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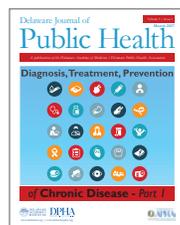
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COVER

Chronic diseases are responsible for the largest number of deaths in the United States each year, and many of these conditions are often preventable. Public health plays an important role in reducing the burden of chronic disease through the promotion of healthy lifestyles and the identification of environment factors resulting in these diseases. Increased efforts in chronic disease prevention will ensure healthier future generations and reduce growing costs associated with these diseases.

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Submissions: Contributions of original unpublished research, social science analysis, scholarly essays, critical commentaries, departments, and letters to the editor are welcome. Questions? Write chealy@delamed.org or call Liz Healy at 302-733-3989.

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IN THIS ISSUE



Omar A. Khan, M.D., M.H.S.



Timothy E. Gibbs, M.P.H.



Deb Brown

This two part issue of the Journal focuses on chronic diseases and interventions. In part 1, we delve into key chronic diseases- asthma, cardiac diseases, asthma, obesity, diabetes, and CKD- as well as the role of vaccinations in populations affected by them. The important roles of primary care and nursing care are highlighted as well. We also have a special insert on Teen Perceptions of Sexuality which, needless to say, does not directly relate to chronic disease, but does impact pathways to HIV/AIDS.

While we have significant health challenges in Delaware, we also have incredible strengths. The second of the two-issue series will discuss statewide initiatives from the public, non-profit and private sectors. Look for that issue to publish in the third week of April. We include the work of the health systems as exemplified by CareLink; community approaches to diabetes prevention; and the critical foundational role played by collaborative efforts and institutions such as the University of Delaware, Christiana Care, and the ACCEL research program. We close by circling back to the vision of our state's public health department in prevention of chronic diseases.

Moving forward, we have created a new website, dechronicdiseasecollaboartive.org. This website was inspired by the December 2016 Delaware Chronic Disease Summit organized by Deb Brown, President and CEO of the American Lung Association of the Mid-Atlantic. Its focus is Delaware-based data, resources, an easy to understand lexicon of terms, and constantly updated information on legislation, activities, and other information. We are developing a Facebook presence as well which can be found at facebook.com/Delaware-Chronic-Disease-Collaborative.

As you read this edition, please keep the following key points in mind. First, we refer to the Centers for Medicare & Medicaid Services list of chronic conditions throughout this issue and have added Addictions in deference to recent research and policy developments. The resulting list is below.

- | | |
|---|---|
| Addiction | Diabetes |
| Alzheimer's Disease and Related Dementia | Heart Failure |
| Arthritis (Osteoarthritis and Rheumatoid) | Hepatitis (Chronic Viral B & C) |
| Asthma | HIV/AIDS |
| Atrial Fibrillation | Hyperlipidemia (High cholesterol) |
| Autism Spectrum Disorders | Hypertension (High blood pressure) |
| Cancer (Breast, Colorectal, Lung, and Prostate) | Ischemic Heart Disease |
| Chronic Kidney Disease | Osteoporosis |
| Chronic Obstructive Pulmonary Disease | Schizophrenia and Other Psychotic Disorders |
| Depression | Stroke |

The second key point is that our April 2016 issue focused on Sexually Transmitted Infections and covered HIV/AIDS and Hepatitis. A future issue of the DJPH is going to focus on Cancer as a stand-alone topic.

In closing, our greatest opportunity in the battle against chronic disease is prevention. We hope you will join us in advocating for policies and funding that support prevention at local, national and international levels.



**Delaware Center
for Health Innovation**

Top 5 Ways to Enhance
Your Practice in 2017
Within the **Changing**
Health Care Environment

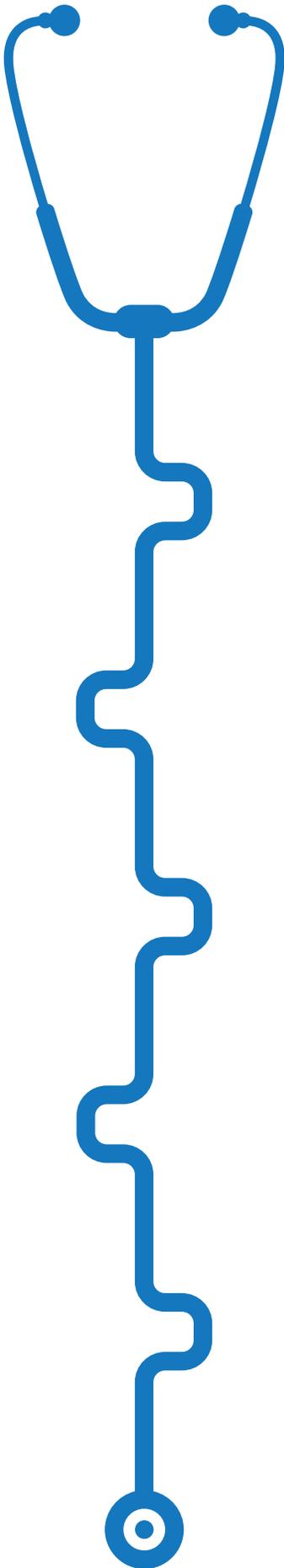
1 New federal payment models (e.g., MACRA) are changing the way physicians are paid for care and providers are encouraged to engage in alternative payment models. The Delaware Center for Health Innovation (DCHI) and the Health Care Commission (HCC) recently hosted a Learning Collaborative on January 24th, which included an introductory session on MACRA and a discussion on how your practice can be successful in this changing health care landscape. Please visit the DCHI website for summary information from the Learning Collaborative and other helpful resource information on the changing landscape.

2 More advanced payment models - specifically two-sided or capitated models - are being implemented nationwide and considered by payers and providers in Delaware. The HCC's and DCHI's Practice Transformation program pairs primary care practices with vendors who can help to better position your practice (e.g., new workflows and billing processes, new team structure) to enable success in adopting increasingly advanced payment models. DCHI can also work with your practice to determine alignment with Patient-Centered Medical Home or Accountable Care Organization models. The Common Scorecard can also reduce burden for your practice by showing performance across a set of metrics for all payers in a single scorecard.

3 Integration and team-based care are increasingly recognized as key to high-quality primary care. The Practice Transformation and Workforce Curriculum programs offered by HCC and DCHI can support your practice in developing the processes and capabilities necessary to deliver integrated and team-based care. Please visit www.choosehealthde.com for detailed information on both of these programs.

4 Currently, reforms at the federal level offer payment to physicians for providing behavioral health integration services to their Medicare beneficiaries. The intent of this initiative is to improve access to high-quality care and encourage commercial payers to offer similar payment options moving forward. DCHI published a consensus paper on implementing behavioral health integration in Delaware and is in the process of engaging primary care practices interested in exploring the operational feasibility of Behavior Health Integration.

5 While connecting patients and consumers to appropriate community-based resources can be a tall order, these resources can make the difference in an individual's ability to get and stay healthy. DCHI's Healthy Neighborhoods Committee was established in part to support community based initiatives to address social determinants of health issues and is currently working with community partners in all counties to identify appropriate resources and supports to meet patients and consumers where they are and to enable access to services and programs that can address a variety of needs related to their health and the health of the community.



Delaware Survey of Children's Health: Childhood Asthma in Delaware

Zhongcui Gao, M.S., Marlon Satchell, M.P.H.,
Danielle Haley, M.P.H., and Kristina Olson, M.H.S.



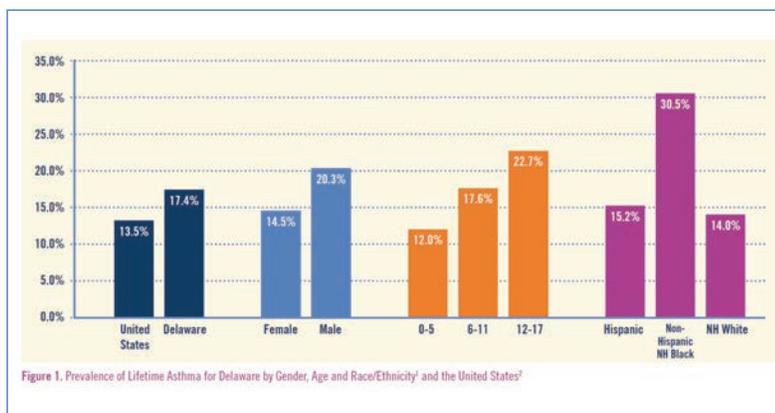
The Delaware Survey of Children's Health (DSCH), sponsored by Nemours Children's Health System (Nemours), is one of the most comprehensive health surveillance instruments for Delaware children, with results from more than 2,600 households with children ages birth through 17 in 2014. Administered in 2006, 2008, 2011 and 2014, the DSCH provides valuable data on multiple aspects of children's health — including general health status, weight status (BMI), physical activity, healthy eating, health conditions, and children's family and neighborhood environments — that can be used to inform data-driven decisions to improve children's health.¹

The 2014 administration of the DSCH was the first to include questions regarding childhood asthma. Childhood asthma is a lifelong, chronic disease impacting nearly 10 million children in the United States in 2014.² Asthma can impact a child's quality of life; however, symptoms can be controlled and asthma attacks can be avoided through patient compliance with prescribed medications and avoidance of asthma triggers such as dust mites and tobacco smoke.³ This data brief highlights the prevalence of lifetime asthma, defined as children who had ever been diagnosed with asthma; asthma management through education; barriers to asthma medication management; the relationship between lifetime asthma and weight status; and the prevalence of lifetime asthma and physical activity limitations.

Lifetime Asthma Prevalence in Delaware: Higher Than the National Prevalence & Varies by Demographic Group

To assess lifetime asthma prevalence, parents were asked, "Has a doctor, nurse or other health professional ever told you that [your child] has asthma?" DSCH data show that 17 percent of Delaware children, ages 0-17, had ever been diagnosed with asthma (referred to as "lifetime asthma") in 2014. This is higher than the national prevalence of 14 percent.²

Data from DSCH show statistically significant differences ($p < .05$) by gender, age and racial/ethnic groups regarding lifetime asthma prevalence (Figure 1).



- Male children were more likely to have lifetime asthma (20 percent), compared to female children (15 percent). However, there is some variation in gender differences by race. Among non-Hispanic Black children, ages 0-17, females were more likely to have lifetime asthma (38 percent) than males (23 percent);

- Adolescents ages 12-17 were more likely to have lifetime asthma (23 percent) than children ages 6-11 (18 percent) and children ages 0-5 (12 percent);
- Non-Hispanic Black children were more likely to have lifetime asthma (31 percent) than Hispanic children (15 percent) and non-Hispanic White children (14 percent).

There were no significant differences among four locations within Delaware, although the highest lifetime asthma prevalence was observed in the City of Wilmington (24 percent), followed by Kent County (19 percent), New Castle County excluding the City of Wilmington (17 percent), and Sussex County (14 percent).

Asthma Management Through Education

Asthma education can lead to enhanced asthma management, improved health outcomes and lower utilization of emergency health care services.^{4,5}

The 2014 DSCH data provide information on the extent to which health professionals are educating parents of children with lifetime asthma to manage their child's asthma, including how to recognize the signs or symptoms of their child's asthma episodes; what to do during their child's asthma attack; how their child should use a peak flow monitor to adjust daily medications; and how to make changes to their child's environment (e.g., home, school) to improve their child's asthma. The findings are encouraging and suggest areas of opportunity to manage children's asthma.

Among children ages 0-17 with lifetime asthma, 88 percent of parents were taught to recognize early signs or symptoms of asthma episodes by a health professional. Significantly more parents of adolescents with lifetime asthma, ages 12-17, were taught to recognize early signs or symptoms of asthma episodes (95 percent) compared to parents of children ages 6-11 (84 percent), or parents of children ages 0-5 (83 percent) ($p < .05$). In addition, 92 percent of parents of children with lifetime asthma, ages 0-17, were taught what to do during an asthma attack.

However, according to DSCH data, fewer parents of children (62 percent) with lifetime asthma, ages 0-17, were taught how their child should use a peak flow meter, a device that measures how much air people can blow out of their lungs to adjust daily

medications. Additionally, only half (50 percent) of parents of children with lifetime asthma, ages 0-17, were advised by a health professional to change things in their child's home, school or other environment to improve the child's asthma (Figure 2). Examples of environmental changes to improve asthma include family members not smoking inside the home, cleaning the environment of dust, and addressing mold and mildew issues.

Barriers to Asthma Medication

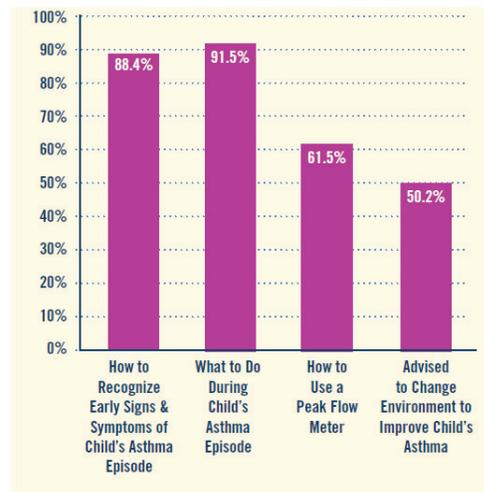
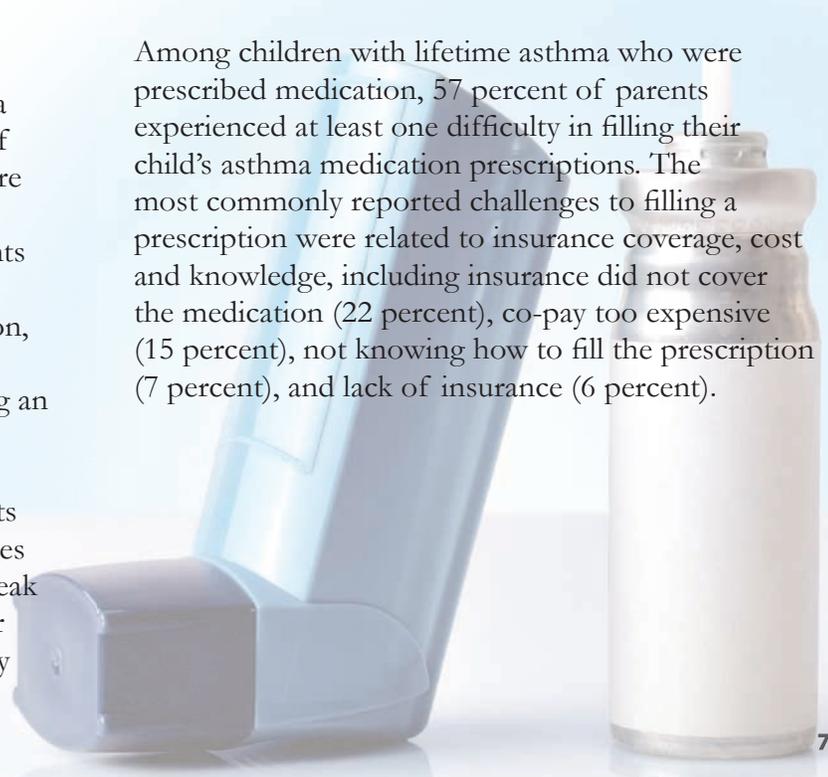


Figure 2. Parent Education to Manage Their Child's Asthma¹

Management

Results from DSCH indicate that nearly two-thirds (65 percent) of children, ages 0-17, with lifetime asthma had an asthma-related visit with a health professional in the past year. Most (93 percent) of these children were prescribed medication for their asthma.

Among children with lifetime asthma who were prescribed medication, 57 percent of parents experienced at least one difficulty in filling their child's asthma medication prescriptions. The most commonly reported challenges to filling a prescription were related to insurance coverage, cost and knowledge, including insurance did not cover the medication (22 percent), co-pay too expensive (15 percent), not knowing how to fill the prescription (7 percent), and lack of insurance (6 percent).



Of note, the location of the household was associated ($p < .05$) with insurance coverage for the medication. Parents of roughly one-third (34 percent) of children in New Castle County, excluding the City of Wilmington, indicated that insurance did not cover their asthma medication, followed by Kent County (11 percent), Sussex County (11 percent), and the City of Wilmington (3 percent).

Lifetime Asthma and Weight Status

Similar to previous studies, the 2014 DSCH results point to an association between lifetime asthma and weight status among Delaware children, ages 2-17 ($p < .05$).^{6,7,8} The DSCH data indicate that children, ages 2-17, who were obese were more likely to have lifetime asthma (26 percent) compared to normal weight children (17 percent) (Figure 3).

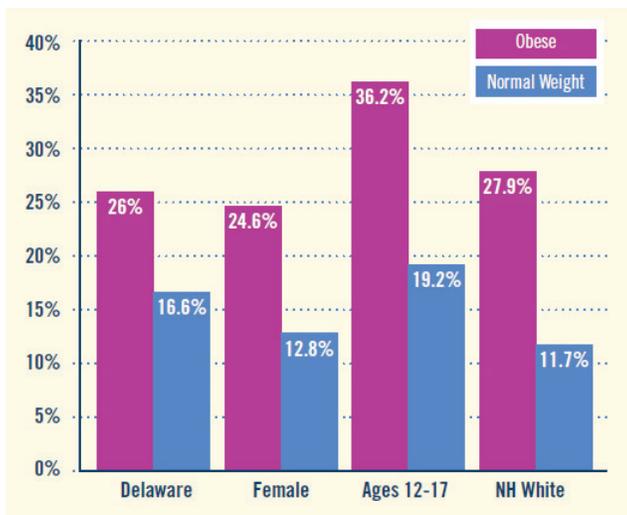


Figure 3. Asthma Prevalence by Weight Status¹

When stratified by weight status, there were statistically significant differences ($p < .05$) among female children, adolescents and non-Hispanic White children regarding lifetime asthma prevalence, according to the survey results.

Obese vs. Normal Weight Status

- Female children, ages 2-17, who were obese were more likely to have lifetime asthma (25 percent) compared to female children, ages 2-17, who were normal weight (13 percent);
- Adolescents, ages 12-17, who were obese were more likely to have lifetime asthma (36 percent) compared to normal weight adolescents (19 percent) of the same age group;
- Non-Hispanic White children, ages 2-17, who were obese were more likely to have lifetime asthma (28 percent) compared to non-Hispanic White children, ages 2-17, who were normal weight (12 percent).

Lifetime Asthma and Physical Activity Limitations

Parents were asked if their child was limited from mild activities or moderate-to-vigorous activities because of their asthma or to prevent an asthma attack during the past two weeks (from the time the survey was taken). Sixteen percent of children were “very limited” or “limited some” or “limited a little” from moderate-to-vigorous activities (jumping, dancing, swimming, climbing, crawling or running fast, playing sports, or walking upstairs), and 84 percent of children were not limited at all (Figure 4). Children, ages 2-17, with any limitations from participating in moderate-to-vigorous activities had a higher prevalence of obesity (50 percent) than children who were not limited from those activities (24 percent) (Figure 5). It is important to note, however, we cannot determine from this data if asthma, physical activity and obesity have a direct effect on each other.

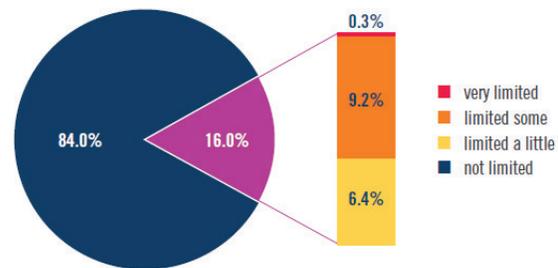


Figure 4. Distribution of Children with Asthma Limited from Moderate-to-Vigorous Activities¹



Figure 5. Obesity Prevalence by Limitation from Moderate-to-Vigorous Activities (Among Children with Asthma)¹

Eleven percent of children were “very limited” or “limited some” or “limited a little” from mild activities (such as walking, being outside, playing gently) because of their asthma or to prevent an asthma attack, and 89 percent of children were not limited at all (Figure 6). However, there were no differences in obesity prevalence between the children, ages 2-17, limited

from mild activities and the children without mild activity limitations.

Summary

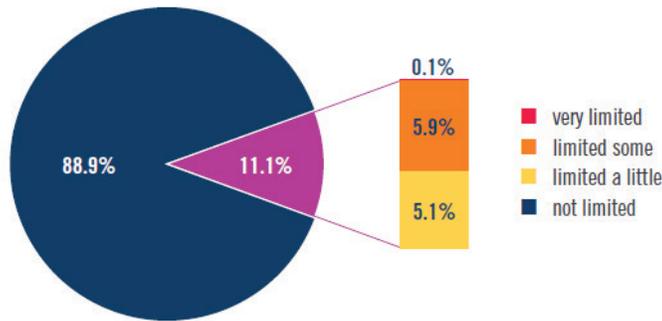


Figure 6. The Distribution of Children with Asthma Limited from Mild Activities¹

The usefulness of a surveillance tool such as the DSCH lies in its ability to draw attention to important patterns. The prevalence of lifetime asthma, defined as ever being diagnosed with asthma, among Delaware children is higher than the national prevalence and it varied within Delaware by age, gender and race/ethnicity. A relationship between children's weight status and asthma prevalence was observed; and a higher obesity prevalence was observed among the children with asthma who were limited from moderate-to-vigorous activities compared to those who were not. The DSCH is one of the most comprehensive health surveillance instruments for Delaware children. Nemours hopes that by administering the DSCH and publicizing the findings, more data-driven decisions will be made in the field of child health promotion. The statewide sample was specifically designed to allow for the analysis and comparison of children living in five geographic locations: New Castle County, the City of Wilmington, New Castle County excluding the City of Wilmington, Kent County and Sussex County. The sample also supports comparisons among children of various age groups (0-5 years, 6-11 years and 12-17 years), and racial and ethnic groups (Hispanics, non-Hispanic Blacks, non-Hispanic Whites and non-Hispanic Others). The Nemours Health & Prevention Services (NHPS) Datacenter allows for further comparison, download and visualization of the DSCH data. For more information about the DSCH, please visit the NHPS Datacenter <http://datacenter.nemours.org>, call (302) 298-7600, or email nhps_info@nemours.org.

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Zhongcui Gao, M.S., an Evaluation and Research Scientist, has been working for the Division of Health & Prevention Services at Nemours Children's Health System since 2010. Major roles include cleaning, analyzing and reporting Delaware Survey of Children's Health data, FitnessGram data from the Delaware Department of Education and Electronic Health Record data from Nemours.



Marlon Satchell, M.P.H., is an Evaluation and Research Scientist in the Nemours Children's Health System Division of Health and Prevention Services. Marlon joined the Nemours team in 2012 as the evaluator for a Centers for Medicare and Medicaid Services Innovation award. Some of her current responsibilities include providing quality improvement data assistance for the Practice Transformation and Patient-Centered Medical Home teams. Marlon has a Master of Public Health degree from Drexel University.



Danielle Haley, M.P.H., is a Special Projects Coordinator at Nemours Children's Health System in the Division of Health and Prevention Services. She has over ten years of experience within the healthcare industry focusing on advocacy, communications, research, and education. She holds a Master's degree in Public Health and a Bachelor of Science degree in Health & Physical Education.



Kristina Olson, M.H.S., is an Evaluation and Research Scientist within the Division of Health & Prevention Services Department of Population Health at Nemours Children's Health System. Prior to joining Nemours, she was a Research Associate at the Social Marketing & Communication Department of FHI 360, a non-profit human development organization in Washington, DC. She holds a Master's of Health Science degree in Health Education & Health Communication from the Johns Hopkins Bloomberg School of Public Health.

INTRODUCTION

It has been estimated that globally 300 million people have asthma¹ In the United States approximately 24 million individuals have asthma.² This is 7.4 percent of adults and 8.6 percent of children. Asthma has been increasing since the early 1980s in all age, sex and racial groups.³ Asthma causes almost 2 million emergency room visits each year.⁴ Each year, asthma causes more than 14 million doctor visits and 439,000 hospital stays.⁵ In 2014, 3,651 people died from asthma. Many of these deaths are avoidable with proper treatment and care.⁵ The annual cost of asthma in the U.S is about \$56 billion.⁶ Direct costs were nearly \$50.1 billion. Hospital stays were the largest part of these costs. Indirect costs, like lost pay from illness or death, were \$5.9 billion.⁷ Ethnic differences in asthma frequency, illness and death are highly connected with poverty, city air quality, indoor allergens, not enough patient education and poor health care.⁶ African American children have recently seen the greatest rise in asthma. Sixteen percent of African American children have asthma. Eight percent of white children have asthma.⁴ Women are more likely to have asthma than men.⁶ In 2011, 8 million women had an asthma attack. Only 5.1 million men had asthma attacks.⁴ Women have almost 65% of asthma deaths overall.⁷ Children have the greatest incidence of asthma. An average of 1 out of every 10 school-aged children have asthma.⁶ Asthma is the third-leading cause of hospital stays in children.⁶

DEFINITION

The sources of information that clinicians in specialist settings use to diagnose asthma are: a history of the characteristic symptoms such as cough, particularly when awakened at night; wheeze, breathlessness (particularly in young children), and objective evidence of a spontaneously variable or reversible airflow obstruction measured using spirometry; a bronchoconstrictor response to histamine, methacholine, or mannitol; or daily or diurnal variability in peak expiratory flow rates. In primary

care, the symptoms of wheeze and cough are often used to determine whether a patient has suspected asthma, and a recording of clinician-diagnosed asthma is made if a patient responds to a bronchodilator (airways reversibility) or an inhaled corticosteroid.⁸

ASTHMA PHENOTYPES

As yet, there is no universally agreed upon asthma phenotype.⁹ The currently recognized phenotypes include early-onset, preadolescence asthma, which is mostly allergic in nature and driven by T-helper type 2 (Th2) processes. The later-onset eosinophilic phenotype is more common in women and adults older than 20 years and is pathologically associated with a thickening of the basement membrane zone and characterized by the presence of eosinophilia as determined by sputum, bronchoscopy, or blood analysis.

Other phenotypes include: (1) exercise-induced asthma, a non-Th2 asthma where reactive bronchoconstriction occurs in response to sustained exercise, often found in individuals with mild asthma; (2) obesity-related asthma; and (3) neutrophilic asthma, in which neutrophils are prominent in airway secretions during acute, severe asthma exacerbations and patients are relatively corticosteroid resistant.¹⁰

Other asthma phenotypes include aspirin intolerance, asthma related to chronic or persistent respiratory infections and steroid-resistant asthma, which has several subtypes and is thought to be characterized by the genetic background of the individual.¹¹ The key clinical features of asthma include:

1) Variable airway obstruction. Airway obstruction in asthma, as measured by spirometry, may vary spontaneously from none to severe in the course of minutes to hours, and improves after suitable therapy. Breathlessness, impaired exercise tolerance and a feeling of tightness of the chest, which may be perceived as wheeze.

2) Nonspecific bronchial hyper reactivity. Nonspecific bronchial hyper reactivity refers to the tendency of the smooth muscle cells of asthmatic airways to constrict in response to a very wide variety of nonspecific (i.e., nonimmunological) environmental as well as pharmacological stimuli (including, for example, cold air, smoke, exercise, aerosol sprays, and dust) that do not cause clinically significant bronchoconstriction in nonasthmatics. The mechanism of this remarkable

Asthma
Asthma (from the Greek "panting") is the common inflammatory disease characterized by variable symptoms, reversible obstruction, and bronchospasm.

phenomenon remains obscure. It is further exacerbated by excessive mucus production and edema of the airway mucosa, both of which further narrow the internal airway lumen, increasing the degree of obstruction produced by a given degree of smooth muscle constriction.¹²

HISTOPATHOLOGY

Asthma is invariably characterized by inflammatory changes throughout the submucosa of the airways, but not the alveoli or the lung parenchyma. This has naturally led to the assumption that this inflammation is primarily responsible for the clinical features of the disease, although the evidence to support this assertion remains largely circumstantial.^{12,13}

Immunopathogenesis

The first principal characteristic of asthmatic inflammation is mucosal infiltration with inflammatory cells, particularly mononuclear cells (macrophages and cluster of differentiation 4 [CD4+] T lymphocytes) and granulocytes (eosinophils and neutrophils). Some severe asthmatics appear, in addition, to have elevated numbers of mucosal mast cells, but this is not universal.¹⁴

The second principal characteristic of asthmatic airway inflammation is the variable presence of structural changes in the airways, collectively termed remodeling.⁽¹⁵⁾ These include hypertrophy and hyperplasia of the airway smooth muscle cells, increased numbers of mucous goblet cells in the airway epithelium, deposition of extracellular matrix proteins (including collagen, fibronectin, and tenascin) beneath the epithelial basement membrane and in the submucosa, and neovascularization resulting in a proliferation of the vascular capillary beds within the submucosa. Some of these changes are not specific for asthma; for example, many chronic inflammatory processes involving the bronchial mucosa (asthma, COPD, bronchiectasis) are associated with mucous hypertrophy. Smooth muscle hypertrophy, hyperplasia and extracellular matrix protein deposited within the mucosa of the airways appear to be more asthma specific.¹⁶

Despite these observations, there are still many doubts about the cause and effect relationship between inflammation and remodeling largely because it is so difficult to characterize the natural progression of these two phenomena.

Role of Immunoglobulin (IgE)-Mediated Mechanisms

IgE-mediated mechanisms, and in particular the IgE-mediated degranulation of mast cells and basophils by cross-linking surface-bound, allergen-specific IgE leading to the release of histamine and other mediators, have been traditionally considered the central contributing factor.¹⁶

Role of Leukotrienes

More recently, T-helper type 2 (Th2) T lymphocytes and associated inflammatory pathway involvement of CD4+ Th2 T lymphocytes with their capacity to secrete a wide variety of cytokines and chemokines, have also risen to prominence.¹⁷

They are not only able to promulgate the inflammatory granulocyte infiltrate which characterizes asthma, including mast cell, eosinophilic and basophilic inflammation, but also B cell switching to IgE synthesis and a range of asthma-associated remodeling changes in the airway mucosa.¹⁶ Many, but not all of the key cytokines implicated so far in the pathophysiology of asthma include those encoded in the IL-4 cluster on chromosome 5q31: IL-3, IL-4, IL-5, IL-9, IL-13, and granulocyte/macrophage colony-stimulating factor (GM-CSF).¹⁶ The role of leukotriene IL-5 in the pathogenesis of asthma with eosinophilia has been confirmed with treatment by mepolizumab.¹⁸ This agent blunts eosinophil-related inflammation and improves severe asthma with high eosinophilia refractory to oral glucocorticoid steroids.

Genetics and Asthma

Since the beginning of genome-wide studies in asthma, several genes/chromosomal regions have been consistently associated with asthma susceptibility in multiple ethnic groups: ORMDL3/GSDMB, IL-33, IL-1RL1, RAD50/IL-13, HLA-DR/DQ, TSLP, and SMAD3.^{19,20} In most cases, the effect of each individual genetic variant is relatively small, suggesting that the additive effect of multiple risk variants should be evaluated.

GUIDELINES

Following a review of 59 evaluations that met rigorous scientific criteria, Grimshaw and Russell concluded that almost all of the guidelines on various conditions including asthma were associated with an improvement in medical practice, while the size of the improvements in performance varied from one intervention to another.²¹ Wide variations have been observed in the

translation of current guidelines into care, particularly primary care, and various care gaps persist.²² The translation of recommendations into care by practitioners is influenced by their level of knowledge and their attitudes, skills, beliefs, and values.²³ Content of current asthma guidelines is voluminous and is beyond the scope of this chapter. We will stress some general principles and commonalities of the current guidelines.

Environmental Triggers/ Control Causing Asthma Exacerbation

Allergy sensitivity can be diagnosed by prick skin tests and serum-specific IgE tests.

Pollen and Mold

Detailed descriptions of the complexities involved in pollen and mold species are beyond the scope of this chapter. However, pollen and mold spore exposures can trigger asthma exacerbations or worsen the symptoms in sensitized individuals. In most parts of the United States, trees pollinate in the spring, grass pollinates from late spring to early summer, and weeds pollinate in late summer through fall.²⁴ Fungal spores are responsible for both seasonal and perennial allergy symptoms.²⁵ Outdoor spores peak in mid-summer and diminish with the first hard frost in regions that experience cold winter seasons. Dry-air spores, including *Alternaria*, *Cladosporium*, and *Epicoccum*, peak in the afternoon hours under low humidity. Wet-air spores peak during the predawn hours with high humidity and include ascospores and basidiospores (mushrooms, puffballs). *Alternaria* is the most prevalent mold in dry, warm climates

Dust mite, pets, cockroaches

Dust mite exposure leads to sensitization and asthma.²⁶ There are several approaches to house-dust mite remediation and experts agree that a comprehensive strategy is best. This would include the use of dust mite encasings for mattresses and pillows,¹⁰ washing linens weekly in hot water greater than 130°F, the removal of carpeting especially in the bedroom, keeping humidity levels in the home to less than 50%, and using a high-efficiency particulate air (HEPA) filter vacuum on a weekly basis.

*Exposure to cockroach may lead to sensitization and asthma.*²⁷ It is important to perform a careful inspection to detect insect hiding places and travel routes, and to identify food sources (grease, cooking debris). Remove sources of food and household food wastes (do not keep garbage cans inside, avoid exposed pet food and snack food containers). Apply insecticides using gels or baits, in selected areas including the kitchen.

*Pets: Exposure to dog, cat mouse and other pets leads to sensitization and asthma.*²⁸

While the best way to eliminate a pet allergen is to remove the pet from the home, this is often difficult for families. If the pet remains, it is generally recommended to remove the pet from the bedroom and confine it to one area of the home as much as possible. Other effective strategies include the removal of all carpeting, the use of allergen-proof encasings for mattresses and pillows, and the use of HEPA filters.

Environmental Pollutants:

Epidemiological evidence from the last two decades has shown that environmental pollutants such as ozone, particulate matter, diesel exhaust, and biological/microbial agents contribute significantly to the morbidity associated with asthma, including increasing exacerbation frequency.²⁹ More recently, some pollutants, such as ozone, are now being implicated as causal agents in the development of new-onset asthma. Moreover, studies have now focused on certain exposure locations, such as living near busy roadways or high traffic areas, as places of particularly high risk to suffer the deleterious effects of air pollution.³⁰ Public health measures need to be implemented to reduce these environmental pollution exposures.

Viral Triggers

Respiratory viruses cause asthma exacerbations and are associated with an increased risk of developing asthma. Common respiratory viruses such as HRV and RSV are most frequently implicated, but many additional respiratory viruses have recently been identified using newer molecular virus detection methods.³¹ Exercise-Induced Bronchoconstriction EIB is defined as a transient narrowing of the lower airway with an associated increase in airway resistance, during or following exercise.³² There are two forms of EIB: EIB in patients who do not have evidence of chronic asthma (called EIB alone); and EIB in patients who



also have chronic asthma (called EIB with asthma). The more common condition, EIB with asthma, is seen in as many as 90% of asthmatic patients.^{1–3} The more severe the EIB is, the more poorly controlled the chronic asthma will be.³³ A history of respiratory symptoms alone, during or following exercise, is not reliable for the diagnosis of EIB. EIB is identified by establishing objective evidence for a fall in post exercise FEV₁ of at least 10% from its pre-exercise value, after 8 min of strenuous aerobic exercise.³²

Treatment for EIB

Beta-agonists, either inhaled short-acting beta-agonists (SABAs) or long-acting beta-agonists (LABAs) can be administered 15–30 min prior to exercise on an intermittent basis in the majority of individuals.³⁴

Anticholinergic agents, such as ipratropium bromide, have been inconsistent in attenuating EIB; Leukotriene receptor antagonists (LTRAs) such as montelukast and zafirlukast and 5-lipoxygenase inhibitors such as zileuton provide approximately 60% protection against EIB.

