

Abstract

The purpose of this metasynthesis was to describe the hope experience of family caregivers of persons with chronic illness. Fourteen studies were included in the metasynthesis. All studies described the importance of hope to the family caregivers of relatives with chronic illness regardless of age, relationship, or setting. Several derived themes arose from the metasynthesis: (a) transitional refocusing from a difficult present to a positive future; (b) dynamic possibilities within uncertainty; (c) pathways of hope; and (d) hope outcomes. Hope was defined as transitional dynamic possibilities within uncertainty. A new conceptual model of hope was developed that provides a foundation for future research and practice. The metasynthesis findings indicate factors influencing hope and the outcomes of hope might play a role in assessing hope, and differing pathways of hope might provide a foundation for future hope interventions.

Keywords: *caregiving; informal; hope; metasynthesis*

Family members of persons with chronic illness, such as cancer, have similar distress levels as the person for whom they are caring (Cochrane & Lewis, 2005). A key psychosocial resource among family caregivers to manage and deal with their caregiving experience is hope (Borneman, Stahl, Ferrell, & Smith, 2002; Herth, 1993; Holtslander, Duggleby, Williams, & Wright, 2005). Hope has been defined as a “multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving future good, which to the hoping person is realistically possible and personally significant (Dufault & Martocchio, 1985, p. 380).”

Studies of hope and family caregivers have been descriptive and exploratory in nature. They have focused on describing the hope of family caregivers of persons who are receiving critical care (Gelling, 1999; Patel, 1996), chronic care (Parse, 1999), and palliative care (Borneman et al., 2002; Herth, 1993; Holtslander et al., 2005). They have also described the hope of homeless families (Herth, 1996) as well as family members caring for persons with dementia (Irvin & Acton, 1997), HIV/AIDS (Kylma, Vehvilainen-Julkunen, & Lahdevirta, 2001a); sickle cell anemia (Forte, 1997) and family caregivers who have become bereaved (Holtslander & Duggleby, 2009). Studies of family members of advanced cancer patients suggest hope is important in helping them deal with the caregiving experience (Borneman et al., 2002; Herth, 1993; Holtslander et al., 2005; Wennman-Larsen & Tishleman, 2002).

Although studies of hope in family caregivers of persons with chronic illness support the importance of hope for this population, findings vary significantly. This variation might be the result of many factors, including the type of illness experienced by the patient as well as the methodological approach used to study the caregivers' experience. It might also result from the lack of clarity of the concept of hope in family caregivers caring for persons with chronic illness. Metasynthesis is a method that brings together qualitative exploratory studies to enhance their contribution to the development of more formalized knowledge (Zimmer, 2006). Two hope metasyntheses have been reported in the literature; one explored hope and expectations in people recovering from illness (Wiles, Cott, & Gibson, 2008) and the other despair and hopelessness in the context of HIV (Kylma, 2005). Both noted the lack of clarity about hope. Given the complex construct of hope and the importance of hope to family caregivers, the development of

knowledge in this area is critical. The purpose of this metasynthesis study was to describe the hope experience of family caregivers of persons with chronic illness.

Method

The metasynthesis of qualitative research studies on hope and family caregivers of persons with chronic illness followed the procedures outlined by Sandelowski and Barroso (2007). The procedural steps were: (a) comprehensive search, (b) appraising reports of qualitative studies, (c) classification of studies, and (d) synthesis of the findings.

Sample

Eight databases were searched: Medline, CINAHL, and Embase were chosen for their focus on health issues; PsycINFO for its coverage of the psychological literature; Sociological Abstracts for sociology; ATLA Religion Database for theological literature; Dissertations & Theses to capture Master's and PhD theses that might not be included in other databases, and Web of Science for its extensive coverage. All databases were searched from 1987 to the present by an experienced medical librarian. Each search used a combination of subject headings, keywords, and words in title, according to the database searched. The Boolean operators "and" and "or" were used to combine the distinct concepts, "hope", "caregiver", and "family" or "friend", and all variations of these concepts. Qualitative studies were not identified in the literature search because of the difficulty of locating searches with keywords; instead, team members perused titles and abstracts of all studies, and identified appropriate studies based on the inclusion/exclusion criteria.

