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Children's anxious reactions to an invasive medical procedure: The role of medical and non-medical fears

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Abstract

This study investigated the relationship of medical and non-medical fears to children's anxiety, pain, and distress during an invasive medical procedure, the voiding cystourethrogram. Parents of 34 children completed the Fear Survey Schedule-II prior to their child's procedure. Child distress behaviors during the procedure were audiotaped and coded using the Child-Adult Medical Procedure Interaction Scale-Revised. Ratings of child procedural anxiety and pain were obtained from children, parents, and examining technologists within minutes following the procedure. Associations were observed between medical fears, procedural anxiety (parent and staff reports), and coded distress behaviors. Findings may inform preparation efforts to reduce anxiety around invasive medical procedures.

Keywords

anxiety, children, medical fears, medical procedures, voiding cystourethrogram

Children's responses to invasive medical procedures can vary widely. While some children experience anxiety and distress, others exhibit calm and cooperation. One medical procedure known to cause particularly intense and potentially enduring anxiety in children is the voiding cystourethrogram (VCUG), a fluoroscopic study of the urinary tract that involves catheterization, filling of the urinary bladder with a room-temperature radiopaque liquid, and voiding of the liquid by children while lying on a radiographic table. Anecdotal reports suggest that the VCUG, while generally considered less painful than many other medical procedures, may be perceived by children as more distressing due to its invasiveness (Stashinko and Goldberger, 1998). Indeed, in one study, approximately

61 percent of non-sedated children experienced serious or severe distress while undergoing a VCUG (Herd et al., 2006). This distress may linger and manifest itself in other negative ways, such as sleep disturbance, bedwetting, and other

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behavioral problems, in the days and weeks following the VCUG (Phillips et al., 1996). A subset of children has even demonstrated symptoms resembling a post-traumatic stress reaction after their VCUG, including upsetting memories and acting out the procedure in their play (Stashinko and Goldberger, 1998).

Predicting reactions to the VCUG

As a result of the variability in children's responses, there may be significant value in identifying factors which predict anxiety and distress during the VCUG and similar invasive medical investigations. Previous research has explored how children manage their emotions and behavior during the VCUG. Salmon and Pereira (2002), for example, examined various coping behaviors (e.g. distraction). Interestingly, children's coping attempts were not linked to their procedural distress. This may suggest that, aside from exploring how children manage their distress during the procedure, emphasis should be on identifying factors that affect children's initial reactivity to potentially threatening situations and inhibit children from properly executing or benefitting from coping strategies.

Less is known about which factors place children at risk for increased reactivity to the VCUG and subsequent anxiety and distress. Merritt et al. (1994) did show that two traits of temperamental reactivity, adaptability and approach, were negatively associated with children's fear during the VCUG, suggesting that children who typically adapt less easily to and withdraw from new or uncertain situations may experience more unpleasant reactions to the VCUG. Beyond temperamental style, it may also be important to consider possible triggers for reactivity to the VCUG in the form of the content of children's fears. Children with some type of marked fear (e.g. fear of hospitals) may be prone to a particularly negative reaction to the VCUG. Fearful children may also be less likely to implement or benefit from typical coping strategies (e.g. distraction) employed during VCUGs and similar procedures (Blount et al., 1990).

The role of fears

Fears can be a normal facet of life for many children. For some youth, however, fears can develop into more serious forms of psychological distress, such as specific phobias. It remains less clear as to which types of fears influence the intensity of children's anxiety and distress responses to an acute medical stressor. Given that some children exhibit a heightened fear response during and after VCUGs, knowledge of the fears children bring with them into the procedure room may help us better understand the pathways leading to increased reactivity.

Medical fears, defined as fears linked to "any experience that involves medical personnel or procedures involved in the process of evaluating or modifying health status in traditional health care settings" (Steward and Steward, 1981: 70), may be a likely source of anxiety for children who undergo VCUGs. Children predisposed to anxiety in medical settings may be provoked by the intense nature of the procedure and the demands it places on them. Evidence suggests that fears of injections and operations are among the most common medical fears reported by healthy children (Broome and Hellier, 1987). Although no published research has investigated the role of medical fears during children's VCUG experiences, support has been demonstrated for the relationship between medical fears and children's anxiety and pain during immunizations (Broome, 1986) and venipunctures (Jacobsen et al., 1990).

