Research Square

Preprints are preliminary reports that have not undergone peer review.
They should not be considered conclusive, used to inform clinical practice,
or referenced by the media as validated information.

Weight Outcomes During and After A Family-accompanied Residential Program for Prader-Willi syndrome: A Cohort Study in China

Yi-Xuan Fu
Children's Hospital of Zhejiang University
Xiao-Jing Lin
Zhejiang Prader-Willi Rare Disease Care Center
Fang-Ling Xia
Children's Hospital of Zhejiang University
Yi-Ming Zuo
Children's Hospital of Zhejiang University
Yun-Qi Chao
Children's Hospital of Zhejiang University
Chao-Chun Zou
zcc14@zju.edu.cn

Children's Hospital of Zhejiang University

Research Article

Keywords: Prader-Willi syndrome, Obesity、Weight reduce、Family-Accompanied Center Program

Posted Date: November 3rd, 2026

DOI: https://doi.org/10.21203/rs.3.rs-11349996/v1

License: This work is licensed under a Creative Commons Attribution 4.0 International License.
Read Full License

Additional Declarations: No competing interests reported.

Abstract

Background Weight management is a lifelong challenge for individuals with Prader-Willi syndrome (PWS) and their families. Structured residential settings may facilitate dietary control through scheduled meals, restricted food access, and regular weight monitoring. However, evidence from family-accompanied residential programs remains limited, particularly in China, and little is known about post-discharge weight outcomes. We retrospectively analyzed records from PWS Home, a family-accompanied nonprofit program run by the China PWS Patient Association and our clinical unit, between August 2018 and August 2026. Eligible completed stays with valid admission and discharge weights were included. Percentage body-weight change was evaluated using a linear mixed-effects model accounting for repeated stays. Caregiver follow-up assessed post-discharge weight status and management practices. Separate generalized estimating equation logistic models, adjusted for age at follow-up and follow-up duration, explored associations between family and social management practices and weight regain.

Results A total of 110 individuals contributed 121 eligible completed stays. Body weight decreased during all stays. Median residential duration was 35 days, and median percentage body-weight change was − 12.3%. The model-estimated mean change was − 13.75% (95% confidence interval [CI], -15.17% to -12.34%), with similar estimates in sensitivity analyses. Caregiver follow-up covered 59 post-discharge episodes from 57 participants. Weight regain was reported in 35 episodes (59.3%); the remaining 24 (40.7%) showed continued weight loss or weight maintenance. Full maintenance of a fixed meal structure (adjusted odds ratio, 0.08; 95% CI, 0.01–0.44) and regular body-weight monitoring (0.21; 0.05–0.95) were associated with lower odds of regain, whereas school or work management difficulties were associated with higher odds (8.76; 1.95–39.29). Associations for fixed meal structure and school or work difficulties persisted in sensitivity analyses.

Conclusions Our findings illustrate the challenge of transferring weight-control practices from a structured setting to everyday family and social environments. Continuity of meal routines and coordination of food management across home, school, and work settings warrant further investigation as components of longer-term support for individuals with PWS.

Introduction

Prader-Willi syndrome (PWS) is a rare genetic neurodevelopmental disorder characterized by hyperphagia, food-seeking behavior, and a high risk of obesity. It is known to be the most common syndromic cause of life-threatening obesity. [1] As one of the principal features of PWS, obesity contributes substantially to a serious of complications, including type 2 diabetes mellitus, metabolic syndrome, syndrome of sleep apnea, cardiovascular disease, and overall health burden. [2] Despite the application of pharmacological and surgical treatment of obesity, nutritional strategy remains to play a major role in the management of obesity in PWS. However, as hyperphagia and food-seeking behavior are persistent in patients with PWS [3], sustained dietary restriction is difficult to achieve through individual self-regulation alone. Long-term weight management therefore relies heavily on structured

meals, restricted access to food, caregiver supervision, and consistent food-management practices across home and social settings. [4]

Multidisciplinary clinical care and family-based dietary management are central to PWS care [5]. Miller et al. reported more favorable weight and body-composition outcomes among children whose families followed recommendations for both energy intake and dietary composition [6]. Nevertheless, persistent hyperphagia makes consistent food management across everyday settings difficult. Structured residential and specialized care settings have therefore been explored, with reductions in weight or BMI reported in PWS-specific hostels and full-time care services [7, 8]. Beyond PWS, a randomized trial of childhood obesity evaluated a residential family camp with follow-up support, although it did not demonstrate superiority over outpatient treatment for the primary BMI standard deviation score outcome at two years [9]. These approaches differ in population, staffing, and caregiver participation. Evidence from Chinese center-based programs in which caregivers stay with participants remains limited.

After discharge, patients return to family, school, work, and community environments where food access and routines are less controllable. Maintaining food security outside a structured setting can be challenging, because management must remain consistent across caregivers and environments, while extended family involvement, school and social food exposure, holidays and other celebrations, and persistent food-seeking behaviors may complicate dietary control. [10] [5, 11] Existing literature has described caregiver burden and family food-management challenges. However, limited evidence is available on post-residential weight outcomes and the family and social management challenges encountered after individuals with PWS return to the home environment.

Xiaopang Home (hereafter, PWS Home) is a nonprofit, centralized residential program in Hangzhou, China, established to serve individuals with PWS and their families. Within the Chinese PWS community, the term “Xiaopang” is commonly used to refer to individuals with PWS. Participants reside at the center with a parent or primary caregiver. The program provides centrally prepared meals, restricted food access, and daily weight monitoring, while caregivers retain substantial responsibility for daily care. This study examined body-weight change during residence, post-discharge weight outcomes, and associations between post-discharge family and social management factors and weight maintenance or regain.

Materials and Methods

Study design

This was a single-center, non-interventional retrospective observational cohort study with caregiver follow-up. The study consisted of two complementary components: (1) retrospective analysis of body-weight changes during structured residential management at PWS Home, and (2) caregiver follow-up to assess post-discharge weight changes and family and social management factors. Stays completed on or before August 15, 2026 were eligible for the residential weight-change analysis if valid admission and

discharge weights were available. Stays ongoing at the cutoff date were excluded from the completed-stay analysis.

