Does Assessing Health Related Quality of Life by Parent Proxy Identify Common Patterns Across a Sample of Children Living in Transitional Housing

Susan VonNessen-Scanlin

Rutgers, The State University of New Jersey-School of Nursing

DNP Chair: Susan Salmond, EdD, RN
DNP Team Member(s): William Holzemer, PhD, RN
Date of Submission: August 23rd, 2019
Table of Contents

Abstract 3
Background and Significance 4
Problem Statement 5
Needs Assessment 6
Objectives and Aims 7
Review of Literature 7
Theoretical Framework 15
Methodology 16-22
  Setting 18
  Population 18
  Interventions 19
  Outcome Measure 19
  Subject Recruitment 19
  Risks or Harms 20
  Consent Procedure 21
  Subject Costs and Compensation 22
  Project Timeline 22
  Resources Needed/Economic Consideration 22
Evaluation Plan 22
Data Maintenance/Security 22
Data Analysis 23
Findings 23
Recommendations and Discussion 27-32
  Economic/Cost Benefit 27
  Impact on Healthcare Quality and Safety 27
  Policy Implications 27
  Translation 30
  Dissemination 31
  Professional Reporting 32
References 33
Appendices 38
Abstract

Social determinants of health directly impact the physical health, social and emotional development, and educational achievement of children. Health care needs of children affected by social determinants may not always be identified during routine health exams. Assessing health related quality of life may provide the information needed prior to designing interventions for specific populations. The PedsQL™ Generic parent proxy survey was administered, to 22 parents of children residing in transitional housing in Newark, New Jersey, to assess if common patterns, which could be considered risk factors impacting health of children 0-18 years of age, could be identified. A convenience sample of 22 parents completed the survey. The mean scores across all age groups were: Total: 67.68, Physical Health: 65.93, Psychosocial Health 69.43. This pilot project demonstrated that the information reported by parents via the PedsQL™ Generic parent proxy inventories implied that the HRQOL, of the sample, of children living in transition housing had mean scores at or below those of children with chronic and acute health conditions. The children in the transitional housing could all benefit from regular screenings and the implementation of activities to target the patterns identified.

Keywords: Pediatrics, Health-related Quality of Life, Peds QL™ Poverty, Social Determinants, Toxic Stress, EBD Framework, Health Equity
Background and Significance

The overarching goals of Healthy People 2020—the United States’ 10-year agenda for improving the nation’s health—are underpinned by two critically important patterns: social determinants have a profound effect on health, and quality of life is a key concept in understanding health (Office of Disease Prevention and Health Promotion, 2016). Stressing the role of social determinants in health, the Healthy People 2020 goals are to “Create social and physical environments that promote good health for all” as well as “Achieve health equity, eliminate disparities, and improve the health of all groups.” Capturing quality of life, the Healthy People 2020 goal is to “Promote quality of life, healthy development, and healthy behaviors across all life stages” (Office of Disease Prevention and Health Promotion, 2016). All goals recognize health as a broad concept, similar to the classic World Health Organization (WHO) definition of health as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (WHO, Constitution, 2019). The Constitution of the World Health Organization further states that “The early child period is considered to be the most important developmental phase throughout the lifespan” (WHO, 2019).

The Centers for Disease Control (CDC), The Department of Health and Human Services (DHHS), the American Academy of Pediatrics (AAP), and the Secretary of Health all confer that the burdens of disease in the United States are largely influenced by social and environmental determinants (Krisberg, 2016). These agencies further argue that a key goal to improve health is to manage poverty and social determinants through investing in and leveraging initiatives that promote health and wellbeing for communities (Krisberg, 2016). The relationship between poverty, social determinants and a child’s health, wellbeing, ability to learn and grow up as a productive member of society as long been established. The American Academy of Pediatrics’
Council on Community Pediatrics recent policy statement, regarding the organizing principles for children’s health in the United States, specifically points out that children who experience poverty are at an increased risk for poor health throughout their lives (2016). The American Public Health Association further argues that rather than focusing on disease and illness-specific interventions to improve health, it is essential to focus on the social, behavioral and environmental influences that are largely responsible for the burden of illness. The first five years of a child’s life are the most formative in terms of shaping a child’s future, thus a child who experiences toxic stress is more likely to have long-term negative effects. Given the amount of time providers spend with children in the first five years of their lives, the AAP (2016) has charged pediatric providers with the responsibility of identifying and mitigating the social determinants that affect the patients they serve.

**Problem Statement**

It is hypothesized that children affected by social determinants may have health care needs or vulnerabilities, expressed as alterations in health related quality of life (HRQOL) that may not be identified and therefore are not addressed in the routine primary care health setting. Given the attention to comply with state and federal regulations for standards—such as immunizations, or mandatory dental screenings—sometimes the subtler HRQOL needs, which may have long-standing implications for a child’s health and wellbeing, may go unrecognized and unaddressed. This project seeks to answer the question: Does the administration of the PedsQL™, Health Related Quality of Life parent proxy inventory, to the parents of children, age 0-18 years of age, living in transitional housing, in Newark, NJ identify common patterns associated with risk factors affecting their children’s HRQOL?
Health Related Quality of Life

Needs Assessment

Many of the children who reside in the city of Newark are challenged by a host of social determinants. According to Advocates for Kids in New Jersey (2018), 64% percent of children living in Newark reside in single parent households. Seventy-percent live in poverty compared to the 32% state poverty average, and 11% experience abuse (2018). While across the state conditions for children are improving, conditions for children in Newark have remained virtually unchanged for the last 10 years (Advocates for Kids in New Jersey, 2018). According to the recently released Medicaid 2.0 Blueprint for the Future (2017), there are 103,696 children enrolled in Medicaid in Essex county, which includes the city of Newark. Children who live in a transitional housing neighborhood, which can be defined as housing that assists families move from homelessness to permanent housing and from dependency to self-sufficiency, was used for this pilot project. This transitional housing community is the largest transitional living facility in the country. With the capacity to house 102 families in individual apartment units and a host of on-site social services, these accommodations provide much more than a shelter. This community offers stability to families facing seemingly insurmountable barriers and enables them to restore their lives. The length of stay in this community is determined by individual circumstances with the average length being six to nine months.

Collectively the children who reside in this community endure a host of social determinants on a regular basis as part of their everyday life circumstances, which is assumed to put them at risk for alteration in HRQOL and as a result, poorer predicted health outcomes. Assessing HRQOL, through the use of a simple questionnaire can identify risk factors which may not routinely be identified. Tools, such as the PedsQL™ Generic are currently used across the United States by some health departments, clinical practitioners and school districts as a way
to monitor the health of children within their communities, with the intent that the data will guide policy and program development as well as resource allocation (Seid, Varni, Cummings, & Schonlau, 2006).

