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Review article

“Timing It Right”: A conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home

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Abstract

Objective: Discuss family caregivers of stroke survivors’ changing needs for education and support across the care continuum.

Methods: Conceptual review.

Results: Stroke is a serious, sudden onset illness requiring care across the care continuum. The focus of care, the individuals primarily responsible for providing that care, and patients’ self-care abilities change across care environments. Often family members who provide support also experience changes in their caregiving role. To date, however, interventions for family caregivers have not explicitly considered their changing support needs.

Our “Timing It Right” framework highlights family caregivers changing experiences and corresponding support needs across the care continuum. Five different phases of caregiver support are discussed: (1) event/diagnosis; (2) stabilization; (3) preparation; (4) implementation; (5) adaptation. The first two phases occur during acute care, the third occurs during acute care and/or in-patient rehabilitation, and the final two phases occur in the community.

Conclusions: Application of this framework has the potential to benefit future intervention efforts by identifying gaps in caregiver education, training, and support.

Practice implications: Recognition of family caregivers changing support needs across the care continuum will assist health care professionals to provide more timely and appropriate support.

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1. Introduction

Health care professionals and policy makers recognize the importance of enhancing the continuity of care across the care continuum and have emphasized models of integrated service delivery to achieve good health outcomes [1–4]. Yet despite this, health care delivery systems continue to lack continuity across services and are often criticized for shortening hospital length-of-stay and for offering limited community services

[1,5,6]. These gaps in care are occurring at the same time as population aging trends find increasing numbers of people experiencing potentially serious, age-related health conditions like stroke, Alzheimer’s disease, cancer, heart disease and other chronic conditions. Currently, when individuals who experience a sudden onset chronic health condition are discharged from hospital, they commonly rely on family members and friends (referred to here as caregivers) for assistance with daily activities and to navigate complex health care services [7]. In Canada, an estimation of one in eight adults provides support to individuals residing in the community with a variety of serious health conditions [8]. Estimates are similar for other industrialized countries [9,10].

In particular, stroke is a leading cause of adult disability [11]. The trajectory of care for stroke is often characterized by

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sudden onset, acute hospital care followed by rehabilitation and return to community living. Of new stroke survivors, an estimated 56% go directly home after acute care, 32% go to inpatient rehabilitation, and 11% go to long-term care facilities [12]. Stroke survivors returning to the community often have difficulties performing every day activities like dressing, eating, and mobility that can last well into the first year post-stroke [13]. It is also commonly associated with cognitive changes (e.g., 26.3% of ischemic stroke survivors are diagnosed with dementia [14]). Caregivers provide essential support to these individuals when they return home with varying levels of physical and cognitive difficulty.

Restructuring professional health care services to enhance the continuity of care across the care continuum for patients has implications for caregivers that have not been fully discussed in caregiving research or addressed in caregiver interventions. In general, caregivers rarely receive preparation for their role and, as a result, they often experience stress and negative health consequences [15–18] that can additionally contribute to poor patient rehabilitation outcomes [19] or threaten the sustainability of home care [20,21]. The objective of this paper is to present a framework for addressing and evaluating the changing needs of stroke caregivers across care environments. Caregiver needs across five phases are discussed in terms of: (1) their timing and association with care recipient health care needs; (2) care setting; (3) professional and family care roles; (4) caregiver support. The framework draws upon existing observational research and the clinical care pathway of stroke. Outcomes relevant to caregivers at different phases of care are also discussed in an effort to inform future research.

2. Background

To enhance family members' transition into a caregiving role, numerous interventions have been developed (see reviews [22,23]). These interventions commonly focus on providing information to care recipients and their caregivers about the particular health condition and its treatment [24–26] or existing community services [27]. Some interventions also aim to address caregivers' personal needs by providing counselling and training in problem solving [25,28–30]. Most interventions are implemented during or shortly after discharge from acute care or rehabilitation with few interventions offered in the community [22]. Among those interventions that have been evaluated, small to moderate improvements in caregiver burden, emotional distress, psychological well-being, and quality of life have typically been found [23]. Larger improvements are observed in interventions that are tailored to specific caregiver needs and that are psychotherapeutic, psychoeducational, or multi-component in nature [23].

