

It's a Burden But...

Having a Sibling with Prader Willi Syndrome: Stress, Growth, and Perceived Burden

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Abstract

Prader Willi Syndrome (PWS) is a rare genetic disorder affecting approximately 1 in 15000 live births worldwide that presents a spectrum of physiological and neurological-related health challenges. PWS has been extensively studied as it affects parents, however, research on sibling interaction is limited. This study examined to what extent neurotypical siblings with a brother or sister with PWS experience stress in daily life, is there a feeling of growth as a result, and are feelings of burden higher when compared to the general population. Using the Perceived Stress Scale 10, the Post Traumatic Growth Inventory, and the Zarit Burden Interview questionnaires, a comparison between families with a neurotypical -PWS sibling dynamic and non-PWS – sibling dynamic was conducted. The findings between the control and experimental groups indicated similar stress levels, and both groups indicated a moderately high level of stress. No statistically significant difference in personal growth was present. The perception of burden was significantly higher for the neurotypical-PWS group versus the control group. The details of the results indicated that the relationship dynamic between PWS-neurotypical siblings requires further research, and the use of different survey tools may be warranted to better explore this population.

Keywords: Prader Willi syndrome, sibling, atypical development, stress, burden, growth

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List of Abbreviations

ASD	Autism Spectrum Disorder
BCPWSA	British Columbia Prader-Willi Association
BSI	Brief Symptom Inventory
DS	Down Syndrome
DSM IV	Diagnostic and Statistical Manual of Mental Disorders Fourth Edition
DUA	Developmental Disability with Unknown Aetiology
HRQoL	Health-Related Quality of Life
PDD	Pervasive Developmental Disorder
PedsQL	Pediatric Quality of Life Inventory-Parent Proxy
PSDI	Positive Symptom Distress Index
PSI/SF	Parenting Stress Index Short Form
PSS 10	Perceived Stress Scale 10
PST	Positive Symptom Total
PTGI	Post Traumatic Growth Invention
PWS	Prader Willi Syndrome
UCLA PTSD-RI	University of California at Los Angeles Posttraumatic Stress Disorder Reaction Index
UPD	Uniparental Disomy
ZBI	Zarit Burden Interview

It's a Burden But...

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Caregiver is typically a term used to describe the parent-child relationship. But a caregiver can include other family members, such as an aunt, uncle, grandparent, or sibling (Sullivan & Miller, 2015). A large body of research focuses on how the presence of a neuroatypical individual may affect the caregiver relationship (Barros et al., 2019; Hidangmayum & Khadi 2019; Sullivan & Miller, 2015). Additional family challenges, such as raising a neuroatypical child, have consistently been associated with higher than typical family stress levels in effected families (Davis, & Neece, 2017). While the effects of neuroatypical children on parental caregivers has been extensively researched, the sibling dynamics associated with these families has largely been ignored in the literature. This research focused on Prader Willi Syndrome (PWS), a rare genetic disorder, occurring in approximately 1 in 15,000 live births (Dimitropoulos et al., 2019) and explored the caregiver role a sibling may experience for a brother or sister with PWS,

PWS is a complex genetic disorder and is considered extremely rare as it affects between 1 in 10,000 to 1 in 30,000 live births (Key et al., 2021). PWS occurs due to a phenomenon known as gene silencing that affects an area located on chromosome 15q11-13 (Dimitropoulos et al., 2019). This chromosomal silencing has three mechanisms of occurrence: by deletion of the gene 65-75% (of cases), by uniparental disomy 15 (UPD; 20-30% of cases), or through a defect in imprinting (1-3% of cases; Cassidy et al., 2012). While PWS was first described in 1956 (Pardner et al., 1956); it was not until almost 40 years later that a diagnostic tool was developed highlighting 27 items, known at the time, common to PWS (Holm et al., 1993). Since this PWS criteria table was created by Holm et al. in 1993, a large body of research has been dedicated to

exploring different aspects of PWS. Research has included the medical and genetic nature of PWS (Cassidy et al., 2012), behavioural aspects an individual with PWS may display (Holm et al., 1993; Cassidy et al., 2012), and the effects raising an individual with PWS has on families (Mazaheri et al., 2013; Meade et al., 2021).

At birth, individuals affected with PWS typically display low muscle tone (hypertonia), poor feeding ability, and failure to thrive (Magill et al., 2020), resulting in delays in reaching common milestones. As an individual with PWS ages, other symptoms begin to develop; including hypogonadism, intellectual delay, lack of growth hormone production, scoliosis, sleep issues, hyperphagia, and maladaptive behaviours such as compulsive behaviour, stubbornness and extreme temper tantrums (Cassidy et al., 2012). An examination of 248 individuals with PWS by Dykens et al. (2011), found that compulsive behaviours manifest in a variety of ways with varying degrees of frequency and combinations. These behaviours include skin picking, hoarding, ritualized eating, constant repeating and checking, a need for symmetry, fear of losing items, and obsession with food and food-related topics. The many behavioural abnormalities present in individuals with Prader Willi Syndrome are not fully understood. However, research has shown positive correlations associated between a defect in the hypothalamus-pituitary function and behavioural observations common to PWS (Yamada et al., 2021).

While not all symptoms common to PWS occur in every individual, one consistent symptom is hyperphagia (Kayadjanian et al., 2021). Hyperphagia is characterized as an insatiable hunger and manifests in children with PWS at an average age of 8 years old. Hyperphagia is accompanied by a reduced metabolic rate that functions at 60% of the typical level seen in the general population (Butler et al., 2017). These factors combine to result in recommendations for specialized diets to maintain weight control (Miller et al., 2013).

Individuals with PWS are also at a high risk of accidental deaths from choking, accidents, and gastrointestinal perforation, which are strongly associated with hyperphagia and the food-seeking behaviours common to PWS (Butler et al., 2017). Without security measures in place for an individual with PWS, food consumption levels and the associated behaviours can be life-threatening (Key et al., 2021).

According to Kayadianian et al. (2021), the constant need to monitor food intake for individuals with PWS may contribute to increased feelings of caregiver burden. Perception of caregiver burden was previously measured for families with an individual with PWS using the Zarit Burden Interview (ZBI) (Kayadjanian et al. 2018), finding that participants of the study reported negative impacts to sleep, mood, work-life, and romantic relationships while caring for a person with PWS. This study was expanded to include more types of family members; the categories included mothers (82%), fathers (8%), relatives (7.8%), and non-guardian relatives (< 2%); however, for this study, siblings were not explicitly accounted.

Caregiver stress as it pertains to raising neuro-atypical children is a commonly studied phenomenon. Stress levels have been shown to be higher for families raising children with Pervasive Developmental Disorder (PDD), now commonly referred to as autism spectrum disorder (ASD), compared to caring for a neurotypical child (Davis & Neece, 2017). A study by Hidangmayum and Khadi (2019) explored the topic of mothers and fathers raising neuro-divergent children revealed that 64 percent of fathers and 68 percent of mothers reported having clinically significant stress levels. Wong et al. (2020) conducted a study on parental stress levels in families raising children with PWS. Using the Parenting Stress Index Short Form (PSI/SF), it was demonstrated that high levels of stress are experienced with parenting children with PWS. O'Neill & Murray (2016) conducted a study comparing anxiety and depression levels for neuro-

typical adult siblings for one of four groups: Having a brother or sister with PWS, Autism Spectrum Disorder (ASD), Down Syndrome (DS), and Developmental Disability with Unknown Aetiology (DUA). The participants in the PWS category indicated significantly higher levels of anxiety when compared to the control group.

