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The Burden of Child Sexual Abuse in Connecticut Emergency Departments, 2011 to 2014

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The Burden of Child Sexual Abuse in Connecticut Emergency Departments, 2011 to 2014

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I.   Introduction

Child sexual abuse (CSA) is a serious and detrimental public health problem in Connecticut and the United States.[1–4] Due to the hidden nature of CSA and difficulty surrounding disclosure[5–11], prevalence estimates are biased, making the true prevalence unknown. Information on the scope of child sexual abuse is predominately garnered from studies using child welfare data, community informants or victim self-report.[6] Variability in study methodology within the literature likely contributes to variable estimates reported[6,12–15], with prevalence estimates ranging from 2% to 62%.[16] Retrospective studies based on self-report suggest that the magnitude of CSA is significantly greater than what is shown by child protective service (CPS) data or informant studies.[17–21] A meta-analysis of 217 publications found the CSA prevalence by self-report studies to be 20.1% (95% CI: 18.1-22.4%) for females and 8.0% (95% CI: 6.2-10.2%) for males in the United States and Canada.[20] In this meta-analysis, self-report studies had 30 times higher total prevalence of CSA (12.7%) than informant studies (0.4%).[20] Additionally, a comparison of adolescent self-reports of abuse with CPS substantiations found that rates of sexual abuse by self-report were 4 to 6 times higher[21], suggesting significant underestimation of rates by CPS. The most recent child welfare data identified 391 substantiated cases of CSA in Connecticut during 2015[1], approximating to 0.05% of the population.[22] In contrast, the last National Survey of Children's Exposure to Violence (NatSCEV), which used telephone interviews to obtain information from children and caregivers, found 5% of children 0-17 years old experienced a sexual offense in the last year.[23] Comparing self-report estimates to informant studies and child welfare data underscores the potential magnitude of under-ascertainment of this problem, and highlights a need to explore other surveillance methods to increase case detection.

Surveillance is vital to combatting CSA because it provides a comprehensive assessment of the magnitude, distribution, and potential determinants of the public health problem.[24] This information can then be used to inform resource allocation, population-level prevention efforts, and policy work.[25]

Hospital-based surveillance of child maltreatment, including sexual abuse, is emerging as an alternative source of data on CSA that may complement other surveillance sources.[26–37] As CSA is complex, surveillance can be optimized by combining data sources[38,39], which may aid in the identification of CSA victims that would otherwise go undetected. Importantly, information compiled from multiple data sources may increase the specificity (true negative rate) and sensitivity (true positive rate) of detection strategies, elucidate demographic characteristics that are pertinent in the identification of victims and inform interventions for children and families in need.

Therefore, the purpose of this project is to provide a comprehensive review of CSA surveillance including case identification and management within the various medical, state and national systems. The report highlights the need for better detection of CSA and how medical data from the Emergency Department holds promise to detect cases through explicit and suggestive medical diagnosis codes for CSA. Our study aims to conducts innovative surveillance on the magnitude and distribution of CSA in Connecticut Emergency Departments (ED) from 2011 to 2014.

II.   Specific Aims

This study seeks to:

1. Calculate the frequency and prevalence of Emergency Department (ED) visits assigned an explicit child sexual abuse (CSA) medical diagnosis code in Connecticut from 2011 to 2014.

2. Examine whether the use of suggestive CSA medical diagnosis codes results in a higher frequency and prevalence estimate.

3. Compare the demographic profile of ED visits with a suggestive CSA code(s) and ED visits with an explicit CSA code only for children <10 years old.

4. Compare the demographic profile of ED visits with an explicit CSA code and ED visits with no CSA code (explicit or suggestive) for children ≤17 years old.

III.   Background

    a.   Scope of the Problem

Child sexual abuse is defined by the Centers for Disease Control and Prevention (CDC) as any "completed or attempted (non-completed) sexual act, sexual contact with, or exploitation (eg, non-contact sexual interaction) of a child by a caregiver."[40] A child is defined as any person age 0 to 17 years old.[40] Caregivers include individuals in a "permanent or temporary custodial role," such as parents, relatives, legal guardians, teachers, coaches, clergy, babysitters and others.[40] Child sexual abuse can also vary in severity, including any attempted or completed sexual act involving penetration (eg, genital to genital contact), any sexual contact with no penetration (eg, intentional touching), or non-contact sexual interaction (eg, pornography, filming, sexual harassment, or commercial sexual exploitation).[40] Child sexual abuse can occur between a child and caregiver, or a caregiver may coerce a child to engage with another person (child or adult).[40]

Child sexual abuse is categorized under the umbrella term of child maltreatment, which encompasses four major forms of abuse: physical abuse, sexual abuse, psychological or emotional abuse, and neglect.[41] Compared to the different forms of child maltreatment, CSA may be of unique concern considering the cumulative impact of traumatic sexualization and associated feelings of betrayal, powerlessness, and stigmatization on a victimized child.[42] Feelings of shame, when mediated by cognitive attributions of self-blame about the abuse can lead to poor psychological adjustment later in life.[43] Sexual abuse with other co-occurring types of maltreatment may exacerbate conditions of poor health, and has previously been associated with heightened risk for negative sexual health outcomes[44], mental health concerns such as depression, anxiety disorder, conduct/anti-social personality disorder, substance dependence, suicidal ideation, suicidal attempts[45], and trauma symptomology.[46] The high frequency of co-occurrence of other forms of maltreatment with sexual abuse makes assessing its independent impact more difficult.[46]

However, after controlling for co-occurring abuse, CSA has been associated with greater risk for internalizing and externalizing behaviors when compared to other forms of child maltreatment.[47]

Child sexual abuse is associated with multiple negative social, behavioral and health outcomes through the lifespan.[48–66] For example, sexually abused children are more likely to suffer from gastrointestinal and gynecological problems, obesity, asthma, fibromyalgia, sexually transmitted infections (STIs), neurological disorders, asymmetrical stress responses, somatization, depression, low self-esteem, headaches, anxiety disorders, eating disorders, post-traumatic stress disorder, substance abuse, suicidality, and maladaptive sexual development.[48–63] Victims are also more likely to be a victim and/or perpetrator of future sexual violence, and to experience adolescent pregnancy, lower educational attainment, and higher rates of healthcare utilization.[48,54,64–70] Given the impact of CSA on numerous health outcomes, more attention needs to be directed towards understanding the scope of the problem and implementing prevention measures.

   b.   Risk Factors of Child Sexual Abuse

An examination of risk factors for child sexual abuse is valuable to consider how victims differ from the general population. This information may inform efforts aimed at identifying CSA victims. Females are considered to be at higher risk of CSA compared to males.[71–73] However, males may be less likely to disclose abuse compared to females, which may partially explain the perceived lower incidence of CSA among males.[74,75] Vulnerable groups of children with physical and mental disabilities have been shown to be at increased risk for CSA.[76–78] Risk of CSA victimization has been shown to increase with age[79,80], and this relationship may affected by the intersection of race and family structure.[81] Familial risk factors include the absence of one or both parents, presence of stepfather, living without a biological parent, poor parenting, and parental conflict.[73,79,80] Evidence about the effect of race and ethnicity on risk of CSA is inconsistent[82,83]; yet, cultural norms may play into a child's willingness to disclose sexual abuse.[84] Neighborhood poverty has been associated with combined outcomes of child maltreatment (physical,

sexual, psychological or emotional and neglect)[85], but the connection between CSA specifically and poverty is not supported.[86] By examining the demographic profile of ED visits with diagnosis medical codes for CSA in the current study, this information will enable comparison between CSA cases identified in the ED and cases identified elsewhere through other methodology.

c. Child Protective Services

National child welfare data is obtained from state-based child protective service (CPS) agencies and is typically considered the official source for child maltreatment surveillance. Therefore, it is important to understand the process of how CPS agencies become involved in cases of child maltreatment. Each U.S. state has a governmental system requiring the reporting of suspected child maltreatment, including sexual abuse, to a CPS agency.[1] In 2015, professionals made the majority of referrals (63.4%); including educational personnel (18.4%), legal and law enforcement personnel (18.2), social services professionals (10.9%), medical professionals (9.1%), mental health personnel (5.8%), child daycare providers (0.6%), and foster care providers (0.4%).[1] After referral, the agency will either screen-in or screen-out the case. When the case is screened-in, it becomes an official report to CPS and will receive either an investigation or alternative response.[1] An investigation determines evidence of maltreatment or risk of maltreatment, whereas an alternative response is a family-centric approach that does not seek to determine maltreatment or future risk.[1] In Connecticut and other U.S. states, the alternative response option is not considered appropriate for CSA and CSA cases should receive an investigation only.[87,88] Lastly, if the investigative process reveals evidence of maltreatment, then the case is considered to be substantiated.

d. Current Major Forms of Surveillance

The National Child Abuse and Neglect Data System (NCANDS) is a voluntary and federally sponsored surveillance system that integrates child maltreatment data from all 50 U.S. states, the District

of Columbia and Puerto Rico.[1] Annually, child protective services (CPS) data on state-specific counts of child maltreatment reports and substantiations are collected, analyzed and disseminated by the NCANDS. The minimum definition for child maltreatment to be used by state-based CPS agencies is established by the Child Abuse and Prevention Act (CAPTA) (42 U.S.C.§5101)[89], as amended by the CAPTA Reauthorization Act of 2010 (P.L. 111-320). The objective of the NCANDS is be able to systematically track the magnitude and characteristics of all child maltreatment cases reported to child welfare services in the U.S each year. This information provides a basis for subsequent secondary analyses and generates a number of publications or reports, including reports to Congress and the *Child Maltreatment* report series. NCANDS data points include report characteristics, victim and perpetrator demographics, maltreatment types, fatalities, risk factors for child and caregiver, and services provided. During 2015, the NCANDS found 57 286 cases of CSA were substantiated in the United States; 391 of these cases occurred in Connecticut.[1] However, the *Child Maltreatment* 2015 report does not provide demographic information by maltreatment type; therefore, more specific information on CSA beyond case count can only be identified by access to and analysis of the raw data.

