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BRIEF REPORT

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Psychiatric care for people with Prader-Willi syndrome—characteristics, needs and barriers

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Abstract

Background: Prader-Willi syndrome (PWS) is commonly associated with intellectual disability, but also with a specific behavioural phenotype and a high predisposition to psychiatric comorbidity. This study examines the psychiatric care situation of people with PWS.

Method: A structured online questionnaire was administered to carers of people with PWS living in Germany, asking about demographic, diagnostic and treatment parameters as well as personal experiences.

Results: Of 77 people with PWS, 44.2% had at least one psychiatric comorbid diagnosis. The main reasons for seeking psychiatric care were emotional outbursts and aggressive behaviour. 34.9% reported that they were currently seeking psychiatric care without success. However, 32.5% of PWS had been treated with psychotropic medication, mainly antipsychotics.

Conclusions: Psychiatric comorbidity appears to be undertreated in PWS, especially in the ambulatory setting. Uncertainty among mental health care providers may also lead to frequent off-label use of psychotropic medications.

KEYWORDS
intellectual disability, Prader-Willi syndrome, psychiatric care, psychiatric comorbidity, psychotropic drugs

1 | INTRODUCTION

Meta-analyses have shown a significantly increased co-prevalence of psychiatric comorbidity of 33.6% in people with intellectual disability (ID), and they were also significantly more likely to be treated with psychotropic medication than the general population (Mazza et al., 2020; Weih et al., 2022).

People with neurogenetic syndromes such as Prader-Willi syndrome (PWS) often have intellectual disability but with considerable variation in behavioural phenotype and predisposition to psychiatric comorbidity.

With an estimated prevalence of 1 in 10,000–30,000 births (Angulo et al., 2015), PWS is based on the loss of paternally expressed genes on chromosome 15q11-13, a region subject to genomic imprinting, with the genetic subtypes of paternal deletion (delPWS), maternal uniparental disomy (mUPD) and imprinting centre defects. In addition to PWS-typical hyperphagia, people with PWS often have a behavioural phenotype, typically with stubbornness, emotional outbursts, and repetitive, ritualised behavioural patterns. The PWS behavioural phenotype can be ICD-coded as a diagnosis of Personality Change Secondary to a Medical Condition. However, psychiatric

comorbidities such as affective and autistic spectrum disorders and psychotic episodes are highly prevalent, with differences between genetic subtypes (Soni et al., 2008). Preliminary studies from different countries have described prevalences of psychiatric comorbidity in PWS between 50% (Feighan et al., 2020) and 89% (Shriki-Tal et al., 2017), depending on the age group. Compared to other neurogenetic disorders, the prevalence of psychiatric comorbidity in people with PWS appears to be particularly high (Glasson et al., 2020).

Germany has a sectoral system of psychiatric care. It is essentially divided into professional inpatient, semi-inpatient, and outpatient (more commonly referred to as ambulatory in Germany) services. Ambulatory services include treatment by specialists in psychiatry and psychotherapy, the outpatient departments of psychiatric hospitals, home psychiatric care and sociotherapy (van Treeck et al., 2017). One goal of these services is to help people with intellectual disabilities integrate into daily life and the community, and to enable them to live as independently as possible. In the authors' experience, many people with PWS in Germany live in long-term residential care facilities. The actual level of care and therapeutic support can vary depending on the needs of the individual and the characteristics of the facility. Most of these facilities are nursing homes that provide 24-hour personal care. In addition, there are care facilities in Germany that are specifically designed to meet the needs of people with PWS. Facilities that specialise in PWS primarily provide the food-secure environment that most people with PWS need. Otherwise, the main difference between PWS-specialised and regular care facilities is the special activation for physical activities. Occupational therapy and, in some cases, psychological support are tailored to PWS. Special attention is given to dealing with the behavioural phenotype typical of PWS. There are also a few assisted living facilities where people with PWS live in their own homes without 24-h care.

This study aims to investigate the psychiatric care situation of people with PWS through a survey of caregivers of people with PWS in Germany to identify PWS-specific characteristics and needs.

