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Dear Readers,

It is a wonderful privilege to be able to live a full life, in good company and in good health. Someone once said that getting to old age is a combination of luck and good decision-making. While the former may be true, it is really the latter that we have control over.

This issue explores the health decisions we make from childhood through adulthood and into old age. Our issue begins with Dr. Art Elster’s exploration of the very beginnings of our development and how our internal and external environments influence our ability to make health decisions. As we transition into the interview with Dr. Bonnie Spring, we tap into the many issues facing older adolescents and adults. Dr. Spring discusses the myriad of novel health technologies becoming available for both cardiovascular and mental health management as well as the socioeconomic implications of health access. Finally, we explore the challenges we face in old age. Dr. Amy Eisenstein and Nissa Romanski spotlight the needs of older adults in the Chicagoland community, while Maggie Walker addresses end of life care in rural America.

Throughout every stage of our lives, we are faced with decisions about our health and well-being; some decisions easier than others. From this issue, we hope you take away the idea that our health behaviors are indeed modifiable, both by creating a safe and beneficial environment and by guiding personal decision making.

We wish to thank all of our contributors and a special thank you to the students of the University of Illinois Chicago Biomedical Visualization program for their beautiful illustrations to accompany the pieces throughout this issue.

In Health,
The NPHR Editors-in-Chief
Nelly Papalambros and Simona Morochnik
Cover Artist Statement

I have an old dad. He was forty-six when I was born, and he’s always been older than the fathers of my peers. In his seventies now, he is navigating the complexities of the medical system, health, and aging. I illustrated this piece with him in mind.

When I think about aging, I immediately picture a grandmother sitting in a rocking chair, crocheting. This cliché became the basis for an illustration about positive steps people can take for their health as they age. Meaningful hobbies can make a big difference in quality of life. Additionally, I wanted to depict heart health as something people can work on regardless of how old they are, just as they would work on a project they’re passionate about.

The illustration serves as a reminder that everyone has the power to make positive changes to their health. The muted colors and saturation were used to elicit a feeling of comfort in the viewer and a soft yellow light radiates from the bottom right corner to give the image a hopeful mood.
You’re welcome, Dad.

About

Liza started her undergraduate education as a Drawing and Painting major at Purchase College in New York, but switched to studying Psychology and Biology with a concentration in Cognitive Neuroscience. After graduating, she realized she wanted a career that incorporated all of her interests, and now she attends the University of Illinois at Chicago as a Biomedical Visualization graduate student. As a medical illustrator, Liza is predominantly interested in building interactive applications and games for medical education. She enjoys reading, playing videogames, and singing in a bluegrass band.
“America created the teenager in its own image--brash, unfinished, ebullient, idealistic, crude, energetic, innocent, greedy, changing in all sorts of unsettling ways. A messy, sometimes loutish character who is nonetheless capable of performing heroically when necessary, the teenager embodies endless potential not yet hobbled by the defeats and compromises of life. The American teenager is the noble savage in blue jeans, the future in your face” [1].
This is quite a colorful characterization of teenagers making the physical, emotional, and social transition from the dependency of childhood to the independence of living in the adult world. How did we come to view teenagers in such a passionate and value-laden manner and, more importantly, why does it matter?

The concept of adolescence as a special population is a 20th century American phenomenon. Social-cultural changes in society and technological and scientific advances all helped focus attention on the role of youth as a special population. We now appreciate both the promise and the problems associated with today’s teenagers and strive to learn more about the many factors that influence health, both positively and negatively.

A myriad of factors shape the development of the modern teenager, and while this is not a comprehensive review of science literature, here I will attempt to clarify how and why individual characteristics develop within the rubric of a clearly defined youth culture that simultaneously glorifies the beauty, energy, and idealism of youth and condemns youth for the ills of society. Development is complex, encompassing many layers that are neither rigid nor stable, and care must be taken not to over-simplify the process. My discussion will be organized on Urie Bronfenbrenner’s ecological model of development that posits how socio-environmental systems influence development. This model is best understood as concentric layers of an onion, with the teen at the center and progressive systems surrounding this core.
Our genetic and biological makeup at birth determines not only our intellectual capacity, gender, race and ethnicity, and risk for certain physical and emotional disorders, but it also contributes to our personality. Thus, starting in early childhood we develop gender-based roles and behaviors, and exhibit variations in development based on gender. Race and ethnicity, independent of socioeconomic status, also have a major influence: “High scores on ethnic identity scales moderated youth’s ability to cope with daily stress. This finding suggests that a strong ethnic identity encourages emotional resiliency for youth even when the stress is independent of ethnic or racial status” [2].

Variations in IQ status, physical stature, temperament, timing of puberty, and genetic potential for chronic diseases, such as diabetes mellitus and obesity, vary greatly. Each child, then, is influenced perhaps in different ways by their proximal and distal environment and becomes, as least to some extent, a product of the interaction of their genetic and biological makeup and the environmental systems I will continue to discuss.

The people who teens interact with on a regular basis comprise the social-environmental Microsystem. These people include parents, grandparents, friends, teachers, coaches, religious leaders and many others who influence attitudes and behaviors, provide sources of emotional support, serve as role models, and offer a glimpse of what life can be as an adult. Youth who experience a predominance of positive experiences from their Microsystem are likely to have more confidence, better self-esteem, make healthier decisions, and have better mental health.

But, a youth’s Microsystem can also work to undermine healthy development and result in feelings of psychological insecurity, a need to “prove oneself” through aggression and risk behaviors that may adversely affect themselves and others, and other developmental consequences that portend less success as an adult. We perhaps have all known a teen who was raised in a toxic family environment yet performed well academically and made a successful transition to adulthood. The term often applied to these teens is resilience, and we wonder what made a difference in these teens’ lives, but not in other teens’ lives. Perhaps it was an understanding teacher at school, a supportive coach, or a friend’s parents.

