 Outcome of community based planned intervention targeting perceptions, attitudes and health seeking behaviour regarding cancers in New Delhi, India

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ABSTRACT

Background: Cancer prevention and control needs to be based on effective implementation of all approaches. Community as well as individual level interventions to increase knowledge and early reporting have shown effectiveness. A community-based intervention trial was conducted to design, implement and test short-term outcomes of evidence based preventive strategies.

Methods: A mixed methods, three phased study was conducted in three districts of Delhi, which were selected by a random process. Two randomly selected districts out of these three were intervention districts while third was the control. A total sample of 500 in each district was studied in quantitative pre and post -intervention phases. Multistage, stratified, cluster sampling was utilized. Pre-tested and validated tools were used.

Results: Post intervention, statistically significant higher scores were observed in all domains in intervention districts as compared to control (p<0.01). Though comparison of slum versus non-slum showed significant increment in knowledge and practice scores, with higher scores for non-slum respondents, the attitudes were very similar (p>0.05). The increment score changes between males and females was similar in all classes of society versus control district. Comparison within the intervention and control groups revealed increased scores in intervention districts and decreased scores in control district, in all domains (p<0.05).

Conclusions: Our study has helped in understanding the determinants of perceptions, attitude and practices regarding cancer in the community, This, helped in formulating the need-based intervention strategies. Testing the short-term outcome of intervention showed it to be effective.

Keywords: Attitude, Cancers, Cancer control programme, Community based intervention, Knowledge, Practices

INTRODUCTION

Cancer prevention and control, a complex issue needs to be based on effective implementation of preventive, promotive, treatment and rehabilitative approaches. Additionally, palliative care is required for improving quality of life of patients in incurable terminal stages. In the context of limited resources in LMIC countries like India, appropriate planning, strategies and their effective implementation can lead to remarkable results in
prevention, early diagnosis and management with considerable benefits in terms of disease burden, mortality and finances.

It is estimated that there are 2.4 million cancer patients in India with 0.8 million new cases in a year. It is now the third major cause of death with 0.4 million deaths per annum and the age standardized incidence rate of cancers per 100,000 is 100.4 among men and 109.3 among women. With increasing longevity, urbanization and changes in lifestyle the incidence of cancer is increasing rapidly. It is estimated by WHO that by the year 2020 the number of cases of cancer will double in developing countries.\textsuperscript{1-2} In India, it was noted that approximately 30\% of cancer cases in men are related to the Lung, Larynx and Oral cavity (all tobacco related) with about 25\% cervical cancer and a further 30\% breast cancer in females.\textsuperscript{3} Tobacco-related cancers are amenable to primary prevention (48\% in men, 20\% in women), oral cancers can be diagnosed early and treated successfully, 13\% cervical cancers and 9\% of breast cancers in women can be detected early and treated.\textsuperscript{4}

However, most cancers in India present in advanced stages when only palliative care can be offered, 40-50\% cannot benefit from curative therapy due to this delayed presentation. Cancer outcome depends on the stage of cancer e.g. cervical cancer is 100\% curable in stage I, while stage IIIB cervical cancer only 35-50\% five- year survival rates are found.\textsuperscript{5} The cost of treatment is very high for an individual and a huge financial burden to the nation. Most of these cases are preventable, if the level of awareness is improved about these cancers amongst the public and primary level health care professionals.

Indian studies regarding Knowledge, Attitudes and Perceptions (KAP) about cancers in the community have shown that knowledge, attitude and practices about common cancers were poor, and even a high degree of awareness regarding the harmful effects of tobacco in schoolchildren did not stop them from smoking.\textsuperscript{6,7}

Community as well as individual level interventions to increase knowledge and early reporting have been conducted in various countries. These have shown varying results and outcomes but with common theme of the interventions being effective despite limited evidence.\textsuperscript{8-14} Interventional and in-depth studies for formulating evidence based comprehensive and effective programme for prevention and early detection of common cancers utilizing a multi-pronged awareness intervention strategy targeting community, health care workers and cancer control program functionaries are lacking in India. Furthermore, the effect of implementation of such interventions have not been studied leading to paucity of information for planners for making evidence- based decisions for National Cancer Control Program.\textsuperscript{15} Hence this community-based intervention trial was conducted to first understand community needs and perceptions, secondly to design and implement evidence based preventive strategies, and lastly to test the short-term outcome of these strategies in the field. The aim was to provide evidence-based data to programme planners and an eventual goal of decreasing human suffering and the burden of cancer utilizing a multi-pronged awareness intervention strategy.

