

A Comprehensive Review of Quality of Life Surveys for Trauma-Affected Communities

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Abstract

Research shows that exposure to community and domestic violence leads to psychological trauma from childhood through adulthood, which can lead to poor health and early death. A team of health information management (HIM) professionals reviewed existing surveys to determine their suitability for assessing the quality of life (QoL) of people in trauma-affected communities (TACs). Keywords were used to search for papers describing validated QoL surveys. The obtained papers were screened, reviewed, and summarized to determine if they include the aspects needed for assessing QoL in TACs. Survey items from 20 surveys were identified as relevant to this study. Most of these 20 surveys cover one or two domains of QoL, and none of them were specifically designed for people in TACs. Therefore, it is necessary to develop a psychometrically sound assessment tool to quantify the levels of trauma, resilience, and well-being in TACs. HIM professionals have the required skills for this task.

Keywords: quality of life (QoL) assessment; trauma-affected community; literature review

Introduction

Trauma is defined as an episode or recurring event where the individual's ability to encapsulate the emotional experience is overwhelmed and the individual experiences (either objectively or subjectively) a threat to life, body, or the life or body of someone important, such as a family member.¹

A trauma-affected community (TAC) is a community with a shared experience of suffering that characterizes the personal experiences of many in the community, such as chronic unemployment, crime, drugs, homelessness, hunger, abuse, poverty, and radical isolation. Therefore, trauma is the foundation upon which the community worldview forms.

Research has demonstrated that traumatic life experiences, such as physical and sexual assault,² exposure to domestic violence,³ traffic-related injuries,⁴ critical illness,⁵ sexual abuse and military combat,⁶⁻⁹ have a negative impact on quality of life (QoL). In four of these studies,¹⁰⁻¹³ poor QoL is associated with posttraumatic stress disorder (PTSD).¹⁴ Other life events, such as the end of a relationship or exposure to violence, have also been associated with reduced QoL.¹⁵

Traumatic experiences are associated with negative health outcomes, problems with alcohol and drug abuse, other mental health diagnoses (such as depression), and an increased need for healthcare services, which are often not readily available in TACs.¹⁶ According to the Offices of Minority Health, non-Caucasian communities experience substantial challenges in accessing behavioral health services.¹⁷ For instance, PTSD is often underdiagnosed and untreated in racial and ethnic minority populations.¹⁸

The research literature clearly indicates that disparities exist within the current healthcare system for racial/ethnic minorities.¹⁹ It also suggests that social determinants may influence disparities.²⁰ Social determinants may include poverty, access to resources, education, institutionalization, and housing status.²¹ These issues, along with adverse experiences such as interpersonal violence, victimization, mistrust, and racism, contribute to barriers to treatment and help to shape the characteristics of TACs.²²

To reduce and eventually remove these disparities, one early step is to determine the QoL of people in TACs. The results from this step may guide us to determine the correct approaches for helping people in TACs across the country.

The purpose of this study is to use health information management (HIM) professionals' expertise to perform a literature review of existing QoL surveys and, utilizing HIM professionals' survey development skills, determine if the surveys are suitable for assessing the QoL of people living in TACs. If no suitable survey is available for that purpose, HIM professionals can utilize their expertise to develop a psychometrically valid scale and deploy the survey in the right medium to ensure the security, privacy, and confidentiality of sensitive information collected from the survey. In addition, HIM professionals can perform statistical analysis on the data collected from the survey and interpret the results.

Background

QoL and Well-Being

QoL is a broad concept covering all aspects of human life, such as the quality of the physical, behavioral, environmental, financial, and social domains of life.²³ To evaluate QoL, one must include all areas of life and have a measure for each of them.

QoL is generally considered subjective or value-based, dynamic in the sense that it will vary over time, and multidimensional because one can refer to different aspects of life, such as physical, psychological, social, and spiritual, when evaluating QoL.

