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Effects of community-based care on quality of life among adolescent and young adult Ebola survivors in Democratic Republic of the Congo.

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ABSTRACT: Studies have been conducted on the Ebola virus epidemic in sub-Saharan Africa, but few have looked at how community-based care affects the quality of life of adolescent and young adult Ebola survivors in the Democratic Republic of Congo, the focus of our study. The study was carried out in eastern Democratic Republic of the Congo's North-Kivu province using mixed method quasi-experimental study design. The study was carried out after the Ebola outbreak of 2018-2020.Participants were 10 to 24-year-old Ebola Virus Disease (EVD) adolescent and young adult survivors. Quantitative data was collected at the baseline and endline of the intervention. After the intervention, there was a 13.03% improvement in quality of life. Compared to the baseline, Ebola survivors had a 1.58 (p=0.036) higher likelihood of having a good quality of life. Difference-in-difference estimator was also 1.89(p=0.036), indicating interaction. Multivariate logistic regression revealed that social support 2.19 (p=0.04) and confusion 0.26 (p=0.001) were variables that influenced the quality of life among adolescent and young adult Ebola survivors. The study demonstrated that the quality of life of adolescent and young adult Ebola survivors is significantly improved by community-based care.
KEYWORDS: Adolescent, Community-based Care, Ebola Virus Disease, Quality of life, Young adult.

I.INTRODUCTION

People who suffer an infectious and fatal disease generally experience impacts that go beyond their physical symptoms [1]. Studies on other infectious viruses are more extensive and give a basis for evaluating the impact of a disease and a person's quality of life, in contrast to the relatively few studies published on the impact of EVD on the quality of life of adolescents and young adults [2, 3]. It has been demonstrated that elements like trauma, mental issues, and stigmatization have a detrimental effect on the quality of life of people with HIV/AIDS. Due to its aggressive and turbulent nature, EVD is regarded to be different from other hemorrhagic diseases. Despite the differences in these diseases' traits, they all have a few things in common, including the ability to spread from person to person through bodily fluids, and the lengthy incubation periods through which testing is challenging. Furthermore, the contemporary epidemics of HIV/AIDS and EVD continue to be stigmatized by society, leading to conflict, isolation, and a low quality of life [2]. These illnesses have a negative impact on adolescents and young adults' physical, psychological, social, emotional, and economic health, which lowers their quality of life. The Ebola epidemic in West Africa from 2013 to 2016 was the most prevalent in the disease's history. The fourth Strategic Response Plan (SRP-4) was implemented by the Ministry of Health of the Democratic Republic of the Congo in response to reports of an Ebola crisis in the provinces of North Kivu and Ituri[4]. However, many EVD survivors are reportedly dealing with short- and long-term medical and emotional problems as a result of their ordeal, including musculoskeletal pain, vision issues, confusion, convulsion, headaches, fatigue, stigma, depression, anxiety, and post-traumatic stress disorder [6, 7]. Even though numerous study has been done on the health issues that EVD survivors face, there is minimal understanding of their experiences and challenges, which has a negative impact on their quality of life [8]. Many adolescents and young adults in Sub-Saharan Africa are more susceptible to communicable diseases that cause early deaths and poor quality of life, mostly because they have limited access to treatment and a lack of social supports that make them vulnerable to stigma [10]. Furthermore, there are no studies on the quality of life of adolescents and young adults who have survived the Ebola virus and which may provide a basis for intervention. Several studies have been carried out in Sub-Saharan

Africa to evaluate the quality of life of various segments of the population however they do not include the effect of community-based care on the quality of life. In view of such, the purpose of this study was to determine how community-based care affects the quality of life of young adults and adolescents who survived the Ebola virus.

II. METHODS

2.1 Study area and design

This study was carried out in the North-Kivu province in the health zone of Beni and Katwa health zones, in the towns of Beni and Butembo. The two health zones are separated by 54 kilometers. The two communities in the selected health zones were comparable in terms of socioeconomic status and culture.

The study used both qualitative and quantitative methodologies in a mixed-method, quasi-experimental study design. The experimental design aimed to ascertain if a policy or intervention had the desired causal effect. The comparison of a control group and an intervention group's designs was our main focus. Groups of subjects were created based on variables that were not randomly chosen [11]. Intervention group was chosen in the Beni health zone and then the control group in Katwa health zone.