**Objectives and Aims**

The purpose of this project is to identify the common risk factors that influence HRQOL, and which could further influence longitudinal health outcomes of children living in transitional housing. Specifically, this project will assess if the administration of the PedsQL™ Generic parent proxy to the parents of children living in transitional housing community in Newark NJ, will identify common patterns influencing risk factors impacting HRQOL in this population.

The specific aims of this project are to:

1. Gather basic HRQOL demographic information about the children who reside in the transitional housing community in Newark, NJ through the administration and anonymous completion of the PedsQL™, Parent Proxy Pediatric Quality of Life Inventory.

2. To use the PedsQL™, Parent Proxy Pediatric Quality of Life Inventory to identify common patterns, which could be considered risk factors, impacting the health of children 0-18 who live in transitional housing community Newark, NJ, and which may be used to develop strategies to mitigate these risks.

**Review of Literature**

**Social Determinants of Health**

For the last two decades’ interdisciplinary teams of scientists and clinicians have been working together to better understand the elements and effects of social determinants on children and their influence on long-term health outcomes, brain development, cognitive development,
HEALTH RELATED QUALITY OF LIFE

overall functional ability, and neurobehavioral regulation. A new field of science called eco-bio-
development (EBD) (See Figure 1) has evolved, to study these elements. Specifically, the EBD
framework focuses on child development, education, economic productivity, productive
membership in society and lifelong health (Shonkoff et. al., 2012). The EBD model attempts to
explain the evolution of health. Essentially the framework brings together basic science, physical
health, genomics, and environmental sciences to explain the complex relationship among
ecology (social and physical environment), biology, health and development. Roberts, Ferguson
and Crusto (2013) agree with the American Academy of Pediatrics, that the EBD framework
proposes an explanation of the biologic mechanisms that demonstrate the physiologic effects the
environment and social determinants influence and the impact HRQOL has on the developing
child. The National Scientific Council on the Developing Child (2014) demonstrated that there
is longitudinal evidence documenting that exposure to trauma (toxic stressors) categorized as
social determinants, has long-standing effects on a child’s health outcomes across their lifespan.

Toxic Stress

Toxic stressors are described as experiences which can alter brain chemistry and/or brain
architecture (Roberts et al., 2013; Shonkoff et al., 2012). Research has demonstrated that toxic
stress early in life negatively influences the development of the central nervous system.
Research performed by the CDC and the Kaiser Permanente Foundation reported that more than
60% of adults’ experience lifelong chronic physical and mental health conditions related to
biological and physiologic changes in the brain and body as a result of the exposure to toxic
stress as children (Felitti et al., 1998). These exposures are referred to as adverse childhood
experiences (ACES) and according to the AAP are “new morbidities” (Garner et al., 2012).
Exposure to toxic stress can augment brain development by increasing the neural pathways in the
HEALTH RELATED QUALITY OF LIFE

areas of the brain which control impulse, fear and anxiety. As a result, the areas of the brain which regulate planning, reasoning and control are underdeveloped (Perry & Conners-Burrow, 2016).

Hope and Resiliency

According to Banyard, Hamby and Grych (2017) children who are exposed to such toxins or social determinants such as poverty, food insecurity, lack of nurturing, and violence, have been shown to have insults in the architecture of their developing brains, which further interferes with the child’s ability to self-regulate their response to stress, impulse reactions and problem solving. The biology and physiology of the developing brain and central nervous system can be physiologically impacted by the toxic/traumatic stress endured by social determinants. Their findings suggest that the constant exposure to toxic stress further compounds the long-term physical and mental health of these individuals.

Perry and Conners-Burrow (2016) demonstrated that the developing brain is malleable, thus early intervention can blunt the biological response to stress, such as the release of stress hormones which influence impulse control, thus influencing the remapping of the brain to reduce these negative effects. These researchers further validated that embedding early childhood mental health consultation dramatically impacted the brain resiliency in children exposed to toxic stress.

Early recognition of toxic stress and targeted interventions in young children can enable life altering positive effects on health (American Academy of Pediatrics, 2012). The data reveals that early intervention provides an opportunity to mitigate the negative effects caused by social determinants. Interventions such as providing a stable home environment, ensuring that food will always be available, providing consistent positive interactions with adults at school, and
Health Related Quality of Life

Reducing exposure to violence, can stabilize or impede the negative physiologic consequences caused by toxic stress. Implementing screenings that assess for exposure to social determinants is a proactive way for health care providers, to identify risks that would likely not be determined through a routine physical health exam.

The American Academy of Pediatrics (2016) has advocated for greater assessment and understanding of social determinants and quality of life when providing care for children. They encourage an increased awareness among primary care providers regarding the effects that poverty and related social determinants have on the quality of life of children and the influence on their health. Social determinants of health directly impact the physical health, social and emotional development, and educational achievement of children. The Academy’s goal for increasing awareness of the social determinants of health is intended to assist healthcare providers in developing interventions and developing interventions that can intercept and redirect the negative effects and thus, improve the health-related quality of life for children.

Health Related Quality of Life (HRQOL)

HRQOL is a subset of quality of life. It is a multidimensional construct consisting of the aspects of overall quality of life that can be shown to affect physical or mental health. It encompasses the domains of physical, mental, emotional, and social functioning and goes beyond direct measures of population health, life expectancy, and causes of death. It focuses on the impact that health status has on quality of life (ODPHP, 2016). In children, HRQOL is an important indicator of everyday functioning. Any relevant reductions in these functions are critical to the child’s well-being (Coker et al., 2011).

Measuring HRQOL should not be limited to the five percent of children diagnosed with disease conditions. Rather, direct measures of HRQOL should focus on at risk populations to
ensure insight into addressing unmet health-related needs (Solans et al., 2008). These measurements should not be assumed or interpreted from the perspective of a provider but gathered from an emic perspective—as perceived from the child or child’s caretakers. Measurement in these pediatric populations or communities may prove to be a critical indicator for the recognition of children at risk for health inequity and disparities that further impede their physical and emotional health and development (Banyard et al., 2017).

Using a screening tool to assess the HRQOL in children who are exposed to toxic or traumatic stressors may provide important information about their physical, emotional, learning and social needs. It is speculated that early identification of deficiencies in a young child’s HRQOL may provide an opportunity for meaningful and timely interventions to reduce some of the long-term sequela attributed to toxic stress. Measuring HRQOL could also provide important data to identify need, inform policy, and advocate for the allocation of resources to improve the health and wellbeing of children who reside in conditions that put them at risk for long term exposure to toxic stress, such as poverty, homelessness, violence and food scarcity (Casey et al., 2005).

