

**LONGSCAN: Longitudinal Studies of Child Abuse and Neglect, or Long Suffering
Child Abuse Nomenclature?**

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Abstract

This paper is intended to share some of the author's observations following 16 years' experience with a longitudinal child maltreatment study. The North Carolina local site of LONGSCAN has been following children born in 1985-87 with risk factors for a maltreatment report. Implications for the CIS and the QIS include the importance of seeing the big picture, and of taking the child's point of view. One should not to over-analyze the data. Rather, consider the possibility that the precursors of maltreatment may be sufficient by themselves to explain the adverse consequences associated with maltreatment.

Good morning. I am happy to share with you this morning some of my experiences in the vineyards of longitudinal child abuse and neglect research. My name is Jonathan Kotch, and I am a pediatrician by training, not a researcher. Despite my best efforts, I have been the Principal Investigator of what has become known as the North Carolina local site of LONGSCAN, also known as Longitudinal Studies of Child Abuse and Neglect. My study actually began four years before LONGSCAN, but now we are proud to be one of five local sites operating under common policies and procedures.

LONGSCAN was initiated in 1990 with grants from the National Center on Child Abuse and Neglect of the Administration on Children and Families of the US Department of Health and Human Resources (DHHS) to a coordinating center (“the Core”) at the University of North Carolina at Chapel Hill and five local sites, including the North Carolina local site. Each site is conducting a separate and unique research project on the etiology and impact of child maltreatment (Runyan et al., 1998). While each project can stand on its own merits, LONGSCAN is a collaborative effort that uses common instruments and measures, similar data collection methods and schedules, and pooled analyses. Although LONGSCAN is a nation-wide study, it is not meant to be representative. Each site occupies a different point on a continuum of risk, from a population selected at birth because of risk of abuse or neglect, to a population selected because the subjects had to be placed in foster homes due to severe abuse or neglect. In no site is the population a representative sample of the general population.

In this paper I hope to share with you some the lessons from our experience in North Carolina. I will take this opportunity to think aloud with you, both about some of methodological concerns that we have encountered along the way, and also about the

analytic strategies that we have used with some success. I hope that some of this may be useful in consideration of where to take the Canadian Incidence Study (CIS) and the complementary EIQ study in Québec. Most of all, I hope to convey a sense of humility that 16 years in this business has left me with.

Unlike the CIS and the EIQ, in North Carolina we began with a systematic sample of 842 mother-infant pairs born between 1985 and 1987 in North and South Carolina, none of whom had been reported for maltreatment. We deliberately chose the subjects based on risk criteria that we believed would result in a high rate of child maltreatment reports. We were right. By the age of 8, nearly 50% of the subjects had been reported for child maltreatment at least once. Our selection tool is being adapted by researchers at the Duke University Center for Child and Family Policy for its community-based trial of primary and secondary child abuse prevention.

In both states, as in every state in the US, child maltreatment reporting is mandatory. We have followed our cohort by reviewing every 6 months the State of North Carolina's Central Registry of Child Abuse and Neglect, the database where all investigated reports of child abuse and neglect allegations are archived. We lost the South Carolina sample, which only numbered about 54, because the state of South Carolina did not retain unsubstantiated cases in its Central Registry (CR). We had the notion then that being the subject of an unsubstantiated report was not qualitatively different from being the subject of a substantiated report, and we did not want to lose the unsubstantiated subjects. Later in this paper I will share some preliminary results of our research, which would seem to bear this out.

Like the CIS and the EIQ, for the first four years of our study, the only source of our child maltreatment outcome measure was the official report to Child Protective Services (CPS). In most cases in North Carolina these reports are made to local CPS agencies, which in turn report investigated cases to the state Division of Social Services, which maintains the CR. In North Carolina there are no records kept of reports that were screened out and therefore never investigated. Despite the fact that one can find an estimate of the number of reports screened out in North Carolina in the federal government's official report on child maltreatment investigations in the US, I recently heard a North Carolina official freely admit in a meeting that the figure for screened out reports was made up. I commend those of you from Québec who have included screened out reports in the EIQ.