Inclusion criteria for the metasynthesis were: (a) studies of the hope experience of primary caregivers (all genders) caring for or had cared for persons of all ages with chronic illnesses, (b) studies published in all languages and countries, (c) published and unpublished studies, (d) qualitative and mixed methods designs, and (e) studies published between 1988 and 2008. Abstracts, metasyntheses, and secondary analysis studies were excluded.

The database search returned 1115 studies of which 13 articles and one dissertation met the inclusion criteria. Hand searches of the references of the selected articles yielded only one additional

study. One article was written in German and was excluded as translation was not available. Authors of the remaining 14 studies were contacted and asked if they had additional articles accepted for publication which they were willing to share. All but two of the 14 authors responded, yielding two additional articles in press which have since been published. Two articles were excluded as they reported data from the same study, so in total, 14 studies were used in this metasynthesis.

Procedures

Appraising reports of qualitative studies. The purpose of the appraisal was to become familiar with the reports and to evaluate them for their quality. All studies were appraised using Sandelowski and Barroso's (2007) reading guide. In addition, the studies were evaluated for their quality using the Critical Appraisal Skills Program (CASP). The CASP is a recommended tool of the Joanna Briggs Institute and provides a standardized mechanism for appraising qualitative studies using metasynthesis (Feder, Hudson, Ramsay, & Taket, 2006). The CASP was used to describe the quality of the studies as the context for the metasynthesis findings. Studies were not excluded based on the CASP score.

The CASP consists of ten questions: two for screening out inapplicable studies and eight regarding the research design, data collection and analyses, ethics, reflexivity, and implications of qualitative research studies. Initially 3 articles were assessed using CASP. The members of our group then met and discussed a method for quantifying our comments from the CASP to obtain an overall score of quality. A three-point rating system was developed and used to determine scores for each article for each of the CASP's eight questions. A weak score (1 point) was assigned to articles that offered little to no justification or explanation for a particular issue (e.g., where, when, or how the data were collected was not mentioned). A moderate score (2 points) was given to articles that addressed the issue but did not fully elaborate on it (e.g., the justification for using constant comparisons was presented but the procedure itself was not explained). A strong score (3 points) was assigned to articles that extensively justified and explained the issue at hand (e.g., the authors explained that semi-structured interviews were used, transcribed verbatim, and modified part way through the study, and then offered some example interview questions). The scores from all eight questions were totaled for each article, with a maximum score of 24.

Classifying the findings. The findings of the studies were then classified using Sandelowski and Barroso's (2007) classification system. The purpose of this procedure was to reveal the actual analytic work performed (vs. what was stated). As suggest by Sandelowski and Barroso, topical survey studies would have been excluded from the metasynthesis. None were excluded for this reason.

Synthesis of findings. Synthesis of the findings was achieved using taxonomic analysis, constant target comparison, and reciprocal translation. The purpose of the taxonomic analysis was to identify significant underlying concepts and conceptual relationships. The study findings were then evaluated for similarities and differences to clarify defining and overlapping attributes of hope and discern relationships among the interpreted concepts. Reciprocal translations of the concepts were then used to integrate the metasynthesis findings.

Validity

The descriptive validity for this metasynthesis as suggested by Sandelowski and Barroso was maintained by (a) a comprehensive search for literature, (b) team discussion and decisions on search terms and inclusion criteria, (c) appraisals by two members of the team, (d) contacting authors for additional information, and (e) keeping an audit trail of search results and decisions. The team also discussed findings of the studies and themes until agreement was reached through consensus. Expert consultation on the methodology was also sought.

