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Introducing Screening for Family Risks in Young Children in Primary Care

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Date of Submission: May, 2018

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Abstract

Background: One in four children in the United States under the age of five is at risk for developmental, behavioral or social delay. Genetics and environment, including exposure to adversity, play a major role in healthy neurological development. The Survey of Well-being of Young Children (SWYC) as a screening instrument was developed to address perceived barriers and standardize physiological, psychosocial and family risks screening in primary care to identify those who would benefit most from early intervention.

Methods: This quality improvement project involved an information session for providers and staff at a Federally-Qualified Health Center in Western Massachusetts to introduce standardized adversity screening in the pediatric population. A workflow was developed for regular screening and the SWYC was incorporated into all preventative health exams for children under age 5 ½.

Results: The SWYC forms are now a part of the electronic medical record for use by all providers in this clinic. Developmental and behavioral screening with the SWYC effectively identifies those children at risk for delay, provides a valuable longitudinal snapshot of their development over time, and referrals to early intervention services has increased upon implementation. Limitations include increased work for support staff, a consensus that caregivers are not forthcoming in their answers about family risks and a paucity of trauma-informed medical professionals in the area able to support positive adversity findings.

Conclusion: Standardizing screening for family risks allows providers to assess the impact of home environment on their patient's future health while addressing many of the perceived barriers that have prevented childhood adversity screening in the past. Evidence-based, easily accessible mental health care needs to be more readily available for screening to be effective.

Keywords: *Childhood adversity, Survey of Well-being for Young Children*

Introducing Screening for Family Risks in Young Children in Primary Care

Screening for family risks such as smoking and/or substance abuse in the home, food insecurity, caregiver depression, and parental discord in primary care is important due to the impact that family and community health contributes to the overall wellbeing of children under the age of five. Several tools have been introduced to screen for childhood adversity, the Survey of Well-being of Young Children (SWYC) has measurement properties that were stringently vetted and have been established through peer-reviewed research. This quality improvement (QI) project involved introducing the SWYC into a Federally-Qualified Health Center in Western Massachusetts.

Background

Recent studies have shown that up to 25% of children in the United States under the age of five are at risk for developmental, behavioral or social delays (U.S. Department of Health and Human Services (HHS), 2014). There are many factors that influence development including genetic, relationships with caregivers, and community. Environmental stress (acute or chronic) can alter neurobiological development effecting individuals throughout their lifetime (Nakazawa, 2016).

According to the Child Trends Databank and National Survey of Children's Health (2013), children living below the poverty line are at increased risk for impaired development, while Hispanic and black children in the United States are more than twice as likely as their white counterparts to have a high risk for delay, 17% and 13% respectively compared to 7% for Caucasian children. Between 2003-2013, risk for developmental delay in Hispanic youth increased from 11% to 17%.

The American Academy of Pediatrics (2012) recently expanded their recommendations on early screening for autism spectrum disorders, language, motor and cognitive delays to include screening for socioemotional health and toxic stress. Early identification of risks can reduce the negative health outcomes associated with childhood adversity, yet evidence shows that only approximately one-third of primary care providers (PCPs) routinely screen for adversity, trauma and family health (Kalmakis, Chandler, Roberts, & Leung, 2016; Kerker et al., 2016). Effective screening can identify patients for whom ongoing clinical surveillance of psychosocial/behavioral problems, anticipatory guidance, and timely early intervention are indicated (Glowa, Olson & Johnson, 2016).

While many providers are comfortable screening for developmental milestones, perceived barriers to screening for childhood adversity and family health include the belief that inquiry about psychosocial issues are beyond the PCPs scope of practice, there is insufficient time during visits, concern for retraumatization of the patient and/or provider, lack of resources and a feeling that there was little that could be done with the information (Kalmakis, Chandler, Roberts, & Leung, 2016; Kerker et al., 2016). The SWYC, developed at Tufts Medical Center, standardizes screening for behavioral and developmental milestones as well as family context in children ages 2 months to 5 years. Family context includes screening for parental mental health concerns, substance use, family violence and food insecurity.

Problem Statement

The risk of unhealthy behaviors and chronic illness among children younger than five who experience adverse childhood events is indicated by the absence of screening risk during primary care visits. Educating providers and standardizing screening and treatment recommendations are the first steps needed in addressing this problem.