The impact of PWS on family life was examined by Mazaheri et al. (2013). Their research specifically targeted 12 mothers and 13 siblings having a family member with PWS. Using the Brief Symptom Inventory (BSI), the study scored results according to the Positive Symptom Total (PST), the Global Severity Index (GSI), and the Positive Symptom Distress Index (PSDI). Self-report methods were used to measure the post-traumatic stress effect in the non-PWS siblings. Participants also used the University of California at Los Angeles Post-Traumatic Stress Disorder Reaction Index for DSM IV (UCLA PTSD-RI). The 20 items on the UCLA PTSD-RI were used to detect the association of traumatic experiences with post-traumatic stress. Three quality of life questionnaires were also administered: the Pediatric quality of life Inventory-Parent Proxy (PedsQL) (completed by mother participants), the PedsQL-Family Impact Model (completed by mother participants), and the PedsQL-Child/Teen Report (completed by siblings). Qualitative data was also gathered by an interview process for all participants and analyzed. The participant siblings' self-report of the PedsQL indicated a lower quality of life than a control group. The study results also suggested that in comparison to typical populations, mothers perceived the unaffected sibling's health-related quality of life (HRQoL) as lower than did the siblings' perception. The finding of quality of life being perceived as low by both the parent and the sibling directed our research toward wanting to understand how the perception of burden felt is by siblings and if there is a perception of growth felt because of the sustained exposure to stress.

The overall family impact of PWS and perception of burden was also investigated by Meade et al. (2021). Areas of caregiver burden were classified into 6 categories pertaining to an individual with PWS needs: Medical/nursing tasks, family disruptions due to childcare needs, physical issues needing care, restricting social and school events, concern over long term health issues, and the child's potential psychological problems. Parent caregivers reported extreme levels of concern regarding impact to quality of life and preserving family functioning. A sample of five siblings of children with PWS from the same research article, also consistently reported quality of life scores as poorer when compared with peers. Possibly due to the family situation; a sibling may feel the same caregiver related burden parents feel regarding an individual with PWS, including expectations of helping with medical/nursing tasks, helping their sibling with physical needs, or a similar level of concern toward their sibling that parents would feel toward their child. This study will explore the sibling relationship in the context of an individual being placed into that caregiver situation.

Another frequently studied variable for families with children with PWS is stress as it pertains to parents (Wong et al., 2020). Hypothesising that there will also be elevated stress levels in the sibling dynamic regarding PWS we believe this area is an essential variable to measure. Specifically, we measured psychological stressors perceived by an individual, for example, those caused by external stimuli such as major or minor life events (Segerstrom, & O'Connor, 2012). Therefore, electing to utilize the Perceived Stress Scale 10 (PSS 10) was deemed a logical tool.

The PSS 10 has been deemed superior to other PSS survey versions and has acceptable psychometric properties (Lee, 2012). The PSS 10 uses a tallied score approach, with higher scores indicating higher perceived stress levels out of a maximum of 40 points. The PSS 10 has

been used to determine levels of sibling stress for subjects between 12 and 18 years with a sibling with autism spectrum disorder (ASD) when compared to individuals with siblings with Down syndrome (DS) (Shivers et al., 2019). The results supported a higher level of stress for individuals with a sibling with ASD (mean score = 20.23) versus individuals with siblings with DS (mean score = 16.58).

The next variable of interest is perceived burden. Perceived burden is a major component of the caregiver experience regarding children with PWS (Meade et al., 2021). Sullivan and Miller (2015) define the role of a caregiver as anyone aiding in caring for family members in need of extraordinary care and outline the potential for negative impacts to social relationships, physical and mental health, and impacts to emotions. It is our belief that siblings of individuals with PWS are sometimes exposed to roles in the family that are typically considered a caregiver role and therefore will experience an increase in perceived burden. Burden itself can be defined as the extra care an individual with a chronic condition may require by another party (Javalkar et al., 2017). For PWS the extra care required is typically monitoring dietary intake/food security, dealing with behavioural and psychological challenges, providing daily injections of medication, or helping with physical challenges (Meade et al., 2021). These daily demands placed on individuals in a caregiver role have been shown as predictors of stress.

A common measure of perceived burden is the Zarit Burden Interview (ZBI). The reliability of the ZBI has been determined to fall within acceptable parameters for research (Bachner & O'Rourke, 2007). The ZBI has been used in previous studies involved with determining caregiver burden for families with an individual with PWS (Kayadjanian et al. 2018; Kayadjanian et al. 2021) and in a comparison study assessing caregiver burden for individuals with cerebral palsy, down syndrome, autism spectrum disorder, and people without disabilities

(Barros et al., 2019), making this questionnaire an appropriate measure to determine if siblings of individuals with PWS perceive an impact of caregiver burden.

The last variable of interest is post traumatic growth. As discussed, increased burden may lead to increased stress (Meade et al., 2021). Exposure to sustained periods of stressful situations has been linked with post traumatic growth (Sanders & Szymanski, 2013). Post traumatic growth, a concept developed by Tedeschi and Calhoun (1996) can be defined the positive psychological change within the individual which results from life circumstances that introduce highly challenging struggles (Tedeschi, 2018). Previous research has suggested that parents of a PWS child do experience consistent levels of stress and burden (Kayadjanian et al. 2021; Wong et al. 2020). It is logical that siblings of an individual with PWS will be exposed to similar levels of stress and burden and potentially also experience post traumatic growth (positive psychological outcomes) as a result.

For examining the presence of post traumatic growth, the Post Traumatic Growth Inventory (PTGI) is an appropriate measure. The PTGI has been determined to have good internal consistency and satisfactory test-retest reliability (Tedeschi & Calhoun, 1996). A study by Sanders and Szymanski (2013) utilized the PTGI to determine the posttraumatic growth for siblings of people with a diagnosed mental disorder. Thirty-three participants were assessed and divided into the categories that identified as “caregiver” and “non-caregiver” (Sanders & Szymanski, 2013). The mental health disorders included diagnoses of schizophrenia, bipolar disorder, anorexia, intellectually disability, generalized anxiety disorder, borderline personality disorder, and major depressive disorder (Sanders, & Szymanski, 2013). The findings were that the “non-caregiver” group of siblings indicated higher personal growth than the “caregiver” group in four of the five categories the PTGI evaluates. Sanders and Szymanski (2013) had a

small sample size with a variety of mental health disorders, and we believe that an increase in sample size focusing on PWS will enhance their findings with one distinction; we believe because of the complexities associated with PWS the personal growth for siblings will be present regardless of caregiver versus non-caregiver role.