A major limitation of the NCANDS is that many CSA victims are never identified by CPS, and consequently are not represented in the data.[5,8,21] For example, a retrospective study based on self-report found that less than 10% of former CSA victims had contact with CPS.[8] Furthermore, involvement was associated with younger age and lower socioeconomic status, suggesting that CPS data may be biased towards a particular subset of cases.[8] Importantly, the NCANDS data includes only cases that receive an investigation or alternative response, which likely represent only the most severe cases.[1,6] In Connecticut, more than half (55.7%) of referrals for child maltreatment (all types) were screened-out from receiving a response in 2015[1], although they had raised sufficient suspicion for a referral. Despite the suspicion of abuse, characteristics of the victimization may affect the likelihood of a case receiving a response by CPS. Demographic and circumstantial factors may also affect the substantiation process, with one study finding a higher proportion of substantiations with female victims and when the source was a mandated

reporter.[90] As a consequence of being reliant on CPS data, NCANDS misses CSA victims, with a lack of sensitivity leading to underestimation of the full scope of CSA.

Additionally, in order for a case of child maltreatment to come to the attention of a CPS agency, there must be reasonable suspicion of abuse. The most common way that suspicion is generated is through disclosure by the child.[91] Consequently, the opportunity for detection and provision of services by CPS is diminished when disclosure is impeded. This is problematic for surveillance purposes as non-disclosure among CSA victims is very common.[92,93] A study by Smith et al[5] on severe sexual abuse found that 47% of study participants never disclosed for over 5 years post-rape, and a separate 28% never disclosed to anyone prior to the study period. Qualitative studies have found that victims do not disclose for a variety of reasons including incomprehension, social stigma, cultural norms, fear of repercussions for the family, unequal power dynamics, weak social networks, and lack of opportunity to disclose.[9–11] Moreover, victim characteristics, such as younger age and familiarity with the perpetrator, have been shown to independently predict a delayed disclosure.[5] Research on systematic differences between disclosers and non-disclosers supports that not disclosing is associated with younger age[94–96], and also the occurrence of severe sexual abuse.[97,98] Therefore, non-disclosing CSA victims who suffer injuries due to the severity of sexual abuse may have a higher chance of detection by the presence of physical symptoms in the Emergency Department (ED). Altogether, these prior studies show evidence that data based on CPS reports may miss or bias the detection of cases[5,6,8,21,90], and medical records from Emergency Department data may provide an alternative method to identify and gain information on the undetected cases.

A number of procedural or administrative attributes of the NCANDS exist that may limit its consistency of data collection and completeness of data. For example, CPS agencies are not mandated to report their information to NCANDS, leading to an inconsistent number of agencies reporting each year.[99] The type of information reported also varies, as some agencies report data on all cases referred for suspected abuse and some report only on substantiated cases. Although there are minimum requirements for the definition of child maltreatment (P.L. 111-320)[89], there is still variability in definitions among CPS agencies.[99] Inconsistent data sources and operational definitions complicate comparisons across agencies,

states, and time.[99] Additionally, child protective services data has indicated a recent decline in CSA[1,100–102], which may be a true decline in occurrence, or alternatively, may be a consequence of procedural changes that created the appearance of decline. When questioned about underlying factors contributing to past periods of decline, CPS officials have cited both a true decline brought on by advancements in prevention efforts, as well as alternative reasons for an artificial decline.[103] These reasons included caution due to legal ramifications for caregivers, increased thresholds for investigation and higher substantiation requirements.[103] Without attention and consideration to these process changes, interpretation of trends is compromised. In previous reports, the NCANDS did not take these external, systemic factors robustly into consideration[104], which negatively affected completeness of detection. These studies suggest that procedural or administrative shortcomings of NCANDS may affect the accuracy of detection, and further justify the need for more comprehensive surveillance approaches.

The National Incidence Study of Child Abuse and Neglect (NIS) is another congressionally mandated study which aims to determine the incidence of child maltreatment, including CSA, in the United States.[105] Unlike NCANDS data which relies exclusively on CPS reports, the NIS study includes data on both cases that were involved and not involved with CPS.[106] For NIS-4, which was the last cycle of the NIS, information was collected from a nationally-representative sample of 122 counties, comprising 126 local CPS agencies, and 1094 community agencies during a 3 month study period.[106] To identify additional children who did not receive a referral, or were screened-out or unsubstantiated by CPS, the NIS employed community informants or "sentinels" to lookout for victims of suspected child maltreatment.[106] Eligible sentinels were routinely in contact with children and families by the nature of their work and included professionals such as police, teachers, social workers, nurses, and child care providers. To maintain consistency across CPS agencies and sentinels, information from data forms was compared against standard definitions for child abuse and neglect.[106] After data collection was complete, the data was unduplicated to avoid over counting by data source, weighted to reflect national estimates and annualized to provide yearly estimates from the 3-month period.[106]

Despite the advantages of a sentinel survey methodology to ascertain cases undetected by CPS, the NIS has noteworthy limitations that affect completeness of data collection. The NIS could still miss cases which are not directly identified by sentinels, which may be limited by a lack of disclosure by the child, sentinel's attention bias, index of suspicion, and the scope of interaction with the child. Additionally, the last cycle, NIS-4, was produced over a decade ago, and there were large time lapses between previous periods of data collection (~6-12 years). Therefore, the NIS is not able to compare time trends annually, and has limited applicability as an active surveillance source. Unlike the NCANDS which reports on true counts of reports, NIS study methodology involves the selection of a nationally representative sample, which is then weighted and annualized to give an estimate of the total number of maltreated children in the U.S. in one year.[6] As a result, the NIS provides a calculated estimate of child maltreatment by nationally representative data but does not offer information on the actual state-specific counts of abuse per year, limiting the use of the results to inform local public health activities. Lastly, out of all hospitals that were invited to participate in the NIS-4 study, 68% of hospitals provided data[106], which was weighted to a 81% participation rate. Although the majority of hospitals responded, valuable information could be missing from hospitals that did not respond and could otherwise be captured by hospital-based surveillance.

      e.   Surveillance in the Emergency Department

The ED is acknowledged as a frequent means of entry to an integrated system of health care, social work support, and CPS and/or law enforcement for victims.[107] It is proposed that allegations of sexual abuse present to the ED in four ways: (1) a disclosure of abuse; (2) a CPS or law enforcement referral for medical evaluation, evidence collection or crisis management; (3) behavioral or physical symptoms suspicious for CSA; or (4) the child presents with an unrelated complaint and further evaluation reveals additional behavioral/physical signs of abuse.[108] The ED provides a unique opportunity to conduct an evaluation for the child and detect abuse-related injuries or medical conditions.

The American Academy of Pediatrics has stated that sexually abused children are more likely to present to a pediatrician after a direct disclosure to another person and less commonly for abuse-related medical symptoms.[109] Although medical symptoms are understood to represent a small number of CSA cases[91,110–112], they are still highly relevant to victim identification.[108,113–115] Healthcare settings remain the proper place for an assessment of any abnormal injuries and other medical conditions. Additionally, medical interview, which occurs in the healthcare setting, is considered crucial to the identification of victims.[116,117] For example, the medical interview can uncover information on past episodes of sexual abuse, physical symptoms (eg, ano-genital pain, bleeding, itching discharge, painful urination or defecation), psychological or emotional symptoms (eg, depression or suicidal ideation), changes in behavior (depression, sleep or diet changes), social conditions (eg, changes in peer relationships or family dynamics).[107] An analysis of factors associated with the likelihood of disclosure in a medical interview included older age, presence of sibling at home, history of oral-genital sex, penetration and/or past disclosures, positive physical findings, and if the interview was conducted by the physician or nurse who performed the physical examination.[95] Therefore, health care providers may have an advantage over social workers or psychologists when interviewing children and may be more likely to encourage a disclosure of sexual abuse.

