

# DEVELOPMENT OF CHRONIC ILLNESS IDENTITIES AMONG WOMEN

by

HEATHER ADAMS

(Under the Direction of Layli Phillips)

## ABSTRACT

The current qualitative study employed a modified form of constant comparative analysis to produce a model of the processes of developing chronic illness identities among women. Detailed interview data was collected from three participants, with part of the interview centering around the discussion of photos previously taken by the participant of events, people and things she felt were relevant to her chronic illness. Synthesis of the participant's experiences produced a series of models of developmental experiences, including both phases and potentially influential factors. Of particular interest were findings of the potentially influential role played by disclosure experiences. In addition, developmental processes within the proposed model consisted of both a linear and a non-linear component. Although none of the findings can be taken as conclusive, due to the small sample size, several interesting areas for further inquiry were raised.

**INDEX WORDS:** Identity development, Chronic illness, Women, Qualitative, Participant-driven interview format

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A.B., The University of Georgia, 1995

M.S., The University of Georgia, 2001

A Dissertation Submitted to the Graduate Faculty of The University of Georgia in Partial  
Fulfillment of the Requirements for the Degree

DOCTOR OF PHILOSOPHY

ATHENS, GEORGIA

2004

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## DEDICATION

This paper is dedicated to my family, for all of their support. To my mother Penny Adams, and my brother, Brent Adams, for all of their confidence in me throughout my educational career, and especially this last hard push through graduate school. They have always been there to celebrate my success with me, both the big ones and the little ones, to empathize with my problems and have believed in me when I periodically lost faith in myself. In addition to all this emotional support, my mother has repeatedly supported me financially, bailing me out of more financial disasters, both big and small, than I care to recount. I am not sure I would have been able to do this without the two of you backing me up - truly a team effort. And finally, to my father, Russell Adams, whose emotional support and confidence in me these past few years has meant a lot because of its previous absence. I wish you could have lived to see this daddy, as I know you would have been so proud, and I have always tried so hard to make you proud of me.

## ACKNOWLEDGEMENTS

Aside from my family's contribution, stated in the dedication, there are many people who helped to me succeed in my academic career. The first of these must always be Layli Phillips, my amazing major professor, who has supported and guided me throughout this whole experience. It was my undergraduate research work with her that first prompted me to pursue a graduate career in psychology research, having caught the first hint of the thrills this type of career has to offer while working on her research. Since then she has been a wonderful mentor, both encouraging and critical of my work, requiring a high degree of ethics. Whatever I become as a researcher, (and I hope it is something good) a large part of it will always be due to Layli. My other committee members, Lynda Walters and Patricia Miller, have also played important roles in my academic career through research supervision, course work, and personal suggestions and guidance. Another part of my academic family who have played important roles in making my academic career a success are my friends and colleagues, Blaise Parker, Sarah Peck, Tim Brigham, Valli Parthasarathy, Paul Schmidt, George Felis, Diane Byrd. By sharing our periods of excitement, despair, and apathy, we have helped each other through the long stretches between academic landmarks, while making graduate school a fun experience as well. A special thank you goes to Blaise Parker, who has walked beside me hand-in-hand through most of graduate school, sharing many of the same trials and success together (I'm glad to say I don't think we've had any failures yet!).

Many people outside of academia have also helped me with my academic career. The first of these is my therapist Sylvia Knight, whose support and guidance has helped me not only to manage the stresses of graduate school and life, but also to become a happier, more peaceful

person. Since I feel that a person's work as a researcher flows from who they are as a person, my research will always be influenced by Sylvia's presence in my life. I also must thank my medical specialist, Glenn Parris, whose assistance in managing my illness made it possible to attend graduate school at all. I am deeply appreciative of his efforts to not only treat my illness, but also to help me reach my life goals, even when these two goals were in some degree of conflict. Reaching back a long way, I also want to thank my high school English teacher, Roger Bailey, who set me on the course of writing for a career, as well as providing me with the skills I needed most to succeed in undergrad and grad school, the arts of reading and writing. And last, but not least, there are all of my non-academic friends who have always had confidence in my ability to succeed and who have provided invaluable assistance in helping me keep graduate school in proper perspective by contributing to times of delinquency and fun. Thank you Steve Lotti, Rebecca Frank, Scott Raymond, Rosalind Decker, John Leseman, and Rachel Luna-Victoria.

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## Introduction

Currently, in the United States of America (USA), approximately 100 million people, many of them women, are living with a chronic illness, as defined by National Institute of Nursing Research. Our expanding knowledge and understandings of the experiences of these women not only has the possibility of playing vital roles in public policy formation and therapeutic interventions, but when disseminated to the population members themselves, it offers a peer-group knowledge about the meanings of living with a chronic illness which may assist the individual in constructing her own meanings. The importance of developing a personal knowledge of what it means to live with a chronic illness (which interconnects with but is not equivalent to medical knowledge) is evident in its association with decreases in blame and conflict (Charmaz, 1997). Furthermore, knowledge or experience about expectations and alternatives functions as an important constraint on behavior changes (Kearney & O'Sullivan, 2003). A model of the development of chronic illness identities among women would offer knowledge regarding these possible meanings, expectations and alternatives, but is currently unavailable. This study begins to address this gap by presenting an outline of such a model.

### *Subjectivities*

The theoretical frameworks of poststructuralism, feminism, and dynamic systems theory, along with my own experiences and perspectives as a woman with a chronic illness disability, have guided my selection of literature, locations of emphasis, methodology, and presentation of findings. Poststructuralism holds that all knowledge is socially constructed to some degree (through the parameters of the languages we use), precluding any discussion of essences or universal, a historical and object "Truths" (with a capital T) as meaningless or misleading (Butler, 1995; Derrida, 1974/1967; Gergen, 2001; Kelly, 1997; St. Pierre, 2000). From this

perspective, there can be only local, specific, subjective “truths” (with a lower case t) (Gergen, 2001; Kelly, 1997; St. Pierre, 2000). Furthermore, if there is no essence of “reason” that exists separate from the reasoner, then all knowledge is subjective, being shaped by the inquirer’s unique experiences (Gergen, 2001; Kelly, 1997; St. Pierre, 2000). Moving from this perspective, I have a) drawn primarily from authors who considered the socially constructed aspects of their topic, b) avoided the monolithic terms of “self” and “identity” in preference for the plurality of “selves” and “identities”, c) discuss the locations of both myself and others authors within our inquires, d) maintained a subjectivities journal (Peshkin, 1993) to clearly record and track my subjective influences on this inquiry, and e) include contextual considerations in my final model.

An important issue in feminism is that of power and control, with one aspect of this being who has the authority to speak for and define a population and its experiences (Reinharz, 1992). This concern is reflected in attention to insider/outsider issues, an emphasis on the voices of the population members, and interviewing formats that increase the interviewee’s control over what is and is not discussed (Reinharz, 1992; St. Pierre, 2000). Incorporating this perspective, I have a) discussed the location of the researcher(s), b) drawn from writings that are grounded in the voices of the participants, c) paid special attention to identity interconnections – and issue raised by feminist women of color, and d) employed a new type of interview format that is partially participant-driven. This new interview format, based on the work by (Allen, Fabregas, Hankins, Hull, Labbo, Lawson, Michalove, Piassa, Piha, Sprague, Townsend, & Urdanivia-English, 2002; Clark, 1999; Harper, 1998) consisted of a participant-driven component, where we discussed six photos taken by the interviewee of people, events, things, places or metaphors that she felt represented her experiences of chronic illness, balanced by an interviewer-driven component of

semi-structured open-ended questions posed by the interviewer. This format was employed in an effort to decrease the power difference between interviewee and interviewer.

Dynamic systems theory (DST) is usually associated with inquiries of motor skill development and learning, but is also applicable to macrolevels of inquiry such as social development (Thelen & Bates, 2003; Van Geert, 2001). As a case study paradigm, DST places an emphasis on collecting a great deal of information about a few individuals, especially unique cases that offer insights into revisions for existing theories or models (Lee & Karniloff-Smith, 2002; Thelen & Smith, 1998). Incorporation of this perspective is evident in a) the small sample size of three (several groundbreaking DST studies have sample sizes of four - Corbetta & Thelen, 1996; 1999; Spencer & Thelen, 2000; Spencer, Vereijken, Diedrich, & Thelen, 2000; Thelen, Corbetta, Kamm, Spencer, Schneider & Zernicke, 1993; Thelen, Corbetta, & Spencer, 1996), b) the extensive information collected about each participant, and c) the reconsideration of what constitutes development. I have also modified the method of constant comparative analysis to facilitate the inclusion of unique information from each participant.

Along with my theoretical frameworks, I also bring my experiences and perspectives as a bisexual, White woman with a chronic illness, which serves as both a catalyst and a guide to points of inquiry. It was my own disappointment in the lack of information available, along with my lack of resonance with some of the traditional views that has led me to a) devote time and energy to this inquiry, and b) shift my foci of inquiry – specifically with regard to the personal tragedy approach to chronic illness experiences. Combined together, these frameworks and my personal experiences as a population member inform every level of this inquiry.

*Current models of the development of chronic illness identities*

Experiences of chronic illnesses are locations rich in identity developmental processes. According to Kathy Charmaz, one of the leading researchers in this area, as the individual repeatedly experiences losses of health and ability, she or he must repeatedly negotiate identity questions and potential identity changes – both personal and social (1997; 1999). Charmaz has constructed two models of these processes, one specific to men and the other non-gender specific.

In the men-specific model (1997), the first process, Awakening to Death, immediately follows a life-threatening medical crisis. At this time, men experience a profound sense of vulnerability, connecting death with their personal identity. Initially perceived as a discrete event limited to the initial crisis, as daily obstacles continue, men become aware that the illness remains. During this time, presence or absence of support and care of family members impacts his personal sense of worth and identity. During the process of Accommodating to Uncertainty, men bracket their illness, lessening its impact on their identity and defining the boundaries of this uncertainty. Acknowledgement of the continuing uncertainty may produce epiphanies, such as reappraisals of what he defines as valuable and a resolve to live in the present. Normalization of symptoms and regimens also occur at this time.

