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Résumé

Le recours systématique à la rétention d'information chez les cliniciens : comment la volonté de protéger nuit aux besoins en information des adolescents atteints de cancer

Ignasi Clemente

La présente étude qualitative porte sur le recours à la communication partielle des renseignements chez les cliniciens et ses conséquences sur la capacité des adolescents à participer à la gestion de leur propre thérapie contre le cancer. L'auteur a observé pendant dix-huit mois, dans le cadre d'une étude ethnographique menée dans un hôpital de Barcelone, dix-sept jeunes patients atteints de cancer, leurs proches et les professionnels qui les traitaient. Il analyse d'un point de vue microsociologique et longitudinal les interactions observées au cours des activités médicales et sociales qui se sont déroulées pendant les 86 heures d'enregistrements vidéo qu'il a recueillis. Il constate que les cliniciens font appel à quatre stratégies pour éluder les questions directes posées par les adolescents : réponses évasives; réponses circonscrites; réponses qui n'en sont pas; et anticipation des questions. Selon lui, la rétention d'information limite grandement la capacité des adolescents de participer à leur propre thérapie; même si ses buts implicites sont de protéger le patient et de réduire l'incertitude et l'anxiété, elle ne les atteint pas. S'ils tenaient compte des besoins individuels en matière d'information, conclut l'auteur, les cliniciens sauraient mieux évaluer quels renseignements divulguer, comment s'y prendre et à quel moment intervenir.

Mots clés : jeunes patients atteints de cancer, communication, incertitude

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Clinicians' Routine Use of Non-disclosure: Prioritizing "Protection" over the Information Needs of Adolescents with Cancer

Ignasi Clemente

This is a qualitative study of clinicians' use of partial information disclosure and its consequences for adolescents' ability to participate in the management of their cancer treatment. A total of 17 pediatric cancer patients, their families, and clinicians were observed during 15 months of ethnographic fieldwork in a hospital in Barcelona, Spain. Eighty-six hours of videotaped medical and social activities were analyzed micro-interactionally and longitudinally. Clinicians used 4 strategies to evade direct answers to adolescents' questions: contingent answers, narrow answers, non-answer responses, and question forestalling. Information withholding by clinicians was shown to greatly limit adolescents' ability to participate in the management of their treatment and to be ineffective in its implicit goals of protecting the patient and containing uncertainty and anxiety. The author concludes that if clinicians were to integrate adolescents' individual information needs into their communicative practices they would be able to better assess what information to disclose as well as how and when to disclose it.

Keywords: Children and adolescents with cancer, communication, information needs, uncertainty, disclosure, truth-telling

Introduction

In this article, I examine clinicians' practices of partial information disclosure to adolescents with cancer in a hospital in Barcelona, Spain. Partial disclosure, defined as the selective combination of information disclosure and evasion, is not limited to deception by means of a false diagnosis or collusion by means of a misleading prognosis. It often takes the form of smaller, seemingly more mundane practices such as minimizing the information given to the patient or delaying its delivery. Much research has focused on the role of physicians in the delivery of bad diagnostic and prognostic news. Such a focus overlooks two facts: (1) this brief information event is often just part of the clinical work of informing the patient over an extensive period; and (2) while physicians may take the lead in breaking bad news, nurses play a central role in managing information before, during, and after the initial news delivery. Within a complex temporal framework, the pediatric nurse's multifaceted role of facilitator, supporter, counsellor, educator, teacher, and child advocate is more salient (Price, McNeilly, & Surgenor, 2006). Since nurses must deal with the management of *when*, *what,* and *how* to answer adolescents' questions, an analysis of physicians' routine use of partial disclosure and its consequences will help nurses to improve their communication skills and quality of care.

Partial disclosure may fail to reduce anxiety in adolescents with cancer as well as prevent them from taking part in treatment decisions, which has been shown to improve adherence and health outcomes in adults (Kaplan, Greenfield, & Ware, 1989; Roter et al., 1998). Patients' participation is key, because, while children are overcoming cancer more than ever before (Pizzo & Poplack, 2005), survivors have significant knowledge deficits regarding basic aspects of their diagnosis and treatment, which "could impair survivors' ability to seek and receive appropriate long-term follow-up care" (Kadan-Lottick et al., 2002, p. 1832).

