*Résumé*

# Principaux aspects de l'autonomie des aidants d'après les chefs de file en matière de soins à domicile : soins palliatifs et maladie chronique

## Kelli I. Stajduhar, Laura Funk, Faye Wolse, Valorie Crooks, Della Roberts, Allison M. Williams, Denise Cloutier-Fisher, Barbara McLeod

Les personnes qui s'occupent d'un membre de la famille à domicile reçoivent souvent l'assistance d'un service de soins, dont le but est de promouvoir la santé en renforçant l'autonomie des individus. Pour cette étude, les auteurs ont choisi une approche interprétative et une série d'entretiens qualitatifs approfondis. Ils ont examiné la façon dont les chefs de file et les gérants dans le domaine des soins à domicile décrivaient comment ils renforçaient l'autonomie des aidants dans la province de la Colombie-Britannique (Canada). Dans un contexte de restrictions budgétaires où les individus préfèrent se soigner eux-mêmes et mourir à domicile, les participants à l'étude ont décrit comment les infirmières à domicile les aidaient à devenir autonomes. Elles éduquent et informent les aidants, les font participer à la planification et à la prise de décision et les rassurent en leur disant que leur rôle est gérable et appréciable. Si certains participants considéraient que leur autonomie était renforcée (en temps de crise, p. ex.), d'autres pensaient le contraire (l'aide qu'ils recevaient encourageait leur dépendance). On considérait qu'un aidant était autonome quand il était capable de fournir des soins à domicile, avait confiance en ses capacités et pensait que son travail était positif et utile. À long terme, le renforcement de l'autonomie se traduisait par des clients qui étaient capables de se soigner eux-mêmes ou de s'occuper d'un membre de leur famille et qui étaient beaucoup moins dépendants des services officiels.

Mots clés : renforcement de l'autonomie, infirmières à domicile, aidants d'un membre de la famille

# Core Aspects of "Empowering" Caregivers as Articulated by Leaders in Home Health Care: Palliative and Chronic Illness Contexts

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Home-based family caregivers are often assisted by home care services founded upon principles of health promotion, such as empowerment. Using an interpretive approach and in-depth qualitative interviews, the authors examine descriptions of family empowerment by leaders and managers in the field of home health care in the province of British Columbia, Canada. In a culture of fiscal restraint, dying at home, and self-care, participants described how home care nurses empower family caregivers to meet these objectives. This involves educating and informing caregivers, engaging them in planning and decision-making, and reassuring them that their role is manageable and worthwhile. Though some participants viewed providing supports as empowering (e.g., during times of crisis), others viewed them as disempowering (by promoting dependence). Empowered caregivers were characterized as able to provide home care, confident of their capabilities, and believing that their work is positive and beneficial. The long-term goal of empowerment was characterized as client self-care and/or family care and decreased dependence on formal services.

Keywords: empowerment, home health services, home care nursing, family care-givers

In Canada, family caregivers (FCGs) play a critical role in supporting chronically ill and dying persons in the home. FCGs perform their work in the context of home care services founded upon health promoting models of delivery that strengthen one's capabilities to take control of one's health and health care. It has been suggested, for instance, that a health promoting approach to palliative care helps to foster a sense of control in terminally ill patients (Kellehear, 1999). Patient and family empowerment is viewed as promoting physical and mental health, enhancing the quality of care, promoting autonomy, and containing service-delivery costs (Ashworth, Longmate, & Morrison, 1992; Langer & Rodin, 1976; Tulloch, 1995). The concepts of choice, autonomy, and participation are emphasized in definitions of empowerment; however,

how "family empowerment" is enacted in clinical practice, within orga-
nizations, and by practitioners is not always clear. It could mean, for
example, involving FCGs as "co-workers" in a partnership model (Ward-
Griffin & McKeever, 2000) or involving them in decision-making
(Drought & Koenig, 2002).

