Once the investigator chooses the examples and accompanies them with concise descriptions, these findings are presented for other investigators to peruse. The purpose of these presentations is to allow others to validate the observations made by the initial investigator. McQuown (1971a) outlined this validation process in his summary of *The Natural History of an Interview*:

Uncertain though our interpretations of behavior might be, we may now produce a corpus of specified behavioral phenomena on which such interpretations are based, a corpus which is available to all for repeated examination for correction where correction is demonstrably necessary, for refinement where refinement is desired, and for the testing of new interpretive hypotheses where the old ones have proven to be unjustifiable. (p. 8)

The purpose, then, is: (a) to present distinctions drawn from the talk of parents about their child's heart murmur, (b) to accompany these distinctions with surrounding talk from the interviews so as to provide needed context, (c) to supply descriptions or rationales for these distinctions, and (d) to allow readers the opportunity to judge the validity of the conclusions drawn from the talk. This mode of presentation allows for the type of refinement that McQuown (1971a) suggested above.

In Chapter 4, what was taken to be the most pronounced features of families' understandings of the context of referral and their concerns about their children will be displayed. Part of what made these features prominent was the poignancy of their expressions, something that would not have been revealed in other sorts of research into this problem. Also, however, this analysis indicated a number of points of divergence between the medical view of referral that was reviewed above, and the experiences of the families interviewed. These, too, were salient features to be displayed.

Chapter 4 Analysis and Interpretation

INTRODUCTION

The analysis in this chapter is presented through three, intertwining threads: (a) exemplars (Hopper, 1988) chosen to represent distinctions discovered in or constructed from the 32 family interviews, (b) descriptive passages which attempt to highlight the distinctions found in the exemplars and illustrate relationships between different exemplars and between exemplars and points made in the literature, and (c) Recursive Frame Analysis (RFA) (Keeney, 1990a, 1990b) passages which attempt to describe the distinctions drawn in the interaction between the interview exemplars and the descriptive paragraphs. None of the threads have hierarchy over the other two: Each informs the others and are, in turn, informed by the others. The three strands are woven together to produce a pattern which strives to represent the stories of the families in the study. The tales are the families' interpretations of their experiences during the referral process to a pediatric cardiologist. For all of the families, the reason for referral to a heart specialist is the same: A child in the family has been diagnosed as having a heart murmur. The following is a presentation of these stories.

The subsequent exemplars were chosen from various transcripts of the family interviews. Certain conventions were used in the presentation of these exemplars: (a) Names of the speakers and medical personnel were deidentified so as to protect their confidentiality, (b) abbreviations were used to designate the speakers (M for the mother, F for the father, and I for the interviewer), (c) material inserted into the exemplars to show emphasis (i.e., italics added), or to expand the utterances so as to make the meanings clearer (i.e., in the cases of indexicality or ellipsis) were placed in brackets.

DISCOVERY AND REFERRAL

The first part of each interview focused on how family members discovered or became aware of their child's possible heart murmur. In analyzing the interviews, two distinct patterns of discovery emerged.

For some families, the heart murmur was first identified during the medical consult which lead to the referral to the pediatric cardiologist. These discoveries took place under varying circumstances: during football physicals, regularly scheduled checkups, and appointments for other illnesses such as ear infections.

Excerpt A

- (01) I: Okay a a few questions just to kind of begin is what happened
- that brought you here today with your son?
- (03) F: Well he went to take a physical to play football [the doctor
- discovered he had] a little heart murmur.

- (01) I: So when you took uh Susie to Dr. Girardi, he was doing I guess a
- three-week check up maybe.
- (03) M: Yeah, two weeks.
- (04) I: ... So what did he tell you?
- (05) M: Her heart was beating too fast.

While the discovery in the last example (B) came early in the child's life (at "a three-week check up"), for some families (Excerpt C), the heart murmur was discovered even sooner while their child was a newborn and was still in the hospital after delivery.

Excerpt C

- (01) M: Well, uh, when he was born the pediatrician was on call (.)
- noticed a small heart murmur and said it was a small hole in the
- (03)back of (()) chamber and he just wanted us to check it out and
- made an appointment and that's what we are here (.) just checking it out.

For other families, there had been prior knowledge of irregularities in their child's heart, but the identification of a heart murmur represented a change from a previous diagnosis. Excerpt D was from a mother who had noticed that her son had "an irregular heartbeat." She had made her discovery while playing with a stethoscope the family owned. Her son had had a couple of appointments over several months and none of the medical personnel had mentioned anything about her son's irregular heartbeat. In the quote, the mother tells how "irregular heartbeat" was rediagnosed as "heart murmur."

Excerpt D

- (01) M: ... and so this time I asked the doctor myself, I said it has never (02)been brought to my attention I said but he does have an irregular
- (03) beat. And she says "well it's just a murmur" and I said "well I've
- (04)never been (.) told that he had a heart murmur"

In contrast to these families, other families had knowledge of a heart murmur prior to the medical consult with the referring physician.

Excerpt E

- (01) I: What's your understanding of what is going on with Tim?
- (02) M: I really don't know, his doctor just told me, his pediatrician, that
- ... visible at school... Tim has bad knees and all ... said that (03)
- she heard a click, and she said that it may be due to his chest (04)
- kind of goes in, and she said that sometimes this happens, she (05)
- didn't think it was anything serious but she wanted it checked (06)
- he's had a heart murmur when he was smaller, he was born with (07)
- one but that accounts for . . . she called it a micro . . . valve or (08)
- something like that, I don't know. (09)

Excerpt E illustrated some aspects of the discovery process that were common to many of the families interviewed: The families questioned their knowledge of what was happening with their child: "I really don't know, [italics added] his doctor just told me" and "she called it a micro ... valve or something like that, I don't know" [italics added] and they seemed to be caught up in a "yes, but" -type of experience: "she didn't think it was anything serious but [italics added] she wanted it checked out."

Excerpt F was another example of the "yes, but" scenario: "she [the doctor] didn't say it was anything serious but [italics added] she thought that maybe it's just a good idea to go ahead and check it out . . ." The last part of the mother's statement was also interesting. Although some families had considerable exposure to heart-related medical care, others had neither the personal/familial nor the medical context from which to understand the current happenings. For this mother, there appeared to be little prior contact ("II never had anything like that happen to my kids") that would have helped her during the discovery/referral procedures.

Excerpt F

- (01) I: What did Doctor Carter say at the time (()) she presented to you
- (02)
- (03) M: Well she didn't say that it was anything serious but she thought
- that maybe she it's just a good idea to go ahead and check it out (04)
- (()) see what's going wrong it's gonna be I I never had anything (05)
- like that happen to my kids (06)

In Excerpt G, the mother described how she had her husband call the doctor the evening the referral decision was made. The mother and/or father were not sure that the mother had correctly understood the doctor's rationale for referral: "I wanted to know for sure I had not misinterpreted anything she [the doctor] had told [mel. . ."

MEDICAL DISCOURSE AND SYSTEMIC FRAMES OF COMPREHENSION

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Medical Discourse and Systemic Frames of Comprehension

Excerpt G

(01) I: Okay, so what your husband knows is what you reported to him?

(02) M: Yeah. Well he also talked with the doctor. He called her that evening and they discussed Tim also.

(04) I: Okay . . . you wanted to find out more or what . . .

(05) M: Well, I wanted to know for sure I had not misinterpreted anything

she had told . . . you know . . .

Like the mother in Excerpt G, many parents discussed their sense of not knowing whether they understood either the diagnosis and/or the decision whether or not to refer. In Excerpt H, the mother demonstrated her lack of certainty concerning the diagnosis: "he [the doctor] called it a benign murmur that is what I'm thinking [italics added]" and "That the blood might [italics added] be rushing too fast. . ." This hesitancy or hedging was understandable given that she had not heard the conclusive word from the cardiologist. But what was also curious in the quote, was how she recalled the doctor's use of a disclaimer (Hewitt & Stokes, 1975): "but he [the doctor] said I don't know." Hewitt and Stokes (1975) described as "an interactional tactic employed by actors faced with upcoming events or acts which threatened to disrupt emergent meanings and discredit cathected identities" (p. 1). By qualifying his statement with an utterance such as he used, the doctor could have been preserving his identity as a doctor (i.e., an expert): He was such an expert that he could predict when he was going to be wrong. If his diagnosis turned out to be correct, then the disclaimer could have been dismissed as being a necessary caution.

Excerpt H

(01) I: Did they talk to you about it?

(02) P: Briefly (.) I asked them what it was and they told me that the

sound makes my heart go boom boom uh okay

(04) I: So they explained

(05) M: he called it a benign murmur that is what I'm thinking

(06) I: Oh

(07) M: That the blood might be rushing through too fast but he said I

(80) don't know

With some of the discovery sequences, such as the one illustrated in Excerpt H, there seemed to be an interaction of dual unbalancing acts. On one hand, the family members were introduced to new information which altered the ways in which they viewed their child: a child with no heart murmur to a child with a heart murmur. The discovery of a heart murmur unsettled or unbalanced the status quo for many families interviewed in the study. On the other hand, the referring physicians

were not so certain of the heart murmur's innocent nature. If the doctors were certain of the insignificance of the murmur, they would not have referred the family to the heart specialist. The referring physicians, like the families, were also in a knowing/not knowing oscillation.

