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RESEARCH ARTICLE

ORAL HEALTH LITERACY INTERVENTION AMONG CAREGIVERS OF HIV POSITIVE CHILDREN - AN ALTRUISTIC STEP IN DENTAL CARE FOR SMILE FROM WITHIN

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ABSTRACT

Background: HIV is one of the leading causes of death globally with approximately 10% mortality in pediatric population. Pediatric HIV infection is associated with a wide spectrum of lesions in the oral cavity and more than 90% of HIV infected patients will have at least one HIV related oral manifestation in the course of their disease. The rationale behind this study is to create awareness about oral health knowledge among the caregivers of the children living with HIV.

Objectives:

1. To determine the oral health knowledge among the caregivers of HIV positive children using a questionnaire.
2. To provide oral health education among the caregivers of HIV positive children.
3. To assess the impact of oral health knowledge among the caregivers through the same questionnaire after oral health literacy intervention.

Methods: A Pre post intervention trial was done using a self- structured questionnaire comprising of 24 questions to determine the oral health knowledge among the caregivers of HIV positive children and also to assess the impact of oral health knowledge among the caregivers through the same questionnaire after oral health literacy intervention.

Results and Interpretation: It was found that the difference in knowledge after the intervention was found to be statistically not significant for few questions and statistically significant for few questions as part of the Questionnairre using Wilcoxon Signed rank test.

Conclusion: The study reveals that caregiver's of HIV positive children lacked adequate knowledge on the oral health prior to the health education and post education a significant outcome on the knowledge increase among the caregivers was noticed.

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INTRODUCTION

Oral health is a significant integral part of systemic health. HIV is one of the leading causes of death globally with approximately 10% mortality in pediatric population. (Peterson, 2006) Pediatric HIV infection is associated with a wide spectrum of lesions in the oral cavity (Naidoo and Chikte, 2004; Ramos *et al*., 1996; Pongsiriwet *et al*., 2003) and more than 90% of HIV infected patients will have at least one HIV related oral manifestation in the course of their disease. (Mc Carthy, 1992) Untreated oral lesions such as oral candidiasis are strongly associated with immune suppression (Ramos, 2002) and have been shown to progress to an AIDS diagnosis within an interval of 2 years. (Neilson *et al*., 1994) The data regarding worldwide status of Pediatric HIV infection reveals that approximately 2.3 million under the age of 15 years have been found to be living with HIV and the highest burden is faced by Africa and Asia with around 1.9 million constituting 83% at a global level. (Guha and Sardar, 2011) Ultimately the final outcome has been reflected by approximately 13 million pediatric population orphaned. (Gregson *et al*., 1994) The rationale behind rise in Pediatric HIV infection has been explained by the fact that the ratio of females being affected are twice that of males which clearly indicates the relationship between mother-to-child transmission in majority of pediatric cases accounting approximately to 90%. (Carovan, 1997) HIV/AIDS has been found to be the fourth leading cause of death globally accounting to 7.7% in pediatric population less than 5 years of age and 19% in infants. (Tindyebwa *et al*., 2005) The earliest pediatric HIV case report in India dates back to 1987. India ranks third in the world next to South Africa and Nigeria with respect to HIV infected population. In India pediatric HIV epidemic accounts to 4%. Annually approximately 21,000 pediatric new HIV cases are diagnosed

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in India and it is significant to note that 5,000 pediatric HIV patients progress to AIDS. The burden of pediatric population living with HIV in India annually accounts to 7000 children. However only 4% pediatric HIV patients are receiving HAART therapy. (Singh *et al*., 2008) An altruistic scientific team approach has always been a supportive solution for the management of multifarious medical conditions and management of HIV is one of the most significant among it due to the fact that HIV is the leading cause of the death in the world (Kolisa and Yusuf, 2013) wherein as part of altruistic step, caregiver's play a very significant role. A caregiver is a person from the community (ancillary or auxiliary) who worked at the chosen palliative care institutions and provided comprehensive health care and support for people infected and affected by HIV. The role of caregiver's is emphasized because as part of human history, worldwide HIV is considered as a complex and worst disaster affecting individuals, families, friends and community as a whole. (Amosu *et al*., 2011) The rationale behind this study is to create awareness about oral health knowledge among the caregivers of the children living with HIV and it is an accepted fact that caring for good health is reflected by smile which is a blissful expression. The science of dentistry plays a significant role in providing this expression through various strategies. However it is an overlooked fact that smile is an expression of the internal mind. This study is a small altruistic step in dental care towards this ultimate expression by training the caregivers of HIV positive children through oral health literacy intervention.