The California State Children’s Health Insurance Program administered the PedsQL™ Generic (quality of life scale) and other assessments of HRQOL (such as number of school days missed) to a large statewide sample of healthy children and children with chronic conditions enrolled in the program (Seid et al., 2006). Their findings demonstrated that the tool was valid and reliable in identifying HRQOL status in children with chronic conditions. The tool also demonstrated sensitivity in identifying the HRQOL status in individuals who were assumed to be healthy. Other researchers were able to document subtleties impacting a child’s health and wellbeing which might otherwise go unrealized, such as food scarcity, exposure to violence, and
feeling scared when using the same tool (Roberts et al., 2013). Wong and colleagues (2015) demonstrated a relationship between HRQOL, poverty, and associated social determinants. They found subtle physical health differences between the population of children living in poverty and those who lived above the poverty level. These findings are relevant and point out that often times a provider might see a child for a routine health exam, determine that the child’s baseline physical health metrics are within the expected norm, and determine that the child was not at risk—when, in fact, the child was experiencing exposure to toxic stress but the symptoms were too subtle to be identified by routine methodologies.

Casey and colleagues (2005) used the PedsQL™ Generic parent proxy inventory to assess the association between food insecurity and HRQOL. They assessed 399 children, 25% were noted to come from food insecure homes. They found a statistically significant difference in the HRQOL between the children from food insecure homes verses those from non-food insecure homes. Children from the food insecure homes were noted to have statistically significant lower physical and psychosocial scores compared to their peers from food secure homes (Casey et al., 2005). By administering a HRQOL assessment, the provider is more likely to identify the child who—although growing as expected—is having some degree of altered HRQOL. The findings suggest that if providers only look at basic health metrics to determine a child’s overall health-related status and do not evaluate HRQOL, they could miss the important health-related stressors, which can have immediate and long-standing implications for the health and well-being of the child. Many children experience traumatic stress on a daily basis related to food insecurity, violence or poverty, yet their physical health exams may appear normal. Research has also demonstrated that without evaluating HRQOL, policy assumptions may be flawed and precious funds funneled into poorly designed or unneeded services may be
HEALTH RELATED QUALITY OF LIFE

underutilized? (Wong et al., 2015).

**Chronic Illness**

Poverty and lack of access to healthcare have been identified as playing keys roles in the health and HRQOL for children and have effects like those caused by having a chronic health condition (Gupta et al., 2007; Shonkoff et al., 2012). Newacheck et al. (2000) reported that 7.3% of children living in the United States will have at least one unmet health need. Children living in poverty or who are uninsured are three times more likely to have unmet health care needs (Newacheck et al., 2000). Poverty and associated social determinants impact not only physical health, but social, emotional and learning. Thus, strategies to manage a chronic health condition must include strategies that address all HRQOL domains not just physical health.

Often there is a lack of awareness or attention paid to the factors that play a critical role in not only a child’s health and wellbeing, but coping and feelings of empowerment. For example, most often children are concerned not only with the course of their physical illness, but the impact their disease is having on their ability to participate in activities such as school, extracurricular activities and friendships. Peterson, Huus, Akesson and Enskar (2016) point out that often there is a disparity in the information providers give to children and the information children need to feel empowered to cope with their situation. Attention to the perspective of the child and how the child defines wellness is essential. Often providers only assess laboratory data and physical examinations, rather than understanding the effects chronic health conditions and/or social determinants have on a child’s ability to function and their quality of life. Peterson et al. (2016) found that implementation of a HRQOL assessment into practice had two major outcomes: children felt that their concerns were heard and understood, which enabled them to feel like they were taken seriously and therefore were more engaged in shared decision making;
and second, children gleaned new insights about their health, which served to motivate and empower them to change their behavior to further promote their own health. Improving quality of life for children whether they have a chronic disease or suffer from social determinants, takes a village. The village members are not just those who provide health, they are those who create the community. They are educators, police officers, neighbors, non-profits, policy makers, family. The solutions are not prescriptive and they are not always difficult.

**Population Health & Quality of Life**

The definition of population health is ever-evolving. Kindig and Stoddart (2003) and the Institute of Healthcare Improvement (IHI) defines Population Health as the “health outcomes of a group of individuals, including the distribution of such outcomes within the group. These groups are often geographic populations such as nations or communities, but can also be other groups such as employees, ethnic groups, disabled persons, prisoners, or any other defined group” (p. 381). Of equal importance is the recognition of the impact social determinants play in the short and long-term health and wellbeing, specifically of the child. Assessing, HRQOL provides important information which may potentially identify potential health risk factors in a population.

Exposure to chronic toxic stress such as poverty and associated social determinants has been shown to negatively affect HRQOL and the over-all health of populations (Holzer, Schanzenbach, Duncan, & Ludwig, 2008). Extensive research over the last two decades on the effects of chronic stress is now being referred to as traumatic stress (Frank, 2014). Traumatic stress is thought to be caused by ongoing exposure to toxic stress such as social determinants and changes quality of life.

The future of navigating population health and the larger impact on society, health and
economics, will be influenced by our ability to manage the social determinants responsible for much of the costly inequities and disparities influencing health in the United States. The implications that toxic and traumatic stress plays on quality of life and an individual’s functionality, has a large impact on society. Many individuals who experience long-term traumatic stress may not be productive members of society and they may create a costly burden on society from both a health care resource perspective and a social welfare perspective. There is hope. Evidence has demonstrated that intervention within the first five years of a child’s life can mitigate the effects of toxic stress and influence the biological changes in a child’s brain therefore reducing some of the longer term negative sequela caused by exposure to toxic stress (Shonkoff et al., 2012).

**Theoretical Framework**

The Eco-bio-developmental (EBD) Model of Human Health and Disease is the theoretical framework used to guide this project (see Figure 1). EBD is a widely supported framework for explaining the evolution of health and disease across the lifespan (Shonkoff et al., 2012). The model suggests that there is a causal relationship among epidemiology, developmental psychology, and longitudinal physical and mental health outcomes and that these outcomes are influencing changes in the human genome. Simplistically, the model is suggesting that there is a relationship between the ecology of childhood, influenced by physical and social environments, which further influences developmental outcomes and life and health trajectories (Shonkoff et al., 2012). Specifically, exposure to toxic stressors in children have been shown to be associated with the manifestation of chronic physical and mental health disease and in general poorer longitudinal health and well-being later in life. These biological phenomena are noted to not only be influence the health of individuals, but change the human genome.
The EBD Model describes relationships across the continuum of health which could potentially be engaged to mitigate these circumstances and reverse the negative effects and promote lifelong well-being. For purposes of this project the EBD model will be used as the framework which describes the relationships among the risk factor patterns identified by the PedsQL™ Generic parent proxy, and their potential insult on development. These relationships provide a starting point to develop programs to mitigate the effects of the identified risks.

