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Full Length Research Paper

Impact of information leaflet on human immunodeficiency virus (HIV) related information and self management in HIV positive adolescents

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This study evaluates the effectiveness of a peer support intervention on human immunodeficiency virus (HIV) related information and self-management in HIV positive adolescents. Adolescents in this study referred to children in the age group 11 to 16 years. An intervention study, with outcomes assessed the intervention and immediately post-intervention. Participants aged 11 to 16 years (N = 114) were recruited from three antiretroviral treatment (ART) clinics in Lusaka, and interviewed using semi-structured questionnaires. Information on HIV and acquired immune deficiency syndrome (AIDS) was given using an information leaflet entitled 'Let's Talk about HIV and Living positively; How can young people with HIV live normally?' After the intervention, the findings showed that 96% of the participants were knowledgeable that unprotected sex was the most common route of transmission of HIV. The belief that people with HIV should stop ART when they feel better; and that ART can have unwanted side effects decreased amongst the participants. Overall after the intervention, knowledge and belief about HIV and ART; and self-management improved. Peer support intervention using information leaflets seems to be useful strategy in improving knowledge and self management in HIV positive young people.

Keywords: HIV, young people, self-management, information.

INTRODUCTION

Globally, 35.5 million people were living with human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) at the end of 2012 (UNAIDS, 2012), and 25 million of them lived in Africa (UNAIDS, 2012). In 2010, young people aged 15 to 24 accounted for 42% of new HIV infections in people aged 15 and older. Among young people living with HIV, nearly 80% (4 million) live in sub-Saharan Africa (UNAIDS, 2010). For some years it has been reported that young people seem to be the fastest growing age group of HIV positive individuals all over the world (Jaspan et al., 2006). Zambia is one of the countries that bear the greatest burden of HIV and AIDS, it is estimated that 95,000 children aged 0 to 14 years are and 14.6% of young adults in the economically active age range of 15 to 49 years are HIV positive. The prevalence amongst young people aged 15 to 19 years was 9% (Zambia Demographic and Health Survey, 2007). The world is

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now in an era where an enormous amount of information is available on HIV and AIDS and the care of HIV positive individuals. Besides health problems, HIV and AIDS also lead to a wide spectrum of other problems such as inequity, discrimination and abuse. Adolescents in most developing countries are challenged by issues related to HIV (WHO, 2005).

It is also challenging to address self-management and the psychosocial difficulties related to HIV in adolescents (Domek, 2006). Self-management has been identified as best practice in the care of people with chronic health conditions. WHO (2001) and Swendeman et al. (2009) have highlighted the need for a multidimensional approach to HIV care which both empowers patients to take control of their illness and also addresses the psychosocial impact. However, there has been very little research on self-esteem of HIV positive adolescents and strategies to enhance self-management in adolescents. Many factors need to be considered when considering self-management in HIV positive individuals including: adherence to the rigid antiretroviral treatment (ART) regime and coping with its dietary guidelines and side effects; stigma related to it; and problems related to illness disclosure (Wagner, 1998). It is also challenging to address self-management and the psychosocial difficulties related to HIV in adolescents (Domek, 2006). Self-management has been identified as best practice in the care of people with chronic health conditions and in this respect WHO (2001) and Swendeman et al. (2009) have highlighted the need for a multidimensional approach to HIV care which both empowers patients to take control of their illness and also address the psychosocial impact.

A recent report published by the National AIDS Council, Zambia (2010) indicated that only about a third a of young people aged 15 to 24 could correctly identify ways of preventing the sexual transmission of HIV, and rejected major misconceptions about HIV transmission. This was an indicator of low knowledge of HIV in this population. The National AIDS Council in Zambia (NAC) in its report also recommends tailored sexual and reproductive health information and services for young people. HIV and AIDS education has been identified as a key method of improving sexual and health related attitudes in HIV positive children including adherence (Thorne et al., 2002; Pontali, 2005; Weiss et al., 2003). Although, there has been a substantial government initiative to raise awareness of HIV in Zambia (Zambia Ministry of Health/National AIDS council, 2010), information and support for adolescents suffering from the disease seem to be lacking.