Although there are many influences that directly impact youth, here are four examples that will clarify the power of the Microsystem.
Parenting Style
A wealth of research over the past 30 years has clearly demonstrated that parenting style often thought of as “overall climate of parent-child interactions” affects socio-emotional development [3-5]. As initially described by Baumrind, parenting varies on two major dimensions: Acceptance and warmth that relates to the extent to which parents foster individuality, self-regulation, and self-assertion by being responsive, supportive, and understanding of their teens’ special needs and demands; and, demandingness or behavioral control that refers to the control that parents exert on their teens to become integrated into the family through their supervision and discipline.

Research strongly indicates that compared to teens raised in authoritarian, permissive, or uninvolved households, teens raised in authoritative families (i.e., high level of acceptance plus high control) tend to exhibit better success academically, have stronger self-esteem, and have better emotional health. Environmental context is also important to consider. Thus, parents from lower socioeconomic communities exercise a greater degree of authoritarian behavior (low level of acceptance plus high control), for instance a “shorter lease”, on where and when their teens can visit the neighborhood, probably due to safety concerns. Although such parenting might have adverse consequences on teens raised in other environments, a high level of control seems to have no such consequence on teens raised in more dangerous neighborhoods.

Peer Influence
Risk taking behaviors such as smoking, drinking, drug usage, and unsafe sex increases between childhood and adolescence, and then diminishes as youth reach their third decade of life. More recent research has expanded our understanding of adolescent development to include the way peer influence interacts with neurodevelopment [6]. We now know that the brain’s limbic system, the region of the brain that promotes aggression and impulsivity, is relatively over-developed during the early and mid-adolescent years compared to the frontal lobe, the region that promotes reasoning. This part of the brain only becomes fully developed during the latter stages of adolescence, around the mid-twenties. Thus, early to mid-age teens (i.e., 12-16) exhibit greater social independence, experience more social–behavioral influences from the media and entertainment, and spend more time with their peers versus their family while, simultaneously, their limbic system is developing and exerting greater influence on how they process decision-making.

Social Connectedness
Resnicks and associates, in a seminal study, found that being socially connected with family, school, and their faith (i.e., Microsystem) were powerful protective factors in helping youth navigate through the negative influences of adolescence [7]. Teens with stronger feelings of connectedness, especially with schools, are more likely than other youth to have better psychological adjustment and are less likely to engage in many risk behaviors, including early sexual initiation, alcohol, tobacco, and other drug use, and violence and gang involvement; and these effects are likely to last over time [8]. Efforts of schools to promote connectedness may be especially important for students who are marginalized or “feel different”, such as students with emotional or physical disabilities, students with chronic medical diseases, students who are lesbian, gay, bisexual, transgender; and students who are homeless [9].

Adverse Childhood Experiences
Lastly, pioneering work by Felitti and Andaers has shown the powerful impact that a constellation of adverse childhood experiences (ACEs) has not only on adolescent health and development, but also on adult emotional, physical, and behavioral health [10-11]. Events such as childhood abuse (physical, sexual, and emotional) and neglect, and household events (domestic violence, divorce, parental substance abuse, and parental mental illness) affects a wide range of health problems including adult smoking, drug abuse, depression, suicide attempts, heart disease, and obesity. The more ACEs in a child’s early environment, the greater the risk for morbidity and premature mortality throughout life. The association is found across socioeconomic strata [12].
**Third Layer: Exosystem**

The Exosystem includes an array of influences that affect a youth's social environment, but with which the youth will not have direct interaction. The Exosystem works by influencing components in the Microsystem that, in turn, affect the teen both positively and negatively. Safe neighborhoods with ample community resources provide assets that promote positive adolescent development, while adolescents who live in violent neighborhoods with poorly functioning schools and few community resources must deal with fear and insecurity and lack of a “safe haven”. Other examples of the Exosystem include:

**School Policies**

School policies affect teens in many ways. One example is when schools adopt a policy on zero tolerance. Schools use this policy to suspend or expel youth for actions (i.e., fighting, carrying a weapon) that officials believe distracts from the school learning environment. A growing number of advocates view this policy as not only ineffective in ensuring a safe school, but also believe it may promote the “school to prison pipeline”. This may be especially concerning for academically marginal students and ethnic minorities for whom being out of school exposes them to negative social influences [13].

**Employment and Workplace**

Workplace schedules influence a teen's home environment through the availability of parents to monitor, supervise, and provide guidance. The availability and quality of employment opportunities influences the economic stability of both parents and teens. Layoffs and relocations also can have a major influence on an adolescent's emotional state.

**Mass and Social Media**

Much has been written about both the positive and negative effects of mass media (including television, video games, film, and the internet) on the psychological development of youth [14]. Messaging serves to change or reinforce attitudes and beliefs that influence behavior. Mass and social media can teach youth acceptable social norms and behaviors, expand perspectives on events outside of the local community, and promote health beliefs. Mass and social media, however, can also normalize aggressive behavior; glorify sexual behavior, drinking and smoking; promote sedentary behavior; provide an anonymous vehicle for cyberbullying; and influence emotional depression for youth who, through social media, view their life less favorably compared to others (i.e., Facebook depression).