Because VCUGs are considered more distressing than painful, certain non-medical fears may also aid in the prediction of children's fearful reactions to elements from the procedure that, while potentially distressing, may not be connected to pain. For example, the lack of privacy during catheterization, along with the step requiring patients to void in front of others, may elicit greater anxiety in children with previously developed fears of embarrassment and negative evaluation. Although social fears are not experienced with regularity until adolescence (Gullone and King, 1992), younger

children with well-developed social fears may have particularly anxious reactions to a VCUG.

In contrast, anticipatory fears frequently occur in children between ages 4 and 8 (Gullone and King, 1992), also a common age range during which children receives VCUGs. Anticipatory fears, characterized by exaggerated perceptions of threat and danger, are closely linked to anxiety in children (Muris et al., 2000). In some respects, the VCUG itself may be considered analogous to threatening situations where children perceive their safety to be at risk. Marked fears of threat and danger may, therefore, contribute to how children react before, during, and after the VCUG. Fear of the unknown, for example, has been identified as a prominent fear in adult patients undergoing endoscopy without preparation (Drossman et al., 1996). To date, however, no studies have evaluated the impact of danger and other non-medical fears in the prediction of children's anxiety during VCUGs or other medical procedures.

Aims and hypotheses

The primary aim of the present study was to investigate the relationship between fears, both medical and non-medical, and children's anxiety during an invasive medical procedure. It was hypothesized that medical, social/embarrassment, and danger fears would be associated with greater child anxiety during VCUGs, as rated by children, parents, and examining technologists. Given that VCUGs are regarded as less painful but more emotionally distressing than other commonly studied procedures (e.g. venipunctures), this study also examined the relationship between various types of fears and children's pain during the VCUG. Pain, while serving as a point of contrast from anxiety, was not expected to correlate with medical or non-medical fears.

Finally, while it is common to utilize Likert-type and analog scale ratings from multiple informants in studying children's behavior during medical procedures, there has been limited investigation of the level of agreement among informants in rating children's anxiety and pain

during the VCUG. Therefore, a secondary aim of this study was to examine agreement between child, parent, and medical staff ratings of children's procedural anxiety and pain, as well as to compare these ratings to a standardized observational assessment of procedural distress.

Methods

Participants and recruitment

Participants were recruited from an initial group of 213 children scheduled to undergo a VCUG at a regional medical center in upstate New York. Upon scheduling their VCUGs, families were mailed study information letters. Of the first 53 families that received letters, three contacted the project coordinator to express interest and subsequently completed the study. Due to the low response rate, the recruitment procedure was modified, such that families received a self-addressed stamped postcard that provided them the option to decline participation or express interest. After 1–2 weeks, the project coordinator called to discuss the project with families who did not return the postcard and families whose returned postcards expressed interest. Of the 160 families that received postcards, 57 declined to participate, 31 agreed to participate, and 72 were not reached prior to their children's VCUGs. No age or gender differences were found between children whose parents agreed, declined, or were unreachable.

The final sample included 34 children (32 females) between the ages of 4 and 10 ($M = 5.68$, $SD = 1.74$). The majority of the children were Caucasian (30 of 34; 88.2%), one was African American (2.9%), one was Hispanic (2.9%), and two were identified as biracial (5.9%). Of the 29 families who provided information regarding income status, 45 percent reported more than US\$80,000 in total income, 41 percent reported between US\$40,000 and US\$80,000, and 14 percent reported less than US\$40,000. Six children had never previously undergone a VCUG, 11 had undergone one, 6 had undergone two, and 11 had undergone three or more.

Measures

Demographics. Parents completed a questionnaire to provide demographic information, including their child's age and ethnicity. In addition to reporting their child's number of previous VCUGs, parents rated the distress their child exhibited during the most recent past procedure on a five-point scale from 1 (*not distressed*) to 5 (*extremely distressed*).