During the process of Defining Illness and Disability, men view their condition as an enemy, an ally, an invasive presence, or an opportunity. These views are not static, nor are they mutually exclusive. Each view or combination of views may raise or resolve different identity dilemmas. Men seeking to make the illness meaningful will eventually alter their view from that of an enemy/intrusive presence to an experience with positive consequences. Finally, during the

process of Preserving Self, men strive to maintain continuity throughout the past, present and future. A key part of this is the muting of the illness effects on socializing and work.

Turning to the non-gender specific model (1999), in the first process, Becoming and Being Ill, the type of illness onset has important implications for the individual's identity development processes. With a gradual onset, she or he may be left in a diagnostic limbo, questioning the reality of her or his experiences, and thus unable to incorporate the illness experiences into her or his identity. If, on the other hand, the onset is sudden and acute, events may topple upon each other so quickly that redefinition of the self as critically ill may not occur. Another possible experience is a sudden, episodic onset, where the event may be seen as extraordinary and thus not related to the self. Fourth, diagnosis occurring before any disruptive symptoms produces the greatest disparity between the diagnosis (as a label or identity applied by others) and her or his self-concepts.

After diagnosis, individuals begin to engage in the process of Managing the Illness, which includes learning what the illness means through experience. This process includes coming to define the changes in one's body as related to the illness, thus making the illness relevant to the self. In the absence of this perception, she or he does not incorporate the illness experiences into her or his senses of self. As the adaptations and modifications necessitated by the chronic illness become normalized, the individual comes to see her- or him-self as normal and as living a normal life. According to Charmaz, this perception of normality despite restrictions and limitations is due to the individual's shrinking world and frames of reference, associated with contracting senses of self. Thus, the individual does not realize she or he is restricted in her or his options (including identity options) because her or his frames of reference are themselves shrinking.

The third process is Stigmatism and Stigmatism Control. Experiences of stigmatism increase the individual's vulnerability to negative social identities and self-definitions.

According to Charmaz, a stigmatizing label may become so strong that it defines the person, influencing all of her or his definitional characteristics, making it a master identity. Stigmatism can be divided into two types, with enacted stigma as experiences of discrimination, while felt stigma is the experiences of fear of discovery and shame regarding one's differences. By dramatizing difference and magnifying one's senses of loss, enacted stigma is a powerful type of experience that shapes an individual's senses of self. Felt stigma influences the person senses of self through the limitations she or he self-imposes in an effort to decrease the opportunities for enacted stigma to occur. Concerns regarding both enacted and felt stigma influence decisions about what, where and to whom an individual may disclose information about her or his chronic illness.

Both of these models make valuable contributions to our understandings of the development of chronic illness identities, but neither addresses several of the unique experiences of women. One of these is speed of illness onset. The chronic illnesses most common among men are those with a sudden, debilitating onset (e.g., heart attack), producing a sudden, shocking awakening to death, while a high percentage of women's chronic illnesses are degenerative in nature (e.g., auto-immune system diseases), beginning gradually and moving into progressive deterioration (Charmaz, 1995). Differences in onset are addressed in the non-gender specific model (1999), but lack incorporation within the context of other experiences of women with a chronic illness, which could provide new insights into developmental process and outcomes.

Another unique component not addressed by either model is length of time between onset of symptoms and diagnosis. Since women experience greater difficulty in getting physicians to



view their symptoms as real, despite severity of symptoms, they may experience a longer time period of health disruptions without a legitimizing diagnosis (Charmaz, 1995). This may result in concerns by the woman and others around her that her symptoms may be fabricated or attribution of the symptoms to causes other than a chronic illness (Charmaz, 1995). This lack of accurate diagnosis may inhibit her ability to incorporate the illness experiences into her identity (Charmaz, 1999).

My inclusion of a third experience unique to women comes from my own experiences rather than the literature. Due to the severity of my symptoms and the toxicity level of the drugs I must take to control the progression of my illness, pregnancy is potentially life threatening. Thus, following my doctor's recommendations, I have had my tubes tied. Although this experience is not discussed in the literature, it is doubtful that I am the only woman who has had to forgo the experiences of pregnancy. Given the heavy emphasis placed on motherhood in our society as a defining component of being a woman, a health-related choice to not conceive a child is likely to impact a woman's senses of self, perhaps both as a woman and as a person with a chronic illness. These differences in speed of onset, duration between onset and accurate diagnosis, and safety of pregnancy point to the necessity of developing a model addressing women's unique processes of developing chronic illness identities.

#### *New directions*

In addition to focusing on women as a unique population, I have taken new directions with regard to what I consider development and the foci of my inquiry into the experiences of people living with chronic illnesses.

*A new definition of development.* Approaching the traditional definitions of development (Sroufe & Rutter, 1984) from a consideration of Normal/Abnormal binaries and the

marginalization of populations placed within the Abnormal category (Foucault, 73; 83; 88; 95), the criterion of elaborative change (e.g., a change that increases the size, diversity, or complexity of organization of a person or her or his characteristics, capabilities, and relationships with their environments [Ford & Lerner, 1992]) is revealed as problematic. By excluding decremental change (e.g., a change that reduces the size, diversity, or complexity of this organization or characteristics, capabilities, and relationships [Ford & Lerner, 1992]), traditional definitions of development privilege one type of change over others while relegating individuals who experience decremental changes to the category of the Abnormal, with all its attendant implications of deviancy and deficit and thereby excluding their experiences from the scope of developmental psychology.

Furthermore, recent studies in DST and connectionism have raised important questions about the meaningfulness of the elaborative criterion. Studies employing a DST approach to changes in both cognition and action have shown that episodes of increased performance on tasks as variable as infant locomotion and learning rules of mathematics are preceded by short episodes of decreased performance on these tasks (Thelen & Smith, 1994). To apply the elaborative criterion would exclude part of the process and would certainly not produce an accurate representation of the change processes occurring. The argument that the overall end-product is an increase is dependent on the determination of the beginning and ending point of a particular process and the theoretical bases for determining these points. Turning to connectionism, researchers working in this area have devised dynamic mathematical equations whereby a single equation can generate both an increase and subsequent decrease in performance (Elman, Bates, Johnson, Karmiloff-Smith, Parisi, & Plunkett, 1998). This raises the question that if a single equation can generate both outcomes, are they then not part of the same

process? If so, any division between the increase and decrease may be artificial, external, and more representative of the preconceived ideas of the researcher than a reflection of change process itself.

These theoretical concerns, combined with the documented damage such a binary creates (Bornstien, 1994; Fausto-Sterling 1998; Guthrie, 1998; Haeberls, 1998; Jarman et al, 2002; Katz, 1995; Linton, 1998; Lorde, 1984; Tavris, 1992; Valian, 1998) cause me to question the appropriateness of including the elaborative criterion. In response, I purpose a modification of Ford and Lerner's (1992) definition. I start with their definition because it disrupts several of the structures that support the power of the Normal/Abnormal binary. Specifically, by defining developmental change as successive, rather than progressive, this definition eschews the assumption that all development proceeds toward a particular universal end point or goal. This shift away from universal models of development, with their evaluative value judgments and resulting social injustices, addresses one of the points of change recommended for disrupting the power of the Normal to direct the field of developmental psychology (Burman, 1994). As part of this shift, Ford and Lerner's model (1992) also places a balanced emphasis on both biological and environmental (i.e., social-contextual) factors, again disrupting the power of the Normal by de-emphasizing evolutionary-biological causations (Burman, 1994).

I have altered their definition only to include decremental changes and processes of maintenance. This new definition specifies that "individual human development involves incremental and transformational processes that, through a flow of interactions among current characteristics of the person and his or her current contexts, produces" (p. 49) either a succession of relatively enduring changes to (elaborative or decremental), or maintains "the person's previous structural and functional characteristics and the patterns of their environmental

interactions while maintaining coherent organizations and structural-functional unity of the person as a whole” (p. 49). Along with including decremental and elaborative changes, this alternative definition also includes processes that maintain the person’s structure and characteristics. The decision to include maintenance processes derives from both a process-oriented approach to development (rather than an orientation focused on outcome) and a consideration of Baltes, Staudinger, & Lindenberger’s (1999) discussion of the aging process among humans. Inclusion of decremental and maintenance processes allows for the incorporation of the experiences of people with chronic illnesses and other disabilities within the field of developmental psychology, where they have been previously excluded. Specific to the topic of the current study, it allows for the consideration of all identity processes, opening the area of inquiry to include processes that involve recycling or patterns of non-linear change.

*Shifts in foci.* In addition to focusing on women as a unique population, I have also chosen to include the previously marginalized analysis topic areas of: a) gains and growth, as well as losses and limitations, b) interconnections with other identity domains, and c) disclosure experiences. The following is a brief synopsis the importance and implications of these shifts in foci for the study of chronic illness identities. The traditional personal tragedy models present the development of chronic illness identities as a series of responses to the ever-dwindling resources available for her or his construction of valued senses of self and social identities (Charmaz, 1999). However, John Swain and Sally French (2000), suggest that these models are more the product of the perceptions of able-bodied people than a reflection of the lived experiences of disabled people themselves. Their contention is supported by the voices of people with various disabilities, who include becoming more independent, becoming a better person, growing spiritually, and the acquisition of skills and abilities in their discussion of

disability experiences (Boswell, Knight, Hamer, & McChesney, 2001; Olney & Brockelman, 2003). Paying heed to the voices of the population members themselves, myself included, I determined to pay equal attention to experiences of both gains and losses during analysis, approaching the topic from the perspective of trauma and transformation (Tedeschi & Calhoun, 1995).