In order to obtain access to Central Registry records, we of course had to be approved by the School of Public Health's Institutional Review Board for the Protection of Human Research Subjects, obtain a Certificate of Confidentiality from the federal government, and obtain the permission of the Director of the State Division of Social Services. All of our publications to date, both those that precede LONGSCAN and those that include data that have been collected, via face to face interviews, with LONGSCAN support, use Central Registry reports as our sole measurement of child abuse and neglect. I have three observations to share with you about these initial research papers. First of all, it helps to have a theoretical model. As I said at the beginning, I was not a researcher to begin with. Colleagues who ran the gauntlet of dissertation research swear by theoretical models, and in order to get our initial funding from the Maternal and Child Health Bureau of the US DHHS, I needed to have one. We (my former co-Principal

Investigator Dorothy Browne and I) developed a model based on the ecological model of child abuse and neglect etiology.

Based on this model, the focus of our research since 1985 has been the interaction of stress and social support. Like the weather, everyone talks about stress and social support, but nobody actually has done anything about it. I believe that Dr. Browne and I, in our first three papers, were the first to demonstrate in a longitudinal study that, even in the absence of main effects, there is a stress and social support interaction that is predictive of child maltreatment reports. So pay attention to theoretical models. One worked for us. I note that there is a “few social supports” variable in the CIS. This risk factor, by itself or in an interaction with one or more other independent variables, is likely to be a fruitful potential predictor to pursue.

Regarding analysis strategies, in this series of papers as well as in our paper about school performance (Zolotor et al., 1999), our favorite analytic tool has been logistic regression using generalized estimating equations (GEE). Recommended by our statistical consultant, this technique lends itself to our early preference for simple, categorical outcomes, which usually take the form of “report, yes or no.” GEE also has the advantage of being able to handle multicollinearity problems that are inherent in longitudinal research, since the same subject will have values at two or more points in time. Multicollinearity may be an issue that the CIS and the EIQ needs to pay attention to, given that the same child may appear in the analysis more than once since the investigation, not the report, is the unit of analysis.

More recently we have attempted to be more sophisticated by using a three level variable, unreported, reported and unsubstantiated, and reported and substantiated, in our

most recent attempt to describe the outcomes of maltreatment. In any case, we realize that we are not truly studying the phenomenon of maltreatment, but only the phenomenon of maltreatment known to official agencies. Nevertheless, this is an important domain to capture, as you are doing in the EIQ and the CIS. We do need to remember to qualify our reports by reminding our readers, and ourselves that we do not claim that our results are generalizable to the child population at large. They are relevant and important for the large numbers of children known to Departments of Social Services (DSS) across the US.

Recently all of the LONGSCAN local sites and the Core, under the leadership of Dr. Desmond Runyan, undertook jointly to analyze and compare three ways of measuring maltreatment. In addition to reports recorded at the state level in the respective Central Registries, all of the LONGSCAN sites also abstract data from CPS records at the county level, not unlike the process described for the CIS and the EIQ. Through the diligent work of Dr. Diana English and her colleagues at the Department of Social and Health Services of the State of Washington, LONGSCAN developed a data coding sheet for classifying local CPS records both according to the child maltreatment classification scheme of Barnett, Manly and Cicchetti (1991; 1993), and also according to the child maltreatment definitions of the 2d National Incidence Study (NIS2, USDHHS, 1988), conducted by Dr. Andrea Sedlak, who joins us at this meeting today. These coding schemes are far more complete and detailed than the “yes, no, somewhere in-between” nature of the Central Registry variable that the North Carolina local site had used before LONGSCAN.

Since this process is most similar to the CIS and EIQ data collection procedures, I will discuss it in more detail for a few minutes. The actual data collection forms, based

on NIS2 and Barnett, Manly and Cicchetti, were developed by Diana English and her team at the LONGSCAN northwest local site. The instrument allows for coding from CPS records using both coding schemes. Barnett, Manly and Cicchetti is more detailed than NIS2. The LONGSCAN adaptation of Barnett, Manly and Cicchetti allows for coding subtypes of abuse, severity, chronicity, and frequency of maltreatment, along with information about the child's developmental age and the perpetrator. There are a total of 27 subtypes of maltreatment, which can be coded.

Training for using this instrument takes a whole day, and after training data collectors have to submit practice coding sheets based on standardized vignettes. These are compared to the "gold standard" coding sheets filled out by LONGSCAN trainers. Data collectors have to achieve an accuracy score of 90% on 10 vignettes before they are let loose to abstract CPS records of LONGSCAN subjects. Once they are in the field, data collectors have to submit 10 of every 50 cases they code for a validity check. If they fall below the 90% accuracy criterion, they have to repeat the practice codings of the standardized vignettes until they get it right.