Leaflets are generally considered to be an effective method of educating patients (Wilkinson et al., 1981; Sandler et al., 1989) which improves compliance (Ley, 1982). They are especially useful in developing countries due to their low technological requirements (Newton et al., 1998) and because they can be taken away from the "stressful environment of the consultation room" and re-read when needed (Kenny et al., 1998). In preliminary research conducted in schools, HIV and AIDS information leaflets were shown to be effective in improving HIV and AIDS related knowledge, and reducing stigma towards *the* individuals suffering from HIV (Menon et al., 2010). Peer support interventions also seem effective in HIV positive adolescents. Peer support groups among HIV positive youths are based on the notion of universality (Yalom, 1985), in which individuals with a common issue can relate to shared experiences. Herman (1992) suggested that solace and comfort results from being with others who have experienced a similar situation. Therefore, for HIV positive adolescents, who may similarly face isolation, stigma and fear, peer support groups could function as an opportunity to share emotions and experiences (Gossart-Walker and Moss, 1998). Relationship with peers is a key component of development. Adolescents when accepted by their peers are likely to be involved in interactions that result in positive developmental experiences and better mental health (Rubin et al., 2006). Therefore, interventions that promote peer interaction may be beneficial for HIV positive adolescents.

The objective of this research was to evaluate the effectiveness of a peer support intervention using information leaflets, on psychological well-being, self-esteem, psychiatric outcomes, HIV related information and self-management of HIV positive adolescents. This was a part of a larger study, the outcome measures reported in this paper were only those from qualitative data regarding HIV information and self-management.

METHODOLOGY

Design

An intervention study design, with outcomes assessed before the intervention, and immediately post-intervention after 10 weeks was utilized. The data presented in this study was collected using semi-structured interviews.

Participants

One hundred and fourteen participants were recruited from three ART clinics in Lusaka namely: University of Zambia clinic, Pediatric Centre of Excellence- University Teaching Hospital and the Clinic at SOS village. Recruitment of participants was done with the assistance of Medical Officers at the ART clinics. The inclusion criteria for the study were that the participants must be English speaking, HIV positive sero status, with knowledge about their HIV status, aged from 11 to 16 years and on anti-retroviral treatment for at least one year. Those without parental consent, and who did not give verbal assent were excluded.

Measures

Measures included personal data sheet, semi-structured interview schedule to measure self-management and HIV related information,

Table 1. Socio-demographic characteristics of the participants.

Parameters	Intervention group (n= 63)	Wait control list group (n= 51)
Gender		
Male	25	27
Female	38	24
Residence		
Both parents	27	28
Mother only	14	2
With relatives	3	6
Others	4	4

this was previously used in a study with HIV positive adolescents in Zambia (Menon et al., 2007), the interview schedule was further revised and pre tested in a sample similar to the proposed sample (N=7). Those who took part in the pre test were not included in the main study. The semi structured interview schedule contained questions about HIV related information, the extent to which the individual had control over their health and played an active role in issues concerning their health.

Procedure

Approval was obtained from the University of Zambia ethics committee and Ministry of Health prior to commencement of the study. Parents or guardians of the children meeting the inclusion criteria were informed about the study and asked if they would be willing to participate in this peer support group intervention study. Signed consent was obtained from children and parents/guardians, and verbal assent from children below 16 years. Children were grouped by age and gender, through picking up numbered slips of paper (1 for intervention, 2 for control group) and were then assigned to either the intervention or control group. A ten week intervention, with 1 meeting every week involving reviewing group rules, imparting information on HIV and AIDS, participating in child-initiated talk time, group activity, free play, and snack time was initiated. Information on HIV and AIDS was given using an information leaflet entitled, 'Lets Talk about HIV and Living Positively; How can young people with HIV live normally?.' The HIV information leaflet has been previously evaluated with HIV positive adolescents (Menon et al., 2010). The researcher talked through the different parts of the leaflet with the participants and stimulated discussions on issues covered by the group. The participants were also given a leaflet to take home and read at their convenience and/or discuss with their parents/caregivers. The leaflet contained an outline of what HIV is and those at risk, information regarding anti-retroviral therapy, social support and guidance on how an individual can modify behaviours to improve their health.

Data analysis and management

The data from each participant was coded to ensure confidentiality and identifying details were stored separately from the data. Interviews were subjected to content analysis and emerging themes related to HIV Knowledge and Self- Management was identified and analysed using examples of quotations from each theme.

