



March 2003

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Recommended Citation

Bell, Nancy M. and Campbell, Marie L. (2003) "A Child's Death: Lessons from Health Care Providers' Texts," *The Journal of Sociology & Social Welfare*: Vol. 30 : Iss. 1 , Article 7.

Available at: <http://scholarworks.wmich.edu/jssw/vol30/iss1/7>

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A Child's Death: Lessons from Health Care Providers' Texts

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This article originates from a research study that explores 'what happened' to a 10-year-old child with Rett syndrome, who died from "severe malnutrition" according to a Coroners Service inquest jury. The inquest evidence analyzed, using institutional ethnography, shows that approximately one week prior to this child's death three health care providers (an emergency physician, a hospice volunteer and a home care nurse) conducted individual assessments of the child. Child protection workers were also involved. Textual analysis of the health care providers' records shows how the child was officially and textually constructed as 'dying from a terminal illness' in contrast to the subsequent Coroners Service finding. The authors argue that although professional and organizational texts are a routinely 'taken for granted' component of professional practice, they need to be understood as active in the relations of care or service provision. The article supports this argument by demonstrating how the home care nurse's response to the child was textually coordinated with the other two health care providers' actions and how this coordination resulted in the 'proper' enactment of a Do Not Resuscitate order, leading to courses of action or inaction resulting in the child's death. The lesson offered highlights the problems that can arise when textual realities routinely are given authoritative status and displace other forms of knowing in health care.

Introduction

Several years ago, a ten-year-old child with a disability—Rett Syndrome—died at the home of a family friend. At the conclusion of a seven week inquest, a Coroners Service jury determined that the child's death resulted from "severe malnutrition as a result of inadequate nutritional intake over a period of time caused directly or indirectly by the actions of other persons" (Coroners Service Jury Recommendations, 1997, p. 1). In the weeks prior to her death, this child (whom we call "Nina") had become the focus of a child protection investigation for possible parental neglect, which had led to her contact with three health care providers—an emergency physician, a hospice volunteer and a home care nurse—approximately two weeks before she died. While these three health care providers and approximately 17 other professional service providers knew about Nina during those two weeks, Nina died without any service intervention directed at responding to her malnourished condition. As a result, the circumstances related to Nina's death garnered much attention from the professional communities involved together with the general public. One of the authors of this article, Nancy Bell, conducted research into 'what happened' to Nina for her Masters of Arts degree thesis. In drawing from her work, this article addresses the topic of the routine use of health care records, or 'texts,' in the provision of medical services and the possible implications for patients.

During the weeks prior to her eventual death, Nina lost a considerable amount of weight. In retrospect, it appears this weight loss may have been related to her childcare worker's absence over a six-week period. The childcare worker had become ill and unable to continue with her daily responsibilities, which included feeding, dressing and transporting Nina to the school Nina attended as a full time student in Grade 3. At the school, the childcare worker was also employed as Nina's teacher's aid, assisting with the implementation of Nina's independent educational plan. On the day the childcare worker returned to care for Nina and took her to school after both person's four week absence, a concerned community citizen phoned provincial child protection social workers to report Nina's emaciated condition. This contact resulted in health care provider and social worker

involvement. Approximately two weeks later, Nina died at the home of her mother's friend who lived in a nearby community. In response to the circumstances related to Nina's death, a number of official investigations ensued. Rather than addressing those investigations, what was found or what went wrong, however, our article queries what can be learned about 'what happened' from the health care providers' records generated immediately prior to Nina's death.

Our article is premised on the notion that health care provider records are central to professional work processes, including therapeutic interactions, to the extent that the practitioner may completely overlook, or underestimate, their impact. These records may be designed to support professional practice, for example, by jogging the practitioner's memories about the essential elements of an assessment. Besides their clinical uses, records and record-keeping involves the practitioner in multiple and layered organizational actions (Campbell, 1994; 2001). For instance, the categories of an organizational record, common to structured 'forms,' may refer to features of a patient's story that allow the practitioner to establish eligibility for a particular treatment or service. Moreover, an organizational form may become part of a process of accounting for agency activities and their costs, laying the groundwork for efficient handling of this patient's circumstances. Information from one organizational form may be aggregated with others, offering the possibility of more general, statistical description of patients like her that is useful for a large number of organizational decisions (Rankin, 2001). The development of information systems of this kind is a special field of competence. But in any health or social service agency, after a system is implemented it is up to the practitioner to incorporate the use of these forms and records into her work processes. Just how that happens, and with what results, we believe is a matter for inquiry. Institutional ethnography is a useful methodology for such inquiry.

