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Abstract

This qualitative study is grounded in the diagnosis of Disorders of Extreme Stress - Not Otherwise Specified (DESNOS). This diagnosis is under review to appear as a subcategory of Post Traumatic Stress Disorder (PTSD) in the upcoming DSM-V. This study evaluates DESNOS symptoms exhibited in children who have experienced interpersonal traumatic events, specifically domestic violence or sexual abuse. Outcomes suggest that children indeed display characteristics of DESNOS soon after an interpersonal trauma. The findings suggest a need for more research on techniques and treatments that can be used to help children exhibiting symptoms of DESNOS.

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THE STUDY OF THE PREVALENCE OF DESNOS SYMPTOMS IN
TRAUMATIZED CHILDREN

By

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The Study of the Prevalence of DESNOS Symptoms in Traumatized Children

A Qualitative Study

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Eastern Michigan University

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Abstract

This qualitative study is grounded in the diagnosis of Disorders of Extreme Stress- Not Otherwise Specified (DESNOS). This diagnosis is under review to appear as a subcategory of Post Traumatic Stress Disorder (PTSD) in the upcoming DSM-V. This study evaluates DESNOS symptoms exhibited in children who have experienced interpersonal traumatic events, specifically domestic violence or sexual abuse. Outcomes suggest that children indeed display characteristics of DESNOS soon after an interpersonal trauma. The findings suggest a need for more research on techniques and treatments that can be used to help children exhibiting symptoms of DESNOS.

***Key Words:** disorders of extreme stress not otherwise specified, posttraumatic stress disorder, children, interpersonal traumatic events, domestic violence, sexual abuse*

The Study of the Prevalence of DESNOS Symptoms in Traumatized Children

A Qualitative Study

Literature Review

DESNOS in the DSM-IV is listed under “associated features of PTSD.” Thus DESNOS is not a distinct diagnosis, but rather a branch of PTSD (Luxenberg, 2001, p. 374). DESNOS has existed under a variety of other names, including complex PTSD (CP), complicated PTSD, and disorders of extreme stress (DES) (Roth, 1997). Currently a qualified study panel is determining if DESNOS should exist as its own diagnosis in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V). First, however, it is important to understand the distinguishing characteristics of PTSD and DESNOS.

According to the DSM-IV-TR, to be diagnosed with PTSD an individual has experienced, watched, or learned of a single event that threatened or actually damaged their or someone else’s life, safety, or physical integrity (American Psychiatric Association [*DSM-IV-TR*], 2000). Terrorist attacks, a car crash, or the sudden and violent death of a family member are traumatic events that have the potential to cause PTSD. In reaction to this extreme trauma the individual experiences a sense of intense fear, hopelessness, or horror. Additionally the individual re-experiences the traumatic event, tries to avoid anything that reminds them of it, and exhibits signs of continual arousal and anxiety: Such as having trouble sleeping, or heightened startle responses (American Psychiatric Association [*DSM-IV-TR*], 2000). These symptoms persist for at least one month and cause clinical distress in important areas of functioning. If symptoms of PTSD last longer than 16-18 months following the trauma, or emerge after a delayed basis, the disorder may be diagnosed as chronic PTSD. Once deemed chronic, the PTSD tends to be

refractory to treatment because of its ongoing symptoms and deteriorating psychosocial adjustment. Even in the best results from studies on chronic PTSD they show that chronic PTSD patients rarely benefit from intensive psychotherapy (Ford, 1998). Although there are differing opinions on this; “There is a good rationale for using supportive therapy to treat PTSD as social support has been shown to be one of the best predictors of recovery in PTSD” (Ehlers, 2010, p. 3). It does not negate the fact that there is still a need for a more specific diagnosis and treatment criteria for chronic PTSD, which often overlaps with DESNOS.

Most often PTSD sets in after a non-interpersonal traumatic event, like a severe car crash, where as DESNOS arises after an interpersonal traumatic event that transcends a period of time. DESNOS symptoms usually appear in people who have been abused by their caregiver, have been battered (domestic violence), or are survivors of genocide, torture, terrorism, and kidnapping (Trappler, 2009). DESNOS is more than an anxiety disorder; it is a posttraumatic self-dysregulation that involves overwhelming emotional distress, severe disassociation, lack of trust in relationships and in the meaning of life, and chronic health problems that have no medical explanation (Ford, 2006). Symptoms are experienced for a prolonged period of time, from months to even years.

Judith Herman (1992) compiled a list of six areas of functioning when diagnosing an individual with DESNOS. The first area being an alteration in regulation of affect and impulses, the individual has trouble managing their emotional experiences. Often have trouble processing minor stresses, have trouble calming themselves, and at times may use self-destructive measures, such as self-mutilation (Luxenberg, 2001). In addition to showing signs of affect regulation, an individual demonstrates the following: modulation

of anger, self-destructive tendencies, suicidal preoccupation; difficulty modulating sexual involvement; or excessive risk taking. The second function is alterations in attention or consciousness. The individual may have both amnesia, and transient dissociative episodes (Roth, 1997). A third characteristic is an alteration in self-perception. The individual demonstrates two of the following: ineffectiveness, permanent damage, guilt and responsibility, shame, the feeling that nobody understands, and minimization of the trauma. Ultimately they view themselves as helpless, ineffectual, damaged, and/or undesirable to others (Luxenberg, 2001).

