Utilizing role theory to help employed parents cope with children’s chronic illness

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Abstract

Role theory is utilized to detail a six-step process for developing balanced coping through role negotiation. As applied in this paper, the role theory framework provides health educators with a useful tool for helping employed parents cope with a child’s chronic illness. The emphasis is on partnering with parents or primary caregivers to identify, understand and manage the multiple role demands of working parents with chronically ill children. Role theory suggests ways health educators can support balanced coping by educating families about the demands of a child’s illness, and helping to reduce those demands, helping to increase family resources, supporting parents and facilitating role negotiation. The ultimate goal is the development of balanced coping strategies that (1) meet the medical and emotional needs of the ill child, (2) allow parents to maintain their physical and mental health, and (3) enable parents to meet the demands of their other roles (e.g. paid employment).

Introduction

In 1993, the American Academy of Pediatrics reported that 10–20 million American children and adolescents had a chronic health condition or impairment. Of these, 1–2 million children nationwide had a chronic condition severe enough to impact their daily activities. Data from the Centers for Disease Control and Prevention’s 1996 National Health Interview Survey (NHIS) (Centers for Disease Control and Prevention, National Center for Health Statistics, 1996) indicated that 6.1% of American children experienced limitations in activity due to chronic health conditions. The percentages were higher for black children (8.4%) and children living below the poverty level (9.8%). A chronic condition is typically defined as a health condition that is expected to last 3 months or longer (American Academy of Pediatrics, 1993; National Health Interview Survey, 1996) that also involves one or more of the following: limitation of age appropriate functions, disfigurement, dependency on medical technology, medication, special diet, more medical care than is usual for the child’s age or special ongoing treatments (Jackson and Vessey, 2000). A few examples of chronic conditions affecting children include asthma, diabetes, juvenile rheumatoid arthritis, cystic fibrosis, spina bifida, seizure disorders, neuromuscular diseases and congenital heart diseases. Based on an analysis of NHIS data from 1992 to 1994, Newacheck and Hafon (Newacheck and Hafon, 1998) concluded that impairments of speech, special senses, and/or intelligence, mental and nervous system disorders, and diseases of the respiratory system are among the most prevalent chronic condition categories restricting children’s activities.

In addition to limiting a child’s daily activities, a child’s chronic illness can put the mental and physical health of the entire family at risk. Parental stresses and strains increase as the caregiving burden increases, often leading to depression and...
marital discord (Quittner et al., 1998; Cohen, 1999). Other children’s needs may be neglected as parents focus on caring for the ill child (Quittner et al., 1992). As the family’s stress increases, the likelihood of treatment compliance for the ill child decreases (Brand et al., 1986; Patterson et al., 1990; Hamlet et al., 1992; Kager and Holden, 1992). For some illnesses, psychological stress directly affects the physiological processes that regulate symptom expression. Asthma symptoms, for example, can be exacerbated by stress. Thus, the potential for a vicious circle is created as coping with a child’s illness heightens family stress, which in turn reduces treatment compliance and increases the occurrence of symptoms, which may then further heighten family stress, and so on.

Health educators can play a vital role in preventing and breaking this vicious circle by helping families develop balanced coping strategies that (1) meet the medical and emotional needs of the ill child, (2) allow caregivers to maintain their physical and mental health, and (3) enable caregivers to meet the demands of their other roles (e.g. paid employment). This paper details a six-step process, theoretically grounded in role theory, that health educators can use to help families achieve balanced coping. Utilizing a role theory framework sheds light on the multiple demands faced by working parents as they attempt to meet their children’s chronic health needs and the type of guidance health educators can provide to assist them.

Standards of practice in coping with chronic childhood illnesses

Jackson and Vessey provide a detailed review of the current standards of practice in helping families cope with chronic childhood illness (Jackson and Vessey, 2000). Present standards emphasize educating families about the child’s illness and its management. This includes ‘anticipatory guidance’ that reinforces the need for health maintenance to help prevent the need for crisis care. The importance of effective coordination of care is also stressed and efforts are made to incorporate family members as an integral part of the care plan.

