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## A Conceptual Framework on the Process of Personal Transformation in a Primary Health Care Context for Living with a Chronic Illness

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### **Objective**

The objective of this study is to propose a conceptual framework that could explain the process of personal transformation within a Primary Health Care context for people living with chronic illnesses

### **Theoretical Framework**

The concept of transformation has received considerable attention as a focus of research in health care, particularly in studies involving people living with chronic illnesses. A chronic health condition is a condition such as asthma, diabetes or arthritis, in which a person will need to learn to change their lives in ways to deal with the symptoms of the condition throughout their lives. For example someone living with diabetes will need to change their diet. In this context, transformation often refers to people being transformed by the experience of living with chronic illnesses so that they are able to move beyond focusing on the burden and suffering associated with living with chronic illnesses. Although transformation is commonly held to be central to the experience of living with chronic illness, the conceptualization of this term and the identification of its elements and attributes remain elusive for people living with chronic illnesses. For example, transformation can be thought of both as a process and as an outcome. In the field of chronic illness, many researchers have focused on a description of transformation that is most often not informed by any particular theory. As well, this body of research has not produced definitive recommendations for health care practitioners wishing to support personal change of people with chronic illnesses. Health care practitioners attempt to work with people living with chronic illnesses through the provision of patient education and other interventions to help them during this change process. Health care practitioners include audiologists, dieticians, nurses, occupational therapists, physical therapists, physicians, psychologists, speech pathologists and social workers. Although their primary focus is on the health care of patients, many also have further training in adult education. For example, there are a few researchers in adult education

who are also rehabilitation practitioners, specifically occupational therapists and physical therapists.

Some of these researchers in the field of rehabilitation, work points to the coherence between Mezirow's description of transformation in adult learning as the process of knowledge, beliefs, and values as related to one's actions and the ways in which adults experience transformation in their rehabilitation after an disabling injury or disease. Most notably, Dr. Claire-Jehanne Dubouloz's, an occupational therapist, research has examined the process of change for people living with rheumatoid arthritis (Dubouloz et al., 2007), multiple sclerosis (Dubouloz et al., 2002), a spinal cord injury (Dubouloz et al., 1999) and after a heart attack (Dubouloz, 1997).

The majority of researchers who have attempted to explain this concept have employed qualitative research designs. This growing body of research highlights the need for a conceptual integration of results to develop a framework that could shed light on the influence of context on transformation. Taylor (1998) identifies and calls for more research on the significant influence of context, and the varying nature of the catalyst of the transformative process (p. 61). As reported by Taylor (1998; 2008), very few studies in all fields of enquiry, look at the context of transformation. Within health care, context is very important. Context can refer to where health care services are provided (e.g. in a hospital, clinic, home, community). There is a push throughout the world to look at the role that primary health care plays for people living with chronic illnesses (World Health Organization, 2010). Primary care is defined as '... the element within primary health care that focuses on health care services, including health promotion, illness and injury prevention, and the diagnosis and treatment of illness and injury (Health Canada, 2010).

We therefore wanted to look at how the Primary Health Care context might influence the transformation process for people dealing with chronic health issues. This paper will present the findings of a metasynthesis of qualitative research studies (i.e. primary research studies) studying transformation experienced by adults living with chronic illness. We will present a model of transformation in Primary Health Care that was derived from a larger metasynthesis research project in health.

### **Research Design**

The research project used a particular metasynthesis approach in the tradition of Paterson et al.(2003) to analyze and synthesize this body of published qualitative research related to the process of transformation of adults living with chronic illnesses. This approach is intended to develop theory and to provide insight about the field of research that yields new knowledge for educational or clinical applications. This metastudy combines three analytic phases (meta-data analysis, meta-method analysis and meta-theory analysis) with a synthesis component at the end of the analytic process. The analytic components entail looking at each primary research report separately, in relation to other primary research studies and as a body of research. Meta-data analysis involves reinterpreting the actual findings of primary research by comparing and contrasting the findings with those of other studies. Meta-method involves analyzing the influence of methodological decisions and the research design of particular primary research studies and within the body of primary research as a whole on how the

phenomenon under study is understood. Meta-theory is a critical examination of how the theoretical foundations of primary research studies have shaped research questions, research design and the interpretation of research data within that research. The findings of the analytic phases are used as a foundation for the synthesis phase in which the findings of the analytic phases are considered in light of the historical, sociocultural and disciplinary context in which the primary research was conducted.