Implicit in many empowering approaches is an assumption that all
individuals desire and benefit from active involvement in all aspects of
care and decision-making. Yet research with acute-care patients, residents
of long-term-care facilities, and, to a lesser extent, FCGs suggests that not
everyone desires such involvement (Benbassat, Pilpel, & Tidhar, 1998;
Catalan et al., 1994; Funk, 2004; Ward-Griffin & McKeever, 2000).
Promoting empowerment of FCGs who do not desire it may cause
stress, anxiety, fear, discomfort, and dissatisfaction; may be interpreted
as a lack of care; and may even be unethical (Ashworth et al., 1992;
Guberman, Lavoie, Pépin, Lauzon, & Montejo, 2006; Ward-Griffin &
McKeever, 2000; Waterworth & Luker, 1990).

Understanding the potential benefits and risks of empowerment
requires knowledge of how empowering approaches are implemented in
both chronic and terminal illness situations. If we do not know how
"family empowerment" is understood by decision-makers and clinical
leaders, we will not be able to develop policies and services that effec-
tively promote FCG well-being.

The purpose of this article is to examine the interpretation of
empowerment among home health care leaders and managers in the
province of British Columbia, Canada.

## Literature Review

Empowerment, defined broadly as the ability to control and/or partici-
pate in one's life and environment (Robertson & Minkler, 1994), has
been increasingly emphasized in health-services policy and practice. Most
definitions focus on the psychological outcomes of empowerment, such
as self-efficacy and locus of control, or on behavioural outcomes, such as
self-management. Some, however, place the emphasis on self-determina-
tion (e.g., "the right and ability to choose by and for themselves";
Aujoulat, d'Hoore, & Deccache, 2007, p. 15) or, more broadly, on struc-
tural changes and power relations (Anderson, 1990). Yet others treat
empowerment as a professional intervention or process of "providing the
proper tools, resources and environment to build, develop and increase
the ability and effectiveness of others to set and reach goals" (Hawks,
1992, p. 609). Though there has been less explicit discussion of family
empowerment, its definitions are similarly varied. These include a sense
of control and self-efficacy in providing care (Che, Yeh, & Wu, 2006;

Hulme, 1999; Magill, 2009; Wilkes, White, & O'Riordan, 2000); perceived positive benefits of care provision (Jones, Winslow, Lee, Burns, & Zhang, 2011); "experiences of inner strength and power and of participation in care" (Wahlin, Ek, & Idvall, 2009, p. 333); and "balance of knowledge, status, authority, and hence, power" (McWilliam, Ward-Griffin, Sweetland, Sutherland, & O'Halloran, 2001, p. 50).

Many authors have critiqued the application of empowerment approaches, suggesting that they ignore power differentials between professionals and individuals, minimize structural barriers and determinants of behaviour, and may be "mis-used" by policy-makers to justify cutbacks in formal services or by nurses as a control strategy (Anderson, 1996; Falk-Rafael, 1995; Robertson & Minkler, 1994). Others argue that true empowerment rarely occurs in practice because of a focus on compliance with health-service objectives (Aujoulat et al., 2007).

Empowerment tends to be interpreted at the level of health-service policy and management, imposed on families in the form of health-care interventions and delivery approaches. To understand the potential benefits and drawbacks of empowerment approaches, we need knowledge about how such approaches are understood by health professionals. Empowerment is an abstract ideal, and there is little clarity around what strategies are empowering, "what actually is covered by the term 'enabling role' and what kinds of skills are required to perform such a role" (Andrews, 1999, p. 280). For instance, empowerment has been operationalized within various types of interventions, from health education designed to enhance self-care, to the promotion of power-sharing in health-care interactions (Johnston Roberts, 1999), to the involvement of families in decision-making and/or the direct provision of care (Li et al., 2003). Empowerment equated with the downloading of responsibilities to families to contain costs may differ from strategies to increase choice in terms of services or care provider. In one study (Funk, Stajduhar, & Purkis, 2011), home care nurses (HCNs) conceptualized family empowerment as respecting and accepting decisions and promoting choice and independence, yet differing and sometimes conflicting interpretations of these ideals were noted, particularly with respect to palliative and chronic illness situations. Other research suggests that HCNs might misinterpret empowerment (McWilliam et al., 2003) as meaning that clients have to "survive the health care system on their own" (Brown, McWilliam, & Ward-Griffin, 2006, p. 164). HCNs may also receive conflicting messages about empowerment in service delivery.

