

Physical Illness, Pain, and Problem Behavior in Minimally Verbal People with Developmental Disabilities

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Abstract There is growing interest in the role that physical illness and pain might play in exacerbating problem behavior in individuals with developmental disabilities. Assessment of these factors, however, is often difficult since many individuals have minimal verbal communication skills. In response to this difficulty, we developed a sequential method of assessment involving retrospective and prospective measurement strategies. We found that the frequency and intensity of problem behavior was greater on “sick” days than on “well” days. Further, the higher the level of pain, the greater was the frequency and intensity of problem behavior. We discuss the concept of pain as a setting event for problem behavior and the intervention strategies that follow from this conceptualization.

Keywords Developmental disabilities · Problem behavior · Physical illness · Pain

Problem behaviors such as aggression, self-injury, and tantrums are a major focus of intervention in developmental disabilities. The reason for this focus is that such behavior often compromises quality of life by serving as a barrier to successful education, employment, socialization, and community integration (Koe-

gel, Koegel, & Dunlap, 1996). Importantly, as we noted in a previous meta-analysis of the research literature, successful intervention is built on careful assessment of the factors that predict and maintain problem behavior (Carr et al., 1999). One set of factors that has increasingly attracted the attention of researchers involves physical illness and discomfort.

For some time, it has been known, from the general pediatric literature, that typically developing children often show elevated rates of problem behavior in association with physical illness. Thus, de Lissovoy (1962) noted increased rates of head-banging in infants suffering from otitis media (middle ear infection). Likewise, Hart, Bax, and Jenkins (1984) observed that two- and three-year-old children who engaged in temper tantrums at least once per day were more likely to suffer from upper respiratory infections than those who engaged in tantrums less frequently.

Significantly, physical illness is very common in people with developmental disabilities. In fact, a number of studies have documented substantially higher rates of both chronic and acute medical conditions in people with developmental disabilities as compared to the general population. Thus, Minihan (1986) found that 99% of individuals in a state institution had at least one chronic medical condition requiring regular follow-up (e.g., cardiac conditions, diabetes, ulcers, chronic otitis media, recurrent pneumonia, and progressive renal failure). Asberg (1989) noted that 80% of people with developmental disabilities admitted to hospitals in Uppsala, Sweden had at least one chronic medical condition and that the rate of hospital admission for people with developmental disabilities was three times that of the general population. Likewise, an Australian study (Beange, McElduff, & Baker, 1995) found that

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people with developmental disabilities had increased cardiovascular risk factors, higher rates of medical consultation and hospital admission than the general population, and averaged 4.5 medical disorders per person. Finally, Cooper (1998), studying health care needs across the lifespan for a population of people with developmental disabilities in Leicestershire, England found that the number of associated medical conditions was higher for people with developmental disabilities than the general population.

Interestingly, as was the case for people without disabilities, noted earlier, a number of studies suggest that there also appears to be an association between physical illness and problem behavior in people with developmental disabilities. Specifically, problem behavior has been linked to conditions as diverse as constipation (Lekkas & Lentino, 1978), allergies (Kennedy & Meyer, 1996), and premenstrual syndrome (Taylor, Rush, Hetrick, & Sandman, 1993). The possibility that physical illness may be causally linked to problem behavior is supported by studies documenting a reduction of such behavior following appropriate medical intervention (Ghaziuddin, Elkins, McNeeley, & Ghaziuddin, 1993; Gunsett, Mulick, Fernald, & Martin, 1989; Peine et al., 1995). For example, Gunsett et al. (1989) observed a decrease in problem behavior following medical treatment for urinary tract and ear infections.

Plausible mechanisms accounting for the putative association between problem behavior and physical illness have yet to be identified. Intervention studies demonstrate that, while some people with developmental disabilities show decreased problem behavior following medical intervention, others do not (Ghaziuddin et al., 1993; Peine et al., 1995). Such studies raise the question of what factors might determine when physical illness does and does not exacerbate problem behavior. One plausible mechanism that has been proposed relates to the notion that it is not physical illness per se that may be important but, rather, the degree of pain or discomfort that the individual is experiencing at a given time (Horner, Vaughn, Day, & Ard, 1996; Kennedy & Thompson, 2000). If so, then it might be useful, clinically, to monitor the degree of pain that an individual is experiencing to see whether pain itself is correlated with problem behavior. Successfully monitoring pain or discomfort with some degree of reliability is a complex process. In typically developing populations, a variety of assessment strategies are commonly used, including a “pain thermometer” on which higher ratings indicate more intense pain, Likert scales in which specific numerical scores are associated with specific verbal descriptions of pain, symptom checklists from which individuals select somatic and behavioral

items that pertain to their illness, and detailed structured interviews with the person experiencing the pain (Mash & Terdal, 1988; Sarafino, 1994). Of course, all of these methods are dependent upon a reasonable level of communicative skill and cognitive ability (e.g., reading items from the checklist, understanding the concept of a “pain thermometer”) on the part of the person being assessed. Unfortunately, as is well documented in the literature (Schreibman, 1988; Wetherby & Prutting, 1984), people with developmental disabilities often lack the communicative and cognitive skills that would permit direct assessment of pain using the patient scale, checklist, and interview strategies previously described. This fact may be especially important given recent data suggesting that people having severe cognitive impairments and few communicative abilities are likely to experience the most pain over time (Breau, Camfield, McGrath, & Finley, 2003).