Choosing the appropriate time to break bad news, and the amount of information to provide, is a difficult task (Buckman, 1984; Fallowfield & Jenkins, 2004). Moreover, what constitutes sufficient and honest information and who should decide whether to disclose it remain controversial issues (Groopman, 2005). Cultural variations in the disclosure of cancer information add to the difficulty of managing information (Fallowfield, Jenkins, & Beveridge, 2002; Holland, Geary, Marchini, & Tross, 1987; Moore & Butow, 2004; Mystakidou, Parpa, Tsilika, Katsouda, & Vlahos, 2004; Surbone, 2004). In Britain, most cancer patients, regardless of whether they are receiving curative care or palliative care, want to have all possible information, both good and bad (Fallowfield et al., 2002; Jenkins, Fallowfield, & Saul, 2001). In Spain, however, only 25 to 50% of cancer patients are informed fully and directly about their diagnosis, 61 to 73% of relatives are opposed to such disclosure, and a substantial number of cancer patients do not wish to be informed (Centeno Cortés & Núñez Olarte, 1998).

In the case of adolescents with cancer, the challenge is all the more daunting because the patient is often not the primary decision-maker. Clinicians may delay informing the adolescent in order to spare him or her additional suffering, while parents tend to monitor the information provided to their child throughout the entire cancer trajectory (Young, Dixon-Woods, Windridge, & Heney, 2003).

Despite research evidence showing that withholding information may not prevent pediatric cancer patients from learning about the gravity of their illness (Bluebond-Langner, 1978) or from experiencing distress (Allen, Newman, & Souhami, 1997; Claflin & Barbarin, 1991; Last & van Veldhuizen, 1996; Slavin, O'Malley, Koocher, & Foster, 1982), in general parents do choose to withhold information from their children (Chesler, Paris, & Barbarin, 1986).

Families of chronically ill children may favour limited information disclosure in order to protect each other, preserve a sense of "normalcy," and prevent the illness from becoming the focus of their lives (Bluebond-Langner, 1996). Bluebond-Langner (1978) argues that when a chronically ill child is dying, parents, clinicians, and the dying child him/herself engage in mutual pretence (i.e., the parties are aware that the child is dying but act if as s/he were not) because "interaction could take place as long as everyone acted as if they still had their social roles" (p. 232). Dying children conceal their awareness of their terminal prognosis because they are responsive to their parents' need to preserve their social roles and identities as caregivers. Bluebond-Langner and Perkel (1990) contend that, in light of the complexity of communication in the caring of chronically ill children, "the issue is not 'to tell or not to tell' but rather what to tell, how to tell, and who should do the telling" (p. 337).

To investigate what children and adolescents with cancer are told, as well as what they want to be told, I analyzed the patterns of disclosure vis-à-vis the specific cancer trajectories of a group of 17 patients in Spain (Clemente, 2005). The degree of disclosure varied with the particular medical and social circumstances of each child at each point in his/her treatment. Clinicians, parents, and patients constantly negotiated the limits of disclosure: Although they agreed on the need to limit information, they did not agree on what constituted sufficient information.

Non-disclosure was associated with a desire to protect patients not only from bad news but also — and more importantly — from a pervasive sense of anxiety caused by multiple, overlapping, and variable uncertainties related to diagnostic procedures, re-adjustment of treatment schedules, and the future. Based on my finding that adolescent patients often imagine worse scenarios than suggested in the information given later on by clinicians, I conclude that non-disclosure is an ineffective communication strategy for containing uncertainty.

Data and Methods

The present analysis of clinicians' use of partial disclosure was part of a qualitative study examining the participation of pediatric cancer patients in the management of information about their treatment. In order to analyze prospectively how children negotiate what they are told, I conducted an ethnographic study of the relationship between disclosure (i.e., the social process of communication regulation) and uncertainty throughout unpredictable cancer trajectories from diagnosis to long-term remission, relapse, or imminent death. An ethnographic approach, characterized by participant observation in situ (Spradley, 1980), was chosen in order to qualitatively ground pediatric cancer patients' lived experiences in the activities and interactions within which they occurred, took shape, and acquired meaning (Woodgate, 2006a, 2006b; Woodgate & Degner, 2002).

Seventeen (10 boys and 7 girls aged 3–18) Spanish- and Catalan-speaking cancer patients, their families, and a clinical team at a hospital in Barcelona participated in the study. Purposive sampling was used for maximum variation (Patton, 1990) to identify a wide range of communication patterns. Because of the hospital's field of specialization, most participants were adolescent boys with bone tumours undergoing first-line multimodal therapy. Adults completed IRB-approved consent forms. Children over 7 years of age provided written assent. Pseudonyms are used and some personal information has been modified to protect the identities of participants but no medical information has been changed.