### **Data Collection**

A literature search of articles published from 1990 to 2007 in the Cumulated Index to Nursing and Allied Health Literature (CINAHL), Education Resources Information Center (ERIC), Healthstar, MEDLINE, PsycINFO, dissertation abstracts and SocINFO databases, was conducted to identify qualitative research studies investigating personal change in chronic illness. The inclusion criteria for individual published primary research articles were that each report: (a) included components of perspective transformation, personal change or learning processes; (b) addressed any health condition involving a loss of function or role; (c) dealt with an adult population; (d) used one or more qualitative research approaches; and (e) included findings supported by the primary data. Five hundred and fifty-six articles were identified.

Then two members of the team examined the 556 abstracts and selected 176 of them from a first reading according to the inclusion criteria identified. Then, three members refined the selection by sharpening the definition of three of the inclusion criteria that proved to be particularly challenging: (1) the requirement to include transformation, as identified by the primary authors; and (2) addressing a chronic illness as identified by the primary authors and categorized according to International Classification of Functioning, Disability and Health (World Health Organization, 2001) and (3) taking place in a health context.

Using the above criteria, 11 papers were found to have a focus on transformation in a health context. For the second criteria, to help us to reach our research goal to develop a model of the process of transformation in a primary care context, papers were next classified according to the health context in which the research was completed. Classifying the research reports according to health context in which the research was conducted resulted in 5 of these 11 studies occurring in a primary care context and 6 in a rehabilitation context (participants were involved in a structured rehabilitation program). A separate model has been developed from the articles dealing with the transformation process in a rehabilitation context (Dubouloz et al., 2010a)

### **Data Analysis**

These five studies were analyzed according to Paterson's approach. One component of this approach is to use an analytic guide, the analytic appraisal tool used for this study was modified from the Paterson's tool (a copy of the tool can be found in (Dubouloz et al., 2010b; Dubouloz et al., 2010b; Dubouloz et al., 2010b). The tool allowed researchers to record from each article the research approach and design, theoretical framework, health context, major findings. As well the specific findings from the primary studies were extracted. This information was set up in a table format for ease of use. The 6 researchers used a constant

comparison method. This included comparing data among all of the studies without dividing them further into such things as diagnoses of chronic illness of the participants. This process occurred through face- to –face meetings of all of the research team.

The unique composition of the research team was interdisciplinary (health care, adult education), interprofessional (nurse, occupational therapists and physiotherapist), and linguistic diverse (French and English). This richness of team membership also was strengthened by having both novice and experienced researchers.

### Findings and Conclusions

This paper presents a model of the conceptualizations of transformation in the context of Primary Health Care with individuals living with a chronic illness. In this model, transformation is presented as a process of learning about self and about how to live with a chronic illness. Both components are iterative and continually change manner. The model identifies three phases of the transformation process, initial response, embracing the challenging and integrating new ways of being. These three phases clearly illustrate the complex nature of this phenomenon that each of the individual studies has attempted to reveal within specific patient populations living with different chronic illnesses. Context of Primary Health Care has its greatest influence on critical reflection, which occurs essentially during the first phase (initial response).

