

Assessing Determinants of Perceived Quality in Transitions for People with Dementia: a Prospective Observational Study



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ABSTRACT

Background

The trajectory of dementia through time is characterized by common transitions which are difficult for persons with dementia (PWDs) and their families and friends. Our study sought to identify determinants for the quality of transition outcomes.

Method

A 24-month, prospective, longitudinal design identified specific transitions as they occurred in 108 person-with-dementia/caregiver dyads, and assessed the perceived transition quality from the perspective of the caregiver and what we denote as the ‘summative’ transition quality outcome variable (as explained in the Data Processing section under Methods).

Results

Among caregivers and during the authors’ deliberations of the summative transition quality outcomes, good transition quality was associated with the PWD’s baseline Disability Assessment for Dementia (OR 1.04, 95% CI 1.02-1.06 per increase in percent score based on summative assessments), and with the PWD’s higher baseline quality of life scores (OR 1.11, 95% CI 1.05-1.18 per increase in unit of score in QOL-AD based on summative assessments). Caregiver-perceived better outcome quality was associated with lower caregiver burden, (OR 0.97, 95% CI 0.95-0.99 per unit CBI score increase).

Conclusion

Identifying determinants of successful transitions is feasible and may be translated into practical guidance for use in clinical encounters. Those with worse prior quality of life or worse performance in activities of daily living appear to require specific support during transitions, as do those whose caregivers report higher levels of burden.

Key words: aged care, quality of life (QoL), dementia, carers, primary care

INTRODUCTION

Dementia is common, increasing in prevalence,^(1,2) long-term, progressive and debilitating,⁽³⁾ and costly to health and social systems. Increasing lay involvement in care^(4,5) may lead to both caregivers and the people with the condition encountering difficulties navigating common and predictable transitions in service provision and organization.

Previous research has identified specific interventions,^(6,7,8) strategic approaches to transitions management,⁽⁹⁾ personal characteristics,⁽¹⁰⁾ and organizational factors⁽¹¹⁾ which appear to improve the quality of transitions in people with dementia or their caregivers. We sought to understand whether there were predisposing factors among people with dementia which were associated with ‘good’ or ‘bad’ transition quality.

Transitions

From the work of Meleis *et al.*⁽¹²⁾ we adopted the general conceptualization of transition as a complex, multifactorial, and imprecise process of change. We defined transition as

any change in state related to time, place, people, agency, organization, or health condition. Our study focused on nine common transitions experienced by people with dementia and their caregivers. These were identified by an international expert panel of clinicians and researchers each of whom had personal experience of a family member with dementia.⁽¹³⁾

1. initial problem identification
2. requiring support for activities of daily living from an extra-familial source;
3. driving cessation;
4. loss of financial autonomy;
5. acute hospital admission;
6. change in caregiver;
7. relocation to new community-based accommodation;
8. relocation to long-term residential care; and
9. entry to palliative or end-of-life care.

These transitions were judged to be common, important, identifiable, and difficult for people with dementia, caregivers, and practitioners alike.

The Framework for Outcome Measurement⁽¹⁴⁾ provided the conceptual basis for the study. This was developed broadly from the International Classification of Functioning, Disability, and Health.^(15,16) Within the Framework, ‘functioning’ encompasses all body functions (e.g., memory), activities (i.e., what people can do) and social participation (i.e., what people actually do in their social context) in their ‘environment’ (i.e., the immediate physical and social environment of the person, as well as the formal and informal health and social structures, services and systems, and ‘personal’ factors including gender, race, age, morbidity, education or coping style). Each functional, activity-based, social and environmental component influences, and is influenced by, the mutual interactions that occur between them. We judged that such a relational and inclusive approach was important in understanding the subjective and nuanced experience of quality.

Research Question

Our study was designed to answer the following question: Through the course of the disease, are clinical and social variables associated with the perceived quality of transitions experienced by people with dementia and their caregivers?

METHODS

Study Design

We integrated a prospective longitudinal design with a cross-sectional aspect, to explore the transitions as they occurred. Longitudinal data were collected on cognitive function, depression, disability, and quality of life of the person with dementia. Among caregivers, we studied burden and quality of life. Social factors we explored included educational

attainment (a proxy for socioeconomic status), kinship, and living circumstances (live-in or live-out caregiver).