A second area of focus is interconnections between identity domains, a topic first raised by African American and Chicana feminist and later by Native American two-spirit, lesbian and gay people (Combahee River collective, 1983; Garcia, 1997; Lorde, 1984; Tafoya, 1997; Wilson, 1992). People from these populations argue that their experiences and identities are vulnerable to misinterpretations unless placed within the contexts of their unique locations at the crossroads of two or more identity domains. Within the area of disability studies, interconnections between disability and spirituality, as well as disability and sexual orientation have been noted, suggesting that here too misunderstandings are possible without consideration of interconnections (Boswell et al., 2001; Butler, 2001; O'Neil & Hird, 2001). Research on the development of chronic illness identities has noted important differences due to gender, socio-economic class, marital status and age, and in this study I expanded this further to address all other potential identity domains, including those presented as such by the participant but not treated as an identity domain within traditional developmental psychology.

I derived my third shift in focus, disclosure experiences, from consideration of the Cass Model of Homosexual Identity Development (1979). Theoretical comparisons by disabled researchers (Garland Thomson, 1997; Linton, 1998; Reeve, 2002) and self-comparisons by individuals with disabilities (Olney & Brockelman, 2003) suggests that there is sufficient overlap in some experiences to warrant garnering insights from one to explore with regard to the other.

Of the six stages of development of lesbian and gay identities, two appear to have particular relevance to people with a chronic illness. In Identity Acceptance, the third stage of this model, the individual discloses her or his new emerging identities with selected members of the dominant group. Supportive, non-discriminatory responses from dominant group members increases both the individual's likelihood of additional disclosure and her or his positive feelings toward their emerging identities, along with decreasing feelings of alienation. In contrast, discriminatory or hostile responses result in the reverse. Disclosure also occurs in the fourth stage of the model, Identity Tolerance, where the individual seeks out others who she or he perceives as sharing these emerging identities. Inclusive, friendly, sharing interactions with other individuals with whom she or he shares these non-apparent marginalized identities contributes to the development of a positive view of this group and thus a positive self-image. Withdrawn, combative, discriminatory interactions result in the reverse. If these patterns hold true for the disclosure of other non-apparent, marginalized identities, then disclosures of chronic illness and resulting responses from both dominant group members and other members of the marginalized group may influence both the course and the timing of the development of these identities. Issues of disclosure to dominant group members are included in some models (Charmaz, 1997; 1999) as part of several themes, but are not explicitly addressed as developmental processes, while issues of disclosure to other members of the non-apparent marginalized group are not currently addressed. The voices of people with chronic illnesses or other disabilities suggests that efforts to create an accurate understanding of their experiences need to explore growth as well as loss experiences, interconnections with other identity domains, and the developmental possibilities of disclosure experiences.

Shaped by the theoretical frameworks, and guided by a shift in foci, this inquiry is guided by the following researcher questions:

1. How do women experience the development of their chronic illness identities?
2. What does chronic illness mean to women?

## Methods

### *Research Design*

This qualitative study utilized a constant comparative analysis method, modified in the following manner: (a) each interview was not analyzed prior to conducting the next interview; (b) comparison across interviews occurred only after an individual model was constructed for each participant; and (c) differences and similarities were given equal emphasis.

### *Participants*

Three women with a chronic illness (two with lupus, one with multiple sclerosis), with an age range of 42 to 56, and current careers of either graduate school (two) or nursing (one) participated in this study. Of these, one is African American, one is lesbian, two are married, and two have children. All participants were recruited through personal contacts of the first author and were compensated \$30.00 and offered a copy of any publications produced from their data.

### *Materials*

A disposable camera was provided for all participants, though one chose to use her own digital camera. All interviews were recorded and initial interviews were transcribed.

### *Procedure*

*Data Collection.* An initial pre-interview conversation was conducted seven to ten days before the interview. During this conversation, we discussed the purpose and structure of the study, reviewed and signed the informed consent, reviewed the guidelines for taking photos, made arrangements for photo collection and development, and made an appoint for the interview. As noted under feminist subjectivities, these interviewee photos were used as the bases of the discussion during half of the interview in an effort to share power during that



process. Specifically, the participant was told that the purpose of the photos was to allow her to create visual images that she felt were related to her experiences as a woman with a chronic life-illness, and that we would discuss them during the interview. The guidelines asked her to take pictures of events, things, people, places, etc. that she felt were meaningful to her experiences with her chronic illness, along with engaging in some self-reflection about her experiences and taking photos relevant to these reflections, while emphasizing that the decisions and ideas of what to photo should be solely hers. The content of these photos is summarized in Table 1. Meeting at a previously agreed time and location for the interview, the participant selected a pseudonym to identify all of her information, before proceeding to the interview. During the first half of the interview, the participant and first author discussed each of the six photos in the order selected by the participant, with the first author prompting for further details, related events, meanings, and emotions. The second half of the interview consisted of a series of semi-structured, open-ended questions posed by the first author.

Upon completion of the author-constructed group model of developmental experiences, the first author met again with each participant for a follow-up interview, which centered around the participant's critique of the model, with a focus on its quality of fit with the participant's experiences. In addition, the interviewer asked for clarification or elaboration on points raised during her analysis. The participant was compensated at the end of the follow-up interview and arrangements were made to mail copies of published manuscripts.

*Data Analysis.* Informal, preliminary analysis naturally occurred as the primary author conduct the interviews. Following the example of Miles and Huberman (1994), formal coding of the first interview began with a "start list" of broad codes drawn from the review of the literature, along with a code of "new" for material that did not fit within this start list codes. Start list codes

were: a) gains and losses, b) disclosures, c) interconnections, d) life guidelines, and e) others.

These codes were designated by colored lines alongside the text. Due to the nature of the field of psychology, which requires a review of the current literature before initiating investigation, we felt that efforts to initiate the inquiry without any pre-existing knowledge of the topic and allowing participant-raised topics to determine the direction of the inquiry (Glaser, 1992 as cited by Dey, 1999; Glaser & Strauss, 1967 as cited by Dey, 1999; Strauss & Corbin, 1990 as cited by Dey, 1999) would be artificial. This start list of broad categories was employed as a method of breaking the large data sets into more manageable pieces (Coffey & Atkinson, 1996; Miles & Hubberman, 1994; Weaver & Atkinson, 1994). It was anticipated that additional general codes generated from the “new” dialog would be used during analysis, but I decided that these pieces of dialog did not contribute additional information relevant to the developmental focus of the current inquiry.

All dialog grouped within a start list code was then chunk coded for specific events (Coffey and Atkinson, 1996), rather than the line coding recommended by Glaser (1992 as cited by Dey, 1999), Glaser & Strauss 1967 as cited by Dey, 1999) and Strauss & Corbin (1990 as cited by Dey, 1999). These chunk codes, varying in size from 2 to 30 lines of text, were generated through immersion in each interview. They included events that reflected our interests as researchers (i.e., self-esteem), summary glosses of what the participant is referring to (i.e., work), and those that come directly from the participant’s dialog (i.e., opening and closing doors) (Coffey & Atkinson, 1996). Once generated from any one interview, all other interviews were explored for experiences reflective of the new code.

When an interview had been completely coded, the chunk codes for that interview were then organized within a separate table for a) disclosures, b) gains and loses, and c) roles, with a

figure for interconnections. A personal model of the participant's experiences of chronic illness was then constructed from these consolidated representations. Sections of data from the three personal models were then synthesized to produce the final figures presented below. During the construction of the personal models, the emphasis was placed on constructing a detailed flowchart of the participant's experiences. However, during the construction of the final figures, the emphasis was placed on the experiences that appeared to influence the development of chronic illness identities.

Due to the focused nature of the follow-up interviews and the first author's already deep immersion in the topic from the initial interviews, this data was audio-coded only, without transcription. In addition, suggested either the participant or the primary author drew modifications onto the preliminary models during the follow-up interview, so that at the conclusion of the interview, the participant had co-produced a model that reflected her experiences. These modifications were then incorporated into the final models, with dialog from both the initial and follow-up interviews incorporated into the results. Following the recommendations of Strauss and Corbin (1990) the first author engaged in detailed memo writing throughout the data analysis process.

## Results

Synthesis of the three individual models, combined with further information collected during follow-up interviews, produced two models. Figure one presents a model of the overall pattern of the development of chronic illness identities experienced by the participants, focusing on the phases of Refusal and Temporary. Figure two presents the possible courses and outcomes from disclosure to a non-chronically ill person, or dominant group member (dgm). Figures three and four present more detailed pictures of the developmental movements that occur during the

phases of Tentative Internalization and Definitive Internalization respectively. For figures one, three and four, the developmental pathway of each participant is presented in the model along with factors associated with movement between phases and sub-phases. For purposes of simplicity, factors that are theorized but not directly supported by the data are not included in the model of identity development (figures one, three and four), but are addressed in the discussion section. Upon reviewing the initial models, the two participants able to engage in the follow-up interviews expressed their enthusiasm and felt they were a good reflection of their personal experiences.

...This is very, very good. (Linda)

...This really represents the complexity of the process of chronic illness. (Chana)

...(referring to figure two) all of these things have happened to me. (Linda)

Incorporation of their further information collected during the follow-up interview has hopefully produced an even closer fit between the final models presented here and their developmental experiences.

#### *From Symptom Expression Begins to Temporary and Refusal*

The model starts with Symptom Expression Begins, which eventually leads to a medical Diagnosis of the chronic illness. This Diagnosis produces an Acknowledgement of the chronic illness as a potential cause, but does not produce acceptance of this illness as the causative agent of her bodily experiences. Three developmental courses from Diagnosis to Tentative Internalization were evident in the participants' experiences. One path movement was from Acknowledgement to the phase Temporary, where she accepted the illness as only a transient event.

I think it was just not wanting to accept that I had the illness...that it's just going to go away. This is just temporary... I'm not 'gonna have this for long. (Linda)

Linda had a clear diagnosis of her chronic illness and did not recount questioning the diagnosis, but due to her previous experience with another chronic illness (diabetes) that disappeared after a period of time, she accepted her lupus as only a temporary event.

