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Chapter 8

# Decision Makers in the Treatment of Childhood Illness in Madrid, Tenerife, and Chapel Hill

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There are many studies relating to medicine use during childhood; however, most of them focus on structural factors such as the influence of drug advertising (Atkin 1978; Rossiter and Robertson 1980), the quantity and type of medicines prescribed to children (Fosarelli, Wilson, and DeAngelis 1987; Naqvi et al. 1979; Sanz, Bergman, and Dahlstrom 1989), the efficacy and innocuousness of medicines in children (Olive 1989; Rubio González et al. 1989), and adverse drug reactions (McKenzie et al. 1976; Mitchell, Lacouture, and Sheehan 1988). Some studies have been devoted to exploring the psychosocial components related to illness and medicine use in childhood. Among these, Bush and Iannotti (1992) pointed out that children have more autonomy in the use of medicines than most adults would expect, and Bush and Iannotti (1988) addressed the maternal influence on children's orientations toward medicines in childhood. Other studies have explored children's concepts about health and illness focusing on the children's capacity to make decisions (Lewis and Lewis 1982; 1989), and social learning and cognitive development (Campbell 1975). However, only a few studies explored conceptual and ideological factors related to medicine use

as they are reported by children, placing such factors in the context of health and sickness behaviors within the larger cultural setting (Sachs 1990; Trakas 1990).

Our study is based on the idea that children's behaviors relating to health and medicines are developed early in life, and these behaviors are a reflection of their cultures. Therefore, differences in knowledge, behavior, and attitudes regarding treatment and the use of medicines during childhood illness should be expected across cultures.

This chapter focuses on the role of children and their caregivers regarding the use of medicines, home remedies, and medical services for the treatment of children's illnesses. Data gathered at the study sites of Madrid (Spain), Tenerife (Canary Islands, Spain), and Chapel Hill (North Carolina, USA) were used to draw out similarities and differences taking into account cultural factors.[1]

Some of the questions that were addressed are: Who decides when the child is sick? What type of therapy should be used? When is medication given? Who prescribes the medicines? The decision process is described from both the children and their parents' perspectives. Information about similarities and differences across cultures regarding the decision-making process in treatment and the roles played by the decision partners should help develop health education programs that take into account sociocultural factors.

## *METHODOLOGY*

Methods of data collection in the three study sites have already been described in an earlier chapter (see Chapter 2, this volume). The following adds information about the samples studied:

Sample size:

- Madrid: 100 children (62 boys and 38 girls) from second and fifth grades and their primary caregivers.
- Tenerife: 115 children (63 girls and 52 boys) from second and fifth grades, and 88 primary caregivers.
- Chapel Hill: 103 children (51 boys and 52 girls) seven and ten years old, and 102 primary caregivers. Only 57 children (29 boys and 28 girls) participated in the drawing interview).

Number of primary caregivers who worked outside the home:

- Madrid: 66 (66.0 percent)
- Tenerife: 54 (61.3 percent)
- Chapel Hill: 88 (86.3 percent)

This chapter presents data gathered via drawing–ethnographic interviews with the children, fever questionnaires for children and parents, an autonomy index for children, and a questionnaire of health and medicine use for parents (not used in Chapel Hill). Missing data have been omitted for each question and each site; therefore, frequencies and percentages are based on available data.

Two approaches were used for the analysis of the data: (1) "triangulation" to compare information gained from a variety of research instruments, and from parents and children as participants; and (2) "cross-cultural comparison" using both qualitative and quantitative data from the three sites. These two approaches required the use of observational and basic statistical techniques (frequencies and percentages) for the analysis of the data.

