

Community-based Participatory Research: Development of an Emergency Department– based Youth Violence Intervention Using Concept Mapping

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ABSTRACT

Objectives: Emergency departments (EDs) see a high number of youths injured by violence. In Ontario, the most common cause of injury for youths visiting EDs is assault. Secondary prevention strategies using the teachable moment (i.e., events that can lead individuals to make positive changes in their lives) are ideal for use by clinicians. An opportunity exists to take advantage of the teachable moment in the ED in an effort to prevent future occurrences of injury in at-risk youths. However, little is known about perceptions of youths, parents, and community organizations about such interventions in EDs. The aims of this study were to engage youths, parents, and frontline community workers in conceptualizing a hospital-based violence prevention intervention and to identify outcomes relevant to the community.

Methods: Concept mapping is an innovative, mixed-method research approach. It combines structured qualitative processes such as brainstorming and group sorting, with various statistical analyses such as multidimensional scaling and hierarchical clustering, to develop a conceptual framework, and allows for an objective presentation of qualitative data. Concept mapping involves multiple structured steps: 1) brainstorming, 2) sorting, 3) rating, and 4) interpretation. For this study, the first three steps occurred online, and the fourth step occurred during a community meeting.

Results: Over 90 participants were involved, including youths, parents, and community youth workers. A two-dimensional point map was created and clusters formed to create a visual display of participant ideas on an ED-based youth violence prevention intervention. Issues related to youth violence prevention that were rated of highest importance and most realistic for hospital involvement included mentorship, the development of youth support groups in the hospital, training doctors and nurses to ask questions about the violent event, and treating youth with respect. Small-group discussions on the various clusters developed job descriptions, a list of essential services, and suggestions on ways to create a more youth-friendly environment in the hospital. A large-group discussion revealed outcomes that participants felt should be measured to determine the success of an intervention program.

Conclusions: This study has been the springboard for the development of an ED-based youth violence intervention that is supported by the community and affected youth. Using information generated by youth that is grounded in their experience through participatory research methods is feasible for the development of successful and meaningful youth violence prevention interventions.

Key words: violence, adolescent, community-based participatory research

Youth violence is an immense burden in North America. Despite declining overall homicide rates, youth homicide rates have increased over the past decade.¹ In Ontario, the most common cause of injury for youths visiting emergency departments (ED) is assault.² Multiple studies have determined that initial injury is an important risk factor for subsequent injuries (“trauma recidivism”).^{3,4} Repeat visit rates for subsequent violence-related injury are estimated to range from 22% to 44%.⁴⁻¹⁵ Given the high recidivism rate, youth seen in EDs for injuries due to violence present an opportunity for secondary interventions.

Youth violence prevention programs come in many forms. Secondary prevention strategies using the *teachable moment* (i.e., events that can lead individuals to make positive changes in their lives) are ideal for use by clinicians.¹⁶ These strategies can be applied to groups at risk of violence, given the fact that victims of violence are more likely to become repeat victims of violence and often become perpetrators of future violence.¹⁷ However, it is unclear how to effectively intervene in a way that takes advantage of this teachable moment. At present, little is known about perceptions of youths, parents, and community organizations about such interventions in the ED setting.

The primary objective of this study was to engage youths, parents, and frontline community workers in designing a hospital-based intervention that will assist in the prevention of violence recidivism in Toronto, Ontario, Canada. Our secondary objective was to determine outcomes of a hospital-based violence prevention intervention that are important to our stakeholders. Such a community-based participatory research approach facilitates access to the lived experience and perceptions of youth and other community members regarding factors that can prevent or contribute to youth violence. We anticipate that the community voice generated through this research will create highly relevant and actionable findings for the concerned community.¹⁸

METHODS

Study Design

We used concept mapping, an innovative mixed-methods research approach that creates a visual display of how a group views a topic, to achieve our objectives. Concept mapping is an emerging method in public health research with which to gather important community knowledge on health-related topics.¹⁹ The approach incorporates participatory, qualitative methods to collect data, such as brainstorming on group perceptions and group sorting to identify themes. It uses quantitative techniques such as multidimensional scaling and hierarchical clustering to analyze and create maps that illustrate patterns of relationships between themes.^{20,21} Concept mapping involves multiple structured steps: 1) brainstorming, 2) sorting, 3) rating, and 4) interpretation. For our study, the first three steps occurred with participants online, and the fourth step occurred during a community meeting. Ethics approval was obtained from the St. Michael's Hospital Research Ethics Board.

