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Predictors of Intervention Adherence among Young People Living with HIV

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Abstract

Objective: To examine adherence to a 23 session intervention for young people living with HIV.

Methods: 208 HIV-positive youth were assigned by small cohort to a behavioral intervention.

Results: Youth with more personal strengths were more likely to attend the intervention; those with more competing environmental demands (e.g., employment, school) were less likely to attend the intervention. Using a social support, spiritual hope, or self-destructive and escape coping style was associated with attendance. Youth who reported many sexual partners attended fewer sessions. Adherence varied by cohort assignment.

Conclusion: When designing future interventions, high attendance should be considered as a goal.

Keywords

HIV; intervention; adherence; youth living with HIV

Over the past decade, most adolescent HIV prevention programs have been effective in reducing risk, yet the effect sizes have been relatively small.¹ As 25% to 50% of new HIV infections are among adolescents, efforts to improve HIV prevention for young people are needed. To enhance the effectiveness of interventions, researchers have identified participant attendance as one of the critical determinants of effective programs.^{2,3} Not only may non-compliance lead to adverse clinical consequences, but our ability to assess an intervention's impact can be reduced.^{2,4} Participant withdrawal reduces statistical power and threatens the external validity of the results, although using an intent-to-treat analytic strategy may reduce this selection bias.⁵ Understanding the demographic and behavioral factors that influence participation is critical for the development and implementation of HIV risk-reduction interventions.²

The problem of adherence is heightened among adolescents, because group formats are typically used in adolescent HIV prevention studies.^{6,7} Group interventions involve complex

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recruitment, randomization, and retention difficulties, especially across multiple sessions. Given the importance of understanding attendance in HIV risk-reduction interventions, this study identifies the environmental, personal, and situational factors that influence intervention attendance among young people living with HIV (YPLH).

Time conflicts are routine environmental barriers to an intervention's implementation. Program participants must balance between 2 potential benefits: attending an intervention to acquire new skills or fulfilling responsible social roles. Given this conflict, it may be hypothesized that youth who are in school or employed may be less available to attend interventions, as the diminished free time associated with work means that the costs of attending the intervention are higher.

Similarly, young people's personal characteristics may influence attendance. Two competing hypotheses are possible: 1) those who have strengths build on these strengths, suggesting that the youth with the fewest problems and greatest resources may be those most likely to attend the intervention; 2) those in the greatest need attend the intervention, in which case youth with the most problems would attend the most sessions and those with the least constructive styles of coping may be more likely to attend the intervention. Based on the first hypothesis, young people with higher self-esteem, fewer conduct problems, and less depression would be most likely to attend the intervention. Several prosocial strategies exist for coping with HIV/AIDS illness, including seeking social support, spiritual hopefulness, or taking positive actions. Self-destructive styles of coping with stress include feelings of depression or avoidance of conflict and problems (often by using drugs or alcohol). If intervention attenders build on existing strengths, those using more prosocial coping styles would also be more likely to attend the intervention. Attenders would be more likely to be those who seek social support, take positive actions, and have spiritual hopefulness.

Three situational predictors were examined: cohort, social network, and disclosure. "Cohort" reflects factors such as the group leader, size of the small groups, or gender balance, which were examined as predictors of adherence. We could not isolate each of the factors because the leadership and group membership varied over time. We could examine, however, a marker of these differences, the cohort to which each youth was assigned. Although leadership or attendance varied over time, youth remained in specific cohorts, reflecting a unique combination of situational factors.

The characteristics of a youth's social network may also impact intervention attendance. Young people with larger social resources would have less need for attending a supportive intervention. In addition, because HIV-related stigma is high,⁸ we hypothesized that youth may not attend a group intervention. When youth enter a group setting, their serostatus is disclosed. If youth were reluctant to disclose their serostatus, particularly if the site for the intervention delivery is one in which they received other social services (eg, drop-in groups, substance abuse treatment), they would be less likely to attend the intervention.⁹ Thus, environmental, personal, and situational determinants were examined as predictors of adherence.

In this study, we examined predictors of 2 types of "attendance" outcomes: 1) never versus ever attendance, and 2) among "ever-attended", the number of attended sessions. Results of the first outcome will provide information for improving the recruitment of seropositive youth in HIV intervention programs. By understanding the factors that influence "dosage effect," we may be able to enhance the development and participant retention of future HIV interventions.