2 | METHODS

An online questionnaire survey with 55 partially open and closed questions was conducted. The questionnaire was developed using SoSci survey (Leiner, 2019). The questionnaire was sent to carers of people with PWS (via the German PWS Association). All participants gave written informed consent to participate in the study. The project was reviewed and approved by the local ethics committee (approval number: 8129_BO_S_2020) and adhered to the Declaration of Helsinki.

The carers were asked closed questions about demographic, diagnostic and treatment parameters related to the person with PWS. In addition, open-ended questions were asked about personal experiences and wishes regarding diagnosis and treatment. The survey was carried out between March 2020 and February 2021.

A translation of the original German questionnaire is included as supplementary material (Data S1). The translation was AI-supported by the program DeepL Translate (DeepL SE, Cologne, Germany).

SPSS Statistics 27 was used for statistical analysis and RStudio for graphing. Descriptive statistics and χ^2 tests for independence were used to compare groups. In addition, qualitative assessment of open-ended questions was performed.

3 | DEMOGRAPHICS

Data were collected from 77 people with PWS (42.9% female, 57.1% male) with an average age of 23.1 years (minimum 3 years, maximum 58 years). 36.4% were minors (< 18 years). Of the minors $n = 5$ (6.5%) were <6 years, $n = 9$ (11.7%) <12 years and $n = 14$ (18.2%) <18 years old. 57.1% of people with PWS lived in a family environment, 41.6% in residential care facilities (defined as long-term care in a residential setting, level of care not specified). Of these, 81.3% lived in residential care facilities stating to be specialised in PWS care. 65.3% of adults, but none of minors, lived in residential care facilities.

The diagnosis of PWS was made in 63.6% within the first year of life (mean age 2.3 ± 1.8 years). The genetic subtype was determined in 68.9% (delPWS 35.1%, mUPD 26.0%, IC 7.8% of cases).

Of those who completed the questionnaire, 98.7% were parents of the person with PWS (72.7% mothers, 10.4% fathers, 15.6% jointly) with a mean age of 52.6 years.

4 | RESULTS

4.1 | Comorbid diagnoses

In the entire group, 44.2% were reported to have at least one comorbid psychiatric diagnosis. Psychiatric entities accounted for 30.8% of all current comorbid diagnoses (Figure 1a). Figure 1b shows the proportion of each psychiatric comorbid condition within the subgroup of those with at least one comorbid psychiatric diagnosis. The most common was impulse control disorder in 25% ($n = 13$), followed by psychotic episodes in 21.2% ($n = 11$) and depression in 15.4% ($n = 8$) of comorbid psychiatric individuals with PWS. Women had slightly fewer psychiatric diagnoses than men (39.4% vs. 47.7%), but the effect was not statistically significant. Impulse control disorder ($n = 8$ males, $n = 5$ females) and psychosis ($n = 8$ males, $n = 3$ females) were more common in males, whereas depression was more common in females ($n = 2$ males, $n = 6$ females). People with the delPWS subtype had the highest percentage of psychiatric comorbidity (55.6%) compared with mUPD (45.0%) and IC (33.3%), with no statistically significant effect. A significant group difference in psychiatric comorbidity was found only between age groups, with a significant clustering of psychiatric comorbidity in adults with 53.1% ($n = 26$) compared to 28.6% ($n = 8$) in minors, $\chi^2(1) = 4.334$, $p = .037$.

