

RESEARCH ARTICLE

DementiaNet facilitates a sustainable transition toward integrated primary dementia care: A long-term evaluation

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Abstract

INTRODUCTION: Care integration is a promising strategy to achieve sustainable health-care systems. With DementiaNet, a 2-year program, we facilitated collaboration between primary health-care professionals. We studied changes in primary dementia care integration during and after DementiaNet participation.

METHODS: A longitudinal follow-up study was performed. Networks started between 2015 and 2020; follow-up ended in 2021. Quantitative and qualitative data were collected annually to assess quality of care, network collaboration, and number of crisis admissions. Growth modeling was used to identify changes over time.

RESULTS: Thirty-five primary care networks participated. Network collaboration and quality of care of newly formed networks increased significantly in the first 2 years (respectively, 0.35/year, $P < .001$; 0.29/year, $P < .001$) and thereafter stabilized.

CONCLUSION: Primary care networks improved their collaboration and quality of care during DementiaNet participation, which persisted after the program ended. This indicates that DementiaNet facilitated a sustainable transition toward integrated primary dementia care.

KEYWORDS

dementia, integrated care, networks

1 | INTRODUCTION

Providing dementia care in the home setting is complex and requires the involvement of many different primary health-care professionals.¹ Primary care could benefit from care integration across disciplines. Care integration is a continuum of care and support provided by professionals. However, health-care professionals rarely structure their collaboration, because they are employed in different organizations

and focused on their own discipline.^{2–4} Additionally, they experience an increased workload that will increase due to a shortage of staff. This leads to poor continuity of care and low satisfaction with the provided care among professionals, persons with dementia, and their informal caregivers.^{5,6} This care fragmentation and inability to provide coordinated timely support may also contribute to the increasing number of impactful and costly crisis admissions of persons with dementia to hospitals or nursing homes.^{7,8}

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Improving interprofessional collaboration and coordination of primary care can contribute to a more sustainable health-care system delivering high-quality care and being able to cope with this expected rising care demand.^{9–12} It can improve quality of life of persons with dementia, reduce caregiver burden, and lead to more satisfaction among professionals.^{10,13} However, as integrated care is an emergent and dynamic property of a complex system of the professionals and services involved that is at the same time inseparable from context,¹⁴ designing an effective improvement program remains challenging. Consequently, earlier programs designed to implement integrated care in the dementia care setting did not lead to improvements in collaboration or patient outcomes.^{1,15–17} Current health-care systems thus seem to be far away from strategies that ensure a sustainable transition toward more integrated primary care.

We therefore designed the DementiaNet program, a network-based approach focusing on improving interprofessional collaboration by facilitating network development of medical-, care-, and welfare professionals in primary care.¹⁸ A short-term evaluation study with a small number of networks already showed positive results regarding collaboration, quality of care, and satisfaction of health-care professionals.^{13,19} Currently, networks have been followed up to 6 years, several years after the 2-year support program had ended. This enables study of sustainability of the DementiaNet program. Therefore, our aim is to evaluate the long-term development of quality of primary dementia care, network collaboration, and number of crisis admissions in networks during and after their participation in the DementiaNet program.

2 | METHODS

2.1 | Study design

A longitudinal follow-up study was performed. Networks started between 2015 and 2020, and consequently follow-up of the networks varied between 1 and 6 years. This approach mimics an interrupting time-series analysis that can point at causality by close correlation of the intervention and aimed outcome changes. We chose this design over a randomized controlled trial (RCT) for the following reason. In the Dutch health-care system, the care for people with dementia living at home is in constant health-care system-based transition, which made it impossible to select regions and communities where “care as usual” would stay unchanged, with controlled conditions for intervention and data collection within the 6-year timeframe for which the data collection was planned. The study protocol was reviewed by the local ethical committee, and they declared that formal judgment was not required according to the Dutch law (protocol number: 2019-5599).

