# Transcendence and Transformation in the Life Patterns of Women Living with Rheumatoid Arthritis

Considering personal life stories as the context for health transitions can enhance understanding of what is meaningful in living with chronic illness. Informed by Margaret Newman's theory of Health as Expanding Consciousness, this interpretive study described the life patterns of three women with rheumatoid arthritis as a process of expanding consciousness. The women's stories revealed transcendence of self-boundaries and personal transformation as new ways of living, including "simple pleasures" and "being positive." Through understanding life patterns within caring nursing partnerships, transitions in an entire life story can be appreciated as complex processes involving transcendence and transformation. Key words: expanding consciousness, life patterns, rheumatoid arthritis, self-transcendence, transformation, transition

Jane Neill, RN, PhD, FRCNA
Senior Lecturer in Nursing
School of Nursing and Midwifery
Flinders University
Adelaide, Australia

ERSONAL life stories provide a rich Context for understanding what it is like to live with chronic illness, and they highlight the importance of caring, healing relationships in nursing. Such stories can inform nursing practice, but these accounts should not be limited to the events of illness. Life patterns can reveal how people respond to transitions and enhance awareness of the whole person. This is useful in nursing practice because there is not only acknowledgment of individuality, but also a wider context for understanding the person experiencing illness. In understanding transitions, nursing practice needs to be informed not only by the story of illness that a person relates, but also by what illness means in the context of each life story.

The work described here began as a personal journey toward appreciating the complexity of living with a chronic illness. Partnerships with the women in my doctoral study and Margaret Newman's theory of Health as Expanding Consciousness<sup>1</sup> helped me recognize the importance of self-

transcendence and personal transformation to transitions in life patterns. Transitions have been defined in various ways, but usually as processes of change occurring over time, involving directional development or movement between life phases.<sup>2</sup> Apart from normative changes in relationships, roles, identities, and abilities, transitions can refer to situational, health/illness, or organizational changes.2 In the context of expanding consciousness, however, transitions are most obvious as one life pattern shifts to another. The process of expanding consciousness occurs continuously throughout life, and greater complexity evolves during sequential transitions through times of adversity and their subsequent resolution.

Life patterns have not been described for people experiencing autoimmune illnesses. Rheumatoid arthritis is one chronic autoimmune condition with the potential to restrict movement through its systemic, degenerative, inflammatory effects on joints and connective tissues. Concerns of women with this illness are not always distinguishable in the literature from those of men, and although plenty is written about rheumatoid arthritis from psychosocial or biomedical perspectives, there is little unitary-transformative nursing research in this area.<sup>3</sup> The study described here elucidates life patterns of women with rheumatoid arthritis, achieved through a nursing partnership embodying the theory of Health as Expanding Consciousness. It illuminates health transitions and discusses evidence for self-transcendence and personal transformation in the process of expanding consciousness.

#### THEORETICAL FRAMEWORK

Research drawing on a unitary-transformative worldview has contributed theoretical and methodological traditions unique to nursing's central concern with people and how they experience living in the world. This paradigm considers the wholeness of the person,<sup>4</sup> and nursing relationships can facilitate conditions for individual, family, or community change. These conditions occur when individuals or groups gain insight into their unfolding pattern of interaction with others.<sup>1</sup> Change is regarded as unpredictable, but indicative of increasing complexity; it is consistent with unfolding patterns in life processes.<sup>5</sup>

Margaret Newman's ideas about health and illness as unitary and transformative processes helped me rethink my previous understandings of these concepts as separate and causal. Her initial flash of insight "revealed health and illness as a single process and, like rhythmic phenomena, became manifest in ups and downs, or peaks and troughs, moving through varying degrees of organization and disorganization, but all as one unitary process." 1(pxxv) Subsequent synthesis of ideas brought the concepts of "all that is disease" and "all that is not disease" together as a unified theory of health<sup>1,6</sup> that she conceptualized as a process of expanding consciousness.

Consequently, Newman regarded any manifestation in a person's life as expressing an unseen, underlying pattern, and of providing meaningful information about interactions between people and their environments as a whole. These interactions can be understood as unfolding life patterns changing their expression over time and enfolding previous manifestations. For this reason, understanding health as the expansion of consciousness and recognizing unique life patterns render chronic illness meaningful in this unitary context of wholeness—a truly liberating idea.

Expanding consciousness is an irreversible but continuous process that unfolds throughout life in which transitions to greater levels of complexity are evident. In her early work, Newman9 described seven stages to this process with a developmental flavor, although they do not necessarily correspond with chronologic life stages. 10,11 While these stages are often depicted as having a certain linear order, they are not definitive categories or grades. They represent a general direction for expanding consciousness, from increasing disorder and restriction in movement before a critical point toward increasing order and freedom in space and time through self-transcendence and personal transformation. People are unique in their ongoing evolution of consciousness, and there are no standards for progress.1 Congruent with Rogers'5 view of all life as dynamic, non-linear change in the direction of increasing complexity and diversity, there is no strict succession of events, although the process occurring in expanding consciousness is irreversible. Life patterns reveal individual transitions toward more complex and diverse lives, and they indicate transcendence and transformation in the process of expanding consciousness.

### Transcendence and transformation

At least once in life, but sometimes more often, there is a turning point, then a critical choice point in the evolution of consciousness. For this reason, the stage of *Movement* in Health as Expanding Consciousness<sup>1,9</sup> is perhaps the most interesting and relevant to transitions, for it concerns the process of finding more complex, higher-order solutions to disordered or uncertain situations. This does not mean a particular event causes change, but rather it provides the conditions for individuals to see situations differently

and make deliberate choices for action. Newman<sup>12</sup> theorized that extreme instability and turbulence in human lives, for example during illness, despair, disablement, or death, precede resolution to a more harmonious state or higher level of complexity, known as expanded consciousness. The main task is tolerating ambiguity and uncertainty in order to learn new ways of being that transcend previous constraints, especially when there is a tendency for holding on to former patterns.<sup>1</sup>

Disorder, turbulence, chaos, and restriction to movement in space and time are important precursors to new order and greater complexity. Insight reveals alternatives, such as living with chronic illness differently by making new life choices, and offers potential for personal transformation by releasing previous preoccupations with the self and transcendence of previous limitations through inner growth. Consequently, self-transcendence and transformation are important aspects of transition to greater complexity, and thus of expanding consciousness.