METHODS

Participants

From 1994 to 1996, the study was conducted in 9 adolescent clinical care sites in 4 AIDS epicenters (Los Angeles, Miami, New York, and San Francisco). Three hundred-ninety- 3 HIV-infected youths aged between 13 to 24 years who received care at these sites were approached, and 351 enrolled in the study after giving informed consent; 25 refused participation, and 17 were too ill to participate. The informed consent was obtained from all participants, and parental consent was obtained for youths under 18 years. Prior to consent, recruitment materials emphasized the opportunity to meet other YPLH in a structure support group environment. The informed consent also included information about the duration of weekly intervention sessions, food, and small cash incentives. (More details are described in Rotheram-Borus and Miller.¹⁰)

Two baseline assessments were conducted at a 3-month interval to establish the stability of risk behaviors, with an incentive of \$20 to \$25 per assessment. Successful HIV interventions with youths have generally been delivered in a small-group format^{11,12}; following this design, we delivered our intervention in small groups (cohorts). Cohorts of about 15 HIV-infected youths each were assigned sequentially to the intervention and control conditions. It took several months to assemble a sufficient number of youths to form a cohort; in 7 of 9 sites, the last cohort was assigned to the intervention condition. Therefore, across the 9 sites, there were 16 cohorts in the intervention condition (n=208) and 9 cohorts in the control condition (n = 102).

A detailed manual (available online at <http://chipts.ucla.edu>) guided the 2 intervention modules, which comprised 23 sessions of 2 hours each. Quality assurance ratings were conducted from randomly selected videotapes of sessions; ratings for more than 80% of the sessions exceeded criteria for content and process measures of fidelity. On assessments conducted at sessions 5 and 11 of each module, youths in the intervention reported liking their sessions (mean = 4.2 on a scale of 1–5); they also rated their facilitators as highly trustworthy (mean = 4.2 on a scale of 1–5).

As shown in Figure 1, 5 youths were too sick to participate and 36 were lost to follow-up before the intervention assignment in a multiple baseline design, resulting in 310 youths who participated in the study. There were no significant differences in demographic characteristics between participants and those who were lost to the study prior to randomization. Cohorts of approximately 15 youths each were sequentially assigned into either the immediate intervention (n=208) or the lagged intervention (n=102) condition. The current analysis included 203 YPLH of the immediate intervention group; 5 youths were excluded that might have been restrained from attending the intervention sessions (Figure 1) due to illness, death, or institutionalization during intervention Modules 1 and 2 (23 sessions).

Procedure

Young people in the immediate intervention condition participated in the intervention following the baseline interview, while participants in the control condition received the intervention 24 months later. Interventions were delivered in a small group format. Youth in the intervention condition received the 2 modules of the intervention, and each module was delivered over a 3-month period. The complete description of the study design is presented by Rotheram-Borus and colleagues.^{7,13} Two facilitators led the intervention sessions in each module. In many cases, different groups of facilitators conducted the first and second modules.

Intervention

Module 1 (“Stay Healthy”) consisted of 12 intervention sessions targeted at health care utilization and health behaviors and Module 2 (“Act Safe”) consisted of 11 sessions aimed at reducing transmission acts. The content of each session is described in Rotheram-Borus and Miller;¹⁰ the intervention manual is available at <http://chipts.ucla.edu>. Each session was opened once a week, with average sessions lasting 2 hours. Each module was conducted during a 3-month window with a 3-month gap between modules. Facilitators were selected based on the demonstrated ability to deliver the intervention with fidelity and their ability to build rapport and manage group dynamics with YPLH. They completed at least 3 days of training prior to implementing each module. Training included practice in conducting the intervention session and review of the study goal, the intervention manual, and videotapes of model sessions. Facilitators received ongoing supervision, and randomly selected sessions were videotaped to assure quality of the session. Participants received \$10 for the first intervention session they attended, and the incentive increased by \$2 for each additional session attended.

Assessments

Personal factors—*Sociodemographic characteristics.* Background characteristics, including age, gender, ethnicity, and living situation were collected from participants.

