

Social work practice in the chronic care model: Chronic illness and disability care

Journal of Social Work

2014, Vol 14(1) 83–95

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DOI: 10.1177/1468017313475381

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Abstract

- *Summary:* Maintaining good quality of life and health in face of living and/or aging with a chronic illness and/or disability can be challenging. The health care and related education and training of these individuals to become proactive partners in their ongoing care is the cornerstone of most chronic care models.
- *Findings:* Social workers are not specifically mentioned in most chronic care models. However, as the health and social care processes can become complicated if the individual has barriers to partnering roles necessitated by chronic care models, a role for the social worker should be more clearly defined. Examination and application of the ecosystems perspective defines a clear role for social work to work collaboratively with other health professionals within a chronic care model.
- *Application:* This paper explores how social work's ecosystems model can interface with Wagner's Chronic Care Model to fill the void that some individuals may experience in seeking and maintaining care to provide a useful framework to facilitate interventions within that model.

Keywords

Social work, disability, chronic illness, ecosystem, health care, care coordination

Introduction

The number of individuals living with chronic illness in the United States has significantly risen over the past several decades as medical science dramatically increased its ability to extend lives with advances in medical technology and most recently through the implementation of chronic care treatment models

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(Anderson, Herbert, Zeffiro, & Johnson, 2004; Bodenheimer, Wagner, & Grumbach, 2002a, 2002b; Glasgow, Orleans, & Wagner, 2001; Lorig, Sobel, & Stewart, 1999; Rothman & Wagner, 2003; Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997; Wagner, 1998). While these models are showing effectiveness for some, they are heavily medically focused with no clear definition of the role of the social worker, even though social workers are still maintaining a front-line presence in health, mental health, and psychological services referrals in the US health care system (Gehlert & Browne, 2006). Working with complex clients places social workers in pivotal roles to support and empower their clients to engage in care in face of challenging circumstances. In this article an argument is made for the development of a conceptual role for social work in a medically based chronic care model to fill the gap that most medically-based chronic care models lack. The explicit incorporation into these models of how social workers can actively engage clients and their systems into proactive patient roles is not made clear. Furthermore, particular attention is needed for clients with barriers (i.e. cognition, family support, financial resources) that may further inhibit active participation. The aim that underpins this article is to explore how social work can integrate the ecosystems perspective of social work into a chronic care model as a way to actively engage a patient with a chronic condition into evidence-based chronic care.

Chronic illness care

In 2005, 133 million Americans, or nearly 1 out of every 2 adults, had at least one chronic illness; by 2020, this number is projected to increase to 157 million (Centers for Disease Control, 2010a). Currently, one out of every five Americans has more than one chronic condition, representing a challenge for the public health system (Benjamin, 2010). The care of an individual with a chronic illness can be challenging on both a personal/patient level as well as dealing with the health care system (Gehlert & Browne, 2006). Caring for an individual with a chronic illness is different than an acute injury or condition, the care is ongoing and requires a variety of health care providers and other resources. There is also a shift in focus of care emphasis from provider-dependent care to self-care (Thorne, 2006) that occurs when the patient is outside of the hospital setting (Gately, Rogers, & Sanders, 2007).

Chronic illness care needs to be planned and proactive and not reactive; it has been finally being placed at an urgent level of prominence for health care policy makers (Centers for Disease Control and Prevention, 2010). This urgency was fueled by the high cost of chronic care (Vogeli et al., 2007). Chronic care treatment/management models were developed to create a more systematic way to treat patients that use the most current scientific evidence base for care and involve health care providers, hospital and community resources, and the patient operating in partnership. This perspective is what lead to the development of the Chronic

Care Model Wagner (1998), a leading model (Figure 1) currently used across the United States (Robert Wood Johnson Foundation, 2011).

