



Family Environment of Rural Women Affected by HIV/AIDS and undergoing Antiretroviral Therapy

Sudharshana, H. M* & Venkatesan, S**

*Research Scholar, Department of PG Studies in Psychology, University of Mysore, Mysore, Karnataka, India

**Professor, All India Institute of Speech and Hearing, Mysore, Karnataka, India.

Abstract

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This paper aims to sketch the self reported family environment of 60 rural women afflicted by HIV/AIDS and undergoing Antiretroviral Therapy. Data collection involved the use of 'Demographic Profile Sheet' and 'Family Environment Scale'. Results portray a distinctive profile of the affected woman as illiterate, monogamous, single, or aged between 40-50 years and belonging to low-income group. Whatever remains of their family environment is ridden by conflicts, leaving no opportunity for personal growth and pursuit of leisure. Although only a pen picture, these findings invite ecosystems therapies for enablement of the affected women to raise their voice against HIV/AIDS in the country.

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Acquired Immuno-Deficiency Syndrome (AIDS) is the late stage of infection caused by Human Immunodeficiency Virus (HIV). There are approximately 39.5 million people living with HIV around the world (UNAIDS, 2006). This includes 17.7 million women, 37.2 million men and 2.3 million children. This snapshot excludes about 3 million AIDS death every year. The situation is not different in our country (Chandrasekaran et al. 2006). Increased mobility of inhabitants in villages along highways has contributed to dissemination of HIV infection from urban to rural areas (Godbole & Mehendale, 2005). Despite recent reduction of HIV in general population and high-risk groups following Antiretroviral Therapy (ART), its spread among Indian women currently estimated at 39% is higher than men. The risk behaviors of infected husbands combined with unprotected extramarital sex and sex with commercial sex workers is the most likely source of infection even as 90% of HIV-positive Indian women are themselves monogamous (Silverman et al. 2008; Newmann et al. 2000).

Social psychology has always evinced interest in the characteristics of strong and successful families. It is difficult to picture the plight of rural women infected by HIV/AIDS (Joseph & Bhatti, 2005; Majumdar, 2004). Several factors like illiteracy, poverty, skewed power equations and meager family supports blend to jeopardize these women into double disadvantage. Gender differences in family reactions to diagnosis, acceptance, and prognosis for their disease outcomes are noted (Kalichman et al., 2003; Serovich et al., 2001). There are indications that drastic changes occur following diagnostic disclosure of HIV/AIDS for a female member of the family (Serovich, Craft & Yoon, 2007; Krishna et al., 2005; Carr & Gramling, 2004). Differences in treatment compliance are reported across gender and residence (Kumarasamy et al., 2005; Nischal, Khopkar & Saple, 2005; Pallikavadath et al. 2005; Abel, 2003).

Various constructs can be explored in the context of family vis-à-vis rural Indian women affected by HIV/AIDS. Different methods of study have been envisaged depending on its scope, depth and range of concepts to be measured, whether large scale surveys or direct observation techniques are preferred. The Family Adaptability and Cohesion Evaluation Scales (FACES III; Olsen, 1982) tests the Circumplex Model on two main dimensions: cohesion and

adaptability operationalized into constructs, such as, commitment, encouragement of individual members, time together and social connectedness. Beavers Timberlawn Family Evaluation Scale (BTFES; Lewis, 1989) uses observation to assess total family functioning and interactions across several dimensions. Moos' Family Environment Scale (FES; Moos, 1990; Moos & Moos, 1986) consists of three subscales focusing on cohesion, expressiveness, conflict, control and organization. McMaster Family Assessment Device (FAD; Epstein, Baldwin & Bishop, 1983) and Self Report Family Inventory (SFI; Beavers & Hampson, 1995; Hampson, Hulgus & Beavers, 1991) are other examples that can be added to this list.