Organizational “Gap” Analysis of Project Site

This QI project was done at a Federally-Qualified Health Center in Western Massachusetts that provides primary care to patients of all ages. The pediatric and family practice departments are composed of physicians, family nurse practitioners (NPs), pediatricians, pediatric NPs, nurses, medical assistants, and community workers who all work together to provide patient-centered medical care. These providers see children from birth through adolescents with greater than 75% of the patient population being Hispanic and many bilingual. Currently the practice uses the Parents’ Evaluation of Developmental Status (PEDS) screening instrument for identifying possible impaired development and the Modified Checklist for Autism in Toddlers (M-CHAT) to identify behavior delay, with no standardized screening to look at family/socioeconomic risks. The American Academy of Pediatrics (2012) recommends pediatric practices implement standardized measures to identify family or community-factors that increase a child’s risk of toxic stress. Reasons for the organizational evidence-based gap in practice at this site include logistical barriers, incomplete knowledge of evidence-based research on childhood adversity, lack of mental health resources and subsequent concerns about how to address revealed adversity.

Review of the Literature

A review of literature was conducted using PubMed, CINAHL, and PsychInfo databases. The search terms “childhood adversity screening,” and “Survey of Well-being of Young Children” were used, and publications were included up to April 2018. Greater than 400 articles resulted. A snowball technique allowed the search to expand to additional pertinent literature. Articles were included according to these criteria: research on adversity/trauma screening in primary care, health outcomes associated with childhood adversity, and neurobiological

development in young children; published in peer-reviewed journals; and written in English between 1998 and 2018.

Childhood Development

The first few years of life are the most active for brain development, more than one million new neural connections are formed every second (Center on the Developing Child, 2007). Simple connections and skills form first, building a strong foundation for which more complex connections and skills to expand upon. Genetics are the blueprint for our neural scaffolding, but our experiences and environment dictate which circuits and connections get more use, grow strong and become more permanent, while those that are used less fade away from neural pruning (Nakazawa, 2016).

It is at this young age that connections are made for emotions, motor skills, behavioral control, logic, language and memory. The brain is more malleable in early life and able to adapt to varying input, but becomes less receptive to change with maturation. Strong and efficient neural connections developed before five years of age are a determinate of later emotional and physiological health. If a child is emotionally preoccupied with fear and anxiety or dealing with considerable stress at this age, no matter how genetically gifted they may be, their learning and development will be effected by that emotional experience (Center on the Developing Child, 2007).

Therefore, the parent-child relationship is a central component in development and the clinical status of very young children, highly contributing to risk and in promoting resilience (Middleton, Kelly, & Gleason, 2017). Extending beyond the primary caregiving environment, extended family, out-of-home care, neighborhood context and culture also influence development.

Adverse Childhood Experiences

Felitti and colleagues conducted a large-scale study with adults (n=17,421) screening for the prevalence of chronic illness and adverse childhood experiences (ACE) (Felitti et al., 1998). These authors found that exposure to abuse and/or family dysfunction correlated with an increased prevalence of heart disease, cancer, stroke, COPD, diabetes, liver dysfunction and skeletal fractures. Pervasiveness of disease increases with number of adversity exposures.

Since this original research, ACEs have been expanded to include a wide variety of stressors. Wade, Shea, Rubin and Wood (2014) conducted focus groups with low-income urban children in Philadelphia and found that witnessing violence, feeling discrimination based on race/ethnicity, feeling unsafe in one's neighborhood, being bullied, and living in foster care were common adverse experiences in addition to abuse and family dysfunction. Iniguez and Stankowski (2016) found emotional abuse to be the most common childhood adversity reported, followed by exposure to household substance abuse. When comparing exposure to abuse versus household dysfunction, there is no difference in the prevalence of illness in adulthood. ACE exposure is linked to an increase in psychological health consequences, health-risk behaviors, developmental disruption, healthcare utilization and cost (Kalmakis & Chandler, 2016).

Timing of exposure negatively effects health outcomes, with early exposure an important risk factor for health-risk behaviors. MRI studies show developmental differences in the prefrontal cortex (decision-making and self-regulatory skills) and the amygdala (fear processing center) in those children with ACE exposure versus those without. With chronic unpredictable stress, adolescent's autonomic response goes into overdrive hindering their ability to respond appropriately to future stressors (Dube et al., 2009).

In 2016, Sun and colleagues investigated parental depression, exposure to ACE and their relation to child food insecurity. Caregivers who reported depressive symptoms and exposure to 4 or more ACEs were 17.6 times more likely to report household and child very low food security than those without. There is a profound association between food insecurity and poor child health and development, especially in families with very young children. Their research shows that “caregivers’ childhood experiences are carried into adult household hardship and may be transferred to children in the form of food insecurity, among other stressors” (Sun et al., 2016, p. 569). Trauma and adversity exposure during the most critical periods of development disrupt education, important life transitions and limit coping mechanisms needed for later relationships and responsibilities that effect economic stability and wellbeing.