Existing interventions have drawn substantially from research on social support and aim to provide different elements of support including emotional (e.g., providing comfort, listening to problems), instrumental (e.g., providing training, organizing services, helping with household chores), informational (e.g., providing information about illness and services), and appraisal support (e.g., providing feedback about

their caregiving activities) [31]. Studies find that support is most beneficial if it is closely matched to individuals' current needs [32]. This reinforces the need to more closely examine caregivers' support needs over time when designing interventions. The focus on support needs over time also can help guide the selection of outcomes that can be used to assess interventions [33].

The growing number of longitudinal studies also highlights the potentially dynamic and changing nature of the caregiving experience. For example, in progressively deteriorating conditions like those often facing the frail elderly, caregivers' emotional distress tends to increase over time [34]. Gaugler et al. [35] identified increasing behavioral problems in individuals with Alzheimer's disease to be associated with increases in caregiver overload over time. In stroke, where few longitudinal caregiving studies have been conducted, caregiver depression may actually decrease as stroke survivors abilities improve [36].

In stroke, changes in caregiver well-being also may correspond to changes in the focus of professional care related to survival and stabilization in the acute care environment, relearning the skills of independent living during rehabilitation, and adaptation and implementation of skills in community living. In acute care and rehabilitation, physicians, nurses, and allied health professionals (e.g., occupational therapists, physiotherapists, social workers, and speech language pathologists) provide substantial care for patients. In contrast, when stroke survivors return home, family members often assume the role of caregiver due to the limited availability of community-based formal health care services [6,37,38].

Changes in care received by patients across care environments are mirrored in corresponding changes in the roles of caregivers. During acute care and in-patient rehabilitation, caregivers commonly provide emotional support, assistance with activities of daily living and communication, and advocate for patients' well-being. At home, the balance of care shifts with caregivers becoming primarily responsible for supporting patients' recovery and rehabilitation. The many changes in caregiving experiences and roles across the care continuum suggest caregivers' needs for education and support will also change. However, intervention research has not generally focused on the diverse aspects of the care situation that may be associated with differences in, and ultimately changes in, caregiver well-being. Moreover, a conceptual framework that draws on existing research and the stroke clinical care pathway to begin to systematically differentiate changes in care needs and the implications for caregivers is lacking. Such a model has the potential not only to guide intervention efforts, but also to identify gaps in research knowledge and assist with evaluation of interventions through the selection of appropriate outcomes.

3. "Timing It Right" framework

To inform this conceptual review, we conducted a review of the literature, using Medline, CINAHL, and Psychinfo, and the following search terms: stroke or cerebrovascular accident and caregiver or carer and support needs or information needs or

emotional needs or training needs. Quantitative and qualitative studies were included if they specifically discussed family caregiver support needs and indicated when in the care or illness trajectory these needs occurred. Studies discussing support needs but without specific reference to timing in the care trajectory were not included. Although there are numerous studies describing caregivers support needs, only a small number of studies made specific reference to the time in the illness trajectory that these needs occurred. Therefore, we used primarily 11 studies in combination with the clinical course for stroke to inform the TIR framework [28,39–48].

In these next sections, we draw on this previous research to describe the major phases that often confront stroke survivors and their caregivers starting with the illness event through to community adjustment. Specifically, we reviewed caregiver support needs and organized them by when in the care trajectory the needs occurred. The result was the identification of five phases with distinct support needs. These five phases are discussed along with their setting and the emphasis of care by health care professionals and family caregivers. After describing each phase, we discuss the kinds of support needs that caregivers may have at each phase and potential outcomes that could be used to evaluate interventions addressing these support needs. Table 1 summarizes the key characteristics of each phase including the timing, setting, care focus, caregiver support needs, and outcomes. It is important to note the discussion of phases in our model is not intended to represent a series of stages that all caregivers will experience in an invariant order. Instead, the phases are intended to provide a general guide to the types of experiences that may be associated with differing caregiver needs over time.

