PREVALENCE AND FUNCTIONS OF SELF-INJURIOUS BEHAVIOR IN THE PRADER-WILLI SYNDROME

By

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Individuals with Prader-Willi syndrome, a genetic disorder characterized by mental retardation, excessive overeating, and extreme obesity, commonly engage in numerous forms of self-injurious behavior (SIB). In the current study, we attempted to identify the prevalence and functions of SIB in the Prader-Willi syndrome. In Study 1, we administered a questionnaire to the care provider/residential living agencies registered with the National Prader-Willi Association of the USA. The questionnaire was designed to identify the prevalence of SIB in individuals with Prader-Willi syndrome, as well as the topography, frequency, and severity of SIB. Study 1 showed a relatively high prevalence of SIB in PWS (58%). Skin picking was the most commonly reported topography. In Study 2, we conducted functional analyses with a subset of individuals from Study 1 to identify the most common variables responsible for the maintenance of SIB. Results showed the majority of SIB was maintained by automatic reinforcement and, to a lesser extent, social positive reinforcement. Results are discussed in terms of implications for treatment development.

CHAPTER 1
INTRODUCTION

Self-injurious behavior (SIB) is defined as any behavior that produces injury to an individual's own body (Tate & Baroff, 1966). Commonly observed topographies include head-banging, self-biting, and self-scratching (Rojahn, 1994). The estimated prevalence of SIB is reported to be between 5% to 23% among individuals with developmental disabilities (DD) (Griffin, Williams, Stark, Altmeyer, & Mason, 1986; Jacobson, 1982; Maurice & Trudel, 1982) but can vary widely in different subgoups. For example, SIB has been found to occur almost universally with individuals with Lesch-Nyhan syndrome but has been found to occur infrequently in other disabilities such as Down syndrome except in cases of severe to profound mental retardation. (Thompson & Caruso, 2002).

Thompson and Caruso (2002) suggested several distinguishing characteristics of SIB in the DD population (particularly among individuals with moderate to severe intellectual disabilities) that can be considered distinct from SIB observed in individuals with psychiatric disorders (e.g., self-mutilation). First, the behavior typically involves repetitive movements of body parts (e.g., limbs, head, trunk, etc.) that produce physical damage. Second, the behavior is episodic (i.e., occurs in discrete bouts) and occurs many times per day.

There are significant health risks associated with SIB. Commonly observed physical injuries include tissue lacerations and contusions, permanent scarring and callus formation, and retinal detachment (Hyman, Fisher, Mercugliano, & Cataldo, 1990). In addition to the injury that it may cause, SIB often interferes with academic, self-care, or vocational instruction and may limit an individual to restrictive living placements (Rojahn & Esbensen, 2002). Further, Favell, McGimsey, and Schell (1982) suggested that physical and chemical restraints often

required for protection may not only prevent engagement in therapeutic learning activities, but may themselves result in physical damage (e.g., muscle atrophy, medication side effects, etc.).

Although drugs and chemical and physical restraint have been used in attempt to eliminate SIB, the greatest success has been found using methods based on operant conditioning (Iwata, 1994), although the specific forms of intervention have changed over the years. Johnson and Baumeister (1978) reviewed studies published from 1965 to 1976 and found electric shock to be the most commonly reported treatment for SIB, followed by differential reinforcement. Gordan-Smith and Matson (1985) reviewed studies published from 1976 to 1983 and found that overcorrection had replaced shock as the most common treatment for SIB. Kahng, Iwata, and Lewin (2002) reviewed studies published from 1964 to 1999 and found that studies on reinforcement and punishment were published at roughly equal rates throughout the 1970s and 1980s; however, a sharp increasing trend in the use of reinforcement-based studies was observed since the early 1990s, while a gradual decreasing trend in punishment-based studies was observed. The increase in reinforcement-based research has been, at least in part, influenced by the development of procedures designed to identify the causes of SIB rather than merely the evaluation of procedures to reduce the behavior (Pelios, Morren, Tesch, & Axelrod, 1999). In fact, Kahng et al. (2002) noted a high degree of correspondence between the use of functional analysis assessment procedures and the selection of reinforcement-based interventions in their review.

In a conceptual review of research on SIB, Carr (1977) suggested several potential determinants of SIB including the social positive reinforcement hypothesis (SIB functions to produce assess to environmental events via a social agent), the social negative reinforcement hypothesis (SIB functions to terminate or avoid an aversive environmental stimulus), the self-

stimulation hypothesis (SIB functions to produce tactile, vestibular, or kinesthetic stimulation), and the organic hypothesis (SIB is a product of aberrant physiological processes of a genetic origin, as in Lesch-Nyhan syndrome, or of nongenetic origin, as in elevated pain thresholds or medical conditions). A number of empirical studies demonstrated relations between a specific environmental event and SIB (Lovaas & Simmons, 1969; Carr, Newsom, & Binkoff, 1976; Weeks & Gaylord-Ross, 1981). However, Iwata, Dorsey, Slifer, Bauman, and Richman (1982/1994) described the first comprehensive functional analysis model to assess multiple sources of reinforcement for SIB. Nine participants were observed during brief, repeated exposure to a series of 4 conditions consisting of the delivery of attention contingent on SIB (test for social positive reinforcement), the removal of task demands contingent on SIB (test for social negative reinforcement), a relatively barren environment in which no consequences were delivered following SIB (test for automatic reinforcement), and a control condition in which no tasks were presented and access to leisure materials and attention was available on a noncontingent basis. Six of the 9 participants exhibited higher rates of SIB in one of the test conditions, indicating that SIB can be maintained by different sources of reinforcement.

Functional analysis methodology has become the assessment tool of choice in applied behavior analysis because it identifies environmental events that influence problem behavior and provides an empirical basis for developing treatments that alter the contingencies directly responsible for maintaining problem behavior. Over the past 20 years, functional analysis methodology has been successfully extended from its initial focus on SIB to other populations and forms of problem behavior (Derby et al., 1987; Mace & Knight, 1986; Northup et al., 1995; Northup, Cigrand, & Asmus, 1992; O'Reilly, 1995). The result has been the widespread adoption of functional analysis methodologies by both researchers and clinicians. The 1989

National Institute of Health (NIH) consensus panel on the treatment of destructive behaviors in the DD population recommended that treatment of severe behavior disorders be based on the results of functional analyses (NIH, 1989). Similarly, the 1997 reauthorization of the Individuals with Disabilities Education Act contained a mandate requiring the use of a functional behavior assessment prior to a change in placement for a student with a behavior disorder.

Although functional analysis research typically focuses on assessment and treatment of problem behavior at the level of the individual, the methodology might also serve as a means for conducting epidemiological studies of behavioral function. That is, accumulation of experimental data over time with a large number of subjects would be helpful in establishing a data base on the functional characteristics of SIB that would be difficult to establish over the short intervals of time typically used in studies of incidence or prevalence (Iwata et al., 1994). Several large-scale studies have been conducted to identify the most common functions for SIB in the DD population. Iwata et al. (1994) summarized data from 152 functional analyses drawn from the same sample and noted that social negative reinforcement was the most common function of SIB. In a subsequent meta-analysis of the treatment literature on SIB, Kahng et al. (2002) examined 265 data sets from 396 studies. That is, only experimental data sets were included in the meta-analysis; studies that included indirect or descriptive functional assessments were excluded. The analysis also indicated that social negative reinforcement was the most common. In a more general review of the literature on functional analysis, Hanley, Iwata, and McCord (2003) summarized 536 data sets and found similar percentages for both social positive reinforcement and social negative reinforcement. Finally, Kurtz et al. (2003) summarized 30 data sets, in which the analyses focused specifically on young children under the age of four, and found social positive reinforcement as the most common function.

As previously mentioned, the appearance of SIB has been correlated with several genetic syndromes such as Lesch-Nyhan syndrome (reported prevalence is 100%; Anderson & Ernst, 1994), Prader-Willi syndrome (reported prevalence is 60-80%; Symons, Butler, Sanders, Feurer & Thompson, 1999), Smith-Magenis syndrome (reported prevalence is 50% to 70%; Smith, Dykens, & Greenberg, 1998), and Rett syndrome (reported prevalence is 30% to 40%; Sansom, Krishnan, & Corbett, 1993). The focus of this study is on SIB in the Prader-Willi syndrome.

Prader-Willi syndrome (PWS) is a genetic disorder involving chromosome 15 (Prader, Labhart, & Willi, 1956). PWS is reported to occur in approximately 1 in 20,000 births, though this may be an underestimate because many individuals with PWS are believed to be undiagnosed (Whittington et al., 2001). Most individuals with PWS function in the mild range of intellectual disability (Dykens & Shah, 2003). There are a number of common behavioral characteristics of the syndrome, the most striking of which is hyperphagia (excessive eating). Individuals with PWS often display food-related problem behaviors that include overeating, food stealing, and pica. They are also reported to engage in ritualistic, repetitive, and other problem behaviors including aggression, tantrums, and property destruction, and SIB.

Skin picking has been reported to be the most common topography of SIB in the PWS population, with an estimated prevalence ranging from 65% to 97% (Dykens & Shah, 2003). Wigren and Heimann (2001) noted that skin picking in PWS typically occurs before age 11 and that the behavior tends to remain stable over time, though there seems to be some variability in terms of both incidence and frequency. A number of authors have suggested that the occurrence of skin picking seems to be independent of both gender and level of intellectual functioning (Dykens & Cassidy, 1995; Stein et al., 1994; Wigren & Heimann, 2001). PWS practitioners commonly refer to such picking as an “obsessive-compulsive” behavior inherent to the syndrome

(Dykens & Shah, 2003). This conceptualization seems to imply that the behavior is reflexive or biological in nature and raises questions about the behavior's sensitivity to environmental variables. Additionally, it is unclear whether individuals with PWS also engage in SIB topographies commonly reported in the DD population as a whole, such as head banging, self-biting, etc.

Given both the reported high prevalence of SIB (most notably skin picking) in PWS and the success of functional analysis methodology as a tool for identifying determinants of SIB, the purpose of this study was two-fold. The purpose of Study 1 was to identify the prevalence of SIB in individuals with PWS, as well as the topography, frequency, and severity of SIB. The purpose of Study 2 was to identify functional characteristics of SIB with a subset of these individuals.

