Paterson-Passaic County/ Bergen County HIV Health Services Planning Council

2015

HEALTH LITERACY ASSESMENT REPORT
Executive Summary

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Bergen-Passaic Transitional Grant Area
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PATERSON-PASSAIC COUNTY – BERGEN COUNTY HIV HEALTH SERVICES PLANNING COUNCIL
HEALTH LITERACY ASSESSMENT
EXECUTIVE SUMMARY

In 2015, the Planning Council determined that an assessment of health literacy among persons living with HIV/AIDS (PLWH) in the Bergen-Passaic Transitional Grant Area (TGA) is needed in order to assist a population that not only may have educational and verbal challenges but also must contend with difficult medical terminology associated with serious chronic illness. With health literacy skills, adherence and ultimately health status are likely to improve.

Once recognized as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions,"[1] the definition of health literacy now focuses more on the skills required to navigate the health care system and the importance of clear communication between providers and patients. Health literacy requires a complex group of reading, listening, analytical, and decision-making skills, and the ability to apply these skills in health situations. It includes the ability to understand instructions on prescription drug bottles, appointment slips, medical education brochures, doctor's directions and consent forms, and the ability to negotiate complex health care systems.

This study aims to assess current levels of health literacy among PLWH receiving Ryan White care and services in the Bergen and Passaic TGA and to assess the level of proficiency among Ryan White providers to assist with building health literacy skills. The goal is *to determine whether existing capacity is adequate to address health literacy skills in the TGA*. The assessment attempts to provide a baseline of information about health literacy among Bergen-Passaic PLWH, leading to self-efficacy with informed decision-making related to HIV care and support.

Five objectives frame the assessment:

1. Assess the current level of health literacy among Bergen-Passaic PLWH.
2. Review available health literacy resources available and distributed by the Part A providers.
3. Assess the extent to which Bergen-Passaic Ryan White providers receive training and/or technical assistance as professionals dealing with health literacy.
4. Identify the major areas of health literacy deficiencies and recommend solutions.
5. Develop an action plan for improved health literacy.

The methodology consisted of a literature review, key informant interviews, focus groups and a consumer survey.

[1] T. Selden et al, *Health Literacy: A Prescription to End Confusion."* Institute of Medicine (2004).

KEY INFORMANT PERSPECTIVES

Four personal interviews with experts in health literacy were conducted, each of one hour duration and one with written correspondence. Key informants spoke with authority about the present state of health literacy, both locally and regionally. Their observations were considered equally valid in Bergen-Passaic. They assessed health literacy levels among PLWH as generally below average. Numeracy presents the greater challenge, but all aspects of health literacy need to be addressed as well.

Key informants spoke about health literacy levels across special populations, identifying foreign language speakers, low income and low educational attainment among those with lowest health literacy competencies.

According to key informants, improving health literacy is a provider's responsibility. It is one that has not received sufficient attention, however. Provider training in health literacy is a relatively new offering and one that many providers have not yet taken.

PROVIDER PERSPECTIVES

To gain information about the views and knowledge surrounding health literacy, two focus groups were conducted with supportive service professionals in the Ryan White Program. Topics included assessment of clients' health literacy, case manager capacity and training and consumer resources.

Clinical staff and case management providers expressed concern about their patients' abilities to understand medical forms, prescriptions, written directions, etc. Most important, however, providers felt that insurance health literacy constitutes the most common and urgent issue for their patients. Other forms of health literacy, while not to diminish their importance, are less urgent. The implementation of the Affordable Care Act leading to insurance options, previously a rare concern to Ryan White enrollees, presents new challenges that require basic understanding of insurance coverage and terminology.

According to focus group respondents, improving health literacy is a provider's responsibility. Focus group participants uniformly spoke of the need for additional training.

Focus group participants also indicated that health literacy assessment was not a formal or required component of the case management care plan. While case managers may informally review their clients' health literacy, a structured assessment tool is not in place.

CONSUMER CAPACITY

To measure the health literacy capacity of persons living with HIV/AIDS, a short survey was undertaken with enrollees of the Bergen-Passaic Part A Program. Questions were derived from validated surveys available in the public domain. The sample consisted of 129 respondents; 92 (71%) took the survey in English and 37 (29%) completed it in Spanish. Ninety-four (69%)

resided in Paterson or other parts of Passaic County. Bergen County was home for 35 (27%) of the respondents.

In general, survey respondents displayed average or below average competencies with regard to health, numeracy and health insurance literacy. While variations were noted, the overall results were consistent:

- Comprehension of simple reading materials were mostly adequate.
- Although respondents felt comfortable with reading health related materials, marginal or inadequate literacy levels were identified for more than fifty percent of respondents.
- Numeracy proficiency posed the greatest challenge for nearly all respondents.
- Health insurance literacy presented challenges to most respondents. For nine of ten questions pertaining to insurance health literacy, survey respondents scored below the national average.