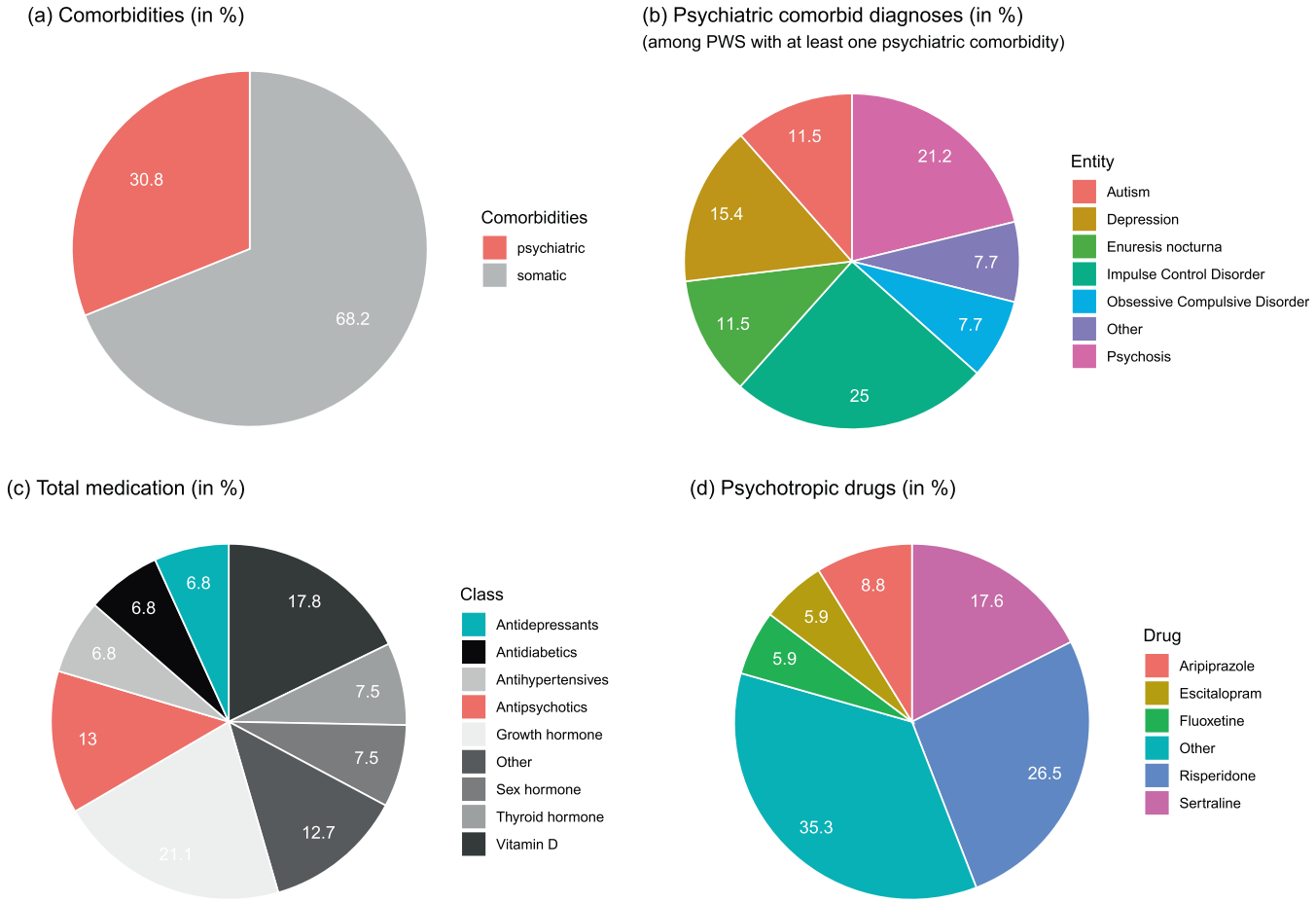

FIGURE 1 Proportion of psychiatric comorbid diagnoses and psychotropic medication among people with PWS in Germany: (a) Percentage of psychiatric comorbidity diagnoses out of all current comorbidity diagnoses. (b) Percentage share of each entity in the current psychiatric comorbidity diagnoses among PWS with at least one psychiatric comorbidity. (c) Percentage share of each drug class in current total medication. (d) Percentage share of antipsychotics and antidepressants in all currently administered psychopharmaceuticals.

4.2 | Use of psychiatric services

44.2% of people with PWS had at least one ambulatory psychiatric consultation and/or treatment during lifetime (including visits by an external psychiatric specialist in a residential care facility), including 12.1% ($n = 4$) specialist PWS consultations. The mean age at first presentation was 15.1 ± 8.4 years. The most common reasons were emotional outbursts or aggressive behaviour (35.3%, $n = 12$), but also depression (14.7%, $n = 5$). In 55.9% ($n = 19$) of these cases, a subjective improvement in symptoms was reported as a result of ambulatory treatment. Among people with PWS who had never received ambulatory psychiatric treatment ($n = 43$), 34.9% reported that they were currently seeking such treatment without success. In the qualitative analysis of the questions about reasons, refusal due to lack of experience with the diagnosis of PWS by potential treatment providers was often reported.

