*Original Article*

# QUALITY OF LIFE AND COPING STRATEGIES AMONG ACID SURVIVORS

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## ABSTRACT

***Background:*** Acid Violence is one of the worst form of violation of basic human rights and a major public health issue. Though the prevalence has dropped dramatically after the enactment of two important laws against this crime in Bangladesh the victims in this country are still leading a disastrous life. The present study aimed to identify the score of Quality of life and to find out the coping strategies among acid victims.

***Methods:*** This cross sectional study was conducted from July to September, 2019 among purposively selected 101 acid victims in four districts of Bangladesh. Data was collected through face-to-face interview by using SF-36 Health Related Quality of Life scale and Brief Cope Inventory (Carver).

***Results:*** About 82% of the acid victims were female, 51.49% were illiterate, income of 69.3% respondents were below 5000 Taka, 80.2% got married before the age of 18 years. Apart from Physical functioning (63.66±32.124) and Social functioning (60.89±39.198), all the domain of the QOL score remains below 30, the score of General health is 27.97±30.791. Active coping was followed a lot (43%) among all the other coping strategies. There was positive correlation with active coping and social functioning(r=0.359, p=0.000) and physical functioning (r=0.288, p=.003).

***Conclusion*:** Even after many years of the violence, the acid victims have not regained a good quality of life. Community support and frequent motivational campaigns can help the acid victims to cope up with their situation more positively and thus improve their quality of life.

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## INTRODUCTION

Acid attack is one of the most heinous form of violence which violates the basic human rights. Acid burns can erode the skin and other tissues down to the bone and requires expensive medical care and treatment most of the time. There is less chance for a person to die after being attacked by acid, but the consequences are life-long. The scars left by the acid are not just skin deep; the victims suffer rest of their life, become burden to the family, society and the nation.[1] The victims experience excruciating physical pain along with the unbearable mental stress compounded social rejection even by their own families. The victim of acid attack suffered physically, psychologically, socially and economically. The physical effects of such chemical burns are devastating, with blindness due to corneal perforation, nasal deformity, microstomia, and debilitating contractures amongst the complications documented. In addition, the long term social and psychological impact for sufferers is huge, with impaired ability to find employment, social isolation

and depression all common in the aftermath of an attack. They have been ignored and neglected by some portion of the people.[2]

Most survivors of an attack are forced to give up their education, their occupation and other important activities in their lives. This is because recovering from the trauma takes up most of their time and because the disfigurement they have to bear debilitates and handicaps them in every conceivable way. The survivors could never return back to their previous life before the attack where they lived with the supports from family and community. Thus, their human rights were not ensured properly.[3] Approximately 1500 acid attacks are recorded worth wide annually. More than 400 such attacks were recorded in the six months to April (2017), an average of two a day. Bangladesh, India, Pakistan, Nepal, Cambodia and Uganda are countries with the highest reported incidence. Statistics from the Acid Survivors Foundation (ASF) indicate that during 1999-2018, 3782 people were attacked with acid in 3404 separate incidents in Bangladesh. However, in 2002, Bangladesh enacted two laws- one that heightens criminal penalties and improves criminal procedures and another that attempts to decrease the availability of acid. In 2002 the Bangladesh Government passed two Acts, the Acid Control Act 2002 and the Acid Crime Prevention Acts 2002 (1st and 2nd Act), restricting import and sale of acid in open markets.[1]

The root causes of acid violence differ from society to society. The cause of acid violence in Bangladesh is interlinked with various social problems of the country. The root causes were patriarchal society which developed based on power. The most important causes were dowry, family dispute, property dispute, material dispute, refusal of love etc.[4] More than one person could be attacked by a single incident; as such, more people's life and livelihood could be spoiled due to one incident of acid violence.[5] A large number of acid victims are cared by organizations, such as the ASF, the first contact often being referral from one of the few burn centers in Bangladesh. The ASF undertakes long-term rehabilitation of the patient, in addition to both funding and organizing further reconstructive surgery.[6] The consequences of an acid attack haunts a victim for a lifetime. They struggle at every stages of their life after being a survivor. From home to outside, they are ignored and neglected by some portion of the people. Thus rights were not ensured for the acid survivors. They could never return to the previous life where they lived with all the support from family and community. The acid attack didn't only disfigure their bodies, but ruined the full and secure life over a multitude of dimensions.[5]