Aim

To assess the impact of Oral health literacy intervention among caregivers of HIV positive children

Objectives

1. To determine the oral health knowledge among the caregivers of HIV positive children using a questionnaire.
2. To provide oral health education among the caregivers of HIV positive children.
3. To assess the impact of oral health knowledge among the caregivers through the same questionnaire after oral health literacy intervention.

Review of literature

Atkinson *et al*. (2001) determined the role of caregivers towards HIV positive children and also studied about secondary infections in HIV affected patients and its implications on the family and society. Ademola *et al*. (2011) assessed the role of caregivers in HIV/AIDS infected patients with respect to care and compassionate support which in turn could not only raise the morale and self esteem of the patients but also have a significant impact on the quality of life of the patients. Atul *et al*. (2013) emphasized the relevance of awareness and knowledge among caregivers with respect to modes of transmission of HIV and the associated preventive measures and precautions. Peterson *et al*. (2009) stressed on the significance of oral health care with respect to the general health of the HIV patient. Quand *et al*. (2009) studied the impact of HIV related oral lesions on eating, drinking and ultimately impairing the nourishment thereby resulting in cachexia. Ranganathan *et al*. (2006) gave an overview of oral manifestations of HIV infections with special focus on dental caries, gingivitis, periodontitis and oral mucosal lesions. Coogan *et al*. (2005) highlighted the relevance of oral lesions as early indicators of HIV infection and also its association with progression to AIDS. The study also emphasized the significant role of Oral health education in the caregivers of HIV patients. Venkatesh, (2012) studied the correlation of CD4 count with dental caries in HIV positive patients. He also studied the association between antiretroviral therapy with xerostomia and dental caries. Yolanda *et al*. (2013) studied the significance of oral hygiene measures in patients with oral manifestations and also explored the referral procedures in HIV patients. Malgalhaes *et al*. (2001) explored the fact that the progression of HIV infection is rapid and intense in pediatric group due to the immature immune system. Ramos – Gomez *et al*. (2000) have highlighted the commonest pediatric oral manifestation which includes Oral candidiasis, herpes simplex virus infection, recurrent apthous ulcer and linear gingival erythema. The significance of oral manifestations is that early recognition of these lesions helps in the early management and improved prognosis. Ultimately it results in considerable decrease in mortality and increase in quality of life. Orne – Glieman *et al*. (2008) indicated that as part of pediatric HIV infection the prognostic difference is indicated by oral lesions such as oral thrush (acute pseudomembranous candidiasis) signaling disease progression and deterioration of immune system. On the contrary a better prognosis is signaled by major salivary gland enlargement especially parotid gland in a study by Katz *et al*. (1993). It has been noted that Oral candidiasis apart from burning sensation in the mouth is associated with taste changes and nutritional disturbances in studies by Orne – Glieman *et al*. (2008). Frenzzini *et al*. (2006) related that dry mouth can have an impact on chewing, swallowing and taste sensation apart from dental caries. The study also observed that xerostomia is more common in pediatric HIV infection than in adults which can be due to several causes such as HIV infection itself, therapeutic antiviral and antimicrobial drugs, prophylactic medications, antiretrovirals, gamma globulin, or lymphocytic infiltration of the major salivary glands.

MATERIALS AND METHODS

Study design

Pre post intervention trial.

Study population

With the help of yellow pages followed by personnel visit 7 HIV care centers which included 1 in Pondicherry and 6 in Chennai were identified. The study group included 50 caregivers of HIV positive children below 18 years of age. Quota sampling was done till 50 willing caregivers were identified.

Data collection

A self- structured questionnaire comprising of 24 questions was developed which was subjected to validation**.** The following considerations were given importance before framing the questionnaire. Bearing in mind, that oral health and dental consultation is a significant part of general health as part of HIV infection, a knowledge about HIV related oral symptoms and oral manifestations of HIV infection as per EC Clearing house (Bodhade *et al*., 2011; Prabhu *et al*., 2013), modes of transmission, other related infections, preventive steps and oral health care access centers knowledge were all incorporated. (Petersen, 2006; Petersen, 2008; Kajubi *et al*., 2014)