The ED setting may also be an ideal place to detect victims because medical records encompass a large pediatric patient population. In 2012, children visited Connecticut EDs at a rate of 406 visits per 1,000 children under 18 years old.[118] Therefore, a victim may visit the ED for either CSA-related or un-related symptoms and be detected. Besides the acute nature of an injury or medical condition, other factors that increase ED utilization and thus may aid detection include lack of access to primary care and location proximity.[119] As mandated reporters, medical professionals in the ED have an opportunity to identify CSA victims in a safe, resource-intensive environment.[120] Physicians are generally viewed as honest professionals that maintain high ethical standards[121], and act in the best interest of their patients.[122] Therefore, a physician's relationship with patients and families may foster a unique opportunity for disclosure. Additionally, individuals with a history of CSA have been shown to be more likely to use the

ED than the general population[123–125], suggesting that the ED may be an opportune place to identify current or former victims.

The literature demonstrates an association between CSA victimization and medical utilization, particularly with co-occurring physical abuse. In a study by Walker et al,[123] female HMO members who reported CSA were almost twice as likely to visit the ED compared to non-maltreated (8.4% vs 4.4%; OR=1.91; 95% CI: 1.33-2.73; $P < .001$). Additionally, victims of substantiated CSA had higher rates of ED visits (5.1 visits per 10 000 days) compared to non-abused controls (3.9 visits per 10 000 days).[124] When evaluating co-occurring abuse types, it was found that women with a history of both physical and sexual child abuse were at higher risk for ED utilization (RR=1.86; 95% CI: 1.47-2.35) compared to women with no history.[125] However, women with only CSA ED utilization were not at higher risk (RR=1.16; 95% CI: 0.97-1.40)[125], suggesting poly-victimization increases risk for ED utilization. Depending on the time frame of abuse and resulting symptomology, increased ED utilization by CSA victims may provide an opportunity to detect current victims and interrupt ongoing abuse. Additionally, a review of hospital-based child maltreatment surveillance found that physical and sexual abuse were more frequently identified abuse types as compared to neglect and psychological abuse.[37] As mentioned by Karatekin et al[37], this distribution among child maltreatment types is not typically seen by self-report/informant studies[1,20], supporting the notion that the ED is an appropriate setting to surveille for child sexual abuse.

Surveillance in the ED has the potential to address some of the drawbacks of the child welfare data. Suspected cases of CSA detected in the hospital should be reported to CPS, but are not necessarily substantiated, as substantiation may be selective of only the most severe cases.[6] A study linking medical records to CPS data found that medical records increased case detection by 12%, and the majority of these newly identified cases were unsubstantiated (70.3%).[30] Results suggest that medical data may provide new information on this group of non-substantiated CSA cases, adding information that is not available through NCANDS. CPS data may also disproportionally represent certain demographic groups, and evaluation of the same characteristics with medical data may uncover unique subsets of the CSA

population. A study comparing CPS and medical data of child maltreatment victims (all types) found that the medical data (hospital and ED) identified 585 unique maltreatment cases (56% of all medical cases of child maltreatment), and proportionally more children who were African American ($P < .001$), physically abused ($P < .001$), and from urban geographic areas ($P < .001$) compared to substantiated CPS cases.[30] This discrepancy suggests that hospitals and CPS agencies detect children from different demographic backgrounds, and that surveillance of both data may increase overall detection.

f.   Clinical Management & Evaluation of Child Sexual Abuse

Given the rate of CSA in the U.S. population[20], pediatric clinicians will likely treat a child who is sexually abused during their clinical practice.[108] In order to detect CSA when present, clinicians need to be able to routinely identify children who are suspected or at risk for sexual abuse. Identification is contingent on index of suspicion, clinical knowledge and skills to identify suspected CSA. Subsequently, to be able to evaluate a child for sexual abuse, clinicians need to possess adequate skills and experience to conduct an evaluation for CSA, including obtaining an oral history, conducting a physical examination and performing laboratory tests (if indicated).[109,117] The knowledge required to appropriately provide a medical evaluation includes an understanding of normal and abnormal sexual behaviors, physical symptoms of sexual abuse, accurate identification and interpretation of physical findings and the potential need for diagnostic testing for STIs.[109] Factors that may indicate need for sexually transmitted infection testing include child disclosure of contact sexual abuse, genital and/or anal discharge, unexplained genital and/or anal injury, and known or suspected contact with infected perpetrator.[126] If untrained in this evaluation, clinicians need to know how to respond to suspected CSA by reporting the case to CPS and referring the child for evaluation by another medical professional with appropriate expertise.[109]

Pediatric clinicians play a vital role in the identification and treatment of suspected child sexual abuse.[117] However, considering that these cases can be extremely sensitive and clinically complex, pediatric clinicians are faced with many challenges with the initial detection of CSA and the subsequent

clinical and administrative decision-making process. Many pediatric clinicians lack the scientific knowledge and do not feel clinically prepared to provide the appropriate medical assessments.[108,127–130] Clinicians do not always receive formal specialized training in child abuse, which has been linked to under-reporting, over-reporting and misdiagnosis of abuse.[131–134] For example, a survey of 139 pediatric chief residents found that one-half of respondents viewed their professional training in CSA as inadequate for clinical practice, and one-third were unable to accurately label genital anatomy (hymen) in a photograph.[128] Pediatricians also have been shown to misjudge the magnitude of child maltreatment and do not consistently screen for adverse childhood experiences.[135,136] Although clinicians may not recognize infections, injuries and/or other medical conditions as suggestive of sexual abuse, they are obligated to document any findings in the medical record. Therefore, the use of suggestive medical diagnosis codes, in addition to the explicit code, may capture a broader range of cases in the current study.

Clinicians must also decide if a report to CPS or referral to another medical professional for a medical evaluation is warranted, which can be a difficult decision. The concept of "reasonable suspicion" is not entirely straight-forward, as varied interpretations have been observed among medical specialties[137], and even child abuse clinical and research experts.[138] Alternatively, even when a physician identifies the social circumstance or medical condition as suspicious for abuse, they may not involve CPS.[139] Despite their professional responsibility as mandated reporters[120], medical providers do not always report cases of suspected abuse and may prefer alternative management strategies for children.[139] Providers may fail to report to CPS due to the additional time it requires, lack of experience, confidence or training in the reporting process, previous experience with CPS, reluctance due to legal ramifications and/or perceived negative consequences for themselves, patients and families.[132,140,141] In 2015, 9.1% of CPS reports came from medical professionals, a lower percentage than those from social services, education, and legal and law sectors.[1] Suspected cases that are not reported to CPS are excluded from official statistics from the NCANDS or NIS studies, but may be identified by medical diagnosis codes in medical data.

g. Clinical Management of Child Sexual Abuse in Connecticut

In Connecticut, there are two Child Abuse Centers of Excellence located at Connecticut

Children's Medical Center (CCMC) and Yale New Haven Hospital that provide expert services in the

evaluation and treatment of CSA victims.[142] At these centers, specialized clinicians provide in-patient and

out-patient medical services to children and families, participate in routine child abuse team meetings to

review medical records, collaborate with community multidisciplinary teams, consult on cases with

community providers, and provide training and educational outreach.[142] Other Connecticut health care

facilities can contact the Centers of Excellence to request consultation for the management of sexual

abuse cases, which depending on the circumstance, may lead to a referral (oral communication with Dr.

Livingston). In addition to the Centers of Excellence, there are several practicing physicians in the state

who serve as regional sexual abuse medical examiners, providing outpatient sexual abuse evaluations and

participating with regional multidisciplinary teams. These physicians collaborate with providers at the

Child Abuse Centers of Excellence for regular statewide peer review activities. Given the small number

of specialized providers at limited locations, resources are concentrated in particular areas and are not

universally distributed across the state.

There are a select number of health care facilities across the state that have memorandums of

understanding with the Office of Victim Services (OVS) to provide on-call specialized services to victims

of acute sexual assault (Appendix A, Table 1).[143] The OVS is based out of the State of Connecticut

Judicial Branch and provides forensic exams through the SAFE program, which stands for sexual assault

forensic examiner.[143] To be eligible for the SAFE program, patients need to be 13 years or older, consent

for a forensic exam and evidence collection, and must visit a participating health care facilities within 120

hours of the sexual assault.[143]

If deemed appropriate for the child, the examining physician, nurse, SAFE or SANE (sexual

assault nurse examiner) will perform a Sexual Assault Evidence Collection Kit (CT100) and complete a

Sexual Assault Medical Report Form (CT100) to be added to the patient's medical record (CGS §19a-

112a).[144] In 2013, the State of Connecticut updated the technical guidelines for the health care response to victims of sexual assault. The guidelines provide detailed instructions on sexual assault evidence collection, guidelines for toxicology screening, the documentation process and billing requirements.[145] Most children and adolescents seen in an ED for acute evaluation are referred for follow up to one of the expert examiners noted above. By law, victims of sexual assault cannot be billed for a sexual assault forensic exam and evidence collection and payment is covered by state funding through the OVS (CGS §19a-112a).[144] Victims of acute sexual assault under the age of 13 years old who need evidence collection performed are not eligible for the SAFE program and require a referral to the Emergency Department at one of the Centers of Excellence (Connecticut Children's or Yale).