CHAPTER 2
STUDY 1: PREVALENCE OF SELF-INJURIOUS BEHAVIOR IN THE PRADER-WILLI SYNDROME

Method

Subjects

In an attempt to identify a national sample of individuals with PWS, we contacted the care-provider agencies registered with the Prader-Willi Syndrome Association of the USA (PWSA USA). PWSA USA was organized in 1975 as a resource for education and information about PWS to parents, professionals, and other interested parties. Fifty agencies were identified from the provider database maintained by the PWSA USA website. The coordinators/administrators of these agencies were asked to complete and return a survey for each individual with PWS that they served.

Surveys were received from 28 of the 50 service providers yielding a subject sample of 203. The average subject age was 32 years (range, 11 years to 58 years). Demographic characteristics of the sample (i.e., gender, level of functioning, presence of sensory impairments, and genetic subtype of PWS) are shown in Table 2-1. The sample consisted of 89 males and 112 females (the gender of 2 individuals was not reported). The majority (83%) of individuals were classified as having mild-moderate mental retardation. The genetic subtype of PWS was identified in only 50% of cases. Over half of the individuals exhibited problem behaviors other than SIB, with the exception of stereotypy, which was reported in 23% of the population. Of the 203 subjects surveyed, 117 (58%) were reported to engage in SIB.

Survey Instrument and Procedure

A Survey on Self-Injurious Behavior (SIB) in the Prader-Willi Syndrome (PWS) was developed for the purposes of the current study. Surveys were sent via post and electronic mail to the coordinators/administrators of each agency registered with PWSA USA, who were asked

to complete and return a survey for each individual with PWS whom they served. A letter detailing the purpose of the survey and general instructions for survey completion accompanied the survey.

The survey was a 3-part questionnaire. Part 1 requested basic information about the individual (gender, age, level of functioning, presence of sensory impairments, genetic subtype of PWS, and presence of maladaptive behaviors). Respondents were instructed to complete the final two sections of the survey only for subjects who had displayed SIB within 6 months of the time of survey completion. Part 2 requested a specific description of the topographies of SIB exhibited by the individual. Respondents indicated which, if any, self-injurious topographies had been observed, and then used a numeric scale to describe the frequency of each topography of SIB (1-5, 1 = hourly, 5 = less than monthly). A list of topographies of SIB was developed from a review of responses reported by several studies of SIB in the DD population (Barron & Sandman, 1984; Griffin et al., 1986; Iwata et al., 1994; Rojahn & Esbensen, 2002). The list consisted of 22 topographies, as well as the option to report other forms of SIB not included. Because the risk associated with SIB has been reported to vary widely (Hyman et al., 1990; Wigren & Heimann, 2001), Part 2 of the survey requested that respondents use a numeric scale to describe both the level of physical injury (1-3, 1 = SIB produced loss of sensory or motor function, 3 = SIB produced no permanent damage) and the medical care requirements (1-3, 1 = SIB required hospitalization or surgery, 3 = SIB did not require care of medical professional) associated with the topographies of SIB a subject was reported to exhibit. Finally, Part 3 requested information about current treatment, if any, for SIB in terms of prescribed medication for SIB, use of physical restraints or protective equipment, medical treatment (e.g., wound care

by nurse) for SIB, and formal behavior management programs specifically designed to reduce SIB. A copy of the survey is provided in Appendix A.

Results and Discussion

Self-injurious behavior was reported to occur in 117 of the 203 subjects surveyed, indicating an SIB prevalence of 58% in this sample of individuals with PWS. The average age of subjects exhibiting SIB was 29 years (ranging from 11 years to 56 years).

Table 2-2 shows the results of the prevalence findings for topography, frequency, injury severity, and medical care requirements. The most common topography of SIB was skin picking, reported to occur in 75% of the sample. The average frequency level of skin picking was 3 (occurs at least once a week but not daily), the modal severity level was 3 (has produced no permanent damage), and the modal medical care level was 3 (has not required any care by a medical professional). Other topographies of SIB were reported to occur much less frequently. Of the 22 possible self-injurious behavior topographies on the survey, over half were reported to occur in less than 10% of the sample.

These findings are unusual in several respects. The overall distribution of SIB topographies reported in this PWS sample is very different than that reported in the DD population as a whole. Table 2-3 shows the prevalence for several SIB topographies in the current study with individuals with PWS as compared to the prevalence findings of several other studies with individuals with DD.

A much higher prevalence of skin picking, orifice digging, and rumination was observed in the PWS relative to the DD population, which averaged 22%, 10%, and 10%, respectively. On the other hand, the prevalence of head hitting, biting, and head banging was reported to be much higher in the DD population, which averaged 45%, 39%, and 20%, respectively. However, all of

these topographies were reported in 17% or less of this PWS population. Nevertheless, the data indicate that individuals with PWS engage in a wide range of SIB in addition to the commonly reported skin picking topography.

Although skin picking was associated with the highest prevalence, it was not reported to be frequent or severe for the most part. That is, skin picking in this sample occurred infrequently and was not severe in terms of injury or medical care requirements. However, there were reports of more frequent, severe skin picking. Figure 2-1 depicts frequency plots of the survey results for skin picking in terms of frequency (top panel), injury severity (middle panel), and medical care requirements (bottom panel).

Finally, results of Part 3 of the survey indicated that the most common treatment for SIB in PWS was some type of formal behavior intervention program. Table 2-4 lists the frequency of reported treatments for SIB. These findings are consistent with previous reports that treatment of SIB in the DD population typically involves operant conditioning (Iwata et al., 1994), although it is noted that very few respondents reported details regarding behavior program components or relative effectiveness.

Study 1 identified a relatively high prevalence of SIB in PWS (58%). Additionally, results indicated that individuals with PWS engage in a number of topographies of SIB (most notably skin picking). However, the determinants of SIB in this population remain unclear because attempts to identify the functional characteristics in SIB are essentially nonexistent. Wigren and Heimann (2001) included in their survey questions soliciting parental opinion about situations in which SIB was typically displayed. However, no experimental analysis of variables that might influence SIB has been reported in the PWS literature. Therefore, the purpose of Study 2 was to

conduct functional analyses with a subset of individuals from Study 1 to identify environmental determinants of SIB in individuals with PWS.

Table 2-1. Demographic characteristics of subject sample

Characteristic		Number of subjects	Percent of sample
Gender	Male	89	44%
	Female	112	55%
Level of functioning	Mild/moderate MR	168	83%
	Severe MR	7	3%
	Profound MR	1	1%
	Unknown	27	13%
Sensory impairments	Hearing deficit	6	3%
	Vision deficit	57	28%
Type of PWS	Paternal Deletion	38	19%
	UPD	21	10%
	Imprinting defect	2	1%
	PWS Like	15	7%
	Translocation	2	1%
	Unknown	101	50%
Maladaptive Behavior	Hoarding	91	45%
	Stealing	161	79%
	Tantrums	159	78%
	Aggressive behavior	112	55%
	Disruptive behavior	108	53%
	Noncompliance	122	60%
	Stereotypy	47	23%
	SIB	117	58%

Table 2-2. Frequency and percent of SIB topography, frequency, severity, and medical care

Topography	Number of subjects	Percent	Frequency (Average)	Severity (Mode)	Medical Care (Mode)
Skin picking	88	75%	3	3	3
Orifice digging	33	28%	3	3	3
Biting	20	17%	4	3	3
Hair pulling	18	15%	4	3	3
Body banging	16	14%	5	3	2
Body hitting	15	13%	4	3	2
Bruxism	15	13%	3	3	2
Rumination	15	13%	3	3	3
Head banging	14	12%	4	3	3
Polydipsia	10	11%	4	3	3
Pica	12	10%	4	3	3
Head hitting	11	9%	4	3	3
Nail pulling	10	9%	4	3	3
Aerophagia	7	6%	4	3	3
Cutting	7	6%	5	3	1
Choking	6	5%	5	3	3
Eye poking	6	5%	4	3	3
Neck whipping	6	5%	4	3	3
Teeth pulling	6	5%	5	3	2
Vomiting	6	5%	4	3	3
Hand mouthing	5	4%	5	3	3
Other	5	4%	4	3	3
Throat gouging	4	3%	5	3	3

Table 2-3. Comparisons of SIB prevalence findings by topography

Topography	Neidert (Current) *N* = 117	Griffin (1986) *N* = 184	Emberson (1990) *N* = 163	Rojahn (1984) *N* = 60
Skin picking/scratching	75%	26%	16%	25%
Orifice digging	28%	10%	Not reported	<10%
Biting	17%	39%	37%	40%
Rumination	13%	<10%	Not reported	<10%
Head banging	12%	29%	<10%	Not reported
Head hitting	9%	37%	29%	70%

Table 2-4. Frequency and percent of reported treatment for SIB

Treatment	Number of subjects	Percent
Medical intervention	35	30%
Physical restraint or protective equipment	15	13%
Medical care	40	34%
Formal behavior program	76	65%