I had diabetes when I was first diagnosed with Lupus. The diabetes disappeared about a year after I was diagnosed with the lupus, so I thought, okay, lupus was going to disappear too. (Linda)

Another developmental course was movement from Acknowledgement to Refusal, where the individual did not accept the reality of her chronic illness, an experience which she self-labeled as a period of denial.

... I think I even went into denial, "I don't have lupus. I don't have this. [The doctors] are wrong." (Jennifer)

This appears to be due to a lack of clarity and confidence in attributing her bodily experiences to the chronic illness, with several factors contributing to this confusion. The first of these is the type of diagnosis she received, which was a default diagnosis produced solely by the elimination of other potential causative agents

...The first couple of years I had the lupus, it was hives, and my [general practioner] thought I had an allergic reaction to something ...tried me on antihistamine medications...they didn't' help. [Took] some lupus tests... they all initially came out negative and [the doctor] said it was because I was on steroids and antihistamines. They could not get a true test because I could not stay off of them long enough. Then he sent

me to an allergists to make sure it wasn't something I was allergic to ...there wasn't anything that I was allergic to...finally they said that I had lupus. (Jennifer)

It is logical that this type of diagnosis may leave lingering doubts. In Jennifer's case, this combined with her work experience in the medical profession to further decrease her confidence in her medical diagnosis.

... I am a nurse and I see where people are misdiagnosed a lot. [Doctors] don't know, they think, but they don't know. (Jennifer)

A third factor that appears to play a role in her confusion was the overlap of illness symptoms and the processes of aging. She returns to this question repeatedly during the interview.

... I am not sure this joint problem is related to the lupus or if it is just that I am getting older... (Jennifer)

In addition, Jennifer perceived a lack of fit between her bodily experiences and the reported symptoms of others diagnosed with her chronic illness.

...All the literature that I had read on it, I rally wasn't having any of those symptoms. In fact, i think I even went into denial, "I don't have lupus...they are wrong. ( Jennifer)

Finally, interacting with these other experiences were Jennifer's experiences of disclosure to dominant group members (dgms), or people without a chronic illness. These disclosure events may be either voluntary or forced, and usually occur in relation symptom expression. The variety and frequency of these events in the participants' dialog allows construction of a detailed flowchart of the possible courses each experience may follow (figure 2).

#### *Disclosure Experiences with Dominant Group Members*

The flowchart in figure two starts with the participant's disclosure to a dgm, who attributes her symptoms to either the chronic illness or to another causative agent. In both

instances, she may either accept and internalize or reject the authority and correctness of the dgm's assessment. In the case of the dgm attributing her bodily experiences to causes other than the chronic illness, her acceptance and internalization of this assessment cause her to question the causative agent of her bodily experiences, which appears to contribute to a lack of clarity about the reality of the chronic illness. This pattern is clearly evident in the experiences of one participant, who repeatedly experienced this type of dgm attribution.

... (dgm's assessment) [my daughter] does not understand. She will just say I am a hypochondriac or something...(internalization) [in response to interviewer's query "How does that make you feel?"] Sometimes it does make me feel like I'm a hypochondriac. (Jennifer)

... (dgm's assessment) The other thing that I disliked when I first started with the lupus was a couple of [co-workers] who had known me for years...they thought it was an emotional disease and I hated that... (internalization)... I have taken myself off the prednisone several times, thinking that [the doctors] were wrong, that maybe this was just some emotional thing. (Jennifer)

... (dgm's assessment)I had met somebody [at the time the symptoms started] and was dating... he thought it was some sort of self punishment, that I could make myself break out...(internalization) I had done some things that I was ashamed of... and I thought that maybe this was some sort of self punishment, these symptoms that I was having, and that [the doctors] were wrong, I didn't have lupus. (Jennifer)

The influence of these alternative attributions in hindering her assessment of the chronic illness as real was evident in her repeated reports of stopping her medication and questioning her

doctor's diagnosis. I theorize that this internalization of the assessment by some dgm's occurs in conjunction with the rejection of the assessment of other dgm's.

The influential nature of assessments by dgm's was also evident in the dialog of another participant. Although her experience related to issues of self-esteem rather than causation of bodily experiences, I include it here as a further example of the strength of this effect.

...(dgm's assessment) family member's telling me "your life is over".. even my husband's mother, she actually told me "you have no worth"...(participant's reflection of influence) So in other words, it was a big problem with my self-esteem at first 'cause I was really internalizing this stuff that people were saying and I was actually taking it literally and feeling like I'm worthless...I was seeing a counselor for awhile because I just felt like I was not a good person. (Linda)

As presented in figure one, this lack of clarity or confidence in the attribution of her bodily experiences to the chronic illness contributes to her Refusal of the chronic illness.

Another possible course of experiences is her rejection of the dgm's assessment and determination of her own assessment of causation. This rejection may occur directly in response to the dgm's attribution, or after first accepting the dgm's assessment.

...(dgm's assessment) [her family] brought a minister over...[he] actually came over to me and said, "What did you do to God? What did you do to deserve this?"... (internalization)...At one point I had to go to therapy because I felt like I was just not a good person. I was starting to believe that stupid minister that said I did something to deserve this, trying to figure out why did I have this illness. (rejection) I stopped doing that. (Linda)



... So I went to see this other guy that's a neurologist, that was an idiot, and he told me that I needed a psychiatrist. His exact words were, "I don't know what you think you're problem is, but usually people have learned how to cope with life by the time they're in their late teens or early twenties, and I you're, ahem, forty. Well, I guess you can't teach an old dog new tricks." ... Then he told his assistant to give me the name of a psychologist. And I quite frankly told his assistant I had just seen a psychologist, to make sure that this was not in my head, and he suggested that I go to a neurologist.

(Chana)

A lack of further discussion of a dgm's attribution of her bodily experiences to causes other than the chronic illness may also be inferred from a lack of further discussion of the proposed cause.

... (dgm's assessment) I actually had one person who thought I was an alcoholic, anorexic because I am this thin. (Linda)

... (dgm's assessment) Of course my family doesn't accept it. They just say, "Oh, she's just mentally ill. She doesn't really have a disease." (Linda)

Again, I theorize that these experiences of rejecting the assessment of one dgm occur in conjunction with the acceptance of another dgm's assessment. In many instances, the dgm's assessment who is accepted here is a medical doctor, but as Chana's experience demonstrated, this is not always the case. Comparing Jennifer's continuing uncertainty about the causes of her bodily experiences with Linda's and Chana's attributions solely to their chronic illness, I theorize that rejection of the correctness of dgms' attribution of her bodily experiences to causes other than the chronic illness, combined with her self-determination of causation, and the internalization of the assessments of other dgms who attribute these experiences to the chronic illness, would lead to attribution to the chronic illness. As presented in figure one, this clarity

and confidence in the attribution of her symptoms to a chronic illness contributes to her movement into the phase of Tentative Internalization.

Turning to the course of events that follow after a dgm attributes her bodily experiences to the chronic illness, she may either accept and internalize or reject the authority and correctness of the dgm's assessment. Dgms' attribution of symptoms to the chronic illness was either a) implied by their supportive or assisting actions, which were notably absent in every recounting of dgms' who attribute her bodily experiences to causes other than the chronic illness or b) are explicit in the case of a doctor's diagnosis.

... [the nurses she works with] know that I have lupus... I have talked with the nurses I work with and they do not lock the second door [on the narcotics cabinet] because I can't turn the key...I think most of the nurses are sympathetic...they know that I give good patient care. (Jennifer)

... finally [her doctor] said that I had lupus (Jennifer)

... I told my husband I really wanted to go to college before I die, because he and I both thought I was going to leave this earth. He said ok...my husband would read the textbooks to me while I was in bed...walk me to class... read over my notes for me and everything...He still has this idea that it's going to go away. He still holds on to, "Oh, you're going to get totally well one day." (Linda)

In figure two, I have theorized that she may internalize the dgm's assessment, in which case she would attribute her bodily experiences to the chronic illness. This step in the model is not directly supported by data from the interviews, but rather is theorized to exist as a mirror event of the internalization of dgms' attribution of her bodily experiences to causes other than the chronic illness. It is possible that collection of data that would support this theorization may be difficult,

and it can not be inferred by the absence of self-questioning about symptom causation, as all participants experienced dgms' attribution of symptoms to causes other than chronic illness. Once again, this process is co-produced by her rejection of the assessment of dgms who attribute her bodily experiences to causes other than the chronic illness and her own determination of causation. This clarity and confidence in the attribution of her symptoms to a chronic illness contributes to her movement into the phase of Tentative Internalization.

Another possible course of experience is that she may reject the dgm's assessment and determine her own assessment of her bodily experiences. This rejection may occur directly in response to the dgm's attribution, or after first accepting the dgm's assessment. One participant shows this pattern of rejection after first internalizing a dgm's assessment

... I have taken myself off the prednisone several times, thinking that [the doctors] were wrong, that maybe this was just some emotional thing. (Jennifer)

Although immediate rejection of a dgm's attribution of the symptoms to her chronic illness was not directly supported by data from the interviews, I theorize it to exist as a mirror event of the immediate rejection of the authority and correctness of the dgm's attribution of her bodily experiences to causes other than the chronic illness. It is possible that further collection of the experiences of women with chronic illnesses may produce accounts of this particular type of experience. Once again, her rejection of one dgm's assessment is co-produced with her acceptance of other dgms' assessments and her own determination of causation. I theorize that this would contribute to her lack of clarity in attributing her bodily experiences to the chronic illness, which, as seen in figure one, contributes to her Refusal of the chronic illness.

*Movement from Temporary and Refusal to Tentative Internalization*

Two factors appeared to contribute to the individual's movement into Tentative Internalization. The first of these, continuation of the symptoms over time, was particularly relevant for the participant who, due to a previous experience with diabetes, anticipated that her new chronic illness, lupus, would also disappear after a period of time.