Reichman et al. (2018), using data from the Fragile Families and Child Wellbeing Study, found a link between disabling infant health conditions and a child’s exposure to ACE at the age of five. They found an 83% increase in ACE exposure in children who were disabled in infancy, highlighting the importance linking childhood developmental and adversity exposure.

Screening

Standardized and comprehensive developmental screening is necessary to identify delay and children who are at risk for ACE. The American Academy of Pediatrics (2012) recommends developmental and behavioral screening with a standardized developmental screening tool at 9, 18, and 24 or 30 months of age. Massachusetts requires screening at every visit in the pediatric periodicity schedule (Perrin, Sheldrick, Visco, Mattern, 2016). There is no universally accepted screening instrument appropriate for all populations and ages. Broad screening tools should be culturally and linguistically appropriate and address fine and gross motor skills, language and

communication, problem solving/adaptive behavior and personal-social skills (Council on Children with Disabilities, 2006).

Toddlers and preschoolers express themselves through a combination of language, play and creative activities, so observation is key to understanding health. Caregivers report observations through a lens of their own perceptions, which are influenced by their past experiences, relationships, health and education (Middleton, Kelley & Gleason, 2017). A study by Sheldrick, Neger, and Perrin (2012) found that after asking parents to fill out a questionnaire about developmental concerns in their children (i.e. PEDS), rather than filling out a developmental screener (i.e. Ages and Stages Questionnaire-3, Ages and Stages Questionnaire: Social-Emotional), there was only a moderate agreement in parent's concerns and results of the screener. Standardized developmental screening is necessary to recognize growth, identify gaps in parental knowledge about development and provide an opportunity for dialog about physiological milestones, age appropriate behavior, emotional expression and social interaction (Whitesell, Sarche & Trucksess, 2015).

Among the many hurdles to regular standardized screening are: patient access, accurate screening tools, and comprehensiveness with respect to age (Rumbaugh Whitesell, Sarche & Trucksess, 2015). Logistically, screening tools often take too long to complete, require specific props (e.g. blocks), scoring requires specialized training and there is a cost for use - all deterrents in a busy primary care health center. When patient access is available, many providers perceive barriers in screening for adversity and family health. Only one-third of PCPs regularly screen for childhood adversity (Kalmakis, Chandler, Roberts & Leung (2016); Kerker et al., 2016). Perceived barriers include insufficient time, discomfort with inquiring about psychosocial issues, concern for retraumatization, a feeling that there was little they could do with information

(Kalmakis, Chandler, Roberts & Leung, 2016), and risk of harm to the physician-parent relationship in the event of mandated reporting of child abuse and neglect to authorities (Kuhlman, Robles, Bower, & Carroll, 2018). There is also profession-wide indecision about what adversities to assess for and when to screen in order to identify youth who may disproportionately benefit from preventative programs. Early childhood interventions are most effective in remediating the association between adversity exposure and a long-term negative health trajectory (Center on the Developing Child, 2007). However, disclosures at this age are reliant on the parent or caregiver.

In a large study addressing ACE exposure and adult health, Kuhlman, Robles, Bower, and Carroll (2018) found that 8.8% of their 4036 participants reported their first adversity exposure before the age of five, 37.0% reported exposure before the age of thirteen, and 56.1% reported adversity exposure before the age of eighteen. Women were more likely to report ACE before the age of five than men. These authors found that most adverse events in this population occurred between the ages of five and thirteen, with a 318% increase in individuals exposed in this timeframe, indicating screening in early adolescence may yield the largest number of individuals for triage into prevention and intervention programs.

The Survey of Well-being of Young Children

The Survey of Well-being of Young Children (SWYC) was developed by researchers at The Floating Hospital for Children at Tufts Medical Center because of “the importance of early child development, the long-term effects of adverse childhood experiences, and the challenges of establishing a coordinated and comprehensive system of care” (Perrin, Sheldrick, Visco, & Mattern, p. 1, 2016). It is not a diagnostic tool, but a developmental-behavioral screening instrument for children under 5 ½ years of age intended to help PCPs determine areas of a child’s

functioning that may require further assessment. It is freely available, designed to be easy to read and completed by memory in ten minutes or less.