Over a period of 15 months of ethnographic fieldwork in 2000–01, I used a range of ethnographic methodologies to observe children's cancer trajectories, including daily participant observation of medical and social activities, biographical questionnaires, unstructured and semi-structured interviews, and videorecordings by the patients and myself. In addition to extensive fieldnotes written both to document activities and to develop analytical categories inductively (Emerson, Fretz, & Shaw, 1995), this period of observation resulted in a corpus of 86 hours of recordings, including 14 hours of medical conferences.

Two complementary analyses were carried out to integrate the different data sets. The first was conducted with a subsample of 12 adolescents (aged 11–18) and the second with all 17 participating patients (aged 3–18). The first analysis examined adolescents' questions during 70 medical conferences, primarily daily ward rounds and outpatient visits. These conferences were the focal points around which treatment was organized, decisions made, and patterns of information disclosure established. They were also one of the few medical events at which parents, patients, physicians, and nurses were all present. The conferences exhibited the conventional practice of the physician playing the leading role in the delivery of information, particularly when the news is bad (May, 1993; Peel, 2003; Price et al., 2006; Ptacek & Eberhardt, 1996). In the vast majority of cases, the adolescents directed their questions at the physicians, the physicians responded, and the nurses took on a supportive role, listening and occasionally adding to the physicians' responses. As May (1993) points out, because of the emphasis placed on nurses' refraining from contradicting physicians, the manner in which physicians manage information during such medical conferences affects nurses' individual interactions with patients.

A total of 500 questions posed by adolescents were examined using the qualitative method of conversation analysis (Goodwin & Heritage, 1990). I focused on adolescents because they were the largest age group in the data set and the most active in terms of expressing their information needs and pursuing information. In conversation analysis, the sequential organization of talk makes it possible for the researcher to observe how a speaker publicly interprets what the previous speaker has said and done. The researcher primarily relies on how speakers display for "each other the meaningfulness of a prior action" instead of relying on accounts related during interviews (Goodwin, 2006, p. 6). Conversation analysis has been used extensively to study medical communication (Heritage & Maynard, 2006; Maynard, 2003).

In the second analysis, adolescents' questions were examined in conjunction with the data collected from the entire sample (aged 3–18). Two analyses were developed to contextualize the isolated micro-interactional examination of adolescents' questions. *Temporal contextualization* located the questions within individual cancer trajectories, relying on the contextual natural history mode (Briggs, 1998) and the illness trajectory approach (Bluebond-Langner, 1996, p. 13; Charmaz, 1991; Kleinman, 1980). *Communicative contextualization* analyzed the patterns of information compartmentalization, disclosure, and collusion (Bluebond-Langner, 1978, 1996; The, Hak, Koëter, & van der Wal, 2000).

Results

I identify four strategies used by clinicians to avoid answering adolescents' questions: *contingent answers, narrow answers, non-answer responses,* and *question forestalling.*

Contingent Answers

A contingent answer is accurate but highly flexible and open, with a provisional statement that is dependent upon certain conditions. An answer such as *if/when X happens, then Y will happen* is both uncertain and specific. It is uncertain because it is subject to revision if the underlying condition is not met. A contingent answer does not provide a specific date or commit the clinician to a specific course of action. At the same time, it is specific to the extent that it sets a sequential ordering of future events, imposing a logical order on an unknown and uncertain future.

In extract 1, Tony, a 15-year-old boy with Hodgkin's disease, asks a question about a severe infection that he has developed. Tony has relapsed once already, and although he does not present with swelling or lump masses in the head or neck area, many of his infection symptoms closely resemble common symptoms of Hodgkin's disease (Steen & Mirro, 2000, pp. 338–339). His pediatric oncologists know neither the cause of the infection nor how to treat it. Tony has been hospitalized for almost a week at the time of this interaction, receiving different courses of treatment. He is now on a new course of antibiotics that shows some promise. Tony has just asked how many days he has to remain in hospital for the intravenous antibiotic treatment. He has given a rationale for his question: He has told the clinicians he wants to calculate the number of days of total hospitalization. Tony was then given a contingent answer: It will depend on the presence or absence of fever.