The sample sizes for the study by O'Neill & Murray (2016) that specifically involved PWS was small (n=26 for the PWS group versus n=67 for the control group). Our study endeavors to enhance these findings through an increase in sample size. Unlike O'Neill & Murray (2016) The study we conducted does not focus on anxiety specifically through the three chosen questionnaires, as it was designed to provide insight to multifaceted aspects of how having a sibling with PWS impacts daily life. Qualitative data, however, was collected to provide insight into specific sources of stress, potentially how the perception of burden manifests in daily lives, and any possible growth that results from having a sibling that requires extreme levels of care and consideration.

With a lack of data targeted to the sibling relationship for families with children with PWS, there is a real need to add to the growing body of research related to them. Our primary goal is to highlight potential indicators of stressors for early intervention strategies for siblings that may have been exposed to the caregiver experience by virtue of having a sibling with PWS. This research project seeks to use self-report survey methods to examine several important questions related to having a sibling with PWS when compared to a sample of siblings with a neurotypical brother or sister.

Q₁: How is stress connected with having a sibling with Prader Willi Syndrome?

H₁: Siblings with a brother or sister with PWS will have higher self-reported stress levels than siblings without the concern of PWS of a family member.

Q₂: Is there a feeling of burden associated with having a sibling with PWS?

H₁: Burden scores will be significantly higher for siblings with a brother or sister with PWS when compared to siblings that do not have a PWS sibling.

Q₃: Is there a sense of overall personal growth involved with having a sibling with PWS?

H₁: Perception of growth scores will be higher in siblings with a brother or sister with PWS than those with neurotypical siblings.

Methodology

Design

This study was conducted using a mixed-method survey design. Quantitative surveys can be rigid in scoring systems and therefore a qualitative portion was added to each section of the survey to allow participants to provide context for their answers. The predictor variable of interest was the presence of PWS which was analyzed for its relationship with the outcome variables of perceived stress, personal growth, and perceived life burden.

Data collection of this survey was from 31 October 2021 until 15 December 2021. Distribution of the survey was conducted using two methods. A convenience sample of university students identifying as having a sibling was drawn from the introductory psychology research pool. Additionally, subjects with neuroatypical siblings, including siblings with PWS, were recruited using social media. University students are known to experience prominent levels of stress especially when transitioning from high school to university (Hicks & Heastie, 2008), making this population sample ideal for comparison. Participants were allowed to provide

qualitative data to enhance the answers provided for the Likert Scale surveys. Each survey has been used in previous studies concerning PWS, but siblings of individuals with PWS have not previously been the focus of research.

Participants

Subjects were recruited from two groups. Group one consisted of siblings within a family containing an individual with Prader Willi Syndrome. Group two consisted of individuals with a neurotypical sibling. Obtaining participants for this study was achieved through online outreach using social media platforms (Facebook and Twitter). From the social media platforms, a link was provided to access the survey material. The British Columbia Prader-Willi Association (BCPWSA) was enlisted to reach potential candidates for this study. Using BCPWSA allowed for access to a larger population of families with an individual with PWS. MacEwan University students were recruited using the SONA psychology participation resource to widen the sample pool for the control group. The study presented to potential subjects was titled “Stress and Siblings” to draw attention to any participants that may have a sibling. For the non-university student participants, no compensation was offered to take part in this survey. For the MacEwan University student participants taking part in this survey, each participant was awarded a compensation of 2 percent. This participant credit was awarded regardless of completion or withdrawal from the study.

Prior to beginning the study, participants were presented with a statement of consent/assent to continue. For both the control group and the experimental group, the following question was asked after consent/ascent was granted: “Do you have a sibling that is considered neuro-atypical? If yes, is it one of the following: Autism Spectrum Disorder, Downs Syndrome,

Obsessive-Compulsive Disorder, Prader Willi Syndrome, Intellectual Disability, other (please specify)?” The age of participants for this study was 16 years or older. With the age of participants being 16 years or older, the possibility of a participant being a parent is present. Therefore, the question “Do you have a neuro-atypical *child* with Downs Syndrome, Autism Spectrum Disorder, Prader Willi Syndrome, Obsessive-Compulsive Disorder, Intellectual Disability, other (please specify)?” was also asked. Participants were additionally asked the following Yes/No questions: “Do you currently live with a neuro-atypical sibling?”, “Do you have a *child* with a major medical, physical illness?” and “Do you have a *sibling* with a major medical, physical illness?” Identifying individuals within the control group with a neuroatypical sibling or child allowed for identifying potential confounds, controlling for other possible stress factors. The demographic questions asked also allowed for a means of categorizing each participant into one of three groups. The three groups were participants with neurotypical siblings, participants with neuroatypical siblings specific with PWS, and participants with a non-PWS neuroatypical sibling. The third group consisting of neuroatypical non-PWS siblings was a control measure and not included in the comparisons between group one and group two. Participants were divided into two age categories: 16 to 17 years of age and 18 years and older. Age categories were applied to both the families with an individual with PWS and the families not containing an individual with PWS. Age was not a variable for this study. The age minimum of 16 years was chosen as a reasonable starting point for an appropriate amount of life experience regarding sibling interaction and the willingness to communicate those life experiences with us.

Using the estimated prevalence within a population of 1 in 15000 individuals having PWS (Magill et al. 2020), it may be predicted that approximately 2500 individuals in Canada

have PWS. Based on this number, the ideal sample size would be 334 individuals to reflect the PWS population. The sample size for the population without family members with PWS was assessed at 385 to reflect a population of 37 million. These numbers were calculated using SurveyMonkey sample size calculation tools (SurveyMonkey, 2021). Participation for the survey consisted of 310 total subjects. The actual sample size for group one was $n=28$ (PWS sibling), for group two was $n=220$ (neurotypical sibling). The third group of non-PWS neuroatypical siblings was $n=18$ which was excluded from further analysis.

Exclusion Criteria

Participants 15 years or younger were excluded from this study. The reason for excluding this age category was that the articulation by participants for qualitative data was deemed more likely from a more mature sample pool. Participants under the age of 16, being a protected population, also require deeper levels of ascent and parental consent, creating barriers to access.

Materials/Procedure

The data for this research was collected through an online survey created using the Qualtrics Software Company. The initial survey questions consisted of the five previously described demographic questions. These were followed by three separate surveys. Each survey was followed by a brief qualitative question. The qualitative procedure is detailed in the next section.

Survey one was the PSS 10. The PSS 10 is a 10-question survey used to determine the perceived stress of an individual using a straightforward format, scored with a 5-point Likert scale. The 5-point Likert scale uses the terminology of “0” never, “1” almost never, “2” sometimes, “3” fairly often, and “4” very often. The PSS 10 asks 6 negatively worded questions and 4 positively worded questions. The positively worded questions are questions 4,5,7 and 8

and are reverse scored. The highest possible score for the PSS 10 is 40. A higher score on the PSS 10 translates into higher perceived stress of an individual. Scores from zero-13 indicate low stress, 14-26 indicate moderate stress, and scores from 27-40 indicate a high perception of stress. The PSS 10 has been deemed superior to other PSS survey versions and has acceptable psychometric properties (Lee, 2012).