> Safe neighborhoods with ample community resources provide assets that promote positive adolescent development.
Fourth Layer: The Macrosystem

The Macrosystem is the outermost layer in the child’s environment and is comprised of cultural values, customs, and laws that surround the teen. The effects of the principles defined by the Macrosystem have a cascading influence throughout the interactions of all other layers. Examples of this system include:

Regulations and Laws
Laws and regulations at the local, state, and national level affect teenager development and behavior in many ways. Although the legal age of majority is usually set at 21 years of age, jurisdictions around the country and court rulings have created many exceptions to this standard. Thus, in response to parents’ need for help with transportation, sixteen year olds can obtain a driver’s license; in response to high rates of teen pregnancies and sexually transmitted diseases including HIV, states grant minors (i.e., teens under the age of 18) the legal right to receive contraceptive services, pregnancy testing, and HIV treatment without parental consent; in response to concerns about alcohol abuse and traffic crashes, states raised the age of purchasing and possessing alcohol to 21; and lastly, although the legal age of purchasing and possessing tobacco products around the country is generally 18, some states have raised this age to 21. As a result of Supreme Court rulings over the past several decades, minors are protected from capital punishment, provided due process in legal matters, provided limited free speech in schools, protected from unreasonable searches in school, and permitted to have an abortion without parental consent. These exceptions to the traditional age of majority have led to the concept that teenagers are viewed from a legal perspective as a “semi-autonomous” state--- they are not considered exclusively as minors, but have constitutional rights (albeit somewhat limited) usually restricted to adults [15]. This change, from viewing teenagers as legally incompetent minors to understanding and accepting the value that teenagers provide to society, provides youth (as a population) an identity and sense of self-worth.

Ethnic and racial health beliefs
Think here of the lasting effect of the Tuskegee Syphilis study on the trust that African Americans have with our medical system, or the role that folk medicine plays in some ethnic minorities.

Unexpected environmental changes
Terrorist attacks, natural disasters, and the 2008 economic depression. Each of these events has ripple effects throughout the entire socio-environmental model and may impact teens directly through feelings of vulnerability and through family and community life.

Ideological political positions on national issues such as gun control, abortion, gay rights
For example, consider the 2015 Supreme Court decision legalizing gay marriage. Same-sex marriage may affect teens by stabilizing family life and by providing legal rights that were previously denied such as the right to health insurance and to social security and other federal government benefits in cases where the non-biological parent dies.
# Conclusion: Teenagers in a Life-Span Perspective

The period of adolescence plays a central role when viewing development and health from a life-span perspective. Preconceptual and prenatal factors influence early child development that, along with the bio-social-ecological determinants discussed previously, influence adolescent development, behavior, and health. In turn, the emotional, psychological, mental, and physical health of youth play a determinative role in the health and developmental trajectory of adults. This critical role of adolescence in human development is well described by G Stanley Hall, a noted psychologist (1846-1924) of the early 1900s [16]. Hall, known as the father of adolescent psychology, is credited with helping shape educational, psychological, and cultural themes that define today's policies and beliefs of the American teenager.

He held that while children were primitive beings and adults were set in their beliefs, adolescence was a period of emerging emotional, cognitive and moral transition and, therefore, ripe for intervention. Hall promoted compulsory education as the strategy to mold teenagers to hold higher moral values, thus transforming the values of the society as a whole. Although over the past several decades there has been increasing emphasis on the development of the very young (i.e., Head Start, early preschool programs), those in public health are keenly aware of the value of improving the developmental well-being of teenagers as a key step in promoting health over the lifespan.

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**References**

An Interview with

Bonnie J. Spring

By Nelly Papalambros and Simona Morochnik

Bonnie Spring, Ph.D. is Director of the Institute for Public Health and Medicine (IPHAM) - Center for Behavior and Health. She is Professor of Preventive Medicine (Behavioral Medicine) in the Department of Psychiatry and Behavioral Sciences at Weinberg College of Arts and Sciences at Northwestern University.

Nelly Papalambros (NP): Can you tell me a little about what type of work you do in the field of health behavior?

Dr. Bonnie Spring (BS): The department of Preventive Medicine has many observational academiologists, but I’m an interventionist. I like to produce health behavior change. Often we try to make the solution to health promotion an ‘either or’. We’re either going to change policies and the environment or we’re going to change individuals’ behaviors. But we really need to do both.

One question we address is ‘whether it’s all over by the time you are an adult?’. For example, if you’ve established bad health habits, have you done irreversible, undoable cardiovascular damage? Or can you reduce or reverse the damage by making healthy lifestyle changes? I kept saying to my Northwestern colleagues, ‘look, you have these huge population studies, why can’t you find people who made healthy lifestyle changes?’ Many [of my colleagues] argued that it was unlikely that people made healthy lifestyle changes late in life; if anything they got worse. But one of the advantages of having these cohorts of thousands of people is that there’s got to be some variation in behavior. Sure enough, when we broke down the data in the Coronary Artery Risk Development in Young Adults (CARDIA) study—around 25% of the people actually did improve their behavior; a third stayed the same, and the rest got worse. But that’s enough of a distribution to see a dose-response association with their likelihood of having subclinical atherosclerosis. Those data suggest a couple of things: (1) even if you’re an adult and you improve your health behaviors, it’s helpful and (2) there’s no safe period. Just because you get to adulthood and you’ve been living a healthy lifestyle doesn’t mean you’re out of the woods. You have to keep it up. We can’t just attend to the healthy lifestyle habits of kids. We have to think about our whole lifespan.

“We can’t just attend to the healthy lifestyle habits of kids. We have to think about our whole lifespan.”
NP: What types of behavioral interventions are you currently working on?

