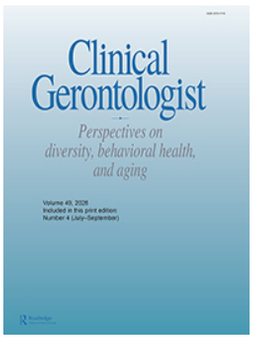

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The Development and Validation of Sexuality and Intimacy in Dementia Questionnaire (SIDQ)

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ABSTRACT

Objectives: To develop and validate the Sexuality and Intimacy in Dementia Questionnaire (SIDQ), an observational instrument for assessing verbal and physical expressions of intimacy and sexuality in nursing home residents with dementia.

Methods: The SIDQ was developed through expert review, content validity assessment and face validity testing. Data were collected from 62 questionnaires across seven nursing home organizations. Construct validity was evaluated using exploratory factor analysis. Internal consistency, inter-item correlations, and test–retest reliability were assessed following COSMIN and DeVellis guidelines.

Results: Content and face validity showed that the SIDQ was clear, relevant and acceptable for using in dementia care. After removing items with low communalities, exploratory factor analysis revealed two factors: verbal intimacy and sexuality (2 items) and physical intimacy and sexuality (4 items). These explained 79.41% of the variance. Internal consistency was good ($\alpha = .72$ and $\alpha = .84$). Test–retest reliability was excellent (ICC= .95, 95% CI: .875–.991).

Conclusions: The SIDQ showed good preliminary psychometric properties and provides a structured way to assess observable expressions of intimacy and sexuality in people with dementia.

Clinical Implications: The SIDQ may support nursing staff in recognizing residents' intimate and sexual needs, facilitate communication within care teams and with families.

KEYWORDS
Dementia; intimacy; sexuality

Introduction

Dementia is a progressive neurodegenerative syndrome affecting an estimated 55 million people worldwide, with numbers expected to rise substantially in the coming decades (Claes & Enzlin, 2023; World Health Organization [WHO], 2021). In long-term care settings, between 60% and 80% of residents live with moderate to severe dementia, often accompanied by significant cognitive, behavioral, and functional impairments (Prince et al., 2015). These impairments influence not only memory and executive functioning but also the capacity to express emotional, intimate, and sexual needs (Torrisi et al., 2016; van de Beek et al., 2020).

Intimacy is defined as the experience of emotional closeness, affection, trust, and connectedness between individuals. It is expressed through affectionate touch, eye contact, verbal warmth, and shared presence, and does not necessarily involve sexual activity (Reis & Shaver, 1988). Sexuality is understood as a broad, multidimensional construct that includes sexual desire, identity, sensuality, physical closeness, and sexual expression. According to the World Health Organization, sexuality encompasses "sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction," and is not limited to sexual intercourse (WHO, 2006). Both constructs are deeply personal and shaped by cultural, relational, and individual factors. Research shows that many older adults, including those living with dementia, continue to value intimate and sexual expression as part of their identity and well-being (Roelofs et al. 2019; Sandberg, 2020).

However, dementia can alter the ways in which individuals express these needs (Roelofs et al. 2019). Differences in dementia etiology, such as Alzheimer's disease, vascular dementia, or frontotemporal dementia, may influence behavioral expression (Mahieu & Gastmans, 2015). For example, frontal lobe dysfunction may lead to disinhibition, impulsivity, or socially

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inappropriate sexual behavior (Series & Dégano, 2005). Severity of cognitive impairment also matters: individuals with mild dementia may verbalize their needs, whereas those with moderate or severe dementia may rely primarily on observable behaviors, non-verbal cues, or physical proximity to communicate intimacy or discomfort (Lichtenberg, 2014; Mahieu & Gastmans, 2015). Functional status (e.g., independence in ADLs), verbal ability, and emotional regulation further shape how needs are expressed and interpreted by caregivers (Mahieu & Gastmans, 2015).

