Published in final edited form as:
J Clin Nurs. 2008 April ; 17(0): 177–187. doi:10.1111/j.1365-2702.2007.02244.x.

Chronic illness: the process of integration

Robin Whittemore, PhD, APRN [Associate Professor] and
Yale School of Nursing, New Haven, CT, USA

Jane Dixon, PhD [Professor]
Yale School of Nursing, New Haven, CT, USA

Abstract

Aim—The aim of this study was to explore how adults with a chronic illness integrate the illness experience into their life context.

Background—Adults with chronic illnesses are challenged to learn self-management strategies to prevent complications and achieve an acceptable quality of life. Integration represents the process undertaken by an individual to achieve a sense of balance in self-managing a chronic illness and living a personally meaningful life.

Design—A mixed-method descriptive design was employed to recruit English-speaking adults with a chronic illness. A semi-structured interview was completed, transcribed verbatim and content analysed. Descriptive data were collected on demographics, co-morbidity and depressive symptoms. The research was undertaken in Connecticut, USA.

Results—The sample ($n = 26$) was diverse with respect to age (25–80 years), education (8–24 years), duration of illness (1–39 years), gender (63% female) and ethnicity (63% white). Participants reported a mean of four chronic illnesses and 31% of the sample had increased depressive symptoms. The process of integration was complex and multifactorial. Themes of integration included: shifting sands, staying afloat, weathering the storms, rescuing oneself and navigating life. Numerous factors including treatment side effects, a progressive or uncertain illness trajectory, co-morbidity, bad days, financial hardships and interpersonal/environmental challenges contributed to a disruption or difficulty in the integration process.

Conclusion—All participants made considerable effort to integrate the illness into their life context and participate in a personally meaningful life. However, it was easy to be consumed with ‘living an illness’ as the daily tasks, the changing symptoms and the fluctuating emotions could be overwhelming. There was a complex co-existence between ‘living a life’ and ‘living an illness’.

Relevance to clinical practice—There were numerous challenges to the process of integration and ongoing self-management, psychosocial, vocational and existential support appears indicated, particularly with individuals with multiple chronic illnesses, progressive chronic illnesses and limited resources.

Keywords

chronic illness; integration; nurses; nursing; psychosocial adjustment; self management

---

Correspondence: Robin Whittemore, Yale School of Nursing, 100 Church Street South, New Haven, CT 06536-0740, USA, Telephone: +203 737 2351, robin.whittemore@yale.edu.

Contributions
Study design: RW, JD; data collection and analysis: RW and manuscript preparation: RW, JD.

Introduction

Chronic illnesses, such as cardiovascular disease, cancer, arthritis and diabetes, are among the most prevalent and costly of all health problems globally. In the USA, chronic illnesses are the leading cause of death and disability, accounting for seven of every 10 deaths. The prolonged course of illness and disability results in pain, suffering and decreased quality of life for over 90 million Americans. Chronic illness costs account for more than 70% of the nation's medical care costs (Centers for Disease Control 2005).

Chronic illnesses are caused by pathological changes in the body that are nonreversible, permanent or contribute to residual disability (Funk *et al.* 2001). As a result, chronic illnesses may contribute to impaired physical functioning, limitations in activities of daily living, loss of independence, pain, emotional distress and changes in self-identity (McBride 1993, Lubkin 2005). Thus, chronic illnesses have a major impact on all aspects of an individuals' life, affecting physical, psychological, social and vocational functioning (Livneh & Antonak 1997).

While each chronic illness has problems specific to the aetiology and pathophysiology of the disease, common challenges and needs across chronic illnesses have been identified. Commonalities of the chronic illness experience include recognising symptoms and taking appropriate actions, using medications effectively, managing complex self-management regimens, making difficult lifestyle adjustments and developing strategies to deal with the psychological consequences of the illness (Strauss *et al.* 1984, Wagner *et al.* 2001, Department of Health 2003). Thus, individuals with all chronic illnesses need to learn how to care for themselves best within the context of their own life. Numerous complex socio-political, community and cultural factors interact to influence health outcomes in adults with a chronic illness. In addition, self-management has been identified as an important strategy to enhance health outcomes and quality of life in conjunction with traditional medical care of chronic illnesses (Lorig 1993). Self-management in chronic illness is a dynamic active process of learning, practicing and exploring the skills necessary to create a healthy and emotionally satisfying life (Lorig 1993, Kralik *et al.* 2004). Self-management interventions aimed at assisting individuals with a chronic illness have demonstrated reduced pain, reduced healthcare visits, improved decision-making and improved quality of life (Lorig & Holman 1993, Barlow *et al.* 2000, Norris *et al.* 2001).

Successful self-management requires that new health behaviours are assimilated into the context of daily life. Self-management requires ongoing adjustment as a result of changing life circumstances, and significant psychosocial difficulties have been reported. For example, adults with type 2 diabetes report stress, anxiety, frustration and difficulty coping with the daily self-management demands (Polonsky *et al.* 1995, DeCoster 2001). Price (1993) described a difficult trial and error phase in which adults with diabetes attempted to discover a self-management regimen that allowed them to feel good physically and at the same time was minimally disruptive to their lives. Thus, emotional work must also be undertaken to carry out self-management tasks and achieve an acceptable balance between the demands of the illness and one's desired life.

Integration is an emerging concept in the healthcare literature that is relevant to understanding self-management and chronic illness. Westra and Rodgers (1991) examined a broad base of literature (i.e. health care, social sciences and education) and characterised the concept of integration as the merging of two or more elements whereby a newly formed unity is achieved. They defined integration as a human– environment interaction whereby new life experiences (i.e. illness) are reconciled with past and present identities and roles.