The fourth area of functioning is an alteration in relations with others. The individual shows either the inability to trust others, re-victimization, or the victimizing of others. People who have been chronically traumatized often have difficulty building a template for interpersonal interaction. Thus they may not see danger signs, or may feel powerless to act against them. Somatization, the fifth area of functioning studied, occurs when individuals demonstrate two of the following criteria: problems with their digestive system, chronic pain, cardiopulmonary symptoms, conversion symptoms, and/or sexual symptoms (Herman, 1992). Chronically traumatized individuals often respond poorly to medical treatment, and frequently report unusual symptoms for which there can be no obvious physical cause (Luxenberg, 2001). The last area of functioning that is evaluated is alterations in systems of meaning. The individual show signs of despair and hopelessness as well as loss of previously sustaining beliefs. They tend to view the world through a dark lens; they no longer believe that their life has purpose (Ford, 2006).

The diagnosis of PTSD was first introduced in 1980 by the American Psychiatric Association in the third issue of the Diagnostic and Statistical Manual of Mental

Disorders (DSM III). DESNOS is a relatively new psychological diagnosis; its premise has been evolving over the past 20-30 years. Before the diagnosis of DESNOS researchers attempted to identify other diagnoses to address the psychological aftermath of trauma that was left unaddressed by PTSD. In 1985 the “National Summit Conference on Diagnosing Child Sexual Abuse” proposed the new disorder: Sexually abused child’s disorder. The primary focus of this disorder included age-inappropriate sexual behavior or awareness, dissociation and/or difficulty discussing the abuse. Similarly, Burgess and Walker (1984) coined the “rape-trauma syndrome,” as well as the “battered woman syndrome” and associating symptoms (Pelcovitz, 1997, p. 4). They related these two subjects because their symptoms at times mirrored each other.

In an effort to capture the unique nuances of symptoms experienced by those exposed to chronic trauma, Terr (1991) identified two types or classifications of reactions that children have to trauma. Terr (1991) first labeled Type I Trauma. Type I Trauma is typically seen after a single traumatic event (e.g., vehicle accident, natural disaster), which is thought to result in symptoms of PTSD. Type II Trauma is associated with long-term traumatic exposure (e.g., child abuse, domestic violence), that when experienced during childhood may compromise self-development (Pelcovitz, 1997). Type II Traumas are associated with high levels (50%-70%) of PTSD prevalence. Further it is associated with chronic self-regulatory deficits, substance abuse disorders, anxiety and affective disorders, and medical morbidity (Scoboria, 2008).

DESNOS is a formulation of all of these symptoms, but with it not in existence yet, what were psychologists supposed to refer to it as? Certainly some researchers have examined this topic (Allen, 2007), however a large gap exists in their field. PTSD

captures only a limited portion of posttraumatic psychopathology, especially in children (van der Kolk, 2005). Even though this gap is evident, it has received little attention. In PTSD literature, whatever did not fall under the PTSD realm was classified as a “comorbid condition” (Scoboria, 2008). This classification is alarming because it leaves many persons without the correct diagnosis and treatment. With a commitment to gain an accurate understanding, the author of the DSM, The American Psychiatric Association engaged in field trials.

In one field trial on PTSD (1990 to 1992), 540 participants were tested. The field trial investigated a) alternative versions of the PTSD stressor criteria, b) the validity of items across the stressors, c) the adequacy of the three-way division of symptoms, and d) potential changes in the minimum required PTSD symptoms (Roth, 1997). Thus prolonged trauma, particularly at an early age, may have significant effects on psychological functioning that is above and beyond the realm of a PTSD diagnosis.

The field trial included a literature review on trauma in children, female victims of domestic violence, and concentration camp survivors. A team of researchers identified a list of 27 criteria and compiled the “Structured Interview for Disorders of Extreme Stress” (SIDES; Trappner, 2009). The outcome of the DSM-IV field trial showed that all three of the groups of subjects 15 years and older who had experienced prolonged or a high magnitude of interpersonal trauma showed significant elevation of scores on the SIDES scale. There was a clear divide between individuals who had reported interpersonal violence before the age of 14, individuals who reported it after the age of 14, and the individuals that were victims of natural disasters who did not report any history of interpersonal violence. Sixty-one percent of the individuals with early onset

abuse and 33% of individuals with late onset abuse showed signs of both PTSD and DEPNOS where as only 8% of natural disaster victims showed both PTSD and DEPNOS (van der Kolk, 2005). The DSM-IV field trial supported the hypothesis that trauma, particularly when prolonged, that first occurs at an early age and is of interpersonal nature, can have immense effect on an individual's psychological functioning that is beyond the scope of PTSD diagnosis (van der Kolk, 2005). The results also suggest that physical and sexual abuse are risk factors for CP/DEPNOS in women. When these are combined, they pose a greater risk than when the abuse is singularly physical (Roth, 1997).

