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Nurses' support needs in providing high-quality palliative care to persons with dementia in the hospital setting: A cross-sectional survey study

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Abstract

Background: Since dementia is an irreversible progressive disease characterized by a decline in mental functions and overall health, a palliative care approach is recommended. Nevertheless, many persons with dementia experience burdensome hospitalizations in end-of-life care. Their quality of life during hospitalization can be improved by palliative nursing care that suits their fragile health.

Aim: To explore hospital nurses' perceived support needs while providing high-quality palliative care for persons with dementia and to identify differences between nurses in different ward types and at different educational levels.

Design: Cross-sectional, multicenter survey study.

Method: Between January 2021 and April 2021, a convenience sample of Dutch hospital nurses received a web-based questionnaire on the topics of palliative caregiving, communication, collaboration, and hospital admissions. The data were analyzed using descriptive statistics.

Results: The survey was completed by 235 nurses. The most frequently endorsed support needs were "communicating with persons with severe dementia" (58.3%), "appointing a permanent contact person in the care for persons with dementia" (53.6%), and "dealing with family disagreement in end-of-life care" (53.2%). If nurses had more time to provide care, 66.4% of them would prioritize providing personal attention. Most support needs identified by nurses were similar.

Conclusion: A heterogeneous group of nurses demonstrates overall similar support needs in providing palliative care for persons with dementia and their families in the hospital setting.

Clinical Relevance: Nursing practices should implement dementia-friendly interventions to improve the quality of dementia care in the hospital.

KEYWORDS
dementia, hospitals, nursing, palliative care, supporting needs assessment

INTRODUCTION

Dementia is a progressive irreversible disease characterized by the decline of cognitive functions such as memory, language, and orientation (World Health Organization, 2019). Although a palliative care approach is recommended for persons with dementia, many persons with dementia experience burdensome hospitalizations in end-of-life care (Lopez et al., 2017). Hospitalizations are often confusing for persons with dementia, as normal daily structures are disrupted. This disruption may lead to problems with following treatment advice and restlessness in persons with dementia. The most common reasons for hospitalization of persons with dementia are pneumonia, cardiovascular events, and dementia-related conditions such as dehydration (Ma et al., 2019). Persons with dementia have a greater risk of health deterioration and dying during hospitalization compared to persons without dementia (Moon et al., 2018). Between 2008 and 2018, 11.6% of all deaths among persons with dementia in the Netherlands occurred in a hospital setting (Joling et al., 2020). From the moment of diagnosis, a palliative care approach should be introduced in the care of persons with dementia and their families. Early adoption of palliative care may enhance quality of life, reduce the experience of burden among their family members, and prevent undertreatment of symptoms as well as overtreatment with burdensome medical interventions (Eisenmann et al., 2020).

Retrospective research has indicated that the palliative care provided in a hospital setting is more likely to be rated as poor by families of persons with dementia than by families of persons without dementia. Families believe that nurses and other hospital staff treat persons with dementia with less respect and dignity compared to those without a dementia diagnosis (John & Koffman, 2017), as dementia is often not recognized by hospital staff as a terminal illness (Mataqi & Aslanpour, 2020).

Nurses strive to provide high-quality palliative care by applying a holistic approach and managing symptoms (Monthaisong, 2018). Evidence shows that persons with dementia benefit from a palliative nursing care approach during hospitalization (Sleeman et al., 2018). Palliative nursing care strives to improve the quality of life by applying care that suits their fragile health. Nursing interventions can be targeted at anticipating physical, psychosocial, and spiritual aspects of end-of-life care (Moon et al., 2018). However, nurses reported that they had limited opportunities to address professional support needs for practice development in palliative dementia care (Sleeman et al., 2018). A lack of training is considered a barrier to nursing practice development in palliative care across all settings (Schroeder & Lorenz, 2018). Further training in palliative nursing care is needed to create a more suitable care environment for hospitalized persons with dementia in particular (Eisenmann et al., 2020). The quality of palliative dementia care during hospitalization can be improved by addressing nurses' specific support needs (Monthaisong, 2018).