Ruffing-Rahal (1991) developed a self-report instrument to measure integration in older individuals with chronic illness and disability. In this study, integration was defined as qualitative well-being or a component of quality of life. A major assumption of this definition was that the perception or experience of integration was embedded in daily living and was contingent upon the activity, meaningfulness and synthesis of changing life circumstances.

The concept of integration has also been identified in numerous middle-range theories over the past decade. Fleury (1991), in a study of adults participating in a cardiac rehabilitation programme, reported that integrating change was a key aspect to the development of new and positive health patterns that promoted health. Hernandez (1995) developed an instrument to measure integration specific to diabetes in which integration was defined as the ongoing process in which the two selves (the diabetic and the personal) more fully merge to create an individual who is healthy, mentally and physically. In a subsequent study with exemplars in diabetes self-management, Hernandez (1996) identified integration as the central component to living successfully with diabetes. Integration, in this study, was defined as a ‘science of one’, whereby a person takes ownership of diabetes self-management, focusing on living, but not to the detriment of diabetes control. Medich *et al.* (1997), in a study exploring the experience of cardiac rehabilitation, identified integration as the central theme to explain healing and engagement in health promotion behaviours. Dungan (1997) deductively proposed a model of dynamic integration in which integration was defined as optimum functioning and the integrity of one’s body, mind and spirit within a constantly changing environment. Whittemore *et al.* (2002) specifically explored the process of integration in women with type 2 diabetes who were participating in a lifestyle change programme. In this study, integration was reported to be a process of reconciling emotions, composing a structure, striving for satisfaction, exploring self and conflicts, discovering balance and developing a new cadence to life. A recent synthesis of this literature on integration resulted in a definition of integration as a complex person–environment interaction whereby new life experiences (i.e. transitions, illness, self-management) are assimilated into the self and activities of daily living resulting in an overall life balance (Whittemore 2005).

Results of theoretical and empirical work in the past decade related to the process of integration suggest that integration may be an important aspect of adjusting to and living with a chronic illness. The process of integration has also been proposed to be very difficult and potentially distressing. An investment of time, attention and work is required to develop new life patterns that incorporate previous lifestyle activities as well as newly acquired needs. To develop interventions that promote integration and self-management, a greater understanding of the process of integration is warranted. Therefore, the purpose of this study was to explore how adults with a chronic illness integrate the illness experience into their life context and to describe their psychosocial adjustment.

Aim

The study aimed to explore how adults with a chronic illness integrate the illness experience into their life context.

Method

A generic qualitative descriptive methodology based on well-established qualitative analysis techniques (Miles & Huberman 1994, Sandelowski 2000) was used to capture the experience of integration in adults living with a chronic illness. Additionally, descriptive data were collected to describe the sample and the psychosocial adjustment of participants.

Data were collected via interviews and self-report questionnaires at a private location of the participant's choice.

Participants

Maximum variation sampling, a type of purposive sampling, was used to select adults with a chronic illness to participate in the study. The goal of the sampling mix was to have participants vary with respect to gender, age, education, ethnicity, type of chronic illness, duration of chronic illness and ability to manage their chronic illness. As specified with this qualitative methodology, data collection and analysis occurred currently. Therefore, sample size was determined by data saturation, when incoming data provided no new information.

Adults with chronic illnesses were recruited through a variety of primary care clinics and residential communities in urban, suburban and rural areas in Connecticut. Inclusion criteria were that participants had a diagnosis of a chronic illness for at least six months duration and were able to speak English. Chronic illness was defined as a longstanding illness or disability requiring medical, psychological or social intervention over an extended interval affecting many aspects of an individual's life (Lubkin 2005).

Procedure

The study was approved by an institutional review board. Informed consent from participants was obtained and a semi-structured interview was completed at a quiet, convenient and private location of participant's choice (i.e. clinic conference room, participant's home). Participants were asked to reflect on their experience of incorporating their chronic illness into their lives and their sense of self. Interview questions are identified in Table 1. All interviews were audio-taped and completed by the PI or a trained research assistant. Participants also provided descriptive data on demographics, co-morbidities and psychological adjustment. Participants were provided with $20·00 to thank them for their time. Field notes and theoretical memos were recorded upon completion of the interview.

Instruments

Data were collected on demographic and clinical information that included information on age, education, ethnicity, income, marital status, dependents, religion and health history (Table 2).

'Health status' was measured with the Co-Morbidity Questionnaire, an 11-item self-report scale that provides an index of the number of comorbid diseases. Respondents answered 'yes' or 'no' to items of health status and diagnosis. The total score ranges from 0–36, with higher scores indicative of greater co-morbidity. High test-retest reliability ($r = 0{\cdot}91$) and concurrent validity with a chart-based co-morbidity index has been established ($r = 0{\cdot}63$) (Katz *et al.* 1996).

'Psychosocial adjustment' was measured by the Center for Epidemiologic Studies – Depression Scale (CES-D), a widely used scale (Radloff 1977). The CES-D consists of 20 items that address depressed mood, guilt/worthlessness, helplessness/ hopelessness, psychomotor retardation, loss of appetite and sleep disturbance. Each item is rated on a scale of 0–3 in terms of frequency of occurrence during the past week. The total score may range from 0–60, with a score of 16 or more indicating impairment. High internal consistency, acceptable test-retest reliability and good construct validity have been demonstrated in clinical and community samples (Lewinsohn *et al.* 1997, Posner *et al.* 2001).