The CCM was designed to address the key longer term components for -improving care which include the community, the health system, self-management support, delivery system design, decision support, and clinical information systems health systems. As illustrated in the figure, the CCM seeks to engage the community and the health systems and services in a way that leads to productive interactions between the active (i.e. informed, empowered) patient and the prepared, proactive clinical provider team; critical to the model is that every change component is derived from an evidence-base (Wagner, 1998; Wagner, Austin, & Von Korff, 1996). Six major areas of focus are articulated in the model: (1) the health system and organization of care; (2) self-management support for patients to participate in managing their own care; (3) a delivery system design that supports proactive decision making for addressing health care needs; (4) decision support for the health care providers that is based on evidence-based practice; (5) clinical information systems that allow access to patient population data; and (6) linkages

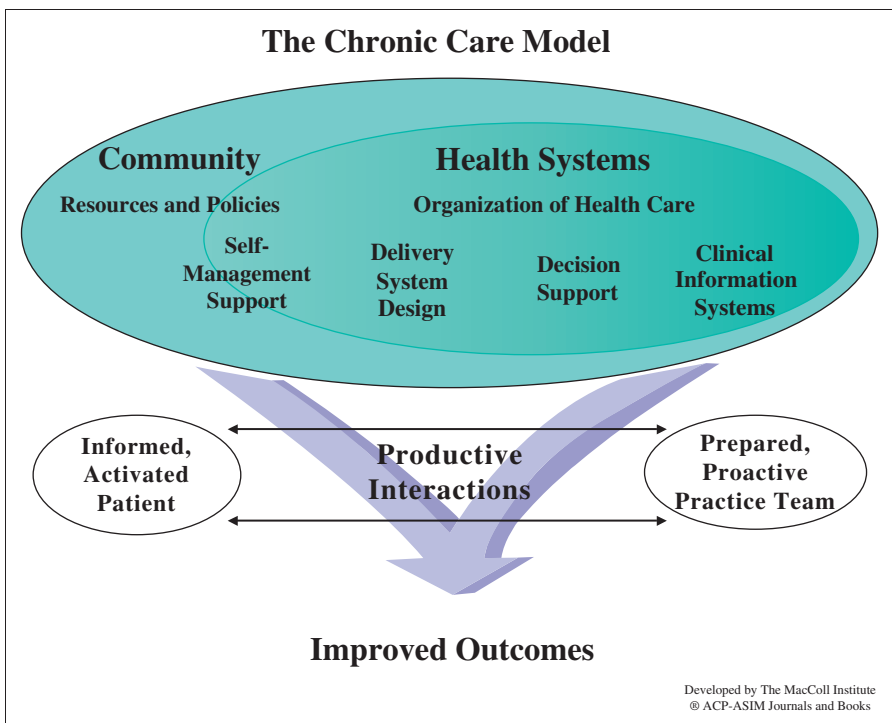


Figure 1. Wagner's chronic care model.

Source: Reproduced with permission from Wagner (1998).

to community resources to facilitate care beyond the scope of the clinical environment (i.e. housing, social services) (Robert Wood Johnson Foundation, 2011).

The CCM has been adopted by many US health care systems to improve chronic health care delivery and to reduce associated costs of that care (Bodenheimer et al., 2002a); by 2008, a Robert Wood Johnson grant helped to implement the CCM in 22 medical school and teaching institutions' ambulatory care settings across the US with demonstrated improvement in care delivery (Robert Wood Johnson Foundation, 2011). Moreover, the CCM has been shown to be effective in numerous studies across various chronic illness diagnostic groups. Vargas et al. (2007) reported that in a controlled pre/post intervention trial addressing the 10-year risk of cardiovascular disease, both the CCM treatment/intervention group and the usual care control group reported improved blood pressure, lipid levels, and HbA1c levels during the observation period, however, the CCM treatment group had 2.1% (95% CI -3.7%, -0.5%) greater reduction in predicted risk for future cardiovascular events when compared to the control group. Schonlau et al. (2005) found in a sample of individuals with asthma that the overall process of asthma care improved significantly using an intervention based on the CCM; the intervention compared with the control group found significant change (change of 10% vs 1%, $p = 0.003$). These researchers also found that individuals in the intervention group were more likely to attend educational sessions, have a written action/treatment plan, set goals, and monitor peak flow rates than those in the control group. Also, those in the collaborative treatment group were significantly more likely to be satisfied with clinician and lay educator communication (62% vs. 39%, $p = 0.02$).

