Preventive Blindness and Social Work: Exploring the Needs and Scope from Rural Indian Perspective with Special Reference to Cataract Patients

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***Abstract*: Prevalence of cataract related blindness in India accounts for 62.2 per cent of the blindness. As catarct develops with ageing which gradually reduces the quality of vision, factors causing cataract is preventable with early detection and timely surgery of it with the replacement of the old lens with the intraocular lens. The National Programme on Conrol of Blindness (NPCB) in India stresses on expanding cataract surgery to rural and tribal areas by availing modern medical facilities in the sector. This requires the social work interventions on various levels to achieve the programme objectives. To understand the pre-surgery and post surgery status of the cataract patients and to discuss the possible scope of social work intervention, this study was carried out in a backwa district of Odisha state. For the study data was collected through interview schedule and informal discussions with key informants. The study found pre-surgery psychological barriers and quality of services as constraints to achieve programme objectives and suggests the social work means for proper implementation of the programmes.**

***Keywords:* Preventive blindness, cataract surgery, rural perspective, social work intervention**

INTRODUCTION

As per the recent global data on blindness, there are 36 million blind persons and 217 million with moderate or severe visually impairment in the world (Bourne, 2017). There has been a steady decline in the prevalence of blindness and visually impairment because of the initiatives in the field by the respective countries but, there is increase in absolute numbers of blindness and visually imapairment. The contributive factors to it include increase in elderly population worldwide and population growth. The global data also presents that prevalence of conditions like trachoma and onchocerciasis as causes of blindness have declined, but at the same time it shows that there have been rise in prevalence of eye diseases such as - glaucoma, diabetic retinopathy, and age-related macular degeneration along with slight increase in cases of cataract and refractive error (Flaxman et al., 2017). However, cataract remains one of the prime cause of the global blindness and around 50 to 80 per cent blindness cases worldwide are found in South East Asian region (WHO, 2002). The National Blindness Survey, 2007 states that 8 per cent individuals above 50 years in India are blind in which cataract accounts for 62.6% of all blindness affecting 9-12 million bilaterally blind persons (NPCB, 2007). As per estimation each year around 20 lakhs new cases of cataract are added to the blindness burden (Murthy et al., 2005).

The World Health Organization's Global Action Plan (GAP) 2014-19 aimed at reducing the prevalence of visually impairment cases by 25% by the year 2020 by emphasizing on availing comprehensive eye care facilities through health system approach to the people (Khanna, Marmamula and Rao, 2017). World Health Organization under Universal Eye Health Coverage (UEHC) emphasizes on "ensuring that all people have access to needed promotive, preventive, curative and rehabilitative health services, of sufficient quality to be effective, while also ensuring that people do not suffer financial hardship when paying for this services" (Flaxman et al., 2017). This connotes that all people should have access to a comprehensive, equitable, high quality and affordable health care that includes eye care too.

India with its limited health care facilities, shares a disproportionate global blindness and visually impairment. To counter the issue, government of India has taken initiatives through its National programme for control of blindness (NPCB) since 1976 for reducing the prevalence of blindness and visually impairment in the country. The NPCB mainly aims to "strengthen the existing and developing additional human resources and infrastructure facilities for providing high-quality Eye Care in all Districts of the country". At present the main causes of blindness in the country accounts for 62.6 % cases for cataract and rest includes refractive error (19.70%) corneal blindness (0.90%), glaucoma (5.80%), surgical complication (1.20%) posterior capsular opacification (0.90%) posterior segment disorder (4.70%), and others (4.19%) (NPCB&VI, 2018). This shows that cataract as one of the major contributive eye issue in the country to its number of blindness which is preventable in nature if detected and treated in its early stage. The Government of India through NPCBVI has now laid down a target for reduction in the prevalence of blindness to 0.3% against the rate of prevalence of blindness of 0.45% by 2020 (NPCB, 2018).

Cataract caused blindness in the country represents the problems of human morbidity and social burden. Hence, India has undertaken a long-term initiative to expand the capability of cataract surgery and services along with financial assistance from the World Bank. The important features of the initiative is to extend the cataract blindness programme in rural and tribal areas, to avail modern advanvced extracapsular cataract extraction with intraocular lens implantation for patients, developing coordination and collaboration in between non-government organizations and the public sector to expand the services to the most disadvantaged communities and strengthening institutional capacity, and to organise intensive awareness campaigns on cataract blindness at both

the national and state levels. As of the social, economic and environmental factors contribute to catarct blindness, such initiative is significant mainly in the rural India context.

