Family Caregiver Assessment in Health Care Settings

Summary of The Change Foundation’s Literature Review and Environmental Scan Project

August 2016
A. Introduction:

The Change Foundation’s strategic goal is to improve the experience of family caregivers as they help their family member transition through and interact with Ontario’s health care systems (see Out of the Shadow and Into the Circle for more information). The Foundation sponsored a narrative review of the literature and environmental scan to identify tools to assess the needs of family caregivers in health care settings. We were interested in assessment tools for general needs, preparation for caregiving, or assessment of skills, knowledge and training for caregiving.

This paper is a summary of key findings from the narrative review and environmental scan. The full report - including the search strategy, selection criteria, and references - can be accessed on our Caregiver Resource Hub. The paper provides descriptions of caregiver assessment tools, as well as links to additional information where available.

In general, the review and scan revealed the following:

- Caregiver assessment has mixed meanings - ranging from being defined as a screen of caregiver burden to a multi-dimensional assessment of caregiver training needs and service support.

- Most of the existing assessment tools focus on analyzing stress or burden with few available tools to address how to work with providers in health care settings.

- Caregiver assessment does not necessarily translate into improved care and support for caregivers.

- There are a number of barriers to conducting caregiver assessment:
  - caregivers often do not self-identify;
  - reliance on self-identification can result in a low uptake of caregiver assessments;
  - there is often a lack of recognition that caregivers have separate needs from patients;
  - there is limited time and resources allotted for assessment; and
  - staff often feel unprepared to deal with the process of caregiver assessment.

- Barriers can be addressed through multi-pronged caregiver identification strategies:
  - changing how caregivers are asked if they are helping a loved one (i.e., instead of asking if someone is a caregiver, ask “are you looking after someone?”);
  - shifting to treating caregivers as equal partners and key players in the care process;
  - considering the caregiver as a potential client in their own right;
  - increasing knowledge of caregiver issues through staff education and training; and
  - integrating caregiver assessment into existing processes and assessments.

- Legislation requiring caregiver assessment is a strategy used in the UK and more recently in the US. However, legislative requirements have not translated into changes in practice in
interactions with caregivers—partly due to deep-rooted practitioner ambivalence towards caregiver assessment and partly due to lack of services and supports for caregivers.

- Key findings from the literature include:
  - There are a limited number and scope of tools available for examining the skill and training needs of a more general population of caregivers.
  - There is consensus about principles of caregiver assessment and domains of questions that should be considered.

- Gaps in the current literature include:
  - Training and skill assessment applicable to a general population of caregivers as opposed to disease specific groups of caregivers;
  - A lack of clarity about what constitutes a caregiver assessment in a health care setting, and determining in what health care settings assessments of caregivers are most likely to be successful and beneficial for caregivers; and
  - Limited use of partnership models for caregiver assessment, including partnerships where caregivers are viewed as co-experts.

B. Description of Assessment Tools in Health Care Settings:

Six assessment tools were identified through the narrative review and environmental scan. The tools fall under two major categories: (i) multi-dimensional caregiver assessment tools; and (ii) tools aimed at caregiver preparation for caring. Additional details about these tools are provided in Appendix 1.

1. Multi-dimensional Caregiver Assessment Tools

Two multi-dimensional caregiver assessment tools were found that have been piloted in home care settings. Both the C.A.R.E. tool and the FCSA tool require training and take on average 90 minutes to administer—a potential limitation in a health care context. However, both tools are well researched and could be useful for organizations aiming to focus on multi-dimensional caregiver assessment as an intervention for improving supports for family caregivers.

(i) Caregivers Aspirations, Realities and Expectations (C.A.R.E.) Tool:

The C.A.R.E. Tool was developed for use in publicly funded home care agencies by a team of researchers in Nova Scotia and Quebec. It is designed for use by practitioners in home and community care settings with family caregivers, and requires training for practitioners to use it. The goal of the tool is to facilitate a conversation about care. The intended outcomes of the assessment are that areas where the caregiver is experiencing difficulty are summarized, services and support needs are identified, and a care plan is recommended.
There are ten sections, including both open and closed questions, aimed at seeking out the caregiver’s perspective of their situation: demographic information; caregiving work; informal and formal support; living arrangements; other responsibilities; financial contribution; physical and emotional health; family relations; crisis and long-term planning; and service support.