Another possible, complicating factor in the discovery to referral workings was the rapidity of the process. The quick pace at which the proceedings were sometimes carried out could be seen in Excerpt I. With this family, the physician who originally discovered the heart murmur was also the doctor who subsequently referred the family to a specialist.

Excerpt I

The sixteenth. Okay. And then how soon after did Dr. Carlisle (01) I: discover the murmur. (02)

Okay. That same day she came in and told us that she thought (03) M:

there was one. And then had us an appointment for the next day (04)at her office to come in there. And she heard it again and let us (05)

(06)listen to it.

After running a few more tests, the doctor then referred the family to the pediatric cardiologist. The discovery/referral time frame for this family was quite rapid. The child was born on a Tuesday. The murmur was first discovered that same day. The child was reexamined on Wednesday. Tests were run on Friday and the child was seen by the cardiologist that Monday; six days from birth to visiting a heart special-

Excerpt J also showed the swift turnaround faced by some families:

Excerpt I

(01) M: He didn't. He just said, "When can you go to Lubbock?" I said,

"Tomorrow if I have to." (laughter)

(03) I: When was this? (04) M: Thursday.

(05) F: Thursday.

Okay so it was as soon as you could come that you did come.

(07) M: Um hum.

As stated above, the rapid pace of the referral workings, as experienced by some families, was indeed bewildering. In addition to the rate at which the families had to assimilate the considerable flow of information, there was also the question of the symbolic meaning the prompt calling for referral had for the families. At one instance, the doctor was describing the murmur as being inconsequential, while at the same time, the referral sequence was being carried out at a rapid rate. Of course, for some families, the process was not being completed quickly enough:

(01) M: Really our family life hasn't changed, you know . . uh . . I try the worrying I do . . I try to do by myself . . and uh . . as far as the worse thing I can think of . . this is probably so minor is the way . . you know . . this right here [coming to the heart specialist], its really getting to me (laughter) . . you know cause I'm here and I want to find out what's wrong and I want it yesterday . . that's my problem.

Another contrast between the families during the discovery process was the amount of investigating that was completed by the referring physician prior to the referral being made. For some of the families in the study, the physician detected the murmur with the use of a stethoscope and then made the decision to refer the child. Tests, commonly used in the confirmation of an innocent heart murmur such as a chest X ray or electrocardiogram (ECG) (Kiester, Jr., 1982), were not conducted.

Excerpt L

(01) F: Well, he recommended us to come out here. If he ran a test up (02) there, he had to send us here anyway.

But for other families, standard tests such as the ECG were carried out and the family was still referred to the cardiologist.

Excerpt M

(01) F: we took her to the doctor cause of that ear infection right

(02) M: Mm hmm

(03) F: and then there they did some tests on em and they said she had a

(04) heart murmur

Excerpt N

(01) M: ... they ran they ran an EKG and some x-rays there. She said (02) that she thought it [the murmur] looked fine but she'd rather a cardiologist look at it.

For families like the two of these, the referring physician went beyond the stethoscope in order to diagnose the heart murmur. But in both cases, the doctors were still unable to make a definitive statement without the input from a heart specialist: "She [the doctor] said she thought it [the murmur] looked fine but [italics added] she'd rather a cardiologist look at it."

As was seen in these discovery scenarios, the process varied from

family to family in terms of prior knowledge of the heart murmur, period of time between discovery and referral, and reason for seeing the eventual referring physician. Despite these differences in discovery, the families in this study had one common characteristic: They all had a child with a heart murmur that was worthy of referral to a pediatric cardiologist.

RFA of Discovery and Referral

As was discussed in the previous chapter, RFA was used to describe the parents' talk about their experiences with referring physicians and other concerned parties because RFA was a way to present interaction-in-context (Keeney, in press). The recursive relationship between interaction and context was brought into focus by the simple action of drawing distinctions (Spencer-Brown, 1972). The observer or, in this case, the researcher drew distinctions (frames) to understand how the parents organized their interactions-in-context.

To illustrate the distinctions drawn in the parents' talk, the following RFA conventions were used:

1. Upper- and lower-case letters F/f were used to designate a word or group of words as a frame (e.g., F: She didn't think it was anything serious.). The lower case f was used to demonstrate that one frame (f) was taken to be embedded within another frame (F):

F: She didn't think it was anything serious. f: she heard a click.

The configuring of the preceding frames would represent that the hearing of the click was meant to be understood as not being anything serious.

2. An upper-case letter G was used to represent a word or group of words as a gallery (e.g., G: Healthy child). Numbers were used with the upper case G's to represent shifts in the discourse from one context or gallery to another context or gallery:

G1: Healthy child G2: Unhealthy child.

Frames listed under a gallery were meant to designate that those frames were to be understood within the context of that gallery:

G1: Routine Check up F: Routine referral. The configuration of the preceding gallery and frame represented that the frame of routine referral was meant to be understood within the context of the routine check up gallery.

3. Indentation was meant to represent embeddedness of frames and galleries:

G1: Routine Check up
F: Listening to heart

f: Hearing heart murmur.

The preceding configuration represented that the hearing heart murmur frame was meant to be understood within the context or frame of listening to the heart, and both of these frames were meant to be understood within the larger, encompassing context or gallery of routine checkups.

By using the conventions outlined above, the RFA researcher was interested in portraying ways in which families framed the discovery of the heart murmur and how they contextualized the ongoing interaction with the doctors. The process folded back upon itself as the discovery of the parent of new or different information about their child's heart lead to their (re)contextualization of the ongoing medical process.

Each new discovery made by the parents lead to new (re)contextualizations of the ongoing medical process. A focus on a circular organization of contextualizing-interacting-(re)contextualizing helped the researcher to begin to understand a context in which the concerns by parents made sense and, in other instances, contexts in which the lack of concerns by parents also made sense.

For some families in the study, the process of discovery/referral began during a routine medical check up (Gallery 1, or simply G1). From a context or gallery of a usual doctor's appointment, the parents had had certain expectations or frames (F) which they anticipated during the examination:

G1: Routine Medical Checkup

F1: Listen to heart F2: Listen to lungs F3: Look at eyes F4: Look at ears

With the families who had no prior knowledge of any irregularities, the gallery of routine checkup included an unexpected frame (f): a heart murmur.

G1: Routine Medical Checkup

F1: Listen to heart

f: "a little heart murmur" (Excerpt A)

f: "Her heart was beating too fast" (Excerpt B)

f: "noticed a small heart murmur" (Excerpt C)
f: "a small hole in the back (()) chamber" (Excerpt C)

Given the discovery of these new frames (f's), the families could have questioned the initial gallery of routine medical encounter.

G1a: Routine Medical Checkup

F1: Listen to heart

f: Hear heart murmur.

G1b: Routine Medical Checkup?

As new information was added, the resiliency of the context (Tannen & Wallat, 1986) as being routine was tested. Maisede (1987, p. 68) called this process "permanent context construction" or "the indexicality of context." By this, Maisede meant "that while the ongoing interaction depends on social context, it simultaneously generates, reproduces, and changes the context" (p. 68). The permanent context construction of Maisede contrasted well with what Keeney (1983) described as the nature of circularity, repetition or pattern:

These terms suggest that ideas, experience, and social events do more than stretch out in lineal time. When a process folds upon itself, we speak of recursion. The image of a circle is probably not the best way to think of recursion since we are not really referring to an original beginning point in time. Each recursive loop does imply a different beginning, although in terms of the pattern of organization, it is simply recycled [italics added]. (pp. 58–59)

Following this line of reasoning, each time the family received new information about their child's heart, the gallery of routine was/could have been questioned. If the context of routine medical procedures was/could have been maintained by the doctors and the families, then succeeding frames such as more tests, more exams, and referral were/would have been understood as being routine. If the context of routine medical procedures was not/could not have been maintained, then the subsequent moves of more tests and referral were/would have been contextualized as being something other than routine.

For each family in the study, the question became, "Did the gallery of routine medical encounter fit with the frames being presented during the visit with the doctor?" Agar (1985, p. 149) described this process as the interaction between institutional frames and client frames. In the discourse collected in this study, there were examples of parents' and doctors' attempts to maintain the gallery of routine.

There were numerous instances where parents and physicians helped each other maintain the routineness of the process. In Excerpt

D, Line 03, the mother recalled the doctor's phrasing of the murmur discovery: "And she says 'well it's just a murmur' " [italics added]. The use of the word "just" when she announced the discovery of the murmur, could have been a way for the doctor to help maintain a gallery of routineness by framing the condition in a matter-of-fact fashion.