Questionnaire / Study tool

1. Do you consider that oral health is a significant part of general health as part of HIV infection? (Yes/No/Don't know)
2. Do you consider that dental consultation is important for HIV positive children? (Yes/No/Don't know)
3. Do you consider periodic consultation to dentist is important even in the absence of oral complaints in HIV positive children? (Yes/No/Don't know)
4. Are you aware that oral cavity can be affected in the initial stage of HIV infection? (Yes/No/Don't know)
5. Do you know about oral symptoms related to HIV infection? (Yes/No/Don't know)
6. Do you know that there can be burning sensation in the mouth? (Yes/No/Don't know)
7. Do you know that there can be dryness of mouth? (Yes/No/Don't know)
8. Do you know that there can be difficulty in swallowing? (Yes/No/Don't know)
9. Are you aware that burning sensation, dryness of mouth and difficulty in swallowing can have an impact on nutrition, weight and even affect taking the medication? (Yes/No/Don't know)
10. Do you know about oral signs related to HIV infection? (Yes/No/Don't know)
11. Are you aware of curd like white patch that can occur in the mouth as part of HIV infection? (Yes/No/Don't know)
12. Are you aware of the red band that can occur in the gums as part of HIV infection? (Yes/No/Don't know)
13. Are you aware of the cracks that can occur in the corner of the mouth and stripes that occur in the sides of the tongue as part of HIV infection? (Yes/No/Don't know)
14. Are you aware that prolonged hours of bottle feeding in infants affected by HIV can cause decayed teeth? (Yes/No/Don't know)
15. Do you know that decayed teeth can result due to dryness of mouth as part of HIV infection? (Yes/No/Don't know)
16. Do you know that decayed teeth can result due to increased sugar content in the medicines used to treat few infections associated with HIV infection? (Yes/No/Don't know)
17. Are you aware of the preventive measures for decayed teeth? (Yes/No/Don't know)
18. Are you aware that bleeding gumscan be associated with HIV infection? (Yes/No/Don't know)
19. Are you aware that loose teeth can be associated with HIV infection? (Yes/No/Don't know)
20. Are you aware that there can be mouth ulcers, swellings in the mouth/ face as part of HIV infection? (Yes/No/Don't know)
21. Are you aware of the modes of transmission of HIV infection and its preventive measures? (Yes/No/Don't know)
22. Are you aware that certain infections resulting from HIV infection can spread? (Yes/No/Don't know)
23. Do you consider that constant monitoring of signs by trained examination and recognition of symptoms by you is important for early referral to oral physician? (Yes/No/Don't know)
24. Are you aware of any Pediatric HIV infection oral health care centre? (Yes/No/Don't know)

Prior to the study, an informed consent was taken from the caregiver's and ethical clearance to conduct the study was obtained. Following it, permission and appointment with each of the 7 centers was taken and the caregivers were recruited with different appointment dates being allotted for the different centers. The caregivers were explained about the purpose of the visit wherein the investigator told the caregivers about the intention of the oral health literacy intervention after which the questionnaire was distributed and the investigator waited till the caregivers completed their questionnaire. Caregivers were told to ask for clarity without hesitation which they encountered with the questionnaire and significant concern was given wherein discussion or communication among the caregivers in filling the questionnaire was not allowed as it would lead to bias or influence the individual caregiver's response. The questionnaire was piloted at 1 of the HIV care center to test for reliability, validity, feasibility, comprehension and the degree to which the questions were understood and interpreted by the caregivers. It also served to access the time taken for completion of the questionnaire which approximately ranged from 30 - 45 minutes. As part of the questionnaire the caregivers were instructed to give a response as Yes/No/Don't know. At baseline oral health knowledge of the caregivers regarding HIV infection was assessed with the questionnaire. .Following the pre assessment, oral health literacy talk on HIV was carried out by the investigator for duration of 45 minutes using charts, posters, photographs, models and videos and power point. Following the oral health education, its impact was assessed through the same questionnaire at the end of 2months.

RESULTS

The study was carried out during the time period from July to August 2015. The results of the study relating to Pre education response and Post education response are represented graphically.