Study Setting and Population

A purposive sample was recruited in Toronto through posters at schools, community partner sites (youth violence prevention agencies), and online networking sites (Facebook and MySpace). Given the sensitivity of the subject, participation was anonymous. Participants could partake in any or all steps of the concept mapping process. Participants were provided with a choice of gift card to a coffee shop, grocery store, bookstore, or music store to compensate them for the time they spent participating in the study. When participants completed the online section, they were automatically directed to a separate, secure site that was not connected to the data collected. Gift cards were either mailed if they provided a name (or nickname) and address or provided for pick-up (by name or nickname) at one of three locations. While it was impossible to determine if someone participated more than once given our requirement for anonymity, only one gift card was provided per name and contact location. For the online brainstorming, we endeavored to reach over 40 participants to ensure a wide variety of opinions. For the online sorting and rating processes, we sought to recruit at least 40 participants, as the concept mapping literature demonstrates that there is minimal variance after 40 sorts.²² We aimed to recruit between 20 and 30 participants for the interpretation step based on the concept mapping literature, which suggests that meetings should include participation of greater than 10 persons but less than 40 to ensure a variety of opinions, while still enabling good group discussion and interpretation.²⁰ Anonymity at the meeting was maintained by allowing participants to use nicknames.

Study Protocol

Brainstorming. The brainstorming portion was available online for 8 weeks. Participants were asked to enter statements responding to the prompt “Hospitals try to help by treating the physical injuries of youth who are injured by violence but they could also help these youth avoid future violence by” Participants were able to view other participants’ statements as part of the computer program. This was meant to reproduce an in-person group brainstorming session. At the conclusion of the brainstorming step, two youths were invited to participate in consolidating statements. The youths were recruited by one of our partner agencies. Their only qualification was that they were under the age of 19 years. They were trained by the investigators in their role of ensuring language used in the final statements were youth appropriate, and no changes to the meaning of the statements were to occur. Statements were consolidated by removing overlap between statements, splitting statements that included two or more topics, and ensuring that the language was accessible to youth. Any changes to statements were done by the entire team. Decisions were made by consensus. The consolidated brainstormed statements were then uploaded onto the website for the sorting stage.

Sorting and Rating. During sorting, each online participant was asked to sort the brainstormed statements

into piles and to provide a name for each pile. Participants were then asked to rate each of the statements based on importance (1 = not at all important to 5 = extremely important) with the focus prompt “For each of the following items, please rate how important it is that hospitals deal with this issue” and realism (1 = not realistic to 2 = very realistic) with the focus prompt “For each of the following items, please rate how realistic it is that hospitals could help with this issue.” This online step was completed concurrently with the sorting step and remained available to participants online for 6 weeks.

Interpretation Session. Online participants were invited to attend the interpretation session as part of a community meeting. At the interpretation session, after a brief introduction to concept mapping as a research tool, participants were presented with the point map that was generated as part of the sorting process. Participants discussed why certain statements were located close to each other on the map. The various cluster solutions, or statements grouped together in the sorting process, were then presented to participants by a trained facilitator (MK). After the final cluster group was chosen by the participants, the group decided on the final cluster names based on the themes represented by the grouped statements within. Participants then reviewed the ratings and discussed why they felt most online participants had rated them in the various ways. All group decisions were made by consensus.

Participants then formed four smaller groups to discuss topics related to each cluster. Participants self-selected their groups based on their interests, and therefore the small groups ranged in size from three to eight participants. The groups then reported back to the larger group. The larger group reconvened and concluded the meeting by addressing the questions: “How do we know that our hospital-based youth

violence intervention worked? What should we measure and how?”