Given the lack of consensus on the definition and operationalization of empowerment (particularly family empowerment), the definitional vagueness that creates space for wide-ranging interpretations, and the risks and potential benefits of empowerment approaches, this study was

guided by a single question: *How is family empowerment interpreted and implemented at the management and leadership levels of home care nursing?*

## Methods

To address our research question, we applied an interpretive approach, which is well suited to examining participant accounts as constructions of reality and meaning. However, we were also influenced by a critical lens in interpreting participant responses within our knowledge of the political and economic context of home health care in Canada.

We recruited 13 volunteers (3 males, 10 females) from three health-care agencies similar in size. Purposive sampling was used to select participants in a variety of leadership roles: four managers, four directors, one executive director, one social worker, one community resource nurse, one senior home care nurse, and one physician. The participants ranged in age from 42 to 62 years (average = 51) and had, on average, 25 years' experience in the field of health care. Inclusion criteria were that the person (a) hold a management or clinical leadership position at one of the three selected health-care agencies, and (b) be able to comment on the conceptualization and/or implementation of health promoting policies or practices within their organization.

In-depth, qualitative interviews were conducted with the participants by phone. With their consent, the interviews were audiorecorded and transcribed verbatim. The interviews were semi-structured, guided by "trigger questions" designed to elicit data that would help us to understand the philosophy and implementation of empowerment at the organizational level. Questions included the following: What does family empowerment mean to you? How is the notion of family empowerment meaningful to your organization and home care nursing practice? Participants were asked to consider care for both chronically and terminally ill clients in their responses and to focus on family caregiver (rather than client) empowerment.

Guided by an interpretive descriptive approach (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997), members of the research team read the transcripts several times to identify recurring, converging, and opposing themes and patterns of empowerment, illustrative examples, and linkages to theory and the literature. Analytic questions focused on how the concept of empowerment, and its goals or outcomes, were described; whether the concept was adopted by managers; the kinds of HCN work that are described as empowering; and identified facilitators of and barriers to empowerment. Initial transcript review and analytic reflection informed preliminary coding categories applied to the data set in NVivo 8. Pieces of data within each code or theme were reviewed, compared,

linked, and contrasted within and across transcripts, the purpose being to develop new codes, refine existing codes and conceptual frameworks, and identify areas for further exploration.

The following strategies were used to enhance the rigour of the study: ensuring that the participants could speak freely by phone at a secure location and transcribing their accounts verbatim; using a trained and experienced interviewer, who also recorded her own "debriefing" field notes for each interview; involving three team members in data analysis; and providing the draft findings to all team members (including those with extensive clinical backgrounds), to inform the development and identification of interpretations and implications.

## Findings

### *The Context: Self–Care and Family Care*

Participants' accounts were firmly rooted in a philosophy of home-based self-care and independence: "My job is to try to ensure that you can remain as independent as possible, to live at home for as long as possible." This philosophy extended to the importance of family care, particularly for terminally ill clients wishing to die at home. One participant said that, though the agency supported families, "we try to empower them to . . . manage as much as possible on their own until they're no longer able to." A general imperative of self-care and family care was linked by some to pressure to discharge patients from hospital, "tighten up" home support resources, and reduce home support hours. One participant elaborated: "Where resources are much more scarce . . . the expectation becomes quite high that the . . . loved one and family . . . need to take a large component of this on and/or will have to think of another plan of care." Another noted that in the current resource context HCNs are "being told, 'You've got to pull in the reins, you've got to make sure these people aren't abusing the home support; we've got way too big a home support budget so we need to start cutting back'." Other participants believed that self-care and family care should be promoted as part of a home health care philosophy, regardless of available resources.

### *The Work of "Empowering"*

In the context of a culture of fiscal restraint, dying at home, and self-care, participants described several ways in which HCNs empower both clients and families. In speaking of HCN empowerment work, they frequently described how HCNs educate FCGs, providing them with information about the disease (expected illness progression), care (potential problems and solutions), and resources (negotiating the health-care system; available resources). One participant cited the need to educate the

public about the limits of health-care resources. In addition, they explained that nurses teach and "upload" skills to clients and FCGs, mentoring, demonstrating, and modelling care tasks. However, one participant added that it is important not to "overload" FCGs with information and thereby overwhelm or frighten them.

