

Toward holistic care: Integrating process and content

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Abstract

As a result of the last decade of social and economic change, our traditional concept of caregiving may need broadening to encompass the needs of physically, emotionally, and economically vulnerable individuals and families. Using the lens of ecological systems theory, this paper proposes a holistic framework that takes into account the multifaceted care needs of vulnerable populations as well as the cadre of resources available through personal networks and the broader care community.

Keywords

care, management, system, resources, demands

Introduction

The traditional concept of caregiving among family and consumer professionals may need to be revised in order to address the scope of issues vulnerable individuals and families face in today's social and economic climate. That traditional concept has been influenced primarily by family caregiving, and it has focused largely on meeting the physical needs of the recipient of care.

While physical needs are indeed important, formal and informal care managers must also address a host of additional needs—needs that are often overlooked under that traditional thought paradigm. Mental and emotional fragility often precipitates or contributes to the need for care. Increasingly in today's economy, the emotional stresses of family dissolution or financial crisis make intervention or assistance necessary for family stability, even if families have few or no health issues. In order to optimize the total response to vulnerable individuals and families, care managers find themselves crossing several domains—physical, economic, and interpersonal.

The domain of health and physical comfort includes not only palliative care but also the resources and demands created by the broader physical environment including shelter, food, transportation, infrastructure, and natural and built environments.

The care manager must also deal with economic factors that include personal finances as well as local, national, and global economic changes. To manage effectively in the economic domain, consideration must be given to the availability of cash and other personal assets along with access to assistance from family, community, and government. Management of the economic domain also includes the demands of financing the normal and ongoing needs for food, shelter, and clothing as well as those created by any circumstances requiring physical caregiving. In the case of individuals and families lacking financial resources, assistance providers or the broader care community may engage in the actual provision of normal and ongoing needs for food, shelter, and clothing.

Finally, the care manager must consider personal relationships and networks as well as the larger socio-cultural environment that includes institutions, government, and mass media. Management within this domain involves balancing resources in the form of assistance or nurturing with demands created by role expectations, reciprocal exchange, and qualification criteria and requirements.

By taking a more comprehensive approach to caregiving, we as family and consumer professionals can respond more appropriately to the complex requirements of those who no longer have the capacity to satisfy their own economic, social, environmental, or physical needs and more efficiently use scarce care resources. Using the lens of ecological systems theory, this paper proposes a holistic framework that takes into account the multifaceted demands of care provision as well as the cadre of resources available through personal networks and the broader care community. In doing so, two conceptualizations are proposed:

- **The management of care.** The first conceptualization depicts care management as the **process** of the individual's manipulation of available resources to meet demands.

- **The ecology of care.** The second conceptualization nests the care management process in the **context** of an ecological framework. It is when these two concepts (process and context) are looked at in tandem that a holistic approach is realized. The process and context of care are discussed, along with how the integration of the two might help individuals and institutions develop effective care management plans.

Theoretical background

Both conceptualizations draw from established theory:

The **management of care** conceptualization draws primarily from Deacon and Firebaugh's (1988, 3-27) description of the Family Resource Management subsystem. Deacon and Firebaugh describe management as "a process of thought and action through which **resources** are utilized in the meeting of **demands**" (1988, 21). "Management," they note, "helps people control the events of life and influence the outcomes of situations. It influences the quality of life of the individual and the family through the way resources are directed toward goals" (1988, 3). Deacon and Firebaugh characterize the management system as having (1) input, consisting of matter, energy, and information and (2) output, the transformation in matter, energy, or information occurring as a result of management within the system (1988, 8-9). This contextual focus facilitates efficiency in management—the **process** through which resources are used to satisfy or alter demand.