...But after a year went by and nothing happened, and I just realized that [the lupus] is not going to go away and I need to change my lifestyle. (Linda)

The other influential factor was her perception of the effectiveness of the medication.

...then I found out that taking the medicine made me feel better and I didn't have to be in bed as long. So that was the next process. (Linda)

... So I was in denial with it for awhile, but when I tried to come off the prednisone, bamm, right back again. (Jennifer)

*Tentative Internalization to Definitive Internalization*

The third course of development was a direct and almost immediate movement into the Tentative Acceptance sub-phase of Searching for Information. The third participant immediately began focusing on the chronic illness, search intensely for information through websites, literature, medical sources and support groups, with this search nearly dominating her life.

...it seems that as soon as I got the diagnosis that was all I focused one...reading every book I could get my hands on, on every internet website, was doing literature searches in the medical journals for what was going on...spending a lot of time on that, almost obsessively. (Chana)

Chana had a clear diagnosis, but due to the nature of her chronic illness, multiple sclerosis, a clear prognosis was not available, which led her to search for and create her own guidelines of

what she could expect to happen in her life. Chana used the medical statistical norms to create this beginning map of what she could expect.

...the doctor could not give me any kind of prognosis, I think I was trying to determine my own, because this is a disease that no one knows what will happen from one day to the next...so trying to figure out what's next...without knowledge of what is coming next, it is kind of hard to determine what plans you need to make. (Chana)

She was also motivated to learn more about her chronic illness in an effort to better manage her disclosure experiences.

...almost as though [I was validated] with an actual diagnosis...I wasn't a head case. And so if anybody asked what I had, I could actually answer like I knew what I was talking about. (Chana)

Through this search for information, she was able to match her bodily experiences with the reported symptoms of others with the chronic illness, increasing her clarity and confidence in attributing her bodily experiences to the chronic illness. She found this experiences very fulfilling.

...looking for identification, yeah I had that [symptom] too...maybe the doctors are right. (Chana)

As presented in figure one, Chana recounts this as a cycling experience, with repeating matches between her experiences and those of other people with multiple sclerosis layering upon one another until she was finally confident in accepting the diagnosis. Chana's experience of Accepting however, was qualitatively different from that of Linda's or Jennifer's, and I have characterized it as Accepting with Focus. For her, Accepting involved a continued search for information, but with a change in focus on the type of information sought out, with her beginning

to pay greater attention to coping strategies, tips and tools that she could use to minimize the impact of some of her symptoms.

...It really was a change in focus from learning about what is going on to more coping strategies. (Chana)

For Chana, movement from Accepting with Focus to Definitive Internalization was “a no brainer”, appearing to flow from her acceptance of her chronic illness. Thus, Accepting with Focusing may function not only as a sub-phase, but also as a developmental catalyst.

Participants moving from a Temporary or Refusal phase into the Tentative Internalization phase appear to enter a sub-phase of Accepting without Focusing. Participants in this phase attribute their bodily experiences to their chronic illness, but may actively try to ignore the illness, refusing to make changes in how they live their lives.

... You want to forget about it. You try to put it on the back burner and say, “Well so what, I’ve got it.”...I was actually trying not to focus on it. It was more like being in denial... (Linda)

...stage where, though you know you are ill, you try to have the same lifestyle before you got ill. (Linda)

What changes they do make are efforts to maintain their pre-illness lifestyle and routine.

...There’s little tricks that I have learned in pulling patients up, where I don’t have to use a lot of grip with my hands...put the head of the bed down and the foot up...draw sheets (used to pull the patient up in the bed)...I have to double it...gives me more strength...I have talked to the nurses I work with and they do not lock the second door, because it is a circular lock and I can’t turn the key, I don’t have the grip. (Jennifer)

These changes are likely to be adaptive and assist her in managing her illness, but they differ markedly from the overarching lifestyle changes individuals engage in during Definitive Internalization discussed below. Although Linda categorizes this phase as a type of denial, this may be more of a product of her current location within Definitive Internalization. For an individual who is just entering this phase from Refusal or Temporary, this experience is likely to be perceived as a move away from denial.

In the current study, an increase in performance demand was the only factor that appeared to contribute to an individual's movement from Accepting without Focusing to Definitive Internalization.

... It is kind of easy [ to forget about the lupus] when you work a job and you're at home...it's kind of easy to just go through a routine. But when I went to grad school ...[the lupus] interfered quite a bit. Then it became just a big thing with me having lupus because I had to pay attention to [the lupus] if I wanted to get through grad school ...It became a big part of my life again ...I think that really helped me because before I went to grad school I tried to forget about It (Linda)

Linda's experience of maintaining a routine and how it facilitated her ability to "not focus" on her chronic illness and "keep it on the back burner" prior to the increase performance demands of graduate school, are similar to Jennifer's current experiences, where she appears maintain her career and routine by making a few modifications.

... There's little tricks that I have learned in pulling patients up, where I don't have to use a lot of grip with my hands...put the head of the bed down and the foot up...draw sheets (used to pull the patient up in the bed)...I have to double it...gives me more strength...I

have talked to the nurses I work with and they do not lock the second door, because it is a circular lock and I can't turn the key, I don't have the grip (Jennifer)

### *Definitive Internalization*

Both participants who moved into Definitive Internalization first entered the sub-phase Making Lifestyle Changes, where they made overarching, frequently pro-active, changes that effected several aspects of their lives.

... That's just to say that everyday I have to think about my illness...The reason I do that is that I have to make sure I maintain a certain type of lifestyle so that I do not have flare-ups. Part of that lifestyle requires me to take medications everyday...I hate medication...I actually hate it and it is very difficult for me...I've had to get a better diet...I have had to increase vegetables. I hate vegetables...And exercise is another thing that I do now...It also requires me to think about my activity level...I actually plan out what I am going to do...I have to actually plan my day around my illness. I know that sounds like it is controlling me, but no, I don't feel like my illness is controlling me. I just feel that I have to adapt to it and part of that requires me to think about what I'm going to do everyday so that I don't have a flare-up. (Linda)

... My house...is built literally with a change in perspective toward the future. I also live with someone who has a chronic disease, and in the beginning we'd say, "You know, we may or may not need to have accommodations, but we're going to build a house that we will both live in for the rest of our lives...we built this house handicap accessible ...like making sure the doors are wide enough (for a wheelchair)...it's got high toilets in it. They didn't put any rails in there, but the studs are there. It's got a big tub in the corner with steps up to it. Made sure the [carpet edger's] are low and flat, low-pile carpet or



hardwood in everyplace (so a wheelchair could move easily)... instead of using doorknobs, levers, because they're much easier to open a door and it doesn't require any grip coordination, so there were a lot of little details. (Chana)

Linda explicitly describes her modifications as a lifestyle change, while during the follow-up interview, Chana agreed with the assessment that her considerations in designing her home were also lifestyle changes. These modifications are qualitatively different from Jennifer's changes, which were relatively separate events that do not fit together to produce an overarching change in her lifestyle.

... I have always been a cleaner...since I've had lupus, I have not been that way...

(Jennifer)

...There's little tricks that I have learned in pulling patients up, where I don't have to use a lot of grip with my hands...put the head of the bed down and the foot up...draw sheets (used to pull the patient up in the bed)...I have to double it...gives me more strength...I have talked to the nurses I work with and they do not lock the second door, because it is a circular lock and I can't turn the key, I don't have the grip (Jennifer)

Participants in this sub-phase also experienced a daily focusing on the illness.

...thinking about it everyday... (Chana)

One participant also experienced a redefining of the selves, with the chronic illness becoming part of one's own self definitions.

...another phase that I was going through was to define myself at that time. It was almost like I first had to redefine myself... as a unique individual with a chronic illness (Linda)

The next sub-phases experienced by both participants was Decreasing Focus, where she is no longer thinking about the illness daily and it is no longer of overriding importance in her daily life.

...thinking about it everyday and now, reached a point where I don't want to think about it everyday. (Chana)

... I think that is the phase that I am just entering now...got rid of my handicap license plate...going to start taking the stairs again at work...I want to go back on my old bike [instead of recumbent trike she bought when she began to have balance problems]...so again you've got that struggle between my perception of me and other people's perception of me...whether or not I'm sick enough...its a real battle quite frankly.

(Chana)

However, this differs from a potential return to Tentative Internalization (which was not demonstrated by any of the participants) in that the individual continues some of her previous lifestyles changes. This Decreasing Focus involves not only the absence of daily thoughts about the illness, but as evident in Chana's dialog above, efforts to decrease it's impact on her life by reclaiming previously relinquished activities or forgoing previously accepted modifications. This may be characterized as a testing previously accepted limitations, which appears to be tied to one of the social factors prompting movement into this sub-phase; a lack of relevant life guidelines and thus a need to develop one's own boundaries.

... See, I don't have the foggiest idea how I'm supposed to feel about [MS] or how I'm supposed to act about it, I really don't...I went to the support group for people with MS. Me and the new guy are the only two in the room still working...one's in a scooter, one's in a wheelchair...I'm not blind yet, am one of only three people in my group who are not

blind...there is only one other woman in my group and she is 83...[MS] is much more progressive for men. (Chana)

Thus, although Chana is a member of support group for people with MS, her unique location in her disease progress, compared with the locations of other group members, decreases the relevancy of their life guidelines for her. Another factor that may contribute to Decreasing Focus is that the lifestyle changes she has made have become routine, and thus no longer involve conscious thought.

...You don't even have to think about it, its just part of your life. (Linda)

A final factor is the structure of the medical regiment, with invasive, daily medical interventions making it difficult to not think about the illness on a daily basis, while monthly interventions facilitate a movement away from daily focus.