A previous study explored the support needs of nursing staff in providing palliative care for persons with dementia in the home care setting and nursing home setting (Bolt et al., 2020). Hence, this follow-up study will provide insight into nurses' support needs in the hospital setting. Knowledge about nurses' support needs and the current obstacles they face in providing palliative care for persons with dementia may inform tailored care improvement initiatives (Kelley et al., 2021). This study aimed to identify nurses' perceived support needs in providing palliative care for persons with dementia in the hospital setting and to establish whether there were differences between the support needs of nurses with different educational levels and nurses working on different ward types.

Ethical considerations

The Medical Ethical Review Commission Zuyderland concluded that this study is not subject to the Medical Research Involving Human Subject Act (Central Committee on Research Involving Human Subjects, 1998). Respondents provided consent for the use of their data for scientific research. The study procedure was in line with the General Data Protection Regulation (European Parlement, 2016).

METHOD

This explorative, cross-sectional, multicentre survey study was part of the Desired Dementia Care Towards End of Life (DEDICATED) project. The study was an amendment to a former study within the DEDICATED project, which was performed in the nursing home setting and home care setting (Bolt et al., 2020). DEDICATED is situated within the Living Lab in Aging and Long-Term Care and aims to develop a tailored approach to empower nurses in providing high-quality palliative care for persons with dementia. The data were collected via a web-based questionnaire.

To identify hospital nurses' perceived support needs in palliative dementia care, this study used a previously developed questionnaire of the DEDICATED project (Bolt et al., 2020; Khemai et al., 2020). The content validity of the questionnaire was examined during the previous study by consulting healthcare professionals and patient representatives (Bolt et al., 2020). The questionnaire was designed to survey nurses in the home care setting and nursing home setting. Therefore, the researchers adjusted the questions to fit the hospital setting, (e.g., adjusting terminology to reflect care provision in a hospital). These adjustments were made in consultation with nurses, geriatric and palliative nurse specialists, and researchers. These adjustments were made after consulting with the questionnaire developer, in consideration of the existing literature, and had no adverse effect on subsequent interpretation and replication. This ensured the content validity of the questionnaire.

Before starting the questionnaire, respondents were requested to confirm that they had provided nursing care to persons with dementia in the hospital setting in the past 10 years. If a respondent did not confirm the inclusion criteria, the questionnaire could not be continued. The questionnaire started with demographic and work-related questions (answer options were numerical or categorical) covering age, sex, current work environment, job title, years of

experience, and additional training in dementia or palliative care. The additional training had to be completed in the past 2 years and had to last at least 2 h. All scales on which the respondents were requested to assign a number in this questionnaire were ranked from 0 (very bad) to 10 (excellent) (e.g., self-perceived competence level). The respondents have presented lists of items on palliative caregiving, end-of-life communication, collaboration, nurses' needs while providing care during a hospital admission, and forms of support. All items on nurses' needs were preceded by the following sentence: "Regarding the provision of palliative care to persons with dementia in the hospital setting, I am in need of…." Respondents could select multiple needs, and individual needs were not prioritized on importance. The last two questions were aimed to provide insight into missed topics and which nursing interventions respondents would apply if they had more time to provide palliative care. The answer options to these questions were derived from a previous study (Bolt et al., 2020), in which the questions were open-ended and answers were thematically analyzed. The rationale for quantifying these questions (using the previously derived themes) was to enable a comparison between the hospital setting and the nursing home setting and home setting.

Sample, recruitment, and procedure

The convenience sample used in this study included Dutch hospital nurses. This study was performed in one university hospital and two regional hospitals in the southern part of the Netherlands. Nursing staff were eligible to participate if they were graduated, worked in a hospital setting, and provided care to persons with dementia in the hospital setting within the last 10 years. Dutch hospitals provide both inpatient hospital care (e.g., intensive care unit, cardiac nursing unit, or pulmonary care unit) and outpatient hospital care (e.g., regular check-ups with physicians, home-based oncology treatments, or psychiatric nursing care during home visits). Data were collected from January 2021 through April 2021. Nurses provided digital informed consent for anonymous processing of their data before accessing the questionnaire by checking a box stating "agreed" and submitting the answer. At the beginning of the questionnaire, nurses were requested to confirm that they met the inclusion criteria.