In light of the issues just raised, the purpose of the present study was two-fold. First, we wished to develop a reliable method of assessing the presence of physical illness and pain in a sample of individuals with severe developmental disabilities who had minimal communicative skills. Second, we wished to determine whether there was a positive association between level of pain and level of problem behavior.

Method

Participants

Participants included individuals with developmental disabilities and relevant informants. The second author met with psychologists, behavior specialists, nurses, and program coordinators affiliated with two agencies that served people with developmental disabilities in community residences and schools. These staffs were asked to nominate individuals whose problem behavior, in their judgment, appeared to worsen during illness. Additionally, staffs were asked to identify those people (potential informants) who best knew the individuals with disabilities. This process produced a list of participants that included target individuals (persons with developmental disabilities) and informants (parents, teachers, and community residence staff).

Of the 19 target individuals identified, two were subsequently unavailable because they moved, and five, because their parent/guardian failed to return the consent form. The 12 remaining individuals were the focus of the present study.

Informants were chosen based on how many years of direct experience they had with the target

individuals as well as their willingness to participate and their time availability. If two or more informants were equally available, the one who had the longest experience with the individual in question was chosen. This procedure resulted in the selection of seven teachers, one parent, and three community residence staff who had 4–8 years of experience with the target individuals. As described later, the informant who had the second longest experience with a given individual (or equal experience in the case of a parent) served as the reliability observer in the final (prospective) phase of the study. These informants had 1–6 years of experience with the individual. The main inclusionary criterion for informants to move from the initial retrospective to the final prospective portion of the study was that there had to be a guarantee on the part of the agency administration that the relevant teachers and community residence staff would continue to be assigned to the target individuals for the entire duration of the prospective portion of the study. An assignment break of 3 months or more in duration would have defined the exclusionary criterion; however, this situation did not occur. Likewise, had the parent informants separated for a period of 3 months or more, they too would have been excluded from further participation but, again, this situation did not develop. The criteria just described ensured that data could be collected in a continuous and consistent manner throughout the prospective phase of the study.

Informants were initially asked to fill out a retrospective screening questionnaire on the target individuals. Those individuals who met certain criteria were included in the final, prospective phase of the study. One individual did not meet these criteria and was excluded from further participation. The retrospective questionnaire and inclusion criteria are described later.

Table 1 displays information on gender, age, diagnosis, and type of problem behavior shown by the 11 target individuals who met the screening criteria. There were nine males and two females who ranged in age from 4 to 21 years. They had received diagnoses of mental retardation and/or autism/PDD. Due to the severity of their disabilities as well as their lack of cooperation, including outbursts of problem behavior, none of the individuals could be assessed with a comprehensive set of standardized cognitive and language tests. As Table 1 indicates, the level of mental retardation was determined for six of the participants using the Leiter, and for two others, using the WPPSI-R or Bayley. The remaining three participants were untestable and their level of mental retardation was estimated by the school psychologist using the narra-

tive criteria specified in DSM-IV. With respect to communication ability, Vineland communication scores were available for three of the participants. Specifically, JT received an age equivalent score of 2 years 2 months at a chronological age (CA) of 10 years; ET, an age equivalent of 1 year 3 months at a CA of 6 years; and CM, an age equivalent of 1 year 6 months at a CA of 4 years. Two of the participants (CM and ET) spoke in 3–5 word utterances, but infrequently. The remaining nine were mute, or used an occasional single-word utterance. For example, some could request a limited set of highly preferred items (i.e., “chips,” “juice,” “candy”) but none could indicate the presence of illness or pain. Finally, with respect to augmentative/alternative communication abilities, three participants (JT, JW, and ET) used a simplified version of the Picture Exchange Communication System (PECS). In sum, the severity of language deficits made it impossible to interview the target individuals directly to determine whether they were ill, or in a state of pain or discomfort, hence the necessity for using informants.

None of the participants were on medication for the control of problem behavior. However, as per agency policy, all of the participants had explicit behavior support plans in place to address their problem behaviors. These plans had four basic elements. First, there was a focus on “Catch ‘em being good;” that is, relevant staff (including parents) were instructed to identify at least six opportunities per day in which appropriate social, academic, or self-help behaviors would be reinforced with praise and/or tangibles as appropriate. Second, staffs were instructed to place minor episodes of problem behavior (e.g., nagging, whining, negative verbal behaviors) on extinction and avoid attending to such behaviors since attention would likely increase the probability and intensity of the behavior. Third, if the first two elements failed to prevent serious problem behavior, staffs were instructed to redirect the participant to activities known to be discriminative stimuli for prosocial behavior (e.g., if a participant had a tantrum during leisure time, a staff member might engage the individual in a gardening task known to generate compliance from that individual). Finally, there was a default crisis management strategy. Specifically, individuals whose aggressive behavior could not be mitigated, and posed a threat to others, were removed to a “quiet” area, away from others, for a period of time sufficient for them to calm down. Then, they were returned to the activity in which they had most recently participated. The behavior support plan just described was in place throughout the study.