2.2 | Study population and setting

Networks were all composed of primary care professionals in the Dutch primary dementia care setting (Appendix A in supporting infor-

RESEARCH IN CONTEXT

- 1. Systematic Review:** Integrated care is an emergent and dynamic property of a complex system of the professionals and services involved that is at the same time inseparable from context. Literature shows that designing an effective improvement program remains challenging. Consequently, earlier programs designed to implement integrated care in the dementia care setting did not lead to improvements in collaboration or patient outcomes.
- 2. Interpretation:** The DementiaNet program improved collaboration and quality of care, which persisted after the DementiaNet development program ended indicating that the program facilitates a sustainable transition toward integrated primary dementia care.
- 3. Future Directions:** Future studies should focus on identifying the effects of network-based care on the prevention of crises, other outcomes relevant to patients and caregivers, and on cost effectiveness. Organizational and financial reforms should be stimulated to achieve a sustainable transition to network-based care.

mation). Participation in the DementiaNet program was voluntary and we actively recruited professionals that wanted to form a local network. New and existing local collaborations of primary care professionals with a shared caseload of dementia patients could join. Most of the networks had between 10 and 35 shared patients. Network composition was based on local preferences and availability of professionals and therefore networks could differ in size, represented disciplines, and level of pre-existing collaboration. We stimulated the networks to include at least one professional of the medical (e.g., general practitioner), care (e.g., community nurse), and social discipline (e.g., social worker). All participating networks were located in the east of the Netherlands.

2.3 | DementiaNet program

The DementiaNet program was developed to facilitate a transition toward integrated care using a network-based approach based on the collaboration theory of Kaats and Opheij.^{18,20} This stepwise, bottom-up program consisted of four key elements to support networks to become self-organizing, sustainable, and interprofessional collaboratives.¹⁸ First, a network had to be formed with professionals in the community who were willing to invest in achieving structured, interprofessional collaboration and continuity of care. Second, one or two of the network participants were appointed as network leaders. Third, networks were trained in applying quality improvement cycles, using their yearly collected data for quality improvement plans.^{21,22} Fourth, networks were invited to engage in interprofessional education

about self-selected topics. Networks received support on these key elements of the DementiaNet program during a period of 2 years. This support was tailored to the specific contexts and needs of the networks.¹⁸ These networks decided upon their meeting frequency, but they were stimulated to plan at least three meetings per year.

2.4 | Measurements and data collection

Networks started between January 2015 and March 2020 with the DementiaNet program. Data on network collaboration, quality of care, crisis situations, and network characteristics were collected yearly between January 2015 and December 2021.

2.4.1 | Network collaboration

To assess network collaboration in primary dementia care, no validated instruments were available when this study started. We therefore developed a mixed-method measurement approach²³: we quantitatively rated network maturity in transcripts of yearly semi-structured interviews on a scale of 1 to 4 based on the eight domains of the Rainbow Model of Integrated Care (RMIC).^{21,24}

These yearly semi-structured, face-to-face interviews with the network leader(s) were conducted by trained researchers (IM or DO). They used a topic list based on the eight domains of the RMIC: person-focused care, population-focused care, clinical integration, professional integration, organizational integration, system integration, functional integration, and normative integration²⁴ (Appendix B in supporting information). The first interview took place after 12 months, combining baseline (T0) and 12 month (T1) information on network collaboration. Interviews were audio recorded, varied in length between 20 and 60 minutes, and were transcribed verbatim. Prior to the interview, network leaders gave written informed consent.

The qualitative information in the transcripts was quantified by rating the eight domains of the RMIC²⁴ on four predefined network maturity levels: 1 = ad hoc, 2 = defined, 3 = controlled, and 4 = synchronized collaboration²⁵ (Table 1). Scores ranged from 1 to 4 (including half points) and a higher score indicated higher maturity. To minimize information bias, two researchers (DO and AH or ST) independently and blindly rated the interviews using an extensive protocol (available upon request). In case of disagreement, discussion led to consensus. After two thirds of the interviews, the second researcher only checked the ratings of the first researcher.

2.4.2 | Quality of care and crises

Data on quality of care and crisis situations was self-reported based on the general practitioner (GP)'s electronic medical record and was assessed yearly using a registration file filled in by the network leader(s) for their shared caseload of dementia patients. A researcher (DO, AR) was available to assist with data collection. Quality of care

indicators were (1) case manager appointed, (2) diagnosis in primary care, (3) discussed during multidisciplinary meeting, and (4) pharmacotherapeutic meeting during the last 12 months; these measures were scored absent (= 0) or present (= 1). We defined a crisis situation as an acute (needed within 24 hours) consultation or admission to a hospital or nursing home. The total number of crisis situations per patient in the last 12 months was collected.