Data collection

To systematically distribute the questionnaire in each participating organization, each organization appointed a contact person, and all contact persons applied a uniform strategy. These contact persons were nurses with a special interest in research and palliative dementia care. The contact persons distributed the invitation for this study along with an information letter, poster, and the digital access link to the questionnaire. The questionnaire was accessible from any location, time, and computer device via a hyperlink and QR code. The contact persons distributed invitations by email as well as via digital newsletters, information posters, and posts on internal websites. Furthermore, the contact persons actively motivated nurses in their organizations to participate in this study by visiting nurses, speaking at meetings, and distributing invitations.

Analysis

Data were analyzed using SPSS version 27.0 (IBM Corp.). Respondents were included if they had completed the lists of support needs in palliative caregiving and end-of-life communication. Available case analysis per item was applied. Nurses' demographic and work-related characteristics were analyzed with descriptive statistics. Nurses' self-perceived competence levels in providing palliative dementia care were compared between educational levels and ward types using an analysis of variance. The following ward types were included in the analysis: regular nursing units, specialized nursing units, and outpatient clinics. The following levels of education were included in the analysis: master's degree, bachelor's degree, and a secondary vocational degree. Cronbach's alpha was applied to calculate the reliability of the whole questionnaire by including each individual need and per topic by including only the related needs to the topic. The nurses' support needs and preferred forms of support were prioritized by calculating frequencies of item endorsement. Differences in support needs between nurses of different educational levels and different ward types were explored with chi-square tests. The Bonferroni-Holm method was used to correct multiple testing. The answers to the final questions (i.e., on additional support needs and on what respondents would do with more time) were prioritized with frequency analysis. The level of statistical significance was established at $p < 0.05$.

RESULTS

Of the 325 nurses that started the questionnaire, ninety were excluded due to incomplete responses. The mean age of the remaining 235 nurses was 39.9 years (SD = 13.7), and their average experience in caring for persons with dementia was 15.7 years (SD = 12.2). Most of the nurses (91.9%) worked in a regional hospital (Table 1) and most (67.6%) worked at regular nursing units. Most of the nurses had a secondary vocational degree (48.9%), while 34.9% had a bachelor's degree, and 16.2% had a master's degree. A minority of the nurses had additional training in dementia care (17.4%) or palliative care (16.2%).

Nurses rated their mean self-perceived competence level in providing palliative dementia care at 7.4 (SD = 1.1). Nurses in regular nursing units rated their self-perceived competence level with an average score of 7.5 (SD = 1.1), nurses in specialized nursing units rated their self-perceived competence level with an average score of 7.2 (SD = 1.0), and nurses in outpatient clinics rated their self-perceived competence level with an average score of 7.1 (SD = 1.4). Nurses working in regular nursing units reported a

TABLE 1 Demographics of the respondents

Demographics of the respondents (N = 235) (%)	
Sex	
Female	212 (90.2)
Male	22 (9.4)
Unknown	1 (0.4)
Hospital setting	
Regional hospital	216 (91.9)
Academical hospital	19 (8.1)
Educational levels	
Secondary vocational degree	115 (48,9)
Bachelor's degree	82 (34.9)
Master's degree	38 (16.2)
Ward types	
Regular nursing units	159 (67.6)
Specialized nursing units	26 (11.1)
Outpatient settings	50 (21.3)
Additional training in palliative care	
No	197 (83.8)
Yes	38 (16.2)
Additional training in dementia care	
No	194 (82.6)
Yes	41 (17.4)

significantly higher self-perceived competence level in providing palliative dementia care than those working on the other ward types (F = [2232] = 3.162, $p = 0.044$). No significant difference was found between the self-perceived competence level of nurses with different educational levels (F = [2232] = 2.986, $p = 0.052$). The reliability of the questionnaire displayed a Cronbach's alpha value of 0.851. All identified support needs are displayed in the supporting information (table S1)

Needs for support in palliative caregiving and end-of-life communication

The most frequently endorsed support needs in providing palliative nursing care for persons with dementia were "communicating with persons with severe dementia" (58.3%) and "recognizing and dealing with challenging behaviors" (52.3%) (Table 2). The reliability of the palliative caregiving topic displayed a Cronbach's alpha value of 0.667. The most frequently identified support needs in end-of-life communication were "dealing with family disagreements" (53.2%) and "involving persons with dementia in end-of-life decision making" (46.4%) (Table 3). The least frequently endorsed support needs were "providing daily care/assisting in self-care" (5.1%) and "deciding on the right time to initiate end-of-life communication" (21.3%). The reliability of the end-of-life communication topic displayed a Cronbach's alpha value of 0.501.