Study made by Aarthi et al. (2015) on prevalence, barriers and facilitating factors related to cataract health services in a rural community of India reveals that the prevalence of cataract was 62.8%. They found a significant increase in cataract with increase in age ($P < 0.001$) and only 13% of the respondents with cataract made use of cataract surgery programme. The major barriers they found were no body to accompany during surgery (25.5%) and absence of felt need (22.6%). Less than one-fifth (17.8%) responded the awareness of cataract as a condition affecting eye. Whereas, the facilitating factors were noted sush as free surgery in eye camps (83.7%), self-decision due to defective vision (69.7%) and quality of service provided by the respective hospitals (65.1%). Similarly Flecher et al. (1999) investigated on service uptake in a rural Indian population served by outreach eye camps and found that out of 749 adults with eye issues, only 6.8 % attended the eye camps. Out of 552 adults who did not attend the eye camps, through the out reach programmes, 197 (38.5%) were recommended for a cataract surgery. As barriers to the low uptake he found fear of eye damage, fear of surgery related pain, expensive surgery cost, attitude of coping, negligence, having low vision as natural ageing process are the existing factors in rural India. This states that a good proportion of people who can be benefited from eye treatment are not making use of available eye-care services. Against these backdrop, this paper aims to propose a set of roles to be made by social workers in the eye care sector ultimately contributing to reduce the cases of avoidable blindness in the country.

RESEARCH OBJECTIVES

Sri Jagannath Netralaya (SJN) in the study area has been implementing a project to deal with preventable blindness and the problem of cataract surgery with help of funding by State Bank of India. Having two core purposes of eradicating preventable blindness from rural areas of Kalahandi district and making Kalahandi cataract-free through providing eye surgery and eye facility to rural poor, SJN strives to avail eye care facilities to the people under the project. To understand the need of such project, the constraints in the way of the project implementation, and the scope of social work intervention in this regard, this study was made having the following objectives -

The objectives of the study were:
1. To understand the pre-cataract surgery psychological and functional status of the cataract patients.
2. To assess the post-surgery satisfaction and functional status of the patients.
3. To findout the ground needs for social work intervention for the cataract patients.

METHODOLOGY

The present study adopts both descriptive and explorative research design. The study was made on the cataract patients from poverty-stricken areas of Kalahandi district of Odisha, India. Sri Jagannath Netryalaya – an eye hospital situated at Bhawanipatna, Kalahandi has been conduting free cataract surgery of the poor patients throughout the district. Out of the twelve blocks in the district three blocks namely, Bhawanipatna, Junagarh and Narla were randomly selected for the study. A total of 336 respondents (Bhwanipatna-107, Junagarh-109 and Narla-120 based on their availability during the study) who had undergone the cataract surgery under the project by Sri Jagannath Netralaya were selected through simple random sampling method.

The data for the study was collected through an intensive interview schedule (consisting of questions as well as some rating scales) and informal discussions with key informants (local leaders and SJN staff) in the study area. Each respondent under the sample group was interviewed individually to satisfy the research objectives.

RESULTS AND DISCUSSIONS

The study was concerned to understand the pre-cataract surgery status and the post surgery status of the cataract patients along with possible social work intervention. From the rural Indian perspective, the study found that there are certain specific areas of blindness control projects where social workers can intervene to contribute to achieve its objectives by overcoming the constraints in implementation of such projects. The key findings of the study are discussed below.

Pre Cataract Surgery Status of the Respondents

Evaluating the pre-surgery life of the respondents treated by the SJN is crucial to understand the post-surgery life of the treated respondents. The pre-surgery condition involves quality of eye-sight before surgery, functional problems faced before surgery, psychological stress during pre-eye-surgery and level of productivity before surgery.
The study found that all most all the respondents were having sight issues of different levels. Fig. no. -1 presents on the sight issues of the respondents that shows 47.0 per cent of the respondents were having poor sight (Table No. -1), 17.3 per cent of respondents responded having average sight and 33.9 per cent were not able to see before surgery due to cataract. This reflects how cataract affects the normal living of the individuals, which in turn makes them visually handicapped.