Data analysis

Interviews were transcribed verbatim and checked for accuracy. ATLAS.TI (5.0) (Atlas.ti, Berlin, Germany), a software program designed to manage qualitative data, was used to facilitate the data reduction and analysis process. Data analysis initially involved coding significant statements of participants using a descriptive word or phrase to describe the statement. Codes were then collapsed and iteratively clustered into themes according to similarity of meaning (Miles & Huberman 1994). Within-case analysis was then undertaken to identify clusters of themes by participant. Data display matrices were created to compare and contrast individual cases. Efforts were undertaken to ‘bracket’ the previous concept analysis results during the content analysis process. An audit trail was maintained to document supportive evidence of themes identified. Ten transcripts were coded by two reviewers and compared to verify that all significant statements were coded and that clarity of codes was achieved. Quantitative data were entered into a database (SPSS, version 13.0) (SPSS Inc., Chicago, IL, USA) and checked for accuracy. Mean substitution was used for missing data <15% on the CES-D. Descriptive statistics were completed to summarise demographic and clinical characteristics of the sample.

Results

Sample description

The sample (*n* = 26) was diverse with respect to age (25–80 years), education (8–24 years), duration of illness (1–39 years), gender (63% female), race/ethnicity (63% non-Hispanic white) and income (66% ≤$39 999) (Table 2). A wide variety of chronic illnesses were represented including, diabetes (*n* = 6), cancer (*n* = 6), substance abuse or mental health disorders (*n* = 6), musculoskeletal disease (*n* = 5), cardiovascular disease (*n* = 5), neurological disease (*n* = 3), spinal cord injury (*n* = 2) and HIV (*n* = 1). Most participants had more than one chronic illness (*n* = 18) with a mean comorbidity of four chronic illnesses. Thirty-one per cent of the sample demonstrated elevated depressive symptoms.

Process of integration

The process of integration was complex and multifactorial. A considerable amount of continuous time and effort were required to integrate an illness into participant’s life context. Phases of integration included ‘shifting sands’, ‘staying afloat’, ‘weathering the storms’, ‘rescuing oneself’ and ‘navigating life’ (Fig. 1). Weathering the storms was a critical phase as numerous factors challenged participants’ efforts to manage their illness and integrate it into their life context.

Shifting sands—All participants told a story about the diagnosis of their chronic illness(es), their emotional responses, and the initial experience of facing a changed life and many personal losses. One participant provided the metaphor for this theme:

> I remember once telling people that I felt like I was standing on a sandbar and the sand was washing out beneath my feet…that’s the metaphor that came to mind, for being on extremely shaky ground and needing to get a grip or not. (004)

Another participant stated:

> It was the most traumatic experience that I ever (had). You know, I was prepared for it because I was at high risk for the diagnosis…but when it happened it was just, it overwhelmed the senses almost…it was almost like it was a surreal moment. (003)

Numerous emotional responses were expressed including fear, anger, sadness, depression, anxiety, apathy, and denial. “When I was diagnosed, I just didn’t care…I got mad because ‘why me?’…it wasn’t fair…I was real angry, really, really angry.” (010) Another participant stated:

> At first it was very hard for me to deal with…it was very depressing. For a while, I couldn’t sleep. I was having anxiety attacks…I went on a pity party and you know at one point I just said, ‘well if this is the way I’m going to die, I’m going to just die this way’. (015).

Emotional responses often resulted from the changes in participant’s bodies, and changes in their ability to experience life, as well as their perceived losses. Loss of body function, life activities, time and loss of control were expressed. Physical limitations were expressed as being difficult for many participants ($n = 15$):

> I’m not able to do a lot of things that I used to be able to do. I can’t do a lot of walking. I can’t do a lot of lifting. So, I have to be cautious of everything I do now… (012)

> The difficulty, I will tell you what the most difficult thing is. I was diagnosed at the age of 18. I remember life without it. I remember traveling. I rode horses. All these things I would do (crying). (002).

> I realised that I am not in the drivers seat of my life anymore and that the diseases are and they control me. You know, I don’t control my life. You lose control and that is the biggest issue that I find. (027)

For some participants, the life changes were immediate and unchanging (i.e. spinal cord injury); for others the illness caused an immediate life change with either a positive trajectory (i.e. CVA) or with a negative trajectory (i.e. multiple sclerosis, emphysema). For others, life changes and losses were sporadic and often related to side effects of treatment (i.e. corticosteroids). However, across all participants, a change in one’s body, self, and life associated with a chronic illness caused a change in life as known, including losses, which often challenged participants’ ability to pursue meaningful or enjoyable activities.

Staying afloat—This phase of integration represented the considerable work that was required for participants to begin to understand their self-management needs and come to terms with what it meant to live with a chronic illness. Participants described daily attention to learning and experimenting, managing their illness, using resources, expressing emotions and developing coping strategies. This was a difficult phase for many participants which varied depending on the illness experience as well as internal resources (coping strategies, personal characteristics) and external resources (others, environment).