### **Self-transcendence**

Self-transcendence refers to acceptance of adverse situations that cannot be changed and a reorientation toward hopeful participation in life. It results from intrapersonal, interpersonal, and temporal experiences that expand the boundaries of self-concept.<sup>17</sup> It is characterized by connectedness, giving and

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#### Personal transformation

embodied preoccupations.

Transformation is recognized as a process of living with limiting, long-term or life-threatening illness, as well as an outcome of confronting an illness-related challenge. 25,26 It is thus well described as a journey with no final destination.<sup>27</sup> During the process of transformation, "earlier developmental forms of the self (old ways of thinking and being) that limit one's ability to integrate new life experiences" are transcended.<sup>28(p3)</sup> For people living with diabetes, periods of disequilibrium and threats to self-integrity follow an illness-related challenge, then an episode of insight resulting in "new ways of being and doing in living with diabetes" is central to transformation. 25(p795) This accords with Newman's idea of disorder providing opportunities to recognize and change previous ways of being. The literature identifies phases of transformation closely resembling the process of expanding consciousness.

### PREVIOUS RESEARCH WITH HEALTH AS EXPANDING CONSCIOUSNESS

The theory of Health as Expanding Consciousness has wide application in research and practice. Most examples supporting the theory were drawn from people in crisis or experiencing illness. Life patterns and the process of expanding consciousness have been described for people experiencing ovarian and breast cancer, human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS), heart disease, chronic lung disease, and mental illness, 10,11,14,16,29–31 as well as issues for women during midlife. These studies all reveal the relevance and breadth of application of the theory to the concerns of nursing.

In addition, the theory of Health as Expanding Consciousness has been useful in assisting individuals or their families to construct meaning from the experience of illness through caring partnerships with nurses. 10,14,16,29,33 Participants were asked to reflect on the most meaningful people and events in their lives, and each had the opportunity to recognize his or her own unique pattern of expanding consciousness through a process of dialogic engagement with a nurse researcher. Women experiencing ovarian cancer<sup>29</sup> and men experiencing HIV disease<sup>16</sup> were able to find meaning in their illness and to make choices about changing their present life situations. This included feeling empowered to take opportunities discounted previously, deepening spirituality, and being more open to sharing with, and caring about, others. Some individuals experienced insight into their lives through pattern recognition, through which they developed greater connectedness with others.

Insights appreciated through recognizing pattern can be empowering for people and mutually transformative for nurses. Through creative movement and dialogue, midlife women realized the importance of connectedness, and insight about challenges such as loss, illness, or threats to their relationships contributed to their expanding consciousness.32 Pattern recognition can be empowering for families, too. In situations where a woman who had cancer and her family were experiencing crisis, recognizing a pattern of interaction among family members helped them express trust and caring for each other through greater connectedness.<sup>33</sup> Distressed families whose children were repeatedly hospitalized also were empowered by new insights; through pattern recognition in partnership with a nurse, they transformed their family circumstances.34 Embodying the theory in a healing encounter, a nurse specialist helped an isolated, older woman experiencing chronic venous ulcers reveal her story of childhood sexual abuse,35 indicating the mutually transformative nature of expanding consciousness.

Conversely, people do not necessarily experience insight or find meaning in their illness through recognizing the patterns in their lives. Some people experiencing chronic lung disease or coronary heart disease manifested patterns indicating difficulty moving beyond the consequences of isolation, abandonment, loss of individual identity, and lack of connectedness. 10,11,14 Consequently, they were unable to change their usual ways of living with minimal complexity, illustrated particularly by a pattern of "isolation and being closed in" for people experiencing chronic lung disease.<sup>11</sup> Themes presented in these studies reveal individual processes of expanding consciousness. People experiencing personal transformation through illness or difficult life events found meaning in their lives through transcending self-boundaries, <sup>10,14,16,29</sup> whereas others experienced continuing turmoil until death <sup>14,29</sup> rather than personal transformation through new life choices. Although most of these studies elucidate life patterns, few others describe the lives of women with rheumatoid arthritis through Health as Expanding Consciousness.

One study by Schorr,36 using the theory of Health as Expanding Consciousness, explored the effect of music as a unitary-transformative nursing intervention. The chronic pain experiences of 30 midlife and older women living with rheumatoid arthritis were studied using a quasi-experimental design. The music intervention was successful in reducing the pain experience during and for a short time after the intervention.<sup>36</sup> Schorr suggested the environmental pattern could change the pattern of the person toward greater comfort. Although these findings are useful, they do not enhance understanding about the life patterns of women living with rheumatoid arthritis. It also is difficult to appreciate people as unitary human beings when they are studied in subject-object relationships, rather than engaging in mutual sharing of pattern that can be empowering in people's lives. No previous studies of life patterns for women with rheumatoid arthritis were evident in the literature; hence, this study was undertaken.

### **METHODOLOGY**

In my doctoral study, seven women who knew what it was like to live with autoimmune illnesses—rheumatoid arthritis or multiple sclerosis—volunteered to share

their life stories. From this work I sensed both life patterns and underlying patterns of the whole person.<sup>3</sup> One of the women with rheumatoid arthritis and one with multiple sclerosis had similar life patterns, though very different life stories. In general, the women's life patterns revealed unique expressions of self-transcendence and personal transformation. Underlying patterns also were unique, though all the women shared two patterns of "energy-fatigue" and "giving-receiving." These expressions are consistent with Newman's view of health and disease as manifestations of an unseen, underlying pattern of the whole person, and therefore inseparable.<sup>1,9</sup> Because of the intensity of their stories, in this article I focus on three women with rheumatoid arthritis to highlight the usefulness of life stories and patterns to understanding health transitions.