Table 1 Participant characteristics and number of sick/well days evaluated for each participant

Gender	Age	Diagnoses	Problem behaviors	Sick days ^c
M (CD)	18	Moderate to severe mental retardation and autism ^a	SIB—Head-slapping, self-pinching, self-biting AGG—Grabbing, pinching, biting	3
F (JT)	10	Moderate to severe mental retardation and autism ^d	SIB—Head-hitting, chin-hitting AGG—Scratching, kicking, hitting, pinching	2
M (AN)	21	Moderate to severe mental retardation and autism ^a	AGG—Hitting, kicking, scratching, pushing PD—Throwing objects	2
M (DK)	18	Severe mental retardation and autism ^a	SIB—Self-biting, hitting AGG—Biting, pulling hair, scratching, pinching STR—Rocking, hand-flapping	1
M (JO)	20	Moderate to severe mental retardation and autism ^a	SIB—Hitting leg, head, and arms AGG—Hitting PD—Tearing items, throwing items	2
M (JW)	9	Moderate to severe mental retardation and autism ^d	SIB—Biting hand and arm AGG—Scratching, pinching, kicking, hitting	4
M (PM)	17	Profound mental retardation ^a	AGG—Hitting, kicking, pulling hair	2
M (MG)	17	Profound mental retardation ^d	SIB—Biting arms, dropping to knees PD—Biting clothing	4
M (ET)	6	Mild to moderate mental retardation and pervasive developmental disorder ^b	SIB—Head-banging, head-hitting AGG—Kicking, hitting, biting PD—Throwing objects, tearing paper	3
F (CM)	4	Moderate to severe mental retardation and pervasive developmental disorder ^c	TAN—Screaming, crying, dropping to the floor PD—Throwing objects, tearing paper DISROBING	4
M (JU)	20	Severe mental retardation and autism ^a	AGG—Slapping, scratching, pinching, biting SIB—Biting arm, knee, and shoulder	5

Note. M, Male participant; F, Female participant; Letters in parentheses, initials of participants; SIB, Self-Injurious Behavior; AGG, Aggression; PD, Property Destruction; STR, Stereotypic Behavior; TAN, Tantrum

^a Level of retardation based on Leiter

^b Wechsler preschool and primary scale of intelligence-revised

^c Bayley scales of infant development

^d Estimates using DSM-IV narrative criteria

^e The number of sick days always equaled the number of well days because of the yoking procedure used as described in the text

Procedure

The study was comprised of two phases. First, as already noted, the target individuals chosen to participate were initially identified through a retrospective screening questionnaire administered to relevant informants. Then, a prospective questionnaire was administered to the same informants to ascertain the reliability and validity of the information derived from the retrospective questionnaire.

Initial Identification of Participants: Retrospective Screening

A retrospective screening questionnaire was developed to aid in the initial identification of those individuals whose problem behavior appeared to increase in frequency or intensity when they were physically ill or in pain. This questionnaire (Appendix A) provided preliminary information (questions 1–3) from informants who described how often the individual was sick, the

types of sicknesses that the individual typically had, and the specific topographies of problem behavior that the individual displayed when he/she was sick versus well. Also, informants reported (questions 4 and 5) on how the individual typically indicated that he or she was sick (e.g., through verbalizations, or through a gesture such as touching the affected body part). If an individual had not been sick over the past 2 years and/or did not display externalizing problem behavior (aggression, self-injury, tantrums, or property destruction), he/she would have been excluded from the study. However, all participants passed these two criteria. Retrospective ratings of the frequency and intensity of problem behavior for days when the participant was sick versus days when the participant was well were also recorded. Target individuals were included in the study if their reported frequency and/or intensity of problem behavior on days with physical illness/pain was at least two-points greater on a seven-point Likert scale (questions 6–9) than the frequency and/or intensity of their problem behavior on well days. As noted

previously, one of the original 12 target individuals failed to meet these criteria and was therefore eliminated from further participation. Subsequent prospective assessment allowed us to determine whether the initial retrospective information was reliable and valid.

*Daily Behavior Questionnaire Administration:
Prospective Assessment*

Prospective assessment involved systematic, ongoing observation in the school, home, or community residence settings. Across individuals, the mean duration of the prospective assessment was 14 months (range = 12–20 months). The duration of the study (termination point) for a given participant was determined by the point of time at which the individual was about to transition to a new teacher or new group home staff member. In other words, we wanted to ensure that the persons who were the data collectors (informants) were unchanged throughout the course of the study. As per school policy, children who became too ill to remain in class on a given day, in the judgment of the nurse, were sent home and not assessed again until they subsequently returned to school. If a child was sent home prior to completion of the school day, data were not collected on that day. This data collection requirement was put into effect to ensure that all children would be rated across equivalent periods of time (i.e., completion of an entire school day). As long as this requirement was met, data were collected on all illnesses, major or minor, by the relevant informants.

