THE ECOCULTURAL FAMILY INTERVIEW: NEW CONCEPTUALIZATIONS AND USES FOR THE STUDY OF ILLNESS

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Prof. Vanna Axia was a remarkable researcher, scholar, clinician, teacher, and person. Among all her many talents and skills was her ever-present concern for the experience, emotions and feelings of the parent or child. What was a medical visit like for them? How were they experiencing shyness, or suffering from cancer, or trauma, and how were they doing? Her very strong interest in the science of human development was always combined with this personal feeling, a deep and sincere empathy, for what mattered to the people and families who participated in her research.

Perhaps this is among the reasons for her early and strong interest in the Ecocultural Family Interview (EFI), the role of culture, and the creative and sensitive ways that she adapted this method for her studies in Italy. In this essay, I will review some of this work and provide a background and overview of the EFI, emphasizing the ways that Vanna and her students adapted the EFI for use with difficult and sensitive clinical studies. This was among her real contributions to the EFI work both for the empirical findings that resulted and for the theoretical and methods innovations that emerged from this work.

The Ecocultural Family Interview

A mother of a child with developmental disabilities living in California was asked at a parent-practitioner conference to describe her "needs", assessed using a stress and coping scale. She commented as follows:

> Professionals kept asking me what my "needs" were. I didn't know what to say, I finally told them, "Look, I'm not sure what you're talking about. So let me just tell you what happens from the time I get up in the morning until I go to sleep at night. Maybe that will help.
> (Bernheimer & Weisner, 2007, p. 192)

This mother was not trying to evade the question or refuse to answer interview questions or fill out questionnaires. To the contrary, she wanted to really respond to the questions about her parenting, her needs, and her problems. But she needed to break the limitations of the

frame of the standardized survey question, and the conceptual framework of needs or stress in order to fully explain her *habitus* and the impact of the child with a disability on her life. What she wanted to talk about was her experience of establishing and living in the daily routine of life. This context mattered to her experiences of stress and her ability to adapt.

The daily routine consists of the activities that we do each day from the time we wake up to the time we go to sleep again at night. Among the insights Vanna drew from thinking about a particular parent or child nested within their daily routine of activities and behavior settings is that these settings can be richly meaningful and emotionally significant for parents and children – they matter to our sense of well being and can increase or reduce stress and anxiety. Vanna and her students focused on these activities and the feelings and experiences of those in them, in her work with parents and children with cancer, for children with headaches, and children and parents dealing with a catastrophic trauma such as Beslan.

Daily routine: diaries, time allocation, and experience sampling

There are a number of ways to conceptualize the daily routine and ways to measure and assess it. These are all useful in different ways, though only the EFI and other qualitative methods focus on the meanings of the routine and activities to the person. Daily diaries are usually organized within a grid where the rows are the time throughout the day, and the columns are activities, people, and places. Research participants fill these out each day. They might include the people the person is with, the activity that is going on at those times, the tasks and chores that are being done, and perhaps some indication of the difficulty of those activities, how pleasurable or troubling they are to the person, how regular or typical they are for a day or a week, and so forth. Daily diaries allow for quantification of the time spent doing activities, the social context they are done in, the difficulty and emotional valence, how regular they are, how often they are done, and how meaningful they might be to the informant. If several family members fill out a daily diary over the same periods of time, these diaries can be compared. Daily diaries are more reliable and valid estimates of behavior than retrospective reports from a survey, since specific events can be tracked over many days with more or less immediate (same day or evening) recording (Bolger, Davis, & Rafaeli, 2003).

For instance, Telzer & Fuligni (2009) studied patterns of family assistance (chores, tasks, and family obligations and responsibilities) in a large, ethnically diverse (Asian, Latin American, and European) sample of US adolescents ages 14 – 15 in California. The teens filled out a diary checklist each night before going to bed, which took 5 – 10 minutes; project phone calls reminded the teens, and a time stamper was given to each teen that was security coded such that the date and time changed each day, the teen could not change the stamp cycle, and the teen had to stamp and seal each diary entry each day. Youth also reported each day on mood, well-being, and feeling happy or distressed. Family assistance was associated with higher levels of happiness that was in turn is associated with a sense of playing a fulfilling family role.