2.4.3 | Logs and network characteristics

Network characteristics, including network composition at start and end, (changes in) network leader were recorded by the researchers in a log file. These data were also used for the background characteristics of the networks.

2.5 | Analysis

For the network maturity score per network per timepoint, the average score of the eight RMIC domains (score range from 1 = ad hoc, to 4 = structured) was calculated for each network separately.

For quality of care, an average score per network per indicator per timepoint was calculated (score between 0 and 1) using patient data. Thereafter, a sum score per network was calculated by summing up the scores for the indicators case manager, primary care diagnosis, multidisciplinary meeting, and pharmacotherapeutic meeting (range 0 to 4).

2.5.1 | Growth model

A growth model was used to analyze the effects of the DementiaNet program on network maturity, quality of care, and crisis situations over the course of the follow-up, while simultaneously accounting for repeated measures within networks and missing data. For all outcome measures, we first identified whether a linear, quadratic, or spline unconditional growth model best fitted the data to explain the within-network changes over time. We identified if a random intercept and random slope improved the model. Next, we added one-by-one potential predictors to the model and assessed whether this significantly ($\alpha < 0.05$) explained the between-network variance in the random effects. We included relevant factors, based on previous research¹³ collected via logs: already established collaboration before the start with DementiaNet, discontinuity in network leader(s), and the number of network members at start. We used R version 4.1.3 for all analyses.

3 | RESULTS

Forty-four networks started with the DementiaNet program between January 2015 and March 2020. Nine networks ceased active participation within the first year. Reasons were either lack of intrinsic

TABLE 1 Levels of network collaboration.

Level	Collaboration	Description
1	Ad hoc	The network works from its primary, clinical, and basis care tasks. Most professionals work monodisciplinary and only ad hoc collaboration takes place with other professionals. The organization focuses on the individual patients.
2	Defined	Several professionals in the network start making work arrangements. The collaboration between professionals is mostly based on informal, still new contacts and is not yet structured. The network focuses on the individual patients and the organization focuses more on the population-based care.
3	Controlled	Collaboration is more formalized and the network works with uniform processes, procedures, and systems around the frail older adults with dementia. The professionals in the network share information and work structurally together to improve population health.
4	Synchronized collaboration	The network is fully integrated in the local context. The organization level has included partners from the local context to optimize population health. Systems and processes are internally and externally embedded. Together the triple aim goal is being realized.

TABLE 2 Baseline characteristics of the DementiaNet primary dementia care networks.

	No collaboration before start (networks = 29)	Pre-existing collaboration before start (networks = 6)
Median number of professionals at start, n (range)	10 (4 - 17)	7 (6 - 22)
Median number of professionals at end, n (range)	10 (4 - 25)	7 (5 - 41)
Number of networks with active general practitioner at start, n (%)	23 (79%)	6 (100%)
Number of networks with welfare professional involved, n (%)	18 (62%)	4 (67%)

motivation, lack of time, or a vacancy for network leadership resulting in insufficient momentum for a transition process. Some networks have delayed or missing data on one (or more) timepoint(s) due to factors including COVID-19 and lack of time.

We followed 35 networks longitudinally for a period of 1 to 6 years with a median of 3 years (interquartile range: 2 to 5). Networks without a collaboration before start had a median of 10 professionals and networks with a pre-existing collaboration a median of 7 professionals (range 3 to 41). The number of disciplines involved in the networks ranged between 3 and 16. The majority of the networks included a GP, practice nurse, community nurse, and case manager. Sixty-three percent of the networks had a welfare worker (Table 2 and Appendix C in supporting information).

3.1 | Network collaboration

To determine the change in network collaboration over time, we first identified the unconditional spline growth model (Appendix D: model 1, graph and Appendix E in supporting information). The best fitted model contained two linear splines representing linearly improving scores in

the first 2 years and a more or less stable score trajectory after 2 years (Appendix D model 2 and 3).

We found a large negative correlation between random intercept and random linear slope for network maturity score, meaning networks with a higher network maturity score at start tend to show less increase in network maturity score (model 1). This correlation is smaller in model 2 and 3 after we adjusted for pre-existing collaboration, implying that, as expected, networks with an already existing collaboration could only achieve limited improvement in their collaboration.