4. Phase characteristics

4.1. Phase one: event/diagnosis

A sudden onset health event or diagnosis often signals the first phase of the family care trajectory. This phase often results in hospitalization where the focus of treatment is on survival and then stabilization of the patient. It is usually of short duration, lasting from a few days to a few weeks. Patients' physical and cognitive abilities will be most impaired at this time unless followed by a new negative health event. At this time, caregivers often focus on the current health event and treatment and whether or not the event is deemed life threatening by health care professionals. Little thought is generally given to the long-term future [39,40]. This phase may be characterized by a high degree of uncertainty [40]. Caregivers are often anxious and express concern for their family member's immediate survival. This phase is consistent with caregivers desire to understand "What's it all about" [41].

4.2. Phase two: stabilization

Once a patient's medical condition has stabilized caregivers generally move into a new, transitory phase. In this stabilization

phase, acute care centres on the time and efforts needed to initiate the recovery process in the acute care hospital. This phase is again relatively short, consistent with many health care systems preferences for shortening hospital length-of-stays. Health care professionals also determine the extent of the disability resulting from the stroke. They focus on specific markers for patient improvement such as mobility, communication, and cognitive functioning. Patients may begin to show some improvement in their functional abilities. Caregivers often appear calmer or express some relief in this phase, but they generally have yet to realize the extent of the physical and cognitive disability experienced by their relative and what it will mean in the patient's or their own lives when the stroke survivor returns home. During this phase, caregivers often seek information from clinical staff about the particular effects stroke has had on aspects of their relatives physical and cognitive abilities including mobility, self-care, memory, speech, swallowing, and mental health [39,43]. Many caregivers also wish to participate in the rehabilitation process with health professionals [42] and want to receive reasonable estimates of the extent of their family members' likely recovery [43]. However, anxiety and worry may begin to increase if information on the impact of the stroke is not immediately available and a waiting period ensues while tests and assessments are being made.

4.3. Phase three: preparation

The preparation phase occurs before the patient returns home. This phase can be short if the patient is going home from the acute care environment or extended if they are going to in-patient rehabilitation. At this time, the patient's medical condition has stabilized and the clinical emphasis is on preparing the patient to ultimately return home. This includes health care professionals monitoring stroke survivors' abilities to safely perform activities of daily living and starting to introduce aspects of secondary prevention including medication adherence and dietary and lifestyle change. As discharge approaches, caregivers become increasingly concerned about their abilities to provide care in the home and wonder if they will be "up to the job" [39]. They specifically want information and training from health care professionals to assist with the provision of physical care in the home [39,41] and to learn about signs of potential problems that could signal new adverse health events. Many would also like to receive appraisal and feedback about their caregiving activities to enhance their skills and build their confidence in performing these activities [41]. Caregivers may also seek information about community services and assistance so they can submit applications to appropriate organizations or plan ahead [43]. By this time, many caregivers will also have spent considerable amounts of time in the acute care setting, having temporarily forgone many other external demands and responsibilities. In addition to preparing for their relative's return home, many caregivers may experience additional strain as they struggle to partially re-establish existing family and work routines.