Participants learned about their illness, symptoms and treatment from several sources including family, friends, support groups, media and healthcare professionals. Two participants with spinal cord injury spoke of how beneficial their initial rehabilitation programme was to facilitate their ability to care for themselves and to identify community resources accessible to them. Other participants learned about their illness as they went along:

> If I want to know something…my Mom and I are both on the internet…and if I don’t know, I’ll ask the doctor. I’ll say, ‘Put it in terms that I understand. I need to know exactly what is going to happen. (005)

Learning and experimenting over time contributed to increased confidence with managing an illness. Managing an illness consisted of the specific tasks that participants engaged in such as attending regular appointments with healthcare professionals, taking medications, and modifying food and activity patterns. Some participants also managed their illness with a health promotion perspective of eating healthy, exercising, maintaining their weight, getting sufficient sleep, and prevention of other illnesses or complications. In addition to these behavioural tasks, considerable attention was required for body monitoring, managing symptoms and side effects, making choices, asking for help, problem-solving and prioritising. For some, this involved complex decision-making, often on a daily basis. For many participants, it took several years to learn how their body would respond as well as how to plan, prioritise and solve problems.

Attention to the physical aspects of a chronic illness was not sufficient to integrate an illness into one's life context successfully. Attention to the emotional aspects of living with a chronic illness was equally important as ongoing challenges associated with living with a chronic illness contributed to feelings of sadness, depression, anxiety, anger, frustration and fear. Changes in roles and relationships often occurred.

Resources were a critical aspect of managing one's illness and working through emotional issues. Most participants identified family and friends as their major sources of support. Family and friends provided instrumental support with activities of daily living, running errands, managing illnesses and maintaining a home. They provided emotional or interpersonal support by allowing participants the opportunity to share and discuss personal issues and by demonstrating love, care and concern. In addition family and friends provided companionship, fun, encouragement and positive energy:

> I have wonderful friends…they come over and visit and we have supper or whatever and maybe just sit and have a glass of wine and some crackers or, and then you know we talk about different things. I mean we don't dwell too much on illnesses and things like that,…but I really believe…friends are very, very important and friends get you through a lot, a lot of things… (001)
>
> My wife….she didn't leave me. You know what I mean. Hey, that's a big, big, big thing. I'll tell ya. I give her credit. I mean she had it just as rough as I did, except she wasn't paralysed. She wasn't in a wheelchair, but she went through the same thing that I did. Plus, she took care of the kids. …But if I didn't have her, it would be a whole different ball of wax. I mean who knows what might have happened. I mean I don't know. Would I drink myself to death or shoot myself or get in the car and just smash into a tree?… If I didn't have a family and if I didn't have my wife, it would be a whole different story. No doubt about it. (022)

Balancing dependence and independence issues was often required as participants expressed difficulty in asking for help or not wanting to be a burden to others. Dependency on others also affected participants' ability to be spontaneous and conflicted with their desire for independence:

> Well, one of the things that happens is you run out of milk. You used to get in your car and you'd go get it. Or you need a prescription filled. You get in your car and you go get it…You can't do those anymore. In fact I sold my car….Sometimes you just have to do things for yourself, but you also have to know when to ask for help because it's beyond your ability to do and I think you learn that too. (009)
>
> I'm very dependent on things like, dependent on the person to come get me up, dependent on my chair to make sure it works or the device that transfers me from my bed to my chair. If I want to go somewhere, I need my van to work and also if I'm going somewhere I need the person that's coming during the day to come. So I depend on a lot of things and I try not to think about how much I depend on them… but when they are functioning well, I can be independent. (018)

Other sources of support for participants included one's self, healthcare providers, support groups, church members and school advisors. The most common were support groups and counsellors, indicating the assistance required in dealing with emotions. Technology was also a resource to many and included such things as magnifying glasses, voice-activation devices, wheelchairs, braces, and for those with diabetes, insulin pumps.

Specific coping strategies were also identified by participants as being beneficial to begin the integration process. Spirituality, humour, focusing on the positive, self-talk, pets, and creative pursuits (i.e. journaling, cooking, crafts) were important positive strategies that participants used to cope with and live with a chronic illness. Spirituality appeared particularly important to participants of diverse race/ethnicity and participants of lower socio-economic status. Negative coping strategies expressed included alcohol consumption, smoking and withdrawal.

Weathering the storms—Storms represented the numerous barriers to integration including treatment side effects, a progressive or uncertain illness trajectory, co-morbidity, bad days, financial hardships, and interpersonal/environmental challenges. There was a continual tension between an individual's ability to stay afloat and move forward in the integration process which depended on the number and intensity of barriers and the availability of resources. Barriers occurred for all participants at varying stages of their illness trajectories:

> The hardest thing is when I wake up in the morning I don't know what shape I'm going to be in. … I think it's like a see-saw. For me it's up and down. Just when I think I got this under control, I'm dealing with it, I'm okay with it. Boom. Something hits me and I'm upset again. (011)

> I don't feel stable at any given time because there are constant changes. The ebb and the flow of the illness itself makes you crazy. Sometimes you think you're losing your mind. …but it's like, okay, what am I going to do today? What is my body going to let me do today? What is my mind going to let me do today? It gets to be long day sometimes. …so I'm dealing with two animals, the bipolar and the MS and they're both battling and they're winning. (016)

Rescuing oneself—Conscious effort and creativity were required to weather the storms and re-engage in a meaningful life which required: working at health, participating in life, connecting with others, developing new coping strategies and finding purpose or meaning. All aspects of living were affected by a participant's chronic illness, thus engaging in a meaningful life was a challenging process. For example, several participants engaged in meaningful work through volunteering instead of working due to the unpredictability of their illness. Others had to limit their time or responsibilities at work. Many had to limit social activities because of physical or emotional symptoms related to their illness. Sometimes previous coping strategies no longer worked because of illness symptoms or side effects, thus the development of new coping strategies was required. For all participants, re-engagement in life activities that provided enjoyment or meaning was an important aspect of the integration process, albeit a sometimes difficult thing to do:

> It's just very hard living with it..it's easier said than done…(021). It's hard, it really is (023). Right now it's hard (017). It's lot of hard work (003).

