

Guest Editorial

HIV/AIDS and employment: The continuing challenge

Brent Braveman and Gary Kielhofner

Department of Occupational Therapy, University of Illinois at Chicago, Chicago, IL 60612, USA

This special issue of *WORK: A Journal of Prevention, Assessment and Rehabilitation* is devoted to an exploration of issues related to employment in persons living with HIV/AIDS. It is estimated that at the end of 2003 there were more than 37.8 million persons living with HIV/AIDS worldwide [5] and that over 1 million of these persons resided in the United States [6]. Moreover, it is estimated that more than 40,000 additional persons become infected with HIV each year [3].

It is now a little over a decade since the introduction of new pharmacological treatments that lead to the commonly used highly active antiretroviral therapy (HAART). In that time, AIDS has been transformed from a fatal illness to a chronic one. Persons living with HIV/AIDS, often diagnosed in the first few decades of their lives, may now face decades more of life while managing the illness. Increasing numbers of persons are living with the disabling aspects of the disease and numerous associated conditions continue that pose challenges to occupational participation [11, 13, 16].

Like any potentially disabling condition, the ramifications of living with HIV/AIDS go far beyond those of a medical nature. Increasingly, the population of persons with HIV/AIDS consists of women, persons of color, and persons who have poor social supports and limited education and financial resources. Additionally, many persons living with HIV/AIDS also struggle with the challenges associated with mental illness, substance abuse, homelessness and other co-morbid conditions. This population is also characterized by low economic status, limited education, and limited work

experience [9,10,15]. Not surprisingly, then, people with HIV/AIDS struggle to overcome significant challenges that affect their abilities to live independently and return to the workforce.

Obtaining and maintaining employment is a major and ongoing obstacle faced by persons with all types of disabilities. Ten years after the introduction of the Americans with Disabilities Act (ADA) the US Census Bureau estimated that according to the 2000 census figures only 56.6 percent of working-age Americans with disabilities were employed compared with 77.2 percent of non-disabled Americans [17]. Over the last decade, increased attention has been paid to assisting persons living with HIV/AIDS to obtain and maintain employment as a means to live independently in their communities and to foster the physical, mental and social benefits that come with improved socio-economic status. Efforts have included educational and other forms of programming funded by the Federal government as well as by non-profit and private agencies around the country [4,7,11,18]. Additionally, coalitions of researchers, programmers, consumers and administrators of AIDS service organizations have formed in the U.S., Canada, and other nations to share information and strategies for facilitating successful return to work by persons living with HIV/AIDS. For example, the *National Working Positive Coalition* (NWPC) promotes research, development and implementation of effective practices in employment services for persons living with HIV/AIDS [14]. The NWPC grew out of the Working Positive Summit Conference, which was convened in Philadelphia in April, 2003 to compile in-

formation about evidence-based and experience-based best practices in employment services for people living with HIV/AIDS.

While the body of literature providing empirical evidence on effective vocational programs for persons living with HIV/AIDS is limited, it is beginning to grow. In addition to journals specifically dedicated to the topic of HIV/AIDS, such as *AIDS Care*, other journals have recently focused on HIV/AIDS and employment. Just as this issue was being finalized, a special two volume issue of *The Journal of Vocational Rehabilitation* was devoted to a discussion of issues of HIV/AIDS and employment including barriers to working and descriptions of effective interventions to aid persons living with HIV/AIDS to explore employment.

We are pleased to be able to add to the growing body of literature related to HIV/AIDS and employment in this special issue of *WORK*. The papers included in this issue represent a range of topics related to employment and understanding the person living with HIV/AIDS who must decide if they can pursue employment, and if so, how they might succeed.

Two literature review articles are included: one by Charlene Vetter attempts to address the major medical, psychological and psychosocial challenges related to living long-term with HIV/AIDS and consider how they may present obstacles to attainment of educational and vocational goals for HIV-positive individuals. Implications for service providers and suggestions for future research are discussed and an exploratory study of needs assessment is proposed. A second article by Brent Braveman, Mara Levin, Gary Kielhofner and Marcia Finlayson provides an overview of literature related to the employment needs, challenges and services provided thus far to persons living with HIV/AIDS.