Other ways in which the doctors framed the discovery and referral as being routine/non-problematic were evident in Excerpts C and E. In RFA terms, Excerpt C was understood as follows:

G1: "The pediatrician was on call." (routine)

F: "noticed a small heart murmur"

f: "he wanted us to check it out and made an appointment" G2: "we are here (.) just checking it out" (routine)

G2 was represented as being embedded in G1 because the mother seemed to maintain the theme (Agar, 1979) of routine. The pediatrician on call (routine) wanted the parents to have the small heart murmur checked out (routine) and the parents did just that ("we are here (.) just checking it out") (routine).

In Excerpt E, the doctor's attempt to frame the discovery as being routine or nonproblematic had a leak (Keeney, 1990a) in it. At first the doctor framed the discovery of the heart murmur as being nonserious.

F: She didn't think it was anything serious. f: she heard a click.

Then the mother recalled the doctor saying, "but she wanted it checked out." That phrase could have been taken as another frame contextualized by the previous frame, i.e., the heart murmur was not anything serious, or the use of the word "but" could have helped to create a side-by-side construction.

F: She didn't think it was anything serious

F: She wanted it checked out.

The use of the word "but" helped to create two possible contexts: one characterized as being nonserious; the other characterized as being something different from being nonserious. The mother had been presented with a choice: not serious/possibly serious. Depending on how

the mother understood the doctor's use of the word "but", the gallery of routine was either maintained or thrown into question.

One way parents employed to get out of making the choice between one side or the other in a side-by-side was to draw a distinction which questioned the validity of the side-by-side frame itself. In Excerpt G, both the mother and father challenged the mother's presentation of the frames she had heard in the doctor's office. They both questioned the rims of the frames (Keeney, 1990a). Keeney, following Goffman (1974), described the rim of a frame as an indication of "how the content was to be taken, typically in terms of 'real' or 'fiction' " (p. 64). In Excerpt G, the parents suggested that the content of the frames might be highly questionable because the mother might have misinterpreted the doctor's talk about the heart murmur. If the rims throw doubt on their contents, then the information as presented by the mother could not challenge the routine gallery and the gallery was maintained.

The final transcription of the previous section (N) clearly illustrated how openings were created during the discovery/referral process. Keeney (1990a) stated that openings were frames in one gallery that provided doors, leaks, or transitions to new, different galleries. The discourse uttered in one gallery would be understood differently from those of the other gallery. In Excerpt N, the mother presented a series of frames which helped to maintain the routine gallery:

G1: Routine Medical Checkup

F: "they ran an EKG"

F: "some X ravs"

F: "she thought it [the murmur] looked fine"

Then the mother added another frame:

F: "but she'd [the doctor] rather a cardiologist look at it"

The last frame was called an opening because it could have allowed the flow of discourse to follow a path which would have taken it out of the routine context/gallery. What did the phrase "but she'd rather a cardiologist look at it" mean? Did it mean that having a cardiologist was more of the same (i.e., routine) or did it mean that something was amiss with the process (i.e., not routine)? How was involving a cardiologist presented so that the gallery of routine could have been maintained, or how was referring to a pediatric cardiologist mentioned so as to provide a leak in a routine gallery? The same dilemma was also seen in the presentation of what was and was not a referable heart murmur.

REFERABLE HEART MURMURS

In this study, two different groups were identified: those families with prior knowledge that their child had a heart murmur and those who had no such awareness. But in either case, all the families were faced with a new perspective: Their child was now being diagnosed as having a referable heart murmur, a medical situation which required the expertise of a pediatric cardiologist. As shown above in Excerpt E, one family, who had come to see the doctor about their teenage son's bad knees, had known of their son's heart murmur since he was a small child, but their current physician now contextualized the old label (heart murmur) with a new set of procedures (referral to a pediatric cardiologist). This shift in how the child was being treated can be unsettling to the family: What is now known about the child's condition which mandates a visit to a heart specialist? In the interviews, family members expressed different ways in which learning of the referable heart murmur was discomforting.

For some families, the news of a referable heart murmur brought to light a contrast between the parents' observations of their child's seemingly healthy behavior and the label of referable heart murmur.

Excerpt O

(01) M: ... even with Robert we haven't noticed anything wrong with

him, he seems just as normal as any other kids. I sure don't stop

(03)him from jumping around and running around all day long.

In Excerpt O, the mother, after learning that her son had a heart murmur, voiced doubt about her and her husband's perception of their son's health: "he seems [italics added] just as normal as any other kids." In Excerpt P, the mother and father, whose son's diagnosis was changed from irregular heartbeat to heart murmur, had not thought much about their son's heart because he had always been quite active.

Excerpt P

(01) M: Okay. (.) And so I said you know we really didn't think much

about because he's very active he's never tired unless (.)

(03) F: He's bored

(04) M: if he's bored, he's tired. You know and as long as he's having fun we know that he thinks about you know (.) hurting or anything

(06)like that or getting chest pains or anything like that. I didn't

(07) . worry about it but and also I didn't worry about it because I had

noticed that when they do a nose and (.) ear (.) check and throat

(09) I: Uh hum

(10) M: Uh they usually do an (()) pulse . . .

For most of the families in the study there were no observable physical abnormalities. This could have confused the families in light of what the physicians were now saving in regards to the children. Kreps and Thornton (1984, p. 100) referred to such situations in health communication as double-binds. Families were faced with a situation in which they needed to reconcile two seemingly contradictory positions: the doctor's diagnosis of a referable heart murmur and the family's observations of what they believed was a healthy child.

Another source of uneasiness for the family was the contradiction between referable and nonreferable heart murmurs. A nonreferable heart murmur was most likely one of the innocent variety (McNamara, 1987b) and one which should have caused little concern for the family. But what about a referable heart murmur? As stated earlier, a referable heart murmur could be a significant murmur, an indicator of serious heart problems (Paraskos, 1988). Such a heart murmur would be cause for alarm and worry on the part of the family.

In Excerpt O, the mother not only expressed her worry over her child's condition, she also voiced her concern over which of the doctor's seemingly contradictory messages to follow: The doctor said not to worry and the doctor referred my child to a heart specialist. This left the mother with a variety of choices: (a) to worry over her child's condition, (b) not to worry over her child's condition, and (c) to worry over whether or not she should worry over her child's condition.

Excerpt Q

(01) I: But there's still a little bit of

(02) M: of doubt yeah (.)

something (03) I:

(04) M: cuz there there's a doubt in my mind (.) that it is (.) she [the

doctor] wouldn't have it [referred my child] if there isn't anything (05)

(06)wrong (.) so (.) I don't know I guess we'll find out today fer sure (.)

Okay .hhh so even they say even though they said don't worry (07) I:

(80) it's nothing serious it's (.)

(09) M: I worry

why would they say it if

(11) M: right I worry

(12) I: There must be some reason there's a heart murmur you

(13)

(14) M: Mm hmm (.) right (.)

Excerpt R also clearly illustrated how families could react to the double-bind message that "the heart murmur was not serious, but your child should be sent to a heart specialist in order to be really sure." Both the father in Line 02 ("We didn't know what to think.") and the mother in Lines 08 and 09 ("So we didn't react.") expressed the paralyzing qualities of being caught in a double bind. Again, in Lines 05 through 09, the mother clearly expressed the oscillation that families might have gone through as they tried to decide which of the two contradictory messages they should follow: "We know that it's serious [It's a referable/noninnocent heart murmur.] but we didn't know how to react if it was a serious thing [It's a referable/noninnocent heart murmur.] or just you know like a functional murmur [It's a referable/innocent heart murmur.].

Excerpt R

- (01) İ: I can imagine how you felt, but can you say it too now you felt at (02) the time?
- (03) F: We didn't know what to think.

(04) M: I didn't (laughter)

(05) F: We didn't know how serious [it would be]

- (06) M: We didn't know whether to take it seriously or (.) We know that (07) its serious but we didn't know how to react if it if was a real
- (08) serious thing or just you know like a functional murmur. So we
- (09) don't didn't react. We were in a state of just there (laughter).

(10) F: (()) see what happens.

In Excerpt S, the family expressed reactions similar to those stated by the parents in Excerpt R. When faced with the dilemma of how to feel about the referral, these families chose not to feel ("I don't know how to feel," "On hold," and "...numb"). The mother and the father in Excerpt S were able to delay the decision of whether to worry or not until they received more information because as the mother said, "Nothing you can do one way or the [other] just (.) live with it (laughter)."

Excerpt S

- (01) I: How do you mean, haven't felt?
- (02) M: I don't know how to feel, you know like I said earlier, I don't
- (03) know how to feel about this. I'm just gonna take it as it goes, one day at a time.
- (05) I: It's almost kind of, not even having enough information to know
- what to feel. So more . . . numb? Is that it, or on hold?
- (07) M: On hold, yeah.
- (08) I: Does that kind of fit for you too?
- (09) F: I think so.
- (10) I: Kind of on hold until you get some more answers.
- (11) F: Yeah, I don't want to get (.) too excited, and it might not be
- (12) nothing to get all excited about. (()) Just stay cool.
- (13) M: Nothing you can do one way or the [other] just (.) live with it (14) (laughter).