Fear Survey Schedule for Children-II Parent (FSSC-IIP). Between 2 to 3 weeks prior to their child's VCUG, parents completed the FSSC-IIP, a parent-report survey of children's fears (Bouldin and Pratt, 1998; Gullone and King, 1992). A downward extension of the Fear Survey Schedule, the FSSC-IIP contains a list of stimuli and experiences that may cause fear in younger children. Some items from the original Australian version of the FSSC-IIP were reworded for use with children from the United States (e.g. changing dingoes to dogs), in accordance with modifications by Burnham (2005) and Burnham and Gullone (1997). For each item, parents rated their child's level of fear by choosing among four options (*not scared*, *scared*, *very scared*, and *not applicable*) to describe how their child usually behaves in response to the item. If parents selected "not applicable" (i.e. the item had not arisen), that item was provided the same score as an item in which parents selected "not scared." Three FSSC-IIP subscales were completed: death and danger (28 items, e.g., being kidnapped; $\alpha = .92$), failure and criticism (14 items, e.g., looking foolish; $\alpha = .78$), and medical (7 items, e.g., getting a shot; $\alpha = .67$). The medical subscale exhibited a lower alpha coefficient, which is expected for scales with fewer items and does not eliminate their utility (Kline, 2000).

Child-Adult Medical Procedure Interaction Scale-Revised. Vocalizations during VCUGs of 27 participants were recorded and coded using the Child-Adult Medical Procedure Interaction Scale-Revised (CAMPIS-R), a standardized rating scale for assessing verbal interactions

during pediatric medical procedures (Blount et al., 1997). The CAMPIS-R categorizes child vocalizations into three broad categories: distress, coping, and neutral. Since the coping and neutral categories were not the focus of our analyses, they will not be presented here. The distress category is comprised of eight individual behavior codes: crying, screaming, verbal resistance (e.g. "stop"), emotional support seeking (e.g. "hold me"), information seeking (e.g. "when will you be finished?"), verbal fear (e.g. "I'm scared"), verbal pain (e.g. "that hurts"), and verbal negative emotion (e.g. "I don't like doing this"). In the present study, three codes (crying, screaming, and verbal pain) were collapsed into one code because of difficulty discriminating among them on audio recording.

Trained research assistants, blind to participant FSSC scores and procedural ratings, coded all occurrences of the six vocalizations within 5-second intervals across the entire VCUG. Coding was initiated when the examining technologist asked the child to lie down on the X-ray table, continued during each element of the procedure (e.g. catheter insertion), and concluded with the final X-ray picture followed by a statement from the technologist to the child confirming the procedure was finished. *Child distress* was calculated for each participant by summing the frequency of all 5-second intervals featuring at least one distress behavior and dividing it by that participant's total number of intervals. To assess inter-rater reliability, 20 percent of the recordings were randomly selected and coded by two independent raters. Agreement was very strong ($r = .94, p < .001$).

Procedural ratings (child). Within 15–30 minutes following completion of their VCUG, children rated their procedural anxiety and pain on 10-in paper thermometer, ranging from 1 (e.g. "not at all anxious") to 10 (e.g. "extremely anxious"). Pictorial scales, such as thermometers, faces, and visual analog scales, have been successfully utilized as a means of increasing understanding of dimensional rating systems in children as young as three (Chen et al., 2000; Jacobsen et al., 1990). Research staff provided

a standardized description of the thermometer rating system to all participants. To assess anxiety during the VCUG, children were asked "How worried were you when you had the x-ray of your belly?" The term "worried" was chosen instead of "anxious" as it was felt to elicit greater comprehension in younger children. To assess pain, children were asked "How painful was the x-ray of your belly? How much did it hurt?" The use of "x-ray of your belly" was intended to provide an age-appropriate description of the VCUG, although research staff explained to all children that the questions were in reference to the entire VCUG.

Procedural ratings (parent and staff). After 10–30 minutes of completion of the VCUG, parents who had been present for the VCUG, along with each participant's examining technologist, completed a paper-and-pencil questionnaire. Questions included "How anxious was your (the) child during the procedure?" and "How painful was the procedure for your (the) child?" Parents and staff rated the children's anxiety and pain during the procedure on a Likert-type scale from 1 (*not at all*) to 5 (*extremely*).