...when I was taking my shot everyday, you know that's always going to remind you of the illness, so it is hard not to think about it daily. But now I go up to [large city] and get an IV infusion once a month, and I find I sometimes go two or three days without really thinking about the MS at all. (Chana)

A third sub-phase is Refocusing, where the individual once again begins thinking about her chronic illness on a daily basis. Both participants were clear that they saw this as "very different" from Making Lifestyle Changes, specifying that they were already bringing previous lifestyle changes with them into this phase.

...not a whole lot of information or identification seeking as much as there is, ok, assume this is the disease, let's do something about it and bet back on our feet as quickly as possible...but there can be lifestyle changes that go along with that, its not happened to me but I have seen it in others. (Chana)

Movement into this sub-phase appears to be prompted primarily by an increase in symptoms expression through a relapse, flare-up, or seasonal changes.

...I think there is a loop that goes on, at least for people that have relapsing, remitting progressions, that when the disease raises it head again, it brings it back into focus, at least temporarily. (Chana)

As evident in Chana's dialog above, participants experienced the connections between Decreasing Focus and Refocusing as a re-occurring loop, with Linda also stating that she "has gone back and forth several times". Linda's explanation of the difference between Decreasing Focus and Synthesis suggests that efforts to develop one's own guidelines are one of the driving forces behind this loop.

...I have already established my own boundaries or guidelines, so [Synthesis] is really very different because I know what I can and can't do and what I need to do. (Linda)

Synthesis appears to be a sub-phase where the individual negotiates her identities as a person with a chronic illness in relation to other aspects of her selves, with relatively equal focus on each of them.

...I'm not only a person with a chronic illness, but I'm a person who has other unique qualities. (Linda)

Movement into this phases was prompted by an event that increased her awareness of her other unique identities; involvement in a support group for women with chronic illnesses. This group membership heightened her awareness of parts of her selves that differed from those of other members.

...it made me pay attention to a lot of other things in my life, like who I was as a person, not just a person with a chronic illness, but who I am as an African-American

person...who I am as a married woman...I just started thinking about that. The reason that I started doing that was because when I went to the support group, these people that had these illnesses, they had other backgrounds than me...it just opened my eyes to see that I'm not only a person with a chronic illness, but I'm a person who has other unique qualities. (Linda)

For Linda, this resulted in an exploration of other parts of her identities, decreasing her focus on her chronic illness and eventually producing an experience of integration of her chronic illness and other aspects of her selves.

A final sub-phase is Wishful Thinking, where she engages in wishful or hopeful thinking that somehow the illness will go away, that she could do things that are restricted by her illness.

... just wishing some miracle would make it go away or even trying to make it happen, saying "I don't feel very well, but I'm still going to go out anyhow." (Linda)

During further inquiry about the distinction between this and other sub-phases, such as Decreasing Focus, it became clear that the distinction was the individual's response to bodily cues. In Wishful Thinking, she ignores bodily cues indicating a need to change her behavior due to the illness, where as in other sub-phases she would have acknowledged the cues and made the necessary adjustment. Both Linda and Chana described these sub-phases as occurring throughout their experiences of other sub-phases, as indicated in figure four by the connection of this sub-phase with all others through double-headed arrows.

### *Myself within the Model*

My own experiences of developing my chronic illness identities charts a fourth course through the model. Similar to Chana, I moved almost immediately from Diagnosis and Acknowledgement to Tentative Internalization, but unlike her I feel that I moved into the sub-

phase of Accepting without Focusing. I strove to live my life the same as before the onset of the illness, only begrudgingly making changes forced upon me by the illness. After a couple of years I moved in the Definitive Internalization sub-phase of Making Lifestyle Changes. Like Linda, this change occurred in response to my increasing performance demands resulting from entering graduate school, where I realized that I would have to make significant adaptations to the illness if I wanted to succeed in graduate school. These adaptations progressed into lifestyle changes, many of which I maintain today. I have experienced all of the sub-phases of Definitive Internalization except Synthesis. I feel that my own experiences of re-cycling through Decreasing Focus and Refocusing match those of both Chana and Linda, and agree with their assessment that these sub-phases are driven by efforts to establish one's own guidelines and boundaries.

### Discussion

One experience shared by all participants was negotiating acceptance of the illness as real, and permanent, and thus relevant for their selves. The primary influential factor for Accepting was a clear and confident attribution of her bodily experiences to the chronic illness. This appears to be necessary for movement into either of the Accepting sub-phases, and thus movement into the phase Definitive Internalization, suggesting that this may be a type of threshold event. This fits with Charmaz's finding in her non-gender specific model (1999) that coming to define the changes in one's body as related to the illness and thus making the illness relevant to the selves is necessary for incorporation of the illness into one's sense of selves (Managing the Illness). The presence of similar experiences and outcomes in both Charmaz's non-gender specific model and the current women-specific model strengthens the likelihood that this is a reliable and important component of the development of chronic illness identities. The

absence of a comparable phase in Charmaz's men-specific model (1997), suggests that this may be a phase more relevant to the experiences of women than men, but further exploration between the genders would be necessary before making this conclusion.

Unlike the Charmaz model, the current study differentiates between two different types of incorporation of the illness, or Accepting. The current data suggests that an individual's Accepting experiences and attitudes are influenced by her previous phase or sub-phase. Thus, when one participant accepted her illness as real and permanent, she maintained her previous efforts of the Temporary phase of not focusing on the illness. Similarly, another participant's acceptance of her illness maintained her previous efforts of the Searching for Information sub-phase of focusing on the illness. In this way, different outcomes are apparently produced by the same processes, with differences attributable to previous differences in location.

The current study also presents some of the societal factors that appear to influence a woman's clarity and confidence in attributing her bodily experiences to the chronic illness. One factor whose influential absence and presence were both evident in the data was her perceived match between her bodily experiences and the symptoms reported in connection with the chronic illness (by either the medical literature or others with the illness). One participant specifically described finding repeated matchings as part of her identification process, whereas another participant presents her lack of matching as one of the reasons for her periodic doubts about her diagnosis. Another factor whose influential presence was evident in the data was an overlap between aging and chronic illness symptoms. The hindering influence of the presence of this factor is suggested by its association with one participant's continued cycling between Refusal and Accepting without Focus. A mirroring of this would suggest that a lack of this overlap would facilitate her attribution of her bodily experiences to the chronic illness. A third factor

was type of diagnosis. Similar to overlap with aging processes, the hindering influence of a diagnosis by default (based solely on the elimination of other plausible causes) is suggested by the association of this type of diagnosis with one participant's continued cycling between Refusal and Accepting without Focus. A mirroring of this would suggest that a direct diagnosis (including meeting diagnostic criteria on specific tests) would facilitate her attribution of bodily experiences to the chronic illness. Other factors that appeared to exert an influence were previous experiences with another chronic illness and previous medical experience. In the current study, both of these appeared to hinder the participant's attribution of her bodily experiences to the chronic illness. However, this is likely due to the nature of these previous experiences, and thus different previous experiences with a chronic illness or the medical profession may produce different outcomes.

Participants' experiences also suggest that disclosure to dgm's plays a hither-forth unnoticed role in this attribution of symptoms. As detailed in figure two, after an individual has disclosed to a dgm, usually in connection with explaining symptom expression, the dgm may either attribute her bodily experiences to the chronic illness or some other causative agent. The individual may then either accept and internalize the dgm's assessment or reject it, with the final outcome either increasing or decreasing her attribution of her bodily experiences to the chronic illness, which in turn either facilitates or hinders her Accepting the chronic illness. Comparing this to the Cass Model of Homosexual Identity Development (1979) reveals that although disclosure experiences play important parts in both models, their resulting outcomes are markedly different. In the Cass Model, the responses of dgms either facilitated or hindered further disclosures, along with influencing the individual's perception of the value of the non-dominant group with which they identify, and thus by association their own self-value. By



facilitating or hindering further disclosures, these experiences would influence the individual's ability to create a harmony between their personal and social selves, to the extent that she or he cannot create social identities as lesbian or gay without disclosing to dgms. This differs from the current study, where disclosure experiences with dgms appear to interact with other factors to influence whether or not she attributes her bodily experiences to the chronic illness. An equivalent event in the Cass Model would be if the disclosure experience influenced the individual's self-perception as lesbian or gay. Thus, although disclosure experiences appear to play a vital role in the development of both lesbian and gay and chronic illness identities, the ways in which they influence the identity development processes appear to differ significantly.

Another important component of the Cass Model is disclosure to same-group members and their resulting responses. Although all participants experienced disclosures to same-group members, either through support groups or in a one-on-one basis, it was not apparent how they may influence the developmental processes of chronic illness identities. This lack of clarity regarding influence may be due to either the sparse data available, compared with the number of disclosers to dgms experienced, or the possibility that these same-group disclosures may exert an influence indirectly through self-esteem, which was a component not addressed in the current study.

Figures one, three and four suggest that two types of movement occur during the development of chronic illness identities. The first of these is the linear movement from Symptom Expression begins to Definitive Internalization's sub-phase of Making Lifestyle Changes. Although participant's followed various courses in this movement, with some cycling, the order is relatively sequential. This differs from the movement within Definitive Internalization, where participants appear to move from one sub-phase to another without any set

order and apparently involving a greater deal of cycling. It is also interesting to note difference in phase and sub-phase experiences during components of apparent linear and un-linear development. Not all phases or sub-phases prior to Definitive Internalization were experienced by all participants or myself, but rather each person appeared to chart their own unique course, experiencing only a few of these phases or sub-phases. In contrast, all the sub-phases except Synthesis were experienced by myself and both participants who moved into Definitive Internalization. However, these suggestions should be viewed cautiously, as other factors besides the developmental processes may have produced these results. Since one participant did not appear to have experienced Further Internalization, I had less data to work with for this phase, which may have hindered my ability to establish a clear direction. Further inquiry into the experiences of Definitive Internalization is needed to further illuminate and clarify the process occurring with this area.