A major challenge in dementia care is the frequent misinterpretation of intimate or affectionate behaviors as inappropriate or pathological. Studies show that nursing staff often feel uncertain about how to interpret residents' behaviors, and may label expressions of intimacy as "problem behavior," particularly when erotic or sexual elements are present (Benbow & Beeston, 2012; Ward et al., 2005). These interpretations are influenced by personal beliefs, cultural norms, religious values, and institutional policies (Pinho & Pereira, 2019). LGBTQ+ residents may face additional barriers, including heteronormative assumptions, stigma, or lack of institutional guidance on supporting diverse sexual identities (Brotman et al., 2007; McGovern, 2014; Simpson et al., 2018).

Ethical considerations further complicate the assessment of intimacy and sexuality in dementia. Issues of consent and assent are central: a resident may express sexual interest toward a spouse, partner, or another resident, but cognitive impairment raises questions about capacity, voluntariness, and vulnerability (Lichtenberg & Strzepek, 1990; Syme et al., 2016). Staff must balance residents' rights to intimacy with the need to protect them from harm, coercion, or exploitation. Complex situations, such as a married resident forming a new intimate relationship in the nursing home or a nonverbal resident engaging in sexual activity with a visiting spouse, require nuanced assessment and clear institutional guidance (Mahieu & Gastmans, 2015; Syme et al., 2016).

Despite the importance of these issues, research shows that the intimate and sexual needs of persons with dementia are often overlooked, minimized, or avoided in clinical practice (Chen et al., 2017; Vandrevala et al., 2017). One contributing factor is the lack of validated tools that help caregivers systematically observe and assess residents' needs in this domain. Several instruments exist that measure knowledge, attitudes, or organizational policies related to sexuality in later life, such as the Sexuality Assessment Tool (SexAT; Bauer et al., 2014), the Sexual Behavior and Intimacy Questionnaire (SIQ; Ahmed et al., 2015), the Intimacy and Sexuality Expression Preference tool (ISEP; Jones et al., 2023), the Health and Social Care Professionals' Knowledge and Attitudes Towards Later-Life Intimacy and Sexuality scale (HSCP-KALLIS; Chen et al., 2024), and the Aging Sexual Knowledge and Attitudes Scale (ASKAS; White, 1982). However, none of these instruments are designed to assess observable expressions and needs for intimacy and sexuality in persons with dementia who cannot reliably self-report. Moreover, no Dutch instrument exists that captures these needs in a structured, clinically applicable manner.

Given the centrality of intimacy and sexuality to person-centered care, and the absence of a suitable Dutch observational tool, there is a clear need for an instrument that helps nursing staff identify residents' intimate and sexual needs, understand behavioral expressions, and support individualized care planning. Therefore, the aim of the present study was to develop and validate the Sexuality and Intimacy in Dementia Questionnaire (SIDQ), an observational instrument designed to assess verbal and physical expressions of intimacy and sexuality in persons with dementia living in long-term care. We evaluated the SIDQ's content validity, face validity, usability, construct validity, internal consistency, and test – retest reliability.

The development and validation of the SIDQ took place during the COVID-19 pandemic, which substantially restricted access to nursing homes and limited the availability of nursing staff for research activities. These circumstances affected the pace of data collection and the feasibility of recruiting a larger sample, and should therefore be considered an important contextual factor when interpreting the methodological choices of this study.

Method

Design

This study employed a methodological instrument development design, following established

frameworks for scale development and validation (DeVellis, 2017;Mokkink et al., 2018; Terwee, et al., 2018). The study consisted of four sequential phases: (1) item generation, (2) content validity evaluation by experts, (3) assessment of face validity and usability by nursing staff, and (4) psychometric evaluation including construct validity, internal consistency, and test – retest reliability.

Development of the instrument

Item generation

A preliminary pool of 12 items was developed drawing on qualitative research on intimacy and sexuality in dementia care (Roelofs et al., 2017), the WHO definition of sexuality, existing instruments such as the Sexual Behavior and Intimacy Questionnaire (SIQ; Ahmed et al., 2015), and the clinical experience of the research team in dementia care. The items were formulated as observable behaviors related to intimacy and sexuality and were rated on a 5-point Likert scale (1 = never, 5 = always). Based on theoretical considerations, the items were initially organized into four conceptual domains: touch, feeling of safety, communication, and sexuality.