In fact, acid burns don't cost more life but disfiguration, disability and post-burn complications like hypertrophic scars, keloid formation, acute and duodenal ulcer, Marjolins ulcer, protein losing enteropathy, chronic renal failure, immune deficiency are usual. The patients suffer from physical and psychological disability for whole life.[7] Social burden from acid burns affects both the victim as well as their family. It hampers the acid survivor's employment and carrier. Quality of life is deteriorated. The acid attack survivors suffer from various mental agony, physical pain, psycho-social stresses. Family harmony is disrupted. Social stability is decreased by divorce, or breaking intrafamilial relationship. Lifestyle is also altered by social isolation and ultimately the patients dissolute or becomes orphan or window.[4] An acid victim receives extensive counselling, training in new skills and education and particular focus is upon development of social interaction through group sessions and workshops. Even after such positive measures, the acid survivors face societal isolation and ostracism.[1] The consequences of acid violence is numerous and thus this study was done with the view to know about their quality of life after years of living with this situation and their coping strategies to find out the way they deal with it.

## METHODS

This cross sectional study was conducted from July 2019 to September 2019 at Dhaka, Sylhet, Cumilla and Bogura. Purposively selected acid victims were above 18 years of age and registered under Acid Survivors Foundation Bangladesh. Prior to data collection, informed written consent was obtained from the respondents. Ethical approval for the study was granted by the ethical committee of NIPSOM and neither any intervention nor invasive procedure was given. The study instrument comprised a structured questionnaire which includes demographic information, including age, sex, religion, education, marital status, age at marriage, monthly income, perpetrator of the attack and motive of the attack.

Respondent's quality of life was assessed through the SF-36 Health related quality of life scoring. The 36-Item Short Form Health Survey questionnaire (SF-36) in Bangla is a validated and popular instrument for evaluating Health related Quality of Life. It measures eight health concepts: physical functioning, bodily pain, role limitations due to physical health problems, role limitations due to personal or

emotional problems, emotional well-being, social functioning, energy/fatigue, and general health perceptions. It also includes a single item that provides an indication of perceived change in health. Scoring the 36-Item Health Survey is a two-step process. First, pre-coded numeric values are recoded per the scoring key given. Note that all items are scored so that a high score defines a more favorable health state. In addition, each item is scored on a 0 to 100 range so that the lowest and highest possible scores are 0 and 100, respectively. Scores represent the percentage of total possible score achieved. In step 2, items in the same scale are averaged together to create the 8 scale scores. Items that are left blank are not taken into account when calculating the scale scores. Hence, scale scores represent the average for all items in the scale that the respondent answered.

Respondent's coping strategies were measured by The Brief COPE Inventory which consists of only 28 statements, across two scales, and is more focused on understanding the frequency with which people use different coping strategies in response to various stressors. Participants using the inventory, score themselves from 1 to 4 with 1 being '*I haven't been doing this at all*' and 4 being '*I've been doing this a lot.*' Scales are computed as follows (with no reversals of coding): Self-distraction, items 1 and 19 Active coping, items 2 and 7 Denial, items 3 and 8 Substance use, items 4 and 11 Use of emotional support, items 5 and 15 Use of instrumental support, items 10 and 23 Behavioral disengagements, items 6 and 16 Venting, items 9 and 21 Positive reframing, items 12 and 17 Planning, items 14 and 25 Humor, items 18 and 28 Acceptance, items 20 and 24 Religion, items 22 and 27 Self-blame, items 13 and 26. After collection, data were thoroughly checked for consistency and completeness. Then cleaned, edited, processed in the form of categorizing, coding and analysis was done. Frequency of the socio-demographic characteristics were seen. Then Correlation, t-test and ANOVA was done for qualitative analysis by using Statistical Package for Social Sciences (SPSS) version 23.