Results

Sample

Characteristics of the 14 studies are represented in Table 1. Three were considered thematic surveys and were descriptive in nature. Three were conceptual thematic studies and eight were interpretive studies. Across all 14 studies, CASP scores ranged from 9 to 24 with a mean of 17.94. A variety of methodologies were used in the hope articles: seven studies used grounded theory, three used phenomenology, two mixed methods, one thematic analyses, and one ethnography. The total sample from the studies was 178 participants. Studies were conducted in the following countries: four in Canada, four in the United States, three in Finland, one in Belgium, one in Britain, and one in Australia. Not all studies

reported data on age, gender, length of time caregiving, or relationship to patient. Available data indicate caregivers ranged in age from 17 to 84 years with a mean of age of 47, more caregivers were female (131 vs. 47 male), and the length of time that participants had been caregivers ranged from less than a month to 42 years. Caregiver to patient relationships included 85 spouses, 15 children, 37 parents, one grandparent, five siblings, five other relatives, four friends, and 18 volunteers. The studies focused on caregivers for persons with a variety of different illnesses: HIV/AIDS (3), unspecified diagnoses (3), advanced cancer (2); persons in coma (1), mental illness (1), severe brain injury (1), sickle cell anemia (1), and dementia (1). One study was conducted with bereaved caregivers whose family member was deceased. The setting in which caregiving occurred also varied: eight studies in a home setting; two in a critical care unit; one in a chronic care facility; and three in an unspecified setting.

INSERT TABLE 1 ABOUT HERE

Context of Studies

The focus of this metasynthesis was qualitative studies of hope in family caregivers of persons with chronic illness as such also included literature regarding families care-giving for persons with terminal illnesses. As a result, the context of all the studies was a situation of loss and grief. The losses described were both actual and potential. For example, actual loss occurred as roles and relationships changed. Potential losses were associated with the caregiver realizing the patient would become more dependent with the progression of disease. The context also included the uncertainty experienced in the lives of the caregivers and the ongoing changing nature of their situations as the patient's illness progressed. Caregiving experiences were influenced by the illness of the patient; as caregiver hopes and experiences were interconnected, the nature of hope could not be separated from this experience. As described by Bland and Darlington (2002), "hope was clearly worked out in the context of coping with and adjusting to the ongoing process of their relatives' illness (p. 63)." The results of the metasynthesis were interpreted within this context.

Findings

All 14 studies described the importance of hope to the family caregivers of persons with chronic illness regardless of age, relationship, or setting. Although study findings varied, several derived themes arose from the synthesis: (a) transitional refocusing from a difficult present to a positive future, (b) dynamic possibilities within uncertainty, (c) pathways of hope, and (d) hope outcomes.

Transitional Refocusing from Difficult Present to a Positive Future

A shared finding of hope in all 14 studies was the transitional refocusing by family caregivers from a difficult present to a positive future. Hope was described as a positive future, compared to a difficult present. Concepts of hope (possibilities and positive future, transitions, realistic: grounded in the present) that comprise the overall of transitional refocusing and data examples from the studies are presented in Table 2.

INSERT TABLE 2 ABOUT HERE

The transitional nature and future orientation of hope was also reflected in descriptions of different types of hope. Table 3 presents types of hope from the 14 studies, including specific concrete hopes (short and long term), as well as lost, old, and new hopes. Specific/concrete hopes were often described as goals, task specific hopes, or desirable outcomes—they were what family caregivers were “hoping for” (Borneman et al., 2002; Forte, 1997; Gelling, 1999; Verhaeghe, van Zuuren, Defloor, Duijnste, & Grypdonck, 2007). Family members had specific hopes for themselves, for their ill relative and for their other family members. For example, studies reported family caregivers hoping to continue caregiving and to make a difference in the life of the person for whom they were caring.

INSERT TABLE 3 ABOUT HERE

Specific hopes were transitional, situational, and temporal in nature, and the definition of future determined whether specific hopes were short or long term. For example, when the future was defined as moments, hours, or days, specific hopes were short term in nature; when the future was defined as months or years, hopes were long term in nature. Caregivers whose coping strategies involved living day by day, a shorter timeframe for defining future were formulated. For these caregivers contemplating a future that was more than a day was difficult at times (Herth, 1993; Holtslander et al., 2005; Duggleby et al., 2009).

The transitional nature of hope was also reflected in the categorization of specific hopes into lost, old, or new hopes. As situations changed, some hopes were lost and new hopes emerged.

Specific hopes contributed to an overall feeling of hope. This overall feeling of hope reflected a continuum of weak to strong hope as study themes included “losing hope”, “fading” or “weak” hope, and “strong” hope. All types of hopes occurred concurrently, and were not mutually exclusive.