The conceptualization of the **ecology of care** is the result of combining elements from ecological systems frameworks used in the fields of rural sociology (Loomis and Beegle 1957), family resource management (Knoll 1963; Maloch and Deacon 1966; Deacon and Firebaugh 1975; Paolucci, Hall, and Axinn 1977) and human development (Bronfenbrenner 1979). These frameworks had origins in earlier and parallel work on general systems theory (von Bertalanffy 1950, 1972) which during the 1960s became an influential interdisciplinary paradigm in fields ranging from the physical and biological sciences to psychology and sociology (Buckley 1968). Ecological systems theory emphasizes the interrelated and bi-directional nature of the relationships of the individual with his or her near and far environments. According to ecological systems theory, factors as near as immediate family and those as distant as political structures may act upon the individual, creating demands and supplying resources to meet his or her needs and wants. In the context of the near and far ecology, systems theory provides a lens for identifying the **resources** available to address the economic, social, and physical needs of the individual. Sources of support for addressing these needs extend far beyond the immediate family to include peer groups, social service agencies, and communities of faith. Systems theory also provides a framework for considering **demands** from the near and far environments on which limited resources can be expended. The paper will draw from this paradigm to develop an ecological framework for care.

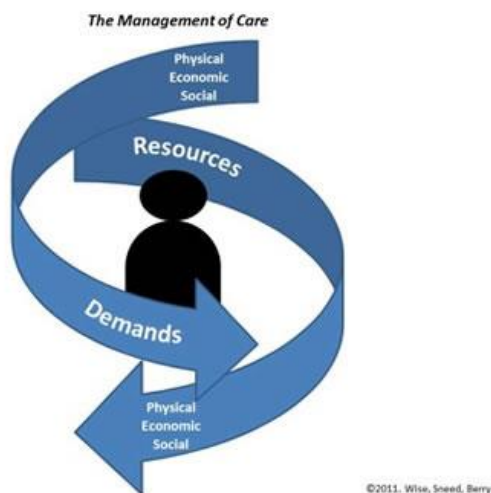
The management process

Figure 1 illustrates the care management process itself. Its central figure depicts the individual care manager, who is surrounded by flows of resources and demands represented by arrows curving around the figure. The notations “physical,” “economic,” and “social,” on the arrows themselves denote that resources and demands stem from these sectors of the individual’s environment. To the extent that the recipient of care has the functional ability to assume them, ultimate care management decisions as well as decisions to accept or reject help or assistance lie with that individual. However, this conceptualization also applies to the individuals at many levels who make care management decisions in the context of environmental demands and resources. For example, a social worker may need to decide the feasibility of providing care at home. A minister may need to respond to a request for financial assistance. A physician may be asked to determine eligibility for hospice care. An agency director may be tasked with developing eligibility criteria. Each would consider both the demands placed upon them by the care situation and the resources available to meet those demands. Each would also consider not only those resources under the direct control of the individual making the care decision, but those of the broader care community represented in the contextual framework to follow.

When managing care, the individual (1) identifies needs/demands, (2) identifies resources available, and (3) manipulates resources to meet demands. This results in change which may satisfy or alter demands and in feedback that may supply new insights for more effective management. All of this is set in the context of a dynamic environment of ever-changing demands and resources.

Figure 1: Process model (The Management of Care).

[Alt tag content for Figure 1: Stylized graphic of human figure enclosed by two flowing arrows]



The ecological context

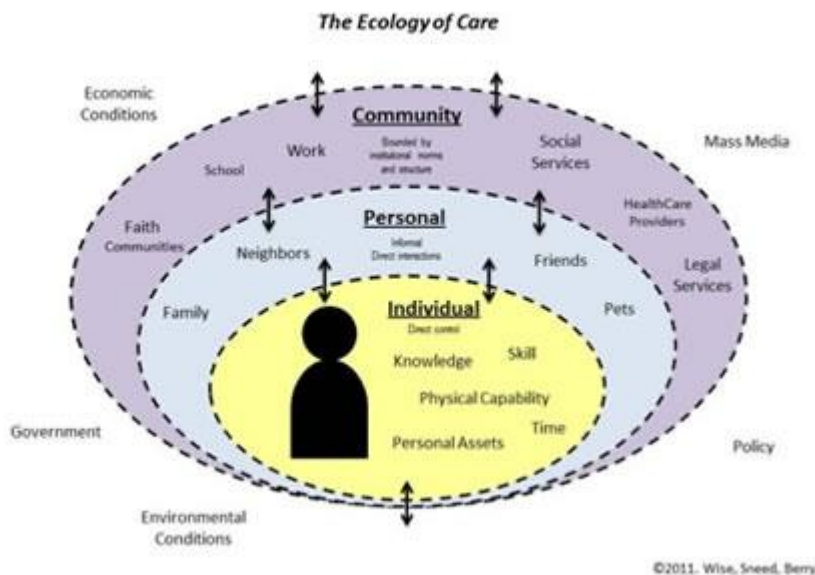
Managing the demand and resource flow as depicted in Figure 1 does not occur in a vacuum. Rather, this management process is set in the context of near and far ecological environments depicted in Figure 2. The figure consists of three concentric circles representing three levels of the individual's ecology of care—the innermost (Individual), the middle (Personal) and the outside (Community) level. The bi-directional arrows across the boundaries of these levels represent the exchange of information and interaction between each level. The figure of concentric circles is placed on a broader plane representing the Macro-environment.