TABLE 2 Support needs in palliative caregiving

Support needs in palliative caregiving	N = 235 (%)
Communicating with persons with severe dementia	137 (58.3)
Recognizing and dealing with certain behavior, such as agitation or aggression	123 (52.3)
My personal contribution to meaningful activities for persons with dementia	43 (18.3)[a]
Involving families in the entire care process	40 (17)[a]

[a]Implicating a significant difference between ward types.

TABLE 3 Support needs in end-of-life communication

Needs in end-of-life communication	(%)
Dealing with disagreement between families about end-of-life care	125 (53.2)
Involving persons with dementia in end-of-life decision making	109 (46.4)
Deciding on the right time to initiate end-of-life communication	50 (21.3)

TABLE 4 Support needs in collaboration

Support needs in collaboration	N = 217 (%)
A permanent contact person in the care for persons with dementia and their families	126 (53.6)
Explicit information transfer	92 (39.1)
Regularly discussing and (if necessary) adjusting care arrangements	45 (19.6)[a]
Consult with colleagues from other nursing units	23 (9.8)

[a]Implicating a significant difference between educational levels.

A significant difference was found between nurses working on different ward types regarding "contributing to meaningful activities for persons with dementia" (X^2[2] = 8.565, $p = 0.014$). This item was endorsed by 15.8% of the nurses working on regular nursing units, 2.1% of the nurses working in outpatient clinics, and 0.4% of the nurses working in specialized nursing units. A significant difference was also found between nurses working on different ward types regarding the item "involving families in the entire care process" (X^2[2] = 6.399, $p = 0.041$). This item was endorsed by 11.9% of the nurses working on regular nursing units, 3.4% of the nurses working on specialized nursing units, and 1.7% of the nurses working in outpatient clinics.

Needs for collaboration

The most frequently endorsed support needs in collaboration in palliative care for persons with dementia were "appointing a permanent contact person in the care for persons with dementia" (53.6%) and "explicit information transfers" (39.1%) (Table 4). The least frequently

endorsed need was "consulting with colleagues from other nursing units" (9.8%). The reliability of the collaboration topic displayed a Cronbach's alpha value of 0.791.

A significant difference was found between nurses with different educational levels regarding "regularly discussing and adjusting care arrangements" ($X^2[2] = 9.300$, $p = 0.010$). This item was endorsed by 8.9% of the nurses with a secondary vocational degree, 6.0% of the nurses with a master's degree, and 4.7% of the nurses with a bachelor's degree.

Needs during hospital admission

Nurses rated the quality of the nursing documentation received during a hospital admission of a person with dementia at 6.2 (SD = 1.64). Nurses rated the quality of nursing documentation handed out at the moment of discharge at 6.8 (SD = 1.29). The most frequently endorsed needs during hospital admissions were "transparency of end-of-life agreements from the start of admissions" (51.1%) and "tips and advice in guiding persons with dementia and their families during a hospital admission" (37.0%) (Table 5). The least frequently endorsed need was "practical advice to prepare myself for an admission" (6.0%). The reliability of the hospital admission topic displayed a Cronbach's alpha value of 0.480.

A significant difference was found between nurses working on different ward types regarding the item "tips and advice in guiding persons with dementia and families during a hospital admission" ($X^2[2] = 9.420$, $p = 0.009$). This item was endorsed by 29.3% of nurses working on regular nursing units, 4.2% of the nurses working in outpatient clinics, and 3.4% of the nurses working on specialized nursing units.

Preferred forms of support and additional needs

With regard to forms of support in providing palliative nursing care for persons with dementia, most nurses preferred "classroom education" (49.8%) and "joint case discussions" (46.0%), the least frequently preferred were "emotional support from the organization" (4.3%) and "professional emotional support" (1.7%) (Table 6).