Networks without a collaboration before start significantly improved their collaboration in the first 2 years, thus during participation in the DementiaNet program, with 0.35 ($P < .001$) per year (Figure 1 and Model 3 in Appendix D). Networks with an existing collaboration also significantly improved their collaboration with 0.17 network maturity points ($P = .03$), but over the first 2 years, this increase was significantly lower than networks without a pre-existing collaboration (0.36, $P = .027$). Larger networks showed higher increase in network maturity scores (0.009 per extra network partner, $P = .03$) than smaller networks. After 2 years when the program had ended, a stabilization was found for both newly formed networks (0.043 difference in network maturity per year, $P = .251$) and networks with

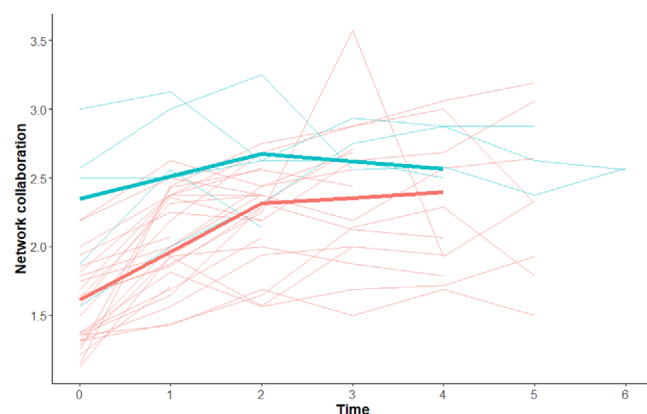


FIGURE 1 Graph of the network maturity score over time of the DementiaNet networks (model 3). Red lines indicate networks without pre-existing collaboration and blue lines indicate pre-existing collaboration. Bold lines indicate the mean.

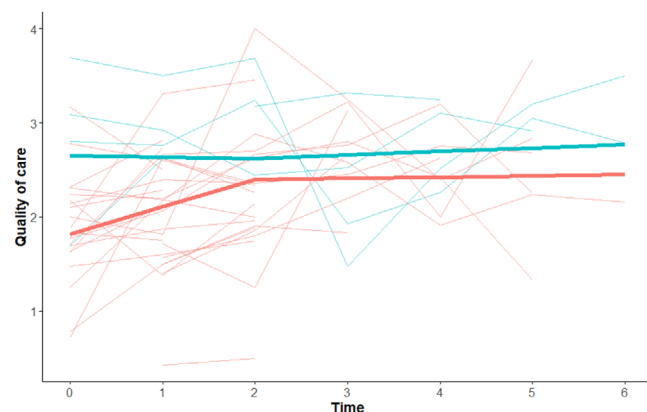


FIGURE 2 Graph of the quality of care over time of the DementiaNet network (model 3). Red lines indicate networks without pre-existing collaboration and blue lines indicate pre-existing collaboration. Bold lines indicate the mean.

an existing collaboration before start (-0.056 difference in network maturity per year, $P = .306$).

3.2 | Quality of care

For quality of care, we first identified the unconditional spline growth model (Appendix F: model 1, graph and Appendix G in supporting information). The best fitted model contained two linear splines (Appendix F model 2 and 3) and a random intercept.

Networks without a collaboration before start ($n = 4$) that enrolled in the DementiaNet program significantly improved their quality of care in the first 2 years with 0.29 ($P < .001$) per year (Figure 2 and Model 3 in Appendix F). After the 2 years, a stabilization occurred (0.014 , $P = .084$). Networks starting with already existing collaboration did not significantly increase their quality of care in the first 2 years (-0.017 , $P = .92$), nor in the period after the program had ended (0.04 , $P = .68$).