Preparing FCGs by engaging them in planning and decision-making was characterized as an important aspect of empowering. In this respect, participants spoke of developing relationships; assessing preparedness, wishes, and needs; helping families to draw up a care plan; "prompting" families to prepare; and "planting the seed" for future independent decision-making and active problem-solving. FCGs are encouraged to contribute input and express their wishes. HCNs encourage the family to make informed long-term decisions about care challenges and to identify potential problems and solutions. The approach is subtle, with the nurse presenting options and discussing risks, perhaps describing possible scenarios, and encouraging the family to reflect and make choices. This may also involve negotiating with families to match their wishes to, in the words of one participant, "what we can actually provide." Other participants placed greater emphasis on, for example, "discussion with the family members around what their level of involvement is or what they want it to be: listening to them."

Reassuring FCGs was another frequently cited component of empowerment. This included quelling their fears about making mistakes, handling crises, or the quality of their care. Nurses' empowering work involves promoting the idea that family care at home is manageable and beneficial and can be a positive experience. For instance, one participant spoke of indicating to "the family that they are providing really good care, as good [as] if not even better in many ways than an institution could provide for them." Participants said it was important to reassure FCGs that experienced professionals are available to assist them in managing situations, "to let them know that we do have a plethora of other professionals, other clinical support behind us, to draw upon." For one participant, offering reassurance was more than telling families "they can do this"; it was also letting them know that options are available and "it's okay to change their mind." Nurses also reassured FCGs that "it's okay to be worried, it's okay to be concerned" — for example, in instances where clients choose to live at risk.

Other aspects of empowerment work were described to a lesser extent. These included advocating for families' wishes within the health agency; providing formal supports to let the family provide care at home for as long as possible (e.g., in times of crisis); and encouraging FCGs to seek other sources of support if needed and to care for themselves. Some participants referred in a more abstract way to promoting self-care, inde-

pendence from formal services, and family provision of care. For example, one participant referred to teaching as "you're kind of weaning them into different tasks" such that the family will be able to take over:

> *Whenever there's something that can be handed off, you try to do that. So, as much as possible . . . while you're doing the tasks, if you happen to be the one having to preload all the medications, or you're doing a dressing or you're addressing issues, you try . . . to provide the education that's neces-sary, so they can do this when you're not there — and be confident doing it.*

### Facilitators of and Barriers to Empowerment

Participants' perceptions regarding facilitators of and barriers to empow-erment depended in part on their definitions of empowerment. Some perceived client health as influencing empowerment, since illness, and terminal illness in particular, can generate feelings of loss of control and strong emotions within the family. In some cases the empowerment process takes longer. For example, an FCG may need to be instructed about medications multiple times before absorbing the information. The client's wish to remain at home can facilitate empowerment. One partic-ipant said that strong client wishes in this regard lead to firmer team attempts to empower the family. Further, to empower families, HCNs need to be able to talk with them about the client; this requires (and is facilitated by) the client's permission.

Participants indicated that a nurse's ability to empower families is affected by FGC capacity: availability, involvement, willingness, health, stress level, prior knowledge, and external resources. With respect to pal-liative situations, however, one participant noted a potential barrier: "In our culture we've tended to isolate ourselves from the dying process, so there aren't a lot of people that feel overly empowered when it comes to palliative care." Nurses try to work with those family members who are the "most receptive, most able to absorb and process, and [most avail-able]." When the FCG's capacity is low, the nurse faces more challenges and needs more time to empower, or must use different strategies (e.g., encouraging the FCG to seek outside help).

Empowerment work was also characterized as dependent on HCN skill and experience. As one participant stated, highly skilled and experi-enced HCNs can promote a "sense of power" in families. Personal qual-ities are also potential influences. For example, it was explained that some HCNs may avoid discussing death with families facing terminal illness because of their own discomfort. Emotional familiarity between the family and the nurse was identified as a barrier to empowerment, as the nurse can become "overly involved in things that really aren't her role."

The clinical tools available to HCNs are important; one participant referred to the lack of "best practice" guidelines for empowering families and the lack of tools for assessing family coping. Lastly, those in management positions referred to their role in hiring nurses with teaching skills and in providing leadership and mentorship for nurses, with a view to an empowerment nursing approach.