The study was conducted in three urban sites in Canada (Calgary, Edmonton, Ottawa), and was approved by the University of Calgary Conjoint Health Research Ethics Board, the University of Alberta Health Research Ethics Board, and the Common Research Ethics Board of the University of Ottawa.

Participants

Research assistants enrolled participants as person-with-dementia and their principal caregiver ‘dyads’, while they attended memory or geriatrics outpatient clinics or Alzheimer Society meetings in the three study centres. Persons with dementia were eligible for inclusion if they were aged 65 years or older; had received a diagnosis of Alzheimer’s disease, vascular dementia or mixed dementia; were not living in a nursing home; were able to complete the Montreal Cognitive Assessment instrument (MoCA)⁽¹⁷⁾ in English or French; were able to consent or assent to study participation; and had a primary caregiver who also consented to participate. Persons with dementia provided advanced consent for their continuing inclusion as their disease progressed. The status of their capacity to consent was reviewed by caregivers and research staff annually to ensure that their participation remained ethically and methodologically appropriate.

Participants were allowed to remain in the study if they missed a data collection point. Persons with dementia who moved into long-term care or were hospitalized were not interviewed, but their caregiver continued to provide information on their status whenever possible. In four cases a caregiver substitution took place during the course of the study. Since these substitutions were not associated with changes in the recorded health of those receiving care, data from the new caregivers were included in the analysis as though no substitutions had occurred.

Recruitment and Data Collection

A research coordinator in each centre was tasked with recruitment. In-person contacts were arranged with participants every six months for up to 24 months in order to derive repeated measures data and assess whether a transition of interest had occurred. The instruments we selected allowed for the assessment of a person with dementia’s clinical condition indirectly through their caregiver reporting on their behalf. During each cycle of data collection, caregivers were asked to report on their own condition and on that of their care recipient.

Instruments used to gather data about persons with dementia included the Cornell Scale for Depression in Dementia (CSDD) (19-item interview focusing on mood, behavioral disturbance, physical symptoms, cyclic functioning and ideation),⁽¹⁸⁾ the Quality of Life-Alzheimer’s Disease (QoL-AD) instrument (13 self- or interviewer- completed items

measuring physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self and overall life satisfaction),^(19,20) the Montreal Cognitive Assessment (MoCA) (10-minute screening tool for cognitive impairment covering short-term memory, executive functioning, attention, concentration, working memory, language, orientation to time and place),⁽¹⁷⁾ and the Disability Assessment for Dementia (DAD) (40 items investigating basic and instrumental activities of daily living).⁽²¹⁾

Instruments used to collect data about caregivers included the Caregiver Burden Inventory (CBI) (24 items relating to time-dependence burden, developmental burden, physical burden, social burden, emotional burden),⁽²²⁾ and the Euro-QoL Quality of Life Scale (EQ-5D) visual analogue section measuring general health status.⁽²³⁾

All measures used are well-known with established validity and reliability. Demographic variables were self-reported by participants. Categories of ethnicity were those used in the Canadian census, with participants asked to indicate the category with which they most strongly identified. In addition, every month each dyad was contacted by telephone and asked to describe in their own words any significant changes in status or circumstance in relation to the index transitions, using a structured, open-ended questionnaire. These data were used in assessing transition quality.

Data Processing

All data were transferred to the Department of Family Medicine at the University of Calgary, using secure electronic file transfer protocols including encryption and password-protection. A unique study number identified each person with dementia and caregiver.

In order to identify the ‘quality’ of the process associated with each of the transitions, an adjudication panel (LM, LG, KM, TX, ND) independently reviewed the text data that described the transition experiences of participants. In making these assessments, the judges were asked to consider a general question about whether the quality of each transition had been essentially “good” or “bad”, or whether they were “unable to decide”. This question was answered from two perspectives: that of the caregiver, and that of the investigators taking into account the interview data and their knowledge of the real-life circumstances, exigencies, and imperatives of the disease and the Canadian health system. We have designated this as the ‘summative’ transition quality outcome variable. In classifying transition quality, the judges relied on the explicit expressions of the participants in the transcripts, particularly responses to an open question about what participants thought or felt about the transition, while also taking into account the nature of transition process, systemic context, and the existential outcome. This created a composite variable summarizing the overall quality of the transition.