Further studies indicate that symptoms of DEPNOS have been found in survivors of domestic violence, childhood abuse, hostage taking, and prisoners of war (Choi, 2009). Studies with children are few in number. One study on children examined the relationship between the type of trauma exposure and the onset of PTSD symptoms among urban children. This study does not reference DEPNOS, but it found that when a child experienced sexual abuse, physical abuse, or witnessed domestic violence, they exhibited an increased number of PTSD symptoms (Luthra, 2009).

Research Question

It was hypothesized by researcher that children, when living in a domestic violence home environment, would be found to exhibit symptoms or signs of DEPNOS. As discussed above, when participants met diagnostic criteria for PTSD, they were compared with those who had met the DEPNOS diagnostic criteria. It was found that only 6.2% of the treatment sample and only 4% of the community sample did not have

lifetime DESNOS without PTSD. Therefore it was rare for individuals with DESNOS symptoms to not suffer also from PTSD (van der Kolk, 2005).

Methodology

Agency

The data were collected from an emergency women's domestic violence shelter located in the Midwest in a city of over 10,000 people. At this shelter women can come to stay in a safe environment along with their children after an altercation with their partner. Most of the women who stay were either sexually or physically abused; sometimes their children witnessed or were victims of the abuse. This is a voluntary program and participants may leave at any time and can stay up to thirty-five days or longer depending on their circumstances. Counseling services, legal advocacy, and support groups are offered at the shelter.

Sample

The sample for this study is a convenience sample. The research participants are willing, voluntary residents of the domestic violence shelter. All participants are women and at least 18 years old or older and have at least one child staying with them. A flyer was posted and five residents responded and agreed to participate in the study. In total the five women had eleven children: six males and five females. The children ranged in age from two to twelve years old. The sample was both diverse in age and race. Collecting and analyzing the socio-demographic data provided a descriptive understanding of the participants and their children (See Table 1, p. 23).

Participants self-selected to be part of the study. They were further informed that once they began the study, or upon completion, they would be afforded the opportunity to remove themselves and have any and all data destroyed.

Data Collection

The data collection took place at a scheduled interview. All interviews took place in a public but confidential setting (such as a park or library). The interview began with a script (See Appendix A) and followed a specific list of questions, which were all read out loud to them (See Appendix B). If consent was granted, the interviews were recorded for transcription purposes only, and were transcribed by the researcher.

Instrument

The questionnaire and interview questions were all developed from pre-existing tools to determine if symptoms of DESNOS were present. The Structured Interview of Disorders of Extreme Stress (SIDES) was designed to measure current and lifetime presence of DESNOS, as well as current symptom severity. SIDES is currently the only research tool that has been validated for the purpose of diagnostic assessment of DESNOS (Luxenberg, 2001).

Protection of Human subjects

The consent of the adult participants was obtained before the questionnaire was completed. The consent form clearly stated that participation is voluntary and participants could withdraw at anytime without negative consequences (See Appendix C).

The confidentiality of the participants is guarded. The consent forms are locked in a file cabinet and its key stored in a separate place. When participants signed the consent

form their identities became coded with this list being kept locked in separate file cabinets.

Data Analysis

Once all of the interviews were completed the socio-demographic information was organized, and the DESNOS symptom data were arranged according to the corresponding DESNOS symptom category. The information was listed under six categories: alterations in regulation of affect and impulses; alterations in attention and consciousness; alterations of self-perception; alterations in relations with others; somatization; and alterations in systems of meaning. The data collected in each category were tallied and then converted into percentages. The interviews were then compared and the similarities and differences were noted. These findings were compared to other DESNOS research that involved adults. The prevalence of the DESNOS symptoms in the children were compared and analyzed to the prevalence of the symptoms in adults diagnosed with DESNOS.

Results

The qualitative results were assessed based on the data collected from the five in-person interviews with the mothers and information provided by them. This information was analyzed individually and in aggregate. Although it was not the original intent of the study to unearth patterns, it became obvious that there were certain symptoms that all children exhibited and other symptoms that none of the children showed. Thus patterns emerged. It became apparent that none (0%) of the children exhibited any signs of the DESNOS symptom "Alterations in Attention or Consciousness." Further over half (55%) of the children displayed symptoms from the "Alterations in Systems of Meaning." These

and the rest of the DESNOS symptoms' are detailed below and are illustrated in Figure 1 (see Figure 1).