Rhinitis and Asthma

Rhinitis and asthma frequently occur as comorbid conditions in adults and children as manifestations of the same inflammatory disease continuum. Rhinitis is a predictor of future asthma. It impacts negatively on asthma, leading to more severe disease, worse asthma control, and impaired quality of life, despite adherence to asthma treatment. Good treatment of rhinitis is likely to improve asthma control and outcomes.³⁵ Patients with asthma and rhinitis should be treated for both conditions. Relevant allergens and triggers should be sought and excluded. The combination of intranasal and inhaled corticosteroids for persistent rhinitis and asthma should be considered, with the addition of other drugs including anti-histamines, cromones, and LTRAs as appropriate.³⁶

PHARMACOTHERAPY

The following is a summary of the individual asthma therapies.

Short-acting beta2-adrenergic agonists (SABAs)

Beta2-agonists stimulate beta-adrenergic receptors and increase cyclic adenosine monophosphate (cAMP), causing a relaxation of the airway smooth muscles and thus reversing bronchoconstriction.³⁷ Albuterol, salbutamol, levalbuterol, and pirbuterol are all drugs of choice for the immediate relief of symptoms. SABAs should only be used as rescue medications and not

continuously for disease control. Higher frequency usage is a warning sign for loss of disease control and an increased risk for an exacerbation.

Long-acting beta2-adrenergic agonists (LABAs)

LABAs have an increased lipophilic nature and thus have prolonged retention in the lung tissue with a duration of action of up to 12 h.¹³⁸ Salmeterol has a slower onset of action than formoterol, which some studies support using as a rescue inhaler when combined with ICS. Side effects include tachycardia, a prolonged QTC interval, and hypokalemia. LABAs should not be used as monotherapy, and when used with ICS there is an improvement in both the impairment and risk domains.³⁹

Corticosteroids

Corticosteroids have multiple mechanisms of action: suppressing cytokine release, decreasing the recruitment of airway eosinophils, and inhibiting the release of inflammatory mediators. They help diminish airway hyper responsiveness and decrease lung inflammation.⁴⁰

Corticosteroids can be administered via different routes: inhaled, oral, intramuscular, or intravenous. Inhaled corticosteroids are the mainstay of asthma therapy and may be combined with LABAs for patients with more severe asthma. (They generally improve lung function and airway responsiveness, reduce and prevent asthma symptoms, and prevent exacerbations.⁴¹

Oral candidiasis and dysphonia can be controlled by washing the mouth after each use and by using a spacer.⁴² Severe and difficult-to-control asthma warrants the possibility of using oral corticosteroids for long-term symptom control but side effects must be considered. Systemic side effects, seen more commonly with the prolonged use of oral corticosteroids, include Cushingoid features associated with adrenal gland suppression, hypertension, uncontrolled blood sugars, cataracts, a fatty liver, and proximal muscle weakness.⁴²

Leukotriene Modifiers

Montelukast and zafirlukast block the effects of the CysLT₁ receptor (approved for use in childhood asthma) and zileuton inhibits the 5-lipoxygenase pathway. The use of zileuton requires close monitoring of liver function tests. Leukotriene modifiers can be used in mild persistent asthma as a monotherapy and in addition to ICS for more severe disease.⁴³ Certain phenotypes show a better response, including patients with a smoking history, obesity, aspirin-exacerbated disease, and ICS insensitivity.

Methylxanthines

Sustained-release theophylline is a mild to moderate bronchodilator that can be used for mild asthma or in addition to ICS in more severe disease. It is essential to monitor the serum levels of theophylline because of its narrow therapeutic range and side effects, including arrhythmias and seizures.⁴⁴ Theophylline levels between 8 and 13 µg/mL are considered therapeutically effective and safe.

Omalizumab

Omalizumab is a recombinant IgG humanized monoclonal antibody to the Fc3 portion of the IgE antibody. It decreases the binding of IgE to the surface of mast cells, leading to a decrease in the release of mediators, in response to exposure to any allergen. It is recommended as an adjunctive therapy for patients with perennial allergies and those who have moderate to severe persistent asthma. There is a small but significant improvement in lung function (approximately 6%), a decrease in the number of exacerbations, and in the capacity to decrease the dose of oral corticosteroids.⁴⁵

Anticholinergic agents

Ipratropium bromide inhibits muscarinic cholinergic receptors and reduces the intrinsic vagal tone of airways. This is a quick-relief medication used either as an additive to SABA or as an alternative to SABA in patients who cannot tolerate SABAs. Recently, long-acting muscarinic antagonists (tiotropium) have shown benefits equivalent to LABAs in patients on ICS.^{17,18} The addition of tiotropium to a combination therapy with ICS plus LABA has shown improved FEV1 values.⁴⁶

Cromolyn Sodium and Nedocromil

Here, the mechanism of action is through blocking chloride channels and modulating the release of mast cell mediators and eosinophil recruitment. Both agents inhibit broncho-spasm caused by exercise or cold air and prophylactically prevent allergen-induced asthma worsening. Their safety profile is very good and they can be used as a maintenance therapy especially in childhood asthma.⁴⁷ However, they are no longer available in the United States.

Allergy Immunotherapy

Both subcutaneous and sublingual immunotherapy have been shown to decrease asthma-related symptoms and improve lung function and bronchial hyperreactivity. However, anaphylactic reactions (primarily in subcutaneous immunotherapy) can occur and therefore

immunotherapy should only be used in patients whose asthma is controlled and who have an FEV1 of >70% predicted normal. Studies in children have shown a decrease in the incidence of asthma exacerbations with immunotherapy and the ability to prevent new sensitizations and the progression to newly diagnosed asthma in patients with allergic rhinitis.⁴⁸

Bronchial Thermoplasty

A novel approach to treating severe asthma is through bronchial thermoplasty, which involves a bronchoscopy and administering thermal energy to the airways. It is believed to work by reducing the airway smooth muscle mass. While there has been no decrease in airway hyperresponsiveness or an improvement in FEV1, there has been a significant improvement in patients' quality of life.⁴⁹

EMERGENCY MANAGEMENT

A severe attack may be suggested by the patient's difficulty in completing sentences and diaphoresis. Respiratory distress at rest can present with using the accessory muscles of respiration, an increased respiratory rate of >28, tachycardia, and alternating abdominal and ribcage breathing. Indication for admission include: FEV1 of 30% of predicted values; Arterial blood gas PaO₂<60 mmHG; increasing PaCO₂ secondary to fatigue. Management consists of intensive bronchodilator therapy, oxygen, and systemic corticosteroids. Even though there are several complications associated with mechanical ventilation, such as barotrauma, hypotension, and infections, it can be lifesaving in patients with severe exacerbations. Identifying the precipitating cause of the exacerbation is the next step after stabilizing the patient, in order to dictate the most appropriate immediate and prophylactic therapies.⁵⁰

Inhaler Devices

Pressure MDI (pMDI), Dry powder (DPI), Breath activated (BA pMDI), and Soft mist (SMI) pMDI is a portable multi-dose device that utilizes a propellant under pressure to generate a metered dose of an aerosol through an atomization nozzle. CFC propellants have, in most cases, been replaced by hydrofluoroalkane (HFA) propellants that do not have ozone-depleting properties. Despite numerous advantages of pMDIs, many patients have difficulty coordinating actuation with inhalation.⁵¹ Spacers can assist the patient to inhale without coordination concerns. Breath-activated MDIs and Dry Powder MDIs overcome coordination issues. Dry Powder MDIs require patients to inhale quickly and forcefully.

Dry Powder Inhalers

Generally, DPIs have many advantages over pMDIs. DPIs are actuated and driven by the patient's inspiratory flow; consequently, DPIs do not require propellants to generate the aerosol, removing the need to coordinate inhaler actuation with inhalation. However, a forceful and deep inhalation through the DPI is needed to de-aggregate the powder formulation into respirable-sized particles as efficiently as possible and, consequently, to ensure that the drug is delivered to the lungs.⁵² Soft Mist MDI use liquid formulations similar to those in nebulizers, but they are generally multidose devices. Individual doses are delivered via a precisely engineered nozzle system as a slow-moving aerosol cloud (hence the term soft mist).⁵³

ASTHMA EDUCATION

There is unequivocal evidence to support asthma self-management education and its ability to improve the morbidity of this disease in both children and adults; as such, asthma self-management education is fundamental to optimal asthma management.⁵⁴ Self-management support is defined as “the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support. Self-management is defined as the tasks that individuals must undertake to live well with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management, and emotional management of their conditions.” (55)

The most effective programs include the transfer of information, skills training, regular medical follow-up, the delivery of written asthma action plans (WAAPs), and regular monitoring of symptoms or lung function by the patient. These are achieved through effective therapeutic patient–clinician partnerships using a person-centered approach. Adequate skill in the use of inhaler devices is integral to achieving good asthma outcomes.⁵⁶

Self-Monitoring

Self-monitoring is the regular self-recording of symptoms and/or peak expiratory flow (PEF)

measurements that patients perform in their home and work or school environment. WAAPs are developed by a medical practitioner or an accredited nurse practitioner to provide patients with written instructions, either in the form of text or as pictorial information, about their maintenance treatment and instructions for the escalation of treatment during both moderate and severe asthma exacerbations.⁵⁶



Hippocrates said

... to be alert to the faults of the patients which make them lie about their taking of the medicines prescribed and when things go wrong, refuse to confess that they have not been taking their medicine.

- Hippocrates. Decorum, c 200 BC.⁵⁷



ADHERENCE

It is well known that adherence in chronic disease can be poor, and this is particularly true in chronic respiratory conditions. In a meta-analysis of 569 studies, adherence to therapy in respiratory diseases ranked poorly, with a mean adherence rate of 68.8%, which was fifteenth out of seventeen different diseases.⁵⁸

A prospective study of asthma found that 24% of severe exacerbations were attributable to nonadherence.⁵⁹ There are two distinct patterns of behavior associated with non-adherence, which are referred to as intentional and unintentional nonadherence.⁶⁰ Understanding the behavior pattern of non-adherence in individuals will guide their education and help develop adherence-aiding strategies.⁶¹

Intentional non-adherence occurs when patients make purposeful decisions to take and perform treatments in a way other than that prescribed. This often refers to the self-adjustment or titration of treatment according to the patient's symptoms or beliefs, or the cessation of treatment earlier than prescribed.⁶⁰ Intentional non-adherence usually results when the patient weighs the risks against the benefits of taking medication and makes a decision based on his or her reasoning. While intentional non-adherence may result from a

balance of reasoning, the decision could result from poor knowledge about the treatment, or an erroneous understanding regarding the nature or consequence of the problem, the prescribed therapy, and the potential benefit of treatment. Therefore, this form of non-adherence can often be addressed through strategies that improve patients' knowledge and influence their health beliefs and concerns.⁶¹

Unintentional non-adherence occurs when patients do not adhere to treatment advice due to reasons out of their control.⁶⁰ These are often related to cognitive impairments, language barriers, and physical disabilities. In the case of an older person with asthma, this could relate to impaired vision or musculoskeletal problems affecting his or her ability to use inhaled medications. Further unintentional non-adherence could also result from ineffective communication or inaccurate recollection of the prescribed treatment prescription.⁶¹

Studies of how well patients retain health information suggest that less than 50% of the information conveyed by the physician is recalled immediately after an office visit.⁶⁰ Recognizing non-adherence, establishing the reasons for non-adherence, and working with patients to improve their adherence are essential elements of asthma education.⁶²

Monitoring of Asthma

Often, asthma control is poorly assessed, which can lead to under treatment and an increased risk of severe events. This is often due to the poor use of control criteria and objective measures that assess airflow obstruction. Spirometry should be regularly measured, ideally at each visit and at least once a year.⁶³ If spirometry is not available, PEF measurements with devices such as the Mini-Wright peak flow meter should be utilized. Measures of airway inflammation (i.e., induced sputum and exhaled nitric oxide) have been proposed, particularly for moderate to severe asthma, to titrate the treatment, and these measures have resulted in the reduction of exacerbations.^{64, 65}

Management of Exacerbations: The Asthma Action Plan

Since the late 1980s, consensus reports recognize that asthma is a chronic disease whose seriousness can fluctuate on a daily basis and that asthmatics should know how to modify their treatment accordingly. Written action plans are recommended for all asthmatic patients, indicating when and how to intensify their anti-inflammatory therapy according to asthma

control criteria, when to introduce oral corticosteroids, and when to seek medical advice. Action plans based on symptoms are as effective as those that are based on PEF monitoring. Although much remains to be evaluated in regard to the optimal action plan, the most important strategies to include in action plans have recently been formally evaluated.⁶⁶ Clinicians may need to consider other factors that may aggravate asthma include rhinosinusitis;⁶⁷ obesity;⁶⁸ gastroesophageal reflux;⁶⁹ or other associated respiratory conditions such as smoking-induced COPD⁷⁰ and obstructive sleep apnea.⁷¹

Diagnosis of asthma in preschool age children

The diagnosis of asthma in childhood is primarily based on the frequency, quality, variability, and severity of the symptoms in addition to a family history and other allergic comorbidities. Asthma Predictive Index (API) was developed uses a combination of clinical and easily available laboratory data to help identify preschool-age children at risk for developing persistent asthma.⁷ The index requires recurrent wheezing in the first 3 years, plus one major (parental history of asthma or physician-diagnosed atopic dermatitis) or two of three minor (eosinophilia $\geq 4\%$, wheezing unrelated to a viral URI, and/or allergic rhinitis) risk factors. Children with a positive API were up to 10 times more likely to have active asthma at some time during grade school compared with those with a negative API. In addition, both the negative predictive value and the specificity for the API were greater than 80%, indicating that the vast majority of preschool-age children with recurrent wheeze and a negative API will not have asthma at school age.⁷²

The response to therapy can be especially helpful in younger children where pulmonary function testing may not be feasible. The differential diagnosis of recurrent wheezing is large especially in younger children and testing to rule out other conditions should be performed in a thoughtful manner.⁷³ (See Table)

Diagnosis of Asthma in Older Children and Adults

The diagnosis of asthma in older children and adults is made by the presence of symptoms consistent with asthma and the demonstration of variable airflow obstruction. The presence of the characteristic symptoms alone is not sufficient for an accurate diagnosis, as these are not specific for asthma. Variable airflow obstruction is usually documented by demonstrating changes in spirometry, particularly FEV1 and VC, and the ratio of

these numbers. The currently accepted definition of an improvement in FEV1 that is consistent with asthma is >12% and >200 mL.⁷⁴

In some instances, however, an improvement in FEV1 is only demonstrated after a more prolonged period of treatment with inhaled or oral corticosteroids (as in the case presentation). In patients with mild asthma, or those on an effective treatment, spirometry can be normal. In these situations, measurements of PEF over several weeks, or the documentation of airway bronchoconstriction after exercise or inhaled mannitol, can establish the diagnosis.

Making the diagnosis of asthma can be challenging in patients who cannot reproducibly perform spirometry, and in adults with a smoking history and in whom there is fixed airflow obstruction (not reversible even after optimal treatment has been administered for a period of time). The presence of fixed airflow obstruction suggests a diagnosis of COPD, but this should be confirmed with ancillary testing such as lung diffusion capacity. See Table for differential diagnosis for asthma.⁷⁵

Assessing and Monitoring Asthma Severity, Control, and Responsiveness in Managing Asthma

Asthma control is defined as the extent to which the effects of the disease are reduced or removed by treatment. Since the disease is inherently variable over time, an assessment of asthma control should address both the current state of a person's asthma as well as accounting for the risk of problems in the future. Hence, the terms current control and future risk have been advocated.^{76,77}

Future risk refers to the risk of adverse outcomes in the future, including exacerbations, the risk of accelerated lung function decline, or even the risk of side effects from medications. Poorly controlled asthma is a known risk factor for future exacerbations. In particular, nighttime symptoms and more frequent short-acting beta-agonist (SABA) use are strongly associated with an increased risk for a future exacerbation.

The current emphasis on asthma control in clinical management differs from the earlier emphasis on asthma severity. Asthma severity was previously defined in terms of its clinical features before any treatment; this was thought to reflect the intrinsic qualities of the disease.⁷⁷ However this definition was impractical once patients started regular treatment.

To appreciate the importance of assessing asthma control one must understand the impact of asthma on the patient; to predict the risk of future adverse outcomes; to guide treatment and monitor treatment response; and to facilitate patient–doctor communication about asthma management. The impact on quality of life may include: missed work or school from asthma; reduction in usual activities; disturbance of sleep.⁷⁹ Instruments that measure asthma control include: Asthma Control Questionnaire⁸⁰ and the Asthma Control Test⁸¹.

The concepts of severity and control are used as follows for managing asthma:⁸²

- During a patient's initial presentation, if the patient is not currently taking long-term control medication, asthma severity is assessed to guide clinical decisions on the appropriate medication and other therapeutic interventions.
- Once therapy is initiated, the emphasis thereafter for clinical management is changed to the assessment of asthma control. The level of asthma control will guide decisions either to maintain or adjust therapy.
- For population-based evaluations, clinical research, or subsequent characterization of the patient's overall severity, asthma severity can be inferred after optimal therapy is established by correlating levels of severity with the lowest level of treatment required to maintain control. For clinical management, however, the emphasis is on assessing asthma severity for initiating therapy and assessing control for monitoring and adjusting therapy.

NHLBI Expert Panel Report 3 has determined guidelines for the management of asthma in different age categories. These are provided in Tables at the end of this publication. These include a step-wise approach to manage; classify severity and initiating treatment; assessing control and adjusting therapy.⁸²

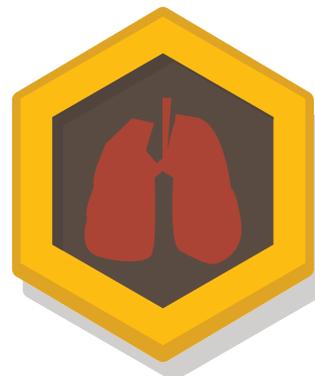
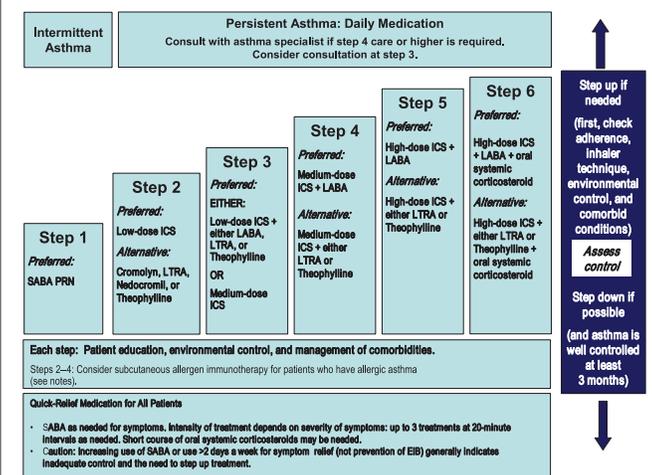


FIGURE 4-1b. STEPWISE APPROACH FOR MANAGING ASTHMA IN CHILDREN 5-11 YEARS OF AGE

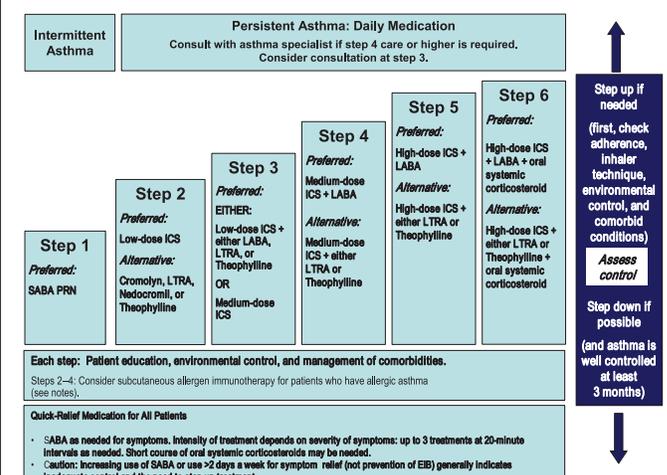


Key: Alphabetical order is used when more than one treatment option is listed within either preferred or alternative therapy. ICS, inhaled corticosteroid; LABA, inhaled long-acting beta₂-agonist, LTRA, leukotriene receptor antagonist; SABA, inhaled short-acting beta₂-agonist

Notes:

- The stepwise approach is meant to assist, not replace, the clinical decisionmaking required to meet individual patient needs.
- If alternative treatment is used and response is inadequate, discontinue it and use the preferred treatment before stepping up.
- Theophylline is a less desirable alternative due to the need to monitor serum concentration levels.
- Step 1 and step 2 medications are based on Evidence A. Step 3 ICS + adjunctive therapy and ICS are based on Evidence B for efficacy of each treatment and extrapolation from comparator trials in older children and adults—comparator trials are not available for this age group; steps 4-6 are based on expert opinion and extrapolation from studies in older children and adults.
- Immunotherapy for steps 2-4 is based on Evidence B for house-dust mites, animal danders, and pollens; evidence is weak or lacking for molds and cockroaches. Evidence is strongest for immunotherapy with single allergens. The role of allergy in asthma is greater in children than in adults. Clinicians who administer immunotherapy should be prepared and equipped to identify and treat anaphylaxis that may occur.

FIGURE 4-1b. STEPWISE APPROACH FOR MANAGING ASTHMA IN CHILDREN 5-11 YEARS OF AGE



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FIGURE 4-2a. CLASSIFYING ASTHMA SEVERITY AND INITIATING TREATMENT IN CHILDREN 0-4 YEARS OF AGE

Assessing severity and initiating therapy in children who are not currently taking long-term control medication

Components of Severity		Classification of Asthma Severity (0-4 years of age)			
		Intermittent	Mild	Moderate	Severe
Symptoms	Symptoms	≤2 days/week	>2 days/week but not daily	Daily	Throughout the day
	Nighttime awakenings	0	1-2x/month	3-4x/month	>1x/week
Impairment	Short-acting beta ₂ -agonist use for symptom control (not prevention of EIB)	≤2 days/week	>2 days/week but not daily	Daily	Several times per day
	Interference with normal activity	None	Minor limitation	Some limitation	Extremely limited
Risk	Exacerbations requiring oral systemic corticosteroids	0-1/year	≥2 exacerbations in 6 months requiring oral systemic corticosteroids, or ≥4 wheezing episodes/1 year lasting >1 day AND risk factors for persistent asthma		
		← Consider severity and interval since last exacerbation. Frequency and severity may fluctuate over time. →			
Recommended Step for Initiating Therapy (See figure 4-1a for treatment steps.)		Step 1	Step 2	Step 3 and consider short course of oral systemic corticosteroids	
		In 2-6 weeks, depending on severity, evaluate level of asthma control that is achieved. If no clear benefit is observed in 4-6 weeks, consider adjusting therapy or alternative diagnoses.			

Key: EIB, exercise-induced bronchospasm

Notes:

- The stepwise approach is meant to assist, not replace, the clinical decisionmaking required to meet individual patient needs.
- Level of severity is determined by both impairment and risk. Assess impairment domain by patient's/caregiver's recall of previous 2-4 weeks. Symptom assessment for longer periods should reflect a global assessment such as inquiring whether the patient's asthma is better or worse since the last visit. Assign severity to the most severe category in which any feature occurs.
- At present, there are inadequate data to correspond frequencies of exacerbations with different levels of asthma severity. For treatment purposes, patients who had ≥2 exacerbations requiring oral systemic corticosteroids in the past 6 months, or ≥4 wheezing episodes in the past year, and who have risk factors for persistent asthma may be considered the same as patients who have persistent asthma, even in the absence of impairment levels consistent with persistent asthma.

FIGURE 4-2b. CLASSIFYING ASTHMA SEVERITY AND INITIATING TREATMENT IN CHILDREN 5-11 YEARS OF AGE

Assessing severity and initiating therapy in children who are not currently taking long-term control medication

Components of Severity		Classification of Asthma Severity (5-11 years of age)			
		Intermittent	Mild	Moderate	Severe
Symptoms	Symptoms	≤2 days/week	>2 days/week but not daily	Daily	Throughout the day
	Nighttime awakenings	<2x/month	3-4x/month	>1x/week but not nightly	Often 7x/week
Impairment	Short-acting beta ₂ -agonist use for symptom control (not prevention of EIB)	≤2 days/week	>2 days/week but not daily	Daily	Several times per day
	Interference with normal activity	None	Minor limitation	Some limitation	Extremely limited
Risk	Exacerbations requiring oral systemic corticosteroids	0-1/year (see note)	≥2/year (see note)		
		← Consider severity and interval since last exacerbation. Frequency and severity may fluctuate over time for patients in any severity category. Relative annual risk of exacerbations may be related to FEV ₁ . →			
Recommended Step for Initiating Therapy (See figure 4-1b for treatment steps.)		Step 1	Step 2	Step 3, medium-dose ICS option	Step 3, medium-dose ICS option, or step 4
		In 2-6 weeks, evaluate level of asthma control that is achieved, and adjust therapy accordingly.			

Key: EIB, exercise-induced bronchospasm; FEV₁, forced expiratory volume in 1 second; FVC, forced vital capacity; ICS, inhaled corticosteroids

Notes:

- The stepwise approach is meant to assist, not replace, the clinical decisionmaking required to meet individual patient needs.
- Level of severity is determined by both impairment and risk. Assess impairment domain by patient's/caregiver's recall of the previous 2-4 weeks and spirometry. Assign severity to the most severe category in which any feature occurs.
- At present, there are inadequate data to correspond frequencies of exacerbations with different levels of asthma severity. In general, more frequent and intense exacerbations (e.g., requiring urgent, unscheduled care, hospitalization, or ICU admission) indicate greater underlying disease severity. For treatment purposes, patients who had ≥2 exacerbations requiring oral systemic corticosteroids in the past year may be considered the same as patients who have persistent asthma, even in the absence of impairment levels consistent with persistent asthma.

FIGURE 4–3a. ASSESSING ASTHMA CONTROL AND ADJUSTING THERAPY IN CHILDREN 0–4 YEARS OF AGE

Components of Control		Classification of Asthma Control (0–4 years of age)		
		Well Controlled	Not Well Controlled	Very Poorly Controlled
Impairment	Symptoms	≤2 days/week	>2 days/week	Throughout the day
	Nighttime awakenings	≤1x/month	>1x/month	>1x/week
	Interference with normal activity	None	Some limitation	Extremely limited
	Short-acting beta ₂ -agonist use for symptom control (not prevention of EIB)	≤2 days/week	>2 days/week	Several times per day
Risk	Exacerbations requiring oral systemic corticosteroids	0–1/year	2–3/year	>3/year
	Treatment-related adverse effects	Medication side effects can vary in intensity from none to very troublesome and worrisome. The level of intensity does not correlate to specific levels of control but should be considered in the overall assessment of risk.		
Recommended Action for Treatment (See figure 4–1a for treatment steps.)		<ul style="list-style-type: none"> Maintain current treatment. Regular followup every 1–6 months. Consider step down if well controlled for at least 3 months. 	<ul style="list-style-type: none"> Step up (1 step) and Reevaluate in 2–6 weeks. If no clear benefit in 4–6 weeks, consider alternative diagnoses or adjusting therapy. For side effects, consider alternative treatment options. 	<ul style="list-style-type: none"> Consider short course of oral systemic corticosteroids. Step up (1–2 steps), and Reevaluate in 2 weeks. If no clear benefit in 4–6 weeks, consider alternative diagnoses or adjusting therapy. For side effects, consider alternative treatment options.

Key: EIB, exercise-induced bronchospasm

Notes:

- The stepwise approach is meant to assist, not replace, the clinical decisionmaking required to meet individual patient needs.
- The level of control is based on the most severe impairment or risk category. Assess impairment domain by caregiver's recall of previous 2–4 weeks. Symptom assessment for longer periods should reflect a global assessment such as inquiring whether the patient's asthma is better or worse since the last visit.
- At present, there are inadequate data to correspond frequencies of exacerbations with different levels of asthma control. In general, more frequent and intense exacerbations (e.g., requiring urgent, unscheduled care, hospitalization, or ICU admission) indicate poorer disease control. For treatment purposes, patients who had ≥2 exacerbations requiring oral systemic corticosteroids in the past year may be considered the same as patients who have not-well-controlled asthma, even in the absence of impairment levels consistent with not-well-controlled asthma.
- Before step up in therapy:
 - Review adherence to medications, inhaler technique, and environmental control.
 - If alternative treatment option was used in a step, discontinue it and use preferred treatment for that step.

FIGURE 4–3b. ASSESSING ASTHMA CONTROL AND ADJUSTING THERAPY IN CHILDREN 5–11 YEARS OF AGE

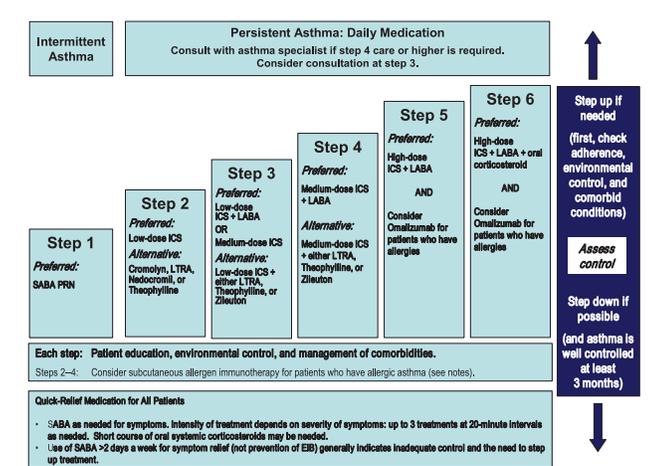
Components of Control		Classification of Asthma Control (5–11 years of age)		
		Well Controlled	Not Well Controlled	Very Poorly Controlled
Impairment	Symptoms	≤2 days/week but not more than once on each day	>2 days/week or multiple times on ≤2 days/week	Throughout the day
	Nighttime awakenings	≤1x/month	>2x/month	>2x/week
	Interference with normal activity	None	Some limitation	Extremely limited
	Short-acting beta ₂ -agonist use for symptom control (not prevention of EIB)	≤2 days/week	>2 days/week	Several times per day
	Lung function	<ul style="list-style-type: none"> FEV₁ or peak flow >80% predicted/ personal best FEV₁/FVC >80% 	<ul style="list-style-type: none"> 60–80% predicted/ personal best 75–80% 	<ul style="list-style-type: none"> <60% predicted/ personal best <75%
Risk	Exacerbations requiring oral systemic corticosteroids	0–1/year	≥2/year (see note)	
	Treatment-related adverse effects	Evaluation requires long-term followup. Medication side effects can vary in intensity from none to very troublesome and worrisome. The level of intensity does not correlate to specific levels of control but should be considered in the overall assessment of risk.		
Recommended Action for Treatment (See figure 4–1b for treatment steps.)		<ul style="list-style-type: none"> Maintain current step. Regular followup every 1–6 months. Consider step down if well controlled for at least 3 months. 	<ul style="list-style-type: none"> Step up at least 1 step and Reevaluate in 2–6 weeks. For side effects, consider alternative treatment options. 	<ul style="list-style-type: none"> Consider short course of oral systemic corticosteroids. Step up 1–2 steps, and Reevaluate in 2 weeks. For side effects, consider alternative treatment options.

Key: EIB, exercise-induced bronchospasm; FEV₁, forced expiratory volume in 1 second; FVC, forced vital capacity

Notes:

- The stepwise approach is meant to assist, not replace, the clinical decisionmaking required to meet individual patient needs.
- The level of control is based on the most severe impairment or risk category. Assess impairment domain by patient's/caregiver's recall of previous 2–4 weeks and by spirometry/peak flow measures. Symptom assessment for longer periods should reflect a global assessment such as inquiring whether the patient's asthma is better or worse since the last visit.
- At present, there are inadequate data to correspond frequencies of exacerbations with different levels of asthma control. In general, more frequent and intense exacerbations (e.g., requiring urgent, unscheduled care, hospitalization, or ICU admission) indicate poorer disease control. For treatment purposes, patients who had ≥2 exacerbations requiring oral systemic corticosteroids in the past year may be considered the same as patients who have persistent asthma, even in the absence of impairment levels consistent with persistent asthma.
- Before step up in therapy:
 - Review adherence to medications, inhaler technique, environmental control, and comorbid conditions.
 - If alternative treatment option was used in a step, discontinue it and use preferred treatment for that step.

FIGURE 4–5. STEPWISE APPROACH FOR MANAGING ASTHMA IN YOUTHS ≥12 YEARS OF AGE AND ADULTS



Key: Alphabetical order is used when more than one treatment option is listed within either preferred or alternative therapy. EIB, exercise-induced bronchospasm; ICS, inhaled corticosteroid; LABA, long-acting inhaled beta₂-agonist; LTRA, leukotriene receptor antagonist; SABA, inhaled short-acting beta₂-agonist

Notes:

- The stepwise approach is meant to assist, not replace, the clinical decisionmaking required to meet individual patient needs.
- If alternative treatment is used and response is inadequate, discontinue it and use the preferred treatment before stepping up.
- Zileuton is a less desirable alternative due to limited studies as adjunctive therapy and the need to monitor liver function. Theophylline requires monitoring of serum concentration levels.
- In step 6, before oral systemic corticosteroids are introduced, a trial of high-dose ICS + LABA + either LTRA, theophylline, or zileuton may be considered, although this approach has not been studied in clinical trials.
- Step 1, 2, and 3 preferred therapies are based on Evidence A; step 3 alternative therapy is based on Evidence A for LTRA, Evidence B for theophylline, and Evidence D for zileuton. Step 4 preferred therapy is based on Evidence B, and alternative therapy is based on Evidence B for LTRA and theophylline and Evidence D for zileuton. Step 5 preferred therapy is based on Evidence B. Step 6 preferred therapy is based on (EPR—2 1997) and Evidence B for omalizumab.
- Immunotherapy for steps 2–4 is based on Evidence B for house-dust mites, animal danders, and pollens; evidence is weak or lacking for molds and cockroaches. Evidence is strongest for immunotherapy with single allergens. The role of allergy in asthma is greater in children than in adults.
- Clinicians who administer immunotherapy or omalizumab should be prepared and equipped to identify and treat anaphylaxis that may occur.