Identity interconnections where other identity domains influenced the developmental processes of chronic illness identities were evident in several places within the model. As previously noted above, one participant's work identity as a nurse appeared to have decreased her confidence in her medical diagnosis. A second location of change occurred within Definitive Internalization, where one participant recounted that through her experiences in a chronic illness support group she came to realize that she had other unique aspects of her selves (age, marital status, ethnicity) that differentiated her from other members of this group. Shifting her focus from her chronic illness to these other aspects of her selves, she experienced a Synthesis, where her chronic illness became only one of several important identity components. A third area of expected identity interconnections raised in the beginning of the study, but which was not apparent in the data, was that of mother and its heavy association with a person's

identities as a woman. Lack of these experiences in the current study is most likely due to characteristics of the sample, where two participants had already had children before Symptom Expression Begins, while the third is a lesbian. Future inquiries with younger women, and perhaps especially those that have recently married may reveal important interconnections between these two identity domains.

The conclusions of this current study are restricted by a few limitations but also have several strengths. One limitation is the lack of individual differences factors. The models produced in the current study emphasize social factors, and although they suggest areas of individual differences relevant for further study, due to the difficulty in assessing these differences through interview data, these factors are not incorporated into the current models. The second limitation is the inability to generalize these conclusions to individuals outside the study, due to the small sample size. However, it is this small sample size that facilitated the deep immersion in the data necessary to produce such a detailed model of experiences and ground the analysis in the voices of the participants. In addition, this study was produced from an insider's perspective, producing both a high degree of rapport between the interviewer and participants (as evident in the length, detail and content of the interviews), along with an approach to the data that differed from that of other previous researchers. These strengths are evident in the participant's positive follow-up assessments of the initial models, which were then further modified to provide a more accurate reflection of their experiences. Furthermore, inclusion of an interviewee-driven component of the interview that involved previous reflection on the topic produced both a heavy cognitive engagement during the initial interview, as evident by epiphanies expressed by each participant, along with facilitating the inclusion of topics beyond the researcher's points of inquiry.

Perhaps the largest contribution of this study is the many new directions it offers for further inquiry. Further data needs to be collected with this same population and methodology, incorporating each individual model into the end-product model of the current study in an effort to produce a more generalizable model, to clarify finding suggested by the current data, and to add greater depth to the understanding of experiences of Further Internalization. The results of this study also suggest a need for a greater focus on the potential influences of disclosure experiences with both dgms and group members. Specifically, a dependent T-test design that collected before and after data regarding strength of attribution of symptoms to chronic illness, with an independent variable of response from dgm, would facilitate understanding of this event as a potentially causative factor in the development of chronic illness identities. Also, potential connections between self-esteem and chronic illness identities need to be explored. This study also suggests specific areas of individual differences that may be influential in the developmental processes. For example, it is possible that locus of control (internal/external) may influence the degree to which a person would internalize another's attribution of her bodily experiences. In sum, I offer the findings of this study as a first step in developing a more detailed, representative model of women's development of chronic illness identities in the hopes that dissemination of future research guided by the directions suggested by this model will provide population members with new ways to think about themselves, their lives and their futures.

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Table 1

*Content of Participants' Photos Produced for Discussion during Initial Interview*

Participant Pseudonym	Description of Photo
Linda	Self opening and closing a door (symbolic)
	Self during a "sick day", at home in a bathrobe
	Self with an indoor plant
	Self with a sheet of music for singing
	Self with a bottle of medication
	Self in front of her computer
	Self with her Bible
Jennifer	Bottles of medications on a counter
	Her dog laying on the carpet
	Her grandson playing outside
	Her bathroom
	Her bedroom
	A collection of cleaning supplies
	Her some of her co-workers at work
Chana	Her three-wheel bicycle that helps with her balance
	Her new house
	The sign where she turns to go to her support group meetings
	A handicap parking sign
	Her medication on the kitchen table
	Her wedding photo and Jewish religious items on the mantel