Procedure

Institutional review boards for the collaborating university and medical center approved all procedures for this project. Parents were mailed a consent form and questionnaire packet to complete within 4 weeks prior to their child's VCUG. Most parents returned signed consent forms and completed questionnaires to research staff by mail within 2 weeks prior to the VCUG, although a few parents returned them on the day of the procedure. Participation was voluntary, requiring written consent from parents and assent from children in either verbal (children between ages 4 and 8) or written form (children ages 9 and 10). Verbal assent was obtained from younger children in person by reading to them a standardized description of the procedures before and after their VCUG. For each part of the study, families were read a standardized set of instructions and told that their responses would be kept confidential.

Results

Preliminary analyses

No demographic variables (e.g. age) were associated with any procedural anxiety or pain variables. Although the number of participants' previous VCUGs was not associated with any procedural variables, parent-rated child distress during the most recent past VCUG was associated with child anxiety during the current VCUG, as rated by children ($r = .37, p < .05$) and staff ($r = .45, p < .05$), and child-rated pain ($r = .42, p < .05$).

Comparison of child, parent, and staff procedural ratings

Mean differences. Comparison of mean procedural ratings of anxiety and pain by children, parents, and staff was conducted via a series of paired samples *T*-tests (see Table 1). For this comparison, children's ratings were adjusted to the same 1-to-5 scale used by parents and staff (e.g. ratings of 1 and 2 converted into 1, 3 and 4 to 2, etc.). No significant differences were found between child-rated anxiety ($M = 3.00, SD = 1.50$) and either parent-rated ($M = 3.26, SD = 1.19$) or staff-rated ($M = 2.59, SD = 1.31$) child anxiety. Children's self-rated pain ($M = 3.59, SD = 1.37$) was higher than both parent ($M = 2.82, SD = 0.87$) and staff ($M = 2.00, SD = 0.87$) pain ratings. Parents, compared to staff, provided higher ratings of children's anxiety and pain. In addition, parents ($t = 2.33, p < .05$) and staff ($t = 3.04, p < .001$) rated anxiety higher than pain. No difference was found between child-rated anxiety and pain ($t = -1.43$), however.

Correlations and agreement. Table 1 also displays Pearson *r* and intra-class correlation (ICC) coefficients of self, parent, and staff ratings of children's anxiety and pain during the VCUG. Pearson *r* values indicate covariation among scores, whereas ICCs provide information about absolute agreement. Analyses revealed that child-rated anxiety was associated and concordant with staff-rated but not parent-rated anxiety. Child-rated pain was not associated with staff-rated

Table 1. Pearson correlations, intra-class correlations, and mean differences between child, parent, and staff Procedural ratings.

	Child versus Parent			Child versus Staff			Parent versus Staff		
	Pearson <i>r</i>	ICC	<i>t</i> value	Pearson <i>r</i>	ICC	<i>t</i> value	Pearson <i>r</i>	ICC	<i>t</i> value
Anxiety	.20	.20	-.90	.34*	.33*	1.49	.64***	.56***	3.70**
Pain	.27	.20+	3.15**	.18	.09	6.00***	.41*	.29**	5.00***

+*p* < .10, **p* < .05, ***p* < .01, ****p* < .001.

Table 2. Correlations among FSSC-IIP fears, CAMPIS-R distress, and child, parent, and staff procedural ratings.

	Child		Parent		Staff		CAMPIS-R
	Anxiety	Pain	Anxiety	Pain	Anxiety	Pain	Distress
Death and danger fears	.23	-.12	.17	-.11	.44*	-.06	-.14
Failure and criticism fears	.16	.11	-.06	-.08	.09	-.26	-.15
Medical fears	-.01	.08	.36*	.23	.45**	.33+	.42*

FSSC-IIP: Fear Survey Schedule for Children-II Parent; CAMPIS-R: Child-Adult Medical Procedure Interaction Scale-Revised.