There are 12 age specific SWYC forms to be given at each well-child exam from 2 to 60 months (i.e. ages 2, 4, 6, 9, 12, 15, 18, 24, 30, 36, 48, & 60 months). Each form contains questions pertaining to *development*, *behavior/emotion* and *family stress*. Studies verifying the reliability and validity of each section have been conducted: Milestones (Shedrick & Perrin, 2013), Parents Observations of Social Interactions (POSI) (Smith, Sheldrick & Perrin, 2013), Baby Pediatric Symptom Checklist and the Preschool Pediatric Symptom Checklist (PPSC) (Sheldrick et al., 2012), and Family Questions (Black et al, 2008, Winickoff, 2008). In these studies, the SYWC compared favorably with the Ages and Stages Questionnaire (ASQ), the Child Behavior Checklist and the M-CHAT (Whitesell, Sarche & Trucksess, 2015). Race, ethnicity, gender and socioeconomic status have not shown to disproportionately affect positive and negative results (Perrin, Sheldrick, Visco, Mattern, 2016).

One feasibility study by Whitesell, Sarche and Trucksess (2014) noted the potential of discomfort for parents in answering the Family Questions (see Appendix A), but noted that this section was important “to make parents aware of how their behavior might affect their children... and that even if they do not answer these questions honestly, screening might plant seeds that would encourage them to consider seeking help” (p. 492). Many in this study agreed that the SWYC opened the door for “teachable moments” for parents about healthy childhood development (p. 493).

Summary

The healthy development of children under the age of five is vulnerable to both genetics and environmental exposures, and is highly predictive of emotional and physiological health in

adulthood. Early family health screening is necessary to identify and address risks for a negative health trajectory, and interventions in this age group have been found to be the most fruitful (Savageau et al, 2014). There is no recommended childhood adversity screening tools for PCPs, so individual practices are responsible for finding instruments that work best for the population of patients they are catering care to.

The SYWC addresses many of the perceived barriers to standardized screening including access, feasibility and comprehensiveness. It is formatted to screen children under six years of age, when providers have the most frequent contact with patients and their caregivers. Provider education is necessary to overcome perceived obstacles to standardized screening.

Theoretical Framework

Lewin's Change Theory (1951) is the theoretical foundation upon which this quality improvement project was based. Lewin's theory suggests that there are driving and resisting forces in change. To shift the balance towards planned change a 3-step model utilizing "unfreezing, change, and refreezing" can be used (Kritsonis, 2005). See Appendix B.

Unfreezing

Unfreezing involves shifting the equilibrium of an existing status quo and is Lewin's first step towards change. Unfreezing consists of motivating individuals by identifying factors that are driving forces towards change (verifying problems, highlighting what works well in an organization) and reducing restraining forces towards change (individual resistance, group conformity) (Kritsonis, 2005).

Change

Change is the transition phase of Lewin's theoretical model and is the most difficult because of the unpredictability of how people react and adapt to change. In this phase, the goal

of stakeholders is to move the equilibrium to a new target level. It involves persuasion that the existing model of behavior is not beneficial, encouraging stakeholders to view the problem from a fresh perspective and initiating group work towards a new goal (Kritsonis, 2005). Support is important in this phase.

Refreezing

The final step in Lewin's Change Theory is refreezing, which involves integrating new values into an existing community and establishing a new equilibrium (balancing driving and resisting forces) after change has taken place by revising policy and procedures (Kritsonis, 2005).

Lewin's Change Theory Applied

The unfreezing stage of this project involved working with administrators and staff at a primary care health center to recognize the importance of using a standardized developmental screening instrument that includes family risk questions. Once there was approval to move forward with this quality improvement change, this DNP student developed a workflow to look at how the SWYC screening instrument could be implemented into the health center's pediatric and family practice departments.

The identified resisting forces to possible change were largely logistical (who will give the forms to caregivers, can this be done electronically, how will it be stored, who will score the instrument, and can the practice bill for this specific screening instrument). The largest driving force was provider interest in addressing adversity in a high-risk community of children.

Lastly, education was disseminated to all stakeholders (physicians, NPs, nurses, and ancillary staff) involved in this process to persuade them that this change will be beneficial. Individual stakeholders need to find meaning and express value within the process of change

(Porter-O'Grady & Mallach, 2015). Involving all stakeholders in the process of change leads to efficiency.

The change phase of this project involved trialing the SWYC screening instrument in the pediatrics department prior to rolling it out organization-wide. This allowed a chance to provide support through the change, listen to stakeholder feedback and adapt workflow as necessary. The DNP student worked with information technology and the office manager to get the SWYC forms added to the electronic medical record (EMAR). Providers were then interviewed after implementation to help through the transition phase (Questions, Table 1).