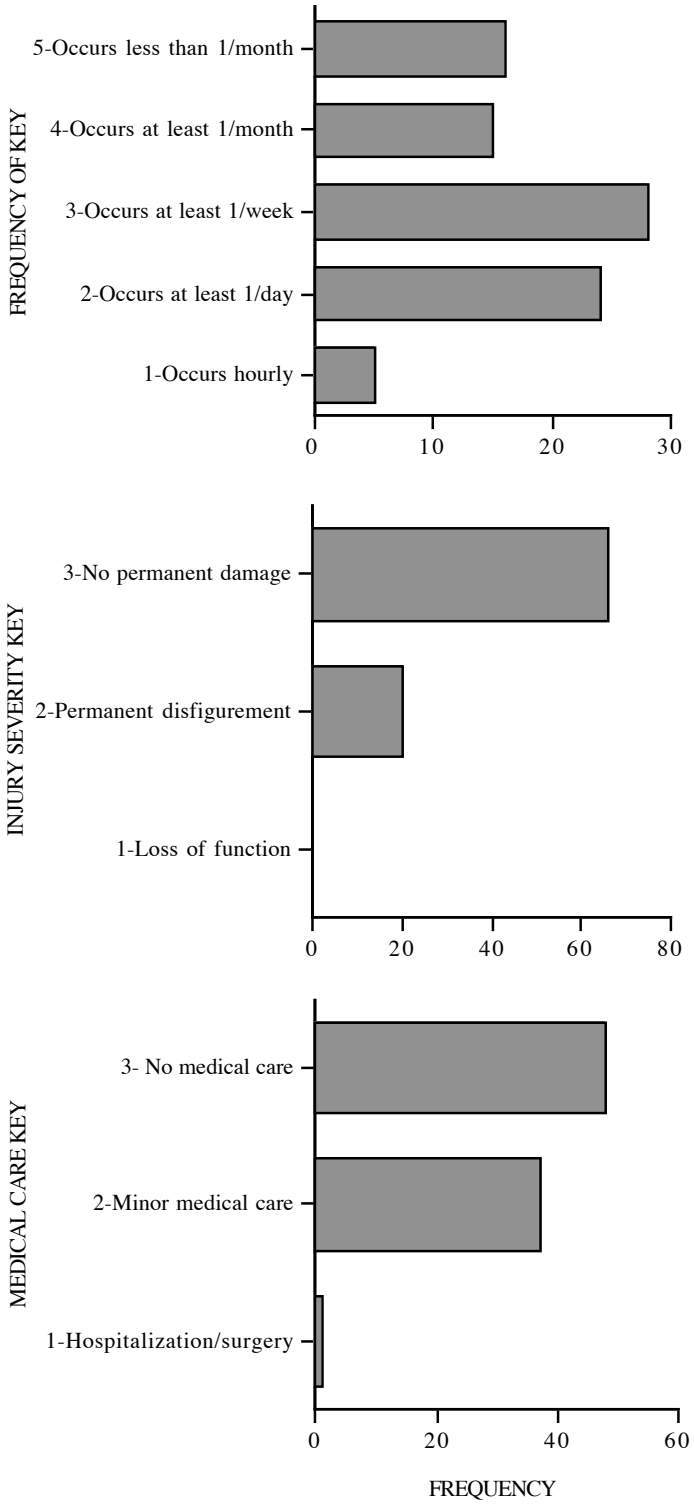

Figure 2-1. Frequency plots of skin picking frequency, injury severity, and medical care requirements

CHAPTER 3
STUDY 2: PREVALENCE OF FUNCTIONS OF SELF-INJURIOUS BEHAVIOR IN THE PRADER-WILLI SYNDROME

Method

Subjects and Settings

Subjects were 25 individuals with PWS who lived and worked at a local adult program for individuals with developmental disabilities. These subjects were reported by staff to have a history of engaging in SIB. Additionally, all subjects' behavior intervention plans at the program included SIB as a target problem behavior. Sessions were conducted at the day program in therapy rooms containing tables, chairs, and session materials relevant to the specific assessment conditions. Sessions lasted 10 min and were conducted three to five times per day, 4 to 5 days per week.

Self-Injury Trauma (SIT) Scale

The Self-Injury Trauma (SIT) Scale is a rating scale for collecting data on surface tissue damage caused by SIB (Iwata, Pace, Kissel, Nau, & Farber, 1990). The scale classifies and quantifies tissue damage according to topography, location of the injury on the body, type of injury, and number of injuries. A copy of the SIT Scale is provided in Appendix B. The SIT Scale was conducted for two reasons. First, the information allowed identification of a given individual's specific topographies of SIB. Second, the SIT Scale provided an overall risk estimate such that appropriate safety precautions could be taken during the course of the functional analysis. Prior to the start of a subject's functional analysis, two behavior analysts administered the SIT Scale. First, the topographic aspects of SIB were identified via record review of the subject's behavior intervention plan. In addition, physical evidence of healed injuries (e.g., scars, permanent disfigurement, etc.) was documented. Second, current injuries

were observed and recorded. For each area of the body containing a current (unhealed) injury, observers used a scale (1, 2, or 3) to record the number of wounds at that particular location. Observers then noted the type and severity of the most severe wound at that location, identified the wound as either an abrasion/laceration or a contusion, and used a numeric scale (1, 2, or 3) to indicate wound severity. Finally, the information was summarized to provide an overall risk estimate. For example, a high overall risk estimate, which consisted of an extensive abrasion or deep laceration, a contusion resulting in tissue rupture, or extensive swelling on the head, would likely require immediate medical attention and subsequent prevention of the behavior such that safely allowing the behavior to occur during the functional analysis would be difficult. For individuals with a high risk estimate, functional analysis sessions were conducted only during times in which a nurse was available. Additionally, sessions were terminated (and the nurse was notified) if the response produced visible injury (e.g., blood, redness, swelling). Conversely, a low to moderate overall risk estimate would likely require medical attention as needed (e.g., administration of minor first aid procedures by either the behavior analyst or nursing staff member following a block of sessions), but could be allowed to occur during the functional analysis without resulting in more serious trauma.

The age, functioning level, targeted topographies of SIB, and overall risk estimate (as determined by the SIT scale) for each subject is reported in Table 3-1.

Response Measurement and Reliability

Target behaviors were selected for subjects on an individual basis and are listed in Table 3-1. Skin picking was defined as any nail-to-skin contact producing visual displacement of the skin or touching existing wounds. Hair pulling was defined as using hands to forcibly pull or remove hair from the head. Biting was defined as insertion of a body part in the mouth such that

the upper and lower teeth made contact with the skin at that location. Rectal digging was defined as insertion of the subject's hands inside their pants past the elbow. For all subjects, skin picking was the most commonly observed topography; hair pulling, biting, and rectal digging were rarely observed. Therefore, data are reported as a combined measure of SIB. Trained graduate and undergraduate students collected data on the occurrence of SIB (as defined for each subject) on handheld personal digital assistants (PDAs). Frequency data collection was used for subjects whose SIB had a discrete onset and offset. Interval data collection was used for subjects whose SIB occurred at extremely high rates or occurred for extended periods of time. Data were converted to either number of responses per minute (rpm) or percentage of intervals occurrence of SIB for purposes of data analysis.

Interobserver agreement was assessed during an average of 42% of sessions for all subjects by having a second observer simultaneously but independently collect data with the primary observer. Sessions were divided into 10-s intervals, and data were compared on an interval-by-interval basis. Agreement coefficients were calculated by dividing the smaller number of responses in each interval by the larger number of responses; these fractions were averaged across intervals and multiplied by 100%. Mean agreement scores for SIB were above 90% for all subjects.

Procedures

A functional analysis (Iwata et al., 1982/1994) was conduced for each subject to identify the consequences that maintained SIB. Three test conditions (alone, attention, and demand) and a control condition (against which levels of SIB in the test conditions were compared) alternated in a multielement design. The conditions of the analysis were presented in a fixed sequence (alone, attention, play, demand) to arrange a strong establishing operation for the reinforcer in a

given condition by preceding that condition with a condition in which the reinforcer was absent (deprivation).

During the alone condition, the subject was alone in an otherwise barren room (i.e., no materials were present). No programmed consequences were arranged for occurrences of SIB. The purpose of the alone condition was to determine if SIB was maintained by automatic reinforcement (i.e., the behavior persisted in the absence of social contingencies).

During the attention condition, the subject and a therapist were in a room. The therapist asked the subject to play independently with materials, then ignored the subject except to deliver attention (i.e., brief physical interruption of the response, verbal reprimand, and statement of concern) following occurrences of SIB. The purpose of the attention condition was to determine if SIB was maintained by social positive reinforcement (access to attention).

During the demand condition, a therapist presented academic (e.g., math problems, reading comprehension questions, spelling tasks, etc.), vocational (e.g., assembly tasks, cleaning tasks, etc.), or hygienic (e.g., brush hair, rub lotion on hands, etc.) tasks to the subject using a three-step prompting sequence (verbal, gestural, physical prompts). Compliance with the task resulted in verbal praise; SIB resulted in a 30-s break from the task. The purpose of the demand condition was to determine if SIB was maintained by social negative reinforcement (escape from demands).

During the control (play) condition, a therapist and the subject were in a room. No task demands were presented, and preferred toys and attention were continuously available. No programmed consequences were arranged for SIB. The purpose of the play condition was to serve as the control condition, against which the test conditions were compared.

Whenever possible, specific stimuli, including therapists, colored shirts, and session rooms, were correlated with the different functional analysis conditions to facilitate discrimination. Additionally, alone sessions were conducted in a room equipped with a hidden camera. A hidden camera was used in favor of the more traditional one-way mirror because of the pattern of behavior displayed by one of the first individuals for whom a functional analysis was conducted (Subject PM). Figure 3-1 shows the results of this Subject PM's functional analysis. The top panel shows frequency of SIB during several alone sessions. The bottom panel shows cumulative frequencies of SIB during those sessions. The first alone session conducted with Subject PM was conducted in a room equipped with a one-way mirror (Room A1). A total of 19 occurrences of SIB were observed during this session. However, the cumulative graph shows that SIB occurred at a high rate during this session in Room A1 until approximately minute 2, at which point the behavior stopped occurring for the remainder of the session. Subsequently, alone sessions were conducted in a different room, Room B, also equipped with a one-way mirror. The same pattern of responding was observed. That is, a relatively high frequency of SIB was observed; however, the within-session pattern of responding shows that all behavior occurred within the first three minutes of session. To control for the possibility that the subject had detected the presence of the observer behind the one-way mirror, sessions were subsequently conducted in a room equipped with a camera hidden inside a nonfunctional smoke detector. The top panel shows a moderate frequency of SIB during the first session conducted in this room (Room C). Within-session data analysis showed that responding continued to occur throughout this session and continued to occur during all subsequent alone sessions conducted in this room. Finally, an additional session was conducted in the original session room (Room A2) following completion of the functional analysis in which alone sessions

were always conducted in the hidden camera room. An immediate elimination of SIB was observed that maintained throughout the session. Further, zero levels of SIB maintained during four additional sessions (data not shown). Given these findings, the hidden camera room was used as the setting for alone sessions conducted with all subsequent subjects.

Functional analyses were considered complete when differential responding was observed after at least 3 complete sets of conditions or following the completion of 5 sets of conditions. Higher levels of SIB in any of the test conditions relative to the control condition suggested the reinforcer responsible for behavioral maintenance.