BS: In some interventions, we take advantage [of the fact] that someone is in the right space to exercise. For example, we have a study in the field with college students called the NUYou study. This is with NU freshman and sophomores. It is a very important age group—one we’ve taken a very long time to recognize is important because the age between 15 and 25 is when people pick up a lot of their bad habits—habits they will keep for the rest of their lives. It isn’t only that you have to get through childhood [healthy], but you have to get through those college years! We have an ongoing study where we try to prevent people from picking up health risk behaviors: smoking, becoming physically inactive, developing a poor quality diet, or weight gain. Other behaviors we’re trying to preserve are sun protection, safe sex, vehicular safety and hydration. Physical activity in particular falls off pretty quickly in college. We can prompt people with suggestions about when they can get in physical activity. It helps to know that they’re not in class and that they might be near a gym or that the weather outside is nice. So the technology is pulling from their calendar and GPS to let us know, are you available now? We’ll leave you alone if you’re in class...(if you’re really in class!)

NP: This is great because they’re not kids anymore, but potentially still malleable.

BS: And they’re still healthy! What our focus groups told us was pretty spooky. We can see this is the age when you are losing 28% of your cardiovascular health. We think students should be worried about this, but it’s very clear it’s just not on their minds. They care about academic success, about future professional success, about saving the world, and about having a big impact on public welfare. The things that they tell us are important to them are reasonable, but not to the exclusion of their long-term health.

“...this is the age [15-25] when you are losing 28% of your cardiovascular health.”

We had to learn to frame their health in ways that align with what they value, what they care about. We are having them assess their health behaviors, stress, and cognitive function on an app so that they can track how their behaviors impact their stress and cognitive performance. They can actually see that when they’re living a little healthier there are benefits that they care about.

NP: This type of self-tracking intervention is great, because you can see what you’re doing now has immediate consequences now, rather than 30 years from now. Do you have any projects focused on nutrition or weight management? There is a lot of information out there (some contradictory) about nutrition. It can be overwhelming.

BS: It is overwhelming! I think that is part of the reason why healthy eating is the worst behavior from a public health standpoint. Less than 2% of the population is adherent to nutritional guidelines. In part, it is because of the complexity [of the knowledge] needed to eat healthy. There’s got to be some way to simplify and make healthy eating accessible and feasible for people.

In our research group, we do interventions in diet, physical activity, smoking, and weight loss. We work with the most prevalent health risk behaviors, with people who are eating too much saturated fat and not enough fruits and vegetables, who are not getting enough moderate physical activity or getting too much sedentary time.
What's interesting about these behaviors is they fall into two types. One type of behavior has a low rate problem—it's a healthy behavior that doesn't occur often enough (like fruit and vegetable intake or physical activity). The other type is an unhealthy behavior that happens too much which means that the interventions are sort of opposite. So it's been interesting to ask questions like ‘is it easier to increase something (give me something to do) or is it easier to cut something down?’ The answer seems to be it’s a mix. Having people increase fruits and vegetables is wonderful. Almost everybody can do it and it's very reinforcing.

On the other hand getting someone to increase their physical activity is much tougher. There, it’s much easier to have them cut down their sedentary time. So we look at these tradeoffs. Basically, the problem we are trying to resolve is: if you deal with the basic reality that most people have more than one bad health habit, how do you manage to maximize the healthy change across the board, on multiple behaviors? Usually, we will use an intervention to try to change at least two of them with the least burden. For example, if we can get people to increase their fruit and vegetable intake, it crowds out and cuts down their saturated fat without them having to think about it.

NP: I can see why it’s challenging. There are plenty of interventions I’ve seen that tackle just one issue, but two at a time, yikes!

BS: That’s precisely the challenge with these studies of multiple health behavior changes. We can get people to be more physically active and increase their fruits and vegetables but…*whispers* they’re not going to lose weight! Or we can get them to lose weight by cutting down their saturated fat and increasing their physical activity, but they won’t maintain it.

How to maximize the portfolio of health behaviors is a tricky [problem]. So far, we’ve gone about health behavior change by using treatment packages that include bundles of treatment components such as 16-45 in-person group sessions, telephone coaching, text messages, tracking technologies, perhaps financial incentives. Treatment works but it’s really burdensome and expensive. We don’t know which treatment components are really essential and whether some could be removed to make intervention less expensive and demanding.

“...is it easier to increase something (give me something to do) or is it easier to cut something down? The answer seems to be it’s a mix.”
The research methods that I’m heavily into now try to learn how to optimize interventions and make them more efficient—both in terms of the burden they place on people and their resource utilization. All the studies we have now are coming out of that framework. For example, we have a weight loss study that is literally turning on, and off, different components in the kitchen sink of behavioral interventions to see which have an impact on weight change. People either get 12 sessions or 24; they get feedback sent to their primary care doctor or not; they get meal replacement recommendations or not; they get text messages or not; their buddy gets supportiveness training or not. Each component will have a certain effect size and a certain cost and we will reverse engineer the maximum amount of weight loss that we can get for the least cost. This way, we’ll assemble the leanest and meanest intervention package we can before testing it in a clinical trial. In the old days, we’d throw the kitchen sink of components into the intervention to be sure to have an effect. But the intervention would be so unweidly and burdensome that it just sat on the shelf. No one used it.

Another kind of problem we deal with is the fact that one size doesn’t fit all. We know that. But we don’t have treatment algorithms that tell us who needs what or what to do when the treatment is not working. Our other trials assess what treatment is the best first step, what to try next if it doesn’t work, how much to step up, when to step down, by how much.
NP: This technique goes along with the personalized medicine approach, what everyone hopes is the future. Is there anything else you feel is important to discuss in terms of the future of medical sensing?

BS: I think you picked right up on this when you talked about the fact that we’ve got all this continuous big data. The other thing that’s changing in this space is that sensors are getting better and better, they’re getting smaller and smaller, more wearable. Rather than a chest strap, very soon you’ll probably be able to get a wristband, and then probably a little flexible tattoo. This is what we should expect to continue to progress in the future.