The overarching culture (reflected in individual values) was also an influence, particularly for those who perceived empowerment as self/family care and reduced dependence on formal services. Participants referred to the cultural shift away from "dependence on the system" and towards self-management and "supporting their own community" as facilitating empowerment. Home care nursing culture was another factor cited, as it is manifested in HCN role expectations. HCNs who view their role as supporting and teaching facilitate empowerment; barriers include HCNs who adopt a paternalistic "doing for" role (reflective of a traditional, paternalistic service-delivery culture and a medical–bureaucratic, acute-care model) and parallel public expectations "that we . . . do more for people rather than empowering people to do for themselves."

Some participants viewed formal services, including "too much" support or "over-servicing," as potentially disempowering (promoting dependence and discouraging self-care). In contrast, for those who defined empowerment as involving the receipt of formal services (such as intensive in-home nursing care during crisis periods) and the investment of HCNs' time, constraints on such services (e.g., limited financial resources) were viewed as a barrier. For instance, one participant referred to the health-care agency's elimination of the shift-care nursing option (continuous 8- or 12-hour in-home care by a registered nurse for up to 3 consecutive days). This type of intensive support during times of crisis was said to empower FCGs by helping them to cope, thus facilitating caregiving on their own or with minimal support.

Other ways that formal services can facilitate or impede empowerment were also described. Two participants, defining empowerment as decision-making and choice, cited a provincial government program that empowers some clients by allowing them to make service decisions and to directly pay their formal caregivers from designated monies. Another participant, who defined empowerment as having choice, acknowledged that not all families want to be "empowered" to perform care tasks; from this perspective, limited choice within the health-care system is a barrier to real empowerment. Finally, one participant, when asked about health-care policies that support empowerment, cited the Chronic Disease Self-Management Model, explaining that "it affects your care even around palliative patients . . . that approach starts to permeate your practice."

A lack of time was a commonly cited barrier to family empowerment: "In order to empower family members, they need to be given a lot more time with the patient to establish those relationships, to deal with the family to start planning and preparing and educating and modelling." Even in palliative situations, participants noted the importance of having enough time "to work with [family members], and gradually, as there's decline, they're able to take over." The lack of time was linked in part to resource constraints (e.g., on nursing hours and length of visits). One participant suggested that the empowering work of HCNs requires substantial resources (e.g., hours) but viewed this as a barrier in the current context: "I don't think [the health agency] wants to put any extra resources into empowering families . . . with the current budget restraints." In palliative situations, a lack of time also results from the added complexity, the illness trajectory, and late referrals that allow little time for the gradual process of teaching family members. One participant suggested that empowering families takes up more hours in palliative situations due to the intense emotions involved. Late referrals for palliative clients (even though these clients may receive more visits) can impede empowerment, as noted by another participant: "We are under the gun . . . a really short timeline to weave our education and help the family learn at the family's pace." In these situations HCNs may adopt a "doing for" approach, whereas in chronic illness situations they can "be proactive in the teaching, pace ourselves around what the family can manage." Consistency of HCN time with a family can also facilitate empowerment; one participant emphasized this for families that are under stress or that require more direction or connection to one HCN who is familiar with their situation.

### The "Empowered" Caregiver

Participants viewed the ideal outcome of the empowerment process as an empowered family caregiver. In this respect, the emphasis was on two goals, capability and confidence, and to a lesser extent on feeling supported and having choice.

One identified goal of empowerment was to enhance FCGs' ability to deliver care. An empowered person was seen as possessing the knowledge, "ability, [and] skills to . . . manage, not just [think] about being able to do something." This included being able to access information, make informed decisions, ask the right questions, and know when to ask for help; perform care tasks (e.g., administer medication, change bandages); care for oneself; cope with often uncertain situations; negotiate the health–care system; and communicate with providers. A few participants said that some individuals, especially those with socio-economic resources, already possessed such capabilities. Most, however, spoke of

empowerment as something to be generated rather than as existing qual-
ities.