Finally, in the refreezing phase the plan is for SWYC to go live organization-wide as a permanent part of all well-child exams for children under 5 ½ years of age.

Table 1. Implementation of Lewin's Change Model

Unfreezing	<p>Identify resisting and driving forces to change.</p> <p>Resisting: Staff workflow, how will forms be stored in EMAR, billing</p> <p>Driving: Provider interest in identifying children at risk for ACE</p> <p>Education for stakeholders.</p>
Change	<p>SWYC added to EMAR</p> <p>Trial implementation with provider interview.</p> <p>Interview Questions</p> <ol style="list-style-type: none"> 1. Did you feel supported in learning how to use the survey? 2. Did you feel listened to in your feedback? 3. Was the tool easy to use? 4. Do you find that the SWYC identifies children at risk for developmental/behavioral delay?

	<p>5. Do you find the SWYC helps recognize patients at risk for adversity exposure?</p> <p>6. Do you find caregivers forthcoming in answering “Family Questions?”</p> <p>7. What are some limitations to the SWYC?</p> <p>8. What are barriers to implementation of the SWYC?</p>
Refreezing	Implementation of the SWYC organization-wide.

Methods

The objective of this QI project was to recognize the importance of regular and standardized developmental and family health screening for young children, introduce a screening tool that was comprehensive but does not increase provider work stress, and to do so as efficiently as possible.

The first step was to develop a workflow in which to implement the SWYC into the pediatric department of a primary care health center with common referrals for positive results (i.e. CHD Early Intervention, Behavioral Health Network, substance abuse and food insecurity programs) included. Next, an educational presentation about childhood adversity and health, the importance of standardized adversity screening, and the SWYC was created for providers and staff. After education, the SWYC screening instrument was trialed in practice.

Design

“Quality improvement is a formal approach to the analysis of performance and systematic approach to improving it” (Olafson, n.d). This QI project involved: 1) addressing the gap in care, 2) reviewing literature and identifying relevant evidence based practices, 3) utilizing quality improvement tools, and 4) measuring the impact of change.

The current PEDS developmental screener used for infants, toddlers and preschool-aged children at the health center does not address socioeconomic or family risks – which is the identified gap in practice. To address this gap, a literature review was done and an informational packet for providers developed addressing the importance of standardized adversity screening in a practice where the population is at particularly high risk for adversity and developmental delay. The quality improvement instrument chosen by providers and administration was the SWYC. Although this instrument has been praised for its ease of use, designing a workflow, ensuring appropriate scoring and discussing how to address results involved focus groups and interviews with all staff partaking in the process. After implementing the SWYC screening instrument, providers were surveyed for ease of use, utility in screening and any perceived improvement in quality of care.

Setting

The primary care health center where this QI project was implemented is located in Western Massachusetts. According to the United States Census Bureau, as of July 2016, the population of this city was 40,280. Approximately 7% of the population are children under 5 years of age, 48% are of Hispanic or Latino origin, the median household income was \$36,608, and 23% of the population hold a Bachelor's degree or higher.

It is a Federally-Qualified Community Health Center that provides medical, dental, pharmacy, eye care, insurance enrollment, behavioral health and community program services based on a Patient-Centered Medical Home model. The pediatrics and family practice departments employ family practitioners, pediatricians, pediatric NPs, nurses, medical assistants and community health workers who help manage complex care cases. Providers and staff work hard to make this facility work smoothly. In the summer of 2017, after Hurricane Maria

devastated Puerto Rico, there was an influx of Puerto Rican families into this community, a large number without insurance or documentation of past medical history. Many of these patients came to seek health care at this primary care office overwhelming a lot of their resources for the next couple of months.

Currently when a patient comes to the office with their caregiver they are greeted by staff at the front desk where they are given personal information confirmation and screening instruments to complete. A medical assistant then brings the patient and caregiver into an exam room, reviews paper work and informs the provider when the patient is ready for their exam. The provider then goes to conduct their history and physical exam. For this QI project, each person in the office was included in the workflow design and provided some education of the SWYC screening instrument

Implementation was based on the Plan, Do, Study, Act(PDSA) strategy, which is a four-step improvement model utilized to carry out and test change based on observation and learning from consequences (IHI, n.d.). Planning started four months before implementation and involved research, education, and approval to change standard protocols. With providers and administration, the feasibility of change, cost of change, and ways that new protocols have been implemented into practice in the past were discussed.