But a referable heart murmur could also be an innocent heart murmur. The referring physician just wanted to confirm the diagnosis. The physician may not have had either the confidence, time, expertise, and/or equipment to make a definitive statement on the murmur; therefore, to be absolutely positive, a referral was made. For some families, there was a need to know more about the circumstance surrounding the referral. In Excerpt T, the mother attempted to elicit more of this type of information from the doctor and his staff.

Excernt T

- (01) M: I asked the receptionist and she said you know cause I asked her,
- (02) "Is him sending him to Lubbock does it signify anything?" And
- (03) she says "no not really, she said we really can't say anything
- (04) until we get the results of the test."

As the mother recalled in Excerpt T, the receptionist's answer of "no not really" to the question whether the referral was worthy of worry was contradicted by her subsequent stating "we can't say anything until we get the results of the tests." If the doctor and staff could not say anything until they received the test results, how could they be sure that the referral did not signify anything to be worried about; the results could show that the murmur was significant.

Situations such as the one described above in Excerpt T, helped to create additional concerns on the parts of the parents: If the referring physician did not know enough to make the diagnosis himself or herself, did the referring physician know enough about what he or she does and does not know? Is it a question of whether or not general practitioners know what they don't know? If the families were in doubt about what the non-heart specialist knew about the heart, then the families might doubt the label of "innocent" for the heart murmur.

In Excerpt U, the mother and father discussed their interpretations of the referring doctors' diagnosis of their child's heart murmur. The parents had been concerned about the lack of information they had received from the physicians. At first, the couple considered that the doctors were withholding information—information that might have alarmed them. In Lines 11 and 12, the father offered an alternative understanding of the lack of information: "because I don't think they [the referring physicians] knew all that much about it [the heart murmur] (.)." It was not clear from the parents' conversation if their questioning of the doctors' knowledge caused them to doubt the validity of the referral or if the referral made perfect sense given the doctors' alleged ignorance of heart murmurs.

Medical Discourse and Systemic Frames of Comprehension

Excerpt U

(01) I: So it wasn't even clear answers saying I don't know but kind of

(02) M: right

(03) I: evasive or hedging or unclear

(04) M: just more like

(05) F: yes

(06) M: saying

(07) F: take her and get it checked out some more

(08) I: See someone else we did

(09) F: who knows more about her problem

(10) I: Mm Hmm

(11) F: because I don't think they [the referring physicians] knew all that

much about it [the heart murmur] (.)

Families had certain expectations of what physicians should be able to do as far as providing medical services were concerned. Some families believed that doctors should be experts for all areas of the body. Of course, all physicians cannot be experts or specialists for all areas of medical concern. In the case of cardiological knowledge, it was not uncommon for families to expect that the primary care physician know as much about the heart as he or she knew about any other organ system (McNamara, 1987b). When a physician appeared to be hesitant or uncertain with a diagnosis, this might have suggested to the family that something was being held back from them or what was being said was not enough for the family to be satisfied.

Given their understanding that the doctor was supposed to know about their child's condition, the families in the next two excerpts (V and W) gave accounts (Scott & Lyman, 1968) for why the doctors were unable or unwilling to give parents their anticipated answers. Scott and Lyman (1968) described an account as "a statement made by a social actor to explain unanticipated or untoward behavior-whether that behavior is his [sic] own or that of others . . ." (p. 46). In the case for these families and others in this study, the untoward or unanticipated behavior was that of the expert (the doctor) not acting like an expert (not knowing all of the answers).

The family in Excerpt V gave an account for the doctor's hesitancy (Lines 10-11). The mother offered that the doctor might have tried to explain, but had been unsuccessful (Lines 07-08) and that telling the family certain information might not have been the doctor's place (Lines 15-17). Stokes and Hewitt (1976) also called these types of account-giving, aligning actions: "largely verbal efforts to restore or assure meaningful interaction in the face of problematic situations of one kind or another . . . , formulating the definition of a situation and talking about motives illustrate a dual process of alignment" (p. 838). In Excerpt V, the father identified a problematic situation: "the questions that the doctor never told her [the man's wife] that (.) what could be done to help her [his daughter]. Later, the wife supplied possible motives why the doctor would have behaved in such a manner: maybe it was not the doctor's place to have told her the needed information (Lines 15-17).

Excerpt V

(01) I: Okay (.) has it been anyone who's made it hard or difficult (.) or

confusing (02)

(03) M: no not really (())

(04) F: Just the questions that the the doctor never told her [his wife]

that (.) what could be really done to help her [his daughter] (05)

(06)

(07) M: I mean I think that they should've (.) more of less tried to explain

something to me

So then not explaining made it more difficult (09) I:

(10) M: I guess Doctor Flemons (.) may have tried but he was (.) hesitant

for some reason (.) to me he was (11)

(12) I: Okay

(13) M: for some reason he was

(14) I: (()) to both of you okay

(15) M: ah huh (.) I don't know why but (.) I'm hoping it's not for any (.)

I figure that he should've told me to begin with whether (.) it was

his place or not (.) (17)

In Excerpt W, the mother gave accounts for why she was unable to get information from her doctor: "he's strange," "he's always in a hurry," "He kinda talks funny," and "Yeah, kind of evasive." As was also seen in Excerpt V, when faced with a situation in which the expert (the doctor) did not have all the answers, these families attempted to supply excuses or accounts in order to help make sense of a problematic situation.

Excerpt W

(01) M: I really didn't have time to think about it. Cause I volunteered to

work at the clinic that day, so I was busy . . .

(03) I: Oh, you were working . . .

(04) M: I was busy with other students.

(05) I: So probably as soon as you could you got out of there and said

let's go check it out more.

(07) M: Yes. Exactly. (laughter)

Did you ask him any other questions?

(09) M: Uh um. Nothing. Dr. Girardi is very (.) he's strange and he doesn't really, he's doesn't really he's always like in a hurry so you really

(10)

- don't have time to corner him (laughter) and ask him questions.
- (12) F: He kinda talks funny, you got to really, he's one of (())
- (())
- (14) F: ((Talks)) ((he's a pretty good doctor))
- But sometimes hard to get hold him down to get answers (()).
- (16) F: Yeah, kind of evasive (()).

In Excerpt X, the mother expressed her concern about what the referring physicians might not know about her child; maybe there was something more to be known about the case and that new knowledge might have contradicted the innocent heart murmur label.

Excerpt X

- (01) I: Did you ask them when you were with the other doctors
- (02) M: I asked (.) well (what it is but) its like (.) they don't (.) its (.) well
- its not like they're giving you the runaround it's (.) I guess unless
- they don't know why it it does sound to me like they don't know
- like they don't know okay (05) I:
- (06) M: if they cuz if they knew they would have told me something and
- (.) you know (())

By not receiving the expected answers, the family members may have become frustrated with the physicians. As seen above (Excerpt X). the mother began to speculate possible reasons for the doctor's clinical uncertainty (Brenner, Ringel, & Berman, 1984). She was having trouble reconciling not hearing what she wanted to hear (i.e., definitive answers on her child's heart) and the fact that the doctor had earlier told her that there was nothing about which to worry. So when the general practitioner announced the decision of referral to the heart specialist by saying, "It's nothing to worry about," the families could still choose to be worried. They were able to question the non-heart expert's position on really knowing whether they should worry or not. In addition, the family members could have questioned the incongruity between the doctor's "not-to-worry" statements and the doctor's actions of referring the family to a specialist so as to be really sure.

Excerpt Y

- (01) I: Anything about the experience that has tripped you up or
- frustrated you or anything like that?
- (03) M: I guess I was concerned (.) I was hearing it was something he
- would grow out of and I guess maybe just thought of following
- up on it maybe it might be serious.
- So even though it was something that he would grow out of it (.) it was a developmental thing normal thing you still need to come
- (80)in for an appointment . . . (09) M: It was something you know why make an appointment if its
- normal (.) why not make it [the appointment] a year [from now]

The mother in Excerpt Y became concerned because not only was the doctor referring her child for "something he would grow out of," but this referral was one that could not wait ("why not make it [the appointment] a year [from now]"). Many families found the referral process ambiguous and, as seen above, "referral" could mean many different things. Barnlund (1984), when addressing ambiguity in medical settings had stated,

If so many words are vague in their reference, messages composed of such ambiguous elements will be even less precise. Nearly every statement can support many legitimate and even contradictory interpretations. In some respects the vocabulary of illness constitutes a special case. (p. 45)

RFA of Referable Heart Murmurs

How a referable heart murmur was defined either maintained the gallery of routine/nonproblematic medical encounters or created openings to alternative galleries of nonroutine/problematic medical encounters for the families. At the center of the defining was the relationship between frames and events.