## *RESULTS*

In relation to the question, "Who decided that the child was sick?" the children in both Madrid and Chapel Hill identified three main figures: the mother, the doctor, and the child her/himself. (Data from Tenerife were not available.) Even though children in both Madrid and Chapel Hill considered the mother as the one who decides in most cases that the child is sick, this seems to be more obvious in the Madrid sample (45 percent) than in the Chapel Hill sample (33 percent). One child said, "My mother knows when I feel bad and she tells me if I have fever or not." Another child said, "My mother knew it first because she saw me coughing a lot." The doctor also plays an important role in this decision in both samples; however, this is more evident in the Chapel Hill sample. The percentage of children who identified themselves as the ones who recognize the illness state was larger in the Chapel Hill sample (25 percent) than in the Madrid sample (12 percent). In Madrid, sometimes the mother confirmed the child's own diagnosis as shown in the following ex-

TABLE 8.1. Person First Noticing Child Had Fever According to the Children

| Person | Location* | | |
|---|---|---|---|
| | Ma | Te | CH |
| Mother | 61% | 65% | 56% |
| Father/both parents | 18% | 3% | 8% |
| Other relative/various people | 12% | 6% | 7% |
| Child | 4% | 11% | 10% |
| Other | 3% | 11% | 19% |
| Don't know | 2% | 4% | 0% |

* Ma: Madrid; Te: Tenerife; CH: Chapel Hill.

ample: "I told my mother that I was feeling sick, and she told me that I had a cold because she saw me coughing a lot."

The data from the fever instrument showed that in the three samples the mother was viewed by most children as the one who told them that they had a fever (Table 8.1). The father appeared to be more involved in the Madrid group than in the other two sites, and more children considered themselves as the ones who identified the fever in Chapel Hill and Tenerife than in Madrid.

As shown in Table 8.2, when a similar question was posed to the caregivers, their responses were consistent with the children's responses. More mothers in Madrid and Tenerife reported that they first noticed that the child had a fever, and more mothers in Chapel Hill than in the other two sites viewed the children as the ones who first noticed the fever.

Many children in the three samples stated that their parents noticed they had a fever by touching their foreheads and finding them warm (Madrid, 37 percent; Tenerife, 33 percent; Chapel Hill, 12 percent). Most parents and other caregivers agreed with the children in the way they noticed the child's fever (Madrid, 25 percent; Tenerife, 22 percent; Chapel Hill, 39 percent). Also, some parents reported that the child tells them that she or he has fever. The percentage was relatively high in the Chapel Hill sample (Madrid, 12 percent; Tenerife, 14 percent; Chapel Hill, 21 percent).

TABLE 8.2. Person First Noticing Child Had Fever According to the Caregivers

| Person | Location* | | |
|---|---|---|---|
| | Ma | Te | CH |
| Mother | 72% | 63% | 55% |
| Child | 11% | 13% | 23% |
| Father/grandparent | 9% | 15% | 9% |
| Other | 4% | 2% | 10% |
| Don't know | 4% | 7% | 3% |

* Ma: Madrid; Te: Tenerife; CH: Chapel Hill.

The majority of the children in the three sites recalled that the last time they had a fever, their mother measured their temperature with a thermometer (Madrid, 73 percent; Tenerife, 70 percent; Chapel Hill, 66 percent). Participation of the fathers was low (Madrid, 7 percent; Tenerife, 11 percent; Chapel Hill, 5 percent).

When the Madrid children talked about "Who helped them when they were sick?" 43 percent of them mentioned their mother together with the doctor, 21 percent reported both parents and the doctor, 17 percent only the mother, and 11 percent both parents. The children interviewed in Chapel Hill reported most frequently the mother (47 percent), followed by both parents (25 percent), but just a few of them (6 percent) mentioned the doctor or nurse as the one who helped them during the recorded illness episode. No data from Tenerife were available.

When questioned about who cared for the child when he last had a fever, most caregivers in the three samples named the mother (Madrid, 61 percent; Tenerife, 31 percent; Chapel Hill, 60 percent). The father seemed to be less involved in Madrid (16 percent) and in Tenerife (16 percent) than in Chapel Hill (33 percent). The main caregivers in Spain got help from relatives and other people such as friends and neighbors (Madrid, 19 percent; Tenerife, 43 percent), which did not seem to be the case in the Chapel Hill sample (6 percent).