The PTGI was the second set of survey questions participants completed. The typical use of the PTGI is centered around traumatic events and personal growth. The use of the PTGI for this study was applied with the rationale that prolonged life events that may be a potential source of stress (i.e., having a sibling with rare health considerations) may have an impact on personal growth. The PTGI is a 21-item inventory scored through a 6-point Likert scale. The 6-point Likert scale uses the terminology of; “0” I did not experience this change as a result of my crisis, “1” I experienced this change to a very small degree as a result of my crisis “2” I experienced this change to a small degree as a result of my crisis, “3” I experienced this change to a moderate degree as a result of my crisis, “4” I experienced this change to a great degree as a result of my crisis and “5” I experienced this change to a very great degree as a result of my crisis. Each response of the PTGI is assigned to one of five categories of personal growth: relating to others, new possibilities, personal strength, spiritual change, and appreciation for life. Scores were tallied, with a high score reflecting more significant personal growth in the corresponding category (Tedeschi & Calhoun, 1996). The PTGI has been determined to have good internal consistency and satisfactory test-retest reliability (Tedeschi & Calhoun, 1996). The original wording for the instructions of the PTGI is stated as follows; “Indicate for each of the statements below the degree to which this change occurred in your life as a result of the crisis/disaster, using the following scale.” The wording was altered to repurpose the PTGI to pertain to the

experiences of having a sibling to the following: “Indicate for each of the statements below the degree to which this change occurred in your life as a result of your sibling, using the following scale.”

The last set of survey questions were from the ZBI questionnaire. The ZBI is a 22-item survey used to determine the burden an individual is perceived as experiencing (Bachner & O’Rourke 2007). The ZBI uses a 5-point Likert scale. The 5-point Likert scale uses the terminology of “0” never, “1” rarely, “2” sometimes, “3” quite frequently, and “4” nearly always. Tallied scores are assigned into the categories of 0-21= “little or no burden,” 21-41= “mild to moderate burden” 41-61= “moderate to severe burden,” and 61-88= “severe burden.” The reliability of the ZBI has been determined as falling within acceptable parameters (Bachner & O’Rourke 2007).

The total number of respondents for the survey’s questions of the ZBI, PSS 10 and the PTGI totalled 266 completed surveys with a breakdown of 28 individuals with a sibling with PWS, 18 individuals with a sibling identified as having a major medical physiological or neurological consideration, and 220 respondents identifying as having a typical sibling.

Qualitative Survey

A qualitative question was added at the end of each series of surveys to allow subjects to expand on any answers from the PSS 10, PTGI, and the ZBI. Participants were informed before the survey that they would be allowed to expand on any answers they feel important to add context for at the end of the survey questions. Adding the qualitative question was a measure used to mitigate the confining nature of questionnaires that use the Likert scale.

For the qualitative portion of the PTGI survey, 45 individuals submitted written responses. The written responses for the PTGI were then broken down into 113 separate phrases

and categorized into 66 positive statements, 33 negative statements and 14 neutral statements. 23 different themes were detected from each positive statement such as growth, love, support, or appreciation. It was noticed that the list of 24 positive themes could be recategorized into the 5 factors of the PTGI. For example, a positive partial phrase from one subject wrote *“I believe that having siblings has helped develop my social skills, empathy, and understanding of others...”* (French & Rogers, 2022). This phrase was initially given a theme of growth. Upon further analysis, with the participant mentioning an increase in social skills, empathy, and understanding others, a logical fit for recategorization was the PTGI “relating to others” factor. All remaining positive phrases followed the same protocol of initial theme detection, to recategorization into the 5 factors of the PTGI.

Twenty-three themes were detected for the 33 negative statements on the PTGI and were then recategorized into negative feelings toward: relating to others, new possibilities, personal strength, spiritual change, and appreciation for life. For an example of theme detection for the negative statements, a partial phrase from a subject said, *“I am less compassionate to people with disabilities”* (French & Rogers, 2022). The statement was initially given the theme, lack compassion. Upon further analysis it was recategorized into “relating to others.” The same protocol was followed for the remaining phrases of initial theme detection, then recategorization into negative feelings to the five PTGI factors.

The neutral statements of the PTGI were categorized into four statements providing background information with neither positive nor negative statements, and then recategorized into low effect, unclear impact, or background information. There were 14 statements considered neutral; four statements were considered low effect; one statement was designated as unclear impact and nine statements were categorized as providing background information. These

phrases tended to have no statement of positive or negative feelings and did not fit into the five factors of the PTGI. An example of a neutral statement is “*My older sister has Diabetes Mellitus Type I.*” (French & Rogers, 2022). The statement made was in isolation, only mentioned a fact, and did not provide personal feelings.

The ZBI consisted of 52 individuals providing qualitative data broken down into 117 total phrases indicating 22 positive, 46 neutral and 49 negative responses. There were 19 initial categorization of the negative responses that were then divided into 6 categories of sources of burden; responsibility, stress, worry, social interaction, grief, and frustration. Negative statements about responsibility represented most themes. Within the statements, phrases referring to extra responsibilities being placed on the subject would be placed in the initial theme of extra responsibility. Extra responsibility phrases were then classified into the category responsibility. A specific example of a phrase being categorized as extra responsibility then into the responsibility group would be “*I do sometimes feel as if (I’m) the parent*” (French & Rogers, 2022).

Positive responses of indicated on the ZBI were initially divided into 14 categories. Similarities between the 14 categories yielded 4 common groups: connection, gratefulness, responsibility, and hopefulness. Connection was the most common classification. For example, the phrase “*Everything that I do for my sibling is done through love, I’ll never feel burden by it*” (French & Rogers, 2022) was initially given the heading of love. After comparing it to similarly themed phrases a common grouping of connection was formed.

The neutral statements were categorized into seven statements providing background information with neither positive nor negative statements, and then recategorized into low effect,

unclear impact, background information and a single statement pertaining to positive validity of the ZBI questionnaire. The single statement validating the ZBI was “*All the questioned applied – especially going into adulthood*” (French & Rogers, 2022). The remaining neutral ZBI statements were divided as follows: 24 background information statements, 17 low impact statements and four unclear impact statements.

Fifty-nine individuals responded with qualitative data for the PSS 10. The 59 responses were then broken down into 143 separate phrases initially assigned as a positive, negative, or neutral response. Consistent with PTGI and the ZBI, a thematic approach was conducted to categorize each type of phrase. The 19 different phrases assigned to the negative response category were then recategorized into 9 groups. The groups included stress related to work, family, school, finances, change, health, mental health, seasonal, and non-specific. The most mentioned stressor mentioned by subjects was school. The statement “*I have been going through a divorce I initiated and my ex moved out in the past month,*” (French & Rogers, 2022) was initially given the designation “Relationship.” After detecting common elements of other phrases, the statement was then grouped into category “Change.”