4.4. Phase four: implementation

The implementation phase occurs when patients return to the home environment. At this time, the responsibility for providing care shifts from health care professionals to family caregivers. Patients are learning how to adapt to living in their home environment. Caregivers are “learning the ropes” as they

attempt to apply the skills they have learned in the acute or rehabilitation environments to helping their family members in the home environment. Their focus is often on the provision of physical care as they attempt to develop routines [41,43]. Caregivers often find coordinating family physician follow-up, assisting with mobility and transportation, and supporting secondary prevention (e.g., coordinating medications, diet and

Table 1
 “Timing It Right” model for family caregiver intervention research

Phase	Time	Setting	Care focus	Caregiver support needs	Caregiver outcomes
Event/diagnosis	Acute phase of illness Short duration	Acute care hospital	Professional care Focus is on diagnosis and surviving the current event Family care Concern for survival Not aware of what the IC role may entail as a result of this illness event	Information: diagnosis, prognosis, and current treatment Emotional: someone to talk to Training: not required at this time Appraisal: not required at this time	Knowledge: survival/prognosis Enhanced informed decision making regarding treatment Emotional distress
Stabilization	Shortly after patient has stabilized Short duration	Acute care hospital	Professional care Patient has stabilized Focused on specific markers (e.g., mobility) Family care Critical event over Still much uncertainty about future	Information: cause of event, current care needs Emotional: someone to talk to Training: initial training to assist with ADL and rehab therapies Appraisal: not required at this time	Information outcomes: awareness about cause Training outcomes: confidence in supporting ADL activities Emotional distress
Preparation	Before patient goes home Short to moderate duration	Acute care hospital or rehabilitation facility	Professional care Clinical emphasis on discharge or in-patient rehab Safety in ADL Secondary prevention introduced Family care Shift focus to care needs when CR returns to community Concerns about ability to meet care recipients needs in community	Information: availability and how to access community resources Emotional: mounting anxiety and uncertainty about the future, social support Training: some practice of new ADL skills and rehab therapies Appraisal: feedback about ADL supporting activities	Knowledge re community resources Caregiving confidence/self-efficacy Emotional distress Anxiety Perceived social support
Implementation	First few months after patient returns home Moderate duration	Home	Professional care Adaptation to community living Community services Family physician Medications Secondary prevention Family care Learning the ropes and recognizes there is still much to learn about providing care Interaction with community services Start to recognize the personal costs of caregiving (e.g., lifestyle and emotional health)	Information: everyday management of ongoing activities Information: potential impact of providing care on caregiver everyday life and health Emotional: fear and anxiety of adapting to providing care in the home Training: additional support to manage care in the home Appraisal: feedback on how they are managing in the home	Improved self-efficacy in managing care Use of community services Perceived social support Emotional distress Psychological well-being

Table 1 (Continued)

Phase	Time	Setting	Care focus	Caregiver support needs	Caregiver outcomes
Adaptation	After a period of adjustment in the home Long duration	Home	Professional care Care recipient has adapted to living in the home Limited professional care Community reintegration Secondary prevention Family care Concern for care recipient community reintegration Caregivers increasingly confident in their caregiving activities Caregivers experience personal consequences of care Focus on future caregiving needs, their own needs as well as the care recipient	Information and training: focus on caregiver participation in valued activities and interests Information: accessible work and community options (e.g., movie, restaurants) Information: recognition of and planning for the future including future health crises/events that may change caregiving demands, what if caregiver gets sick? Emotional: support from others in similar situations, e.g., support groups Emotional: relationship changes Training: assisting with SS community reintegration Appraisal: continued feedback on how they are managing in the home	Patient community reintegration Perceived social support Decrease in emotional distress Increase in psychological well-being Increased participation in valued activities

lifestyle changes) difficult to manage [42,43]. Emotionally, caregivers may be anxious or uncertain about their caregiving abilities and may have feelings of inadequacy [41]. In some research, caregivers who felt that they were poorly prepared during acute care and/or inpatient rehabilitation reported feeling additional stress and poor confidence when the stroke survivor returned home [39]. At this time, they may also have interactions with community services where many feel that home care services are too restrictive [42]. Professional care during the implementation phase becomes more intermittent and can vary across patients. This may be due to the availability and accessibility of services and the availability of family support. During this phase, caregivers start to experience the personal consequences of providing care including the resulting emotional, physical, social, and role changes [44]. The duration of this phase can vary, but often lasts for several months after a patient has returned home.