While current standards of practice emphasize knowledge about the illness, maintenance care and coordination of care, there is a simultaneous recognition that the child’s illness must not be allowed to dominate family life. This perspective, referred to as ‘balanced coping’, acknowledges that the functionality of the family system is critical to effectively managing the illness and that the demands of the illness need to be met without sacrificing the individual needs of family members (Cohen, 1999). Families consumed by an illness ultimately break down in ways that have negative impacts on children’s health.

There is much to applaud in the current standards of practice for helping families cope with chronic childhood illness. The balanced coping perspective, in particular, has an important tempering effect on health education and promotion practices that might otherwise overwhelm and undermine the family system (e.g. inundating families with too much detailed information). Current standards clearly acknowledge the importance of parents as primary caregivers and partners in the child’s health management. However, present standards fail to fully take into account the other substantial role responsibilities of caregivers, especially employment-related demands and the impact work responsibilities may have on the effective management of a child’s chronic health condition.

Parental employment and child health

Working parents are a reality in today’s society. The US Department of Labor reports that 80% of fathers and 60% of mothers with children under the age of 6 are employed (US Department of Labor, Women’s Bureau, 1994). An ample body of literature discusses the stresses encountered by parents as they attempt to manage their work and family lives (Greenhaus and Beutell, 1985; Frone et al., 1992; Parasuraman et al., 1992; Bernas and Major, 2000). Although routine childhood illnesses certainly produce temporary disruptions in a parent’s work life (e.g. missing work, changing hours), this is not the same as facing the demands of a
child’s chronic illness. When a child is chronically ill, the mother’s employment status tends to change the most, either reducing the number of hours worked or giving up a job altogether (Hauenstein, 1990; Fewell, 1993; Freedman et al., 1995). However, fathers’ employment is also affected by a child’s illness. Like mothers, fathers also miss work to care for ill children (Thompson, 1993; Hardy et al., 1994; VandenHeuvel, 1997). They also may find that meeting caregiving responsibilities limits their opportunities for career development and advancement. For instance, some fathers report that the need to maintain a child’s health insurance coverage and the need to remain in a specific geographic location for a child’s care prevent them from changing jobs and accepting promotions that require relocation (Freedman et al., 1995).

When a child is chronically ill, parental employment may be simultaneously a burden and a necessity. However, parental employment also seems to offer substantial benefits. Indeed, some parents report that being able to go to work provides a reprieve from the intensity of caregiving (Thompson, 1993). This is consistent with the argument that occupying multiple roles (e.g. parent, employee) contributes to well-being. For instance, research suggests that having multiple roles increases sources of identity, self-esteem and privileges (Thoits, 1983). Working mothers report that the rewards of juggling multiple roles tend to outweigh the costs (Crosby, 1991). Mothers in the labor force enjoy better mental and physical health than those who are not employed (Barnett and Baruch, 1985; Barnett and Marshall, 1991).

Although how employment is managed ultimately must be determined by parents and the unique needs and circumstances of individual families; health educators can help working parents develop coping strategies that meet their needs and ensure children’s health. Thus, for parents who want or need to maintain employment, the health educator’s task is to find ways to make that possible while still effectively meeting children’s health needs. Building upon the balanced coping perspective, role theory provides tools to accomplish this goal.

A role theory framework
The role theory perspective emerged simultaneously across disciplines in the social sciences during the 1920s and early 1930s. Biddle concisely defines role theory as ‘...concerned with the study of behaviors that are characteristic of persons within contexts and with various processes that presumably produce, explain, or are affected by those behaviors’ [(Biddle, 1979), p. 4]. Role theory has been applied in the ‘helping professions’, including counseling, social work, education and healthcare [e.g. (Rheiner, 1982; Hardy and Conway, 1988; Payne, 1988)].

A role is an expected pattern or set of behaviors associated with a particular position or status. Here, the focus is primarily on roles in the family and work domains, considered to be the two most central institutions in people’s lives (Howard, 1992). ‘Parent’ and ‘employee’ are both examples of roles, and each carries with it certain behavioral expectations from the larger social system in which the role is embedded. Roles also become personalized for individuals. For instance, not all parents are subject to identical expectations and they all do not enact the parental role in the same way. Different families may have different expectations based on their own particular needs. Those people whose expectations shape and define an individual’s role are known as the role set (Merton, 1957). This includes the individual role holder who is generally referred to as the focal person. As part of the role set, the focal person also has his or her own beliefs and expectations about fulfilling a role.