A significant difference was found between nurses with different educational levels regarding the item 'E-learning' ($X^2[2] = 7.053$,

TABLE 5 Support needs during hospital admissions

Support needs during a hospital admission	(%)
Transparency from the start of hospital admission about previously made end-of-life agreements	120 (51.1)
Tips and advice in guiding persons with dementia and families during a hospital admission	87 (37.0)[a]
Practical information and advice to prepare myself for an admission	14 (6.0)

[a]Implicating a significant difference between ward types.

TABLE 6 Preferred forms of support

Forms of support	N = 212 (%)
Classical education (e.g., clinical lessons)	117 (49.8)
Jointly discussing cases	108 (46)
E-learning's	97 (41.3)[a]
Coaching in daily practice (coaching on-the-job)	65 (27.7)[a]
(Being referred to) professional emotional support	4 (1.7)

[a]Implicating a significant difference between educational levels.

$p = 0.029$). This form of support was endorsed by 17.9% of the nurses with a secondary vocational degree, 13.6% of the nurses with a bachelor's degree, and 9.8% of the nurses with a master's degree. Another significant difference was found between nurses with different educational levels regarding the item 'coaching in daily practice' ($X^2[2] = 9.506$, $p = 0.009$). This form of support was endorsed by 13.6% of the nurses with a bachelor's degree, 9.4% of the nurses with a secondary vocational degree, and 4.7% of the nurses with a master's degree.

The most frequently identified additional needs were "more specific knowledge in palliative dementia care" (36.2%) and "family involvement in ethical issues" (30.2%). If nurses had more time to provide care, 66.4% would prioritize giving more personal attention and 39.1% would invest more time in involving families.

DISCUSSION

This study aimed to identify the overall support needs of hospital nurses in providing palliative care for persons with dementia. The most frequently identified support needs were communicating with persons with severe dementia, dealing with family disagreements, appointing a permanent contact person for persons with dementia, and transparency regarding end-of-life agreements from the start of hospitalization. Nurses preferred classroom training and joint case discussions as forms of support in providing palliative dementia care. Nurses' recognition of some individual support needs differed significantly between nurses from different ward types and with different educational levels. If nurses had more time to provide care, the majority would prioritize providing more personal attention. This is in line with the previous study performed in the nursing home setting and home care setting (Bolt et al., 2020).

The findings of this study are in line with other studies that suggest that palliative dementia care in the hospital setting should focus explicitly on dealing with challenging behavior, improving communication skills, and signaling behavioral and psychological symptoms (Yang et al., 2020). Dealing with challenging behaviors during hospitalizations requires multiple professional dementia care skills, such as communication and observation techniques, knowing the person with dementia, and focussing on personalized care (Ooi et al., 2018). Evidence shows that improving communication skills in nurses leads to improved scores on relevant quality of life outcomes for persons with dementia and nurses' self-perceived competence

levels (Gilmore-Bykovskyi et al., 2017). This study demonstrates that, respectively, only 16.2% and 17.4% of the nurses had recently attended additional training on palliative care or dementia care. Additional training in communication with families about end-of-life care is needed to improve the quality of life for persons with dementia (Ooi et al., 2018).

The support needs to involve families in the entire care process of a person with dementia differed significantly between nurses working on different ward types, supporting that interventions that increase family involvement should be tailored to individual ward types (Kelley et al., 2021). This significant difference could be explained by the degree of specialized nursing care and the experience of nurses with family involvement in hospital care. Family disagreements are recognized as a well-known problem in dementia care (Fukui et al., 2018), which nurses also expressed in the home care setting and nursing home setting (Bolt et al., 2020). The current findings show that this is a pressing issue in the hospital setting as well.

Deciding on the right time to initiate end-of-life communication was the least frequently endorsed support need. This is in contrast with other studies that suggest that deciding the right time to initiate end-of-life communication is an obstacle in palliative dementia care (Ooi et al., 2018). Nonetheless, 21.3% of the nurses endorsed this support need. The need for one permanent contact person for persons with dementia and their families corresponds to earlier findings, showing that fragmentation in dementia care delivery and nonpersonalized care is a well-recognized obstacle (Khemai et al., 2020). By appointing one permanent contact person, different responsibilities between healthcare professionals become more clear and information between healthcare professionals might be shared more effectively (Khemai et al., 2020). Persons with dementia are particularly vulnerable to the consequences of fragmented care, especially during end-of-life care. Persons with dementia and their families should be guided by nurses to adjust care to a person's wishes and therapy goals (Mataqi & Aslanpour, 2020). Most of the nurses in this study indicated that they would use the additional time to pay more personal attention and to discuss a person's wishes and care goals. Evidence suggests that nurses are better able to involve persons with dementia in end-of-life care decisions if they are able to invest in person-centered care during hospitalizations (Kelley et al., 2021).