Positive responses were initially divided into 11 positively associated phrases. The 11 phrases were then assigned one of four categories: In control, love, growth, and coping. The statement “*and besides that I live a pretty stress-free life*” (French & Rogers, 2022) was initially categorized as stress free, but then determining common elements of similar phrases the group heading of in control was formed with the mentioned statement being placed in that category.

Statements deemed neutral for the PSS 10 had the similar categories of the PTGI; background information, low impact and unclear impact, consisting of 15 neutral responses. 10

responses were categorized into background information four responses were placed into unclear impact and one response was deemed low impact.

Results

The data gathered from our research was used to answer our three research questions: First; how is stress connected with having a sibling with PWS? The hypothesis was that siblings with a brother or sister with PWS will have higher self-reported stress levels than siblings without the concern of PWS of a family member. We failed to reject the null hypothesis. In other words, our data did not support our hypothesis. Second, is there a feeling of burden associated with having a sibling with PWS? The hypothesis was that burden scores will be significantly higher for siblings with a brother or sister with PWS when compared to siblings that do not have a PWS sibling. The data supported our hypothesis. Third, is there a sense of overall personal growth involved with having a sibling with PWS? Our hypothesis was perception of growth scores will be higher in siblings with a brother or sister with PWS than those with neurotypical siblings. We failed to reject the null hypothesis indicating the data did not support our hypothesis.

Data was analyzed from 248 completed PTGI and ZBI surveys. 220 participants identified as having a neurotypical sibling, 28 identified as having a sibling with PWS. Eighteen participants identified as having a neuroatypical sibling not specific to PWS were not analyzed with the data. The PSS 10 was completed by fewer individuals identifying having a PWS sibling at n=26. Using JASP version 0.16 a multivariate analysis of variance (MANOVA) was conducted using the Pillai Trace test. The Pillai Trace test was used as it balances type I and type II errors in the presence of assumption violation (Ateş et al., 2019). The initial findings suggested there was a statistically significant difference after completing the MANOVA test.

An overall statistically significant difference between the groups was detected, Pillai's Trace = 0.057, $F(1, 244) = 4.845$, $p = 0.003$. (See Table 1).

Table 1

MANOVA: Pillai Test

Cases	df	Approx. F	Trace _{Pillai}	Num df	Den df	p
Sibling Type	1	4.845	0.057	3	242.000	0.003
Residuals	244					

After detecting a statistically significant difference, an analysis of variance (ANOVA) was run separately for each survey to locate the source of the group differences. The PTGI and the PSS10 results revealed no statistically significant differences between groups one, and two. $F(1, 244) = 0.382$, $p = 0.537$. (See Tables 2). $F(1, 244) = 0.493$, $p = 0.483$. (See Table 3).

Table 2

ANOVA: PTGI_Tot

Cases	Sum of Squares	df	Mean Square	F	p
Sibling Type	228.980	1	228.980	0.382	0.537
Residuals	146161.040	244	599.021		

The overall mean score on the PTGI, a measure of highly challenging struggles resulting in a positive psychological change within the individual, was 49.52 ± 24.24 (range 0-105.00). The averages of each group broke down into the following:

Group 1, consisting of a neuroatypical sibling with PWS, had a mean score on the PTGI of 51.79 ± 23.74 (range 15.00-102.00).

Group 2, consisting of a neurotypical sibling, had a mean score on the PTGI of 48.48 ± 24.45 (range 0-105.00).

Table 3

ANOVA: PSS10_Tot

Cases	Sum of Squares	df	Mean Square	F	p
Sibling Type	22.319	1	22.319	0.493	0.483
Residuals	11036.889	244	45.233		

The overall mean score on the PSS 10, a measure to determine perceived stress over the course of the previous 30-day period was, 21.76 ± 6.79 (range 4.00-36.00). The averages of each group were as follows:

Group 1 (PWS): 21.04 ± 7.69 (range 6.00-35).

Group 2 (Typical): 22.02 ± 6.61 (range 4.00-36.00).

The ANOVA conducted on the ZBI did detect a statistically significant difference in scores related to sibling type $F(1, 244) = 11.537, p < 0.001$. (See table 4).

Table 4

ANOVA: ZBI_Tot

Cases	Sum of Squares	df	Mean Square	F	p
Sibling Type	3167.769	1	3167.769	11.537	< .001
Residuals	66994.312	244	274.567		

The overall mean score on the ZBI, a measure to determine levels of burden experienced by an individual, was 21.81 ± 16.98 (range 0-88.00). The averages of each group were:

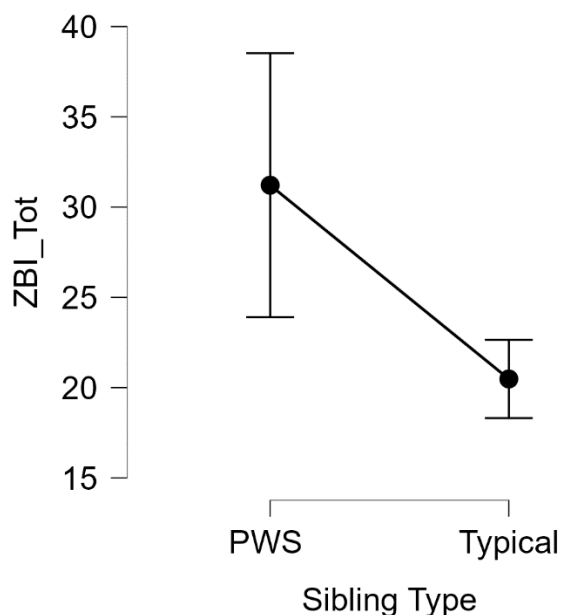
Group 1 (PWS): 31.21 ± 18.85 (range 0-67.00).

Group 2 (Typical): 20.48 ± 16.34 (range 0-88.00).

The results between groups 1 and 2 are notable in that the error bars do not overlap, reinforcing the participants with a sibling with PWS present a statistically significant difference between the 2 subject groups. (See figure 1).

Figure 1

Zarit Burden Interview Groups with Error Bars



A post hoc analysis was conducted using Bonferroni for the ZBI resulting in $t=3.22$, $p=0.001$ and displayed a mean difference between group one and group two of 10.73. (See table 5).

Table 5

Post Hoc Comparisons for Sibling Type

		Mean Difference	SE	t	p_{bonf}
PWS	Typical	10.732	3.337	3.216	0.001

The qualitative responses provided a wealth of data about the subjects' individual perceptions of the experience of having a sibling. An examination of the responses following the PTGI revealed; that 44% of the subject replies indicated positive feelings toward personal strength, 33% indicated positive feelings toward relating to others, 18% indicated positivity toward an appreciation for life, 3% for spiritual change and less than 2% for new possibilities. The breakdown of negative statements was as follows: 42% relating to others, 27% personal strength, 18% appreciation for life, 9% for new possibilities, and less than 5% for spiritual change. Neutral statements consisted of approximately 28% low effect, 64 % background information, and less than 8% unclear impact. The total number of PTGI statements equaled 113. Of those 113 statements, four individual participants from the PWS group accounted for four positive, 10 negative and two neutral statements. For the control group with typical siblings, 56 individual participants made, 56 positive statements, 22 negative statements and 11 neutral statements.