Role negotiation
The process by which roles develop is referred to as role making or role negotiation (Turner, 1956; Graen, 1976; Graen and Scandura, 1987). These terms emphasize the fact that role development is more involved than the focal person simply understanding and complying with the expectations of the role set. Instead, the focal person and other members of the role set actively and collaboratively work to define the role in a way that is mutually satisfactory. As shown in Figure 1, the role
demands, resources and barriers that exist in each role domain (i.e. the work and family arenas) influence the role negotiation process. As will be discussed in detail, health educators can facilitate role negotiation by helping parents identify role demands, resources and barriers that will affect their ability to meet children’s health needs. As illustrated in Figure 1, ineffective role negotiation results in ‘unbalanced’ coping strategies that have negative repercussions for child health management, caregiver well-being and role fulfillment. Effective role negotiation, on the other hand, yields balanced coping strategies. As described at the outset, the outcomes of balanced coping include (1) meeting the medical and emotional needs of the ill child, (2) allowing caregivers to maintain their physical and mental health, and (3) enabling caregivers to meet the demands of their other roles (e.g. paid employment).

Roles are dynamic and can be renegotiated as relevant circumstances change. For instance, when a child is diagnosed with a chronic illness, families begin making a number of substantive changes in the role responsibilities of family members (Hauenstein, 1990; Schumacher, 1995). A child’s illness tends to change the rules about ‘who does what’ and what needs to be done (Cohen, 1999). Different or additional behaviors may be needed and expected. The time allocated to the role may be altered. Investment in the role may change. Changes in any one of an individual’s roles are likely to impact the enactment of other roles, both within and across domains. In the case of work and family life, stresses originating in one domain
commonly spill over into the other (Frone et al., 1997). Thus, a child’s illness does not only affect the parental role. It also may affect the way other roles (e.g., spousal) are enacted in the family domain and may alter one’s ability to meet role expectations in the work domain.

Effective coping through role negotiation

Health educators can use role theory as a framework for partnering with parents to develop balanced coping strategies that are appropriate and functional given the family’s particular circumstances. Respecting parents as knowledgeable authorities about their own families’ circumstances and needs sends the empowering message that parents can make important contributions in determining care for their children. In their discussion of building effective helping relationships with adult clients, van Ryn and Heaney (van Ryn and Heaney, 1997) caution health professionals to recognize that, as outsiders, we cannot know how meeting health-care needs and our suggestions for doing so will impact other aspects of the clients’ lives. The same applies to the family systems of ill children. Through partnerships with parents, we gain a more comprehensive view of the family system and how to best utilize it to enhance coping.

While parents are the ‘family experts’, health educators are ‘health experts’ who understand the demands of the illness and the resources likely to be required to meet them. The more parents and health educators are able to share information from their relative areas of expertise, the better the chances of devising workable plans. Health educators need to be skilled in probing for information and stimulating parents’ thinking regarding their own resources, and helping to secure additional resources.

Role theory does not yield any ‘one best coping strategy’ suitable for all families; instead, applying role theory provides a guide through the critical issues that must be considered in the development of effective coping strategies. Individuals are likely to vary in the extent to which they are capable of readily applying the role theory framework themselves. Stress, low self-efficacy and limited resources may inhibit the extent to which parents can fully comprehend their circumstances and thoroughly explore their options. Thus, health educators are likely to be important facilitators who help parents engage in role negotiation to develop effective coping strategies. The goal is not to ‘rescue’ parents from their caregiving responsibilities, but rather to help empower them to find workable solutions.

Table I outlines a six-step process that details how health educators can facilitate role negotiation to ensure adequate coping. Each step is discussed in detail below.