Content validity

Content validity was assessed by a multidisciplinary expert panel ($N = 11$), including elderly care physicians ($n = 3$), psychologists ($n = 5$), and nursing staff ($n = 3$), supplemented by two family members and two client representatives affiliated with the Elderly Care Network (UNO-UMCG). Experts represented seven nursing home organizations in the northern Netherlands. They rated each item on relevance and clarity using a 5-point scale ranging from "not relevant" to "very relevant." Qualitative feedback was used to refine items; due to the small and heterogeneous panel, content validity indices were not calculated quantitatively but were used qualitatively to guide revisions.

In addition to comments on item clarity, the expert panel also expressed qualitative concerns about the potential emotional burden associated with the questionnaire. These concerns related in particular to situations in which family members might be asked to complete the questionnaire, as reflecting on or evaluating sexual expression could be emotionally challenging for them. Experts further noted that some items might evoke discomfort among nursing staff, given that sexuality in the context of dementia can be a sensitive topic. The panel also indicated that the initial layout lacked sufficient visual structure. Based on this feedback, the layout was revised by improving readability through clearer headings, the use of bold text and italics, and a more structured presentation of items.

Feedback additionally indicated that some concepts, such as "contact" and "security," were perceived as vague. As a result, item wording was clarified, for example by revising "seeking comfort" to "seeking comfort in a cuddle toy," and five new items were added to improve coverage of verbal intimacy, physical intimacy, and sexuality. This resulted in a 17-item version of the SIDQ (see Table 1).

Face validity and usability

Face validity and usability were evaluated by nursing staff using four questions assessing clarity, comprehensiveness, relevance, and difficulty of responding. These were rated on a 5-point Likert scale (1 = strongly disagree, 5 = strongly agree).

Participants and setting

Participants were nursing staff working in seven elderly care organizations in the northern Netherlands. A total of 62 nurses completed the SIDQ. Following recommendations for methodological studies (10 participants per item) (Nunnaly, 1978), a target sample of approximately 170 responses was intended; however, COVID-19 restrictions limited recruitment and access to nursing homes. To enhance observational accuracy, two nurses independently completed the SIDQ for each resident. These paired ratings were used to strengthen the quality of observational input, but were not used to compute-inter-rater reliability. Nurses completed the SIDQ for 10 residents with dementia. Three weeks later, the same nurses completed the SIDQ again for the same residents to assess test – retest reliability. Nurses were instructed to base their ratings on observations from the previous two weeks.

Table 1. Preliminary 17-item version of the sexuality and intimacy in dementia questionnaire (SIDQ) *(English translations; not validated).*

Item no.	Item (English translation)	Category
1	Does the resident seek verbal contact with other people?	Verbal intimacy
2	Does the resident enjoy verbal contact with other people?	Verbal intimacy
3	Do you observe limitations in the resident's ability to engage in verbal contact?	Limitations
4	Do you observe inappropriate behavior when the resident engages in verbal contact?	Inappropriate behavior
5	Does the resident seek physical contact with other people?	Physical intimacy
6	Does the resident seek physical contact with nursing staff?	Physical intimacy
7	If applicable: Does the resident seek physical contact with their partner?	Physical intimacy
8	Does the resident enjoy being touched?	Physical intimacy
9	Does the resident enjoy touching other people?	Physical intimacy
10	Does the resident seek comfort in holding, for example, a (cuddle) toy?	Physical intimacy
11	Do you observe limitations in the resident's ability to touch other people?	Limitations
12	Do you observe limitations in the resident's ability to touch themselves?	Limitations
13	**Do you observe inappropriate behavior when the resident touches other people?**	**Inappropriate behavior**
14	**Do you observe inappropriate behavior when the resident touches themselves?**	**Inappropriate behavior**
15	Do you observe sexual behavior?	Sexuality
16	Do you observe inappropriate sexual behavior?	Inappropriate behavior
17	**If applicable: Do you observe changes in the resident's intimate or sexual needs according to their partner?**	**Partner-reported changes**

Note. All items were rated on a 5-point Likert scale (1 = never, 5 = always). Items in bold were added after the content validity review. This table presents the preliminary 17-item version of the SIDQ. Only a subset of items was included in the psychometric analyses, as described in the Methods and Results sections.

Ten residents were selected by participating organizations based on:

- a confirmed diagnosis of dementia,
- residence in a dementia special care unit,
- inability to reliably self-report intimate or sexual needs, and
- availability of two nurses familiar with their daily care.