Keeney (1990a) outlined the different distinctions which were possible considering the relationship between frames and events. The possibilities were

Same Frame; Same Events Different Frame; Same Events Same Frame: Different Events Different Frame; Different Events

Same Frame referred to the continuance of a context whereas Different Frame meant that there had been a recontextualization.

In connection to heart murmurs, Same Frame meant that the child's diagnosis remained unchanged through the process: The child had been previously diagnosed as having a heart murmur and that diagnosis was upheld by the referring physician. Of course, the opposite could also have been true: The child could have been previously diagnosed as not having a heart murmur and that diagnosis was also upheld. The involvement of such a child in this study was highly unlikely, but it could have occurred due to a miscommunication or mishearing (e.g., A family could have come to the pediatric cardiologist by mistake or the interviewers in the study could have mistakenly interviewed a family not designated for this study).

Different Frame meant that there was a difference between the diagnosis of heart murmur and how the families perceived their child's heart prior to the diagnosis. For instance, before the referral to the pediatric cardiologist, the family may have had no awareness of a heart murmur in their child or there could have been other heart diagnoses (e.g., irregular heartbeat). Different Frame could also have meant that there was a shift from a heart murmur diagnosis to no heart murmur in the diagnosis or to another heart diagnosis. These transforms will be the focus in a later section of this chapter.

The other side of the distinction, Events, referred to a change or stabilization of content in relation to the Same or Different Frames. Same Events in this study meant no change in treatment for the child (i.e., no referral of the child, no involvement of additional medical personnel, etc.). Different Events was taken to mean that a change in treatment had occurred (i.e., the child had been referred to a pediatric cardiologist). All of the families in the study would have fallen under this last distinction. The point of making this distinction was that it was based on observable behavior and not on semantics. In other words, the act of the family coming to the hospital was taken to be Different Events, whether or not the families considered this to be a change for them. This was done in order to investigate variations in how the families contextualized their visit. They could have negated the Different Events label or they could have described the meaning of the label, but the focus of the study was on the coming to the hospital.

Given the two sides of the relationship (Frame/Events), and given the two distinctions on each side (Same/Different), there were four groups possible, but only two were likely to be represented in this study due to the restriction that the sample was to be composed of *only* children with

Same Frame / Different Events
Prior Heart Murmur Diagnosis / Referral to Pediatric Cardiologist
and

Different Frame / Different Events

No Prior Knowledge of Child's Heart Murmur / Different Events / Referral to Pediatric Cardiologist

For the Same Frame / Different Events group, there was a change in treatment (referral) and for the Different Frame/ Different Events groups, there were two changes: a change in diagnosis and a change in treatment. It could be argued that there were two changes for both groups because the change in events (referral) could have recontextualized the original heart murmur diagnosis

F: Referable f: heart murmur

if the act of referral was taken to mean something different for the family (i.e., nonroutine). That was the main question or concern of this study: "How would the referral to a pediatric cardiologist be contextualized by the family?" The question was extremely important when the larger context of routine/nonroutine was considered. If the gallery of routine medical encounters (G1) was not maintained, then what would be the repercussions in the larger context? G1 was most likely embedded in a larger gallery of a healthy child (G0). Depending on how the referral was handled, the gallery of

G0: Healthy child G1: Routine Check up F: Routine referral

healthy child would have been maintained or it would have leaked.

G0: Healthy child
G1: Routine checkup
F: Routine referral / Nonroutine referral

Excerpts O and P were good examples of how families began to question the fit between the gallery of healthy child with the frame of referral: "even with Robert we haven't noticed anything wrong with him, he seems just as normal as any other kids" (O) and "he's very active he's never tired unless—he's bored" (P). Some families had to struggle with what they saw as contradictory frames: healthy child/referable heart murmur.

The struggle came from the ambiguity of what was a referable heart murmur: was there a referral to confirm innocence or a referral to confirm significance?

F: Referable Heart Murmur? (A little doubt)
f: innocent
They said it's not serious
She wouldn't have referred it if?

In contrast to the family in O were the mother and father in Excerpt R. When faced with the choice between innocent and significant, they made the choice of not making the choice: "So we didn't react." The same phenomenon was seen in Excerpt S: "Nothing you can do one way or the [other] just (.) live with it (laughter).

Another dilemma faced by families who strived to end the oscillation was the referring physician's ability to know what he or she did and did not know. It was another rim-of-the-frame situation: Was the doctor a heart expert and therefore the diagnosis was unquestionable or was the doctor a nonheart expert and therefore the diagnosis was questionable?

In the previous situation, both frames were the same, but the meanings were very different.

Rim: Doctor as expert F: Innocent heart murmur F: Innocent heart murmur

Rim: Doctor as nonexpert

It was also a question of fit for the mother in Excerpt Y:

Rim: Expert /Nonexpert

F: Something he would grow out of / just follow up on it

F: It was something you know why make an appointment if it's normal (.) why not make it [the appointment] a year [from now]

The mother felt that there was an incongruity between a frame of it's normal and another frame make an appointment now. For many parents, the lack of fit between frames lead them to try to make sense of the difference they perceived between the frame of the murmur as not being serious and the frame of the murmur needs to be heard by a cardiologist. Two ways in which families went about dealing with this problem were to transform the meaning of the heart murmur and to seek out alternative sources of information.

TRANSFORMS

Faced with such dilemmas of interpretation, what choices have families had in attempting to understand seemingly ambiguous messages? One possibility was to transform either the act of referral or the label of heart murmur into more serious acts and/or labels. Families might have created a series of "what if's" in response to hearing that their child had a referable heart murmur. For example, in the two following transcriptions (Z and AA), one mother feared that the next logical step in the referral process could have been surgery for her child and another mother expressed concern about what it would mean if the pediatric cardiologist had to ask the family to come back to the hospital again.

(01) I: So you're afraid not only about the surgery, but also like what if

something more happened.

(03) M: Yeah, (.) yeah.

(01) M: We don't wanna have to come back again (.) cuz I know he if we come back again it's just gonna mean that they're gonna have to

do something different (03)

The following excerpt (BB) illustrated how one mother transformed the meaning of what a referable heart murmur was for her. The decision to see the heart specialist was decided because "it was something that couldn't wait your heart is the only thing that keeps you going."

(01) I: ... what kinds of things went into the decision to go ahead and

make the appointment to come here

(03) M: I felt like it was something that couldn't wait your heart is the only thing that keeps you going I wanted to get it done before

school started and wanted to know how bad it was (05)

As stated earlier, a referral which focused on an individual's heart could cause concern (Hersher, 1988). The ambiguous nature of heart murmurs was such that it was quite normal for families to associate an innocent heart murmur with either a significant heart murmur, heart disease, or even death (Bergman & Stamm, 1967; Hersher, 1988). The pathologizing of a benign condition such as an innocent heart murmur helped to create what Meador (1965) termed as nondisease. A nondisease occurred when individuals acted as if they had a condition which should have been treated as a disease when in reality they did not have that disease. Bergman and Stamm (1967) warned that when families were referred for innocent heart murmurs there should be an "appreciation of the morbidity possible in cardiac nondisease" (p. 1012). Families whose children did not have heart disease might have begun to treat their child as if he or she had a disease as a result of the diagnosis of an innocent heart murmur.

One possible indication of parents' perceiving that their child was vulnerable is that they would begin to treat their child as if he or she really did have a serious heart condition (e.g., special treatment at home). As seen in the next passage (CC), a mother recalled how a referring physician had to work very hard in order to stave off the parent's attempts to seek permission to treat her child as if the diagnosis was something more serious than a heart murmur.

(01) M: Yeah (.) and I'd ask Dr. Benjamin if I needed to treat him Excerpt CC

different, I mean do something different. When she first told us in the hospital, cause I went home before he was even 24 hours old. (02)(03)

I said "Do you think we should stay here." "No, there's no need to stay." And then in her office I asked her again well, "Should I (05) do anything ah different?" And by that I meant you know like (06)keep him away (from) people, was what I was getting at. "Not (07)

here's nothing different to do." And she explained that one's that (80) had real bad heart murmurs, looks different, and she could feel (09)

(10)the heart murmur from outside the chest. She gave us several

different symptoms all of which she said he didn't have. She said (11)

"we wouldn't even know he had [one], if we didn't have the (12)stethoscope to hear it." So that that part helped, when she

(13)explained it that way.

(14)

RFA of Transforms

Within the gallery of healthy child, some parents began to transform the meaning of innocent heart murmur into something much more severe (for example, significant heart murmur, heart disease, death). This process of transforming, in some cases, helped to shift parents' discourse from a gallery of healthy child to a gallery of unhealthy child.

The beginnings of this transforming process were found in the initial side-by-side distinction set up with the dilemma of what was a referable heart murmur:

F: innocent F: significant f: heart murmur f: heart murmur F: referable heart murmur

f: innocent f: significant

The basic distinction was between the absence of pathology (innocent) and the presence of pathology (significant). Many parents kept oscillating between the two sides of the same distinction, but some transformed one type or class of the nonpathology/pathology distinction (innocent/significant) to another class of the same basic nonpathology/pathology distinction.