Health status. Three aspects of health were rated: 1) HIV symptoms classed participants as asymptomatic, symptomatic, or having AIDS; 2) physical health symptoms were assessed by a summary count of 23 physical symptoms ($\alpha = 0.88$, $r = 0.70$ with chart review of 31 HIV-infected youths¹⁴; and 3) a physical health distress score was calculated by a mean of the intensity (ranged 0–5) of each symptom ($\alpha = 0.90$).

Brief Symptom Inventory (BSI). Emotional distress (ie, depression and anxiety) was measured using the 53-item BSI.¹⁵ Degree of distress during the previous week was reported for each symptom on a scale ranging from 0 (not at all) to 4 (extremely), with higher scores indicating severe depression or distress.

Conduct problems. Were measured by a sum of the presence (1) or absence (0) ($\alpha = 0.77$) of a sum of 18 conduct problems (eg, stealing, fighting, and vandalism).

Sexual risk acts. Two indices of risk were documented as present (1) or not (0): a) lifetime experience of bartering sex (for money or drugs), and b) 3 or more sexual partners over the past 3 months.

Substance use. Four substance use indices were recorded as present (1) or absent (0): a) use of alcohol, b) use of marijuana, c) use of hard drugs, and d) a sum of the number of different drugs used over the past 3 months.

Rosenberg's Self-Esteem Scale. Is composed of 10 items assessing positive self-affirmation on a scale of 1 (strongly disagree) to 4 (strongly agree), with higher scores indicating better self-esteem ($\alpha = 0.85$).¹⁶

Coping style. Was assessed with a modified version of the dealing-with-illness inventory,¹⁷ which consists of 37 items ranging from 1 (never) to 5 (always). Seven factors are derived: positive action (10 items; $\alpha = 0.88$), depression/withdrawal (4 items; $\alpha = 0.66$), self-destructive escape (5 items; $\alpha = 0.81$), social support (5 items; $\alpha = 0.77$), spiritual hope (4 items; $\alpha = .74$), nondisclosure/problem avoidance (4 items; $\alpha = .66$), and passive problem solving (5 items; $\alpha = .75$).

Situational—Cohort refers to the initial subgroup (1 to 24 cohorts) each youth was assigned; cohorts were mixed gender and became infected through different pathways.

Social Networks were measured by the self-reported number of important people classified in 3 domains: (a) family member (eg, parent, brother/sister, grandparent), (b) friends, including boyfriend, girlfriend, or lover, and (c) professional (eg, teacher or therapist).

HIV Status Disclosure was assessed as the percentage of people in the youth's social network to whom they disclosed their HIV serostatus.

Environmental—Full-time job status was defined as present (1) or absent (0). Criteria for full-time work was either (a) working more than 30 hours or (b) working more than 10 hours and attending school.

Data Analysis

A 2-part model^{18,19} was chosen to investigate the characteristics related to intervention attendance. It first examined predictors of ever attending the intervention using a logistic model, which we have labeled the “ever-attended” model. The second step, labeled the “dose effect” model, applied a mixed effects model to analyze variables related to the number of sessions attended among participants who actually attended the intervention. In these models, univariate analyses were first conducted to uncover possible related variables. The multivariate 2-part model considered variables with p value <0.10 in the univariate analyses, and the final model included only significant variables.

As the intervention was conducted in cohorts, cohorts were considered random in the dose effect model. The group effect was not included in the ever-attended model because participants did not have information about their group before the intervention started.

RESULTS

Among 208 YPLH in the intervention group, 30% were African American, 33% were Hispanic, and 38% were White or of another ethnic group. Their mean age was 21 years ($SD = 2.05$), and 71% were male. Among males, 84% identified themselves as homosexual or bisexual. More than half (58%) were asymptomatic for HIV infection, 33% were symptomatic, and 9% were diagnosed with AIDS. One fourth of YPLH were clinically diagnosed with depression based on the BSI for the past 3 months, and 38% had attempted suicide in their lifetime. About one-fourth (27%) bartered sex during their lifetime, and 25% reported 3 or more recent sexual partners (ie, past 3 months). About half (49%) used marijuana recently and 35% reported hard drug use.