To help ensure that informants accurately completed questionnaires on sick days, the second author met directly with the teachers, group home staff, and parents as well as the classroom behavior consultant and group home manager to discuss each element of the behavior questionnaire and clarify any ambiguities or definitional issues raised. A list of common, observable and measurable, symptoms of illness was provided. These symptoms included: running nose, coughing, congestion, sneezing, tearing eyes, vomiting, diarrhea, repeated rubbing of nose/ears/eyes, presence of cuts or swelling, extensive bruising, three consecutive days without a bowel movement, and/or presence of a fever. On days in which either an observable (e.g., vomiting) or measurable (e.g., fever) symptom of illness occurred, informants completed a behavior questionnaire (Appendix B). Specifically, informants recorded the nature of the individual's illness, the illness symptoms, and the source of this information (question 1). Additionally, because it was hypothesized that medication might affect the individual's behavior, medication information was also recorded on the questionnaire

(e.g., if an individual was given Tylenol for a fever, this treatment could reduce the individual's discomfort, and, therefore, might also reduce problem behavior). Therefore, informants recorded any medications that the individual received for physical illness, the purpose of the medication, the times that the medication was administered, and the effect that the medication had on participant problem behavior (question 2).

Importantly, informants also recorded (questions 3 and 4) the frequency of observable motor and vocal pain behaviors (as described by the informants themselves on the retrospective screening questionnaire and also adapted from rating scales developed by Ahles et al., 1990; Bodfish, Harper, Deacon, & Symons, 2001; Breau et al., 2003; and LeBaron & Zelter, 1984). To help informants identify pain behaviors, we provided them with an extensive list of examples of both motor and verbal pain behaviors in questions 3 and 4, respectively. Since many individuals with developmental disabilities, including those who participated in the present study, are unable to communicate their physical discomfort to caregivers (Gunsett et al., 1989; Kennedy & Thompson, 2000), information on motor and vocal pain indicators was recorded to determine whether individual pain behaviors might be associated with illness. The frequency of these *pain behaviors* was recorded on a seven-point Likert scale that ranged from "not at all" to "all the time."

Also, as shown in Appendix B, the frequency of participant *problem behaviors* was scored on a seven-point Likert scale that ranged from "not at all" to "all the time" (question 5). Informants were asked to describe the specific problem behaviors that the individual displayed. The intensity of problem behavior was scored on a seven-point Likert scale that ranged from "mild" to "severe" (question 6). Of course, intensity would not have been scored if the informant had indicated that the frequency of problem behavior (question 5) was zero ("Not at all") on a given day. For three participants (PM, MG, and AN), data were collected in their group home placements by group home staff. For one participant (CM), data were collected at her family's home by her parents. For all other participants, data were collected by classroom teachers and teacher aides. Informants were instructed to complete the questionnaire at the end of the school day (for teachers, in the school setting), at the end of the staff member's shift (for staff, in the community residences), or at the individual's bedtime (for parents, in the home). This procedure was put into effect to maximize the amount of time that the informant had available each day for observing the totality of behavior episodes that occurred on a given day.

Informants completed a prospective behavior questionnaire for each “sick” day that the target individual displayed observable or measurable symptoms of illness. Sick days were designated as those days, in which observable or quantifiable symptoms of illness or pain were identified, such as coughing, diarrhea, fever, bruising, or other symptoms previously noted. Additionally, questionnaires were completed for an equal number of yoked “well” days. Well days were designated as those days in which no observable or measurable symptoms of illness were noted. In illustration, if an individual experienced three consecutive sick days, questionnaires were also completed for three consecutive well days. Data for well days were collected after a minimum period of five consecutive well days had elapsed following the illness in order to increase the probability that the individual had enough time to recover fully from the effects of the illness. Given that the target individuals were typically unable to communicate their pain or discomfort, the lapsed days procedure just described was necessary to maximize the likelihood that the individuals were not still experiencing illness symptoms that were unobservable, but that might nonetheless be creating pain or discomfort.

Reliability

As noted previously, the informant who had the second longest experience with a given target individual (or equal experience, in the case of a parent) served as the reliability observer in the prospective assessment phase of the study. Specifically, reliability data were collected by the teacher’s aide in the classroom setting, by an alternate staff member in the community residences, and by a second family member (parent) in the home environment. The two observers (i.e., the primary and reliability informants) independently completed prospective behavior questionnaires on 23% of the observation days across the 11 participants, reliability being obtained on a minimum of one sick day and one well day for each participant. It should be noted that the variability in the number of sick/well days across participants (Table 1) represented a challenge to the assessment of reliability, particularly for participants who had few sick days in which case greater measurement error would be expected. Since we did not have a larger sample with closely matched sick/well days across participants, we attempted, as described earlier, to partially address this measurement issue by carefully yoking the number of sick/well days for each participant in our sample.