> I just get up and eat, talk to my friends, go out there, go to the park, go, you know, even if you can't play baseball but you can, you know, watch it play. I like to fish. I can't fish no more, but I go to watch those guys fishing. (013)

> Well, because I believe that God puts no more on us than we can bear and there is a purpose for everything in life and maybe this was one of God's ways of testing me, testing my faith and testing me for my trials and tribulations in life. (015)
>
> It felt great (going back to work…volunteering) I felt part of, I felt productive. Felt like I was something, you know, I had a purpose, a reason, all of that. (011)

Navigating a life—Participants fluctuated between 'living a life' and 'living an illness' as a result of a changing and unpredictable illness experience. Days of adjusting, inner peace and positive self-worth were intermixed with days of struggling, frustration and isolation for many participants. Participants were faced with ongoing emotional, physical and spiritual challenges that required attention. Some struggled. One participant spoke of her illness as 'a battle' and 'something to conquer'. Another participant stated:

> I think about it every day, and I don't want to, but it's just there. I find that most people just integrate it and move on. Maybe I'm stuck in it…I always say the joke, I work (everyday) but my full-time job is diabetes, because you know I get up, I eat breakfast, I workout and I am always thinking when is my next meal? Do I have my meal with me? Do I have my strips? Do I have batteries for my pump? Do I have a needle in case my pump breaks?… I get engulfed in the disease and dealing with it. (002)

Despite the numerous challenges and the pervasive cognitive, behavioural, and psychosocial work required to integrate an illness into one's self and life context, some continually adjusted and demonstrated resourcefulness and accomplished lives:

> It's a balancing…I mean you suffer and you come to adjustments and then you suffer again and maybe come to some more adjustments…it kind of gets back to what I was saying about control and the battle. How do you live without control? How do you surf the chaos that's going on around you and under you? It's like, you know, you're riding on a wave on a hypothetical surfboard…and you're sitting at the peak of the whole convergence of forces that you have nothing to do with really and you're just lucky to be up there able to keep your balance on all this stuff going on. I mean you had no idea necessarily when the convergence and play of forces is going to change and dump you and that's life…that elusive balance that keeps slipping away at the top of the wave. Yeah, it keeps slipping away or it keeps coming back…The trouble with balancing is you have to keep going. (004)
>
> I've accepted my (illness). I don't fight it. I'm not angry about where it came from. I'm not looking for that cure so my life can change. I'm sort of living in the between and the now…I think I have learned to live with myself in general…I can't believe that I'm actually going to say this, but I'm actually a pretty cool person.…. I have great friends. Great love. …. You know, I can't be that horrible of a person to have all those things in my life, so I feel like there's something right… Like I'm supposed to be where I'm supposed to be with what I'm supposed to have. (003)

Discussion

The process of integrating a chronic illness into one's life and self-identity was complex and challenging. Considerable daily effort was required by participants to manage their illness(es) or overcome unpredictable physical or emotional challenges. Psychosocial difficulties were common.

All participants made considerable effort to integrate the illness into their life context, participate in a personally meaningful life, and achieve a satisfactory quality of life. However, it was easy to be consumed with ‘living an illness’ as the daily tasks, the changing symptoms, and the fluctuating emotions could be overwhelming at times. Thus, there was a complex co-existence between ‘living a life’ and ‘living an illness.’ Integration was a nonlinear and unpredictable process.

Previous research on adjustment to chronic illness has identified the fluctuating tension between living a life and living an illness (Table 3). Paterson (2001) described the process as ‘illness in foreground’ or ‘wellness in the foreground’. ‘Illness in the foreground’ was when individuals with a chronic illness were absorbed in the illness and ‘wellness in foreground’ was when individuals envisioned opportunity and possibility despite illness. Kralik (2002) identified the process ‘extraordinariness’ and ‘ordinariness’ as central to adjusting to a life with a chronic illness. Extraordinariness was a phase of turmoil and distress while ordinariness was a phase of reconstructing one’s life after illness. Lastly, Jarrett (2000) described the process of adjusting to a chronic illness as having four stages: uncertainty, disruption, striving to regain self and regaining wellness. While all of this research suggests distinct phases to the adjustment process of chronic illness, adults with chronic illness continuously shift between perspectives to address immediate life or illness circumstances (McWilliam *et al.* 1996, Paterson 2003). Results of this study begin to identify some of the active processes undertaken by individuals when they are shifting between the different phases of adjusting to a chronic illness.

Previous research on adjustment to chronic illness has also delineated the significant and persistent effort an individual living with a chronic illness must undertake to regain wellness or find a place for the illness to fit into their lives. The model proposed by this analysis is congruent with previous longitudinal research by Charmaz (1991) which delineated the challenges of good days-bad days, existential dilemmas, and the considerable work of chronic illness. Corbin and Strauss (1991) articulated the necessary work of chronic illness as work aimed at managing the illness, keeping a household and managing one’s life, and biographical work of maintaining one’s mental and psychological concerns. More recent studies, including results of this study on the process of integration, have begun to specify further the work of chronic illness (Table 4).