Ever-Attended

One-fourth of YPLH (26%) attended neither the Module 1 nor the Module 2 intervention (Figure 2). Only 46% attended both modules of the intervention. Module 1 attendance was related with attendance of Module 2. Most YPLH who did not attend the Module 1 intervention (82%) also did not attend Module 2 (Table 1). Among Module 1 intervention attenders, 67% attended Module 2. Those who attended 50% or less of Module 1 (≤ 6 sessions) were less likely to ever attend Module 2 (41%), and those who attended more than 50% of Module 1 (> 7 sessions) attended Module 2 in most cases (85%).

Table 2 presents the univariate analysis evaluating intervention attendance with each of the variables considered. Youths who did not have a full-time job have a significantly higher probability of attending any intervention sessions ($OR = 2.24$; $P = 0.020$). Using the social support style of coping was also a significant positive factor for attending the intervention ever

(OR = 1.58; $P=0.006$). Coping style with depression withdrawal (OR = 1.93; $P=0.090$) and passive problem solving (OR = 1.30; $P=0.087$) tended to be positively related, while alcohol use for the past 3 months tended to be negatively associated (OR = 0.55; $P=0.098$). The disclosure rate, social network, and BSI were not significantly related to intervention attendance.

In the multivariate analysis, we simultaneously considered variables with $P<0.10$ in the univariate model. In the final model, with only significant variables (Table 3), youths who did not have a full-time job had a 2.12 times higher probability of attending any intervention sessions (95% CI = 1.05–4.30; $P=0.037$). Using social coping style was significantly related to the decision to attend the intervention sessions; one scale increase on the social support coping scale was associated with a 1.56 times more chance to attend any intervention (95% CI = 1.13–2.17; $P=0.008$).

Dose Effect

The Module 1 and 2 intervention sessions consisted of 12 and 11 sessions, respectively. The percentage of attenders was not very different over each session, even though the percentages were slightly higher in some of the Module 1 sessions (Figure 3). There were 138 YPLH who attended the Module 1 intervention, and their mean number of Module 1 sessions attended was 7.5 (SD = 3.59). Among 105 Module 2 attenders, the mean number of Module 2 sessions attended was also 7.5 (SD = 3.10). Among 150 YPLH who attended any intervention session, the mean number of sessions attended was 12.2 (SD = 7.09). The distribution of the number of attended sessions among attenders is shown in Figure 4.

The number of attenders in each cohort ranged from 2 to 16, and their mean number of attended intervention sessions were significantly different across cohorts ($F = 3.18$, $P<0.0001$), ranging from 5.0 to 17.5. Therefore, the following analyses incorporated the cohort effect in the model.

Table 2 represents the univariate analysis result of evaluating the dose effect for each variable. Gay or bisexual males attended fewer sessions ($b = -2.97$; $P=0.017$). Reporting a self-destructive and escapist coping style was inversely related to the number of attended intervention sessions ($b = -3.22$; $P=0.011$), while a spiritual hope coping style was positively related ($b = 1.27$; $P=0.010$). Youths with 3 or more sexual partners for the past 3 months attended significantly fewer intervention sessions ($b = -3.07$; $P=0.016$). Youths reporting alcohol use for the past 3 months tended to attend fewer sessions ($b = -1.85$; $P=0.099$). The number of family members that participants thought were important in their life tended to be positively related to the attended number of sessions ($b = 0.41$; $P=0.081$).

The multivariate analysis simultaneously considered variables with $P<0.10$ in the univariate model. In the final model (Table 3), having a self-destructive and escapist coping style was inversely related to the number of sessions attended ($b = -2.62$, $P=0.040$). Coping by seeking spiritual hope was positively related to the number of attended sessions ($b = 1.02$, $P=0.041$). High-risk sexual behaviors tended to be negatively related to the number of sessions attended: youths who reported at least 3 sexual partners for the past 3 months attended fewer sessions ($b = -2.28$, $P=0.079$). The intraclass correlation coefficient (ICC) was estimated as 0.128, indicating the cohort effects.

Discussion

Researchers typically design and discuss their interventions in terms of the impact on changing a targeted behavior. In the case of YPLH, the targeted behaviors were increases in health behaviors and decreases in sexual and substance use transmission behaviors.¹³ Yet, there are at least 2 separate outcomes implicit in each intervention: adherence to the intervention and

maintenance of behavior change over time.³ This article examines the predictors of ever attending any intervention session, as well as predictors of the specific number of sessions attended.