According to the Centers for Disease Control and Prevention, a working definition of well-being is "a dynamic and relative state where one maximizes his or her physical, behavioral, and social functioning in the context of supportive environments to live a full, satisfying and productive life."²⁴

Well-being indicators measure when people feel healthy and satisfied or content with life, measuring constructs such as their positive emotions, resilience, the quality of their relationships, and realization of their potential.²⁵ Attributes of well-being are associated with many benefits related to work, family, health, and economics. People with high levels of well-being are likely to contribute more in their communities, have better relationships, and be more productive in their lives.

Childhood Trauma

A child's physical and emotional development depends on safety and stability.²⁶ Complex trauma describes both the child's exposure to traumatic events, which are often invasive and of an interpersonal nature, and the lasting impact of this exposure.²⁷ Children with complex traumatic histories experience a range of traumatic events, such as physical, emotional, and sexual abuse, witnessing of violence in the home and neighborhood, separation from family members, and revictimization by others.²⁸ These events are harsh and inescapable, and therefore these events can have an overwhelming effect on children's cognitive and emotional abilities, as well as their relationships with others. As they become adults, complex trauma correlates with an array of chronic physical problems as well as emotional problems including addiction.²⁹

Adverse Childhood Experiences

Adverse childhood experiences (ACEs) include several types of abuse, such as verbal, physical, or sexual abuse, as well as family dysfunction, including incarceration, mental illness, substance abuse and domestic violence among family members, or absence of a parent due to divorce or separation.³⁰ An increase in ACEs has been associated with a variety of poor health outcomes in adulthood, including

depression, substance abuse, cardiovascular disease, diabetes, cancer, and early death.^{31–33} The relationship between the number of ACEs and various risk factors shows a strong and graded correlation. Risk factors include alcoholism, depression, drug use, intimate partner violence, cigarette use/abuse, suicide attempts, and chronic obstructive pulmonary disease. Unhealthy risk factors such as alcohol or drug abuse were not the only reason for the propensity of chronic disease in adults. Children with seven or more ACEs, who did not engage in the above-mentioned risk factors and were otherwise healthy, had a 360 percent higher risk of heart disease than those with no ACEs.³⁴ ACEs can harm a child's developing brain so profoundly that the effects of the trauma will appear in adulthood and cause chronic disease and mental illness, which are at the root of most violence.³⁵

Resilience

Although traumatic events, especially during childhood, can have a profound impact on one's health, not everyone eventually develops physical or mental issues. The difference exists in the individuals' resilience. "Resilience is essentially a set of skills—as opposed to a disposition or personality type—that make it possible for people not only to get through hard times but to thrive during and after them."³⁶ Resilience can improve QoL in adults with traumatic histories. Therefore, resilience appears to be the antidote to the effects of the trauma experienced by individuals and should be measured in a QoL survey.

Methods

A variety of surveys exist to measure QoL in various settings, and they are either disease-specific or generic. Generic QoL surveys work well in measuring broad concepts in larger populations. The advantages of generic QoL surveys include their suitability in a variety of circumstances.³⁷ Additionally, an important characteristic of a survey is its ability to capture even small changes, which may influence a person's general QoL. Generic QoL surveys may lack responsiveness to these changes but are used because they provide an acceptable way to compare certain cohorts across larger communities.³⁸

Disease-specific QoL surveys are more sensitive to change than are generic ones.³⁹ They measure concerns that are important to a given population, such as people with a medical condition such as diabetes or cancer. The disadvantage is that they are narrow in focus, usually center on one disease or medical condition, and therefore are not used across diverse populations. Thus, a combination of generic and disease-specific surveys is preferred in research.

Many HIM professionals have administered generic and disease-specific QoL surveys in their career, and they also perform management and analysis of the collected survey data. In other words, many HIM professionals are familiar with QoL surveys. However, without a thorough literature review, no one can immediately determine whether a QoL survey that is suitable for people in TACs is available. After all, many QoL surveys are available, and people typically utilize a few widely used ones. Therefore, a team of HIM professionals conducted the literature review described below.