Once it was decided that the SWYC would be used organization-wide, the DNP worked with the staff in the pediatrics department to trial the screening instrument in practice. Workflow was designed with staff input, education provided based on role, the SWYC forms engineered into the EMAR for charting and reimbursement purposes, and the instrument was tested with pediatric patients and their families. After trialing the SWYC, perceived pros and cons of this

screening were addressed by surveying providers about the instruments ease of use, added time to patient visit, and readiness for permanent implementation into practice.

Qualitative data from this QI project (provider and staff interviews) were summarized in an effort to capture key variables (i.e. plan for change, ease of screening tool use, barriers to implementation, suggestions for change) and distributed among providers for review.

Ethics and Human Subjects Protection

This QI project was reviewed by the UMass Amherst Institutional Review Board (IRB) (Appendix C). All patients who are given the SWYC screening instrument will be protected by the Health Insurance Portability and Accountability Act of 1996 (HIPAA) which, among other guarantees, protects the privacy of patients' health information (Health and Human Services Department, 2013). Additionally, the DNP student and practice personnel carefully conduct this project following the *Standards of Care* for practice in a primary care office.

All information collected as part of evaluating the impact of this project were aggregated data and did not include any potential patient identifiers. Screening tools were provided and assessed by PCPs and were not seen after they being filled out, protecting patient-provider privacy. The providers were asked to disregard identifying patients when discussing the screening instrument after the trial period had taken place.

Results

This is a busy Federally-Qualified Health Center that provides care to individuals of all socioeconomic backgrounds, many bilingual, and more recently displaced families from Puerto Rico. There are 5 clinicians who work in the pediatrics department (4 physicians and 1 pediatric NP), one took on the challenge of trialing the SWYC screening instrument during the transition phase. This process started in early September 2017, education for staff was in November and

the screening went live in January 2018, the SWYC was added to the EMAR in March. Currently this group is working towards putting the SWYC on tablets so that forms can be completed and scored electronically by caregivers prior to entering the exam room, taking out a step in the workflow process and making screening more efficient. For now, caregivers are given paper forms that are scored by medical assistants and reviewed by providers.

Providers were surveyed regarding the implementation of the SWYC into practice, some thoughts included: a) a feeling that change in developmental and adversity screening within the practice was necessary, b) staff were supported in learning to use the instrument, c) feedback was listened to and used to create change, d) the instrument effectively identifies those at risk for developmental and/or behavioral delay, e) caregivers are not forthcoming about family risks, and f) the instrument is complicated for support staff to manage and score.

The pediatric NP that trialed the SWYC screening instrument found that it did not take more time to address than the PEDS/M-CHAT when discussing developmental, behavior and family concerns, and she had more referrals to early prevention programs with the SWYC than when using the previous screening instruments. Her responses included:

“Caregivers very rarely answer the family risks questions positively, but it is a good way to initiate a discussion about how home environment positively or negatively affects their child’s health throughout their lifetime”.

“While many parents are aware of the possible negative psychological health consequences related to childhood adversity exposure, many are unaware of the physiological health consequences such as increased risk of heart disease and cancer. Parents are not our patients, but with this screening we are able to educate and steer them towards resources that might benefit them and their children’s health in the future.”

Throughout this process a few themes have emerged;

- a) asking about a child's exposure to adversity is difficult,
- b) resistance to change is strong,
- c) providers are overwhelmed by quality control measures,
- d) there is still some controversy about when to start adversity screening,
- e) caregivers are not willing to honestly answer questions about personal health and family dysfunction, and
- f) there is a need for a more trauma-informed health model within primary care.

These themes are a part of the ongoing discussion as the SWYC is introduced and implemented in other departments and practice locations. This screening has now been implemented in the pediatrics department- Four out of five of the pediatric providers at the health center have started using the SWYC.

Discussion

In the past, the conversation about family dysfunction would come about organically during a well child exam when a problem was prominent, but very few providers brought the topic up routinely. Kalmakis et al. (2016) found that nurse practitioners lack confidence in screening adults for histories of child abuse, so asking caregivers about their children's risks is likely just as difficult. In this study, NPs indicated that addition of an assessment tool within the EMAR would help initiate this challenging conversation.

Screening for developmental, behavior and family risks and resilience within the same instrument, as in the SWYC, may help providers discuss challenging topics and educate caregivers about the close relationship between adversity exposure, strengths, and physical and emotional health. Changing protocols, especially when utilizing an electronic medical record,

can require additional support and delayed implementation. The large influx of new patients within the past year also effected implementation of this QI change.