4.5. Phase five: adaptation

After the period of adjustment that signals the implementation phase, many caregivers report an adaptation phase. In this phase, out-patient rehabilitation programs are usually completed and improvements in patients’ abilities tend to have stabilized. Professional care commonly consists of health monitoring by family physicians. The availability of ongoing professional services and programs in the community is limited [6,37,38]. At this point, many caregivers have become confident in their ability to support activities of daily living and begin to shift their emphasis to helping stroke survivors resume participation in valued activities and interests (i.e., community reintegration). As a result, caregivers may report the need for additional information to help the stroke survivor to resume participation in social activities, driving, sex life, employment and travel [43]. Caregivers also become increasingly aware of the personal consequences of providing care. For example, they may take

greater notice of the restrictions that caregiving has imposed on their own abilities to socialize with family and friends [45]. Many caregivers report needing a break from their caregiving activities and begin to report difficulties dealing with competing demands and roles in their lives [46]. Caregivers who have put other family responsibilities on hold during the period after their family member’s stroke often feel the need to resume these responsibilities. At this time caregivers may also begin to think about the future as they realize that either new adverse health events could occur or changes in their own health or circumstances may preclude their ability to continue to care for their relative in the future. Some caregivers report that they cope with uncertainty in the future by “taking one day at a time” [46].

5. Phase-specific support needs

As the above descriptions of the different phases indicate, the experiences of caregivers providing support, assistance, and care for individuals who have experienced a sudden onset health problem like stroke can involve numerous changes over time. In the next section, we return to each of the five phases and describe in greater detail the types of support that may be needed by caregivers. The four key areas of social support commonly experienced in caregiving (i.e., informational, emotional, instrumental, and appraisal [31]) will be discussed. Informational support needs can include information about the causes of stroke, its differential impact on body systems and activities, and treatment options. Emotional support is generally aimed at helping people to reduce feelings of distress and upset. Instrumental support can include help with tasks and planning or training to improve a caregivers’ management of the care recipient. Appraisal support includes feedback or an evaluation of caregivers’ efforts in order to validate their experiences and to help improve their caregiving abilities. In this section we also discuss modifiable outcomes that could be

used to facilitate the evaluation of interventions provided at each phase of the care trajectory.

5.1. Phase one: event/diagnosis

Caregiver support needs in the event/diagnosis phase centre around the acute event and include the need for emotional support as caregivers struggle with the stressful experience, as well as, specific information regarding the condition, its prognosis, and treatment options. Caregivers may need emotional support to assist them in managing their own emotional reaction to their family members' stroke and the uncertainty surrounding it. In many acute care environments these needs are fulfilled by a variety of professionals, including physicians, nurses, allied health professionals (e.g., social workers, case managers) and hospital clergy. Individualized written information about their family members illness, prognosis and treatment, may also be provided to address these needs [40,44]. Central outcomes to be examined during this phase should focus on the receipt of information and emotional support and include the perception of emotional support, experiences of emotional distress, and knowledge about the illness and treatment to facilitate informed decision-making. Instrumental and appraisal support are less relevant during this phase.

5.2. Phase two: stabilization

In the stabilization phase, caregivers are often ready to learn more about the cause of the event and the individual's current care needs. However, definitive information on the impact of the event may not yet be available, resulting in continued anxiety among caregivers. Where information is not available, continued emotional support and discussion of likely scenarios may help put caregivers' mind at ease. Information regarding markers of progress, tests and assessments needed, and their timeline may also be helpful. This may also be a good time to start training caregivers in assisting with basic activities of daily living and rehabilitation therapy. For example, members of the acute care team could instruct caregivers in the physical aspects of care and rehabilitation therapy. From an emotional perspective, caregivers may need someone to speak with and share their feelings and concerns about the patient's well-being, as well as, their own personal concerns. Social workers, as well as family and friends, may provide this emotional support. Physicians, nurses, and allied health professionals (e.g., occupational therapists, physiotherapists, speech language pathologists, social workers, case managers) often continue to provide information about the illness and treatment during this phase. Intervention outcomes of interest could include knowledge about causes and treatments for stroke, assessments of caregiver confidence in supporting activities of daily living and rehabilitation therapies, perceptions of emotional support, and assessments of distress.