I used a variation of Newman's research protocol,¹ incorporating the use of reflective photographs to identify life patterns in the women's stories. This methodology is derived from the theory of Health as Expanding Consciousness and is consistent with the unitary-transformative paradigm. The research approach is not therapy in the sense of advice to people or intervention in the way they lead their lives, but the process of pattern recognition allows people to see their situations differently and illuminates action for transforming their lives.

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Hearing each woman's life story and sharing pattern insights required the establishment of mutual relationships. In the beginning, we had different interests in working together. Toward the end of the study, however, I sensed that our relationships had become reciprocal and were mutually transformative. The women remarked that they had experienced a catharsis and could now move on, or they saw things differently.3 In turn, I reflected on my life, and each story shared enabled me to recognize my own patterns. Subsequent reflections on the study revealed all of us had experienced it as a time of healing. Consequently, I refer to the mutual relationships that developed with the women during the study as partnerships. I introduce the women here to emphasize their importance to the methodology.

### THE WOMEN IN THIS STUDY

All the women were living in the community at the time of this study. Each of them responded to an advertisement in a local newspaper, and each met inclusion criteria for participation. Isabella was in her late 40s, Penny her late 50s, and Gwen was nearly 80 when the study commenced. They had known of their rheumatoid arthritis for between 19 and 38 years and, while they suspected illness for some time before diagnosis, their initial symptoms had not been taken seriously. Penny and Isabella were taking medication for their condition at the time of the study, but all of them had endured the side effects of long-term medication. None of these women were involved with the Arthritis Foundation. Isabella, particularly, was critical of its usefulness; since the organization was not involved in the

study, she found the freedom to express her frustration.

All the women were of white, European descent. Penny was raised in an Australian capital city, and her family had lived in Australia for several generations. Isabella and Gwen grew up in small English villages and later migrated to Australia. They left secondary school at or close to the minimum age to marry, or entered the workforce prior to marriage, and now had children leading independent lives. Gwen was recently widowed from her husband, Isabella had been widowed then divorced, and Penny had divorced and remarried.

Penny had always provided unskilled manual labor for others. Her father was a skilled worker, though the family could not afford luxuries during her early life. As a child she helped care for her siblings, missed a lot of school, and left school at the minimum age. Then she worked in her first husband's small business in a remote town. Later, Penny started her own successful business, so she and her second husband improved their economic circumstances over time. Eventually she reduced her hours in the business, and her husband considered early retirement from public service. Penny was in her mid-30s when rheumatoid arthritis was diagnosed, but she was in remission at the time of the study. The disease had affected mainly the joints in her hands and feet, and she had undergone various surgical procedures to correct joint deformities, but not all of them were successful. She continued to have trouble with certain manual tasks, but she always found alternative ways of achieving things.

Gwen grew up in England after World War I, where her mother served the landed gentry after her husband deserted. After

World War II, when she worked in a factory, Gwen took any unskilled work available to women, sometimes working at night to support her children and husband's business. In Australia, she drew the age pension. Gwen had lived with rheumatoid arthritis for half her lifetime, having developed it around the age of 40. Her joints were now misshapen, she had difficulty with some movements, and she experienced recurrent leg ulcers from the disease and previous steroid use. She felt her disease had "burned itself out," as she no longer needed medication for joint pain and inflammation. Gwen loved to remain active, and she was able, with savings or family assistance, to make modest plans for traveling in her retirement.

Isabella was adopted in infancy, so she knew no family history of rheumatoid arthritis, but had experienced symptoms since childhood. It was not until she was a young woman, however, that her illness was recognized as rheumatoid arthritis. She now had an advanced, systemic form of rheumatoid arthritis, so pain, fatigue, or malaise made activities of daily living a constant struggle. She also had chronic lymphocytic leukemia diagnosed around midlife. Isabella's adoptive parents were middle-class people of some means. After her first husband's death, however, Isabella worked to support her daughters, and she experienced some economic stress before her second marriage to an Australian. After her divorce, she was supported by a disability pension, though she still felt disadvantaged by not earning a wage. At the time of the study, she was taking a college course in fine arts to improve her financial prospects. Isabella was the only woman of the three who used services for people with disabilities, but attempts to have her disabilities

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### METHODS AND PROCEDURES FOR LIFE PATTERN RECOGNITION

Three methods for illuminating the women's life patterns were used. I recorded unstructured interviews and drew on my field notes and photographs taken by the women. Letters, e-mail, or telephone conversations provided additional information, and these were subject to the same ethical considerations as interviews and photographs, all of which were approved by the Flinders University Social and Behavioral Sciences Ethics Committee. Furthermore, I addressed rigor in this study by:

- sharing pattern analyses with the women
- discussing with them a reconstructed life story incorporating recognized patterns
- exercising self-critical reflexivity<sup>37,38</sup> in the ways I struggled with representation and ethical issues
- documenting my decisions thoroughly<sup>39</sup>
- writing in the first person to convey my personal involvement<sup>40</sup>
- considering specific criteria for judging the rigor of research with Newman's theory of Health as Expanding Consciousness<sup>3</sup>

The research design involved up to four in-depth interviews following a preliminary meeting to establish partnerships of mutual concern. In-depth interviews entailed the following:

- conversing about the most important people and events in their lives
- sharing the recognition of life patterns

- discussing meaningful photographs, further reflecting on life patterns and on the study
- sharing the story, reflecting on our relationship and closure

The first two interviews were close together, while the last two occurred after the opportunity for reflection. The study continued for 2 years, but my contact with the women lasted longer.