Ethical considerations

Ethics approval was sought from the University of Zambia Research Ethics Committee. Prior to data collection, informed consent was obtained from parents or guardians and assent was obtained from the participants and the participants were assured that they could withdraw from the study at any point without having to give any explanation and without suffering any consequences. Confi-dentiality of information was maintained throughout the study and the names of the participants were removed from the records. A counseling referral service was available at the UNZA clinic that could be accessed by the participants if necessary.

RESULTS

Characteristics of the sample

There were 114 children in the age group of 11 to 16, comprising of 52 males and 62 females recruited to the study from 3 ART clinics in Lusaka. Of these, 63 were randomized into intervention group and 51 into the wait list control group. All participants attended school and were in grades ranging from 3 to 12 (Table 1).

Knowledge on HIV transmission

At baseline, in the intervention group, 73% of the participants indicated ‘unprotected sex’ as being the most common route for HIV transmission and 9% also reported ‘kissing’ to be a mode of transmission. At baseline 18.2% of the participants responded that ‘someone can get HIV through witchcraft’, while at end line only 6.6% responded that ‘may be someone can get HIV through witchcraft’. Results from the follow-up indicated that the knowledge of HIV transmission after the intervention improved. Knowledge increased from 69 to 98% for healthy looking person can have HIV and AIDS, 72 to 96% for common way to get HIV and AIDS and 67 to 92% for HIV can affect anyone at any age, respectively. The perception that a person can get HIV through witchcraft reduced from 18 to 7% (Figure 1).

Knowledge and belief about ARVs

Seventy-three percent of the respondents during the

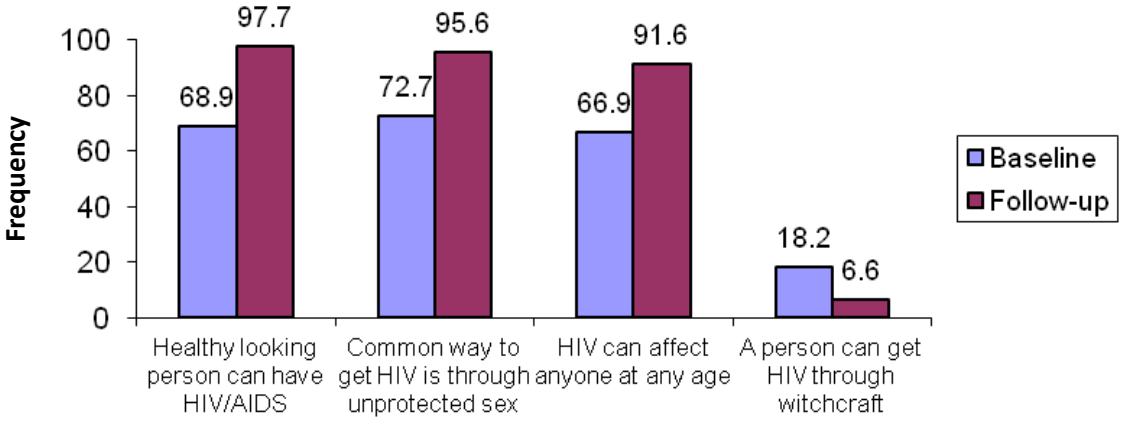

Figure 1. Change in knowledge about HIV transmission before and after the intervention