Reliability raters consistently reported the same illnesses for individual participants (Appendix B, question 1). That is, informants recorded the same illness (e.g.,

allergies, cold) on independently completed behavior questionnaires (100% agreement). Likewise, with respect to medications (Appendix B, question 2), reliability raters were consistent (i.e., 100% agreement) in noting the presence or absence of medication for individual participants, the specific type of medication used (e.g., Tylenol, Pepto Bismol, Bactine), and whether or not the individual’s behavior appeared to improve following medication.

To enhance reliability measurement (informant training) for pain behavior, we carefully reviewed, with the informants, all of the examples of motor and vocal pain behaviors shown in questions 3 and 4 prior to the first time the informants were to respond to these questions. To enhance reliability measurement for problem behavior, we provided the informants with specific examples to illustrate each category of problem behavior (e.g., self-injury could include hitting, biting, or punching oneself, or banging body parts against objects or surfaces; aggression could include hitting, biting, punching, kicking, grabbing, or shoving others; property destruction could include striking, throwing, or destroying an object; and tantrums included more than 5 s of screaming accompanied by throwing oneself on the floor and/or flailing the arms and legs).

Reliability was calculated separately for each of the four target behaviors shown on the prospective behavior questionnaire: motor pain behavior, vocal pain behavior, frequency of problem behavior, and intensity of problem behavior (Appendix B, questions 3–6). The Likert scale data across the two observers were used to generate Pearson correlations and were subjected to a two-tailed test of significance. The reliability ratings were statistically significant for all four target behaviors: for motor pain behavior, $r = .67$, $P < .01$; for vocal pain behavior, $r = .71$, $P < .01$; for frequency of problem behaviors, $r = .88$, $P < .001$; and for intensity of problem behavior, $r = .92$, $P < .001$.

Results

Informants reported six categories of illness during 32 sick days across the 11 target individuals: ear infection (1 day), allergies (7 days), colds and flus involving fever, congestion, coughing, and/or sneezing (14 days), viruses involving vomiting, fever, or diarrhea (6 days), constipation (3 days), and injury events involving bleeding cuts, bumps, and bruises (1 day).

Medical records and questionnaire data (Appendix B, question 2) showed that target individuals received medications to reduce pain and discomfort on 17 of the 32 days in which illness was observed. The types of medication included: non-prescription drugs for colds,

viruses, and flus (e.g., nasal sprays, Tylenol, Motrin, Benadryl, various cold medicines, and anti-diarrheal medications), and prescription antibiotics. Problem behavior and pain were reported to improve on 6 of the 17 days on which medication was administered.

Table 1 presents the number of sick days observed for each participant. Overall ratings (Appendix B, questions 3–6) for pain behaviors (vocal and motor) and problem behavior (frequency and intensity) were averaged for 32 sick days and 32 well days across the 11 participants. Ratings ranged from 1 (no problem behaviors, mild behavior intensity) to 7 (frequent problem behaviors, severe intensity).

In Fig. 1 (top panel), mean ratings for motor pain behavior are presented for sick versus well days. The mean rating for motor pain behavior was 4.72 on sick days (range = 1–7) vs. 1.75 on well days (range = 1–5). In Fig. 1 (bottom panel), mean ratings for vocal pain behavior are presented. The mean rating for vocal pain behavior was 4.19 on sick days (range = 2–7) vs. 1.75 on well days (range = 1–5).

In Fig. 2 (top panel), mean ratings for the frequency of problem behavior on sick versus well days are presented. The mean rating for problem behavior was 4.73 on sick days (range = 2–7) vs. 1.75 on well days (range = 1–5). In Fig. 2 (bottom panel), mean ratings for the intensity of problem behavior are presented. The mean rating of problem behavior intensity was 4.13 on sick days (range = 1–7) vs. 1.38 on well days (range = 1–4).

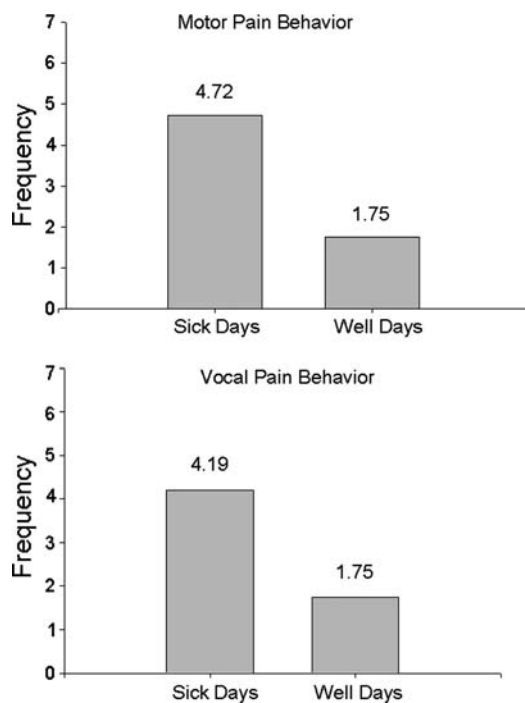


Fig. 1 Mean ratings across participants for motor pain behavior and vocal pain behavior on sick days versus well days

One-way analyses of variance were conducted separately for each of the four categories of behaviors just described to determine whether the Likert scale ratings were higher on sick days than on well days. The comparisons were significant for motor pain behavior ($F(1, 20) = 64.5, P < .001$), vocal pain behavior ($F(1, 20) = 34.3, P < .001$), frequency of problem behavior ($F(1, 20) = 84.4, P < .001$), and intensity of problem behavior ($F(1, 20) = 65.7, P < .001$).