Figure 1: Eco-Bio-Developmental Model of Human Health and Disease

**Methodology**

This project utilizes a quantitative descriptive research design to interpret data obtained through the use of the PedsQL™ Generic parent proxy HRQOL inventory survey. The investigator sought to identify common patterns, corresponding to HRQOL risk factors, among and across the various domains measured by the Peds QL™ HRQOL parent proxy inventory survey for children living in transitional housing. The literature demonstrates that these risk factors may influence longitudinal health outcomes. Specifically, this project will assess if the administration of the PedsQL™ Generic parent proxy to the parents of children age 1 month to 18 years of age, living in transitional housing in Newark NJ, will identify common patterns
impacting HRQOL.

The Peds QL™ Generic tool, is an inventory of HRQOL assessments that can be used across the life span. The tool has been studied extensively across populations considered healthy and those with documented acute and chronic health conditions and has been translated into multiple languages. The tool is a series of age appropriate parent proxy inventory and stand-alone surveys that can be administered to the following age groups: Adult->25, Young Adult 18-25, Teens 13-18, Child 8-12, and Young Child 5-7. Parent proxy only inventories exist for use with infants 1-12 months or 13-24 months, and toddlers 2-4 years. The validity and reliability of the PedsQL™ Generic parent proxy tool has been assessed across multiple studies (Huang, et al. 2008; Desai, et al. 2014; Varni, et al., 2001; Varni et al. 2003; Varni, et al. 2006). It has consistently been shown to be both reliable and valid with internal consistency between the parent proxy and the self-report exceeding the minimum reliability standard of 0.70 required for group comparisons (Varni, Limbers, & Burwinkle, 2007). The scoring across the age subgroups exceeds the $\alpha$ coefficient of 0.90, which is the internal consistency reliability criteria for analyzing individual patient scale scores, and is consistent with the FDA guidelines (Varni et al., 2007). For purposes of this project, the following parent proxy surveys will be used: Teen = 13-18, Child = 8-12, Young Child = 5-7, Toddler 2-4 years, Infant 13-24 months, and Infant 1-12 months.

The surveys are divided into four domains: physical functioning, emotional functioning, social functioning, and school functioning. Each domain has a list of activities. Parents are asked to rate their child’s situation, focusing on “my child has trouble with” on a Likert scale ranging from 0=never, 1=almost never, 2=sometimes, 3=often, and 4= almost always. The parent proxy teen, child and toddler inventories have 23 items and the infant inventories have 45 items. In
addition to completing the inventory, parents were also asked to indicate their child’s age and if they thought their child had any health problems.

The inventories were scored according to the PedsQL™ Generic scoring guidelines. If greater than 50% of the items in one domain were missing, a score was not calculated. The scores for each domain were totaled and reversed scored, according to PedsQL™ Generic guidelines. Scores were linearly transformed to a scale of 0-100. Scores were transcribed as follows: 0=100, 1=75, 2=50, 3=25 and 4=0. A total score for each domain was calculated as well as the mean score. The emotional, social and school functioning domains were combined to compute the Psychosocial Health Summary Score. The Physical Health Summary score was based on the score of the physical functioning domain (Varni, 2018). The scores for psychosocial health and physical health are combined to provide a total score. A higher score corresponds to a better HRQOL.

The surveys were scored as a measure of the population rather than as a measure of an individual child. The total score, mean score, and standard deviation for each domain was calculated.

**Setting**

The project took place on site at a transitional housing community in Newark, NJ. All parents residing in the transitional housing were asked to participate. The transitional housing community, engaged for this study, is the nation’s largest transitional housing program for families in the United States. The CEO and the Chief of Health and Human Services at the organization were engaged and approved this project and the distribution of the parent proxy survey.

**Population**

A convenience sample of parents of children one month to 18 years of age, currently
residing in transitional housing community were asked to complete the Parent Proxy Survey, on behalf of their child. The transitional housing community has the capacity to house 102 families in individual apartment units. All resident families need to qualify for residing in the community. The qualifications include currently or soon to be homeless. All families have incomes at or below the poverty level. A convenience sample of 21 was obtained during a regularly scheduled mandatory resident meeting. When families enter the transitional housing they undergo a brief health screening. At the time of this survey there were no children identified as having acute chronic disease, thus children living in the community were identified as a healthy population.

**Inclusion Criteria**

All parents and guardians, of all children one month to 18 years of age, currently residing in the transitional housing community in Newark, NJ, were eligible to participate in the project during a regular mandatory resident meeting. If unable to complete the survey at that time, parents were offered an additional data collection date. The survey was distributed in English, thus if a parent did not read or speak English they were not included in the study. The researcher was available to administer the survey in the event a parent had difficulty reading and understanding the inventory.

**Exclusion Criteria**

Parents who were not able to read and speak English were excluded.

**Interventions**

The researcher presented the purpose of the project to all potential participants during a regularly scheduled transitional housing resident meeting. In addition, more detail was provided about the impact quality of life has on health, especially with regards to children. Parents were
HEALTH RELATED QUALITY OF LIFE

notified that the survey typically takes less than 5 minutes to complete. All parents were given a non-signature consent form. The researcher read the contents of the form to the parents. It was communicated to parents that the survey is anonymous, and further explained this means they and their child will not be identified. The researcher informed families that the results of this pilot project will be presented at a future transitional housing community resident meeting. The researcher also provided an opportunity for the parents to ask questions.

Parents who wished to participate in the project were provided with a copy of the PedsQL™ Generic inventory parent proxy appropriate to the age of their child. In order to maintain anonymity, the researcher provided packets which contained the age appropriate parent proxy, a pencil, and a return envelope. Interested parents selected and completed the contents of a packet which contained the survey which corresponded to the age of their child. Parents were provided the following instructions:

“This is not a test, and there are no right or wrong answers. Please be sure to read the questions carefully and choose the response that is the closest to how you truly feel about your child experiences over the last month. The investigator is interested in your individual perspectives. When your survey is completed please put it in the envelope and seal the envelope before returning it to the investigator. When the envelopes are returned you will receive a gift card to compensate for your time and participation. If you have any questions, please let the investigator know”

Parents were instructed that if they were completing the inventory for more than one child to put all the surveys in one envelope. Parents who completed the survey received a $10 gift card.

Benefits/Risks

The PedsQL™ Generic was used as an anonymous questionnaire, seeking to understand the needs of a population. There are minimal risks associated with answering the survey. It was communicated to parents that discussion about exposure to chronic stress and HRQOL could cause them to worry about the health of their children. The benefits of answering the survey
HEALTH RELATED QUALITY OF LIFE

were also shared and included the provision of valuable information which can be used to inform
development and design of services and programs to reduce identified risk factors.