Clearly there is behavioural work associated with managing a chronic illness, psychological work associated with coping with a chronic illness, and social or vocational work associated with maintaining one’s roles and responsibilities. In addition, it appears as if there is considerable existential work required in recreating and living a meaningful life while simultaneously self-managing and adjusting to a chronic illness. While numerous definitions have been proposed for self-management and chronic illness (Koch *et al.* 2004, Kralik *et al.* 2004), self-management primarily focuses on the behavioural and psychological work of chronic illness. The process of integration appears to include self-management work, while also encompassing the social, vocational, and existential challenges represented by a chronic illness and the associated self-management needs. Thus, results of this study corroborate previous research on the considerable work of chronic illness. Better specification of the work of chronic illness has the potential to provide direction for assessment criteria and intervention development to assist adults with a chronic illness in the overall process.

Self-managing an illness and integrating an illness into the context of one’s life can be arduous tasks. Increased depressive symptoms are evident in adults with a chronic illness and depressive symptoms can compromise self-management and integration efforts (Cicutto *et al.* 2004). Thirty per cent of participants in this study reported elevated depressive symptoms. Ongoing resources and support appear to be critical factors in supplementing individual's efforts in living with a chronic illness and in providing assistance in processing difficult emotions and beginning to shift their focus from illness towards wellness. Research indicates that friends, family, peers and health professionals provide essential advice, support and assistance related to self-management and integration in chronic illness (Gallant 2003; Predeger & Mumma 2004).

Collectively, the research on the adjustment to chronic illness suggests the need for an expansion of current models of health care. It appears that individuals would benefit from a multi-disciplinary approach providing assistance with respect to the integration process, a process that encompasses the physical, emotional, social, vocational and existential work of chronic illness adjustment. Rehabilitative programmes, health promotion programmes and more involvement from health professionals, particularly nurses, have been advocated as potentially important services for adults with chronic illness to learn to optimise life with chronic illness (Shaul 1997, Stuifbergen & Rogers 1997, Thorne *et al.* 2003). In cancer care, an innovative model of care has been developed and is being provided in select clinical sites to meet the complex care needs of individuals who are survivors of cancer. Centres have been developed that promote a multi-disciplinary approach to help prevent, detect and treat complications from cancer across the age spectrum. In addition, at these centres, services are provided to empower survivors to learn how to maximise their health, quality of life and longevity. Services include personalised wellness education and psychosocial support in addition to physical rehabilitation (National Cancer Institute 2007, Yale Cancer Center 2007). It is reasonable to suggest that adults with all types of chronic illness are survivors who would equally benefit from such a comprehensive model of care. In addition, as chronic illnesses often contribute to physical limitations affecting multiple spheres of an individuals' life, social and vocational rehabilitation services, as well as services to assist individuals to explore health promotion and existential issues, appear to have the potential to be beneficial.

Conclusion

Despite the modest number of participants from one geographical area, results of this study provide insight into the process of integration across multiple chronic illnesses with an ethnically diverse sample. While the heterogeneity of the sample, particularly with respect to type of illness, income, age and ethnicity precluded saturation for some variations within themes, commonalities of the chronic illness experience were able to be determined. Adults living with a chronic illness were remarkably resourceful in developing attitudes and strategies to assist them in integrating the illness into their life context. There were numerous challenges to the process of integration, and ongoing self-management, psychosocial, vocational and existential support appears indicated, particularly with individuals with multiple and/or progressive chronic illnesses and limited resources. Further research on the process of integration and interventions to promote integration is warranted.

Acknowledgments

This work was supported by a grant from the Yale School of Nursing, Center for Self and Family Management of Vulnerable Populations, P30NR008999. Special thanks to Siobhan Thompson, MPH, Brandi Parker, MSN candidate, and Allison Proto, BA.

References

Barlow J, Turner A, Wright C. A randomized controlled study of the Arthritis Self-Management Program in the UK. Health Education Research. 2000; 15:665–680. [PubMed: 11142075]

Centers for Disease Control. [accessed 18 April 2005] Chronic Disease Overview. 2005. Available at: http://www.cdc.gov/nccdphp/overview.htm

Charmaz, K. The Self in Chronic Illness and Time. Rutgers University Press; New Brunswick, NJ: 1991.

Cicutto L, Brooks D, Henderson K. Self-care issues from the perspective of individuals with chronic obstructive pulmonary disease. Patient Education and Counseling. 2004; 55:168–176. [PubMed: 15530751]

Corbin JM, Strauss A. A nursing model for chronic illness management based upon the trajectory framework. Scholarly Inquiry of Nursing Practice. 1991; 5:155–174.

Davis R, Magilvy JK. Quiet pride: the experience of chronic illness by rural older adults. Journal of Nursing Scholarship. 2000; 32:385–390. [PubMed: 11140203]

DeCoster VA. Challenges of type 2 diabetes and role of health care social work: a neglected area of practice. Health and Social Work. 2001; 26:26–37. [PubMed: 11338276]

Department of Health. [accessed 28 April 2005] The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century. 2003. Available at: http://www.doh.gov.uk

Dungan JM. Dungan model of dynamic integration. Nursing Diagnosis. 1997; 8:17–28. [PubMed: 9110744]

Fleury JD. Empowering potential: a theory of wellness motivation. Nursing Research. 1991; 40:286–291. [PubMed: 1896327]

Funk, SG.; Tornquist, EM.; Leeman, J.; Miles, MS.; Harrell, JS. Key Aspects of Preventing and Managing Chronic Illness. Springer Publishing Company; New York: 2001.

Gallant MP. The influence of social support on chronic illness self-management: A review and directions for research. Health Education & Behavior. 2003; 30:170–195. [PubMed: 12693522]

Hernandez CA. The development and testing of an instrument to measure integration in adults with diabetes mellitus. Canadian Journal of Diabetes Care. 1995; 19:18–26.