Results and Discussion

Three general patterns of responding for the current subjects were observed. First, four subjects showed SIB maintained by social positive reinforcement. These subjects displayed higher levels of SIB in the attention condition, in which SIB produced attention from another person, relative to all other conditions. Figure 3-2 shows the results of the functional analyses for these four subjects (JC, PP, AB, TH). Subject JC (top left panel), did not exhibit SIB in any condition until session 10 (attention). Subsequently, JC exhibited consistently higher levels of SIB in the attention condition as compared to the other conditions. A similar pattern of responding was observed for subject PP (top right panel). Initially, a clear function was not identified during the multielement functional analysis for subjects AB and TH (bottom left panel and bottom right panel, respectively). Both subjects engaged in SIB to some extent in both the attention and demand conditions; however, levels of SIB were not consistently higher in these conditions across sessions, and SIB decreased to near-zero levels during the final sessions of the multielement comparison. Subsequently, a pairwise comparison (Iwata, Duncan, Zarcone, Lerman, & Shore, 1994) was used to clarify the function of SIB for these two participants. The

pairwise design consisted of several phases in which the independent variable was implemented in a sequential (A-B-C) fashion, as in the reversal research design. However, each phase consisted of both a test and a control, alternated in a multielement format. During the pairwise comparison, subject AB and subject TH displayed consistently higher levels of SIB during the attention condition relative to the control condition. Further, equally low levels of SIB were observed in the demand and control conditions for both subjects, suggesting SIB was not maintained by social negative reinforcement.

Six subjects engaged in SIB to some extent in more than one functional analysis condition. However, levels of SIB were higher in the alone condition relative to the other conditions. This pattern of responding suggests that SIB is maintained by automatic reinforcement (i.e., behavior persists in the absence of social consequences). Figure 3-3 shows the results of the functional analyses for these 6 subjects (DP, BR, CM, DH, AC, and PM). Subject DP (top left panel) engaged in SIB across all conditions during the course of the analysis. Subject BR (top right panel) initially engaged in higher levels of SIB during the alone, attention, and demand conditions. However, SIB decreased to near-zero under both the attention and the demand condition over the course of sessions, yet consistently high levels of SIB persisted in the alone condition. Similar patterns of responding were observed for the other 4 subjects (CM, DH, AC, and PM). That is, SIB occurred to some extent in more than one condition initially, but decreased to near-zero levels over the course of the analysis in all conditions except the alone condition.

Finally, 13 subjects engaged in SIB either exclusively or almost exclusively in the alone condition, also suggesting SIB maintained by automatic reinforcement. Figures 3-4 and 3-5 show the results of the functional analyses for these 13 subjects (EM, KBL, KB, KD, KT, MJG,

KM, AR, JB, BG, JS, JL, and JG). Subjects EM and KBL (top left and top right panels of Figure 3-4, respectively) displayed variable levels of SIB. However, when SIB did occur, it was observed almost exclusively (i.e., with the exception of a few instances in one other condition) in the alone condition. The other subjects displayed high consistent levels of SIB in the alone condition, for the most part to the exclusion of all other conditions.

Functional analysis results were unclear for two subjects behavior they did not engage in SIB (LT) or exhibited it sporadically (LN) during the analysis. Figure 3-6 shows the results of the functional analysis for these 2 subjects.

In Study 2, sources of reinforcement for SIB were identified in 92% of cases. That is, SIB was not observed (or observed extremely infrequently) for only 2 of the 25 subjects in the study. Self-injurious behavior was maintained by social positive reinforcement in 17% of cases in which the reinforcer was identified, whereas SIB was maintained by automatic reinforcement in the overwhelming majority of cases (83%). No cases in which SIB was maintained by social negative reinforcement was observed. Table 3-2 summarizes the distribution of behavioral functions for SIB for the 25 PWS subjects in the current study, as well as the distribution of functions reported in four large-scale prevalence studies on SIB in the DD population. These other studies covered the entire field of developmental disabilities. Although it is possible that individuals with PWS were included in the studies, no information regarding individual subject diagnoses was provided. The findings for the PWS population in the current study are considerably different from the distribution of functions typically reported for SIB in the general DD population.

The highest percentages reported in previous studies of SIB in the DD population were associated with social reinforcement, and three of the studies reported high percentages for SIB

maintained by social negative reinforcement. Surprisingly, no cases of SIB maintained by social negative reinforcement were identified in the current PWS population. Hanley et al. (2003) and Kurtz et al. (2003) reported social positive reinforcement as the most common function for SIB in the DD population. However, only a small percentage (17%) of the cases in the current study were associated with attention-maintained SIB. Finally, all of the previous studies reported SIB in the DD population to be maintained by automatic reinforcement in approximately 25% of cases or less. However, the overwhelming majority of cases in the current study (83%) were cases of automatically-maintained SIB.

Table 3-1. Subject characteristics

Subject	Age	Functioning Level	Self-injury	Risk Estimate
JG	11	Mild/Moderate MR	skin picking, hair pulling	low
KM	14	Mild/Moderate MR	skin picking, biting, head banging	low
EM	14	Mild/Moderate MR	skin picking	low
JC	16	Mild/Moderate MR	skin picking, biting	low
AC	18	Mild/Moderate MR	skin picking, biting	high
BG	18	Mild/Moderate MR	skin picking	low
LT	18	Mild/Moderate MR	skin picking	low
JS	20	Mild/Moderate MR	skin picking	low
AB	21	Mild/Moderate MR	skin picking, head banging, biting	-
KB	21	Mild/Moderate MR	skin picking, biting	low
KT	21	Mild/Moderate MR	skin picking	low
LN	22	Mild/Moderate MR	skin picking	low
MJG	24	Mild/Moderate MR	skin picking	low
BR	24	Mild/Moderate MR	skin picking, biting	moderate
KD	25	Mild/Moderate MR	skin picking	low
TH	26	Mild/Moderate MR	skin picking	low
KBL	26	Mild/Moderate MR	skin picking, biting, rectal digging	low
DH	29	Mild/Moderate MR	skin picking	low
JL	29	Mild/Moderate MR	skin picking	low
DP	32	Mild/Moderate MR	skin picking	high
JB	33	Mild/Moderate MR	skin picking, biting	low
PM	37	Mild/Moderate MR	skin picking	low
AR	38	Mild/Moderate MR	skin picking	low
CM	42	Mild/Moderate MR	skin picking	low
PP	56	Mild/Moderate MR	skin picking, hair pulling	low

* MR = mental retardation

Table 3-2. Distribution of SIB functions in current PWS population compared to DD population

Function	Neidert (current)	Iwata et al. (1994)	Kahng et al. (2002)	Hanley et al. (2003)	Kurtz et al. (2003)
Social positive reinforcement	17%	26.3%	26.4%	39.2%	37.9%
Social negative reinforcement	0%	38.1%	31.3%	29.3%	3.4%
Automatic reinforcement	83%	25.7%	27.5%	24.8%	13.8%
Unknown (No SIB)	8%	9.9%	7.9%	5.5%	37.9%

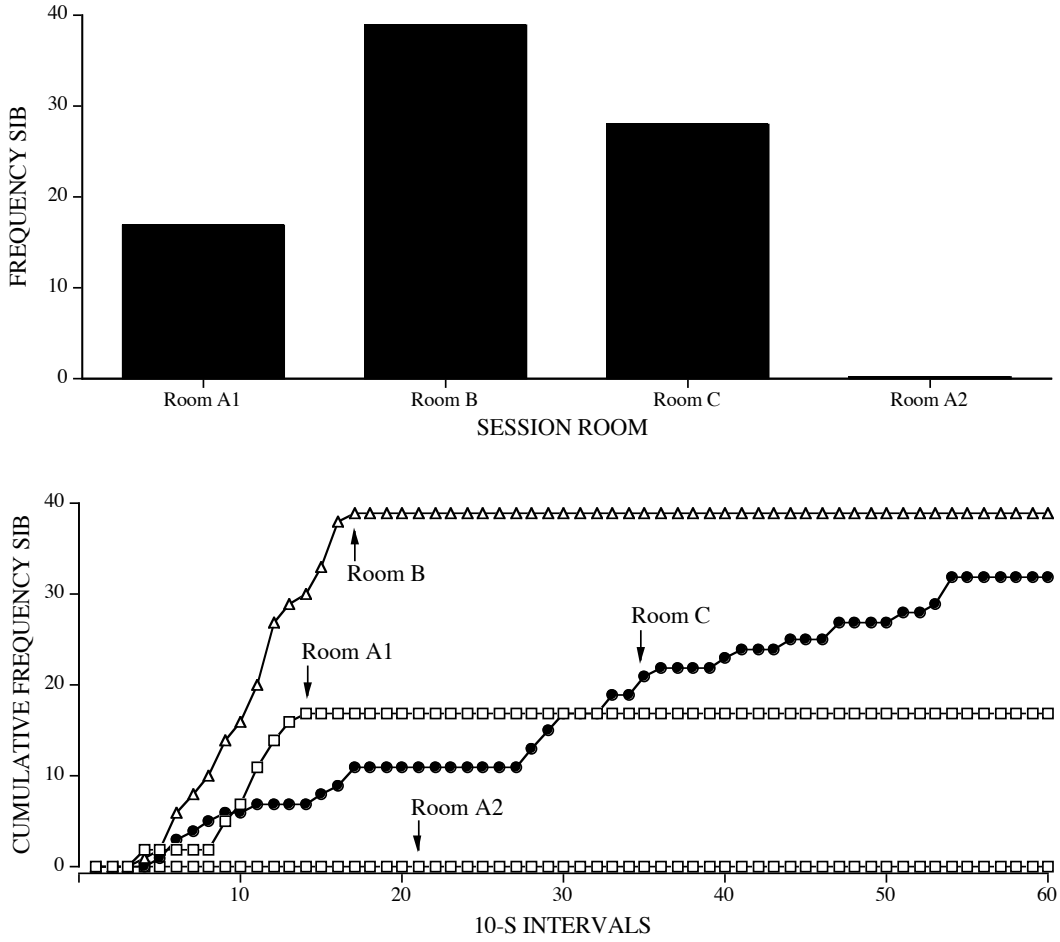

Figure 3-1. Frequency of SIB during first alone session conducted in three different session rooms (top panel). Cumulative frequency of SIB during consecutive 10-s intervals of alone session in each of the rooms (bottom panel).