With advances in the field of chronic illness, CCM model experts noted the model needed refinement, thus, the CCM was updated by experts in 2003 (Robert Wood Johnson Foundation, 2011). The updated model includes five additional areas: Patient Safety (in Health System); Cultural Competency (in Delivery System Design); Care Coordination (in Health System and Clinical Information Systems); Community Policies (in Community Resources and Policies); and Case Management (in Delivery System Design). These additions make the model more patient-centered, timely and efficient, evidence-based and safe, and coordinated. The model continues to assert that ongoing chronic care needs require planned, evidenced-based routine care for the individual and interaction between health care providers, caregivers, and the patient emphasizing the patient's functional abilities and prevention of further deterioration of function. Brodenheimer et al. (2002) set forth.

According to the Chronic Care Model, optimal chronic care is achieved when a prepared, proactive practice team interacts with an informed, activated patient. The new patient-physician relationship for chronic disease features informed activated patients in partnership with their physicians. (p. 2469)

The importance of an enhanced patient–provider relationship has been shown to improve collaborative care in primary care settings for patients with depression in underserved populations (Palinkas, Eli, Hansen, Cabassa, & Wells, 2010).

The activated patient

The *activated patient* is one that is an engaged participant in his or her care making and keeping regularly scheduled appointments with recommended specialists, utilizing community health resources such as gyms or other exercise facilities, maintaining medication and nutrition regimens as prescribed, and following through on any other recommendations by the patient’s care team (Wagner, 1998; Wagner et al., 1996). Good communication is essential to support an activated patient (Thorne, 2006). The speed at which patients are moved through out health care system can sometimes leave patients questioning provider recommendations, missing pieces of important information, and misunderstanding information that may be hurtful to the patient. Research has revealed that active communication in chronic illness care is not to be overlooked. Newer evidence finds good communication between chronically ill patients and their healthcare providers to support coping, self-care management, and the highest levels of quality of life. On the other hand, if the communication is poor it can be detrimental to the individual’s overall care (Thorne, 2001). This evidence supports the role of strong and active communication in the chronic care models.

Communication in chronic care programs has been used to teach self-management skills that help to manage symptoms of a variety of chronic diseases such as arthritis, diabetes, lung and heart disease (Centers for Disease Control, 2010b). Teaching is focused on medication use, exercise, nutrition, and treatment evaluation. Many programs see the crux of the self-management component of the CCM as strategies for the development of skills for self-care and wellness through the provision of information and enhancing life skills (Barr et al., 2003). It has been documented that teaching skills does enhance the patient’s ability to care for him/herself and to make health behavior changes (Von Korff et al., 1997), but as needs vary, it has been suggested that services should be available to assist the client ranging from minimal self-help methods to intensive case management (Von Korff et al., 1997).

The process to transform a patient into an activated patient relies on helping the patient feel empowered in a situation where they may feel he/she may have very little control. Self-management techniques have been shown to facilitate active engagement of the patient in his or her care (Atkin, Stapley, & Easton, 2010), particularly when personal community resources are utilized that encourages freedom of choice and reduction of reliance on health care resources (Kendall et al., 2007). Gately et al. (2007) point out that the self-management relationship is fundamentally linked to the patient–provider contact and that relationship needs ongoing negotiation to ensure optimal care for the patient. So despite the shifting of care to the individual patient, the care is actually more complicated as the care is

reliant on sustained communication with the health care provider; the patient's personal and social resources need evaluation to promote this type of ongoing communication, for some this may require support in order to make this evaluation and negotiate the available resources. However, it also means nurturing the relationship with the physician and being aware of barriers that might exist. Blakeman Macdonald, Bower, Gately, and Chew-Graham (2006) report that these barriers can be related to physicians' lack of communication skills, the conflict that some physicians may feel between their professional patient-care values and what they can relinquish to patient control, and contextually barriers such as cost, incentives, and other bureaucratic policies. Finally, just being involved in self-management does not mean the patient is emotionally ready for the experience, now will he/she fit into a generic self-management program. The patient needs to come to terms with the individual social meaning of his or her condition, therefore a self-management program cannot just be a singular template; it needs to be adjusted to meet the client where the client is at accommodating adjustment and promoting coping (Atkin et al., 2010).