Hernandez CA. Integration: the experience of living with insulin (type 1) diabetes mellitus. The Canadian Journal of Nursing Research. 1996; 28:37–56. [PubMed: 9128475]

Jarrett L. Living with chronic illness: a transitional model of coping. British Journal of Therapy & Rehabilitation. 2000; 7:40–44.

Katz JN, Chang LC, Sangha O, Fossel AH, Bates DW. Can comorbidity be measured by questionnaire rather than medical record review? Medical Care. 1996; 34:73–84. [PubMed: 8551813]

Koch T, Jenkin P, Kralik D. Chronic illness self-management: locating the ‘self’. Journal of Advanced Nursing. 2004; 48:484–492. [PubMed: 15533086]

Kralik D. The quest for ordinariness: transition experienced by midlife women living with chronic illness. Journal of Advanced Nursing. 2002; 39:146–154. [PubMed: 12100658]

Kralik D, Koch T, Price K, Howard N. Chronic illness self-management: taking action to create order. Journal of Advanced Nursing. 2004; 13:259–267.

Lewinsohn PM, Seeley JR, Roberts RE, Allen NB. Center for Epidemiologic Studies Depression Scale (CES-D) as a screening instrument for depression among community-residing older adults. Psychology and Aging. 1997; 12:277–287. [PubMed: 9189988]

Livneh, H.; Antonak, RF. Psychosocial Adaptation to Chronic Illness and Disability. Aspen Publishers Inc; Gaithersburg: 1997.

Lorig K. Self-management of chronic illness: a model for the future. Generations. 1993; 17:11–16.

Lorig K, Holman H. Arthritis self-management studies: a twelve year review. Health Education Quarterly. 1993; 20:17–28. [PubMed: 8444622]

Lubkin, IM. hronic Illness: Impact and Interventions. 6. Jones & Bartlett; Boston: 2005.

McBride, AB. Managing chronicity: the heart of nursing care. In: Funk, SG.; Tornquist, EM.; Champagne, MT.; Weiss, RA., editors. Key Aspects of Caring for the Chronically Ill. Springer Publishing Company; New York: 1993. p. 8-20.

McWilliam CL, Stewart M, Brown JB, Desai K, Coderre P. Creating health with chronic illness. Advances in Nursing Science. 1996; 18:1–15. [PubMed: 8660008]

Medich CJ, Stuart E, Chase SK. Healing through integration: promoting wellness in cardiac rehabilitation. Journal of Cardiovascular Nursing. 1997; 11:66–79. [PubMed: 9095455]

Miles, MB.; Huberman, AM. Qualitative Data Analysis. Sage Publication; Thousand Oaks: 1994.

National Cancer Institute. [accessed 27 June 2007] Cancer Centers List. 2007. Available at: http://cancercenters.cancer.gov/cancer_centers/cancer-centersnames.html

Norris SL, Engelgau MM, Narayan KM. Effectiveness of self-management training in type 2 diabetes: a systematic review of randomized controlled trials. Diabetes Care. 2001; 24:561– 587. [PubMed: 11289485]

Paterson BL. The shifting perspectives model of chronic illness. Journal of Nursing Scholarship. 2001; 33:21–26. [PubMed: 11253576]

Paterson BL. The koala has claws: applications of the shifting perspectives model in research of chronic illness. Qualitative Health Research. 2003; 13:987–994. [PubMed: 14502963]

Polonsky WH, et al. Assessment of diabetes-related distress. Diabetes Care. 1995; 18:754–760. [PubMed: 7555499]

Posner SF, Stewart AL, Marin G, Perez-Stable EJ. Factor variability of the Center for Epidemiological Studies Depression Scale (CES-D) among urban Latinos. Ethnicity and Health. 2001; 6:137–144. [PubMed: 11488294]

Predeger E, Mumma C. Connectedness in chronic illness: women’s journeys. International Journal for Human Caring. 2004; 8:13–19.

Price MJ. An experiential model of learning diabetes self-management. Qualitative Health Research. 1993; 3:29–54. [PubMed: 8457791]

Radloff LS. The CES-D scale: a self-report depression scale for researching the general population. Application of Psychological Measures. 1977; 1:385–401.

Reynolds F, Prior S. Sticking jewels in your life: exploring women’s strategies for negotiating an acceptable quality of life with multiple sclerosis. Qualitative Health Research. 2003; 13:1225–1251. [PubMed: 14606411]

Ruffing-Rahal MA. Initial psychometric evaluation of a qualitative well-being measure: the integration inventory. Health Values. 1991; 15:10–20.

Sandelowski M. Whatever happened to qualitative description? Research in Nursing and Health. 2000; 23:334–340. [PubMed: 10940958]

Shaul MP. Transitions in chronic illness: rheumatoid arthritis in women. Rehabilitation Nursing. 1997; 22:199–205. [PubMed: 9275811]

Strauss, AL.; Corbin, J.; Fagerhaugh, S.; Glaser, BG.; Maines, D.; Suczek, B.; Wiener, CL. Chronic Illness and the Quality of Life. The CV Mosby Company; St Louis, MO: 1984.