Most interviewed parents in Madrid and Tenerife mentioned the mother as the main caretaker when the child is sick, followed by

both parents (Table 8.3). In Madrid the father seemed to play a more important role as main health care provider than in Tenerife.

"The General Questionnaire on Health and Medicines for Parents" also revealed the importance of the role played by the mother in Madrid (43 percent) and Tenerife (37 percent) regarding the persons who take care of the child when she or he is sick, but it shows that mothers get help from the fathers (Madrid, 24 percent; Tenerife, 17 percent) and grandparents, other relatives, and other people (Madrid, 23 percent; Tenerife, 45 percent) in order to take care of a sick child when sick. No data from Chapel Hill were available.

Soon after the illness episode is identified, there are some decisions to be made. Should the child go to bed? Should the child stay home and not go to school? Should a doctor be called or visited? Will medicines and/or home remedies be used?

Eighty-five percent of the children from Tenerife stated that they stayed in bed the last time they had a fever. The percentage was lower in Madrid (62 percent) and Chapel Hill (55 percent). In the three samples it was clear that, according to children, this decision was mostly made by mothers (Madrid, 58 percent; Tenerife, 54 percent; Chapel Hill, 61 percent). In some cases, both parents (Madrid, 12 percent; Tenerife, 8 percent; Chapel Hill, 7 percent), or the father (Madrid, 7 percent; Tenerife, 11 percent; Chapel Hill, 2 percent) decided that the child should stay in bed. A significant percentage of children in the three sites considered themselves as the

TABLE 8.3. Main Health Care Provider According to the Caregivers

| Person | Location* | |
|---|---|---|
| | Ma | Te |
| Mother | 74% | 67% |
| Father/both parents | 23% | 15% |
| Various people | 1% | 13% |
| Other | 2% | 5% |

* Ma: Madrid; Te: Tenerife; No data from Chapel Hill available.

ones who made the decision to stay in bed; however, this percentage was higher in the Chapel Hill sample (Madrid, 12 percent; Tenerife, 11 percent; Chapel Hill, 19 percent).

Resting appeared to be the most frequent form of nonpharmacological therapy in the three samples according to the children's interviews (Madrid, 39 percent; Tenerife, 51 percent; Chapel Hill, 41 percent). Special diet as well as drinks were more popular among Madrid (42 percent) and Chapel Hill (28 percent) samples than the Tenerife sample (11 percent). The percentage of children who reported beverages as a therapeutic method was higher in Madrid (25 percent) than in Tenerife (3 percent) and Chapel Hill (16 percent). Honey for colds, water with lemon, and chamomile for upset stomach were among the most common home remedies used by Madrid families, as reported by children. Only 1 percent of the Madrid and 3 percent of the Chapel Hill children stated that home remedies were not used, while 22 percent of the children in Tenerife mentioned that this type of therapy was not used during the described illness episode.

According to the reports of caregivers in the three sites, the mother (Madrid, 50 percent; Tenerife, 29 percent; Chapel Hill, 59 percent), followed by both parents (Madrid, 23 percent; Tenerife, 27 percent; Chapel Hill, 18 percent), decided in most cases that the child with fever should stay home. More doctors made such decisions in Tenerife than in the other two sites (Madrid, 4 percent; Tenerife, 27 percent; Chapel Hill, 3 percent).

According to the children who were interviewed in the Madrid study, doctors were not consulted in 21 cases (21.0 percent). They explained that the mothers' knowledge and experience were the reasons for not seeking professional help, as seen in the following response: "My mother, as she knows what, she gave me aspirins." When doctors were not consulted but children took medicines, mothers made the decision in all cases about what medicines to give them. Data from Tenerife and Chapel Hill were not available. However, in the general questionnaire for parents, most caregivers in Madrid (55 percent) and Tenerife (56 percent) agreed with the children's opinions from the Madrid sample; when the child is sick he or she usually is taken to the doctor. And when they are not taken, it is because the parents believe they know what medicines

the children can take and what home remedies to use. Data from Chapel Hill were not available.