PWS Home

PWS Home is a nonprofit residential support organization for individuals with PWS, located in Hangzhou, Zhejiang Province, China. Established in 2018, PWS Home is now operated by Mr. Lin, a parent of an individual with PWS. Families typically contact the organization through PWS patient-support groups or its official WeChat account. Individuals with a diagnosis of PWS are eligible to stay, and the duration of stay is determined according to individual and family needs. A parent or primary caregiver accompanies the participant throughout the stay and remains primarily responsible for daily care.

The general management framework has remained broadly stable since the establishment of PWS Home in 2018. The residential setting provides a structured food environment. Meals are centrally prepared by staff and are provided at four scheduled times each day: breakfast, lunch, an afternoon fruit serving, and dinner. Portion sizes of meals are adjusted according to age and individual needs. The kitchen is locked, and participants are not allowed unrestricted access to food. Off-site outings and eating outside the residence are generally discouraged or not permitted. However, because caregivers stay with participants, some aspects of food access remain under caregiver discretion, and the organization does not impose absolute control over food provided privately by caregivers. Medications and other individual medical management areoverseen by accompanying caregivers.

As for physical activities, participants may use on-site exercise equipment, engage in activities arranged by caregivers, and participate in weekly rehabilitation-led activities. Daily routines outside scheduled meals are not rigidly fixed. Volunteer-led recreational activities are also provided occasionally. Body weight is measured every morning in the fasting state using the same electronic scale; discharge weight is measured under the same conditions on the morning of departure. Caregivers also participate in educational or practical activities related to dietary management, rehabilitation, and behavioral or emotional management.

Participants

Individuals with at least one completed residential stay during the study period and reliable admission and discharge body-weight measurements were eligible for the residential weight analysis.

Participants who had at least one residential stay between June 2023 and June 2026 constituted the recent-stay cohort for caregiver follow-up. Caregivers were contacted remotely and voluntarily decided whether to provide follow-up information. Caregiver responders were defined as those who completed at least the core questions on post-discharge family management, whereas nonresponders were those who provided no analyzable follow-up information after the standardized contact process. Participants who had returned home for at least 3 weeks by the data-freeze date and for whom either an objective

body-weight measurement or a reliable report of weight trajectory was available were considered evaluable for post-discharge weight maintenance.

Participants who had returned home before June 2023 were considered historical participants. They were not approached for caregiver follow-up because they fell outside the prespecified recall window, but remained eligible for the residential weight analysis if reliable admission and discharge weights were available. Likewise, participants whose only residential stay occurred after June 2026 were not included in the caregiver follow-up cohort because the available post-discharge follow-up period was considered too short for meaningful assessment.

Residential records

Residential records were retrospectively extracted from routinely maintained PWS Home records. Variables included demographic information, dates of admission and discharge, admission and discharge body weights, and repeated residential stays. Records with unclear dates or potentially duplicated stays were reviewed and verified when possible.

Caregiver follow-up

Caregivers were contacted remotely and asked about post-discharge body weight or weight trajectory, dietary routines, food-access management, physical activity, weight monitoring, food seeking, behavioral difficulties, and challenges encountered in family or social environments.

Clinical background and medication data

Clinical background information, including PWS genetic subtype, major comorbidities, and selected treatments relevant to body-weight regulation or general disease management, was collected from available medical records, genetic test reports, and caregiver-provided information. Genetic subtype was categorized as deletion, maternal uniparental disomy, imprinting defect, other/atypical subtype, or unknown, according to the most specific information available. The source of genetic information was recorded separately, and caregiver-reported subtype information was not upgraded to a more specific category when documentary confirmation was unavailable.

Major comorbidities of interest included diabetes or hyperglycemia, obstructive sleep apnea, scoliosis and other skeletal issues, hypothyroidism, epilepsy or seizure disorders, and other major chronic conditions considered potentially relevant to weight management or physical activity. Medication data focused on therapies with potential effects on body weight or metabolic status, including growth hormone, glucose-lowering medications, anti-obesity medications, thyroid hormone replacement, and selected psychotropic medications. For post-discharge analyses, major initiation or change of weight-affecting medication after discharge was additionally recorded and considered in sensitivity analyses.

Outcomes and measurements

Height was not consistently recorded at admission, discharge, or post-discharge follow-up. Outcomes were therefore assessed using body weight rather than BMI or age- and sex-standardized BMI measures. Post-discharge weight regain was used as a descriptive term for an increase relative to discharge weight and was not interpreted as a measure of increased adiposity or recurrence of obesity.

The primary outcome was percentage change in body weight during residential management, calculated as [(discharge weight−admission weight)/admission weight] × 100%. Negative values indicated weight loss. Secondary outcomes included absolute weight change during residence, calculated as discharge weight minus admission weight, and post-discharge weight status.

Post-discharge weight status was determined using the most recent approximate body weight reported by the caregiver at follow-up, relative to discharge weight. Percentage post-discharge weight change was calculated as [(follow-up weight − discharge weight) / discharge weight] × 100%. Each post-discharge episode was classified as continued weight loss if this change was < 0%; weight maintenance if it was ≥ 0% but < 2%; mild weight regain if it was ≥ 2% but < 5%; moderate weight regain if it was ≥ 5% but < 10%; and marked weight regain if it was ≥ 10% the corresponding admission weight. Episodes meeting the criterion for marked weight regain were assigned to that category regardless of the percentage increase from discharge weight.

The interval between discharge and caregiver follow-up was calculated separately for each post-discharge episode.

Family/social variables

Family and social management variables were obtained from caregiver follow-up and were grouped into several prespecified domains reflecting post-discharge weight-management practices and environmental challenges. These included dietary structure and portion control, restriction of food access at home, regular physical activity, body-weight monitoring, food provision by relatives, difficulties related to school or other social settings, eating outside the home or during holidays, food-seeking behavior, and behavioral or emotional difficulties.

Caregiver responses were converted into structured variables according to a prespecified coding framework. Variables were generally coded as present, absent, or unknown when the available information was insufficient for classification. Missing or unclear responses were not assumed to indicate absence of the corresponding management practice or difficulty.

For participants with multiple residential stays, family and social management variables were referenced to the period following the prespecified index stay used for the post-discharge analysis. These variables were examined descriptively and, where sample size permitted, explored for associations with post-discharge weight status.