DISCUSSION

Death rates of children related to AIDS related illness has declined from 3,20,000 in 2004 to 2,60,000 in 2009. It is expected that by 2015 the cases of Pediatric HIV infection cases shall be reduced by 90% and mother to child transmission shall decline by 5%. As part of pregnancy health seeking behavior only 50% seek skilled care among 27 million pregnant patients in India every year. It is a distressing fact that less than 50% among them undergo HIV testing and counseling. It has been estimated that the risk of mother to child transmission without intervention is approximately 20 – 45%.[32] Altruism is defined as a behavior that simultaneously entails fitness costs to the behaving individual and fitness benefits to individuals on the receiving end of the behavior.[33] Beyond the pathological manifestation the psychological and social burden of HIV is reflected in children by stigma related pressure to drop out from schools; witnessing the various manifestations of HIV and AIDS and ultimately coping up with the fact that it is incurable and death is the destiny. More precisely approximately 6,200 children are diagnosed as new HIV patients every day. The role of altruism is to overcome the sorrowful shades of the bidirectional relationship between HIV and mental health wherein depression, hopelessness, anxiety, pressure due to economic burden, evaporation of resources and poor mental health is overcome by the caring and inspiring behavior of the caretakers. With improvement in access to Anti retro viral therapy psych socio economic care is sought for and is the expected healing factor beyond scientific support.

Ultimately resilience is the root support for the depressed patients which can be considered as a socio ecological model.
As part of Oral manifestations, Oral candidiasis accounts to 70%; Linear gingival erythema has been reported to be around 24- 27%; Oral hairy leukoplakia is found in 0-26% of cases, Herpes simplex related oral ulcerations occurs in upto 78% and oral pigmentations are seen in 23% of children.[35-44] EC Clearing house and WHO collaborating centre have classified Oral manifestations in pediatric HIV infection as three groups namely Group 1: Lesions strongly associated with HIV infection Group 2: Lesions less commonly associated with HIV infection Group 3: Lesions seen in HIV infection in studies by Coogan *et al* (2005) which are elaborated as follows:

Oral lesions commonly associated with paediatric HIV infection

Candidiasis- Pseudomembranous, Erythematous Angular cheilitis, Herpes simplex viral infection, Linear gingival erythema, Major salivary gland enlargement, Recurrent aphthous ulcers - Minor, major, and herpetiform

Oral lesions less commonly associated with pediatric HIV infection

Bacterial infections, Periodontal diseases, Necrotizing ulcerative gingivitis (NUG), Necrotizing ulcerative periodontitis (NUP), Necrotizing stomatitis (NS), Viral infections (cytomegalovirus, human papilloma virus, varicella zoster virus, molluscum contagiosum) Xerostomia

Oral lesions strongly associated with HIV infection but rare in children

Kaposi's sarcoma, Non-Hodgkin's lymphoma, Oral hairy leukoplakia, Tuberculosis-related ulcers

Oral conditions with increased severity in paediatric HIV infection

Gingivitis and periodontitis (increased gingival and plaque indices), Over-retained primary teeth, Delayed eruption of primary and permanent teeth, Primary dentition caries.

Pre and Post education response to questionnaire: Before and after Oral health literacy intervention regarding HIV infection

In response to question 1 - The difference in knowledge after the intervention was found to be statistically not significant using Wilcoxon Signed rank test p value = 0.106

In response to question 2 - The difference in knowledge after the intervention was found to be statistically not significant using Wilcoxon Signed rank test p value = 0.394

In response to question 3- The difference in knowledge after the intervention was found to be statistically significant using Wilcoxon Signed rank test p value = 0.000

In response to question 4 - The difference in knowledge after the intervention was found to be statistically significant using Wilcoxon Signed rank test p value = 0.002

In response to question 5 -The difference in knowledge after the intervention was found to be statistically not significant using Wilcoxon Signed rank test p value = 0.330

In response to question 6 - The difference in knowledge after the intervention was found to be statistically not significant using Wilcoxon Signed rank test p value = 0.371

In response to question 7 - The difference in knowledge after the intervention was found to be statistically not significant using Wilcoxon Signed rank test p value = 0.732

In response to question 8 - The difference in knowledge after the intervention was found to be statistically significant using Wilcoxon Signed rank test p value = 0.031

In response to question 9 -The difference in knowledge after the intervention was found to be statistically not significant using Wilcoxon Signed rank test p value = 0.757

In response to question 10 - The difference in knowledge after the intervention was found to be statistically significant using Wilcoxon Signed rank test p value = 0.016

In response to question 11- The difference in knowledge after the intervention was found to be statistically not significant using Wilcoxon Signed rank test p value = 0.079

In response to question 12 -The difference in knowledge after the intervention was found to be statistically significant using Wilcoxon Signed rank test p value = 0.007