Dynamic Possibilities Within Uncertainty

A derived theme of hope was dynamic possibilities within uncertainty. Although hope was not always clearly defined, the majority of the studies referred to hope as possibilities for a better future (Duggleby et al., 2009; Forte, 1997; Kylma, Vehvilainen-Julkunen, & Lahdevirta 2001 a; Kylma et al., 2003; Parse, 1999; Verhaeghe et al., 2007). Two referred to hope as expectation (Gelling, 1999; Herth, 1993). Possibilities were grounded in the present, realistic, and potentially achievable within certain conditions. These conditions were situational as well as dependent on internal and external factors influencing hope (Table 4). Internal factors (within the individual) influencing hope were (a) positive outlook, (b) spirituality and faith, and (c) physical and psychosocial well-being. External factors (outside the person) included: (a) level of support, (b) situational events, (c) illness of family member, (d) relationship with family member, and (e) information about the patients’ condition. The findings suggest internal and external factors might have either a positive or negative impact on the specific hope of family caregivers, reflecting a dynamic interaction of possibilities.

INSERT TABLE 4 ABOUT HERE

A major factor influencing hope was uncertainty (Gelling, 1999). Uncertainty is a cognitive state where insufficient clues are available to make sense or formulate meaning of a situation (Mishel, 1990). Uncertainty was a precondition for hope as hope was about possibilities (Verhaeghe et al., 2007). For family caregivers of persons with chronic illness, uncertainty is an ongoing state as the illness of the person continuously fluctuates. Based on the degree of uncertainty, hope would either begin to fade until it became old or lost, or would remain strong and unchanged.

Pathways of Hope

Depending on the degree of uncertainty that their hope is achievable, different hope pathways emerged, such as “Hanging on to Hope” (Holtslander et al 2005), “Renewing Hope” (Duggleby et al., 2009), and “Searching for New Hope” (Holtslander and Duggleby, 2009). These three pathways described in three of the studies reflect many of the processes described in other studies. For example, common to all of the pathways was the appraisal of the conditions of hope and awareness of changes in the conditions. Also shared was the cognitive reappraisal that occurred so family caregivers would have a positive view of their situation and find possibilities. The concept of different pathways explains the shared findings of processes and variations in the processes of hope within the studies. The processes of these hope pathways are outlined in Table 5.

INSERT TABLE 5 ABOUT HERE

Hope Outcomes

Table 5 outlines the outcomes of hope as synthesized from the study findings, including coping with the family member’s illness / dealing with difficult situations, regaining control / decreasing uncertainty, and decreasing loss and grief. Conversely, these outcomes were negatively impacted when family caregivers felt they were losing hope. Some factors influencing hope also were described as outcomes of hope. For example, physical and psychosocial well-being was also positive outcomes of having hope. This overlap illustrates the circular and complex nature of hope, where the outcomes of hope impact conditions influencing specific hopes.

Hope: Transitional Dynamic Possibilities within Uncertainty

Conceptually integrating the synthesized themes found in studies of family caregivers of persons with chronic illness are relationships between the factors influencing hope, appraisal of hope, hope pathways, specific hope, overall hope, and hope outcomes. Figure 1 illustrates the interaction and interrelationship of these themes as derived from the metasynthesis. Internal and external factors influencing hope interact with the appraisal of hope, pathways of hope, specific hopes, overall feelings of hope, and hope outcomes. Depending on the appraisal of the conditions of hope and the degree of uncertainty that hope is achievable, a different hope pathway might be used (hanging on to hope,

renewing hope, or searching for new hope). Each pathway results in specific hopes that comprise the overall state of hope, which might be considered strong or weak by the caregiver. A strong overall feeling of hope has outcomes of increased feelings of control, decreased feelings of loss and grief, improved physical and psychosocial well-being, and feelings of coping with their situation. All of this occurs within a context of uncertainty.

INSERT FIGURE 1 ABOUT HERE

Discussion

The findings of the metasynthesis suggest hope of family caregivers of persons with chronic disease is a dynamic experience of possibilities within uncertainty. Hope is grounded in the present with possibilities of positive future outcomes within certain conditions. These conditions include internal, external, and situational factors that influence hope. The focus of caregivers' hope changes with these conditions. The degree of uncertainty with respect to achieving their hopes determines which pathway or processes of hope in which they will engage to strengthen their hope.