In making their judgments, the adjudicators invoked a fundamental aspect of naturalistic ethnography by attempting to understand the content, meaning, and relevance of the

transitions as those who directly experienced them understood them.^(24,25) At least three judges were allocated to rate each transition from each perspective, without knowledge of the ratings given by the other judges. In combining their individual judgments, a simple majority was accepted as definitive. In the event that no majority was arrived at, a fourth judge independently reviewed the transition in question, thus ensuring a majority.

Analysis

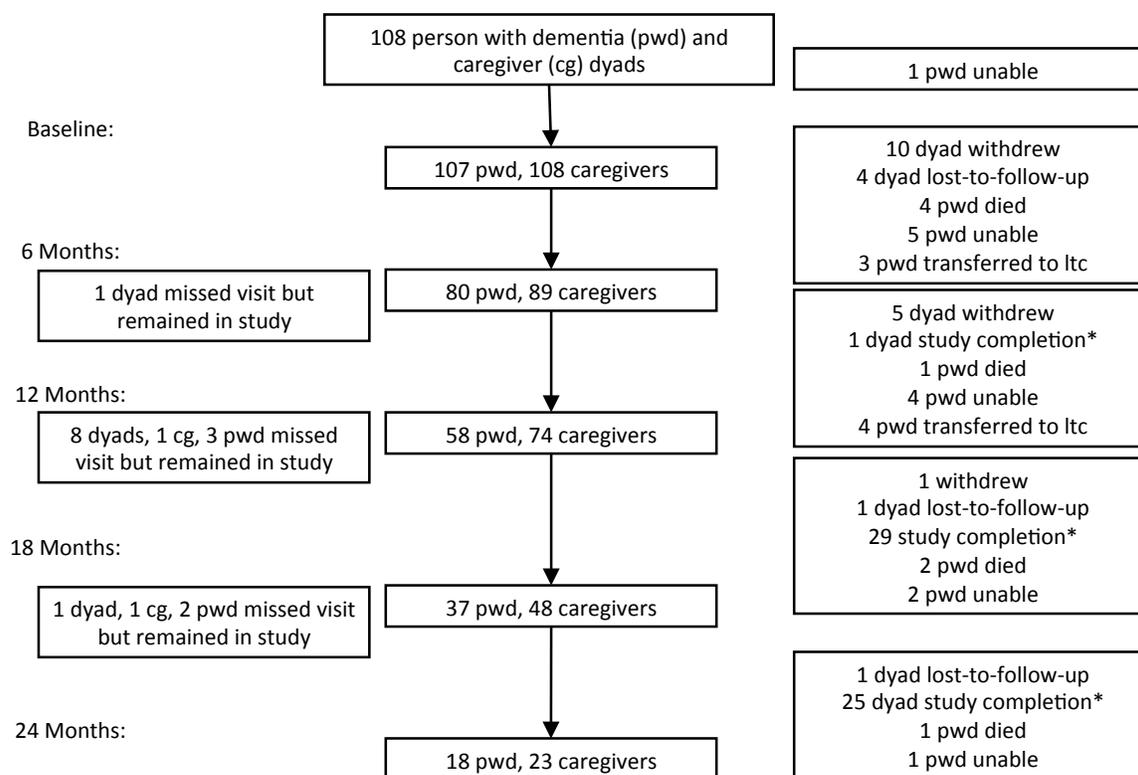
Associations between demographic characteristics or baseline health status and subsequent transition quality in those who had experienced transition were subjected to exploratory data analyses. To accommodate repeat transitions by the same dyads, generalized estimating equations (GEE) with a logit link and an exchangeable correlation were used to calculate odds ratios with 95% confidence intervals (CIs) for good transition quality. We used a GEE approach because a full likelihood-based solution using generalized linear mixed models was not available with our large number of clusters. Also, we were interested in population-averaged coefficients, and appreciated that the “robust” sandwich-type standard errors produced by a GEE model provide valid asymptotic confidence intervals even if the correlation structure specified in the model is not correct.

Because the number of events was low, only univariable analyses were performed. Separate analyses were carried out for caregivers, and the composite summative assessment. Analyses were done using Stata version 12.1 (StataCorp, College Station, TX, USA).