Our article takes up how the three health care providers who saw Nina approximately two weeks before her death (each person conducted one assessment) came to know and respond to her as a child *dying from a terminal illness*, in sharp contrast to the Coroners Service jury's retroactive finding that Nina's death resulted from

“severe malnutrition.” Institutional ethnography allows us to display how the texts generated by the health care providers as they recorded involvement with Nina (and her mother) brought the health care providers, all of whom had no or brief telephone contact, into relation with each other. In our analysis, we show how the health care providers and, in particular, the home care nurse, incorporated those texts into their practices and how Nina’s relationship with them altered as she became known to them as ‘dying from a terminal illness.’ As this article will demonstrate, Nina disappeared from the attention of the health care providers, whose work processes centred upon the ‘proper’ use of texts in compliance with related policies and practices.

Our analysis also demonstrates how an enacted Do Not Resuscitate (DNR) order—a culminating and highly significant text—provided an authorized view of Nina as ‘dying from a terminal illness’ and guided the remaining course of professional intervention, redirecting the medical and child protection investigation focus from concern about neglect and Nina’s malnourished condition to the provision of palliative care. In arguing that texts objectify people, suppressing their subjectivity, we illustrate how Nina did not receive medical treatment for her malnourished condition that she urgently required but how, instead, she became the objectified focus of a palliative care intervention.

Theoretical/Methodological Framework

A conventional understanding of the reading and writing of health care and other professional/organizational texts is that people write in them simply to record what happens or what they observe. Other people read them to find out ‘what really has happened’ and what has been observed. That is, the traditional sense of such texts is that they convey factual information, professional judgements, and so on, from here to there, reporting and communicating among people who have some authorized need to know. A text’s status as factual is often not questioned unless it is somehow improperly completed. Often, health care providers omit noting the relational aspects of texts.

One of the central themes in institutional ethnography is the “phenomenon of textually mediated communication, action, and

social relations" (Smith, 1990b, p. 209) and the way in which texts, as objectified forms of socially organized knowledge, permeate every aspect of our daily lives, including professional practice. Elaborating on this notion, Smith contends that texts should be understood as "speakers in a conversation" that readers enter when they engage with a particular text. Smith claims that knowledge, and the use of knowledge in textual form, coordinates activities among professionals and within organizations. Rather than assuming that words and ideas arranged in textual form can stand alone, the notion of a conversation implies *a relation that is being enacted* among writers and readers in which the text, too, is consequential and, as Smith suggests, *active*. Institutional ethnography makes use of Smith's theory of the social organization of knowledge (1990a and b, 1999) to query the factual reading of such texts. Methodological interest in the social relations of texts creates a capacity to learn new lessons from studying their everyday use.

Institutional ethnography also provides a particular method of interrogating the objectivity of such taken for granted use of texts and of textual information. Smith has written that "the artifice of the text detaches it from the local historicity of living and activity, or it seems so" (1999, p. 135). Institutional ethnographers, on the other hand, understand texts to be socially organized, products of actual people, and situated in time and space. The making of any text is "work done in actual settings by one or more people and as part of a course of action, whether of an individual, a group, an organization of some kind, or of an extended social relation concerting the activities of many" (Smith, 1999, p. 135). The people who enact texts, and their particular uses of the texts and the multiple purposes to which a text is put are all material for the analysis. This insight also offers the ground for an inquiry into the text as a social product—contributing to the social relations of a setting or settings.

We have already alluded to texts as part of conversations among those people who complete and refer to them. One of the features of textual conversations is that they standardize the almost limitlessly various understandings of readers; that is, they bring a similar understanding of what is read about to all those professionals who read the same text. This is, of course, one

of the key benefits of categorizing information that information systems make use of. Our article takes up this insight. As we shall see, the part of the health care providers' conversation in which Nina was constructed as 'dying from a terminal illness' standardizes how she was understood, just as Smith has suggested, "across multiple conversations in different local settings and at different times" (1999, 128). Whereas the routine reading of professional/organizational texts takes the objectivity of the text for granted, in treating the text as a substitute for the person described, we problematize this reading. We argue that as Nina became a textual object and her subjectivity suppressed, the texts of her care were substituted for the actual child living her life in the way she was. And, as the health care provider texts came into existence, creating an authorized view and identifying the 'proper' intervention, any alternative accounts and action were suppressed.