The C.A.R.E. Tool Short Version was developed in response to concerns about the time required to administer the original tool. It contains the same 10 sections but with fewer questions. Example items include:

- How and why did you become the main person responsible for the care recipient’s care?
- Who do you feel you can really count on for support?
- On a scale of 1 to 10, where would you put your need for support in your care giving work?
- Do you feel you are getting enough information from professionals about your care recipient’s health problems or condition?

(ii) Family Caregiver Support Agreement (FCSA) Tool:

The FCSA Tool is used to assess the support needs for caregivers of an aging relative at home, and to facilitate the implementation of support and services to meet these needs. The term ‘agreement’ reflects the partnership aspect of the tool where the caregiver actively participates in the completion of the tool together with the health care provider. The FCSA tool is a Canadian adaption of the Carers Outcome Agreement Tool (COAT) developed as part of a caregiver assessment project in the United Kingdom and Sweden. COAT evolved from research on caregiver assessment. It is based on a model where caregivers are co-experts who work with practitioners to agree on goals and supports needed to achieve them.

The FCSA tool contains 38 items and open ended questions in four dimensions: (i) helping the caregiver care for their relative with questions about the different kinds of information that could be useful in caring for their relative; (ii) making life better for their relative; (iii) making life better for them; and (iv) expectations about quality of help.

Example items include:

- It would be useful for me to have more information on my relative’s illness and treatment.
- It would be useful for me to learn the skills I need to provide care to my relative.
- It would make my life better to have more free time for activities I enjoy.
- For those providing help to value my knowledge and expertise as caregiver.

An action plan is developed following negotiation between the practitioner and the caregiver identifying goals for each need; types of help to meet needs, who will provide
it, when it will be offered; date for a follow-up meeting to discuss whether the help has met the caregiver’s needs; and adjustments to the action plan.

A practitioner with at least 6 months experience working with an elder clientele is required to participate in a one-day training session using role playing and learning about the partnership model and process. The FCSA tool and training kit for health care providers can be purchased online.

2. Family Caregiver Preparation, Skills, and Knowledge Tools

Four tools were identified that measure some aspect of preparation or skill that can be used across a general population of caregivers. These four tools are the most promising options for use in a healthcare setting given the short administration times and the focus on preparation of the caregiver for their caregiving tasks. As well, these tools can be self-administered and discussed with a care provider at a later date.

(iii) Family Caregiver Preparedness Inventory Tool (FCPI):

FCPI is an eight-item scale that measures the perceived readiness for multiple domains of the caregiving role such as providing physical care, providing emotional support, setting up in-home support services, and dealing with the stress of caregiving. There is a final open-ended question about anything else for which the caregiver would like to be better prepared. Response choices range from 0 (not at all prepared) to 4 (very well prepared). The higher the score the more prepared the caregiver feels for caregiving. Example items include:

- How well prepared do you think you are to take care of your family member’s physical needs?
- How well prepared do you think you are to find out about and set up services for him or her?
- How well prepared do you think you are to respond to and handle emergencies that involve him or her?
- How well prepared do you think you are to get the help and information you need from the health care system?

The strength of the tool is that it has been used in a variety of practice settings representing different caregiving situations including cancer, palliative care, and persons with dementia. The tool has been well validated. However, information about administration time could not be found, and FCPI is a uni-dimensional measure.

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1 See Innovative Collaborations between Family Caregivers and Health Care Providers: Summary of The Change Foundation’s Literature Review and Environmental Scan Project for a description of a Family-centered Function Focused Care initiative which used the FCPI tool.
meaning it might not meet the needs of projects or care settings requiring more details about caregivers’ current caregiving circumstances.

The FCPI tool is publicly available. Click here for the FCPI tool.

(iv) **Family Caregiver Activation in Transitions (FCAT) Tool:**

FCAT™ is a 10-item tool developed to promote more productive interactions between health care providers and family caregivers during care transitions from acute care to home and community care. FCAT guides health care providers to better understand family needs and in response, arrange appropriate resources.\(^2\)

Family caregivers are asked to indicate the extent of their agreement or disagreement to a set of questions about challenges commonly faced by family caregivers during care transitions. Example items include:

- I am able to make sure my loved one goes to every scheduled medical appointment.
- I know what things to watch for that would mean my loved one’s condition is getting worse and how to respond.
- I understand which of the instructions in my loved one’s care plan are most important and need to be completed first and which instructions are less urgent.
- If my loved one needs help from a healthcare professional, I am confident I can insist until I get what is needed.

The tool was designed for administration by a health professional or to be self-administered by the family caregiver. An important component is that the care team addresses the challenges identified at the point of care, in this case during pre-discharge instructions.