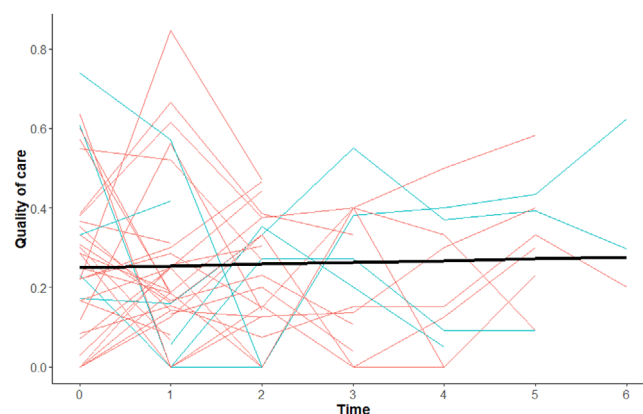


FIGURE 3 Graph of the crisis situations over time of the DementiaNet networks. Red lines indicate networks without pre-existing collaboration and blue lines indicate pre-existing collaboration. Black line indicates the mean.

3.3 | Crisis

For crisis situations, we first identified the unconditional growth model. No significant effects of time were found. The number of persons with a crisis situation appears to be stable over time; per year around 25% of the caseload had one or more crisis situations (Figure 3).

4 | DISCUSSION

Primary care networks participating in the DementiaNet program improved their network collaboration and modestly enhanced quality of primary dementia care. These improvements were mainly seen during the first 2 years when the networks received support, and specifically went for networks without pre-existing collaboration. Changes persisted after the network development program ended, even up to 6 years. These results imply that the DementiaNet program led to a successful transition to more integrated primary dementia care. The number of crisis situations did not change over time.

The short-term benefits of the DementiaNet program, previously found in 13 networks,¹³ could be replicated in our larger sample and sustained several years after the program ended. In networks with a pre-existing collaboration, quality of care did not increase during the study period. As their number was small, analyses in this subgroup were likely underpowered.

These mainly positive findings may be attributed to the multifaceted nature of the program, which contrasts with previously described programs that focused primarily on interprofessional education or case management and showed less favorable results regarding implementation and sustainability of improvement.^{26,27} Our sustainable outcomes may also result from our focus on transition instead of quick implementation, by designing a 2-year facilitation program. Implementation periods and follow-up are usually too short to establish and assess the effects of interprofessional collaboration.^{3,15,28–30} Time for this tran-

sition is needed for network members to get to know each other and build trust.^{19,31}

Stabilization of network maturity levels after 2 years suggests that a certain level of network maturity is sufficient to maintain active collaboration and gain quality of care. Networks improved their network maturity from ad hoc to a defined or controlled level, which is a relevant increase to more structural collaboration. This is concordant with critical transition theories that state that the likelihood change will sustain increases when a so-called tipping point is reached.³² Networks did not reach the maximum score of 4. This is likely due to the fact that local networks cannot achieve total integration by themselves, as integration on the organizational and system level (policy level) is partially beyond their influence.³³

Even though network collaboration increased, the occurrence of crisis situations in our networks did not change, whereas previous studies found a reduction in the number of emergency room visits in older persons as a result of collaboration.^{34,35} The absence of similar findings may be explained as follows. As dementia care and crisis events are complex, many context-specific variables influence their occurrence. The total number of crisis situations in the dementia population has increased the past years^{36,37} especially during the COVID-19 pandemic. The stable number of crisis events in our study may, in absence of a control group, thus be a positive result. Last, we used self-reporting data of crisis as an outcome instead of defining it as specific as an admission.

4.1 | Strengths and weaknesses

The key strength of this study is its extensive follow-up period of up to 6 years, needed to investigate the sustainability of integrated care implementation by our 2-year DementiaNet program. The within-network comparisons in multiple complex network contexts allowed us to describe and analyze the process of transition facilitated by our multi-faceted and long-term DementiaNet program. It enabled us to make a reasonable case for the positive effects of the program despite the lack of a control group. In this design, we were also able to incorporate the complex circumstances and the long time needed to induce change, which complicate traditional evaluation methods such as RCTs. Moreover, this study design gave insight in and incorporated the large variation during the network development (graph 1 and 2) that an RCT could not have accounted for.