> nonpathology pathology F: significant F: innocent F: heart nondisease F: heart disease F: death F: life

Significance, heart disease, and death were all on the same side of the nonpathology/pathology distinction but were all in different classes. Transforming a significant heart murmur to heart disease was a simple manner as parents followed the nonpathology/pathology to a logical conclusion. As the talk shifted to the graver classes of this distinction, the gallery of healthy child was also transformed to a gallery of unhealthy child. This was what Bergman and Stamm (1967) and Hersher (1988) warned about when they cited the vulnerable child literature (Green & Solnit, 1964) as having relevance with referable heart murmurs.

The recursive nature of frame and content of frame would be such that something like a vicious circle (Watzlawick, 1984) would be created. Watzlawick descibed the phenomenon of a vicious circle as

the sequence of events which was not rectilinear, but in which the effect fed back upon its own cause. This happened in nearly every marital conflict that turned and turned on itself in the same vicious manner, whose starting point was beyond recall and, even if recalled, no longer matters. (p. 65)

Watzlawick went on to say that the notion of the vicious circle was similar to the how Heinz von Foerster (1984a) defined cognition (i.e., "computations of computations of computations . . . p. 48), and that "once established, such a circle was beyond beginning and end, and beyond cause and effect" (p. 65). The healthy child context/healthy child discourse shifted to unhealthy child context/unhealthy child discourse, and this oscillation (healthy to unhealthy) could have continued until some sort of intervention could have been made which might have been able to disrupt the cycle.

Excerpt CC was a good example of how the parents' talk was clearly in the gallery of unhealthy child and how the doctor created opening or leaks in that gallery which allowed the mother to leave the unhealthy child gallery and return to the gallery of the healthy child.

G: Unhealthy Child

F: I'd ask Dr. Benjamin if I needed to treat him different, I mean do something different (mother)

f: Should we stay her [in the hospital] (mother) f: No, there's no need to stay (Doctor) - LEAK

F: Should I do anything different?

f: Keep him away (from) people

f: No - real bad heart murmurs, looks different - LEAK

f: She could feel [a real bad heart murmur] - LEAK

f: symptoms he didn't have - LEAK

So that part help, when she explained it [the innocent heart murmur] that way [The murmur was not significant.] - GALLERY EXIT to Gallery of Healthy Child

The doctor in Excerpt CC presented frames which helped to switch the talk from a gallery which focused on the pathology side of the distinction to one on the nonpathology side. Another way to describe what the doctor did was to say that she was involved in the process of frame destruction (Keeney, in press): the deliberate eradication of a context. (In this case, the context was that of an unhealthy child,) If the doctor was unable to turn the flow of talk over to the nonpathology side, the rest of the referral process might have been understood by the parent as being in a context or gallery of an unhealthy child.

It would be unwise to think that this would be the last time that this or any parent would question the healthy child/unhealthy child distinction during the referral process. There were many potential leaks and opening in the families' discourse ecology that would threaten the maintenance of the healthy child as the families continued to interact with each other. In addition, parents talked with other people, read articles, or consulted with medical books. All of these alternative sources of information were potential leaks and potential maintainers to the families' galleries.

ALTERNATIVE SOURCES OF INFORMATION

Another reaction families had after hearing that their child had a referable heart murmur was to seek out corroborating evidence that would help them decide how to contextualize the medical news they had heard from the referring physician. An obvious choice was for families to go seek out other primary care physicians before seeing the pediatric cardiologist and this was done by a few of families in this study.

Besides other physicians, families also went to other available health care professionals for facts. The mother in the next segment (DD) worked at a hospital and was able to go to nurses with whom she worked. The nurses provided the mother with additional and possibly contradictory information from what the doctor had told the mother.

Excerpt DD

(01) M: And uh, uh I asked what it was. See I work I'm a nurse's aide and I work at Greenfield Hospital and I asked a few nurses and

they said a heart murmur and they told me that the heart was (03)

weak. (04)

Some families sought out additional information from medical books and reference materials. The mother in Excerpt EE referred to a book she had on childhood diseases. The book could have been any one of a number of popular reference books on family health and care, [e.g., The American Medical Association Family Medical Guide (Kunz & Finkel, 1987); Better Homes and Gardens New Family Medical Guide (Kiester, Jr., 1982); Good Housekeeping Family Health & Medical Guide (1979)], available in most libraries or bookstores. The mother, having recalled reading that "50% of all children under 13 or something had heart murmurs at some time," seemed to be able to contextualize her child's heart murmur as not being so worrisome.

Excerpt EE

- (01) M: We talked to your parents, anybody, family, friends. Have they been supportive, helpful in this?
- So rather than saying, "I don't know, I don't know, I don't

know." Wait till you . . .

(05) M: Right. Yeah. Cause you know people are concerned and they don't. They'd probably ask me stuff and just upset me, or tell me

stories. So we just don't say anything (())

- (07)So really wanting to hear it from the expert, from Dr. Smith, what (08) I: she has to say. (09)
- (10) M: Right. Yeah. And it helped (()) doctor when home and pulled
- out my book, you know on childhood diseases, you know. (11)

(12) I: Um hmm

- (13) M: Cause that helped some. You know, and it was saying 50% of all children under 13 or something had heart murmurs at some time. (14)
- But you know I still don't understand what kind it was cause you (15)
- know it talked about the ones like my daughter had that are (16) acquired or whatever

(17) Um hmm (18) I:

(19) M: And then the ones that are congenital. And I understand what I

was reading (())

In contrast to the effects reading additional material had on the mother in excerpt EE was the reaction that the father in the next transcription (FF) had to reading a pamphlet on heart murmurs. While waiting in an office prior to being interviewed for this study, the father picked up a leaflet which discussed heart murmurs, both innocent and significant. Until reading this material, the father had not been worried about his daughter's heart murmur. He had had a heart murmur when he was a child and there had not been any serious complications for him resulting from having had a heart murmur as a child. But when reading the pamphlet, he discovered that some heart conditions associated with (significant) heart murmurs had to be corrected by heart surgery. This information provided the father with another prognosis for having a heart murmur, one which he had not considered before and one which caused him alarm.

Excerpt FF

(01) F: Yes but you know me having one and growing up with it (.) no

I'm not worried too much until I read that pamphlet

(03) I: Okay so this is what scared you the most right now the pamphlet

(04) F: The pamphlet what's bothering me what's it stating

McNamara (1987a, 1987b, 1988) had recommended that families be given written material by the referring physician to help the parents and/or patient better understand the heart murmur diagnosis and referral. Being able to take a handout home would enable parents to have the physician's words at their disposal in case any scares, like the one mentioned above, occurred. If the parents heard or read any information on heart murmurs that might have led them to understand that their child's innocent heart murmur was significant in any way, all the parents would have to do was read over the doctor's expert opinion on murmurs and the crisis would be eliminated.

In addition to seeking out facts from other doctors, medical personnel, and reference books, families went to other, nonmedical sources in attempts to find expert information that would provide definitive answers for them. One popular source for material was friends and neighbors. In some cases, these nonmedical sources provided examples and anecdotes which put families at ease. The following quote (GG) showed how learning about the seriousness of a friend's child's heart condition helped one mother put her child's heart murmur into perspective.

Excerpt GG

(01) M: ... Well, we also have some good friends that just had a baby

with some real serious heart problems. So you know this is

(03)nothing. (laughter)

For another family, consultation with other sources only clouded the issue more. In the next transcription (HH), the good news of one neighbor was counterbalanced by two not as favorable reports from some other friends.

Excerpt HH

(01) M: Not really because they contradict each other. Some, my neighbor,

(02)her his little child it's the same age as his she's the same age as (03)Roman and she was born with one but hers went away and she

(04)say's he say's "Oh it's nothing, he'll outgrow it." And then my

(05)other friend, she says, "Well, my cousin had one, but he had (06)surgery and then some other one, an aunt I think she said . . . "

(07) I: This is (())

(08) M: Just a friend of mine.

(09) I: Oh.

- (10) M: That hers was controlled with medication
- Oh her cousin.
- Um hum. (12) I:
- (13) M: You know so it's they contradict each other.
- So you don't know who to believe. Or they're both right, but it
- doesn't help you. (15)

Besides consulting with friends, the parents also drew upon their own family history for information. Some families had considerable experience with heart problems in their families and even in their own lives. Again, as with the information from the friends and neighbors, the familial knowledge could have been contradictory: One relative had good results with heart problems while another relative died due to heart-related matters. For example, in the next two transcriptions, the mother in Excerpt II found her positive outcome with her own heart murmur to be a valuable resource for her during the referral process, while the mother in Excerpt JJ, even after hearing positive information from her own mother, still needed to wait for word from the doctor before she could stop worrying.