FIGURE 4–6. CLASSIFYING ASTHMA SEVERITY AND INITIATING TREATMENT IN YOUTHS ≥12 YEARS OF AGE AND ADULTS

Assessing severity and initiating treatment for patients who are not currently taking long-term control medications

Components of Severity		Classification of Asthma Severity ≥12 years of age			
		Intermittent	Mild	Persistent Moderate	Severe
Impairment	Symptoms	≤2 days/week	>2 days/week but not daily	Daily	Throughout the day
	Nighttime awakenings	≤2x/month	3–4x/month	>1x/week but not nightly	Often 7x/week
	Short-acting beta ₂ -agonist use for symptom control (not prevention of EIB)	≤2 days/week	>2 days/week but not daily, and not more than 1x on any day	Daily	Several times per day
	Interference with normal activity	None	Minor limitation	Some limitation	Extremely limited
Risk	Exacerbations requiring oral systemic corticosteroids	0–1/year (see note)	≥2/year (see note)		
	Treatment-related adverse effects	Consider severity and interval since last exacerbation. Frequency and severity may fluctuate over time for patients in any severity category. Relative annual risk of exacerbations may be related to FEV ₁ .			
Recommended Step for Initiating Treatment (See figure 4–5 for treatment steps.)		Step 1	Step 2	Step 3	Step 4 or 5
		In 2–6 weeks, evaluate level of asthma control that is achieved and adjust therapy accordingly.			

Key: FEV₁, forced expiratory volume in 1 second; FVC, forced vital capacity; ICU, intensive care unit

Notes:

- The stepwise approach is meant to assist, not replace, the clinical decisionmaking required to meet individual patient needs.
- Level of severity is determined by assessment of both impairment and risk. Assess impairment domain by patient's/caregiver's recall of previous 2–4 weeks and spirometry. Assign severity to the most severe category in which any feature occurs.
- At present, there are inadequate data to correspond frequencies of exacerbations with different levels of asthma severity. In general, more frequent and intense exacerbations (e.g., requiring urgent, unscheduled care, hospitalization, or ICU admission) indicate greater underlying disease severity. For treatment purposes, patients who had ≥2 exacerbations requiring oral systemic corticosteroids in the past year may be considered the same as patients who have persistent asthma, even in the absence of impairment levels consistent with persistent asthma.

FIGURE 4-7. ASSESSING ASTHMA CONTROL AND ADJUSTING THERAPY IN YOUTHS ≥12 YEARS OF AGE AND ADULTS

Components of Control		Classification of Asthma Control (≥12 years of age)		
		Well Controlled	Not Well Controlled	Very Poorly Controlled
Impairment	Symptoms	≤2 days/week	>2 days/week	Throughout the day
	Nighttime awakenings	≤2x/month	1-3x/week	>4x/week
	Interference with normal activity	None	Some limitation	Extremely limited
	Short-acting beta ₂ -agonist use for symptom control (not prevention of EIB)	≤2 days/week	>2 days/week	Several times per day
	FEV ₁ or peak flow	>80% predicted/ personal best	60-80% predicted/ personal best	<60% predicted/ personal best
Risk	Validated questionnaires			
	ATAQ ACQ ACT	0 ≤0.75* ≥20	1-3 ≤1.5 16-19	3-4 N/A ≤15
	Exacerbations requiring oral systemic corticosteroids	0-1/year	≥2/year (see note)	
Recommended Action for Treatment (see figure 4-5 for treatment steps)	Progressive loss of lung function	Evaluation requires long-term followup care		
	Treatment-related adverse effects	Medication side effects can vary in intensity from none to very troublesome and worrisome. The level of intensity does not correlate to specific levels of control but should be considered in the overall assessment of risk.		
		<ul style="list-style-type: none"> Maintain current step. Regular followups every 1-6 months to maintain control. Consider step down if well controlled for at least 3 months. 	<ul style="list-style-type: none"> Step up 1 step and Reevaluate in 2-6 weeks. For side effects, consider alternative treatment options. 	<ul style="list-style-type: none"> Consider short course of oral systemic corticosteroids. Step up 1-2 steps, and Reevaluate in 2 weeks. For side effects, consider alternative treatment options.

*ACQ values of 0.76-1.4 are indeterminate regarding well-controlled asthma.
Key: EIB, exercise-induced bronchospasm; ICU, intensive care unit

- Notes:**
- The stepwise approach is meant to assist, not replace, the clinical decisionmaking required to meet individual patient needs.
 - The level of control is based on the most severe impairment or risk category. Assess impairment domain by patient's recall of previous 2-4 weeks and by spirometry/peak flow measures. Symptom assessment for longer periods should reflect a global assessment, such as inquiring whether the patient's asthma is better or worse since the last visit.
 - At present, there are inadequate data to correspond frequencies of exacerbations with different levels of asthma control. In general, more frequent and intense exacerbations (e.g., requiring urgent, unscheduled care, hospitalization, or ICU admission) indicate poorer disease control. For treatment purposes, patients who had ≥2 exacerbations requiring oral systemic corticosteroids in the past year may be considered the same as patients who have not well-controlled asthma, even in the absence of impairment levels consistent with not well-controlled asthma.
 - Validated Questionnaires for the impairment domain (the questionnaires do not assess lung function or the risk domain)
 - ATAQ = Asthma Therapy Assessment Questionnaire® (See sample in "Component 1: Measures of Asthma Assessment and Monitoring.")
 - ACQ = Asthma Control Questionnaire® (user package may be obtained at www.qoltech.co.uk or juniper@qoltech.co.uk)
 - ACT = Asthma Control Test™ (See sample in "Component 1: Measures of Asthma Assessment and Monitoring.")
 - Minimal Important Difference: 1.0 for the ATAQ, 0.5 for the ACQ; not determined for the ACT.
 - Before step up in therapy:
 - Review adherence to medication, inhaler technique, environmental control, and comorbid conditions.
 - If an alternative treatment option was used in a step, discontinue and use the preferred treatment for that step.

REFERRAL FOR SPECIALIST INVESTIGATIONS

The majority of patients with asthma have mild to moderate disease and can be managed in primary care. However, some patients benefit from referral to a respiratory specialist for assessment and management. Specifically, patients should be referred if they experience recurrent exacerbations, significant limitation of activity due to asthma, frequent symptoms despite normal lung function, or frequent symptoms despite treatment with ICS/LABA after confirming that their inhaler technique and adherence are adequate. Patients with more severe or difficult-to-treat asthma may benefit from more detailed lung function testing to optimally assess their asthma control and guide treatment strategies. Studies may include: allergy testing to identify causes for symptoms;⁸³ high-resolution computed tomography chest scans;⁸⁴ bronchial provocation testing breath testing for exhaled nitric oxide;^{85, 86} and sputum induction for inflammatory cell count.⁸⁷

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Andrew Weinstein had been an allergist and clinical immunologist for 30 years in Delaware. He is an Associate Clinical Professor of Pediatrics at Thomas Jefferson Medical College and is also the President of Asthma Management Systems. Dr. Weinstein was responsible for developing multiple research and training programs focused on asthma adherence and outcomes. He is currently directing two population health research projects funded by the NIH and Merck to examine the effectiveness of the asthma adherence management model he developed.

Managing hypertension prevents life-threatening complications

Persons with high blood pressure are four times more likely to die from stroke, and three times more likely to die from heart disease. Heart disease and stroke are the second- and fourth-leading causes of death in Delaware

One-third of Americans with high blood pressure (hypertension) are unaware they have the condition. An ideal blood pressure is less than 120/80 but 140/90 is considered the earliest stage of hypertension, often called the silent killer. However, hypertension can be managed and prevented.

Supported by funding from the Centers for Disease Control and Prevention (CDC), DPH and Quality Insights (QI) offer physician practices hypertension management tools. To date, 85 practices use QI's electronic educational modules that include patient reminders, apps, podcasts, and videos; weekly news bulletins, and hands-on technical assistance.



Seven physician offices loan blood pressure monitors so hypertensive patients can call in their readings from home. Patients learn to lower their blood pressure with prescribed medicine; by losing excess weight; and by being physically active, eating healthy meals, and not smoking.

"In my work with underserved communities, I frequently saw the serious impact that uncontrolled blood pressure has on patients' overall health," said Department of Health and Social Services Secretary Dr. Kara Odom Walker. "I'm very pleased that through our partnership with Quality Insights, we are able to offer these important tools to physicians to improve health and longevity."

Providers interested in learning more about the QI program should contact Ashley Biscardi at Abiscard@qualityinsights.org. To register for DPH's free classes to control high blood pressure, call the Bureau of Chronic Diseases at 302-744-1020.



DELAWARE HEALTH AND SOCIAL SERVICES
Division of Public Health



East Millsboro Elementary School student Hajra Sultan, at left, smiles during her screening with Registered Dental Hygienist Ashley Hudson, center, and East Millsboro Nurse Erica Jester. Submitted photo.

DPH dental program launches Delaware Smile Check in schools

The Division of Public Health's (DPH) newest school-based oral health outreach program is Delaware Smile Check (DSC). The grant-funded program provides under-served children with screenings, coordinates emergency dental treatment, and finds them dental homes.

To date, a DPH hygienist has screened 1,018 students at seven schools and applied preventive fluoride varnish to strengthen teeth against decay. Students take home oral health report cards. DSC suspected cavities in 206 students and assisted 217 in finding dentists to treat them immediately. So far, 46 dentists accept insured and uninsured students referred by DSC to ensure they receive treatment and establish a dental home.

"[DSC] has opened my eyes to the importance and genuine need of access to care, dental education, and dental disease prevention among children," said Ashley Hudson, RDH, BSDH, a participating Sussex County dental hygienist.

Dental Health Products, Inc. (DHPI) donated fluoride varnish, toothbrushes, and toothpaste.

"...DHPI is a partner for a common cause to improve oral health care for all ages," said LaDeana DeClark, special markets representative with DHPI.

Schools interested in participating in this program should contact Gena Riley in DPH's Bureau of Oral Health and Dental Health Services at Gena.Riley@state.de.us or 302-744-4554.



PARTNERS IN RESEARCH:

Developing a Patient-Centered Research Agenda for Chronic Kidney Disease

Claudine Jurkowitz, M.D., M.P.H., Sarahfaye F. Dolman, M.P.H., M.T.A., Holly Archinal

Chronic kidney disease (CKD) was the 9th leading cause of death in the United States in 2014.¹ In the U.S., more than 20 million people over the age of 20 have CKD. The highest rates of CKD are seen in individuals over 60 years of age², and diabetes and hypertension are the *most frequent causes* of CKD in the U.S.² CKD and end-stage renal disease are very costly to treat. Medicare spending for beneficiaries ages 65 and older who have CKD, prior to reaching end-stage renal disease, exceeded \$50 billion in 2014, representing 20% of all Medicare spending in this age group.² In addition, even though the end-stage renal disease population represents less than 1% of the total Medicare population, it has accounted for about 7% of Medicare fee-for-service spending in recent years (over \$30 billion).²

Inequities in CKD and end-stage renal disease incidence, risk factors and disease treatment have been consistently reported in diverse socioeconomic racial and ethnic groups within the U.S. population.³⁻⁵ A recent study showed that rates of kidney function decline were higher in Blacks compared to Whites and that kidney disease incidence was higher in Blacks and Hispanics.⁶ Compared with White patients, Black patients are less likely to have pre- end-stage renal disease nephrology care,⁷ receive adequate dialysis treatment,⁸ have an arterio-venous fistula placed for dialysis access⁹ and have access to kidney transplantation.¹⁰ Moreover, non-English speaking patients with end-stage renal disease are less likely to be placed on a transplant list than English speaking patients.¹¹

Low socio-economic status is a well-known risk factor for CKD,¹² and has been linked to increase in albuminuria and low kidney function in multiple studies.¹³⁻¹⁷ Among patients at high risk of kidney disease, those without health insurance are more likely to die or to progress towards end-stage renal disease than insured patients.¹⁸ Likewise, increased neighborhood poverty is strongly associated with higher end-stage renal disease incidence and a lower chance of being placed on a transplant list.^{19, 20}

Because CKD patients have multiple comorbid conditions, they see diverse healthcare providers in various settings, which can lead to adverse consequences such as conflicting medications and redundant testing.²¹ Poor communication between primary care physicians and specialists is an issue for patients with multiple comorbidities and may threaten quality of care.²² Health care providers have different electronic health records systems that do not “talk to each other,” leading physicians to spend countless hours “chasing data” in order to provide appropriate care for their patients. Additionally, the care of CKD patients – before and after starting renal replacement therapy (dialysis or transplantation) – remains *highly fragmented*, creating a high burden of disease on patients and the healthcare system as a whole.²³ For instance, most patients with CKD report having a primary care physician, but only a small percentage is likely to have seen a nephrologist. This lack of specialist care is most likely due to barriers such as insufficient insurance coverage or low awareness.^{2, 24} As illustrated in *Figure 1*, awareness of kidney disease is very low among individuals with low kidney function. Less than 50% of individuals with severe loss of kidney function (stage 4) are aware of their kidney disease.

Hospitalizations are frequent in patients with CKD. The rate of all cause hospitalizations increases with

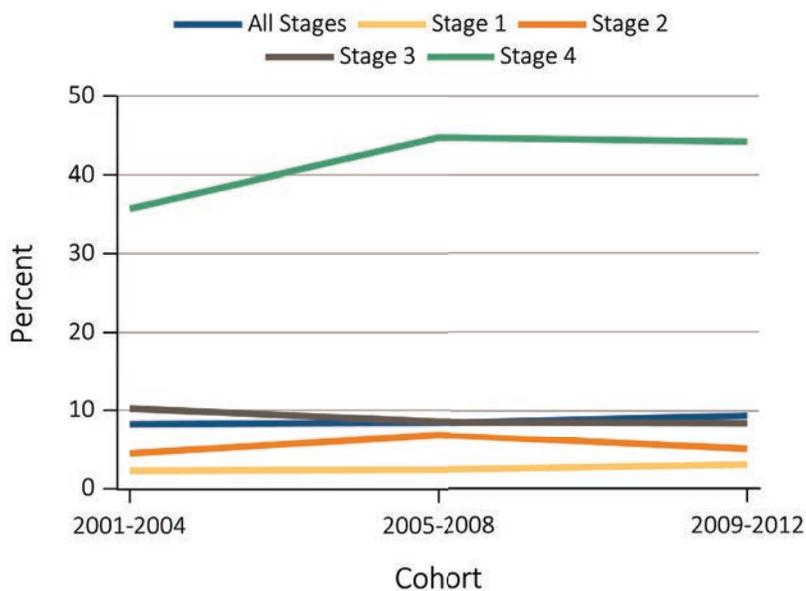


Figure 1. Awareness of kidney disease among NHANES participants with CKD

Data Source: National Health and Nutrition Examination Survey (NHANES), 2001-2012 participants aged 20 & older. From USRDS 2016 Annual Data Report.² NHANES is a representative survey of the United States population

CKD stages represent levels of kidney function according to glomerular filtration rate (GFR) and presence of kidney damage such as albuminuria. Stages are numerated from 1 to 5, with 5 representing the lowest kidney function.

Stage 1: Kidney damage with normal kidney function- GFR ≥ 90 mL/min/1.73m²

Stage 2: Kidney damage with mild loss of kidney function- GFR 60- 89 mL/min/1.73m²

Stage 3: Mild to moderate loss of kidney function- GFR 30-59 mL/min/1.73m²

Stage 4: Severe loss of kidney function- GFR 15-29 mL/min/1.73m²

Stage 5: Kidney failure- GFR <15 mL/min/1.73m²

worsening of kidney function^{2, 25, 26} and with the number of comorbidities.²⁷ The rate of hospitalizations for patients with CKD is as high as 430 per 1,000 patient-years. Cardiovascular events and infections are the most frequent causes of hospitalizations and death in CKD patients,^{2, 25, 26} and patients with CKD are more likely to die of a cardiovascular event prior to reaching end-stage renal disease than to reach end-stage renal disease.²⁵

Chronic diseases and end-stage renal in Delaware

Chronic diseases are prevalent in the state. In 2015, 25.2% of White, 27.1% of Black, and 16.9% of Hispanic/Latino adults were diagnosed with diabetes, cardiovascular disease or asthma, compared to 21.4%, 24.5% and 17.1% respectively in the United States.²⁸ The prevalence of diagnosed diabetes among Delaware adults doubled from 4.9% in 1991 to 11.5 % in 2015.²⁹ Adults diagnosed with diabetes are more likely to be overweight or obese.²⁹ Obesity among Delaware adults has more than doubled from 13.0% in 1992 to 29.7% in 2015.²⁹ About 34.5% of adults in the state have high blood pressure, well above the national average of 30.9% and the Healthy People 2020 Target of 26.9%.³⁰ In addition, 17.6% of adults in Delaware self-report fair or poor health compared to only 12.6% nationally.²⁸

In 2013, there were 2,287 patients in chronic renal replacement therapy in Delaware. Of those, 46.1% were Black and 51.5% were White, 59.1% were male, 40.9% were female. The majority of the patients were in hemodialysis (63.9%), some in peritoneal dialysis (8.0%) and 27.9% had a kidney transplant. Diabetes and hypertension were the primary causes for ESRD in these

patients and both were more prevalent among Blacks (38.1% and 28.5%, respectively) than among Whites (33.5% and 14.9%).²

Linking Data for Kidney Care

The project “Linking Data for Kidney Care,” led by Dr. Claudine Jurkovitz, MD, MPH, a senior Investigator in the Value Institute at Christiana Care, was awarded a two-year pilot grant from the Delaware Center for Translational Research (CTR) ACCEL Big Data Pilot program at the end of 2014. The objectives of this project are: (1) To build a CKD registry by joining the electronic health records (EHRs) of multiple sources to build longitudinal records of care for patients with CKD; (2) To reduce hospitalization rates of patients with CKD by predicting their risk of hospitalization within a defined time-frame after an office visit; (3) To examine transitions of care of children with CKD to adult care.

Care coordination is especially important for young adults with CKD who transition from the nurturing environment of pediatric care to the independent environment of adult care. Continuity of complex multidisciplinary care is therefore of concern for these patients.³¹ Many of these children, as they become young adults, may have impaired cognitive function leading to difficulty in keeping physician appointments and adhering to their medication prescriptions.^{32, 33} Medication adherence is a major issue when considering the long term outcomes of young adults with CKD transitioning to adult care.^{34, 35}

The ultimate long term goal of “Linking Data for Kidney Care” is to improve care coordination of patients with CKD by providing real-time access to patients’ information across providers. By linking data from the Nephrology Associates P.A., practice, the Christiana Care transplant practice and the records of the Nephrology practice at Nemours/Alfred I. duPont Hospital for Children, Dr. Jurkowitz and colleagues have illustrated a proof of concept for the patients with CKD in the state of Delaware by transforming these EHR systems into a common model and then merging disparate systems into a unified database. They hope to ultimately use this framework and the methods applied to build a statewide CKD registry. All of the partners involved in the pilot project use comprehensive EHR systems containing demographic, clinical, laboratory and treatment information. These records were linked to the records of the Medical Group of Christiana Care (MGCC) to explore follow-up of these patients, Christiana Care acute care to assess hospitalizations, the United States Renal Data System, for renal replacement therapy patient history, Medicaid claims data, for assessing resource utilization, and the Social Security Death Index (SSDI), to ascertain death. Analysis of the database is ongoing.

Eugene Washington Engagement Award

While the ACCEL Big Data Pilot Grant Program provided funds to develop the research infrastructure and preliminary data necessary to solicit independent external support to expand the CKD database to other sources of data and include real-time transactions, this funding did not support stakeholder outreach and engagement. The research team recognized that in order for a statewide CKD registry project to be successful and useful to patients and health care providers, they needed to solicit the input and buy-in of all stakeholders including patients, health care providers, payers, and administrators.

Aside from a few notable examples such as the Patient Centered Outcomes Research Institute (PCORI)-funded Patient Powered Research Networks, Big Data and registry projects are often undertaken without patient and key stakeholder input and buy-in despite the recent push for patient engagement and concerns regarding data security, privacy and stewardship. Developing patient and stakeholder trust and soliciting their input and direction are invaluable to understanding how to design and evaluate registries. For example, patients may have specific concerns about data security and sharing that they could not otherwise express. Other stakeholders, such as physicians and payers, may have an interest in patient perspectives, but not have the

resources or knowledge of how to cultivate a group of actively engaged patients. Because of this, registries are often designed to address gaps in the evidence without significant input from patients, stakeholders, or knowledgeable partners.

In February 2016, a team of stakeholders led by Dr. Jurkowitz applied to PCORI for a Eugene Washington Engagement Award. The goals of the Eugene Washington Engagement Awards are to facilitate expansion of patient-centered outcomes research/clinical comparative effectiveness research (PCOR/CER) and to encourage active integration of patients, caregivers, clinicians, and other healthcare stakeholders as members of the research process (www.pcori.org).³⁶ The project “Engaging Stakeholders for a Patient-Centered Research Agenda for Chronic Kidney Disease in Delaware” received two years of funding in the Spring of 2016. The overall goal of this project is to cultivate a network of stakeholders, patients, health care providers, payers, and hospital administrators, who are invested in using the Statewide CKD registry framework to design and implement PCOR projects for patients with CKD. More specifically, the objectives of this project are:

- To inform all stakeholders of the CKD registry project
- To better understand which outcomes patients, payers, and physicians are most interested in, how a registry could be useful to them, and what additional data are important for PCOR in this community
- To teach Academic and Community Investigators to conduct research and write grants together
- To solicit feedback on research designs that could be used to compare outcomes; data security, sharing and privacy issues in the context of research projects; and registry sustainability for research

Partnering with the Community

The project kicked off with a conference on September 16, 2016 titled “Partners in Research: Developing a Patient-Centered Research Agenda for Chronic Kidney Disease.” The purpose of this conference was two-fold: *first* to inform stakeholders on the CKD registry project, on the state of CKD in Delaware and nationally, on the issue of disparity in CKD, on PCOR and CER in CKD, and *second and most importantly* to begin a conversation with patients, their caregivers, healthcare providers and all other stakeholders about research questions and outcomes that are most important to them. Morning speakers were followed by moderated afternoon workshops where stakeholders proposed research questions and outcomes of interest.

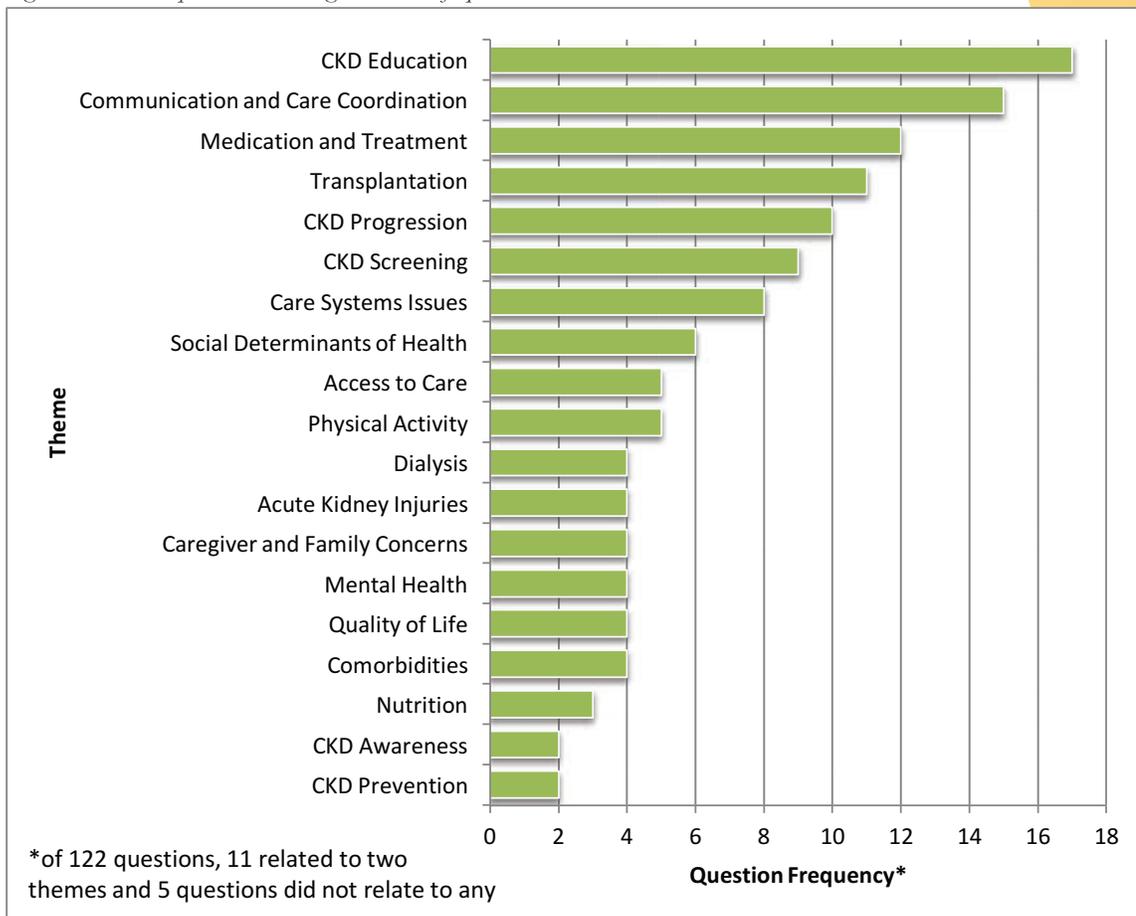
There were five separate workshops centered on CKD, one on transplantation, and one on dialysis. There were 10-14 participants per workshop and workshops were assigned based on preference. Moderators encouraged all group participants to propose questions. During later analysis, keywords were assigned to each question then categorized into themes and the frequency of themes was analyzed. From a total of 122 proposed questions, 19 themes were identified: CKD education, communication/care coordination, medication/treatment concerns, transplantation, CKD progression, CKD screening, Care systems issues, social determinant of health, physical activity, access to care, comorbidities, quality of life, mental health, caregiver/family concerns, acute kidney injury diagnosis, dialysis related issues, nutrition issues, CKD prevention, and CKD awareness. Questions related to CKD education and communication/coordination of care were the most frequently raised and were shared across 6 and 5 workshops, respectively. Despite being in geographically distinct groups, stakeholders raised common concerns: how to educate patients, physicians, and the community about CKD, how to improve communication between patients and providers and how to improve communication and coordination of care between providers (Figure 2).



“Engaging Stakeholders for a Patient-Centered Research Agenda for Chronic Kidney Disease in Delaware” Leadership.

From left to right: Tim Gibbs; Joanne Smith; Nancy Scott; Heather Bittner-Fagan; Claudine Jurkowitz; Shay Scott

Figure 2. Theme Importance according to number of questions



Coordination of care between primary care physicians and specialists was further discussed at the first Partners in Research Town Hall meeting on January 24, 2017. Patients pointed out that most of the time, they were in charge of keeping all their providers in the loop, and regretted that there was no direct and better communication between physicians. In many cases, faxing information from one practice to another is still used but is not a reliable method as paper can be lost and the information may not be entered into the electronic health record. Everyone agreed that improving electronic health records systems connectivity would be key, but other methods such as texting or emails could be used as long as the information was transmitted in a secure, confidential and reliable way. Additional Town Hall meetings will be held on March 21, April 19 and May 24 and will cover topics such as comparative effectiveness research, end of life issues in patients with end-stage renal disease, and confidentiality and security of data. The goal of these town hall meetings is to engage all interested stakeholders in discussing these issues together. Too often, people tend to debate issues within their own professional group or network and are not afforded the opportunity to share their perspectives with others from different backgrounds.

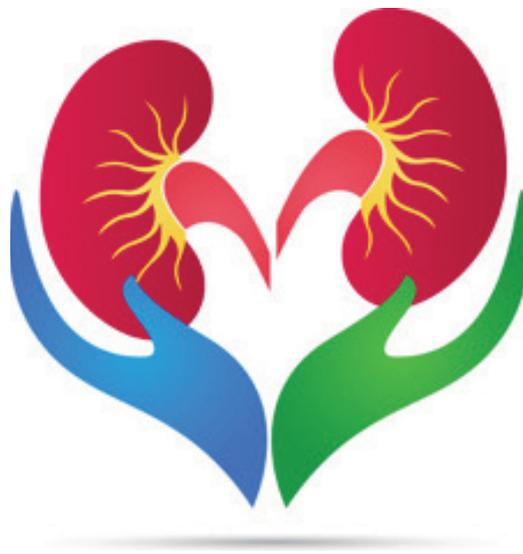
The Partners in Research team is also preparing to begin the Community–Academic Partnered research training on March 2, 2017. The first session will include a discussion about the IRB and ethics in research followed by a review of community-based participatory research principles. Subsequent sessions on March 16, March

21 and April 19 will focus on how to design a research question and specific aims, comparative effectiveness research, qualitative and quantitative methods, program evaluation, study design, and a dissemination of results panel discussion. The goal of this training is for the community and academic investigators to learn to design research projects and write grants together.

Finally, the Partners in Research leadership team is organizing a second conference, which will be held on September 15th, 2017, at the Christiana Care John H. Ammon Education Center. The second conference will focus primarily on information sharing and dissemination. The participants of the Community–Academic Partnered research training will report back about their experience in the training and the Town Hall meeting discussion points will be summarized.

These conferences and meetings bring together multiple stakeholder groups to better ensure that the CKD registry is designed to improve the health and healthcare of individuals living with CKD and that future research involving the CKD registry is generated from the common voice of all stakeholders. We anticipate that this will lead to patient-centered and comparative-effectiveness research that generates knowledge that is useful and pertinent to patients' lives and directly impacts their health and quality of life.

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Claudine Jurkovitz, M.D., M.P.H.

Dr. Jurkovitz is Senior Physician Scientist in the Value Institute at Christiana Care and Investigator in the Epi/Biostat core of the Delaware ACCEL Center for Translational Research. She is also an active member of the steering committee of the INBRE Bioinformatics Network of Delaware (BiND). As a Nephrologist Epidemiologist she has actively developed her own research interests, mostly in the field of chronic kidney disease (CKD) and health services research. She is currently the PI of the ACCEL-CTR funded Big Data Pilot grant: "Linking Data for Kidney Care". Prior to her role at the Value Institute, Dr. Jurkovitz held the position of Director of Operations for Christiana Care's Center for Outcomes Research.



Sarahfaye F. Dolman, M.P.H., M.T.A.

Mrs. Dolman is currently a Research Associate in the Value Institute at Christiana Care Health Services. She holds a Master of Public Health from the University of New England, and completed her undergraduate degree in Psychology at the University of Delaware. She also holds certificates in Editing from the University of California, Berkeley, and in Clinical Trials Management from the University of Delaware. Mrs. Dolman spent six years working under the direction of Dr. Carroll Izard at the University of Delaware on an NIMH-funded longitudinal trial examining the underlying mechanisms of a classroom-based intervention program designed to educate preschool children about emotion knowledge before joining the Value Institute. Mrs. Dolman is an experienced project coordinator with strengths in data management, data quality and reporting, program evaluation, and enhancing collaboration.



Holly Archinal is a Research Intern at Christiana Care Value Institute who has just finished her post-baccalaureate pre-medical studies at the University of Delaware. Prior to premedical studies, she was writer and producer in sports television and independent film. She has a certificate in Film from New York University and graduated from Bryn Mawr College with a BA in English Literature.



*87th Annual Meeting
and
Awards Ceremony*

WEDNESDAY, MAY 17, 2017
5:30—9:30 p.m.

Keynote Speaker

VICTOR J. DZAU, M.D.

President

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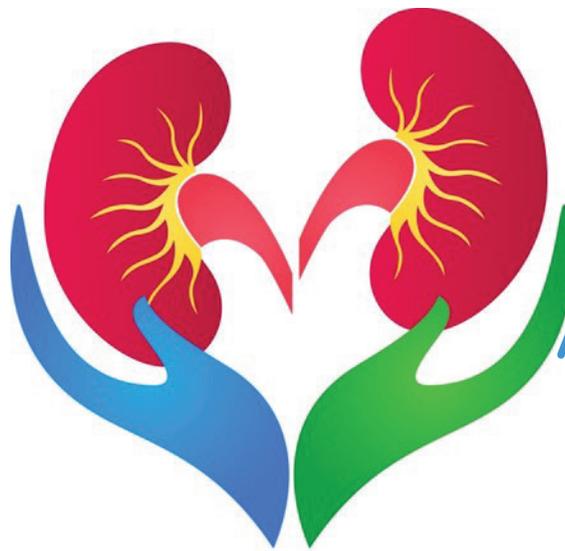
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WHAT

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information
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WHEN
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Apr 19 @ 5pm
May 24 @ 5pm

delaware-ckd.org

WHERE



Come to: Christiana Hospital,
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OR



Online at <http://bluejeans.com/101777621>

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Cardiovascular Disease in Delaware

*Edward Goldenberg M.D., F.A.C.C., Elisabeth G. Bradley M.S., A.P.R.N.,
Denise Taylor M.S., R.D., and Janice Anderson, M.S.N.*

The Center for Heart and Vascular Health
Christiana Care Health System

¹Cardiovascular Disease is the leading cause of death in Delaware, the United States and the world. Stroke is the 5th leading cause of death in the United States and the leading cause of disability. ²In Delaware, the 2015 cardiovascular death rate was 247.5 per 100,000 with the best state at 188.2 per 100,000 ranking Delaware the 28th state.

Over the past 2-3 decades there has been a steady decrease in age adjusted cardiovascular mortality from 342.9 per 100,000 in 2000 to 223.9 in 2013. In 2013 for the first time more men (402,851) died from cardiovascular disease than women (398,066). This year marks the end of a 26-year decline in the rate of cardiovascular deaths. In the past year, the national cardiovascular death rate has increased from 250.8 to 251.7 deaths per 100,000. The 26 year decline has been attributed to improved care of acute coronary syndrome, myocardial infarction, congestive heart failure, and primary and secondary prevention. The growing epidemic of obesity and Diabetes Mellitus contribute to the recent increase in CVD mortality. ³The adjusted population attributable risk factors for CVD mortality were 40.6% for hypertension, 13.7% for smoking, 13.2 % for poor diet, 11.9% for insufficient physical activity and 8.8% for abnormal glucose.

⁴In Delaware, 34.5% of the adult population has been told by a medical professional that they have hypertension. Behavioral risk factors include poor diet, high salt intake, physical inactivity, obesity, excessive alcohol consumption and tobacco use. Other risk factors are age, race/ethnicity, family history of hypertension and genetic factors, lower education, socioeconomic status, psychosocial stressors and sleep

apnea. Of those Delaware adults who know they are hypertensive, almost 79% are currently taking medicine. According to data from NHANES 2003 to 2004 compared to 2011 to 2012 hypertension control rates improved from 39.45 to 51.8%. Awareness increased from 75.2% to 82.1% and treatment improved from 65% to 70.4%

⁵ ⁶Obesity(BMI>30) is of pandemic proportions and has contributed to the most recent increase in age adjust mortality in the United States. Obesity among Delaware adults has more than doubled from 13 % in 1992 to 29.7% in 2015. The prevalence of obesity in New Castle County is 28%, Kent County 31.3% and Sussex County is 32.3%. Obesity is generally caused by regular consumption of more calories than the body is able to burn. Over the past decades the average number of calories has increased, the percentage from fats has decreased and the percentage from carbohydrates has increased. Additional contributing factors include genetics, prenatal and early life influences, unhealthy diets, insufficient sleep, and the social and physical environment. The percentage of adults who eat an ideal diet has increased from 0.7% to 1.5% and in children from 0.2% to 0.6%. There is a huge opportunity to educate the public on the principles of nutrition and examine the barriers of achieving an ideal diet. Less than 21% of US adults and 29.4% of Delaware adults met the US Department of Health and Human Services physical activities recommendations (minimum 150 minutes weekly).