Time allocation is another way to understand how daily activities may affect children, parents and families. The number of minutes that a person is involved in certain kinds of activities can be calculated from survey questions in which the respondent summarizes their daily activities and either reports the time spent or fills out an averaged activity schedule over a week (Bianchi, Robinson, & Milkie, 2006). Over the past 50 years in the US, such surveys have asked respondents what they will be doing tomorrow or did yesterday, and for how long, who was with them and their location either in person or by telephone (more recently). The activities are fixed categories in the survey, and include paid work, family care work, personal care (sleep, meals), and "free time" (religion, visiting, TV, etc.). The American Time Use Survey is an example of this approach. As US mothers increased market work in the past 30 years, for example, these women reduced their reported time doing housework, but not their time doing childcare. Reported housework hours dropped from 32 on average in 1965 to 19 hours in 2000; market work increased by 14 hours at the same time period. Childcare hours reported went up – and did so for working and non-working mothers alike, so the work time pressure on employed mothers increased. Fathers increased housework some, but unlike mothers, their childcare hours did not change much to compensate (Bianchi, 2010).

Experience sampling methods or ESM are an online blend of these other approaches (Larson, 1989; Larson & Verma, 1999). Participants in a study are given a beeper, or phone or smartphone or other device, and agree to be nudged electronically with a contact from project teams. The participants are then asked a brief series of questions about their emotional state, attention, activities currently engaged in, and the behavior setting and social context the informant is in at that moment.

ESM contacts can be on a variety of scheduling regimes (times of the day, frequency of contacts, types of prompts). Participants can talk to the researcher on the phone, or type in their responses while being prompted. Even more advanced methods use smartphones, body sensors, GPS monitors and other approaches using the web (Schneider, 2008; Swendeman & Rotheram-Borus, 2010). These current approaches include ecological momentary assessment methods (EMA) for the study of social settings, and Mobile Personal Sensing (MPS) for intervention studies in which the target subject is located and monitored continuously using smartphones and cellphones with GPS and other visual aids (DeCaro & Worthman, 2007; Shiffman, Stone, & Hufford, 2008).

The EFI family interview

The EFI situates the parent and child in their daily routine of activities, as these other measures do, but then asks the participant to "tell me about your day:" "Walk me through your day from the time you get up in the morning, until you go to sleep at night," "What are the first activities that start your day in the morning?" These kinds of prompts begin a conversational, guided interview, in which the informant talks about the events that make up their day, the important aspects of their routine, their concerns about their routine, how they would like to change some aspects of their routine and the activities in it if they could, what happens if their routine is disrupted and how and why that happens, and which are the most positive and rewarding, or least so, of the activities of their day (Axia & Weisner, 2000; Weisner, 2002; Weisner, Matheson, Coots & Bernheimer, 2005).

The routine is described and evaluated from the point of view of the participant, including the concerns, experiences, intentions, motivations and engagement of the person in these activities. The EFI produces a narrative, a series of vignettes and descriptive stories and accounts of the day. Diaries, ESM methods, or time allocation reports cannot provide evidence of this kind, but when the EFI is paired with survey or questionnaire data on the routine, the combination can produce a far richer account than using these other methods without an EFI narrative. The EFI is adapted for the topic of the interview. The framework and guides are similar, but a study of family responses to cancer, for example, focuses on those themes and topics; a study of poverty in the lives of working families lives brings the conversation around to those issues (Duncan, Huston, & Weisner, 2007); a study of families with

children with disabilities asks about adaptation to those circumstances (Gallimore, Coots, Weisner, Garnier & Guthrie, 1996).
The EFI illuminates the features of context and experiences that matter for parents and infants (Super & Harkness, 1997). Vanna's work with Italian families and infants and their home cultural ecology illustrates this approach (Axia & Weisner, 2002). Infant quieting during pediatric exams in which babies were given vaccinations, which were stressful for babies at five and twelve months of age, were influenced by parental reports of the home family environment. If daily activities accommodate more to the infant's routine, babies take less time to quiet after vaccinations. Early expectancies of parental support and empathy, and organization of the routine around baby needs and schedules, were associated with shorter time to quiet after vaccinations. Eighteen features of the home cultural ecology were scored, validated and rated to create the EFI scale for this study. Patterns of close parental proximity to the baby, strong family support for caretakers, and cultural goals favoring a "vivace" (lively, socially engaged) infant influenced infant quieting.
Vanna and her students' series of studies of children with childhood cancer took these concerns over stress and distress into the clinic. Vanna and her research teams interviewed parents of children with cancer as they dealt with the initial shock and responses to the onset of the disease, doing the EFI-Cancer (EFI-C) interviews (Tremolada et al., 2009). This series of studies showed the importance of parental social engagement with staff, understanding the nature of the medical procedures, the social support of staff, families and friends, and the importance of appropriate disclosure to the child. Most of all, it brought the experiences and perspectives of the parents into the study of family stress and responses to a crisis such as cancer in a way that existing scales had not done up to that time. The EFI-C adds value to questionnaire methods alone.