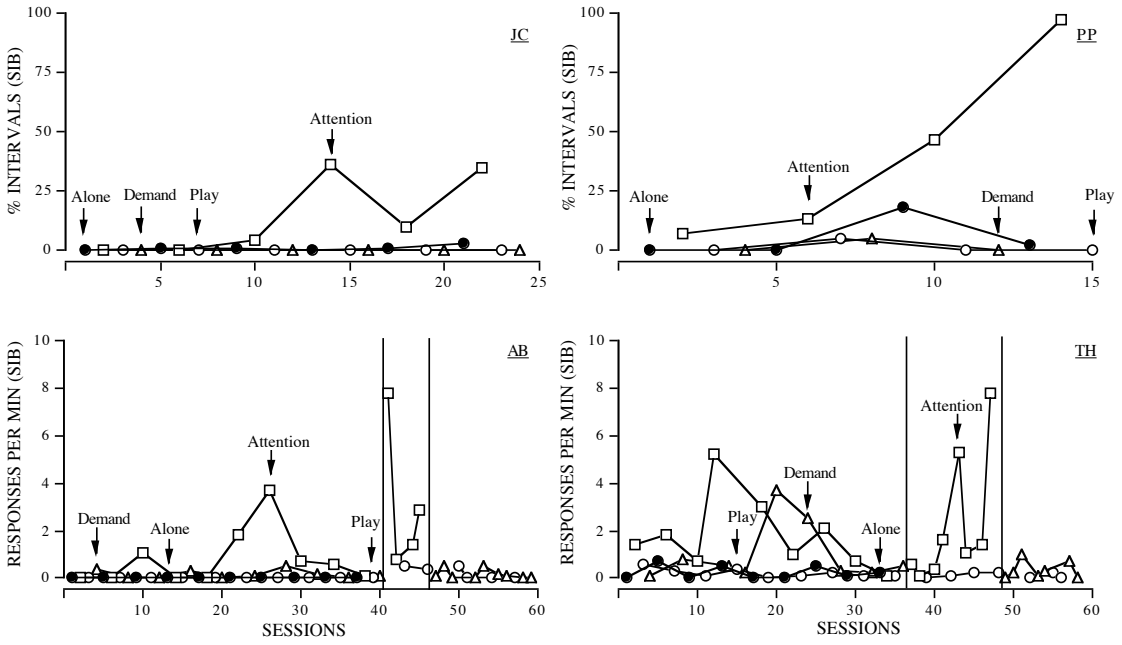

Figure 3-2. Percentage of intervals (subjects JC and PP) and responses per minute (subjects AB and TH) across sessions and experimental conditions for cases of SIB maintained by social positive reinforcement.

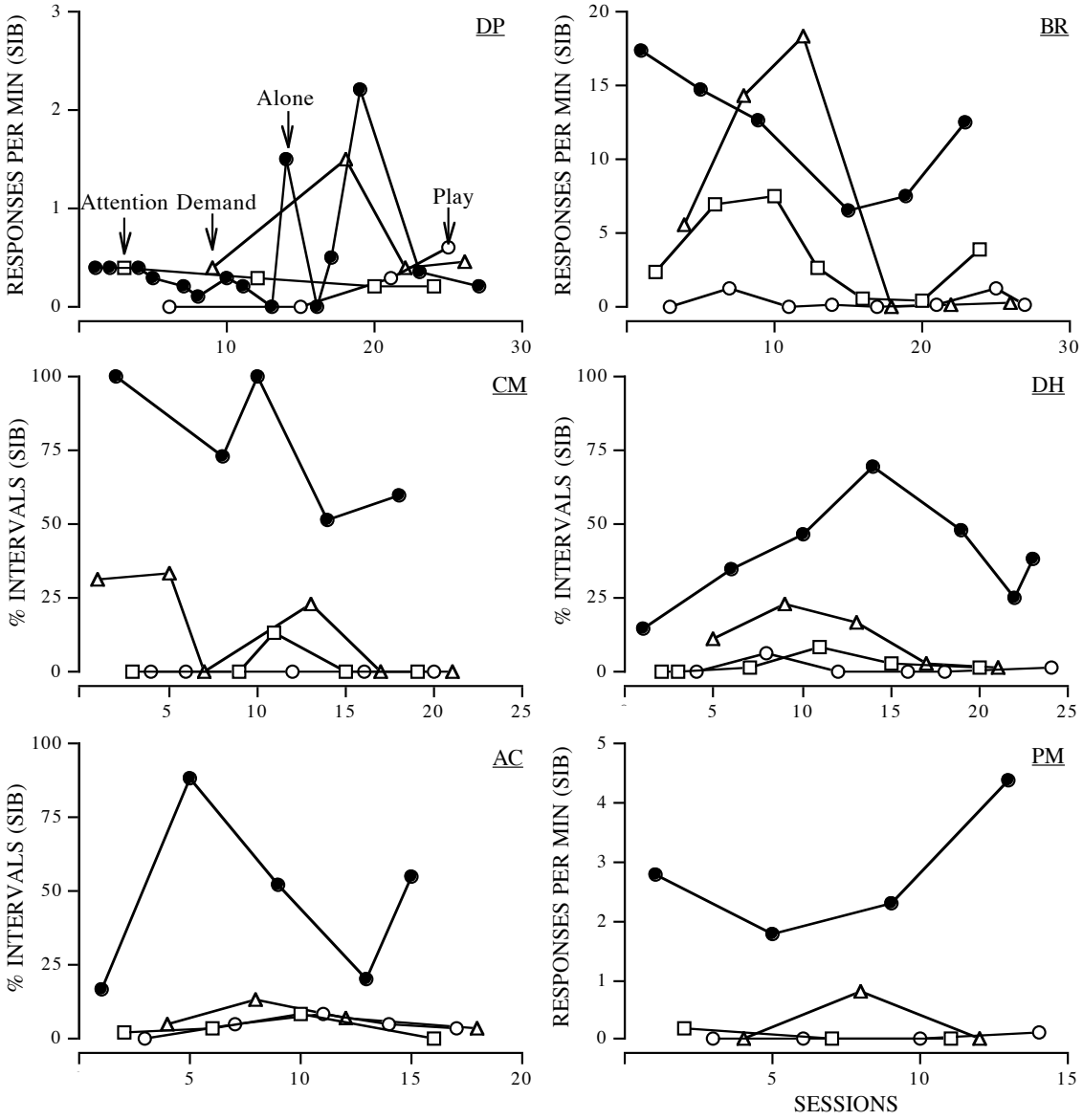

Figure 3-3. Responses per minute (subjects DP, BR and PM) and percentage of intervals of SIB (subjects, CM, DH, and AC) across sessions and experimental conditions for cases of automatic reinforcment.

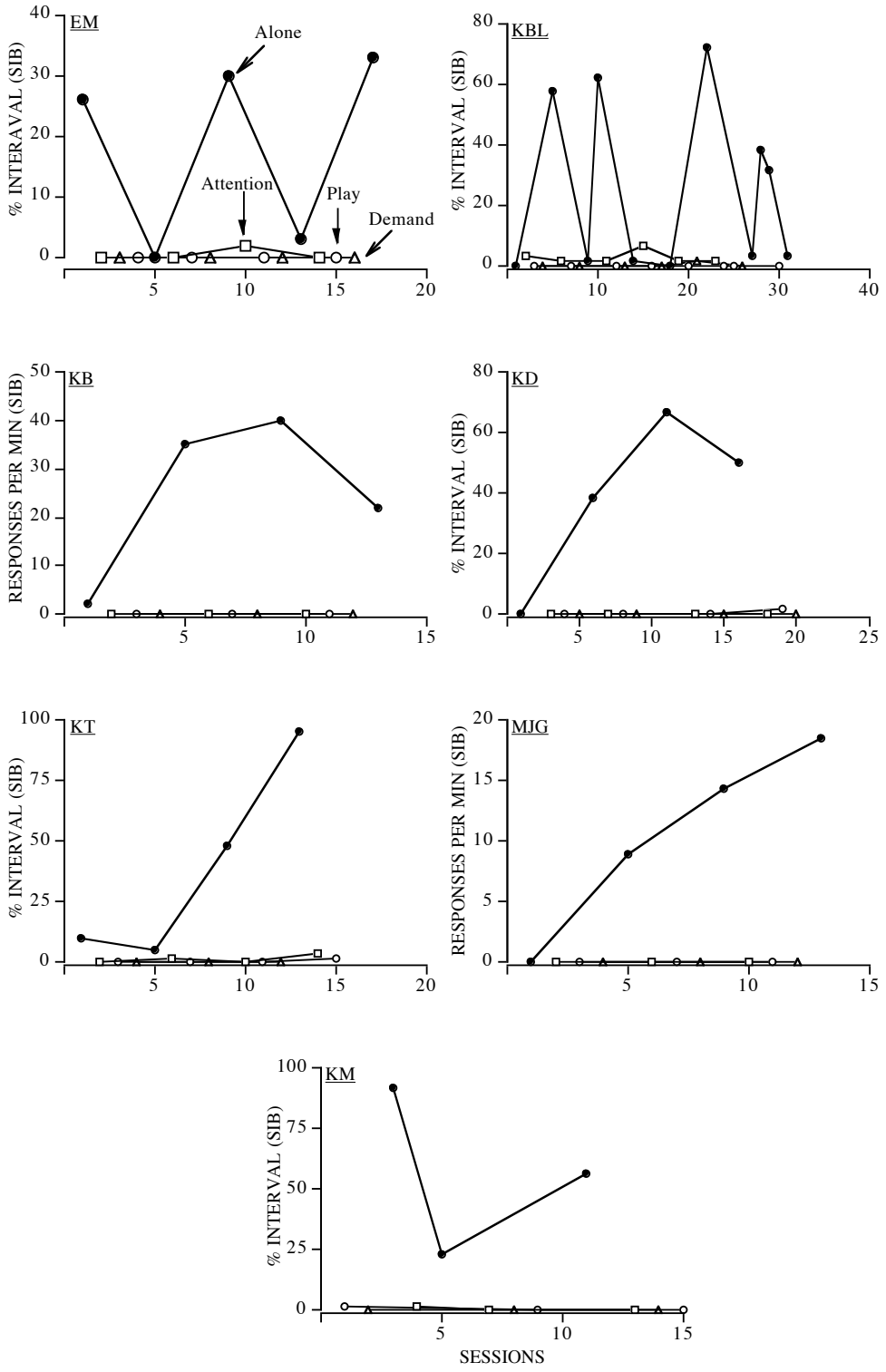

Figure 3-4. Responses per minute (subjects KB and MJG) and percentage of intervals of SIB (subjects EM, KBL, KD, KT, and KM) across sessions and experimental conditions for cases of SIB maintained by automatic reinforcement.