The growing number of obese individuals contribute to the increase incidence of Diabetes Mellitus.⁷ There are 9.9% Diabetics in the United States and 11.5 % in Delaware placing us 39th in the United States. ⁸The prevalence of Diabetes in New Castle County is 28%, Kent County 31.3% and Sussex County is 32.3%. The

2015 Delaware Behavioral Risk Factor Surveillance System provides information about compliance with recommendations of care for people with Diabetes; 51% say they have taken a course in how to manage Diabetes, 63.2% say they check their blood sugars daily, 72% see their healthcare providers at least twice a year, 71.3% had an eye exam at which time their pupils were dilated, 81% said they had their feet checked at least once in the past year, and 94.45 had their HgbA1c checked at least once in the past year.

⁹ ¹⁰Tobacco is the leading cause of preventable and premature death, killing an estimated 443,000 Americans and 1,400 Delawareans each year. Cigarette smoking costs the nation \$96 billion and Delaware \$532 million in direct medical costs \$95.6 million is paid by Delaware Medicaid. Nationally there is \$97 billion and in Delaware \$391.2 million in lost productivity annually. In Delaware 17.4% of the population report that they are current smokers. Those groups which have higher rates of smoking include males 20.9%; age group 25-34 22.2%; age group 45-54 21.7%; age group 55-65 21.7%; less than a high school diploma 27.8%, high school diploma 22.2%. The rate of smoking also varies with income: less than \$15,000 32%; \$15,000-\$24,999 18.7%; \$25,000-\$34,999 26.9%; \$35,000-\$49,999 18.6%; \$50,000-\$74,999 17.5%; greater than \$75,000 9.9%.

In addition to the billions in medical costs and lost productivity, tobacco is exacting a heavy toll on young people. ¹¹2015 is the most recent Delaware Youth Risk Behavior Survey. The prevalence of current cigarette smoking among Delaware high school students dropped from 32.2% in 1999 to 9.9% in 2015. There are new products and trends in tobacco use. They are marketed heavily without restrictions, untaxed or have minimal taxes and are dangerous and addicting. Total tobacco use among Delaware high school students (cigarettes, cigars, little cigars and smokeless tobacco) declined from 26.6% in 2003 to 20.3% in 2013. However, from 2013 to 2015 the use of “Vape” e-cigarettes have increased 44% from 7.1% to 23.5%. In 2015, 29.8% of all high school students and 36.5% of high school seniors used any form of tobacco.

¹²In Delaware in 2015 the tobacco industry spent \$44.8 million dollars on tobacco advertising and \$9.5 billion nationally. This does not include the smokeless tobacco companies who do not need to report their advertising budget. Each day in the United States, over 3,800 young people and 400 Delaware children under 18 years of

age smoke their first cigarette. The vast majority of Americans who begin daily smoking during adolescence are addicted to nicotine by young adulthood. If current rates persist, more than 5.6 million children alive today and 17,000 Delaware children will die prematurely of tobacco-caused diseases.

¹³Each year, the American Lung Association evaluates each state’s efforts in smoking prevention. As a state, Delaware has a lot of opportunity to improve. Our tobacco prevention and cessation funding was graded a D. The state tobacco related revenue was \$136,800,000. The total funding for state tobacco control was \$7,065,443. Of that \$7,065,443, \$6,357,600 was from state funds and \$707,843 from federal funding. This is only 54% of the Centers for Disease Control and Prevention (CDC) recommended level of funding for tobacco prevention. The level of our tobacco taxes was rated a F, access to cessation services was rated a C and smoke free air was rated an A. The American Lung Association in Delaware calls for the following three actions to be taken by our elected officials to reduce tobacco use. Increase the excise tax by \$1.00 per pack of cigarettes and create tax parity between the tax on cigarettes and other tobacco products. Fund tobacco prevention and cessation programs at the CDC recommended level; and increase the sales age for tobacco products to 21 years old.

¹⁴In 2015, 39.1% of Delaware residents age 18 years and older reported they had been diagnosed with high cholesterol. ¹⁵The 2013 ACC/AHA guidelines and the 2016 update suggest high intensity statins for patients with established vascular disease or diabetics with a greater than 7.5% 10 year cardiovascular risk. The goal of therapy is a 50% reduction of LDL or an LDL < 70mg% and a non-HDL less than 100 mg%. ¹⁶Of those patients on high intensity statins, 31.9% had an LDL < 70mg% and 68.8% an LDL < 100mg%. 35% of Diabetics were not on a statin. Of those Diabetics on a statin 32.5% were on a high intensity statin, 34.2% achieved an LDL < 70mg%, 73% achieved an LDL < 100mg% and 27% had an LDL > 100mg%. As clinicians there is room for improvement in meeting the evidence based guidelines.

¹⁷Thomas R. Frieden’s (Medical Director of CDC) health pyramid (fig1) best describes what we as a population need to do to improve the health of our community.

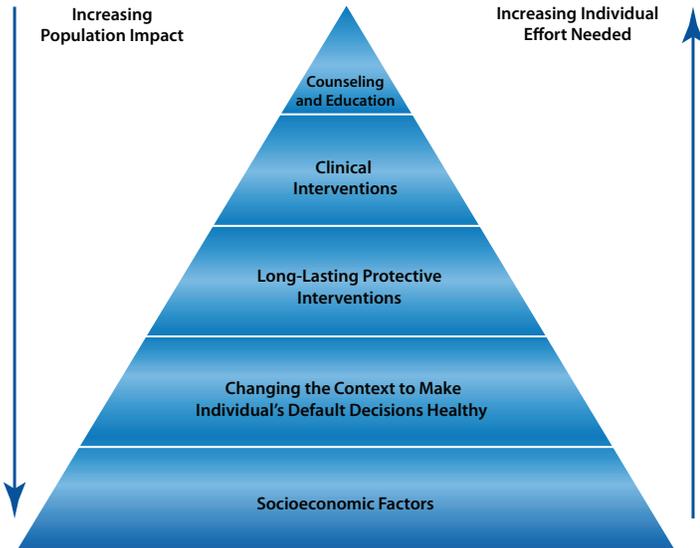


Fig. 1

¹⁸“Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.” ¹⁹Improved health outcomes depend upon a coordinated effort (department of health, government, business, hospitals and healthcare providers) to address the health determinants of behaviors, community, environment, policy and clinical care. Clinical care only contributes approximately 20% to health outcomes

The United States spends 16% of our GDP on healthcare, more than any other industrialized countries. (fig.2) Although other countries spend less of their GDP on healthcare compared to the United States, they spend more of their GDP on social care. As a result, 79 years of age the life expectancy of the United States is 34th in the world²⁰, our infant mortality of 32/100,000 births is 2nd highest in the OECD²¹, and we rank 11 out of 11 compared internationally in the quality of our healthcare²². We need to improve our efforts in preventing disease. This will require addressing the social determinants of health, the base of the health pyramid.

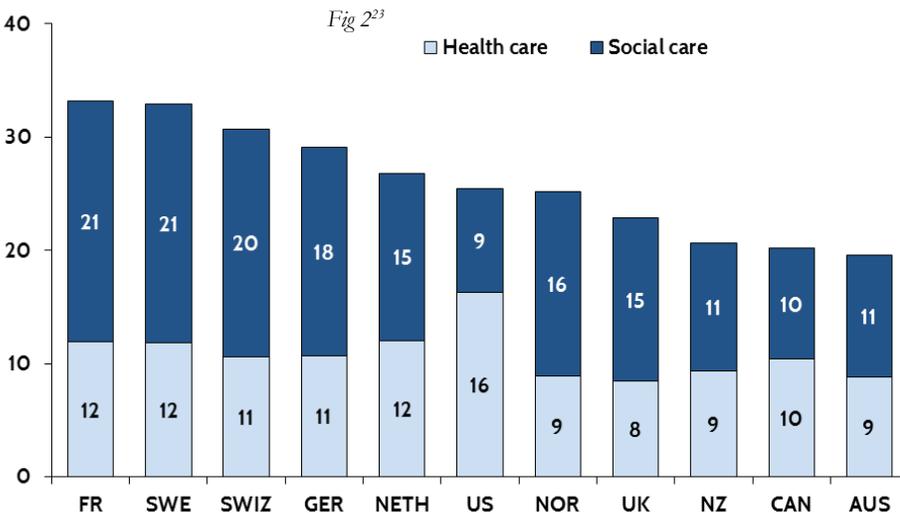
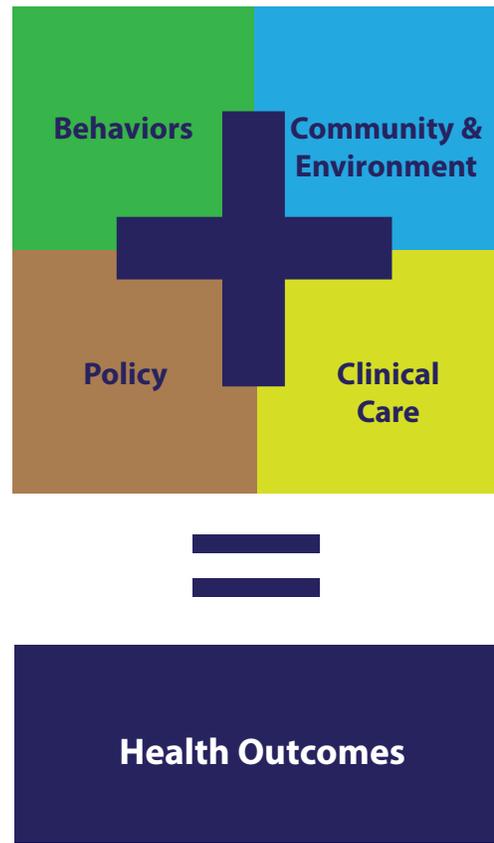


Fig 2²³

Are there other opportunities to decrease the morbidity and mortality from CVD in Delaware? The medical profession needs to focus on prevention; effectively treating the risk factors of hypertension, hypercholesterolemia, obesity and tobacco addiction. However, what is most needed if we are going to decrease the prevalence of cardiovascular risk factors and engage the population in their treatment is a cooperative effort of health care systems, health care providers, State Government, and the business community addressing behaviors, community, environment and policy. (Fig. 3)

Fig 3



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Edward Goldenberg M.D., F.A.C.C., is currently the Director of Preventive Cardiology at Christiana Care. Dr. Goldenberg is board-certified in cardiology and internal medicine. He is a fellow of the American College of Cardiology, the American College of Physicians, the American Heart Association and the Society of Cardiac Angiography and Intervention. His specialty interest is in patient care, cardiovascular health and lipid management.v



Elisabeth G. Bradley M.S., A.P.R.N., is the Lead Clinical Nurse Specialist for the Cardiovascular Prevention Program at Christiana Care.



Denise Taylor M.S., R.D., is a Project Manager with Cardiovascular Prevention, Christiana Care Health System.



Janice Anderson, M.S.N., is the manager of the Cardiac Rehabilitation and Secondary Prevention Program at Christiana Care Health System.



Arthritis and its Public Health Burden

Guy S. Eakin, Ph.D.¹, Kayla L. Amodeo, Ph.D.¹, Randeep S. Kahlon, M.D.²

¹Arthritis Foundation, Atlanta, GA., ²First State Orthopaedics, Wilmington, DE.

Introduction

Arthritis is well known in all cultures, with medical descriptions of inflammatory arthritis dating as early as the writings of Hippocrates (Entezami, Fox, Clapham, & Chung, 2011), and paleontological evidence dating back 150 million years (Sassoon, Noè, & Benton, 2012). Today, the data regarding the prevalence of these diseases remains scant, but suggest that close to 300 million people around the world live with arthritis (Briggs et al., 2016). In terms of years lived with disability (YLD), arthritis and allied disorders account for 21.2%, second only to mental health issues (March et al., 2014). Though often associated with aging, in reality, arthritis can manifest at any age, even in childhood. In the US, approximately 300,000 children are affected by pediatric forms of arthritis (Sacks, Helmick, Luo, Ilowite, & Bowyer, 2007).

In the modern era, the term “arthritis” refers to more than 100 conditions that involve gradual erosion of and pain in joints. Arthritis remains the most prevalent cause of disability in the US, affecting 1 in 5 adults (Centers for Disease Control and Prevention (CDC),

2009, 2013). This includes an estimated 52.5 million Americans with a doctor diagnosed arthritis, and 22.7 million with activity limitations due to the disease (Centers for Disease Control and Prevention (CDC), 2013). In the next two decades, the number of people affected by arthritis is expected to approach a quarter of the population (Hootman, Helmick, Barbour, Theis, & Boring, 2016).

Types of arthritis

In general terms, the many types of arthritis can be grouped into a handful of broad classes, the most prevalent of which are osteoarthritis and a separate class of autoimmune disease types such as rheumatoid arthritis.

Osteoarthritis (OA) is, by far, the most common form of arthritis, affecting as much as 13% of the population (Cisternas et al., 2016). On the basis of Framingham Study data, approximately a third of adults show radiographic signs of OA (Felson et al., 1998). At ages greater than 65, 80-90% of adults may show signs of OA, even if no symptoms are present (Roberts

Amongst environmental exposures, smoking is the best-documented environmental risk (Källberg et al., 2011).

Though diagnosing RA can be a difficult process, early diagnosis and treatment (within the first 6-months of symptom onset) is associated with better long-term health outcomes. Often, RA diagnosis is challenging, particularly in its early stages, because symptoms may share features with both other autoimmune diseases and many other musculoskeletal disorders (such as tendonitis or synovitis). As no one test is pathognomic for RA, physicians often rely on the history, physical examinations, blood tests, and radiographic imaging to diagnose RA. The 2010 American College of Rheumatology (ACR) and European League Against Rheumatism (EULAR) classification criteria for rheumatoid arthritis are the standard for diagnosis and study of RA (Aletaha et al., 2010)

RA is often only one of multiple disease processes ongoing in a patient. According to the 2007 National Health Interview Survey, 47% of US adults with any form of arthritis have at least one additional

comorbidity. Focusing on RA, on average, an established RA patient will commonly have two or more additional comorbid conditions (Michaud & Wolfe, 2007). Chronic respiratory conditions, diabetes, cardiovascular disease, and mental health conditions are the most common comorbidities but autoimmune disorders and even osteoarthritis are not uncommon.

Like OA, RA imposes a significant impact on quality of life for those diagnosed. A study that examined self-reported quality of life for people with RA reported that people were 30% more likely to need help with personal care and twice as likely to have activity limitations when compared to controls (Dominick, Ahern, Gold, & Heller, 2004). Several studies have documented significant negative impact on the work lives of people diagnosed with RA. Early and aggressive treatment of RA reduces risk of developing work disabilities – very much akin to the improved health incomes mentioned above (ter Wee, Lems, Usan, Gulpen, & Boonen, 2012).

There are several treatments available for RA. To address the musculoskeletal symptoms, the non-pharmacologic mainstays used for OA are often also useful in RA (weight loss, joint bracing, self-management, education & exercise). In addition the same first line pharmacologic treatments used to for both primary and secondary OA (mostly NSAIDs) is often trialed for RA. However, the main recommended approach for the treatment of RA includes non-biologic DMARDs to reduce disease activity and prevent joint damage, usually prescribed within the first 3 months of diagnosis. If treatment with a non-biologic DMARD is unsuccessful, the ACR guidelines recommend graduating to a biologic DMARD (Singh et al., 2016). There are several biologic DMARDs available to patients; prescribers must consider disease activity, signs, symptoms, and patient preference when selecting a treatment.

Transition to a biologic is not curative but rather is an attempt to put the autoimmune disease process into remission for that specific patient. In fact, there is a high failure rate of biologic drugs in RA (and all autoimmune) patients. Of rheumatoid arthritis patients who took a first-generation biologics for at least 6 months, approximately 40-50% failed to meet the American College of Rheumatology criteria for 50% improvement. Of those patients who failed to meet this improvement criteria threshold on the initial on biologic, 40% were switched to another biologic by

their rheumatologist (“Consumer Reports Health - Best Buy Drugs - Using Biologics to Treat: Rheumatoid Arthritis. Comparing Effectiveness, Safety, Side Effects, and Price,” 2013). Overall, only a third of patients will achieve remission early in the course of the disease, necessitating frequent experimentation and switching between medications (Barnabe et al., 2015) function and quality of life over the first two years of early rheumatoid arthritis (ERA

Economic Costs and Public Health Impact

In Delaware, 2015 data suggests approximately 193,000-207,000 people with arthritis, of whom 42% are inactive. This data positions Delaware as having an intermediate burden of arthritis relative to other states. Estimates of the total direct and indirect costs due to arthritis in Delaware total \$363 Million annually. (Barbour, 2016; “State Data Tables | Data and Statistics | Arthritis | CDC,” n.d.). Across the nation, these estimated costs annually total more than \$580 Billion for arthritis and related conditions (“Arthritis and Joint Pain,” n.d.). In general, these numbers suggest arthritis costs states about 1% of GDP (Centers for Disease Control and Prevention (CDC), 2007) potentially limiting affected persons from walking a few blocks or climbing a flight of stairs. Using Medical Expenditure Panel Survey (MEPS. In reality, health care costs and volumes, particularly for pharmacologic treatment of inflammatory arthritis and surgical treatment of OA, have risen dramatically, and these numbers are likely to underestimate expenses. Direct costs related to arthritis and related disorders are staggering, accounting for as much as 7% of total aggregate hospital costs, and represent one of the most expensive conditions (OA) billed to private insurers (Torio & Moore, 2016). These hospital numbers also do not account for post-hospital costs such as nursing home, assisted living or home health costs. Severe osteoarthritis and mobility issues remain amongst core factors in decisions regarding nursing home placements (Van Rensbergen & Nawrot, 2010). Indirect or secondary costs due to arthritis also contribute significantly to health care costs but are harder to track due the nature of coding for both diagnosis and treatment. For example, costs related to falls are a significant cost driver and data shows arthritis patients are substantially greater risk (Barbour et al., 2014) but which of those falls is primarily due arthritis complications versus other medical complications (such as syncope, hypoglycemia, arrhythmias) are harder to track.

Out of pocket expenses to patients are also costly. Evidence exists to show that increases in out-of-pocket expenses result in significant increases in abandonment of disease modifying RA therapies (Hopson et al., 2016) with clear implications for health outcomes. People with arthritis are also heavy consumers of complementary and alternative medicines (CAM). Approximately 41% of patients use some form of CAM, with a quarter of patients self-managing with vitamins, supplements, and other biologically based modalities (Quandt et al., 2005), representing additional elective expenses related to arthritis self management.

Despite the heavy costs of care, Federal spending on arthritis research in FY17 is estimated at \$222 million (“NIH Categorical Spending -NIH Research Portfolio Online Reporting Tools (RePORT),” n.d.). Conservatively, this suggests a ratio of only one dollar spent on therapeutic research for every 600 dollars spent on care. The public health implications of arthritis are not limited to physical manifestations. One third of patients experience significant anxiety or depression, with anxiety being approximately twice as prevalent as depression (Murphy, Sacks, Brady, Hootman, & Chapman, 2012). In these patients, several factors may contribute to the depression, including reductions in physical activity and social support, as well as chronic pain and functional disabilities. Furthermore, the fact that arthritis affects juvenile populations markedly ties arthritis to other issues of national public health debate, namely sports safety and obesity.

Limited mobility creates a “vicious circle” in the context of arthritis, contributing to weight gain, which in turn is a risk factor for osteoarthritis. Modest weight loss may have dramatic consequence on pain and OA risk (Felson, Zhang, Anthony, Naimark, & Anderson, 1992) based on a sample of a defined population. \nPATIENTS: Women who participated in the Framingham Knee Osteoarthritis Study (1983 to 1985, though correlation to OA progression remains an area of debate (Deveza & Hunter, 2016).

Long-term consequences of sports injuries are particularly pronounced. In women, knee injuries sustained in their late teens and early twenties place them at a 51% risk for secondary (post-traumatic) OA by the time they reach their 30s. This is equivalent to the risk of primary (degenerative) OA seen in women in their 70s and 80s (Lohmander, Östenberg, Englund, & Roos, 2004).

Public Health Priorities

In light of the soaring public health consequences of arthritis, the CDC and Arthritis Foundation (AF) partnered in 2010 with academic researchers to focus attention on specific public health recommendations related to osteoarthritis. “A National Health Agenda for Osteoarthritis 2010” makes 10 specific recommendations for public health policy following three main themes (reviewed in Lubar et al., 2010).

- Establish supportive policies, communication initiatives and strategic alliances for OA prevention and management
- Initiate needed research to better understand the burden of OA, its risk factors, and effective strategies for intervention.
- Ensure the availability of evidence-based intervention strategies—such as self-management education, physical activity, injury prevention, and weight management and healthy nutrition—to all Americans with OA.

Available Interventions

Providers have many opportunities to offer public health interventions in their communities. In general, most interventions focus on promoting self-management and arthritis appropriate exercise. The CDC provides a compendium of recommended evidenced based interventions, and a separate group of emerging programs with promising, but more limited supportive data (**Table I, Figure 1**) (“Intervention Programs | Arthritis | CDC,” n.d.).

While these tools may not be available in all communities, there are resources such as State Coordinators (https://www.cdc.gov/arthritis/partners/state_coordinators.htm) or the Arthritis Foundation “Arthritis Resource Finder” (<http://resourcefinder.arthritis.org/>) that have been developed to help providers and patients find local Arthritis Foundation and other community programs (*Figure 2*). In addition, the AF also provides both a rich resource of online information, including exercise and pain management toolkits to assist the patient community (<http://www.arthritis.org/living-with-arthritis/tools-resources/>) and a 24 hour seven day a week hotline (**1-844-571-HELP**), staffed by licensed social workers, to help connect patients with resources.

Education and Advocacy

Education

Improving the quality of life for people with arthritis in the United States is the top priority for CDC’s arthritis program (“Intervention Programs | Arthritis | CDC,” n.d.) The CDC Arthritis Program recommends evidence-based programs that are proven to improve the quality of life for people with arthritis. The AF and the CDC work in tandem to disseminate life-changing information and resources, provide access to optimal care, create advancements in science, and facilitate robust community connections. Specific partner projects include providing consumer arthritis information and referral services through a toll-free helpline, collaborating with the National Council on Aging to market and promote evidence-based online arthritis and chronic disease self-management education

Table I. CDC Recommended and Promising intervention programs for self-management and arthritis appropriate exercise. Adapted from (“Intervention Programs | Arthritis | CDC,” n.d.).

	Physical Activity	Self Management
Recommended	Active Living Every Day	Arthritis Self-Management Program Chronic Disease Self-Management Program Tomando Control de su Salud (Spanish Chronic Disease Self-Management Program) Programa de Manejo Personal de la Artritis (Spanish Arthritis Self-Management Program)
	Enhance Fitness	
	Fit & Strong!	
	Walk With Ease (Group-Delivered)	
Promising	Arthritis Foundation Aquatics Program	The Arthritis Toolkit
	Walk with Ease (Self-Directed)	Better Choices, Better Health (Internet-delivered)
	Arthritis Foundation Exercise Program	

programs, dissemination of the AF's Walk with Ease program through large and multisite work site systems, and collaborating with the University of North Carolina and others to facilitate national public health action addressing Osteoarthritis through the Osteoarthritis Action Alliance.

Advocacy

People with arthritis face unique barriers to care including high costs of treatment, difficulty accessing medications, scarcity of specialists and coinsurance that limits access to treatment. It is hard for any patient to fight the battle alone. Advocacy can be a significant force for influencing health policy and increasing the understanding and visibility of the patient experience. The topic of health is often a political endeavor as much as a medical one causing lawmakers to rethink their relationships with the populations they serve (Wallack, 1993). Public health advocates need to ensure individual patient stories are being heard and told from the patient's point of view.

Through the AF's nationwide network of committed Advocates and annual events arthritis patients, caregivers, providers, and supporters learn to raise their visibility by addressing key policy issues on both the state and federal levels with lawmakers, insurers, employers and regulators. With the help of advocates AF fights to conquer all types of arthritis and make a positive impact on the lives of those affected, pushing for policies and laws that make health care more accessible.

Delaware Education and Advocacy

The Arthritis Foundation has widespread impact in the state of Delaware. With the help of almost 300 AF Delaware advocates, important patient-centric legislation has been successfully passed in the state. In 2013, Out of Pocket Cost Limits (Senate Bill 35) passed and went into effect in 2014. The law is significant because the specialty drug copayment or coinsurance limitation caps out of pocket costs to no more than \$150 per month per specialty-tier medication (e.g., biologics). In 2014, DE Biosimilars (Senate Bill 118) was successfully passed and made effective in 2015. This law allows pharmacists to substitute biologic medications with new, interchangeable and potentially less expensive biosimilar medications when they arrive on the market. Bill 118 also ensures patients and their physicians are notified when a substitution occurs, resulting in a complete and accurate patient medical record. And, if a physician

does not recommend a substitution for clinical reasons, they can stipulate that the prescription be dispensed as written. Both pieces of legislation increase access to life saving treatments for patients with arthritis and help lower the cost of arthritis care in Delaware. Through these kinds of advocacy efforts, arthritis patients now have access to these new life-changing medications and the arthritis cost curve has been bent in Delaware.

Additionally, the Arthritis Foundation is committed to providing educational tools to DE residents. In 2016, more than 7,830 individuals accessed the foundations online support tools and nearly 3,000 residents received *Arthritis Today* magazine. Further, specific to Delaware there are many local education and advocacy opportunities. The Arthritis Foundation hosts the Walk to Cure Arthritis, Juvenile Arthritis Family Days, and the annual Bone Bash gala in Delaware (*Figure 3*). Through Arthritis Foundation events, educational resources, and advocacy tools people living with arthritis learn how to get more involved, have a chance to connect with others, and effectively influence health policy that reduces barriers to care.

Side Bar: Recent Advances in Research

- Tissue engineering offers significant promise for future patients. St. Louis researchers recently reported development of a resurfacing strategy for compromised joints. This strategy may offer patients alternatives to total joint replacement, and use adult stem cell technologies to control future inflammation (Moutos et al., 2016). Future OA clinical trials will require novel biomarkers to monitor disease progression beyond radiographic data. Significant strides were recently reported for sports injury, where sophisticated MRI techniques were used for the first time to demonstrate early evidence of developing OA in high risk individuals (Gallo et al., 2016; Russell et al., 2016).
- In RA, two new drugs baricitinib (Eli Lilly) and sarilumab (Sanofi/Regeneron), are nearing final FDA review. If approved, these new drugs would offer new opportunities to the current panel of DMARDS, particularly for patients with difficult to treat disease.

Side Bar: Key Messages

- Arthritis in the US is the second leading cause of disability (affecting 21.2% of the population) one of the most common, and most costly, chronic diseases (at a cost of over \$796.3 billion or over 5.5% of the entire US GDP IN 2011 dollars).
- Whereas substantially improved medications are now available for rheumatoid and other inflammatory arthritis types, progress in osteoarthritis medications remains behind.
- A combination of self management, weight loss, physical activity and pharmacologic interventions have been shown to be effective in managing symptoms of arthritis. Surgical treatment is both for mechanical symptom management and for joint death when non-operative treatments have failed.

Walk with Ease | Arthritis Foundation™

Experience the Walk With Ease Program
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"When I started the program, I was afraid to walk very far because of my knee pain. But Walk With Ease helped me start slow and build up gradually. Now I am confident in my ability to walk easily without making my arthritis worse."

— Walk With Ease participant

Figure 1.

The Arthritis Foundation Walk With Ease Program is an evidence-based self-guided or community exercise program recommended by the CDC ("Physical Activity Programs | Intervention Programs | Arthritis | CDC," n.d.). This multilingual program has been shown specifically to reduce pain associated with arthritis (Callahan et al., 2011) Walk With Ease (WWE) and improve work place activity limitations (Nyrop et al., 2011).

Arthritis Resource Finder

FIND LOCAL RESOURCES TO LIVE BETTER



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wilmington, de
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Enter a Name

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Maryah Mansoor MD

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Location: 501 W 14th St, S
Wilmington, DE 19801
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Eric Marc Russell, DO

Distance: 1.0 Miles
Location: 501 W 14th St, SE35
Wilmington, DE 19801
Phone: (302) 428-7490

Philip S Schwartz MD

Distance: 1.0 Miles
Location: 1902 N Scott St,
Wilmington, DE 19806-2358
Phone: (302) 655-0121

Figure 2.

The Arthritis Foundation Resource Finder tool for can be used to find local physicians, as well as arthritis appropriate community programs.



Figure 3.

The Wilmington Delaware Walk To Cure Arthritis offers exercise and social engagement is support of arthritis community advocacy and research

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Guy S. Eakin, Ph.D., is the Senior Vice President, Scientific Strategy at the Arthritis Foundation where he leads the Foundation's research program. Dr. Eakin is the staff lead for the osteoarthritis clinical trials initiative, and major scientific partnerships. Previously, as vice president of scientific affairs, for the BrightFocus Foundation, he led \$85 million of international biomedical research initiatives for Alzheimer's, macular degeneration and glaucoma. Guy earned his PhD from Baylor College of Medicine and pursued research at Memorial Sloan Kettering Cancer Center and the University of Texas MD Anderson Cancer Center.



Kayla L. Amodeo, Ph.D. is the Legislative Research Manager at the Arthritis Foundation. Dr. Amodeo specializes in health issue research and developing the evidentiary basis for Arthritis Foundation public policy positions. Dr. Amodeo produces the Arthritis Foundation bi-monthly Advocacy in Action publication. She is an adjunct professor of Concordia University of Chicago Exercise Science program. Prior to her work at the Arthritis Foundation, Kayla served as a professor at Northern Virginia Community College Physical Education Department. Dr. Amodeo earned her PhD from the University of Alabama.



Randeep S. Kahlon, M.D. is a board certified orthopedic surgeon with First State Orthopaedics in Newark, Delaware, and adjunct associate professor in the Department of Physical Therapy at the University of Delaware. Dr. Kahlon specializes in hand and upper extremity surgeries, sports medicine, arthroscopic surgery, microvascular surgery and trauma. He is a past president of the Medical Society of Delaware and currently sits on the Arthritis Foundation, National Board of Directors, and Highmark Blue Cross Delaware Board of Directors. Dr. Kahlon has previously served on the Prescription Drug Action Committee, and the Delaware Medical Relief Team for Haiti.

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Vaccines and Chronic Disease

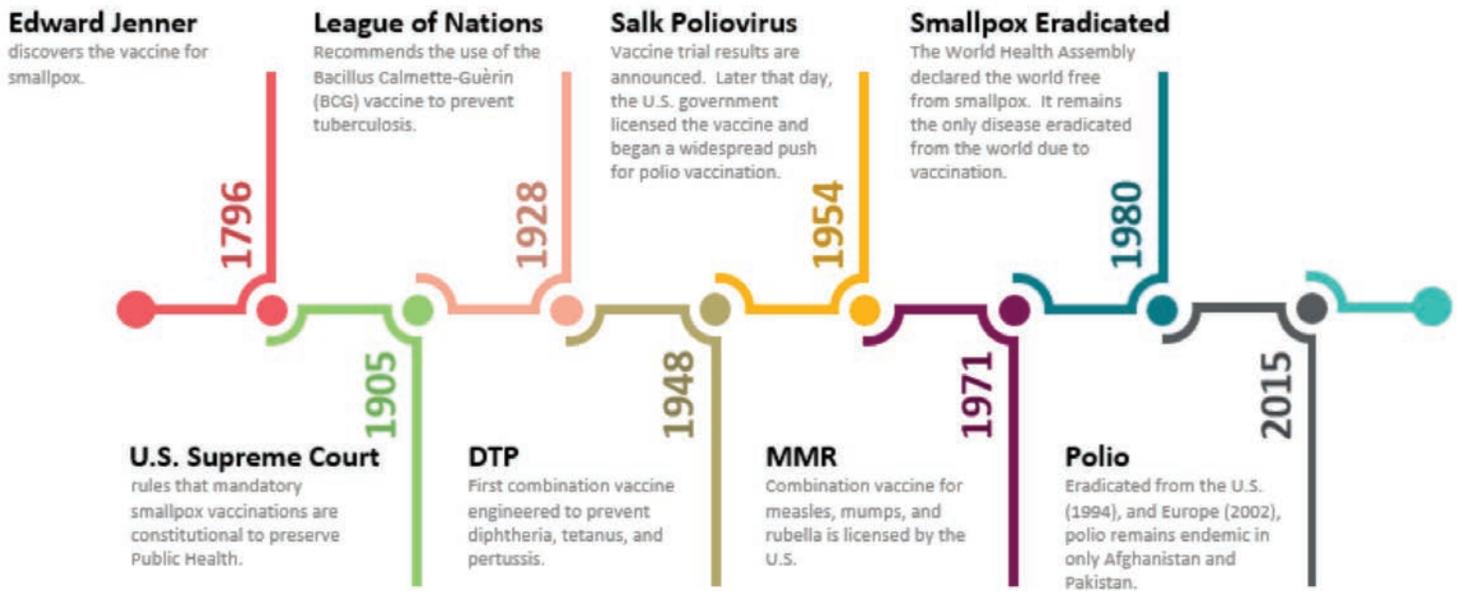
Katherine Smith, M.D., M.P.H.

IMMUNIZATION AND CHRONIC DISEASE MANAGEMENT

The Centers for Disease Control and Prevention (CDC) recommend that all adults continue to receive certain vaccinations throughout their lives. These vaccinations limit the spread of, reduce the severity of, and strengthen an adult's immune response to an infectious disease. There are certain vaccines recommended for all adults, but those with chronic diseases must be even more vigilant.

HISTORY

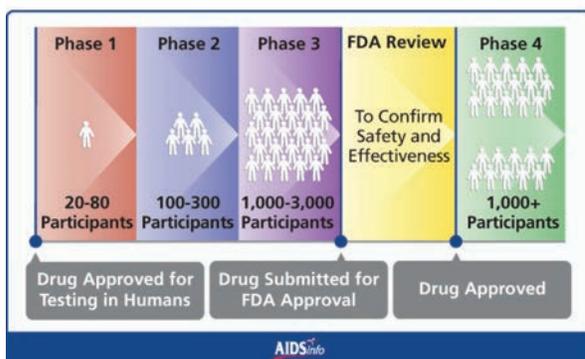
At the beginning of the 20th Century, diseases like smallpox, measles, diphtheria, and pertussis ran rampant throughout the United States, and killed many of the population. Although Edward Jenner had discovered the vaccine for smallpox in 1796, the use of the vaccine was not widespread enough to control the disease.⁸



Data from the College of Physicians, 2016.