The strengths of the tool are: it is quick to administer (under 3 minutes); it applies to a broad base of caregivers; and it was developed with input and testing from family caregivers. It is a self-report tool so there is the risk that family caregivers will overestimate their abilities or that they may be unsure of what they don’t know. The tool is also not a full caregiver assessment.

Click here for the FCAT tool.

(v) **What Do I Need as a Family Caregiver? Tool:**

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\(^2\) See Innovative Collaborations between Family Caregivers and Health Care Providers: Summary of The Change Foundation’s Literature Review and Environmental Scan Project for a description of the Enhanced Care Transitions Intervention which developed and uses the FCAT tool.
This tool focuses on the needs of family caregivers during transition from a hospital based setting to the community. The tool was developed as part of the United Hospital Fund’s Next Step in Care guide and website. Family caregivers are encouraged to fill out the tool with a discharge planner or case manager. If this cannot be arranged, caregivers are advised to fill the form out on their own and ask for time to talk about it with their discharge planner.

The tool contains 36 items in 4 sections:
- ‘About You as the Family Caregiver’ - asks background demographic questions (e.g., employment, children);
- ‘About Helping Your Family Member’ – includes a list of the different kinds of caregiving activities that might be required, and caregivers are asked about their ability to perform tasks related to care of the recipient, choosing from three response options: I am able to help WITHOUT training; I am able to help WITH training; I am unable to help (e.g., items about toileting, mobility, medications, coordinating care, making and keeping appointments, helping with transportation);
- ‘About Services at Home/Community’ - encourages discussion about the types of services that the care recipient had before the hospital admission; and
- A list of common worries that the caregiver can add to as well (e.g., how to get time off, how to manage medications, how to pay for care, what to do if my family member needs end-of-life care).

This tool is publicly available online, and has been translated into a number of languages (English, Spanish, Chinese, and Russian).

(vi) **Family Preferences Index (FPRI):**

FPRI is a 14-item tool to measure family preferences through an exploration of caregivers’ personal choices for participating in the care of a hospitalized family member. It was designed for use with families of hospitalized older adults. The goal is for a health care provider to use the responses to plan care that builds a partnership with the family.

It contains 14-items that require a yes (score of 1) or no (score of 0) response, and an open ended item at the end where the family member can raise other concerns. The total score suggests the degree of caregiving involvement desired by a family member, with higher scores indicating a greater preference for participating. Items ask about direct care, support care, collaboration with the health care team and care for the caregiver. Example items include:

- Which of the following things would you prefer to do for your hospitalized elderly relative:
  - Helping with eating, drinking, moving, bathing, toileting or dressing?
• Providing information to the health care team about my family member?
• Learning from the health care team about my family member’s needs?
• Taking care of myself while I am at the hospital?

The tool can be administered in an interview format or self-administered as a questionnaire. If it is self-administered, the preferences indicated by the caregiver should be discussed between the care provider and the caregiver. It can also be administered either individually or in a group setting. Ideally, the health care provider would check in with the family member throughout the hospitalization, as preferences can change as caregivers gain confidence or become anxious about aspects of care.

Click here for the FPRI tool.

A summary of the key components of the six tools is presented in Table 1.

Table 1 – Summary of Key Components of Tools Included for Review

<table>
<thead>
<tr>
<th>Tool</th>
<th>Caregiver Involvement in development</th>
<th>Explicit caregiver as partner approach</th>
<th>Option to self-administer</th>
<th>Relevant Health Care Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. C.A.R.E Tool – Short Form</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Home &amp; community care (potentially other settings)</td>
</tr>
<tr>
<td>2. FCSA Tool</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Home &amp; community care</td>
</tr>
<tr>
<td>3. FCPI</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Multiple Settings</td>
</tr>
<tr>
<td>4. FCAT</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Hospital based (care transitions)</td>
</tr>
<tr>
<td>5. What do I need? Tool</td>
<td>Not stated</td>
<td>No</td>
<td>Yes</td>
<td>Hospital based (care transitions)</td>
</tr>
<tr>
<td>6. FPRI</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Hospital based Older Adults</td>
</tr>
</tbody>
</table>

The following (Table 2) is a summary of key domains of caregiver assessments, example constructs of key domains, and itemization of the six tools included in this review (i.e., whether the tool includes items pertaining to the domain).