My first meeting with the women was preliminary to the study, in which I conveyed my genuine interest in engaging with them as unique human beings over an extended time frame, rather than simply wanting to collect information from them as quickly as possible. Although I had expected to keep the conversation informal at this first meeting, all of the women surprised me by disclosing not only how they discovered their illness, but also other intimate aspects of their lives and relationships. In a reciprocal way, I disclosed about myself whatever seemed appropriate in the circumstances, and I explained that my interest in their experiences developed from caring for my mother. Following a more detailed explanation of the study in plain language, each of the seven women gave their informed consent to be involved. On completing the preliminary interview, I felt their willingness to tell their stories and my interest in ongoing relationships with them were the ingredients for authentic, mutual partnerships.

### **In-depth interviews**

### First interview: A natural conversation about their lives

In the first recorded interview, I asked the women to recall the most important people and events in their lives. At first they found the question too broad and began with a brief synopsis, including a statement about their children or partners being most important to them. Eventually, they began to focus on these people and related events in more detail, and they began to talk descriptively about their lives. These interviews lasted around 2 hours each, not including breaks; sometimes we talked further after switching off the tape-recorder. All the women requested copies of their transcripts, but the material I worked with after returning these contained only pseudonyms.

### Second interview: Sharing the recognition of life patterns

The main purpose of the second interview was sharing with each woman my analysis of her story in terms of life pattern analysis and prepared diagrams I made from her reflections on people and events. Most second interviews were 1 or 2 hours in duration. After these concluded, I asked the women to reflect on the life patterns we had discussed, or on meaningful aspects of their lives, by taking some photographs with a small disposable camera. None of them found it easy to write because of joint changes, but each embraced the idea of using the camera. I told them these photographs should represent their continued reflections, and the images could be symbolic or not, as they desired. When they had used all the exposures, I collected the film, arranged for processing, and returned the prints to them directly. The women contacted me following this to arrange for the third interview, during which I asked them to select their most meaningful photographs to share in discussion.

# Third interview: Discussion of photographs, reflection on life patterns and the study

When discussing the photographs with the women in the third interview, it became clear what was most important to them could not be portrayed in a single image. Most of the women photographed people, pets, landscapes, or still-life images. Understanding them was a hermeneutic and dialectic process because new interpretations evolved during these discussions. I also asked what had been happening in their lives since our last meeting, which opened the conversation to new directions, but I focused on whether they expressed patterns shared in the last interview, or whether new ones were evolving. Furthermore, I asked their thoughts about involvement in the study, and they noted the beneficial effect of talking in depth with someone who was interested in their experiences.

### Final interview: Sharing the story, reflecting on our relationship and closure

Prior to the last interview, I shared a draft of the life pattern story. In the final interview, I asked them to comment on this story. I was concerned about representing them in my interpretations as they would wish, and I regarded them as having a right to know what I had produced from studying their life stories. Although this was not part of the original study design, they responded enthusiastically to my suggestion. Generally the women identified with my interpretive account, appreciated the life patterns, and regarded the whole story as a memento of their lives. The last interview also was an opportunity to review our research partnerships and to close the formal part of the study. The women reflected positively on our tentative beginnings, developing mutuality, and eventual friendships, but ending the study after knowing the women for so long and sharing so much was not easy for any of us.

### Analysis and interpretation of life patterns

Discerning patterns from the life stories of the women occurred concurrently with further data generation, as I prepared, analyzed, and interpreted the information obtained from interviews, field notes, letters, and photographs. Pattern analysis occurred between the first two interviews, theoretical analysis occurred after the second interview, and intuitive analysis followed the third or reflective interview. Both pattern and theoretical analyses involved a similar process to that described in Newman's protocol and illuminated life patterns as themes; the intuitive analysis enabled me to see underlying patterns as abstract constructs recurring through the interviews.

Pattern analysis involved preparing the interview transcripts so patterns were recognizable. As I reread each transcript, I highlighted significant sequences in our conversations and created a paraphrase that preserved meaning without the distraction of digressions, interruptions, or non-verbal expressions. Significant sequences were statements relating to people, events, situations, and the women's thoughts, feelings, and perceptions about them. Following this, I changed the order of these sequences to represent the women's lives chronologically as a "long story line," since stories are rarely told chronologically.<sup>41</sup> Eventually I saw patterns in the information before me, as an "all-at-once" phenomenon. Then I condensed the "long story line" into a "short story line" (to make the information manageable) by selecting statements appearing to represent the main themes of the pattern, which is also known as "core story creation" in narrative analysis. 41 When discussing their life pattern stories, I used diagrams to highlight relationships and connections evident in the short story line that the women found particularly interesting. During the theoretical analysis, I identified sequences from the life pattern stories indicating self-transcendence and personal transformation to illustrate expanding consciousness.

Each story described not only life patterns but also underlying patterns of the whole person. These interpretations occurred during the intuitive analysis phase, using an iterative or abductive approach to writing the women's stories. The main underlying patterns for the three women with rheumatoid arthritis included the two shared patterns of "energy-fatigue" and "givingreceiving" mentioned previously and another of "rejecting-accepting" for Isabella alone. The remaining underlying patterns of "vulnerability-resilience," "control-release," and "being silent-speaking out" were specific to the women with multiple sclerosis,3 but all are expressed as dialectic phenomena in a similar way to Newman's fusion of "disease-non-disease."6 Although I used the theory of Health as Expanding Consciousness a priori to inform the study and engage with the women, it has no prescriptions for identifying underlying patterns. Using the complete data set, apart from the underlying patterns, I also distinguished turning points from choice points in the women's life patterns, which denote refinements of the theory of Health as Expanding Consciousness.<sup>3</sup> In the next section, I concentrate on life patterns of the three women with rheumatoid arthritis, although their underlying patterns also are evident in these descriptions.

## LIFE PATTERNS OF WOMEN LIVING WITH RHEUMATOID ARTHRITIS

Analysis of life stories for each of the women with rheumatoid arthritis produced two or more life patterns (Table 1) that reveal the importance of self-transcendence and personal transformation to the process of expanding consciousness. Disorder and uncertainty at particular times in their lives provided opportunities for reorganization through personal choice. Beyond one or more turning points, there was an identifiable choice point for all the women. A process of personal transformation began at this choice point, and it was expressed through transcendence of self, space, and time. Gwen reached a choice point during the course of the study, while Penny and Isabella had reached a choice point in the past. Nevertheless, all three women found new ways to live with rheumatoid arthritis that helped them find purpose and meaning in their experiences.