5.3. Phase three: preparation

Caregivers' support needs increase during the preparation phase. They require information about resources available in

the community to support the care recipient and themselves including how to access these resources. The types of resources include access to community care agencies, on-going rehabilitation, and support groups. Caregivers need continued practice in supporting stroke survivors' in their activities of daily living and would benefit from the opportunity to test their skills in the home environment under the supervision of rehabilitation professionals and/or nurses. These professionals could appraise and provide feedback about their caregiving activities with the aim of enhancing caregivers' skills and confidence. Emotionally, caregivers need support from social workers and/or family and friends to manage their mounting anxiety and uncertainty about providing care in the community. If the stroke survivor attends in-patient rehabilitation, there are opportunities to continue to support and train caregivers prior to discharging the stroke survivor home [46]. Intervention outcomes include continued assessments of knowledge about stroke and techniques that support managing everyday activities, as well as, knowledge about community resources. Outcomes could also include caregiving confidence in supporting ADL and rehabilitation therapy, assessments of emotional distress and anxiety, and perceptions of social support.

5.4. Phase four: implementation

As caregivers begin to provide care in the home, their support needs are comprehensive. From an informational perspective, they may require guidance with the every day management of ongoing activities as they pertain to the home environment. Caregivers often report that they did not receive enough training prior to hospital discharge and had to learn caregiving activities by trial and error in the home [39]. Training received in hospital or rehabilitation settings may not easily adapt to the home environment. For example, in the home environment bathrooms may be smaller, hallways may be narrower, carpets may be difficult to manage, and stairs may be difficult to negotiate. The sudden transition to the home with an absence of health professionals with whom to consult as needed may also make caregivers anxious. As a result, caregivers may need advice from peers and/or health care professionals on how to manage the care recipients' various needs, they may require additional training, and they may need additional emotional support to address fears and anxiety associated with starting to provide care in the community. During this phase, it will be important for caregivers to also receive appraisal and feedback from health professionals about their caregiving activities with the aim of addressing any potentially problematic activities before they cause harm to either the patient or the caregiver (e.g., transfers) and to enhance caregiver's confidence in their caregiving activities. Although support groups for caregivers are often proposed when care recipients return to the community, the extent of care provided by caregivers at this time may make attendance at support groups or educational sessions difficult. Telephone support (e.g., [28]) or other technology-based interventions (e.g., Internet [45,48]) may be an effective way to intervene during this phase of the care

trajectory. At this time, some caregivers also become more aware of the personal consequences of providing care (e.g., not having time to pursue their own valued activities and interests). Consequently, this may be the time to begin to provide some strategies to assist caregivers in managing these personal consequences (e.g., accessing respite, utilizing other sources of support including family and friends). Outcomes of interest during this phase include confidence in providing care, use of community services, perceptions of social support, level of emotional distress, and extent of community participation.