## RESULTS

Among the respondents, 30.7% of the respondents were within the age group 35-44 years. The average age was 42.56years with SD ± 13.026years and the range was 18 to 55 years, 82% were female and 96% were Muslims. 51.49% of the acid survivors were illiterate and 61.4% of the respondents were married. Almost 80.2% of the respondents got married before they were 18 years old. Mean age at marriage was 15.25 years with SD ± 3.454 years. 69.3% of the respondents' monthly income was below or equal to Taka 5000 and mean income of the respondents was Taka 6242.57 with SD ± 10682.840 Taka. 36.6% of the respondents were attacked by neighbors, 35.6% were attacked by their in-laws, 22.8% were husband and 20.8% were own family members. 46.5% of the acid survivors were attacked by acid due to family and property related dispute. About 20% of the attacks were for dowry, 14.9% of the respondents were attacked for refusing marriage proposal. 11.9% and 5.9% of the respondents were attacked with the motive of money and power related conflict and drug abuse [Table-1].

**Table-1: Socio-demographic characteristics of the acid victims**

| Characteristics | Frequency | Percentage (%) |
|---|---|---|
| **Age of the respondents (in years)** | | |
| <25 | 12 | 11.9 |
| 25-34 | 11 | 10.9 |
| 35-44 | 31 | 30.7 |
| 45-54 | 25 | 24.8 |
| >=55 | 22 | 21.8 |
| **Sex** | | |
| Female | 83 | 82 |
| Male | 18 | 18 |
| **Religion** | | |
| Muslim | 97 | 96 |
| Hindu | 4 | 4 |
| **Education** | | |
| Illiterate | 52 | 51.49 |
| Primary | 35 | 34.65 |
| Secondary | 8 | 7.92 |
| Higher Secondary | 1 | 0.99 |

| | | |
|---|---|---|
| Graduation | 2 | 1.98 |
| Post-Graduation | 3 | 2.97 |
| **Marital Status** | | |
| Unmarried | 8 | 7.9 |
| Married | 62 | 61.4 |
| Divorced | 10 | 9.9 |
| Separated | 9 | 8.9 |
| Widow/Widower | 12 | 11.9 |
| **Age at marriage (in years)** | | |
| <18 years | 81 | 80.2 |
| 18 years and above | 12 | 11.9 |
| Unmarried | 8 | 7.9 |
| **Monthly income (in Taka)** | | |
| <5000 | 70 | 69.3 |
| 5001-10000 | 14 | 13.9 |
| 10001-15000 | 8 | 7.9 |
| Above 15000 | 9 | 8.9 |
| Mean (SD) (in Taka)- 6242.57±10682.840 | | |
| **Perpetrator of the attack** | | |
| Family member | 21 | 20.8 |
| Husband | 23 | 22.8 |
| In-laws | 36 | 35.6 |
| Neighbors | 37 | 36.6 |
| **Motive of the attack** | | |
| Dowry | 21 | 20.8 |
| Drug abuse | 6 | 5.9 |
| Family and property related conflict | 47 | 46.5 |
| Marriage proposal refusal | 15 | 14.9 |
| Money and power related conflict | 12 | 11.9 |

Out of all the domains of Quality of life, the score of Physical functioning is highest 63.66±32.124. Score of social functioning is 60.89±39.198. The score of Energy/Fatigue, Emotional wellbeing and Pain is 34.38±31.445, 33.07±30.935 and 30.69±32.332 respectively [Table-2].

**Table-2: Distribution of the respondents according to their Quality of life**

| Domains of Quality of Life | Mean | SD |
|---|---|---|
| General Health | 27.97 | 30.791 |
| Physical functioning | 63.66 | 32.124 |
| Role Limitations due to Physical Health | 25.00 | 42.788 |
| Role Limitations due to Emotional Problems | 28.67 | 44.952 |
| Social Functioning | 60.89 | 39.198 |
| Pain | 30.69 | 32.332 |
| Energy/Fatigue | 34.28 | 31.445 |
| Emotional Wellbeing | 33.07 | 30.935 |

Most of the respondents 42.6% use Active Coping as their coping strategies by doing it a lot. None of the respondents use Denial or Substance use a lot as a coping strategy, but a little bit 75% and 75% respectively. 100% of the respondents do not imply Behavioral disengagement and Acceptance as their coping strategies [Table-3].