**METHODS**

The study was divided into three phases and a mixed methods approach was utilized to assess community needs, design appropriate interventions and assess their short-term impact.\textsuperscript{16}

In consonance with most international large-scale surveys we adopted a multi-stage, stratified, cluster sampling for our study. Since the proportion of slum population across each district varied and since we wanted to maintain a balance between the number of individuals surveyed from slum and non-slums areas, stratification was introduced during each phase of the survey. Appropriate weights were assigned to the data generated from slum and non-slums areas in order to offset any design effects of the entire multi-stage, stratified, cluster sample used for our study.\textsuperscript{17}

A brief overview of methodology is being presented here as detailed methodology has been published elsewhere and is available in open access.\textsuperscript{18}

Three districts of Delhi were selected by a random process after listing all the districts of Delhi. Two randomly selected districts out of these three were intervention districts and one district was used as control. The study was conducted from the year 2010 to 2014.

The study was divided into three phases. The Phase I of the study included quick assessment of facilities (part one), community needs assessment utilizing qualitative (part two) as well as quantitative (part three) methods. Part I involved assessment of resources and methods available for implementation of the intervention. Part II, Qualitative assessment was carried out to assess the perceptions of the community on cancer. Part III involved Quantitative assessment of the knowledge, perceptions and practices of the community regarding common cancers. Phase II involved implementation of the intervention and again had two parts. In Part I, the intervention was designed based on Qualitative and Quantitative assessment findings of Phase I. Part II dealt with the actual implementation of the intervention in two districts of Delhi. Phase III, post intervention assessment was carried out using quantitative methods.

**Sample size calculations**

As per available literature, approximately 50\% of individuals in the community had adequate knowledge regarding etiology, prevention and early diagnosis of common cancers. The available literature also showed
that prevalence of correct attitudes and practices was much lower than the correct knowledge. Community based short term intervention leading to only 10% increase in prevalence of KAP are also of much importance. The sample size was calculated using this as the basis because the researchers wanted to capture even this much change. Moreover, the attitude and practices are also not expected to change more than this immediately and this sample size was appropriate to estimate the difference in the attitude and practices consequent to the intervention. To cater for refusals / semi filled questionnaires, 10% of the total was added to the calculation.

The number of subjects required per group (intervention and control) to test the hypothesis of this study were calculated using the software "Acluster" which is specific for design and analysis of cluster-based studies in health research. For the sake of convenience, 25 clusters were selected in each group (each district) and 20 subjects chosen from each cluster. These 20 subjects were from the age group of 15-49 years. Out of which, 10 were males and 10 females. Thus, a total sample of 500 in each District was studied in pre-intervention phase and similar number was studied in the post intervention phase.

Pre-tested and validated (validity testing including construct validity was carried out during pilot) tools (assessment sheets, questionnaires - close ended) were used for this study for rapid assessment involving all stakeholders and activities of the programme. Same instruments were utilized for pre and post phases of the study and also for the intervention as well as control areas.

A database was created in MS Access and analysis conducted using SPSS Ver 13 and STATA ver 10. Initially, phase I quantitative data were analyzed as per objectives. Later, comparisons were made between pre and post intervention in the intervention areas and the control area. Appropriate statistical tests were used as per the scales of measurement and distribution. Comparison of intervention and control areas were also carried out before and after the intervention. Hierarchical modeling of the data was done for evaluating the effects of intervention. A p value of less than 0.05 was considered significant.

RESULTS

For the quantitative phases of the study, the total participants were 3100 of which 1600 were surveyed in pre and 1500 in post-intervention phase. A minimum of 500 subjects were surveyed from each region during each phase of the study. A total of 1618 males and 1482 females were surveyed. The mean±SD age of our total population was 34.14±13.585 years (median 31 years; range: 10-98 years). Accordingly, we surveyed 1721 subjects from various slums populations and 1379 subjects from non-slum populations across the three survey districts.