Alterations in Regulation of Affect and Impulses. This category detects if an individual has trouble managing their emotional experiences. Actions and difficulties exhibited that are outside the normal development of a child were explored. Outcomes indicate that some children reacted to mild stressors in an exaggerated fashion and needed assistance in calming down (54%). As detailed by one mother whose child is 2-years-old:

“My baby starts to cry hysterically when he goes into a small room. If a door is closed he will do everything he can to open it. If I leave his side for a second he starts lookin’ for me. If he can’t see me he begins to cry and scream..it’s the most terrifying scream you ever heard”.

Other parents indicate that their child is “very jumpy and curious” when a loud noise is made.

When inquiring about risk behavior, parents of the three eldest children (ages: 12, 12, 10) in the sample stated that they had begun disobeying more.

Alterations in Attention of Consciousness. As previously stated, research has shown that in order to qualify as having an altered state of consciousness one must have both amnesia and experience transient dissociative episodes. The researcher asked questions that varied by degree in severity. Questions include: Has your child become more forgetful? Do they have a hard time remembering a certain portion of their life? Have they ever described feeling as if they were outside of their bodies?

Each participant said “no” to all of these questions. They noted that at times their child could be forgetful, but attributed that to normal childhood forgetfulness.

Alterations of Self-Perception. This category is detailed as a child ultimately feeling helpless, damaged, and unwanted. In order to *have* this symptom the children must view themselves differently than they did before the abuse or other interpersonal trauma occurred. According to parent report, 24% of the children exhibited this symptom.

When asked one mom explained:

My kids are now competing for my attention. There is four of them, how am I supposed to do that? I can't be with all of them all of the time, so yeah, I bet they do feel unwanted. And I bet they feel abandoned by their Dad.

One question asked if the child had difficulty taking responsibility for their actions. Two sets of siblings (with 2 siblings each) noted that the oldest children (male: 7, female: 6) blamed the younger children when they got in trouble, which comes into stark contrast when another set of two siblings showed the opposite. The elder sibling, who is a 12 year-old male, feels even more responsibility of taking care of and protecting his younger brother instead of blaming his younger brother for his own wrongs.

Alterations in Relations with Others. When people have been traumatized it often affects how they interact with others. Thirty two percent of the children in this study showed evidence of this symptom. Three out of five mothers answered, “yes” when the question was asked if their children had difficulty trusting and interacting with others. There were variations. One mother noted that her child had fear and mistrust of persons not known before the abuse. Two of the mothers stated that it was only their eldest son

who had difficulty trusting older males. Lastly, one mother described her son as not being able to trust (or be with) anyone besides her and her mother (his grandmother).

When asked if their children victimized others more than half had not (72%). Of those that had (3 out of 11), their intent was questionable. According to one mother, her two eldest girls (ages 12 and 6) display some of the same manipulative behaviors as their father:

My ex used to interrogate my children for information on what I was doing and who I was talking to. He even used to give them money to get information. He bribed them. Now I see my girls manipulatin' people into doing what they want. It's not really obvious, but I can see them laying on the guilt just like their dad used to do to them.. it breaks my heart.

Somatization. Thirty percent of the children displayed some somatization symptoms, although mild to moderate in nature. These include complaining of headaches and/or stomach aches. In these cases the mothers attributed the behavior to the want/need for attention. When asked if their child has become more irritable, impulsive, or aggressive, the mothers offered a wide array of responses. The most common response was that older siblings were more irritated/annoyed/angry with their younger siblings than before the abuse. The moms described this as, "having less patience." Another theme that became apparent was that the elder children were also playing rougher with the younger children, and needed to be reminded to "take it easy." This occurred in four out of the five families interviewed.

Alterations in Systems of Meaning. To begin the questioning under this category the researcher read the following definition of hope to the mothers: "Hope is a belief in a

positive outcome related to events and circumstances in one's life. Hope is feeling that something desired might happen, when the outlook may or may not warrant it." This definition was read as an explanation because this category captures signs of despair and hopelessness. Individuals often see the world through a dark lens, no longer believing in previous sustaining beliefs. According to the parent report, 55% of the eleven children (n = 6) displayed some kind of alteration in systems of meaning.

Most commonly, older siblings had lost hope in their father. They could not imagine things getting better than before the move to the shelter. They did, however; retain hope in their friends and school. School, in particular, is a large driving force. They continually talk about how they are doing in school, what subjects they like, and what they would want to pursue in the future. When asked if any of the children had experienced change in their mood or overall well-being the mom of the two-year-old said:

Deep down, he is still the same boy as before, I can see it, but...but something's changed. He cries all of the time; he used to be such a happy baby. I just wish other people could see him, the way he was before.

Not all of the children's mood and affect has changed this drastically, but most (n= 8) have changed in some way or form. Most have less patience, crave more attention, or get up-set easier.

Alterations in Systems of Meaning (7+ years). Only five of the eleven children were asked three questions related to loss of religion, life aspirations, and helplessness/inability to make decisions. Due to the abstract nature of this question, it

was not appropriate for young children. When asked these three questions 27% of the five children showed some type of alteration.