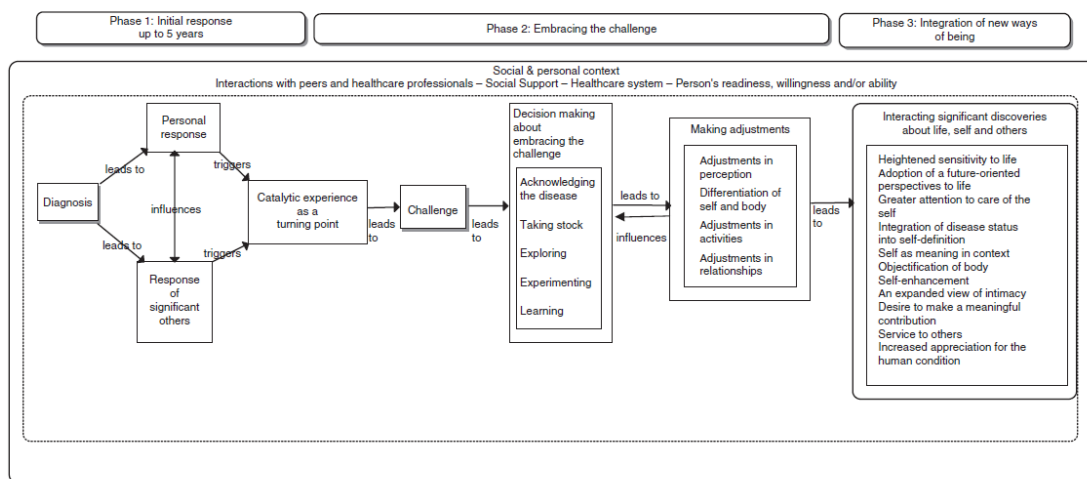


FIG. Process of transformation model: chronic illness and primary care.

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### Implications for Adult Education Theory and Practice

This model illustrates the complex processes that occur for someone living with a chronic illness. Health practitioners and Health educators of adults who understand why and how people transform their meaning perspectives in living with chronic illnesses will be able to apply this model in determining collaboratively people's needs and how to assist people during the transformative process. This process is identified by participants as a meaningful way of gaining empowerment in their daily living.

The metasynthesis described in this paper represents a unique attempt to synthesize related research in chronic illness within a Primary Health Care context. This research has systematized five unique research studies in one comprehensive description. We made the choice to consider the common experience of chronic illness and transformation with two illnesses that normally are not seen as similar. Although there were two diagnoses, HIV and diabetes, we found through the metasynthesis process, we were able to uncover the commonalities of experience of living with a chronic illness such as having to acknowledge their condition as life long, interact with healthcare professionals and peers and manage their condition. This systematization helps adult educators and health care professionals to have a broader vision of the reality of living with a chronic illness.

Although adult educators may not be seeing people living with chronic illnesses in a primary health context, given the increases in diagnoses of chronic illness such as diabetes and arthritis throughout the world, it would be more than probable that many of the adult learners that adult educators interact with are living with chronic illnesses. Therefore this model may help adult educators gain some insight into what adult learners are going through, both outside the “classroom” but more importantly how their chronic illnesses experience maybe affecting their learning, or how their learning may be affecting their chronic illness experience. Studies with adult learners in literacy programs who also had chronic illnesses have found that as the learners improved their literacy ability and through attending class, they felt more comfortable and confident to interact with the health care system and health care professionals (King & Taylor, 2010).

Therefore future research is needed to examine the model further including attempting to identify the specific components of learning using a taxonomy such as Bloom’s (1972) or Kolb’s (1984). We need to find out how much more a person that is going through a process of change as a result of a diagnosis of a chronic illness can be asked to do. The model demonstrates 3 distinct phases. Further research is needed to identify what a phase a person may be in. This may also include what type of teaching approaches and learning objectives would be most helpful and effective for people in the different phases.

For example in Phase 1: Initial response, can the learner even engage in learning or is the chronic illness diagnosis affecting learning. What are the specific triggers that allow for a person to accept the challenge of the chronic illness and entering into Phase 2: Embracing the challenge. What are the social supports needed? How can their decision making be supported? If the person is in Phase 3: Integration of new ways of being. How can adult educators as well as health care providers help them with integration of their disease status into self-definition and improve their self-enhancement.

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