The activated patient is an ideal in the CCM, but social workers would realize that for many individuals, the support offered by the chronic care team might be enough to motivate the patient for compliance and adherence. However, when the individual has a pre-existing condition that reduces independence in performing required activities, this is the when attention to an individual's social support systems becomes much more important as well as direct work with the patient to facilitate coping and adaptation. For example, a client may have a brain injury that limits comprehension of the education that is being provided for his newly diagnosed diabetes, or have physical impairments that restrict the client's ability to return to the hospital or clinic for the education and follow up for the outpatient testing that is prescribed, or have financial or emotional issues that limit his or her acceptance of the services being provided for this new an overwhelming diagnosis. Such circumstances could reduce the effectiveness of the CCM without a fully engaged and proactive patient. Whereas Von Korff et al. (1997) did make the call to the field noting that it is critical that the support services offered to patients need to be customized to the individual patient's motivation and readiness to change, focus on coping and adjustment to the chronic condition does not appear to have an explicit role in the CCM from the lack of studies in the literature addressing this point and in discussions of the model (Robert Wood Johnson Foundation, 1996, 2011). This is where social work could facilitate the care given to clients using the full scope of client's available systems as mostly clearly articulated in the ecosystems perspective of social work (Compton & Galaway, 1994).

The ecosystems perspective

The ecosystem perspective is similar to a person-in-environment perspective with the focus on the client in his/her environment, but it broadens the approach by giving attention at levels of systems as the macro (i.e. the cultural context of the

individual), meso (i.e. interactions between families and formal systems), and micro (i.e. the setting where the individual lives) levels of interventions (Meyer, 1983). The ecosystem perspective articulates the interrelatedness or interdependence of human problems/issues, life situations, and the social conditions in the individual's life (Shatz, Jenkins, & Sheafor, 1990) where the individual's situation can be assessed for both strengths and weakness in these interactions as well as any distortions (Meyer, 1983). Rooted in this is the understanding the individual's issues are intertwined with the social environment in which he or she needs to operate, and it not limited to the intricacies of specific settings (Meyer, 1983). Most notably, the perspective sets forth boundaries that allow the social worker to see the client in his or her own sociocultural environment (Coady & Lehmann, 2008), which provides a tremendous amount of flexibility to accommodate individual needs.

Use of an ecosystem perspective can help to empower an individual within the health care system. This perspective has become influential in the curriculum of US Schools of Social Work (Payne, 2002). Ecological thinking recognizes that variable *A* does not always create effect *B*; this would be linear thinking, instead, ecological thinking places *A* and *B* in a reciprocal relationship where *A* may lead to a change in *B*, and the change in *B* leads to a change in *A*. This reciprocal action diminishes the emphasis on causes and places the emphasis on what has happened, or the effect (Gitterman & Germain, 2008). Therefore, the ecological model, with a focus on 'what' rather than 'why' something has occurred allows for more purposeful interventions. It also reduces the importance of personality factors and increases the impact of the environment in the development and maintenance of a chronic illness as the perspective sees the individual in the context of bi-directional relationships in the individual's social networks. For example, if a patient is not compliant with a medication regimen, the perspective suggests that it is far more valuable to focus on what has occurred and what might be changed to in the individual's environment to address what may be preventing him or her from acquiring or taking the recommended medication. It does not simply label the patient as 'non-compliant' due to a personality flaw.

This broad systems thinking enhances the perspective's flexibility to create client-specific treatment approaches. Also, since the ecosystems perspective is just that, a perspective by which to 'organize and conceptualize complexity' (Meyer, 1983, p. 219), and not a treatment model, the worker is able to use which ever treatment model/theory he or she feels is most beneficial for the client based on the evidence base. The perspective includes no constraint of time, it does not require that the work only involve the present time, it includes the individual's history as well as his or her future in projections of possibilities (Coady & Lehmann, 2008).