The need for explicit information transfers also resonates in nurses' ratings of the quality of nursing documentation in hospital admissions and discharges. Inadequate communication between the hospital and other healthcare services can lead to longer hospitalizations, medication errors, unnecessary use of medical interventions, and readmissions (Gettel et al., 2019). During hospitalizations, information concerning previously established agreements about end-of-life wishes does not reach all involved healthcare professionals. Nurses require skills in and knowledge about optimal collaboration between healthcare services and universal nursing documentation systems are needed to ensure high-quality transfers (Khemai et al., 2020).

Nurses need to be facilitated and motivated for interprofessional interaction to develop clinical competencies in palliative dementia care (Yang et al., 2020). In this study, both classroom education and joint case discussions were preferred. By developing a mutual supporting culture of working and learning together, an optimal learning environment can be ensured (Nevalainen et al., 2018). Subsequently, a mutual supporting culture could lead to more nurses who experience and openly express the need for emotional support (Lee et al., 2019).

This study demonstrated a significant difference between nurses on different ward types and the self-perceived competence level of nurses in palliative dementia care. Working within a nursing unit where palliative dementia care is more common, intermittent education in palliative care and frequent contact with a palliative care team are significant predictors of an increasing self-perceived competence level (Yang et al., 2020). However, the evidence does not describe a consistent relationship between different ward types or self-perceived competence levels and different support needs in palliative dementia care.

Limitations

The web-based questionnaire was widely shared and had digital open access, which resulted in an unclear response rate (Blumenberg & Barros, 2018). Fewer nurses may have had the opportunity to participate due to an increased workload, due to the COVID-19 pandemic. The representation of different nursing functions in the sample does not correspond with the population (e.g., uncertified nursing assistants were underrepresented), which may have caused selection bias. Nurses were asked in the introduction of the questionnaire to provide answers based on "the average case." However, recall bias may have been present, as "atypical cases" may have a greater impact on the interpretation of palliative dementia care compared to "typical cases" (Mishra et al., 2019). Although the questionnaire as a whole showed excellent reliability (0.851), the two specific topics of support need in communication (0.501) and during hospital admission (0.480) showed poor reliability. This could be caused by a more limited number of item options in these support needs topics. Respondents were not asked to quantify the exact hours they spent on palliative dementia care in the hospital setting, as the aim of this study was to identify overall support needs.

Recommendations

Support in palliative care for persons with dementia must be tailored to nurses' specific needs. The preferred forms of support in end-of-life care for persons with dementia should be applied in professional training programs. Nurses in this study endorsed the additional wish to give more personal attention to persons with dementia and to involve families more intensively during hospitalizations. A systematic review suggested that dementia-friendly hospitals establish a culture of care that supports nurses in providing palliative dementia

care with personal attention and that stimulates family involvement (Gilmore-Bykovskyi et al., 2017). Hence, nursing research should focus on the relationship between further application of dementia-friendly interventions and relevant quality of life outcomes in the hospital setting.

CONCLUSION

The most urgent support needs of hospital nurses in palliative dementia care are communicating with persons with severe dementia, appointing a permanent contact person, and dealing with family disagreements in end-of-life care. Similar support needs were expressed by a heterogeneous group of nurses. Further improvements in palliative dementia care in the hospital should be tailored to the specific support needs of these nurses. This support would give nurses the opportunity to overcome current obstacles in palliative dementia care in the hospital. Thereby, palliative nursing care could be improved for persons with dementia in the hospital setting and their families.

CLINICAL RESOURCES

- Alzheimer's Association. Professionals. www.alz.org/professionals.
- European Association for Palliative Care. Palliative care for older people: better practices. www.eapcnet.eu/eapc-groups/archives/task-forces-archives/older-people-better-practices.
- World Health Organization. www.who.int/news-room/fact-sheets/detail/palliative-care

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SUPPORTING INFORMATION

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

Table S1

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