Table 2: Key Domains for Caregiver Assessment
C. **Other Considerations:**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Example Constructs</th>
<th>Corresponding Tools</th>
</tr>
</thead>
<tbody>
<tr>
<td>Context</td>
<td>Duration of caregiving; employment status, relationship</td>
<td>C.A.R.E. What Do I Need…?</td>
</tr>
<tr>
<td>Caregiver values and preferences</td>
<td>Preferences for scheduling and delivery of care and services</td>
<td>C.A.R.E. FCSA, FPRI</td>
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<tr>
<td>Well-being of the caregiver</td>
<td>Self rated health, depression</td>
<td>C.A.R.E. FCSA What Do I Need..?</td>
</tr>
<tr>
<td>Consequences of caregiving</td>
<td>Challenges such as social isolation and strain; benefits such as satisfaction and developing new skills</td>
<td>C.A.R.E. FCSA</td>
</tr>
<tr>
<td>Skills, abilities, knowledge to provide care recipient with needed care</td>
<td>Caregiving confidence and competencies; knowledge of medical care tasks</td>
<td>C.A.R.E. FCSA, FCP, FCAT What Do I Need..?</td>
</tr>
<tr>
<td>Potential resources that caregiver could choose to use</td>
<td>Formal and informal helping network; existing strengths</td>
<td>C.A.R.E. FCSA What Do I Need..?</td>
</tr>
</tbody>
</table>

(i) **Caregiver Screeners:**

Screeners can provide valuable information about family caregivers and their interactions with different health care settings. For example, the recently developed interRAI caregiver screener consists of 4 items that identify informal caregivers at low, moderate or high risk of adverse outcomes such as poor quality of life and decline in physical and mental health. It could potentially be used to select family caregivers that have higher needs of respite and require further assessment.

Caregiver screening might be more realistic but without a strategy for: a) what happens when caregivers are identified as high risk; and b) accessing resources to meet those needs, this approach could result in limited action or minimal change. While screening for high-risk caregivers represents a degree of proactivity, a truly upstream approach would involve connecting with caregivers over time and not necessarily just when they are at risk of burning out.

(ii) **Self-assessment Tools:**

The [American Medical Association Caregiver Self-Assessment Questionnaire](#) is an 18-item caregiver self report measure intended as a way of helping physicians to assess the stress-levels of family caregivers who accompany chronically ill older adult patients to their medical appointments.
visits. Caregivers can score the tool themselves and caregivers are encouraged to reach out to their doctor for a check up if they score highly stressed.

The Carers UK Upfront tool is a 3 minute online assessment that provides a tailored information plan for caregivers to help direct them to the right information and supports. As well, a 6-item Carer Self Assessment is available through a NHS website that provides immediate support suggestions and guidance for caregivers.

Beyond the individual screeners, there are various tools to measure burden and strain as useful for screening caregivers (e.g. the Zarit Burden Scale, the Caregiver Strain Index). In fact, some of these tools are in use across Canada as a means of screening caregivers. Less clear is what currently happens after caregivers are identified as being at high risk.

(iii) Assessment Tools in Social Care Settings:

In some jurisdictions, caregiver assessments occur in social care settings as opposed to health care settings. The UK has been leading the way in terms of carer assessment since the 1990s. The UK focuses on identification, screening and referral of caregivers in health care settings, and conducts comprehensive multi-dimensional assessments within social care settings. The Care Act, introduced in April 2015, includes the right to an assessment for all carers, whether they request the assessment or not. The legislation is aimed at making it easier for all carers to get a timely assessment that considers the impact of their role on all aspects of their life. 4

D. Concluding comments:

A multi-phased caregiver assessment strategy including improved identification of caregivers, screening and full assessment within health care settings could be implemented, in part, by drawing on lessons from other jurisdictions. The use of tools that address the skill and training needs of family caregivers is essential in a health care setting, with full consideration of both the task oriented nature of caregiving and the relational and emotional aspects of caregiving. The use of a partnership model in caregiver assessment and moving towards the assessment of the network of care and support involved in caregiving situations would represent a significant innovation in caregiver assessment.

3 “Carer” is the term used in the UK, throughout Europe, Australia and New Zealand to refer to family caregivers. The term was adopted by the Canadian Caregiver Coalition in February 2016 when it became Carers Canada.

