



## Role of positive deviants among Leprosy self-care groups in Leprosy settlement, Zaria, Nigeria.

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### Abstract

**Background:** Positive deviants (PD) are described as a group of individuals having similar risks or conditions, but with few of the members doing something different from the main group to avoid the effect of the common condition or perform better under the same condition. The aim of this paper is to describe the possible roles of PD among Leprosy self-care groups.

**Methods:** A prospective descriptive study was conducted among Leprosy self care group for a period of six months.

**Results:** A total of 26 ex-Leprosy patients agreed to form a self care group, 15 (58%) were females. Six (23%) of the group members had ulcers, out of which two had two ulcers on the feet, making a total of eight ulcers among the six ex-patients. Twenty one (81%) of them had visible deformity either on their eyes, hands or feet (defined by W.H.O as grade 2 disability). Using the total sum scores of impairment and deformity for all the three organs (Eyes, Hands & Feet) the EHF sum score, 50% of the patients had scores between 1-4. Six months later, a total of four ulcers (50%) were healed at home with the support of self care group members, of which two patients healed their ulcers (33%). There was no change in the disability grading among all the patients, even though two (15%) patients with EHF score between, 1-4 had zero score at the end of the six month period. The group observed general improvement in hygiene, protective foot wear utilization and willingness to support each other in the group within the period of the six months.

**Conclusion:** Patients could heal their ulcers at home using group support and practicing different approaches that were not necessarily taught to them by health care workers.

**Key words:** Leprosy, self-care, positive deviants

## Introduction

Positive Deviants are described as a group of individuals having the same risks or conditions, but with few of the members doing something different from the main group to avoid the effect of the common condition or perform better under the same condition.<sup>1</sup> Self-care groups are groups of patients/individuals taking responsibility for the management of their basic medico-social problems (e.g. anaesthetic hands and feet, simple ulcers and common eye problems) with the support of health workers who provide the basic knowledge and skill of the process.<sup>2</sup> Self-care is defined as “health care, which the individual provides to him/herself without outside professional assistance”. Such care may be based on instruction provided by professionals<sup>3</sup>. The strategy of self-care is for patients to use common, simple, available and sustainable tools in their homes and surroundings to prevent or manage their basic medico-social problems with less dependence on hospital facilities.<sup>4</sup>

While self-care groups are a form of support group; a medico-social group with specific aim of helping group members (e.g. leprosy affected persons) take care of their medical or social problems. Similar groups exist around the world, e.g. mental health groups, diabetic associations; HIV/AIDS support groups, cancer groups, and sickle cell groups.<sup>5</sup> Groups as seen by social psychologists involves regular contacts between members, fairly small size (8-20 members), involves cooperation, sharing some common goals and having a rough idea of what other peoples roles are in the group.<sup>6</sup>

There is evidence that self-care groups among leprosy patients bring about decline in ulcers (41%), increase use of foot wears (43%), and significant proportion of families practicing and helping each other. A study by DFIT in India showed a reduction of prevalence of plantar ulcers by 50%.<sup>4,7</sup> Group members in a study done in Ethiopia also reported increased confidence to participate in the society, restoration of dignity, self-respect and sense of belonging within the community.<sup>5</sup>

## Methodology

The study was a prospective descriptive study among leprosy self-care group in Saye Leprosy settlement in Zaria. The settlement has over 200 ex-leprosy patients and their families. The settlement is less 500meters to the National TB and Leprosy training centre, Zaria.

The concept of self-care group was introduced to the community by staff of the National TB and Leprosy centre. It was conducted by organizing a meeting with the community to describe its importance, and to emphasize that membership was voluntary and that no financial incentive would be provided for membership. Two months later, with the support of health care workers a group was formed, functions for each group member was described and it was determined that leadership of the group should be rotational.

Baseline data was established at the commencement of self-care group using the routine leprosy monitoring forms, with each patient being assessed for ulcer, impairment and visible deformity on the eyes, hands or feet. WHO disability grading was used, with 0 meaning no visible deformity and no anaesthesia, 1 present of anaesthesia without visible deformity and 2- obvious visible deformity. The WHO grading uses the highest of the score in any of the three organs (eyes, hands & feet). However for monitoring purposes, a total sum score of each of the three organs is used, called the EHF sum score.

The group agreed to meet fortnightly and during the meeting all members sat in a circle and were inspected in turns by group members, looking at general hygiene, eyes, hands, feet and foot wears. Group members discussed and advised each other based on their observations and experience with similar situations. Advice given was mostly what individuals had tried differently and has healed or prevented the occurrence of ulcers.

One health care worker was always in attendance at the meetings as an observer and was responsible for monthly monitoring of the patients' data (ulcer, WHO disability grading and EHF scores). The patients were all re-

assessed at the end of six months and data was compared with the initial assessment. A focus group discussion was also held to discuss their experiences and benefits of the self care group. Data was analysed using excel and tables to compare any change within the six months period.