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These insights and changes represent transition to greater complexity and illustrate health as expanding consciousness.

### Penny's story: Everything happens for a reason

Penny's life story resolved into two principal life patterns. The first of these, "Giving without Receiving" began with a turning point when her brother died as a child and left Penny without control over subsequent life-changing events. During this pattern, helping her mother with home duties and taking responsibility for raising her younger siblings overwhelmed her. She missed a lot of school and felt she did not have a young person's life. While she was struggling to come to terms with bewilder-

**Table 1.** The life patterns of three women with rheumatoid arthritis

	Childhood	Youth	Young adult	Midlife	Late adult	Older age
Penny	Giving without Receiving		Restoring the Balance			
Isabella	Seeking Connection	Seeking Protection	Seeking Answers	Seeking Acceptance		
Gwen	Broken Connections	Making Connec- tions	Losing Connections	Rebuilding Connections	Disrupted Connections	Finding new Connec- tions

ing role changes in her family, however, a good friend in her neighborhood offered her some words of comfort that became very important in her subsequent responses to illness: "[She instilled in me that] everything happens for a reason . . . and that's the way I live my life, with that in my mind" (Penny, Interview 3). When she started work as well as caring for her sisters at home, Penny began to develop painful migraine headaches. She stated she felt overburdened with work, as some days her head was literally splitting from responsibilities, and she was "sick of it all." Hypnosis banished the migraines, and later Penny learned yoga techniques she used in future years to rest and control pain. In this first life pattern, the underlying patterns also concerned giving out but not receiving, and of expending energy without sufficient rest or enjoyment.

The pattern of "Giving without Receiving" continued when Penny married and moved to a remote township. She managed hard manual labor in the family business, volunteered for the ambulance service and at the district hospital, started a tennis club and a local scouting group, organized meetings for the country women's association, taught yoga classes, and looked after the schooling for her two children. She was always busy, often working until exhausted and leaving no time for rest. At a second turning point, Penny developed rheumatoid arthritis following a bout of influenza, but she connected the development of her illness with giving too much time and energy to these activities and not receiving enough rest or time to herself: "I blame myself for getting rheumatoid arthritis because to my mind, I burnt the candle at both ends. . . . I stretched my lifestyle a little bit too much. And the body just said: 'Well okay, you're not being fair to me'" (Penny, Interview 1). Her husband was neither sympathetic to her need for sleep when there was work to be done, nor supportive of her as she sought help for pain and fatigue. Moreover, it was difficult accessing specialist care in this remote area, and some medical practitioners denigrated her concerns: "I got to a point where I really felt that I was going bananas. One doctor even said to me: 'You're just a bored housewife looking for sympathy.' I've never forgotten that. That was something that just wasn't me" (Penny, Interview 1).

Eventually Penny made a choice that transformed her life. She realized she was not making any progress by remaining in the country, and she did not have limitless energy to spend on helping her husband and others. Fatigue now dominated her life. More important, she recognized the pattern of self-sacrifice no longer served her well. She was very ill by this stage, and her life seemed totally chaotic, out of control, and constrained. The pain and fatigue of illness enabled her to make the difficult choice to leave her husband in the country and to seek help from her family in the city. After this choice point, a new life pattern of "Restoring the Balance" unfolded, and Penny developed different ways of living with her illness involving greater order and complexity. She found someone who restored her confidence, remarried, began her own business, and accepted her mother's help for this. The underlying patterns of "givingreceiving" and "energy-fatigue" had manifested throughout her life in various ways.

Penny's reflective photographs were all of her family members, animals, friends, and customers involved with her business, which represented the most important connections in her life. She reflected that, in spite of the pain and difficulties she encountered through having rheumatoid arthritis, she also had learned a great deal through the experience, recognized her inner strength, and had developed a philosophy of positive living: "But . . . getting back to that old saying—everything happens for a reason—because of that problem, I grew, grew up, grew in strength, grew in knowledge" (Penny, Interview 1). After reading her life pattern story, Penny affirmed it by saying: "This is really me."

### Gwen's story: Family has always been first

Gwen was the only woman in the study to have lived as far as old age, so her story provides insight into the patterns of a woman's entire life. Six life patterns spanned seven decades, all concerning connections to her family. In Gwen's first life pattern of "Broken Connections," her father deserted the family when she was 2 years old. Later in childhood, she and her sister boarded with another family while her mother lived and worked in a different town. As a young woman, Gwen began training as a children's nurse (nanny) but had to leave it for factory work during World War II. She met her husband during the war, but as she established her own identity as a wife and mother in her second life pattern of "Making Connections," Gwen worked increasingly hard and long hours, both inside and outside the home, because of financial pressures. In the pattern of "Losing Connections" her children left home, her mother died, and around this midlife period, she developed rheumatoid arthritis and needed prednisolone:

I was on that for 8 years. Sure it killed the pain, a lot of it, but umm, oh it's got some disastrous side effects. . . . It was far too long really. I was told I'd never get off it . . . [so] I couldn't be too sure about stopping because I didn't know how to do it. I was taking 25 tablets a day, . . . which is crazy. I mean I look back and I think oh, how did they allow me to do it? Anyway I decided I must get off these tablets and I gradually did. Because I had ulcers on my legs, high blood pressure . . . and sometimes you feel absolutely on "cloud nine," which is very dangerous. And sometimes I think I had so many drugs, I didn't feel normal apart from all the pain. (Gwen, Interview 1)

After stopping prednisolone, Gwen journeyed to Australia to visit her children and discovered that the climate reduced her symptoms of rheumatoid arthritis. She decided to move closer to her children and grandchildren, but her choice was initially frustrated by the need to wait for her husband to retire. After 5 years, however, they moved to Australia and reconnected with family, in the pattern of "Rebuilding Connections." Although "things seemed to fall into place" and they were happy in retirement, Gwen continued to feel guilty about putting her own needs first and insisting on the move. The life pattern of always putting family first was well entrenched by this stage. As the years passed and Gwen found she had more time available to herself, however, she rediscovered her love of traveling with friends. The rheumatoid arthritis that had plagued her in midlife had "burned itself out," according to her.