CURRENT RECOMMENDATIONS

The United States Advisory Committee on Immunization Practices (ACIP) consists of 15 people responsible for making and approving vaccine recommendations.² Fourteen of them have degrees in vaccines, immunology, pediatrics, internal medicine, nursing, family medicine, virology, public health, infectious disease, and preventive medicine. One member is a representative of the general public. This committee works with highly regarded professional health and medical organizations – like the American Academy of Pediatrics (AAP) and the American Academy of Family Physicians (AAFP) – to discuss research and scientific data related to vaccine safety, effectiveness, clinical trial results, and labeling and package information.^{2,31}



The ACIP approves the childhood and adult immunization schedules recommended by the CDC based on the safety and effectiveness of the vaccine at given ages, the severity of the disease, the number of people who would get the disease if there was no vaccine, and how well a vaccine works for people of different ages.^{2,31} They also monitor how rigorously a vaccine manufacturer conducts studies to prove that a vaccine is safe for the public.^{2,31} These clinical trials, or medical research studies, are conducted in phases, to determine the safety, efficacy, and side effects of a drug or vaccine.²⁶ These trials are considered by

the Federal Drug Administration (FDA) as part of the approval process for new medications, and all treatments, medications, and vaccines in the United States must go through this process before being approved for use.^{26,31}

RECOMMENDED VACCINES FOR ADULTS

Every year, thousands of adults in the U.S. are hospitalized and die from diseases for which vaccines are available.^{11,12} Although vaccines have greatly reduced or eliminated many diseases that plagued humanity in the past, the viruses and bacteria that produce many of these diseases are still present in the world and can infect those who have not been vaccinated.^{11,12,30} Some vaccinations require an additional dose to remind the immune system of the disease and keep it in the forefront of the immune system's memory.²⁹ Other infections are extremely detrimental to those adults with heart, lung, and immune system disorders. For these reasons and others, the ACIP and the CDC recommend all adults receive the following vaccines.^{11,12}

INFLUENZA

Influenza is a respiratory disease that attacks the nose, mouth, and throat and is caused by a family of viruses. It is contagious, and millions of people in the U.S. will contract the disease each year. Since 2010, flu-related hospitalizations in the U.S. have ranged from 140,000 – 710,000 people, and deaths due to flu range from 12,000 – 56,000 patients. Since anyone can get the flu, the CDC recommends that everyone over the age of 6 months get a flu shot every year.^{11,12}

PNEUMOCOCCAL DISEASE

Pneumococcal disease is caused by *Streptococcus pneumoniae* bacteria that can spread from person to person through close contact, and can lead to serious infections of the lungs, blood, and spinal cord. About 900,000 people will contract pneumococcal disease every year, and approximately 18,000 older adults will die from the disease. There are two kinds of pneumococcal vaccines, and recommendations on receiving one over the other are based on age, medical conditions, and lifestyle choices.^{11,12}

SHINGLES

Adults are at an increased risk of shingles as they age, and the CDC recommends all adults over the age of 60 receive the vaccination. Shingles infection is due to the herpes zoster virus. This virus causes a painful

BOOSTER SHOTS

Some vaccines, like the ones for diphtheria, meningitis, and cervical cancer (HPV), may require booster shots to remain effective during a person's lifetime because the disease progression is too fast for the memory response to occur in time. For slow moving infections like hepatitis, polio, measles, mumps, and German measles [Rubella] immune memory is activated within plenty of time to prevent the disease after a person has been vaccinated and booster vaccines are not needed.

Michael Pichichero, MD, Director, Rochester General Research Institute, 2009

rash to develop on one side of the body, generally over the torso, but sometimes affecting the face as well. This rash usually clears up in a few weeks, but some adults are at risk of developing Post-Herpetic Neuralgia (PHN), pain at the site of the rash that can last for years.^{11,12}

TETANUS, DIPHTHERIA, AND PERTUSSIS (TDAP)

Tdap is one of two conjugate vaccines approved by the CDC and ACIP to prevent against multiple diseases.^{2,11} The tetanus, diphtheria, and pertussis booster is recommended for all adults at least once every ten years. A booster shot is given, in this case, because the immune response memory weakens over time.²⁹ Additionally, adults in close contact with newborns should receive a pertussis (whooping cough) booster to keep from infecting the infants too young to be vaccinated.^{11,12}

CHRONIC DISEASE

The World Health Organization (WHO) defines a chronic disease as a disease of long duration, slow progression, and one that is not passed from person to person.³⁵ Chronic diseases are responsible for 38 million deaths each year. Although diseases like addiction, arthritis, autism, osteoporosis, and various psychotic disorders are considered chronic and affect thousands of people in the United States each year, the CDC does not recommend any vaccines specifically for the people suffering with those diseases beyond those recommended for all adults.^{2,12} People suffering from these diseases should check with their doctor regarding vaccines appropriate for their lifestyles.¹²

The WHO recognizes four main categories of non-communicable diseases: cardiovascular disease (17.5 million deaths per year), cancer (8.2 million), chronic respiratory disease (4 million), and diabetes (1.5 million).³⁴ The CDC does recommend additional immunizations for people with these diseases because of the complications that may develop when both the chronic disease and the vaccine preventable disease are present inside the body.¹²

CARDIOVASCULAR DISEASE

Cardiovascular diseases are the number one global cause of death.³⁵ The term heart disease describes an array of disorders affecting the heart. These diseases can include disorders of the blood vessels, heart rhythms, and defects of the heart.²⁴ According to the CDC, the most common type of cardiovascular disease in the United States is coronary artery disease (CAD), which can lead to a heart attack.^{10,34}

Atherosclerotic Disease. Diseases of the blood vessels fall under the category of atherosclerotic disease. These disorders - coronary heart disease, cerebrovascular disease, and peripheral arterial disease – narrow, block, or stiffen blood vessels, preventing the brain, heart, or other parts of the body to receive less blood.²⁴

Arrhythmia. An abnormal heartbeat, or arrhythmia, can lead to shortness of breath, racing or slowing heartrate, fainting, and dizziness. This speeding up or slowing down of the heart rhythm can cause problems with the distribution of blood throughout the body.²⁴

Defects. Heart defects can be congenital or acquired, and can change the flow of blood through the heart. Rheumatic heart disease occurs after a bacterial infection causes structural damage to the heart muscle and valves.³⁵ The American Heart Association (AHA) has stated that congenital defects (present from birth) affect 8 out of every 1,000 newborns.⁵ Many of these defects are not life-threatening, and can be monitored by a health professional.

Stroke. A stroke occurs when blood flow to an area of the brain is cut off, causing the cells in that area to die. Once an area of the brain has died, the abilities of that area of the brain (like memory, or muscle control) are lost. This can lead to memory loss, loss of motor function, loss of language. This group of symptoms is known as dementia.²⁷

DEMENTIA

Dementia is a general term that describes a group of symptoms (like memory loss, loss of motor control, loss of language) due to the permanent damage or death of brain cells.

One of the most common causes of dementia is due to ischemic stroke. Other causes of dementia include alcohol and trauma.

Alzheimer's Disease is the most common cause of dementia in people over the age of 65.

The Alzheimer's Foundation, 2016

There are two types of stroke. A hemorrhagic stroke is due to a weakened or burst blood vessel, and will most likely cause death. An ischemic stroke occurs when a blood vessel carrying blood to the brain is blocked, either by a blood clot or due to plaque build up in the vessels. Ischemic stroke is the leading cause of adult disability in the United States, and up to 80% can be prevented.²⁷

RECOMMENDED IMMUNIZATIONS

Heart disease can make it more difficult to achieve a full immune response to certain diseases, and make it more likely that an infectious disease will lead to serious complications. For this reason, the CDC recommends that individuals with heart disease get vaccinated against influenza, pneumococcal disease, and whooping cough.^{11,12} Additionally, inflammation is thought to play a large role in CAD development and complications. Many vaccine-preventable diseases can lead to inflammation, and the CDC suggests immunization against these diseases if someone has neither previously been immunized nor contracted the disease.¹²

Influenza. Among adults hospitalized with the flu in the 2015-2016 flu season, 41% had heart disease. The CDC notes that "influenza is associated with an increase of heart attacks and stroke."¹¹ Influenza vaccination has been proven to decrease the frequency of future ischemic events.¹³ It was also determined that administering the influenza vaccine to patients with acute coronary syndrome (ACS) had a

protective effect, and reduced the incidence of major cardiovascular events in these patients.²⁸ A systematic review and meta-analysis found that “the use of influenza vaccine was associated with a lower risk of major adverse cardiovascular events.” The prevention of influenza with the yearly vaccine was seen with greatest effect in high-risk patients with active coronary disease.³²

Pneumococcal disease. The United States Department of Health and Human Services (DHHS) recommends that one dose of the pneumococcal polysaccharide vaccine PPSV23 be given to anyone age 2 to 64 years with a long term health problem, such as heart disease.¹⁹ Pneumococcal disease, if left untreated, can enter the bloodstream and cause bacteremia – an infection in the blood.¹² For patients who already have some degree of cardiovascular disease, this can be deadly.

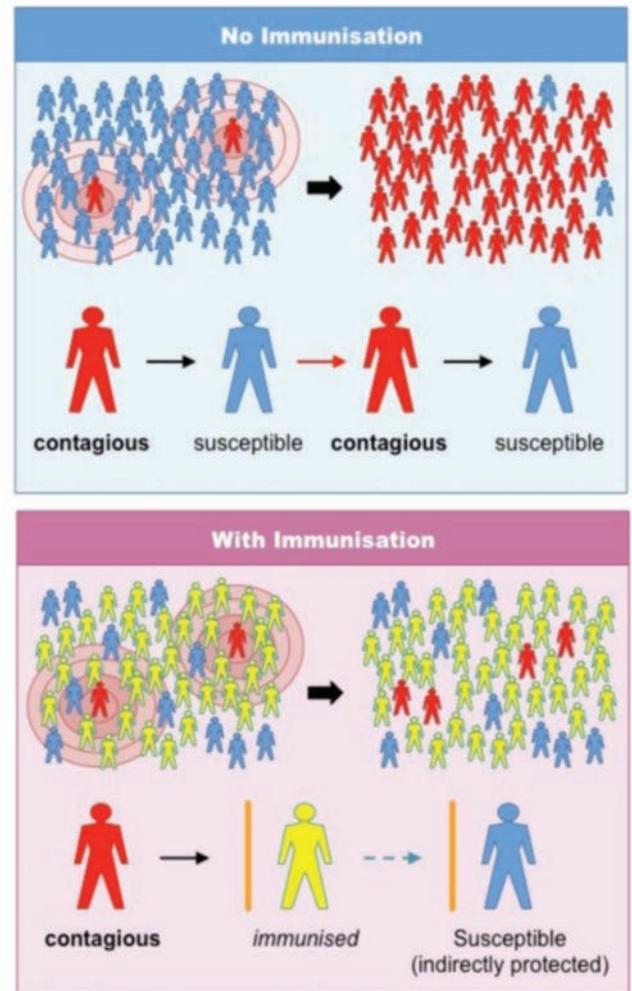
Other vaccine preventable diseases. Any infection causes inflammation, and this inflammation can be dangerous for patients with a weak cardiovascular system.^{11,12} Inflammation is common in heart disease and stroke patients, and is thought to be a response to a build-up of plaque in the arteries.⁶ It is therefore critical that patients with heart disease receive vaccinations for infectious diseases like shingles (if they are 60 years or older), as well as the Tdap (tetanus, diphtheria, and pertussis) booster.¹²

DISEASES SUPPRESSING THE IMMUNE SYSTEM

The immune system is a network of cells, tissues, and organs in the body that work together to protect the body from bacteria, viruses, fungi, and other forms of infection. Bone marrow creates stem cells, which are primitive cells that have the ability to turn into different kinds of cell. One type of stem cell in bone marrow turns into immune system cells (white blood cells): monocytes, macrophages, neutrophils, basophils, eosinophils. Another kind of stem cell will become lymphocytes (T cells, B cells, and natural killer cells). Both lymphocytes and white blood cells are important components in a healthy immune system.¹

HERD IMMUNITY

The primary function of the immune system is to protect the body from foreign organisms. Deficiency or suppression of the immune system leaves the body open to attack from bacteria, viruses, fungi, and other disease causing organisms.¹ For this reason,



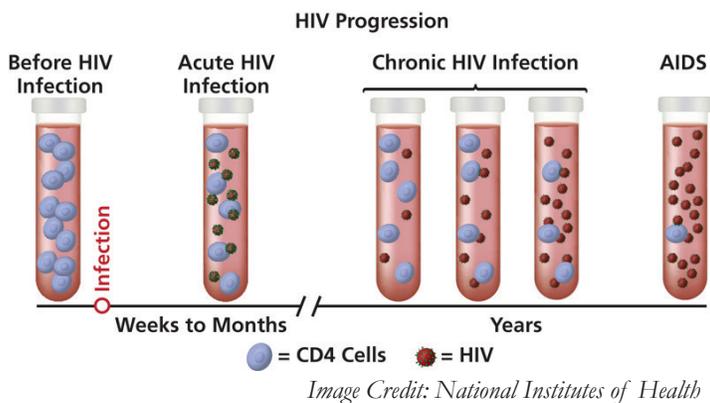
Picture credit: Bioninja.com, 2016

public health depends on a form of immunity called ‘herd immunity’ to keep these immunosuppressed people protected from disease. Herd immunity occurs when a high percentage of a population is vaccinated against a certain disease: this provides a measure of protection for those people who are not or cannot be vaccinated like newborns, pregnant mothers, and those people with suppressed immune systems.³³ In order to have as little contact as possible between the disease and those susceptible, most experts agree that vaccination rates should be as high as 80-95% to have a protective effect.¹⁵

Cancer. Cancer is the second-leading cause of death in the United States.²³ The National Cancer Institute (NCI) defines cancer as a disease in which cells in the body do not stop dividing, and become immortal.²⁵ These cells eventually spread into the surrounding tissues.²⁵ This spread of cells can lead to tumors in the body, as well as the blood and lymph nodes. Signs and symptoms of cancer will vary depending where the dividing cells are located in the body, but can

range from fatigue and unexplained fevers and joint pain to lumps, skin changes, cough and hoarseness, or changes in bowel and bladder habits.²³ Older age, lifestyle choices like drinking alcohol, excessive sun exposure, and unsafe sex, as well as family history and environment can be risk factors for various cancers.²³ Surgery, chemotherapy, and radiation therapy are the most common treatments for cancer.⁴ Radiation, chemotherapy, or both may be used before the surgery to shrink a tumor by targeting the immortal tumor cells for destruction.⁴ Chemotherapy drugs cannot tell the difference between cancer cells and healthy cells, and so may damage normal cells as well as the ones causing the tumor. The most common cells to be targeted by chemotherapy drugs are those that grow and reproduce quickly: blood-forming cells in the bone marrow, hair follicles, and cells in the mouth, digestive tract, and reproductive system.¹ Because the bone marrow is one of the targets of chemotherapy, immune system suppression is a common side effect of these drugs.⁴

HIV & AIDS. Human Immunodeficiency Virus (HIV) attacks the CD4 cells (T cells) that make up part of the body's immune system. HIV reduces the number of T cells in the body, making that person more likely to contract an infection.^{1,18} If enough of these cells are destroyed, the body is unable to fight off even the simplest of infections.¹ These simple, opportunistic infections signal that a person has so little of their immune system functioning (less than 200 T cells per cubic millimeter of blood) that they have reached the last stage of HIV infection, Acquired Immune Deficiency Syndrome (AIDS).^{1,18} Not every person with HIV will progress to this stage of the disease, and many of the current drug therapies – such as antiretroviral therapy (ART) – can keep people healthy, prolong their lives, and decrease their chance of transmitting the virus.¹⁸



RECOMMENDED VACCINATIONS

Because cancer treatment often leads to immune system suppression, any infection can be a dangerous one.⁴ For this reason, the CDC recommends that anyone with a suppressed immune system get a yearly flu shot, a Tdap booster, both types of pneumococcal vaccine, and the HPV vaccine (up to 26 years of age).^{11,12} Additionally, the CDC recommends that patients with HIV and CD4 counts greater than 200 get the Hepatitis B vaccine, the MMR vaccine (if they were born after 1957 and have not had the disease or vaccination), and the varicella (chicken pox) vaccine in an effort to prevent a future infection with these diseases.¹²

LUNG DISORDERS

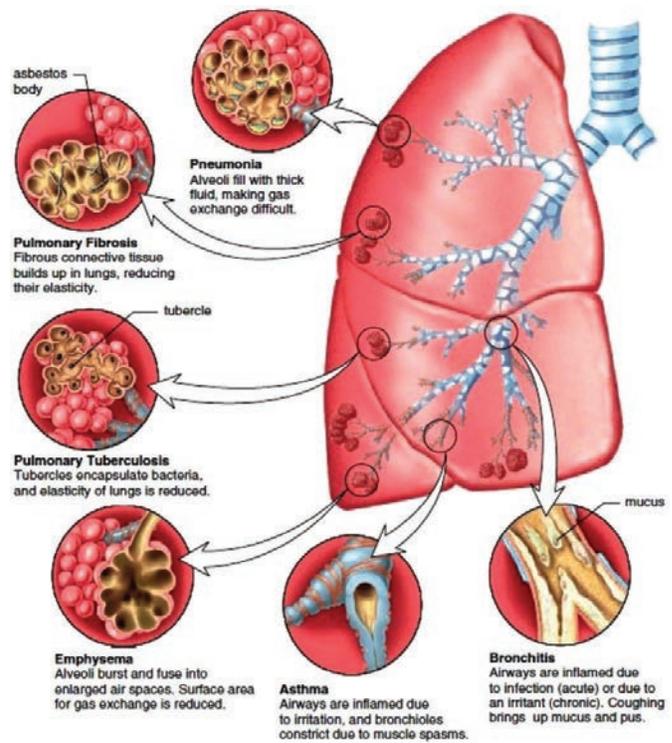


Image Credit: Clipart Kid, 2016

Lung disorders like Asthma or Chronic Obstructive Pulmonary Disease (COPD) are at a higher risk of hospitalization and complications from certain vaccine-preventable diseases, especially influenza and pneumococcal disease.^{11,12}

Asthma. Asthma is a lung disease due to chronic inflammation of the airways. Inflammation leads to the swelling and tightening of the airways – an “asthma attack.” These attacks can be triggered by infections, allergies, air pollution, and other irritants, but they can be prevented by limiting exposure to these triggers.²⁰

Chronic Obstructive Pulmonary Disease. COPD is a term used to describe progressive lung diseases like emphysema, chronic bronchitis, refractory or non-reversible asthma, and some forms of bronchiectasis.¹⁷ Mild chronic inflammation throughout the airways that can lead to damaged lung tissue is characteristic of COPD.²⁰ COPD affects 30 million Americans, and one major risk factor for these diseases is the inhalation of pollutants, especially cigarette smoke.¹⁷

RECOMMENDED VACCINES

Influenza. An influenza infection can be more serious for people with asthma or COPD because the flu can produce further inflammation of the airways and lungs. Infection with the influenza virus can trigger an asthma attack, worsening of symptoms, and is more likely to lead to pneumonia than in those without a lung disease.^{11,12}

Pneumococcal Disease. Pneumococcus bacteria is one of the most common causes of severe pneumonia. Since people suffering with asthma and COPD already have inflamed lungs, any additional inflammation can lead to serious side effects, like pneumonia, which may require hospitalization.¹²

Additional Recommendations. As with all adults, the CDC recommends a shingles vaccine (for people 60 and older) and a Tdap booster.^{11,12}

DIABETES

Diabetes mellitus (DM) is a group of metabolic diseases sharing the characteristic of high blood sugar, or hyperglycemia. Chronically high blood sugar may lead to complications in the eyes, kidneys, nerves, and blood vessels.²² These complications can lead to high cholesterol, high blood pressure, heart disease, stroke, blindness, kidney disease, and even amputations due to nerve disease.⁹ In 2014, it was estimated that 29.1 million people in the U.S. had diabetes, but only 21 million of them had been diagnosed.⁹ Each year, it is estimated that an additional 800,000 people will develop diabetes, and 54,000 will die from diabetes related complications.²¹

Type I diabetes. Previously called insulin dependent diabetes or juvenile onset diabetes, type I diabetes develops when the cells in the pancreas that produce insulin are destroyed by the body's own immune system, and is considered an autoimmune disease.²¹ Insulin is a hormone that is required to lower blood

sugar, or glucose. Glucose is the primary energy source for all the cells of the body, and insulin is the hormone that transports the glucose into the muscle, liver, and fat cells.²¹ Without this insulin, people with type I diabetes will suffer from hyperglycemia and its complications. The only treatment for type I diabetes is insulin injection.⁹

Type II diabetes. Also known as non-insulin dependent diabetes or adult onset diabetes, type II diabetes accounts for 90-95% of all diagnosed diabetes cases.⁹ In this type of diabetes, a person's body becomes resistant to the insulin their body is producing. The cells within the person's muscles, liver, and fat do not use the insulin properly and the glucose cannot leave the blood to enter the cells. The body's feedback mechanisms recognize this hyperglycemia and signal the pancreas to produce more and more insulin. Gradually, the insulin-producing cells lose the ability to produce sufficient insulin, and the body's ability must be supplemented by oral medications. Older age, obesity, a family history of diabetes, a history of gestational diabetes, and physical inactivity are all risk factors for type II diabetes.⁹

Gestational diabetes. Gestational diabetes is diagnosed during the second or third trimester of pregnancy, and is a form of glucose intolerance. Increasing blood levels to both the fetus and the mother can increase the risk of complications during gestation and birth, and may necessitate treatment with diet, exercise, or insulin. After giving birth, 5-10% of women with gestational diabetes continue to have hyperglycemia and are diagnosed with type II diabetes.⁹

RECOMMENDED VACCINES

Diabetes, and hyperglycemia, can make it harder for an immune system to fight infections, and can in fact exacerbate immune system disorders. Long-standing diabetes tends to lead to poor blood flow, which can increase the risk of infection. Diabetic neuropathy (the loss of nerves in the hands and feet due to hyperglycemia) can also lead to sores and cuts in the feet that go unnoticed, increasing the risk of infection.²¹

Influenza. Many illnesses can increase blood glucose, and in those people with hyperglycemia, this can lead to dangerous conditions. The flu shot is recommended for all diabetics.¹²

Hepatitis B. People with diabetes must constantly check their blood glucose levels by way of a finger prick. There have been hepatitis B outbreaks associated with blood glucose monitoring procedures, and for this reason, the CDC recommends all diabetics receive the hepatitis B vaccine.¹²

Pneumococcal. Due to the high amounts of blood sugar, poor blood flow, and other complications of diabetes, people with the disease are at an increased risk of pneumonia, bacteremia (blood infection), and meningitis (infection of the lining of the brain and spinal cord). For this reason, the CDC recommends a pneumococcal vaccination for diabetics.¹²

Other recommendations. The CDC also recommends a Tdap booster and a shingles (zoster) vaccine for diabetics. These vaccines are recommended for all adults, but diabetics are at an increased risk of infection owing to the high amounts of sugar in their blood.¹²

CONCLUSION

Immunizations are not only for children. Adults are an important part of herd immunity, and should continue to make their health a priority by keeping up to date with their vaccines. Influenza; tetanus, diphtheria, and pertussis; pneumococcal disease; and shingles are vaccines recommended for many adults. Those adults with chronic diseases can manage their illnesses by talking to their doctor, and following suggested guidelines for vaccinating themselves.

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Katherine Smith, M.D., M.P.H.

Dr. Smith has a background in medicine and public health, and has led research projects on foreign and domestic immunization practices. The results of her research have led to new practices for heat-stable vaccines and high-heat cold chain breaks in New South Wales, Australia. She is currently the program manager for the Immunization Coalition of Delaware, and works to increase the public's knowledge of vaccines and their role in increasing a community's overall public health.

DTC

BRINGING ACCESS TO AFFORDABLE, WORLD-CLASS, PATIENT-CENTERED HEALTHCARE THROUGHOUT THE STATE



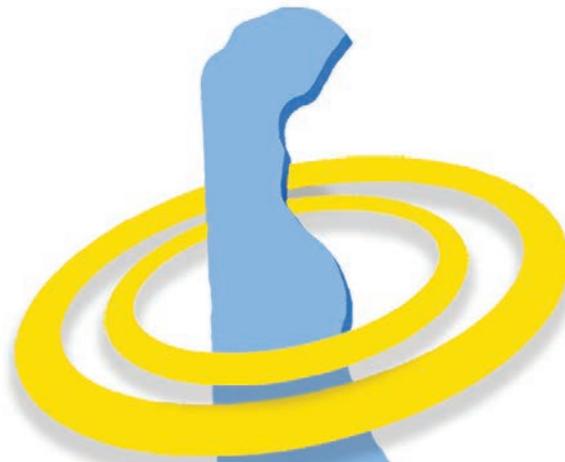
Who we are

The Coalition is a diverse group of healthcare stakeholders, including state agencies, local healthcare organizations, non-profit groups, commercial technology organizations, and members of the community.

To facilitate the use of telehealth to improve access to high quality healthcare throughout Delaware

Vision Statement

Telehealth will be fully integrated into Delaware's healthcare system so that all residents will have equitable access to affordable, world-class, patient-centered healthcare throughout the state.



DEDICATED TO IMPLEMENTING THE LATEST TELEHEALTH TECHNOLOGIES

Become a part of the initiative to incorporate telemedicine into Delaware's healthcare system and join the DTC as a representative of your agency, organization, or group. The DTC meets semi-annually to engage in collaborative activities and discuss the implementation and use of telehealth technologies so that Delawareans are delivered the best health services available. Smaller workgroups meet more frequently than the entire coalition to address issues that are vital to the advancement of telehealth in Delaware and to implement the Delaware Strategic Action Plan (SAP). All members will receive pertinent emails regarding the DTC's upcoming events and advancements in telemedicine.

From the Editors:

Strictly speaking, the Centers for Medicare & Medicaid Services do not include obesity as a chronic condition. They do, however, include hyperlipidemia. The editors provide the following context for the inclusion of the article titled "Cookfresh: Feasibility and Acceptability of Teaching Cooking Skills To Adolescents with Obesity." Obesity in children is defined as a BMI greater than or equal to the 95th percentile based on age and sex. (https://www.cdc.gov/nchs/data/hestat/obesity_child_07_08/obesity_child_07_08.pdf)

Obesity is the condition of weighing more than what is considered healthy for a given height. Body Mass Index (BMI) is used as a screening tool: a BMI of 30.0 or higher is considered obese. In 2013 the American Medical Association officially recognized obesity as a chronic disease. Their rationale was that defining obesity as a disease should spur physicians and patient – and insurers – to regard it as a serious medical issue. One in three Americans are obese, according to the Centers for Disease Control and Prevention. (CDC) (<https://health.clevelandclinic.org/2013/06/>

obesity-is-now-considered-a-disease/) Hyperlipidemia is a diagnosis based on a blood test indicating an abnormally high concentration of fats or cholesterol in the blood. Dyslipidemia is a condition marked by an abnormal concentration of lipids or lipoproteins in the blood, be that concentration high or low.

Thin people can have a diagnosis of hyperlipidemia and technically obese persons may have normal concentration of fats in their blood stream. However, there is a correlation between obesity and hyperlipidemia, however that relationship is weak and influenced by age. Importantly, the specific distribution of body fat seems to be important. (<https://www.ncbi.nlm.nih.gov/pubmed/1950659>)

Klop, Elte, and Cabezas published in 2013 in the journal *Nutrients* that "Obesity increases cardiovascular risk through risk factors such as increased fasting plasma triglycerides, high LDL cholesterol, low HDL cholesterol, elevated blood glucose and insulin levels and high blood pressure." (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3705344/>).



COOK Fresh

Feasibility and Acceptability
of Teaching Cooking Skills
to Adolescents with Obesity

*Michell Fullmer R.D., L.D.N., C.S.P., C.N.S.C.,
Mary M. Stephens M.D., M.P.H.,
P. Babu Balagopal Ph.D., Karen Anthony M.S.,
and Sandra Hassink M.D., M.Sc., F.A.A.P.*

Introduction

The prevalence of childhood obesity remains at approximately 18% among adolescents despite stabilization in its rates between 2007 and 2010.¹ Adolescent obesity is associated with an increased risk of severe obesity in adulthood and higher prevalence of obesity related comorbidities, particularly cardiovascular disease (CVD), and Type 2 Diabetes Mellitus (Type 2 DM)^{2,3,4}. Lifestyle factors play a major role in the development of obesity and its progression to comorbidities such as CVD and Type 2 DM.^{5,6,7,8,9,11} Adolescents with obesity frequently display unhealthy eating habits including irregular eating patterns such as skipping breakfast, late-night eating⁶, frequent intake of fast food⁷, eating in response to emotional issues or boredom, excessive intake of high-sugar beverages⁸, inappropriate portion sizes⁹, and lacking adequate intake of fruits, vegetables, and nutrients¹⁰.

Alterations in various risk factors and/or biomarkers of CVD are evident at an early age in the clinical course of obesity,^{12,13,14} but lifestyle interventions based on diet and physical activity have been shown to have favorable effects, both with and without weight reduction¹⁵. The development of cooking skills at an early age may play an important role in promoting a healthy lifestyle, but this has been given limited attention in studies examining the impact of lifestyle approaches in the management and/or prevention of adolescent obesity.^{16,17} In one study, lack of cooking skills was inversely related to consumption of fruits and vegetables in college students.¹⁸ A few studies have also suggested that interventions targeting cooking skills could be an effective strategy to promote healthy eating.¹⁹

Cookfresh was designed to study the effect of - as well as feasibility and acceptance of - a community-based cooking skills program, including meal planning and an actual shopping experience, on healthy behavior, quality of life, and health status including Body Mass Index (BMI) and specific biomarkers of cardiometabolic disease.

Materials and Methods

Participants in a pediatric weight management clinic were screened to determine eligibility by a study investigator and offered participation via letter to their home. Participants for the study were identified

through review of the electronic medical record by a study investigator over a three month period. This study was approved by the Institutional Review Board. An initial patient contact letter was sent to eligible patients. Adolescent assent and parental written consent were obtained at the first study visit. The study design, implementation and data collection took place from 2008 to 2012.

Inclusion criteria included age 13-17 years, BMI > 95th% for age and sex, family history of diabetes, and evidence of metabolic abnormalities including one of the following: elevated insulin (fasting insulin >20uU/l), acanthosis nigricans, impaired glucose tolerance (2 hour glucose >140mg/dl on 2 hour glucose tolerance test), elevated blood pressure (>90% for age and sex), polycystic ovarian syndrome, dyslipidemia (Triglycerides >150 mg/dl, HDL cholesterol <40mg/dl, Total cholesterol >170mg/dl), or non-alcoholic steatohepatitis (elevated liver function tests twice normal values in absence of other known cause). Exclusion criteria included diagnosed Type 2 DM, reading level below the fifth grade, inability to travel to location, behavioral/psychiatric condition limiting group participation, and/or pregnancy.

Program Delivery and Intervention

The intervention program was designed to enhance the standard lifestyle-based multidisciplinary medical approach to management of adolescent obesity.^{20,21} The focus was on developing specific skills for cooking, food shopping, and meal planning that are not involved in the current standard clinical approach. Adolescent learning was enhanced by fostering independent decision-making skills. Families were engaged with concurrent educational sessions and sent home examples of appropriately portioned, healthy meals prepared by the adolescents to be eaten with their family.

The Cookfresh intervention consisted of nine food preparation sessions conducted in a community-setting, with a kitchen and a classroom, under the direction of a registered dietitian over a 9 week period (Table 1). Each session was limited to 10 participants, lasted approximately two hours, and was focused on specific skills related to healthy eating. There was a consistent instructor, who was also a study investigator, for all program sessions to maintain



Eat **5 or more** fruits and veggies a day. They fight disease and are full of natural energy. Plus, many farmers' markets accept EBT cards as payment. Visit de.gov/buylocal and download the Delaware Fresh app to find fresh produce near you.



Limit yourself to **no more than 2 hours** of screen time each day (this includes TV, computer and gaming).



Get **1 or more** hours of physical activity each day. Delaware is full of parks and playgrounds. Visit dnrec.alpha.delaware.gov/play-outside to see the map and find some outdoor fun.



Stay away from sugary drinks. They're OK as a once-in-a-while treat, but too much sugar can make you gain weight and lead to diseases like diabetes.

5-2-1-Almost None; Logo and materials copyrighted by Nemours Health and Prevention Services (NHPS). For queries or possible use, please contact Nemours Health and Prevention Services, Attn: Regulatory Compliance, 252 Chapman Road, Suite 200, Newark, DE 19702

the integrity of the information provided during the sessions. During each session, in addition to the intervention focus on food purchase and cooking skills, other topics such as body image, goal planning, label reading, mindful eating, importance of nutrient dense foods and the 5-2-1 Almost None (Figure 1) concept were discussed. Empowerment and self-sufficiency were overarching themes. The participants chose the foods that would be prepared for each session in which food preparation took place.

A pre-test/post-test design was employed to evaluate dietary and health status outcomes as well as cardiometabolic markers and anthropometric measures. The primary outcome measures included improvement on "Rate Your Plate",²² improvement in dietary and healthy behaviors as measured by the Cookfresh Questionnaire, and improvement in health status as measured by the Pediatric Quality of Life Questionnaire.²³ Secondary outcomes included BMI, waist circumference, blood pressure and biomarkers of CVD.

Program acceptability and feasibility were determined by an end of program questionnaire, feedback from participants during the intervention, cost, and investigator analysis of process.

Measures

"Rate Your Plate" is a validated 22-item questionnaire about foods that are typically eaten such as red meat intake, serving sizes of meats, eating out, consumption of fried foods and types of grain products. A score of 55-69 is indicative of making healthy choices, while lower scores indicate there are many healthier choices that could be made.

The Cookfresh Questionnaire is a six-item non-validated survey created for this study, with five choices per item that rates total hours of screen time, total minutes of physical activity, number of 8-ounce sugared beverages consumed on a daily basis, number of days per week breakfast is eaten, number of days per week families eat a meal together, and how 'in charge of healthy eating' a participant feels.

The validated Pediatric Quality of Life questionnaire (Version 4.0, teen report ages 13-18) is a 23-item questionnaire that asks participants to rate items related to their health and activities (physical functioning), feelings (emotional functioning), how they get along with others (social functioning) and school life (school functioning) on a scale of 0 (never) to 4 (almost always). Higher responses indicate that an item is more of a problem, such as "It is hard for me to do sports activity or exercise."

BMI, waist circumference, and blood pressure were measured at baseline, three months, six months and twelve months. Blood samples were also collected at each of these time points after an overnight fast (~10 hours) for the measurement of biomarkers of CVD. Methods for the measurements were as follows: glucose (hexokinase assay), insulin (chemiluminescent immunometry), leptin and soluble leptin receptor (sOB-R by radio-immuno assay – RIA), adiponectin (both total and high molecular weight), retinol binding protein 4 (RBP4) and interleukin-6 (IL-6) by enzyme-linked immunosorbent assay (ELISA), and high-sensitivity C-reactive protein (hs-CRP) (immunonephelometry). The homeostasis model assessment – insulin resistance (HOMA-IR) was calculated using the formula: fasting glucose (M) x fasting insulin (uU/mL)/22.5.

Analysis

Descriptive statistics, including means and standard deviations for continuous variables and counts and percentages for categorical variables, were calculated for all baseline data. Change in primary and secondary outcome variables was analyzed by repeated measures analysis of co-variance from baseline to three, six, and twelve months post-enrollment adjusting for sex. Comparisons of inflammatory markers at specific post-intervention times with baseline were made by paired T-tests with a Bonferroni correction for multiple testing. Other continuous variables were analyzed in the same way.