Data Analysis

Concept mapping was completed using the CS Global software (Concept Systems, Ithaca, NY). The CS Global software uses multidimensional scaling by combining the sorting of all participants to develop simple point maps where each statement represents a point on a map. Points sorted into the same category by many people are closer to each other on this simple map. Stress values are then calculated. A low stress value demonstrates better overall fit. A meta-analytic study of over 36 concept mapping studies estimated an average stress value of 0.285 with 95% of concept mapping projects yielding stress values between 0.205 and 0.365.²² The software then produces a hierarchical cluster analysis to sort this simple map into clusters. Various cluster solutions are produced and are then shared with the participants in the interpretation step. The software also analyzes the rated data to provide average ratings for each statement. Pearson correlation coefficient was calculated to assess correlation between ratings.

RESULTS

Participants

There were 48 participants in the online brainstorming session, 103 participants in the online sorting session, 102 participants in the online rating step, and 25 participants at the in-person interpretation session. Participants included youths, parents, and community youth workers. Over 54% of online participants had been exposed to violence, over 63% of online youth participants were in school, and over 55% of online youth participants were employed (at least part-time). Participant characteristics for online sessions are shown in Table 1. Given our aim to maintain anonymity at the in-person interpretation session, we did not collect

Table 1
Online Participants

	Brainstorming	Sorting	Rating
Number of participants	48	103	102
Role			
Youth	40 (83.3)	60 (58.3)	60 (58.5)
Parent of youth	1 (2.1)	20 (19.4)	20 (19.6)
Community youth worker	5 (10.4)	17 (16.5)	16 (15.7)
Other/did not complete	2 (4.2)	6 (5.8)	6 (5.9)
Median age, yr (if youth) (range 12–24)	20	20	20
Race			
Black or African American	11 (22.9)	28 (27.2)	28 (27.5)
White	17 (35.4)	30 (29.1)	30 (29.4)
South Asian	6 (12.5)	6 (5.8)	6 (5.9)
Other Asian	5 (10.4)	13 (12.6)	13 (12.7)
Other (other race, mixed race)	6 (12.5)	17 (16.5)	17 (16.7)
I would prefer not to say	3 (6.3)	9 (8.7)	8 (7.8)
Exposure to violence	29 (60.4)	57 (55.3)	56 (54.9)
Enrolled in school (if youth)	28 (63.6)	38 (67.9)	37 (67.3)
Employed (full or part time) (if youth)	26 (59.1)	31 (55.4)	31 (56.4)
Data are reported as <i>n</i> (%).			

demographic information from these participants. As subjects were not tracked due to the requirement for anonymity (this would have required an e-mail address) we are unable to determine how many participants participated in all four steps.

Brainstormed Statements

Participants brainstormed 48 statements. These were condensed to 44 statements by the research team and two youths from our community partner agencies, to remove overlap and to ensure appropriate language.

Point Map

A two-dimensional point map, developed through multidimensional scaling analysis, was plotted using data from the brainstorming and sorting stages of concept mapping (Figure 1). This map has a stress value (a measure of overall fit) of 0.22. Points that appear closer together were more often sorted together by participants, compared with those points that are far apart. For example, as can be seen in Figure 1, statement 17 (“training doctors and nurses to listen to the patient”) is close to statement 18 (“training doctors and nurses to ask questions about what happened”), but is not close to statement 12 (“connect to education”).

There was general consensus by participants that most statements were appropriately placed on the map in relation to each other. Two statements, “keep confidentiality from police” and “keep confidentiality from parents,” were discussed at length. It became clear that participants were confused about the interpretation of these statements. Many were unaware that health care workers are required to maintain confidentiality from both parents (if the patient is competent) and police. Many participants felt that they and other participants may have sorted and rated these statements differently had they been aware of the confidentiality requirements. Many participants felt that there may be an

opportunity to involve police in a positive way during the ED visit.