2.2 Study intervention

Over the course of a four-month period, adolescents and young adults, caregivers, and community health care providers received four training sessions. Sessions were typically held once a month. Adolescent and young adult Ebola survivor, caregiver and community health workers 'intervention was composed of a variety of approaches, including the provision of safe spaces, the development of life skills and social assets, their engagement in relationships with mentor who was assigned to each group of survivors, caregivers, and community health workers. The aim of training sessions was to help community health workers, adolescents, and young adults build social networks with peers, strengthen a positive mentee-mentor relationship, and gain confidence in addition to introducing caregivers and community health workers to caregivers and adolescent and young adult survivors. The discussion groups served as a platform to talk on how to keep caring for adolescent and young adult Ebola survivors, as well as to help empowerment, and well-being of the adolescent and young adult survivors. Adolescents and young adults in the intervention and control groups completed baseline and final surveys prior to and following the intervention.

2.3 Study population

In the Eastern DRC's Beni and Katwa health zones, this study focused on adolescents and young adults who had survived EVD. All adolescents and young adults who was infected by Ebola virus and had survived EVD outbreak of 2018-2020 and were between 10 and less than 18 years of age as well as those between the ages of 18 and 24 met the inclusion criteria. Additionally, those under 18 years must have given their assent, while those over 18 years must have given their consent to participate in the study. Adolescents and young adults who had not contracted the EVD or who had chronic health problem before EVD 2018-2020 outbreak were not included in the study.

2.4 Sampling

A random sampling technique was used to select participants for quantitative data and to reduce bias and ensure the validity of the study findings. At baseline, 46 interviews were conducted for both the intervention and control groups while at endline, 45 interviews were conducted for both the intervention and control groups. The objectives of this study were met by the use of comprehensive questionnaires that adhered to the WHO criteria for quality of life where a sum of 78 or higher indicated a high level of quality of life [12]. This study measured the degree to which data collected through questionnaires accurately reflected a certain domain or the content of a particular notion [13].

2.5 Sample size and Data collection

The study utilized a sample size estimation formula [14] to calculate the sample size of 94 participants as follows:

$$n = \frac{(Z_{\frac{\alpha}{2}} + Z_{\beta})^2 \{P_1(1 - P_1) + P_2(1 - P_2)\}}{(P_1 - P_2)^2} * D.E$$

Where:

n= minimum number of study participants in in both the intervention and the control groups.

P_1 is average proportion of outcome in the population (intervention) at baseline (0.50)

P_2 is average proportion of outcome in the population intervention at endline (0.80)

Zα is normal variate at 5% (1.96)

Zβ is the power at 80% (0.84)

P_1-P_2 is the Effect Size, the expected change due to the intervention (0.3)

D.E is the Design Effect. The effect of non-random sampling in the study design (1.5)

After correcting for a 30% non-response rate, 46 participants were placed in both the intervention and the control groups. Interviews with adolescent and young adult EVD survivors were conducted by qualified study assistants under the supervision of the principle investigator. Utilizing CommCare by Dimagi.Inc. lastest Version 2.52.1, the research assistants gathered quantitative data.

2.6 Data Analysis

Descriptive analysis was undertaken to determine the quality of life of adolescent and young adult EVD survivors. The Pearson correlation coefficient was utilized to check whether the predictor variables were multicollinear. The absolute correlation coefficient amongst predictors was 0.7, indicating the effects of community-based care on the quality of life of adolescents and young adults EVD survivors. The regression analysis produced the crude odds ratio (COR), adjusted odds ratio (AOR), at 95% confidence interval (CI), and a statistical p-value significance of 0.05. The final multivariate model contained variables that were significant in the bivariate analysis. The research used the assumption that each pair of outcomes had a proportional chance of being either a bad or good quality of life.

Likelihood ratio test was utilized to verify the proportionate odds assumption, which showed that it is true. The outcome variable among adolescent and young adult EVD survivors was quality of life. The respondents were divided into two groups based on their quality of life: bad and good. A person had a bad quality of life if they were unable to maintain a reasonable standard of living, had poor physical and mental health, had low levels of education, and were unable to support their families. A person had a high quality of life if they were able to support their family, maintain a decent level of living, were in good physical and mental health, and was able to engage in leisure activities in accordance with the four domains. The quality of life was evaluated using the Linkert scale, which has a range of 1 to 5. The ranges were as follows: 1- not at all, 2- slightly, 3- moderately, 4- extremely, and 5- fully.