Exploring our research question of whether there is a sense of overall personal growth involved with having a sibling with PWS, we noticed positive statements that centered around a protective feeling and a desire to see their sibling do well for themselves. Negative statements concerning group one included feelings of anger, lower compassion toward people with disabilities because of their negative experience, and one subject, indicating they did not live with their sibling mentioned their answers would have been “*dramatically different*” (French & Rogers, 2022) had they still been living with them. The thematic qualitative analysis is not complete; however, the initial difference detected was that group one (PWS siblings) did not mention personal growth, where as group two (typical siblings) consistently mentioned positive learning experiences from their sibling.

The qualitative data for the ZBI resulted in the following distribution of positive phrases: connection 41%, grateful 32%, responsibility 18%, and hopeful 9%. The negatively associated phrase breakdown consisted of approximately 47% responsibility, 10% stress, 14% worry, 10% social interaction, 4% grief, and 14% frustration. Neutral statements consisted of approximately 37% low effect, 52 % background information, 9% unclear impact and 2% stating validity of the ZBI. The total number of ZBI statements equaled 117, consisting of eight positive, 18 negative and 10 neutral statements for the PWS group. The control group consisted of 13 positive, 29 negative, and 34 neutral statements. 13 individuals accounted for 36 total statements from the PWS group. 35 individuals accounted for the 76 responses from the control group.

In reference to the research question of whether there a feeling of burden associated with having a sibling with PWS, we noticed negative comments by subjects mentioned feelings of resentment, embarrassment, and directly stating the burden of helping to care for individuals with PWS. Four participants did indicate positive outcomes in group one, mentioning

gratefulness, pride, and the love they feel toward their sibling. One individual commented that they have become more independent because of the responsibility incurred by caring for an individual with PWS. Comments from the control group reported a much broader field of burden including nonspecific irritation, frustration, issues dealing with a siblings' substance abuse, being placed in the role of caregiver, and nonspecific concern for their sibling.

Qualitative data elicited from the PSS 10 contained the following distribution for the 21 positive phrases: approximately 48% in control, 9% love, 5% growth, and 38% coping. The 107 negative phrases associated with stress were broken down into: 28% school, 17% family, 13% mental health, 13 % non-specific, 10% change, 9% health, 5 % work, 3% financial, and less than 2% seasonal. The neutral category consisted of a total of 15 phrases with 67% assigned to background information, 27% unclear impact, and 6% low impact. There were 143 written responses from the 3 groups. From group 1, six positive, 15 negative, and 5 neutral phrases were recorded from 11 participants for the PSS 10. 43 participants from the control group responded with 13 positive, 90 negative, and nine neutral phrases for the PSS 10.

In the context of the research question “How is stress connected with having a sibling with PWS?”, group one, in some cases, cited a sibling with PWS as a source of stress, but most comments indicated other sources including dealing with a sudden death of a family member, personal struggles with mental health issues, relationship breakdown, and in one case stresses due to school. The control group overwhelmingly indicated school as the primary source of stress. Other sources of stress indicated by group two were, sudden death of a family member, relationship breakdown, Covid 19, and work-related stress. Specific to sibling stress, three participants from the control group were linked to 6 phrases that directly named a sibling as a source of stress due to acting as a caregiver for a sibling.

Appendix A lists a full breakdown of the thematic coding scheme with examples of phrases that qualified for each corresponding category. Analysis of the qualitative data is in the initial stages and more thorough investigation into the implications of the data collected is planned.

Discussion

We asked three questions in pursuit of widening our knowledge about the intricacies of sibling relationships as it pertains to Prader-Willi syndrome:

- How is stress connected with having a sibling with PWS?
- Is there a feeling of burden associated with having a sibling with PWS?
- Is there a sense of overall personal growth involved with having a sibling with PWS?

We hypothesised that stress would be higher for our experimental group versus the control group according to the PSS 10. We determined that there was no statistically significant difference between the two groups. However, both groups did report moderate stress levels according to the scoring of the PSS 10 (Lee, 2012) with the PWS siblings' group reporting a mean of 21.04 and the control group reporting a mean of 22.02. Looking at the qualitative data, one respondent indicated their sibling as a source of stress, but many comments from other participants included various recent life events as the stress source. In the control group, three participants reported their sibling as a source of stress because of acting as a caregiver, but the control group overwhelmingly reported university as a source of stress with a wide variety of other life events following.

University students made up a significant portion of our control group sample. University students are a known sample source that carries higher than typical stress levels when compared

to non-university students (Hicks & Heastie, 2008). Both the control group and the experimental group having similarly moderate stress levels may indicate that the experimental group carries a higher degree of daily stress than the typical population. It is possible the PSS 10 was not the appropriate tool for measuring stress for the experimental group. The PSS 10 asks questions pertaining to the previous 30 days prior to completing the survey. For individuals not living with their sibling, the siblings themselves may not have impacted feelings of stress to the degree we expected. A more appropriate tool, measuring perceived stress over a longer duration, should be considered for future investigations.

The second question asked was if there were feelings of burden associated with having a sibling with PWS. We hypothesised that burden scores from the ZBI would be significantly higher for siblings with a brother or sister with PWS when compared to siblings that do not have a PWS sibling. The ZBI supported a statistically significant difference in caregiver burden for the PWS group compared to the Typical Sibling group. The mean score for the PWS group was 31.21 versus the mean of the Typical Sibling group 20.48. The mean score for the PWS group indicates “mild to moderate burden”, whereas the mean score for the control group indicates “little or no burden” (Bachner & O'Rourke 2007). The qualitative data provided by the PWS group stated feelings of resentment, frustration, embarrassment and one comment directly stating the burden they incur because of their sibling. Comments reported from the Typical Sibling group reported a broader field of feelings of burden such as, feelings of concern for their sibling due to substance abuse, irritation at being placed in a caregiver role for their sibling, and non-specified frustration.

Previous research indicated high levels of caregiver burden through the lens of a parent caring for individuals with disabilities (Barros et al., 2019), and specifically caring for children

with PWS (Kayadjanian et al., 2018). It is logically not surprising that a high level of burden is experienced for non-parent members of the same household.

The third question we asked was whether there a sense of overall personal growth involved with having a sibling with PWS. Using the PTGI, we measured each group's perceptions of growth through adversity. We hypothesised that prolonged exposure to an individual requiring extra care considerations would increase the perceptions of growth in the PWS sibling group compared to the Typical Sibling group. No statistically significant differences were found between subjects with siblings with PWS and the control group. The mean scores for the PTGI were 51.79 for the PWS group and 54.78 for the control group. The qualitative data revealed that the PWS group did not report feelings personal growth, whereas the control group consistently reported positive learning experiences because of their sibling.