RESULTS & DISCUSSION

Attrition from the sample is described in Figure 1. 108 dyads were enrolled in the study at baseline. Of these, 90 experienced a total of 166 transitions during the two-year study period, (Mean = 0.92 transitions/dyad/year), of whom 87 patients experienced 157 transitions which could be judged as being “good” or “bad” based on the data available. Nine transitions either lacked data or the assessors were unable to make a judgment. Of these 87 dyads, 41 patients experienced only 1 transition type during the study period which could be judged good or bad. The other 46 dyads experienced between 2 and 5 transition types during the study period. In the four instances in which a dyad experienced the same transition on two occasions, we included only the first instance in the analysis. Supplementary Table S1 details the patterns of transition types experienced over the course of the study period (based on summative outcomes).

Table 1 shows the demographic characteristics of the overall sample of 108 dyads, and the characteristics of the analysis sample (n=87). Persons with dementia and caregivers were mainly female and most lived in their own homes. Most caregivers were either the spouses or adult children of



Note that caregivers are included if the person with dementia had withdrawn from the study.

FIGURE 1. Participant flow diagram

the persons with dementia, and cohabited with them. Caregivers reported higher educational attainment than persons with dementia. The sample most commonly identified itself as of Canadian ethnicity.

Outcome quality data were not present for every transition, nor from each perspective. Of the 157 transitions with a summative outcome (Table 2), 107 (68.2%) were judged as being “good”. Of the 149 transitions with caregiver-reported data, 111 transitions (74.5%) were judged to be “good”. Most transition types had more “good” quality transitions than bad. The exception to this was type 5, “acute hospital admission,” which had more negative than positive outcomes, particularly from the summative perspective.

Table 3 presents a univariable analysis of predictors of perceived transition quality. Good perceived transition quality was associated with persons with dementia having greater caregiver-reported quality of life based on both caregiver assessments and summative assessments (OR 1.11, 95% CI 1.05-1.18 per increase in unit score in QOL-AD based on summative assessment). It was also associated with higher competence in activities of daily living (OR 1.04, 95% CI 1.02-1.06 per increase in percent score based on summative assessment). Caregiver-perceived good transitions were associated with lower caregiver burden (OR 0.97, 95% CI 0.95-0.99 per unit CBI score increase), with this association being suggested by the summative assessments as well (OR 0.98, 95% CI 0.95-1.00 per unit CBI score increase).

The final analysis was to measure any association between a good outcome for transition 1 (diagnosis of dementia), and all subsequent transitions. There were 56 dyads that had an outcome for transition 1 and any other caregiver-reported transition outcomes. There were 59 dyads that had an outcome for transition 1 and any other summative transition outcomes. None of the associations were statistically significant (estimated ORs between 2.55 (95% CI 0.48-13.67; $p=.273$) and 3.23 (95% CI 0.64-16.44; $p=.157$)).

Interpretation

We collected health status data using valid instruments and experiential data using a standard questionnaire at points very close in time to the transitions themselves. Our sample of 157 transitions in 87 person-with-dementia/caregiver dyads is relatively large in relation to previous longitudinal research focused on care for people with dementia. While recognizing that the nature and impact of dementia-related transitions differ according to individuals and their circumstances, we believe that creating a more objective understanding of the predictors of perceived quality common to transitions is helpful, given their significance and frequency, and contributes substantively to the development of methods for estimating the outcomes of transitions in ways relevant to people with dementia and their caregivers in particular.

Our finding that, although most transitions were rated positively, acute hospital admission was rated poorly by caregivers and summatively is important, though the caregivers' assessments were less critical about the quality of the

transition than the summative ones were. This may reflect differences in expectations of care: caregivers' expectations may be low, but they may see themselves as benefiting anyway; professionals may expect a certain performance