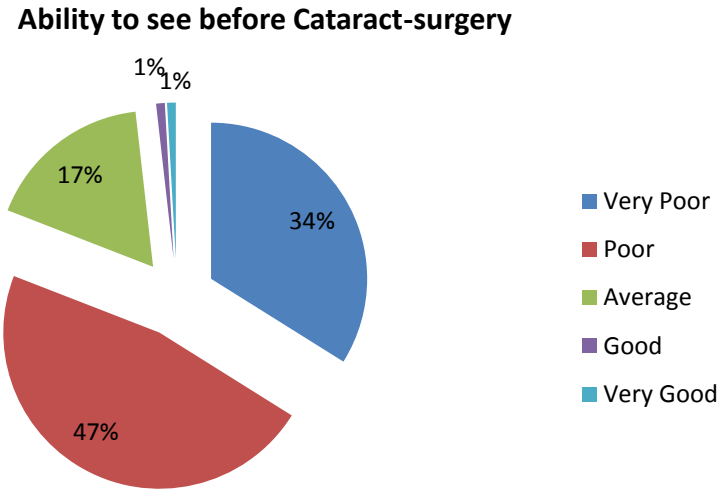

Fig. no. 1: Sight issues among the respondents

The visual complications resulting from cataract among the respondents, the study tried to find out different types of problems the respondents used to face in their day to day activities hereafter termed as functional problems or functional difficulties. A general functioning scale was devised for getting the appropriate responses from the respondents. The general functioning scale contained 15 (fifteen) components such as – respondents facing problems in climbing stairs, making out with bumps and holes on road while walking, seeing animals/vehicles when walking, finding the way in new place, going to social functions, going out at night, recognising people from a distance, recognising a person standing nearby, locking and unlocking the doors, doing usual work, working up to usual standards, searching for things at home, seeing in bright sunlight, differentiating between colours, coins or notes.

The functional problems faced by the respondents before cataract-surgery (Table no. 1) it was found that an average of 5.9 per cent of the respondents were not at all able to function in the lines of items included in the scale whereas an average of 52 (29+23.6) per cent of the respondents interviewed were facing difficulties in lines of items included in the scale.

Table No. 1
Functional problems faced by respondents before surgery

Sl. No.	General Functioning Scale (Problems in...)	Not at all	A Little	Quite a bit	A lot	Cannot do for the problem in eye-sight
1.	Climbing stairs	19 (5.6)	127(37.8)	89(26.5)	83(24.7)	18(5.4)
2.	Making out bumps and holes on the road while walking	25(7.4)	108(32.2)	112(33.3)	77(22.9)	14(4.2)
3.	Seeing animals/vehicles when walking	23(6.8)	96(28.6)	119(35.4)	86(25.6)	12(3.6)
4.	Finding the way in new place	52(15.5)	87(25.9)	104(30.9)	76(22.6)	17(5.1)
5.	Going to social functions	55(16.4)	81(24.1)	80(23.8)	76(22.6)	44(13.1)
6.	Going out at night	46(13.7)	144(42.9)	88(26.2)	39(11.6)	19(5.6)
7.	Recognising people from a distance	57(16.9)	170(50.6)	70(20.9)	28(8.3)	11(3.3)
8.	Recognising a person standing nearby	25(7.4)	65(19.4)	111(33.0)	118(35.1)	17(5.1)
9.	Locking and unlocking the doors	25(7.5)	77(22.9)	97(28.9)	112(33.3)	25(7.4)
10.	Doing usual work	43(12.8)	80(23.8)	106(31.5)	98(29.2)	09(2.7)
11.	Working upto usual standards	27(8.0)	79(23.5)	117(34.8)	97(28.9)	16(4.8)
12.	Searching for things at home	20(5.9)	91(27.3)	131(38.9)	74(22.0)	20(5.9)
13.	Seeing in bright sunlight	35(10.4)	122(36.3)	77(22.9)	82(24.4)	20(6.0)
14.	Differentiating colours	55(16.4)	117(34.8)	73(21.7)	63(18.8)	28(8.3)

15.	Differentiating coins or notes	35(10.4)	97(28.9)	93(27.7)	81(24.1)	30(8.9)
Mean (X)		36.1(10.7)	102.7(30.6)	97.8(29.0)	79.3(23.6)	20(5.9)