Consent Procedures

Parents/Guardians were provided with a copy of a non-signature consent and informed of
the voluntary nature of the project. They were assured that all surveys would be anonymous.
Because no identifying information was collected, a non-signatory informed consent was used.

Data Collection

The appropriate Peds QL™ Generic parent proxy questionnaire was distributed to each
participating parent/guardian based on their child’s age. The instructions for completing the
survey were located at the top of the survey and communicated by the researcher.
Parents/Guardians were asked to carefully choose the response that is the closest to how they
truly feel about their child (Varni, 2018). The researcher was available to administer the survey
individually for any parent who could not read or understand the survey, however this did not
occur. Upon completion, the inventories were placed in an envelope and sealed by the parent
before they were returned.

Parents/Guardians who were not in attendance during the resident meeting, but who
communicated a willingness to participate were given an opportunity to participate during a
second meeting arranged, by the investigator at a mutually agreed upon time. No families opted
for this option.

Subject Costs and Compensation

There were no associated costs incurred by the participants. A 10 dollar gift card was
provided to all parents who completed the survey.
**Project Timeline**

The proposed project was submitted and approved by the Rutgers IRB prior to the initiation of this project. The parent organization, does not have an independent IRB, therefore they deferred to the Rutgers IRB. A copy of the letter of approval from the IRB is located in Appendix A. A copy of the letter of support from the and a copy of the approval to use the Peds QL™ Generic is also located in Appendix A.

Upon receipt of IRB approval, the investigator confirmed attendance at the next regularly scheduled transitional housing community resident meeting. Surveys were distributed and collected following this meeting. The inventories were scored according to the PedsQL™ Generic scoring guidelines, within a week of the surveys being returned. The outcome of the surveys were presented to the Chief of Health and Human Services and will be presented at the August transitional housing community resident meeting.

**Resources Needed/Economic Considerations**

<table>
<thead>
<tr>
<th>Budget</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Expense / resource</td>
<td>Cost</td>
<td>Funding Source</td>
<td></td>
</tr>
<tr>
<td>Peds QL™ inventory</td>
<td>0</td>
<td>unfunded research is free</td>
<td></td>
</tr>
<tr>
<td>$10 gift card x 22 participants</td>
<td>$220</td>
<td>Investigator</td>
<td></td>
</tr>
<tr>
<td>Statistician $50-$100/ hour x 5hrs</td>
<td>$500</td>
<td>Investigator</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>$720</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Evaluation Plan**

**Data Maintenance/Security**

The surveys were anonymous, thus there was no protected health information collected.
HEALTH RELATED QUALITY OF LIFE

The surveys were placed in envelopes, by the parent, prior to being returned to the investigator, to maintain anonymity. The data was recorded, stored and analyzed on a secure encrypted computer. The paper surveys will be stored in a locked file cabinet, behind a locked door in the Rutgers School of Nursing, Office of Advanced Practice, in the Stanley Bergen Building, 65 Bergen St., Newark, NJ. The data will be maintained for seven years per the IRB and compliance regulations.

Data Analysis

The scores for each domain were reversed scored and totaled. Specifically, they were linearly transformed to a scale of 0-100. The scores were translated as follows: 0=100, 1=75, 2=50, 3=25 and 4=0. A total score for each domain was calculated. The Emotional, Social and School functioning domains were combined to compute the Psychosocial Health Summary Score. The Physical Health Summary score is the score of the Physical Functioning domain. The summary scores were combined to calculate the total HRQOL score. A higher score corresponds to a better HRQOL (Varni, 2018).

Descriptive statistics were used to describe mean scores, standard deviations for each domain, summary, and total HRQOL scores. This information was further used to identify commonalities and priorities for intervention based on each domain (Varni, 2018).

Findings

Thirty families attended the monthly resident community meeting. The project was explained to the audience and those who wished to participate did so following the meeting. The researcher was present to answer parent questions. There were no questions. Twenty-two unique envelopes were returned; thus it is assumed that 22 unique families participated in the survey. One parent turned in a blank survey, which was excluded from the results, yielding a
70% parent participation, for a total of 21 completed surveys. Parents were instructed to place sibling surveys in one envelope, thus, it is assumed that because 22 envelopes were returned that 22 families participated. However, given the anonymous nature of the project it could be that a parent returned more than one envelope. Six of the Peds QL™ Generic parent proxy inventories were used, corresponding to the age of the children. Seventy-one percent of the children were identified as female and 29% as male. Forty-three percent of the parents indicated that they thought their child had health problems; however specific problems were not identified in this project.

Table 1 represents the total composite score for the entire sample of 21 children. The scores of the elements in each domain ranged from 0-100. The total mean scores across all ages was 67.68 with a range mean score of 44.56-100 and a standard deviation of 17.75. The mean scores and standard deviation for the physical and psychosocial health domains demonstrated a wider range of values as indicated by the higher standard deviations. The mean scores were lower than the averages reported in the literature for healthy populations. Total mean composite scores for healthy populations have been reported to be in the range of 80 and above. (Huang, et. al., 2009; Varni, Bureinkle, & Seid, 2005; Varni, 2018).

<table>
<thead>
<tr>
<th>Scores</th>
<th>N</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Score</td>
<td>21</td>
<td>67.68</td>
<td>17.75</td>
<td>0-100</td>
</tr>
<tr>
<td>Physical Health</td>
<td>21</td>
<td>65.93</td>
<td>26.59</td>
<td>0-100</td>
</tr>
<tr>
<td>Psychosocial Health</td>
<td>21</td>
<td>69.43</td>
<td>22.37</td>
<td>0-100</td>
</tr>
</tbody>
</table>

Tables 2 and 3 represent the mean and standard deviations of the HRQOL scores by age and inventory. The mean scores of the infant group were noted to be higher than the average of the entire group or any subgroup. The surveys were then evaluated according to the
HEALTH RELATED QUALITY OF LIFE

age of the child (Table 4). The infant group age 13-24 months were noted to have scores for total HRQOL and composite scores for physical and psychosocial health consistent with healthy children. While children in all other age ranges, from 1 month-12 months and 2-18 years of age, scored at or below the ranges noted in the literature for children with acute and chronic health conditions. (Huang, et. al., 2009; Varni et al., 2005; Varni, 2018).