2.7 Ethical consideration

Prior to data collection, a research permit from National Ethical Committee of Research of Democratic Republic of the Congo and Great Lakes University of Kisumu, Kenya, helped to alleviate mistrust and allowed the participants to reveal much of the information required for the study. Since some of the data to be gathered were sensitive, the researcher had a moral obligation to handle the information with the utmost propriety. Throughout the study, participants' privacy and confidentiality were respected.

III.   RESULTS

3.1 Quantitative findings

Ninety-two adolescents and young adults at baseline survey and ninety adolescents and young adults at endline survey participated in this study (Table 1). A total of 46 participants were evaluated at the baseline and 45 at the endline of the study about their quality of life before and after the counseling intervention. At baseline 65.22% (30) and endline, 64.44% (29) of the adolescents and young adults in the intervention group were between the ages of 18 and 24, compared to 69.57% (32) at baseline and 71.11% (32) at endline in the comparison group. In the intervention group, females were 60.87% (28) at baseline and 60% (27) at endline, whereas in the comparison group, they were 58.7% (27) at baseline and 57.78% (26) at endline.

Table 1: Socio-demographic characteristics of the adolescents and young adults by study groups

Variables	Intervention				Control			
	Baseline (n=46)		Endline (n=45)		Baseline (n=46)		Endline (n=45)	
	n	%	n	%	n	%	n	%
Age								
10 - < 13	11	23.91	11	23.91	4	8.70	4	8.89
13 - < 18	5	10.87	5	10.87	10	21.74	9	20.00
18 - 24	30	65.22	29	64.44	32	69.57	32	71.11
Sex								
Female	28	60.87	27	60.00	27	58.70	26	57.78
Male	18	39.13	18	40.00	19	41.30	19	42.22

3.1.2 Quality of life of adolescent/young adults Ebola survivors between control and intervention at baseline and end-line by study groups

According to table 2, for the intervention group, the proportion of adolescents and young adults who had a good quality of life was 60.87% (28) (at baseline and 82.22% (37) at endline, while in the control group, it was 71.74% (33) at baseline and 36 (80%) at endline (Table 2). The quality of life improved by 21.35% in the intervention group while only 8.26% changed in the comparison/control group resulting in a difference of 13.09% which was insignificant

Table 2: Quality of life of adolescent/young adults Ebola survivors between control and intervention at baseline and end-line by study groups

Quality of life	Intervention				Diff	Control				Diff	DID
	Baseline(n=46)		Endline (n=45)			Baseline (n=46)		Endline(n=45)			
	n	%	n	%	%	n	%	n	%	%	%
Poor	18	39.13	8	17.78		13	28.26	9	20.0		
Good	28	60.87	37	82.22	21.35	33	71.74	36	80.0	8.26	**13.09**

3.1.3 Community-based care characteristics of adolescents and young adults

There were 71.74% (33) adolescents and young adults in the intervention group who had encountered stigma at baseline compared to 44.44% (20) at endline, while there were 65.22% (30) at baseline and 77.78% (35) at endline in the comparison group (Table 3). At baseline, there were 58.70% (27) individuals in both the intervention and control groups who had experienced stress; by the conclusion, there were 44.44% (20) in the intervention group and 40%(18) in the control group. Drug usage to manage stress was 17.39%(8) in the intervention group at baseline and 22.22%(10) at endline, compared to 15.22% (7) in the control group at baseline and 11.11% (5) at endline. In the intervention group, sexual activity was reported by 43.48%(20) at baseline vs. 55.56%(25) at endline, and by 47.83%(22) at baseline vs. 40% (18) at endline. In the intervention group, condom use increased from 23.91% (11) at baseline to 28.89% (13) at endline, but in the comparison group, it decreased from 12 (26.09%) at baseline to 26.67%(12) at endline (Table 3).