N.B.: Parentheses include the percentage

Blindness or partial blindness due to cataract creates difficulties in mobility. It was found that two-thirds of the respondents (33.3per cent) faced quite a bit and 32.2per cent of respondents faced a little problem while climbing stairs; 7.4per cent of respondents did not face any problem while climbing stairs. Whereas, around 22.9per cent of respondents faced severe problems while climbing stairs and rest of the 4.2per cent respondents could not even climb stairs because of their problems in eye-sight. The study also found that majority of the respondents having vision problem due to cataract were facing difficulties in making out bumps and holes on the road while walking. Assessment reveals that 4.2 per cent of the respondents were completely not able to identify bumps and holes. 32.2 per cent faced a little, 33.3 percent had a problem quite a bit and 22.9 per cent had severe difficulty in making out bumps and holes on the road. Only 7.4 per cent of the surveyed respondents were not experiencing any such difficulty.

With blindness or partial blindness when somebody cannot see animals or vehicles on the road may meet an accident. The more vulnerable groups were categorised as 'quite a bit' and 'a lot' as they are more prone to accidents when they rely on their own eyes for their mobility. These groups constitute 61.00 per cent when we combine both the parameters. 28.6 percent of the respondents were facing problem slightly in identifying animals and vehicles on the road. 3.6 percent respondents were not at all able to see while walking on the road. Since they were completely not able to identify animals and vehicles, while moving, they need assistance of family members. Most of the respondents also had experience of difficulty in finding a way in the new places before surgery. 25.9 per cent respondents had experienced a little difficulty and 53.5 per cent (combining the categories 'Quite a bit' and "A Lot') were experiencing more difficulties in finding their ways in a new places before surgery which was restricting their normal mobility to new places.

Individuals having cataract were found to be deprived of merry making and enjoy their life by participating in social functions before eye surgery. Social functions or ceremonies create opportunities to interact with the fellow kin members and as well as other members of the society. Study found that 16.4 per cent of the respondents having manageable sight did not have the problem in participating in social function. 13.1 per cent of the total surveyed was totally deprived to be part of social functions due to vision issues. Remaining others (70.5 per cent) having 'a little' and 'a lot' like response were experiencing difficulties in participating in social functions before their eye surgery thus, kept themselves away from such social events and felt lonely.
Regarding difficulties in going out at night, 42.9 per cent of the respondents were found to face a little difficulty while moving out at night. 26.2 per cent and 11.6 per cent respondents were facing 'quite a bit' and 'a lot' difficulties respectively. Another 5.6 per cent were completely not able to move out at night before their eye surgery. Most of the villages in the study area were having interrupted electricity supply. Most of the families were not having toilets in their house. So, it was difficult for the respondents with low vision to move outside for defecation or urination at night.
Similarly, a significant number of respondents were facing in recognizing people from a distance. It was found that 50.6 per cent had experienced slightly, 20.9 per cent faced quite a bit where as 8.3 per cent of the respondents had more severe problems in identifying persons or objects from a distance. On recognising a person standing nearby, 5.1 per cent respondents were found to be totally unable to identify them. The difficulty was severe for 35.1 per cent respondents due to cataract.
On performing common daily activity of locking and unlocking the doors, 7.4 per cent respondents were found not able to perform the activity. Majority of the respondents (85.1 per cent) in the category of "a little" to "a lot" were found to experiencing the problem of locking and unlocking the doors. The study found that many respondents were facing problems while doing usual works in their day to day life. It was 29.2 per cent respondents who had severe problems whereas 2.7 per cent of the respondents were not at all able to do usual works due to the severity of their cataract problem. Consequently, this also had affected the standard of work they were doing. In searching things at home, 38.9 per cent had quite a bit problem, where as 22 per cent were facing more problems, but 5.9 per cent were not at all able to find out things at home. Respondents having no support system in their families had to face much difficulties in managing their life with poor eye sights.

Respondents with cataract had also faced problem seeing outside in bright sunlight. 36.3 per cent and 22.9 per cent respondents had experienced problems in facing sunlight 'a little' and 'quite a bit' respectively. 24.4 per cent respondents had severe difficulty in facing the sunlight. Colour differentiation was also the problem experienced by the respondents before eye surgery. 8.3 per cent respondents were not at all able to differentiate it while 18.8 per cent had more difficulties. Similarly, about differentiating coins and notes, it was found that 80.7 per cent respondents had the problem of differentiating coins or notes ranging from "a little" to "a lot" difficulties. These categories of respondents were likely to be cheated by the people while making monetary transactions in the day to day living.

