

The Role of Children in the Dietary Management of CF

**Eileen Savage, University College Cork
& Peter Callery, University of Manchester**

Acknowledgment of Funding:

An Bord Altranais (Doctoral Scholarship 1998-2000)

Health Research Board (Ireland) (Research Fellowship
in Nursing 2000-2002)

What is Known?

- **Optimal Nutrition** - Growth, Pulmonary Function, and Survival (Corey et al. 1988; Zemel et al. 2000).
- **Dietary Intakes** -Inadequate (eg Anthony et al. 1998)
- **Dietary Behaviours** -Noncompliance, “Maladaptive”; Ineffective management (mothers) (e.g Sanders et al.1992 ; Crist et al.1994; Stark et al.1995)
- **Interventions** - Behavioural; Self Management (Singer et al. 1991; Stark et al, 1996; Bartholomew et al. 1991, 1997)

Little Known about:

Parents' and Children's Perspectives
of the everyday practicalities of
implementing CF dietary
recommendations for a high fat -energy
diet *e.g.*

Little Known about:

Broader Context of Dietary Management:

- Chronic Illness Experiences
- The Role of Children as Active Participants

Theoretical Framework: Symbolic Interactionism

Focus on:

- Actions based on meanings
- Meanings derived out of social interactions
- Meanings handled/modified -interpretive process
- “Joint Action” (Blumer, 1969)

Ethnography as an Approach to Inquiry

“the ethnographer first describes the local world and then, even if he or she is interested in particular persons, gives primacy not to the subjective reality of a single individual but to the social reality of a particular group. For the ethnographer the local world that encircles the group may be a village or a neighborhood or even a social network”

(Kleinman 1992, 129).

Methods

- **Sample:** __ 32 children (6-14 yrs)
& their parents (2 CF centres)
- **Data Collection:** Interviews (x 60),
Participant Observation (Home & Clinics
(21)); Document Review.
- **Data Analysis:** Constant Comparative
Method incl Discourse analysis (for clinic
consultations)

Parents' Approaches to Feeding

Primary Objective



Keeping the Weight Up

Keeping the Weight Up

- Piling on a High Fat diet
- Deciding on high fat diet
- The Distress of Seeing Children lose weight

Ensuring Children's Co-operation

- Working with Children's Preferences (conditional)
- Getting Strict
- Battling with Children to Eat
- Taking the Pressure Off (Tube feeding)

Children's Perspectives

Dietary Choices based on Likes #& Dislikes

Little understanding of the concept of Weight

Little awareness of gaining/losing weight from bodily experiences

Focus on Health as Being Active and Energetic and Not Weight Gain

What Use it Weight?

Sinead: No idea (laughs), all I know is I have to put my weight up...well to make myself healthy really I think, I don't really know. (C14, 11 years)

Differing Perspectives

Parents

Keep the Weight Up

Children

Active & Energetic

Implications for Practice

Implications for Practice

- Active participation of children
- The role of bodily experiences in children's understandings about health
- Child centred dietary advice applied to Being Healthy - "Active & Energetic"
- Support & Educate Parents and Children to work in collaboration in managing CF diet