Statistical analysis

Continuous variables were summarized as mean ± standard deviation (SD) for approximately normally distributed data and as median with interquartile range (IQR) for skewed data. Categorical variables were summarized as counts and percentages.

All eligible completed residential stays were included in the primary residential weight analysis and summarized at the episode level. Residential duration was calculated inclusively from admission through discharge. Absolute weight change was calculated as discharge weight minus admission weight, and percentage body-weight change was calculated as [(discharge weight − admission weight)/admission weight] × 100%, with negative values indicating weight loss. Because some participants contributed more than one eligible stay, an intercept-only linear mixed-effects model with a participant-specific random intercept was fitted to percentage body-weight change. The model was estimated using restricted maximum likelihood, with Satterthwaite degrees of freedom used for statistical inference. The distribution of residential duration and percentage body-weight change was additionally examined using descriptive scatterplots.

For caregiver follow-up, post-discharge information was linked to the corresponding residential stay whenever the caregiver could clearly distinguish the post-discharge period following that stay. A participant could therefore contribute more than one post-discharge episode when sufficiently detailed episode-specific information was available. Episodes for which post-discharge information could not be reliably attributed to a specific residential stay were not used in episode-specific analyses. The interval between residential discharge and caregiver follow-up was calculated separately for each post-discharge episode.

Post-discharge weight status was summarized according to the prespecified categories of continued weight loss, weight maintenance, mild weight regain, moderate weight regain, and marked weight regain. For association analyses, continued weight loss and weight maintenance were grouped as no weight regain, whereas mild, moderate, and marked weight regain were grouped as weight regain.

Family and social management variables were summarized descriptively and explored for associations with post-discharge weight regain. Each management factor was evaluated in a separate generalized estimating equation logistic model with participant ID as the clustering variable, an independent working correlation structure, and robust covariance estimation. Models were adjusted for age at caregiver follow-up and follow-up duration, expressed per 6-month increment. Adjusted odds ratios (aORs) with 95% confidence intervals (CIs) were reported. Because of the limited sample size and the number of comparisons, these association analyses were considered exploratory, and P values were not adjusted for multiple comparisons.

Potential response bias was assessed among caregivers who had been approached for follow-up by comparing responders and nonresponders using characteristics available from residential records.

Continuous variables were compared using the Mann–Whitney U test, and categorical variables were compared using Fisher's exact test, as appropriate.

Sensitivity analyses of the residential outcome (1) retained the most recent eligible completed stay for each participant and estimated the mean percentage body-weight change and its t-based 95% CI using a one-sample t test against zero, and (2) excluded participants flagged as having prolonged continuous residence and repeated the linear mixed-effects model. Sensitivity analyses of post-discharge associations (1) retained one follow-up episode per participant and (2) excluded episodes in which a major weight-affecting medication was initiated or substantially changed after discharge.

All tests were two-sided, with $P < 0.05$ considered statistically significant. Statistical analyses were performed using IBM SPSS Statistics, version 27.

Missing data

Missing data were not imputed. Analyses were conducted using available data for each variable, and variable-specific denominators were reported when observations were missing. Missing or unclear caregiver responses were coded as unknown and were not interpreted as absence of the corresponding characteristic or management practice.

Participants with missing admission or discharge body weight were excluded from the residential weight-change analysis but could remain eligible for other analyses for which sufficient data were available. Similarly, caregiver responders without an available post-discharge body weight were retained in descriptive analyses of family and social management but were not included in analyses of post-discharge weight status. Missing clinical background or medication information did not result in exclusion from the caregiver follow-up cohort.

Ethics

This study was conducted in accordance with the Declaration of Helsinki. The study protocol was approved by the Ethics Committee of the Children's Hospital, Zhejiang University School of Medicine (approval No. 2026-IRB-0329-P-01). Given the retrospective and minimal-risk nature of the study, the requirement for written informed consent was waived in accordance with the approved protocol. For caregiver follow-up, the study purpose and privacy principles were explained, and caregivers voluntarily decided whether to provide information.

Results

Study population and residential cohort characteristics

Between August 1, 2018 and August 15, 2026, 110 individuals with PWS contributed 121 eligible completed residential stays to the primary residential analysis (Fig. 1). The cohort included 63 males

(57.3%) and 47 females (42.7%). Age at first admission was available for 108 participants; the median age was 11.0 years (Q1-Q3, 8.3–13.9 years; range, 4–22 years).

Ten participants contributed more than one eligible completed stay: nine contributed two stays and one contributed three, accounting for 21 of the 121 stay episodes. One additional participant had a repeated-stay history but only one completed stay met eligibility criteria for the primary residential analysis. Three prolonged continuous-residence stays were retained in the primary analysis and prespecified for exclusion in sensitivity analyses. The median residential stay duration was 35 days (Q1-Q3, 26.0-63.5 days), and the median admission body weight was 71.6 kg (Q1-Q3, 55.1–93.4 kg), as shown in Table 1.

Table 1
Study population and residential cohort characteristics

Characteristic	Value
Participant-level characteristics	
Unique participants, n	110
Male sex, n (%)	63 (57.3)
Female sex, n (%)	47 (42.7)
Age at first admission, years, median (Q1-Q3) [n = 108]	11.0 (8.3–13.9)
Participants with a repeated-stay history, n (%)	11 (10.0)
Participants contributing > 1 eligible completed stay, n (%)	10 (9.1)
Participants with prolonged continuous residence, n (%)	3 (2.7)
Stay-level characteristics	
Eligible completed residential stays, n	121
Stays contributed by participants with > 1 eligible completed stay, n (%)	21 (17.4)
Prolonged continuous-residence stays, n (%)	3 (2.5)
Residential stay duration, days, median (Q1-Q3)	35.0 (26.0-63.5)
Admission body weight, kg, median (Q1-Q3)	71.6 (55.1–93.4)

Data are presented as n (%) or median (Q1-Q3), as appropriate. Age at first admission was calculable for 108 participants from available birth information. A repeated-stay history indicates more than one recorded residential stay; one such participant had only one completed stay eligible for the primary residential analysis.