Typical to un-traumatized children of their same ages, the children interviewed expressed their life aspirations and described having a life dream. If the child had religious beliefs prior to the trauma, none of the children abandoned their faith and several further embraced it (2 out of 3). The 27% comes into effect when the mothers describe their children as being unable to make difficult choices and find options when a solution is needed. They may talk about their dreams, but they have no idea how to attain them.

Discussion

Outcomes from this study indicate that as an aggregate group, these children are experiencing mild symptoms of DESNOS. It is detailed through all of the criteria that initially children are showcasing symptoms that many people might overlook: Such as headaches or less patience. It may be that until the problem is glaring them in the face they won't realize there even is a problem. If a child has to wait that long of a time for a certain symptom to arise, or endure significant of abuse, the child may have already suffered irreversible damage.

It was noted over and over that at times the mothers described their children experiencing symptoms, such as forgetfulness or impatience, but not to the degree of outside the normal realm of childhood. If a child cannot depict exactly how they are feeling it is very difficult to understand and find out how they are coping with the stress of the trauma. It was also mentioned many times that children desired more attention. One of the factors to this is the now-absent father figure. This need began to tax the

mothers because if they have multiple children they continually felt as if they were disappointing one of their children.

Although there were commonalities found in this study, it is pertinent to mention that each child deals with what has happened to them in their own way. Some become shyer, others more driven, and sometimes it is hard to even see a change in their behavior. The researcher chose to highlight here two of the separate families studied.

The first family consists of the mother and her two-year-old son. From the interview the researcher gathered that the abuse began shortly after the mother found out she was pregnant. During the pregnancy the abuse came in the form of name-calling and control issues (wanting to know where mom was all of the time). Once the baby boy was born mom went back to work and dad became a stay-at-home dad. It was then that the abuse escalated. Dad would physically keep mom away from the baby; when he would cry dad would hold him and say, "You don't need mommy, you only need me." Dad continued this behavior, as well as his controlling tendencies, until the boy was a year old.

Mom left with her son when he turned one and a half. She began to notice that his behavior was severely erratic and abnormal. He would cry anytime she left his sights. He would scream and wail when in a small room with the door closed. He would throw his food off his plate and refuse to eat. His speech was not developing appropriately. The only other person he would go to was his grandma (mom's mother). It was then determined that he had severe separation anxiety, which was most likely caused by dad's neglect and abuse.

This family exhibited the most extreme symptoms of any family studied. The other ten children did not exhibit this separation anxiety; they were relatively able to engage in normal day-to-day activity. The one factor that could attribute to such severe separation anxiety would be the age at which he suffered this abuse. The first few years of life are imperative when forming attachments, and if this process is disturbed in any way the child may have difficulty developing healthy attachments.

The second family consists of mom, a 12-year-old girl, 10-year-old boy, 6-year-old girl, and five-year-old girl. The parents were married for 13 years and the abuse started at the beginning of their marriage. Dad controlled all of the money in the family and would, at times, bribe his children for information about their mom (e.g., what she had done that day, who she was with, how long she was there, etc). Dad would interrogate mom for hours, throw bricks through her car windshield so she couldn't leave, and stop her from calling 911. During one specific incident the husband pinned the woman on the bed and was screaming at her. The son jumped on the dad and tried to wrestle him off of his mom. Dad used battering tactics not only when he bribed the children, but when he lied to them and manipulated them as well.

Mom described the 12-year-old and 6-year-old daughters as attention-seeking and manipulative. She believes these girls learned from their father how to lie and pit people against one another. The girls have been sent home from school for fighting, lying, and bullying others. Their brother feels and acts like it is his duty to protect his mother and youngest sister. This family depicts how domestic violence is a cycle; in this case, manipulation is a learned behavior. It is concerning to note that out of the 11 children studied, 2 display behaviors and patterns displayed by their father. Understanding the

cyclical/generational nature of domestic violence allows for concern when children demonstrate at young ages similar patterns of behaviors. Although it is not predictive, it does indicate that these children are being affected during and immediately after the abuse.

This study indicates that these children are victims of domestic violence, and that more longitudinal research is needed in order to fully understand just how these symptoms develop or devolve over time. Prevention and prevention services are critical to prevent cycles of abuse. Children are resilient, but they need support to overcome mild forms of DESNOS. Further, the research shows that relationships were impacted the most from the domestic violence. Healthy relationship practices are crucial to the rest of these children's lives and if support and treatment is not given to them, they may have trouble maintaining positive interpersonal relationships.

Limitations

Although this study's findings help identify some key DESNOS symptoms that traumatized children tend to display, it is not without its limitations. Because the sample size is small (5 women, 11 children) and specific (only from one domestic violence shelter) findings from this study can not be generalized. Another limitation is that the children themselves were not the ones interviewed, but rather their parent/caretaker. This provides some second-hand information and limited the data collected. With no chance to observe the children it was difficult to identify all six symptoms of DESNOS with the research constraint.