Participants also indicated that an empowered FCG is aware of and
feels confident in and comfortable with his or her capabilities. Possessing
information (including information about available resources), for
instance, "helps people feel that they can do it, that it's a possibility." One
participant's comment illustrates the outcome of confidence:

> *Often, when you get to the end of your involvement, you have family
> members [who] kind of jokingly say, "I could be a nurse now." They
> would never have imagined that at the start of the process. But over time,
> as the need is required and the nurse walks them through, they gain con-
> fidence.*

Without confidence, the question of actual capability is moot, because
FCGs will not have faith in their abilities, will be frightened or worried,
and may refuse to provide care or may call for help more often. Having
confidence, in contrast, can facilitate family care and make the experience
more positive, comfortable, powerful, and manageable and less frightening
and stressful.

Some participants described an empowered FCG as an FCG who
accepts the client's choice to live at risk and is able to cope with the
attendant worry. Participants also described empowered FCGs as believ-
ing that providing care is a positive, beneficial, and satisfying experience:
"They can feel good about the care that they have been enabled to
provide."

Fewer participants expressed the view that an empowered FCG feels
supported by the home care system; receiving support from home care
nursing, for instance, empowers families "to make it through the next day
and then the next day and then the next day." Others spoke about the
confidence that comes from knowing that help is available if needed.
Though empowered FCGs were characterized as actively seeking infor-
mation, input, and/or involvement, behaviours such as seeking out addi-
tional resources and support from the health-care agency tended to be
described as negative, challenging, or reflecting unrealistic expectations.
Some participants explicitly stated that such behaviours reflect a sense of
entitlement and thus contraindicate empowerment. One participant sug-
gested that empowerment means understanding the limits of health-care
resources and the importance of maintaining a healthy lifestyle in order
to avoid inappropriate use of the system.

Some participants referred to family control and choice as outcomes
of empowerment. An empowered individual might, for example, perceive
that care options exist (such as hospice care as "plan B") and have a sense
of "control to make decisions about what you can and can't do or . . . do

not feel comfortable doing." An empowered FCG makes choices and has them respected. However, the concepts of choice and control were not frequently characterized by participants as family empowerment goals, with perhaps the exception of the need to support the client's choice to stay at home. In addition, wanting too much control was characterized by some as negative or as "over-empowerment."

The longer-term goal of family empowerment was described by many participants as reduced dependence on formal services and increased self-care or family care in the home environment. Participants suggested that, ultimately, empowered FCGs provide care for a longer period (e.g., they assume responsibility and "do whatever they are able to do"). As a result, clients remain at home and die there. One participant, in describing how HCNs are guided in part by the client's wishes with respect to remaining at home, further implied that empowerment can take the family beyond its comfort level: "If you have a patient who kind of goes with the flow either way, then you may not have that same need to . . . change or empower the family to go beyond what they feel comfortable with." For another participant, empowerment was "embedded in a chronic disease self-management approach" in which empowered FCGs and clients are perceived as managing "as much as possible on their own," with reduced dependence on health services.

Other participants added caveats in their talk about empowerment. One, for example, said that, though empowering families "in terms of being caregivers" is a goal, "we need to let them off the hook when they've reached their limit and allow them to resume their role as the wife or husband or daughter, and not the caregiver." Another cautioned against using empowerment language to enact "power over":

> . . . using language like "we're empowering you to do this," when in fact the family has no willingness or ability to take that on, but, because there's no other way that it's going to get done, we're "empowering" you to do it. It's an abuse of the term. . . . when we run up against care needs that the system can't provide and we're looking to the family to do it . . . the risk is that we could use that empowerment language to steamroll patients and families.

## Discussion and Conclusions

This study concerned one geographic region with one particular home care delivery structure. It is possible that participants focused on "official messaging" in their accounts, with less emphasis on what actually occurs in practice. Also, we did not systematically question participants about differences between the contexts of palliative and chronic illness, asking

them only to consider both contexts together in their responses. However, we found no other study that examines how "family empowerment" is interpreted by those who guide and manage home care. This study therefore represents a valuable and unique contribution to both the research literature, which has focused on empowerment as understood by frontline practitioners, and the practice literature.

Though implicit and explicit definitions of empowerment were highly variable (as in the research literature), there were common emphases. There were few alternative definitions. Particularly rare were definitions highlighting FCG choice and control (such as in care options or level of involvement) and those focused on the provision of formal supports to FCGs (or on the advocacy of families in this regard).