Transitional Refocusing

The dynamic, transitional, temporal nature of hope has been described in several conceptual models of hope (Dufault & Martocchio, 1985; Farran, Herth, & Popovich, 1995; Morse & Doberneck, 1995; Synder, 1994). Similar to the findings of this metasynthesis, Dufault and Martocchio (1985) defined hope as the possibility of a positive future outcome and conceptualized the term specific or particular hope. Theories of hope have focused on the specific goal-directed, action-oriented, particular hope and not on the overall feeling of hope (French, 1952; Mowrer, 1960; Stotland, 1969; Synder, 1994).

Dufault and Martocchio suggest particular hopes are of little concern in situations of high uncertainty and rapidly changing conditions. However, the metasynthesis findings suggest specific hopes exist as short term hopes in rapidly changing conditions where the future is redefined in terms of hours and days. The metasynthesis findings link the temporal situational nature of hope to specific hopes. Short term, specific hopes define the future as minutes, hours, or days, whereas long term specific hopes define the future in months or years. The idea of a redefined future in terms of minutes, hours, or days has been

reported in the palliative / end of life literature, as a way to describe the hope of persons and their families at the end of life (Duggleby, 2001; Duggleby & Wright, 2005; Holtslander et al., 2005; Nekolaichuk & Bruera, 1998). However, conceptualizing specific hopes as either short or long term in relation to how the future is defined has not been reported in the literature.

Specific hopes created an overall feeling of hope for family caregivers. This overall feeling of hope differs from Dufault and Martiocchio's (1985)'s concept of general hope which is some sense of beneficial indeterminate future developments. Their conceptualization of general hope might have been present in the data of the 14 studies, but was not discussed in the findings. Elliott and Oliver (Elliott & Olver, 2007; Elliott & Olver, 2002) suggest varieties of hope co-exist and specific hopes (i.e., what people are hoping for) emphasize the positive nature of hope. Our findings might help clarify how varieties of hope co-exist and how specific hopes create the overall feeling of hope. Family caregivers have multiple co-existing hopes that shift in emphasis, become lost, or emerge as new.

Possibilities within Uncertainty

The degree of uncertainty influencing hope and other factors determined whether the overall feeling of hope in family caregivers was weak or strong. Measurement of hope has been based on the idea that overall feelings of hope have varying levels of intensity (Herth, 1992; Miller & Powers, 1988; Synder et al., 1996). However, our synthesis suggests the intensity of level of overall feeling of hope varies with uncertainty. This has not been proposed in other conceptual models of hope, but is supported by studies linking hope and uncertainty, where higher levels of hope are associated with lower levels of uncertainty (Christman et al., 1988; Hilton, 1989; Wonghongkul, Moore, Musil, Schneider, & Deimling, 2000). Moreover, hope in this metasynthesis was found to be defined as possibilities, rather than expectations. Expectations would suggest a more probable outcome and would not be situated within the concept of uncertainty. In addition to the relationship between hope and uncertainty, we suggest the appraisal of hope involves determining the degree of uncertainty of achieving hopes, and this appraisal results in different pathways of hope. The interaction of hope and uncertainty potentially explains the shared and differing processes of the hope of family caregivers as described in the literature.

Limitations

A limitation of the metasynthesis approach is that findings are synthesized from findings of other studies, not actual data. As a result, the assumptions made by the authors are continued in the metasynthesis. The studies reported findings of the hope experience of family caregivers caring for persons with a wide variety of illness experiences and age groups. In particular there was only one study of a family caring for a child with chronic illness. Although the findings from this study were similar to the other studies of family caregivers, future research might report different findings. Another limitation was the differing methodological approaches used by the included studies; some were grounded theory, others phenomenology. These methodologies have different philosophical assumptions and the findings reported by the authors reflect the approaches. Their findings also reflect the context in which their studies were conducted. Lastly, although the studies reviewed ranged in quality, all study findings were included in the synthesis as they contributed to the overall understanding of the hope of family caregivers.