Patricia Bowyer, Gary Kielhofner and Brent Braveman present the results of a qualitative study that sought to identify the perception of interdisciplinary staff members regarding the impact of a model work and independent living oriented program for residents in supportive living facilities. A related article by Brad Egan and Joanne Hoagland presents a program description that addresses the unique manner in which these three supportive living facilities for persons living with AIDS created in-house job programs in the areas of reception, kitchen, and maintenance work. More specifically, this paper will address the strengths, limitations, and ethical considerations that guided program development.

Two papers explore issues related to the relationship between demographic, health and other variables and

the process and outcomes of seeking employment. Lisa Razzano, Marie Hamilton and Judith Perloff present results of an evaluation that investigated factors related to employment status and sources of health benefits and entitlements among people with HIV/AIDS. In addition, results from the study demonstrate differences in employment status, benefit types, and amount of economic support based on gender. David Martin, Paul Arns, Phillip Batterham, Abdelmonem Afifi and Jillissa Steckart examined demographic and health variables in addition to participation in a program designed to assist people with HIV/AIDS return to work to determine whether they predicted successful full- or part-time employment after 24 months of follow up.

Three articles by groups of occupational therapists explore the usefulness of concepts measured by occupational therapy assessments in understanding the experiences and challenges faced by persons living with HIV/AIDS. Navaraj Anandan, Brent Braveman, Gary Kielhofner and Kirsty Forsyth present the results of a study that explored occupational functioning, the various impairments experienced, and the impact of these impairments on the person's competence related to participation in various occupations by exploring the relationship of *competence* as measured by the *Occupational Self-Assessment* and the *Sign and symptom checklist for persons with HIV disease* [1,8]. Brent Braveman, Gary Kielhofner, Gary Albrecht and Christine Helfrich present the results of a prospective qualitative study that examined the experiences of twelve men during a one year period following completion of a vocational rehabilitation program for people with AIDS. Findings illustrate how constructs measured by the scales of the *Occupational Performance History Interview (OPHI-II)* may be helpful in understanding how persons frame past, present and anticipated experiences as they attempt to reestablish a life role lost after the onset of disability [12]. Kirsty Forsyth, Brent Braveman, Gary Kielhofner, Elin Ekbladh, Lena Haglund, Kristjana Fenger and Jessica Keller examined the psychometric properties of the rating scale of the *Worker Role Interview (WRI)* [2]. The study also asked whether the scale's items formed a valid measure of the construct, psychosocial capacity for work, and whether they were targeted to and could effectively discriminate between persons at different levels of psychosocial ability for work

We have also chosen to include an article by Christine Helfrich, Chaula Badiani, and Emily Simpson that while focused on women who have been victims of domestic violence (and are not necessarily living with

HIV/AIDS) fits well in this special edition. These authors report results of a two year qualitative study that explored worker role identity development of seven women with disabilities who experienced domestic violence. Study findings suggest a conflict between a sense of urgency on the part of service providers to support the women's return to work and self-sufficiency and the women's readiness to assume stronger work identities. While this study focused on a different population than the other studies reflected in this issue, the experiences of service providers and the study participants are similar to those of staff and residents in facilities for persons living with HIV/AIDS and therefore we chose to include this article in this special edition.

Two final articles present the results of qualitative studies focused on the process of return to work. Scott Pressnell explores the notion of return to work as narrative theme. A case study highlighting the narrative nature of how return to work might be conceptualized by the HIV positive individual is presented; ahead of a brief discussion as to how the lived reality of combination therapy may impact upon the individual's conceptualization of employment in the broader context of their life story. David Martin, Jillissa Steckart and Paul Arns provide the results of a qualitative study that was designed to provide an initial attempt to study the process of workforce reentry. Abstracted information from the progress notes of 104 people with HIV/AIDS attempting workforce reentry was qualitatively analyzed using a grounded theory approach to identify themes. Three major themes emerged with reliability: Barriers to workforce reentry, staff-identified strengths, and resources used in workforce-reentry efforts.