While compiling research for this study it became apparent that there was very limited research on DESNOS and children. There have been some studies that have

looked at adults and DESNOS symptoms, but because of the limited research there is little opportunity to compare results. Due to the lack of research and DESNOS being so new as its own diagnosis, it is difficult to compile a list of interview questions that would accurately capture DESNOS symptoms in children. The literature does identify the SIDES scale as accurate, but it had only been tested using teenagers fifteen years and older. As a result, it is inappropriate and premature to generalize the findings to all children who have experienced an interpersonal traumatic event.

Recommendations

Although this study was small in nature, it did produce some interesting and important findings. It became clear through the research that children who experience an interpersonal trauma do exhibit signs and symptoms of DESNOS soon after the traumatic event. There is little research on what kinds of effects these symptoms could have on the traumatized children. As a society we must respond to this lack of understanding and knowledge by further researching the long-term effects caused by DESNOS on children. A replication of this study must be done on a larger scale to increase the understanding and validity of its results. As this type of research will take time, a more prompt and direct way to help these children would be to develop community education and resources.

It might be beneficial to these children to develop a sustainable support group that they can attend to begin to process some of the emotions they are feeling as a result of the trauma. The first important step to developing this support group is to identify a format that not only empowers the children, but also helps them to accept and process what they have experienced. It is also imperative that the support group addresses interpersonal

interactions and relationship issues. It is often found in research that children who grow up in homes of domestic violence often engage in domestic violence as adults.

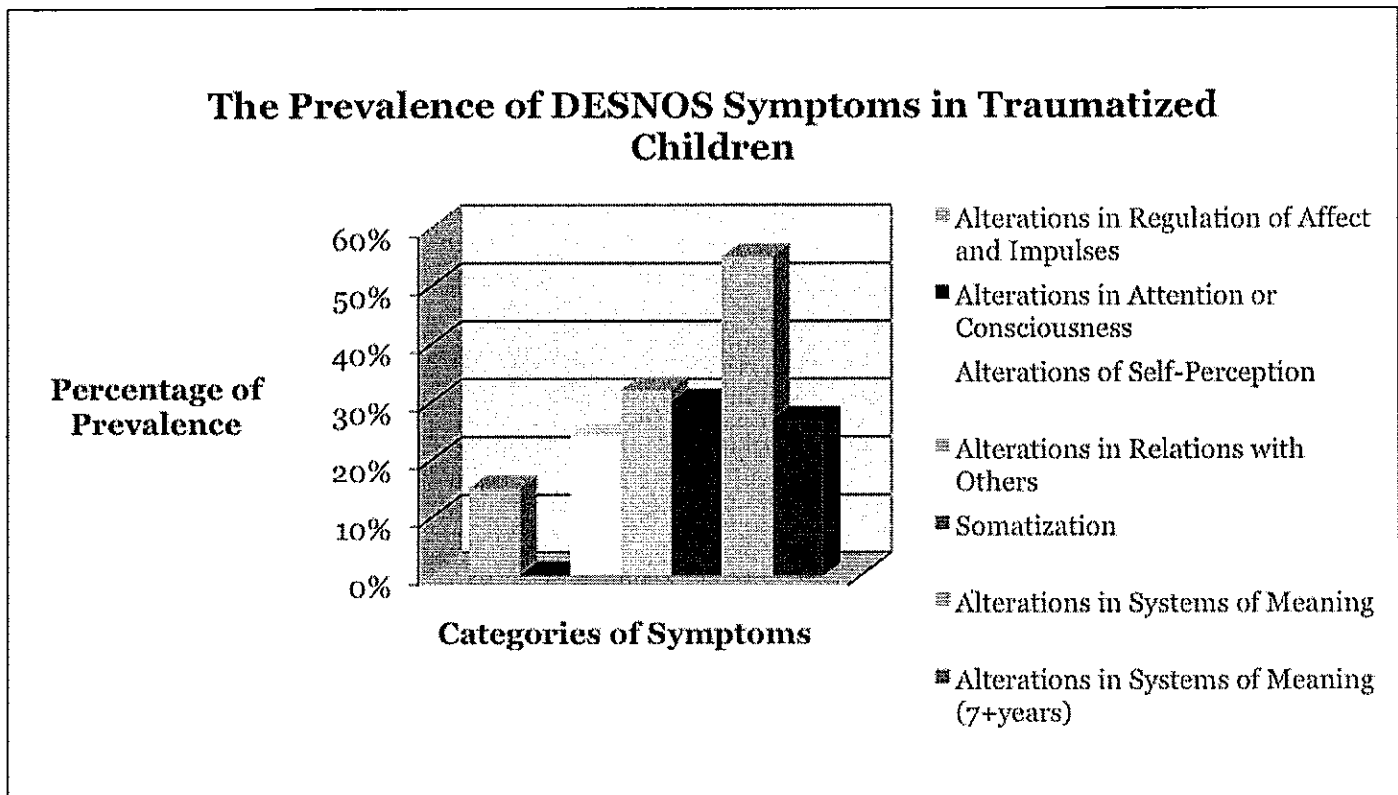
In addition to a support group benefiting the children, it would also benefit them if their caregivers/parents attended some kind of DESNOS awareness program. Their program would focus on how they could provide services and support to their children in order to better help them cope with their interpersonal trauma. By educating caregivers/parents it will better enable the child to develop normally and flourish in everyday life.