The majority of the children in the three sites took medicines during their last fever episode (Madrid, 78 percent; Tenerife, 89 percent; Chapel Hill, 85 percent). There was a difference of 11.0 percent between the highest (Tenerife) and the lowest percentage (Madrid).

Data obtained from the questionnaires about the child's last fever episode revealed that, according to the children in Madrid and Tenerife, the mother was the one who prescribed the medicines (Table 8.4). In most cases, doctors are perceived by children as the second major source of prescription. However, as shown in Table 8.5, according to the caregivers in both sites, the main prescribing source was the doctor, followed by the mother.

Both children and caregivers were questioned about "Who gave the medicines to the children the last time they had a fever?" In the children's questionnaires, the highest percentages identified the mothers in all three sites; however, this was significantly lower in Chapel Hill than in Madrid and Tenerife. On the other hand, more children in the Chapel Hill sample identified both parents and various persons as the ones who gave them the medicines. A very small percentage of children in the three samples recognized that they took the medicines by themselves.

Caregivers agreed with children in that the mothers are the ones in charge of giving the medication to the child (Tables 8.6 and 8.7); however, the percentages were higher than the ones in the children's responses. It was also interesting that for both the caregivers' and children's responses, in Chapel Hill the percentage naming mothers as in charge was lower, and the percentage naming both parents was higher, than in the Madrid and Tenerife samples.

The question about who gave the medicine to the child was posed in the same manner to both the children and the caregivers; a very small percentage of children mentioned themselves as the ones who took the medicine, and no caregivers identified the children as autonomous in this question. However, when a more specific question was posed to the parents, a small percentage recognized that children sometimes took the medicine on their own (Madrid, 7 percent; Tenerife, 8 percent; Chapel Hill, 6 percent).

TABLE 8.4. Person Prescribing Medicines for Fever According to the Children

| | Location* | |
|---|---|---|
| Person | Ma | Te |
| Mother | 42% | 50% |
| Doctor | 32% | 29% |
| Father/both parents | 12% | 8% |
| Other | 11% | 8% |
| Don't know | 3% | 5% |

* Ma: Madrid; Te: Tenerife; No data from Chapel Hill available.

TABLE 8.5. Person Prescribing Medicines for Fever According to the Caregivers

| | Location* | |
|---|---|---|
| Person | Ma | Te |
| Doctor | 50% | 52% |
| Mother | 41% | 36% |
| Father/both parents/relatives | 5% | 6% |
| Don't know | 4% | 6% |

*Ma: Madrid; Te: Tenerife; No data from Chapel Hill available.

The majority of the children in the three samples expressed that they never went to buy medicines by themselves (Madrid, 76 percent; Tenerife, 58 percent; Chapel Hill, 94 percent); the percentage was higher in the Chapel Hill sample, while the lowest corresponded to the Tenerife children. At the same time, a higher percentage of children in Chapel Hill stated that they have physical access to the medicines that are kept at home (Madrid, 74 percent; Tenerife, 65 percent; Chapel Hill, 77 percent), and more children in Chapel Hill (18 percent) than in Madrid (10 percent) and Tenerife

TABLE 8.6. Person Giving the Medicine for Fever to the Child According to the Children

| Person | Location* | | |
|---|---|---|---|
| | Ma | Te | CH |
| Mother | 69% | 72% | 54% |
| Both parents | 10% | 7% | 18% |
| Child/doctor/various people | 6% | 4% | 15% |
| Father/a relative | 12% | 10% | 11% |
| Don't know | 3% | 7% | 2% |

* Ma: Madrid; Te: Tenerife; CH: Chapel Hill.

(12 percent) indicated that they would take a medicine if they were home alone with a bad headache.

## *DISCUSSION*

There are similarities as well as differences among the three samples (Madrid, Tenerife, and Chapel Hill) regarding the process of making decisions during children's illnesses. In general terms, there are more similarities than differences. However, a close look at the data gathered from both children and caregivers by various instruments shows important differences that require further analysis.