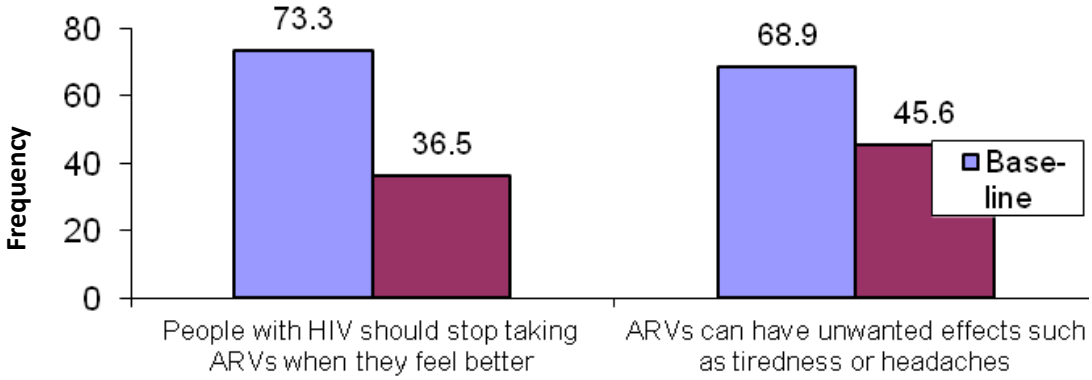

Figure 2. Change on Knowledge and belief about ARVs.

baseline indicated that ARVs should be stopped when they feel better, after the intervention this perception reduced from 73 to 37%. On the other hand, 69% of the respondents reported that ART can have unwanted side effects baseline and after the intervention it reduced to 46% (Figure 2).

One participant in the intervention group said '…ARV's are given in order to boost up the CD4 Count'
Another participant reported 'Yes, they must be taken accordingly, and maintain a balanced diet in order for the drug to work accordingly, if one does not get enough rest, definitely there will be side effects..'

Self-management

After the intervention as shown in Figure 3, the percentage of participants who reported that 'if you are ill it is just a bad luck' reduced from 31 to 11%. The knowledge of respondents who reported eating well can help someone with HIV to stay healthy increased from 58 to 87%. The percentage of respondents who reported that there are many things one can do to keep from getting ill increased from 65 to 95%. The percentage who reported that you can choose how to look after yourself and there are things you can do to control your health increased from 56 to 79% and, 55to 87%, respectively. Examples of responses on self- management:

'…drinking beer is not good for my health'
'… if I drink alcohol it will damage my health. It can also cause someone to do something that is unwanted'.
'… drinking alcohol and having unprotected sex destroy your life; taking drugs will make your life difficult'

DISCUSSION

The objective of the research was to evaluate the effectiveness of a peer support intervention on HIV related information and self-management in HIV positive

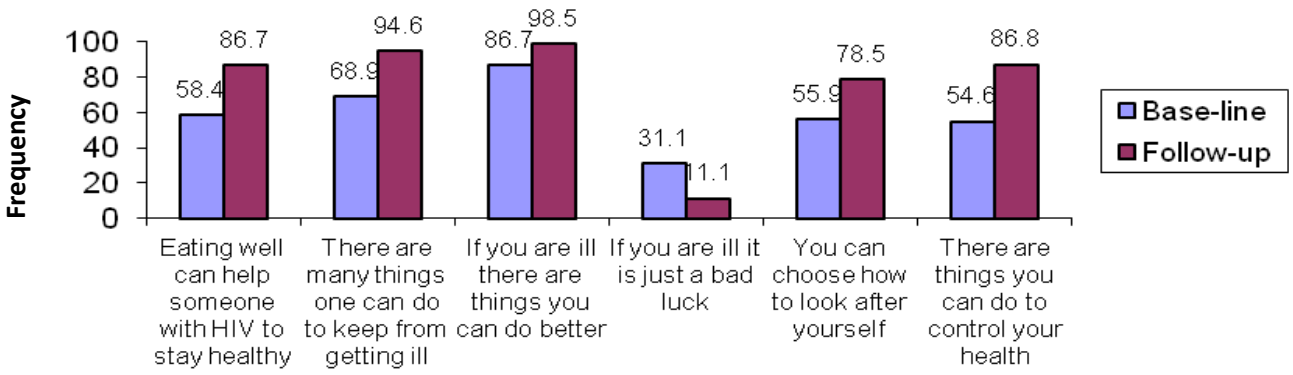

Figure 3. Change in beliefs on self-management.

adolescents in Zambia.