Excerpt II

- (01) M: Really, (.) at this stage, until they tell me that something is wrong
- and that there's something serious that needs to be done, it's (02)because of because what I went through, and because of what I (03)
- remember of having a heart murmur, to me it's not any big deal. (04)
- Simply because, it never nothing ever came of it. So if they tell (05)
- (06)me something's going on and we need to treat it, then we'll take it a little more seriously and do something about it, but until that
- (07)I don't see any point in worrying about. You know, cause they (80)
- just found it, and it's not something that, at this stage, hopefully, (09)
- (10)nothing harmful. So (()) [work with that].

Excerpt II

- (01) M: My mother. And she [her mother] told me something like that in
- (02)lots of cases [the heart murmur] just naturally goes away as the
- child grows, so I don't know anything about it is, I just ah, wait (03)
- for ever the doctor says. (04)

One negative consequence of this searching for answers in their families' medical history had was that parents sometimes tended to blame themselves for their child's heart murmur. Maybe one side of the family had all the heart problems whereas the other side had no such occurrences. Besides blaming heredity, some parents began to reexamine their prenatal activities for possible causes of the heart murmur. Both of the mothers in the following two segments (KK and LL) alluded



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to medication they had taken during their pregnancies as having had some connection with their child's heart murmur.

Excerpt KK

(01) M: And one thing that really concerned me was some medication I had taken while I was pregnant for my for my headaches.

(03) I: Did that maybe uh

(04) M: Right that that might have had an effect on him. Yeah. That was my first thought (.) when they told me the heart murmur, that it

(06)was my fault.

Excerpt LL

(01) M: Uh. I was taking nerve medicine when I had when I was carrying him. So I was wondering if that had any effect.

For some families the innocent heart murmur diagnosis and referral brought a series of worries and concerns. There was doubt on some of the families' part as to why they were being sent to pediatric cardiologists. There were also definite concerns as to the vulnerability of their children. All of these concerns might have contextualized some parents' expectations of the consult with the heart specialist.

RFA of Alternative Sources For Information

The search for information that would have helped families to make a decision as to whether or not their child's heart murmur was significant or not was a good example of the difference between quantity and pattern (Bateson, 1979). If the process of gaining corroborating evidence was governed by notions of quantity, then it would have been a simple matter to decide the nature of the heart murmur: Add up the evidence and see which side had more and that would be the side of the distinction with which the family would have gone. But, in some instances, it only took a couple or even one noncorroborating frame to cause the healthy child/innocent heart murmur relationship to be shaken.

In Excerpt FF, the father had had a heart murmur. His sister had also had one. There were no examples in his familial background that would have prescribed a flip to the pathology side of the distinction. All of this was changed by his reading of a pamphlet in the doctor's office. The information in the pamphlet did not fit with the context he had constructed. It provided the father with a new lens or frame which helped him to create an alternative view of his child's heart murmur (Keeney, 1983). The change of frame or rather the change in the relationship between frame and content had made a difference which made a difference for the father: The father now had a frame of significant heart murmur with which to view the discovery/referral process. Although there was a significant amount of evidence on the nonpathology side, the pattern of frame to content was changed by a single frame which did not fit the previous pattern. This was an important point.

As was stated above, for some families the search for more, or rather, different information was a precarious process. Parents searched for frames which would have helped them out of the contexts of indecision and ambiguity. For the mother in Excerpt GG, the news of her friend's baby's heart difficulties helped her to contextualize her own child's heart situation as being nothing serious:

F1: Nonpathology/pathology ambiguity of own child f: Friend's baby's "real serious problems"

F2: Nonpathology of own child—"So you know that this is nothing serious (laughter)"

The process was similar for those families who searched their own family history in order to alleviate the referable heart murmur ambiguity. One interesting side effect of this search occurred when the talk about the child shifted to the gallery of unhealthy child. Within that gallery, one logical and predictable pattern was for parents to construct causes for the heart murmur. This was another example of what Bergman and Stamm (1967) meant when they cited Meador's (1965) nondisease phenomena. The innocent heart murmur frame was now in the gallery of unhealthy child, and with the shift to a disease orientation, parents naturally attempted to find causes, and in some instances, to lay blame for the heart murmur. Both excerpts KK and LL were examples of this type of talk:

RFA of Excerpt KK

G: Unhealthy child

F: Significant heart murmur

f: "... some medication I had taken while I was pregnant for my headaches"

f: "That was my first thought (.) when they told me the heart murmur, that it was my fault."

and RFA of Excerpt LL G: Unhealthy child

F: Significant heart murmur

f: "I was taking nerve medicine when I had when I carrying him."

f: "So I was wondering if that had had any effect."

If these utterances were spoken in a gallery of healthy child, then the gravity of the prenatal activities would have been reduced: The heart murmur would have been inconsequential. If the talk was in the gallery of unhealthy child, and the discourse remains in that gallery, even if the medical consult with the specialist does not support the unhealthy child context, there could be some serious problems in the family. Would the parent and the child ever be able to leave the unhealthy/ vulnerable child gallery?

The discovery/referral process was laden with many potential problems which would have to be dealt with by the family and the medical system, the referring physician and pediatric cardiologist. Depending on the pattern of leaks and gallery maintenance, the expectation of the parents and the delivery of information by the heart specialist would have produced different patterns.

EXPECTATIONS

For some families, the meaning of the innocent heart murmur had become unclear or remained ambiguous. The nature of what was and what was not a referable heart murmur had clouded the issue for a portion of the families. It was now up to the heart specialist to answer all the questions, to remove all of the doubts, and to clear up the ambiguities associated with referable heart murmurs. Bergman and Stamm (1967) characterized the demystification of heart murmurs as " 'delabeling' children" and wrote that delabeling was "one of the most frequently performed tasks of most pediatric cardiologists" (p. 1008).

Although delabeling was a commonplace occurrence for the cardiologist, it was a new, and sometimes frightening, experience for the parents. Although the mother in the next segment (MM) admitted that there were other serious worries in her life at that time, coming to the hospital to see the specialist had also been a concern for her.

Excerpt MM

- (01) I: Sharon, what are your expectations for this examination (.) what are your expectations at this point?
- (03) M: I'm really upset, I'd be lying if I was not (.)

(04) I: You're upset about? (.)

- (05) M: This is something (.) that (.) and I'm probably stressed out anyway (.) now is a kinda hectic time in our lives (.) school, we
- just bought a house, and we hear about him (.) and they're trying (07)to reduce my cortisone, my medication and this is not period (80)
- now where I'm (.) full-blown (.) with this Lupus (.) my disease, (09)
- (10)and stress (.)
- (11) I: So this is just a bad time (.)

For other families, their expectations were focused on receiving answers from the experts. Earlier in the interview, the mother in Excerpt NN had questioned the referring physician's knowledge of the heart (see Excerpt X). Now, she was anticipating the opportunity to hear from someone who would have medical acumen.

Excerpt NN

(01) I: Be up front up front with you and

(02) M: Right

- from the very beginning
- (04) M: I think that's doctors are (.) are supposed to do

Mm hmm

(06) M: Whether they're heart specialists or not (.)

(07) I: Mm hmm

- (08) M: I think they should if if if they're I'm hopeful we're hopeful that it's that if there was anything that they're (.) that should've been
- (.) said to us (.) they should've told us (10)

Mm hmm (11) I:

- (12) M: He [the first referring physician] didn't and neither did Doctor
- Carlisle [the second referring physician] (.) we have to come all (13)
- the way down here which is it's fine with us because seeing a (14)
- heart specialist is just fine (15)

Mm hmm (16) I:

(17) M: He'll know more about it and we wouldn't have to come down

(18)here

So here today you get the answers (.) (19) I:

(20) M: Yes

The same mother went on to state (Excerpt OO) that her confidence was not only based upon the specialist's knowledge of the heart ("there's doctors that know about the heart and other things"), but also upon the understanding that the cardiologist had the ability to know what she did and did not know about the heart ("I guess if she knows what she's talkin about well I can trust her").

Excerpt OO

- (01) M: But if she [the pediatric cardiologist] knows (.) there's doctors that know about the heart and other things and I guess if she knows
- what she's talkin about well the I think I can trust her (03)

Another expectation a few families had was the worry that the heart specialist would not be able to clear up the ambiguity of the referable heart murmur, or worse, that the cardiologist would discover that the child's condition was graver than had been anticipated by the family. For the family in the next transcription (PP), the concern for bad news and/or complications was quite present.

Excerpt PP

(01) M: Mm hmm so pretty good uh it's far it's been pretty good now it's just waiting for for the doctor we're hoping that it's nothing bad

(03) I:

(04) M: We don't wanna have to come back again (.) cuz I know he if we come back again it's just gonna mean that they're [the pediatric

cardiologists] gonna have to do something different

As has been seen, many families became quite concerned over the news of the referable heart murmur. They sought second opinions from a variety of sources, they questioned their activities during their pregnancies, and they pondered some life and death issues as a result of the referral to a pediatric cardiologist. But in contrast to these responses, there were some other instances during the interviews when families demonstrated how they handled the referral without becoming overly concerned and worried. They were able to contextualize the referral in such a way as to minimize their concerns.