Stuifbergen AK, Rogers S. Health promotion: an essential component of rehabilitation for persons with chronic disabling conditions. Advances in Nursing Science. 1997; 19:1–20. [PubMed: 9161672]

Thorne S, Paterson B, Russell C. The structure of everyday self-care decision making in chronic illness. Qualitative Health Research. 2003; 13:1337–1352. [PubMed: 14658350]

Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A. Improving chronic illness care: translating evidence into action. Health Affairs. 2001; 20:64–72. [PubMed: 11816692]

Westra BL, Rodgers BL. The concept of integration: a foundation for evaluating outcomes of nursing care. Journal of Professional Nursing. 1991; 7:277–282. [PubMed: 1757703]

Whittemore R. Analysis of integration in nursing science and practice. Journal of Nursing Scholarship. 2005; 37:261–267. [PubMed: 16235868]

Whittemore R, Chase SA, Mandle CL, Roy C. Lifestyle change in type 2 diabetes: a process model. Nursing Research. 2002; 51:18–25. [PubMed: 11822565]

Yale Cancer Center. [accessed 21 June 2007] Surviving Cancer: Connecticut Challenge Survivorship Clinic at Yale Cancer Center. 2007. Available at: http://www.yalecancercenter.org/surviving/challenge.html

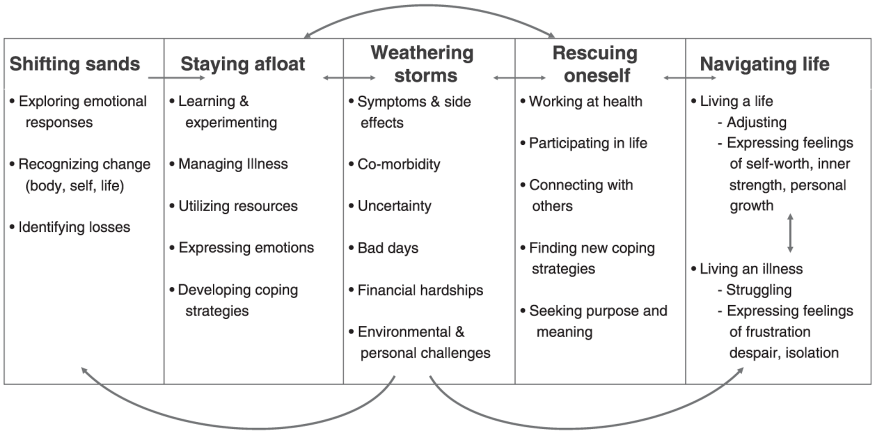

Figure 1.
Process of integration.

Table 1

Interview guide

Interview questions	
1	Tell your story of being diagnosed and living with a chronic illness
2	What were the emotions you experienced?
3	What were the losses you felt as you adjusted to living with your illness?
4	How has your illness affected your roles and relationships?
5	What do you do to take care of yourself and your illness?
6	What support and resources have been helpful to you?
7	How has your illness changed you and your life (positively and negatively)?
8	Do you feel that you have learned to live well with your illness?
9	Do you feel that you have incorporated your health needs into your daily life?
10	Is there anything else you would like to tell me about what it is like for you to live with your illness?

Table 2

Sample characteristics ($n = 27$)

Variable	Range	Mean (SD) or percentage
Age (years)	25–80	54·28 (15·97)
Education (years)	8–24	14·19 (3·84)
Duration of illness (years)	1–39	15·68 (10·81)
Comorbidities	0–9	4·23 (2·78)
Elevated depressive symptoms (CES-D ≥ 16)		30·8%
Marital status	Single, widow, divorced	66·6%
	Married	29·6%
Gender	Female	63·0%
Race/ethnicity	White	63·0%
	Hispanic or Latino	11·1%
	Black	14·8%
	Asian	7·4%
Employment	Employed	40·7%
	Unemployed	25·9%
	Retired	29·6%
Annual income level	<$19 999	33·3%
	$20–39 999	33·3%
	$40–59 000	11·1%
	$60–79 999	11·1%
	≥$100 000	7·4%

SD, standard deviation

Table 3

Phases of adjusting to chronic illness

Paterson (2001)	Kralik (2002)	Jarrett (2000)	Whittemore & Dixon
Illness in foreground – focus on illness, symptoms and negative outcomes of disease. View disease as controlling life. Absorbed in illness.	Extraordinariness – phase of turmoil and distress. State of feeling alienated from familiar life and loss of control over life circumstances.	Stage of uncertainty Stage of disruption	Living an illness – stages of shifting sands, staying afloat, and weathering storms. Focus on illness.
Wellness in foreground – focus on being as well as possible. Emphasis on the self not the diseased body. Envision opportunity and possibility despite illness.	Ordinariness – phase of reconstructing life with illness. Finding a place for the illness to fit into context of life.	Stage of striving to regain self Stage of regaining wellness	Living a life – stage of rescuing oneself and navigating a life. Focus on meaningful life pursuits.

Table 4

Work of chronic illness

	Reynolds and Prior (2003)	**Davis and Magilvy (2000)**	**Kralik (2002)**	**Whittemore & Dixon**
Behavioural work	Managing illness and imiting its impact	Managing daily Self-care	Actively making changes Taking risks	Learning and experimenting Managing illness Using resources Working at health
Psychological work		Balance through negotiation	Research	Exploring and expressing emotions Recognising change Identifying losses Developing coping strategies
Social and vocational work	Maintaining and extending meaningful roles and occupations Dealing with disabling social barriers	Support from family and friends Belonging to community	Relationship work Attending workshops	Participating in life Connecting with others
Existential work	Clarifying personal beliefs and aspirations Consciously valuing and promoting the positive aspects of life	Finding meaning in life	Spiritual work	Seeking purpose and meaning