Tony's pediatricians are identified as DR1 and DR2. Conversations were in Catalan and Spanish but only the English translation is presented here. A simplified version of the conversation analytic transcription conventions (Schegloff, 2007) is used to represent how different parts of talk are produced and related in time. Square left brackets "[" on two successive lines with utterances by different speakers indicate the beginning of simultaneous talk. Equals signs "=" connect two continuous lines by the same speaker, broken up to accommodate the placement of simultaneous talk. Parentheses enclosing certain numbers, such as (0.7) or (0.2), represent silence in tenths of a second — for example, (0.7) indicates 7/10ths of a second of silence. Colons ":" indicate sound stretching — the more colons, the greater the stretching. A hyphen after a word or part of a word indicates a cut-off or self-interruption. Punctuation marks are used not in the grammatical sense but to indicate the intonation contour of a segment of talk. A period indicates a falling intonation contour, a question mark a rising one, and a comma a continuing one. According to these conventions, an interrogative with a falling intonation contour takes a period and not a question mark. Finally, a word enclosed in parentheses indicates unertainty on the part of the the transcriber but represents a strong likelihood.

EXTRACT 1

```
1   TONY:  And if the fever goes but I still have a cou:gh, I would
2          still have to stay here.
3          (0.7)
4   DR1:   If you have no fever: maybe we'll let you go home. But
5          [you'd have to go two or three days without fever=
6   TONY:  [Oh::
7   DR1:   =at least. In other words [count on, if today you=
8   TONY:                            [hm,
9   DR1:   still have a fever, you can count count two or three days
10         here. More.
11  TONY:  Hm: interesting.
```

In line 1, Tony asks a second question to suggest a hypothetical scenario in which he will remain in hospital for as long as he has a cough. He has already been given a contingent answer to his fever question and is now seeking confirmation of an additional condition for having to remain in hospital. Note that Tony's question is itself an *if/then* contingent statement to be confirmed or disconfirmed with *yes* or *no.* Instead of answering *yes* or *no,* Doctor 1 responds to Tony's *if/then* contingent question with a contingent answer. Doctor 1 repeats some elements of Tony's question, but she makes her answer even more contingent. She repeats the structure *if/then* without any reference to the cough, adds a "maybe," which upgrades the uncertainty of her answer, and appends a long, contrastive explanation, prefaced by "but," that includes even more conditions that must be met. Tony's fever must not recur for at least 2 days. The number of *ifs* has multiplied, and, not surprisingly, Tony utters only an ambiguous "interesting," neither accepting nor rejecting the clinician's answer.

Narrow Answers

With a narrow answer, the clinician performs the action of answering but may not answer the question fully. Pedro, a 15-year-old boy with osteosarcoma, has just learned that he has a tumour and is to start chemotherapy immediately. Pedro's parents have opposed informing him about his diagnosis, but the clinicians have argued that it is better to tell Pedro. During the delivery of the tumour diagnosis, the clinicians have focused on the positive aspects of the treatment — for instance, that chemotherapy will reduce Pedro's pain. Pedro, on the other hand, uses his questions to ask about the negative aspects of the tumour and its treatment. In extract 2, Pedro asks if his leg will remain the same after the tumour is surgically removed.

EXTRACT 2

1 PEDRO: And does it remain the same as it was before?
2 (0.3)
3 DR1: More or less.
4 (0.2)
5 DR1: Eh? What happens is that this is a process, (0.2) which is slow and you
6 will also have to collaborate a lot, because you'll have to do a
7 lot of physical therapy.

Pedro's question does not get a *yes/no* answer. Instead, the clinician provides a delayed and vague "more or less." The clinician technically answers, but her answer contains little information and no elaboration of her "more or less." She continues with what sounds like an extension of her answer, but this results in a shift in the conversation, away from speculation about the outcome of the surgery and towards the process of physical therapy. Clinicians avoid giving detailed answers not simply to withhold information relevant to the question but also because a detailed answer might provoke questions on more sensitive topics.

Non-answer Responses

In a non-answer response, the clinician may give what seems like an answer but does not address the question. Reassurances, calls to be stoic and to remain optimistic, invitations not to worry excessively, teasing dismissals, and jocular downplaying of the patient's fears routinely take the place of answers. Clinicians try to convey the impression that there is no reason to worry. They pretend to answer but without providing information. This can fuel the patient's anxiety. In extract 3, Robert, a 17-year-old with osteosarcoma, asks what drug will be administered during his final chemotherapy session.

EXTRACT 3

ROB: And which chemo is th[is.
DR1: [Buagg it's a bomb::, bufshhhh
ROB: But what is it, cisplatin.
DR1: I've told you, if I were you I'd start worrying now.