Cluster Map

The cluster analysis then identified clusters of statements that represent conceptual similarities/groupings of the statements. A facilitated discussion resulted in participant consensus that the seven-cluster model was most appropriate, as this model defined seven distinct concept themes that could not be further reduced or collapsed, with respect to hospital involvement in youth violence prevention (Figure 2). The clusters were then each given a title. For example, Cluster 4 was named “Needs Assessment and Supports” by the group because the cluster comprised highly related statements suggesting the need for implementation of support groups, mentorship training, and counseling for youth affected by violence and their families. Other clusters representing potential hospital intervention included: “engagement resources” comprising ways to engage youth in the community; “personal development,” comprising options for skills development for youth; “increased public awareness,” comprising ways to help decrease the general stigma of youth violence; “staff training,” comprising ways to educate doctors and nurses on how to be more sensitive to the needs of youth affected by violence; and the creation of a “non-judgmental environment,” comprising ways the hospital could improve the victim’s overall experience.

Ratings

Individual statements were then discussed with respect to how strongly they were rated according to importance and realism (Table 2). There was general agreement (Pearson correlation coefficient $r = 0.83$) between the participant ratings of importance and realism for most statements. Issues related to youth violence prevention that were rated of highest importance and most

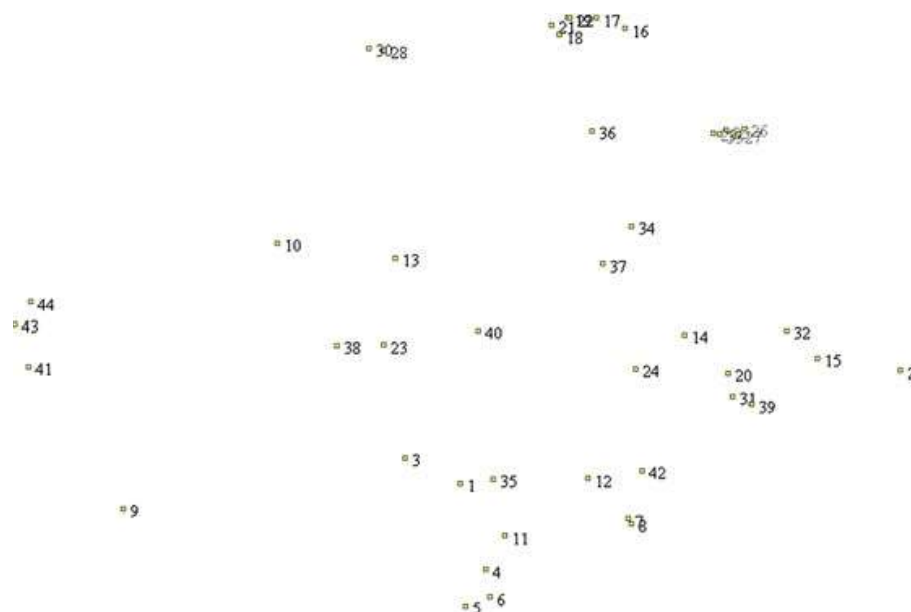


Figure 1. Two-dimensional point map. Each point on the map represents a statement. Points that appear closer together were more often sorted together by participants.