The survey included an analysis of eight special populations:

- Residents from Paterson scored consistently lower when compared with other Passaic County and Bergen County residents.
- We compared race by White, Black and Other Race (as reported by respondents). Results were not uniform across the four health indicators. More often, Whites scored higher than Blacks but this did not hold true for all questions.
- We compared Hispanic respondents with Non-Hispanic respondents. Sixty-four respondents identified themselves as Hispanic. Results across the four health literacy indicators varied, with non-Hispanic respondents recording slightly higher scores on most questions.
- For all health indicators, females scored higher than males with one exception.[2] Differences, however, were not significant.
- Respondents were asked to identify their average annual income. Answers were grouped into four categories ranging from less to $10,000 to greater than $40,000. Respondents were allowed to answer "Don't know" as well. Respondents with incomes below $10,000 scored worse for all questions. Respondents ranging between $20,000 and $40,000 generally scored did not score better than those with lower incomes.
- As might be expected, health literacy correlated directly with educational levels of the respondents. Across all levels of education, Respondents with a Vocational Tech, College or higher education performed better on the survey than their counterparts with a lower level of education.
- We compared responses from those recently diagnosed (after 2010) to those who have been living with HIV/AIDS longer than five years. In general, those recently diagnosed scored higher although not uniformly across all questions. While not statistically proven, we observe that those living with HIV disease for more than five years were generally less health literate than those more recently diagnosed.
- We compared responses of persons infected with HIV through male sex with men (MSM), injected drugs and heterosexual transmission. Overall, results varied.[3] No clear distinctions emerged among the major transmission categories.

[2] Less than five transgender respondents completed the survey. Results are not reported to protect confidentiality.

DISCUSSION, RECOMMENDATIONS AND WORK PLAN

Discussion

The study reveals issues anticipated in the literature and concerns expressed by clinical and case management providers. Key informants spoke with authority about the present state of health literacy, both locally and regionally. Their observations are equally valid in Bergen-Passaic where health literacy levels among PLWH are generally below the average. Numeracy presents the greater challenge, but all aspects of health literacy need to be addressed as well. The consumer health literacy survey results are consistent with key informant opinion.

So, too, are the clinical and case management providers who expressed concern about their patients' ability to understand medical forms, prescriptions and written directions. Most important, however, providers felt that insurance health literacy represents the most common and urgent issue for their patients. Other forms of health literacy, while not to diminish their importance, are less urgent. The implementation of the Affordable Care Act leading to insurance options, previously rarely of concern to Ryan White enrollees, presents new challenges that require basic understanding of insurance coverage and terminology. They are often confusing, not just to PLWH but to the general public as well. However, according to this study, PLWH have greater needs.

The consumer health literacy survey confirms the opinions expressed by both key informants and providers. In general, survey respondents displayed average or below average competencies with regard to health numeracy and health insurance literacy. While variations were noted, the overall results were consistent.

It is safe to conclude that very low income levels and low educational attainment were the most significant contributing factors of health literacy. Language did not emerge as a significant barrier. Hispanics, who were able to complete the survey in Spanish, scored slightly but not significantly lower than Non-Hispanics for the majority of indicator. This may be attributed to the availability of bi-lingual personnel at the provider sites and to attention paid by this TGA to cultural competency.

Recommendations

In 2010, the Planning Council commissioned a two-year task force on cultural competency that culminated in a set of nineteen recommendations to the Part A Program. As health literacy and cultural competency are related, these recommendations are relevant to the discussion here. Bi-lingual assistance, while available across the entire provider network, needs to be tied into health literacy assistance as part of the routine services of the Part A Program. The 2011 Cultural Competency Task Force Recommendations acknowledged this relationship and was explicit in endorsing health literacy improvement in the TGA.

[3] The sample contained 15 respondents injected by drugs using a needle and 15 with "Other" responses. Because of the small sample size, firm conclusions cannot be made for these special populations.

With this in mind, the following recommendations for improving health literacy are offered.

1. Establish health insurance literacy as the priority training needed by consumers and supported by clinicians and case managers.
2. Assess all case management clients for health literacy using a standardized assessment tool. Communicate results to the clinicians providing care. Tools may be selected by the individual agency based on their demographic and cultural client characteristics. However, the selected tool must meet minimum criteria, to be determined in advance, and utilize a scoring method for objective measurement. Provide two or more sample tools to case managers to assist the selection process.
3. Incorporate health literacy improvement into every case management care plan. Notes would include, at minimum, a problem statement identifying the client's health literacy status, goals, improvement strategies and target dates.
4. Require case managers to obtain health literacy training. Internet trainings are available at no cost and can be completed conveniently. For example, the CDC offers a free web-based training program for non-physician professionals along with a certificate of completion. The Grantee should provide recommendations and/or directions for obtaining such trainings.
5. Provide access to health literacy learning aids for all Part A enrollees, and encourage the use of online courses for consumers. Providers should consider having online bi-lingual programs available for viewing at their site.
6. Implement health literacy improvement recommendations from the Cultural Competency Task Force recommendations of 2011.
7. Consider incorporating a health literacy assessment module in eCOMPAS.

Members of the Planning & Development Committee of the Paterson-Passaic County-Bergen County HIV/AIDS Planning Council formulated a work plan based on the findings of this assessment and the recommendations offered. The work plan is presented in the full report.