About one fourth of YPLH never attended any session of the intervention. Non-attendance is much higher than was previously obtained in other intervention trials mounted by the same research group.²⁰⁻²³ At least 2 major factors are associated with never attending any session. Unemployed youth were twice as likely to attend the intervention compared to those who were employed full-time. Simultaneously, youth who were more likely to seek social support as a style of coping were significantly more likely to attend the intervention of small group meetings. These associations suggest that there are both pragmatic barriers (ie, employment) and interpersonal factors that influence intervention adherence to small group interventions.

Having a self-destructive and escapist coping style at recruitment decreased the number of sessions attended. In contrast, those who coped by seeking spiritual hope were more likely to attend more intervention sessions. Youth with high risk sexual behaviors were also less likely to attend more intervention sessions. It appears that those with a greater number of pre-existing strengths were more likely to attend the intervention. Those at greater risk (presumably in greater need of the intervention) were less likely to attend. These data suggest a need to design interventions to be highly attractive and acceptable to those engaging in the highest risk behaviors.

The findings in this study supported our first hypothesis, meaning that those who have strengths built upon those strengths. The result found that YPLH who were more likely to seek social support as a style of coping were more likely to attend the intervention and those who coped by seeking spiritual hope were more likely to attend more intervention sessions. It was also found that those with a more self-destructive coping style and avoidance of conflict and problems (by having more risky sexual behaviors) were less likely to attend more intervention sessions. These findings suggest that the youth with fewer problems and greater resources were adherers.

The intervention was delivered in a small group setting. When youth attended any session, their presence immediately disclosed their serostatus to each person in the group. As HIV-related stigma is known to be high,⁸ we hypothesized that disclosure of serostatus might be related to attendance of youth, but the analysis indicated that disclosure of serostatus was not related to attendance. Our measure of disclosure, however, was based on disclosure within the social network. In addition, the size and composition of the social network was also unrelated to adherence, implying that disclosing behavior of youth might be different for people in their social network compared with unknown people.

Even in large AIDS epicenters, it is difficult to identify sufficient numbers of YPLH to form groups. Often youth are forced to wait several weeks or months to form a group, and this long waiting period might cause lower intervention attendance. Furthermore, small groups are not a viable strategy for delivering preventive interventions to youth in rural settings, where even fewer youth are identified as seropositive. In a recent study conducted by the same group, youth chose individual in-person intervention sessions, resulting in 87% intervention attendance.²⁴ This indicates that time from recruitment to intervention is an important factor related to intervention attendance.

The small number of young people available to form groups also meant that we could not form groups based on same gender or similar socioeconomic status. In particular, the issues of young gay and bisexual men are quite different from the issues facing young women living with HIV.^{25,26} For example, almost all young women consider whether and when they may want to have children; young gay men rarely consider this a salient issue. Yet, when there are small

numbers of YPLH, it is necessary to form groups of young people with very different backgrounds and life goals. Differences in socioeconomic background, in particular, are frequently verbalized as a barrier to sharing life contexts.²⁷

A fairly large proportion of YPLH in this study reported a history of suicide attempt. It would be possible for these youths to have a co-morbid personality state such as borderline personality disorder. However, this study did not include these measures, and an examination of the effect of these measures should be considered in future studies.

Findings indicate that researchers should consider several factors when they design the intervention to improve attendance. If the study involves youths who are in school or employed, researchers should consider that their cost of time to attend the intervention is higher than others without full-time work. Scheduling the intervention during the weekend or another convenient time and providing more incentives might help to increase attendance. Other factors significantly related to adherence were coping styles. This indicates that researchers should consider participants' coping style and make an effort to enhance the adherence of YPLH with certain types of coping styles. It was also found that people with high-risk sexual behaviors were less likely to remain in the intervention. Strategies should be developed to keep these people in the intervention. Finally, considering other factors such as time to intervention or grouping participants with similar backgrounds would likely improve adherence.