19.5% of respondents ($n = 15$, all of them >18 years) reported that the person with PWS had been hospitalised at least once in lifetime for psychiatric disorders (hospital treatment with at least one overnight stay). Of these, $n = 5$ were hospitalised for 1–2 days, $n = 4$ for up to 2 weeks, $n = 2$ for 2–4 weeks, $n = 3$ for more than 1 month, and $n = 1$ for more than 3 months. The mean age at first hospitalisation was 19.6 ± 5.1 years. The most common reasons for hospitalisation were emotional outbursts ($n = 3$), aggressive behaviour towards others ($n = 4$), or self-injurious behaviour ($n = 2$). 40.0% of respondents ($n = 6$) whose person with PWS was hospitalised reported a subjective improvement in symptoms after hospital treatment.

There was no difference between the sexes with regard to ambulatory psychiatric treatment and hospitalisation. However, there were significant differences between age groups for hospitalisation ($\chi^2(1) = 12.341$, $p < .001$) and ambulatory ($\chi^2(1) = 11.541$, $p = .003$) psychiatric treatment, with minors less likely to seek psychiatric help. Comparing types of accommodation, 62.5% of PWS subjects living in residential care facilities were subject to ambulatory psychiatric treatment and 40.6% to psychiatric hospitalisation

TABLE 1 Group comparisons for concomitant psychiatric diagnoses, use of psychiatric care and psychopharmacotherapy.

			Psychiatric treatment (≥1 x)		
	***n* = X (%)**	**≥1 psychiatric comorbidity *n* = (%)**	**Ambulatory**	**Hospital (overnight)**	**Lifetime psychotropic medication (≥1)**
Total	77	34 (44.2%)	34 (44.2%)	15 (19.5%)	25 (32.5%)
Sex					
Female	33 (42.9%)	13 (39.4%)	12 (36.4%)	8 (24.2%)	7 (21.2%)
Male	44 (57.1%)	21 (47.7%)	22 (50.0%)	7 (15.9%)	18 (40.9%)
Test statistic $\chi^2(1)$		0.531, $p = .466$	1.422, $p = .233$	1.510[a], $p = .470$	3.338, $p = .068$
Age					
<18 years	28 (36.4%)	8 (28.6%)	5 (17.9%)	0 (0%)	2 (7.1%)
>18 years	49 (63.6%)	26 (53.1%)	29 (59.2%)	15 (30.6%)	23 (46.9%)
Test statistic $\chi^2(1)$		4.334, **$p = .037$***	12.341, **$p < .001$*****	11.541[a], **$p = .003$****	12.870, **$p < .001$*****
Accommodation					
Family	44 (57.1%)	15 (34.1%)	13 (29.5%)	2 (4.5%)	7 (15.9%)
Care facility	32 (41.6%)	18 (56.3%)	20 (62.5%)	13 (40.6%)	17 (53.1%)
PWS-specialised	26 (33.8%)	15 (57.7)	16 (61.5%)	10 (38.5%)	14 (53.8%)
Non-specialised	6 (7.8%)	3 (50.0%)	4 (66.7%)	3 (50.0%)	3 (50.0%)
Test statistic $\chi^2(1)$		3.703, $p = .054$	8.190, **$p = .004$****	15.628[a], **$p < .001$*****	11.876, **$p < .001$*****
Genetic subtype					
delPWS	27 (35.1%)	15 (55.6%)	14 (51.9)	8 (29.6%)	11 (40.7%)
mUPD	20 (26.0%)	9 (45.0%)	7 (35.0%)	3 (15.0%)	4 (20.0%)
IC	6 (7.8%)	2 (33.3%)	3 (50.0%)	1 (16.7%)	2 (33.3%)
Test statistic (*delPWS* vs. *mUPD*) $\chi^2(1)$		0.512, $p = .474$	1.320, $p = .251$	1.372[a], $p = .242$	2.275, $p = .132$

Note: χ^2 test statistic: a ≥1 cell of the cross-tabulation with expected frequency <5—thus limited statistical significance.
*Bold statistically significant values.

at least once in lifetime, compared with 29.5% and 4.5% of those living with their families.