Deriving theoretical support from ecological systems theory, the domains depicted in Figure 2 have the following characteristics:

- **Individual level.** At the core of the concentric circles, the Individual level, is the figure representing the individual care manager from our management figure (Figure 1). The notation, “Direct control,” indicates that the individual is often able to exercise direct control over the factors depicted at that level—knowledge, skills, time, and personal assets. A key component within this level is the functional capability of the individual to effectively deal with management decisions.
- **Personal level.** The middle circle represents the Personal level, where “informal and direct interaction” takes place. The relationships contained in this level are not bound by social mores or organization norms. Instead these relationships are organic, developing over time out of informal social exchanges. Examples include neighbors, friends, family, and pets.
- **Community level.** The outside level of the concentric circle represents the Community level. Unlike the personal level, community level relationships are characterized by “institutional boundaries and more formal interaction.” This level includes such structured relationships as faith communities, school, work, social services, health care providers, legal services, and other institutions.
- **Macro-environmental context.** The plane that represents the Macro-environmental context notes that it includes economic conditions, government, environmental conditions, mass media, and policy. This broader context houses the ecological system of care depicted by the concentric circles.

Figure 2: Context Model (The Ecology of Care).

[Alt tag content for Figure 2: Three concentric circles with innermost circle containing human figure from Figure 1]



This framework illustrates the individual's place in the larger care environment with the demands and resources produced at the Individual, Personal, Community, and Macro-environmental levels. It provides an organized way of looking at the multi-level factors that confront the individual. In addition—and perhaps of most importance—this holistic approach provides a context for identifying diverse resources that might be overlooked from the perspective of any of the unique levels. The individual's ability to identify and harness resources at all levels can make the difference in whether he or she receives adequate or inadequate care. For example, an individual in need may expect all of his or her care needs to be met through family and friends without being aware of the community and governmental resources available. On the other hand, community care providers may be ignorant of assets and capabilities the individual possesses to meet his or her own needs. A comprehensive look at care available at all levels can dovetail with support and avoid duplication of effort among the care respondents—all without depleting the resources of any one care provider.

In many cases, individuals in social service agencies and communities of faith in all good intent waste precious support and resources responding to need that might be more effectively met by other providers and in other ways. If these individuals have little prior experience providing help, they may try to meet multiple needs without considering all available resources. Given that most small caregiving organizations do not have resources to help in a comprehensive way,

understanding how to tap resources of the larger local care community (including government assistance) in order to leverage the limited assistance they can provide becomes critically important.

Application

In order to see how we might apply the proposed frameworks, let us analyze a hypothetical need scenario from the approach proposed.

Need scenario. Juanita Brown has found herself in both a financial and a medical crisis. A single mother supporting two sons, ages four and seven, she is well-educated and has been self-sufficient up to now but was laid off from her job as a computer analyst in 2009. Since that time, Juanita has only been able to find part-time temporary work as a call center employee. Because she is getting paid only slightly more than minimum wage, she works as many hours as possible — often at night. So far, because Juanita's mother was also laid off, she has been able to watch Juanita's sons at night, but her mother now has an opportunity to return to work on an evening shift, so Juanita needs to find alternative child care.

Juanita has juvenile-onset diabetes, which she has always kept under control through a disciplined food and exercise routine. Since she has been working so many hours and at irregular times, she has not been able to keep her condition well-controlled. She's been experiencing fluctuations in blood sugar, and one morning her oldest son had to call for help when Juanita did not awake to get him ready for school because of a drop in her blood sugar.