Knowledge about HIV transmission

Knowledge that adolescents have on HIV and AIDS influences their perception of HIV risk and risk behavior. The results of the current study show that at baseline, the participants had quite a good knowledge on the mode of the transmission of HIV. The results of this study show that at baseline the participants had quite a good knowledge on the mode of the transmission of HIV. This is exemplified by the fact that at baseline about three quarters of the respondents indicated that the common further increased to 96% at end line suggesting that after intervention only a very small percentage of the participants were still not knowledgeable that unprotected sex was the most common route of transmission of HIV. Similarly, the knowledge that even a healthy looking person can have HIV and HIV can affect anyone at any age, also improved. These findings are however contrary to the findings by the National Aids Council (2010) that only a third of young people aged 15 to 24 could correctly identify ways of preventing the sexual transmission of HIV. This difference in findings could be due to a substantial government initiative to raise awareness of HIV in Zambia (ZMOH/NAC, 2010). These findings are in agreement with the studies showing that HIV and AIDS education is a key method of improving sexual and health related attitudes in HIV positive children including adherence (Thorne et al., 2002; Pontali, 2005; Weiss et al., 2003). Belief in witchcraft and superstition regarding disease causation has been common in various African societies, including Zambia. In the current study, almost one fifth of the participants affirmed that one can get HIV through witchcraft whereas after intervention this figure reduced to 7%, with only a small percentage of participants still erroneously believing that one could contract HIV by being bewitched. Earlier studies (Tenkorang et al., 2013) have shown that men who believed AIDS can spread through witchcraft and other supernatural means were less likely to have used condoms during their last sexual intercourse. Such findings are important to consider especially when designing HIV awareness information. The above results indicate that the participants in the current study had reasonably good knowledge at baseline which further improved after intervention.

Knowledge and belief about ARVs

Almost three quarter of the participants at baseline indicated that people with HIV should stop ART when they feel better, whereas after the intervention this figure dropped to 37%. This suggests that the participants had become more knowledgeable that one should not stop taking ARVs because they now start feeling better**.** Research findings support the need to continue with ART (WHO, 2009). ART involves the provision of antiretroviral drugs (ARVs) to people living with HIV and AIDS to improve their quality of life and decrease patient mortality and morbidity (WHO, 2009). The side effects of ARVs are varied and extensive including skin rashes, dizziness and nightmares. Painful feet are some of the common side effects of the patients on ART. At baseline, almost 70% of the participants perceived that ART can have unwanted side effects but this reduced considerably after interventions (46%). The above findings is supported by Thorne et al. (2002), Pontali (2005) and Weiss et al. (2003) who also reported that HIV and AIDS education is a key method of improving sexual and health related attitudes in HIV positive children including adherence of ARVs. On the knowledge and beliefs about ARVs it can be concluded that the intervention yielded positive and intended results of giving factual information about ART. Perception of excessive side effects of ART can be a barrier to the management of HIV, since these perceptions are often related to non adherence to ART (Ammassari et al., 2001).

Self management

At baseline slightly more than half the participants had knowledge about the importance of eating well so as to remain healthy, this knowledge further rose to 87% after intervention. Having such knowledge is an indication of the capacity of the participants to be involved in self management of their condition and this is especially important since HIV is now being considered as a chronic illness that requires lifelong management. At baseline, almost 70% of the participants indicated that 'there are many things one can do to keep from getting ill' and this figure increased to 95% after intervention. Although it is widely recognized that ART has transformed HIV from an acute to a chronic illness, it is less often recognized that with this change, a different model of care is required. People living with chronic HIV must function independently, and take responsibility for their care (Gifford and Groessl, 2002). On whether one could choose how to look after her/himself, 56% agreed with this statement at baseline and this figure rose to 79% after intervention indicating that more participants got the message that one can choose how to look after oneself. Finally before intervention, 55% of the participants agreed that there are things you can do to control your health and this figure rose to 87% after intervention. These results are in agreement with the notion stated by WHO (2001) that Self-management is best practice in the care of people with chronic health conditions.

CONCLUSION

Based on the results, the intervention worked in all instances prompting us to come up with the conclusion that there was a positive impact on the knowledge base of the participants because of the use of the customized information leaflet on HIV entitled "Lets talk About HIV and Living Positively." It is recommended therefore that similar booklets geared towards positive behavioral modification in terms of self- management should be produced to help young people living with HIV and AIDS live a much more productive life.

Conflicts of interest

The authors declare that they have no conflicts of interest.

REFERENCES

Ammassari A, Murri R, Pezzotti P, Trotta MP, Ravasio L, De Longis P (2001). Self-reported symptoms and medication side effects influence adherence to highly active antiretroviral therapy in persons with HIV infection. J. Acquir. Immune Defic. Syndr. 28(5):445-449.

