Living Well with Chronic Illness

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Sue Mills presented an overview of her PhD research, entitled "Living Well with Chronic Illness: Aligning Tensions, Attitudes, Strategies and Meanings". Thank you to Sue for preparing this summary report.

It is often assumed that the lives of people living with chronic illness only encompass economic hardship, pain, suffering, and disability. Yet, research increasingly shows that some of the women and men have positive experiences and a good life amidst the enormous challenges that long term conditions bring. Consequently, we need to develop understandings of what living well entails for persons with chronic illness and gain insights into how this kind of experience develops in the presence of disease. My doctoral research explored these questions by conducting interviews with 27 women and 4 men who self-identified as living well and had a diagnosis of lupus, multiple sclerosis, or scleroderma.

Findings showed that living well was having meaningful experiences amidst the daily struggles the participants faced such as disease-related tensions and loss, and difficult life events (divorce; loss of child, spouse, or parent; and physical and/or emotional abuse). They made decisions and choices about how to live with these challenges in relation to their goals and values rather than in relation to just managing, coping, or adapting to these illness and life-related difficulties. To attain these meaningful experiences, the women and men used a wide number of attitudinal perspectives (living life orientation; optimistic outlook; pragmatic, proactive and problem solving perspective; taking control and shaping life attitude; and determination and drive) as well as behavioural strategies (developing knowledge; managing disease; using assistive aids, devices and services; reconnecting with old activities and developing new ones; changing relationships; and choosing when to hide or disclose illness). In addition, they changed their understandings of the kinds of experiences that were important and meaningful when they encountered situations and losses they could not overcome using attitudinal or behavioural approaches. Consequently, the nature of living well, and the means by which they attained it in daily life, differed amongst the participants and varied over the course of their individual lives.