It should be noted that the ecosystems perspective has been criticized in recent decades. Most notably, Wakefield's articles published in *Social Service Review* (Wakefield, 1996a, 1996b) where the model has been criticized for encouraging adaptation. The criticism lies in that clients are 'encouraged to accommodate to oppressive circumstances' (Coady & Lehmann, 2008, p. 92); however, in working with those with chronic illness, this is very appropriate as the individual does need

to adapt to a new and potentially changing health condition. For example, Atkin et al. (2010) report that individuals with encephalitis (a life-threatening neurological condition that affects the brain) do have to constantly alter what to expect from themselves based on the progression of their condition, with uncertainty about their condition being part of their daily life. This means these individuals had to adapt to their present condition while experiencing their loss of functioning.

Disparities and how to work with them is a function of social justice components of the ecosystems perspective (e.g. attempting to confront disempowerment, marginalization, and oppression), and diversity is an area of training for social workers giving them a keen awareness of disparity (Hepworth, Rooney, Dewberry-Rooney, Strom-Gottfried, & Larsen, 2010). The social worker might find him or herself advocating for care or confronting systematic barriers that may be biased and cause patients to 'fall between the cracks' suffering from health care inequities. For example, race and ethnicity, religion, education, language, income levels, and sexual orientation may influence the care individuals receive within the system, how they are perceived by the system, and how they themselves desire, accept, or understand the care (Conron, Mimiaga, & Landers, 2010; Smedley, Stith, & Nelson, 2003). According to the perspective, unmet needs reflect an imbalance in the interactions between the person and his or her environment. This incongruity is caused by either a lack of resources leading to a lack of sustainability of the interaction over time (Johnson & Yanca, 2010). Social workers have skills in cultural awareness and cultural competence, in which social work practice respectfully responds to and affirms the worth and dignity of people of all cultures, languages, classes, ethnic backgrounds, abilities, religions, sexual orientation, and other diverse features found in individuals (National Association of Social Workers [NASW], 2001). With their knowledge and training, social workers can help mediate between systems when diversity issues become a barrier to receipt or access to care.

Social workers in the chronic care model

Wagner (2000), himself, reported that although social workers are considered key members of the evaluation and management teams for individuals with chronic illness, few empirical studies exist on the utility of social workers' involvement in patient care teams. However, it is clinically clear that social workers could play a key role in the CCM. The needs of the CCM with respect to the proactive patient are congruent with social work principles that support an empowered client; social workers facilitate the acquisition of community resources and they integrate patients back into the community. 'Professional social workers are well equipped to practice in the health care field, because of their broad perspective on the range of physical, emotional, and environmental factors that have an effect on the well-being of individuals and communities' (NASW, 2005). Social workers are trained in the theories of human behavior,

empowerment, discrimination, cultural awareness, family relations theory, and interpersonal communication, all important factors in working with clients with chronic illnesses.

Utilizing the model levels

Another important consideration with the involvement of a social worker is that social workers can be flexible and work at multiple levels simultaneously to facilitate the client's movement through the health care system into recovery and to the highest levels of functional status. Table 1 depicts the crosswalk between the key components of the CCM and the systems level at which the social worker could intervene with individual clients. The table suggests a variety of roles for social workers with some social workers potentially playing a variety of roles, but most having a singular focus such as policy, case management, or advocacy.

Table 1. Chronic care model crosswalk with the ecosystems perspective.

<i>Chronic Care Model Key areas</i>	<i>Area focus</i>	<i>Level of Social Work Intervention</i>
Health System/ Organization of Care	Create and foster an environment that values quality and system change to promote high quality of care.	Mesosystem
Self-Management Support	Patients participating in the management of their own health care.	Microsystem
Delivery System Design	A team focus with interventions that are evidenced-based and includes regular follow up by the team.	Macrosystem
Decision Support	The use of evidence-based guidelines on care delivery, and sharing these guidelines with patients and specialists to encourage collaborative care.	Macrosystem
Clinical Information Systems	Timely reminders for care activities and the monitoring of care delivery to assess team and care system performance	Macrosystem
Community Resources and Policies	Help patients engage with community-based services as well as develop partnerships on the provider level to support advocacy.	Macrosystem