In response to question 13 - The difference in knowledge after the intervention was found to be statistically not significant using Wilcoxon Signed rank test p value = 0.161

In response to question 14 - The difference in knowledge after the intervention was found to be statistically significant using Wilcoxon Signed rank test p value = 0.034

In response to question 15 -The difference in knowledge after the intervention was found to be statistically significant using Wilcoxon Signed rank test p value = 0.004

In response to question 16 - The difference in knowledge after the intervention was found to be statistically significant using Wilcoxon Signed rank test p value = 0.001

In response to question 17 - The difference in knowledge after the intervention was found to be statistically significant using Wilcoxon Signed rank test p value = 0.016

In response to question 18 - The difference in knowledge after the intervention was found to be statistically significant using Wilcoxon Signed rank test p value = 0.004

In response to question 19 - The difference in knowledge after the intervention was found to be statistically significant using Wilcoxon Signed rank test p value = 0.003

In response to question 20 - The difference in knowledge after the intervention was found to be statistically not significant using Wilcoxon Signed rank test p value = 0.059

In response to question 21 -The difference in knowledge after the intervention was found to be statistically not significant using Wilcoxon Signed rank test p value = 0.637

In response to question 22 - The difference in knowledge after the intervention was found to be statistically significant using Wilcoxon Signed rank test p value = 0.091

In response to question 23 - The difference in knowledge after the intervention was found to be statistically significant using Wilcoxon Signed rank test p value = 0.009

In response to question 24 - The difference in knowledge after the intervention was found to be statistically not significant using Wilcoxon Signed rank test p value = 0.131

As part of the study, the impact of Oral health literacy intervention regarding HIV infection resulted in an overall positive effect among the caregivers. However complete positive effect was observed in response to question 21, which was associated with awareness of the modes of transmission of HIV infection and its preventive measures – wherein all the 50 caregivers gave a 100% positive response to the oral health education. It is a major strength of the outcome of the study because it deals with the most important aspects ie, transmission and prevention of the infection. The next maximum effect was observed in response to question 15 which deals with the awareness that decayed teeth can result due to dryness of mouth as part of HIV infection wherein increase in positive response was found to be 40 ie, before oral health education the response was 5; however after oral health education the positive response was given by 45 caregivers which indicated that the difference in knowledge pre and post intervention response was 40. It is an interesting rise in positive response which deals with the effect of Anti - retroviral therapy on the decayed status of teeth due to dryness of mouth associated with the medication rather than local factors. Following this, the major effect was observed with respect to question 4 and 20 wherein increase in positive response was found to be 39 ie, before oral health education the response was 9; however after oral health education the positive response was given by 48 caregivers. A positive impact of oral health literacy intervention with respect to question 4 is very significant and relevant because the increase in knowledge is related to the important prognostic fact that oral cavity can be affected in the initial stage of HIV infection which is very helpful for the early diagnosis and better prognosis. The next positive outcome was observed with respect to question 18 and 22 wherein increase in positive response was found to be 37; a positive impact of oral health literacy intervention with respect to question 18 is important because it is related to the common feature of bleeding gums in HIV infection which is related to the disease itself rather than local irritating factors which indicates that this knowledge shall help in distinguishing local factor and HIV induced bleeding gums. Also a positive effect was noted with respect to question 9,16,19,23 wherein increase in positive response was found to be 36; a positive impact of oral health literacy intervention with respect to question 19 is important because it is related to another common feature of loosening of teeth in HIV infection which is related to the HIV infection per se rather than local causative agents which indicates that this oral health education shall help in the maintenance, prevention and rehabilitation of teeth. An almost equal positive effect was noted with respect to question 10 and 8 wherein increase in positive response was found to be 35 and 34 respectively. The following questions namely question 5, 7, 11, 12, 14 and 13,1 had almost a near positive effect which ranged from 31 -33.

Conclusion

The study reveals that caregiver's of HIV positive children lack adequate knowledge on the oral manifestations; oral symptoms and they lack the awareness regarding the significance of the oral health status as part of the general health status. Also they have relatively less knowledge of the effect of anti - retroviral drugs on the oral health which is a major setback because it is an added burden on the disease which already comprises the immune system of the patient who is unable to resist other diseases. On an overall basis the impact of oral health literacy intervention regarding HIV infection produced a significant outcome on the knowledge increase among the caregivers which reflected that the purpose of the study was met.

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