Table 2:

<table>
<thead>
<tr>
<th>Scores</th>
<th># of Items</th>
<th>N</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Score</td>
<td>45</td>
<td>8</td>
<td>80.91</td>
<td>18.46</td>
<td>0-100</td>
</tr>
<tr>
<td>Physical Health</td>
<td>19</td>
<td>8</td>
<td>79.86</td>
<td>15.87</td>
<td>0-100</td>
</tr>
<tr>
<td>Psychosocial Health</td>
<td>26</td>
<td>8</td>
<td>86.17</td>
<td>19.06</td>
<td>0-100</td>
</tr>
<tr>
<td>Emotional Functioning</td>
<td>12</td>
<td>8</td>
<td>76.17</td>
<td>21.42</td>
<td>0-100</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>5</td>
<td>7</td>
<td>82.32</td>
<td>21.95</td>
<td>0-100</td>
</tr>
<tr>
<td>Cognitive Functioning</td>
<td>9</td>
<td>7</td>
<td>90.21</td>
<td>12.95</td>
<td>0-100</td>
</tr>
</tbody>
</table>

*missing value in Social and Cognitive Functioning

Table 3:

<table>
<thead>
<tr>
<th>Scores</th>
<th># of Items</th>
<th>N</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Score</td>
<td>23</td>
<td>13</td>
<td>60.10</td>
<td>16.41</td>
<td>0-100</td>
</tr>
<tr>
<td>Physical Health</td>
<td>8</td>
<td>13</td>
<td>56.96</td>
<td>32.70</td>
<td>0-100</td>
</tr>
<tr>
<td>Psychosocial Health</td>
<td>15</td>
<td>13</td>
<td>63.50</td>
<td>22.85</td>
<td>0-100</td>
</tr>
<tr>
<td>Emotional Functioning</td>
<td>5</td>
<td>13</td>
<td>69.66</td>
<td>26.08</td>
<td>0-100</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>5</td>
<td>13</td>
<td>59.90</td>
<td>22.52</td>
<td>0-100</td>
</tr>
<tr>
<td>School Functioning</td>
<td>5</td>
<td>13</td>
<td>66.96</td>
<td>21.00</td>
<td>0-100</td>
</tr>
</tbody>
</table>

The smallness of the sample size allowed all of surveys to be reviewed to better understand the lower scores and more specifically identify common patterns. Thirty-eight percent (n=5) of children age 2-18 were noted to always have problems walking, running and participating in play or sports activities. This percentage increased to 53% (n=7) when the
HEALTH RELATED QUALITY OF LIFE

group who often had problems with running, walking and participating in play or sports activities was included in this measurement. Fifty-three percent (n=7) of the children ages 2-18 had difficulty getting along with and playing with other children. Thirty percent (n=4) were reported to not be able to keep up with peers, or do things other children of the same age can do. Thirty percent (n=3) of the infants were noted to have recurring rashes. Although only two children were in the age grouping of 13-18, both scored in the healthy range for physical HRQOL, but very poorly for social and school functioning.

Table 4:

<table>
<thead>
<tr>
<th>Scale descriptive for Peds QL™ 4.0 Generic Core Scales Parent Proxy: All groups by tool</th>
<th>Infants 1-12 Months</th>
<th>N</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Score</td>
<td>5</td>
<td>72.01</td>
<td>10.54</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Physical Health</td>
<td>5</td>
<td>73.46</td>
<td>11.63</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Psychosocial Health</td>
<td>5</td>
<td>70.57</td>
<td>19.36</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Infants 13-24 Months</td>
<td>3</td>
<td>89.81</td>
<td>12.18</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Physical Health</td>
<td>3</td>
<td>86.30</td>
<td>21.31</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Psychosocial Health</td>
<td>3</td>
<td>93.26</td>
<td>6.30</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Toddlers 2-4 Years</td>
<td>5</td>
<td>57.35</td>
<td>20.21</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Physical Health</td>
<td>5</td>
<td>43.12</td>
<td>33.10</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Psychosocial Health</td>
<td>5</td>
<td>74.57</td>
<td>18.14</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Young Child 5-7 Years</td>
<td>4</td>
<td>64.94</td>
<td>18.41</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Physical Health</td>
<td>4</td>
<td>68.48</td>
<td>22.00</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Psychosocial Health</td>
<td>4</td>
<td>60.88</td>
<td>32.76</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Children 8-12 Years</td>
<td>2</td>
<td>49.45</td>
<td>0.76</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Physical Health</td>
<td>2</td>
<td>56.25</td>
<td>35.35</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Psychosocial Health</td>
<td>2</td>
<td>45.83</td>
<td>20.03</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Teens 13-18 Years</td>
<td>2</td>
<td>67.93</td>
<td>9.99</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Physical Health</td>
<td>2</td>
<td>78.12</td>
<td>30.93</td>
<td>0-100</td>
<td></td>
</tr>
<tr>
<td>Psychosocial Health</td>
<td>2</td>
<td>58.73</td>
<td>4.14</td>
<td>0-100</td>
<td></td>
</tr>
</tbody>
</table>
Recommendations and Discussion

The project was limited by only using a parent proxy tool. Use of a parent proxy tool and a self-report tool together may have provided a stronger analysis and a child-centric perspective. The lack of detailed demographics and health history information further limited the study outcomes. It could be that the population assessed had significant acute and or chronic health conditions which are the result of the low HRQOL scores. Use of a convenience sample could also have skewed the outcomes, as potentially, the parents who have a higher level of functional status may be working or in school during the resident meetings and thus did not complete the survey.

Although the sample size was small and the standard deviations wide to be considered generalizable and statistically significant, the scores across all age groups, except 13-24 months, consistently demonstrated lower than average HRQOL mean scores for healthy children. The total mean score for children age 2-18 years of age in this project was 60.10. This is approximately 20-30 points below the scores noted in the literature for healthy children. Healthy children on average have a total mean score in the 80’s, while children with acute and chronic conditions have been noted to have total mean scores in the 70’s and below (Havermann et al., 2014; Huang et al., 2009; Varni et al., 2005; Varni, Seid, & Kurtin, 2001). The children in this study age 2-18 had a total mean score 10-15 points below that of children with acute and or chronic health conditions. The physical and psychosocial health composite mean scores and the individual domains within the composite scores were also consistently at or below the ranges reported in the literature for children with acute and chronic health conditions.
This pilot project demonstrated that the information reported by parents via the PedsQL™ Generic parent proxy inventories implied that the HRQOL of the sample of children living in transition housing had mean scores at or below those of children with chronic and acute health conditions. The children in the transitional housing could all benefit from regular screenings and the implementation of activities to target the challenges identified.

The literature demonstrates chronic exposure to poverty and social determinants, such as food insecurity and lack of stable housing can negatively impact both short and long-term physical and mental health (AAP, 2016; Franke, 2014; Garner 2012). The PedsQL™ Generic is a tool which can be easily used to screen for deficits in HRQOL.