A quick review of the literature to look for surveys developed to measure QoL and the effects of trauma in TACs produced no such surveys; therefore, the authors performed a descriptive review of the literature with the purpose of identifying the domains and subdomains desired in the assessment of QoL among members of TACs. Keywords such as "quality of life," "well-being assessment," and "trauma-affected community" were used to search in databases such as PubMed and Google Scholar for papers describing the currently available and well-validated QoL surveys. No time frame was used in the search, as many psychometrically sound scales have been developed over a long period of time. Several of these scales have become the gold standard upon which external validation studies are done to compare newer scales with psychometrically sound ones. The obtained papers were screened, reviewed, and summarized to determine if they include the aspects needed for assessing QoL in TACs.

In the selection of papers and surveys for review, the following selection criteria were applied:⁴⁰

- The construct of interest is clearly defined.
- The design of the survey should consider the format of the questions, their response options, and the written instructions to complete the survey.

- The survey should be at least pilot-tested on a small number of respondents who review the items, and changes can occur prior to implementation.
- A sample of the population should complete the survey.
- The survey should be psychometrically validated.⁴¹
- The survey is in English.

The reviewed papers and surveys are summarized mainly according to the domains covered by those surveys and whether they are applicable for assessing QoL in TACs. After all, the population to be surveyed is one of the biggest factors to consider when determining what type of measurement tool to use.

Results

In the thorough literature review, 99 papers and their corresponding QoL questionnaires were identified. After the selection criteria (listed above) were applied to these papers and questionnaires, 54 questionnaires were found to be psychometrically sound QoL surveys.

The review of these 54 surveys and the papers about these surveys indicated five major domains of well-being assessment: the physical, behavioral, social, spiritual, and socioeconomic domains. Below are the definitions of these domains:

- **Physical domain**—defined as pertaining to the physical health of the individual, including concepts of mobility, sleep, exercise, diet, and adverse behaviors such as smoking cigarettes, excessive use of alcohol, and taking street drugs.
- **Behavioral domain**—defined as the mental characteristics possessed by the individual, such as positive and negative emotions, traumatic life events, and resilience characteristics.
- **Social domain**—defined as one's social characteristics characterized by the quality of relationships, interpersonal skills, social networks, and the ability to get along with others and rely on others when needed.
- **Spiritual domain**—defined as a protective factor in opposition to life's adversities, including concepts of a connection to a spiritual being, the ability to rely on inner spiritual strength for acceptance of life's circumstances, and participation in a faith community.
- **Socioeconomic domain**—defined as the economic environment of the individual, including one's financial situation, transportation, housing, and educational and work environments.

The literature also confirmed that these five domains are important for QoL assessment in TACs.^{42, 43} Table 1 shows the number of surveys covering each of these five domains. It is clear that many surveys cover physical, behavioral, and social domains. Only six surveys cover the socioeconomic domain, and two surveys cover the spiritual domain. Forty-one of these surveys cover only one specific domain, and 14 of them cover two or more domains. For instance, the World Health Organization QoL survey (WHOQoL-100) has all five domains. The structure of the WHOQoL-100 reflects the issues that scientific experts and laypeople considered important to QoL.⁴⁴ However, none of these 54 QoL surveys were specifically designed for people in TACs. The literature also does not show that these surveys were used in TACs to measure QoL.