Demographic information (e.g., dementia type, severity, verbal ability, ADL dependency) was collected to contextualize the sample. Partners of residents ($n = 10$) also completed the SIDQ, but due to the small sample size, partner data were not included in psychometric analyses.

Ethical approval was obtained from the Medical Ethical Committee of the University Medical Centre Groningen (reg. nr. 202100229). Written informed consent was obtained from nursing staff and legal representatives of residents.

Procedure

In the first participating organization, a psychologist served as research ambassador and coordinated recruitment. In the remaining organizations, researchers contacted legal representatives and nursing staff directly. COVID-19 restrictions required flexible data collection procedures, including remote coordination and staggered recruitment.

Psychometric analysis

Descriptive statistics

Means, standard deviations, and score distributions were calculated for all items. Skewness was examined visually and statistically. Items showing extreme skewness (e.g., inappropriate behavior items) were dichotomized (yes/no) for descriptive purposes and excluded from factor analysis, as they were conceptually formative rather than reflective indicators (DeVellis, 2017).

Construct validity

Before conducting factor analysis, suitability of the data was assessed using:

- Kaiser – Meyer – Olkin (KMO) measure, with values ≥ .50 considered acceptable (Kaiser, 1974).
- Bartlett's test of sphericity, where a significant result indicates adequate inter-item correlations (Bartlett, 1954).
- Communalities, with values ≥ .60 preferred for stable factor solutions (Costello & Osborne, 2005).

Given theoretical assumptions that items reflect underlying latent constructs, a reflective measurement model was used. Exploratory factor analysis (EFA) was conducted using principal axis factoring (PAF) with oblimin rotation, as factors were

expected to correlate (Fabrigar et al., 1999). Factors were retained based on eigenvalues > 1, scree plot inspection, and interpretability (Cattell, 1966). Items with communalities < .30 or factor loadings < .40 were removed (Hair et al., 2019).

Reliability

Internal consistency was assessed using Cronbach's alpha, with values ≥ .70 considered acceptable for newly developed instruments (Nunnally & Bernstein, 1994). Item – total correlations and inter-item correlations were examined; items with correlations < .20 or >.80 were evaluated for removal (DeVellis, 2017).

Test – retest reliability was assessed using the intraclass correlation coefficient (ICC) based on a two-way random-effects model, with ICC ≥ .70 considered acceptable for temporal stability (Shrout & Fleiss, 1979). All analyses were conducted using SPSS version 28 (IBM Corp.).

Inter-rater realibility was not assessed, as the paired ratings were collected solely to improve observational accuracy than to estimate agreement between raters.

Results

Descriptive statistics

A total of 62 SIDQ questionnaires were completed by nursing staff across seven elderly care organizations. Because each resident was rated independently by two nurses, the dataset consisted of paired observations. For the purposes of factor analysis, each rating was treated as an independent observation; for test – retest reliability, paired ratings were used.

Descriptive statistics for all items are presented in Table 2. Visual inspection of the distributions showed that several items, particularly those assessing limitations and inappropriate behavior (Items 3, 4, 7, 11, 12, 13, 14, 16, and 17), were positively skewed, as expected given the low prevalence of these behaviors in daily care. These items were therefore excluded from factor analysis because they represent formative indicators rather than reflective constructs. Item 17 was excluded from all analyses because it applied only to partners. The remaining items showed acceptable distributional properties for factor analysis.

Validity and usability

Nursing staff rated the SIDQ positively on clarity ($M = 3.93$, SD = 0.86), perceived comprehensiveness ($M = 3.46$, SD = 1.07), and relevance for assessing intimacy and sexuality in dementia ($M = 3.54$, SD = 0.69). Respondents were neutral regarding the difficulty of answering the questionnaire ($M = 2.14$, SD = 1.01). These findings indicate good face validity and usability.

Construct validity

Preliminary checks

The Kaiser – Meyer – Olkin (KMO) measure indicated adequate sampling adequacy (KMO = .73). All individual KMO values exceeded .50. Bartlett's test of sphericity was significant, χ^2 (28) = 197.63, $p < .001$, indicating sufficient intercorrelations among items to justify factor analysis.