Some investigators and their measures focus on assessment of particular aspects of family, such as, communication, cohesion, closeness, warmth, flexibility, adaptability, encouragement, appreciation and commitment. Others dwell on family problem solving, conflict, roles, affective responsiveness, emotional involvement, social connectedness, time-together, behavioral control, or religious orientation. Some studies have attempted cross sectional approaches on small and non-random samples. Others have tried in-depth longitudinal life cycle approaches covering single family studies. Still others have explored inter-correlations among various strengths or weakness within a family. However, none of these explorations have been undertaken in the context of rural Indian women afflicted with HIV/AIDS and undergoing ART. There are several unexplored questions on what happens to the family cohesion in the face of such a life threatening diagnosis on the woman of the household? Does the family experience any inter-personal conflicts or breakdown in communication patterns? Does it disrupt their religious or moral orientation? Are their recreational avenues upset? Does the unique rural-cultural background influence their patterns of inter personal relationship? How does it tell upon their conflict resolution and time use? How do they meet or satisfy the individual needs of its members? Against this backdrop, it was the aim of this study to profile the family environment of rural women afflicted with HIV/AIDS and undergoing ART.

Method

This study uses a randomized cross sectional small group exploratory design. The target group in this study is rural women, which is operationally defined as an inhabitant or generally domicile of a geographical area deemed as village and administered by a local *panchayat*. This contrasts a town and city, which falls under the domain of a municipality, corporation or metropolitan development authorities. The socio-demographic variables addressed in the study include respondent age, occupation, income, educational qualification, family type, marital status, and status of spouse, apart from the stage of their clinical condition and type of ART treatment they were undergoing at the time of data collection.

Participants

The sample targeted 60 rural women diagnosed as afflicted by HIV/AIDS and regularly undergoing treatment as out-patients in ART Clinics at Krishna Raja Hospital, Mysuru Medical College, Mysuru, Karnataka, as well as those who visited the Integrated Counseling and Testing Center (ICTC) in the districts of Mysuru, Chamrajanagar, and Bangaluru, Karnataka, between January, 2013-December, 2013.

Instruments

1. Demographic Profile Sheet: Demographic Profile Sheet was used to elicit personal-social details of the respondent, viz., their age, educational qualifications, occupation, years of marriage, spousal health, type or size of family, housing, etc.
2. The Family Environment Scale (FES; Rey et al. 1997; Moos, 1990; Moos & Moos, 1986) seeks to assess the social climate of all types of families. The tool is an easy way of



examining each family member's perceptions of the family in three ways: as it is (Real), as it would be in a perfect situation (Ideal) and as it will probably be in new situations (Expected). Thus, there are three forms (R, I, or E) of FES for evaluating the social environment of a family as a whole. Administration of a single form is counted as an administration, while administration of all three forms one time is counted as three administrations. If used as per all the three forms, the tool can be also used to examine similarities and/or differences in interpersonal perceptions between the various family members. Item examples from FES-Real Form, which alone was used in this study, involve asking respondents to describe the family as they currently perceive it: (i) Family members really help and support one another (T/F); (ii) Family members often keep their feelings to themselves (T/F). Scoring is carried out as 'true' or 'false' by awarding one mark for reported responses given in the direction of family disturbance. The maximum possible score on each domain in this scale is 9, the overall possible highest score for entire scale is 90, and minimum score can be zero. High scores indicate greater level of disturbance in the family. The results of scores on FES can be interpreted as family profiles, a typology of family environments, and make comparison against normative samples. By interpolation, scores falling <25 % are deemed 'low', those between 26-75 % are assumed to be 'moderately high', and if they are >75 %, they are reckoned as 'pathological'. The 90-items of FES are grouped under ten subscales within three dimensions and ten domains (Table 1).