TABLE 1.
Demographic characteristics and health risk factors of study sample^a

<i>Variable</i>	<i>Original Sample</i>		<i>Analysis Sample</i>	
	<i>Person With Dementia (N=108)</i>	<i>Caregiver (N=108)</i>	<i>Person with Dementia (N=87)</i>	<i>Caregiver (N=87)</i>
Age (year)				
Mean (SD)	79.9 (6.4)	63.3 (15.5)	80.2 (6.0)	63.9 (14.9)
Median (IQR)	80 (8.25)	65 (26.5)	80.0 (9.0)	65.0 (26.5)
Gender				
Male	48 (44.4)	33 (30.6)	37 (42.5)	25 (28.7)
Female	60 (55.6)	75 (69.4)	50 (57.5)	62 (71.3)
Residence				
Own home	92 (85.2)	104 (96.3)	71 (85.1)	83 (95.4)
Assisted/Supportive living	16 (14.8)	4 (3.7)	13 (14.9)	4 (4.6)
Caregiver relationship to person-with-dementia				
Spouse		54 (50.0)		44 (50.6)
Child		43 (39.8)		36 (41.4)
Sibling		4 (3.7)		4 (4.6)
Friend		1 (0.9)		0
Other		6 (5.6)		3 (3.4)
Caregiver living arrangement				
Live-in		75 (69.4)		57 (65.5)
Live-out		33 (30.6)		30 (34.5)
Education				
Elementary	18 (16.7)	3 (2.8)	13 (14.9)	2 (2.3)
Secondary	47 (43.5)	43 (39.8)	39 (44.8)	33 (37.9)
Post-secondary	43 (39.8)	62 (57.4)	35 (40.2)	52 (59.8)
Duration of dementia (year)				
Mean (SD)	1.00 (1.06)		0.88 (0.97)	
Median (IQR)	0.50 (0.83)		0.50 (0.75)	
Ethnic origin ^b				
Canadian	38 (35.2)	46 (42.6)	27 (31.0)	35 (40.2)
British	43 (39.8)	34 (31.5)	36 (41.4)	28 (32.2)
European	26 (24.1)	29 (26.9)	19 (21.8)	21 (24.1)
French	9 (8.3)	11 (10.2)	7 (8.0)	9 (10.3)
North American	4 (3.7)	2 (1.9)	3 (3.4)	1 (1.1)
Aboriginal	2 (1.9)	2 (1.9)	2 (2.3)	2 (2.3)
Other	5 (4.6)	4 (3.7)	3 (3.4)	2 (2.3)

^aData are presented as n(%), unless otherwise stated.

^bParticipants could cite more than one ethnic origin. Respondents recorded their ethnicity/cultural origin according to a closed list of alternatives based on StatsCan procedures.

SD = standard deviation; IQR = interquartile range.

TABLE 2.
Dementia transitions from perspective of caregiver and summatively

<i>Assessment Perspective: Transition\Transition Outcome</i>	<i>Caregiver (n=149)</i>		<i>Summative (n=157)</i>	
	<i>Good</i>	<i>Bad</i>	<i>Good</i>	<i>Bad</i>
1. problem identification	53	17	52	20
2. first requiring support for activities of daily living from an extra-familial source;	8	2	8	3
3. driving cessation;	3	2	6	1
4. loss of financial autonomy;	14	2	12	5
5. acute hospital admission;	10	11	6	15
6. change in caregiver;	3	0	3	0
7. relocation to new community-based accommodation;	11	0	12	0
8. relocation to long-term residential care;	5	3	4	5
9. entry to an end-of-life care program	4	1	4	1
<i>Total (%)</i>	111 (74.5)	38 (25.5)	107 (68.2)	50 (31.8)

standard, but had no personal stake in the actual event. Dementia is an important risk factor for patients being assigned to alternate level of care beds or to inappropriate occupation of beds in acute care.⁽²⁶⁾ Poor admission experiences suggest gaps relating both to the provision of care^(27,28,29) and to patient and caregiver engagement in policy developed for it, with particular implications for quality of life, activities of daily living, and burden. They imply that pragmatic screening for dementia should be undertaken at the very beginning of the admission process for older patients, and that the approach to managing admission should recognize and respond to the vulnerability of those who are cognitively challenged. In practice, this might involve simply asking caregivers whether the person being admitted has symptoms of dementia and, if so, allowing more time for admission processes. Identifying caregivers (and patients, whenever feasible) as members of the care-providing team may be a crucial resource if it enables prevention of acute hospital admission. Preventing admission in people with dementia should be a priority in its own right.

Our study found evidence that better baseline competence in activities of daily living and quality of life in persons with dementia was associated with better perceived transition quality. Higher caregiver burden was associated with perceived poorer transition quality, as reported by caregivers only. People with dementia who have worse prior experience on these dimensions require careful attention, particularly in primary care settings, in preparing and supporting them before, during, and after common and predictable transitions throughout the course of the disease.