Residential weight change

Body weight decreased during all 121 eligible residential stays (Fig. 2). Median admission and discharge body weights were 71.6 kg (Q1-Q3, 55.1–93.4 kg) and 60.6 kg (46.5–79.2 kg), respectively. The median within-stay absolute weight change was − 8.5 kg (-13.9 to -5.4 kg), corresponding to a median

percentage body-weight change of -12.3% (-17.5% to -9.1%). Percentage body-weight change ranged from − 49.5% to -2.2% (Table 2).

Table 2
Residential body-weight outcomes

Outcome	n	Median (Q1-Q3)	Range
Admission body weight, kg	121	71.6 (55.1–93.4)	29.3–178.0
Discharge body weight, kg	121	60.6 (46.5–79.2)	23.8-151.7
Absolute weight change, kg	121	-8.5 (-13.9 to -5.4)	-53.5 to -1.4
Percentage body-weight change, %	121	-12.3 (-17.5 to -9.1)	-49.5 to -2.2

Values are median (Q1-Q3) unless otherwise indicated. Negative change values indicate weight loss. The linear mixed-effects model included a participant-specific random intercept to account for repeated residential stays within participants; the model-estimated mean percentage body-weight change was − 13.75% (95% CI, -15.17% to -12.34%; P < 0.001).

In a linear mixed-effects model accounting for repeated residential stays within participants using a participant-specific random intercept, the model-estimated mean percentage body-weight change during residence was − 13.75% (95% CI, -15.17% to -12.34%; P < 0.001).

The distribution of residential duration and percentage body-weight change is shown in Fig. 3. The three prolonged continuous-residence stays lasted 446, 487, and 521 days, with percentage body-weight changes of − 47.14%, − 49.49%, and − 41.92%, respectively. After these participants were excluded, the remaining eligible stays ranged from 3 to 115 days, and percentage body-weight change ranged from − 28.57% to − 2.18%.

Caregiver follow-up

Among 75 participants who retrospectively met the prespecified recent-stay criteria for caregiver follow-up, 67 caregivers had been approached before the follow-up period closed. Of these, 57 provided analyzable follow-up information, corresponding to a response rate of 85.1% among approached caregivers. An additional eight participants met the recent-stay criteria but were not approached because their residential data became available only after caregiver follow-up had closed. The 57 responding participants contributed 59 analyzable follow-up episodes; two participants contributed two distinct post-discharge episodes.

In the responder versus explicit nonresponder comparison (57 *vs* 10 participants), nonresponders had a higher admission body weight than responders (median, 94.6 *vs* 67.3 kg; Mann-Whitney P = 0.040). No clear between-group differences were observed for age at admission (P = 0.455), discharge body weight (P = 0.091), residential stay duration (P = 0.159), percentage body-weight change during residence (P = 0.093), sex (Fisher exact P = 0.736), repeated-stay status (Fisher exact P = 0.614), or long-term residential status (Fisher exact P = 1.000).

The mean age at caregiver interview was 11.9 years (SD, 3.7), and 28 of 57 participants (49.1%) were female. Among 56 interviews with a recorded respondent relationship, 52 (92.9%) were completed by mothers. Clinical background checks were completed for 49 participants. Among 54 participants with genetic-subtype information, 35 (64.8%) had a deletion subtype, 2 (3.7%) had maternal uniparental disomy, 5 (9.3%) had another non-deletion subtype, and 12 (22.2%) had an unknown subtype. Key clinical and medication characteristics are summarized in Table 3.

Table 3
Characteristics of the caregiver follow-up cohort and post-discharge outcomes

Characteristic	Available n	Value
Participant characteristics		
Age at caregiver interview, years, mean (SD)	57	11.9 (3.7)
Female sex	57	28 (49.1%)
Caregiver respondent: mother	56	52 (92.9%)
Completed clinical background check	57	49 (86.0%)
Genetic subtype		
Deletion	54	35 (64.8%)
Maternal UPD	54	2 (3.7%)
Non-deletion/other	54	5 (9.3%)
Unknown subtype	54	12 (22.2%)
Clinical background		
Diabetes or hyperglycemia	49	16 (32.7%)
Sleep apnea or CPAP use	49	12 (24.5%)
Hypothyroidism or thyroxine use	49	2 (4.1%)
Epilepsy or recurrent seizures	48	2 (4.2%)
Activity-limiting condition	49	16 (32.7%)
Major health event after return home	43	7 (16.3%)
Medication use		
Growth hormone during residential stay	49	22 (44.9%)
Current growth hormone	49	21 (42.9%)
Weight/glucose-lowering medication during stay	49	6 (12.2%)
Current weight/glucose-lowering medication	49	6 (12.2%)
Psychotropic/behavior medication during stay or currently	49	0 (0.0%)
Thyroid medication during stay	49	1 (2.0%)

Values are n (%) unless otherwise indicated. Denominators vary because some clinical background, genetic, medication, and social-management variables were unavailable for some participants. Participant characteristics are summarized at the person level (57 unique responders); post-discharge weight outcomes are summarized at the episode level (59 episodes from 57 participants). UPD indicates uniparental disomy; CPAP, continuous positive airway pressure.

Characteristic	Available n	Value
Participant characteristics		
Current thyroid medication	49	2 (4.1%)
Important medication change after return home	49	9 (18.4%)
Post-discharge follow-up		
Follow-up interval, days, median (Q1-Q3)	59 episodes	312 (166–591)
Weight regain, binary outcome	59 episodes	35 (59.3%)
Five-category weight status		
Continued weight loss	58 episodes	15 (25.9%)
Weight maintenance	58 episodes	9 (15.5%)
Mild weight regain	58 episodes	3 (5.2%)
Moderate weight regain	58 episodes	6 (10.3%)
Marked weight regain	58 episodes	25 (43.1%)

Values are n (%) unless otherwise indicated. Denominators vary because some clinical background, genetic, medication, and social-management variables were unavailable for some participants. Participant characteristics are summarized at the person level (57 unique responders); post-discharge weight outcomes are summarized at the episode level (59 episodes from 57 participants). UPD indicates uniparental disomy; CPAP, continuous positive airway pressure.