Analysis

The child protection social workers responsible for investigating Nina's possible neglect required Nina's mother to have her examined by a physician. Because Nina did not have a regular family physician, her mother took her to the local hospital's emergency department on May 16, two days subsequent to the child protection report. Following the emergency physician's examination and Nina's mother's request to not hospitalize Nina, the emergency physician recommended that Nina's mother provide Nina with a nutritional supplement and return five days later for weighing. On May 18, Nina's mother contacted a volunteer at the local hospice society to report (according to the hospice society records) that the emergency physician had described Nina's condition as a "terminal illness" and to request family services. Following this conversation, on May 20, the hospice volunteer contacted a community home care nurse to make a referral on Nina's behalf. While there is conflicting evidence about the mother's initial representation of Nina's circumstances to the hospice volunteer, the emergency physician did not contradict the mother's representation a few days later, on May 22, when he signed the DNR order. The piece of the analysis that we present in

this section, therefore, sketches the health care providers' textual conversations briefly and illustrates the pivotal role in the textual construction of Nina as 'dying from a terminal illness.' We show how the home care nurse, in particular, drew from information recorded in other texts and communicated to her to constitute Nina's situation as one in which, by following her organizational policy, she would properly enact as "preparing for a death in the home" (Coroners Service Inquest Exhibit 25).

We draw attention to the hospice volunteer's initial work that inscribes language from the palliative care discourse into the textual conversation. The hospice volunteer made handwritten notes of her visit to Nina's home on May 18, two days after Nina's discharge from the hospital's emergency department. These handwritten notes, located in the hospice society records on page 1 near the top of the page, state (with the date May 14 incorrectly referenced):

Dr. [H]: Saw [N] @ emerg. on Tues. May 14th. He has said her condition is terminal. He has asked to see her again on Tues. 21st.
(Coroners Service Inquest Exhibit 22)

On the last page of this four page record, the words "terminal illness" appear. Here is how the word "terminal" enters the textual conversation. It appears in the hospice society records (purportedly originating with the emergency physician) and introduces the palliative care discourse into the hospice volunteer's subsequent telephone conversation with the home care nurse when she called to make a referral. The home care nurse referenced the telephone conversation, dated May 20, in the home care nursing records as "T/c from hospice worker [SP] [phone number] regarding HNC referral for [Nina]" (Coroners Service Inquest Exhibit 23). This telephone conversation, recorded in home care nursing records prior to the home care nurse's home visit on May 21, guided her work. Her notes refer to Nina as "dying," for instance. The home care nurse's choice of what to record can be traced to the health care record's categories originating from the provincial and local health care policies that established the criteria for palliative care. Those particular palliative care policies provided the 'lens' through which the home care nurse conducted her assessment.

Ten year old girl—who is dying from Rett syndrome apparently was diagnosed [with] disease at 18 month states mother needing support re: care of child—child apparently not eating only taking sips of [water]— + sleeping for hours at a time—Hospice worker states mother needing to have [Nina] weighted tomorrow and was hoping that Rn could visit + do weight—otherwise was having to take child to hospital to be weighed—child apparently unable to stand and weighs approx 22 lbs

(Coroners Service Inquest Exhibit 23)

Note the word “disease” written on the second line. This word fits within the provincial health care policy criteria, for example, that establishes certain signs and symptoms or conditions, including the commodious category “other end-stage diseases,” that indicate when palliative care is appropriate. To ‘see’ Nina’s condition as a disease and link it with other information such as “dying from Rett syndrome,” “not eating,” “only taking sips of water,” “sleeping for hours at a time,” “unable to stand,” and “weighs approx 22 lbs” supported the construction of a child who was “dying.” This textual construction affirming Nina’s supposed need for palliative care happened very quickly despite the vagueness of the phrase “dying from Rett syndrome”—her disability since she was 18 months old—which did not explain what aspect of Rett Syndrome appeared responsible for Nina’s condition. Also notable in its absence is any reference to the “possible neglect” of Nina, despite the information provided by Nina’s mother to the home care nurse that child protection workers had contacted her.

On May 22, when the home care nurse arrived at Nina’s home to conduct her initial assessment, she produced a DNR order form for signing by Nina’s mother as an initial step in the authorizing process. After viewing Nina and obtaining information from Nina’s mother, the home care nurse began to ‘fill in’ the categories in the organizational home care nursing records. The home care nurse’s competence in working in words and text allowed her to construct Nina as a member of the class or category “palliative care.” It is this work that objectified Nina. In the home care nursing record section “Assessment Data,” for example, she recorded words and phrases such as: “recent weight loss of 10 lbs over 2 months,” “gone from 32 lb to 21 lb,” “drinking liquids and taking