In the intervention group, there were (28.26%) (13) people with social support at baseline compared to 57.78% (26) at endline, while in the comparison group, there were 39.13% (18) participants at baseline compared to 35.56% (16) at endline. Drug abusers in the intervention group ranged from 23.911% (11) to 26.67%(12) at baseline, while in the control group, they ranged from 39.13%(18) to 35.56% (16) at baseline. When compared to the comparison group, the proportion of people who had anxiety episodes in the intervention group was (50%) 23 at baseline and 66.67% (30) at endline, while it was 47.83% (22) in the baseline and 26.67% (12) at the endline. (Table 3).

Table 3: Community-based care characteristics of the adolescents and young adults by study groups Eastern DRC,2022

Variables	Intervention				Control			
	Baseline (n=46)		Endline (n=45)		Baseline (n=46)		Endline (n=45)	
	n	%	n	%	n	%	n	%
Stigma								
Yes	33	71.74	20	44.44	30	65.22	35	77.78
No	13	28.26	25	55.56	16	34.78	10	22.22
Experienced Stress								
Yes	27	58.70	20	44.44	27	58.70	18	40.00
No	19	41.30	25	55.56	19	41.30	27	60.00
Drug for stress management								
Yes	8	17.39	10	22.22	7	15.22	5	11.11
No	19	41.30	10	22.22	20	43.48	13	28.89
Missing	19	41.30	25	55.56	19	41.30	27	60.00
Sexual activity								
Yes	20	43.48	25	55.56	22	47.83	18	40.00
No	26	56.52	20	44.44	24	52.17	27	60.00
Use condom								
Yes	11	23.91	13	28.89	12	26.09	12	26.67
No	9	19.57	12	26.67	10	21.74	6	13.33
Missing	26	56.52	20	44.44	24	52.17	27	60.00
Social support								
Yes	13	28.26	26	57.78	18	39.13	16	35.56
No	33	71.74	19	42.22	28	60.87	29	64.44
Drug abuse								
Yes	11	23.91	12	26.67	14	30.43	17	37.78
No	35	76.09	33	73.33	32	69.57	28	62.22
Confusion								
Yes	21	45.65	7	15.56	20	43.48	25	55.56
No	25	54.35	38	84.44	26	56.52	20	44.44
Anxiety attacks								
Yes	22	47.83	12	26.67	23	50.00	30	66.67
No	21	45.65	33	73.33	23	50.00	15	33.33

3.2. Community-based care factors associated with quality of life

The characteristics of community-based care included social support, perplexity, and anxiety episodes (Table 4). In the intervention group, survivors who reported having social support were 3.44 (p=0.02) times more likely than those who did not report as having a high quality of life. Social support was not statistically significant in the control group. But in contrast to those who did not receive social support, individuals who did receive social assistance were 1.38 (p=0.54) times more likely to have a high quality of life. In the intervention and control groups, adolescents and young adults who survived confusion had 0.18 (p=0.001) and 0.36 (p=0.05) times less likelihood of having a good quality of life than those who did not, respectively. Both the intervention group and the control group experienced severe confusion. Anxiety attacks reach a statistically meaningful level in only the intervention group. In this group, participants who had anxiety attacks were 0.3 (p=0.01) times less likely to have a high quality of life than those who did not. When compared to those who did not, control group survivors who had anxiety attacks were 0.74 (p=0.56) times less likely to have a high quality of life. Stigma, stress, sexual activity, and drug misuse were the community-based care characteristics that were not statistically significant.

Table 4: Community-based care factors associated with quality of life

Variables	Intervention			Control		
	Unadjusted O.R	95% C.I	*P*-value	Unadjusted O.R	95% C.I	*p* -value
Stigma						
Yes	0.66	0.26 - 1.69	0.38	0.67	0.22 - 2.06	0.49
No	Ref			Ref		
Experienced Stress						
Yes	0.88	0.36 - 2.20	0.79	0.76	0.29 - 2.00	0.58
No	Ref			Ref		
Drug for stress management						
Yes	3.06	0.72-13.01	0.13	1.13	0.25 - 5.12	0.88
No	Ref			Ref		
Sexual activity						
Yes	0.97	0.39 - 3.41	0.95	0.117	0.44 - 3.12	0.74
No	Ref			Ref		
Use condom						
Yes	0.97	0.27 - 3.52	0.97	1.27	0.28 - 5.68	0.76
No	Ref			Ref		
Social support						
Yes	3.44	1.22 - 9.67	**0.02**	1.38	0.50 - 3.82	0.54
No	Ref			Ref		
Drug abuse						
Yes	2.27	0.69 - 7.48	0.18	1.52	0.53 - 4.37	0.44
No	Ref			Ref		
Confusion						
Yes	0.18	0.07 - 0.49	**0.001**	0.36	0.13 - 0.99	**0.05**
No	Ref			Ref		
Anxiety attacks						
Yes	0.3	0.12 - 0.78	**0.01**	0.74	0.28 - 2.00	0.56
No	Ref			Ref		