5.5. Phase five: adaptation

Once caregivers settle into a caregiving routine, their focus often shifts to community reintegration. During this adaptation phase, caregivers need information about options for accessible work and community activities for the stroke survivor. Caregivers need training to facilitate and support stroke survivors' use of these opportunities. In addition, caregivers need education and training to help them recognize the importance of their own participation in valued activities and how to enhance their participation. Caregivers may also need guidance to help manage their competing roles. It is during this phase, when the caregiving demands become more manageable, that caregivers may have more time to participate in support groups where their needs for information and support may be met by others in a similar situation (e.g., [47]). During this phase, caregivers may also need information about future care options and how to plan or prepare for the future. Assistance with future care plans may be best achieved by interactions with health care professionals, for example, family physicians or social workers. Workplace benefits like employee assistance plans, flexible work hours, and workplace health and safety programs may also benefit both caregivers and their family member. Outcomes in this phase include stroke survivor and caregiver community participation, caregiver distress, and perceived social support.

6. Discussion and conclusions

6.1. Discussion

The "Timing It Right" framework presented in this paper addresses the need for more conceptually driven caregiver intervention research [49]. It also addresses the need for appropriately timed interventions. The TIR model is consistent with the central premise of the transtheoretical model of behavior change where behavior change is hypothesized to be more likely when educational strategies are tailored to an individual's current stage of readiness for change [50,51]. Our TIR framework suggests that family caregivers support needs are changing and caregivers will benefit to a greater extent if they receive specific types of support interventions when they are "ready" to receive them. Preliminary cancer education research supports this premise as providing patients with information about the symptoms and side-effects of cancer treatment once the treatment had commenced was associated

with less anxiety and more patient satisfaction compared to providing all the information prior to treatment [52]. In another example from the Alzheimer's caregiving literature, respite care may be introduced too late in the care trajectory as the caregivers who use respite actually institutionalize their care recipient earlier than those who do not use respite [53]. Therefore, the issue of timing is of importance in many different aspects of health care and health education.

Although this research draws on frameworks proposed by other researchers, it also expands upon them. For example, in their research with nurses who support the management of various chronic illnesses, Corbin and Strauss discuss three phases that overlap with our proposed five phases [54]. Their "acute care" phase is characterized by the need to medically stabilize the patient. During the "comeback" phase, the focus is on improving functional abilities and with helping patients to come to terms with the illness and any residual disabilities. The "stabilization" phase occurs when there is little if any change in the patients' abilities or the course of their illness. However, although the characteristics of the phases partially overlap, the TIR framework emphasizes phase-specific support needs and offers suggestions for informational, emotional, instrumental and appraisal support that can be evaluated for their effectiveness across phases. Another example of a trajectory approach to illness management is proposed by Nolan et al. [55]. Their research with Alzheimer's caregivers describes caregiving phases, two of which correspond to the recovery aspect of illness: "taking it on" and "working through it". The "taking it on" phase is characterized by family members' realization that the patient needs care and they must decide if they can take on this role. This phase is often brief as many consider the caregiving role a natural extension of their caring relationship. During the "working through it" phase, caregivers are actively providing care and are learning from health care professionals and other sources. The research by Nolan and colleagues differs from the current framework in that it is focused on progressively deteriorating illnesses like Alzheimer's where there is often a gradual onset and deterioration of individuals with the disease over time. Caregivers in this situation have time to adjust to a gradually worsening condition. In contrast, many illnesses, like stroke, occur suddenly with the potential for patient abilities to improve over time. In these situations, caregivers have little if any time to prepare for a caregiving role where there are considerable challenges in the early stages of the illness.

The objective of the TIR framework is to enhance the preparation that caregivers receive during each phase of the care trajectory. We anticipate that enhanced preparation will also ease the transitions between care environments and, therefore, decrease the occurrence of crises. Crises often occur at transition points in the care trajectory, including between phases, places of care, or changes in the stroke survivor or caregiver's health. This may be particularly true if some phases like the preparation and implementation phases are considered too short by caregivers who are trying to grapple with an abundance of information or learning of new skills. For example in critical illness, transfer anxiety is common when

patients change care environments (e.g., moving from the intensive care unit to the general ward [56,57]). Research suggests that lack of information about these transfers and what to expect is a large contributor to transfer anxiety for patients and their family [56,57]. Our model also suggests that caregivers may have difficulty if phases are too long. For example, if the event/diagnosis or stabilization phases are prolonged and associated with uncertainty, caregivers may experience heightened anxiety or feelings of helplessness making transition to other phases more difficult. Similarly, if the implementation phase is prolonged and caregivers are unable to return to other roles and responsibilities, there may be negative consequences for their health and well-being.