Table 2. Exploratory factor analysis of the SIDQ: Factor loadings, eigenvalues, variance explained and internal consistency.

Item no.	Item (short label)	Factor 1(Verbal intimacy & sexuality)	Factor 2 (Physical intimacy & sexuality)
1	Seeks verbal contact	.64	—
2	Enjoys verbal contact	.91	—
5	Seeks physical contact (others)	—	.94
6	Seeks physical contact (staff)	—	.75
8	Enjoys being touched	—	.79
9	Enjoys touching others	—	.92
	Eigenvalue	3.23	1.54
	Variance explained (%)	53.83	25.58
	Cronbach's α	.72	.91

Note. Extraction method: Principal Axis Factoring; Rotation: Oblimin. Items 10 and 15 were removed due to low communalities (<.30). Items assessing limitations or inappropriate behavior were excluded from factor analysis because they represent formative rather than reflective indicators. Factor correlation was low (r = .18), indicating distinct constructs.

Exploratory factor analysis

An exploratory factor analysis (EFA) using Principal Axis Factoring with oblimin rotation was conducted on the 10 items that conceptually reflected intimacy and sexuality. Two items (Item 10 and Item 15) were removed due to low communalities (<.30), indicating insufficient shared variance with the underlying constructs.

The final EFA included six items and yielded a clear two-factor solution (Table 2). Two components had eigenvalues greater than 1 and together explained 79.41% of the variance. Factor 1 (two items) represented verbal intimacy and sexuality, and Factor 2 (four items) represented physical intimacy and sexuality. The correlation between the two factors was low ($r = .18$), supporting their conceptual distinctiveness.

Reliability

Internal consistency

The internal consistency of the 10-item version of the SIDQ was acceptable (α = .77). After removing Items 10 and 15, Cronbach's alpha increased to .86. Internal consistency for the two factors was good:

- Factor 1 (verbal intimacy): α = .72
- Factor 2 (physical intimacy): α = .84

Inter-item correlations for the six retained items are presented in Table 3. All corrected item – total correlations exceeded .30, except for Item 10, which supported its removal. Items within Factor 2 showed moderate to strong correlations, consistent with a coherent underlying construct.

Test–retest reliability

Test – retest reliability was assessed using the intraclass correlation coefficient (ICC) based on paired ratings collected three weeks apart. The average ICC was .95 (95% CI: .875–.991), $F(10,10) = 18.9$, $p < .001$, indicating excellent stability of the SIDQ over time.

Discussion

The aim of this study was to develop and validate the Sexuality and Intimacy in Dementia Questionnaire (SIDQ), an observational instrument designed to assess verbal and physical expressions of intimacy and sexuality in persons with dementia living in nursing homes. The results demonstrate good face validity, strong construct validity, and satisfactory reliability, supporting its potential usefulness in clinical practice.

Interpretation of findings

The exploratory factor analysis revealed two distinct factors: verbal intimacy and sexuality, and physical intimacy and sexuality. Together, these factors explained a substantial proportion of the variance. The low correlation between the two factors suggests that these domains represent related but independent aspects of individuals' intimate and sexual expression. This distinction is clinically relevant, as individuals with dementia may express intimacy differently depending on cognitive abilities, communication skills, and behavioral tendencies (Mahieu & Gastmans, 2015).

Internal consistency for both factors was good, and the removal of items with low communalities improved the overall reliability of the instrument. The excellent test – retest reliability indicates that

Table 3. Inter-item correlations for the six SIDQ items included in the factor structure.

Item	1	2	5	6	8	9
1. Seeks verbal contact	—	.64	.08	−.03	.16	.08
2. Enjoys verbal contact	.64	—	.16	−.05	.16	.16
5. Seeks physical contact (others)	.08	.16	—	.76	.66	.73
6. Seeks physical contact (staff)	−.03	−.05	.76	—	.61	.69
8. Enjoys being touched	.16	.16	.66	.61	—	.84
9. Enjoys touching others	.08	.16	.73	.69	.84	—

Note. All correlations are Pearson's r. Correlations ≥ .50 are considered moderate; ≥.80 strong. Items 1–2 belong to Factor 1; Items 5–9 belong to Factor 2. Item 10 and 15 were excluded from reliability analysis due to low correlations with other items. Items assessing limitations or inappropriate behavior were excluded because they do not reflect the latent constructs.

the SIDQ provides stable assessments over time, even in a population where behavioral fluctuations are common. Together, these findings support the SIDQ as a psychometrically sound tool for assessing observable expressions of intimacy and sexuality in dementia.