In conjunction with medical clinicians, child advocacy centers (CACs) play a crucial role in the investigation and care of CSA victims. Children with suspected sexual abuse may first present to the ED and then be referred to a CAC for a forensic interview. Otherwise, a child may first make contact with a CAC (referred by CPS or law enforcement) and then receive referral from the CAC to one of the specialized medical providers for evaluation and treatment (oral communication with Dr. Livingston). Medical providers are not directly responsible for the forensic interview, which is typically conducted by a forensic interviewer, CPS or law enforcement[107]; however, within the clinical setting, medical providers will ascertain a medical history during a medical evaluation which may include a conversation with the child and may provide additional information relevant to both medical care and to the investigative proceedings.[107] Children who initially make contact with a CAC and do not visit the ED will not be ascertained by ED surveillance, a limitation to measuring the rate of CSA solely in EDs.

h.   Medical Diagnosis Codes as a Surveillance Tool

In clinical practice, the International Classification of Disease (ICD), Clinical Modification (CM) system functions primarily to identify injury or disease diagnoses for billing purposes in health care settings.[146] Although the ICD coding scheme was not created for the purposes of surveillance, it has the

capacity to function as a surveillance tool by providing information on the scope of child maltreatment and trends over time for those seeking medical care.[147] ICD diagnosis codes are used ubiquitously in U.S. health care settings, and are applied to visits in a routine and timely manner. The usefulness of ICD codes for CSA surveillance is contingent on a combination of clinicians identifying and documenting CSA in a medical record, and the accuracy of coding by medical coders. During the timeframe of this study, hospital coders assigned ICD-9-CM codes to medical records based on the information included in the medical record by the clinician.[146] Importantly for the current study, ICD-9-CM diagnosis codes for child maltreatment (995.50-995.59), including sexual abuse (995.53), already exist in the system.[148]

The Ninth Revision of ICD codes (ICD-9-CM) was used to document diagnoses prior to October 2015.[149] Although ICD-9-CM are not currently used in hospitals, former medical records can be useful to explore the benefits of medical data as a surveillance tool. Researchers can also use ICD-9-CM codes for passive surveillance to estimate CSA rates, describe patterns longitudinally, and identify associated medical conditions and injuries.[147] Types of ICD-9-CM codes include 5-digit numeric codes which describe the general category (eg, illness, injury or disease), and additional specific information (eg, type, location and severity).[150] There are also two alphanumeric codes: (1) E-codes ("external causes of injury and poisoning") and (2) V-codes ("supplementary classification of factors influencing health status and contact with health services").[151]

Despite the potential for ICD codes to contribute to child maltreatment surveillance, their validity as a surveillance tool is not well established in the literature.[28,37,147] The latest research exploring the feasibility of using ICD codes in child maltreatment surveillance is varied in methodology by the specific codes that are applied, and the evaluation of separate maltreatment type, health care setting (eg, in-patient versus ED), age range, sample selection and other descriptive measures (eg, sex, race/ethnicity, income).[26–36] A review of the literature on hospital-based surveillance of child maltreatment by Karatekin et al[37] found that total child maltreatment-related codes were found in <1% of ED visit and hospitalization records, suggesting either a true low number of CSA victims in EDs or under-ascertainment. Under-ascertainment could result from both human and administrative factors, including: a lack of identification and

documentation by clinicians and/or the limited nature of the explicit code to fully capture the scope of CSA cases. Medical coders are professionally trained to convert notes in the medical record to ICD codes based upon a standardized guideline to ensure consistent application.[147] However, if the pediatric clinician is unable to accurately identify and document CSA, the medical coder cannot apply an explicit maltreatment code to the visit. Additionally, if the determination of abuse is made after visit discharge, then the diagnosis code cannot be applied in a timely manner. Therefore, identification of cases by codes that are suggestive of CSA may be needed to increase the sensitivity (true positive rate) of detection.

Medical diagnosis codes need to be both sensitive and specific enough to accurately characterize the population of CSA victims.[152] Sensitivity is defined as the percentage of correctly identified positive cases (true positives) out of all positive cases (true positives and false negatives) (TP/TP+FN). Whereas specificity is defined as the percentage of correctly identified negative cases (true negatives) out of all negative cases (true negatives and false positives) (TN/TN+FP). There is evidence to suggest that ICD-9-CM codes for maltreatment are more specific than sensitive.[30,36,153–155] Considering that medical professionals need to document definitive evidence of CSA in the medical record in order for the explicit code to be assigned[152], they likely exercise caution and under-document cases that are not clear or certain. Therefore, the strict criteria of the explicit CSA code limits identification of all true positive cases (lower sensitivity). However, when an explicit CSA code is applied, it is highly likely to be true CSA and not a false positive (higher specificity). One study reviewing 127 cases coded for maltreatment found that 110 (87%) contained documentation of current maltreatment in the medical record and the remaining 17 (13%) had codes for past maltreatment (100% in total)[30], demonstrating high agreement between a positive test for abuse (code applied) and presence of abuse. Since there were no false positives, this finding indicates higher specificity of maltreatment codes. However, when evidence for CSA is hidden, ambiguous or unconfirmed, the visit may not receive an explicit code, despite the existence of abuse (false negative). For example, one study by Winn et al[153] found that one-quarter (17 of 67) of violence-related cases did not contain the corresponding E-code; they concluded that E-codes for violence were highly specific (99.7%; 95% CI: 99.2-99.9%) but less sensitive (74.6%; 95% CI: 64.1-84.5%). Similar

research by Hooft et al[154] comparing ICD-9-CM codes for physical abuse and records from child abuse pediatrician evaluations, also found ICD-9-CM codes to be more specific (92.4%; 95% CI: 90.0-94.0%) than sensitive (73.5%; 95% CI: 68.2-78.4%). In consideration of the potential for false negatives, the explicit code for CSA is likely insufficient for complete case identification. Additional suggestive codes may be needed to increase the sensitivity of detection. As suggestive codes have less selective criteria, they likely will increase the rate of true positives (sensitivity) but decrease the rate of true negatives (specificity).

i. Suggestive Codes for Child Sexual Abuse

In recognizing the limitations of explicit child maltreatment codes, Schnitzer et al[29] sought to identify and validate a set of suggestive ICD-9-CM codes for CSA intended to increase the sensitivity of detection. In this study, a listing of ICD-9-CM codes that could indicate child maltreatment was formulated through a literature search and guidance from a panel of child abuse and neglect specialists.[29] Additional co-occurring exclusion codes and age qualifiers were paired with suggestive codes to minimize misclassification of non-abusive injuries and illnesses as maltreatment-related. For example, cases with the co-occurring codes for contusion of genital organs and bleeding disorders were removed, considering that a bleeding disorder could cause bruising un-related to abuse.[29] A statewide database containing hospital discharges and ED visits was searched to identify visits meeting the inclusion and exclusion criteria (n=3,684). Medical records for all cases were reviewed by project staff possessing training in research methodology, child maltreatment and data abstraction. Cases were classified by project staff as probable, possible and not likely child maltreatment based on a former categorization scheme by Ewigman et al.[156] Operational definitions were assigned to the three categories (probable, possible and not likely maltreatment) to ensure consistent application of the categories to cases. An ICD-9-CM code was determined to be suggestive of CSA if more than 66% of visits were classified as probable or possible maltreatment, an *a priori* determination made by the authors to indicate a clear

majority. Schnitzer et al[29] identified 68 ICD-9-CM codes, including 5 specific CSA codes, that met the criteria for suggestive of child maltreatment. Suggestive codes for CSA included codes for sexually transmitted infections (eg, genital herpes) and other medical conditions (eg, pelvic inflammatory disease). Considering that each code needed to meet a threshold of 66% of cases being probable or possible of maltreatment, suggestive codes may be less specific and more sensitive than explicit codes. Following this logic, suggestive codes would identify more true positive cases, but may also incorrectly identify more negative cases as positives (false positives). The benefit for surveillance is that suggestive codes, in combination with the explicit code, have the potential to detect CSA in a more comprehensive manner.

The suggestive codes identified in the Schnitzer et al[29] paper have since been applied to national samples of medical records to describe child maltreatment, suggesting their ability to identify additional cases compared to explicit codes alone. King et al[27] examined the Nationwide Emergency Department Sample (NEDS), a nationally representative sample of ED visits, to identify maltreatment-related ED visits of children ≤3 years old from 2006 to 2011. This study identified an annual average of 12 000 ED visits that were suggestive of CSA, which was weighted to represent national estimates.[27] For cases with an explicit CSA code, the probability of sexual abuse increased with age ($P < .01$) and for female sex ($P < .01$).[27] Rates of sexual abuse were found to be relatively low compared to the other abuse forms (3.3% of total maltreatment; n=1,990). As noted by King et al[27], this finding is likely due to the limited age range (0 to 3 years), as CSA risk increases with age.[73] A different study was conducted by Suglia et al[98] using the suggestive codes which aimed to describe time trends for multiple maltreatment forms (physical, sexual, neglect, poly-victimization) of the NEDS data. This study compared secular trends in the number of ED visits assigned a suggestive compared to an explicit code.[157] They found that the prevalence of suggestive child maltreatment stayed constant (3.39% of all ED patients) from 2007 to 2013, while explicit maltreatment declined (1.13% to 0.98%).[157] Additional studies have applied codes for abuse-related injuries to evaluate rates of physical abuse[26,36]; however, less work has been conducted to examine the prevalence of CSA by suggestive ICD-9-CM codes in the ED. Therefore, this gap in the literature provides justification for the current study.