Implementation

Resistance to change is one of the greatest hindrances to change in any organization (Stanley, Meyer & Topolnytsky, 2005). Change is inevitable in health care as the field is adapting to meet new regulations and better serve their patients and stakeholders. Providers in a busy primary care office routinely see 20-24 patients daily, some patients are late, there may be age appropriate resistance to care with young children, and paperwork is not always filled out appropriately. These are just a few of the challenges providers face when delivering quality care, and they develop a routine to cope with these challenges.

Although providers and staff agree that adversity screening is important, an unwillingness to change trumps their awareness because routine is so hard to disrupt in a challenging workplace. The sense of inadequacy that comes with taking on a new challenge is also a deterrent. To promote organizational change, effective, high-quality communication between coworkers is necessary (Barrett, 2017).

Other important factors include training and support, employee engagement at all levels, involvement of a “provider/senior staff champion” during implementation, and identifying health care workers as primary stakeholders. Highlighting these themes going forward within the structure of Lewin’s Change Theory will aid in organization-wide implementation and sustainability of the SWYC.

“Quality measures” are a way for insurers and patients to rate and reimburse medical organizations and providers. Evidence connecting many quality measures with better health outcomes is limited (Saver et al., 2015). Providers may be forced to address issues that are of low

risk to patients because it is required, and not have time to discuss high risk health concerns. The overwhelming number of quality control measures placed on primary care providers in the era of the Affordable Care Act is another deterrent to routine adversity screening, because it is not required by insurers.

Screening for ACE has come in favor within the last two decades because of the strong correlation between experienced adversity and the incidence of chronic disease later in life. Screening at an early age and reversing this negative health trajectory has the potential to save in health-related expenses and in promoting future health and wellness. Developmental and behavioral screening has been widely adopted in medical practice because early intervention is easily accessible in schools and throughout communities. Depression, smoking and substance abuse screening is also widely performed because physician counseling and referrals for evidence-based interventions have proven to help manage symptoms.

Public health screening should address the problems we are screening for with interventions that readily available and proven to improve health outcomes. The SWYC screens for smoking and substance abuse, caregiver depression, parental discord and food insecurity, all exposures addressed by the original ACE study (with the exception of smoking) where interventions are readily available in Western Massachusetts. The SWYC is screening for childhood risk of adversity by asking caregivers about their environment and habits, research regarding provider comfort with screening, as has been done with ACEs in adult primary care, still needs to be conducted.

Adversity, resilience and their effects on health are not well understood by caregivers. Primary care providers bear the responsibility of educating about the negative effects of adversity and the negating effects of building resilience in a child's long term health. Some

providers in this health center hold the thought that with few mental health resources for young children exposed to trauma in the area, screening without access to trauma-informed treatment may be futile. There are also a lot of patients in this practice with whom follow-up is difficult because they are not in a stable home environment. Providers need to understand that routine screening can be a catalyst for behavior changes in the home (Young, 2014).

There is a lot of research still to be done on how to effectively screen for ACEs and risk of adversity (Kalmakis, Chandler, Roberts & Leung, 2016; Kalmakis et al, 2018). According to CDC-Kaiser study on ACE (2016), almost two-thirds of adults have exposure to at least one ACE, yet not all deal with debilitating physical and mental disease in adulthood. This may be because they developed coping mechanisms (from positive factors) in childhood that protected their neurodevelopment and facilitated healthy growth. Protective factors that build resilience are ways to navigate stress using psychological, social, cultural and physical resources (Chandler, Roberts & Chiodo, 2015).

Though the SWYC asks caregivers about personal and family dysfunction, it has not however, been found to better identify those children at risk for adversity. Approaching caregivers by asking about family and community strengths rather than problem-focused screening may shift the focus of care, allowing caregivers to be more open in discussing the reality of children's home environment (Leitch, 2015, 2017). In addition, using a Likert-like scale to normalize and de-pathologize the responses may be more acceptable to caregivers so the questions don't seem so accusatory. For example, asking "in the last year have you ever drunk more than intended," rather than a yes/no response, offer a range of choices on a Likert-like scale, such as: no, sometimes, often, yes.

This may mean adopting a trauma-informed approach to care. The Substance Abuse and Mental Health Services Administration (SAMHSA) lists the key principles of a trauma-informed health model to be safety, trustworthiness and transparency, peer support, collaboration and mutuality, empowerment, voice and choice, and cultural, historical and gender issues.

Conclusion

Pediatricians and family practitioners are the first line of defense against the lifelong negative health sequelae of childhood adversity. Standardized developmental and adversity screening that is comprehensive, inclusive, and feasible is necessary in a dynamic primary care office that cares for an underserved population. Identifying health risks earlier leads to better health outcomes from intervention.