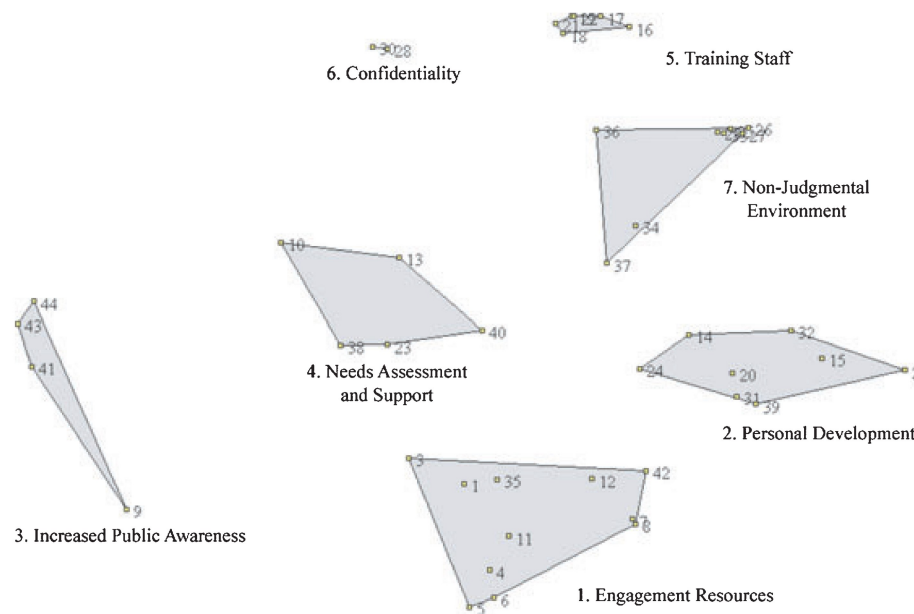


Figure 2. Cluster map. Various cluster maps of statements that represent conceptual similarities or groupings of statements were presented to the group. Participant consensus resulted in the seven-cluster map being chosen as the most appropriate.

realistic for hospital involvement included statements from Cluster 5 (training staff) and Cluster 7 (nonjudgmental environment), such as training doctors and nurses to ask questions about the event, treating youth with respect, developing youth support groups in the hospital, and connecting youth with organizations in the community. Some participants shared experiences of critical behavior by staff in the ED and felt that this negatively affected their care. Some statements were rated as highly important, but only moderately realistic by participants, such as connecting youth with organizations in the community, connecting with education, and educating youth to make use of social services. Participants rated statements suggesting that hospital staff keep details of the violent event confidential from parents and police; the provision of sports, music, and self-defense programming; and the hosting of violence prevention-related community events by the hospital as least important and realistic actions for hospital involvement.

Designing a Future Intervention

To further achieve our first objective of designing a hospital-based youth violence intervention, participants then formed four small groups to address topics that arose from each cluster (Table 3). Given the strong theme regarding a need for hospital staff training and the creation of an environment where youth can feel comfortable, Group 1 was asked to address how to best provide a youth-friendly environment in the hospital. Suggestions such as teaching nonjudgmental approaches, using appropriate language, and informing youth about care plans and procedures were discussed. Group 2 developed a job description for a youth mentor/service provider. This group identified a number of key qualities the service provider should possess, including that she or he be friendly, approachable, and empathetic and have lived experience as a victim of vio-

lence (Table 4). Group 3 identified a list of essential skills-building services and activities for youth within the community. Group 4 developed suggestions for a hospital-led public awareness campaign that could involve youth. These results have all been incorporated in a funding application for an ED-based youth violence prevention intervention.

Determining Relevant Outcomes

To achieve our secondary objective of determining outcomes of a hospital-based violence prevention intervention important to our stakeholders, the larger group reconvened to discuss the question, "How do we know our intervention worked?" The group brainstormed on a number of important outcomes that should be measured, including societal, community-based, and individual health-related outcome factors such as decreased overall violent injury and death, use of referral services, changed perceptions and attitudes toward violence, and rates of return to school. The group also indicated that it was important to assess whether the intervention had a negative impact on the lives of youth (Table 5). This group discussion informed the outcome measures that will be used in a future study of our hospital-based youth violence intervention.

DISCUSSION

This study provides the blueprint for the development of an ED-based youth violence prevention intervention that is relevant to the community. It provides a guide for specific components of the intervention and ensures that affected youth and community are supportive of our efforts.