Pre-eye-surgery is a crucial stage where the respondents are needed to be taken care of properly for preparing the respondents mentally ready for the eye surgery. It was found that often the ignorant and illiterate persons develop psychological stress due to this which affects the surgery process. For this, a psychological impact scale was used to get the responses from the respondents under the study. The psychological impact scale included five items such as – felt frightened to go at night, enjoyed less in social functions, felt ashamed for inability to see, felt a burden on others, and felt frightened of losing remaining vision due to to-be-held eye-surgery (Table no. 2).

Table no. 2

Experience of psychological stress before eye-surgery

Sl. No.	Particulars	Not at all	A Little	Quite a bit	A lot
1.	Felt frightened to go at night	117(34.8)	98(29.2)	88(26.2)	33(09.8)
2.	Enjoyed less in social functions	74(22.0)	99(29.5)	114(33.9)	49(14.6)
3.	Felt ashamed for inability to see	55(16.3)	104(31.0)	119(35.4)	58(17.3)
4.	Felt become burden on others	69(20.5)	71(21.1)	109(32.4)	87(26.0)
5.	Felt frightened of losing remaining vision	100(29.8)	96(28.5)	100(29.8)	40(11.9)
Mean (X)		83(24.7)	94(27.8)	106(31.5)	53 (15.7)

N.B.: Parentheses include the percentage

Regarding psychological stress (fig. No. 2) of the cataract patients before surgery, it was found that an average of 24.7per cent respondents did not have any such stress thus had no impact on their behaviour during pre-eye-surgery, while an average of 27.8per cent of respondents had little impact and an average of 31.5 per cent of respondents were observed with quite a bit impact on their behaviour due to psychological stress out of pre-surgery psychological conditions. An average of 15.7per cent respondents had a severe impact on their behaviour due to their pre-surgery psychological stress.

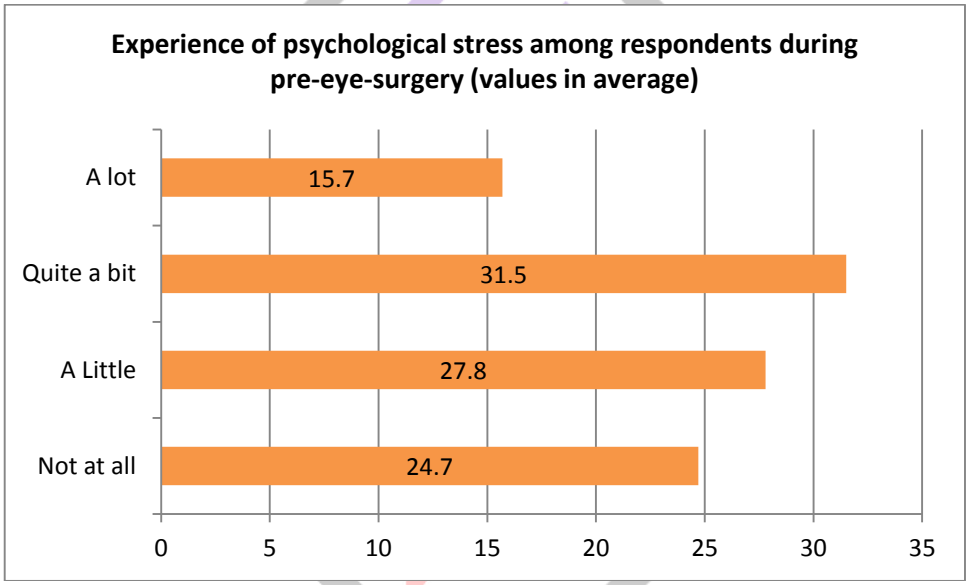

Fig. No. 2: Experience of psychological stress before surgery

It was found in study that 9.8 per cent of respondents severely felt frightened to go at night, 14.6 per cent respondents enjoyed very less in social functions, 17.3 per cent respondents severely felt ashamed for inability to see, 26.0 per cent respondents severely felt that they have become burden on others and 11.9 per cent respondents severely felt frightened of losing remaining vision for to- be-held eye-surgery. With proper counselling and motivation on individual basis by the volunteers of SJN during the pre-eye-surgery period helped the respondents to be prepared and go for eye-surgery which helped them to recover their lost sight.