In her late adult years, Gwen's husband developed cancer and needed hospitaliza-

tion several times before he died. She found it difficult to watch him "go down and down" even though she knew that he no longer wanted to live. Losing her life partner, and being unable to help her sister in England through a disabling illness, in this life pattern of "Disrupted Connections" affected her longest and strongest family relationships. Since Gwen had anticipated her husband's death and had begun grieving during his terminal illness, she remembered having a "delayed reaction" afterward. Not long after the funeral, she embarked on a world tour with her daughter, so the pleasure of travel blocked the pain of bereavement, at least for a while: "The thing to do is keep busy and keep occupied isn't it? That's what I've always tried to do. Push the thoughts you don't want away from you if you can" (Gwen, Interview 1). When she returned to Australia, however, she noticed her husband's absence acutely, and she could not reconcile her life-long pattern of serving others with the absences of significant people in her life. She stated: "Probably why I feel I should be doing something for somebody is because I'm spending too much time on myself" (Gwen, Interview 2). Following the pattern-sharing process, Gwen seemed to let go of old ways of living her life for others, and she made choices to enjoy traveling with friends and accept help her family offered. A new life pattern of "Finding New Connections" emerged from this work as Gwen realized she could now put herself first.

There was a deep and lingering sadness about Gwen when I first met her, but after the third interview I realized her sadness had disappeared. Her reflective photographs were of her garden, which was a burden after her husband died, but had since become a source of enjoyment. When I asked how the study affected her, Gwen said it had given her a different perspective on her life, liberating her from old constraints on enjoying herself. Clearly, the underlying patterns of "giving-receiving" and "energy-fatigue" also permeated Gwen's life and her connections with others.

### Isabella's story: This life of pain

The story of Isabella's life was primarily one of pain and difficulty manifesting in four life patterns. During her childhood and youth, a life pattern of "Seeking Connections" dominated, as Isabella experienced emotional pain from blocked or severed connections with family, friends, or other significant people. She felt unaccountably disconnected from her adoptive parents and in need of loving connections, but trusted nobody. It was in her childhood, too, that Isabella first remembered having episodes of aching, stiff, swollen joints. After she married and had twin girls, a second pattern of "Seeking Protection" unfolded, as she became concerned with her husband and being a successful mother. Around this time, her joint pain became severe, and she was eventually diagnosed with rheumatoid arthritis. Recalling her diagnosis, Isabella felt that for a long time afterward she had not accepted it: "I was in shock and I was in denial . . . I felt embarrassed, and I felt guilty, and I felt awkward, and I felt ugly" (Isabella, Interview 1). As her husband's behavior became more violent, leaving Isabella emotionally vulnerable and spiritually distressed, she sought ways to protect herself. At the turning point of his unexpected death, Isabella was shocked and overwhelmed by guilt because she had prayed for release from her situation.

Subsequently a new pattern of "Seeking Answers" unfolded when she applied for her birth certificate and tried to contact blood relatives: "It's about making links, and making sense of being a human being, and feeling part of the collective" (Isabella, Interview 1). She also sought a spiritual healer for her rheumatoid arthritis and felt "cured," so she decided to realize her dreams for a better life by moving to Australia. After this choice point, she married again and had a third daughter, but then experienced an acute exacerbation of rheumatoid arthritis. This time, she began to care for herself through counseling, personal growth courses, and natural therapies. Her husband did not share her new insights, so she divorced him, spending a long time grieving over the end of her second marriage. Through dreams, visualizations, and meditation, she embarked on a spiritual journey concerning her life of pain.

this golden light seemed to be communicating to me . . . I saw quite clearly a pregnant woman, and I knew that was me in her body. And the message said: "You *chose* this life of pain, you chose it, because . . ." and I got the feeling that at the end of my life would be great rewards . . . that was a very healing process for me . . . then I suddenly had this backlash . . . I don't like it! I wish I hadn't chosen it. It's too hard. I don't want to live this life. . . . But that was actually the beginning of my spiritual journey. (Isabella, Interview 1)

The most recent life pattern of "Seeking Acceptance" coincided with her midlife years. Isabella's spiritual journey led her to seek acceptance of her disabilities as she lived with rheumatoid arthritis and to accept that she would not find the "blood links" of her birth family. Most important, in this pattern Isabella learned to love and accept her-

self. Such acceptance was a considerable struggle but demonstrated expanding consciousness. Learning new ways of being after the choice point entailed trusting her intuition, understanding and having more compassion for herself, and accepting her spirituality. Consequently, she had separated gently from her second husband, wished her youngest daughter well when she left home, and finally released the idea of reunion with her birth mother. Isabella's principal underlying pattern was "rejectingaccepting," depicting a dynamic struggle with these issues throughout her life, although patterns of "energy-fatigue" and "giving-receiving" shared with the others also were evident.

When I first met Isabella she was experiencing a difficult time with a bad exacerbation of her symptoms, taking antidepressants, struggling to use a cane, and being housebound and unable to attend college. All these struggles exaggerated her difficulties and diminished any hope her life might improve:

I've had so much emotional pain, and so much physical pain in my life, that it's at times been *unbearable*. I've been to the edge many times, and even now I have constant counseling and I'm on antidepressants. But it's still really difficult. And I still pray and say: "My life is so *difficult*, please, take me out of this, I'm not strong enough." But obviously somebody thinks I am—because I'm still here. (Isabella, Interview 1)

By the third interview, Isabella had weaned herself off antidepressants. She was still pursuing her spiritual connections, and we discussed her dreams and the new therapies indicating her ongoing search for purpose in life and meaning of her illness. She wished her arthritis could be cured, but admitted she was probably *healing* herself:

"Perhaps healing takes a lifetime anyway . . . the only way I can heal myself is by being in this chronic illness and disease" (Isabella, Interview 3). Her photographs symbolized struggle and kinship issues, depicting the natural world rather than people, and were taken with her artist's awareness of texture, shape, and color.