Domek GJ (2006). Social consequences of antiretroviral therapy: preparing for the unexpected futures of HIV-positive children. Lancet 367(9519):1367-9.

Gifford AL, Groessl EJ (2002). Chronic disease self-management and adherence to HIV medications. J. Acquir. Immune Defic. Syndr. 31(Suppl 3):163-6.

Gossart-Walker S, Moss NE (1998). An effective strategy for intervention with children and adolescents affected by HIV and AIDS. Child Adolesc. Psychiatr. Clin. N. Am. 9(2):331-45.

Herman J (1992). Trauma and Recovery. New York: Basic Books.

Jaspan H, Berwick JR, Myer L, Mathews C, Flisher AJ, Wood R (2006). Adolescent HIV Prevalence, Sexual Risk, and Willingness to Participate in HIV Vaccine Trials. J. Adolesc. Health 39(5):642-8.

Kenny T, Wilson RG, Purves IN, Clark JSR, Newton LD, Newton DP, Moseley DV (1998). A PIL for every ill? Patient information leaflets (PILs): a review of past, present and future use. Fam. Pract. 15:471-479.

Ley P (1982). Satisfaction, compliance and communication. Br. J. Clin. Psychol. 21(Pt 4):241-54.

Menon A, Glazebrook C (2009). Impact of a Yoga peer Support Intervention on the Mental Health of HIV Positive Adolescents. Psychology and Health. pp. 269-270.

Menon A, Glazebrook, C, Campain, N, Ngoma, M (2007). Mental Health and Disclosure of HIV Status in Zambian Adolescents with HIV Infection: Implications for Peer-Support Programs. J. Acquir. Immune Defic. Syndr. 46:349-354.

National AIDS Council (NAC) (2010). Modes of Transmission. UNAIDS and World Bank.

Newton L, Newton D, Clark J, Kenny T, Moseley D, Purves I, Wilson R (1998). Patient information leaflets: Producing understandable PILs. J. Infect. Sci. 24:167-181.

Pontali E (2005). Facilitating adherence to highly active antiretroviral therapy in children with HIV infection: what are the issues and what can be done? Paediatr. Drugs 7(3):137-49.

Rubin KH, Bukowski WM, Parker JG (2006). Peer interactions, relationships and groups. In: Damon W, Lerner RM, Eisenberg N (Eds.), Handbook of child psychology: Vol. 3. Social, emotional, and personality development. New York: Wiley pp. 571-645.

Sandler DA, Mitchell JRA, Fellows A, Garner ST (1989). Is an information booklet for patients leaving hospital helpful and useful? Br. Med. J. 298:870-874.

Swendeman D, Barbara L, Ingram, Rotheram-Borus MJ (2009). Common elements in self-management of HIV and other chronic illnesses: an integrative framework. AIDS Care 21(10):1321-34.

Tenkorang EY (2013). Myths and misconceptions about HIV transmission in Ghana: what are the drivers? Cult. Health Sex. 15(3):296-310.

Thorne S, Paterson B, Russell C, Schultz A (2002). Complementary/Alternative Medicine in Chronic Illness as Informed Self-Care Decision Making. Int. J. Nurs. Stud. 39(7):671-83.

UNAIDS (2010). Report on the Global AIDS Epidemic. Available at: http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/documents/factsheet/2012/20120417_FS_adolescentsyoungpeoplehiv_en.pdf

UNAIDS (2012). Report on the Global AIDS Epidemic. Available at: http://www.unaids.org/sites/default/files/media_asset/20121120_UNAIDS_Global_Report_2012_with_annexes_en_1.pdf

Wagner EH (1998). Chronic Disease Management: What will it take to improve care for chronic illness? Eff. Clin. Pract. 1(1):2-4.

World Health Organization (WHO) (2009). Rapid advice: antiretroviral therapy for HIV infection in adults and adolescents–November 2009. World Health Organization, Geneva, Switzerland.

Zambia Country Report Monitoring the Declaration of Commitment on HIV and AIDS (MOH/NAC) (2010). Zambia Country Report Monitoring the Declaration of Commitment on HIV and AIDS and the Universal Access 2010. Lusaka: NAC, 26.