very small amount of solids," "lying in fetal position," "no verbal response," and "grinding teeth." In the section "other relevant data," the first several categories direct the home care nurse to focus on Nina's physical symptoms connected to her "illness;" these categories include the words and phrases: "medication;" "wound/skin;" "pain;" "signs & symptoms;" "medical supervision/follow up;" "elimination;" and "mobility" (Coroners Service Exhibit 23). While the home care nurse's recording in the "pain" category states "mother feels [Nina] has no pain" (Coroners Service Exhibit 23), there is no additional information to indicate whether the home care nurse consulted Nina directly. Also absent from the record are words and phrases constituting categories that would require the home care nurse to record contextual information about Nina. These categories might include words and phrases such as: significant caregivers and others; school contacts; interests; medical and therapeutic contacts; and other professional involvement (ie child protection workers). Nina—the child who had attended school on a full time basis up to four weeks prior to the home care nurse's assessment—disappeared as a subjective figure. Instead, Nina became textualized, a textual object.

Following the "Assessment Data" section in the home care nursing records is a form directing the actions required to manage a death and linking those requirements to the palliative care policies. This form contains various categories related to anticipated action such as "planning for death" and "who to phone if death occurs at home." On that form, the following categories appear:

Aware of Diagnosis; Expectations—resuscitation;—death at home;—care expectations;—of physicians;—of home nursing; Options Discussed; Planning for Death; Who to Phone if Death Occurs at Home 1) Doctor will make house call or pt to hospital to be pronounced 2) Funeral Home notified 3) Others to call—eg. Minister, friend or volunteer to stay with family.

(Coroners Service Inquest Exhibit 23)

In 'doing her work,' the home care nurse completed this form and inserted information advising the reader that planning for Nina's inevitable death had occurred. This planning occurred five days subsequent to Nina's first contact with a physician about

her emaciated condition and prior to any 'ruling out' of possible neglect.

The Do Not Resuscitate Order

As it will become apparent, the DNR order was a central and key organizing text in the construction of Nina as a child 'dying from a terminal illness.' The authorizing process began when the hospice volunteer referred to Nina as "terminal" (in accordance with what Nina's mother had reported about the emergency physician's determination) and as a "ten year old girl who is dying from Rett Syndrome" (Coroners Service Exhibit 23). This process continued when the home care nurse went to Nina's home on May 21 to conduct her assessment. While there is no information in the home care nursing records to demonstrate that the hospice volunteer had asked the home care nurse to initiate the enactment of a DNR order, those same records show home care nurse arrived at Nina's home on May 21 with the DNR order form. The home care nurse 'saw' Nina as 'dying' and advanced this view in her own recordings beginning May 20. This advancement occurred despite the home care nurse's recording made on that date that Nina's "weight requires monitoring—as so little is known about Rett Syndrome unsure if wt loss is associated [with] progression of disease" (Coroners Service Inquest Exhibit 23). The home care nurse also made recordings that state "no doctors orders at present" and "[Nina] didn't have a fam Dr . . ." (Coroners Service Inquest Exhibit 23). Despite this information, the home care nurse proceeded with arranging to have Nina's mother sign the DNR order form on the same day the home care nurse conducted her initial assessment. This signing constituted the first step required in the order's enactment.

The home care nursing records, with their form structure and predefined categories, guided the home care nurse in her professional work. In the Assessment Data section, for example, there is a category with the heading "projected treatment goals," which contains a box with the words "palliative care." The home care nurse imposed a handwritten mark in the box. On the next page, in a category entitled "Planning for death," the date May 21 appears with the recording "DNR form started mother signed—given to Dr. [H] for signatures."

Client 10 years old unsure what she understands. Mother, sister, brothers aware Rett Synd. Mother wanted [Nina] to die at home—wants no medical intervention (ie) tube feeds. Hospice worker involved. DNR form started. Mother signed—give to Dr. H. for signatures.

(Coroners Service Inquest Exhibit 23)

It appears that the home care nurse's work on May 21 substituted for the emergency physician's further involvement with Nina; an involvement that might have entailed a more extensive and thorough medical examination, hospitalization to employ an aggressive feeding strategy, and/or consultation with a medical specialist. These actions represented options left open at the emergency physician's earlier assessment on May 16.

On May 22, however, the home care nurse assumed responsibility for weighing Nina and Nina did not return to hospital as the emergency physician had suggested. The home care nursing record for May 22 indicates that the home care nurse had a telephone conversation with the emergency physician, Dr. H., after she had placed a copy of the DNR order (signed by Nina's mother) in his hospital box:

states he signed DNR = will return to HNC box at hospital—wanting RN to weigh [Nina] each visit (Tues–Thurs–Sat) to see what her wt. is doing and to provide support to mother.