Nearly 2 years after we first met, Isabella's well-being had improved considerably, and she felt our discussions had provoked considerable thought about accepting increasing disability through a prolonged exacerbation of rheumatoid arthritis. Initially Isabella did not feel she had gained any further insight into her life through the pattern-sharing process. Reading her life pattern story, however, was a form of release, enabling her to move on with her life. When she read it, Isabella stated: "I thought well, that . . . that is exactly my life" (Isabella, Final Interview).

#### DISCUSSION OF LIFE PATTERNS

While all the women had complex and varied life patterns, each story shows they had considerable energy and busy lives before they became ill. They used energy to maintain connections with others, but there was little or no reciprocity in some relationships. Their lives became fragmented by disorder, including illness, exhaustion, abuse, desertion, or death, and all experienced decreased energy. There were several turning points evident, but after making a deliberate choice to change their lives, they learned to live with constant fatigue and to be careful with their energy expenditure, including the energy they invested in connections with others. For this reason, I was able to distinguish turning points from choice points.<sup>3</sup> The importance of reciprocal connections with others—or lack of them—also was a strong theme in the women's life patterns, as has been found in previous Newmanian research, <sup>10,11,14-16,29-35</sup> but it did not appear to be an underlying dialectic pattern.

Through years of living with chronic illness, the women with rheumatoid arthritis learned how much energy they had each day, and they saved it for their most valued activities. They struggled with receiving assistance from others initially, but ultimately they learned to accept help, as they had once given it so freely to others. As their life patterns unfolded, the transitions evident in them concerned change from giving and expending energy in a self-sacrificing way to receiving and conserving energy in a selfprotective way. Although this was more in keeping with the fatigue experienced with rheumatoid arthritis, the women still found ways to help others, and their efforts were reciprocated. Consequently, each of them found considerable meaning in living with chronic illness and learned how to build order and stability when faced with situations of potential chaos.

#### **Self-transcendence**

Changes in the women's lives after a choice point were evident as self-transcendence and personal transformation, as well as expressing expanding consciousness. When this study began, all the women had moved through the early stages of expanding consciousness toward the stage of *Movement* and beyond, which initially involves transcending self-boundaries and eventually transcending space/time boundaries. Elsewhere I have discussed detailed links between stages in expanding consciousness and individual life patterns, but

the patterns described here show how the women addressed unforeseen circumstances, including illness, and made important choices in each transition.

Penny enjoyed working in her own business, accepted everything took longer to accomplish, found different ways to do the same things, and no longer felt she was "drowning without being rescued." She had learned how much she could ask of her body, and she no longer hid her fatigue from others. Her experiences bestowed Penny with sensitivity to other women with problems, and she tried to help them through her work. Through the patternsharing process, Penny realized she no longer had to hide her fatigue or pain and be "nice" about it, so differing family views were reconciled, connections reinforced, and individual strengths appreciated. She tried to see positive aspects of every situation, and she had few regrets, even about difficult aspects of her life, because "everything happens for a reason."

While Gwen was mourning her husband's death and adjusting to living alone, she seemed to prefer less complex ways of being. Movement to greater levels of complexity is more difficult for individuals who spend their entire lives in the service of others and follow the rules of social order without thought for themselves because it is more difficult to relinquish previous ways of living. Nevertheless, known patterns of

Changes in the women's lives after a choice point were evident as self-transcendence and personal transformation, as well as expressing expanding consciousness. self-transcendence for older adults<sup>18</sup> were evident for Gwen during the closing stages of the study, including: (1) Body Transcendence—through the experience of recurrent leg ulcers, she found new ways to move around without driving, placed more value on connections with friends, and decided to enjoy her remaining years; and (2) Temporal Integration of Past, Present, and Future—Gwen began to appreciate her husband's garden, put a lot of sadness behind her, passed her eightieth birthday with family, and planned a return to England to visit her sister and friends in the future.

Through her spiritual journey, Isabella concluded she "chose this life of pain," by being born with the genetic heritage of rheumatoid arthritis and by being adopted at birth, in order to learn certain lessons. These lessons included how she could transform her life of pain, with its fear, anger, grief, and guilt into loving acceptance of herself and others. As her self-transcendence deepened, Isabella realized the most important questions about her life had spiritual rather than material answers. During her latest exacerbation of rheumatoid arthritis, however, Isabella experienced more difficulties, but she found new solutions to these problems by accepting life in an electrically powered wheelchair instead of walking painfully with a cane, relinquishing her driving privileges, having modifications made to doors so she could exit her house easily, and attending college more often. She also used an advocacy service and found the process of getting the college to install facilities for people with disabilities very empowering.

#### Personal transformation

From the life patterns of the three women, discovering "new ways of living" seemed to characterize the process of per44

sonal transformation. In descriptions of Health as Expanding Consciousness, there have been few details about the manifestations of "new ways of living" that develop during personal transformation. Carpenter et al<sup>26</sup> describe the process of positive transformation as a new understanding leading to changes, and eventually to more harmonious lives. Here, two themes reflecting such new ways of living are "simple pleasures" and "being positive."

### Simple pleasures

Transformation for Penny involved healing and strengthening herself by receiving help from others and balancing work she enjoyed with exercise, yoga, and quiet times to herself. She appreciated the simple pleasures of living in the present moment, including relaxing with her cats, helping other women, and enjoying the rewards of working for herself on her own terms. Gwen enjoyed being able to travel with friends, to cultivate the garden that had been her husband's, and to have her family organize birthday celebrations. When we met there were few pleasures in Isabella's life, but she loved art, enjoyed reading, and appreciated insights from her dreams and visualizations.