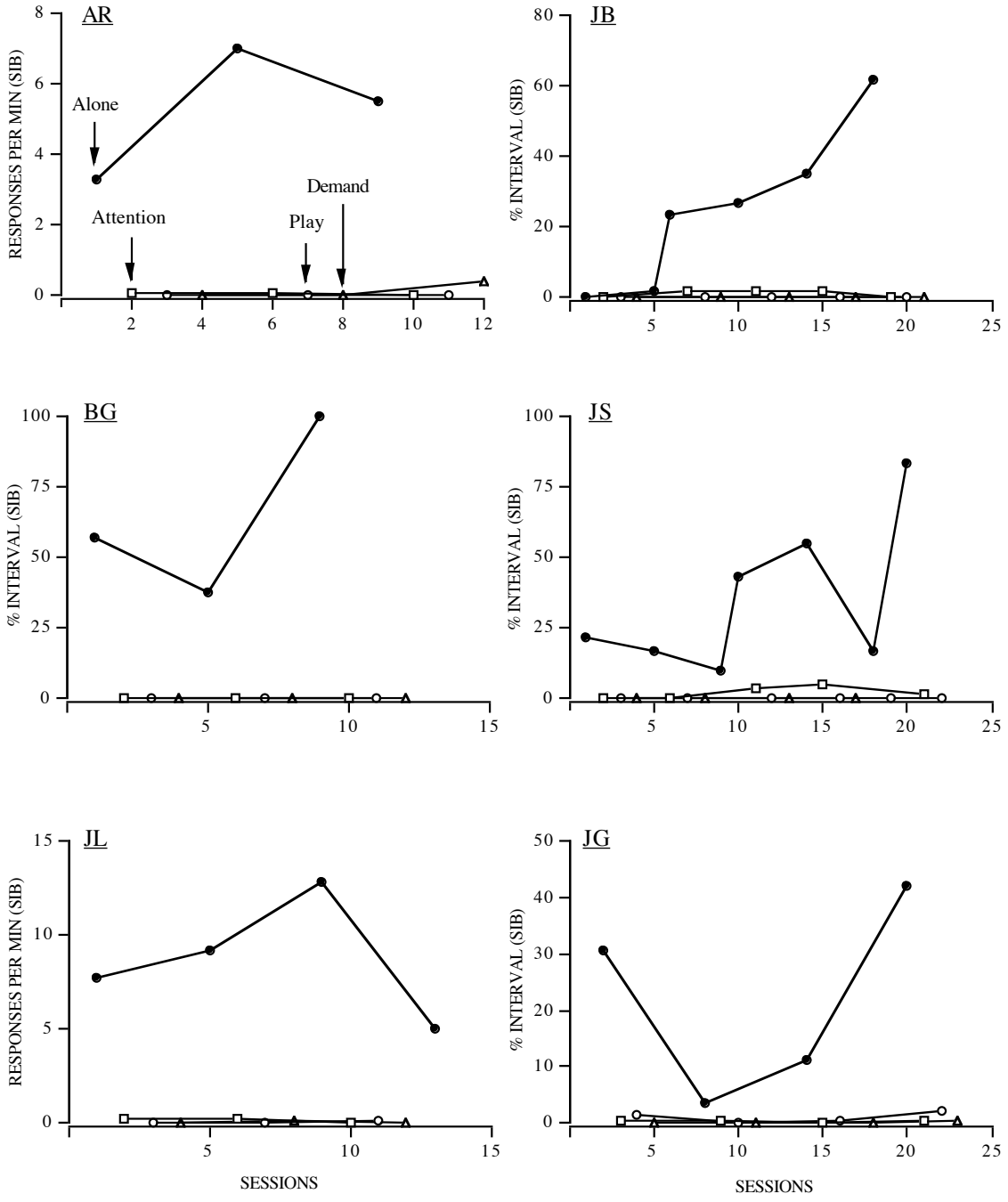

Figure 3-5. Responses per minute (subjects AR and JL) and percentage of intervals of SIB (subjects JB, GB, JS, and JG) across sessions and experimental conditions for cases of SIB maintained by automatic reinforcement.

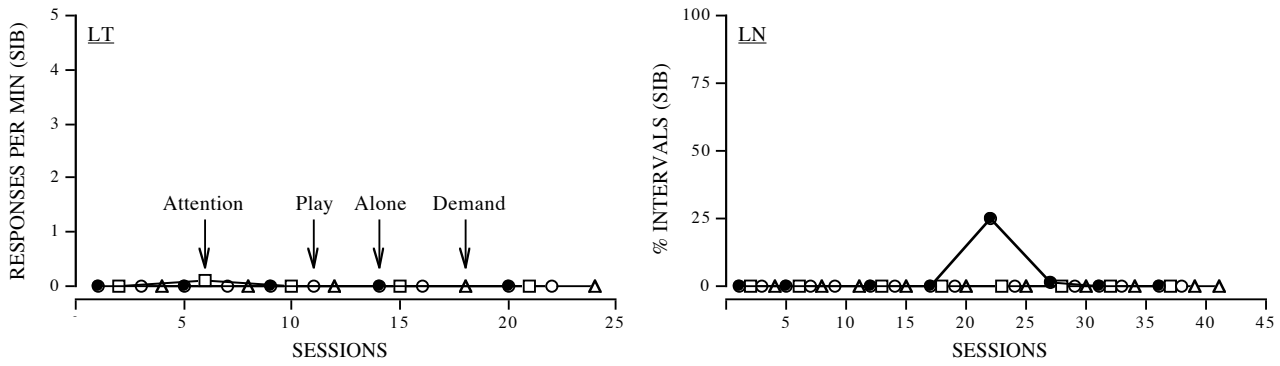

Figure 3-6. Responses per minute (subjects LT) and percentage of intervals of SIB (subject LN) across sessions and experimental conditions cases of SIB in which source of reinforcement was not identified.

CHAPTER 4
GENERAL DISCUSSION

Results of the present studies provide information about the distribution, topographical features, and functional characteristics of SIB in the Prader-Willi Syndrome. The data offer a somewhat different perspective on SIB as a behavior disorder and may be helpful in the development of both clinical and research initiatives.

Study 1 examined the prevalence of SIB among 203 individuals with PWS from 28 agencies registered with the PWS USA. Results showed an SIB prevalence of 58%, which is much higher than that reported in previous studies that surveyed a large number of individuals with DD either across multiple facilities within a state or across facilities from multiple states. The results of several such studies are shown in Table 4-1.

The target populations in the majority of these studies represent total target populations (i.e., existing, often arbitrary, populations) rather than target populations that resulted from sampling strategies (Rojahn & Esbensen, 2002). The exception in the above studies was Hill and Bruininks (1984), who first sampled certain community programs and public residential facilities around the United States, and then identified cases of SIB. The prevalence of SIB estimate in the current study is higher than the estimates in studies in the above table despite similar methods used to identify target population. However, the total number of surveyed individuals in these studies is considerably higher than the number of surveyed individuals in the current study. Additionally, although the population in the current study consisted of individuals from different agencies across different states, one might consider all of these agencies to be segregated facilities containing a relatively homogeneous population of individuals (i.e., individuals with PWS). A number of prevalence studies that surveyed a smaller number of individuals at a single

(segregated) facility have reported higher SIB prevalence estimates than the studies previously mentioned. Table 4-2 shows the results of several of such studies.

The range of SIB prevalence estimates in these studies (31% to 65.9%) is more consistent with the SIB prevalence finding in the current study (58%). Given that surveys from only 28 of the 50 agencies registered with PWS USA were received, the current study may have failed to identify a large proportion of individuals with PWS in the country. It is unclear if a lower SIB prevalence estimate would have been observed if the sample had consisted of a considerably higher number of individuals with PWS. However, the few registered agencies reported served a relatively large number of individuals with PWS. One of the two facilities reported to serve the largest number of individuals with PWS returned surveys for 100% of the individuals they reported to serve. Of the 63 individuals with PWS at facility where this study was conducted, 43 individuals (68%) were reported to engage in SIB.

Of the 117 individuals in the current study who engaged in SIB, 75% were reported to engage in skin picking, much higher than the reported prevalence of skin picking in the general population of individuals with DD, which typically ranges from 16% to 25% (Embersen & Walker, 1990; Griffin et al., 1986; Rojahn, 1984). However, the SIB prevalence estimate of the current study is consistent with studies in the PWS literature, which suggest that skin picking prevalence in PWS ranges from 65% to 97% among children and adults with the diagnosis (Dykens & Shah, 2003; Wigren & Heimann, 2001). It has been suggested that, in addition to topographical differences in SIB, bodily locations of SIB differ among diagnostic groups of individuals with DD (Thompson & Caruso, 2002). For example, Symons and Thompson (1997) found that 80% of injuries exhibited by individuals with severe intellectual disabilities and autism occurred on 5% of the body's surface area (head, hands, finger, and thigh). Yet,

individuals with Cornelia de Lange syndrome typically bite the tips of their fingers (Berney, Ireland, & Burn, 1999), and individuals with Rett sydrome typically either wring their hands scratching hands with fingernails or engage in hand mouthing (Normura & Segawa, 1990). Individuals with PWS have been reported to skin pick their nose, upperarms, forearms, thighs, knees, lower leg, and feet (Cassidy, 1984; Dykens et al., 1997). Although no formal attempt was made to catalogue specific body locations of skin picking in the subject population in Study 1, information from the SIT scale and direct observations of skin picking during Study 2 are consistent with body locations reported in these studies. It has been suggested that differences in SIB topography and bodily location of injury among different developmental disabilities may reflect different different underlying neurochemical mechanisms (Thompson & Caruso, 2002), although there is no empirical evidence at this time to support this conclusion. Results of epidemiological studies of functional analyses (e.g., Iwata et al., 1994; Kahng et al, 2002) often show that individuals with different diagnoses exhibit topographically similar behavior (e.g., self-biting). Further, functional analysis results often show that similar topographies of self-injury serve different functions (e.g., self-biting maintained by social-positive reinforcement vs. self-biting maintained by social-negative reinforcement). Thus, topographical differences associated with different disabilities may simply be correlational.