A key finding of this study is that to successfully intervene with victims of violence, we must address the fact that youth presenting to EDs face negative attitudes from some caregivers. When accessing emergency care,

Table 2
Clusters With Ratings

Statement No.	Importance	Realism
Cluster 1: Engagement Resources		
(12) Connect to education	High	Moderate
(35) Connect youth with organizations in the community	High	Moderate
(42) Help youth get back into school if they want	High	Low
(1) Connecting youth to peer support (youth helping youth)	High	Moderate
(3) Mentorship	Moderate	Low
(8) Connect to programs for housing	Moderate	Low
(7) Connect to programs for employment	Moderate	Low
(11) Connect to various activities	Moderate	Low
(5) Sports programs	Low	Low
(6) Music programs	Low	Low
(4) Physical self-defense	Low	Low
Cluster 2: Personal Development		
(20) Provide youth with options	High	Moderate
(2) Build confidence	High	Low
(24) Encourage youth to make use of social services	High	Moderate
(14) Educate youth on how violence affects others	High	Moderate
(32) Encourage youth to think about consequences of conflict	High	Low
(15) Teach them conflict resolution skills	High	Low
(31) Help youth build listening skills	Moderate	Low
(39) Provide youth with an outlet for their anger	Moderate	Low
Cluster 3: Increased Public Awareness		
(44) Increase public awareness through education	Moderate	Moderate
(43) Increase public awareness through media	Moderate	Moderate
(41) Partnership between youth and hospitals to organize events and fundraisers	Low	Moderate
(9) Host community events	Low	Low
Cluster 4: Needs Assessment and Support		
(13) Help find ways to prevent violence	High	Low
(23) Develop youth support groups in the hospital	High	High
(40) Provide family counseling	High	Low
(10) Find out the cause of the violence	Moderate	Low
(38) Teach those affected by violence (either directly or indirectly) to mentor other youth	Moderate	Low
Cluster 5: Training Staff		
(21) Training doctors and nurses to be understanding	High	Moderate
(19) Training doctors and nurses to not make assumptions	High	Moderate
(22) Training doctors and nurses to stay open-minded to youths' experiences and choices	High	Moderate
(16) Training doctors and nurses to be nonjudgmental	High	Moderate
(17) Training doctors and nurses to listen to the patient	High	Moderate
(18) Training doctors and nurses to ask questions about what happened	High	High
Cluster 6: Confidentiality		
(30) Keep confidentiality from police	Low	Low
(28) Keep confidentiality from parents	Low	Low
Cluster 7: Nonjudgmental Environment		
(29) Treat youth with respect	High	High
(25) Treat youth with an antiracist approach	High	Moderate
(26) Treat youth with an anticlass approach	High	Moderate
(27) Treat youth with an antihomophobia approach	High	Moderate
(33) Treat youth as knowledgeable individuals	High	Moderate
(37) Provide mental health services targeted towards youth	High	Moderate
(36) Create a youth friendly environment in the hospital	High	Moderate
(34) Provide services with no parental involvement necessary	Low	Low
Based on distribution: low = 4.1 and lower; moderate = 4.11 - 4.38; high = 4.39 and higher.		

youth often perceive that caregivers have made assumptions about the circumstances of their visit, and many of these youth perceive this as discriminatory with respect to race, age, and class. Previous studies have demonstrated that racial or ethnic minorities are less likely to receive quality care and are more likely to face stereotyping and racial discrimination when seeking health care.^{23,24} This study finding has resulted in plans by our research group to develop an educational component

for hospital staff on how to create a youth-friendly environment and to educate them on the negative effects of attitudes that youth perceive. Improving the relationship between these patients and ED caregivers is an important step, as it can build the trust and understanding of youths' experience that is necessary to promote involvement of youth in an ED-based violence prevention intervention and also increase access to related preventive services.

Table 3
Small-group Session Topics

Group 1
How do we provide a youth-friendly environment in the hospital? How would you design a program to train health care workers to be more sensitive?
Group 2
What qualities do you want a mentor to have? (i.e., write a job description)
Group 3
What are important skills that these youth should develop? Where do they learn these? Why are they important for avoiding future violence? Which activities should these youth be connected to? Where are these?
Group 4
If you were to develop a public awareness campaign what would it look like?

Table 4
What Qualities Do You Want A Mentor To Have? (What Should Be in the Job Description?)