Across the 59 analyzable follow-up episodes, the median interval from residential discharge to caregiver interview was 312 days (Q1-Q3, 166–591 days), equivalent to 10.3 months (5.5–19.4 months), with a range of 24-1136 days. Five-category post-discharge weight status was classifiable for 58 episodes: 15 (25.9%) showed continued weight loss, 9 (15.5%) weight maintenance, 3 (5.2%) mild weight regain, 6 (10.3%) moderate weight regain, and 25 (43.1%) marked weight regain. Using the prespecified binary outcome, weight regain was observed in 35 of 59 episodes (59.3%), whereas 24 (40.7%) were classified as continued weight loss or weight maintenance.

Family and social management

At follow-up, a fully maintained fixed meal structure was reported in 39 of 59 episodes (66.1%), full home food-security control in 31 of 59 (52.5%), regular physical activity in 39 of 58 (67.2%), and regular body-weight monitoring in 39 of 57 (68.4%). School or work management difficulties were reported in 25 of 50 episodes (50.0%), and relatives providing food was identified as a management issue in 25 of 53 (47.2%). Among episodes with available information, food-seeking behavior was reported as improved in 6 of 52 (11.5%), unchanged in 43 (82.7%), and worsened in 3 (5.8%); behavioral or emotional difficulties were improved in 11 of 52 (21.2%), unchanged in 37 (71.2%), and worsened in 4 (7.7%).

Associations with post-discharge weight regain

In separate generalized estimating equation logistic models accounting for repeated observations within participants and adjusting for age at follow-up and follow-up duration, full maintenance of a fixed meal structure was associated with substantially lower odds of post-discharge weight regain (adjusted odds ratio [aOR], 0.08; 95% CI, 0.01–0.44; P = 0.004). Regular body-weight monitoring was also associated with lower odds of weight regain (aOR, 0.21; 95% CI, 0.05–0.95; P = 0.042). In contrast, reported management difficulties in school or work settings were associated with higher odds of weight regain (aOR, 8.76; 95% CI, 1.95–39.29; P = 0.005). No clear associations were observed for full home food-security control, regular physical activity, or relatives providing food as a management issue (Table 4).

Table 4
Associations of family and social factors with post-discharge weight regain

Factor	Comparison	Weight regain, n/N (%)	aOR	95% CI	P value
Fixed meal structure	Fully maintained vs no/partial	17/39 (43.6%) vs 18/20 (90.0%)	0.08	0.014–0.439	0.004
Home food-security control	Fully implemented vs no/partial	17/31 (54.8%) vs 18/28 (64.3%)	0.73	0.234–2.271	0.586
Physical activity	Regular vs no/irregular	21/39 (53.8%) vs 14/19 (73.7%)	0.51	0.135–1.950	0.327
Body-weight monitoring	Regular vs no/occasional	19/39 (48.7%) vs 14/18 (77.8%)	0.21	0.045–0.946	0.042
School/work management	Difficulty present vs absent	20/25 (80.0%) vs 10/25 (40.0%)	8.76	1.954–39.291	0.005
Relatives providing food	Issue present vs absent	18/25 (72.0%) vs 14/28 (50.0%)	1.75	0.469–6.536	0.405

Each effect estimate was obtained from a separate generalized estimating equation logistic model with participant ID as the clustering variable, an independent working correlation structure, and robust covariance estimation. All models adjusted for age at caregiver interview and follow-up duration (per 6 months). The binary outcome was post-discharge weight regain. P values are nominal and were not adjusted for multiple comparisons; association analyses were exploratory. aOR indicates adjusted odds ratio.

Sensitivity analyses

Sensitivity analyses of the residential outcome produced results consistent with the primary analysis. When the analysis was restricted to the most recent eligible completed stay for each participant, 110 stays from 110 participants were retained. The median percentage body-weight change was − 12.29% (IQR, − 17.46% to − 8.97%), and the mean change was − 13.70% (95% CI, − 15.15% to − 12.26%; P < 0.001). After excluding the three participants flagged as prolonged continuous residents, 118 stays from

107 participants remained. The median percentage body-weight change was − 12.10% (IQR, − 17.38% to − 9.01%), and the mixed-model estimated mean change was − 12.91% (95% CI, − 13.94% to − 11.88%; P < 0.001). These estimates were similar to the primary mixed-model estimate of − 13.75% (95% CI, − 15.17% to − 12.34%).

The principal post-discharge associations were also materially unchanged when analyses were restricted to one follow-up episode per participant. Full maintenance of a fixed meal structure remained associated with lower odds of weight regain (aOR, 0.08; 95% CI, 0.02–0.44; P = 0.003; n = 57), whereas school/work management difficulties remained associated with higher odds of weight regain (aOR, 8.27; 95% CI, 1.86–36.73; P = 0.005; n = 48). Regular body-weight monitoring was also associated with lower odds of weight regain in this participant-level analysis (aOR, 0.21; 95% CI, 0.05–0.85; P = 0.029; n = 55).

In the analysis restricted to follow-up episodes with documented absence of major weight-affecting medication changes after discharge, full maintenance of a fixed meal structure remained associated with lower odds of weight regain (aOR, 0.09; 95% CI, 0.01–0.90; P = 0.040; n = 41), whereas school/work management difficulties remained associated with higher odds of weight regain (aOR, 6.55; 95% CI, 1.31–32.69; P = 0.022; n = 34). The association with regular body-weight monitoring remained in the same direction but was no longer statistically significant (aOR, 0.30; 95% CI, 0.05–1.81; P = 0.191; n = 39).

Discussion

Main findings

In this retrospective observational study, structured residential management at PWS Home was associated with substantial weight reduction: body weight decreased across all 121 stays, with a median reduction of 12.3%. After discharge, 59.3% of follow-up episodes showed weight regain. Fixed meal structure was associated with lower odds of regain and school/work management difficulties with higher odds; both associations persisted in sensitivity analyses. The association with regular weight monitoring was less consistent.

Weight reduction during structured residential management

These residential findings are consistent with reports from PWS-specific services. Hirsch et al. documented sustained BMI reductions in adults living in specialized hostels [7], and Hughes et al. reported weight and BMI reductions after entry into full-time care services [8]. Differences in age, duration, staffing, and outcome measures preclude direct comparisons of effect sizes.