Implications for Practice and Research

This metasynthesis study resulted in a new conceptual model of hope for family caregivers. This model proposes a unique understanding of hope that has not been previously found in the literature. It clarifies the relationships between uncertainty and hope, factors influencing hope and hope outcomes. Understanding hope is about possibilities within uncertainty explains the resiliency of hope in difficult situations. The resiliency of hope is also clarified by the proposed relationship between specific concrete hope and the overall feeling of hope. Different types of hope and different pathways of hope co-exist.

All components of this model provide a foundation for future research to examine the proposed relationships of the concepts. For example studies of interventions fostering hope should consider evaluating their impact on outcomes of hope, such as feelings of control and loss and grief. The conceptual linkage of specific hope to an overall feeling of hope integrated with uncertainty requires future research to delineate its integration and influence on different pathways of hope. Research exploring hope pathways for family caregivers of persons with chronic illness is also needed.

Health care providers can utilize the factors influencing hope and hope outcomes as part of their hope assessment for family caregivers. They also need to consider the family caregivers' degree of uncertainty and which pathway of hope might be most helpful to the family caregiver. The metasynthesis findings also offer a foundation for developing hope-fostering interventions for family caregivers of persons with chronic illness and guidelines to assess hope in this population.

The essential nature of hope to family caregivers of persons with chronic illness was clearly evident in this metasynthesis. By using a metasynthesis approach, qualitative research on hope in this population was used to deepen our understanding of a complex, yet important concept. The findings provide a foundation from which additional research can build and focus on gaps of knowledge in this area. Current theories of hope do not appear to capture the experience of hope of family caregivers as evidenced by the metasynthesis. Continuous building of knowledge in this area is essential if health care professionals are to provide support to family caregivers to foster their hope.

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Table 1: Study Characteristics

| Source | Objective | Methodology | Data Collection Method | CASP Total | Findings Classification |
|----------------------------|-------------------------------------------------------------------------------------------------------------------|------------------------|----------------------------------------------------------------------------------|------------|------------------------------|
| Bland & Darlington, (2002) | To explore the significance and meaning of hope for family caregivers of people with mental illness | Thematic / Descriptive | Semi-structured interviews | 12 | Conceptual / Thematic Survey |
| Borneman et al. (2002) | To explore the concept of hope and how hope is maintained in family caregivers of cancer patients | Mixed Method | Semi-structured interviews Quantitative Questionnaire of Herth Hope Index | 10 | Thematic Survey |
| Duggleby et al. (2009) | To explore the experience of hope for family caregivers of people with dementia | Grounded Theory | Semi-structured interviews | 19 | Interpretive |
| Forte (1997) | To study the meaning of hope in family caregivers of children with sickle cell anemia | Phenomenology | Photo-interviewing | 24 | Interpretive |
| Gelling (1999) | To investigate the experience of hope for family members of people with severe head injury | Phenomenology | Semi-structured interviews | 18 | Interpretive |
| Herth (1993) | To study the meaning of hope and hope-fostering strategies for family caregivers of people who are terminally ill | Mixed Methods | Semi-structured interviews Quantitative | 20 | Thematic Survey |

| | | | Questionnaire of Hope and demographics | | |
|----------------------------------------|------------------------------------------------------------------------------------------------------------------------------------|--------------------|-----------------------------------------------------------------------|----|--------------|
| Holtslander et al. (2005) | To study the experience of hope for informal caregivers of palliative patients | Grounded Theory | Semi-structured interviews, field notes, and journal entries | 22 | Interpretive |
| Holtslander & Duggleby (2009) | To explore the experience and processes of hope for older women after caring for spouses with terminal cancer | Grounded Theory | Journal entries | 20 | Interpretive |
| Kylma et al. (2001a) | To describe the dynamics of hope for people who have or fear having HIV/AIDS and their spouses | Grounded Theory | Semi-structured interviews | 19 | Interpretive |
| Kylma et al. (2001b) | To describe the voluntary caregivers observations on the dynamics of across the continuum of HIV/AIDS | Grounded Theory | Focus group interviews | 20 | Interpretive |
| Kylma (2003) | To describe the dynamics of hope in significant others of people living with HIV/AIDS and persons living with HIV/AIDS | Grounded Theory | Semi-structured interviews | 18 | Interpretive |
| Parse (1999) | To investigate the lived experience of hope for family caregivers of people who are chronically ill | Phenomenol ogy | Dialogical engagements | 9 | Interpretive |