Step 1: Identify caregiver role demands

The health educator’s first step is to help parents understand what the ill child needs. At this initial phase, parents are likely to focus on the characteristics of the illness and should be encouraged to consider how defining features of the illness create certain types of role demands. The severity, predictability and communicability of the child’s illness are examples of characteristics that are likely to have implications for caregiving demands and options. For instance, research shows that unpredictable child illnesses, such as asthma, are particularly likely to create family stress and dysfunction (Gustafsson et al., 1994). Moreover, the characteristics of a child’s illness determine, in part, the viability of various child care options (Thompson, 1993), which in turn affects the need for parental presence and ability to fulfill the work role. Compared to parents of well children, parents of ill children tend to spend more time providing care, making health-related arrangements for their children and coordinating care (Freedman et al., 1995). Parents who are absent from work due to the unpredictability and severity of a child’s illness face the very real possibility of job loss (Williams, 1993; Peterson et al., 1997).

When considering the caregiving demands of a child’s illness, the health educator must not only understand current needs but also help parents anticipate future needs. A debilitating illness that
Table I. A role theory framework for developing balanced coping

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
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<tbody>
<tr>
<td>1</td>
<td>Identify caregiver role demands</td>
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<tr>
<td></td>
<td>Ascertain the severity, predictability and communicability of the child’s illness</td>
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<td></td>
<td>Detail what the child’s illness currently requires of the caregiver</td>
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<td></td>
<td>Consider future caregiving needs</td>
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<td>2</td>
<td>Define role set</td>
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<td></td>
<td>Identify all caregivers (e.g. family members, friends, babysitters, school personnel, etc.)</td>
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<td></td>
<td>Give child an appropriate level of responsibility for his/her own care</td>
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<td></td>
<td>Consider relevant members of work role set, especially those who may need to make accommodations for caregivers</td>
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<td>3</td>
<td>Recognize resources and barriers afforded by existing roles</td>
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<td></td>
<td>Secure sources of instrumental support</td>
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<td></td>
<td>Identify sources of emotional support</td>
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<td></td>
<td>Consider workplace, family, friends and community resource options</td>
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<td>4</td>
<td>Negotiate workable roles</td>
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<td></td>
<td>Detail who needs to do what, when, where, why and how</td>
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<td></td>
<td>Address role ambiguity (i.e. lack of clarity or understanding of demands)</td>
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<td></td>
<td>Avoid role overload (i.e. too many responsibilities)</td>
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<td></td>
<td>Resolve role conflicts (i.e. incompatibilities within or between roles)</td>
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<td></td>
<td>Focus on anticipatory planning</td>
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<td>5</td>
<td>Work toward role integration</td>
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<td>Develop needed role redundancy (i.e. people to provide back up as needed)</td>
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<td></td>
<td>Establish a plan for coordinating the activities of caregivers</td>
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<td></td>
<td>Promote spontaneous helping</td>
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<td>6</td>
<td>Renegotiate roles as necessary</td>
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<td></td>
<td>Attend to the feedback that accompanies role performance</td>
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<td></td>
<td>Accommodate changes in role demands (e.g. changes in child’s health, developmental transitions)</td>
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Creating functional limitations for a child is likely to be experienced as particularly stressful by parents (Silver et al., 1998). Knowing something about the expected course of an illness puts parents in a better position for planning and effective role negotiation.

Although parents should be encouraged to plan and think realistically about their child’s illness, this is not to say that they should become ‘illness-focused’. Balanced coping by ‘putting the illness in its place’ is more functional (Cohen, 1999). Understanding the illness is necessary in order to develop an adequate caregiver role and to find ways to balance the caregiver role with other roles (e.g. employment). However, the illness itself is not the most powerful predictor of family coping. Research shows that family system variables are stronger predictors of adaptation and adjustment than disease factors or illness severity (Cohen, 1999).

Step 2: Define role set
When dealing with a child’s illness, adequately defining the working parent’s role set can be a complex and sensitive issue. The issue is sensitive because a child’s illness may mean that the family’s boundaries become more permeable (Cohen, 1999). That is, in order to provide adequate care for a child, numerous outsiders, including the health educator, need to become involved and become familiar with what would normally be the family’s ‘private business’. The complexity of defining the role set is a function of both the number of members involved and the degree of coordination required. Parents should be encouraged to think through everyone who either has a direct role in caring for the child or who may have an impact on their own ability to provide care. The goal is to ensure that anyone expected to provide care for the ill child is adequately prepared to do so (Hymovich, 1984).
Typical caregivers include the parents, the child, other family members, friends, babysitters, daycare providers, preschool or school personnel and health professionals. Notice that the child is included as part of the role set. This is to acknowledge the active role that a child, especially an older child, will play in determining and meeting his or her own care needs. A child must be educated and empowered to self-manage the illness to the extent possible (Hymovich, 1984).