> [Questionnaires] certainly inform us about the mental functioning of parents of children with cancer and they also inform us about their chances for positive adaptation. However, they tell us little about how parents of children with cancer strive to extract a meaning from their ongoing experience and how they use it to create a routine which can be meaningful to them and their child in the clinic and at home. Everyday life must somehow be lived out, hour after hour. Especially in the face of such an enormous challenge to their child's health and survival,

> families must find a meaning for how they are living and for what they are doing (Tremolada, et al., 2009, p. 34).

The Italian research team conducted 128 qualitative, semi-structured EFI-C interviews with parents of children with leukemia at first hospitalization (Tremolada, Bonichini, Altoe, Carli & Weisner, 2010). From these interviews, a set of 11 psychometrically robust dimensions which characterized the meanings, concerns, and emotional and social engagement of the parents were developed. These included, for example, Parental Emotional Coping (e.g.,focus on child's needs; search for figures to provide a sense of security); Trust in Hospital Community (e.g. feelings of belonging to this community; appreciation); Routine and Time Reorganization (e.g. adaptation between home-hospital settings; maintaining a routine after diagnosis). Three summary factors were also identified: child coping and quality of life; parental coping; and parent's social and other resources. Tremolada et al. (2010) showed that the child's quality of life was associated with these factors, and that several new dimensions, not currently tracked by questionnaires, were also identified:

> ... we can find new variables ... of child and parent coping and adaptation in their routines) which, to our knowledge, were never reported in the literature (i.e., the level of trust they have concerning their medical care and trust in the hospital community; the salience, meaning, and
> consequences of changes in family routine and time reorganization of their home and clinic life). These seem to be two important and meaningful goals for these parents, and they certainly are part of the active search for new everyday life meanings which occur during the first child hospitalization. (Tremolada et al., 2010, p. 3)

These EFI-C interviews offered parental points of view, suggested specific ways to intervene to support parents and children, and the interview itself was valuable for many parents simply by providing the opportunity for parents to tell their story to a sympathetic listener.
A version of the EFI also was used in interviews with 17 survivors of the school siege and catastrophic death, destruction and trauma which ensued in the Beslan terrorism acts of 2004 (Moscardino, Axia, Scrimin, & Capello, 2007; Scrimin, Moscardino, Capello, Altoe, Steinberg & Pynoos, 2010). The Beslan interview themes included parental concerns about their children's health and survival, rethinking of the

parental role, dealing with the loss of loved ones and the search for some kind of meaning for such an event. Spirituality and religion were also significant. One finding emphasized the salience of the disruption of the whole community, and the importance of collective responses such as community mobilization and empowerment during recovery and reconstruction.

Vanna was in the midst of work on developing the EFI for this kind of personal and clinical assessment of child and parental response to distress, pain, and crisis. She most of all wanted to make a difference in the lives of such children and their families through her research. She accomplished a great deal along these lines and she lives on in the work of her many students and colleagues who miss her greatly.

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Non s'intende di scherzi,
stelle, ponti,
tessitura, miniere, lavoro dei campi,
costruzione di navi e cottura di dolci.

Quando conversiamo del domani
intromette la sua ultima parola
a sproposito.

Non sa fare neppure ciò
che attiene al suo mestiere:
né scavare una fossa,
né mettere insieme una bara,
né rassettare il disordine che lascia.

Occupata a uccidere,
lo fa in modo maldestro,
senza metodo né abilità.
Come se con ognuno di noi stesse imparando.
....

Non c'è vita
che almeno per un attimo
non sia immortale.

La morte
è sempre in ritardo in quell'attimo.

Invano scuote la maniglia
d'una porta invisibile.
A nessuno può sottrarre
il tempo raggiunto.

Tratto da "Sulla morte, senza esagerare"
Wislawa Szymborska (1986)