Results

Twenty-eight participants completed the program. Those that did not complete at least 8 sessions were not included in subsequent data collection. Table 2 describes characteristics of the study participants. Follow up data was collected on 27 participants at three months, 22 participants at six months, and 19 participants at twelve months.

Primary Outcomes

“Rate Your Plate”: A significant improvement in aggregate Rate Your Plate score was found at the completion of the course, persisted at 6 month follow up and reverted to pre-course findings at 12 months (Table 3).

Improvement in Dietary and Healthy Behaviors assessment: Analysis of the Cookfresh Questionnaire was notable for trends toward a decrease in screen time, a reduction in number of sugared beverages consumed daily, and an increased frequency of family meals that was still present at twelve months. Quantity of physical activity was unchanged. Tests of statistical significance were not performed.

Quality of Life: There were significant improvements in scores on the teen Pediatric Quality of Life Inventory at the completion of the course (3 months) which persisted at 6 and 12 months (Table 3).

Feasibility: Participant recruitment was affected negatively due to time commitment and transportation requirements. There were a total of 33 participants that had signed parental consent and participant assent, however, three were lost to follow up in the first group and one participant in the second group was excluded at the discretion of the investigator. There was no difficulty delivering the interventions and the study participants did not face any problems during session interventions. There were 27 participants who completed at least 8 out of the 10 sessions. Follow up data was available on 27 participants at three months, 22 participants at six months and 19 participants at 12 months. Due to initial lack of follow up data in the first group, investigators then developed an agreement for parents to sign indicating knowledge of need to participate in all sessions and follow up. Additionally, the local YMCA provided a free three month family membership for participants that completed the

Cookfresh program and follow up research visits. Implementing both of these measures improved the retention of study participants, with only two lost to follow up in the following three study groups. There were no recognized characteristics of those that were retained versus those that were lost to follow up.

The total cost of the program without lab fees was approximately \$670 per participant, including staff time. This may be a factor in efforts to replicate it.

Program acceptance/qualitative feedback:

The questions asked as an evaluation of the program by the teens were:

- 1) I now know how to pick healthy food choices at the supermarket –agree or disagree.
- 2) I now know how to plan my meals to make them healthier—yes, or no.
- 3) The Cookfresh program was too many weeks or not long enough?
- 4) The weekly classes were too long or just enough time?
- 5) Was the facilitator helpful?
- 6) If I could add anything to the Cookfresh program I would add.
- 7) Is there any part of the cook fresh program that you felt was not helpful or necessary?
- 8) What did you enjoy most about the program?
- 9) What did Cookfresh mean to you?

The questions asked as an evaluation of the program by the parents were:

- 1) My family is now making better choices.
- 2) The information and food that was sent home with my child was helpful in learning what healthy foods and portion sizes are.
- 3) The Cookfresh program was too many weeks or not long enough?
- 4) The parent sessions were helpful or not helpful?
- 5) If I could add anything to the sessions I would add.
- 6) Was there any part of the Cookfresh program that you felt was not helpful?
- 7) What do you feel your child learned as a result of being part of the Cookfresh program?
- 8) What did Cookfresh mean to you?

Participant subjective evaluation of the program was uniformly positive. With the exception of recommending the meditation/relaxation portion of the sessions be dropped, both teen and parent comments reflected a desire for additional sessions and a follow-up component to the course. The intimate nature of the intervention (less than 10 participants per session) and open discussion at times led to participants sharing very personal information. Many of the participants developed relationships with each other that continued after the program ended. Most adolescents endorsed wanting to continue the group. The feedback provided by family members about the meals that were sent home were generally positive and made the participants feel empowered to make healthier choices.

Secondary Outcomes

Cardiometabolic risk factors/biomarkers: BMI remained unchanged throughout the study period. Similarly, HOMA-IR and other risk factors of CVD such as adiponectin (total and HMW), CRP, IL-6, leptin, sOB-R, and RBP4 did not show significant differences between baseline and follow up measures at three, six, or twelve months.

Discussion

This study was designed to test the feasibility and acceptability of a nutrition-focused, skills-based cooking intervention with adolescents to determine if such an intervention would lead to beneficial changes in quality of life, BMI and risk factors of CVD. The data demonstrated sustained improvements in quality of life such as, decrease in screen time, reduction in the number of sugared beverages consumed daily, and an increase in the number of family meals - behaviors recommended in expert guidelines for obesity treatment²⁴. BMI and cardiometabolic risk factors during the 12-month period of the intervention did not change. The current study is the one of, if not the first to simultaneously assess the feasibility and acceptability of a nutrition-focused cooking skills intervention and its impact on biological factors including indicators of obesity and biomarkers related to cardiometabolic disease.

In general, this intervention based on developing healthy cooking skills in adolescents was related to overall improvements in behaviors that are closely

related to obesity and its management. The program was viewed positively by both adolescents and their families. In addition to the positive feedback from the formalized questionnaires at the end of the program, the instructors found both teen and parent participants to be engaged while both learning and having fun during the sessions. There were opportunities for sharing, comradery and emotional release.

The Cookfresh pilot intervention demonstrates promise as an adjunct to a traditional weight management program and adds a practical education piece on mindful and healthful cooking that cannot occur in a clinical setting. This approach is unique in that it is skills-based, fosters peer interactions, and is patient- and family- centered. Limitations of the study include the lack of a formal control group, small sample size and the loss of participants to follow up.

Suggested modifications to the intervention would include eliminating the use of biomarkers as they were both costly and difficult to obtain. While it was disappointing that no significant improvement in BMI was demonstrated despite the change in healthy behaviors, one could look at the trajectory of the increase in BMI pre intervention compared with the BMI trajectory post intervention to see if this intervention could lead to stabilization of BMI.

While the pilot focused on cooking skills and family involvement, the program would likely be enhanced by adding an exercise component and focus. While the one year follow up period in this study is likely adequate, a longer curriculum initially along with periodic follow up sessions to function as a maintenance phase, could potentially lead to more clinically significant outcomes as nine weeks is a fairly brief time in which to develop sustained behavior change.

Conclusion

This pilot study demonstrated the feasibility and acceptability of an innovative skills-based intervention for teens. The sustained improvements in quality of life and lifestyle behaviors are significant findings. The concept could potentially be adapted for use in other settings, such as schools, as the Cookfresh approach offers the potential to become a practical mechanism to promote health, social and educational skills to better prepare adolescents for adulthood.

Table 1: Cooking Session Outline

Week	Focus of Each Session Instruction
1	Meal Planning: Distribute cookbooks, discuss how to plan meals, how to shop on a budget and how to make a grocery list. Concurrent adult session on family health history considering cultural preferences regarding body shape.
2	Supermarket tour for parents. Supermarket tour and purchasing of food for participants.
3	Snacking: Preparation of snack as well as discussion on what are healthy snacks and listening to hunger cues. Food safety was also reviewed.
4	Breakfast: Preparation of breakfast as well as discussion on why breakfast is important and ways to overcome barriers to consuming breakfast.
5	Lunch: Preparation of lunch as well as discussion of how to make healthy choices with school lunch options.
6	Dinner: Preparation of dinner as well as importance of a family meal.
7	Giving Back: Preparation of a meal for a shelter / less fortunate. Review of menu and calorie goals for next week's session on dining out.
8	Dining out: Participants and instructor met at a restaurant chosen by the participants. Ways to improve nutritional quality of food choice at a restaurant was discussion during the meal.
9	Family meal: Participants prepared dinner for their family. Importance of family meals were discussed. Concurrent adult session: Discussion on ways to reward and celebrate without food.

Table 2: Group Participants Base Descriptors

Descriptors	Female N	Percent of Total	Male N	Percent of Total		
Sex	19	67.85	9.00	32.14		
Pre-Course N	Minimum	Maximum	Mean	Standard Deviation	Confidence Interval for Mean @ 95%	
Age	27	13	17	14.56	1.22	14.08, 15.04
BMI	28	28.08	54.7	37.70	7.24	34.88, 40.52
BP Sys	28	98	132	113.50	10.21	109.53, 117.47
BP Dias	28	52	102	68.36	10.34	64.34, 72.39

Table 3: Rate Your Plate and Pediatric Quality of Life Analyses at 3, 6, & 12 months

Rate your Plate Comparison at N	Mean	Standard Deviation	Confidence Interval 3-, 6-, and 12- month intervals	for mean @ 95%
RtUrPlt Pre	26	46.58	8.61	46.74, 53.50
RtUrPlt 3-mo	26	50.12	8.37	43.10, 50.06
RtUrPlt Pre	18	45.78	8.56	47.28, 55.05
RtUrPlt 6-mo	18	51.17	7.82	41.52, 50.03
RtUrPlt Pre	17	47.82	9.21	44.14, 53.86
RtUrPlt 12-mo	17	49.00	9.45	43,09, 52.56
PedsQLI Pre-	26	72.99	18.53	46.74, 53.50
PedsQLI 3-mo	26	79.68	16.50	43.10, 50.06
PedsQLI Pre-	19	70.02	19.34	47.28, 55.05
PedsQLI 6-mo	19	77.63	16.73	41.52, 50.03
PedsQLI Pre-	16	68.61	20.49	44.14, 53.86
PedsQLI 12-mo	16	80.04	12.54	43,09, 52.56

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Michell Fullmer R.D., L.D.N., C.S.P., C.N.S.C. is a pediatric dietitian and Nemours/ A I duPont Hospital for Children in Wilmington, DE and is currently serving as Chair of the Pediatric Nutrition Practice Group of the Academy of Nutrition and Dietetics



Mary M. Stephens M.D., M.P.H. is the Medical Director of Christiana Care's School-Based Health Centers and a faculty member in the Family Medicine Residency.



P. Babu Balagopal Ph.D. is the Head of the Obesity & Cardiovascular Research Laboratory and Director of Biomedical Analysis Research Laboratory, Children's Specialty Care & Associate Professor of Pediatrics Mayo Clinic College of Medicine, Jacksonville, FL.



Karen Anthony M.S. is a certified health education specialist. She is the senior program manager at Christiana Care's Eugene du Pont Preventive Medicine and Rehabilitation Institute in the Department of Family & Community Medicine in Wilmington, DE



Sandra Hassink M.D., M.Sc., F.A.A.P. is Adjunct Professor of Pediatrics at the Center for Child Health and Policy, Case Western Reserve, Cleveland OH and past President of the American Academy of Pediatrics (AAP) and serves as medical director of the AAP Institute for Healthy Childhood Weight.



Diabetes in Delaware:

What's Social Support Got to Do with It?

By Madeline Brooks, B.A.

The Burden of Diabetes in Delaware

Delawareans face an insidious threat to their physical, emotional, and financial wellbeing – one that many experience firsthand. Diabetes afflicts nearly 12 percent of Delaware adults age 18 and older, according to 2015 data from the Delaware Behavioral Risk Factor Survey.¹ This means more than 85,000 Delawareans, 90-95 percent of whom are estimated to have type II diabetes.¹ And such diagnoses will likely increase. In 2014, 8.6 percent of Delawareans – or more than 54,700 individuals – reported being told they have “pre-diabetes,” or borderline diabetes.¹ These alarming statistics mean roughly 20 percent of Delawareans have either type I or type II diabetes, or are at high risk for developing type II diabetes.

Diabetes impacts both individuals and the state as a whole. At the individual level, type I and type II diabetes can result in serious complications, ranging from skin, eye, nerve, and foot problems; kidney disease; heart disease; stroke; and even death.² Delaware spends \$1.1 billion a year on costs associated with diabetes – more than it spends on heart disease or cancer, The News Journal recently reported.³

Diabetes and Social Stigma

One complication of diabetes, however, is invisible and carries a high cost. Afflicted by what is sometimes known as the “blame and shame disease,” both type I and type II diabetics can face social stigma.⁴ Type II diabetics and adolescents with type I diabetes often experience disease-related blame, rejection, discrimination, and negative stereotyping.^{4,8}

While not experienced universally by diabetics, stigmatization does not go unnoticed among Delaware healthcare providers. “Some people who find out they have diabetes... tell the whole world about it and ask people to help,” said Dr. James Lenhard, Medical Director of Christiana Care Health System’s

Diabetes & Metabolic Diseases Center. “Other people are embarrassed, ashamed, secretive, and don’t want anybody to know. Some have actually tried not to let their spouse know that they have it.”

“I do think there’s some stigma around diabetes in general, especially if someone has type I,” said Tricia Jefferson, RD, LDN, Director of Healthy Living and Strategic Partnerships at the YMCA of Delaware. “I think they tend to feel outnumbered sometimes because materials say it [diabetes] is preventable, or just reference diabetes without specifying type I or type II.”

The implications of stigma reach further than psychosocial health. Disease-associated stigma may make individuals more susceptible to stress-related illness, or even cause them to delay or avoid seeking treatment so as to distance themselves from a negative label.⁵ Patients with chronic disease who perceive greater stigma from family and friends may experience higher stress, lower social support, and lower satisfaction with their healthcare, all of which combine to reduce quality of life.⁶ Additionally, insulin use is associated with several myths (e.g., admitting failure/guilt in managing diabetes) that may prevent some individuals from undergoing this treatment.⁷ Real and imagined stigma from healthcare providers may make patients less likely to access care, ultimately worsening their chronic disease.⁸

The impact of diabetes extends beyond the personal level, and interventions that draw on interpersonal and community support may offer potential to stem the tide of diabetes in Delaware. This article examines three innovative interventions that draw on social support to manage chronic disease: shared medical appointments, the National Diabetes Prevention Program, and online support groups.

Shared Medical Appointments

Shared medical appointments (SMAs), also known as

group care or group visits, may be an effective means of increasing social support and improving outcomes related to chronic disease. The American Academy of Family Physicians defines SMAs as group visits in which multiple patients are voluntarily seen as a group for follow-up care or management of chronic conditions. Patients receive one-on-one evaluations, but providers also deliver counseling and education to the whole group.⁹ Approximately 10 percent of family physicians conducted SMAs in 2013, up from 5.7 percent in 2005.¹⁰

Studies find that SMAs offer a wide variety of benefits for healthcare providers,¹¹⁻¹³ patients with type II diabetes,¹⁴⁻¹⁶ and adolescents with type I diabetes.¹⁷ Shared visits with a multidisciplinary team offer a greater breadth of information without repetition, increasing efficiency and streamlining care.¹¹⁻¹³ Group visits can provide diabetes education for patients who may not otherwise seek it outside of regular medical care.¹³ SMAs have been shown to help patients stabilize metabolic control,¹⁴⁻¹⁵ reduce BMI,¹⁴ and improve quality of life,¹³⁻¹⁴ knowledge of diabetes, health behaviors,¹⁴⁻¹⁵ and satisfaction with care.¹⁶⁻¹⁷

The benefits of SMAs are accompanied by challenges in coordination and cost. SMAs may not be appropriate for all patients, yet these visits require a high enough census to maintain efficiency and cost savings.¹² Group visits necessitate significant changes to the practice environment and infrastructure.¹⁸ According to Dr. Lenhard, effective SMAs must be tailored to patients with similar health concerns and backgrounds. The expense of hiring a staffer to coordinate such visits may outweigh their initial cost savings. Additionally, SMAs may compete with existing diabetes education programming in the state.

The challenge may lie in reinforcing a shared approach to diabetes at the community, rather than clinical, level. “For some, [diabetes] is pertinent to their particular group, whether that’s their church, club, neighborhood, ethnic background, extended family, or town,” said Dr. Lenhard. “Adopting a more widespread approach is one of the keys to stemming this tide. We need to start reaching out to come of these other groups, and since people have different affiliations and beliefs, it’s going to have to be more than one group.”

The National Diabetes Prevention Program

The National Diabetes Prevention Program (DPP), developed by the Centers for Disease Control and

Prevention and the National Institutes of Health, offers a proven model for group-based lifestyle intervention.¹⁹⁻²¹ The DPP is a year-long educational program to prevent or delay the onset of type II diabetes. The initial study found that one-on-one interventions reduced the incidence of type II diabetes by 58 percent as compared to metformin treatment, which reduced incidence by 31 percent.¹⁹ Ackerman and colleagues later adapted the DPP model to a more cost-effective, group-based delivery through the YMCA.²⁰⁻²¹ They demonstrated the modified program’s success in reducing BMI and cholesterol levels.²¹ Today, more than 1,200 medical and community organizations across the country deliver the program.²²

Delaware is one of only two states to implement the DPP statewide.²³ The program operates through the YMCA of Delaware under the guidance of Tricia Jefferson. The YMCA of Delaware’s DPP is delivered to groups of 10-15 people by trained lay facilitators. Eligible participants must be at least 18 years of age, overweight (BMI > 25), have a confirmed diagnosis of prediabetes (HgbA1C of 5.7-6.4), or be at high risk of developing type II diabetes. Facilitators guide participants through classroom-based discussions on nutrition, physical activity, and behavior modification over 16 core sessions followed by a 6-8 month maintenance program.²⁴

The YMCA of Delaware DPP’s results exceed those of the program’s national averages. Delaware participants spend an average of 165.6 minutes in weekly physical activity (national average = 158.1 minutes), and 67 percent complete use of a food tracker (national average = 64 percent). At the end of the year, participants achieve an average weight loss of 5.7 percent (national average = 5.5 percent). Roughly 90 percent of state participants report that they reduced portion sizes, while about 86 percent report that they improved their overall health and increased their physical activity (n=416).²⁵

Jefferson attributes the program’s success to its cost-effective delivery and group dynamics. Lay facilitators translate structured content in a way that engages the group, and participants engage through discussion. “If anyone’s ever tried to make behavior change, it’s typically very challenging to do it on your own,” said Jefferson. “We’re getting the participant buy-in... that helps to create that network of support because participants are sharing with each other rather than just coming, listening, and leaving.”

Delaware's DPP works in tandem with healthcare providers. Nearly 60 percent of program participants come through provider referrals,²⁵ and providers then receive progress updates via the YMCA's secure electronic health record. "We're a community-based organization," said Jefferson, "but still delivering a lay, evidence-based model, and not replicating what they're doing in the clinical field. We're working side-by-side to make sure that in the community, patients are being healthy and then connecting back with their healthcare provider."

Online Support Groups

Technology can bridge the social support gap from the privacy of one's home. Internet-based interventions for type I and type II diabetics have gained attention for their ability to increase access to health information and social support while minimizing barriers. Such interventions offer education, disease management skills, and peer discussion groups, usually under the guidance of professional moderators or health coaches.²⁶⁻³¹

Several factors enhance the attractiveness of online interventions. Online interventions increase access to diabetes care for those limited by geographic, financial, or convenience barriers.²⁶⁻²⁸ Individuals can easily find and choose their community, then participate at their convenience.²⁶ Online communities offer 24-hour access while preserving user privacy.²⁷

Internet-based interventions offer limited benefits for type II diabetics, which include improvements in perceived social support,²⁶ coping ability,²⁹ disease management,²⁷ and physical activity.²⁸ An online intervention for adolescents with type I diabetes demonstrated improvements in problem solving and self-management adherence, and appeared to offset typical adolescent increases in A1C levels.³⁰

Despite their benefits, online diabetes interventions face several limitations. There is limited evidence detailing their health effects^{26, 28} or the effectiveness of online vs. face-to-face interactions.²⁹ Benefits of online interventions may depend on the presence of professional moderators. Eysenbach and colleagues' review of online consumer-led peer health communities found little evidence that they improve measures of social support and depression.³¹ The development and management of effective interventions places a substantial burden on moderators.^{29, 31} Finally, individuals with limited internet access or technology skills may be unable to take advantage of these interventions.²⁷

Conclusion

The diabetes crisis in Delaware requires a collective approach at the clinical and community levels. Techniques to increase social support can enhance, rather than duplicate, existing services in the state. In doing so, Delaware can reduce stigma and build a shared attitude around chronic disease. Individuals may not benefit from diabetes care or knowledge while hindered by barriers of shame, guilt, or loneliness. By expanding the conversation around diabetes, Delawareans can better work together to manage and prevent this disease.



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Madeline Brooks, B.A.

Madeline Brooks is a Master of Public Health (MPH) candidate at Thomas Jefferson University. She holds a Bachelor of Arts in mass communication from the University of Delaware. She hopes to use her skills in writing, research, administration, and analysis to contribute to the field of public health.

Teen Perceptions of Sexual Activity:

Influences, consequences, realities, and thoughts on safe sexual health practices

Judith W. Herrman, Ph.D, R.N., A.N.E.F., F.A.A.N.



Abstract

Teens' engagement in sexual activity and safe sexual practices is an important public health issue in the US today. This descriptive survey study explored teens' thoughts about the influences, consequences, and realities associated with teen sexual activity and pregnancy and their perceptions of access to sexual health education and contraception. Surveys were administered to 856 Delaware youth in 39 high school health classes from 16 schools. Of the 31 survey items, 25 offered significantly different responses; participants agreed with 16 and disagreed with 9 items ($p < .005$), revealing important findings concerning teen perceptions as the basis for meaningful interventions.

Keywords: teen perceptions, teen sexual activity, safe sexual practices, teen pregnancy

Introduction

Delaware teens report some of the highest rates of sexual activity in the nation (Kann et al., 2014). Although teen pregnancy and birth rates are lower than recent history, teen reports of frequent sexual activity, early involvement in sexual activity and increased reported rates of multiple sexual partners and use of alcohol during sexual activity warrant a shifting focus on promoting teen safe sexual practices (Kann et al., 2014). With this redirection of focus, advocates contend that we need to access teens' own perceptions such that interventions are meaningful and effective (Gallup-Black & Weitzman, 2004; Author & Waterhouse, 2011; SmithBattle, 2009; Tanner et al., 2012). Author and Nandakumar (2012) developed a survey to assess teen perceptions of the impact a birth would have on their lives. As a subscale of this survey instrument, an additional section assessed teen perceptions of the influences, realities, and consequences related to teen sexual activity and their thoughts on access to safe sexual practices. Therefore, the purpose of this descriptive study is to explore teen perceptions of the influences, consequences, and realities of teen sexual decision-making, and youth thoughts on access to sexual health education and contraception.

Table 1. Perceptions of INFLUENCES

Item	% Agree	% Disagree
I have an adult in my life that I respect.*	95%	5%
The media has a great impact on teen sex.*	78%	22%
I know an adult in my life to talk with about sex and birth control.*	75%	25%
Having teen parents talk to teens about what it is like to have their children prevents pregnancy.*	68%	32%
Adults are truthful with teens about sex and pregnancy.***	50%	50%
Boys want their girlfriend to have children.*	15%	85%

*significant at a level of $p < .005$

**largely neutral responses, non-significant findings

***non-significant differences between agreement and disagreement responses

REVIEW OF THE LITERATURE

Studies related to teen perceptions of sexual activity and safe sexual practices provide the foundation for further investigation. This review will discuss studies related to teen perceptions of the influences, consequences, and realities of sexual activity and teen pregnancy and youth thoughts on access to sexual health education and contraception.

Influences

Teens perceive that a variety of influences impact their sexual practices. Albert (2012) identified that teens indicate parents or involved adults as the primary influences on sexual activity. The vital nature of adult role models, the influence of parents and other adults, and the power of adults to influence the lives of youth and sexual behavior are prevalent research findings (Albert, 2012; Author, 2008; Lagus et al., 2011; Lieberman, 2006; Ryan, Franzetta, & Manlove, 2007; Stridham-Hall, Moreau, & Trussell, 2012).

According to Albert (2012), teens noted that parents, in portraying values, communicating with teens, and monitoring their activities, are the greatest influence on their decisions about sex and their engagement in healthy sexual practices. Albert (2012) also noted that parents often underestimate their ability to inform their children's actions.

Teens identified that, in the absence of adult role models, friends and the media served as influences on sexual activity; teens contending that these sources were often inadequate in filling this role (Author, 2008). Although teens often perceived most other teens are having sex and that peers may be a sound source for sexual information, self-report data of sexual activity reflects much lower rates (Albert, 2012; Deptula, Henry, Shoeny, & Slavick, 2006; Kann et al., 2014; Weiss, 2008). Research demonstrates that perceptions of increased sexual activity among peers increases the likelihood for personal participation in sexual activity and beliefs that a peer has a greater number of sexual partners increases the likelihood for multiple sexual partners in teens (Albert, 2012; Ali & Dwyer, 2011; Miranda-Diaz & Corcoran, 2012; Seiving, Eisenberg, Pettingell, & Skay, 2006). The power of peers and partners to influence sexual behavior is noted by teens as a critical element in engaging in sexual activity and safe sexual practices (Author, 2008).

Other researchers discussed the impacts of mass media and media literacy on teen perceptions of sexual health, sexual activity, and learning about sex through television, theatre, movies, and internet (Brown & Witherspoon, 2002; Lagus et al., 2011; Pinkleton, Austin, Cohen, Chen & Fitzgerald, 2008). These researchers substantiated the use of media resources by teens to discover information about sexual activity and safe sexual behavior, but teen perceptions about the value of media and adolescent use of credible internet sites, versus pornography or those sites purporting invalid information about sex, is less known (Pinkleton et al., 2008).

Consequences

Perceptions research about consequences may be divided into teen thoughts on those associated with sexual activity and those related to pregnancy. Researchers exploring teen perceptions of the risks of sexual activity noted that teens often focus on pregnancy or sexually transmitted diseases (STIs), rather than focusing on personal or social consequences (Roye & Seals, 2001). Author (2007) noted that young women may be aware of the consequences of sexual activity, having unprotected sexual activity, or engaging in risky sexual behaviors, but that this awareness may not translate into safe sexual practices. Several researchers affirm the need to consider the dimensions of adolescent reasoning, wherein the less mature brain is unable to appreciate consequences, engage in rational decision-making, or suppress impulsive urges (Author, 2005; 2007; 2008). In addition, the influence of passion, substance use,

Table 2. Perceptions of CONSEQUENCES

Item	% Agree	% Disagree
Teen pregnancy is an important issue.*	94%	6%
Having a baby as a teen is a bad thing.*	70%	30%
Birth control has a bad effect on a girl's body.**	45%	55%
It is okay to have a baby as a teen.*	16%	84%
Children born to teen parents are better off than other children.*	9%	91%

*significant at a level of $p < .005$

**largely neutral responses, non-significant findings

***non-significant differences between agreement and disagreement responses

and succumbing to peer or partner pressure may further tempt teens into engaging in sexual experiences and they may temporarily disregard their own knowledge of consequences. Gender may influence teens' perceptions of the consequences of sexual activity. Researchers found that young men focused on the pleasure, rather than the potential consequences, associated with sexual activity while females were more apt to consider the costs and responsibilities associated with sexual behavior (Deptula et al., 2006).

Studies explored teen parents' thoughts on the impact a teen pregnancy and birth had on their lives, demonstrating a mixed set of perceptions. Some teen parents relayed negative impacts on social life, education, careers, and finances and while others shared positive impacts in such areas as intimate relationships and those with their family (Clemmons, 2003; Author, 2007; Pashkiewicz, 2001; Rentschler, 2003; Rosengard, Pollock, Weitzen, Meers, & Phipps, 2006; Spear, 2004). Most of the positive effects were noted in the area of personal development, noting that having a baby made them more mature, enhanced decision-making, and increased their sense of responsibility and goal-setting for the future (Clemmons, 2003; Author, 2006; Author, 2007; Jewell, Dodge, & Dittus, 2003; Kelly, Lesser, & Paper, 2008; Rosengard et al., 2006).

Researchers found that non-parenting teens perceived mostly negative impacts of the teen pregnancy experience, including a loss of freedom, lack of friends

and social life, sleep deprivation, increased work juggling school and parenting, family discord, financial stressors, and hindrance in pursuing educational and career goals (Gallup-Black & Weitzman, 2004; Hacker, Amara, Strunk, & Horst, 2000; Author, 2008; Author & Waterhouse, 2011; Kegler, Bird, Kyle-Moon, & Rodine, 2001; National Campaign to Prevent Teen and Unplanned Pregnancy, 2006; Unger, Molina, & Teran, 2000). Non-parenting teens also noted positive aspects of having a baby including: the capacity for young parents to mature, recognition of young parents' adult status, maintenance of relationships with partners, monetary gain in the form of child support and governmental subsidies, the potential for young mothers to complete their mothering earlier to allow for later educational and career pursuits, providing purpose to their lives, to gain attention from others, to have a source of pleasure in an otherwise stressed life, or to have someone special to love and cherish (Gallup-Black & Weitzman, 2004; Hacker et al., 2000; Author 2008; Author & Waterhouse, 2011; National Campaign to Prevent Teen and Unplanned Pregnancy, 2006).

Realities

While several studies noted teens' beliefs that teen pregnancy is an important issue, teens' views on the realities of sexual activity are less represented in the literature (Albert, 2012; Author, Solano, Stotz, & McDuffie, 2013; Kegler et al., 2001; Little, Henderson, Pederson, & Stonecipher, 2010) . In a focus group study, young people affirmed that many teens engage

Table 3. Perceptions of REALITIES

Item	% Agree	% Disagree
Most teens have sex.*	87%	13%
Some girls want to get pregnant.*	82%	18%
Teens will get pregnant even if they have access to birth control.*	78%	22%
Teens will get pregnant whether or not they have information about sex or birth control.*	73%	27%
Usually teen sex is unplanned.*	66%	34%
Teens will get pregnant even if they regularly use birth control.**	46%	54%
Teens who have a baby often have another baby during the teen years.**	41%	59%
The children of teen parents later become teen parents themselves.**	37%	63%
Teens are thinking about a baby when they are having sex.*	14%	86%
Teen pregnancies are usually planned.*	13%	87%

*significant at a level of $p < .005$

**largely neutral responses, non-significant findings

***non-significant differences between agreement and disagreement responses

in sexual activity and that this is a reality of current teen behavior, although teens recognize that adults often believe them to be too young or ill-equipped for the responsibilities of sexual activity (Author, 2008).

In addition, although many teens reported that teen pregnancy can and should be prevented to avoid the associated consequences, they also acknowledged many teen parents are very effective in their roles and were noted to discard the stigma associated with early parenting (Author, 2008). For some young people early parenting is a positive way to deal with poverty, a decreased lifespan, and increased morbidity in a community shaped by norms of early childrearing (Author 2006; 2007). Several authors assert that teens believe that some teen pregnancies are inevitable occurrences in our society and, as such, are part of the realities of teen life (Gallup-Black et al., 2004; Hacker et al, 2000; Author, 2008; Weiss, 2012).

Access to Safe Sexual Practices

Review of teen perceptions of sexual health practices includes the research related to access to sexual health education information and to condoms and contraception. Surveys reflected that teens believed they have access to comprehensive sexual education and that education is critical in safe sexual behavior (Albert, 2012; Hacker et al., 2000; Author et al., 2013). Teens also indicated that they had adequate information to avoid an unplanned pregnancy, although many knew “little or nothing about condoms or birth control pills,” raising some concern about teens’ levels of knowledge about contraception and

their ability to translate knowledge to safe practices (Albert, 2012, p. 8). Although teens perceived their parents were resources for information, experts indicate that parents are often embarrassed, lack knowledge, or provide inaccurate information related to sexual activity and access to contraception and that teens may not trust information received from parents (Constantine, Jerman, & Huang, 2007; Eisenberg, Bearinger, Sieving, Swain, & Resnick, 2004; Lagus et al., Eisenberg, 2011).

Studies validate that teens do not believe that access to condoms and contraception increases level of sexual activity (Brown, DiClemente, & Crosby, 2008; Hacker et al., 2000; Author, 2015; Lindberg & Maddow-Zimet, 2012; Roye & Seals, 2001). Teens’ identified barriers to accessing condoms and contraception including cost, access to services, transportation, embarrassment, objections of their partner, threats to privacy or confidentiality, or perceived reduced susceptibility to pregnancy or STIs (Brown et al., 2008; Bell, 2009; Klein et al., 2001; Roye & Seals, 2001). In addition, access to oral contraception was believed to be hampered by cost, parental notification through the insurance or billing processes, and the potential of a pelvic exam, which may or may not be required based on sexual history (Fuller, 2007).

Teens perceived that condoms were not used due to lack of availability, beliefs about decreased sexual pleasure, sexual activity not being planned, substance use, passion, receiving gifts or incentives to forego use, coercion, assumed monogamy, use of other methods

Table 4. Perceptions of ACCESS to Sexual Health Strategies

Item	% Agree	% Disagree
I understand the dangers of unprotected sex.*	94%	6%
I know where to get birth control or protection.*	83%	17%
I received enough sex education in school.*	78%	22%
If my school provided condoms, I would get them there.*	64%	36%
Making birth control available to teens makes teens more sexually active.*	60%	40%
Teens don't like to use birth control.**	42%	58%
Teaching teens about sex and birth control encourages teens to have sex.*	34%	66%
I have searched the internet about sex.*	34%	66%
Telling teens to not have sex (abstain) prevents teen pregnancy.*	24%	76%
Condoms always work.*	8%	92%

*significant at a level of $p < .005$

**largely neutral responses, non-significant findings

***non-significant differences between agreement and disagreement responses

of contraception, desire for increased intimacy, as a demonstration of trust in a long term relationship, desire for a child, perceived ineffectiveness, partner disapproval, inconvenience and hassles associated with condoms, or beliefs that they could not become pregnant (Bauman, Hamilton, & Karasz, 2007; Bolton, McKay & Schneider, 2010; Boyle & O'Sullivan, 2010; Bruckner, Martin, & Bearman, 2004; Klein et al., 2001; Maiden, Gunter, Martin, & Ehrental, 2014; Roye & Seals, 2001; Ryan et al., 2007). Teens contended that using a condom had the potential to be interpreted as suspicion of infidelity, lack mutual trust, or disbelief in the exclusivity of the relationship (Bolton et al., 2010; Boyle & O'Sullivan, 2010; Brown et al., 2008; Roye & Seals, 2001). Negative attitudes toward pregnancy and positive attitudes toward contraceptives were associated with consistent contraceptive use (Bruckner et al., 2004; Ryan et al., 2007). Teens perceived that contraception methods were more likely to be used if they were easily accessible; required low effort and were easy to remember; were discreet from parents and, potentially, partners; and were associated with information to increase confidence and ensure effectiveness (Fuller, 2007).

These insights provide the foundation for further exploration of Delaware teen perceptions about the influences, consequences, realities, and access to sexual health strategies related to sexual activity and teen pregnancy. Although these studies represent important individual contributions to our knowledge of teen perceptions, this review of literature demonstrates the need to explore current and local teens' thoughts. Therefore, the purpose of this study was to determine Delaware teens' perceptions about the influences, consequences, and realities associated with sexual activity and pregnancy, and their thoughts on access to safe practices including access to sexual health education and contraception.

METHODS

Procedure

Following Institutional Review Board approval recruitment emails describing the research and activities were sent to high school health teachers throughout the Delaware. In return for participation, schools were offered a one-time presentation for their students about the costs and rewards of teen parenting and personal life goal-setting by the Principal Investigator (PI). Teachers responding to this solicitation were emailed parental permission

forms and survey/teaching sessions were scheduled. Teachers were motivated to participate in the project because the survey and associated class met a state-required health class standard on the consequences of teen parenting. Teachers demonstrated a high level of dedication to the project, reminding students to return permission forms and offering homework incentives or extra credit, resulting in a high return rate. Students returned the parental permission in a sealed envelope marked with a designated code number and were given the survey with the same code number. Students who completed the survey, implying assent to participate, received a \$5.00 gift card to a local convenience store. The PI conducted the survey within 16 schools in thirty-nine coeducational health classes throughout Delaware. Less than 10 surveys were discarded after they were matched with parental permission forms and very few absences (less than three per class) were reported in each class.