Including other family members in the role set is likely to come naturally for most parents. Research shows that family tends to be relied upon for care when a child is seriously ill and that friends tend to be relied upon for more short-term, minor care needs (Fisher et al., 1988). The health educator may have to overcome parental resistance to including caregivers outside the family in the role set. Sexson and Madan-Swain estimated that chronic illness affects 20% of children in the school-aged population and discussed significant evidence that, in most cases, school personnel are not at all aware of the child’s condition, even when the child could require immediate attention at school (Sexson and Madan-Swain, 1995). Parents often neglect to provide school personnel with adequate means (e.g. prescription medication, medical equipment) to meet the needs of an ill child. Health educators can use their influence to encourage parents to adequately inform the child’s other caregivers, including school personnel, about the child’s health needs.

For working parents, maintaining the work role is likely to mean that at least some members of the work role set have to be informed about the child’s illness and associated caregiving responsibilities, especially if any unique accommodations need to be made (Freedman et al., 1995). The amount of disclosure that is appropriate and necessary at work depends on individual circumstances. Human resource personnel are a good source of information about employer benefits and programs that may be relevant to meeting the child’s needs. They can also explain leave policies. The parent’s immediate supervisor, however, is likely to be more instrumental in creating the accommodations required by specific circumstances (e.g. taking personal calls, leaving for emergencies, schedule flexibility). Co-workers can also facilitate personal accommodations and are likely to be the ones providing ‘back-up’ and making sure the parent’s work role responsibilities are met.

Step 3: Recognize resources and barriers afforded by existing roles

In Step 3, the health educator’s goal is to help parents complete a realistic assessment of barriers and resources in meeting caregiving demands. Resources can generally be categorized into two types of support, instrumental and social. Instrumental support is aimed at helping parents meet the tangible demands of their roles. Social support is a type of emotion-focused coping that attempts to lessen negative feelings and the experience of stress (Thoits, 1986).

The work domain is one potential source of instrumental support. Parents of ill children report that having a good rapport with the supervisor makes it possible to come to work late, bring work home, have time off for appointments during the day and spend time on the telephone (Freedman et al., 1995). Other potential forms of instrumental support include job flexibility (i.e. having control over scheduling work) and employer-sponsored benefits, such as paid sick days and leave to care for ill children, comprehensive health insurance, and child care reimbursement (Marshall and Barnett, 1994; Ulione, 1996; VandenHeuvel, 1997). Unfortunately, for most working families, these resources may not be available. Job flexibility tends to be more characteristic of professional than non-professional positions and lack of flexibility presents a substantial barrier in attempting to meet the needs of ill children (Peterson et al., 1997). As for other benefits, one study that used a nationally representative sample revealed that most mothers of chronically ill children had no sick time at all that could be used to care for sick children (Heymann et al., 1996).

Fortunately, employers are not the only potential source of instrumental support. Parents report relying on several formal (e.g. sick childcare,
transportation services, in-home care) and informal (i.e. friends and family) sources of support (Freedman et al., 1995). In Williams’ study, low-income parents reported that several forms of instrumental support were helpful, including having others care for their well children while they attended to the ill child’s needs, providing money, buying groceries and providing transportation or paying for gas (Williams, 1993).

For all parents of ill children, social support can help alleviate the stresses of caregiving (McCubbin et al., 1983; Fife et al., 1987; Lynam, 1987). Social support may be available from family, friends, members of the work role set, and from more formal sources, such as health educators and other health professionals, social workers, counselors and support groups. The parents of other ill children are often a good source of emotional support because of shared experiences in caregiving (Freedman et al., 1995). Although several potential sources of support exist, research shows that, compared to parents of healthy children, parents of chronically ill children perceive relatively less social support (Ferrari, 1986). Health educators can help parents recognize important sources of social support and assist them in building support networks.