For example, the social worker may work at the macro level to advocate for benefit coverage or include specific concerns in new policies, however, the majority of the care is provided at the micro- and mesolevels by the social worker with the bulk of the focus on the self-management portion, especially when patients have cognitive, physical, or social impairments that limit their participation in the overall care management plan. In the micro level, social workers facilitate adjustment to the chronic illness and support attainment of the highest levels of quality of life (Gehlert & Browne, 2006), areas not explicitly noted in the CCM. Additional work can be done at the mesolevel with family and/or neighbors as key in assisting the client with care needs. The Delivery System Design, Decision Support, and Clinical Information systems components of the CCM are not areas that the social worker would necessarily directly intervene but it would be important for the social worker to have an awareness of these components and how they impact his/her client's care, noting how the components are supporting or not supporting the client's care so changes can be made as necessary.

Conclusions and implications

The identification of the role of the social worker in the health care system is defined to some extent in a reactive status to what the health care system demands of us. Social workers are trained to work within systems, but a model for their role with other professionals within the chronic health care system does not explicitly exist. According to the *NASW Standard for Social Work in Health Care Practice* (NASW, 2005), social workers are tasked with a variety of activities related to discharge planning and continuity of care in the case manager role, tasks that fit very well within the ecosystems perspective. Working in health care is a natural fit for social workers as it draws upon basic values of social work, from promoting an individual's right to self-determination to having an attitude of empathy for the individual while negotiating barriers or advocating for our clients on multiple levels. These levels link well to Wagner's Chronic Care Model (Wagner, 1998), particularly when the patient has cognitive, physical or psychosocial impairments that limit his or her involvement as an activated patient. Working with a patient with a chronic illness taps into so many levels of the social worker's education, as well as points to the needs of the field to ongoing need for timely continuing education to keep social workers in the forefront of medical social work. As the clinical role of social work is evolving in chronic illness care (Auslander, 2001; Gehlert & Browne, 2006), clearly empirical research is also needed to illuminate the aspects of social work that contribute to the CCM.

This article has presented a conceptual model of connecting the social work ecosystems perspective (Meyer, 1983) to Wagner's Chronic Care Model (Robert Wood Johnson Foundation, 2011) to examine ways in which social workers can benefit individual patients, their support systems, and the health care system at large. Social workers have long played a role in health care, even in the very

early 1900s. By the early 1980s, a capitated system for payment of Medicare services in acute health care settings, known as diagnostic-related groups (DRGs) or more generically as managed care, was introduced by the federal government. This new program changed how health care was paid for, the lengths of stay at acute care facilities, and led to a in the role of social workers in acute health care. According to the NASW (2005),

social work services disappeared entirely from some health care settings due, in part, to a lack of data demonstrating the efficacy of social work services and loss of funding for those services. Yet, in other settings, social workers have prospered, gaining recognition through the provision of specialized services in multiple health care arenas such as palliative care, ethics, ambulatory care, rehabilitation, and geriatric services. (p.8)

With the shift in health care from an acute to a chronic focus, and a shift from provider-lead to self-directed care, social work has the opportunity to create a new and specialized role for itself in the care of individuals with chronic illness. The ecosystems perspective is a natural fit into the level of the CCM using the macro-, meso-, and microlevels of social work focus/intervention. Although social workers are ever present in the health care system, there are conflicting values at play in the business of health care. Social workers seek to empower, advocate, and facilitate, but health care may present bureaucracy, bias, rigidity in policy, and sometimes an apparent lack of empathy. These are the challenges to social workers to negotiate the various levels of systems to benefit their clients. The use of the ecosystems perspective can be helpful in teaching new social workers about the levels of intervention as well as explain to interdisciplinary colleagues the breadth of the social worker's scope of practice. Chronic illnesses are on the rise, the role of social workers in the care of these individuals needs to be more clearly defined, and defined in a way that fits the current management models in health care such as the Chronic Care Model, a connection through the ecosystems perspective provides a link that emphasizes strengths of social work professionals.

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