4 As a matter of interest, there have been two recent reports highlighting how the Care Act has had little impact on carer assessments and on meeting the needs of carers (see Carers UK State of Caring 2016 and Care Act for Carers One Year On 2016). For example, Carers U.K. found that only a third of carers who had an assessment felt that the support they needed to look after themselves was adequately considered. Carers Trust reported that 69% of carers noticed no difference since the introduction of the Care Act. The challenges of carer assessment, even with strong legislative support, are evidenced by the continued difficulties faced by caregivers in the U.K.
Moving forward, projects involving caregiver assessment will need to consider a balance between what is feasible within a health care setting with what is needed by family caregivers to result in meaningful change. Partnership approaches, where the type and timing of services are negotiated between health care providers and family caregivers represent a promising approach to working towards this balance.
### Appendix 1:

#### 1. Multi-dimensional Caregiver Assessment Tools:

<table>
<thead>
<tr>
<th>(i) Caregivers Aspirations, Realities and Expectations Tool (C.A.R.E)</th>
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<tbody>
<tr>
<td><strong>General Description</strong></td>
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<tr>
<td><strong>Development of Tool</strong></td>
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<tr>
<td><strong>Items and Administration</strong></td>
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<tr>
<td><strong>Research / Evaluation Studies</strong></td>
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matched to available resources such as respite.

**Psychometric Properties**

The authors report that the reliability and internal consistency tests demonstrated that the C.A.R.E. tool is valid and reliable to understand caregivers’ needs and situations. For example, a reasonable level of agreement between different assessments was found (Keefe et al., 2008).

**Strengths and Limitations**

The extensive research conducted with and about the C.A.R.E. tool has resulted in valuable contributions to the development of caregiver assessment internationally including principles for assessment, and barriers and facilitators to consider (e.g., Guberman et al., 2003). The authors report that the tool has been used across Canada including in Québec, Nova Scotia, Prince Edward Island, New Brunswick, Ontario and Alberta. It has also been adapted for use internationally (e.g., France, Israel, Bermuda and New Jersey) and translated into French, Portuguese, Italian and Hebrew. It was identified as a promising practice in home care by Accreditation Canada in November 2013. While it has been used only in home care settings, the authors suggest it could be adapted for use in other health care settings.

The main limitation of the tool, across all studies, is the length of time to administer. Keefe et al. (2008) suggest integrating the C.A.R.E tool with existing tools; providing training and ongoing support for care providers doing the assessments and ensuring sufficient resources. The creators of the tool stress the importance of agency buy-in at all levels and clarifying the intent of the caregiver assessment through an explicit agency philosophy about the role and responsibility of caregivers (Guberman et al., 2007). Cost per assessment has been reported to range from $128 to $213.00 (Seniors Health Strategy Unit, 2012; Barylak et al., 2006). The initial training cost estimate is $280 per assessor.

(ii) Family Caregiver Support Agreement Tool (FCSA)

**General Description**

The FCSA is for health care providers to use to assess the support needs for caregivers of an aging relative at home with a functional or cognitive impairment, and to facilitate the implementation of support and services to meet these needs. The term agreement reflects the concept of partnership where the active participation of caregivers is sought out to complete the tool together with health care providers.

**Development of Tool**

The tool is Canadian adaption of the Carers Outcome Agreement Tool (COAT), developed as part of an Anglo-Swedish project (Hanson et al., 2006) about caregiver assessment in the UK and Sweden. The development and history of the COAT is firmly situated within the ‘caregivers as experts model’ and a partnership model approach to care and caregiving. It was built in close collaboration with caregivers and practitioners and went through extensive field-testing to determine the relevance, usefulness and acceptability. “Carers and practitioners work together to agree on the type of goals and outcomes that carers see as important and the support needed to achieve these” (Hanson et al., 2006). The theoretical and empirical work underpinning the COAT is extensive (Nolan, Lundh, Grant & Keady, 2003).

**Items and Administration**

The FCSA contains 38 items and, like the COAT, includes four dimensions aimed at improving the quality of life of caregivers. The first domain is 13 items, and is about ‘helping the caregiver care for their relative’. Questions about the different kinds of information that could be useful in caring for their relative are included. Respondents indicate whether each type of information or help presented would be useful for them, whether it is already being received or whether the need does not apply to their situation. The second and third dimensions are about making life better for their relative and then making life better for themselves. Each of
these three sections is followed by open-ended questions asking about other types of help or need the caregiver is experiencing. The final dimension is ‘getting quality help’ and provides an opportunity for the caregiver to discuss the quality of the help they are receiving and their expectations. An open-ended question follows about whether other aspects of services could be improved. If the caregiver is presently receiving no services, they are asked: What do you expect of the help you wish to receive in terms of quality? Example items include:

- It would be useful for me to have more information on my relative's illness and treatment
- It would be useful for me to learn the skills I need to provide care to my relative
- It would make my life better to have more free time for activities I enjoy, to be able to reduce the stress I feel
- For those providing help to value my knowledge and expertise as caregiver.