| | | | | | |
|----------------------------|------------------------------------------------------------------------------------------|--------------------|-------------------------------|----|---------------------------------|
| Patel (1996) | To investigate hope-fostering strategies of people whose spouses are critically ill | Ethnography | Semi-structured interviews | 21 | Conceptual/The- matic Survey |
| Verhaeghe et al. (2007) | To examine the process and meaning of hope for family members of people who are comatose | Grounded Theory | Semi-structured interviews | 20 | Interpretive |

Table 2: Themes of the Transitions from Difficult Present to Positive Future.

| Derived Themes | Data |
|-------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Possibilities and | A belief that things are going to get better (Bland & Darlington, 2002) |
| Positive Future | Looking ahead, looking forward (Borneman et al., 2002) Possibilities of a positive future (Duggleby et al., 2009) Possible future good (Forte, 1997; Holtslander et al., 2005) Future orientated belief in existing possibilities (Kylma et al., 2001a ; Kylma et al., 2003) Positive future orientation (Gelling, 1999) Positive new awareness (Herth, 1993) Anticipation of possibilities (Parse, 1999) Possible positive outcomes (Verhaeghe et al., 2007) |
| Transitional | Temporal nature and reactive nature of hope (Bland & Darlington, 2002) Hope changes (Borneman et al., 2002) Fluid nature of hope (Duggleby et al., 2009) Continuing unfolding and changing (Herth, 1993; Kylma et al., 2003) Dynamic (Forte, 1997; Holtslander & Duggleby 2009; Holtslander et al., 2005) What is hoped for changes (Verhaeghe et al., 2007) |
| Realistic, Grounded in the Present | Hope was grounded in the present (Bland & Darlington, 2002) One day at a time (Borneman et al., 2002; Herth, 1993) Everyday hope (Duggleby et al., 2009) Realistic Goals (Forte, 1997; Gelling, 1999; Verhaeghe et al., 2007) Living in the moment (Holtslander et al., 2005) |

Table 3: Types of Hope

| Types of Hope | Data Examples |
|-----------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Old/Lost Hope and New Hope | <p>Lost hopes (dashed) (Bland & Darlington, 2002; Borneman et al., 2002; Herth, 1993; Verhaeghe et al., 2007)</p> <p>Fading hope and strong hope (Duggleby et al., 2009)</p> <p>Eroding Hope (Holtslander et al., 2005)</p> <p>Less Hope (Holtslander & Duggleby, 2009; Holtslander et al., 2005; Verhaeghe et al., 2007)</p> <p>Hope grows (Holtslander & Duggleby, 2009)</p> <p>New hopes emerge (Holtslander & Duggleby, 2009; Verhaeghe et al., 2007)</p> <p>Initial and later hope (Verhaeghe et al., 2007)</p> |
| Short Term Specific Hope | <p>Short term goals (Gelling, 1999)</p> <p>(Bland & Darlington, 2002; Borneman et al., 2002)</p> <p>Less pain and suffering for person (Holtslander et al., 2005; Patel, 1996; Verhaeghe et al., 2007)</p> <p>Getting through the day, facing each day (Duggleby et al., 2009; Holtslander & Duggleby, 2009; Holtslander et al., 2005; Verhaeghe et al., 2007)</p> |
| Long Term Specific Hope | <p>Long term specific goals of getting better, and returning to work (Gelling, 1999; Borneman et al., 2002)</p> <p>Specific future goals of family and ill member (Bland & Darlington, 2002)</p> <p>Continue caregiving and do a good job (Holtslander et al., 2005)</p> <p>New careers, staying healthy, regaining confidence (Holtslander & Duggleby, 2009)</p> |