The pre-intervention (phase I) survey data were analysed across the three survey districts of New Delhi, including North district (control), South and South-West districts (intervention).

Table 1 shows that there were some baseline differences in the 3 selected districts: the North district had consistently lower scores as compared to the intervention districts in the domains of Knowledge and attitude but had higher scores in practices, though not always statistically significant. The South district had the highest scores in Knowledge and practice, while the score for attitude was higher in the South –west district. The scores were found only after the analysis of the baseline testing was completed and since the districts had been randomized to intervention vs non-intervention this was not changed, as it would have introduced a selection bias.

| Knowledge scores | Mean  | SD   | 95% CI | P value |
|------------------|-------|------|--------|---------|
| North            | 0.499 | 0.084| 0.491, 0.506| 0.673   |
| South+South-west | 0.501 | 0.095| 0.495, 0.606|         |

| Attitude scores  | Mean  | SD   | 95% CI | P value |
|------------------|-------|------|--------|---------|
| North            | 0.382 | 0.117| 0.372, 0.392| <0.001  |
| South+South-west | 0.409 | 0.102| 0.401, 0.413|         |

| Practice scores  | Mean  | SD   | 95% CI | P value |
|------------------|-------|------|--------|---------|
| North            | 0.307 | 0.064| 0.302, 0.313| <0.001  |
| South+South-west | 0.287 | 0.079| 0.282, 0.291|         |

There were also many outliers (respondents who had very different views), in all districts, these are individuals with low scores, or answers that are very different from the mean. These are important as they represent persons with extremely low knowledge or mis-information. They can adversely influence awareness activities and thus were not ignored.

The mean knowledge, attitude and practice scores of all three districts for slums were similar as were those for non slums. The scores of slum vs non slum for all three districts pre intervention showed overall higher scores for knowledge and practices in non slum respondents, but hardly any difference in attitudes. The pre-intervention baseline scores for males in the three districts showed some differences in attitude and practices, this was noted.
and was taken into account while assessing change after post intervention. Similarly, for females there were some difference in practices noted in the districts. However, there was no statistical difference in any scores at baseline between males and females.

Post intervention, a statistically significant higher scores were seen in all domains in intervention districts as compared to control (Table 2). Though comparison of slum versus non slum showed significant increment in knowledge scores and practice scores between them, with higher scores for non slum respondents, the attitudes were very similar and not significant statistically. Post intervention scores for males increased in all intervention districts compared to control district, as did scores for females in all categories. The increment between score changes between males and females was similar-showing equivalent benefit of intervention in both groups, in all classes of society versus control district.

Comparison within the intervention and control groups revealed a statistically significant difference in pre and post scores (Tables 3 and 4). While the intervention districts showed an increase in scores the control district showed a decrease in scores in all domains.

**Table 2: Overall post-intervention district scores.**

|                | Mean  | SD    | 95% CI     | P value |
|----------------|-------|-------|------------|---------|
| Knowledge scores |       |       |            |         |
| North          | 0.412 | 0.097 | 0.403, 0.420 | <0.001  |
| South+South-west| 0.526 | 0.099 | 0.520, 0.532 |         |
| Attitude scores |       |       |            |         |
| North          | 0.351 | 0.085 | 0.343, 0.358 | <0.001  |
| South+South-west| 0.387 | 0.086 | 0.382, 0.392 |         |
| Practice scores |       |       |            |         |
| North          | 0.251 | 0.069 | 0.245, 0.258 | <0.001  |
| South+South-west| 0.361 | 0.106 | 0.355, 0.368 |         |

**Table 3: South+South-west pre-intervention vs post-intervention.**

|                | Mean  | SD    | 95% CI     | P value |
|----------------|-------|-------|------------|---------|
| Knowledge scores |       |       |            |         |
| Pre-intervention | 0.501 | 0.096 | 0.495, 0.506 | <0.001  |
| Post-intervention | 0.526 | 0.099 | 0.520, 0.532 |         |
| Attitude scores |       |       |            |         |
| Pre-intervention | 0.407 | 0.102 | 0.401, 0.413 | <0.001  |
| Post-intervention | 0.487 | 0.086 | 0.482, 0.492 |         |
| Practice scores |       |       |            |         |
| Pre-intervention | 0.287 | 0.079 | 0.282, 0.291 | <0.001  |
| Post-intervention | 0.361 | 0.107 | 0.355, 0.368 |         |