“Rather than a chest strap, very soon you’ll probably be able to get a wristband, and then probably a little flexible tattoo.”

NP: Exactly how are you using these sensing technologies in the field right now?

BS: We know that stress causes all kinds of unhealthy habits such as smoking. So you might think that tells you that whenever somebody’s getting stressed you should reach out to help them. But I’ll tell you what happens to me if I’m stressed and you’re reaching out to help me: I’ll scream! So we are doing these trials now to try to sense when someone is stressed and when they’re not stressed and determine the optimum time to put out an intervention, even if the intervention is something non-intrusive like opening a relaxation app on your phone. These are the kinds of questions that we can now ask, balancing the sensing of when they’re vulnerable (which is when they’re stressed) and when they’re most receptive to being able to benefit from help.

There is a wearable device called an “Auto Sense” chest strap, which senses electrocardiogram signals and respiration. It pulls thousands of signals every minute, while we run an algorithm on the phone in real time to decide “is this a stressed minute or is this a non-stressed minute”? The algorithm learned what stress looks like from laboratory studies in which we had people descend their arm in a bucket of ice water. To tell if a person’s Autosense data matched the stress pattern, it used to be that we’d have to send the data to the cloud to process, which meant that by the time we figured out what was going on, it was too late to intervene. But now, we can do data analysis on the phone in real time.

NP: Socioeconomic and demographic-wise, how do you get to the people that might need intervention the most?

BS: This is a really important question. It is the digital divide question. We were very worried about it at the outset. We used to to gauge the digital divide by disparities in household broad-band internet connectivity. There are massive disparities in that globally and in the U.S. But low broadband access has led to the rise in mobile phone use, particularly among the underserved. Low income populations have always been ahead of the more affluent Caucasian sector in mobile use. It leads to the phenomenon called “smart phone dependence” where you’ve got a large swatch of the population whose
smart phone is their access to the internet. [Mobile] technology has actually been a way to leapfrog over a lot of digital divide issues. You've got a place like Africa where 29% of their roads are paved and 25% of their population has electricity but 80% have a mobile phone. You have the infrastructure built already, and health promotion interventions can capitalize on this.

NP: In your experience, are certain interventions more effective in certain populations?

BS: Technology is new to all of us so we tend to focus on it and we think of it as the thing that’s doing the work. But my view of this is that these [technologies] are simply widgets that are new delivery channels, giving us new information about people.”

A long time ago we learned you do best by giving people whatever channel they are accustomed to using. We used to do everything in person face to face, but some people want their contact to come by telephone, others over email, other others via text. You tailor for whatever the person wants.

Another thing that changes over time is the optimal density of messaging—the pace of communication. Text messaging interventions are being widely used now. But we can’t give as many text messages now as we used to when we first started to do these interventions because people are more overloaded, particularly young people. It’s sort of like when email first appeared, it was just wonderful because only the people you wanted to communicate with [were on it] but now everybody’s on it! And the channels do that, they become saturated and the new generations always hit that saturation point first and go looking for another channel. I think we’re striking a balance between trying to sense when people need help and also trying to sense when they’re receptive to it, so that we’re not going to overburden them and get shut out. With sensor technologies, we are coming closer to being able to do this.

“...the art of optimizing a technology for new generations is really the art of trying to skate to where the puck is going to be.”
NP: What kind of health behavior studies do you do with older populations? Do you employ technologies in these studies?

BS: We have a fair amount of collaboration with people that are working on healthy lifestyle changes for older adults, particularly collaborations with Dr. Mary McDermott, who does exercise interventions with frail elderly. We do use technologies in that study. Actually, our very first study with a mobile health technology was in an older population. I wanted to do that study because I wasn’t convinced that older people could master these technologies with tiny screen sizes. Could they even see it, let alone use it? We did the study when palm pilots—do you remember those?—they were cutting edge. We were working at the VA with older adults not one of whom had ever used a palm pilot. They were in their 60s and needed help with weight loss. I come from the perspective of being a psychologist so I’d like to help everybody in a 50 minute therapy [session], but that’s just not realistic from a public health perspective. For something like making food choices, this [hand held technology] is decision support you can carry around with you. You can look up nutritional information or track how many calories you consumed. The advantage of these technologies is they can be with you all the time when the therapist isn’t there.

Before doing the study, we created focus groups. I will never forget giving them the technology, and watching them try to use it. We were really unsure how well this would go, but it worked great! We learned a couple of really important things. You may be too young to remember when this was really an issue, but when technologies were first coming online they were new to all of us! With technologies, a lot of times you can’t get them to work. We found the main differentiator between generations is that young folks—you keep trying stuff! Eventually you get something to work. Older generations are afraid something is going to break. We learned we would never let somebody go home with a technology until we had sat with them, let them play with it, get them into trouble a few times, help them get out, watch them so they would learn that it didn’t break, and that they should try things. At the end of the day if it wouldn’t work they could call us and it was crucial to have warm tech support on the other end of the phone. Because the worst thing is if you’ve got somebody who’s a little freaked out by technology, and then they’re calling somebody who’s mean to them or saying something complicated; they’re just going to give up. And if we [had warm tech support], it worked fine. In fact, the group that had that technology in that study did better than the people who were recording on paper and pencil. So our very first study was a technology we used for older people and we got great results. They loved it and now we are using more technologies with older participants. For example, [senior citizens are] using fitbits and uploading their data onto tablets. They love the feedback. And they love that they’re wearing the same thing their grandkids are wearing.
Defining the Older Adult Landscape
How an ElderCare organization relies on Research and Data to improve the health of the population

By Amy Eisenstein, PhD and Nissa Romanowski, MPH

As the population of adults over the age of 65 continues to grow, so too does the demand for healthcare and social support. Addressing health and wellness in an older population is complex given the diverse set of needs. While some older adults may seek physical assistance, others may want to enhance their social support network after retirement. Community based organizations often fill the gap in providing long-term support, whether in the form of dementia care, housing, medical care, social support, or assisted living arrangements. CJE SeniorLife is one such organization serving the Chicagoland community. With its own dedicated research department directed by Dr. Amy Eisenstein, CJE is in a unique position to monitor and evaluate unique population needs. In this article Dr. Eisenstein discusses current research and potential applications to better serve the older adult community.