4.3 | Medications

83.1% of people with PWS were currently taking at least one medication regularly. After growth hormone (40.3%) and vitamin D preparations (33.8%), antipsychotics were the most common class of medication with 24.6% ($n = 19$). In fact, antipsychotics accounted for 13% of all drugs currently used on a regular basis. Figure 1c gives an overview of the percentage of different classes of medications in the total medication of all participants. Of those treated with antipsychotics, 47.4% ($n = 9$) were treated with risperidone. In addition, 13.0% ($n = 10$) were treated with antidepressants (all selective serotonin re-uptake inhibitors (SSRI)). Figure 1d shows the proportion of total psychotropic medication prescribed. Overall, 28.6% ($n = 22$) of people with PWS were regularly receiving psychotropic medication at the time of the survey. $n = 9$ of these received more than one psychotropic drug, the maximum found was a combination of five regularly taken psychotropic drugs in one subject (risperidone, chlorprothixene, fluoxetine, biperiden, valproate). Asked for lifetime psychotropic medication (at least one during lifespan), men with PWS were more likely to have received lifetime psychotropic medication (40.9%) than women (21.2%), but this did not reach statistical significance, $\chi^2(1) = 3.338$, $p = .068$. There were again significant group differences between minors and adults in lifetime use of psychotropic drugs. Only $n = 2$ of the minors were receiving any psychotropic medication at the time of the study (both risperidone, one additionally fluoxetine).

Table 1 provides an overview of the group comparisons regarding psychiatric comorbidity, treatment and psychopharmacotherapy.

5 | CONCLUSIONS

The results of this study provide the first overview of the psychiatric care situation of people with PWS in Germany.

The prevalence of psychiatric comorbidity in people with PWS was similar to that found in studies from other European countries (Feighan et al., 2020), but significantly lower than in non-European countries (Shriki-Tal et al., 2017). Overall, however, with a prevalence

of 44.2% of psychiatric comorbidity in PWS, this survey again shows a high prevalence of psychiatric comorbidity compared to the general population or IDD population regardless of origin (Mazza et al., 2020).

According to our data, challenging behaviours such as emotional outbursts or aggression have led to use of the mental health care system. The ICD-10 diagnosis of personality change secondary to a medical condition can be used to describe the behavioural phenotype of PWS, which, however, may not be recognised by all practitioners. These phenotypic symptoms, such as stubbornness and emotional outbursts, are best managed through behavioural and environmental interventions, such as provided by PWS-specialised care facilities, where our data show that many adults with PWS live. However, PWS is moreover often associated with comorbid psychiatric diagnoses, particularly impulse control disorders and psychotic and depressive episodes. These comorbid psychiatric diagnoses appear to be best treated with psychotropic medications, for example, impulsive aggression in autism spectrum disorder may be targeted by risperidone. However, the range of indications for risperidone, the most used psychotropic medication according to this study, is quite narrow in Germany. Children and adolescents with intellectual disability can be treated with risperidone for a short time (up to 6 weeks) if they show aggressive behavioural disturbances. However, there is no such official indication for adults, in whom risperidone is mainly prescribed here (presumably for this purpose). In this respect, this drug is usually used off-label in adults with intellectual disabilities. However, the studies of risperidone conducted to date in PWS suggest positive efficacy, particularly regarding aggressive behaviour (Araki et al., 2010; Durst et al., 2000). Positive behavioural effects in PWS have also been shown for sertraline (mostly at low doses), the most commonly prescribed antidepressant in our data (Deest et al., 2020).

One problematic drug is escitalopram (here in $n = 2$ of the subjects, once in combination with risperidone, once in combination with zuclopenthixol), the simultaneous use of which with other drugs that are known to prolong the QT interval and can lead to serious cardiac arrhythmias is contraindicated. A Direct Healthcare Professional Communication has pointed out in 2011 that combinations with other antipsychotics are among these contraindications. In addition, polypharmacy (e.g., a maximum of five psychotropic medications in a subject's fixed medication here) leads to a potentiation of adverse drug reactions and should be critically scrutinised, but at the very least requires close monitoring. Given the young age, this raises concerns about an increased risk of adverse drug reactions over the lifespan, especially as our data show that psychiatric comorbidity and psychopharmacotherapy increase significantly in adulthood. This is particularly important given that people with PWS were shown to be prone to cardiovascular abnormalities at a young age (Kobayashi et al., 2021), which is moreover one of the leading causes of premature death (Proffitt et al., 2019).