Further review of these surveys and papers indicated that many of these surveys are used for populations with chronic medical conditions/disabilities. Some surveys were designed for clinical diagnosis purposes instead of general QoL assessment (PHQ-9, for instance⁴⁵) and therefore were considered irrelevant to the aim of identifying a QoL survey for TACs. A review of the items in the Beck Hopelessness Survey showed that self-reported hopelessness is used to predict suicide in both psychiatric outpatients and inpatients.^{46, 47} Because our targeted population was not limited to psychiatric patients, those items were considered not relevant to our study and were excluded from the review. Additionally, several surveys have significant overlap in terms of their covered domains and the used items. For

example, the items in the Basic Need Satisfaction in Relationships Scale overlapped with items in other surveys measuring social aspects of self that are worded more appropriately for our population and therefore were selected instead.^{48, 49} Table 2 lists the names of 20 surveys, their measured entity, and their domains.

Based on the large quantity of items found for each domain in these 20 surveys, subdomains of the five domains were created to group similar items together. All domains contained subdomains except for the social and spiritual domains, as the items within each of these two domains were similar and fewer in number. Table 3 shows the subdomains of the physical, behavioral, and socioeconomic domains.

Discussion

The results showed an abundance of QoL surveys; however, most of the currently available QoL surveys covered primarily one domain, such as physical, behavioral, or social. Several surveys have covered multiple domains, but none was specifically designed for people in TACs. Some QoL surveys were designed to cover only one domain to keep the survey focused on one content area, which enables the survey to be shorter, meaning that it will take less time to complete, cost less, and allow for easier interpretation of the survey and results. However, to fully address comprehensive QoL in all dimensions for people in TACs, one domain is not sufficient, and even the physical, behavioral, and social domains are not enough.

Some QoL surveys related to physical trauma are available; however, a survey that compiles multiple domains that address all aspects of what TACs face is not available. This lack of availability could be due to the recent realization of the effect that trauma has on entire communities and how it affects not only behavioral health but also all aspects of health. Therefore, a new QoL survey is needed in order to measure the constructs of physical, behavioral, social, spiritual, and socioeconomic health as well as childhood and adult levels of trauma and resilience skills for people in TACs.

Spiritual as well as resilience constructs are known to be protective factors that can help to counteract the effects of trauma.⁵⁰ Thus, it was important to measure not only the type of trauma experienced but also antidotes to help one thrive despite the effects of the trauma experienced. Socioeconomic status is also a very important domain to include when evaluating the well-being of people in TACs because it plays an important role in their lives and is closely related to their QoL.

A survey addressing relatively distinctive QoL constructs in a specific population, such as the members of TACs, will provide specific and pertinent items that are necessary to produce meaningful results. These results will have a better chance of guiding the development of effective interventions for this population. These interventions may include the common health-related treatment regimens but should also consider education awareness training, mentoring, volunteering, employment support, leadership training, housing development and repair, and so forth. Some of the domains and subdomains in this new QoL survey may include physical health (medications, mobility, sleep, pain, social habits, diet); behavioral health (ACEs, traumatic events, resilience); relationships (positive, negative, family, friends); spiritual health (religion, faith, community); and socioeconomic factors (environment, finance, work, education).

We are currently working on the content of the new QoL survey. As mentioned earlier, HIM professionals have a perfect background to develop and assess new QoL surveys for TACs. After the new QoL survey is validated, HIM professionals can deploy the survey in the right medium and test it for appropriateness. These efforts may include developing a mobile app or a web-based version of the survey for large-scale survey studies. In other words, HIM professionals have a unique background that enables them not only to develop the content for the QoL survey but also to work with information technology professionals and others to make sure that the QoL survey is administered appropriately. Their background in the health sciences, research, health information technology, and systems enables them to know the content, methodology, and proper administration of the survey, which can be a unique skill set when compared with that of other healthcare professionals. HIM professionals should be part of the team that develops, assesses, and administers the QoL survey. Our team includes several healthcare

professionals, HIM professionals, and several students in the fields of HIM, information science, and computer science.

Limitations

This study has some limitations. First, this study is a descriptive review of the literature with the purpose of identifying the domains and subdomains desired in QoL assessment for members of TACs. Among the selection criteria, only psychometrically sound (showing evidence of reliability and validity) surveys, regardless of the age of the scale, were included in this review, to make the review results more meaningful. Second, this study did not include the investigation of the contents of the identified surveys, which can be critical when developing a new QoL survey for people in TACs. We are currently evaluating the content of the 20 selected surveys to compile a new QoL survey for people in TACs.