After going through each domain, an action plan is drawn up following negotiation between the practitioner and the caregiver identifying:

1. Goal of support for each need
2. The type of help that meets the need and the expectations of the caregiver, who will provide it and when it will be offered and how often
3. The date for a follow-up meeting to discuss whether the help has met the caregiver’s needs
4. Adjustments to the action plan

The tool takes 90 minutes to administer. A practitioner with at least 6 months experience working with an elder clientele is required to participate in a one-day training session using role playing and learning about the partnership model and process. The tool and a training kit for health care providers can be purchased online.

<table>
<thead>
<tr>
<th>Research / Evaluation Studies</th>
<th>In a qualitative investigation about practitioner and caregiver experience using the FCSA, caregivers reported being able to express their concerns and participation in the development of an action plan for support. Practitioners used skills such as sensitive listening and enabling questions and reported a better understanding of the caregiving role and the unique needs of caregivers. Use of the tool enhanced partnerships and created genuine alliance between caregivers and practitioners (Levesque et al., 2010). Ducharme et al., 2014 reported that caregivers for persons with early onset dementia would have liked more help from their families and skills training to provide care (59%).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychometric Properties</td>
<td>Ducharme et al., 2014 conducted a transcultural validation with English and French speaking family caregivers and health care providers working in home care, to adapt the original version of the COAT to a Canadian context. This was followed by an ecological validation, described by Ducharme et al. as field-testing with caregivers and practitioners and focus groups and individual interviews to tailor the instrument accordingly. The studies are in French and thus not included in this review.</td>
</tr>
<tr>
<td>Strengths and Limitations</td>
<td>A major strength of the FCSA tool is that it is an adapted version of a tool widely researched and developed based on a caregiver as co-expert and partnership model of care. It takes 90 minutes to administer which can be a limitation in a health care context.</td>
</tr>
</tbody>
</table>
### (iii) The Family Caregiver Preparedness Inventory (FCPI) Tool

<table>
<thead>
<tr>
<th>General Description</th>
<th>The FCPI tool is an eight-item scale developed by Archbold and colleagues (1990). The Inventory was developed to help practitioners identify difficult family situations, areas that are going well and to provide a tool to track changes in family caregiving situations over time. The scale of Preparedness measures the perceived readiness for multiple domains of the caregiving role, such as providing physical care, providing emotional support, setting up in-home support services, and dealing with the stress of caregiving.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Development of the Tool</td>
<td>The items were developed based on some of Archbold’s first qualitative studies with caregivers (Archbold, 1982a; Archbold,1982b). The words of family caregivers were used to write the items which address caregiver’s comfort with various physical and emotional patient needs.</td>
</tr>
</tbody>
</table>
| Items and Administration | It is an 8-item scale with a final open-ended question about anything else for which the caregiver would like to be better prepared. Response choices range from 0 (not at all prepared) to 4 (very well prepared). The higher the score the more prepared the caregiver feels for caregiving. Example items include:  
  - How well prepared do you think you are to take care of your family member’s physical needs?  
  - How well prepared do you think you are to find out about and set up services for him or her?  
  - How well prepared do you think you are to respond to and handle emergencies that involve him or her?  
  - How well prepared do you think you are to get the help and information you need from the health care system? |
| Research / Evaluation Studies | There are several studies using the FCPI, with many identifying associations between preparedness and clinical outcomes such as mood disturbances (Schumacher et al., 2008). It is often referred to in the nursing literature as a recommended screen for caregivers in clinical practice (Hudson & Hayman-White, 2006; Schumacher, 2006). |
| Psychometric Properties | Archbold and Stewart (1995) report on multiple aspects of the psychometric properties in a 20 year review of their research with the FCPI. The most cited property of the instrument is internal consistency, ranging from 0.88 to 0.93 (Archbold et al., 1990; Schumacher, et al, 2007). |
| Strengths and Limitations | The strength of the tool is that it has been used in a variety of practice and disease settings, representing different caregiving situations including cancer (Grant et al., 2013), palliative care settings (Hudson & Hayman-White, 2006) and for caregivers of persons with dementia (Ducharme et al., 2011). It has been well validated. Information about administration time could not be found. It is a uni-dimensional measure so might not meet the needs of projects or care settings requiring more details about caregivers’ current caregiving circumstances. |