Of course, the greatest barrier to effective caregiving is lack of resources. For this reason, health educators need to take special care with low-income families. These families are particularly likely to lack resources, not only because of their own socioeconomic status, but also because other members of their role set (e.g. friends and family) tend to be in ‘the same boat’ in terms of limited resources (Williams, 1993). Moreover, parents with limited resources report feeling scared, overwhelmed and vulnerable when faced with the demands of a child’s illness coupled with other role responsibilities, such as employment and caring for well children (Neal et al., 1997). Under these circumstances, health educators can direct parents to valuable instrumental resources provided by public (e.g. social services) and private (e.g. charitable organizations) support agencies. Health educators should encourage role negotiation devoted to securing crucial resources and eliminating the most debilitating barriers to meeting work and family role demands.

**Step 4: Negotiate workable roles**

Negotiating workable roles means developing a mutual understanding among members of the role set regarding ‘who needs to do what, when, where, why and how’. In creating functional roles across the work and family domains, some common obstacles exist (i.e. role ambiguity, role conflict and role overload). These difficulties are discussed in more detail below, along with techniques health educators can use to help parents address them.

**Role ambiguity**

Role ambiguity occurs when role expectations are vague or unclear. As parents attempt to manage a child’s illness and develop effective coping strategies, they may feel overwhelmed and unsure about what to do. The same can be said for other potential caregivers in the role set, including family members, babysitters, daycare providers and teachers. Moreover, because a child’s illness may be perceived as a sensitive issue, other care providers may feel reluctant to ask parents for information (Sexton and Madan-Swain, 1995).

Health education is an important tool in combating role ambiguity. To feel comfortable sharing information with others, parents must first have an adequate understanding of their child’s illness and care needs. Since mothers tend to be the primary caretakers of ill children and the main representative to health-care providers, they are more likely than fathers to receive information and training related to caring for a sick child (Hauenstein, 1990). One study showed that some fathers did not feel efficacious about caring for sick children and that some mothers viewed fathers as incompetent to provide care for ill children (Thompson, 1993). Providing both parents with adequate training in meeting their child’s health needs not only increases their confidence and competence in caring for the ill child, but also enables them to educate other members of the role set about caring for the child. Parents need to realize that failure
to receive needed support from other members of the role set may be due, at least in part, to uncertainty regarding what types of assistance are needed and how to provide them. Health educators can encourage parents to be proactive about sharing information and to elicit information seeking from other members of the role set.

Experienced health educators recognize, however, that information alone does not ensure adequate coping. For instance, research evidence shows that some caregivers fail to adhere to a child’s asthma treatment plan despite being knowledgeable about care requirements (Zimmerman et al., 1999). Other obstacles in the role negotiation process (e.g. role overload and role conflict) can prevent adequate care, even when the care requirements are clearly understood.

Role overload
Role overload results when role demands are excessive relative to a person’s limited time (Hardy and Conway, 1988). The issue is not that role demands are unclear; the focal person understands and is able to meet each of the demands individually. The difficulty results from role demands being ‘piled on’ in such a way that they cannot be accomplished in the time available, creating a tremendous amount of stress. The child’s primary caregiver, usually the mother, is especially prone to role overload and its associated stresses.

Health educators can help parents realize that combating role overload requires a willingness to delegate and the ability to negotiate shared responsibilities in order to eliminate some of the burden. Again, this may be particularly difficult for some mothers. For example, one way mothers in particular attempt to cope with a child’s illness is by becoming involved and thoroughly understanding the medical situation (Powers et al., 1986). While this tendency is not dysfunctional in and of itself, a mother who ‘wants to do it all’ is setting herself up for role overload. Some mothers refuse to allow their husbands to care for their sick child, believing them to be incompetent (Thompson, 1993). Thus, health educators can help by objectively defining appropriate standards of care. Moreover, health educators must reinforce the notion that delegation means accepting that the way others perform certain tasks may be different than ‘the way you would do it’. Having help does not necessarily mean having it your way.