In terms of the similarities, it is clear that, in all three samples and according to both children and parents, the mother has the primary role as a caretaker during treatment. She is the one who makes most decisions regarding treatment, even though children and caregivers' responses to the following two questions show that doctors share the main responsibility with the mothers: "Who helped the child when she or he was sick?" and "Who prescribed the medicines?" Most parents in the three samples did not seem to realize that children perceive themselves as decision makers and active participants in this process. The children's participation is clearly active in certain cases, such as when they tell their mothers that they want to go to bed, or when they take the prescribed medicine on their own,

TABLE 8.7. Person Giving the Medicine for Fever to the Child According to the Caregivers

| Person | Location* | | |
|---|---|---|---|
| | Ma | Te | CH |
| Mother | 83% | 79% | 64% |
| Both parents | 7% | 5% | 22% |
| Other | 6% | 9% | 14% |
| Don't know | 4% | 7% | N/A |

* Ma: Madrid; Te: Tenerife; CH: Chapel Hill.

as allowed by the caregiver. In other situations, the children collaborate in the process of making decisions in more subtle ways; for example, by reminding caregivers about the time to take the medicine, or by telling their parents that they feel better and they want to go back to school. There is a specific question to which responses showed similarities across sites, but significant differences between children's and caretaker's responses ("Who gave you the medicine?" and "Who gave the child the medicine?"). The responses show that the percentage of caregivers who identified the mother as the one in charge of giving the medication is higher than the percentage of children who named the mother, even though there is agreement that mothers play the major role. Also in the three samples it was observed that caregivers did not spontaneously mention the children as the ones who took the medicine, while a small percentage of children identified themselves as the ones who took the medicine on their own.

Data from Madrid, Tenerife, and Chapel Hill indicate that fathers have a secondary role in this general picture drawn by children and primary caregivers. There was only one question in which, according to primary caregivers in the three sites, fathers play an important role, but after the mothers: "Who decided that the child should stay home and not go to school?" It would be easy to interpret that one possible reason for the fathers' participation in this decision is that routines and schedules change greatly when a sick child stays home.

As was already stated, children's and caregivers' responses coincide on most questions. However, a significant difference was observed across sites regarding the question "Who prescribed the medicine?" Most children pointed to the mother, followed by the doctor, while caregivers named the doctor, followed by the mother (data from Chapel Hill were not available). Who actually prescribes the medicine is not as important here as who children *perceive* as prescribers; and, in that sense their responses are clear: mothers first.

Most children in the three sites stated that they have physical access to the medicines, that they never went by themselves to buy medicines, and they would do something else instead of taking a medicine in the event they were home alone with a bad headache.

As was expected, there were more similarities between the data of Madrid and Tenerife than between the data of the United States and either of the Spanish sites. Data obtained at the two Spanish sites reflected many similarities, which indicates that cultural factors play a major role in the treatment of childhood illnesses.

Some of the major differences between Chapel Hill and the two Spanish sites are noted here. First, Chapel Hill children are more active partners in the decision-making process regarding treatment, and this fact is recognized by both children and caregivers. Also, more children in the Chapel Hill sample reported that if they were home alone with a bad headache they would take a medicine. However, surprisingly, when it comes to the actual fact of taking the medicine, the percentage of children that identified themselves as the ones who actually took the medicine during the fever episode was similarly low in all three sites, and according to parents, fewer children in Chapel Hill took medicines on their own, in spite of the fact that they have more physical access to medicines kept at home than Spanish children.

In general, Spanish children seem to be less active than Chapel Hill children in the process of making decisions about treatment; however, they have more autonomy than Chapel Hill children with respect to taking the medicines (according to parents), and buying medicines by themselves.

Caution should be taken, and health education programs should address the fact that Chapel Hill children recognize that they have physical access to the medicines, and that a significant percentage

in the sample stated that they would take a medicine by themselves if they were home alone with a headache.

The role of the mother is more prominent in the Spanish sample than in the Chapel Hill sample. The traditional role played by Spanish mothers regarding health care is reflected in these data. This role has been kept in spite of the fact that more than half of the interviewed mothers in Madrid and Tenerife were working outside the home.