Limitations

The use of university students may have been a limiting factor, as it may affect the ability to generalize results to the public. Recruiting outside of a university setting may aid in generalizability. Upon a closer examination of the recruitment material and the demographic questions, it became apparent that instructions for the questionnaire may have been presented in a confusing manner. The unclear nature of the questionnaire may have led to individuals answering the survey questions as a parent rather than a sibling. Enlisting a small group of participants to discuss the questionnaire with the researchers prior to releasing it to the public could aid in detecting issues beforehand.

Another limitation is that we did not collect data related to time spent with a sibling. The amount of time spent interacting with a sibling may have an impact on the scores of the three questionnaires. For example, the more time spent together with the family member, the more

opportunity for influencing the survey results. More in depth questions relating to how actively involved an individual is in the life of their sibling may have given us more informed data that could better contrast the experimental group and the control group.

Birth order and sibling number was a factor not considered for the analysis of this research. No demographic data was collected to determine if the person completing the survey was an older sibling, a younger sibling, or had multiple siblings. It is possible that confounds may be related to this aspect of family life.

Lastly, this study did not include more detailed age categories. For example, the data could have been categorized by different age intervals (18 years to 24 years, 25 years to 30 years, etc.). Comparing age groups at different intervals, could possibly have yielded information about different life stages by helping to identify confounds or provide insight into how sibling relationships are impacted over time.

Future Research

Participants were asked whether they lived with their sibling or not. Nine respondents out of 220 from the control group and six respondents out of 28 from the experimental group indicated they lived with their sibling, but we did not analyse the data any further. Future research could be directed toward a “living with” situation. Siblings living together may have different results than are reflected in our data. The PSS 10 is designed to provide results that measure perceived stress in the short term. Using a stress survey that focuses on long term stress events rather than short term stress events may provide a better indication of how siblings impact perceived stress. It is possible that targeting a younger demographic may yield results that indicate siblings at younger ages, than our research accounted for, could be vulnerable to the

effects of prolonged stress and burden. By directing research to include categories below the age of 16 years, early identification of stress and burden in individuals could result.

Conclusion

The data within this research supports that having a sibling with Prader-Willi syndrome carries with it moderate levels of perceived stress and significant levels of burden for participants 16 years and older. These results highlight an important need for identifying those who may require mitigating strategies or supports associated with having consistent levels of moderate stress and high levels of burden. Now that this has become known, efforts can be directed toward considering early intervention strategies to aid those vulnerable to this situation.

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Appendix

Qualitative Themes

1 Positive PTGI

1 Personal Strength

3 Self Care

Example Phrase “I think that reflecting on yourself is a valuable thing to do”

5 Strength

Ex. Phrase “The importance of valuing the way of life and recognizing I have the power to make what I wish come true with a strong support system.”

14 Future Planning

Ex Phrase “my intuition kicks in that he needs this thing and if we do this way, the results will be better for him in future”

15 Providing Care

Ex Phrase “With having siblings I have taken on the role, especially as the oldest, to provide for them”

16 Belonging

Ex Phrase “Having siblings, especially ones that I know I can rely on, does make a difference in knowing that I belong somewhere”

17 Security

Ex Phrase “Even when the outside world seems too tough to handle at times, I know I have them - even if we get on each others nerves often”

18 Trust

Ex Phrase “Since I am able to rely on my siblings, I know that people are capable of relying on others and working together towards a common goal”

19 Wellbeing

Ex Phrase “and I am doing very well for myself”

22 Self Knowledge

Ex Phrase “I believe it's important to know our self worth,”

23 Effort

Ex Phrase “I think it is really important to put effort into your relationships”

2 Relating to Others

2 Protective

Ex Phrase “and protective...”

4 Support

Ex Phrase “and knowing that someone cares for you is the best feeling when you may feel alone.”

8 Growth

Ex Phrase “Adversity in life has blessed me with the opportunity to learn a lot at my age”

9 Empathy

Ex Phrase “You never know what someone is going through, even if it's one of your close friends,”

3 Appreciation for Life

1 Love

Ex Phrase “I love my son”

7 Appreciation

Ex Phrase “I have a sibling that finds joy in really small things in life which allows me to also appreciate certain in things life more”

10 Acceptance

Ex Phrase “but at the same time we must accept that everyone has their own understanding of change.”

11 Connection

Ex Phrase “we managed to connect more so than other siblings”

12 Patience

Ex Phrase “I learned to be more patient because of that”

13 Grateful

Ex Phrase “and I'm glad he's a part of my life”

20 Contentment

Ex Phrase “with the most important part about it being I am content with my position in life.”

21 Happiness

Ex Phrase “It took a while for me to have a realization but I'm happy that I went through it last summer.”

4 Spiritual Change

6 Faith

Ex Phrase “having faith and trusting in my God that everything will work out for better, his plan”

5 New Possibilities

24 Change

Ex Phrase “Though the process is slow, I am picking up on new interests and filling my time meaningfully”

2 Negative PTGI

1 Personal Strength

7 Coping

Ex Phrase “occasionally it becomes too much to handle.”

8 Hardship

Ex Phrase “my family experiences the hardships everyday.”

9 Loss

Ex Phrase “we lost many friends and family”

10 Isolation

Ex Phrase “all of my children have isolated themselves in their own lives and concerns”

11 Health

Ex Phrase “I have significant health issues”

12 Death

Ex Phrase “this is not about a sibling's illness, but about my sister's death.”

13 Low Self Confidence

Ex Phrase “would require a deep understanding of myself and how my past has shaped who I am today, something I can’t confidentially say I have.”

17 Self Harm

Ex Phrase “...even if it hurts me”

20 Balance

Ex Phrase “With the being said, I still lack balance in my life”

22 Self Esteem

Ex Phrase “It has also brought my self esteem so low.”

2 Relating to Others

3 Lack Compassion

Ex Phrase “I am less compassionate to people with disabilities”

14 Strain

Ex Phrase “A strained relationship with one sibling”

15 Conflict

Ex Phrase “...conflicting experiences...”

16 Growth

Ex Phrase “I have realized that after spending so much time with my siblings, it has changed the way I view life and others....”

18 Distant

Ex Phrase “My brother and I weren't close growing up and I resented him for many years.”

19 Resentment

Ex Phrase “This is why my brother isn't responsible for a good majority of the questions I just answered” *(this is a continuation of the “distant statement)

21 Depression

Ex Phrase “and my sister suffers from severe depression”

3 Appreciation for Life

1 Providing Care

Ex Phrase “there is nothing positive about caring for someone with PWS”

2 Anger

Ex Phrase “My sister made me an angrier person”

4 Sympathy

Ex Phrase “I more feel bad for my differently abled sibling”

4 Spiritual Change

23 Faith

Ex Phrase “I am not as strong in my religion as I want to be but “

5 New Possibilities

5 Future Fear

Ex Phrase “when I think about the things that they cannot do or will never be able to do”

6 Avoidance

Ex Phrase “if I am at home I'm trying to find ways to avoid situations”

3 Neutral PTGI

1 Low Effect

Ex Phrase “These have had a more central influence on my perspective than having a sibling with PWS.”

2 Unclear Impact

Ex Phrase “... and so many of my answers were guesses as to what impact my siblings have had in my life because there was no before and after.”