This Federally-Qualified Health Center is a great resource for the community, but as is the case in many other primary care facilities, was not regularly screening for childhood adversity or family risks in their pediatric population. The Survey of Well-being of Young Children is a comprehensive screening tool that is fast to complete, easy to use, and will help providers in this office identify children at risk of developmental delay, initiating additional health services as needed. The issue of the validity of the survey needs to be further studied because caregivers are rarely forthcoming when asked about family dysfunction, or the SWYC is not effective in identifying children at risk for adversity exposure. It does however address providers perceived barriers to screening including discomfort with asking about adversity by standardizing questions within the developmental screener. Adding the SWYC to the EMAR is an additional way to help providers incorporate screening into their visit routine.

Throughout this project, it became clear how difficult it is to implement organizational change, even when there is a consensus that change is important. Going forward in helping to

implement the SWYC screening instrument organization-wide, in other departments and other locations, the focus will be on convincing staff that this change will benefit them and finding “champion” within each discipline (administration, staff, medical assistants and providers) to help with education and encouragement throughout the transition process.

Health care is a unique field where many enter because they want to help others prosper in their health, then get discouraged when they realize patients don't share similar goals. Working with children is different, they don't choose their health circumstances, and as health care providers it is our responsibility to ensure them their greatest chance at healthy development. That's why screening for family risks and resilience, and having difficult and supportive discussions with caregivers is important, because we need to know that we offer children the chance at health and well-being that they deserve.

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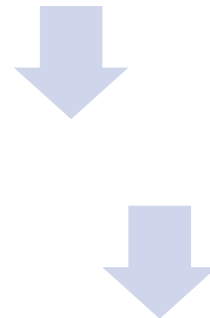
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Appendix A. Family Questions from the Survey of Well-being of Young Children

FAMILY QUESTIONS					
Because family members can have a big impact on your child's development, please answer a few questions about your family below:					
				Yes	No
1	Does anyone smoke tobacco at home?			<input type="radio"/> Y	<input type="radio"/> N
2	In the last year, have you ever drunk alcohol or used drugs more than you meant to?			<input type="radio"/> Y	<input type="radio"/> N
3	Have you felt you wanted or needed to cut down on your drinking or drug use in the last year?			<input type="radio"/> Y	<input type="radio"/> N
4	Has a family member's drinking or drug use ever had a bad effect on your child?			<input type="radio"/> Y	<input type="radio"/> N
5	In the past month was there any day when you or anyone in your family went hungry because you did not have enough money for food?			<input type="radio"/> Y	<input type="radio"/> N
Over the past two weeks, how often have you been bothered by any of the following problems?					
		Not at all	Several days	More than half the days	Nearly every day
6	Having little interest or pleasure in doing things?	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
7	Feeling down, depressed, or hopeless?	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
8	In general, how would you describe your relationship with your spouse/partner?	No tension <input type="radio"/>	Some tension <input type="radio"/>	A lot of tension <input type="radio"/>	Not applicable <input type="radio"/>
9	Do you and your partner work out arguments with:	No difficulty <input type="radio"/>	Some difficulty <input type="radio"/>	Great difficulty <input type="radio"/>	Not applicable <input type="radio"/>

Appendix B. Kurt Lewin's Change Theory

Kurt Lewin's Change Theory



Appendix C. Human Subjects Protection Office, IRB Approval Letter

University of Massachusetts Amherst
Human Research Protection Office
Mass Venture Center
100 Venture Way, Suite 116
Hadley, MA 01035

Office of Research Compliance
voice: (413) 545-3428
fax: (413) 577-1728

MEMORANDUM – Not Human Subject Research Determination

Date: November 10, 2017
To: Sarah Kells, School of Nursing

Project Title: *Screening for Developmental, Behavior and Family Risks in Young Children in Primary Care*

IRB Number: 17-200

The Human Research Protection Office (HRPO) has evaluated the above named project and has made the following determination based on the information provided to our office:

- The proposed project does not involve research that obtains information about living individuals.
- The proposed project does not involve intervention or interaction with individuals OR does not use identifiable private information.
- The proposed project does not meet the definition of human subject research under federal regulations (45 CFR 46).

Submission of an IRB application to University of Massachusetts Amherst is not required.

Note: This determination applies only to the activities described in the submission. If there are changes to the activities described in this submission, please submit a new determination form to the HRPO.

Please do not hesitate to call us at 413-545-3428 or email humansubjects@ora.umass.edu if you have any questions.

A handwritten signature in cursive script that reads 'Iris L. Jenkins'.

Iris L. Jenkins, Assistant Director
Human Research Protection Office