Community based organizations work tirelessly to meet the needs of frail and at-risk populations in their areas, and CJE SeniorLife is no different. Established in 1971 as the Council for Jewish Elderly, CJE SeniorLife (CJE) upholds the famous sentiment of Rabbi Abraham Joshua Heschel, “The test of a people is how it behaves toward the old.” As such, our mission is to enhance quality of life and facilitate the independence of older adults. We are committed to serving older adults and their families regardless of income, religion, gender or ethnicity. Most of our 23,000-plus clients live close to or below the poverty level and participate in free or subsidized programs. At the foundation of CJE is the belief that as people age, they want and need to remain independent to the greatest degree possible. CJE is intent on helping older adults to claim their independence and manage their own healthcare for as long as is feasible. This increases quality of life for individuals and decreases the eldercare burden for society. CJE aims to achieve their mission by striving for excellence through respect, advocacy, compassion, intention, innovation and accountability.

So, how do we help older adults remain independent? One way is through our Center for Healthy Living. The goal of the Center for Healthy Living is to provide education and socialization for older adults who are seeking to stay healthy, independent, and socially engaged. The Center strives to help older adults remain in their homes longer, with improved general health, improved quality of life, and reduced disability. And how does staff of the Center know what programs to offer to our clients? The answer: Staff turn to research and look at the data. For example, results of a CJE Population Health Study showed staff that 49% of CJE’s clients limit their activity due to a fear of falling. Therefore, the Center for Healthy Living added more fall-related programs knowing they are needed and would be well attended. CJE is one of the few social service agencies in the country that has the benefit of an in-house research department, the Leonard Schanfield Research Institute (LSRI). The LSRI has a long history of implementing programs based on the evidence gleaned from its research projects. The LSRI’s work is even more important now that there is less funding to support the development of innovative programs, especially those that focus on an older adult population.

Since the majority of healthcare occurs outside of the hospital, home and community-based services have increasingly become key components to helping patients and providers obtain their clinical and financial goals. Therefore, the future of CJE SeniorLife is dependent upon our ability to foster health and quality of care improvements while managing costs, and upon our ability to track and prove our success in these areas.
To be recognized as a key player in the larger healthcare marketplace, we need to know our clients better. In order to understand the health status of our clients and their risks for negative outcomes and increased costs, we must be able to measure relevant outcomes such as physical and mental health, service utilization, and functional abilities. In addition, with adequate client information we can effectively target interventions at lower costs and begin to use data analytics and technology to proactively intervene and coordinate care.

In mid-April 2015, with the help of a grant from the Michael Reese Health Trust, CJE initiated a data collection and analysis process to better understand diverse aspects of their client population’s health status, including identification of chronic health conditions, healthcare needs, and healthcare providers. Questions focused on the following ten areas:

1. General health status and well-being
2. Quality of life
3. Social Support
4. Chronic conditions and symptoms
5. Functional abilities
6. Mobility and falls
7. Health behaviors
8. Sociodemographics
9. Hospitalizations
10. Healthcare service use

The research department successfully interviewed just over 400 (n=411) CJE clients. Participants were between ages 57 and 97, with a mean age of 78. A total of 74% of survey participants were female. Most of the respondents (85%) were retired, and 67% of respondents live alone. Of the total, 44% were foreign born and 31% were Russian. For at least 35%, English was a second language.

Understanding of how the health of the population CJE serves compares to the national average, helps to identify key areas for concern. For example, 45% of respondents visited the emergency room at least once in the past 12 months, which is much greater than the national average for the same age group of only 21% of adults 65+. On top of this, 26% of respondents had been hospitalized in the past year, compared to the national average of only 15% (National Center for Health Statistics, 2015). These findings highlight the importance of focusing on care coordination and transitional care in order to improve the health outcomes for this population.
In addition to a greater use of the hospital system, CJE’s clients tend to have higher rates of the major health conditions than the US average. The figure to the right shows higher rates of increased blood pressure, osteoarthritis, diabetes, and chronic lung disease among CJE clients as compared to a national sample.

Our clients tend to have greater rates of multiple chronic conditions. These findings pointed us to increasing interventions for self-management of multiple chronic conditions, increasing staff training on how to approach clients with multiple chronic conditions, and helped us narrow in on what areas of prevention to focus on.

Other findings that stood out to CJE as areas of concern for their clients were higher rates of polypharmacy, more falls, and increased rates of social isolation as compared to national averages. In the sample we interviewed, 29% of participants reported having fewer than 2 people that they talk to in an average month. Social isolation has been found to be related to morbidity and mortality, again pointing CJE directly to an area where they could impact the health of the population they serve. Since completion of the population health study, CJE has secured funds to pilot a friendly-visitor program to increase social contacts with low-income older adults in the community.