This study will first seek to determine the frequency and prevalence of visits coded with an explicit or suggestive (no explicit) ICD-9-CM code for CSA in Connecticut Emergency Departments from 2011 to 2014. Next, this study will determine whether the use of suggestive codes, in addition to the explicit code, increases detection of new cases. Although there is an existing body of literature that has used ICD-9-CM explicit child maltreatment codes to describe rates of CSA[30–34,37], less research has been conducted on rates of CSA using both explicit and suggestive codes.[27,157] Since the capability of CSA suggestive codes to identify suggestive cases is not well established, this study will contribute to the literature in this manner. Additionally, comparing the demographic profiles of visits with an explicit and suggestive CSA code (no explicit) may uncover differences between these groups, suggesting that the use of suggestive codes could result in ascertainment of a more complete and representative set of CSA cases. Furthermore, a comparison of the demographic profiles between ED visits with an explicit CSA code and ED visits with no CSA code (non-CSA) may provide insight on patient characteristics as indicators for abuse. Identifying patient characteristics that are more frequently associated with CSA in the ED may contribute to an early understanding of victim risk factors. Prospectively, this information could be used to determine risk of child sexual abuse and aid identification victims in the Emergency Department. Altogether, this analysis will provide information on the burden of CSA in Connecticut Emergency Departments and may support the need for and feasibility of ED-based surveillance.

IV.   Methodology

The current research involved a retrospective secondary data analysis of ED non-admission visits in Connecticut from 2011 to 2014. The Connecticut Hospital Association routinely collects and tabulates data annually on in-patient admissions and ED non-admissions from 27 acute care hospitals statewide (Appendix A, Table 2). The CHIME dataset from 2011 to 2014 was the basis for the work presented here on ED non-admissions. The database contains information from almost every non-federal acute care hospital in the state, and therefore is considered representative of state ED utilization. Visits with non-

Connecticut zip codes were removed from the sample to isolate the state-specific burden. Relevant information contained within the database includes (1) patient characteristics (e.g. age, sex, race/ethnicity, town, zip code, insurance type) and (2) medical diagnosis codes. Each ED visit is assigned up to ten medical diagnosis codes (DX1-DX10). For this study, the database was provided by the Injury Prevention Center (IPC) at Connecticut Children's Medical Center. This work is complementary to research on the other forms of child maltreatment (neglect, physical and psychological or emotional abuse) at the IPC.

The three study groups (explicit, suggestive and non-CSA) were selected from all Connecticut ED visits during 2011 to 2014. The codes considered explicit for and suggestive of CSA can be seen in Appendix B, Table 1. To be included in the explicit code group, the medical record of the ED visit had to possess the explicit code for CSA and the patient had to be 0 to 17 years old, consistent with the CDC's definition of child maltreatment.[40] To be included in the suggestive code group, the medical record of the visit had to possess a suggestive code for CSA and the patient had to be younger than 10 years old. This age qualifier is consistent with the original study that identified and validated the suggestive codes of CSA in this age group[29], and may minimize instances of consensual youth sexual relationships, peer sexual assaults, and dating violence, which do not constitute CSA. The CDC and CAPTA (42 U.S.C §5101) definition also specify that the perpetrator of CSA must be an adult or caregiver.[1,40] To minimize misclassification of suggestive CSA, ED visits with a co-occurring exclusion codes were removed from the sample of study. For example, a child assigned a code for genital herpes (054.1) would be excluded in the presence of code 771.2 (other congenital infections specified to the perinatal period), indicating that infection was acquired at or around the time of birth. The relevant co-occurring exclusion code(s) for each suggestive code can be found in Appendix B, Table 1.

The demographic variables were operationalized in the following manner. Age was categorized into three groups (< 5, 5-11 and 12-17 years old) based on the 2000 projected age distribution by the National Center for Health Statistics.[158] Race and ethnicity were combined and categorized into four groups (White, Black/African American, Hispanic and other). The other category included American Indian or Alaska Native, Native Hawaiian or Pacific Islander, and other unidentified. Sex was defined as

a binary variable (male or female). Insurance type was categorized into four groups: (1) self-pay, (2) private (commercial insurance, Champus/Tricare, Blue Cross and HMO), (3) public/federal (Charter Oak, Medicare, Medicaid, Medicaid Advantage, Title V, PPO and other federal program), and (4) other. Town group was categorized into five groups (suburban, rural, urban periphery, urban core and wealthy) based on the "Five Connecticuts" classification originated by the Center for Population Research at the University of Connecticut[159], and recently updated using 2010 census data (provided by DataHaven).

Descriptive statistics of the population were calculated using frequency and prevalence distributions. Prevalence rates were calculated by dividing the number of visits assigned an explicit CSA code by the total number of ED visits of children aged 17 years old and younger. For the suggestive codes, prevalence rates were calculated by dividing the number of visits coded as suggestive of CSA (without an explicit code) by the total number of ED visits of children under 10 years old. Cases with both a suggestive and explicit code for CSA were unduplicated and included in the explicit group only. Cross-tabulation was used to compare the demographic profiles. The statistical significance of observed differences between groups was assessed using the chi-square (χ^2) test for independence. The null hypothesis (H_o) was that there is no difference in the distribution of the outcome variables (sex, age, race/ethnicity, insurance type and town group) across independent groups. Fisher's exact test was used when cell counts < 5. All statistical analyses will be conducted with SAS version 9.4.

V.   Results

From 2011 to 2014, there were 1 081 603 visits to Connecticut EDs for patients 0 to 17 years old. Almost all visits (97%) were for residents of Connecticut; Non-resident patients (n=34 432) were removed from the study sample. Children treated in the ED were most often males (52%), under 5 years (40%), white (43%), using public insurance (67%) and from urban Connecticut (73%).

A total of 215 ED visits of children 0 to 17 years old were identified by an explicit CSA code. Additionally, 632 individual suggestive codes were identified in visits of children less than 10 years old.

Suggestive codes were identified in approximately three-fold the number of visits (n=630) as compared to the explicit code (n=215). The most frequently identified suggestive codes were contusion of genital organs (n=157) and observation after alleged rape (n=459). The least frequently identified suggestive codes were pelvic inflammatory disease (n=2), gonococcal infection (n=3), and genital herpes (n=11) (Appendix C, Table 1).

Each visit can be assigned a maximum of ten diagnosis codes (DX1-DX10). The first code (DX1) indicates the primary diagnosis, and the remainder (DX2-DX10) are secondary diagnoses. Of the 215 explicit codes, the majority (91%, n=196) were primary diagnoses. For ED visits assigned a suggestive CSA code, the proportion that were assigned a suggestive CSA code as primary varied considerably by the code assigned. All codes for observation following alleged rape or seduction (100%, n=459) and the majority of codes for contusion of genital organs (77%, n=121) were primary diagnoses. The proportion of each code as a primary or secondary diagnosis can be found in the Appendix C, Table 2.

Among the visits with an explicit code, the co-occurring codes with the highest frequency include E-codes of rape (n=92), place of occurrence - home (n=51), perpetrator of child and adult abuse - by other specified person (n=41), place of occurrence - not otherwise specified (n=35), and other external cause (n=33). A listing of the highest frequency co-occurring codes can be found in the Appendix C, Table 3.

In combination, explicit and suggestive codes were identified in less than 1% of all ED visits (Appendix C, Table 4). The majority of visits (n= 628) had one suggestive code, and two visits had two suggestive codes; therefore, 630 visits had at least one suggestive code. One visit had both an explicit and suggestive code and was included in the explicit group only. The prevalence of visits with a suggestive code(s) was approximately five-times more than the prevalence of visits with an explicit code (Appendix C, Table 4). The two visits with two suggestive codes both had the same codes for contusion of genital organs and observation following alleged rape or seduction.

A comparison of explicit and suggestive code groups found significant differences between the distributions of sex and age group ($P < .05$). Visits with an explicit code for CSA were more frequently female children (78%) compared to visits with a suggestive code (65%). Additionally, visits with an

explicit code identified children more frequently in the older age category of 5-10 years (62%) than visits with a suggestive code (50%). Therefore, examination of visits with a suggestive code for CSA identified proportionally more males (35%) and younger children (50%). No significant differences between the groups were observed among variables of race/ethnicity, insurance type or town group (Appendix C, Table 5). Of the 137 visits with a suggestive code and other insurance type, all visits had the suggestive code for observation after alleged rape or seduction.