Finally, a composite pain index was computed by taking the arithmetic mean of the motor and vocal pain scores derived from the Likert scale ratings. The mean composite pain index was 4.57 on sick days (range = 3.38–6.75; SD = 1.06) but only 1.73 on well days (range = 1.00–2.70; SD = .64). A two-tailed *t*-test demonstrated that the composite pain index was significantly higher on sick days as compared to well days, $t(20) = 7.60, P < .001$. The composite pain index was also examined for its relationship (Pearson correlation coefficient) to the frequency and intensity of problem behavior. It was found that the higher the composite pain index, the greater the frequency ($r = .37, P < .05$) and intensity ($r = .52, P < .01$) of problem behavior.

Discussion

The frequency and intensity of serious problem behavior exhibited by individuals with developmental

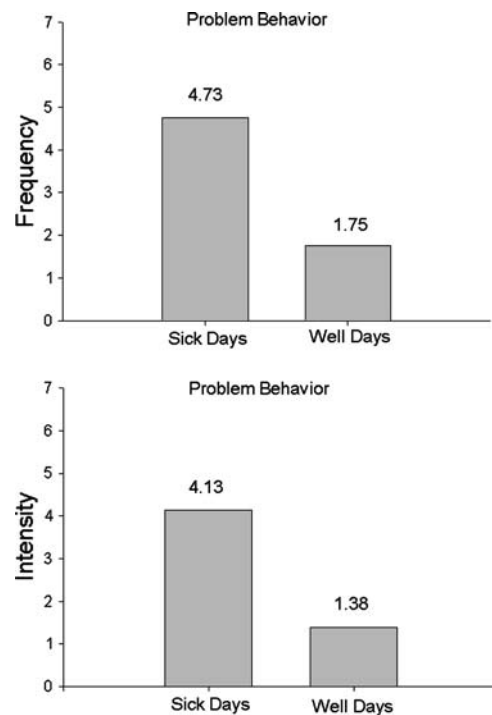


Fig. 2 Mean ratings across participants for the frequency of problem behavior and intensity of problem behavior on sick days versus well days

disabilities was greater on days on which they were sick than on days on which they were well. As expected, sick days were associated with higher levels of pain and discomfort than well days. Importantly, the higher the level of pain, the greater was the frequency and intensity of problem behavior. These results are consistent with the notion that the pain and discomfort associated with physical illness may mediate the display of serious problem behavior. As such, the present study has both assessment and intervention implications.

With respect to assessment, our data suggest that it might be important to monitor pain indicators on a daily basis so that proactive steps could be taken to prevent the emergence of problem behavior related to ongoing pain and discomfort associated with illness. This practice might be especially important given that people with developmental disabilities are more prone to illness, both chronic and acute, than the general population (Cooper, 1998; Minihan, 1986). Of considerable significance is the fact that the main method typically used for ascertaining the presence and intensity of illness-related pain, namely, patient interview, is not applicable to many people with developmental disabilities owing to their poor communicative skills. This issue was particularly relevant for individuals in our study, all of whom evidenced poor receptive and expressive language abilities. Yet, recent research suggests that it is precisely the population of individuals having the greatest impairments who are most likely to experience the highest levels of illness-related pain (Breau et al., 2003).

We attempted to address the difficult assessment issue just described through the development of retrospective and prospective questionnaires that could be administered to knowledgeable informants, thereby avoiding the problems associated with patient interview. The initial retrospective questionnaire was useful in identifying individuals whose problem behavior appeared to be related to pain and discomfort associated with physical illness. However, given the well documented unreliability (Henry, Moffitt, Caspi, Langley, & Silva, 1994) of retrospective reports, we decided to combine our initial assessment with a subsequent prospective questionnaire that allowed us to directly track the association between problem behavior and illness-related pain over a period of 12–20 months. Our ability to monitor pain behavior, on a daily basis, was enhanced by providing informants with a list of motor and verbal pain indicators derived from the pediatric clinical literature (Ahles et al., 1990; Bodfish et al., 2001; Breau et al., 2003; LeBaron & Zelter, 1984). The resulting assessment data proved to be reliable in that informants were able to agree with one another (inter-rater reliability) concerning the presence or ab-

sence of the major variables under study: type of illness, use of medication, motor and vocal pain behavior, frequency and intensity of problem behavior. Thus, the combination of a retrospective and prospective questionnaire appeared useful in identifying the association between illness-related pain and level of problem behavior.