Conclusion

The literature review showed that no existing surveys were specific to trauma-affected populations and measured the five domains of QoL deemed important to this study. Thus, we determined that a new survey would have to be created for that purpose. This study identified the five essential domains to be included in the QoL assessment, and the desired subdomains in each domain. The results of this study will guide the design of a new survey to assess QoL among people living in TACs.

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Table 1

Number of Surveys Covering Each of the Five Domains

Domain	Number of Surveys
Physical	12
Behavioral	43
Social	13
Spiritual	2
Socioeconomic	6

Table 2

Surveys Reviewed and Their Characteristics

Reviewed Scales	Measured Entity	Domain	Year
Impact of Event Scale ^a	Posttraumatic stress disorder symptoms, subjective stress	Behavioral	1979
Adverse Childhood Experiences (ACE) Questionnaire ^{b, c}	Childhood trauma assessment	Behavioral	1998
Life Orientation Test (LOT-R) ^d	Traits of optimism and pessimism	Behavioral	2000
Connor-Davidson Resilience Scale (CD-RISC) ^e	Brief self-rated assessment to quantify resilience in the general population	Behavioral	2003
Differentiation of Self-Inventory–Revised (DSI-R) ^f	Thoughts and feelings about oneself and others based on Bowen’s Theory	Behavioral	2012
DSM-5 PTSD Life Events Checklist (LEC-5) ^g	Levels of trauma	Behavioral	2014
Emotion and Regulation Beliefs Scale (ERBS) ^h	Emotions and beliefs	Behavioral	2015
PROMIS–Physical Function ⁱ	Physical well-being	Physical	2011
McGill Quality of Life Questionnaire ^j	A generic quality of life scale	Physical, behavioral, social	1997
WHO-BREF—a subset of WHOQOL-100 ^k	Perceptions of one’s position in life in context to the culture and value systems in which the individual lives and in relation to the individual’s goals, expectations, standards, and concerns	Physical, behavioral, social, spiritual, socioeconomic	1999
SF-36 ^l	A shortened version of the Medical Outcomes Study	Physical, behavioral	2000
CDC Healthy Days Measures ^m	General self-rated health, physically unhealthy days, mentally unhealthy days, and activity limitation days	Physical, behavioral	2003
PROMIS–Global Health Scale ⁿ	A generic well-being scale	Physical, behavioral	2009
Basic Psychological Needs Scale in General ^o	Satisfaction of needs in specific areas of one’s life, such as interpersonal relations	Social	2000
PROMIS–Social Isolation ^p	Social well-being	Social	2010
PROMIS–Companionship ^q	Social well-being	Social	2013
PROMIS v2.0–Satisfaction with Social Roles and Activities ^r	Social well-being	Social	2016
Basic Need Satisfaction at Work Scale ^s	Feelings about work	Socioeconomic	1993

Urban Poor QoL (UPQOL) ^t	Quality of life of urban poor in Thailand	Socioeconomic	2008
WHOQOL–SRPB (Spirituality, Religiousness and Personal) ^u	Spirituality and religiousness within the individual	Spiritual	2013

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Table 3

Domains and Subdomains in a Desired Quality of Life Survey for Trauma-Affected Communities

Domains	Subdomains
Physical	Overall Health
	Pain
	Fatigue/tired
	Medications
	Sleep
	Stress
	Mobility and exercise
	Drug/alcohol use
	Food/water intake
Behavioral	Positive reactions
	Negative reactions
	Traumatic event—adverse childhood experiences survey
	Trauma—experienced/witnessed/effects of trauma
	Resilience
Socioeconomic	Financial
	Transportation
	Environment (including home and safety)
	Work
	Education