In practice, activities of daily living and quality of life may be estimated through regular use of brief, validated instruments like the EQ-5D⁽²³⁾ or the DAD.⁽²¹⁾ If formal assessment is considered infeasible, primary care providers might at least enquire of people with dementia and their caregivers about experiences of activities of daily living and their quality of life during the course of routine consultations. Clinical experience

suggests that, if the person with dementia is attending with their caregiver, often the latter will not fully disclose burden upon themselves. Acquiring these data from caregivers may require direct personal conversation, probably by telephone. However obtained, such questioning may provide important insight leading to improvement in the quality of transition outcomes.

The distinction between cognitive determinants (which were not associated with transition quality) and functional determinants (which were), may be important in that it reinforces understanding that functional challenges are more easily recognized in people with dementia than cognitive ones, and that functional capacity has a stronger self-reported influence on “life satisfaction” in seniors than cognition.⁽³⁰⁾ Hence, providers should pay close attention to activities of daily living as being predictive of caregiver burden and poorer patient experience in general. Training and support for managing dementia-related transitions is important for professionals and caregivers alike. Recent work exploring contemporary research priorities among patients and caregivers supports an integrated, team-based, person-oriented approach.⁽³¹⁾

Study limitations included loss to follow-up (see Figure 1) and a relatively short observational window of 24 months. Most of the instances of loss to follow-up (51%) derive from the completion of the study, and may thus be considered random events and not a source of bias. Attrition due to ‘active’ withdrawal (15%), death (7%), incapacitation (12%), or to unexplained loss of contact (6%) are indicative of the difficulty associated with conducting research in such a highly vulnerable population. Although every dyad in our study had experienced the dementia onset transition, data about that experience was available from 87 dyads only. Recruitment to the study was made from outpatient clinics and the Alzheimer Society, and the resulting sample may be skewed away from people with dementia managed entirely in primary care. Hence, our sample was probably later in the disease trajectory than those being managed entirely in primary care. We

TABLE 3.
Predictors of transition outcome quality adjudicated by caregivers and summatively, univariable analyses using GEE

Variable	Caregiver Assessment N=148		Summative Assessment N=157	
	Estimated OR of good transition outcome quality (95% CI)	p-value	Estimated OR of good transition outcome quality (95% CI)	p-value
PWD age (year)	1.01 (0.95-1.08)	0.685	1.00 (0.94-1.06)	0.945
Caregiver age (year)	1.01 (0.98-1.04)	0.511	1.00 (0.98-1.03)	0.748
PWD female (vs. male)	1.25 (0.57-2.76)	0.575	0.97 (0.46-2.07)	0.947
Caregiver female (vs. male)	0.40 (0.15-1.08)	0.071	0.63 (0.27-1.47)	0.284
PWD in assisted or supportive living (vs. own home)	0.48 (0.17-1.40)	0.182	0.40 (0.14-1.14)	0.086
Caregiver in assisted or supportive living (vs. own home)	0.77 (0.13-4.53)	0.772	0.57 (0.11-3.10)	0.519
Caregiver is offspring (vs. spouse)	1.62 (0.70-3.75)	0.258	1.05 (0.48-2.32)	0.896
Caregiver is sibling/ friend/ other (vs. spouse)	0.67 (0.14-3.17)	0.615	0.83 (0.22-3.08)	0.777
Caregiver lives-out (vs. lives-in)	1.33 (0.57-3.09)	0.507	1.10 (0.50-2.39)	0.816
PWD post-secondary education (vs. elementary or secondary)	0.54 (0.24-1.20)	0.129	0.54 (0.26-1.13)	0.103
Caregiver post-secondary education (vs. elementary or secondary)	0.79 (0.35-1.79)	0.576	0.87 (0.41-1.86)	0.727
PWD Canadian origin (vs. non-Canadian)	1.50 (0.61-3.68)	0.372	1.88 (0.81-4.37)	0.138
Caregiver Canadian origin (vs. non-Canadian)	1.14 (0.50-2.56)	0.758	1.40 (0.65-3.03)	0.391
Duration of dementia	0.88 (0.60-1.29)	0.511	0.99 (0.67-1.46)	0.963
Baseline assessments:				
QOL-AD, caregiver reported ^a	1.08 (1.02-1.14)	0.012	1.11 (1.05-1.18)	0.001
QOL-AD, PWD reported ^a	1.06 (0.98-1.15)	0.178	1.08 (1.00-1.17)	0.059
MoCA ^a	1.01 (0.94-1.08)	0.907	1.01 (0.95-1.08)	0.710
DAD ^a	1.03 (1.01-1.05)	0.004	1.04 (1.02-1.06)	<0.001
CSDD caregiver reported ^a	0.95 (0.89-1.01)	0.080	0.96 (0.91-1.02)	0.187
CSDD PWD reported ^a	1.03 (0.93-1.13)	0.597	1.03 (0.94-1.13)	0.525
EQ5D ^b	1.05 (0.82-1.34)	0.701	1.13 (0.90-1.43)	0.292
CBI ^a	0.97 (0.95-0.99)	0.029	0.98 (0.95-1.00)	0.055