+*p* < .10, **p* < .05, ***p* < .01, ****p* < .001.

pain, although a marginally significant ICC with parent-rated pain was observed. Parents and staff showed moderate to strong agreement in rating anxiety and pain.

Associations with CAMPIS-R distress. To assess the convergent validity of child, parent, and staff ratings of anxiety and pain during the VCUG, Pearson’s *r* correlations were performed to examine their associations with observed CAMPIS-R child distress scores. CAMPIS-R distress was positively associated with parent-rated anxiety (*r* = .64, *p* < .001), staff-rated anxiety (*r* = .68, *p* < .001), staff-rated pain (*r* = .61, *p* < .001), and child-rated pain (*r* = .43, *p* < .05). It was not linked to child-rated anxiety (*r* = .23) or parent-rated pain (*r* = .24).

Fears and procedural ratings

Table 2 presents Pearson’s *r* correlations between each fear category and procedural anxiety and pain ratings completed by children, parents, and staff, as well as CAMPIS-R child distress scores.

Fears and child ratings. No associations were found between any fear category and child-rated anxiety or pain.

Fears and parent ratings. Medical fears were positively associated with parent-rated anxiety but not parent-rated pain. Neither death/danger nor failure/criticism fears were linked to parent-rated anxiety and parent-rated pain.

Fears and staff ratings. Medical fears were associated with staff-rated anxiety and marginally significant in the association with staff-rated pain. Death/danger fears were linked to staff-rated anxiety but not staff-rated pain.

Fears and CAMPIS-R distress. Medical fears were associated with CAMPIS-R child distress scores. Neither death/danger nor failure/criticism fears were linked to CAMPIS-R distress.

Discussion

The present study examined the relationship between children’s fears and their reactions to a

particularly stressful medical procedure, the VCUG. Overall, findings partially supported our hypotheses. Children with stronger medical fears were more anxious during the VCUG as reported by their parents and examining technologists. Medical fears were similarly associated with children's procedural distress as measured from their vocalizations, indicating that these children were more likely to cry, scream, and make distress-related statements during the VCUG. Consistent with investigations of other medical procedures (Jacobsen et al., 1990), this is the first published study to show a link between children's medical fears and their anxiety during the VCUG. No link was found between medical fears and procedural pain, however, although a trend was observed in the relation with staff-reported pain. These findings may suggest that, especially when parent perceptions are considered, children with medical fears are prone to exhibiting increased anxiety but not pain during the VCUG.

Contrary to expectations, however, death and danger fears were associated with staff-rated anxiety but not observed distress or anxiety rated by children and parents. Perhaps reflecting different perceptions among informants, these findings may suggest that medical staff, possibly shaped by their experiences administering medical tests with a range of children, sense that children who have more anticipatory anxiety in general about dangerous and threatening situations also display negative reactions during invasive medical procedures. In contrast, if parents of these children prepare them more for the stress associated with the procedure, parent and observer ratings may reflect the perception of these children as having coped successfully. Additionally, failure and criticism fears were not linked to any procedural outcomes. Although children with fears of social evaluation were expected to display heightened anxiety given the invasiveness and sensitive nature of the VCUG, it is possible that some were instead cooperative during the procedure to avoid eliciting negative feedback from their parents.

Interestingly, children's own procedural ratings were not related to medical, death/danger, or failure/criticism fears. Because of the variance observed in children's procedural ratings, however, it is important to view analyses of these outcomes with caution. Although pictorial scales are popular in pediatric clinical and research settings (e.g. Chen et al., 2000), they are considered subject to bias (Von Baeyer, 2006). For this study, we chose to be consistent with prior pediatric investigations in the measurement of procedural anxiety/pain as obtained from children, parents, and staff (e.g. Chen et al., 2000). Although it would have been beneficial to utilize other validated child-report measures of pain (e.g. Faces Pain Scale), this method allowed for identical procedures across informants and ratings (anxiety and pain).