On table 5, both period and research had a statistical significance, which means that the intervention had a positive impact on the quality of life of adolescents (OR=1.58, CI=1.06-4.17). Based on the study also the period in which the intervention took place also had an impact with intervention having a 61% higher likelihood of having a better quality of life (OR=1.61, CI=1.26-2.47). The Difference-in-Difference estimator was also significant which meant that the intervention really improved the quality of life.

Table 5: Effect of community-based care intervention on QOL among adolescents and young adults.

	Good quality of life		
	aOR	**95% C.I**	**P value**
Period			
Baseline	Ref		
Endline	**1.58**	1.06 - 4.17	**0.036**
Study-arm			
Intervention	1.61	1.26 - 2.47	**0.027**
Control	Ref		
Interaction	**1.89**	1.08 - 7.43	**0.036**

3.1 Qualitative findings

According to caregivers of adolescent EBV survivors, most of them reported that adolescent EBV survivors dropped out of school due to psychological torture from the community and were unable to finish school. Others reported that Ebola left the adolescents too weak that they could not carry out any activity therefore the caregivers assisted them in doing everything. As a result of being dependent on someone to carry out their daily activities and the psychological torture from the community, most survivors attempted suicide or had suicidal thoughts.

> *"Dropping out of school due to mental torture or psychological problems in the community."* [Caregiver adolescent (10- 18), FGD]
> *"Since their discharge from Ebola Treatment Centers, adolescents have become too demanding and physically weak, which has led to dependency."* [Caregiver adolescent (10- 18), FGD]
> *"Adolescents show suicidal thoughts and behavior."* [Caregiver adolescent (10- 18), FGD]

Adolescent and young Ebola survivors were unable to participate in sports with their friends and peers. One participant, for instance, mentioned that although he enjoyed football, he was unable to play with his friends since he had survived the Ebola virus.

> *"For me adolescents at school abuse me. They say that I still have the Ebola virus and I can infect everyone. They tell me that I can't be married and they can't play with me because they don't want to be infected by the virus. This makes me feel bad and I cry".* [Young adult (18-24) FGD]
> *"For me, I can't play sports yet I like football".* [Adolescent (10- 18), FGD]

Adolescent and young Ebola survivors experienced include forgetfulness, meanness, behavior change, lack of love, and lack of psychological support which resulted in poor quality of life. In addition, EBV survivors highlighted that there was need for counseling sessions and constant religious teachings due to the suicidal thoughts that the survivors had developed.

> *"Adolescents have suicidal thoughts and behavior (it's necessary to teach them the word of God)."* [Caregiver adolescent (10- 18), FGD]

In terms of effects of community-based care on quality of life, the participants gave recommendations that would assist them to have a better quality of life such as creating awareness through community dialogue and sensitization, having efficient referral systems, and the importance of a proper diet.

> *"Ongoing dialogue and sensitization on Ebola disease."* (Proxies young adult, FGD)
> *"Referring the survivors to the health centers after the effects caused by Ebola."* (Community Health Workers, FGD)

Moreover, majority of the participants reported that ongoing communication with the health providers guaranteed answers to their questions, and solved health problems and challenges they were facing. Additionally, they stated that their quality of life increased as a result of heeding the community health worker's advice.

> *"I am a survivor, I talked to a community health worker after which I was satisfied. I thanked him a lot because I did understand why the persistence of the viruses in our bodies but now I understood and I am okay."* (IDI 1)
> *"After talking to a community health worker, my health is fine now and I have sexual intercourse with my boyfriend using a condom and it's very important to have such talks in the community."* (IDI 1)
> *Teaching the survivors importance of a proper diet."* (Community Health Workers, FGD)

In term of social support, the participants also recommended school enrollment for survivors who were not in school because they linked education with good quality of life. They highlighted that medical care of survivors as well as having adequate food were necessary for better health outcomes and hence good quality of life.