Significant differences were observed among variables of sex, age group, race/ethnicity, insurance type and town group between visits with an explicit code and visits with no CSA code (explicit or suggestive) (P <.05). Visits with no CSA code (Non-CSA) were most frequently male children (52%), less than 5 years (40%), white (43%) using public insurance (67%) and from the urban core or urban periphery (73%). Compared to non-CSA visits, visits with an explicit code were more frequently female children (84%) and over 5 years old (81%). Visits with an explicit code were more frequently Black/African American (28%) and Hispanic children (27%), and less often white (32%) compared to non-CSA visits. Additionally, visits with an explicit code had other insurance (26%) more frequently compared to the non-CSA visits (~0%). Although less significant, children of visits with an explicit code were more often from urban core or urban periphery (83%) compared to non-CSA children (73%) (Appendix C, Table 6).

VI.   Discussion

In the current study, the inclusion of suggestive codes, in conjunction with the explicit code, increased the number of visits with a CSA medical diagnosis code detected by three-fold. A similar study by King et al.[27] examining explicit and suggestive codes for child maltreatment found that suggestive codes identified six-fold the number of visits compared to the explicit code alone. Increased case detection by inclusion of suggestive codes suggests that additional codes may be required to more fully describe the scope of CSA in a clinical population. When examining visits with overlapping codes, only

one visit had both an explicit and suggestive code for CSA. Therefore, identification of cases by suggestive codes revealed an almost entirely discrete group of visits compared to visits identified by the explicit code. The lack of coinciding explicit and suggestive codes may suggest that clinicians are not recognizing clinical signs as indicators of CSA or are uncertain about the diagnosis, which would imply a need to increase training of health professionals in the identification and management of CSA victims.

In addition, suggestive codes identified proportionally more visits of younger and male children compared to the explicit code. This finding suggests that although younger and male children are exhibiting symptoms, pediatric clinicians may be less likely to identify them compared to older, female CSA victims. Identification of this subset of children by suggestive codes may decrease the rate of false negatives and provide an opportunity for early recognition and intervention. In totality, these findings provide support to the idea that inclusion of suggestive codes may result in a more complete and representative set of CSA cases.

A comparison of visits with an explicit code and visits with no CSA code is valuable to provide insight to how CSA victims may differ from non-victims in the ED setting. This information can be used to educate pediatric clinicians on the demographic profile of victims in their area of practice and has the potential to aid identification of victims in the ED. In this study, visits with an explicit CSA code were more frequently female children compared to non-CSA visits. This finding is consistent with the previous literature on sex as a risk factor for CSA.[71–73] Visits with an explicit code were more often Black/African American (28%) or Hispanic (27%) children compared to Non-CSA visits (18% and 28% respectively). Research on racial and ethnic backgrounds of child maltreatment victims (all types) have found proportionally more African American/Black and Hispanic children in the clinical setting than the general population[31,32,37], which may suggest differences in maltreatment rates by race/ethnicity. Although beyond the scope of this study, additional factors that could be contributing to this discrepancy include disparate ED utilization and/or bias in reporting and documentation by healthcare professionals. A previous study by Wood et al[160] suggested provider bias as an explanation for higher rates of child maltreatment

evaluation in Black and publically insured infants and under-evaluation in white and privately insured infants. Therefore, bias may affect detection of CSA in healthcare settings.

Additionally, proportionally more visits with explicit and suggestive codes had other insurance type (26% and 22% respectively) compared to non-CSA visits (~0%). In particular, all of the suggestive visits with other insurance (n=137) had the suggestive code for "observation following alleged rape or seduction." As previously mentioned, a forensic exam and evidence collection for sexual assault is financially covered by state funding through the OVS, and victims cannot be billed directly by law. Additional tests or treatments related to sexual abuse (eg, x-rays or stitches) can also be covered by OVS's Victim Compensation program.[143] Therefore, state funding for these services could be influencing the use of other insurance, providing explanation for the difference in distributions of insurance type among the three groups (explicit, suggestive and non-CSA).

Lastly, visits with an explicit or suggestive code were more frequently from the urban core or urban periphery of Connecticut (83% and 80% respectively) compared to non-CSA visits (73%). Differences in ED utilization by location may be explained by population density, socioeconomic status, health care issues and/or heightened service utilization in urban areas. In 2011, approximately two-thirds of Connecticut's total population lived in or around urban areas.[118] Therefore, the higher urban population density should contribute, at least partially, to the higher rates of CSA in urban areas. Moreover, identification of CSA in the clinical setting may be influenced by the availability of specialized providers who have advanced training and experience in the evaluation of suspected CSA. Considering that specialized resources are not evenly distributed across Connecticut, lower rates in non-urban areas may be the result of a lack of resources rather than a true decreased occurrence.

The results of this study indicate a low prevalence of CSA (< 1%) among children seeking medical care at Connecticut EDs. This finding is similar to other studies that have estimated rates of child maltreatment by ICD coding in hospital records[27,30–32,34,35,37], and low rates may a consequence of missed detection. Under-ascertainment may be explained by a variety of reasons, including low rates of identification, lack of documentation and/or the limited ability of ICD-9 codes to function for surveillance

purposes. Under-ascertainment is problematic for surveillance because it does not accurately describe the population rate of CSA, which can be misleading for physicians, researchers and policy-makers. Consequently, fewer resources may be allocated and policies may not be implemented towards addressing the problem. Therefore, in order to avoid the issue of under-ascertainment, future research should focus on how to maximize the use of ICD-9-CM codes to increase the sensitivity and specificity of detection, and work towards consistent application of codes across place and time.

     a.   Strengths & Limitations

There are notable strengths and limitations to using medical data from EDs as a surveillance tool. ICD codes have potential to be a useful surveillance tool for monitoring, considering their routine and timely application throughout healthcare systems in the U.S. Additionally, the unique nature of patient-clinician relationship and the medical environment may make the ED a practical place to surveille for victims. Since the ED setting differs markedly from other environments, medical data has the potential to fill gaps of child welfare and informant data. Another facet of ICD-9 codes is their utility to classify both probable/possible (suggestive) and confirmatory cases (explicit). As previously mentioned, CPS substantiated cases may be biased to only the most select cases, and may be missing cases that are not as severe in nature. With the inclusion of suggestive codes, there is potential to identify a subset of cases that are systematically different than confirmed cases of CSA based on their presenting signs or symptoms. Inclusion of suggestive cases in estimating the prevalence of CSA likely contributes to a higher sensitivity of detection.

Another strength of this project is the CHIME data, which captures almost all non-federal acute care hospitals in the state (n=27). This inclusive catchment area indicates that the data is representative of ED utilization. In an effort to calculate the Connecticut-specific burden, we removed non-Connecticut residing patients from the current study. Due to the 3% prevalence rate of non-residents in the current

study, it is likely that a small percentage of Connecticut residents also visited out-of-state EDs. Missing these visits from the current findings may have underestimated our rates of CSA in Connecticut.

It is also possible that sexually abuse children are more likely to visit another healthcare setting (eg, primary care, psychology or psychiatry) instead of the ED, and would be better identified elsewhere. Particularly in primary care settings, children spend more time with their clinician and receive well-child care, which may provide more opportunity for a disclosure or identification of signs of sexual abuse. According to the national Healthcare Cost and Utilization Project (HCUP), the most common reasons that children visit the ED are injuries and respiratory infections.[161] Since victims of CSA do not normally present with physical symptoms[91,110–112], CSA victims may be identified less often among this subgroup of children.

Considering that ICD-9-CM codes were designed for the purposes of reimbursement and not surveillance, codes lack specific details that may increase the specificity and sensitivity of detection. For example, the Schnitzer et al[29] article identified the co-occurring exclusion code "other congenital infections specific to the perinatal period" (771.2) as the exclusion criteria for the suggestive code, "conditions of genital herpes" (054.1). However, this exclusion code is not specific for perinatal transmission of herpes simplex, and includes transmission of other infectious diseases (eg, listeriosis, malaria, toxoplasmosis and tuberculosis). In select circumstances, application of this exclusion code may incorrectly remove a case of suggestive CSA based on non-specific criteria. The updated system, ICD-10-CM, was revised to contain more specific information for billing and could potentially serve as a more accurate surveillance tool. For example, the ICD-10-CM now contains a specific code for congenital herpes infection (P35.2). Although the current findings suggest that misclassification of genital herpes would have little effect since the medical condition was rare, inadequate detail of ICD coding may occur with other suggestive codes and affect the overall accuracy of detection.

Another limitation of using ICD-9-CM codes in surveillance is that codes are not always appropriately documented and may be disconnected from what is happening clinically. For example, a study by Forjuoh et al[32] found cases that were referred to CPS by the hospital but lacked any

documentation of child maltreatment in the medical record. Additionally, Karatekin et al[37] found a subset

of maltreatment-coded visits that did not contain any evidence of maltreatment in the record. In other

instances, visit received a child maltreatment code but the perpetrator was a boyfriend, girlfriend or peer,

which does not fit the commonly accepted definition of child maltreatment.[40] As mentioned by Karatekin

et al[37], clinicians and coders may not be aware or attentive to the operational definition of child

maltreatment, suggesting overestimation of the current results. In the same study by Karatekin et al[37], the

highest number of maltreatment cases were for the code "Observation of Maltreatment," which is not

confirmatory of abuse. However, among visits where the preceding "Observation of Maltreatment"

eventually lead to a definitive finding of maltreatment, a more specific code was not applied in 88% of

the cases.[37] When the determination of abuse is made after the discharge and billing period, an explicit

code cannot be applied to the medical record. Consequently, the separate timelines of clinical diagnosis

and when ICD codes are applied may lead to underestimation of the rate of child maltreatment. Lastly, the

codes "child abuse, specified" (995.50) and "other and unspecified abuse" (995.59) are non-specific for

maltreatment type, and could indicate either physical abuse, sexual abuse or neglect. These codes were

excluded from this study's analysis, which may have removed some cases of CSA and underestimated the

results.