It may require approximately 15-20 minutes for completing one administration. Items in the original English version of the scale are worded at the level of 6th grade from age 11 to adults. In this study, the items were translated into Kannada-the native tongue of all respondents, by using reverse translation technique and securing a correlation coefficient of 0.96. Reliability estimate for sub scales measurements are consistent, test-retest intervals is significant and validity of the scale is supported by evidence (Boyd et al., 2004; Robertson & Hyde, 1982). Its internal consistency is reported between 0.63-0.74 while test-retest reliability is between 0.59-0.86 (Galea, 2010). A glossary on domains and items of FES is given in Table 1.

Procedure

After obtaining informed permission from participants and by following the mandated ethical guidelines for such research activities (Venkatesan, 2009), data collection involved individualized administration of FES on the respondents in a quiet private milieu. If needed, a female examiner assisted with clarifications during data collection. It was ensured that there is no breach in confidentiality. Statistical treatment on the derived data included multivariate ANOVA to ascertain the influence of secondary variables on FES. Tuckey's Post hoc test was used after obtaining a significant omnibus F value. All the statistical calculations were done using SPSS-Version 16.0 (Pallant, 2013).

Table 1

Glossary and distribution of domains and items on the FES

Dimension	Domain	Description	Item Number	Sample Item
Family Relationship Index	Cohesion	Action or fact of bonding, togetherness, unity or solidarity between members in the family	1, 11, 21, 31, 41,51,61,71, 81	"Family members re-ally help and support one another"
Family Relationship Index	Expressiveness	Show or display of what one thinks/feels openly and directly	2,12,22,32,42,52,62,72,82	"We say anything we want to around home"
Family Relationship Index	Conflict	Extent of friction, argument, disagreement or discord within the family as a group	3,13,23,33,43,53,63,73,83	"We fight a lot in our family"
Personal Growth	Independence	Sense of autonomy, self-determination and initiative in matters of opinion or conduct experienced by family members	4,14,24,34,44,54,64,74, 84	"We think things out for ourselves in our family"
Personal Growth	Achievement Orientation	Disposition regarding cultivation or demonstration of abilities and activities that help members to move ahead in life	5,15,25,35,45,55,65,75,85	"We feel it is important to be the best at whatever you do"
Personal Growth	Intellectual-Cultural Orientation	Family concern and involvement in political, social, intellectual and cultural activities	6,16,26,36,46,56,66,76,86	"We often talk about political and social problems"
Personal Growth	Active Recreational	Family participation in various leisure, sporting and recreational activities	7,17,27,37,47,57,67,77, 87	"Friends often come over for dinner or to visit"
Personal Growth	Moral-Religious Emphasis	Family involvement in moral, ethical & religious activities	8,18,28,38,48,58,68,78,88	"We don't say prayers in our family"
System Maintenance	Organization	Act of planning, arrangement, coordination, administration or running the activities of the household	9,19,29,39,49,59,69,79,89	"We are generally very neat and orderly"
System Maintenance	Control	Power to govern, influence or direct behavior of each member in the family	10,20,30,40,50,60,70,80,90	"There are very few rules to follow in our family"

Results

For overall sample (N: 60) the mean FES score is 38.81 (SD: 13.63; 43.12%). This is interpreted as 'moderately unfavorable levels of self-perception' about their current family climate by the HIV/AIDS affected rural women respondents (Table 2). The mean sub-scores on different domain components of FES show greater problem with respect to 'cohesion' (Mean: 4.67; SD: 1.34; 51.89%), followed by lower scores on 'organization' (Mean: 4.59; SD: 1.35; 51.00%), 'moral-religious emphasis' (Mean: 4.44; SD: 1.26; 49.33%), 'expressiveness' (Mean: 4.24; SD: 1.36; 47.11%)(Table2). The least scores are evidenced for 'intellectual-cultural orientation' (Mean: 2.94; SD: 1.38; 32.67%). These differences are found to be highly statistically significant ($p < 0.001$).