Table 4: Factors Influencing Hope and Outcomes of Hope

| Internal Factors | External Factors Influencing | Outcomes of Hope |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Influencing Hope | Hope | |
| Positive Outlook (Bland & Darlington, 2002; Borneman et al., 2002; Duggleby et al., 2009; Holtslander & Duggleby, 2009; Holtslander et al., 2005; Kylma et al., 2003; Parse, 1999; Patel, 1996; Verhaeghe et al., 2007) | Level of Support From Others (family, friends, Health care professionals and services) (Bland & Darlington 2002; Borneman et al., 2002; Duggleby et al., 2009; Forte, 1997; Gelling, 1999; Herth, 1993; Holtslander & Duggleby, 2009; Holtslander et al., 2005; Kylma et al., 2003; Parse, 1999; Patel, 1996; Verhaeghe et al., 2007) | Coping with the illness of the family member /dealing with difficult situations (Bland & Darlington, 2002; Borneman et al., 2002; Duggleby et al., 2009; Holtslander et al., 2005; Kylma et al., 2003) |
| Spirituality and Faith (Bland & Darlington, 2002; Borneman et al., 2002; Duggleby et al., 2009; Forte, 1997; Gelling, 1999; Herth, 1993; Holtslander & Duggleby, 2009; Holtslander et al., 2005; Parse, 1999; Patel, 1996) | Critical Events and the Illness Experience of Family Member (Bland & Darlington, 2002; Borneman et al., 2002; Duggleby et al., 2009; Gelling, 1999; Herth, 1993; Holtslander et al., 2005; Kylma et al., 2003; Patel, 1996; Verhaeghe et al., 2007) | Regaining Control/Decreasing Uncertainty (Duggleby et al., 2009; Holtslander & Duggleby, 2009; Holtslander et al., 2005; Verhaeghe et al., 2007) |
| Physical Well-Being (Borneman et al., 2002; Herth, 1993; Holtslander & Duggleby, 2009; Patel, | Relationship with Family Member (Bland & Darlington, 2002; Borneman et al., 2002; Duggleby | Increased Physical Well-being (improved strength, energy) (Bland & Darlington, 2002; |

| | | |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1996) | et al., 2009; Gelling, 1999; Kylma et al., 2003; Patel, 1996) | Borneman et al., 2002; Duggleby et al., 2009; Holtslander & Duggleby, 2009; Holtslander et al., 2005; Kylma et al., 2003; Parse, 1999; Verhaeghe et al., 2007) |
| Psychosocial Well-being (anxiety, fear, loneliness, grief) (Borneman et al., 2002; Gelling, 1999; Holtslander & Duggleby, 2009; Patel, 1996) | Information (Bland & Darlington, 2002; Duggleby et al., 2009; Gelling, 1999; Holtslander et al., 2005; Verhaeghe et al., 2007) | Improved Psychosocial Well-being (not giving up, feelings of peace, improved relationships) (Bland & Darlington, 2002; Borneman et al., 2002; Duggleby et al., 2009; Holtslander & Duggleby, 2009; Holtslander et al., 2005; Kylma et al., 2003; Parse, 1999; Verhaeghe et al., 2007) Loss and Grief - Hope decreased loss and grief (Holtslander & Duggleby, 2009). - Losing hope resulted in feelings of loss and grief (Bland & Darlington, 2002; Borneman et al., 2002; Duggleby et al., 2009; Herth, 1993; Holtslander & Duggleby, 2009) |

Table 5: Pathways of Hope

| Pathways of Hope | Shared Processes | Processes |
|---------------------------------------------------------------|--------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------|
| Hanging on to Hope (Holtslander et al., 2005) | Accepting the situation Finding positives | Doing what you have to do (Accepting the situation) Living in the Moment Staying positive Writing your own story |
| Renewing Everyday Hope (Duggleby et al., 2009) | Coming to terms Finding Positives | Coming to terms Finding the positives Seeing possibilities |
| Searching for New Hope (Holtslander & Duggleby, 2009) | Assessing the situation Finding positives | Finding Balance (assessing situation) Finding new Perspectives (positives) Finding New Meaning and Purpose |
| Dynamically Fluctuating Hope (Kylma, 2001a) | Becoming Aware of Illness | Becoming aware of illness, Believing Being directed toward the future Existing possible alternatives |
| Meaning and Processes of Hope (Verhaeghe et al., 2007) | Assessing of family members condition. | Hope changes based on events and information regarding family member's condition. New hope is sought in there is adverse evolution in condition. |