Nevertheless, in examining the agreement between informants in rating procedural anxiety and pain, children's ratings were correlated and concordant with staff ratings as well as exhibited a positive association with an observational measure of procedural distress. This partially supports the convergent validity of children's ratings, although their lack of association with parent ratings is problematic. Children's pain ratings were also higher than pain ratings made by parents and staff. While the VCUG is considered by medical professionals to be more invasive, stressful, and uncomfortable than painful (Stashinko and Goldberger, 1998), children's pain ratings may suggest otherwise. However, it is difficult to ascertain from these findings whether children experienced a high level of pain or simply attributed their distress to pain.

More consistent agreement was found between parent and staff procedural anxiety ratings, which also correlated with observational distress. Taken together, these findings underscore the validity of parent and staff assessment of children's responses to an invasive medical procedure. On average, parents did report their children to have experienced greater anxiety and pain than was reported by staff. Parents experience a wide range of reactions to their children undergoing an invasive procedure that

will produce results with potentially serious health implications. For parents prone to anxiety during this process or in general, it may be expected that they would perceive their children as experiencing anxiety (Giramonti et al., 2012).

Limitations

The present study features several strengths, including its real-world setting and multiple assessment methods and informants. Limitations related to sampling and study procedures should be noted, however. First, the sample was relatively small and comprised largely of females. Recruitment for a study concerning a medical procedure of such a sensitive nature can be difficult. In our case, some parents declined participation because they felt it would cause stress during an already stressful experience. We were also unable to reach a sizable proportion of our recruitment pool despite multiple attempts. Although these difficulties restrict the generalizability of our sample, it is important to note that we found no age/gender differences between participants and those who declined or were unreachable. Additionally, the small sample may raise concerns about low power and Type II error. While some results with low effect sizes were statistically non-significant, moderate effects were present in several significant correlations. Post-hoc analyses suggested power of .67 for those correlations ($r > .35$; $\alpha = .05$ and $N = 32$).

Second, because no method has been developed to reliably code audio recordings for the purpose of measuring anxiety and pain responses, we were unable to provide observational assessment of these variables. Further research is needed to examine these research questions utilizing observational methodology. Third, the assessment of medical and non-medical fears was based solely on parent report. It would be useful to replicate these findings while incorporating children's own fear ratings, although no child-report measure capturing medical and non-medical fears has been validated for young children at this time.

Implications for research and practice

Although this study suggests a link between medical fears and children's anxiety during the VCUG, mechanisms of this relationship remain to be investigated. Therefore, the next step in this line of research may be to examine how medical fears influence the type and effectiveness of coping strategies utilized by youth during invasive medical procedures. Despite evidence suggesting that medical fears may not predict children's use of coping strategies during medical procedures (Broome et al., 1994), it is unclear whether this would apply to young children who typically rely on support from others during the VCUG. Further study is needed to determine whether children with medical fears are less responsive to coping attempts from parents and medical staff.

In light of the high proportion of children who suffer distress during and after their VCUGs, research has been increasingly devoted to investigating programs aimed at minimizing procedural distress. Although sedation is used with about 30 percent of patients (Ellison et al., 2009), evidence is mixed regarding its effectiveness (Ferguson et al., 2011; Herd et al., 2006) and shows it may interfere with certain steps of the VCUG, including children's ability to void (Merguerian et al., 2006). Interventions which provide procedural information, coping skills training, distraction, and/or parent coaching may offer promise for children undergoing invasive procedures (Dionigi et al., 2014; Gebarski et al., 2013; Zelikovsky et al., 2000).

Findings from this study may inform the development of preventive intervention and preparation programs for children undergoing VCUGs or other invasive medical procedures. Although further research is needed, the knowledge that certain fears may be linked with children's reactions to the VCUG may promote successful efforts by medical staff to identify youth who would benefit most from sedation or added preparation prior to the VCUG, rather than providing them universally to youth who may not benefit. Medical staff could be advised, for example, to assess whether children are

worried about certain elements of the procedure or catastrophizing dangers or negative experiences that could arise. Finally, given that patients may suffer less distress when provided information about their procedures (Claar et al., 2002) and sensations they might experience (Poi et al., 1998), children undergoing a VCUG or other invasive procedures may similarly benefit from information targeted to their medical and danger fears. Explanation regarding the procedure and potential for discomfort may help alleviate some of the anticipatory anxiety children carry with them into the procedure room.

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