Table 1

Socio-Demographic Characteristics Symptoms of DESNOS in Traumatized Children

Socio-Demographic Characteristics	N	%
Gender of children		
Male	6	55%
Female	5	45%
Marital status of mothers		
Divorced	3	60%
Separated	1	20%
Single/Never Married	1	20%
Age of mothers		
26-30	1	20%
31-35	3	60%
36-40	1	20%
Age of children		
0-2 years	1	9%
3-5 years	3	27%
6-8 years	4	36%
9-10 years	2	18%
11-12 years	1	9%
Race/Ethnicity of mom		
Caucasian	2	40%
African American	1	20%
Arabic	2	40%
Race/Ethnicity of dad		
Caucasian	2	40%
African American	2	40%
Arabic	1	20%
Race/Ethnicity of child		
Caucasian	1	9%
African American	4	36%
Arabic	2	13%
Bi-Racial	4	36%
First time in domestic violence shelter		
Yes	4	80%
No (2nd or more time)	1	20%
Length of stay at shelter		
0-2 months	2	40%
3-4 months	2	40%
5-6 months	1	20%

Figure 1



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Appendix A

Introductory Script

Hi, my name is Margot Jagodzinski and I am an undergraduate social work major at Eastern Michigan University. This interview we will be having today is part of my senior thesis project that is designed to look at the relationship between Disorders of Extreme Stress- Not Otherwise Specified (DESNOS) symptoms in children and domestic violence in the home. For a quick overview, DESNOS is more than an anxiety disorder; it involves overwhelming emotional distress, severe disassociation, lack of trust in relationships and in the meaning of life, and chronic health problems that have no medical explanation. DESNOS usually arises after an inter-personal trauma, which means when something happens directly to you by another person, like a hostage situation or child abuse. Some of these questions I am going to ask you may be hard to answer, but with your answers more insight will be gained. This insight will help me and other researchers develop useful coping techniques to help children who exhibit symptoms of DESNOS. Do you have any questions about DESNOS or this study? Let us begin.

Appendix B

Interview Questions

Background Basics

1. How many children do you have? If so, what are their names and ages?
2. Are you married?
3. What made you come to SafeHouse? Is this your first time here?
4. How long have you been at SafeHouse?
5. Are all of your children here with you at SafeHouse?
6. Could you describe a typical day at home for your children?
7. For how many months/years did you endure domestic violence?
8. When domestic violence - specifically verbal, physical, or sexual violence was occurring in your home, was your child ever a direct witness? (saw, heard, etc) How often?
9. Did your child ever experience abuse during the times when violence was targeted at you?
10. Did they experience abuse in incidences not related to the violence you experienced?

Now I would like to ask you about your observations and your child/children. We recognize that when children have experienced a variety of difficult childhood events, they impact the way they react, and cope.

One of the things that might strike you as I ask these questions is that you also may have some of these feelings, reactions or coping strategies. Please know that they are normal responses to difficult life events.

Alteration in Regulation of Affect and Impulses

11. Does your child overreact to minor stressors now? Such as a door slamming?
12. After this overreaction do they have trouble calming themselves down? How do they eventually calm down?
13. Has your child showed any signs of suicidal tendencies?
14. Has your child gotten riskier with their behavior? How so?
15. Has your child showed any evidence of drug use or eating disorders?

Alterations in Attention or Consciousness

16. Has your child become more forgetful? Can you give me an example?
17. Do they appear to space out and lose touch with what is going on around them?
18. Does your child have a hard time remembering a certain portion of their lives? A whole school year or summer?
19. Has your child ever described a feeling that felt as if they were not in their bodies? Like they were watching what their body was doing from outside of it?

Alterations of Self-Perception

20. Do you believe your child has been feeling helpless? Damaged? Or unwanted?
21. Have they expressed any thoughts of having caused this mistreatment to themselves?
22. Does your child have trouble taking responsibility for their current actions?
Describe an instance that this occurred.
23. Have they ever said, “No one understands what I’m going through”?
24. Have they downplayed their recent experiences at home? Do they see the move to SafeHouse as “no big deal?”

Alterations in Relations With Others

25. Has your child exhibited difficulty with trusting others?
26. Does your child allow their friends to bully them? Do they let their friends take advantage of them?
27. Have they tried to victimize others as they have been? If so, please describe.
28. Does it seem to you that your child has a difficult time picking up danger signs?