### Being positive

As Penny explained, this was something she worked at continually, but she had learned how to do fewer things, take life more slowly, and "walk a fine line" between rest and work, medication and lifestyle, anger and acceptance. Being positive for Gwen involved finding new ways of occupying her time, managing her leg ulcers, and maintaining her independence. It was not easy for Isabella to be positive, but she was "having to write a new rule book" for

herself, and finding "the things that really make me feel wonderful" (Isabella, Interview 2). When the study ended, Isabella moved around comfortably in her wheelchair, did well at college, and made optimistic plans for the future.

Since transformation is an evolving process unfolding in space/time, these outcomes are not final. The process for all the women is a continuous one and, as a journey of healing, the characteristics of self-transcendence and transformation indicated profound transitions in their lives.

### Cause and effect or pattern and rhythm?

The impact of earlier social and economic circumstances on their lives and development of rheumatoid arthritis is worth considering. Social disadvantage doubles the risk of serious illness and premature death through physiological or psychological fatigue, while strong and supportive social connections improve health outcomes.<sup>42</sup> With each critical transition made in life, there is an opportunity for either improvement or continuing disadvantage. All the women had experienced some degree of socioeconomic disadvantage in their lives, but their present circumstances had improved through social mobility, or were buffered by social security.

Penny had missed vital educational opportunities and spent many years in demanding manual labor with lack of control over her working conditions, which are recognized as risk factors for illness.<sup>42</sup> A supportive family, close friends such as her yoga teacher, and remarrying provided social support, helped her to manage fatigue, and allowed her to work on her own terms. Gwen grew up in poorer circumstances, had

minimal formal education, and worked unsociable hours in unskilled, insecure occupations, as well as having responsibility for raising three children. After moving to Australia, she retired from work and drew the age pension. Her social networks improved, and she gradually learned to let family members support her emotionally, financially, and physically. Isabella's parents provided well for her early physical needs, but her childhood was characterized by long-term anxiety, insecurity about her adoptive status, and poor self-esteem, all known to be detrimental to health.42 After migrating to Australia, Isabella sought love, esteem, and caring from others through her spiritual journey, and she learned to make different choices to conserve her energy. Nevertheless, many issues generated in her early life continued to affect her health in midlife.

Although this perspective is important, understanding life patterns requires a different perspective on health transitions. Rather than a causal view of illness depicted by social determinants of health, the pattern of the whole person is the underlying organizing principle in unitary-transformative nursing. Health is the expansion of consciousness evolving through transitions to greater complexity, regardless of social or economic circumstances in life. One advantage of this is the lack of blame attributable to personal circumstances. The women experienced considerable blame from others operating from a causal worldview, and they blamed themselves accordingly, as is evident in Penny's story.

The unitary-transformative view concerns health as the pattern of the whole.<sup>43</sup> This means health and illness are an inseparable, single process, with rhythm to their

manifestations throughout life. The important point for nurses is revelation of that rhythm, as people tell their life stories, and the opportunities this provides for personal transformation at critical moments and beyond. Furthermore, since pattern is an attribute of wholeness, life patterns reveal the spiral of transitions to expanding consciousness through transcendence and transformation. While many nurses understand cause and effect, pattern and rhythm remain options to be explored.

### IMPLICATIONS FOR NURSING

Reviewing illness stories as nursing relationships develop is useful to avoid overemphasizing the technical aspects of nursing. Nevertheless, illness stories alone can exclude important information that allows people to be appreciated for their wholeness and uniqueness as human beings.<sup>4</sup> Life patterns recognized from an unfolding life story allow attention to focus on broader issues in human experience, of which illness is merely one aspect.

For example, by understanding Gwen's life pattern of giving to others and the importance of family connections, I helped her realize she also could enjoy receiving loving help from others and put herself first. Isabella's life patterns indicated her healing process involved acceptance of the many difficulties in her life, and through our discussions, she realized how to transcend these and make positive changes in her environment. Likewise, Penny's life patterns indicated the need for reciprocity and balance. Our time together seemed to unburden her, change relationships within her family, and open the way for reciprocal communication. For each of the women, insights gained

through sharing their life stories and understanding their life patterns helped them acknowledge strengths and appreciate the remarkable transitions made. Life patterns, therefore, can enhance understanding of health transitions and illuminate the meaning of illness in the context of each life story.

Appreciating the importance of transitions to increasing complexity after critical life events and choices can help nurses initiate caring partnerships with people to support the process of expanding consciousness. Rather than "doing" or "fixing," as occurs in nursing, emphasis on "being" with persons while they struggle with uncertainty and turmoil can lead to insights for change, as Newman has claimed. 1,12,13,43,44 Attention paid to transcendence and transformation as transitions in an entire life story, rather than a focus exclusively on the personal story of illness, is a worthwhile activity for nursing and makes these ways of knowing and being accessible.

The study explained here concerning women with rheumatoid arthritis, and the larger work from which it is drawn,<sup>3</sup> indi-

cates a role for nursing as making a difference in people's lives, as articulated previously by Newman<sup>12,13</sup> and others. My work did not alter their rheumatoid arthritis, for that is not the intention of unitary-transformative nursing, but it did make a difference in their lives. Furthermore, my understanding of life patterns and underlying patterns indicated the potential for nursing in harmony with individual rhythms and patterns; for the first time it allowed me to perceive the wholeness of individuals<sup>4,43,44</sup> and experience nursing as unitary and transformative.

Health as Expanding Consciousness provides a framework for understanding human uniqueness through pattern and shows how evolution to greater complexity occurs through a continuous process involving self-transcendence and personal transformation. Life stories reveal more complexity than illness stories alone, and life patterns give unique meaning to transitions in human lives. The life patterns of women with rheumatoid arthritis described in this article illustrate such transitions and contribute to understanding the process of expanding consciousness.

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