Instead of giving the name of the drug, the clinician makes a teasing remark. Robert then asks about his most feared drug, cisplatin. During the previous administration of cisplatin, Robert developed mouth sores and had to be isolated. Robert assumes that if the clinician is not telling him what drug will be administered it could well be cisplatin. In response to Robert's request that the clinician explicitly confirm whether it is cisplatin, the clinician offers reassurance, jokingly dismissing Robert's fears as unfounded. Robert's fears are not assuaged with such non-answers, and he will continue to pursue information about his chemotherapy (not reproduced here).

Question Forestalling

A fourth communication strategy is to forestall sensitive questions from the outset as a precautionary measure. Two steps are essential in this strategy. First, clinicians may avoid questions that venture into the unknown by adhering strictly to talk about the present course of treatment. Evidence of the success of this strategy is that the adolescents in the present study never asked such questions as What caused my cancer? Why me? Why now? Will I be cured? or Will I die? The range of cancer topics discussed during medical interactions is thus restricted. Second, clinicians may avoid answering non-sensitive questions that might lead to sensitive ones. Extract 4 (below) offers strong support for my argument that a clinician may avoid answering a question not because of its specific subject matter but in order to pre-empt the discussion of sensitive matters later on.

In extract 4 we encounter Tony again, now asking questions about his autologous peripheral blood stem cell transplant, or auto-transplant, which is the last programmed therapy of his second-line treatment. Since he has already been hospitalized for more than a week because of his severe infection and sees no end in sight, Tony makes the assumption that his current infection and its treatment will delay his auto-transplant. Tony's initial question, about whether the auto-transplant has been delayed, is evaded on multiple grounds in 24 turns.

EXTRACT 4

1 TONY: Is the day of the auto-transplant going to be delayed,
2 (0.9)
3 DR2: Let's see, it's not that it's delayed or moved up.
4 (0.2)
5 DR2: We still don't have a date.
6 (0.3)
7 DR2: Because, (0.2) we have to wait first of all, for you to
8 re[cover.
9 DR1: [What kind of questions you[a:sk,
10 DR2: [Then, on the [day of the=
11 MOM: [shsss:
12 DR2: =auto-transplant? It's when you're pe[rfect.=
13 DR1: [Well.
14 DR2: [It- no no it doesn't have to be [delayed, relax.
15 DR1: [No- [No, bu- but listen, and
16 you say it's been delayed. If we still don't know what
17 day[:, [how can it be delayed.
18 DR2: [Of cou[:rse,
19 MOM: [shhh
20 DR2: Uh it's scheduled for when [you are well:.
21 DR1: [(Of course).
22 DR2: Imagi[ne that.
23 DR1: [It's scheduled for whe::n (0.2) whe:n [it's=
24 DR2: [(Look.)
25 DR1: =the moment most suitable.

A detailed analysis of the clinicians' responses is beyond the scope of this article but I will summarize some key observations. First, the clinicians offer Tony little or no time to expand on his question or to say anything else, since their responses continually overlap. Second, Tony's question could have been answered with a simple *yes, no,* or *the auto-transplant has not been scheduled yet.* Third, Tony's question is not as unfounded as the clinicians imply. The clinicians' responses indicate a high degree of uncertainty, as in "it's scheduled for when you are well" and "it's scheduled for when...the moment most suitable." These responses give Tony little information about the actual date of his auto-transplant. Fourth, the clinicians' dismissals of Tony's question implicitly reject any trace of pessimism: There is no reason to question or revise the treatment. However, their efforts to forestall sensitive questions are only partially successful, since Tony later poses another question, "But the sooner the auto-transplant, the better?" This second question (not reproduced here) is also dismissed.

Discussion

This study examined clinicians' use of partial information disclosure — that is, the selective combination of information disclosure and evasion. Specifically, I have analyzed four clinician strategies for evading questions posed by adolescents with cancer: contingent answers, narrow answers, non-answer responses, and question forestalling. In line with previous research, I have shown how partial disclosure often fails to reduce patients' anxiety. Extract 3, in which Robert reacts by asking about the chemotherapy drug he most fears when the clinician evasively responds with a tease, illustrates how adolescents may imagine worst-case scenarios in the absence of adequate information (Chesler & Barbarin, 1987; Orr, Hoffmans, & Bennetts, 1984). Partial disclosure also serves to create three obstacles to adolescents' ability to obtain the information they need and, ultimately, to deal with cancer and its treatment on their own terms. First, patients' accumulated knowledge about their treatment is undermined and the validity of their subjective experiences negated. Second, unless reassurances and teasing remarks are accompanied by information, the patient's information needs remain unmet. Finally, because adolescents routinely rely on questions to tell clinicians what they want, their ability to influence the decisions that parents and clinicians make on their behalf is directly undercut.