At PWS Home, centrally prepared meals, scheduled eating times, portion adjustment, restricted kitchen access, and daily weighing may have supported consistent management. These practices accord with

PWS guidance [5], but their individual contributions could not be determined because intake, activity, and adherence were not quantified. Weight reduction alone does not establish improvement in hyperphagia.

Unlike predominantly adult professional residential services, this Chinese nonprofit program involves caregivers who remain responsible for daily care. Participation may allow families to practise routines, but changes in caregiver skills and their application at home were not evaluated. Comparative effectiveness and the safety or composition of the observed weight loss therefore remain uncertain.

Post-discharge weight trajectories and continuity of management

At a median follow-up of 10.3 months, 59.3% of episodes showed regain and 40.7% showed continued loss or maintenance. Thus, residential reductions were not uniformly sustained. These outcomes differ conceptually from those reported while individuals remain in specialist services with ongoing structured support [7, 8]; they concern the transition back to usual living environments.

Maintaining routines after discharge may require coordination among relatives and school staff. Substantial caregiver burden has been documented in PWS [12], although it was not measured here. The possibility that differences in coordination contributed to post-discharge outcomes is plausible, but was not demonstrated by this study.

Family and social factors associated with post-discharge weight regain

The association between fixed meal structure and lower odds of regain was consistent across sensitivity analyses. A regular schedule may limit unplanned intake, or may reflect broader consistency in portion control and caregiving. Miller et al. linked adherence to energy and dietary-composition recommendations with more favorable outcomes [6], but did not isolate meal timing. Our findings likewise do not establish an independent effect of meal scheduling.

School/work management difficulties were associated with higher odds of regain. Guidance emphasizes food security and coordination with educational settings [5], supporting further evaluation of shared management arrangements. However, the wide confidence interval limits precision, and reported difficulties cannot be interpreted as a demonstrated cause of regain.

Regular weighing was associated with lower odds of regain in the main and participant-level analyses, but not significantly so after excluding episodes with important medication changes. Monitoring may support earlier responses or indicate broader caregiver engagement. A trial in adults without PWS supports a self-regulation program incorporating daily weighing [13], but does not establish the effectiveness of weighing alone in PWS.

No clear associations were found for home food-security control, physical activity, or relatives providing food. Limited sample size and broad caregiver-reported categories may have obscured relevant differences. Each factor was modeled separately, and practices may have changed in response to weight gain; neither independence from other practices nor temporal direction was established.

Strengths and limitations

Strengths include routinely collected records spanning several years, linkage with caregiver follow-up, and analyses accounting for repeated observations. Sensitivity analyses supported the principal associations in a family-accompanied setting underrepresented in previous residential studies.

The retrospective, single-center design and lack of a concurrent comparator preclude causal attribution and limit generalizability. Families attending PWS Home may differ in motivation, resources, or management needs. Intake, activity, and adherence were not systematically measured, preventing assessment of individual program components.

Incomplete height data prevented consistent assessment of BMI or age- and sex-standardized BMI. In this predominantly pediatric population, post-discharge weight gain may partly reflect normal growth and should not be equated with increased adiposity or recurrent obesity. Missing body-composition, nutritional, and adverse-event assessments also limit interpretation of residential weight loss.

Caregiver-reported outcomes and practices were vulnerable to recall, measurement, and social desirability biases. Follow-up intervals varied; adjustment could not fully address these differences. Concurrent assessment of practices and weight outcomes leaves reverse causation possible.

Only a subset of eligible participants provided follow-up. Explicit nonresponders had higher admission weight, suggesting selection bias of uncertain direction. Missing clinical and management information further reduced the available sample sizes.

Finally, the exploratory models were small, had wide confidence intervals, and were not mutually adjusted for management practices. Residual confounding and unadjusted multiple comparisons remain concerns despite sensitivity analyses. Prospective multicenter studies with standardized anthropometry and repeated assessment of practices are needed to confirm these observations.

Conclusion

Substantial weight reduction was observed during residence at PWS Home, but post-discharge weight regain was common. Fixed meal structure and school/work management difficulties were associated with post-discharge outcomes. These exploratory findings support prospective evaluation of coordinated weight-management support across residential, family, and social settings.

Declarations

Acknowledgement

We thank the individuals with PWS and their caregivers, and the China PWS Patient Association, for their participation and support.

Authors' contributions: C.Z. conceptualized the study and reviewed and edited the manuscript. Y.F. wrote the original draft. F.X. prepared the figures. Y.F. and X.L. collected the data. Y.Z. and Y.C. supervised the study. All authors reviewed and approved the final manuscript.

Funding: Supported by the Children's Hospital of Zhejiang University School of Medicine Pre Research Fund (CHZJU2023YY001).

Ethics approval and consent to participate: The study protocol was approved by the Ethics Committee of the Children's Hospital, Zhejiang University School of Medicine (approval No. 2026-IRB-0329-P-01). This study was conducted in accordance with the Declaration of Helsinki. Given the retrospective and minimal-risk nature of the study, the requirement for written informed consent was waived in accordance with the approved protocol. For caregiver follow-up, the study purpose and privacy principles were explained, and caregivers voluntarily decided whether to provide information.

Conflicts of Interest: The authors declare no conflict of interest.

References

1. Angulo MA, Butler MG, Cataletto ME. Prader-Willi syndrome: a review of clinical, genetic, and endocrine findings. J Endocrinol Investig. 2015;38(12):1249–63. 10.1007/s40618-015-0312-9.
2. Muscogiuri G, Barrea L, Faggiano F, Maiorino MI, Parrillo M, Pugliese G, et al. Obesity in Prader–Willi syndrome: physiopathological mechanisms, nutritional and pharmacological approaches. J Endocrinol Investig. 2021;44(10):2057–70. 10.1007/s40618-021-01574-9.
3. Schwartz L, Caixàs A, Dimitropoulos A, Dykens E, Duis J, Einfeld S, et al. Behavioral features in Prader-Willi syndrome (PWS): consensus paper from the International PWS Clinical Trial Consortium. J Neurodevelopmental Disorders. 2021;13:25. 10.1186/s11689-021-09373-2.
4. Di Lorenzo R, Sberveglieri S, Marrama D, Landi G, Ferri P. Weight control and behavior rehabilitation in a patient suffering from Prader Willi syndrome. BMC Res Notes. 2016;9:199. 10.1186/s13104-016-1981-y.
5. Shaikh MG, Barrett TG, Bridges N, Chung R, Gevers EF, Goldstone AP, et al. Prader–Willi syndrome: guidance for children and transition into adulthood. Endocr Connections. 2024;13(8):e240091. 10.1530/EC-24-0091.
6. Miller JL, Lynn CH, Shuster J, Driscoll DJ. A reduced-energy intake, well-balanced diet improves weight control in children with Prader-Willi syndrome. J Hum Nutr Dietetics. 2013;26(1):2–9. 10.1111/j.1365-277X.2012.01275.x.