Validity, in the case of child maltreatment, is in the eye of the beholder. Ultimately we are at the mercy of the CPS worker who made the original entries in the case record in the first place. This for us is no different from the situation of the Canadian social service workers who are completing forms for the CIS and the EIQ. It is important, as difficult as it may be, to try to make the coded data reflect as accurately as possible what is in the record. But neither we, nor our Canadian counterparts have any control over the extent to which what is in the record represents reality, from the child's point of view. At the end of the day, we are recording and reporting agency data, not

community-based data. We need to acknowledge this limitation. Furthermore, is it sufficient to document that an act of omission or commission took place, regardless of intent? Or is it the consequences of the act that determines whether it was maltreatment or not?

To address these questions, each LONGSCAN site took a piece of the definition of maltreatment for special analyses, and we all are using the same pooled data set comprising 545 subjects who had had any report of maltreatment between ages 0 and 8 years. The LONGSCAN core is examining the concordance between the LONGSCAN Maltreatment Coding Scheme (MCS) and the NIS2 on the one hand and official DSS reports on the other. The northern site is looking specifically at neglect. The western site is looking at severity. The northwest site is looking at chronicity. And the midwest site is looking at emotional abuse.

North Carolina chose to explore whether substantiated maltreatment predicts dire behavioral and emotional consequences better than unsubstantiated reports. The preliminary, bivariate analyses performed by my colleague and Co-Investigator, Dr. Jon Hussey, compare the statistical association between behavioral and emotional outcomes at age 8 according to whether children were reported between 4 and 8 years of age, and if so, whether their reports were substantiated. I should point out again that all of the subjects in this series of coordinated studies were reported at least once in their 8 years of life. As it turns out, in this population of high risk children, there isn't any difference in the ability of maltreatment to predict behavioral and emotional outcomes according to whether allegations are substantiated or not. One table from our preliminary results indicates practically identical scores on the Trauma Symptom Checklist for Children

(Briere, 1996) among the unreported, the reported and unsubstantiated, and the substantiated.

Figure 1. Mean Trauma Symptom Checklist Scores by Maltreatment Status (n=545).

<u>Variable</u>	<u>No Maltx</u>	<u>Unsub</u>	<u>Subst</u>
Anger	47.3	47.1	46.8
Anxiety	56.9	55.4	55.6
Depression	53.5	53.0	53.4
Dissociation	54.6	54.6	54.4
P-T Stress	55.3	55.6	54.9

Source: Kotch, J.B., Hussey, J., Marshall J.M., Dubowitz, H., English, D., Lau, A., and Schneider, M.W. *Defining maltreatment according to substantiation: Distinction without a difference?* Paper prepared for the LONGSCAN Executive Committee meeting, Washington, DC, June, 2001.

The preliminary work of the Core has been interesting in that it has forced us to consider the implications of how to interpret the official reports of maltreatment which, for the purposes of the various state and local CPS agencies in the US, have to be forced into categories that are really designed to 1. determine children’s eligibility for services and 2. make administrative data reporting possible. Dr. Runyan’s study (Runyan et al., 2001) will address the question of concordance between MCS and NIS2 definitions of alleged and substantiated maltreatment on the one hand with the official DSS determination on the other. In other words, the one best category of CPS maltreatment type, chosen according to an algorithm based on severity, number of codes per type, and an arbitrary hierarchy (i.e., sexual abuse coded first, then physical abuse, then other) is

compared to the single best NIS2 and MCS type after collapsing the 27 subtypes into 6 types of maltreatment. And as if that weren't enough, in cases where there is more than allegation in the four year study period, these reports need to be collapsed into subject-level, as opposed to report-level, variables. By the time the research team, which includes me by the way, has reduced, collapsed and consolidated the data to the point of being able to determine whether MCS, NIS2 or DSS coding better predicts a child's emotional or behavioral outcomes, the ability of the data to capture the real-life experience of the maltreated child seems stretched beyond recognition.