The results of Study 2 showed that a large proportion of subjects exhibited skin picking primarily when they were alone. One interesting albeit speculative explanation of the topographical difference of SIB in PWS is that perhaps these individual's physiological makeup increases sensitivity to certain types of environmental events as reinforcers. Individuals with PWS are also typically hyperphagic (i.e., they engage in excessive overeating) and, therefore, are typically morbidly obese. The result is large lipoid deposits and excess skin (often substantial

folds of skin are observed especially in those individuals who lose a considerable amount of weight). These unique physiological characteristics may create a unique stimulus that evokes a response (e.g. picking) that, given a genetic sensitivity to automatic reinforcement, strengths that type of response. This may be especially likely to occur in situations in which alternative stimulation is low (e.g., individual is alone without preferred items or activities).

An additional speculation regarding topographical differences between SIB in the PWS and DD populations also relates to the observation that many PWS individuals engage in skin picking when alone. Although such skin picking may be sensitive to automatic reinforcement, the behavior may also be influenced by social attention as punishment. That is, it is possible that these individuals have a long history of care providers socially punishing occurrences of SIB such that the behavior comes under stimulus control (i.e., occurs in the absence of other people but does not occur in their presence). Further, picking specific areas of the body in which evidence of picking (i.e., wounds) is easily hidden from others may avoid social censure. Many of the subjects in Study 2 who engaged in skin picking in the alone condition tended to pick their forearms, stomach, hips, thighs and the bottoms of their feet. Clothing typically covers these areas of the body. Anecdotally, a number of individuals were observed to remove pieces of clothing at the beginning of alone sessions (following the therapist's exit from the room). The end of alone sessions was signaled by a knock on the door and entrance into the room by a therapist; however, data collectors continued to monitor the room via hidden camera. These individuals were also observed to quickly replace their clothing immediately following the knock on the door (either before, or simultaneous with, the therapist's entrance).

Study 2 showed that the majority of cases of SIB (83%) were maintained by automatic reinforcement, whereas only 17% of the subjects exhibited attention-maintained SIB. No cases

of escape-maintained SIB were observed. This distribution of functions also differs noticeably from that reported for SIB in general populations of individuals with DD, for whom the largest percentage of cases was maintained by social reinforcement (Hanley, 2003; Iwata et al., 1994; Kahng et al., 2002; Kurtz et al., 2003).

The fact that several subjects' SIB was maintained by social positive reinforcement calls into question the common conceptualization of SIB as an obsessive-compulsive disorder (OCD). For these subjects, social consequences were directly responsible for the maintenance of SIB, which is inconsistent with a conceptualization of SIB as either "obsessive" or "compulsive". Therefore, these results seem to lend further evidence that SIB in PWS may be sensitive to environmental influences, which underscores the importance of examining environmental correlates of behavior disorders regardless of diagnostic label.

Three patterns of responding during a functional analysis are generally indicative of behavior maintained by automatic reinforcement: (a) the behavior occurs exclusively in the alone condition, (b) the behavior is consistently higher in the alone condition but occurs during other conditions as well, or (c) high levels of behavior occur during all conditions. Although these types of outcomes during a functional analysis effectively rule out social reinforcement as a source of maintenance, they do not identify the specific type of automatic reinforcement produced by the behavior. For example, the behavior could be maintained by sensory stimulation (Kennedy & Souza, 1995; Rincover, 1978) or pain-attenuation (Carr & McDowell, 1980). Although not accounted for by the current study, it is possible that SIB that results in the production of new wounds provides evidence for an automatic positive reinforcement account (sensory stimulation), whereas SIB that aggravates existing wounds is evidence for an automatic negative reinforcement account (pain attenuation). Several individuals in Study 2 exhibited SIB

across assessment conditions. This pattern of responding could be considered consistent with all of the hypothesized sources of automatic reinforcement. It is also possible that this pattern suggests the influence of some other source of reinforcement. Regardless, because the behavior occurred independent of social contingencies and occurred at high rates across all assessment conditions, the reinforcer responsible for behavioral maintenance was always present, and access to alternative sources of stimulation in the other conditions did not compete with the reinforcer maintaining SIB. However, most of the subjects in Study 2 engaged in SIB either exclusively or almost exclusively in the alone condition as compared to the other conditions. This pattern of responding suggests at least two possibilities. First, perhaps access to alternative stimulation (e.g., preferred items in the play condition, task activities in the demand condition, items in the attention condition) suppressed SIB (i.e., competed with the maintaining reinforcer). Second, the presence of a therapist in the attention, play, and demand conditions may have been discriminative for social attention. If these individuals had a history of punishment for engaging in SIB, the presence of an adult may have suppressed SIB in these conditions. To informally determine if access to alternative stimulation per se would compete with SIB, two probe sessions in which preferred items were available but the therapist was absent were conducted with Subject BG who engaged in SIB exclusively in the alone condition of the functional analysis (Figure 3-5, middle left panel). Subject BG never engaged in SIB during these sessions (total time, 30 min). This pattern of responding may have direct implications for treatment of SIB for these individuals. Specifically, programming noncontingent (or perhaps contingent) access to preferred items and activities might successfully compete with the reinforcer responsible for SIB.

As previously mentioned, assessment and treatment of automatically-reinforced behavior can present a challenge because the reinforcer(s) responsible for the behavior are not in direct

control by the therapist. Assessment and treatment is even more challenging when a behavior occurs covertly (i.e., evidence of a behavior is apparent but the behavior is not observed). Several features of the results from Study 2 suggest that a number of the cases of SIB were cases of covert behavior. First, the pattern of responding exhibited by Subject PM (Figure 3-1) was likely indicative of covert SIB. Anecdotally, JM was observed to engage in other behaviors indicating that she had detected the presence of the observers during alone sessions conducted in rooms with observational mirrors. That is, immediately prior to the elimination of responding during these sessions, JM was observed to stare at the observational mirror, knock on the window, and wave. However, responding persisted at high levels during alone sessions conducted in the room equipped with the hidden camera (i.e., the room without an observational mirror). Second, all the subjects who exhibited exclusive (or almost exclusive) SIB during the alone condition immediately ceased to engage in SIB at the start of attention sessions (which were also conducted in the hidden camera room and always conducted immediately following alone sessions). One limitation of the conclusion that these subjects exhibited covert SIB was that Study 2 did not contain an explicit control condition (i.e., a condition identical to the alone condition except for the presence of a therapist). Although it is speculative whether the cases observed were cases of covert SIB, one implication of this finding is that the SIB prevalence findings in Study 1 may actually be an underestimate if the data from Study 2 are representative of the PWS population as a whole.

Future research might focus on improving methods to detect, assess, and treat covert problem behavior. To date, relatively few studies have examined methods to detect covert behavior. We used a hidden camera in the present study; another possibility would be the use of indirect measures of SIB (specifically, the presence of wounds). It has been shown recently that

permanent product measures of SIB are sensitive to treatment contingencies (Twohig & Woods, 2001; Wilson, Iwata, & Bloom, in press); additional data are needed to establish the generality of this finding. It is possible that SIB is sensitive to remote contingencies placed on response products. That is, it is the response product that is actually maintained as compared to the response itself. For example, responding (skin picking) may be suppressed in the presence of others (because of a history of punishment) and begins to occur covertly because the response product (wound) eventually produces social reinforcement. Further, few studies have fully assessed the extent of covert behavior. That is, the assessment of covert behavior in most studies only included an alone condition (similar to Study 2), without the addition of an explicit control condition for covert behavior. One notable exception was a study by Paisey and Whitney (1989), who assessed the pica for a 16-year-old boy with profound mental retardation. The subject was observed during several assessment conditions including a condition in which observers were present but did not intervene or interact with the subject and a condition in which the subject was alone (observers were hidden from view of the subject). The highest level of pica was observed in the alone condition, suggesting that the behavior was covert.

A number of studies have evaluated treatments for problem behavior reported to be covert in nature (though only a few were cases of SIB). Maglieri, Deleon, Rodriguez-Catter, and Sevin (2000) measured food stealing by 1 subject with moderate mental retardation by weighing foods before and after sessions. The authors found similar reductions in food stealing with both within-session and post-session reprimands. Ringdahl et al. (2002) observed the stereotypy (hand flapping) of 1 subject via a camera (not hidden) and found stereotypy to occur only in the alone condition of the functional analysis. Subsequently, a DRO procedure in which the subject earned access to preferred items contingent on the absence of hand flapping was successful in

reducing stereotypy to near-zero. Grace, Thompson, and Fisher (1996) used differential reinforcement of other behavior (DRO), in which reinforcers were delivered contingent on the absence of tissue damage, to reduce covert SIB for 1 subject. Given the relatively few number of existing studies of covert SIB and the fact that most of the existing studies consist of either a single or only a few subjects, further research on detection, assessment, and treatment of covert SIB is warranted.

Table 4-1. Large-*N* studies showing SIB prevalence estimates

Study	Sample #	Setting	SIB Prevalence
Griffin et al. (1986)	2,663	Residential & state schools for MR in TX	13.6%
Hill & Bruininks (1984)	2,271	236 national public & private institutions	14.2%
Maurice & Trudel (1982)	2,858	3 institutions in Quebec	14.1%
Borthwick, Meyers, & Eyman (1981)	6,202	Recipients of DD services in 3 states	19.8%
Ross (1972)	11,139	Residents of CA state hospitals	18.1%
Jacobson (1982)	30,578	Individuals w/MR in NY	8.2%

Table 4-2. Smaller-*N* studies showing SIB prevalence estimates

Study	Sample #	Setting	SIB Prevalence
Rojahn (1984)	91	Residents of a public residential facility with severe/profound MR	65.9%
Bodfish et al. (1995)	210	Residents of hospital for people with MR	46.6%
Emberson & Walker (1990)	525	Residents of a hospital for people with MR	31%

APPENDIX A
NATIONAL SURVEY ON SELF-INJURIOUS BEHAVIOR IN THE PRADER-WILLI SYNDROME

NATIONAL SURVEY ON SELF-INJURIOUS BEHAVIOR (SIB)
IN THE PRADER-WILLI SYNDROME (PWS)

Instructions: Complete Part I for every person you serve. Then examine the list of behaviors in Part II carefully. If the person (a) has not displayed <u>any</u> of these behaviors (or any other self-injurious behavior) for the past six months, <u>and</u> (b) is not currently receiving <u>any</u> form of treatment to manage these behaviors, check the first statement below, then detach and return the first page. Otherwise, check the second statement below, complete Parts II and III, and then return the entire survey with the requested documentation.

