.
15. Krasny-Pacini A, Evans J, Sohlberg MM et al. Proposed criteria for appraising goal attainment scales used as outcome measures in rehabilitation research. *Arch Phys Med Rehabil* 2016;97:157–170.
16. Folstein MF, Folstein SE, McHugh PR. 'Mini-mental state'. A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975;12:189–198.
17. Katz S, Ford AB, Moskowitz RW et al. Studies of illness in the aged. The index of ADL: A standardized measure of biological and psychosocial function. *JAMA* 1963;185:914–919.
18. Kaufer DI, Cummings JL, Ketchel P et al. Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. *J Neuropsychiatry Clin Neurosci* 2000;12:233–239.
19. Thornton M, Travis SS. Analysis of the reliability of the Modified Caregiver Strain Index. *J Gerontol B Psychol Sci Soc Sci* 2003;58B:S127–S132.
20. Benjamini Y, Hochberg Y. Controlling the false discovery rate: A practical and powerful approach to multiple testing. *J R Stat Soc* 1995(B 57):289–300.
21. Bernard HR, Ryan GW. *Analyzing Qualitative Data: Systematic Approaches.* Thousand Oaks, CA: Sage Publications; 2010.
22. Mays N, Pope C. Qualitative research in health care. Assessing quality in qualitative research. *BMJ (Clin Res Ed)* 2000;320:50–52.
23. Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. *BMJ (Clin Res Ed)* 2000;320:114–116.
24. Krasny-Pacini A, Pauly F, Hiebel J et al. Feasibility of a shorter goal attainment scaling method for a pediatric spasticity clinic—the 3-milestones GAS. *Ann Phys Rehabil Med* 2017;60:249–257.
25. Lynn J, McKethan A, Jha AK. Value-based payments require valuing what matters to patients. *JAMA* 2015;314:1445–1446.
26. Bogardus ST, Jr., Bradley EH, Tinetti ME. A taxonomy for goal setting in the care of persons with dementia. *J Gen Intern Med* 1998;13:675–680.
27. Bradley EH, Bogardus ST, Jr., van Doorn C et al. Goals in geriatric assessment: Are we measuring the right outcomes? *Gerontologist* 2000;40:191–196.
28. Ducharme JK, Geldmacher DS. Family quality of life in dementia: A qualitative approach to family-identified care priorities. *Qual Life Res* 2011;20:1331–1335.
29. Kuluski K, Gill A, Naganathan G, Upshur R et al. A qualitative descriptive study on the alignment of care goals between older persons with multi-morbidities, their family physicians and informal caregivers. *BMC Fam Pract* 2013;14:133.
30. Phinney A, Chaudhury H, O'Connor DL. Doing as much as I can do: The meaning of activity for people with dementia. *Aging Ment Health* 2007;11:384–393.
31. U.S. Department of Labor, Bureau of Labor Statistics, Occupational Employment Statistics. May 2017 (online). Available at <https://www.bls.gov/oes/current/oes291171.htm> Accessed May 18, 2018.

## SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article.

**Supplementary Appendix S1:** Goal Inventory for Dementia Care

**Supplementary Appendix S2:** Focus Group Guides for Dementia Care Managers

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