^aEstimated ORs are per unit change from baseline score.

^bEstimated ORs are per increase in 0.1 from baseline score.

GEE =generalized estimating equations; PWD = person with dementia; QOL-AD = Quality of Life–Alzheimer Disease; MoCA = Montreal Cognitive Assessment; DAD = Disability Assessment for Dementia; CSDD = Cornell Scale for Depression in Dementia; EQ5D = EuroQoL Quality of Life Scale; CBI = Caregiver Burden Inventory.

were unable to account for cultural determinants on perceptions of quality, and the influence of urban and rural place of residence on transition quality, nor did we include the onset of behavioural and psychosis-related symptoms associated with dementia, nor the impact of caregiver health status as a modifier of their perception of transition outcome. Future research may address these issues.

Our data on ethnicity is problematic in that self-description as ‘Canadian’ may mask a number of social, cultural, linguistic or racial experiences. Lower representation from those of non-Canadian ethnicity may reflect lower rates of access to dementia services due to stigma, misinformation regarding a diagnosis of dementia, or lower health literacy.

In developing a composite outcome variable which conflated transition process and transition outcome we sought to resolve the paradox that objectively excellent transition processes may be associated with poor subjective outcomes due to factors not associated with process at all. It also reflected the holistic approach encapsulated in the International Classification of Functioning. Use of such a variable introduces risk of bias into the analysis, though the use of an adjudication panel blinded to the judgments of colleagues mitigates the risk. Being developmental in terms of methodology, we chose to apply a categorical, rather than a continuous, scale to assess the quality of transition outcomes because our sample size was somewhat limited and for the sake of conceptual simplicity. Given the inclusion of multiple comparisons, our

analyses are at some risk for type I error. All reported statistically significant results were associated with p-values of less than .05, but we acknowledge that some of these associations may still derive by chance. Inevitable resource constraints led to the study being unpowered for comparatively rare events, like death.

Overall, we believe the pragmatic characteristics of our study strengthen its utility by locating it firmly in real-world clinical and lay contexts. It may be that variables other than those we chose to study are predictive among a similar sample of participants. For example, ‘resilience’ in caregivers has been shown to be associated with less frequent nursing home placement.⁽¹⁰⁾

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CONFLICT OF INTEREST DISCLOSURES

The author declares that no conflicts of interest exist.

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SUPPLEMENTARY MATERIALS

Table S1. Patterns of transition types experienced (using summary data) (N = 87)

<i>I</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>	<i>8</i>	<i>9</i>	Number of Transition Types	Number of Dyads
Problem Identification	ADL Support	Driving Cessation	Financial Autonomy	Acute Admission	Caregiver Change	Community Relocation	LTC Entry	End of Life Care		
X									1	33
X	X			X					2	6
X			X						2	4
X						X			2	4
X	X						X		3	3
X	X								2	3
X	X	X							2	3
X	X		X						3	2
X			X	X					3	2
X			X			X			3	2
X				X				X	2	2
			X				X		2	2
				X					1	2
						X			1	2
X				X					5	1
X	X				X		X		3	1
X		X			X				3	1
X		X	X						3	1
X				X		X			3	1
X				X			X		3	1
X				X				X	3	1
X				X				X	3	1
X	X		X			X			3	1
X			X				X		2	1
X	X		X						2	1
X			X	X					2	1
X			X	X				X	2	1
X				X					1	1
X				X	X				1	1
X							X		1	1
X									1	1
X					X				1	1
X							X		1	1