Participants

This convenience sample (N= 856) was stratified according to the number of teens in each county in Delaware. Participants' ages ranged from 14-17 years with a mean of 15.7 years. The sample was 54% Caucasian, 24% African American, and 22% other, with 7% of the teens indicating Hispanic ethnicity. The sample was 49% male, and 41% female; 10% did not answer the item. Additional questions revealed that 33% believed they were low income, 62% were spiritual or religious, and 46% lived in a home with two parents. According to the teachers and school officials, a very small percentage may have been pregnant or parenting during the data collection period.

Measures

The Thoughts on Teen Parenting Survey was developed by the PI and was used to collect data for this study (Author & Nandakumar, 2012). This survey includes three parts, including Part A (demographic information), Part B (the Thoughts on Teen Parenting Scale), and Part C (general questions). Parts B and C are five-point Likert scales and are scored on a continuum of strongly disagree to strongly agree with the middle option being neutral. Part B assesses teens' thoughts of the impact a teen birth would have on their relationships (with peers, boyfriend/girlfriend, and family), their vocation (related to education, work, and money), and life impacts (effect on personal characteristics and life in general). Part B of this instrument was used in several previous

studies assessing teen perceptions and response to interventions and demonstrated high levels of reliability with Cronbach α levels of .90-.93 (Author, Moore, & Sims, 2013; Author & Waterhouse, 2011; Author & Waterhouse, 2012; Author, Waterhouse, & Chiquoine, 2011). Part C asks general questions about the teens' perceptions of sexual decision-making of the four sub-categories, including the **Influences, Consequences, and Realities** of teen sexual activity and pregnancy and **Access** to sexual health education and contraception (Author & Nandakumar, 2012). Items for the entire survey were developed from previous interview and focus group research (Author, 2006; 2007; 2008), reviewed by an expert panel, subjected to content validity indexing by a national group of four teen pregnancy prevention experts, pretested with a group of 37 teens for readability and authenticity, and piloted with 171 teens as part of a youth health summit and with health class participants to enhance reliability and validity (Author & Nandakumar, 2012). Part B was reported on previously (Author & Waterhouse, 2011); Part C has not been published and is the instrument used in the current study.

DATA ANALYSIS

The 31 items of Part C were individually examined to determine how teens tended to respond to each statement, whether neutral, agreeing, or disagreeing. Response choices were recoded such that strongly agree and agree answers were coded as agreeing and strongly disagree and disagree answers were designated as disagreeing. In this analysis, neutral responses were omitted in order to specifically compare items that were answered with agreeing and disagreeing responses. Items were then compared using a χ^2 Goodness of Fit Test to assess if responses significantly differed between agreeing and disagreeing beyond what would be expected due to chance.

Results

Of the 31 items, five were characterized by neutral responses, which is defined as having the plurality of responses in the neutral category following the recoding of items. One item did not represent significant differences in responses leaving 25 with significant differences. Participants agreed with 16 statements and disagreed with nine items ($p < .005$). Tables one through four reflect the items in each sub-categories of the scale, Influences, Consequences, and Realities related to sexual activity and pregnancy, and

Access to safe sexual practices. Each table includes the percentage of agreement versus disagreement.

Discussion

Analysis of the findings yielded agreement and disagreement items in each of the four sub-categories of the scale, including Influences, Consequences, and Realities of teen sexual health, and Access to sexual health education and contraception. These items are explored in each category and discussed within the contexts of the literature.

Influences on teen sexual activity and pregnancy

Varied perceptions of influences on teen sexual activity and safe sexual practices were identified by this sample and are listed in Table 1. The findings of this study validate those in the literature highlighting the importance of parents in providing information about and supporting teens as they practice safe sex (Albert, 2012; Ryan et al., 2007; Stridham-Hall et al., 2012). The current research revealed that teens had mixed findings about adult truthfulness about sex which may indicate an area for further research. In other studies, teens expressed a desire for parents and other adults to provide information about sex and sexuality and to serve as role models exemplifying positive relationship skills, yet many teens did not believe adults in their personal worlds fulfilled this commitment (Albert, 2012).

Many in this sample indicated that they had an adult in their lives to communicate with about sex and birth control. This finding is promising but also demonstrates that one-quarter of youth believe they do not such an individual in their lives, indicating a need for intervention. Several studies examined the role of teen-adult communication in promoting responsible sexual behaviors in teens, noting more realistic attitudes about pregnancy, fewer pregnancies or intentions to become pregnant, and consistent use of contraception among youth reporting candid conversations with parents or other adults about sexual activity and safe sexual practices (Boyle & O'Sullivan, 2010; Cavazos-Rehg et al., 2013; Hacker et al., 2000; Jaccard, Dodge, & Ditmus, 2003; Ryan et al., 2007).

The current sample of teens reported that the media has a significant impact on teen sexual activity, substantiating Albert's (2012) findings that the media increases awareness about negative consequences of sex and plays a role in stimulating conversations about

responsible sexual behavior. This sample agreed that having teen parents speak with other teens about the realities of teen parenting is an effective way to prevent teen pregnancy, validating other research in this area (Hacker et al., 2000; Author, 2008; Little et al., 2010). The ability for teen parents to share their experiences and the impact of a teen birth on life goals may provide the forum for discussion, skill building, and assessment of values related to life and current behaviors.

Finally, the finding that very few teens believed that boyfriends consciously want girls to become pregnant is validated by the literature. Although this may be true in selected instances, the literature and our sample affirmed that most teens consider the negative aspects of parenting in their reproductive decision-making (Author, 2008; Kegler et al., 2001). Although youth may identify such positives of fatherhood as increased attention, increased masculinity, stabilization of a relationship, or to “be cool,” this sample did not believe that these positives caused boys to want their girlfriends to have a child (Kegler et al., 2001, pg. 249).

Consequences of teen sexual activity and pregnancy

This sample considered teen pregnancy an important issue, a finding validated in the literature (Albert, 2012; Author et al., 2013; Kegler et al., 2001; Little et al., 2010). This sample’s appreciation of the negative consequences associated with teen pregnancy or unsafe sexual activity, as depicted in Table 2, are in line with those noted in the literature (Author, 2008; Author & Waterhouse, 2011; Kegler et al., 2001; Little et al., 2010; Rocca, Harper, Raine-Bennett, 2013).

This group agreed that children of teen parents are not better off than children from adult parents and having a baby as a teen may “be a bad thing” or lead to negative consequences. Most of the participants disagreed with the item asking if it is “okay” to have

a baby as a teen. Although several authors reflected on youths’ ambivalence about teen pregnancy, many teens recognize the obstacles inherent of teen births (Author, 2008; Weiss, 2012).

This group reported neutral responses on the item questioning if birth control has a negative effect on a girl’s body. Several studies report that teens hold misconceptions or exaggerate the negative effects of birth control (Eisenberg et al., 2004; McEneaney & Hong, 2009; Venkat et al., 2008). Others note that family, peer, and local community beliefs often confound messages about the safety of birth control and perpetuate myths, side effects, or information



concerning older hormonal methods but not characteristic of today’s contraceptives (Eisenberg et al., 2004; Venkat et al., 2008). Jaccard et al. (2003) conjectured that some parents of teens overestimate the impact and side effects of birth control when counseling their children in order to deter them from engaging in sexual activity, sometimes undermining the young people’s intentions to act responsibly.

Realities of teen sexual activity and pregnancy

This sample tended to believe that most teens participate in sexual activity and that unintended pregnancy will happen regardless of efforts to provide information and access to birth control, as noted in Table 3. This may reflect an accurate assessment of the sexual activity level of peers or, as previously discussed, be an overestimation of teen engagement in sexual behaviors (Albert, 2012; Kann et al., 2014; Weiss, 2012).

This samples’ beliefs regarding the unplanned nature of teen sexual activity must be considered when developing interventions that attend to teens’ spontaneous participation in sexual activity. Educational interventions, often predicated on pre-planning, deliberate decision-making, and preparation

for sexual activity may not be effective if teen sexual activity is largely unplanned. Teen sexual decision-making may be informed by the negative consequences of actions and yet teens may act in ways that appear to disregard these consequences when faced with other motivations (Author, 2007). Sexual stimulation, peer pressure, partners' influences, and natural pleasure-seeking may override consideration of these consequences during sexual activity, reinforcing the current sample's sentiment that teens are not thinking of having a baby while having sexual activity (Brown et al., 2008; Author, 2007; Ott, Millstein, Ofner, & Halpern-Feisher, 2006; Ryan et al., 2007; SmithBattle, 2009). Rosengard, Phillips, Adler, and Ellen (2004) noted that teens not planning sexual activity or pregnancy, but who believed they were likely to sustain a pregnancy during the teen years, were found to also be less consistent in their contraceptive use. Teens may, due to developmental and societal variables, believe that they lack ability or efficacy to prevent pregnancy and that their personal pregnancy would be somewhat unavoidable despite their knowledge of potential repercussions (Rosengard et al., 2004).

The group largely supported the premises that teens will get pregnant even if they have sexual health education, information about birth control, and access to birth control. These responses may reflect teens' perceptions on the inevitability of teen pregnancy and their resolve that some teen pregnancies will



happen “no matter what.” It also may call attention to a distrust of birth control in general or a recognition that simply teaching about sexual health or having birth control available does not always translate to teen behavior. The group agreed that while some girls become pregnant intentionally, many teen pregnancies are unplanned. These findings concur with the conclusions of previous researchers wherein young people expressed that pregnancies were not intended

but also that efforts were not exerted to prevent pregnancy (Albert, 2012; Author, 2007; Kegler et al., 2001; Little et al., 2010; Maiden et al., 2014; Rosengard et al., 2004).

The teens in our sample demonstrated mixed findings about whether a teen who has one baby was apt to have another, whereas Cavazos-Rehg et al. (2013) noted that young parents tended to have more positive attitudes toward and an increase likelihood to sustain an additional pregnancy. The teens in the current study reflected neutral responses about the transgenerational nature of teen pregnancy. Some sources purport that teen pregnancy is more common in children of teen mothers, whereas other resources reinforce that rather than a transgenerational trend, the effects exerted by poverty and social norms are stronger correlates of teen pregnancy (Author, 2007; SmithBattle, 2009). This study demonstrated prominent teen perceptions related to the inevitability of teen sexual activity and pregnancy in multiple survey items.

Access to sexual health strategies

As listed in Table 4, this sample stated they received an adequate level of sexual health education in school, understood the dangers of unprotected sexual activity, and knew how to access birth control or protection. The current sample agreed with other studies indicating that teaching about abstinence is not effective in influencing teen behavior (Author, 2008) and that comprehensive sexual health education best meets of the learning needs of teens (Albert, 2007). Other authors emphasize that sexual health education needs to be framed within the context of communication, relationships, respect, and responsibility in order to change behavior (Author, 2008).

This sample did not appear to trust the effectiveness of condoms. Fuller (2007) noted that teens believe that condoms often break and have higher rates of failure than the actual failure rates. Resources noted that one of the reasons for lack of condom use is lack of trust in their effectiveness (Bauman et al., 2007; Brown et al., 2008). The group was mixed on whether teens did not like to use birth control, but it is unknown whether this reflects an ambivalence toward hormonal birth control or any method of contraception.

The teens in this study concurred with the idea that they would access condoms if provided at school. This

finding is important since other studies documented that, in order to enhance use of contraception, ease of access is the most critical variable influencing behavior (Hacker et al., 2000; Author et al., 2013; Author, 2015; Maiden et al., 2014; Ryan et al., 2007). Several resources affirmed that, regardless of the location, the emphasis on easy access, confidentiality, respect for confidentiality of services, and lack of ridicule were critical in accessing condoms and other methods of contraception (Bell, 2009; Boyle & O'Sullivan, 2010; Roye & Seals, 2001). This sample largely denied seeking information on sexual health from the internet. Because adults perceive the internet as a prominent source of information for teens about sexual activity and sexual health, this finding warrants additional exploration (Albert, 2012).

The findings of the current study validate other resources that negate the proposal that sexual education increases sexual activity (Brown et al., 2008; Hacker et al., 2000; Author, 2015; Author et al., 2013; Lindberg & Maddow-Zimet, 2012; Roye & Seals, 2001). In fact, several researchers noted that comprehensive sexuality education is associated with delaying sexual activity increased use of contraceptives or a condom at last sexual intercourse, and a decreased likelihood to engage in sexual activity with age discrepant partners (Lindberg & Maddow-Zimet, 2012; Kohler, Manhart, & Lafferty, 2008; Roye & Seals, 2001). The results of one item, identifying a relationship between making birth control available to teens and increasing participation in sexual activity, was unexpected. It is contradictory to the above and to other research that suggests that access to birth control does not increase sexual activity and may actually decrease sexual activity through education and informed decision-making (Author et al., 2013; Author, 2015).

Limitations

This study is limited by several factors associated with data collection. Inherent of any survey or self-report study with teens, there exists the possibility of less valid responses, sample member's desire to select the socially desirable answers, or lack of attentiveness to the research process. The items analyzed here were part of a 75 item survey. During data entry and analysis several items in the later portion of the survey items were randomly left blank, answered with repetitive neutral responses, or the survey was not completed. These appeared to be random errors

without any systematic pattern. Despite the large sample, these threaten the reliability and validity of the survey.

The omission of an item related to the influence of friends on sexual decision-making, sexual activity, and sexual health, which may be added in future replications, offers obstacles in the interpretation of results and represents a limitation in the findings. In addition, the wording of some of the items may have caused teens to answer the rhetorical, socially acceptable response, may have been misinterpreted by participants, or may have caused teens to consider or defend their own family, friends, or background when answering items. Although this study disclosed several insights about teen thoughts from a large sample more in-depth focus groups or individual interviews, which would allow the researcher to further probe issues, could provide richer and more detailed data reflecting perceptions.

Implications

The findings indicate several important avenues for program, policy, and message intervention. Teens and parents need accurate information about abstinence and relationship skills and, for those who choose to be sexually active, safe sexual practices. In addition to an educational focus on relationships, sharing with parents their importance as role models and sexual educators warrants parent-oriented strategies to ensure accurate and developmentally appropriate education. Parents may also advocate for comprehensive sexual education in schools to ensure that teens are prepared when they choose to engage in sexual activity.

Answers to selected questions provide clear direction for youth-informed approaches to promote safe sexual practices. Teens' ambivalence about adults' candidness about teen sexual health precipitates efforts focusing on honestly and developmentally appropriate information. Young people revealed that they believed an important way to promote safe sexual activity is to have teen parents share their experiences and challenges to other teens to authentically represent the realities of teen childbearing. Providing the platform for such an intervention, and ensuring the realistic, respectful, and grounded presentation of the daily responsibilities associated with childbearing may offer teens and teen parents an important learning experience. Continued teaching about the realities of teen pregnancy may attend to our finding related to the

prevalence of young women's wishes for pregnancy during the teen years.

Although many of the safe sexual practice interventions in the United States focus on teaching and rationale decision-making associated with knowledge of the consequences, much of teen sexual activity is spontaneous and impulsive. Adolescent cognitive maturation and the developing ability of the pre-frontal cortex to regulate spontaneous sexual impulses validates this sample's contention that teen sexual activity may be unplanned and their consideration of consequences, as in the possibility of pregnancy, during sexual activity may be forgotten or suppressed (Author, 2005;2007). New interventions related to assisting teens to develop and refine self-regulatory behavior and to practice delaying gratification, negotiation skills, and engage in deliberate decision-making may further inform sexual health innovations. Interventions based on teen brain development and the capacity of teens to control impulses, consider consequences, use future-based goal setting skills, and incorporate kindness into sexual behaviors may change the scientific focus of sexual health education to one of personal and social motivations. Empathy-building skills, also related to brain development, may enhance teens' abilities to place themselves into the perspectives of partners and engage in safe sexual practices to protect their partners as well as themselves (Author, 2005; 2007).

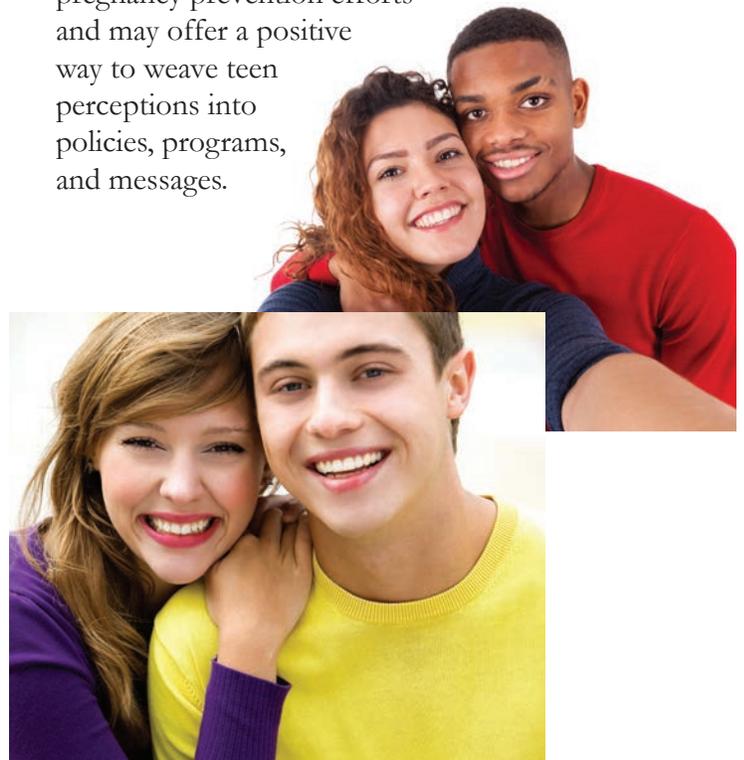
The teens' responses indicating a lack of trust in birth control and condoms, their perception that birth control may have negative effects upon the girls' body, the inevitability of pregnancy despite information about sexual health and birth control, their resistance to abstinence-only education, and their insights into the inevitability of teen pregnancies to occur even with the use of birth control is used highlights further investigation. Teens may not trust birth control or maybe skeptical due to peers reports of pregnancy despite vigilant use; it is not known whether these occur due to user or contraceptive method error.

As noted, teens in our sample believed that they received education about sexual health and knew where to access contraception, and had a good understanding of safe sexual practices. Other responses, including the contentions that teaching about sexual activity and birth control and the availability of birth control increases sexual activity,

call this level of knowledge into question and delineate clear avenues for ongoing teaching efforts. The mistrust of birth control supports the use of long acting reversible contraception methods, such as intrauterine devices and implanted contraceptives along with condoms to prevent exposure to STIs and HIV, which may meet the needs of much of teen sexual activity which may be unplanned, spontaneous, and for which teens may be unprepared (Fuller, 2007). The need for teaching, counseling, and contraception to be easily accessible for teens may illustrate the importance of school-based and wellness center based access and ensuring community resources that are teen-friendly and in close proximity to where teens learn, work, and play.

CONCLUSIONS

Knowledge of adolescent development and youth perceptions are paramount so that safe sexual practice interventions are designed to speak to the realities of teen life. This study revealed several important findings that should inform future efforts. These findings reflect important insights that have their basis in other studies of youth perceptions. Continued research about youth thoughts on sexual health may further inform efforts to promote responsible sexual behavior in teens. Focusing on safe sexual practices is a way to highlight the rights and responsibilities associated with sexual activity, rather than only the consequences inherent of teen pregnancy prevention efforts and may offer a positive way to weave teen perceptions into policies, programs, and messages.



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Judith W. Herrman, Ph.D., R.N., A.N.E.F., F.A.A.N. is an advocate for youth locally and nationally. She currently serves as secretary of the Delaware School Based Health Alliance and is on the Wilmington Teen Pregnancy Coalition. Judy is on the Board of Directors and chairs the Public Policy Committee for the Healthy Teen Network, a national organization charged with promoting better outcomes for adolescents and young adults. She will retire in August 2017 from the School of Nursing at the University of Delaware (UD) after 24 years of teaching and research.



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A Primary Care Nursing Perspective on Chronic Disease Prevention and Management

*Cynthia D. Griffin, M.S., B.S.N., R.N., C.P.H.Q., C.C.M.
Director of Nursing Services*

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EXECUTIVE SUMMARY

Today, there is growing interest in advancing health care outcomes through the utilization of registered nurses in ambulatory settings such as primary care facilities. Western medicine exist a longstanding ethos that promulgates the treatment of acute illnesses and injuries, but as the field progresses, so should our focus. There is a need today to focus on and grow the fields of preventative care and chronic disease management (IOM 2011). In America today we have an aging population. According to the most recent consensus projections, the proportion of the US population aged 65 or older is expected to rise from 12.7 percent to 19.3 percent in 2030 (U. S. Census Bureau, 2008). As the population continues to age a dramatic growth in demand for health care services will be seen (IOM, 20011). Historically, physicians cared for patients individually in their private practices. Due in large part to their smaller size, many of these physician practices, do not utilize RNs and in where RNs are used their primary role is to triage telephone calls. As we move into the 21st century and demands on healthcare systems, physicians, and accountable care organizations are to meet and manage the health care needs of the communities where they are located in the most optimal way possible. (Nursing Outlook, 2014)

This article will explore the importance of the role of the RN in the Primary Care setting and their role in managing and preventing chronic diseases in the population they serve. Primary health care is a conceptual model that is used to describe a holistic structure of health care delivery and focuses on the specific needs of communities. Primary health care encompasses a broad spectrum of services, including disease prevention, health promotion, population health, community development, and target social determinants of health, such as income, housing, education, and environments. In response to the increasing emphasis being placed on the management of patients with chronic diseases in the primary care setting, strategies that enhance the coordination and comprehensiveness of the healthcare delivery to these patients have been developed and will be explored. (JONA, 2014)

INTRODUCTION

According to the American Academy of Ambulatory Care Nursing (AAACN), Ambulatory care nursing is a unique realm of specialized nursing practice. RNs in the ambulatory setting are leaders in their practice settings and are uniquely qualified to influence organizational standards related to patient safety and care delivery in the outpatient setting. (AAACN, 2017) RNs in the inpatient setting are highly regarded as critical thinkers often implementing and providing care utilizing the steps of the nursing process which promote excellent quality care. As more and more patients transition from inpatient to outpatient settings, there is a greater demand for professional nursing services in the outpatient settings. RNs can utilize the same steps of the nursing process, which include assessment, nursing diagnosis, planning, implementing, and evaluation in caring for individuals in the outpatient setting. Tools used to provide care are order sets, protocols, and care plans. Primary Care offices can utilize registered nurses in day to day patient care delivery, education, self –management support, chronic disease care management and care coordination of services, and oversight and collaboration of panels of individuals. Providing these services will make a positive impact on patient outcomes and will prevent chronic diseases. In Canada, payment models have recently been implemented in primary care to address the increasing burden that patients with chronic diseases place on the Canadian healthcare system. (JONA, 2014)

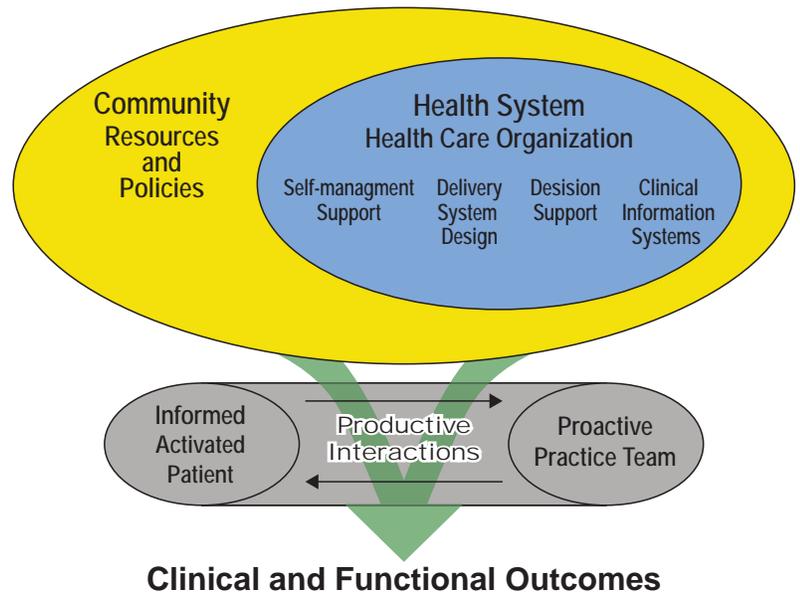
CHRONIC DISEASE

The Chronic Care Model identifies six fundamental areas that form a system that encourages high-quality chronic disease management. Organizations must focus on these six areas, as well as develop productive interactions between patients who take an active part in their care, and providers who have the necessary resources and expertise. The changes listed below for each area of the Chronic Care Model can be applied to a variety of chronic illnesses, health care settings, and target populations.

Changes for Improvement

- Self-Management Support - Patients with chronic illness need support, as well as information, to become effective managers of their own health. In order to meet these needs, it is essential for them to have the following:

- o Basic information about their disease
 - o Understanding of an assistance with self-management skill building
 - o Ongoing support from members of the practice team, family, friends, and community
- Delivery System Design - Designate staff to be responsible for follow-up by various methods, including outreach workers, telephone calls, and home visits.
 - o Identify follow-up needs, such as eye exam, dental care, HbA1c, labs, and visits.
 - o Plan the follow-up approach, including who will contact patients, how, and when.
 - o Use phone, outreach workers, and mailings for follow-up.
 - o Generate reports from the registry to discover those patients in need of follow-up and generate contact lists.
 - o Ask patients for best methods and times to follow-up for check-back visit, pharmacy refills, etc.
 - Decision Support- embed evidence based guidelines into the clinic
 - Clinical Information Systems - A registry — an information system that can track individual patients as well as populations of patients — is a necessity when managing chronic illness or preventive care. The registry is the foundation for successful integration of all the elements of the Chronic Care Model. The entire care team uses the registry to guide the course of treatment, anticipate problems, and track progress.
 - Organization of Health Care - The effort to improve care should be woven into the fabric of the organization and aligned with a quality improvement system.
 - Community - To improve the health of the population, health care organizations reach out to form powerful alliances and partnerships with state programs, local agencies, schools, faith organizations, businesses, and clubs.



Source: Wagner EH. Chronic disease management: What will it take to improve care for chronic illness? *Effective Clinical Practice*. 1998;1(1):2-4.

ROLE OF PRIMARY CARE NURSING IN PREVENTING AND MANAGING CHRONIC DISEASE

Chronic diseases are currently the leading cause of preventable death and disability worldwide and the prevalence and costs associated with chronic conditions are increasing globally. (JONA, 2014). As the prevalence of chronic diseases continues to increase, more emphasis is being placed on the development of primary care strategies that enhance healthcare delivery. Innovations include interprofessional healthcare teams and chronic disease management strategies. In the United States, 117 million people have one or more chronic conditions, with one in four adults having two or more (Nursing Economics, 2017). Technology enhanced interventions such as electronic/virtual visits, patient portals and mobile device applications enhance the ability to improve patient and family engagement in care, provides health monitoring and supports patient self-management. There is evidence that supports positive outcomes associated with these interventions. (Nursing Economics, 2017).

Nurses play a vital role in chronic disease management and are well positioned to enhance the planning and delivery of the healthcare resources in primary care. In Canada, licensed practical nurses or registered practical nurses (LPNs/RPNs), registered nurses (RNs), and nurse practitioners (NPs) all contribute to the delivery of primary care services. (JONA, 2014)



In Ontario, Canada a study was conducted of nurses working in primary care settings, as well as a survey of a random sample of RNs, LPNs, and NPs. The results of the study reported that the nurses were engaged in chronic disease management activities but to different extents depending on their licensure. Chronic Disease management activities include tasks such as:

- vital signs,
- obtaining smoking history,
- encouraging exercise
- wound care
- administering immunizations/vaccinations
- using respiratory peak flow meters
- education on healthy diets,
- lifestyle counseling
- chronic disease education
- chronic disease clinics
- utilizing clinical practice guidelines
- ordering lab tests
- titrating medications (JONA 2014)

Nurse practitioners and RNs deliver care in a variety of settings functioning both independently and collaboratively providing clinical, management, and accountability. Recent emphasis on population health has shifted the focus on health promotion and self-management support. RNs in care coordination and transition management roles provide high value, safe care to at-risk populations such as patients with multiple chronic conditions. (Nursing Economics, 2017)

When RNs assist in the care of patients with chronic conditions, clinical outcomes for these patients improve compared with physician-only care (California Healthcare Foundation, August 2015). RNs at Santa Rosa Community health centers perform chronic care visits, utilizing RN clinical skills, patient education, medication reconciliation, medication adherence counseling, and behavior change goal settings. (California Healthcare Foundations, August 2015).

In addition, many primary care centers have developed complex care management programs within the primary care clinics where RNs with extensive primary care experience care for patients with chronic conditions such as diabetes, hypertension, congestive heart failure, chronic obstructive pulmonary disease, asthma, chronic kidney disease and chronic pain. The RNs work under patient –specific orders allowing them to titrate medications such as diuretics for

patients with CHF or insulin for diabetic patients. Pre and post utilization data collected by the San Francisco Department of Public Health Network show a 50% reduction in hospital days one year after enrollment and a 10% reduction in ED visits. Patients reported that the team helped motivate them to change behaviors and assisted with improved navigation of the health care system. Providers reported having RNs involved with patient care delivery in caring for patients with chronic diseases saved them time. They also felt their patients were receiving better care. While the program's visits and phone calls are not billed, the savings from reduced hospital days are thought to be sufficient to financially sustaining the program. (California Healthcare Foundation, August 2015)

At Community Healthcare Center, Inc, all RN's work as members of the care team and perform independent chronic care visits for patients with diabetes, hypertension, asthma, or COPD. In these visits RNs do patient education, medication reconciliation and adherence counseling, patient goal setting and behavior-change counseling and provide care utilizing provider directed delegated orders. (California Healthcare Foundation, August, 2015)

Assessment skills of RNs promoted early intervention when exacerbation of symptoms of chronic illnesses was identified. RN telephone communication is integral to chronic illness management in the identification of change in symptoms and the need to establish new treatment regimens and initiate referrals. Post- hospital discharge strategies such as transitions of care management are used to reduce readmissions (Nursing Outlook, 2014).

REIMBURSEMENT OPPORTUNITIES

To achieve the goal of reducing cost and improving quality, reimbursement models changes have led to the expansion of cost-effective ambulatory care settings and services. New CMS transitional Care and Chronic Care Management codes implemented in January 2014 and January 2015 respectively, provide an increase in reimbursement for office visits associated with care coordination and transitional care services (Nursing Economics, 2017).

Transitional Care Management (TCM) encounters with patients are both reimbursable and require a licensed nurse or clinician to provide follow-up for post-hospital discharges (Medicare learning network, 2016).

In addition to the TCM codes there are now Medicare's Chronic Care Management codes utilizing RNs in the primary care office. The Centers for Medicare and Medicaid Services recognizes Chronic Care Management (CCM) as a critical component of primary care that contributes to better healthcare for individuals. In 2015 Medicare began paying separately under the Medicare Physician fee schedule for CCM services furnished to Medicare patients with multiple chronic conditions. CCM services may be furnished by clinical staff such as RNs that are working with the billing provider. This will allow for improved management of chronic care and is reimbursable under the Medicare reimbursement Codes. (Medicare Learning Network, 2016)

Performing Annual Wellness Visits plays an important role in preventing chronic disease. These visits are billable for both the RN and NP. Medicare Annual Wellness Visit (AWV) is a visit that provides a personalized prevention plan for Medicare beneficiaries who are not within the first 12 months of their first Medicare Part B coverage period and have not received an Initial Preventive Physical Examination or AWV within the past 12 months. Annual Wellness Visits ensure Medicare beneficiaries are receiving appropriate screenings. In addition, Annual Wellness Visits provides an opportunity to mitigate risks identified during health risk assessments. Medicare encourages patients to have annual wellness visits, reimbursing the clinician. An RN can perform the visit in accordance to CR 7079 who is supervised by a provider - the provider has to be in the building but does not have to see the patient.

The RN can perform this service as long as they are licensed professional for both new patients as well as established patients. (Medicare Learning Network, January 2015)

The increasing complexity of care, along with a need for greater coordination of care, increases the demand for professional nurses in ambulatory settings. Efforts to conserve financial resources and more effectively utilize all members of the health care team have resulted in a need to fully understand the economic impact of RNs in outpatient settings. There is growing evidence that ambulatory care RNs impact patient satisfaction, reduce adverse outcomes, improve quality patient outcomes, and reduce emergency room/hospital admissions through specific interventions.

(Haas, 2008; Laughlin & Beisel, 2010)

Care coordination is foundational to the health care reform goals of improving the quality of care for individuals and populations via the efficient and effective use of resources. The increased complexity of care, growing numbers of patients with chronic disease, and exploding health care costs heighten the need for better integration of care without increased expenditures. In numerous studies and analyses, registered nurses, in partnership with other providers, have integral roles that improve patient care quality through care coordination across health care settings and populations. The studies have provided evidence of the value of care coordination and related modalities to patients with chronic conditions. The American Nurses Association (ANA) position statement, *The Nurse's Essential Role in Care Coordination* (2012), affirms that registered nurses are integral to the achievement of care coordination excellence. The care coordination process is one aspect of professional practice through which registered nurses regularly influence patient care at every level. The value of registered nurses in care coordination roles is demonstrated in numerous health care reform initiatives focused on integrative service delivery. Nurse care coordination for children and youth with chronic conditions has resulted in improved quality and reduced costs. A pilot study, in the form of a randomized clinical trial, was used to test a TEAMcare collaborative care model for patients with depression and uncontrolled diabetes and/or heart disease into routine care of a patient-centered medical home clinic, and compared the experience of patients experiencing this program to individuals receiving usual care. The analysis of pilot results revealed similar benefits with respect to clinical outcomes as achieved by the clinical trial. More appropriate use of health services was found among patients receiving TEAMcare; these individuals experienced fewer emergency department visits, and greater primary care visits and pharmacy dispenses. These results suggest a nurse-led collaborative care program based on the TEAMcare protocol can be practically applied within routine primary settings for patients with complex health care needs and multi-morbidities. Health care systems should consider a greater role for nurses within a collaborative care model to achieve improved clinical outcomes and more appropriate use of health services for patients with multi-morbidities. (Nursing economics 2014)

CONCLUSION

Team based primary care models are becoming more prominent in primary care offices. It is important to clearly understand the nursing contribution to chronic disease management and preventative care in primary care. There are clinical activities such as performing nurse led clinics, utilizing nurse protocols, and performing annual wellness visits, and chronic disease education that are instrumental in the management and prevention of chronic diseases. (JONA 2014)

In addition, there are recommendations that can be considered in changing the RN role for the future, such as providing RNs with additional training in primary care and care management skills for patients with complex health care needs. (California Health Care Foundation).