In PWS, both sex and the underlying genetic subtype also influence psychiatric comorbidity. Manzardo et al. demonstrated that males with PWS exhibit significantly higher rates of externalising behaviour problems, such as aggression and rule-breaking behaviour, while females had higher rates of internalising behaviour problems, such as anxiety and depression (Manzardo et al., 2018). This is corroborated by the findings of our study, which demonstrated comparable sex differences, particularly in the prevalence of psychosis in males and depression in females with PWS. However, the genetic subtype was not determined in almost a third of the participants in this study, which may have contributed to our inability to reproduce the subtype-dependent differences previously found. More widespread identification of the underlying genetic subtype may also allow more specific psychiatric screening, diagnosis and treatment.

The level of specialised residential care for people with PWS in Germany should be highlighted. This seems particularly worth mentioning as research has shown the protective effects of residential care in relation to behavioural problems (Wieting et al., 2021). In a recent study, Hughes et al. demonstrated that individuals with PWS who joined a full-time care service experienced significant reductions in weight and BMI, as well as improvements in behaviours of concern. The effects were particularly pronounced in PWS-specialised care (Hughes et al., 2024). It is regrettable that our questionnaire did not record the age at which the subjects were admitted to residential care. However, according to our data, people living in residential care facilities seem to have easier access to specialised mental health care than people living with their families. There seems to be room for improvement in ambulatory mental health care. At 44.2%, the rate of access to ambulatory psychiatric care was lower than in the comparative study from Ireland (Feighan et al., 2020). Despite the higher prevalence of psychiatric comorbidity among people with PWS in general, the rate of use of psychiatric care in Germany is similar to that of people with unspecified ID (Weih et al., 2022). Among minors, just under a fifth of respondents had contact with ambulatory psychiatric care. Moreover, we observed reluctance to prescribe psychotropic medication to minors ($n = 8$ psychiatric co-morbid diagnoses versus only $n = 2$ minors receiving psychotropic medication). It should be emphasised that a significant number of those who have not yet received outpatient psychiatric treatment are currently trying to find appropriate care, which according to carers is mainly due to a lack of experience of the specific needs of PWS on the part of potential treatment providers. Awareness raising and training of potential outpatient psychiatrists seems desirable in view of this need. In addition, the range of mental health services in Germany can be confusing and, in some cases, poorly networked. The sectorisation of mental health care providers in Germany can make it difficult to find the right contact person, especially in the case of rare conditions such as PWS.

The present study is limited in its statistical power due to the small number of cases, which is within the usual range compared to previous studies. In addition, this survey is based on the subjective assessment of carers, which is a confounding factor due to response or recall bias. Some remaining imprecisions in interpreting the results could not be avoided due to the design of the questionnaire. For example, we assessed PWS who had been hospitalised once in their lifetime and asked about the subjective benefit of this, but they may continue to benefit from overlapping ambulatory treatment or vice versa.

In conclusion, people with PWS have a high need for psychiatric care due to an increased prevalence of psychiatric comorbidities, which currently appears to be under-represented, especially in the ambulatory sector. The authors hope that this study will increase the awareness of potential treatment providers of people with PWS and their specific needs.

AUTHOR CONTRIBUTIONS

JW: Formal analysis; visualisation; writing – original draft preparation. **TH:** Investigation. **SD-G:** Writing – review and editing. **CE** and **SB:** Writing – review and editing. **HF:** Writing – review and editing; supervision **MD**: Conceptualisation; methodology; writing – review and editing; supervision (lead).

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CONFLICT OF INTEREST STATEMENT

The authors disclose any financial or non-financial conflict of interest.

DATA AVAILABILITY STATEMENT

The data on which the results of this study are based can be made available upon individual request, subject to compliance with the European Union's General Data Protection Regulation.

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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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