Table 2

Distribution of scores obtained on the FES

Components of FES	Max.	Mean	S.D	Percent
Cohesion	9	4.67	1.34	51.89
Expressiveness	9	4.24	1.36	47.11
Conflict	9	3.12	1.38	34.67
Independence	9	3.60	1.24	40.00
Achievement orientation	9	4.04	1.39	44.89
Intellectual cultural orientation	9	2.94	1.38	32.67
Active recreational	9	4.04	1.39	44.89
Moral-religious emphasis	9	4.44	1.26	49.33
Organization	9	4.59	1.35	51.00
Control	9	3.13	0.96	34.78
Total	90	38.83.121	13.63	43.12

[F (9, 590): 14.447; P: <0.001]

A series of multivariate ANOVA was undertaken to derive F values between key socio-demographic variables and distribution of FES scores across the various measured components (Table 3). A consistent profile that emerges from the results is that the four *protocols* of ART treatment regimes, viz. D4t+3tc+Nvp, Zdv+3tc+Nvp, Stv+Lmv+Efv and others show differences within the family environments (p: <0.001). While ART is the main treatment available for HIV/AIDS, it is by no means a cure. It can stop people from becoming ill for many years or delay their death. These treatment protocols are arranged in relatively enduring hierarchy. As a patient develops tolerance for the protocol at one lower level, drugs at the next level is tried irrespective of the stage and/or severity of infection (Kiselinova et al. 2014; Kumarasamy et al. 2005). Probably, for this reason, the perceived status of family environment undergoes significant change across various components. As per the official classification of clinical staging for HIV/AIDS infection, the four categories that are recognized are: asymptomatic, mild symptoms, advanced symptoms and severe symptoms (WHO, 2007). Although the protocol of ongoing treatment is noticed to bring about differences, it is seen that there no significant differences in the perception of family climate for various stages of infection (p>0.05).

The *health status of spouse* is another variable that emerges significant across as many domains of FES. The reported family climate of the infected woman appears to worsen wherein both partners are infected (p: <0.001). The most vulnerable age group of rural women with significantly high FES scores and therefore experiencing greater domestic problems is between 36-40 years (p:<0.001). The affected domains are related to conflicts, achievement orientation and active recreational aspects. There are reports of frequent instances of disharmony, discord and disagreements in these families. It is stated that the family situation is not facilitating achievements to move ahead in life. All this appears to be affecting pursuit of leisure, amusement, sporting and recreational activities within such families.

Low income families seem to be at a greater disadvantage for the affected rural women with HIV/AIDS. It appears to affect several components of family environment including bonding between members, open expression for their thoughts, feelings and actions, autonomy or independence of individual members, their moral-religious involvement and organization of routines in the household. With respect to *type of family and marital status*, the single separated women reportedly experience greater conflicts, are unable to achieve much in their life and are deprived of even the fewer opportunities that such women have for their own entertainment or recreation. Educational qualifications of women respondents covered from illiterate to under-

graduate and occupations ranging from being home-makers, unskilled, semi-skilled to professional workers are not seen to influence their family milieu ($p > 0.05$) (Table 3).

A perusal of the content responses of the affected rural women show high scores on FES items under 'cohesion' for a lacking in togetherness, group spirit, back up or mutual help and support from one another. Under the domain of 'organization', there are indications that family activities are hardly planned, occur on time, or get executed neatly and orderly. It appears that, more often, duties are poorly defined, money matters are badly handled, ad hoc decisions are taken, and members change their minds frequently in such families. There is less or restricted 'expressiveness' in the family ambience since members are viewed as keeping their feelings or personal problems to themselves. Whenever it is rarely expressed, everyone is careful about what they say since there is felt risk of inadvertently upsetting somebody. 'Control' mechanisms in the family are seen as being either poor or with rules being almost non-existent. Decision making is single person centric with others having no say in such matters. There are indications that family groupings, outings, pursuit of hobbies, recreational activities, celebrations and festivities are minimal.