(Coroners Service Inquest Exhibit 23)

Also on this date, the recording shows that the home care nurse notified the ambulance and coroner by telephone of Nina's impending death (in accordance with organizational policy and practices, textually established). All participants in the conversation about the DNR order text appeared to treat the DNR order as the dominant interpretation. Again, Nina is not textually represented as a participant in the conversation and there is no textual reference showing that the home care nurse contacted the child protection workers to determine the status of the ongoing child protection investigation.

By May 22, six days after Nina's visit to the hospital emergency room, Nina's mother and two physicians had signed the DNR order. The DNR order was enacted and accomplished as an authoritative cap upon the construction of Nina as 'dying from

a terminal illness.’ We have seen how the hospice worker and the home care nurse took up courses of action that elaborated Nina’s condition in ways that fulfilled the policy of palliative care. Having done so, a predetermined course of action was available and was followed, preparing for a “death in the home.” This medicalized and textualized version of Nina subordinated other possible courses of action that might have addressed the problems with her weight loss. Her weight loss became associated with the diagnosis of Rett Syndrome, a disability she’d had since 18 months of age and the textual construction of Nina as a child ‘dying from a terminal illness’ undermined any interest in an alternative explanation for her malnourished condition.

According to what is recorded in the home care nursing records, the home care nurse did not see Nina after May 21 and the medical and child protection responsibility for investigating Nina’s possible neglect was sidelined. The home care nurse received a telephone call from the Ministry of Social Services social worker on May 28, the day that Nina died. The home care nurse’s recording suggests that the “fact” that Nina was dying and an enacted DNR order existed had already been conveyed to the social worker:

T.C. from [social worker] at Social Services—wanting to know if [Nina] is eating and concerned that competent person feeding her—made aware that [Nina] no longer eating/drinking—social services had been in contact [with][Dr. H] and aware DNR in place and [Nina] is dying—aware HNC will visit and support mother with dying process.

(Coroners Service Jury Inquest Exhibit 23)

While the home care nurse’s words “will visit and support the mother” shows how attention had shifted to the mother and away from Nina as the palliative care patient, it also confirms that the home care nurse had not visited Nina’s home prior to May 28 despite her several recorded attempts to arrange such a visit. The textual construction of Nina as a child ‘dying from a terminal illness,’ entrenched as an official and authoritative view, led the home care nurse to put various plans in place, such as phoning the coroner and ambulance, to support Nina’s ‘inevitable dying process’ rather than ensuring her malnourished condition

was properly diagnosed, treated and monitored by a medical professional. The home care nurse's actions were mandated as proper fulfillment of the policy. 'Neglect,' the central concern of the child protection report, became officially disconnected from and invisible to the health care providers' agenda.

The DNR order form contains the typewritten statement "the above identified patient has been diagnosed as having a terminal illness, or is considered to be near the natural end of their life" (Coroners Service Exhibit 10). Indeed, the home care nurse's last recording states what will happen when Nina dies: "Emergency then will contact pathologist who will prepare for autopsy + will take brain sample for Rett research" (Coroners Service Exhibit 23). This DNR order affirmed and established the 'official view' of Nina as a child dying from a terminal illness, resulting in Nina's disappearance as a subjective child and replacing her with the objectified notion of a potential researchable condition upon her death.

Conclusion

We began by querying what could be learned about 'what happened' to Nina, a 10-year-old child who died from "severe malnutrition, through an analysis of health care provider texts generated approximately two weeks prior to her death. We have shown how the health care providers were brought into relation with each other as they activated texts common to their work processes and how Nina, as object, was brought into a textually mediated conversation in which she was constructed as a child 'dying from a terminal illness.' We displayed how Nina, who was extremely emaciated, was overlooked in this conversation and how Nina, as a subverted subject, was replaced by a constructed view, a category, an authoritative account that articulated her to the palliative care discourse.

We have learned how the provision of health care services can be seen as being 'properly' conducted and yet not result in the best possible outcome for a child such as Nina. Indeed, the health care providers generated an accountable paper trail from policy to practice, through organizational documents. But Nina did not receive the response she needed to address her malnourished

condition and her life was not saved. Constructed as 'dying from a terminal illness,' palliative care was 'properly' offered, subverting a child protection investigation and further medical investigation into the possible causes of her malnourished condition.

By using institutional ethnography as a method of inquiry, we were able to draw attention in our analysis to the power of texts and of professional practice that is text-mediated. We particularly note the inherent danger of objective knowledge, constructed within texts for managing and organizing health care services, having the capacity to subordinate and subvert a wide scope professional interest in a person requiring health care services. These are the lessons that our analysis of the health care providers' texts offers to all service providers.

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