"The key to improved quality of life is schooling for those who are not in school, medical care; Counseling, food availability at home and consuming local foods, teaching the children the vices and virtues for their future, providing friendly a space for children and youth groups." [Caregiver adolescent (10- 18), FGD].

Most of the participants reported that the continuous communication with the health care providers provided answers to their questions and solved the challenges and the health problems they faced and as a result, their quality of life improved.

"I am a survivor, I talked to a community health worker after which I was satisfied. I thanked him a lot because I did understand why the persistence of the viruses in our bodies but now I understood and I am okay." (IDI 1).

"After talking to a community health worker, my health is fine now and I have sexual intercourse with my boyfriend using a condom and it's very important to have such talks in the community" (IDI 1).

IV. DISCUSSION

Community-based care is an essential intervention for EVD adolescent and young adult survivors and has a beneficial effect of enhancing their quality of life. When compared to survivors who did not receive these treatments, adolescents and young survivors who received community-based care reported a higher quality of life. According to the results, the intervention group's percentage rise in quality of life was higher than that of the comparison group. It was, however, a little lower than what had been reported in prior investigations, such as those conducted in the countries of Uganda [15]. This could be as a result of the different participant populations and study location in Eastern Democratic Republic of Congo, where residents have experienced conflict army for a number of years and these factors can affect the outcomes. The findings of this study demonstrated that counseling of adolescents following intervention had a significant, independent, beneficial impact on the quality of life of adolescent and young adult Ebola virus survivors after controlling for other variables. Similar to this, parents said that teens who attended therapy sessions had better health outcomes and consequently greater quality of life. Additionally, a sizable fraction of adolescent and young adult Ebola survivors who received community-based treatment had a higher quality of life than those who did not get any community intervention. The Liberians chose community-based care as an approach for addressing the issue, and a little improvement was recorded. The Liberians supported this intervention [16]. The results of this study support the added value of concurrent community-based care interventions among adolescent and young adult Ebola survivors, their caregivers, and community health workers in settings with limited resources. Participants who received community-based care performed marginally better at four months compared to those who did not get support services.

Findings from a study by Rabelo and others, however, somewhat contradict these findings[17]. Their research states that the majority of Ebola patients who recovered and were released from medical facilities experienced isolation because they were deemed contagious and a danger to their families and the community. These results, however, are consistent with our qualitative research from focus groups with young adults where people were excluded from sports because they were viewed as contagious. Because no one wanted to buy their items at the market or touch their money, some Ebola survivors were forced to get divorced, while others were evicted from their houses or lost their jobs. Other survivors reported that their kids wouldn't eat from them and even relatives avoided them. Our quantitative research revealed that adolescents who took part in the study experienced similar difficulties because other people were unable to exchange goods and items with them which is the same findings as studies done prior [18, 19]. Researchers claim that despite all of these forms of prejudice, community care is not the best treatment for enhancing the victims' quality of life. Consequently, there are differences in how the community-based care intervention is accepted in various countries.

social support and Confusion were also statistically important factors in this investigation. Adolescents and young adults who received social support from their parents, community health workers, or religious leaders were more likely to have a high quality of life than those who did not. A social support group can assist EVD survivors improve their quality of life by strengthening their psychological health, according to studies done in the past. In order to do this, social support encourages survivors to accept their situation and aggressively seek medical attention [20, 21]. However, compared to survivors who did not experience perplexity, those who did had a lower likelihood of having a high quality of life.

V. CONCLUSION AND RECOMMENDATIONS

With an improvement in mean quality of life following intervention, this study demonstrates the significance of community-based care in enhancing the quality of life of EVD survivors in the DRC Congo. The study also revealed that community-based care has a greater favorable impact on the quality of life for adolescent and young adult survivors. According to the study's results, social support and quality of life are significantly positively correlated. Finally, following the findings, there are certain recommendations that arise. The study demonstrates a strong need for increased sustainable social support and confusion management among adolescent and young adult Ebola survivors. There is also need for implantation of this kind of intervention in the communities to optimize on its positive impact on improving the quality of life of EVD survivors in Democratic Republic of Congo.

VI. ACKNOWLEDGMENTS

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