With respect to intervention, once it has been determined that an individual with a history of problem behavior is currently showing symptoms of illness and that these symptoms are associated with one or more pain indicators, then one could take steps to prevent the emergence or escalation of problem behavior. Prevention is a critical issue given the likelihood of problem behavior becoming more strongly established over time (Horner, Carr, Strain, Todd, & Reed, 2002). Although we did not explore this issue in the present study, the wide range of ages of the participants (from 4 to 21 years) may well have been correlated with increasingly severe forms of problem behavior over time, a possibility that would be best addressed by intervening at as early an age as feasible.

We have demonstrated elsewhere a three-fold strategy for addressing pain-related problem behavior: mitigate, redesign the environment, teach coping skills (Carr, Smith, Giacin, Whelan, & Pancari, 2003). With respect to mitigation, the most obvious strategy, one could attempt to attenuate pain symptoms by providing appropriate analgesic medications or altering medications if the current ones appear ineffective. In addition, the use of heating pads, bed rest, dietary change, or other non-drug strategies could be employed, depending on the specific nature of the illness. The purpose of these strategies is not to treat the illness but, rather, to mitigate the level of pain and discomfort associated with the illness, thereby removing a variable shown to be strongly correlated with problem behavior. Of course, correlation is not the same as causality and, therefore, one does not know whether pain mitigation per se would prevent problem behavior. However, the positive correlation between these two variables demonstrated in the present study would suggest that pain mitigation is at least a plausible strategy.

The second strategy, namely, redesigning the environment is predicated on the notion that pain may function as a setting event for problem behavior. Setting events are broad, contextual variables that influence the ongoing relationship between discriminative stimuli, responses, and reinforcers (Bijou & Baer, 1961). According to a setting event model (Carr & Smith, 1995), the presence of pain makes a variety of home, school, community, and work demands that an individual encounters daily, more aversive than they would normally be.

Individuals then respond to the aversive demands by exhibiting problem behavior because such behavior can be successful in causing others to terminate the demand. In illustration, consider a teacher who asks her student to complete a difficult language assignment. Normally, the student complies, albeit reluctantly. However, one day, the student is experiencing pain from an ear infection. On that day, pain (the setting event) may function to make the language task (the discriminative stimulus) more aversive than normal (Horner et al., 1996). In the context of pain-related illness, the language task may become discriminative for problem behavior because, in the past, such behavior caused the teacher to terminate the task. Thus, withdrawal of the aversive task functions as a negative reinforcer for problem behavior, ensuring that such behavior will be exhibited more frequently, in the future, during bouts of illness. This model of problem behavior suggests that redesigning the environment may be a useful intervention strategy. For example, the teacher could delay the language assignment until the child was feeling better, or the teacher could reduce the aversiveness of the assignment by interspersing easier language tasks among the more challenging ones (Dunlap & Koegel, 1980). Alternatively, the teacher could offer the child a choice of tasks in order to maintain academic engagement while waiting for the pain to abate, choice being a procedure known to reduce the likelihood of problem behavior (Dunlap et al., 1994).

A setting event model also suggests the potential utility of a third strategy, namely, an intervention based on teaching coping skills. Thus, in the example just described, the teacher could instruct the student to cope with the language task by requesting short breaks when he/she was in pain, or by asking for help when frustrated by frequent task errors. In other words, the student could acquire a socially appropriate way of dealing with the aversive task, thereby making problem behavior unnecessary. Much research suggests that teaching functional communicative alternatives to problem behavior can be an effective coping strategy that reduces or eliminates such behavior (Carr & Durand, 1985; Carr et al., 1994; Durand, 1990). Importantly, recent research suggests that it can be helpful in dealing explicitly with problem behavior related to pain and discomfort (Carr et al., 2003). Indeed, a functional communication approach could be broadened to address other issues beyond those raised by the example of escape motivated problem behavior just discussed. Some individuals, for instance, might seek attention (nurturance) or tangibles (e.g., specific foods) when ill. If so, then a caregiver or teacher could arrange to teach communicative phrases relevant to obtaining attention or tangibles, thereby further helping the individual to

cope with his/her illness. Perhaps, most critically, however, one might focus on teaching the individual to indicate (if not through speech, then through picture or sign language communication) the body part that hurts (e.g., “tummy sick”), thereby triggering appropriate palliative and supportive behaviors on the part of others. Systematic programs for teaching individuals to communicate complex “feeling” states have been available in the literature for some time (Lovaas, 1981).

The positive results of the present study justify, and indeed require, additional programmatic research to establish the generality of the findings and strengthen the psychometric properties of the assessment instruments developed. With respect to the issue of generality, it would be desirable to explore the relationship between pain and problem behavior with a larger, randomly selected sample to establish how widespread the phenomenon is from a population-level perspective. In order to raise the issue of a pain–problem behavior connection, we intentionally prescreened participants to maximize the opportunity to observe and evaluate this connection. Now that the connection has been demonstrated to be a plausible one, it would be important to avoid the selection bias inherent in our convenience sample by randomly selecting participants from a larger population.

With respect to the psychometric issue, it is necessary to note that the good inter-rater reliability obtained in the present study is only a first step in establishing the formal properties of our assessment strategy. The combined retrospective/prospective approach that we developed would be greatly enhanced by research that focused on classic psychometric issues pertaining to test–retest reliability (to establish the stability of the measures) as well as multiple dimensions of validity, including construct, criterion, and content. This additional research effort would be useful in increasing confidence that the assessment instruments possessed the stability and accuracy needed for widespread clinical use.