## Results

A total of 26 ex-Leprosy patients agreed to form a self care group, 15 (58%) were females and most of the patients (46%) were within the age groups of 40-49 years. See Table 1. Six (23%) of the group members had ulcers, two members had 2 ulcers each, making a total of 8 ulcers among the six ex-patients and all ulcers were on the feet. Ulcers were common among

female patients (67%). Twenty one (81%) of all the members had visible deformities on either their Eyes, Hands or Feet (i.e. WHO grade 2 disability), while looking at the sum total of the impairment and deformity of all the three organs (Eyes, Hands & Feet), 8%, 50% and 42% of the patients had EHF sum score of 0, 1-4 and 5-8 respectively.

Six months later there was no drop out from the group membership. A total of four ulcers (50%) were healed at home using the self care group and its support, of which two patients healed their ulcers (33%). See Table 2. There was no overall change in the WHO disability grading among all the patients, but Table 3 shows that two (15%) patients with EHF sum scores between 1- 4 at the beginning now had zero score at the end of the six month. The group

Table 1: Age/sex distribution among group members

Age	Sex		%
	Male	Female	
<b>30-39</b>	1	3	15
<b>40-49</b>	5	7	46
<b>50-59</b>	4	5	35
<b>60-69</b>	0	0	0
<b>&gt;70</b>	1	0	4
<b>Total</b>	11	15	100

Table 2: Ulcer assessment by sex (Base line and Six months)

Sex	Presence of ulcers			
	Base line		6 months later	
	Yes	No	Yes	No
<b>Males</b>	2	9	1	10
<b>Females</b>	4	11	3	12
<b>Totals</b>	6	20	4	22

Table 3: EHF sum score assessment (base line and after six months)

EHF scores	Assessment period	
	Base line	6 months
<b>0</b>	2	4
<b>1-4</b>	13	11
<b>5-8</b>	11	11
<b>&gt;8</b>	0	0

members observed general improvement in hygiene, protective foot wear utilization and willingness to support each other in the group within the period of the six months.

## Discussion

Self care is one of the Global Strategy for Leprosy Control, where an affected patient takes part in the management of their conditions if educated and supported. The peripheral nerve damage usually leads to dryness, anaesthesia and loss of motor functions of the eyes, hands and feet. These factors are responsible for ulcer occurrence and re-occurrence among leprosy patients. Therefore patients are educated to do daily inspection, soaking, oiling and scraping of their hands and feet and those with simple ulcers to clean with salt water and cover the ulcer with clean cloth.<sup>9</sup> Patients are also provided and advised to use protective wears if having anaesthetic hands and feet. However many patients if left on their own lose the motivation for the self care over time and therefore the establishment of self care group was to get group support.

The patients who had healed their ulcers or improved in their EHF sum scores described to their group members what they did differently, which is the concept of *positive deviants* as follows:

1. Complain from a group member “ my ulcers keep reoccurring despite using the foot wear, because I had to farm”

Response from a member who avoided ulcer occurrence (PD):

“no it is not because you farm, I am sure you use the hospital foot wear to farm. The hospital sandals cannot protect you during farming because your toes are still exposed. *What I do is to use a rubber covered shoe for farming and hospital sandals at home*”

2. Complain from a group member “ i clean my ulcer every day but it still remain the same”

Response from a member who avoided ulcer occurrence (PD):

“How many times do you clean the ulcer in a day? Because I clean my ulcer five times a day

during the routine five daily prayers, the ablution (rituals of washing the face, hands and feet for Muslims) *is an opportunity for me to clean the ulcer more regularly*”

3. Complain from a group member: “ how can your ulcer heal when you always go for begging”

Response from a member who avoided ulcer occurrence (PD):

“No, it is not going for the begging, because I also go begging. But you have to identify the right position where you can only sit and people can still give you charity without walking round the whole market square”

“We can even avoid the begging by simple farming”

Question from a member: “With this hand? Showing clawed hands”

Answer from PD: Yes, is that hand different from my hands? All you need is to discuss with them in the hospital how you can farm without developing ulcers”

The most useful advices were coming from only few of the group members that we consider as positive deviants, but they were only identified during the group process by the members of the groups, in a systematic way as described using the 4Ds, and not by the health professionals<sup>10</sup>

1. Defining the problem that needs to be solved
2. Determining if there are individuals that exhibit the desired behaviour.
3. Discovering the uncommon practices or strategies the deviants use for success.
4. Designing an intervention method through which other members can learn from the positive deviants.

A PD inquiry approach is equally used to identify the PD and their practices and also the negative deviants, using a team of experience individuals on community mobilization, communication skills and knowledge of the condition. This approach is well documented in the field guide for community-based nutrition programme.<sup>11</sup>

The advantages of PD have been documented in many nutritional programmes,

because the actions of the PDs are affordable, acceptable and sustainable as they were already practiced by the people in the community and do *not conflict with the local cultures*. PD has been used in many countries, e.g. Egypt and Vietnam. In Vietnam within two years 80% of the families participating in the project no longer had malnourished children.<sup>12</sup>

## Conclusion

Pds exist among all the leprosy self-care groups and are playing a major role in supporting their and such members should be identified in all leprosy settlement to provide support to other leprosy patients.

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