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Recommended Citation

Baumgartner, Lisa M. and Preissner, Katharine (2015). "Living and Learning with Chronic Disease: Toward Better Methods of Education," *Adult Education Research Conference*. <https://newprairiepress.org/aerc/2015/roundtables/2>

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Living and Learning with Chronic Disease: Toward Better Methods of Education

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Keywords: chronic disease, learning, education, identity

Abstract: Learning to live with a chronic disease is a lifelong endeavor. Literature concerning learning, identity, and education as it relates to chronic illness are reviewed. Session participants will discuss best practices regarding learning and health education for the chronically ill.

Chronic diseases affect nearly half of the non-institutionalized civilian population of the United States and 25% of the population has more than one chronic condition (Ward, Shiller & Goodman, 2014). Roughly 48% of all deaths in the US can be attributed to cancer or cardiovascular disease (Centers for Disease Control and Prevention, 2014). A chronic disease is a disease that cannot be cured that lasts more than three months such as diabetes (MedicineNet.com, 2014).

Learning to live with a chronic illness is a lifetime endeavor. Often, individuals with chronic disease experience psychological and physical changes as they learn to live with their disease(s). Individuals have addressed the types of learning regarding chronic illness including self-directed learning (Rager, 2004) and transformative learning (Merriam, Courtenay & Reeves, 2000). Likewise, concerns regarding chronic illness and identity issues have been addressed (e.g. Thornhill, Lyons, Nouwen & Lip, 2008) as well as the effect of race on living with chronic illness (e.g. Rao, Pryor, Gaddist & Mayer, 2008).

Like learning and identity development, learning and education are similarly intertwined. Peer or professionally-led support/education groups are a topic of interest. Researchers have discussed the effectiveness of chronic disease self-management programs (e.g. Lorig, Ritter & Pifer, 2014). In a literature review of individuals living with cancer, self-management groups decreased “symptom distress, uncertainty” and positively affected “communication” and quality of life (McCorkle, et al., 2011, p. 56). Group-based patient education groups improve individuals’ coping skills (Håkanson, et al., 2011), self-efficacy (Farrell, Wicks & Martin, 2004), and improve health (Chodosh et. al, 2005). Yet, income, education and racial minority status often affects access to correct health information (Kim, Moran, Wilkin & Ball-Rokeach, 2011). In many studies concerning health education, group participants did not appear to have input regarding program content, raising the question about the importance of stakeholders’ voices in program planning (Cervero & Wilson, 1994).

Purpose of Roundtable

The purpose of this roundtable is two-fold: (1) To briefly review literature concerning chronic illness as it relates to learning, identity, and education and (2) to brainstorm adult

education methods or strategies that can be used to improve health education especially as it regards marginalized populations.

Roundtable Activities

Roundtable attendees and the facilitators will be invited to provide examples of challenges they have faced regarding learning about and/or teaching about chronic diseases. It is hoped that this discussion will help those struggling with issues related to chronic illness learning and education as well as provide a forum for potential “best practices” regarding learning about and teaching about chronic diseases. Given the holistic nature of treating a chronic illness it is possible that issues of discussing how best to address aspects of individuals’ experiences such as spirituality, sexuality, and work in a group setting will also be topics of discussion.

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