Professional nurses have the potential for significant contributions to patient-centered, cost-effective

care through the care coordination role. The ANA recommends continued nursing research, education and improvement in professional practices to explore options for nurse led care coordination models. (American Nurses Association, 2012)

The Institute of Medicine report on the future of nursing affirms that “Nurses are being called upon to fill primary care roles and to help patients manage chronic illnesses, thereby preventing acute care episodes and disease progression”. (IOM, 2011)

Primary care practices should consider utilizing nurses in patient care delivery, care coordination, and as leaders supporting office workflows. Overall, nurses play an integral role in preventing and managing chronic diseases. Utilizing nurses will improve patient outcomes, nurse and physician satisfaction, as well as patient satisfaction and improve the health of our communities.

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Cynthia D. Griffin, M.S., B.S.N., R.N., C.P.H.Q., C.C.M., is the Director of Nursing Services for The Medical Group at Christiana Care Health System and Nursing Leader of the Primary Care and Community Medicine Service Line. She has been a registered nurse for over 30 years and has worked in various capacities. Ms. Griffin is a member of the American Academy of Ambulatory Nursing, American Nurses Association and the Delaware Nurses Association and has facilitated many teams in improving processes that lead to safer practices on an organizational level as well as departmentally.

ELECTRONIC

Immunization Record Submission



Let Us Know How You Are Submitting Your Immunization Records to the State

WVMI & Quality Insights is conducting an online assessment to verify how every practice in Delaware is currently sending patient immunization information to the Delaware Division of Public Health (DPH).

Since it is now **mandatory for providers to report all immunizations for both adults and children to DPH's Immunization Program**, it is important for providers to get on track with submitting immunization records electronically as paper submissions will no longer be accepted after December 2017.

Your feedback to this survey will help the DPH determine which practices are still submitting paper reports, which practices are still in the testing mode of electronic submission, and which practices are actively submitting their immunization records electronically.

This online assessment is very brief and should **only take a minute or two to complete**. We greatly appreciate your prompt response.



Did you already receive a printed copy of the Immunization Assessment?



This summer a community health worker hand-delivered informational packets to healthcare provider offices throughout Delaware which contained information and resources about two projects that Quality Insights is spearheading for the Delaware Division of Public Health, the Hypertension and Diabetes Control & Prevention initiative and the Immunization e-Submission campaign. Included in this packet was a printed copy of the Immunization Assessment. **If you have not already completed the assessment, please do so as soon as possible.**

CDC Director Kicks Off 2016-2017 Flu Vaccination Campaign



On September 29, 2016, the Centers for Disease Control and Prevention (CDC) and the National Foundation for Infectious Diseases (NFID) along with other public health and medical groups kicked off the 2016-2017 flu vaccine campaign at a telebriefing held at the National Press Club in Washington, D.C. Members of the public and health care professionals were urged to follow the CDC's recommendation for everyone age six months and older to be vaccinated against influenza each year. CDC Director Tom Frieden, M.D., M.P.H. presented vaccination coverage estimates from the 2015-2016 influenza season, which were released online, and received a flu vaccine. Visit the CDC website to learn more.

Download the CDC's 2016-2017 Influenza Letter to Health Care Providers to learn more about recent updates regarding the 2016-2017 influenza season.

Confirming Your Immunization e-Submit Status Is Easy

Contact Quality Insights of Delaware, a division of WVMI & Quality Insights, today to verify if your practice is still in the testing mode of e-submission or if you are actively e-submitting immunization records to DPH.

If you need assistance transitioning from the test mode to active status, we can help! Contact Ashley Corzine, Quality Insights Practice Transformation Specialist, via e-mail or call 1.877.987.4687 ext. 137.

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The Role of Primary Care Physicians in Managing Chronic Disease

*Margot Savoy, M.D., M.P.H., F.A.A.F.P., F.A.B.C., C.P.E.,
C.M.Q., F.A.A.P.L.; Colleen Hazlett-O'Brien, D.O.;
Jamie Rapacciuolo, D.O.*

Christiana Care Health System Department of Family & Community Medicine

Introduction

Despite being the most expensive in the world, the United States healthcare system continues to lag behind most comparable nations in health outcomes and quality. The IHI Triple Aim is a framework developed by the Institute for Healthcare Improvement that describes an approach to optimizing health system performance. It includes 3 dimensions: improving the patient experience of care (including quality and satisfaction); improving the health of populations; and reducing the per capita cost of health care. (Improvement, 2017) Fortunately, many states, including Delaware, have begun investing in a strong primary care infrastructure which has been shown to be a patient-centered, high quality, cost-effective way to achieve these aims. (Innovation, 2017) Patients with access to a regular primary care physician have lower overall health care costs than those without one, and health outcomes improve. (Starfield B, 2005) Primary care based health systems are associated with lower hospitalizations, less duplication in treatment, more appropriate use of technology, lower Medicare spending, higher quality of care and lower rates of healthcare disparities. (Starfield B, 2005)

What is Primary Care?

Put simply, primary care is the first point of contact and foundation of a person's health care team.

The Institute of Medicine defines primary care as: "The provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community." (Medicine, 1994) The American Academy of Family Physicians describes primary care as a framework centered on patients, coordinated by primary care physicians (Family physicians, Internists and Pediatricians) in collaboration with specialist physicians and non-physician health care providers. More specifically, AAFP states that "Primary care is that care provided by physicians specifically trained for and skilled in comprehensive first contact and continuing care for persons with any undiagnosed sign, symptom, or health concern (the "undifferentiated" patient) not limited by problem origin (biological, behavioral, or social), organ system, or diagnosis. Primary care includes health promotion, disease prevention, health maintenance, counseling, patient education, diagnosis and treatment of acute and chronic illnesses in a variety of health care settings (e.g., office, inpatient, critical care, long-term care, home care, day care, etc.)." (Physicians, 2017)

A common misperception is that primary care practices are only valuable for managing basic conditions like the common cold or ankle sprains when, in reality, primary care practices provide the majority of complex visits (indicated by the number of diagnoses managed during a single visit). (Moore, 2017) As Americans live longer with growing numbers of on-going medical conditions needing to be managed in a patient-centered, cost-effective way, it will be critical for society to continue investing in and strengthening our primary care foundation.

THE GROWING BURDEN OF CHRONIC DISEASE

What is Chronic Disease?

The U.S. National Center for Health Statistics defines a chronic disease as a medical condition lasting 3 months or more. In general, chronic diseases remain permanently, can be managed once they are present but cannot typically be prevented by vaccines, cured by medication, nor do they spontaneously disappear. Health damaging behaviors including obesity, tobacco use, lack of physical activity, and poor eating habits are major contributors to the leading chronic diseases. The standard list of chronic medical conditions typically includes arthritis, current asthma, cancer, cardiovascular disease, chronic obstructive pulmonary disease, and diabetes, but a number of medical conditions including HIV/AIDS and chronic kidney disease are becoming increasingly prevalent. (Statistics, 2017)

The Rise of Chronic Disease

Over 85% Americans over 65 years of age have at least one chronic health condition. Women in all age groups are more likely than men to have one or more, two or more, or three or more chronic conditions. (Statistics, 2017) In 2012 about 50% of all adults were living with a chronic medical condition and 25% of those adults carried a diagnosis of more than one. (Ward BW, 2014) 133 million Americans were living with at least one chronic condition in 2005. In 2020, this number is expected to grow to 157 million. In 2005, sixty-three million people had multiple chronic illnesses, and that number will reach eighty-one million in 2020. (Green, 2000) (Bodenheimer T, 2009)

Chronic Disease in Delaware

Delaware is ranked as the 32nd healthiest state in American's Health Rankings® 2015 Edition, produced by the United Health Foundation with its partners at the American Public Health Association and Partnership for Prevention. Chronic diseases are the leading causes of death nationally and in Delaware. Cardiovascular disease (including heart disease and stroke) remains the leading cause of death followed by cancer, lung diseases and diabetes. (Statistics D. C., 2017) Table 1 provides a brief comparison of common chronic disease risk factors for Delaware and the US. The most recent Behavioral Risk Factor Survey (2008) showed that, in general, Delawareans fare worse than then average American. Diabetes prevalence increased from 4.9% in 1991 to 8.3% in Delaware in 2008. Diabetes prevalence is higher among men than women, and higher among African Americans than among non-Hispanic whites. Obesity prevalence also is higher among men and African Americans, and obesity is a major risk factor for type 2 diabetes. In 2008, 13.6% of Delaware adults reported ever being told by a doctor or health professional that they had or have asthma. Young adults are more likely to report current asthma than older adults. People with low incomes and lower educational levels also are more likely to have current asthma. 4.5% of Delaware adults reported having had, and survived, a heart attack. More men than women report having had a heart attack: 5.6% of men compared to 3.4% of women. There were no statistically significant differences by race or ethnicity; however, people age 65 and older reported by far the highest prevalence at 15.7%. 4.7% of adults in the state reported being told that they have angina or coronary artery disease. Non-Hispanic whites were most likely to report diagnosed coronary artery disease,

Table 1. Prevalence (in percentage) of Selected Risk Factors: DE vs UC (2008 or 2007)
Shading represents where Delaware performed worse or equal to US

Risk Factor	DE	US (median)
Cigarette Smoking	17.8	18.4
Obesity	27.8	26.7
Eat 5 or More Fruits/Veg a day (2007)	21.4	24.4
Recommended Physical activity (2007)	47.9	49.5
Prevalence of Diabetes	8.3	8.3
Prevalence of Current Asthma	9.6	8.8
Ever Had a Heart Attack	4.5	4.2
Told you have Coronary Artery Disease	4.7	4.3

DE Health and Social Services. Behavioral Risks in Delaware 2007-2008. Retrieved February 15, 2017, from <http://www.dhss.delaware.gov/dhss/dph/dpc/files/brfsreport07-08.pdf>

followed by Hispanics and African Americans. 2.9% of Delaware adults reported having been told they had a stroke, and while there were no statistically significant differences by gender or race, age was once again a significant factor. While less than 2% of adults under 45 reported having a stroke, 3.3% of adults 55-64 and 8.2% of adults over 65 reported a stroke.

Of note, Delaware's population is aging more rapidly than the US. Delaware exceeded the national growth rates of 33% for ages 60-84 and 40% for ages 85 or older. From 2000 to 2010-14, the number of people 60-84 years old grew 45% in Delaware, and the number of people 85 or older rose 66%. Younger age groups also grew but more slowly, with 6% growth in people under 20 and 20-39 years old, and 21% in those 40-59. Within Delaware, Sussex County had particularly strong growth in the 85 and older population at 98%, while the City of Wilmington actually lost population in the two youngest age groups. (Statistics D. C., 2017)

The CDC reports that over 85% of all costs of healthcare are related to the treatment of a "chronic medical condition". The total cost of treating heart disease in 2010 was over 300 billion and over 200 billion for the treatment of diabetes.

Access to Primary Care

Access to health care is critical for a community's well-being. In Delaware, 10% of residents lacked health insurance in 2014, below the national rate of 16% and below rates in comparable areas. In addition, since the passage of the Affordable Care Act, insurance coverage has expanded. Nearly 25,000 Delaware residents signed up for a qualified health plan on HealthCare.gov between Nov. 15, 2014, and Feb. 15, 2015, or more than half the state's potential pool of 48,000 people. Of course, having insurance is only part of achieving access. Patients must also have available health care resources.

The Division of Public Health's (DPH) Office of Primary Care (OPC) received a "Primary Care Services Resource Coordination and Development Primary Care Office" (PCO) grant from the federal Health Resources and Services Administration, U.S. Department of Health and Human Services to assess the primary care health needs of Delaware. The report addresses Delaware populations and areas with unmet health care needs, disparities, and access barriers to

support designations of health professional shortage areas and the recruitment and retention of primary care providers. Figure 1 shows the distribution of primary care physicians in Delaware. Note these numbers include OB/Gyn as primary care physicians. About 1,271 persons were served by each full-time-equivalent (FTE) primary care physician in 2013. The number of FTE primary care physicians remained unchanged since the last survey in 2010; however, it does not represent a stagnant pool of physicians. There was a slight increase in Kent and New Castle counties and a slight decrease in Sussex County. Overall 72% of physicians reported expecting to remain active in five years; however, that number was only 58% in Kent County. Between 84 percent and 87 percent of primary care physicians reported in 2013 that they were accepting new patients. Despite the appearance of an adequate number of physicians and open panels, patients in Delaware across all 3 counties are waiting longer than in the past for non-emergent appointments. On average, an established patient will wait about 17 days and a new patient will wait 32 days. (Care, 2016)

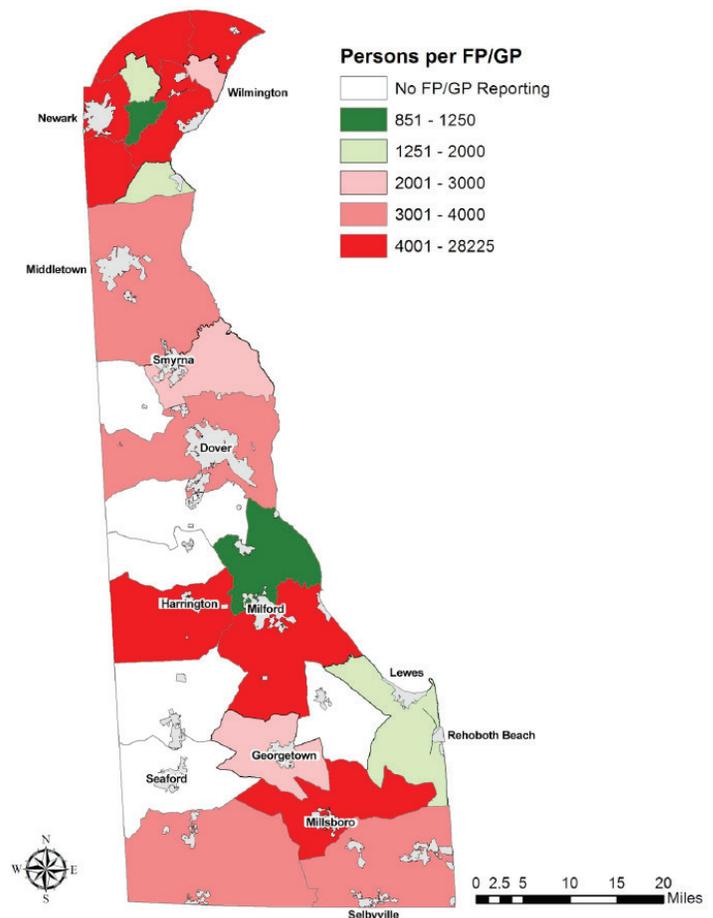


Figure 1: Distribution of Primary Care Physicians in Delaware (2014)

The Evolving Role of the Primary Care Physician

Since 2013, stakeholders across the state have been engaged with the Delaware Center for Health Innovation in securing funding, developing and implementing Delaware's State Health Innovation Plan. A cornerstone to the plan is supporting primary care practices making the necessary transformations to meet the population's growing complex chronic health needs.

The Patient Centered Medical Home

The medical home concept originated in 1967 when the American Academy of Pediatrics (AAP) introduced it to describe primary care that is accessible, family-centered, coordinated, comprehensive, continuous, compassionate, and culturally effective. The definition has evolved yet remains true to the original concept. The Agency for Healthcare Research and Quality (AHRQ), describes the medical home as a model to improve health care in America by transforming how primary care is organized and delivered by encompassing five functions and attributes: comprehensive care, patient-centered, coordinated care, accessible services, quality and safety. (Quality, 2017) As insurers began to look at the PCMH model as a reliable way of identifying practices and clinicians providing enhanced services and likely producing improved quality and care coordination, accrediting bodies began providing certifications and recognitions for achieving PCMH status. The most widely recognized PCMH accreditation organizations include the National Committee for Quality Assurance (NCQA) and the Joint Commission. The first Delaware practice, Christiana Care Family Medicine Center in Wilmington, was recognized in 2011 by the NCQA, and since then hundreds of clinicians across the state have been recognized. While the DCHI supports a number of evidence-based models of practice transformation, the core principles of the PCMH are evident. Table 2 lists the 9 essential capabilities of Primary Care practices set forth in the State Innovation model. It is the vision of DCHI that all Delaware primary care practices will exhibit these abilities and be financially supported across all payers including Medicare, Medicaid and commercial programs.

A New Role for Primary Care Physicians

Re-envisioning primary care practices and their role in chronic disease management means a primary care physicians will need a new set of skills. In addition

to an expectation of regularly managing increasingly complex patients- multiple medical conditions, extensive medication lists and sizable teams of care providers across specialties and sites, primary care physicians will need an evolving set of leadership and practice management skills. Table 3 highlights some these expanded duties. An overwhelming list when considered the roles of one physician, but as the lead of a multi-disciplinary team in partnership with the patient, it is possible to re-envision a new model for delivering primary care services.

Primary Care Practice Innovations to Improve Chronic Disease

In addition to re-considering the role of the physicians, the practice will need to evolve to meet the chronic disease management needs. There many models and tools currently available to us which can assist our patients in achieving the best possible outcomes.

Alternate visit models

Many practices are beginning to explore the benefits of group and mini-group visits vs. the traditional one-on-one visit model. One of the greatest advantages to group visits is that they allow for the patients to interact directly with other people who understand what they are going through. This sense of comradery enables the patients to feel less isolated and allows for collaborative goal-setting. Multiple randomized trials studying the effectiveness of the group visit model have shown that group visits show clinically significant improvements in medical, psychological and behavioral outcomes for patients with chronic disease. (Wong, 2015)

Telehealth visits are another innovation in primary care that have become a useful tool for many providers in managing those with chronic diseases. Many of the services that primary care providers offer their patients do not require a physical examination, such as routine follow up visits, management of medications and labwork, and counseling and educational services. A study conducted in 2014 showed that telehealth visits can provide quality patient centered care while also increasing access for patients to their healthcare providers. (Heckemann, 2016) Telehealth visits allow patients to receive many vital services without having to leave the comfort of their homes which alleviates the stress of getting transportation to and from the physician's office.

Table 2: Delaware State Innovation Plan 9 Capabilities of Primary Care Practices

Panel management	Understanding the health status of the patient panel and setting priorities for outreach and care coordination based on risk. Practices define and identify the highest-risk members of the patient panel. Providers develop and execute on an outreach plan for identified high-risk patients. The practice prioritizes these patients for care coordination, appropriate care interventions, and self-management education.
Access improvement	Introducing changes in scheduling, after-hours care, and/or channels for consultation to expand access to care. Providers develop and implement approaches to expanding access to care, and adapt based on identified patient needs and preferences. Approaches to expanding access may include after-hours and same-day appointments, phone consultations with licensed health professionals, and consultation by email, text or other technology.
Care management	Proactive care planning and management for high risk patients. Practices identify high-risk patients, develop team-based interventions to deliver appropriate care, coordinate resources external to the practice when necessary, and track progress. Providers use information on patients' health risks and tailor responses accordingly.
Team-based care coordination	Integrating care across providers within the practice, across the referral network, and in the community. Practices identify a multi-disciplinary care team that may include physicians, nurses, medical assistants, pharmacists, social workers, and other clinical staff. Practices coordinate activities and promote communication across the team involved in a patient's care and integrate specific approaches for this collaboration into their operating model (e.g., by setting up case conferences). Practices also develop systems to coordinate with external stakeholders, such as outpatient specialists, hospitals, emergency rooms and urgent care centers, rehabilitation centers, community resources, and the patient's support system. Coordination improves care planning, diagnosis and treatment, management through transitions of care, and patient coaching to improve treatment adherence. This capability includes integration of primary care practices with behavioral health providers where possible.
Patient engagement	Outreach, health coaching, and medication management. Practices develop a culture centered on understanding and responding to patient needs. Further, practices offer patient engagement tools and self-management programming. Approaches may include patient education, incentives, and/or technology enablement. Practices develop and execute on patient engagement plans focusing on high-risk patients in particular.
Performance management	Using reports to drive improvement and participation in value-based payment models. Practices integrate a performance management approach into their daily operations, building on Delaware's Common Scorecard. Performance management involves tracking relevant metrics, utilizing performance measurement data to inform, design, and/or improve interventions; and developing a culture of continuous improvement.
Business process improvement	Budgeting and financial forecasting, practice efficiency and productivity, and coding and billing. Practices implement business management and financial planning processes required to participate in incentive payment structures and shared savings models. Practices incorporate budgeting and financial forecasting tools to: 1) develop quarterly and annual budgets; 2) forecast resource allocation required to operate during and after transformation; and 3) estimate financial impact of incentive payments. Practices may consider making structural changes in their workflows to ensure efficient, productive team-based care delivery. Practices also adjust billing and coding processes where necessary to support transformation, including reporting requirements for performance measurement on the Common Scorecard.
Referral network management	Promoting use of high-value providers and setting expectations for consultations. Practices seek out timely information on providers that are part of their patients' extended care teams from open sources as well as Delaware stakeholders (e.g., health systems, payers, other practices) to identify providers that deliver care consistent with the goals of the Triple Aim. Practices regularly strengthen the performance of their referral network through a number of approaches that may include, for example, setting clear expectations for partners, and establishing and tracking performance metrics.
Health IT enablement	Optimize access and connectivity to clinical and claims data to support coordinated care. To coordinate care, practices use health IT tools, including electronic health records, practice management software, and data from DHIN. Practices effectively interpret data, use health IT as a component of their workflow, and support expansion of the Community Health Record with clinical data.

Adapted from DCHI Primary Care Practice Transformation White Paper <http://www.dehealthinnovation.org/Content/Documents/DCHI/DCHI-Primary-Care-Practice-Transformation.pdf> (Accessed 2-19-2017).

Another visit model which has recently increased in popularity is the home visit. It is estimated that house calls increased from 1.4 million in 1999 to 2.3 million in 2009, and are expected to continue to increase in number due to an estimated 70 million Americans who will be over the age of 65 by 2030. Not only can home visits significantly increase patient safety, they foster a deeper trust and connection between provider and patient which will greatly increase the quality of care that the patients receive. (Unwin BK, 2011)

Direct Primary Care is another type of alternative visit model that has gained popularity recently amongst patients and providers. This alternative to a traditional fee-for-service model allows physicians to charge a monthly flat fee, which covers either all or most primary care services. (Physicians, Direct Primary Care, 2017) Patients benefit by having increased access to their providers with longer office visits and more individualized attention. Physicians benefit by having decreased practice overhead, no insurance filing as well as decreased patient load and more time spent with each patient.

Disease Management Programs Improving Self-management

Disease management programs are a series of measures designed to improve quality of life and clinical outcomes for patients with chronic illness. (Physicians, Disease Management, 2017) A good disease management program will reach out to patients in between visits with educational materials, reminders and support. These specific programs utilize a proactive patient centered approach to provide assistance in between provider visits with the ultimate goal of enhancing the patients own self-management of their disease.

Many practices are beginning to use care guides to assist their chronically ill patients. These non-clinical laypeople, are trained to work with patients with chronic illness. Care Guides are able to instruct and motivate patients with aspects of their overall health like nutrition, fitness and stress management. They receive a short period of training in motivational interviewing, behavioral techniques and common

Table 3: Sample Management and Leadership Skills Needed By Primary Physicians

Operations Design	<ul style="list-style-type: none"> - Ability to design and deploy deliberate system/program change - Specifying clinical protocols and the associated medical work flow - Identifying staffing model and task allocation - Determining data requirements and information flow - Identifying the routine for care coordination - Designing the physical layout of the ward, clinic, or office
Data Management	<ul style="list-style-type: none"> - Collect and analyze larger amounts of clinical and financial performance data - Embedding data collection in clinical work flow - Creation of routines for regularly reviewing and reacting to the data - External reporting and internal management (eg. operational control, clinical performance tracking, financial control, pay-for-performance payment contracts)
Human Resources	<ul style="list-style-type: none"> - Recruiting and selection of a wide variety of job roles - Performance assessment and feedback to existing staff - Staff development and succession planning
Managing Teams	<ul style="list-style-type: none"> - Multidisciplinary team design, goal setting, and oversight of teamwork - Managing team size and structure, internal culture, and decision-making processes
Financial Control	<ul style="list-style-type: none"> - Evaluating and managing multiple revenue sources and payment models as they offer services reimbursed in different ways
Negotiation And Conflict Resolution	<ul style="list-style-type: none"> - Capital Allocation Raising, allocating, and financing the capital needed for large investments in staff, information technology, and physical space - Ability to collaborate within larger more complex organizational structures and resolve internal and external conflicts
Innovation And Performance Improvement	<ul style="list-style-type: none"> - Managing innovation - Overseeing performance improvement

Adapted from Bohmer RM. Managing the new primary care: the new skills that will be needed. Health Aff (Millwood). 2010 May;29(5):1010-4. doi: 10.1377/blthaff.2010.0197.

chronic diseases. Care guides can offer individualized attention through evidence-based care, which gives patients the autonomy to manage their own diseases more effectively.

Similar to care guides, the role of the health coach in primary care is also beginning to become popular. The difference between the two positions is that health coaches are typically already part of the clinical staff. Whether they are an MA, a nurse or a Physician Assistant, health coaches also work one-on-one with patients to focus on education and compliance to empower patients and positively affect disease outcomes.

The role of the case manager within primary care can be another beneficial tool for many patients struggling to manage their chronic diseases. Case managers can help educate, motivate and assist with coordinating the care for the most complex of patients, which ultimately can give them the tools they need to manage their own care more successfully.

Health Information Technology

With the ever changing landscape of primary care, the integration of various health information technologies has become a necessary part of managing chronic disease. The electronic health record (EHR), although certainly not without its faults, can be a useful tool for healthcare providers to monitor the quality of care they are providing on a daily basis. Not only does the EHR provide a centralized database where the physician can keep track of their patient panel, it allows physicians to have electronic registries of their chronically ill patients, which can provide reminders about various testing and screening tools that may otherwise be unintentionally overlooked. (Zulman, 2015)

In addition, many EHR's offer a patient portal feature, which allows patients to schedule appointments, request prescription refills, look at lab and imaging results, and directly message healthcare providers via a secure messaging feature. Although they have been met with mixed reviews both from providers and patients, studies have shown that patient portals increase convenience for patients and allow direct access to providers without the hassle of waiting on the telephone for excessive periods of time. (Kruse, 2015)

When assessing the technological innovations in medicine, it is important not to overlook the usefulness of the smartphone, the tablet and their various applications. A study conducted in 2015 showed that mobile health apps were able to increase access for patients to medical information and provide social support to those dealing with chronic illness. (Bauer, 2014) The further development of this type of technology has the ability to increase health literacy and give patients the power to manage their chronic diseases in ways that are convenient for them.

Chronic Disease Care: A Partnership between Patients and PCP

Innovation within primary care can strive to ultimately develop a stronger partnership between patients and their primary care physicians. As we allow our patients to access their doctors and their care teams with more ease, we allow them to get real time information offering opportunity to integrate change more quickly. The patients have a sense of empowerment. They feel a sense of ownership of their health and they have a better understanding of what their own role is, how their choices are impacting their health and what they can control themselves. They also feel more dedication from their physician. Our patients and physicians will have a better understanding of one another and where advice, decisions and information is coming from. The importance of shared decision making has long been accepted. We must continue to strive to find the best practices to do this with and for our patients.

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Margot Savoy, M.D., M.P.H., is a member of the DPHA Advisory Council, past-president of the Delaware Academy of Family Physicians, and her role as medical director of the family medicine centers at Christiana Care allows her to combine her interests in quality improvement, patient-centered care, evidenced-based medicine and leadership development.



Dr. Hazlett-O'Brien is a PGY1 at the Christiana Care Family Medicine Residency Program.



Dr. Rapacciolo is Program Director, Christiana Care Osteopathic Residency Program and Assistant Medical Director of The Family Medicine Center.

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This year, the Delaware Academy of Medicine and Delaware Public Health Association have been afforded a wonderful opportunity to highlight some of the major accomplishments of DAM/DAHPA as well as exhibit many of the medical, dental and nursing memorabilia housed in our collection as well as that of the Medical Society of Delaware, the University of Delaware, the Delaware Historical Society, and several state museums and historical societies. This has been made possible by the excellent, new exhibit space developed by the Delaware Historical Society at its newly renovated space at Sixth and Market Streets in downtown Wilmington.

As part of its mission, DAM/DAHPA believes it is important to preserve and protect the history of the health professions in Delaware. Since its founding in 1930, the DAM has acquired important and mundane equipment, pharmaceuticals, instruments and documents from members and others interested in preserving this history.

For this exhibit, we selected the approximate time frame of 1817-1967, a span of 150 years, which showed major changes in the practice of medicine. Among the items on display are:

- The Margaret Handy-Katherine Esterly collection of infant feeders. These glass, porcelain and other types of bottles and pitchers were used to feed infants prior to the development of the infant bottles we know today;
- A collection of Civil War surgical instruments, primarily used for trauma surgery on wounded soldiers;
- Typical traveling instruments of dentists, opticians and physicians in the days of house calls;
- Nineteenth and early twentieth century microscopes;
- Useful, and sometimes useless or harmful drugs as dispensed by pharmacists, allopathic and homeopathic physicians;
- Nursing uniforms, caps and pins, reminding us of the origins of nursing education in hospitals across the state;
- A look back at the 1962 DAM Health Fair, a massive undertaking put on in the now razed National Guard Auditorium, with over 80 exhibits including the invisible woman, and a replica of the Mercury space capsule;
- Materials relating to the founding of the Medical Society of Delaware, courtesy of the MSD;
- A look back at the development of hospital buildings in Delaware, through pictures and picture postcards;
- A summary of major public health initiatives and programs within Delaware, and nationally.

With some exceptions, the items shown are from a time prior to 1967. It is interesting to contemplate the changes that have occurred in the last 50 years, and then to ponder how these professions will be practiced in 2067, when the items considered state-of-the-art for today will appear in a similar retrospective.

Brian W. Little, M.D., Ph.D.
History and Collections Committee
Delaware Academy of Medicine

Kathryn Lenart, B.A.
Graduate Student in History and Museum Studies
University of Delaware



Brian W. Little, M.D., Ph.D.

Dr. Little has research interests in biomedical imaging, neuromuscular disease and slow virus diseases such as Creutzfeldt-Jakob disease. He has served on several regional and national committees in medical education. From 1995 to 2000 he was a member of the Accreditation Review Committee of the Accreditation Council for Continuing Medical Education [ACCME]. From 2000 to 2006, he was a member of the Board of the ACCME, Chairing the Board in 2006. Other interests include the history of medicine and health care economics.

Dr. Little was Vice President of Academic Affairs and Research for Christiana Care Health Services from October, 2000 to May 2011. Prior to that, he was at the MCP-Hahnemann University School of Medicine, where he was Senior Associate Dean for Graduate and Continuing Medical Education and Affiliate Affairs. In these positions, Dr. Little was responsible for the allied health, undergraduate medical and graduate medical education programs, the clinical research enterprise which involves clinical trials, health services research, the Institutional Research Board and the support infrastructure. Since retirement, Dr. Little has consulted with Universities, Hospitals, Medical Schools and Industry on medical education and research administration.

Dr. Little received his M.D. and Ph.D. (Biochemistry and Enzymology) degrees from the University of Vermont. His undergraduate degree is a BA in Physics from Cornell University. His residency and fellowship training in anatomic and clinical pathology and neuropathology were all at the Medical Center Hospital of Vermont.



Kathryn Lenart

Kathryn Lenart is pursuing a Master's Degree in History and a Certificate in Museum Studies at the University of Delaware. Kate previously completed her Bachelor's Degree in History at Villanova University, where she also studied economics and business. In addition to her studies and related public history projects, she is a founding member of Delaware's Museum Property Law Project, which advocates for legislation regarding abandoned cultural property. Kate's research interests include 20th century popular culture in the United States and the points of intersection between popular culture, politics, and economics. Upon graduation, she plans to pursue a career in public history.

This Exhibit is open to the public through October 2017



Glass Feeder with Attached Nipple
Date Unknown
Delaware Academy of Medicine

This glass model also rests on its side. Feeders like this one were difficult to clean because they only had one opening. Later, bowl-shaped models called Hildburgh feeders, appeared in 1894. With opening on both ends, Hildburgh models were much easier to clean.



Dr. Lewis B. Flinn
c. 1930
Delaware Academy of Medicine Collection

Dr. Lewis B. Flinn was the first President, and driving force behind the development of the Delaware Academy of Medicine. He was a native of Wilmington Delaware. He was the Chief of Medicine at both the Delaware and Wilmington Hospitals, as well as the director of medical education at both hospitals. Among his medical accomplishments was the fact that he was the first physician in Wilmington to administer insulin to a patient. He passed away at the age of 88, in 1986, shortly after having returned from a safari to Africa.



Medical, Dental and Nursing Memorabilia
1817-1967

presented by
 the History and Collections Committee
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The Delaware Academy of Medicine

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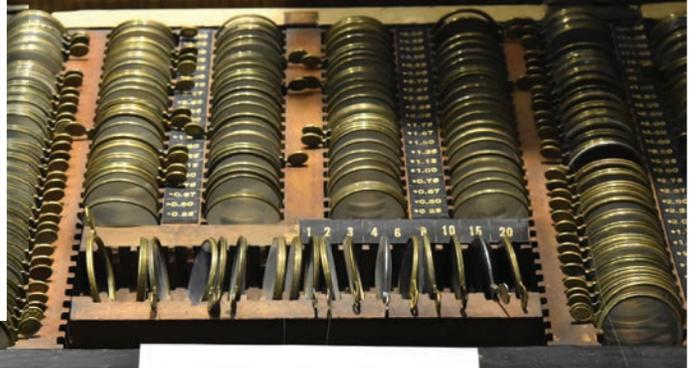




Spring Loaded Blood Lances
c. 1900
Delaware Academy of Medicine

Early electronic ophthalmoscope, American Optical Number 144P Giantscope c. 1945
Delaware Academy of Medicine

Ophthalmoscopes originally used ambient light. With the development of electricity, increased amounts of light could be reflected into the eye, thus increasing the ability of the physician to see the retina, lens and associated structures. This ophthalmoscope was directly plugged into a standard 120 volt outlet. Later, ophthalmoscopes would get electric power from batteries. This model was manufactured from 1945 to 1965.



Ophthalmologists Traveling Lens Kit
c. 1920
Delaware Academy of Medicine Collection

This traveling case includes all the lenses necessary to test for corrective glasses, and write a prescription. The top has been removed. The lenses would be inserted in the accompanying frames for examination.



Cataract and Eye Surgery Instruments
c. 1940
Delaware Academy of Medicine

Cataract surgery was one of the first procedures performed by "eye physicians."

Innovative Discoveries Series



DATE	SPEAKER	TOPIC
3/24/17	Anastasia Hudgins, PhD, Center for Public Health Initiatives, University of Pennsylvania	Fear, Vulnerability and Sacrifice as Factors in ED Use: Ethnographic Research Methods and Their Insights
3/31/17	Neal Goldstein, PhD, MBI, Christiana Care Health System	Social and Spatial Correlates of Infection in the Neonatal ICU
4/21/17	James Mangan, MD, PhD, University of Pennsylvania	Differences in Patient and Physician Perceptions of Care for Patients with Myeloproliferative Neoplasms
5/12/17	Judith Herrman, PhD, MS and Katherine Haigh, MSN, APRN, CNP, University of Delaware & Christopher Moore, BA, Christiana Care Health System	Why Mixed Methods Work in an Evaluation of the Wise Guys Program
5/19/17	Todd Druley, MD, PhD, Washington University	Error-corrected sequencing as a tool to detect residual cancer after treatment

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