Blindness or partial blindness affects productivity level of a person. Regarding productivity level before surgery the study found that productivity level of the 41 per cent respondents was average (fig. no. 3) and 38 per cent respondents was poor while it was very poor for 14 per cent of respondents.

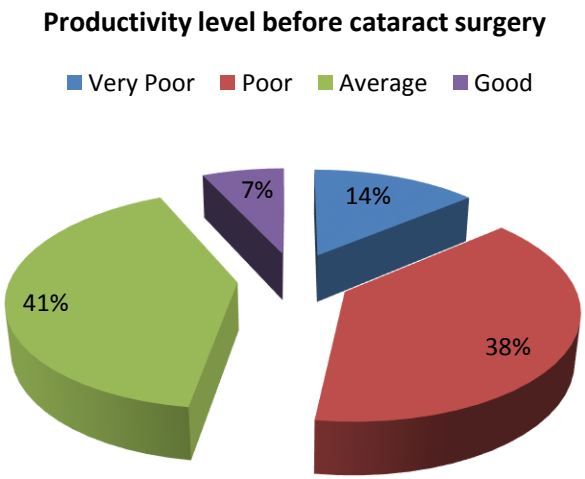

Fig. No. 3: Productivity level

Post-Surgery Functional Status

Having proper post-surgery care and following the 'dos' and 'do nots' for after-surgery to take care of cataract operated eyes, the respondents were found to recover well and live a normal life. Post surgery functional status of the respondents was measured by criteria like - ability to see properly, level of productivity and how independently and comfortably the respondents were able to do their day to day work. For this, the responses were collected from the respondents with the help of rating scales.

Regaining the ability to see after surgery varied among the respondents in the study (Fig. no. - 4). It was highly dependent upon the severity of cataract they had. Cataract if treated in its initial phase, patient has cent per cent chance of gaining full vision after surgery. But, if cataract has alredy affected the eye sight a lot, the patient may fail to regaining vision or regain low vision. The study found 18 per cent of respondents regained average sight after surgery, 53 per cent regained good vision and 21per cent regained very good vision. Thus, the surgery resulted in high rate of success cases proving the operations to be a need to deal with preventive blindness in our country. Exceptionally, as cataract had already affected the complete sight of 8 per cent respondents, even after the surgery they could not able to regain their lost vision.

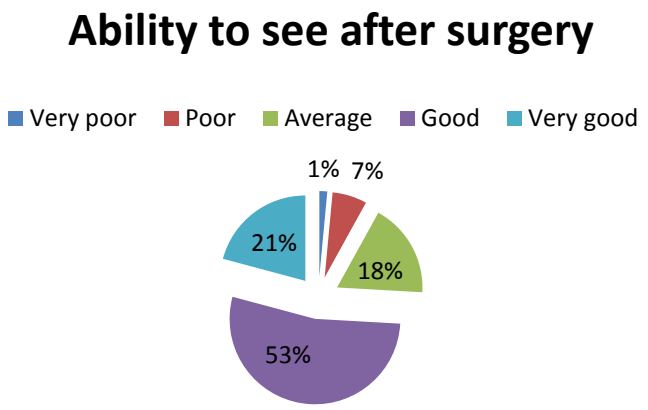

Fig. No. 4: ability to see after surgery

There was a significant decrease in the dependency level of the respondents on their family members after regaining the eye sight after the surgery. As mostly the respondents were old-aged persons their dependency on family members for performing day to day activities such as bathing, moving and doing everyday chores, the dependency level decreased with regaining eye-sights. Only 9 per cent of the respondents found to have inability in performing everyday activities where as, 24 per cent had given an average response, which indicated no much changes in ability in performing the daily activities by their own after surgery. A significant number of respondents (69 per cent) had given positive response i.e., after surgery, they could able to perform their daily activities by regaining the vision and they were no more dependent on family members. Thus, this indicated the increase in functional ability in case of the respondents after regaining the lost vision for cataract with the surgery. Women respondents specifically were found to be able to do household chores or help in that in their family. Even some male respondents were found to have started earning by engaging themsleves in income generation activities. Thus, there was increase in their productivity level as it was found that 91 per cent of the respondents (average and good performance) were found with increase in their productivity level after gaining vision.