Role conflict
Role conflict results when meeting one set of expectations inhibits the ability to fulfill another set of expectations. In coping with a child’s illness, for instance, being unable to both stay home with a sick child and go to work is a form of role conflict. Conflict may also erupt between the parent and spouse roles. Caregiving demands can limit the time that couples have for one another, decrease the number of positive interactions and experiences spouses have together, and increase marital discord (Cohen, 1999).

Role theory has traditionally focused on behavior-based conflicts (e.g. fulfilling two seemingly contradictory demands) and time-based conflicts (e.g. difficulties that arise from the impossibility of being in two places at once). Psychological conflict has been recognized more recently (Nippert-Eng, 1996; Friedman and Greenhaus, 2000). Consider a parent who is expected at work, but has a sick child at home. From a purely behavioral perspective, resolving this conflict between work and family responsibilities may be as simple as providing adequate sick childcare. However, psychological conflict may exist that remains unresolved. Although the demand for the parent’s physical presence has been alleviated by another care provider, that does not necessarily mean that the parent will be psychologically present at work. Psychological preoccupation with the sick child may make it impossible for the parent to concentrate on work activities and responsibilities.

This is not to say that enacting the work role, rather than the caregiving role, always creates psychological conflict for parents. On the contrary, parents report that work is frequently a form of ‘respite’ or a ‘welcome distraction’ from their caregiving responsibilities (Freedman et al., 1995). Psychological benefits include feeling in control and efficacious in dealing with problems. This
can be a contrast to the feelings of futility that sometimes accompany dealing with a particularly difficult and debilitating chronic illness.

Negotiations required to resolve role conflicts may involve one or more of several processes, including altering one’s own expectations, changing the expectations of other members of the role set, modifying behaviors to be more consistent with role expectations, eliminating aspects of the role, delegating certain responsibilities or leaving the role altogether. Many conflicts can be resolved on a “contingency” basis. For example, when two working parents decide who will stay home with an ill child on a particular day, research shows that several different factors are taken into consideration, including the relative importance of the mother’s and father’s work responsibilities on that day, relative job flexibility, and the economic and other consequences of missing work for each (Thompson, 1993). The health educator can facilitate contingency planning that takes into account parents’ multiple role demands, available resources and the child’s health needs.

Anticipatory planning helps prevent role conflict. Having a planned course of action for meeting caregiving needs that are likely to arise, as well as backup contingency plans, reduces the likelihood of a crisis. Most parents in Thompson’s study indicated that when a child was ill the standard plan was for one or the other parent (or a grandparent) to stay home with the child (Thompson, 1993). However, most parents failed to have a ready contingency plan, such as enlisting the help of other family members and friends, for times when the standard plan was not workable. Health educators can encourage anticipatory planning by helping parents think through the caregiving demands likely to arise from a child’s illness and helping parents construct backup plans.

**Step 5: Work toward role integration**

Research on balanced coping shows that the synergy of the total family system is more important to effectively coping with a child’s illness than any isolated family factors (Cohen, 1999). In role theory, the term *role integration* is used to describe a well-ordered social system in which the roles fit and function well together (Biddle, 1979). Attending to role integration involves maintaining appropriate levels of role redundancy and coordinating interdependent roles.

Role redundancy refers to the extent to which the duties of various members of the role set overlap. Ascertaining appropriate levels of role redundancy is dependent on a family’s particular circumstances and is intimately connected to effective resource use. Given the need for contingency or backup plans, some level of role redundancy is clearly desirable. However, too much redundancy wastes valuable resources.

Coordination of care, especially for children who are seriously or chronically ill, is a major role responsibility in itself. Effective coordination begins with adequately identifying members of the role set, but also requires recognition that members of the role set are interdependent partners in caregiving. Facilitating information sharing and making sure that care activities are appropriately sequenced are both important coordination activities. The health educator’s role is to help ensure that these activities are handled in a manner that empowers the primary caregiver. For instance, having a school nurse report directly to a child’s physician may be functional and appropriate under certain circumstances (e.g. helping to reduce the primary caregiver’s role overload). However, it may also diminish a parent’s sense of empowerment, leading to questions about who is really in charge of the child’s care. The same is true of scheduling care activities so that they occur in the appropriate order. For example, it may be important that a child have blood work done prior to a particular procedure. There must be clarity about who will take responsibility for sequencing and scheduling these activities, and sensitivity regarding issues of empowerment.