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### (iv) The Family Caregiver Activation in Transitions Tool ™ (FCAT)

<table>
<thead>
<tr>
<th>General Description</th>
<th>The FCAT™ was developed to promote more productive interactions between health care providers and family caregivers during care transitions from acute care to home and community care; and to guide health care providers to better understand family needs and in response, arrange appropriate resources (Coleman, Ground, &amp; Maul, 2015).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Development of the Tool</td>
<td>The tool was created to fill a gap identified by the authors in their extensive work about improving care transitions for patients and families. They found that despite the importance of family caregivers to the execution of the care plan, there had been limited</td>
</tr>
</tbody>
</table>
attention to strengthening the family caregivers sense of preparation and confidence. Without any type of mechanism to serve as a feedback loop at the point of care, this limited the ability of the care team to understand the family needs and deploy the appropriate resources.

| Items and Administration | FCAT tool consists of 10-items and takes less than 3 minutes to administer. Family caregivers are asked to indicate the extent of their agreement or disagreement to a set of questions about challenges commonly faced by family caregivers during care transitions. Caregivers identified these challenges during a qualitative study exploring caregivers’ experiences of care transitions from an acute setting to home (Coleman & Roman, 2015). Example items include:
- I am able to make sure my loved one goes to every scheduled medical appointment
- I know what things to watch for that would mean my loved one’s condition is getting worse and how to respond
- I understand which of the instructions in my loved one’s care plan are most important and need to be completed first and which instructions are less urgent
- If my loved one needs help from a healthcare professional, I am confident I can insist until I get what is needed.

The tool was designed for administration by a health professional or to be self-administered by the family caregiver. An important component is that the care team addresses the challenges identified at the point of care; in this case, during pre discharge instructions. The tool was designed for use in the Advanced Care Transition Intervention© (Coleman et al., 2015). As part of the preparation to deliver this intervention, care providers using this tool receive extensive training in care transitions and issues faced by family caregivers.

| Research / Evaluation Studies | Two published studies are available including: the use of the tool by transition coaches to track the progress of caregivers during a care transition intervention (Coleman, et al 2015a); and investigating the psychometric properties of the FCAT (Coleman et al., 2015).

| Psychometric Properties | Coleman et al. (2015) concluded that the items were judged to be relevant to experience and easy to understand by family caregivers in a study about the reliability and validity of the tool. The estimated person-separation reliability of the test is reported to be 0.84. As well, the FCAT™ tool items function as a uni-dimensional construct with a high level of reliability (Coleman et al., 2015).

| Strengths and Limitations | The strengths of the tool are that it is quick to administer (under 3 minutes); it applies to a broad base of caregivers (i.e., it is not disease-specific); and it was developed with a great deal of input and testing with family caregivers. Although the authors do not explicitly state that the tool is based on a partnership model, the Care Transitions Intervention is based on a patient centered approach and the intervention requires transition coaches, patients and family caregivers to work together to achieve a successful discharge. As well, recent publications by the lead author, Dr. Coleman, emphasize the importance of relationships and working with caregivers as key partners in care. It is a self-report tool and not performance based so there is the risk that family caregivers will overestimate their abilities or that they may not know what they don’t know (Coleman et al., 2015b). The tool is not, nor does it claim to be, a full caregiver assessment. Currently, it has only been used as a process of care measure but Coleman et al. 2015 note that future studies could explore its potential use as an outcome measure.
| **(v) What Do I Need as a Family Caregiver? Tool** |
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| **General Description** | The “What Do I Need as a Family Caregiver?” tool was developed as part of the United Hospital Fund’s Next Step in Care guide and website. It focuses on the needs of family caregivers during transition from a hospital based setting to the community. The website provides numerous tools, checklists and resources for family caregivers facing care transitions; as well as for health care providers supporting these transitions. |
| **Development of the Tool** | The tool focuses on the needs of family caregivers during transition from a hospital based setting to the community. |
| **Items and Administration** | The tool contains 4 sections: (i) ‘About You as the Family Caregiver’ and asks background demographic questions (e.g., employment, children); (ii) About Helping Your Family Member’ - a list of the different kinds of caregiving activities that might be required, and caregivers are asked about their ability to perform tasks related to care of the recipient, choosing from three response options: I am able to help WITHOUT training; I am able to help WITH training; I am unable to help (e.g., items about toileting, mobility, medications, coordinating care, making and keeping appointments, helping with transportation); (iii) ‘About Services at Home/Community’ - encourages discussion about the types of services that the care recipient had before the hospital admission; and (iv) a list of common worries that the caregiver can add to as well (e.g., how to get time off, how to manage medications, how to pay for care, what to do if my family member needs end-of-life care). There is a final section where the caregiver and health care provider write down who the caregiver can go to about their worries. Family caregivers are encouraged to fill out the tool with a discharge planner or case manager. If this cannot be arranged, caregivers are advised to fill the form out on their own and ask for time to talk about it with their discharge planner. |
| **Research/Evaluation Studies** | In a quality improvement study, findings revealed that uptake for the tool in its entirety was low. Many organizations chose to adapt it or use different forms of assessment preferring to create their own tools based on the feeling that their population was ‘different’ and thus required a tailored assessment tool (Levine et al., 2013). |
| **Psychometric Properties** | Psychometric properties are not reported. |
| **Strengths and Limitations** | It is publicly available for use and has been used in a large quality improvement study. It can be used as a self-assessment tool but should be reviewed with a health care provider so that options can be discussed to meet the caregiver’s needs. Accompanying documents to this assessment include guidance for health care providers about how to approach family caregivers. As well, it was developed with the guidance of a family caregiving and assessment expert, Dr. Carol Levine who has written and published extensively about caregiver support and assessment. Another strength of the tool is the availability in different languages (English, Spanish, Chinese, and Russian). |