The framework has the potential to facilitate the current focus in the caregiver intervention field aimed at targeting interventions to specific caregiving groups and then tailoring those interventions to individual caregiver's needs [23]. Interventions based on the TIR framework can target caregiver supports according to their phase in the recovery trajectory and within each phase interventions can be tailored to caregivers' specific needs. The framework outlines the commonly experienced support needs during the specific phases of the care continuum to provide structure for tailoring the support to individual situations. In fact, a clearer understanding of time-based needs across caregivers may actually decrease the resources needed to provide individualized programs.

More clearly specifying outcomes of relevance across different phases of caregiving also has the potential to improve evaluation of interventions. For example, significant changes in knowledge about the causes and consequences of stroke are likely to be important in evaluating interventions targeted toward phases one to three. Changes in this type of knowledge would be less likely to occur in phases four and five. Emotional distress may decrease in phases one through three as caregivers work closely with health care professionals, but increase temporarily in phase four as the bulk of caregiving shifts away from professional care. The focus on timing and transitions across phases of care underscores the complexity of issues related to caregiving and suggests that continued change or "improvement" may not always be the most appropriate way to assess outcomes related to caregiver interventions.

The "Timing It Right" framework can be generalized to medical conditions beyond stroke, especially when there is a sudden onset and a period of hospitalization. Conditions more commonly experienced by the elderly including falls, heart conditions (e.g., myocardial infarction or heart surgery), or cancer would benefit from using the framework. Other non-age related conditions such as spinal cord, traumatic brain injury, and other critical illnesses may also benefit. At the same time, additional research is needed to validate the framework. Greater clarification of the length of the phases related to different health conditions and the types of support desired by caregivers is needed. There is also a need to refine the model to better understand the role that illness severity, age, gender and culture may play in shaping support. The balance of professional care and family support across the caregiving trajectory, especially in the community, also warrants greater attention.

6.2. Conclusions

Currently, there is an interest in better understanding changes in the caregiving experience over time. To date, however, we lack application of this focus to intervention research. By drawing on existing research and the clinical care pathway of stroke, we developed the "Timing It Right" framework, aimed at enhancing the timing and scope of caregiver intervention research by clarifying the timing, setting, and support needs for caregivers across the care trajectory.

6.3. Practice implications

Health care professionals in acute care, rehabilitation, and community care environments provide education and support to family caregivers. Yet, cuts to health care funding are decreasing the time health care professionals have to interact with families. A more targeted approach to providing education and support is needed to maximize the benefits to caregivers in this environment of scarce resources. Using the "Timing It Right" framework as a guide, health care professionals in each of these care environments can become more aware of family caregivers' phase-specific experiences and corresponding needs for education and support. Specifically, during acute care, family caregivers need to understand the stroke event and what is happening to their family member. After the stroke survivors' condition has stabilized, family caregivers need to know more about stroke and the current treatment plan. As stroke survivors are preparing to return home from either acute care or inpatient rehabilitation, family caregivers need training in supporting activities of daily living, lifestyle changes, and information regarding community-based services. During the first few months at home when family caregivers are learning to support stroke survivors in the home environment, their needs change to the practical tips for providing care in the home. After a longer period of adjustment, family caregivers shift their focus to community reintegration for the stroke survivors and themselves. Increasing the awareness of health care professionals of the family caregivers' needs across care environments will enable professionals to provide the information, training, and emotional support to caregivers in a more efficient manner. Ultimately, the TIR framework will make it easier for health care professionals to enhance the experiences and well-being of family members who take on the caregiving role.

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