

**THE ILLNESS CAREER OF FAMILY SUBSYSTEMS EXPERIENCING DEMENTIA:
PREDOMINANT PHASES AND STYLES OF MANAGING**

By

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ABSTRACT

This two-year exploratory study using a self-selected sample was conducted to gain an understanding of the illness career of thirty-nine family subsystems having an elder member with dementia at home. The focus of the qualitative study was on two questions that have been relatively unexplored in previous research: (1) what is the nature of the family context during the illness career (e.g., definition of events, definitions of self, interaction/relationship styles)?; and (2) what is the interdependence of the identified patient, other family members, and their external context in regard to the contextual changes that occur over time? The two theoretical frameworks that guided this study were a symbolic interactionist-phenomenological perspective and a family systems perspective based on the Calgary Family Assessment Model (CFAM).

Three sets of findings are presented: (1) the background context or pre-illness phase characteristics of the family subsystems; (2) the six phases of the illness career that were identified, including the salient types of destabilizing and restabilizing processes for those phases; and (3) the context and process-based typology of styles of managing that was developed on the basis of a thematic analysis of the family's predominant ways of dealing with the various events during the illness career. The classification

of styles of managing on a continuum from Open to Closed highlights the importance of definitional and family boundary processes derived from the theoretical perspectives that informed this study. The nature of the pre-illness phase attachment patterns of these families is suggested as one possible reason for their predominant style of managing.

This study has implications for sociological theory and methods by affording insights into the distinction between coping as process and coping as outcome. Also elucidated were the nature of, and the interdependence between, the family's perceptions of their situation and the identity of the elder, and their corresponding styles of managing. This study also draws attention to some important research and practice issues with regard to long-term care for contemporary elders and their families. The ways in which sociological insights may help to transform current practice dilemmas, and the implications for the education and recruitment of formal care professionals are outlined.

Outlined in the Table below is a summary of the major differences between families with an open style of managing and those with a closed style of managing. More detailed information can be obtained by contacting the author (cllenave@ucalgary.ca)

TABLE 1: FINDINGS REGARDING THE OPEN/CLOSED CONTINUUM OF STYLES OF MANAGING

OPEN STYLE OF MANAGING	CLOSED STYLE OF MANAGING
<ul style="list-style-type: none"> • Focus* (was either) <ul style="list-style-type: none"> - social system-centered, or - family centered * tended to encourage adaptability: 	<ul style="list-style-type: none"> • Focus* (was) <ul style="list-style-type: none"> ◆ elder-centered ◆ “stability through tradition”
<ul style="list-style-type: none"> • Behavioral Response Patterns (Considerable contact with outside systems for purposes of): <ul style="list-style-type: none"> - Info seeking - Info giving - Organizing / mobilizing services - Supervisory activities 	<ul style="list-style-type: none"> • Behavioral Response Patterns (Limited contacts with outside systems) <ul style="list-style-type: none"> ◆ Doer pattern ◆ Follower pattern ◆ Rehabilitation pattern
<ul style="list-style-type: none"> • Affective Response Patterns <ul style="list-style-type: none"> - affectionate - acceptance, unconditional and realistic 	<ul style="list-style-type: none"> • Affective Response Patterns <ul style="list-style-type: none"> ◆ limited range of feelings expressed or shared within the subsystem and with outside systems ◆ emphasis on “not bothering others” (i.e., those outside the subsystem)

<p style="text-align: center;">OPEN STYLE OF MANAGING</p>	<p style="text-align: center;">CLOSED STYLE OF MANAGING</p>
<ul style="list-style-type: none"> • Communication Patterns <ul style="list-style-type: none"> - empathic - accommodating mutuality evident 	<ul style="list-style-type: none"> • Communication Patterns <ul style="list-style-type: none"> - (for Doer & Follower Pattern group): <ul style="list-style-type: none"> ◆ infrequent direct & indirect contacts with kin ◆ resigned acceptance/passive forbearance ◆ narrow range of emotional communication ◆ limited strategies to address long-standing disagreements with kin/non-kin ◆ direct and clear communication including cognitive, supportive instructions, with the elder, was limited - (for Rehab pattern group) <ul style="list-style-type: none"> ◆ Confrontational approach with family members and non-members outside the subsystem
<ul style="list-style-type: none"> • Rules defining the Elder's participation with outside systems and/or decision-making <ul style="list-style-type: none"> - flexible - emphasis on involving the elder in appropriate outside family/non-family social activities - accorded importance to inviting the elder's participation in decision-making 	<ul style="list-style-type: none"> • Rules defining the Elder's participation with outside systems and/or decision-making <ul style="list-style-type: none"> - (among the Doer & Follower group) <ul style="list-style-type: none"> ◆ unspoken rule about the elder's non involvement with outside systems, except for medical checkups - (for the Rehab Group): <ul style="list-style-type: none"> ◆ limited flexibility ("shape up or ship out")

<p style="text-align: center;">OPEN STYLE OF MANAGING</p>	<p style="text-align: center;">CLOSED STYLE OF MANAGING</p>
<ul style="list-style-type: none"> • Consequences for the subsystem <ul style="list-style-type: none"> - profound sense of appreciation of kin/non-members - feelings of being 'cared about' rather than simply services - sense of security - increase sharing of feelings, both positive and negative - a sense of accomplishment and belief that "we did our best" - increased self-esteem - openness to adopting new ways of relating with the elder and outside systems 	<ul style="list-style-type: none"> • Consequences for the subsystem <ul style="list-style-type: none"> ◆ limited sense of 'mutuality' between subsystem dyad and outside members ◆ feelings of loneliness on part of the significant others ◆ occurrence of a health-related change or major life event that "forced" some of the significant others to become more open to inputs from outside systems
<ul style="list-style-type: none"> • Rules Defining the Elder's participation <ul style="list-style-type: none"> - flexible - emphasis on involving the elder in appropriate outside family/non-family social activities - accorded importance to inviting the elder's participation in decision-making 	<ul style="list-style-type: none"> • Rules Defining the Elder's participation <ul style="list-style-type: none"> ◆ Contingent on appropriate behaviour ◆ limited involvement in decision-making
<ul style="list-style-type: none"> • Possible reasons for this style <ul style="list-style-type: none"> - Pre-illness phase attachment patterns: strong and positive 	<ul style="list-style-type: none"> • Possible reasons for this style <ul style="list-style-type: none"> ◆ Pre-illness phase attachment patterns: weak and/or strong and negative ◆ nature of attribution pattern regarding causes of the elder's behavioral changes: ◆ primarily internally-orientated or characterological causal attributions ◆ limited knowledge of and/or, resources available from their informal social network or the formal service system