While the literature discusses the negative physiological effects on the child and developing brain, related to social determinants, the literature also demonstrates opportunities and activities to mitigate this phenomenon. By definition, residing in transitional housing, living at or below the poverty level puts a child at risk for exposure to those things which are defined as stress and can become toxic stress. However, without measuring, it is difficult to specifically identify that stressors exist and how they are manifesting themselves in the child’s life. It was not intuitive by observing the physical health of the children, who reside in transitional housing, that they are potentially deconditioned and cannot physically keep up with their peers. This could be related to fatigue, nutrition, undiagnosed asthma, obesity or something else. With close to 100 families with children living in the transitional housing, with access to an active after school program and park-like playground, it was alarming to understand that in this project, 53% of the children were reported to have difficulty interacting with and or playing with other children.
The literature demonstrates the ill effects social determinants and poverty have on children. Understanding how these stressors manifest in a child is not intuitive and thus mitigating the stressors caused by the social determinants are not intuitive either. Evaluating a child’s health HRQOL with a simple screening tool and designing programs to mitigate the identified problematic areas could prove to be an important mechanism to improve the health and wellbeing of children who are exposed to environmental and social stressors.

The patterns identified by this pilot project, which included children noted to be potentially physically deconditioned and not able to keep up with peers during play or sport activities, children identified as potentially socially isolated, exampled by having problems getting along with and interacting with peers and an abnormally high number of children described by parents as not being healthy, all indicate that there is some alteration in the health status of these children. These patterns provide insight into potential actions which could be taken to intervene. Simple interventions could have long lasting positive effects on a child’s physical, social and emotional health and cognitive wellbeing.

The housing community offers daily programs for children such as an afterschool homework program, a dinner club, and an early intervention program. The community has a large secure gated playground. There is both the physical space and the organized time when children are brought together, which could be an opportunity to provided targeted structured programs to assess and improved endurance and physical health. Activities targeted at team and interpersonal interactions which are fun and low risk (non-competitive) could teach children how to play, interact and negotiate with each other and build self-esteem. Activities such as these could impact children positively and in fact mitigate some of the long lasting effects caused by chronic stress and alterations in HRQOL.
HEALTH RELATED QUALITY OF LIFE

The PedsQL™ Generic is a simple and inexpensive tool which can be used in many different settings: primary care office, school, social programs to assess HRQOL. Understanding the status of HRQOL and simple interventions could prove to have long lasting positive effects for health outcomes for children. It is recommended that this project be more broadly implemented with the goal of obtaining a statistically significant sample size to further evaluate and generalize the outcomes. It would also be important to gather more specific demographic details, such as ethnicity, economic, health outcomes, grade in school, involvement in extracurricular activities, family composition, a detailed health history and social determinant screening.

Translation

The researcher presented the outcomes and limitations of the pilot project to the Director of Health and Human Services. The Director noted that she was not surprised by the findings and stated, “If you had surveyed 100% of the families she believed the results would be the same.” She went on to share that although the community offers programs for children such as the dinner club, after school program, has a gated park like setting all which could afford opportunity for play and interaction, it is her observation that the children are socially isolated by their parents. She stated that less than 1% of the children participate in the organized programs. The Director felt that the parent’s unwillingness to bring children to the activities plays a key role in the low attendance. She theorized that there is a lack of motivation on the part of parents and thus part of the solution is around parental engagement. The Director of Health and Human Services will be meeting with the Director of the Family Services Bureau for the community, who is a psychologist to further discuss this work and potential interventions. The researcher will also be presenting the outcome of this pilot to the
HEALTH RELATED QUALITY OF LIFE

community members at the August community meeting.

Rutgers Community Health Center, a federally qualified health center, FQHC, with a public housing designation, is located of the transitional housing community, engaged for this research project. The researcher is proposing to implement the PedsQL™ Generic more broadly into clinical practice within the center, where many of these children receive their health care. The researcher has already received approval from the owner of the Peds QL™ to use the tool routinely, free of charge in the FQHC clinical practice for up to 500 children.

Dissemination

As described above the researcher will continue to collaborate with the leadership of the housing community to further evaluate the needs of the residents of the transitional housing community and develop strategies for intervention. The researcher has already engaged leadership and to collaborate on a larger project which will hopefully provide more critical insights into the situation and better inform opportunities and options for intervention.

The researcher is currently working with several New Jersey based foundations: the Nicholson Foundation, the Health Care Foundation of New Jersey, the Greater Newark Health Care Coalition, all of whom have missions which seek to improve health outcomes for children affected by social determinants. Given that there is synergy between this pilot and some of the projects the researcher is currently engaged in with these organizations, the researcher will be sharing the outcomes of this pilot project. The researcher has already begun the dialogue with one of the foundations to understand if it would be appropriate to utilize the Peds QL™ Asthma specific inventory in a current study evaluating environmental interventions and cost of care for
HEALTH RELATED QUALITY OF LIFE

children on Medicaid who have moderate to severe asthma.

**Professional Reporting**

There are plans to publish the outcomes of this pilot as a case study and publish a peer review article, in the future with a large sample size.
HEALTH RELATED QUALITY OF LIFE

References


American Academy of Pediatrics, Committee on Psychosocial Aspects of Child and Family
Health Committee on Early Childhood, Adoption and Dependent Care and Section on
Developmental and Behavioral Pediatrics (2012). Early childhood adversity, toxic stress
and the role of the pediatrician: translating developmental science into lifelong health.


Banyard, V., Hamby, S., & Grych, J. (2017). Health effects of adverse childhood events:
Identifying promising protective factors at the intersection of mental and physical well-

M. (2005). Child health-related quality of live and household food security. *Archives of
Pediatric and Adolescent Medicine, 159*, 51-55.

….Schuster, M.A. (2011). Association of family stressful life-change events and health-
related quality of life in fifth-grade children. *Archives of Pediatrics and Adolescent
Medicine, 165*(4), 354-359.

(1998). Relationship of childhood abuse and household dysfunction to many of the
245-258.


National Scientific Council on the Developing Child (2014). Excessive stress disrupts the
development of brain architecture. *Journal of Children’s Services*, 9(2) 143-153.