These results highlight the importance of researchers addressing intervention adherence as a specific targeted outcome of each intervention designed. An intervention's actual efficacy is based on a combination of the adherence to the intervention, as well as the intervention's impact. When presenting results from a randomized controlled trial, we often do not make distinctions between these 2 influences.³ Research literature must be developed to identify methods of engineering socially desirable, acceptable, feasible, and replicable interventions for both providers and consumers.²⁸ Analyses such as this article will hopefully begin to build such a literature. Findings indicate the importance of pragmatic barriers to intervention attendance and the importance of interpersonal factors such as coping style to intervention attendance as well as intervention dose. Because intervention attendance is directly related to the effect of the intervention, studies should carefully examine the factors related to intervention attendance and apply those factors to boost attendance.

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Figure 1.
Study Design and Intervention Attendance

Figure 2.
Proportion of Participants Attended Module 1 and/or Module 2

Figure 3.
The Percentage of Attenders at Each Intervention Session

Figure 4.
The Number of Intervention Sessions Attended

Table 1

The Number of Participants in Each Attendance Category, Module 1 by Module 2

		Absent	Module 2 1 - 5 sessions	6 - 11 sessions	Total
Module 1	Absent	53	6	6	65
	1 - 6 sessions	33	9	14	56
	7 - 12 sessions	12	14	56	82
	Total	98	32	73	203

Table 2
Univariate Analysis Evaluating Intervention Attendance

Univariate Analysis	Odds Ratio	Ever Attenders Model		Dose-Effects Model	
		Lower	Upper	Estimate	Standard Error
Age	0.96	0.82	1.12	-0.09	0.29
Female	1.40	0.69	2.87	1.68	1.31
African American	1.71	0.83	3.54	0.59	1.20
No Full-time Job	2.24*	1.13	4.41	0.60	1.39
Gay/Bi-sexual	1.32	0.70	2.52	-2.97*	1.23
AIDS (ref.: Asymptomatic)					
Symptomatic	1.40	0.69	2.88	0.83	1.92
AIDS	1.91	0.52	7.08	-1.19	1.22
# of Physical Health Symptoms	1.04	0.98	1.10	0.07	0.09
Physical Health Distress	1.08	0.78	1.51	-0.57	0.60
Suicide Attempts	0.86	0.45	1.64	-1.75	1.12
BSI	1.19	0.75	1.89	-0.17	0.73
Delinquency	1.11	0.92	1.34	-0.35	0.23
Rosenberg Self-esteem	0.65	0.34	1.24	1.01	1.07
Coping					
Positive Action	1.20	0.89	1.64	-0.27	0.54
Depression Withdrawal	1.93 ⁺	0.90	4.13	-0.15	1.23
Self-destructive Escape	1.34	0.61	2.94	-3.22*	1.24
Social Support	1.58**	1.14	2.19	0.48	0.51
Spritual Hope	1.19	0.90	1.58	1.27**	0.48
Non-Disclosure	1.14	0.85	1.54	-0.22	0.50
Passive Problem Solving	1.30 ⁺	0.96	1.75	0.63	0.49
Social Network					
Family	1.01	0.88	1.16	0.42 ⁺	0.24
Friend	0.90	0.76	1.07	-0.32	0.33
Professional	0.96	0.63	1.48	0.45	1.03
% Disclosure	1.49	0.60	3.71	-0.88	1.59
3+ sexual partners (past 3 months)	1.65	0.76	3.58	-3.07*	1.26
Bartering sex (Lifetime)	1.45	0.68	3.08	-1.83	1.28
Alcohol Use (past 3 months)	0.55 ⁺	0.27	1.12	-1.85 ⁺	1.11
Marijuana Use (past 3 months)	0.72	0.39	1.36	-1.51	1.09
Hard Drug Use (past 3 months)	0.84	0.44	1.62	-0.76	1.21
Number of drug use (past 3 months)	0.90	0.73	1.12	-0.29	0.39

**
P <0.01

*
P <0.05

⁺
P <0.1

Table 3
Multivariate Analysis Evaluating Intervention Attendance

Ever Attenders Model	Odds Ratio	95% CI	
		Lower	Upper
No Full-time Job	2.12 [*]	1.05	4.30
Coping: Social Support	1.56 ^{**}	1.13	2.17
Dose Effect Model	Estimate	Standard Error	
3+ sexual partners (past 3 months)	-2.28 ⁺	1.29	
Coping: Self-destructive Escape	-2.62 [*]	1.26	
Coping: Spiritual Hope	1.02 [*]	0.49	

^{**} P <0.01

^{*} P <0.05

⁺ P <0.1