**Table-3: Distribution of respondents according to coping strategies**

| Coping Strategies | not at all | a little bit | medium amount | a lot |
|---|---|---|---|---|
| | f(%) | f(%) | f(%) | f(%) |
| Self-distraction | 8(7.9) | 25(24.8) | 38(37.6) | 30(29.7) |
| Active coping | 14(13.9) | 11(10.9) | 33(32.7) | 43(42.6) |
| Denial | 24(23.8) | 75(74.3) | 2(2.0) | 0 |
| Substance use | 24(23.8) | 75(74.3) | 2(2.0) | 0 |
| Use of emotional support | 8(7.9) | 43(42.6) | 19(18.8) | 31(30.7) |
| Use of instrumental support | 21(20.8) | 40(39.6) | 21(20.8) | 19(18.8) |
| Behavioral disengagement | 101(100) | | | |
| Venting | 51(50.5) | 41(40.6) | 5(5.0) | 4(4.0) |
| Positive reframing | 49(48.5) | 44(43.6) | 1(1.0) | 7(6.9) |
| Planning | 16(15.8) | 58(57.4) | 15(14.9) | 12(11.9) |
| Humor | 74(73.3) | 22(21.8) | 2(2.0) | 3(3.0) |
| Acceptance | 101(100) | | | |
| Religious coping | 3(3.0) | 40(39.6) | 24(23.8) | 34(33.7) |
| Self-blame | 5(5.0) | 56(55.4) | 18(17.8) | 22(21.8) |

**correlation is significant at the 0.01 level (2 tailed)

The Table-4 shows that the correlation between the total score of active coping and the mean score of Physical functioning and Social functioning. The correlation between physical functioning and active coping is statistically significant ($p<.05$). It also shows that the correlation between social functioning and active coping is statistically significant ($p<.05$).

**Table-4: Correlation between Active Coping and Mean Score of Physical Functioning and Social Functioning**

| Active Coping | Physical functioning | | | Social functioning | | |
|---|---|---|---|---|---|---|
| | r | p | N | r | p | N |
| | .359** | .000 | 101 | .288 | .003 | 101 |

## DISCUSSION

In comparison with the mortality rate, the morbidity rate is way higher in case of acid violence.[8] A cross sectional study was carried out to find out the quality of life and coping strategies among the acid victims. According to the study, 30.7% of the respondents were within the age group 35-44 years. In a study,[9] it was shown that the mean age was 20.03±8.8 years, but acid violence has dropped in a significant number after the enactment of Acid Control Act 2002 and Acid Crime Control Act 2002 according to ASF final report 2016. Most of the respondents were female (83%). This finding of the study was consistent with another study[9] where the majority (90%) were female.

In this study 96% of the respondents were Muslim and it was consistent with a study.[9] Bangladesh is an Islamic country and hence this finding. It is observed in the study that most (69.3%) of the survivors' monthly income is below 5000taka. This finding is consistent with the study,[9] where 62.2% of the survivors' income is below 5000 taka. In this study, 80.2% of the respondents got married before the age of 18years, 11.9% were married at the age above 18 years and 7.9% of the respondents were unmarried.

It is evident in the study that 46.5% of the motive of attack was due to family conflict and property related conflict, 20.8% were due to dowry, 14.9% were due to marriage proposal refusal, 11.9% were due to money and power related conflict and 5.9% were due to drug abuse. In rural community acid violence is more (ASF) and family conflict and property conflict is more.

## CONCLUSION

Acid violence not only threatens the health of the victims but also it has a devastating long term effect on their economic and social life. Most survivors have to cope with a dramatic change in their life.

Their future plans and prospects, their long cherished dreams are destroyed. The attack changes their life plans forever. Due to lengthy recovery or permanent disability, the survivors have to interrupt their education or drop out for ever. Disabled, disfigured survivors often face social isolation, which is damaging their self-esteem and effecting their economic opportunities. In a society where the beauty of a woman is her capital, a woman disfigured by an acid attack is unlikely to have a good quality of life. This consequence is particularly harsh in Bangladesh, in a society where women still gain full social acceptance only with marriage and motherhood, and where grown-up children are usually the only economic source of security in old-age. The prevalence of acid violence has dropped tremendously after the enactment of two major laws against acid violence in 2002. Bangladesh is regarded as an example for combatting acid violence among the surrounding south-east Asian countries. However, the funding from international organizations have decreased which had a major impact on the lives of the acid victims, whose life depends on these funds. Due to the lack of rehabilitation facilities the lives of the acid victims remain miserable forever.

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