Solans, M., Pane, S., Estrada, M.D., Serra-Sutton, V., Berra, S., Herdman, M., …. Rajmil, L.
HEALTH RELATED QUALITY OF LIFE


Figure 1: Eco-Bio-Developmental Model of Human Health and Disease

Appendix 1

IRB Approval and Closure

Site Approval

Approval to Use PedsQL™

Study Protocol

Informed Consent
Theory Based Table of Evidence

**Question:** Is there a relationship between effects of toxic stress / SDoH in children and HRQOL. Can it be measured?

<table>
<thead>
<tr>
<th>Source</th>
<th>Study Purpose</th>
<th>Theory Used</th>
<th>How Theory Guided Study</th>
<th>Identify Concepts Used</th>
<th>Results</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Franke, H.A. (2014). Toxic stress: effects, prevention and treatment. <em>Children</em>, 1, 390-402.</td>
<td>Early identification and intervention to decrease effects to toxic stressor.</td>
<td>N/A</td>
<td>Discusses ACE and opportunity to identify and intervene to reduce the burden of toxic stressors as way to reduce negative long term outcomes.</td>
<td>Primary and secondary prevention</td>
<td>Early detection and screening can foster a mitigation plan to reduce or negate the long term negative effects.</td>
<td></td>
</tr>
</tbody>
</table>

**Source Type:** Peer consensus document

**Study Purpose:** Describes the impact of toxic stress and effects including poverty on children’s health in the US. Describes the opportunity to screen, identify SDoH / toxic stressors and during childhood. Articulates the long-term effects of lack of intervention. Describes the state of poverty and effect on children’s health in the US. Describes ACE and opportunity to identify and intervene to reduce the burden of toxic stressors as way to reduce negative long term outcomes. Early detection and screening can foster a mitigation plan to reduce or negate the long term negative effects.
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Source Type</td>
<td>Peer consensus document</td>
</tr>
<tr>
<td>Study Purpose</td>
<td>Understand the long-term ill effects of poverty on the future economy as influenced by negative health outcomes.</td>
</tr>
<tr>
<td>Theory Used</td>
<td>N/A</td>
</tr>
<tr>
<td>How Theory Guided Study</td>
<td>Evaluates the effects of health situations related to social determinants and their long and short outcomes on the economy. An example birth weight, asthma, obesity.</td>
</tr>
<tr>
<td>Identify Concepts Used</td>
<td>Primary and secondary prevention</td>
</tr>
<tr>
<td>Results</td>
<td>There is adequate evidence to conclude a relationship between family income and child development.</td>
</tr>
<tr>
<td>Comments</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Source Type</td>
<td>Review of the literature</td>
</tr>
<tr>
<td>Study Purpose</td>
<td>Link HRQOL and health conditions by establishing clinically relevant cut-off scores for the Peds QI-tool.</td>
</tr>
<tr>
<td>Theory Used</td>
<td>N/A</td>
</tr>
<tr>
<td>How Theory Guided Study</td>
<td>Evaluates the importance of measuring HRQOL. What contexts make a difference. Why it is important to measure.</td>
</tr>
<tr>
<td>Identify Concepts Used</td>
<td>Primary and secondary prevention</td>
</tr>
<tr>
<td>Results</td>
<td>Measuring HRQOL provides an important opportunity to identify risk which impacts HRQOL and future longitudinal health.</td>
</tr>
<tr>
<td>Comments</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Source Type</td>
<td>Peer review; cross-sectional study.</td>
</tr>
<tr>
<td>Study Purpose</td>
<td>To link pediatric HRQOL and health conditions by establishing a clinically meaningful cutoff score for the PedsQL.</td>
</tr>
<tr>
<td>Theory Used</td>
<td>N/A</td>
</tr>
<tr>
<td>How Theory Guided Study</td>
<td>Establish cutoff scores for the PedsQL domains.</td>
</tr>
<tr>
<td>Identify Concepts Used</td>
<td>Social determinants, chronic disease</td>
</tr>
<tr>
<td>Results</td>
<td>HRQOL varied with health conditions. Establishing cutoff scores for the PedsQL total functioning is a valid and convenient means to potentially ID children, with special health care needs and chronic conditions.</td>
</tr>
<tr>
<td>Comments</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Source Type</td>
<td>Peer review/ consensus</td>
</tr>
<tr>
<td>Study Purpose</td>
<td>Understand the long-term ill effects of mental health / SDoH issues in children.</td>
</tr>
<tr>
<td>Theory Used</td>
<td>N/A</td>
</tr>
<tr>
<td>How Theory Guided Study</td>
<td>Study shared best practices to identify ACE in children and shares known strategies for mitigation.</td>
</tr>
<tr>
<td>Identify Concepts Used</td>
<td>Primary and secondary prevention, social determinants of health, ACE</td>
</tr>
<tr>
<td>Results</td>
<td>Identifies resources such as SAMHSA and action oriented strategies to mitigate risk related to mental health related to negative effects of SDoH and ACE.</td>
</tr>
<tr>
<td>Comments</td>
<td></td>
</tr>
<tr>
<td>Source Type</td>
<td>Peer review, cross-sectional study</td>
</tr>
<tr>
<td>Study Purpose</td>
<td>Examine the association of lifetime exposure to traumatic stress and the relationship with HRQOL.</td>
</tr>
<tr>
<td>Theory Used</td>
<td>N/A</td>
</tr>
<tr>
<td>How Theory Guided Study</td>
<td>Study of 170 children and parents to assess traumatic events, through a parent screening inventory.</td>
</tr>
<tr>
<td>Identify Concepts Used</td>
<td>Primary and secondary prevention, social determinants of health, ACE, HRQOL</td>
</tr>
<tr>
<td>Results</td>
<td>Exposure to traumatic events during childhood is associated with less positive HRQOL. Interventions can prevent long-term ill effects.</td>
</tr>
<tr>
<td>Comments</td>
<td></td>
</tr>
<tr>
<td>Source Type</td>
<td>Peer review,</td>
</tr>
<tr>
<td>Study Purpose</td>
<td>This work shares a precedence for why measuring HRQOL in children through the use of a valid tool- PedsQL is important.</td>
</tr>
<tr>
<td>Theory Used</td>
<td>N/A</td>
</tr>
<tr>
<td>How Theory Guided Study</td>
<td>This study studies the demand and need for health outcomes measured and the value of assessing HRQOL.</td>
</tr>
<tr>
<td>Identify Concepts Used</td>
<td>Primary and secondary prevention, social determinants of health, ACE, HRQOL</td>
</tr>
<tr>
<td>Results</td>
<td>HRQOL measured by the PedsQL was documented as an important health outcome measure.</td>
</tr>
<tr>
<td>Comments</td>
<td></td>
</tr>
<tr>
<td>Source Type</td>
<td>Study Purpose</td>
</tr>
<tr>
<td>-------------</td>
<td>---------------</td>
</tr>
<tr>
<td>Peer review</td>
<td>Identify available generic and disease HRQOL tools for children and review their psychometric properties.</td>
</tr>
<tr>
<td>Peer review</td>
<td>Determine feasibility, reliability and validity of the PedsQL generic survey.</td>
</tr>
</tbody>
</table>