Somatization

29. Have you noticed your child being more irritable? Impulsive? Aggressive? Please Explain.
30. Has there been a decrease in your child’s physical health?
31. Has there been any increase in the number of stomachaches? Headaches?
32. Have they reported any symptoms for which there is no found physical cause?
This could be a pain in their back, shoulder, or legs that does not go away. Please explain.

Alterations in Systems of Meaning

We are going to continue on with the questions, but first I wanted to give you the definition of hope to keep in mind. Hope is a belief in a positive outcome related to events and circumstances in one's life. Hope is a feeling that something desired might happen, when the outlook may or may not warrant it.

33. Does it seem to you like your child has lost hope? In your family? Your partner? School? Friends?
 34. Have you noticed a difference in your child’s mood and overall well-being before and after the domestic violence? If so, please describe these differences.
- The following three questions will only be asked if their child is older than 7 years old:
35. Have they started questioning their previous religious beliefs?
 36. Does your child ever tell you about their life dreams or aspirations?
 37. Do they seem helpless to you? Unable to make choices, find options, or make changes?

Other Questions

38. Did your child play a lot at home? If so, what kind of play? Has their type of play changed since moving to SafeHouse?
39. Was this the first time you left? If no, how many times have you tried to leave?
40. Does your child say they miss home? Do they talk about home a lot?
41. Does your child seem happy?
42. How often do they cry? (Excluding when they are hurt)
43. Are they still friends with their friends they had before coming to SafeHouse?
44. Does your child sleep more than normal? (8hr/night) Or do they have trouble falling asleep?
45. Does your child ever have nightmares? Are they re-occurring? Could you describe one of the nightmares for me?
46. Does your child have a bedtime?
47. When and if they play house, what types of scenarios do they use?
48. Do they play violent make believe games?

Appendix C

Consent to Participate in Research**Disorders of Extreme Stress—Not Otherwise Specified
Adult Consent Form**

I invite you to participate in a research study by Eastern Michigan University Undergraduate Social Work Student Margot Jagodzinski. Dr. Tana Bridge is the faculty advisor for this study. Your participation in this study is voluntary. You should read the information below, and ask questions about anything you do not understand before deciding whether or not to participate.

- **PURPOSE OF THE STUDY**

The purpose of this study is to further understand the diagnosis of Disorders of Extreme Stress- Not Otherwise Specified that is being proposed to the DSM-V. It is our job as social workers to provide new and updated techniques to our clients, and this study will help give more insight into DESNOS. It will help support program development as it relates to trauma, loss, and coping in children. At the end of my research, interviews, and observations, I will compose all information into an easy to read pamphlet to you and others who visit SafeHouse.

- **DURATION AND LOCATION**

Your participation in this study will last for approximately a one hour. A questionnaire will be read orally to you and your answers written down and recorded on an audio recorder. The interview will take place in a public, but confidential area agreed upon by the researcher and interviewee, (park, library quiet room, etc).

- **PROCEDURE**

If you volunteer to participate in this study, I would ask you to do the following things:

1. Read this consent form and ask any questions you may have. Then proceed to sign the consent form.
2. Respond to the questionnaire read to you, and if you're uncomfortable with any questions, please say skip or indicate that you would rather not answer and the question will not be asked again.

If you indicate that you would like a copy of the completed study, I will be happy to provide a copy for you.

You have the right to choose not to participate in this study. You may also choose to withdraw at any time from the study.

- **CONFIDENTIALITY**

When the results of the research are published or discussed in conferences, no information will be included that would reveal you or your child's identity. Any audiotape recordings of you will be used only for transcription purposes by the interviewer.

Your information will be kept confidential and secure by locking all forms, interviews, and recordings in a file cabinet. You will be identified only by a code number. The list of code numbers with your name will be kept in a separate lock box in a different location with no identifiable information. All data entered into computers will be password protected. This information will be stored for two years and then destroyed.

- **PARTICIPATION AND WITHDRAWAL**

Your participation in this research is voluntary. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time. Lack of participation will not positively or negatively impact your services with SafeHouse.

- **OFFER TO ANSWER QUESTIONS**

If you have any questions about this study, you may call Margot Jagodzinski at 419-340-1041.

If you have research related questions or concerns, you may call Dr. Tana Bridge at (734) 487-3224.

SIGNATURE OF RESEARCH SUBJECT

This research protocol and informed consent document has been reviewed and approved by the Eastern Michigan University CHHS Human Subjects Review Committee for use from _____ to _____. If you have questions about the approval process, please contact:

Dr. George Liepa
(734.487.0077, Chair of CHHS HSRC, chhs_human_subjects@emich.edu)

I have read the information provided above. I have been given an opportunity to ask questions and all of my questions have been answered to my satisfaction. I have been given a copy of this form.

Yes, I agree to participate _____

No, I do not desire to participate _____

I agree to allow the researcher to tape record _____

No, I do not desire this interview to be tape recorded _____

Name of Subject

Signature of Subject

Date