- Friendly
- Approachable
- History of violence, used to be in that situation but no longer in it
- Empathetic
- Able to relate
- Strong personal skills
- Creative
- Experience or some training in social work (but not necessarily a social worker)
- Wearing street cloths
- Calm
- Good listener
- Not too old
- Comfortable with discussion on violence
- Tactful
- Man or woman—gender irrelevant
- Adaptable to circumstances
- Nonjudgmental
- Up to date on current events in the community
- Role model

Table 5
Determining Relevant Outcomes “How Do We Know That Our Intervention Worked?”

- Decreased overall violent injury and death
- Reduction in repeat injury
- Use of referral services
- Decreased fighting
- Changed perceptions
- Changed attitudes
- Return to school
- Ask about any negative effects the program may have had on the life of a youth

This study also highlights a need for the inclusion of case management, which involves connecting youth to resources in the community, as a key component of a hospital-based youth violence intervention. The importance of case management for youth affected by violence has been found in other programs reported in the

literature.^{25–28} We published a systematic review of ED-based youth violence secondary prevention programs.²⁹ All interventions used case management to link violently injured patients with community services. All programs show promising results in reducing rates of criminal involvement, but none of the studies were large enough to show a statistically significant difference in rates of violence-related reinjury or death.

Our study also demonstrates that it is important that future research outcomes are relevant to the community. In addition to outcomes that continue to be studied in this field, such as changes in attitudes and barriers, criminal involvement, and repeat injury or death, participants identified the importance of studying negative effects an intervention program may have on the life of a youth participant or his or her family.²⁹

Strengths of this study include the high online response rate among a population that is traditionally difficult to study. We used a purposive sampling strategy by recruiting from youth violence intervention programs to ensure that our target group was well represented. With over 54% of the youth involved having been exposed to violence, we can conclude that our results are applicable to youth who will be involved in a future intervention. The online participants belonged to diverse ethnic groups in Toronto.

We used the novel approach of concept mapping to involve youth and community in the development of a hospital-based youth violence intervention. We employed community-based participatory methods to gain access to and give voice to the lived experience of youth and other community members affected by youth violence within their community. This method of research provides context to issues that are difficult, if not impossible, to obtain from quantitative research alone. Our findings will contribute to community empowerment through development of violence prevention programs at hospitals in our city. Community involvement in program development leads to improved uptake and program participation and ensures that program development incorporates the opinions of the targeted group.

LIMITATIONS

A limitation of the software used in this study is a restriction on the number of demographic questions that can be asked. Future studies should include a question on whether they had been treated in an ED (we asked if they had been exposed to violence) or could recruit injured youth and their families directly from the ED. Additionally, despite our attempts to ensure clarity in the statements, it was evident at the interpretation session that the term “confidentiality” had various meanings to the participants. Many participants were unaware of the legal requirement of ED staff to keep youth’s personal and health information confidential from parents and the police, except under specific circumstances such as a lack of competence or under the mandatory gunshot wound reporting law. Once clarified, many participants told us that that they would have rated this higher in the rating step. A further limitation is that few parents were involved in the

brainstorming portion. Given this low participation, we established a new partnership with a parent group whose membership includes parents whose youth have been affected by violence. Parental involvement in the sorting and rating steps was greatly improved through this effort. However, it would have been beneficial to have their involvement in the brainstorming step as well.

This study is an example of community-based participatory research that could be replicated for other ED-initiated programs targeting difficult-to-reach populations. This method brought context to an issue that is difficult to study with more traditional research methods. Involving the community in our research can serve to make our research more relevant and increase the success of ED-based programs. Results of this study will be a springboard for the development of a hospital-based youth violence intervention in our city that is supported by the community and affected youth. We aim to implement this intervention in the near future and will evaluate its success using the outcomes that were developed in this project.

CONCLUSIONS

It is feasible to use information generated by the community to develop meaningful interventions for the ED. This study enabled our group to identify various resources available in our community and helped to develop and formalize the strong relationships necessary to implement an intervention in our ED for youth who have been injured by violence.

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