| **(vi) Family Preferences Index (FPRI)** |
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| **General Description** | The FPRI measures family preferences through an exploration of caregivers’ personal choices for participating in the care of a hospitalized family member. It was designed for use with the families of hospitalized older adults. The goal is for a health care provider (usually a nurse) to use the responses to plan care that builds a partnership with the family. |
| **Development** | The tool was developed by Li (2000), after analysis of qualitative interview and observation data with patients, families and nurses. |
of the Tool

in a hospital setting. Li’s findings suggested that although family members were willing to learn caregiving skills from the health care team, barriers such as caregiver health, obligations and nurses’ attitudes influenced what and how much caregivers preferred to be involved.

Items and Administration

It contains 14-items and the items require a yes (score of 1) or no (score of 0) response. Items are summed to provide a total score that suggests the degree of caregiving involvement desired by a family member; with higher scores indicating a greater preference for participating (Messecar, Powers & Nagel, 2008). Items ask about direct care, support care, collaboration with the health care team and care for the caregiver. Example items include:

- Helping with eating, drinking, moving, bathing, toileting or dressing
- Providing information to the health care team about my family member
- Learning from the health care team about my family member’s needs
- Taking care of myself while I am at the hospital

There is also an open ended item at the end where the family member can raise other concerns. It can be administered in an interview format or self-administered as a questionnaire. If it is self-administered, the preferences indicated by the caregiver should be discussed between the care provider and the caregiver. It can be administered either individually or in a group setting. If more than one family member is involved, individual preferences can be noted (Messecar et al., 2008). The results should be communicated to the rest of the care team so everyone can support and respect the family caregiver’s preferences. Ideally, the health care provider would check in with the family member throughout the hospitalization, as preferences can change as caregivers gain confidence or become anxious about aspects of care (Messecar et al., 2008).

Research/Evaluation Studies

Li et al. (2012) reported use of the FPRI in an intervention to improve outcomes of hospitalized older adults and their family caregivers. It was not clear how this measure was used within the context of the intervention. The FPRI has been profiled and recommended for use by the American Journal of Nursing in a series dedicated to tools that nurses can use to improve support and partnerships with family caregivers (Messecar et al., 2002); and in a series called ‘Try This’ aimed at identifying best practices in nursing care to older adults (Boltz, 2012).

Psychometric Properties

A study using this tool as part of a randomized control trial reported an internal consistency reliability of 0.62 (Li et al., 2012). There are no other psychometric properties reported for this tool. It is recommended that users of this tool focus less on the score and more on using the approach to guide involvement of families in care to facilitate discharge planning (Messecar et al., 2008).

Strengths and Limitations

The strengths of this tool include the ability to identify caregivers who may not want or feel able to participate in their family member’s care prior to discharge to the community. It can flag situations where it might not be safe to discharge an older adult home and if this is revealed early in the hospitalization appropriate plans can be put in place (Messecar et al., 2008). The limitations are the lack of psychometric data.