3 Background Info

Ex Phrase “we talk weekly in a group chat about the news, current events etc., but see each other in person once quarterly”

1 Change

Ex Phrase “Things were different before and way different after his death”

1 Positive PSS 10

1 In Control

1 In control

Ex Phrase “Usually I am fully in control of my life and what is going on in it.”

6 Stress Free

Ex Phrase “and besides that I live a pretty stress-free life.”

8 Happy

Ex Phrase “I feel pretty happy with my life”

10 Perseverance

Ex Phrase “Of course, I did overcome it,”

2 Love

2 Love

Ex Phrase “I love my husband dearly”

7 Support

Ex Phrase “sometimes vent with my siblings about these issues and I know they support me,”

3 Growth

3 Growth

Ex Phrase “when I was still immature and in high school, my answers would have been completely different”

4 Coping

4 Fellowship

Ex Phrase “Through support groups and people wanting to hear about what I am feeling”

5 Coping

Ex Phrase “I have learned to cope with a lot of these things”

9 Acceptance

Ex Phrase “But it is completely ok to not want to solve problems.”

11 managing

Ex Phrase “it is important to understand that most situations are out of our control but that we come out stronger than before by facing the problems head on.”

2 Negative PSS 10

1 School

12 School Stress

Ex Phrase “most if not all of my stresses and anxieties in the last month are school related”

2 Family

1 Death

Ex Phrase “Our dad passed away this year”

9 Grief

Ex Phrase “so I am dealing with grief”

11 Sibling Stress

Ex Phrase “...stems partially from caring for my sibling I believe”

14 Family Stress

Ex Phrase “, taking care of my family members, and other things,”

3 Mental Health

6 Mental Health

Ex Phrase “I have major depression, anxiety, OCD, ADHD. in addition,”

7 Dissimulate

Ex Phrase “This is mainly in part to not opening up”

13 Confusion

Ex Phrase “My brain constantly feels foggy and...”

18 Anger

Ex Phrase “Financial and personal issues caused a lot of anger in my life”

4 Non-Specific

4 General Stress

Ex Phrase “many times I felt very overwhelmed about the things going on,”

5 Change

2 Unexpected Challenge

Ex Phrase “Several issues have arisen, and”

3 Relationship

Ex Phrase “I currently am going through a rough patch with my girlfriend”

5 Pregnancy

Ex Phrase “I am 9 months pregnant and...”

6 Health

8 Substance Abuse

Ex Phrase “and talking about my substance abuse.”

10 Covid Stress

Ex Phrase “which I think has been exacerbated from COVID-19”

17 Physical Health

Ex Phrase “along side experiencing physical health issues which needed surgery.
This month has been difficult in regards to those things”

7 Work

15 Work Stress

Ex Phrase “The difficulties I have experienced in the last month were as a result
of new job training,”

8 Financial

19 Financial Stress

Ex Phrase “Money I also tight right now due to a busy schedule and covid”

9 Seasonal

16 Seasonal Stress

Ex Phrase “Also, things are stressful at work because it is Christmas time.”

3 Neutral PSS 10

1 Background

Ex Phrase “I grew up with a disadvantaged sibling,”

2 Unclear Impact

Ex Phrase “Just moved from my childhood house, parents are finally divorced.”

3 Low Impact

Ex Phrase “I can’t say that I’d feel the same way if I were having to take care of my brother 24/7 like my parents currently do.”

1 Positive ZBI

1 Connection

1 Love

Ex Phrase “Everything that I do for my sibling is done through love,”

6 Connection

Ex Phrase “I think that my sibling is the most wonderful person in the world,”

7 Reliability

Ex Phrase “family will always be by your side”

9 Communication

Ex Phrase “so there are no misunderstandings or confusion on both sides”

2 Grateful

3 Grateful

Ex Phrase “Having two brothers is really a blessing I cannot be thankful enough”

4 Proud

Ex Phrase “...and proud...”

5 Growth

Ex Phrase “to spread awareness about my sisters disability and it has had a positive influence in my personality and who I am as a person.”

8 Independent

Ex Phrase “It's my little brother and he is 18 years old now, luckily he stopped having seizures over 5+ years ago and is pretty independent.”

10 Relief

Ex Phrase “and it was a lot more draining than it is today.”

3 Responsibility

2 Independent

Ex Phrase “This made me into an independent adult...” *(repeated term but 2 different categories)

12 Responsibility

Ex Phrase “I feel that it is important to be willing to care for a loved one in need rather than being forced to or out of obligation”

13 Helpfulness

Ex Phrase “But to make sure your giving someone the best care they can get we must be willing to help.”

14 Capable

Ex Phrase “When taking on responsibility and your family sees you as the most capable person to do the job,”

4 Hopeful

11 Hopeful

Ex Phrase “He is still young and has so much time to find his happiness and purpose in life,”

2 Negative ZBI

1 Responsibility

1 Lack Responsibility

Ex Phrase “Our mom is present but sometimes I feel as if she doesn't do enough to keep her safe(away from food)”

2 Extra Responsibility

Ex Phrase “so I do some times feel as if mi the parent.”

10 Obligation

Ex Phrase “it is hard to say "no," so you do it anyway.”

2 Stress

13 Future Fear

Ex Phrase “Something I feel is missing is the anticipated stress of potentially needing to be the sole care taker of my brother when my parents pass away in the future.”

14 Stress

Ex Phrase “My brother struggles with addiction which blows back on me quite often.”

3 Worry

5 Worry

Ex Phrase “I do worry about what will happen...when my parents pass away”

19 Mental Health

Ex Phrase “Thinking about this all the time does take a toll on my mental health.”

4 Social Interaction

6 Lack of Social Life

Ex Phrase “I have no social life and we cannot have people at the house because (of) the food issues.”

8 Challenge

Ex Phrase “It was hard growing up”

9 Neglect

Ex Phrase “because I always felt neglected and ignored by my parents”

17 Avoidance

Ex Phrase “I want to stay away from extended family”

5 Grief

7 Death

Ex Phrase “My sister passed away September 16th 2021.”

18 Sad

Ex Phrase “It makes me sad”

6 Frustration

3 Embarrassment

Ex Phrase “just general embarrassment of her”

4 Resentment

Ex Phrase “This resentment is still present, though less impactful on my day-to-day life now that I just can ignore her messages and only see her at family gatherings.”

11 Limitation

Ex Phrase “If I would have to I would not be able to do it for long time.”

12 Temperament

Ex Phrase “I get irritated so easily from little things”

15 Regret

Ex Phrase “I think that I should find more time to take care of my relative.”

16 Abuse

Ex Phrase “My relative abused me when we were children”

3 Neutral ZBI

1 ZBI Validity

Ex Phrase “All the questioned applied - especially going into adulthood”

2 Background Info

Ex Phrase “I am not the sole care taker of my younger sister with prader willi”

3 Low Impact

Ex Phrase “My parents provide most of the care so not so much dependent on me but more my parents.”

4 Unclear Impact

Ex Phrase “Relationships also affect our lives and moods”