This preliminary work, which is far from complete, makes me want to join the lumpers of child maltreatment research, rather than the splitters. I realize that, in the CIS and the EIQ, maltreatment is a three level variable. An investigated case can be unsubstantiated, suspected, or substantiated. The proportion of cases substantiated is 45%. This is rather high by our standards, which are closer to 30% substantiated in the state of North Carolina. To me this suggests that, were there any reason to lump the three levels into two, in case one wanted to do a logistic regression with a dichotomous outcome for example, the suspected cases are more likely to be qualitatively similar to the unsubstantiated than the substantiated. But at the same time, I have to admit that I consider deciding where to draw the line along the continuum from unsubstantiated to suspected to substantiated to be arbitrary. In our own research the reported but unsubstantiated subjects are more like the substantiated (Kotch, et al., 2001), and this also seems to be the case in the one other report from the literature we identified that empirically studied the effects of unsubstantiated reports (Leiter, Myers, & Zingraff,

1994). There is something to be learned from this group of unsubstantiated reports. They are not so easily dismissed as “unmaltreated.” Rather, they are merely unproven.

Another lesson perhaps is the importance of interpreting maltreatment from the child’s point of view. This introduces the difficulty of having to assess a child’s perception of the experience, rather than the mere occurrence of the experience. Our first cut at this approach began with the introduction, at the age 12 LONGSCAN interview cycle, a child self-report survey module that was administered via the audio-assisted computer administered self interview technique (ACASI). This exhaustive (and exhausting) instrument asked the child to report his or her own experience of abuse in the past year and in his or her lifetime. A preliminary report of our findings was prepared for presentation at the International Family Violence Research Conference held at the University of New Hampshire in July, 2000. Unfortunately, the first author and presenter, Dr. Hussey, got sick and had to leave before his presentation. In that presentation, Dr. Hussey would have observed that the child’s report of severe physical abuse was remarkably similar to the parent’s report. Only 9% of the reports disagreed with one another. However, the discordance between the child’s report and the official CR report was huge. In a study population of 180 12 year old children in which 53% were known to have been reported to Social Services for maltreatment, only 29% reported a history of maltreatment themselves (Hussey, 2000).

Figure 2. Comparing Child Self Reports of Maltreatment with State Central Registry Reports, Age 12 (n=180).

		Child Report		
		No	Yes	Total
Official Report	No	36%	12%	47%
	Yes	35%	18%	53%
	Total	71%	29%	100%

Source: Hussey, J., Everson, M.D., Knight, E., Kotch, J.B., and Radhakrishna, A. *Measuring maltreatment: Comparing official, parent, and child reports*. Paper prepared for the 5th International Family Violence Research Conference, Durham, NH, July, 2000.

The real measure of the child’s experience of maltreatment seems to me to be what specific consequences, physical, emotional, behavioral, social, academic, can be attributed to child maltreatment over and above the adverse consequences of the risky circumstances that by themselves might result in the same unfavorable outcomes. Along with many others I think of maltreatment along a continuum without discrete boundaries between categories, be those categories unconfirmed, suspected, or confirmed, or physical abuse, sexual abuse, emotional abuse, or neglect. Ultimately it is the child’s perception of being unloved, unwanted, uncared for that counts more than the distinction between a determination of neglect, for parental failure to protect from an abusive beating, a determination of abuse for the beating itself. So may I conclude with a few modest suggestions. First, try to aggregate the data by child, not by report, to get closer to the child’s experience rather than that of the agency. Second, be a lumpner. I am not convinced that our own attempt to define 27 subtypes of maltreatment will really teach us any more than focusing our attention on the three or four major types of maltreatment.

Finally, use the statistical tools at your disposal to consider the precursors of maltreatment as risk factors, not just of the maltreatment, but of the adverse child outcomes which might have occurred regardless of whether the alleged maltreatment happened, or was substantiated. Certainly maltreatment is associated with academic problems, emotional problems, and behavioral problems, but so is poverty; maternal isolation and depression; caregiver stress, ignorance of child development and lack of parenting skills; and caregiver substance abuse and mental health problems. How much more harm does all but the most severe maltreatment really add to this litany of problems? I wonder if in over-analyzing maltreatment, we are under-appreciating what else is going wrong in the lives of these children. Maltreatment, it seems to me, is a symptom of a more profound problem in how our society, at least in the States, organizes itself to raise its children, rather than the problem itself.

Thank you.

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