We are pleased to provide the authors who submitted papers a forum for the presentation of their important work. We hope that you will find this special issue to be informative and thought provoking.

References

- [1] K. Baron, G. Kielhofner, A. Iyenger, V. Goldhammer and J. Wolenski, *A user's manual for the occupational self-assessment (OSA)*. (Version 2.1 ed.) Chicago, IL: The Model of Human Occupation Clearinghouse: University of Illinois at Chicago, 2003.
- [2] B. Braveman, M. Robson, C. Velozo, G. Kielhofner, G.S. Fisher, K. Forsyth et al., *The Worker Role Interview (Version 10)*. Chicago, IL: Model of Human Occupation Clearinghouse: Department of Occupational Therapy, 2005.
- [3] Centers for Disease Control, HIV/AIDS Surveillance Report. Centers for Disease Control and Prevention Website [On-line], 2003. Available: <http://www.cdc.gov/hiv/stats/2003SurveillanceReport.htm>.
- [4] Centers for Disease Control and Prevention, About Business Response to AIDS. Centers for Disease Control and Prevention: Business Responds to AIDS Website [On-line], 2005. Available: <http://www.brta-lrta.org/index.htm>.
- [5] Global Health Council, HIV/AIDS. Global Health Council Website [On-line], 2005. Available: http://globalhealth.org/view_top.php?id=227.
- [6] M. Glynn and P. Rhodes, *Estimated HIV prevalence in the United States at the end of 2003*, Atlanta, Georgia: National HIV Prevention Conference, 2005.
- [7] GMHC, Transitioning to work. Gay Mens Health Crisis Website [On-line], 2005. Available: <http://www.gmhc.org/policy/benefits/work.html>.
- [8] W.L. Holzmer, A. Hudson, K.M. Kirksey, S. Hamilton and S. Bakken, The revised sign and symptom check-list for HIV (SSC-HIV rev), *Journal of the Association of Nurses in AIDS Care* **12** (2005), 60–70.
- [9] J.M. Karon, P.L. Fleming, R.W. Steketee and K.M. DeCock, HIV in the United States at the turn of the century, *American Journal of Public Health* **91** (2001), 1060–1068.
- [10] J. Kates, R. Sorian, J.S. Crowley and T.A. Summers, Critical policy challenges in the third decade of the HIV/AIDS epidemic, *American Journal of Public Health* **92** (2002), 1060–1063.
- [11] G. Kielhofner, B. Braveman, M. Finlayson, A. Paul-Ward, L. Goldbaum and K. Goldstein, Outcomes of a vocational program for people with AIDS, *The American Journal of Occupational Therapy* **51** (2004), 64–72.
- [12] G. Kielhofner, T. Mallinson, C. Crawford, M. Nowak, M. Rigby, A. Henry et al., *A user's manual for the occupational performance history interview (Version 2.0) OPHI-II*. (Version 2.0 ed.) Chicago, IL: The Model of Human Occupation Clearinghouse: University of Illinois at Chicago, 1998.
- [13] C.J. McReynolds and G.G. Garske, Current issues in HIV disease and AIDS: Implications for health and rehabilitation professionals, *Work* **17** (2001), 117–124.
- [14] NWPC, National Working Positive Coalition Mission Statement and Values. National Working Positive Coalition Website [On-line], 2005. Available: <http://www.workingpositive.net/pages/1/index.htm>.
- [15] R. Orenstein, Presenting syndromes of human immunodeficiency virus, *Mayo Clinic Proceedings* **62** (2002), 153–165.
- [16] A. Sankar and M. Luborsky, Developing a community-based definition of needs for person living with chronic HIV, *Human Organization* **62** (2003), 153–165.
- [17] The Center for An Accessible Society, Unemployment Rate for People with Disabilities More than 40 Percent, Census Data Shows. The Center for An Accessible Society Website [On-line], 2005. Available: <http://www.accessiblesociety.org/topics/economics-employment/labor2002.html>.
- [18] Workpositive.com, The positive workplace: Managing HIV at work. Workpositive Website [On-line], 2005. Available: <http://www.workpositive.com/theProgram.html>.