RFA of Expectations

Parents' expectations were dominated by the talk that the pediatric cardiologist would be able to clear up the nonpathology/pathology ambiguity surrounding their child's referable heart murmur. What Bergman and Stamm (1967) called delabeling and RFA would call frame clearing (Keeney, 1990a) what was the parents anticipated from the heart specialists.

For some families, there was great confidence that the specialist would be able to cast all doubts aside because the cardiologist was clearly being identified as the expert on these matters of the heart. As was discussed in the RFA of Referable Heart Murmurs section, the rim of the frame was important in how families interpreted medical news from nonheart specialists: If the rim of the frame was questioned, so too would the content of threat frame. But, with the heart specialist, the rim was that of the expert: "He'll know more about it" (Excerpt NN) and "There's doctors that know about the heart . . ." (Excerpt OO).

One concern with frame clearing was that nonpathology frames could also have been cleared. The gallery of healthy child had been coconstructed by the parents and the non-heart specialists. What would happen if the heart specialist presented frames which did not fit within the healthy child gallery? This type of concern was quite present with some families:

Excerpt PP

G: Healthy child

decisions to worry or not.

F: "it's been pretty good not it's just waiting for the doctor

F: we're hoping that it's nothing bad (Clearing pathology frames)

F: We don't wanna come back (If nonpathology frame is cleared) f: it's just gonna mean that they're gonna have to do thing different"

Other families were able to discuss their expectations of seeing the expert without mentioning concerns or worries that nonpathology frames could be cleared by the heart specialist. These families, for the most part, were able to take a wait-and-see attitude before making

THE CHOICE NOT TO WORRY

In comparison to the times when families discussed their worries at length, there were other occasions when families did not seem to be upset about being referred to a pediatric cardiologist.

For example, the family in the next segment (QQ) had an interesting way of treating the news of a possible heart murmur. Their son had had numerous problems with his leg and so coming to see another specialist, albeit a heart specialist, was considered to be more of the same for them.

Excerpt OO

(01) M: But we've been through years with him and we've been through

his leg he had problems (.) So, it's not you know, we're just kinda

like this is another (laughter).

For families like the one in the next excerpt (RR), the information as explained by the referring physician was enough for them to follow through with the referral without becoming too worried. They did not seem to focus in on the possible symbolic meaning of the referral, but instead, kept to the information provided by the primary care doctor.

Excerpt RR

(01) M: ... because we have had something to base it on instead of just heart murmurs there's something, and Dr. Blake had even said to

me, "Its just, I hear something there, it may be something he'll (03)

outgrow. I just want it checked out." So you know even from (04)

that, it's not a big concern, he just wants it checked. (05)

For other families, there seemed to be a wait and see attitude: any decision to worry would hinge on the word of the expert—the heart specialist. They came to see the pediatric cardiologist to get the matter cleared up, but it was not apparent that they had bought into the referable heart murmur diagnosis of the referring physician.

The mother in the next transcription (SS) questioned the ability of the nurse who had first noticed the child's heart murmur. She seemed to be waiting for an expert's opinion before she decided to worry or not.

(01) M: It takes a medical doctor to see, to tell you if something is wrong with him, cause that is part of the work he does, cause he's all

(03)right. We're really hoping that maybe that nurse that checked him

out was wrong about it. (04)

For the mother in the following excerpt (TT), there appeared to be some concern that she did not have enough information in order to make a decision. Although she stated that she was scared when the doctor talked to her about her child's heart, she still could not recall or understand much of what was said to her prior to coming to see the cardiologist. It was unclear whether she was worried about her child's heart or whether she was worried that she did not have sufficient knowledge of the situation in order to judge the seriousness of the situation.

Excerpt TT

(01) M: Yeah, he (()) the doctor scared me when he was talking about

her heart.

(03) I: Do you remember what kinds of things he said that scared you?

(04) M: No. Not really. I forgot it.

(05) I: Maybe the way he talked or?

(06) M: Yeah, well I couldn't understand him much.

(07) I: Oh.

(08) M: Cause he has an accent.

The mother in the next example (VV) was worried about her child's health, but it was not necessarily because of the heart murmur diagnosis. She had been to another physician before seeing the doctor who successfully referred her to the pediatric cardiologist. Although she had heard about the murmur from the first physician who had referred her, she seemed to have delayed seeing a heart specialist because she felt that what the doctors were diagnosing as a heart murmur was really attributable to other illnesses from which her daughter was suffering at the time.

Excerpt VV

(01) M: ... she had gone in for allergies. She was sick, she had sore

(02)throat and stuff. And then uh they I went back for her uh you (03)know checkup on her, see how she was doing. And the doctor

(04) told me that they had heard a murmur in her heart. And I said no

that was the first time and so they set me an appointment for the (05)

(06) twenty-ninth of June and I didn't make it.

Yet, other families held off worrying because they were waiting for the heart expert to diagnose their child before they decided to worry. They came to the pediatric cardiologist in order to hear whether the referable heart murmur was innocent or significant (i.e., to have the cardiologist delabel the referable heart murmur). The families in this study expressed their desire to hear from the expert and that upon hearing the expert's diagnosis, then the families' worries would hopefully be over.

Excerpt VV

(01) M: But if she knows (.) there's doctors that know about the heart and

other things and I guess if she knows talkin about well then I

(03) think I can trust her

And even if the news was not to be all good, then at least the family knew it was a definitive answer and they would be sure that there was cause for concern:

Excerpt WW

(01) M: So you know we're kind of just real open about it. And if there's

a problem, and the doctors say, "We need to do something about

(03) this now," we'll do it. But until that point we're not going to be

(04)real anxious about it.

RFA of The Choice Not To Worry

Just as ambiguity and indecision made sense for some families in the study, clarity and decisiveness was the presiding logic for other parents. This latter group seemed to be able to keep their talk about their child's heart murmur in the gallery of healthy child. In Excerpt QQ, the family equated the heart murmur with a leg problem the child had had previously. The heart murmur was of a different class of medical problem, but it was understood as being in the nonpathology side as the leg problem which was cured:

The key point was that the talk for this family remained entrenched in the healthy child gallery. One was the healthy child gallery was maintained was that the referral to the pediatric cardiologist was framed as being part of routine medical procedures. The referral, framed as routine, was not worrisome for parents and wold not have created a leak in the healthy child gallery. Excerpt RR was a good example of this logic:

G: Healthy child

F: Routine check up / Routine Referral

f: "'It's just, I heart something there, it may be something he'll outgrow. I just want it checked out.' So you know even from that, it's not a big concern, he just wants it checked."

The mother's framing of the referral as not being a big concern confirmed and was confirmed by the healthy child gallery. For this family, referral to a pediatric cardiologist had a fit in the routine check up frame and in the larger healthy child gallery. The referral was not discussed as being a leak. It maintained and was maintained by the prevailing talk of the child as a healthy person.

Another way families kept from shifting into a pathology view of the heart was to set up a side-by-side distinction which threw doubt on the doctor's selection of the heart as being the cause of the child's ill health. The mother in Excerpt VV did not avoid the unhealthy child gallery, but she did create a distinction which helped her to doubt whether the child was ill due to a bad heart or whether the child's illness was attributable to other conditions:

G: Unhealthy child A child with ill health

F: "a murmur in or F: She was sick, she had a her heart" sore throat

Her child was in ill health (sick) but not an unhealthy child (a bad heart). Whether or not the mother was clinically incorrect, her creation of alternative talk helped her avoid being overly concerned such that she was able to delay seeing the cardiologist the first time she had been referred.

Another way in which families were able to stay out of the oscillation between pathology/nonpathology was to decide to postpone making a decision until the expert had spoken. It was as if the families had set aside a blank frame, a frame whose content could only be filled by the expert—a pediatric cardiologist. The not-hearing of the expert's diagnosis was tolerable to these families because the blank or deciding frame remained within the gallery of healthy child. This concept was similar to what Bateson (1979) discussed when he wrote:

in the circumstance that zero, the complete absence of any indicative event, can be a message. . . . The letter that you do not write, the apology you do not offer, the food that you do not put out for the cat-all these can be sufficient and effective messages because zero, in context, [emphasis from original source] can be meaningful; and it is the recipient of the message who creates the context [italics added]. (p. 51)

To these families, no message was confirmation of a healthy child and they would wait until the pediatric cardiologist supplied them with the definitive confirmation of the lack of a serious heart condition. To paraphrase a rather well-known legal dictum, The heart murmur was innocent until proven serious.

CONCLUSION

This chapter examined the talk of the families about the experiences surrounding their child's referral for a heart murmur. A few basic distinctions were drawn through the use of Recursive Frame Analysis. RFA allowed for a description of the talk which helped to make the flow of discourse understandable. What was not done in this chapter was to use these basic distinctions to help prescribe ways in which discourse could be managed such that families and medical personnel could be helped through the discovery/referral process. Chapter 5 attempts to present ways in which frame management can be applied to this process.