In sum, when detailed, focused assessment indicates that problem behavior is associated with illness-related pain and discomfort, a number of plausible intervention strategies could be initiated, individually or in combination, to preempt or reduce such behavior. The systematic empirical evaluation of the effectiveness of these strategies, when applied to pain-related problem behavior, is an important research priority. Such research could help add to the breadth of intervention options available to practitioners as well as providing a greater understanding of the nature of problem behavior itself.

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Appendix A

Retrospective Screening Questionnaire

Date: _____
 Target individual (initials): _____
 Informant: _____

- (1) Over the past two years, approximately how often was the individual sick (please check one)?
- greater than 24 times per year _____
 - 12-24 times per year _____
 - 6-11 times per year _____
 - 2-5 times per year _____
 - 0-1 times per year _____

(2) When the individual is sick or in pain, what type of sicknesses does he/she typically have?

- (3) What types of problem behavior does the individual typically display:
- (a) when he/she is sick/in pain?: _____
- (b) when he/she is **NOT** sick/in pain?: _____

- (4) What specific modes of communication does the individual typically use to indicate sickness or pain? (please check all that apply).
- (a) verbal _____ (d) pointing/leading _____
 (b) sign language or gesture _____ (e) other (please specify) _____
 (c) picture communication system _____

(5) How does the individual typically indicate that he or she is feeling sick or is experiencing pain? (please describe).

- (6) When the individual is sick or in pain, how frequently does he/she engage in problem behavior (self-injury, aggression, property destruction, and/or tantrums)?
- | | | | | | | |
|------------|---|---|-----------|---|--------------|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| NOT AT ALL | | | SOMETIMES | | ALL THE TIME | |

- (7) When the individual is **NOT** sick or in pain, how frequently does he/she engage in problem behavior (self-injury, aggression, property destruction, and/or tantrums)?
- | | | | | | | |
|------------|---|---|-----------|---|--------------|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| NOT AT ALL | | | SOMETIMES | | ALL THE TIME | |

- (8) When the individual is sick or in pain, how intense are the problem behaviors which he/she displays (how intense is the damage caused by the problem behaviors to self, others, or property)?
- | | | | | | | |
|------|---|---|----------|---|--------|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| MILD | | | MODERATE | | SEVERE | |

- (9) When the individual is **NOT** sick or in pain, how intense are the problem behaviors which he/she displays (how intense is the damage caused by the problem behaviors to self, others, or property)?
- | | | | | | | |
|------|---|---|----------|---|--------|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| MILD | | | MODERATE | | SEVERE | |

Appendix B

Prospective Behavior Questionnaire

Date: _____
 Target individual (initials): _____
 Informant: _____
 Times observations were made (e.g., 9:00 a.m. - 3:00 p.m., 3:00 p.m. - 7:00 p.m.) _____

(1) Is the individual sick today? Yes No

If yes: (a) Type of illness _____
 (b) Symptoms _____
 (c) Source of information? (e.g., Parent report, nurse report, doctors note, observed behaviors, self-report by the individual, etc.) _____

(2) Did the individual receive any medications for his/her physical illness today? Yes No

If yes: (a) What medication did he/she receive for illness? _____
 (b) What was the medication for? _____
 (c) At what time of day did the individual receive the medication? _____
 (d) Did the individual's behavior improve after he/she received the medication? Yes No

*** For questions 3 to 6, please restrict your ratings to the behaviors observed PRIOR to the time that the individual received medication.

(3) **MOTOR PAIN BEHAVIOR** How frequently did the individual display motor pain behaviors (e.g., facial grimacing, gritting teeth, repeatedly pulling ear, wincing, sensitivity to touch/flinching, clenching jaw, holding and/or rubbing affected body part) today?:

1	2	3	4	5	6	7
NOT AT ALL			SOMETIMES			ALL THE TIME

What particular motor pain behaviors did the individual display today? (please list and describe):

(4) **VOCAL PAIN BEHAVIOR** How frequently did the individual display vocal pain behaviors (e.g., sighing, whining/sobbing, moaning, hacking/gagging, groaning, screaming, or verbalizations: "ow," "ouch," "hurts") today?:

1	2	3	4	5	6	7
NOT AT ALL			SOMETIMES			ALL THE TIME

What particular vocal pain behaviors did the individual display today? (please list and describe):

(5) **FREQUENCY OF PROBLEM BEHAVIOR** How frequently did problem behavior occur today (e.g., self-injury, aggression, property destruction, and/or tantrums)?

1	2	3	4	5	6	7
NOT AT ALL			SOMETIMES			ALL THE TIME

What particular problem behaviors did the individual display today? (please list):

(6) **INTENSITY OF PROBLEM BEHAVIOR** How intense were the individual's problem behaviors today (e.g., how intense was the damage caused by the problem behavior to self, others, or property)? :

1	2	3	4	5	6	7
MILD			MODERATE			SEVERE

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