The study has the following limitations. First, despite the advantages of our study design, the lack of a control group hinders firm conclusions on the effectiveness of the DementiaNet program. The lack of a control group may also have led to an overestimation of the outcomes caused by the Hawthorne effect. However, after 8 weeks such effects have usually diminished. Because we followed our networks for 2 to 6 years, it is unlikely that this phenomenon created substantial bias in the context of our study. Second, no validated tool was available to measure network collaboration. As our self-developed method was based on a validated theoretical framework, included independent ratings, and showed consistent changes over time, it is likely that we

were able to measure network maturity as intended. However, it is a limitation that this method only represented the perspectives of the network leaders. Third, validity of the data may have suffered from self-reporting of quality of care and crisis data by professionals. However, stricter protocolization or control of data collection could be considered an intervention on its own and would limit feasibility of broader implementation. Moreover, as networks were their own controls over time (with in-network changes) we were probably able to measure change over time even if they made consistent self-reporting mistakes. Fourth, the COVID-19 pandemic hampered data acquisition in the last 2 years of follow-up resulting in more missing data or larger time intervals between data points. The positive influence of the program might have been underestimated as COVID-19 negatively affected network development: it hindered physical network meetings, such as multidisciplinary meetings. These meetings are essential to get to know each other and build trust.¹⁹ Last, we experienced a drop-out of nine networks. This was due to network factors, for example, no network leader present or not the right momentum for change. It emphasized that the program was only applicable in networks with highly motivated professionals. The fact that our results are based on such a population of early adopters and thus suffers from volunteers' bias, negatively influences the external validity of the results, but is an adequate way to initiate transition toward new health models.

4.2 | Implications for research and practice

This study showed that the DementiaNet facilitates a first step toward the quadruple aim of improving patients' experiences and health, population health and work satisfaction, and reducing costs.^{10,38} Population health improved as we found improvements in collaboration and quality of care improvements, which are likely to have positively impacted work satisfaction.¹³ Identifying patients' and caregivers' experiences in this context is challenging, because they find it difficult to reflect on changes in care they receive. Possible relevant outcomes are caregiver perseverance time or number of crisis situations. A cost-effectiveness study, with a focus on hospital versus primary care costs, could further support the evidence-based and wide-spread implementation of the program. Previous studies on the cost effectiveness of integrated care were of low quality and outcomes were mixed.^{39–44} We therefore conducted a study with insurance company data, comparing admission risks and health-care use of roughly 500 DementiaNet patients to a large matched control group of non-DementiaNet patients in the Netherlands, which was recently submitted for publication. Further exploring the program's impact on work satisfaction is highly relevant in light of the growing shortage of health-care professionals.

The DementiaNet program was developed to include a variety of primary care professionals. In this study, mainly GPs, practice nurses, case managers, and district nurses participated. Future implementation strategies may specifically focus on including additional professionals such as allied health professionals and citizen services officers.

This study's outcomes support large-scale implementation of the DementiaNet program, as it is currently the best available strategy to implement value-based dementia care across the Netherlands. This is enforced by the program's tailor-made approach and generalist elements, which make it applicable to a broad variety of contexts and health-care systems nationally and internationally and to multiple target groups and chronic diseases. We already successfully applied the DementiaNet program in primary care for vulnerable older persons. Large-scale implementation in the Netherlands, however, requires a transition in primary care reimbursement. Currently, activities not directly linked to patients, such as interprofessional meetings, are excluded from reimbursement, resulting in only the intrinsically motivated professionals taking up these tasks. Instead, health-care payers should develop more structural funding for key elements of integrated care programs.^{10,30,44} Changes at the policy level regarding care reimbursement are needed to facilitate this new, network-based way of working.^{44,45}

5 | CONCLUSION

Primary care networks substantially improved their network collaboration and modestly enhanced the quality of their primary dementia care during participation in the DementiaNet program. Newly formed networks benefitted more during the first 2 years of the program than those with a pre-existing collaboration at the start. After the ending of the 2-year program, improvements of care integration and quality of care stabilized, meaning the DementiaNet program has likely facilitated a sustainable transition to integrated primary dementia care. The number of crisis situations did not change during program participation. Future studies should focus on identifying the effects of network-based care on the occurrence of crises, other outcomes relevant to patients and caregivers, and on cost effectiveness. Organizational and financial reforms should be stimulated to support a sustainable transition to network-based care.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare. Author disclosures are available in the [supporting information](#)

CONSENT STATEMENT

As all data of human subjects were collected anonymously, consent was not obligatory according to Radboudumc ethical committee.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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