In addition to the quantitative items on the questionnaire, we used a few open ended questions regarding what clients felt was important for quality of life. There were notable differences between the English and Russian speaking populations. Generally, for the English speaking populations, the most frequent responses related to mobility, medical, and general health. Safety was much more frequently indicated as a contributor to quality of life for the Russian speaking respondents. For example, the response below exemplifies a common response from Russian speaking clients:

“My health, family, wellbeing, safety, and peace in the World.” Examples reflective of common responses from English speaking clients include: “As long as I can do things for myself, this is important.” And “If you can take care of yourself, and do what you need to do to manage your household.”

These qualitative findings push us to better understand the dichotomy of the population we are serving, and what is most important to a diverse population of clients in order to help them achieve the highest quality of life possible. As CJE SeniorLife moves forward, we will continue to use this data to improve our own abilities, to measure our outcomes and impact, to provide care and contribute to the health of the population, and also to express our power and our strengths to strategic partners and policy makers.

Nowadays, much of the programming for frail and at-risk populations is determined by grant and funding availability. In the advancing world of “patient-centered outcomes,” this needs to shift towards addressing each individual community’s unique needs. This can only be done once you know the needs of your target community. Completing a population health study is a first step in the continuous cycle of assessment, reflection, and change to keep up with evolving healthcare demands.

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How would you like to die? When I was a child, I hoped that I would die of old age in my sleep. Simply not waking up one day didn’t seem so scary. However, my transition into adulthood and medicine has forced me to recognize that “old age” has little to do with one’s actual years of life, and it happens to go by a variety of aliases: heart failure, cancer, arthritis, kidney failure, diabetes, and so many more. Today, we have a physiologic understanding of what is happening to the body; we have a thousand different terms to describe the events of living and dying. This expansion of evidence-based medicine has helped to transform end of life rituals, and we have incorporated medicine into every element of dying. However, if we see death as failure, we will always fail.

For millennia, humankind has been trying to understand and interpret death. With this desire for understanding, humans have developed rituals. As one article describes, “A ritual [is] a sequence of activities involving gestures, words, and objects performed in a specific place and sequence of time. Rituals help participants to cross from their present situation to another and, therefore, describe an important change in status.” [1] While end of life rituals have traditionally been steeped in cultural and religious significance, the modern narrative is increasingly dominated by science and medicine. It is the presence of machines and a hospital bed that signals a transition.

One of the most documented and well-characterized end of life rituals is cardiopulmonary resuscitation, better known as CPR. The practice of CPR involves physically pumping an individual’s chest and applying electrical shocks via a defibrillator with the intent of restarting a stalled heart. Gregory L. Larkin expertly frames CPR, “CPR is still regarded more as a part of resuscitation science wherein its chief benefit is in prolonging life. Rarely successful in its scientific role of restarting the heart, CPR may give providers and families themselves the reassurance that we are correct to say goodbye to our loved ones.” [2] Humans need closure at the time of death of a loved one, and intensive CPR has become a symbol of fighting for life. Interestingly, many hospitals now allow families to watch professionals perform CPR on their loved ones to show the dedication and effort that the code team puts into practice. While the family’s presence does not improve rates of survival or overall quality of CPR, it may help the family’s ability to deal with the death [3]. Supporting the notion that when CPR fails, is it okay to let go.
Before CPR becomes an option, older patients or patients who are living with complex medical conditions are often informed of a “do not resuscitate” (DNR) order, which states that an individual does not want CPR, when their heart stops. This conversation itself has become a ritual to many physicians and families. These orders have been subject to large ethical debate, and the consensus is that it must be up to the individual and family. However, physicians often bring their own biases, and the choice to use or deny a DNR can be made without a complete understanding of CPR [4]. DNR conversations are among the many instances in which patients are asked to confront their own mortality. While DNRs and CPR are common rituals at the end of life, they are only a few of the many. Most of the deaths in the United States are from chronic disease with heart disease and cancer topping the list [5]. In the cases of chronic disease, the question becomes at what point should the family, individual, and medical professionals stop fighting for more life and start fighting for a better life? Being a very difficult question to answer, this question is one that must be answered by both the patient and the family.

I am sitting in the passenger side of the car as my mom drives to one of her patient’s houses. She is giving me the basic background of this patient’s diagnosis, prognosis, and life situation. This will be the first time that I see someone who she describes as “actively dying.” My mother is a family doctor in rural Northern Michigan, and she, along with her colleagues, perform house calls when patients are homebound. We arrive at a modest apartment and are greeted by the patient’s best friend. My mom has only a stethoscope; her job is to reassure, to support, to show the patient that she is cared for at all moments of her life. The visit is comfortable. There is no medical equipment, but Christmas decorations are hung and a half-completed Santa puzzle sitting on the dining table. There is no rush. We spend most of the time talking to the best friend about pain control and supporting her in her role as caregiver. From mother to daughter and physician to medical student, I am being shown how to care for patients.

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While CPR is a dramatic and climactic event aimed at lengthening life, there are other medical narratives near the end of life. For the many individuals with a terminal disease, hospice can provide support. Hospice programs are based on a palliative care model in which the goal is to use medical resources to provide comfort as opposed to curing illness. Patients on Medicare (age 65+ or disabled) or who qualify through other insurance programs must have their doctor confirm that they have less than 6 months to live. The patient must also be willing to give up all “lifesaving” or curative treatments [6]. For example, a terminal cancer patient would no longer receive chemotherapy, radiation, or routine scans, but they would have access to pain medication, general quality of life medications, and other palliative procedures (draining fluid off the lungs for example). Hospice programs are independently run, nationally-certified, and typically consist of a team of professionals: doctors, home-visiting nurses, social workers, pharmacists, spiritual counselors, and others [7]. These programs provide a double service of combating high healthcare spending near the end of life while prioritizing family and individual values.