Table 3

Distribution of F-values obtained across components on the FES for various socio-demographic variables

Components	Age	Occupation	Income	Educational Qualification	Family Type	Marital Status	Spouse Status	Clinical Stage	ART Treatment
Cohesion	1.21	4.26	3.74*	1.72	3.02*	0.82	2.90*	1.98	7.84**
Expressiveness	3.57*	1.45	3.01*	0.75	1.91	1.51	7.33**	2.24	10.06**
Conflict	0.78	0.93	0.33	0.42	1.47	3.45*	4.98*	0.11	7.15**
Independence	0.49	0.94	4.61**	1.22	3.32	1.18	2.69*	0.63	7.03**
Achievement orientation	0.86	1.47	0.30	0.97	1.52	3.56*	2.72*	0.59	5.56**
Intellectual cultural orientation	1.43	2.06	0.40	0.67	1.32	1.45	5.32**	1.05	8.74**
Active recreational	0.86	1.47	0.30	0.97	1.52	3.56*	2.73*	0.59	5.56**
Moral-religious emphasis	1.08	1.27	10.01**	2.34	3.89	0.92	2.77*	1.77	5.87**
Organization	2.38	3.13*	2.66*	0.82	6.16*	1.32	2.58*	2.52	6.77**
Control	0.39	5.94**	1.22	4.05	3.73*	2.12	2.58*	1.22	9.08**

Discussion

Strong, healthy, robust and successful families are severally defined. According to Stinnett (1979) such families "create a sense of positive family identity, promote satisfying and fulfilling interaction among members, encourage development of family group and its individual members, and is able to deal with stress". David Olson and colleagues propose that families should be able to: (i) cope with stress and problems in an efficient and effective way; (ii) have and use coping resources both from within and from outside the family; and (iii) have the ability to end up being more cohesive, more flexible and more satisfied as a result of effectively overcoming stress and problems (Olson, Candyce & Douglas, 1989). Their focus is on a family's ability to adjust, in the face of change or crisis, with emphasis on changes across the family life cycle. While these definitions reflect ideal situations or circumstances, the tragedy and plight of the key player in the family being affected by a life changing disease cannot be portrayed by figures alone (Doshi & Gandhi, 2008; Go et al. 2003).

Nonetheless, from the data in this study, it is evident that the characteristic profile of a rural woman affected by HIV/AIDS in our country is one who is pathetically illiterate, single,



separated or divorced. She is belonging to a low income group, monogamous, uncomplaining, adjusting, accepting of the intermittently visiting and equally affected, but possibly polygamous male partner. Such a woman is typically left to fend by herself, is ridden by conflicts, with recurrent instances of intra-familial quarrels, brawls and disputes. These situations do not facilitate any personal growth. Their pursuit of leisure, enjoyment and entertainment is minimal. Similar portrayals have been made out of affected women from several parts of the world. Mitrani et al (2003), for example, used multivariate logistic regression models to discover that family environment has intimate relation even as predictor variable for treatment engagement and outcomes in sero-positive African American mothers. Sharon (2003) found family system could be, both, a source of stress as well as support for these affected women. Robbins & Antoni (2003) examined the role of family functioning and social supports in protecting HIV-positive African American women from the adverse psychological consequences associated with deterioration in their CD4 cell count. Results demonstrated that changes in CD4 cell counts are inversely predictive of psychological distress and were moderated by family functioning and social support satisfaction. Women with good family functioning were less affected by changes in their CD4 cell counts, and women with poor family functioning were more emotionally responsive to changes in CD4 cell count.

To conclude, a family is not to be viewed as equivalent of its individual and dyadic parts. One must view the family in terms of its dynamics as a whole. Any attempt to study the complete family system as a snap shot view would be akin to taking a still photograph of an action in motion. Even though the findings of this study appear to be a still picture, it has implication for planning and implementation of family environment based structured ecosystems therapy for improving psychosocial functioning of the affected women or at least to slowdown their sliding prognosis. It also has repercussion for the ongoing social-cultural movement on advocacy and empowerment of affected rural women in raising their voice against HIV/AIDS in the country.

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