**Table 4: North pre-intervention vs. post-intervention.**

|                | Mean  | SD    | 95% CI     | P value |
|----------------|-------|-------|------------|---------|
| Knowledge scores |       |       |            |         |
| Pre-intervention | 0.499 | 0.084 | 0.491, 0.506 | <0.001  |
| Post-intervention | 0.412 | 0.097 | 0.403, 0.420 |         |
| Attitude scores |       |       |            |         |
| Pre-intervention | 0.382 | 0.117 | 0.372, 0.392 | <0.001  |
| Post-intervention | 0.351 | 0.085 | 0.343, 0.358 |         |
| Practice scores |       |       |            |         |
| Pre-intervention | 0.307 | 0.064 | 0.302, 0.313 | <0.001  |
| Post-intervention | 0.251 | 0.069 | 0.245, 0.258 |         |

**DISCUSSION**

Our study results are comparable with a 6-month, 2-city community intervention trial in Korea. The strategies implemented in the intervention city included community outreach and clinic and pharmacy-based in-reach strategies. The study showed a 20.4% decrease in myths about the link between cancer and breast size, a 19.2% decrease in myths concerning mammography costs, and a 14.1% increase in intention to undergo screening mammography. In the comparison city, smaller decreases and increases were observed.10

Similar to our study findings, a significant increase in knowledge and cessation of tobacco and alcohol was found by a pre and post intervention study in India among women of reproductive age.12

A study in Kenya, specifically for cervical cancers, showed that knowledge Scores increased significantly after the educational intervention. At three months follow-up, Knowledge Scores in the intervention arm increased 26.4% compared to 17.6% increase in the control arm (p<0.01). In this study a single brief health talk significantly increased cervical cancer knowledge and awareness at three months. However, it did not result in higher screening rates.13 Thus, clearly showing need for sustained and tailored interventions.

Our study results are also corroborated by a single-blind randomized controlled trial among female undergraduate students in two selected public universities in Malaysia. The educational program was delivered to the intervention group and the outcome measures were
assessed at baseline, 6, and 12 months after implementing the health educational program. The study showed that mean scores of knowledge on breast cancer (p<0.003), knowledge on breast self examination (p<0.001), benefits of BSE (p<0.00), barrier of BSE (0.01) and confidence of BSE practice (p<0.00) in the intervention group had significant differences in comparison with those of the control group 6 and 12 months after the intervention. Also, among those who never practiced BSE at baseline, frequency of BSE practice increased 6 and 12 months after the intervention (p<0.05).14

Since there had been some differences between baseline scores between districts, we compared each areas and group from their baseline scores. There was significant change in baseline scores with the non-intervention district showing a significant decrease in scores. The reason for this is not known but may be due to negativity towards cancer as repeated questioning without the benefit of intervention, this warrants further investigation, some clues to this can be obtained through the qualitative data analysis of this project, as we have highlighted avoidance as a coping strategy towards cancer.

CONCLUSION

This study has helped in understanding the determinants of perceptions, attitude and practices regarding cancer in the community. This, helped in formulating the need-based intervention strategies. Testing the short-term outcome of intervention showed it to be effective. The study is a first of its kind in India, in designing, implementing and testing the effectiveness of strategies in the community and will help in policy decision making by the planners and administrators of the state.

It has involved an extensive exercise to scrutinize, assess, intervene and reassess the ground level problems impeding positive awareness and knowledge of common preventable cancers, to enable the common man to seek appropriate medical care and health measures for preventing such cancers. Our investigations and multi-pronged stratified intervention strategies have yielded several useful tools, techniques and information to reinforce larger full-scale national and local cancer prevention programs being implemented across India.

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Ethical approval: The study was approved by the Institutional Ethics Committee of All India Institute of Medical Sciences (AIIMS), New Delhi, India

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