As previously mentioned, the current study attempted to increase the accuracy of detection by

minimizing misclassification of visits with co-occurring exclusion codes. For example, the code

"contusion of genital organs" (922.4) contained co-occurring exclusion codes of motor vehicle accidents

(E800-E819), bleeding disorders (286-287) and accidental falls (E880-888). However, other straddle

injuries, which occur when a child straddles a hard object, could be an alternative explanation for trauma

to the urogenital area. Straddle injuries can occur unintentionally during play or other falls, or less

commonly from impalement by sticks, playground equipment, fence posts, or another cylindrically

shaped object.[162–165] Misclassification of straddle injuries as CSA is problematic for surveillance and has

the potential to increase the rate of false positives. An examination of blunt perineal injury in 4,450

female pediatric patients found that assault was the most common mechanism of injury in children 0 to 4

years old[163], suggesting that genital contusion for the 0 to 4 year old age group is less likely due to unintentional straddle injury.[163] In the current study, 48% (76 of 157) of the visits with contusion of genital organs were for children 0 to 4 years old, and it is possible that these children are at a higher likelihood of CSA than the older children. Although this study took steps to minimize misclassification, the exclusion criteria is likely to be incomplete and may be a subject of further investigation.

Additionally, the code for "contusion of genital organs" does not specify the particular anatomical area of injury. This type of detail could provide a basis for distinction between abusive and non-abusive injuries. The recently updated guidelines for the clinical evaluation of child sexual abuse finds that acute bruising of the labia penis, scrotum, perianal tissue or perineum, could be caused by either trauma and/or sexual contact.[115] By evaluating a sample of pediatric ED admissions (n=300), McIntosh and Mok[166] identified specific genital injuries that were more commonly identified in sexually abused patients compared to non-abused controls. In males, penile and scrotal injuries were only present with accidents; however, anal injury was more common after suspected sexual abuse (36%) than accidents (5%). For females, injuries to the perineum and labia were more commonly accidents (32% and 74%) than abuse (2% and 11% respectively). Alternatively, hymenal injuries were more common after abuse (19%) than accidents (1%). Lastly, injury to the posterior fourchette was similarly common for both accidents (17%) and abuse (10%). These findings indicate that information on the particular anatomical structures injured could potentially preclude the occurrence of abuse, lowering the rate of false positives. However, determinations may be further complicated by the fact that there are some findings for which there is no expert consensus regarding specificity for abuse[115] and signs or symptoms may be case-dependent. Therefore, it may be impossible to create this type of stringent criteria.

Another limitation of this study is that the list of suggestive codes used to describe CSA is likely incomplete. A number of ICD-9-CM codes that were identified by the panel of child abuse and neglect specialists in the original study by Schnitzer et al[29] were not found in any visits in their database, and therefore, could not undergo a case review (Appendix D, Table 1). As a consequence, these visits could not be evaluated for probable, probable or not likely of sexual abuse by the Ewigman et al[156]

categorization scheme, and validated as suggestive of CSA. However, some of the codes, including sexual transmitted infections and pregnancy-related variables are considered highly likely or diagnostic of sexual contact by clinical guidelines.[117] Although these conditions are likely to represent a small number of cases[66,167], there is still the potential that cases have been missed from the results of this study. Additionally, the number of records reviewed per suggestive code was low in some cases (<5 records reviewed), warranting a more extensive review in the future.

VII.   Conclusions

The complex and pervasive nature of CSA has posed several challenges to the public health approach of surveillance, leaving the full scope of CSA unapprehended. The practice of surveillance aims to systematically collect, analyze and interpret data to develop an accurate and refined picture of the burden of CSA. Population-level data on CSA is crucial to increase public awareness, maximize use of resources, improve practices in child protection, and promote policy that addresses the needs of maltreated children and families. Child welfare statistics from CPS and informants (NCANDS and NIS) is commonly accepted as the main forms of child maltreatment surveillance. However, data collection systems have limitations that contribute to a severe underestimation of the problem, highlighting a need to explore alternative forms of surveillance.

Hospital-based surveillance has the potential to supplement the current forms of child maltreatment surveillance. The current study demonstrated an ability to conduct innovative surveillance on child sexual abuse by medical diagnosis coding of Emergency Department (ED) visits. An important finding of this study is that the use of both suggestive and explicit ICD-9 codes identified a wider range of cases than the explicit code alone. The implication of this finding is that CSA surveillance in EDs and other hospital settings may be enhanced by the use of additional codes to describe both confirmatory (explicit) and probable/possible (suggestive) cases of abuse. Another important finding is that the demographic profile of confirmed CSA victims differed significantly from non-victims in the ED. This

preliminary analysis of demographic characteristics can contribute to our understanding of victim risk factors and has the potential to aid identification in the future.

a. Future Directions

A crucial future direction for hospital-based surveillance is creating an ICD coding scheme to describe rates of CSA with the current system (ICD-10-CM). One way to identify relevant ICD-10 codes for use in surveillance could be by mapping codes to the current medical guidelines for the evaluation of suspected CSA. ICD-10 codes now in wide use are more detailed than the ICD-9 codes that were utilized during this study period, and may be more easily mapped to specific findings of concern. Medical guidelines are a vital resource to devise case definitions for surveillance because they exemplify a standardized, evidence-based approach for interpreting physical and laboratory findings when CSA is suspected. The guidelines also embody the current literature on CSA and the expert consensus among physicians in the field. Although clinical definitions and surveillance are not identical, linking ICD-10-CM codes to the updated guidelines may lead to the identification of a series of codes that result in a higher specificity and sensitivity of detection. As physicians are now selecting codes directly through the use of electronic medical records (EMRs), additional training for physicians on applying codes in suspected CSA cases could yield more accurate data. Prior to applying the ICD-10-CM codes in practice to describe rates of CSA, it would be important to validate the codes through a medical case review and advisory from experts in child abuse.

Another important consideration for the use of suggestive codes in surveillance the degree of accuracy with which they indicate CSA. CSA cases are complex and require multiple forms of evidence to confirm abuse, including contextual information and a social history, especially in the absence of physical symptoms.[107,108] However when used separately, individual ICD codes only provide a limited amount of information about a visit. In order to improve the system by which cases are classified as suggestive of CSA, future research could focus on creating a validated algorithm which considers the

presence of multiple codes simultaneously. Based on which codes are co-occurring, the algorithm could then compute a positive predictive value (PPV) to determine the probability that a child is a victim of sexual abuse. Based on probability estimates, cases could be separated into a more detailed case classification system. Through the incorporation of more detailed information about visits, this predictive value would provide a more precise estimate of CSA risk to increase accuracy of surveillance. However, based on the limitations of ICD-9-CM codes, such as lack of detail and inconsistent application, this system could misguide research by generating additional false positives (incorrect identification of abuse) and false negatives (incorrect miscounting of abuse).

From the clinical perspective, an important area of future work is increasing the number of expert medical providers providing specialized services to CSA victims in need. In order to build a stronger workforce in this area, promoting awareness, education and exposure to the clinical practice of identifying and evaluating for CSA is essential. This work is necessary across different levels of education and healthcare professional schools (eg nursing, PA and medicine). Subsequently, there must also be opportunities for advanced educational training in child maltreatment, as well as adequate resources and funding to support positions in this area. It is important to have experts because the level of training and experience of a medical provider likely impacts what is detected and documented into the medical record. For example, one study found that patients examined by a sexual assault nurse examiners (SANE) were more likely to have a genitourinary (GU) examination (71% vs 41%; $P < .001$), GU injury documented in record (21% vs 0%; $P = .024$), testing for *N. gonorrhoeae* and *C. trachomatis* (98% vs 76%; $P \leq .001$), serologies for Hepatitis B and C (95% vs 80%; $P = .03$) and HIV (93% vs 72%; $P = .03$) (when deemed eligible for testing).[168] Those evaluated by a SANE nurse were also more likely to receive prophylactic treatment for pregnancy (85% vs 64%; $P = .02$) and referral to a Rape Crisis Center (98% vs 30%; $P < .001$).[168] Additionally, by virtue of their specialization, expert providers in child abuse are likely to have more knowledge on the evaluation of suspected CSA and more likely to make a correct diagnosis. Perhaps unsurprisingly, another study found that child abuse pediatricians scored significantly higher than general pediatricians on an online survey that assessed ability to evaluate for suspected CSA (34.8 vs

30.1; $P <.05$).[134] Another study comparing pediatric ED and CSA-trained physicians' evaluations of the same patients found poor agreement between findings. Out of 46 patients identified by ED physicians to have abnormal genital findings indicative of non-acute sexual abuse, the CSA-trained physicians found 32 of them (70%) to have normal findings upon further evaluation.[131] This finding demonstrate a need to increase the availability of clinicians who have specialized training to ensure children receive an evaluation by a knowledgeable and capable provider. Accurate detection and documentation of CSA is impactful for both clinical practice and surveillance. Since Connecticut has specialized services distributed unevenly across the state, one area of future work could focus on increasing access to specialized providers for patients living in underserved locations. More accurate CSA prevalence information could be used to advocate for allocation of resources to make this work possible.