7. Hirsch HJ, Benarroch F, Genstil L, Pollak Y, Derei D, Forer D, et al. Long-term weight control in adults with Prader-Willi syndrome living in residential hostels. Am J Med Genet Part A. 2021;185(4):1175–81. 10.1002/ajmg.a.62101.
8. Hughes BM, Holland A, Hödebeck-Stuntebeck N, Garrick L, Goldstone AP, Lister M, et al. Body weight, behaviours of concern, and social contact in adults and adolescents with Prader-Willi syndrome in full-time care services: Findings from pooled international archival data. Orphanet J Rare Dis. 2024;19(1):48. 10.1186/s13023-024-03035-x.
9. Benestad B, Lekhal S, Småstuen MC, Hertel JK, Halsteinli V, Ødegård RA, et al. Camp-based family treatment of childhood obesity: randomised controlled trial. Arch Dis Child. 2017;102(4):303–10. 10.1136/archdischild-2015-309813.
10. Wan PM, Ali A, Mognard E, Jegathesan AJ, Lee SL, Ganesan R, et al. Management of food socialization for children with Prader-Willi Syndrome: An exploration study in Malaysia. PLoS ONE. 2024;19(8):e0307874. 10.1371/journal.pone.0307874.
11. Currie G, Estefan A, Caine V. Unable to Feed My Hungry Child: Experiences of Mothers Caring for Children With Prader-Willi Syndrome. Global Qualitative Nurs Res. 2024;11:23333936241242929. 10.1177/23333936241242929.
12. Kayadjanian N, Schwartz L, Farrar E, Comtois KA, Strong TV. High levels of caregiver burden in Prader-Willi syndrome. PLoS ONE. 2018;13(3):e0194655. 10.1371/journal.pone.0194655.
13. Wing RR, Tate DF, Gorin AA, Raynor HA, Fava JL. A self-regulation program for maintenance of weight loss. N Engl J Med. 2006;355(15):1563–71. 10.1056/NEJMoa061883.

Figures

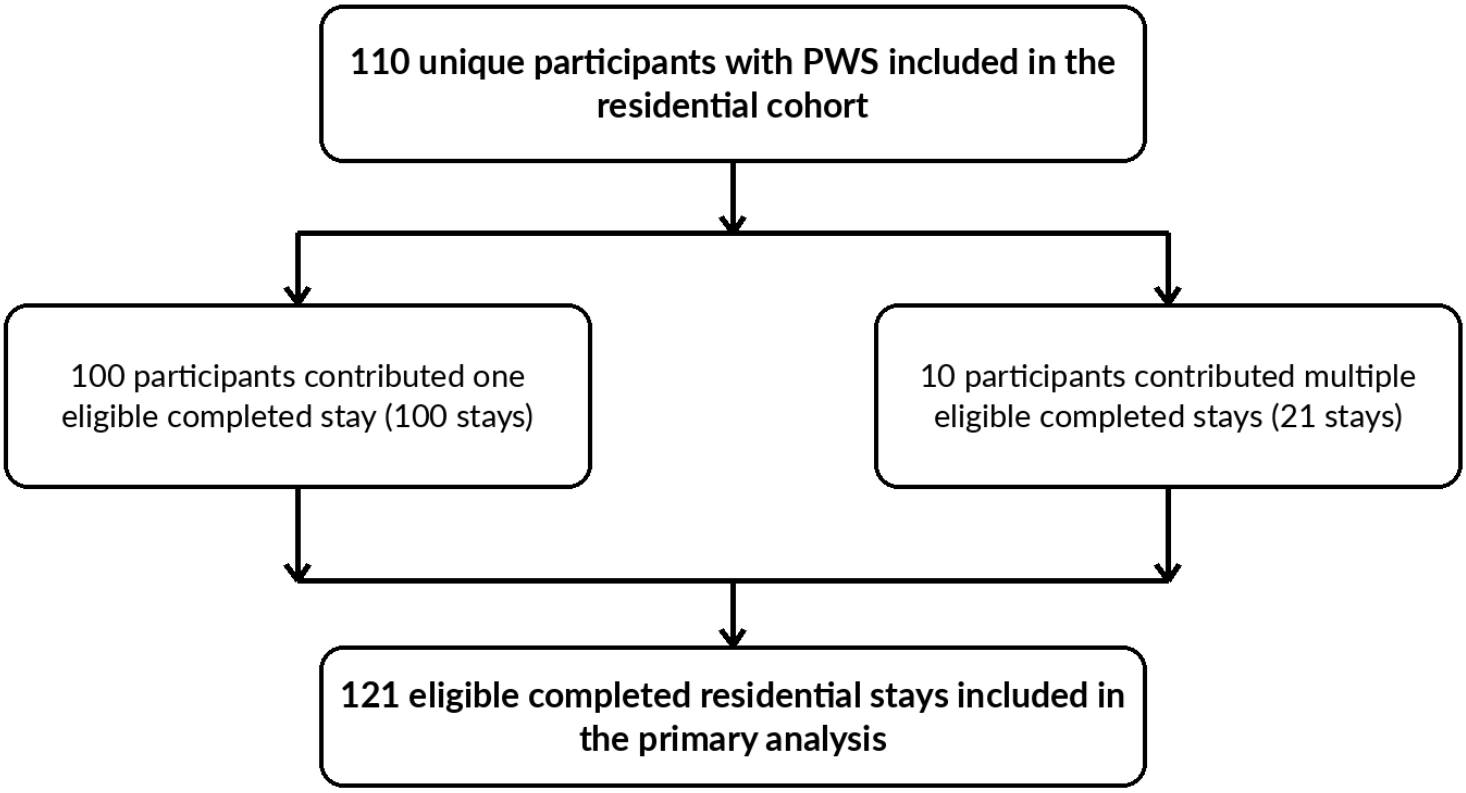


Figure 1

Composition of the primary residential analysis cohort. Three prolonged continuous-residence stays were retained in the primary analysis and prespecified for sensitivity analysis.