As a result of that, their economic lives have benefited in the post-surgery period. Few of the respondents were able to perform the farming activity and back to work as wage labours.

NEED AND SCOPE OF SOCIAL WORK INTERVENTION

To implemement the free cataract operation project of the SJN, it needs to go through several phases of activities such as organizing out reach programmes to identify the people having catarct issues, organizing free eye-check up camps, motivating and counselling the patients to get operated for the issue which is curable in nature, availing and coordinating transport services to the identified patients from their home place to the hospital, managing their fooding and lodging in the hospital premises, contineuous counselling to those who are not willing to get their eye operated out of negative perception or fear and anxiety, conducting operations, giving post operational care, suppy of sun glasses and eye drops, giving instructions on 'dos' an 'do nots' to take care of their operated eye to maintain vision, watching the post surgery complications if any, and having follow-up activities. Doing all these activities needs good number of dedicated human resources. As discussed earlier, a It was found in the study that more than two-third of the respondents (fig. no. 2) were found to experience psychological troubles to get operated, regourous counselling to them could help them having the surgeries. Informal discussion with the SJN staff found that after identification of catarct in the free eye check-up camps, in majority of cases, the patients get frightened to get operated the cataract. Very often they run away from the camp or hospital out of fear. As these patients belong to rural areas, they generally have a fear for operation in lack of proper knowledge and understanding on the fact that cataract can be cured and the resulting blindness can be preventive in nature. They too have certain misconception that they may lose the sight forever if get operated. This also depend on their level of education to have the actual understanding on the issue. Sometimes it becomes extremely difficult for the SJN volunteers to convince and motivate the identified patients for the eye surgery. Mental readyness in case of patients to get operated is highly required for the success of this kind of projects. Conducting all these activities needs the high engagement of social workers in eye-care sector and to contribute for the country to achieve the targets of controlling preventive blindness programmes. Medical professionals are engaged in hospital settings and found to be over-burdened with huge responsibilities catering health services. For conduction of out reach programmes, free eye check-up camps, counselling, motivating, having personal one-to-one relationship with the cataract patients are the areas where the social workers are required a lot to carry forward the projects. Specifically people from rural areas are found to be unaware about such programmes and they lack the information and understanding on it. Against these back drops, social workers in the preventive blindness sector play a vital role to check blindness in the society that can be preventable.

Following are the scope of social work intervention in the field of preventive blindness –

- Awareness generation on eye diseases, eye-care, preventive blindness programmes to the public on micro, meso and macro platforms.
- Organizing community out reach programmes.
- Counselling the persons lacking mental readyness for needed surgery.
- Coordinating qualilty food and lodging services in the hospitals/lodging places before and after surgery.
- Planning innovative programmes on contolling preventive blindness.
- Collaborating with other professionals (like medical) for effective implementation of programmes.
- Fund raising for eye-care programmes if required.
- Providing case work services (one-to-one basis) to patients .
- Providing group work services to the patients if required.
- Conducting follow-up services for the beneficiaries of the programmes and assist them if any prblems found.
- Check the quality of services delivered to the beneficiaries.
- Conducting research studies on specific operational issues in the programmes and
- Evaluation studies on various eye-care progammes to recommend alternatives and generate innovative ideas and suggestions for having new plannings in the field.
- To contribute in effective hospital administration and dealing with management issues.

CONCLUSION

The programmes aiming to control preventable blindness has been the prime focus to reduce the blindness burden in our country. Cataract identification and it's timely surgery is one of the area in this context where social workers can intervene in collaboration with the medical (eye-care) professionals. This will help in identifying the rural constraints in the way of implementing such programmes and prepare the patients to make use of such facilities thereby reducing the number of absolute increase in blindness. Carrying out follow-up of the patients after the surgeries in dealing with their post surgery related complicacies was highly felt during the study as another area of intervention. As a single unsuccessful surgery or experience of unattended post-surgery complicacies in the locality may influence the willingness of rural people to get operated, such follow-ups in turn will help the people in rural communities specifically, to be motivated to make use of community out reach camps in eye-care. At the same time, there is a strong need of awaring rural people on the blindness control programmes and the facilities provided to the poor under such progammes. While implementing the programmes, attention should also be given on the quality of services (food, lodging, transportation etc.) offered to the people with utmost care and as per the needs of people in a given locality.

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