By analyzing in detail these smaller, seemingly more mundane forms of partial disclosure, this study responds to Bluebond-Langner's call for a focus on what to tell pediatric cancer patients, how to tell them, and who should do the telling. More importantly, I extend mutually exclusive definitions of disclosure and non-disclosure (Holland et al., 1987; Mitchell, 1998) to develop a nuanced conceptualization that identifies specific practices within these two extremes. As illustrated in my moment-by-moment analysis, what constitutes sufficient disclosure is debatable — it is in fact the cause of much disagreement among clinicians and patients. If we are to meet the information needs of pediatric patients, we must give their understandings of disclosure priority over any a priori and static definitions. Finally, by examining the actions of clinicians and children in a social context, the study advances research that analyzes chronic illness from the perspective of the child (Beresford & Sloper, 2003; Woodgate, 2006b; Young et al., 2003) rather than that of the parent (Clarke, Davies, Jenney, Glaser, & Eiser, 2005; Dixon-Woods, Findlay, Young, Cox, & Heney, 2001).

The findings have a number of implications for nursing practice. First, the expectation that nurses refrain from contradicting physicians (May, 1993) may lead them to adopt similar patterns of partial disclosure in their own interactions with patients. Second, because nurses often work within the disclosure limits set by family members and clinicians, a patient's "awkward questions" can be particularly stressful for a nurse who has developed his/her own independent relationship with the patient (May, 1990, 1993). Third, disclosure is a temporally unfolding process (Arber & Gallagher, 2003) that extends over the entire cancer trajectory (Clemente, 2005; Good, Good, Schaffer, & Lind, 1990). If nurses play a supportive role during physicians' delivery of news, they are pivotal to the long-term management of information (Price et al., 2006).

Appropriately managed disclosure of information can take place only with the collaboration of nurses. The active participation of nurses in decisions about disclosure is essential to their everyday work and to their role as patient advocates (Price et al., 2006). Nurses may be the health professionals best positioned to assess what pediatric patients know and want to know, as well as to mediate between patients, parents, and physicians. In their role as primary clinical liaison (Coyle, 2001), nurses are taking an increasingly active part in diagnostic and prognostic disclosure (Farrell, Ryan, & Langrick, 2001), which may result in better-informed cancer patients. Nurses and physicians can benefit by integrating the questions of adolescents into the difficult task of meeting their information needs, which will vary with the individual and over time. Since a generic, "one size fits all" approach is ineffective, adolescents' questions can serve to guide clinicians in determining what information they want when they are ready to be informed. In this way, clinicians and parents can decide *with* rather than *for* the patient how much more information he or she needs and is able to handle.

In order to provide comprehensive analyses of information disclosure, future studies should examine nurses' interactions with adolescents who have cancer when physicians are not present, particularly outside ward rounds and outpatient visits. Such research will elucidate how nurses develop communication practices and alliances with pediatric cancer patients within or beyond the limits set by parents and physicians. Future studies should also analyze the relationship between patient satisfaction with information disclosure and the expanding role and responsibilities of nurses (Peel, 2003). Finally, the triangulation of qualitative research methods and analyses (Woodgate, 2000) is necessary to overcome children's and adolescents' reluctance to discuss their cancer experiences, a common research limitation (Bearison, 1991; Phipps, Steele, Hall, & Leigh, 2001). Combining participatory methods of interviewing children (James & Prout, 1997; Pufall & Unsworth, 2004) with other methods, such as conversation analysis (Hutchby & Moran-Ellis, 1998), will provide new insights into how adolescents with cancer construct and experience their social worlds.

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Comments or queries may be directed to Ignasi Clemente, 10940 Wilshire Boulevard, Suite 810, Los Angeles, California 90024 USA. Telephone: 310-794-6290. Fax: 310-794-2954. E-mail: iclemente@mednet.ucla.edu.

Ignasi Clemente, PhD, is Postdoctoral Research Fellow, Pediatric Pain Research Program, Department of Pediatrics, University of California, Los Angeles, United States.