Relevance for clinical practice

The SIDQ addresses a critical gap in dementia care. Existing instruments primarily assess knowledge, attitudes, or organizational policies related to sexuality in later life, but do not capture residents' observable needs or expressions. Because many persons with moderate to severe dementia cannot reliably self-report, caregivers must rely on behavioral cues to understand residents' intimate and sexual needs (Mahieu & Gastmans, 2015). The SIDQ provides a structured framework for these observations, reducing the risk of misinterpretation and helping staff distinguish between normative expressions of intimacy and behaviors that may require intervention. The instrument may also facilitate communication among nursing staff, family members, and multidisciplinary teams. The modified versions can be found in Appendix A (Dutch version) and a translated version in Appendix B (not yet evaluated). By providing a shared language and systematic approach, the SIDQ can help normalize discussions about intimacy and sexuality, topics that are often stigmatized or avoided in long-term care settings (Bouman et al., 2007). This aligns with principles of person-centered care, which emphasize the importance of recognizing and supporting residents' emotional and relational needs (Edvardsson et al., 2008).

Strengths and limitations

A key strength of this study is its methodological rigor, including the use of expert input, multiple forms of validity assessment, and test – retest reliability. The involvement of both clinical practitioners and nursing staff ensured that the instrument reflects both theoretical and practical perspectives. However, several limitations should be noted. First, the sample size was smaller than intended due to COVID-19 restrictions, which limited access to nursing homes and reduced staff availability. Although the sample was sufficient for exploratory factor analysis, replication in a larger and more diverse sample is needed. In addition, a limitation of this study is that detailed demographic and clinical information on both residents and staff was not collected, which limits the ability to contextualize the findings and assess their generalizability. Second, the SIDQ relies on caregiver observations, which may be influenced by personal beliefs, cultural norms, or institutional policies regarding sexuality in dementia (Benítez et al., 2012; Bérengère et al., 2019). Third, items assessing limitations and inappropriate behavior were excluded from psychometric analyses because they represent formative rather than reflective indicators. A further limitation concerns the development process itself. From a person-centered perspective, it would have been valuable to involve individuals with dementia directly in the development of the questionnaire. At the time of instrument development, this was not implemented, and only later did it become clear that such involvement could have enriched the conceptual grounding of the SIDQ. Partners and family representatives were included and provided important experiential input, but the perspectives of individuals living with dementia themselves were not captured directly.

Future directions

Future research should focus on additional steps to strengthen the validation and practical applicability of the SIDQ. A first priority is to replicate the factor structure in an independent and more diverse sample to confirm the generalizability of the instrument's construct validity (Boparai et al., 2019; Rattray & Jones, 2007). It is also important to examine whether the SIDQ is sensitive to changes in people with dementia over time, as responsiveness is a key requirement for instruments intended to support ongoing care. In addition, further psychometric work is needed to determine whether a meaningful total score can be created by aggregating individual item responses, and to evaluate the validity of such a score.

Beyond psychometric refinement, future studies should explore how the SIDQ can be integrated into routine care planning and the broader patient journey of a person with dementia admitted to a nursing home. This includes examining how the instrument influences communication within care teams and

whether its use contributes to improved quality of life. Research should also investigate the cognitions and attitudes of family members and legal representatives regarding intimacy and sexuality in dementia care, as these perspectives shape decision-making and care practices. Finally, qualitative analysis of open-ended responses and contextual narratives may provide deeper insight into the environmental, relational, and organizational factors that influence intimate and sexual expression in dementia.

Clinical implications

- The SIDQ helps nursing staff identify residents' unmet needs for intimacy and sexuality, supporting more person-centered care planning.
- Using the SIDQ provides a structured framework for discussing intimacy and sexuality within care teams and with family members.
- Integrating the SIDQ into routine assessments may reduce misinterpretation of behaviors and improve the emotional well-being of residents with dementia.

Disclosure statement

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Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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