Figure 1: Phases of the Development of Chronic Illness Identities

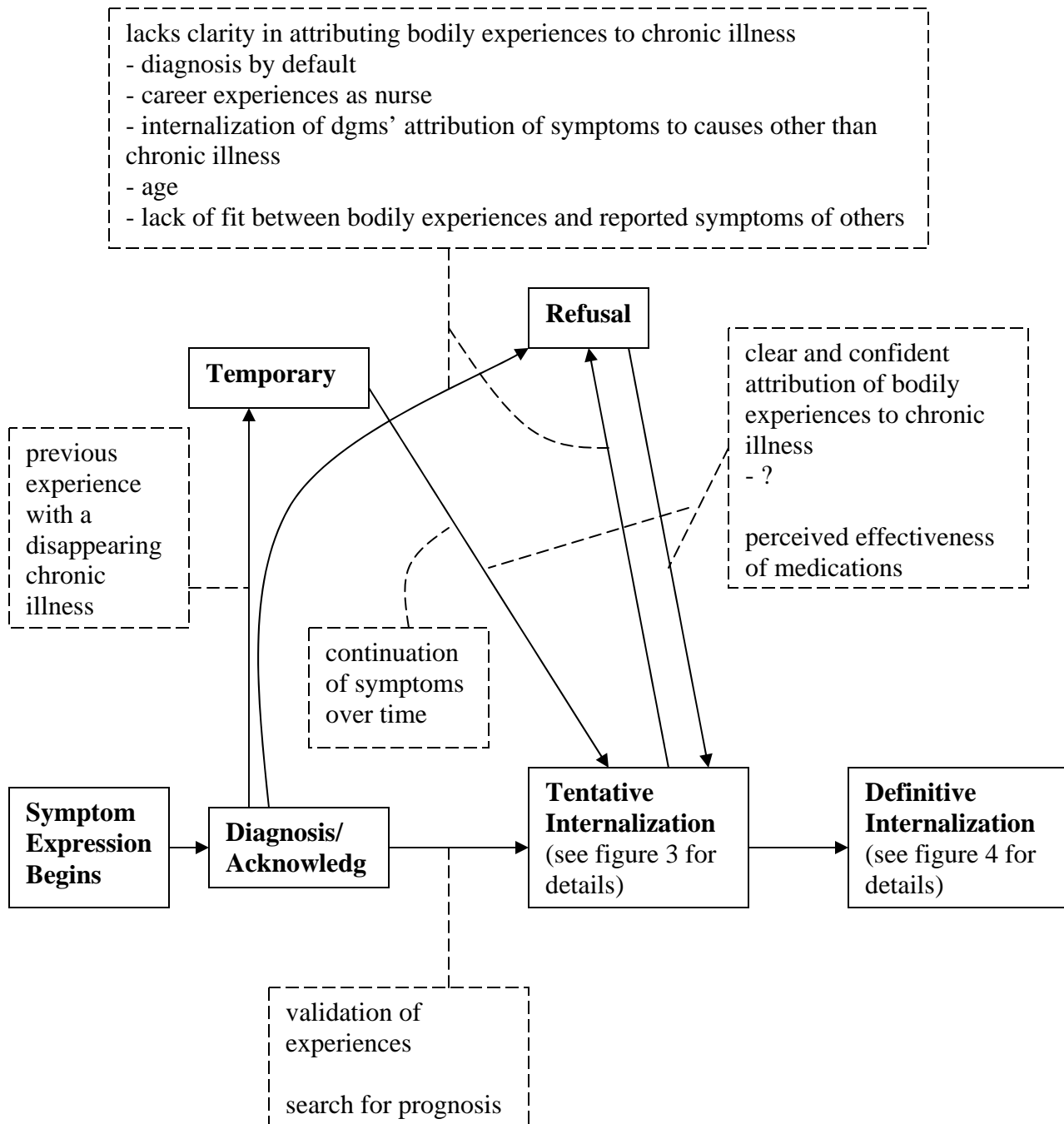


Figure 2: Outcomes of Disclosure Experiences with Dominant Group Members

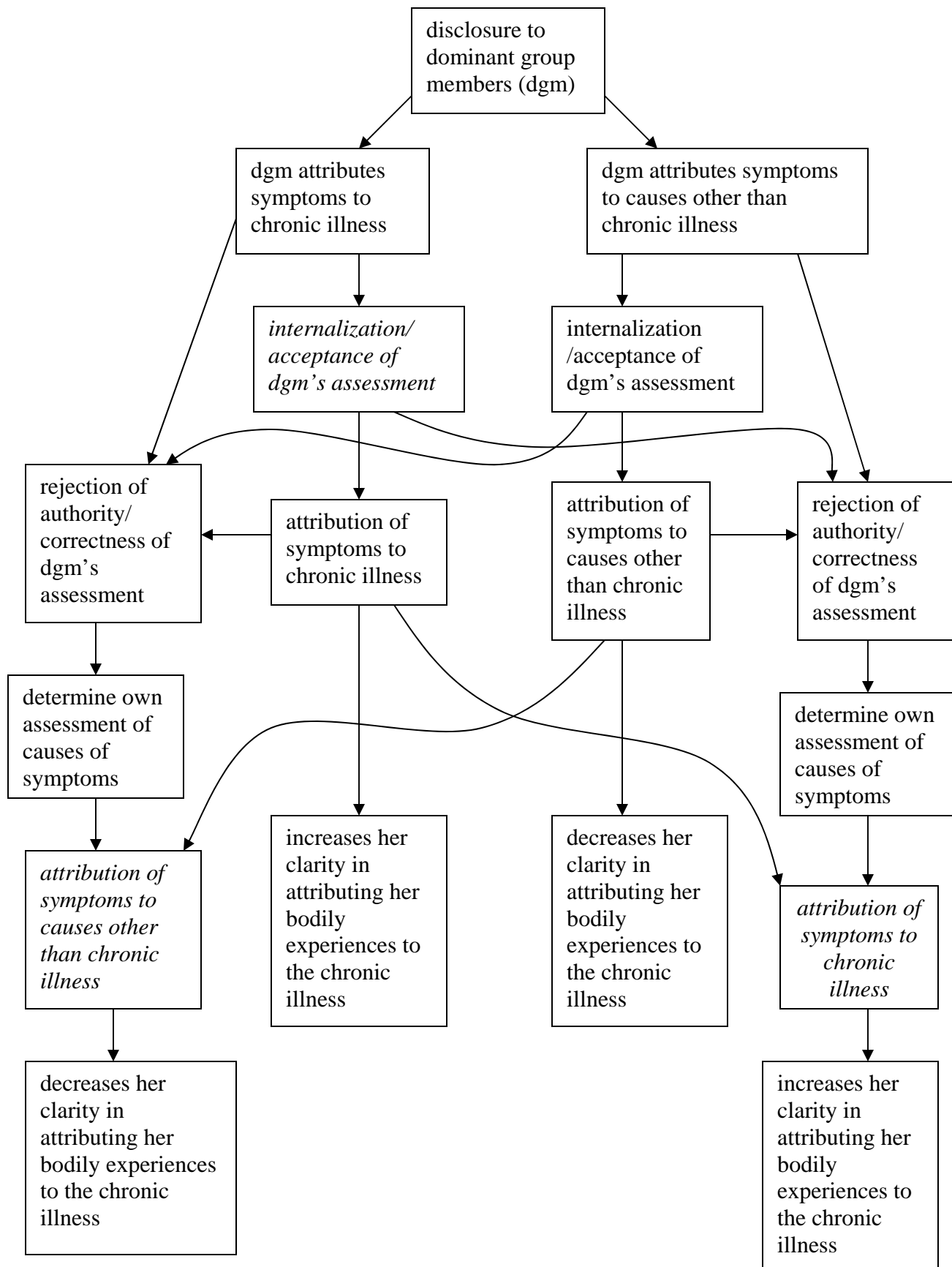
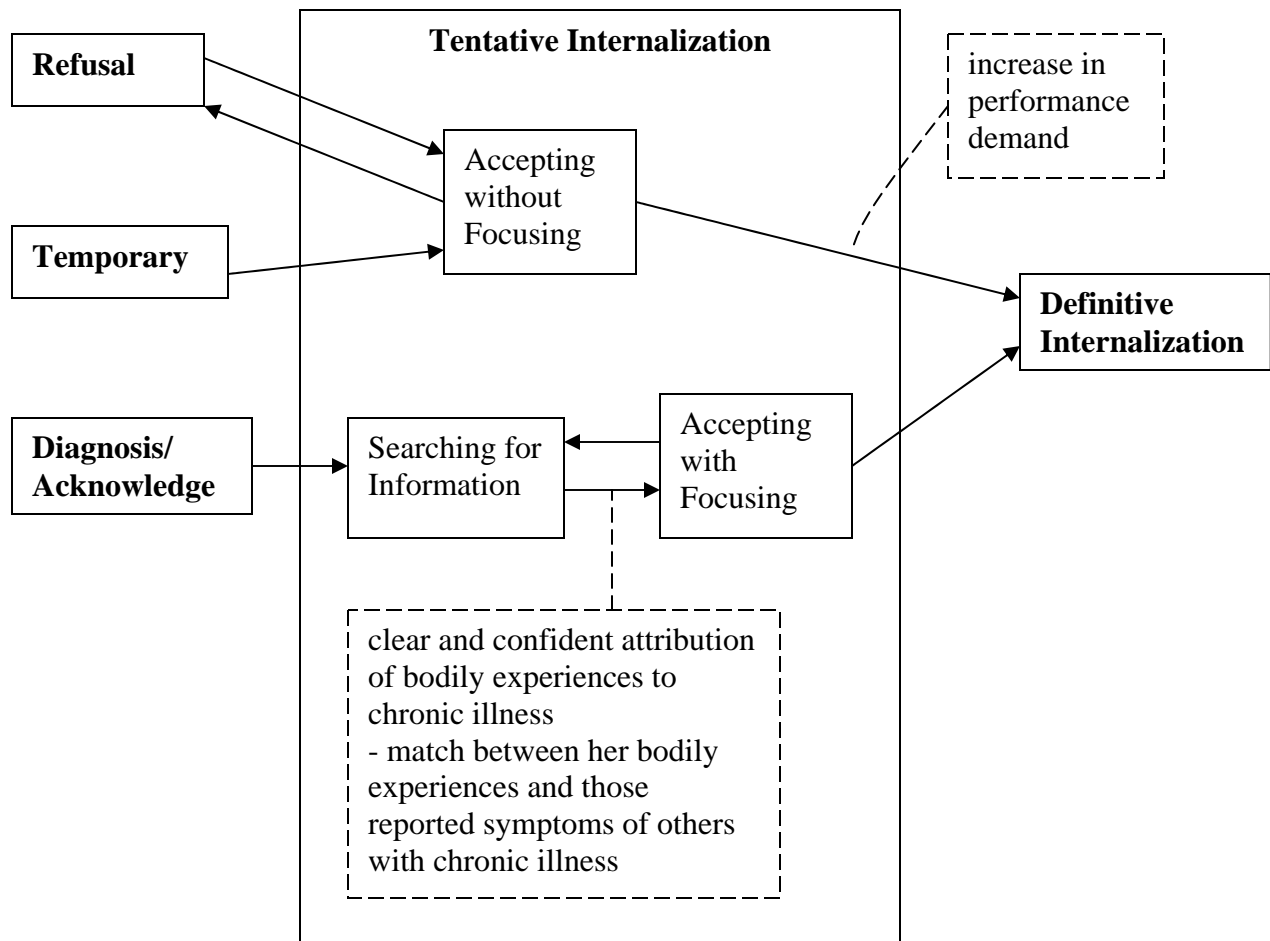




Figure 3. Sub-Phases of Tentative Internalization



**Key:**

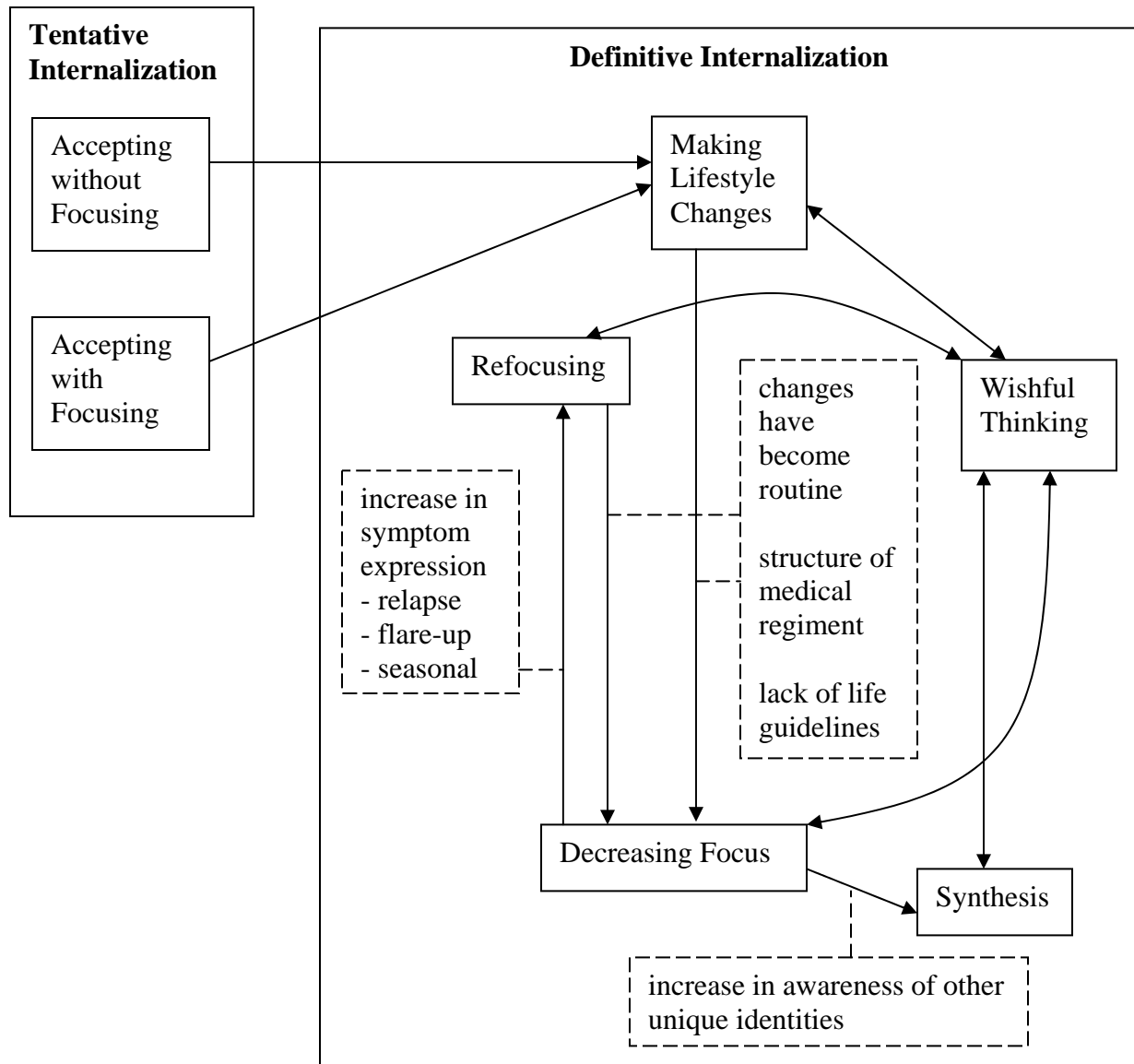
bold are primary phases of the model

un-bold are sub-phases of the model

— solid lines are phases of the model

--- dotted lines are apparent influential social factors

Figure 4. Sub-Phases of Definitive Internalization



### Key

bold are primary phases of the model

un-bold are sub-phases of the model

—— solid lines are phases of the model

---- dotted lines are influential social factors