The greater autonomy of Chapel Hill children could be explained by factors such as: more primary caregivers work outside their homes (which means that when children are ill they have to care for themselves, since parental sick leave does not exist for the great majority of workers and working parents have to use their own sick days–usually two per month–when their child becomes ill); children are more exposed to medicines since medicines can be acquired in places outside drugstores; and there is more drug advertising.

More grandparents and other relatives are viewed as participants in the decision-making process in the Spanish sites than in the Chapel Hill site. Extended families are common in the Spanish culture, and physical closeness allows grandparents and other relatives to be active participants in the treatment of childhood illness. The family support network is usually not present for caregivers from the USA because middle-class people tend to move away from their families for employment.

Similarities among Madrid, Tenerife, and Chapel Hill in the process of making decisions regarding the use of medicines in childhood might be partially explained by the use of a similar Western biomedical model in all three sites. Differences might be explained by cultural factors, since it was observed that responses were more similar between Madrid and Tenerife than between either Spanish site and Chapel Hill.

The question is: What is the basis on which children and caregivers in Madrid, Tenerife, and Chapel Hill make decisions regarding the use of medicines and other types of treatment? In Spain, children's knowledge and attitudes relating to health and sickness and medicine use are developed almost exclusively through personal experience and family influence. There is no health education curriculum for children in the schools, and health education for adults

is very limited and does not include instruction about medicine use. This means that there is no education about medicine use in the schools, and that the information that children get from their parents depends on what their parents know. Drug advertising is also very limited. In Chapel Hill children are more exposed to medicines; there is more advertising, and medicines are available in places commonly visited by children, such as supermarkets. Another factor that might help explain differences between countries is the fact that in Chapel Hill schools have health education programs that might make children more aware of their responsibilities in these matters, even though such programs do not include the topic of medicine use.

Therefore, environmental and cultural factors appear to be fundamental in explaining similarities and differences in the use of medicines during childhood and the process of making decisions about it.

## *IMPLICATIONS FOR HEALTH EDUCATION*

In this final section, some suggestions for the development of health education programs based on the results of the study are presented.

Health Education programs should take into consideration that

1. the main figures involved in the process of making decisions regarding medicine use are the mother, the child, and the doctor;
2. the cognitive development of the child at the different stages allows him/her to comprehend and participate in such a process; and
3. environmental and cultural factors appear to play a major role in the process of making decisions about medicine use.

Children's attitudes and beliefs about medicine use are held together by an internal logic created by them. Parents and doctors should be aware that children seven to eleven years old begin to use the logic to solve problems, and to include internal physiological characteristics in their descriptions of illness causation and effects of medications.

Children's decision-making skills regarding medicine use can be developed through the use of strategies that take into account cultural factors. Some of these strategies are (1) role playing (e.g., recreating

illness episodes and actions of caregivers such as parents, doctors, nurses) which can include recognition of symptoms that need to be conveyed to adults, steps involved in gaining adult permission to take medications, and noting specific amounts and methods of medication administration; (2) verbal persuasion which should be directed toward increasing parental self-efficacy regarding treatment, not only toward explaining the consequences of performing or not in a particular way. Persuasive efforts should also focus on giving children the opportunity to practice the desired behavior and therefore improving their skills and self-confidence (Nader 1985); (3) increase in doctor's role in promoting modeling behavior (e.g., involving children directly in their therapy, showing how to apply cream in appropriate amount, demonstrating how to measure amount of medication, or how to read a thermometer) (Nader 1985).

Children who are able to communicate with their health care providers will grow into adults who can do the same (Igoe 1987). Asking children to engage in the decision-making process related to their own care is evidence that caregivers–including doctors–believe that children are capable of mastering a situation. They have the opportunity to help children improve their self-image and to feel better about themselves (Lewis and Lewis 1990). As a result of this type of communication, children will be empowered to take part in their health maintenance and care into adulthood. Doctors and primary caregivers must make sure that children understand what is said to them–and for this reason, they must listen to the children.

## NOTE

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