Hospice supports over 1.6 million patients every year and is continuing to expand. With the rapid growth, there is an ongoing debate as to how programs fit into our current healthcare system (Figure 1). In 2014 (the last year for which data is currently available through the National Hospice and Palliative Care Organization), the median length of services was 17.4 days, and it has been well documented that patients with shorter stays tend to receive more intensive care including more hospitalizations and ICU stays near the end of life [8, 9]. Patients may enter very close to death because they want to exhaust curative medications and therapies first. This begs the question, should Hospice programs be supplemental or complementary to traditional cure-based care? Short hospice stays may not help families and patients leverage all of hospice’s social and emotional supports such as in-home help, social work services, and respite care, but patients and families may feel that they have gained more time through other medical treatments. Like CPR and DNR orders, families and individuals must determine their priorities; so too must America.

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With hospice’s shifting role in society, Medicare is currently piloting a new program: The Medicare Care Choices Model. In this program, patients can receive traditional hospice services (up to $400 per month) while continuing with curative treatments [10]. This test project is following in the footsteps of another successful study by a large national health plan. The researchers completed a retrospective analysis of patients who all received comprehensive case management consisting of a nurse with palliative care training to help patients navigate and coordinate care. Patients also received either regular hospice benefits or expanded-eligibility hospice benefits in which they did not have to give up curative treatment. In each group, hospice-utilization rates more than doubled, but acute inpatient and ICU stays were halved. The researchers speculate that increased communication between the families, case managers, and physicians helped to drive up hospice utilization rates [11]. With increased communication, patients opted for less expensive and intensive care. Potentially, this shows that more families and individuals want support in the end of life as opposed to more medicine. Moving forward, the US will need to build lasting and effective care programs as our demographics shift towards older ages.

When I was sixteen years old, I began volunteering at my local hospice in-patient facility. With other high schoolers, I helped to put on holiday parties, bake treats, assist the nursing staff, and visit with patients. I still have vivid memories of some of the patients and staff.

I find myself in that same location again, this time, shadowing my mom. We enter the beautiful room filled with people. A single hospital bed has been pulled up to the large window that overlooks the garden. There is a shrunken, peaceful individual lying in the bed surrounded by loved ones. My mom takes her hand and speaks to her. She tells her that she is there and that she wants to say goodbye. After a moment of silence, my mom turns to the patient’s daughter, only a few years older than me, and tells her that this is her opportunity to say goodbye, let her mom know that she will be okay, and tell her that it is okay to let go. This woman died in her sleep surrounded by family, without pain while facing the garden on a beautiful day.
So how exactly does one achieve a “healthy death”? What even is a “healthy death”? From CPR and DNRs to hospice, the decisions lie with the family and the individual. However, these values can only be recognized if discussed in the open. It is the responsibility of healthcare providers to initiate these conversations. Unfortunately, there exist substantial barriers to discussing end of life issues. Periyakoil et al. observed that “99.99% doctors reported barriers [to having end of life conversations] with 85.7% finding it very challenging to conduct [end of life] conversations with all patients and especially so with patients whose ethnicity was different than their own.” [12] However, these incredibly difficult conversations must happen before crisis strikes.

Atul Gawande has written extensively on end of life care issues in his book, “Being Mortal.” He provides very concrete advice on how to frame these conversations. Each doctor simply needs to ask five questions:

1. What is your understanding of where you are and of your illness?
2. What are your fears or worries for the future?
3. What are your goals and priorities?
4. What outcomes are unacceptable to you, and what are you willing to sacrifice?
5. Near the end, what would a good day look like? [13]

These five simple questions can help physicians make informed decisions as well as guide patients to resources that will align with their values. However, humans are fickle, and these conversations must be had repeatedly particularly after a change in health status. Open and continuous conversations help to build the patient-physician relationship while ensuring that the patient’s values are directing the care.

The end of life can be and often is a critical transition period. As patients and their families grapple with mortality, they are also called upon to make a variety of difficult decisions, many related to medical care. Medicine is now a core part of many dying rituals, and healthcare providers must strive to elicit patient values while providing the high-quality care. However, the definition of “high-quality” does not have to mean curative, in fact, it should be defined by the patient.

References

Founded in 1921 by Professor Thomas Smith Jones, the Biomedical Visualization graduate program (BVIS) at the University of Illinois at Chicago (UIC) is one of only four accredited graduate programs in North America providing professional training for careers in the visual communication of life science, medicine, and healthcare. The program’s unique curriculum attracts graduate students from a variety of disciplines such as medicine, life science, art, digital animation, and computer science.

BVIS utilizes the academic resources of multiple departments throughout the UIC campus to support its interdisciplinary studies. A recently revised curriculum strongly emphasizes effective communication and problem solving and provides a solid foundation in medical science, learning theory, and innovative visualization techniques. In addition to illustration and design, course offerings in visualization technology have been expanded to include animation, interactive media, educational gaming, virtual reality, stereography, haptics, and augmented reality.

Close relationships between UIC BVIS and other prestigious Chicago universities and medical centers provide opportunities for student immersion experiences and effective collaboration with peers. For the fifth consecutive year, BVIS students have had the privilege of contributing editorial illustrations for public health to the Northwestern Public Health Review.
The Northwestern Public Health Review (nphr.org) was founded in 2013 by Osefame Ewaleifoh and Celeste Mallama, two public health students at Northwestern University. The mission of the NPHR is to stimulate the exchange and cross-pollination of public health ideas, resources and opportunities across the Northwestern community and beyond. Through multiple channels, the student-run NPHR offers opportunities for learning and reporting on public health issues.