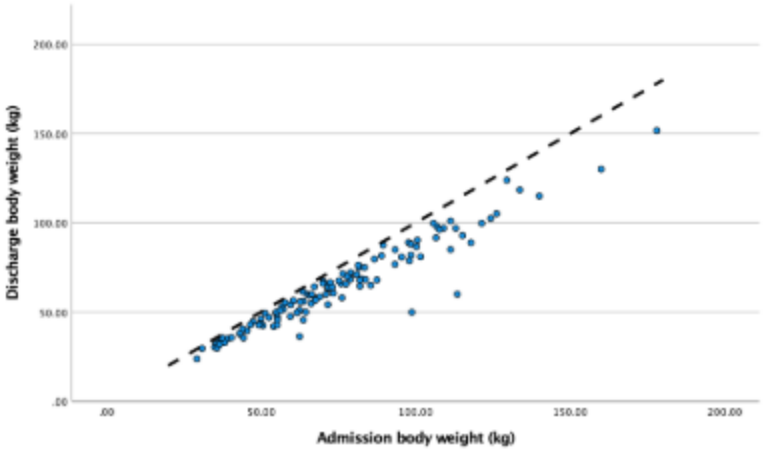


Figure 2

Admission versus discharge body weight across eligible residential stays. Each point represents one completed residential stay (n=121). The dashed diagonal represents no change (discharge weight = admission weight). All observations fell below the line.

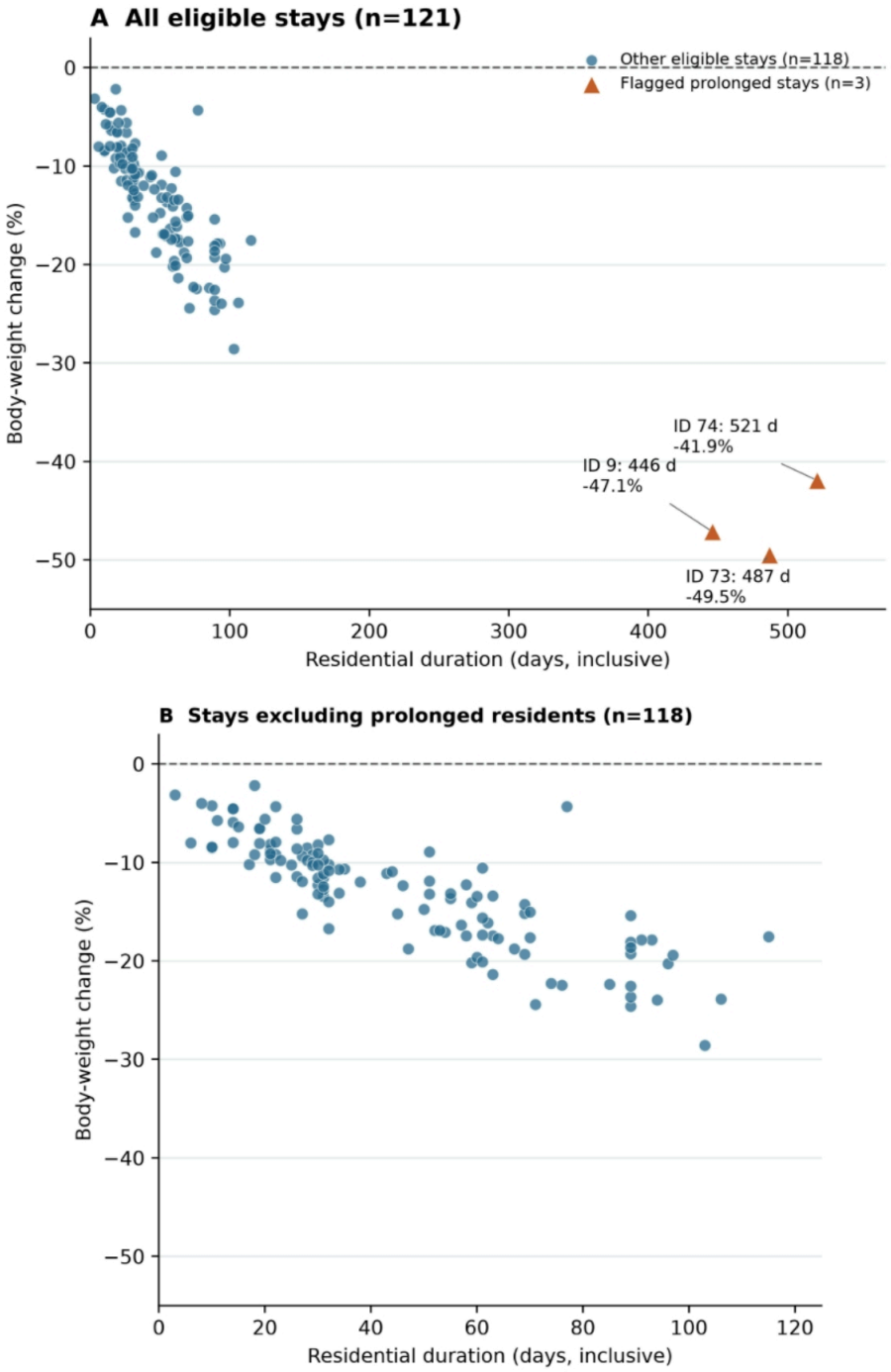


Figure 3

Residential duration and percentage body-weight change during residence. Each point represents one eligible completed residential stay. Panel A includes all 121 stays from 110 participants; the three stays flagged as prolonged continuous residence are shown separately. Panel B includes the 118 stays from 107 participants remaining after exclusion of these residents. Residential duration includes both

admission and discharge dates. Negative values indicate weight loss. The plots are descriptive and do not estimate the causal effect of residential duration.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- Supplementarymaterials.docx