It is important that health agencies, before determining how family empowerment should be implemented in home care, critically reflect on different definitions (including those reported in the literature and those reflected in families' perceptions) and how they might be interpreted. A definition emphasizing reduced dependence on formal services might imply strategies (e.g., in home care guides and public documents) for educating the public about the importance of self-care and family care as well as about realistic expectations of home care roles and responsibilities. In contrast, a definition centring on the role of formal services in empowering families might give more attention to constraints faced in this regard due to budget concerns and home care policies (and strategies for addressing these areas). By discussing and negotiating a standard definition, health-care agencies will be well poised to develop guidelines and best practices for its enactment; this could include considering differences in empowerment approaches and challenges in terminal versus chronic illness situations. In formulating a definition, health-care agencies could (and should) engage in a dialogue with the public.

Participants' comments about family empowerment should be understood alongside their emphasis on independence (including reduced dependence on formal services) and on the client's remaining (and dying) at home by virtue of self-care and family care. Participants focused on HCN work to empower families with respect to these ultimate ends. This includes teaching, training, and promoting the benefits of family care. It also involves reassuring FCGs about their abilities while also reassuring them that help is available if needed. However, as one participant noted, an emphasis on empowerment in the context of independence at home can lead to misuse of the concept ("to steamroll patients and families") in a political and economic climate where families are increasingly expected to provide care. Other studies have also identified the risk of misinterpreting empowerment as compliance (Anderson & Funnell, 2010) or as "power over" (Brown et al., 2006).

Empowerment was seen as facilitated by HCN skills, experience, personal characteristics, and role perceptions. The findings point to the importance of HCN training and communication as well as reflexivity, to promote awareness of how HCNs' own assumptions and comfort levels might influence their approach to family empowerment. Critical thinking must also be encouraged, such that HCNs assess a family's specific wants and needs instead of imposing an empowerment approach on all families.

Successfully empowered FCGs were described as capable of delivering care at home (skilled and knowledgeable; knowing when to ask for help) and confident about (e.g., believing in) their abilities. Equally important, we would argue, are strategies to enhance FCG capabilities and confidence. Failure to focus on both capabilities and confidence could lead to an over-inflated sense of competence in FCGs; those who believe they can manage may not see the need for assistance — which, if they make mistakes or cannot manage, could ultimately result in feelings or defeat or guilt.

Empowered FCGs were described as comfortable with care provision and as experiencing it positively, relatively free of fear and anxiety. The emotional dimension of empowerment was highlighted, with some emotions (e.g., fear and anxiety) described as barriers to empowerment and others (e.g., comfort, satisfaction) as successful outcomes. HCNs need to be skilled in identifying and addressing FCG emotions, as well as in addressing affective (attitudinal) learning outcomes. The deployment of such skills will ensure that reassurance and encouragement do not inadvertently convince FCGs to become "empowered" or coerce them into accepting this role.

Though participants indicated that FCGs should feel supported during crises, they tended to describe advocacy for the support of the health-care agency as challenging and even disempowering. To some extent, empowerment work was seen as inclusive of ensuring that FCG expectations for support match what the system can provide — which has particular implications in the context of health-system reforms that can constrain the availability of resources and services.

FCG capacity (e.g., health, stress level, prior knowledge and ability) was characterized both as an outcome of empowerment and as a baseline factor influencing empowerment. Higher-capacity FCGs (described by some as those with more socio-economic resources) may be successfully empowered more quickly. Therefore, clients in already empowered, higher-capacity families may be more likely to remain at home and die there. Increasing the constraints on HCN time may serve to increase the inequities between higher- and lower-capacity families. One way to reduce such inequities is to assess FCG capacity in a formal and ongoing

way throughout the trajectory and devote more time to working with lower-capacity FCGs.

Participants implicitly and explicitly identified the potential benefits of family empowerment for clients (e.g., remaining at home longer), FCGs (e.g., comfort, confidence, a more positive care experience), HCNs (e.g., less time spent on support), and home care administrators and the health-care system (e.g., less reliance on services, cost savings). Fewer participants acknowledged potential risks or negative outcomes for FCGs in particular (e.g., inadvertently coercing or overwhelming FCGs; contributing to feelings of guilt). Awareness of both risks and benefits is essential, to preserve the autonomy and ensure the well-being of those who provide care to family members at home.

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