PART 1: GENERAL INFORMATION

Company/Organization: _____ City: _____ State: _____

Person completing form: _____ Position: _____

Date form completed: _____ Phone #: _____

Client's initials: _____ Sex: M F Age: _____

Level of functioning: Mild-Moderate / Severe / Profound Sensory impairments: ___ Hearing ___ Vision

Type of PWS:
____ Paternal deletion
____ Maternal Uniparental Disomy (UPD)
____ Imprinting defect
____ PWS Like
____ Translocation
____ Unknown

Maladaptive Behaviors (other than SIB):
____ Hoarding things
____ Food stealing
____ Temper tantrums (e.g., verbal outbursts, dropping floor)
____ Aggression
____ Property destruction
____ Noncompliance
____ Stereotypic behavior (repetitive rituals)

☐ The individual named above **has not** displayed any self-injurious behavior for the past six months, and is not receiving any form of treatment or program to manage such behaviors.

☐ The individual named above **has** displayed self-injurious behavior within the past six months or is currently receiving treatment to manage such behaviors.

PART II: DESCRIPTION OF SIB

Check any of the following behaviors that have occurred during the past six months (check all that apply). For each behavior that has occurred, circle a number to indicate its frequency and severity (see keys below).

Frequency Key:
1: Occurs hourly
2: Occurs at least once a day but not hourly
3: Occurs at least once a week but not daily
4: Occurs at least once a month but not weekly
5: Occurs less than once a month

Injury Severity Key:
1: Has produced loss of sensory or motor function (vision, movement, etc,)
2: Has produced permanent disfigurement
3: Has produced no permanent damage

Medical Care Key:
1. Has required hospitalization or surgical intervention (sutures, cast, etc.)
2. Has required minor medical care only
3. Has not required any care by a medical professional

Behavior	Frequency	Injury Severity	Medical Care
____ **Aerophagia**: Air swallowing	1 2 3 4 5	1 2 3	1 2 3
____ **Biting**: Closure of upper and lower teeth on any part of the body	1 2 3 4 5	1 2 3	1 2 3
____ **Body banging**: Audible/forceful contact of a body part (other than the head) against a stationary object	1 2 3 4 5	1 2 3	1 2 3
____ **Body hitting**: Audible/forceful contact of one body part against another (other than the head)	1 2 3 4 5	1 2 3	1 2 3
____ **Bruxism**: Teeth grinding	1 2 3 4 5	1 2 3	1 2 3
____ **Choking**: Forceful closure of both hands around neck	1 2 3 4 5	1 2 3	1 2 3
____ **Cutting**: Applying sharp instrument to body part w/ slicing or chopping motion	1 2 3 4 5	1 2 3	1 2 3
____ **Eye poking/gouging**: Forceful contact of a finger within the ocular area	1 2 3 4 5	1 2 3	1 2 3
____ **Hairpulling**: Closure of fingers on hair with a pulling motion	1 2 3 4 5	1 2 3	1 2 3
____ **Hand sucking/mouthing**: Wetting of fingers or hand against lips or tongue	1 2 3 4 5	1 2 3	1 2 3
____ **Head or face hitting/slapping:** Audible/forceful contact of a body part against the head or face	1 2 3 4 5	1 2 3	1 2 3
____ **Head banging:** Audible/forceful contact of the head against a stationary object	1 2 3 4 5	1 2 3	1 2 3
____ **Nail pulling**: pulling or pushing of nails away from the skin	1 2 3 4 5	1 2 3	1 2 3
____ **Neck whipping**: Forceful and rapid movement of the head	1 2 3 4 5	1 2 3	1 2 3
____ **Orifice digging**: Insertion of finger or objects into ears/nose/genitals/rectum	1 2 3 4 5	1 2 3	1 2 3
____ **Pica**: Eating nonfood items	1 2 3 4 5	1 2 3	1 2 3
____ **Polydipsia:** Drinking excessive amounts of water	1 2 3 4 5	1 2 3	1 2 3
____ **Rumination**: Regurgitation and reswallowing of previously ingested food	1 2 3 4 5	1 2 3	1 2 3
____ **Scratching**: Raking the skin with fingernail or rubbing against object	1 2 3 4 5	1 2 3	1 2 3
____ **Teeth pulling**: Closure of fingers on teeth with a pulling motion	1 2 3 4 5	1 2 3	1 2 3
____ **Throat gouging**: Audible/forceful contact of hand or finger against the throat	1 2 3 4 5	1 2 3	1 2 3
____ **Vomiting**: Regurgitation (expulsion) of previously ingested food	1 2 3 4 5	1 2 3	1 2 3
____ **Other:** List and describe any other form of SIB not included above _____ _____	1 2 3 4 5	1 2 3	1 2 3

PART III: CURRENT TREATMENT FOR SIB

1. In the past 6 months, has this person received been prescribed medication as treatment of SIB?
   ___ Yes, list drugs: _____
   ___ No

2. In the past 6 months, has this person been restrained or has the person worn protective equipment due to SIB?
   ___ Yes, indicate: ___ Restraint ___ Protective equipment
   ___ No

3. In the past 6 months, has the person received any type of medical treatment for SIB?
   ___ Yes, indicate: ___Hospitalization ___Surgery ___Outpatient visit ___Wound care by nurse
   ___ No

4. Does this person have a formal behavior management program specifically designed to reduce SIB?
   ___ Yes
   ___ No

APPENDIX B
THE SELF-INJURY TRAUMA (SIT) SCALE

Patient:_____Examiner:_____Date:_____

Part 1: General Description and Summary of Healed Injuries

Check or list each type of self-injurious behavior exhibited by the patient. Next, note any physical evidence of healed injuries (scars, permanent disfigurement, etc.), along with the specific site.

Self-Injurious Behaviors (check):

___Air swallowing (aerophagia) ___Forceful contact w/head/face ___Ingestion of inedible materials (pica)
___Biting ___Forceful contact w/other body part ___Scratching, picking, rubbing skin
___Eye gouging ___Hair pulling (trichotillomania) ___Vomiting or rumination

Other (list):_____

Healed Injuries (list):

1. _____ 3. _____
2. _____ 4. _____

Part 2: Measurement of Surface Trauma

For each area of the body containing a current (unhealed) injury, estimate the number of wounds and note the type and severity of the worst wound at that particular location. Use the key below to indicate number, type, and severity.

Number: 1: One wound at location 2: Two-four wounds at location 3: Five or more wounds at location

Type: AL (Abrasion or laceration): A break in the skin caused by tearing, biting, excessive rubbing, or contact with a sharp object. Score severity as: (1) Area is red or irritated, with only spotted breaks in the skin: (2) Break in the skin is distinct but superficial (no avusion); (3) Break in the skin is deep or extensive, or avulsion is present.

CT (Contusion): A distinct area marked by abnormal coloration or swelling, with or without tissue rupture, caused by forceful contact. Score severity as: (1) Local swelling only or discoloration without swelling; (2) Extensive swelling; (3) Disfigurement or tissue rupture.

Location	Number	Type	Severity	Location	Number	Type	Severity
Head:				Lower Torso:			
Scalp	1 2 3	AL CT	1 2 3	Abdomen/Pelvis	1 2 3	AL CT	1 2 3
Ear L/R	1 2 3	AL CT	1 2 3	Hips/Buttocks	1 2 3	AL CT	1 2 3
Eye L/R	1 2 3	AL CT	1 2 3	Genitalia	1 2 3	AL CT	1 2 3
Eye Area L/R	1 2 3	AL CT	1 2 3	Rectum	1 2 3	AL CT	1 2 3
Face	1 2 3	AL CT	1 2 3	Extremities:	1 2 3	AL CT	1 2 3
Nose	1 2 3	AL CT	1 2 3	Upper Arm/Elbow L/R	1 2 3	AL CT	1 2 3
Lips/Tongue	1 2 3	AL CT	1 2 3	Lower Arm/Wrist L/R	1 2 3	AL CT	1 2 3
Neck/Throat	1 2 3	AL CT	1 2 3	Hand/Finger L/R	1 2 3	AL CT	1 2 3
Upper Torso:	1 2 3	AL CT	1 2 3	Upper Leg/Knee L/R	1 2 3	AL CT	1 2 3
Shoulder L/R	1 2 3	AL CT	1 2 3	Lower leg/Ankle L/R	1 2 3	AL CT	1 2 3
Chest/Stomach	1 2 3	AL CT	1 2 3	Foot/Toe L/R	1 2 3	AL CT	1 2 3
Back	1 2 3	AL CT	1 2 3		1 2 3	AL CT	1 2 3

Part 3: Scoring Summary

Number Index (NI)

Add all of the scores in the Number column (above) and enter the total:___

NI (Circle)	Part 2 Total
0:	No injuries
1:	1-4
2:	5-8
3:	9-12
4:	13-16
5:	17 or more

Severity Index (SI)

Enter the frequency of scores in the Severity Column: 1___ 2___ 3___

SI (Circle)	Severity scores from Part 2
0:	No injuries
1:	All severity scores are 1's
2:	One 2; No 3's
3:	Two or more 2's; No 3's
4:	No more than one 3
5:	Two or more 3's

Overall Risk Estimate

Low:	No injuries, or any AL-1, CT-1, or AL-2 except near eyes
Moderate:	Any AL-2 near eyes, Any CT-2 except on head
High:	Any CT-2 on head, Any AL-3 or CT-3

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BIOGRAPHICAL SKETCH

Pamela Neidert began her career in behavior analysis working at the Neurobehavioral Unit at the Kennedy Krieger Institute (KKI) under the supervision of Dr. Wayne Fisher, while simultaneously studying special education at Johns Hopkins University. Upon receiving her M.S. degree in 1999, she began working at the Marcus Institute (MI), under the supervision of Drs. Wayne Fisher and Cathleen Piazza. While at KKI and MI, Pamela conducted research and provided clinical services on assessment and treatment of problem behavior displayed by individuals diagnosed with developmental disabilities. In 2000, Pamela entered the behavior analysis graduate program at the University of Florida (UF) and worked under the supervision of Dr. Brian Iwata. While at UF, Pamela continued to conduct clinical research with individuals with developmental disabilities at various laboratory sites: an adult vocational program, a hospital inpatient unit for children diagnosed with autism, an outpatient clinic for children diagnosed with autism, and a school for children diagnosed with developmental disabilities. While at UF, Pamela received the Behavior Analysis Research Award for contributions to research as a graduate student. Pamela has begun an academic-research career at Florida Institute of Technology specializing in disorders of learning and behavior in developmental disabilities.