Juanita lost her health insurance when she was laid off, and her current job has no benefits. She has exhausted her savings supplementing her current income to buy her medical supplies and continue to make payments on a condo she had just purchased before losing her full time job. She figures that this is the last month she will be able to purchase her medical supplies and make the condo payment.

Although Juanita prizes her independence and ability to provide for her family alone, she feels that she is losing control of her life. She has always been a person of faith and has decided to confide in one of the ministers at her church.

Management process. Given this scenario, the care management process may be applied from the perspective of two individual care managers. The first, and central, is Juanita herself. She is facing care decisions regarding her children as well as her own financial, medical, and emotional issues. The second care manager in this scenario is the minister in whom Juanita is confiding. She must make decisions about her response to Juanita including the types of support and

assistance she or the church can give. She also will need to think about how she and Juanita together might identify other resources they could bring to bear on Juanita's situation.

Ecological context. At the **Individual level**, the two may need to first discuss Juanita's state of mind and capability for dealing with the crisis internally. What specific demands are being placed on her that seem to be unmanageable? Might any of those be mitigated? How might she better manage her health issues? Could she restructure her time or get into a better routine? Does she have additional intrinsic resources that could be tapped? What are her financial skills and does she need financial management advice or counseling?

At the **Personal level**, which needs of her sons are foremost? Does she also feel obligations to other family members or friends that compete for her time and personal and emotional resources? Are there ways that her sons might help with age-appropriate tasks? Might combining households with her mom be a possibility that leverages both their resources? Would friends provide childcare or other help if asked?

Regarding the **Community level**, what demands are Juanita's sons' school and after-school requirements placing on her time and energy? How much time, energy, and resources are being devoted to church, sports, or other community activities? Are they appropriate for her current situation? What sort of relationship does she have with her financial institution? Are her medical needs being met through a care provider? Have assistance programs offered by government and community agencies been fully accessed for her financial and health needs?

In addition to the care decisions Juanita is facing, the minister has her own set of criteria that she must consider. At the **Individual level**, she must evaluate her own capabilities for dealing with Juanita's needs. Does she have the time and emotional and physical energy? Is she dealing with more pressing demands that indicate the need to refer Juanita to someone else for counseling?

At the **Personal level**, the minister might need to consider the expectations of her colleagues regarding her roles in the ministry. Is the time and energy she must devote to Juanita's needs in line with what her family and colleagues expect of her? What informal and personal resources might the minister bring to bear on Juanita's needs? Are there individual church members who might help with child care, auto servicing, or with small financial donations for needs not met in other ways? Does she need to take into consideration guidelines her church or church conference might have for providing assistance? Does she need to involve other colleagues in the decisions? What precedence might any commitments she makes to Juanita set regarding expectations of other congregants in need?

The minister's knowledge about **Community level** care may be the most important factor in her ability to effectively help Juanita. She needs to consider her church's limitations and

expectations as she decides how to best leverage its resources while taking into consideration the types of assistance that can be provided by the broader community of care. If she is tied into a community network of care providers who take a comprehensive approach to assistance, she can take comfort in the fact that it is not up to her church to meet Juanita's multiple and diverse needs.

As both Juanita and the minister wrestle with their care management issues, the macro environment itself may change their circumstances. New regulations or guidelines might impact Juanita's ability to qualify for assistance. Labor demand in Juanita's industry might open new prospects for her employment. Deep federal and state budget cuts might restrict resources available through government programs and social services agencies. An upswing or downturn in the larger economy might precipitate either an increase or decrease in church giving. Political rhetoric regarding public assistance might color the emotional response to Juanita's needs. A pharmaceutical company might offer opportunity to participate in clinical trials that improves control of Juanita's diabetes. Regardless of the fluidity of Juanita's and her minister's management skills and ecological environments, the frameworks proposed provide a methodical context for analyzing demands and identifying resources.

Conclusion and implications

The traditional conceptualization that restricts caregiving to the addressing of physical needs leaves both the individual caregiver and the community of care with few tools and little precedence for managing diverse care needs from a comprehensive perspective. The framework described in this paper is suitable for taking into account the multiple needs of vulnerable populations as well as the comprehensive resources of the broader care community. It is the authors' hope that by focusing on a more holistic approach and creating broader dialogue, more supportive and compassionate care can be provided and care resources allocated in a more efficient and effective manner.

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