Parents report feeling particularly supported when they experience ‘spontaneous helping’ (Williams, 1993). That is, a member of the role set provides appropriate assistance without having to be asked. Indeed, this may be the litmus test for the level of role integration that has been
achieved. When members of the role set understand what they can do to help and are willing and able to do so without being asked, the synergy that ensures effective coping has been created.

**Step 6: Renegotiate roles as necessary**

Role negotiation is a dynamic and largely continuous process. The consequences of role behavior provide feedback to the role system and affect future role behavior. As social constructions, roles tend to evolve over time. For working parents attempting to cope with a child’s illness, there may be points in the trajectory of role development that call for concentrated renegotiation. The most obvious example is when substantial changes occur in the demands of the work and/or caregiving role. A transfer or promotion at work would be a catalyst for role renegotiation, as would significant changes in a child’s health status. For instance, if a child’s condition improves, parents need to make appropriate adjustments to their caregiving behavior. The child’s growth and development is likely to be another major catalyst for renegotiating roles. As children become more mature and self-sufficient, they may take greater responsibility for their own care (Hymovich, 1984). Adolescence can be a particularly challenging time for parents and their children. Teenagers want to assert their independence and may be capable of taking on more responsibility for their own health. However, parents may perceive, often accurately, that their adolescents are less than fully reliable. These are the kinds of role ambiguities and role conflicts that signal the need for renegotiation.

In addition, as children age, certain members of the role set are likely to change. For instance, when a child makes the transition from daycare to school, daycare providers are replaced as members of the role set by teachers, the school nurse and other school personnel. Keeping the role system functioning effectively means engaging in role negotiation and attending to role integration with these new players. Health educators can assist parents by identifying child health catalysts for role renegotiation and helping parents understand resultant caregiving demands.

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**Conclusions**

Role theory builds on the balanced coping perspective by pointing out that if a child’s chronic illness is to be effectively managed without sacrificing the family’s needs, then it is critically important to consider other major role responsibilities of primary caregivers. Since paid employment is a reality and a necessity for many parents, taking into account the demands of the work role is crucial in developing balanced coping strategies that meet both children’s and parents’ needs. As illustrated in Figure 1, effective role negotiation between the work and family domains is the key to balanced coping. This paper has attempted to utilize role theory to articulate the concrete ways in which health educators can facilitate parents’ role negotiation and help ensure balanced coping.

Although the six-step process summarized in Table 1 is broadly applicable, the resultant coping strategies are unique to individual families. The emphasis is on effectively using resources to negotiate the most desirable roles possible under a given set of circumstances. While the health educator facilitates this process, parents must take the lead to determine what is ‘desirable’. Should a parent quit work to stay home and care for a sick child? This is the type of question that can only be answered by the caregiver in the specific context of the family’s needs and resources. To be effective facilitators, health educators must avoid judgmental messages that suggest working parents ‘aren’t putting their child first’ or are unwilling to ‘do whatever it takes’. This only serves to alienate parents and increase their stress, while doing nothing constructive to help them meet multiple role demands. In some situations, maintaining employment may be the very best thing parents can do for themselves and their children. Health educators support balanced coping by educating families about the demands of a child’s illness and helping to reduce those demands, helping to increase family resources, supporting parents and facilitating role negotiation.

Although role theory provides a robust framework with a history of supportive empirical
research, the application to coping with chronic childhood illness has not been directly tested. Thus, future research must be devoted to validating the model proposed here. The greatest research need is to assess the fundamental premise that effective role negotiation leads to balanced coping; this is the heart of the model shown in Figure 1. There is already evidence to suggest that balanced coping has positive effects on child health and caregiver well-being, but the role theory implications remain to be tested. Are parents who engage in balanced coping better able to meet their role responsibilities in both the work and family domains? Provided that the links between role negotiation, balanced coping and role fulfillment are established, then research investigation can begin to consider the relative efficacy of particular tactics and strategies health educators use to facilitate the role negotiation process. Thus, the role theory framework presented here may serve as the impetus for advancements in both theory and practice for health educators committed to facilitating coping with chronic childhood illness.

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