Currently there is no validated screening tool for CSA. However, routine screening has the potential enhance detection in clinical practice, and subsequently, increase case detection in surveillance. The value of screening for child maltreatment (all types) has previously been demonstrated in a study using a screen called the "Escape Form." In this study, medical centers with the screening intervention observed a five-fold increase in detection of child maltreatment compared to controls (0.5% vs 0.1%, $P <.001$).[169] The 6-item screening instrument was found to have high sensitivity (0.80) and specificity (0.98), allowing for accurate identification of high risk children.[170] However, a review of two studies found that while screening increased detection of suspected child maltreatment victims, there was no significant increase in the number of confirmed abuse cases.[171] Without an increase in the number of actually confirmed abuse cases, the screening tool may not provide any real clinical benefit. The current research on the impact of screening is still preliminary and not specific to abuse type.[171] Important considerations for the future include how to maximize the effectiveness of a screening tool in clinical practice and efficiently valuable ED clinician time and resources.

VIII.   Appendix

a.   Appendix A.

Table 1. Connecticut Health Care Facilities in the SAFE Program[143]

Connecticut Children's Medical Center

Hartford Hospital

The Hospital of Central Connecticut (New Britain campus)

Manchester Memorial Hospital

Middlesex Hospital

MidState Medical Center

Saint Francis Hospital and Medical Center

Windham Hospital

University of Connecticut Student Health Services

Table 2. Connecticut Health Care Facilities in Connecticut Hospital Association Data[a]

William W. Backus Hospital

Bridgeport Hospital

Bristol Hospital

Danbury Hospital

Day Kimball Hospital

Greenwich Hospital

Griffin Hospital

Hartford Hospital

The Charlotte Hungerford Hospital

Johnson Memorial Hospital

Lawrence & Memorial Hospital

Manchester Memorial Hospital

Midstate Medical Center

Middlesex Hospital

Milford Hospital

The Hospital of Central Connecticut

Connecticut Children's Medical Center

Norwalk Hospital

Rockville General Hospital

Saint Francis Hospital and Medical Center

Saint Mary's Hospital

St. Vincent's Medical Center

The Stamford Hospital

John Dempsey Hospital (UConn Health)

Waterbury Hospital

Windham Community Memorial Hospital

Yale-New Haven Hospital

[a]0.7% of visits could not be assigned a health care facility

b. Appendix B.

Table 1. Explicit and Suggestive ICD-9-CM Diagnosis Codes for Child Sexual Abuse (CSA)

ICD-9 Inclusion Code	Code Description	Age (y)	ICD-9 Exclusion Code(s)	Code Description
Explicit				
995.53	Child abuse—sexual	0-17		
Suggestive				
54.1	Genital herpes	<10	771.2	Other congenital infections specific to the perinatal period[a]
98			98.4	Gonococcal infection of eye
			771.6	Neonatal conjunctivitis and dacryocystitis
	Gonococcal infection	<10		
614.9	Pelvic inflammatory disease, unspecified	<10		
922.4			E800-E819	Motor vehicle crash(es)
			286-287	Coagulation defects, purpura, other hemorrhagic conditions
			E880-888	Unintentional falls
	Contusion of genital organs	<10		
V71.5	Observation following alleged rape or seduction	<10		

[a]*Non-specific for herpes simplex virus*

c. Appendix C.

Table 1. Frequency of Visits with Explicit or Suggestive Code for Child Sexual Abuse

	Code Description	**# Visits**
Explicit	Child abuse—sexual	215
Suggestive	Genital herpes	11
	Gonococcal infection	3
	Pelvic inflammatory disease, unspecified	2
	Contusion of genital organs	157
	Observation following alleged rape or seduction	459
	Total Suggestive	632
Total		**847**

Table 2. Proportion of Codes as Primary or Secondary Diagnosis

ICD-9 Code	Code Description	# Primary Codes (%)	# Secondary Codes (%)	Total # Codes (%)
Explicit				
995.53	Child abuse—sexual	196 (91)	19 (9)	215 (100)
Suggestive				
54.1	Genital herpes	6 (55)	5 (45)	11 (100)
98	Gonococcal infection	2 (67)	1 (33)	3 (100)
614.9	Pelvic inflammatory disease, unspecified	1 (50)	1 (50)	2 (100)
922.4	Contusion of genital organs	121 (77)	36 (23)	157 (100)
V71.5	Observation following alleged rape/seduction	459 (100)	0 (0)	459 (100)

Table 3. Top 5 Co-Occurring Codes with Explicit Code

ICD-9 Code	Code Description	Total # Codes
E960.1	Rape	92
E849.0	Place of occurrence, home	51
E967.1	Perpetrator of child and adult abuse, by other specified person	41
E849.9	Place of occurrence, unspecified	35
E0008	Other external cause status	33

Table 4. Prevalence of Visits with Explicit or Suggestive Code(s) for Child Sexual Abuse

	# CSA Coded Visits	# Total Visits (per age group)	(# CSA per 10 000 visits)
Explicit	215	1 047 171	2.1[b]
Suggestive[a]	629	646 766	9.7[c]

[a] *Suggestive (no explicit)*

[b] *# divided by total visits < 18 years*

[c] *# divided by total visits < 10 years*

Table 5. Demographic Profile of Visits with Explicit or Suggestive Code(s), Under 10 Years

		Explicit	Suggestive[a]	P [b]
		N (%)	N (%)	
# Visits		110 (100)	629 (100)	
Sex	**Female**	86 (78)	408 (65)	0.0062
	Male	24 (22)	221 (35)	
Age group, y	**< 5**	42 (38)	313 (50)	0.0249
	5-10	68 (62)	316 (50)	
Race/Ethnicity	**White**	35 (32)	243 (39)	0.2704
	Black/AA	32 (29)	134 (21)	
	Hispanic	27 (25)	134 (21)	
	Other	12 (11)	94 (15)	
	Unknown	4 (3)[c]	24 (4)	
Insurance Type	**Private**	68 (62)	359 (57)	0.7648
	Public/Federal	16 (15)	102 (16)	
	Self-pay	6 (5)	31 (5)	
	Other	20 (18)	137 (22)	
Town Group	**Rural**	10 (9)	53 (8)	0.7726
	Suburban	9 (8)	64 (10)	
	Urban periphery	56 (51)	284 (45)	
	Urban core	33 (30)	218 (35)	
	Wealthy	2 (2)[c]	10 (2)	

[a] *Suggestive (no explicit)*

[b] *p values for χ^2 test of independence*

[c] *Cell count <5, Fisher's exact test used*

Table 6. Demographic Profile of Visits with an Explicit or No CSA Code, Under 18 Years

		Explicit	Non-CSA	P_a
		N (%)	N (%)	
# Visits		215 (100)	1 046 327 (100)	
Sex	**Female**	180 (84)	502 924 (48)	< .0001
	Male	35 (16)	543 402 (52)	
Age group[b], y	**< 5**	42 (19)	414 378 (40)	< .0001
	5-11	85 (40)	312 511 (30)	
	12-17	88 (41)	319 438 (30)	
Race/Ethnicity	**White**	68 (32)	452 132 (43)	< .0001
	Black/AA	60 (28)	183 881 (18)	
	Hispanic	58 (27)	238 950 (23)	
	Other	20 (9)	136 288 (13)	
	Unknown	9 (4)	35 076 (3)	
Insurance Type	**Private**	123 (57)	698 222 (67)	< .0001
	Public/Federal	29 (13)	304 082 (29)	
	Self-pay	8 (4)	40 947 (4)	
	Other	55 (26)	3 076 (0)	
Town Group[c]	**Rural**	16 (7)	105 243 (10)	0.0381
	Suburban	17 (8)	147 240 (14)	
	Urban periphery	87 (41)	380 637 (37)	
	Urban core	90 (42)	383 077 (36)	
	Wealthy	5 (2)	30 107 (3)	

[a] *p values for χ^2 test of independence*
[b] *One visit missing from Non-CSA group*
[c] *Twenty-three visits missing from Non-CSA group*

d. Appendix D.

Table 1. Medical Diagnosis Codes that may Indicate Child Sexual Abuse[a]

ICD-9 Code	Code Description
79.98	Chlamydial infection, unspecified
131.01	Trichomonal vulvovaginitis
132.2	Phthirus pubis
632	Missed abortion
634	Spontaneous abortion
666	Postpartum hemorrhage
878.7	Open vagina wound, complicated
V01.6	Venereal disease contact
V08	HIV, asymptomatic
V22	Normal pregnancy

[a] Codes had no visits in Schnitzer et al[29] paper

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