

Home Healthcare and Family Responsibility: A Critical Discourse Analysis of Talk and Text

Soins à domicile et charge familiale : analyse critique du discours parlé et écrit



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Abstract

This paper addresses how families' roles and responsibility for care are constructed within home health (in contrast to the responsibility of home health). A discourse analysis informed by a critical theoretical approach was used to analyze qualitative interviews with 13 home health managers and clinical leaders in British Columbia, alongside home care documents. When referring to family involvement, there was an emphasis on the importance of supporting a client's choice to stay at home. Government and agency documents describe family members as primary providers, with home health having a supplementary role. Agencies seek to avoid "substituting" for family care. Family responsibility is characterized as having both moral and structural value. Nonetheless, some participants advocated flexibility and recognized potential caregiving challenges. Data provide examples of how agency expectations are communicated to clients and families and become embedded within practice and policy. Findings are viewed within the broader organizational context as representing the "responsibilization" of support.

Résumé

Cet article aborde la façon dont le rôle et la charge des familles sont définis au sein des services de soins à domicile (par contraste à la charge des organismes de soins à domicile). Une analyse du discours, sous-tendue par une démarche critique théorique, a été employée pour analyser des entrevues qualitatives auprès de 13 gestionnaires de soins à domicile et responsables de cliniques en Colombie-Britannique, de pair avec de la documentation portant sur les soins à domicile. Là où il y avait référence à l'implication de la famille, j'ai dégagé l'importance de soutenir le choix d'un client de demeurer au domicile. Les documents gouvernementaux et ceux des organismes décrivent les membres de la famille comme principaux fournisseurs de soins, alors que les organismes de soins à domicile jouent un rôle complémentaire. Les organismes ont tendance à éviter d'agir comme « substitut » des soins familiaux. Une des caractéristiques de la charge familiale est qu'elle revêt une valeur à la fois morale et structurelle. Néanmoins, certains participants plaident pour une flexibilité et reconnaissent les défis potentiels auxquels font face les soignants. Les données montrent des exemples sur la façon dont les attentes des organismes sont communiquées aux clients et aux familles et sur comment elles sont enchâssées dans la pratique et dans les politiques. Dans un contexte organisationnel plus général, les résultats sont considérés comme une représentation de la « responsabilisation » du soutien.

FAMILIES – ESPECIALLY WOMEN – PROVIDE MOST OF THE CARE FOR CHRONICALLY and terminally ill Canadians, yet face increasing expectations for their involvement in and responsibility for this care, in part due to changes in healthcare policies and service delivery. Such changes potentially increase burden (Chappell 1993; Fast and Keating 2000: 25). Although many family members welcome involvement, at times some may feel pressured and unprepared, or desire greater support (Björnsdóttir 2009; Stajduhar 2003).

Whether such shifts are accompanied by discursive expectations of family responsibility in home health policy and practice has yet to be fully examined. This study asks: How are families' roles and responsibility in care provision for chronically and terminally ill persons constructed in home health discourse, in contrast to the roles and responsibility of home health? I have applied a critical discourse analysis methodology to interview data from home health managers and clinical leaders in one Canadian province (British Columbia), as well as to relevant home care documents. The analysis focuses on discursive constructions of expected family and home health involvement, interpreted in the broader context of home health and healthcare.

This paper focuses on expectations of family versus government (“home health”) involvement in and responsibility for care provision, as interpreted within home health (by managers and clinical leaders, and in home and community care documents). Examining organizational expectations can help identify ways to mitigate potential negative effects on families, while continuing to promote positive effects (such as empowerment).

Methods

As part of a larger study of empowerment in home care, qualitative interviews were conducted in three health agencies in British Columbia. Potential participants were identified by the project team as regional home care decision-makers and opinion leaders who could describe organizational interpretations of family empowerment in their agencies (a research question of the primary study). To ensure maximum variation, participants from varying position types and levels were included (e.g., managers, clinical leaders, administrators, decision-makers).

Nine documents from all five regional health agencies and the Ministry of Health were also identified. These represented the population of relevant publicly available web- or handbook-based home and community care (HCC) documents in the province at that time (Fraser Health [no date]; Interior Health Authority 2007; Northern Health Authority [no date]; Vancouver Island Health Authority 2009; Vancouver Coastal Health Authority [no date]). They were developed and distributed by the agencies for clients and families, and outline expected roles and available services. Similar material from the provincial government (Ministry of Health Services 2006, 2007) was also included, as were the only two caregiver handbooks developed by any of the agencies that could be located (Fraser Health Authority 2005; Vancouver Coastal Health Authority 2010).

A critical discourse approach guided the analysis (O'Connor and Payne 2006; Powers 1996). This focused on the identification and analysis of meanings and discursive frameworks and the broader contexts shaping these meanings. Attention was paid to statements that appear "natural" or commonsense (Cheek 2004; Smith 2007) as well as keywords, emphasis, ambiguities, contradictions, dichotomies, assumptions and silences (Powers 1996).

Findings

Staying at home as a personal choice, and the best care option

Several participants described how the healthcare system is moving towards a philosophy or policy of "home first" for chronically and terminally ill persons (e.g., initiatives to promote client discharge from institutional care). Participants frequently emphasized the importance of clients' staying at home and suggested that this choice reflects client wishes, healthcare resource limitations and institutional discharge pressures. Public HCC documents, while emphasizing client choices to stay at home, did not mention resource or institutional pressures.

Independence was frequently equated by participants with clients' ability to remain at home. The health agency's role is described as, for example: "to ensure that you [the client] can remain as independent as possible and live at home for as long as possible." Independence was also closely connected to a philosophy of self-care and a self-management model in chronic disease. Service limitations were at times rationalized with reference to the need for self-care, equated with client independence from service use. For example, one manager maintained that providing too much service can create dependence and "the expectation is that we try to empower them to be able to manage as much as possible on their own until they're no longer able to."

One participant, referring to the early discharge of older persons from hospitals, described the implications for families: "It's like, 'these [clients] are going home. You need to provide the care and we can supplement a little.' But I think we're a bit more forceful with pushing families to take people home." However, this participant also noted the existence of practice pressures operating in the reverse direction, to promote hospice admission in cases where families were highly anxious or stressed, because the home care nurses' workload "doesn't allow them the time to respond to that family or see them more frequently."

Having family members take primary responsibility for care

In participant talk, family involvement tended to be interpreted as almost synonymous with client independence and self-care, and in contrast to system responsibility. For instance, in responding to questions about family care involvement, participants commonly invoked the ideal of client independence and self-management. As another example, one HCC guide (Fraser Health Authority [no date]: 5) explained that nurses promote client independence in part by enhancing "client or *their families'* abilities to provide care" (emphasis added).

Alongside constructions of staying at home as clients' personal choice, health agency responsibility was circumscribed and service limitations implicitly rationalized. One specialist characterized the role of the health agency by invoking the idea of goals (i.e., choices): "We will not complete your goal; we will try and help you support what your goal is." In addition, family responsibility was interpreted as a natural consequence of client choices. For example, an ideal of autonomy was used by one manager to justify family responsibility and define the agency's role: "Clients have their own lives. They are responsible for their medications ... we don't 'own' the medications. It's the family's [and client's] responsibility." Family involvement (or privately hired services) was constructed as essential if a client wishes (chooses) to remain at home. Family involvement was viewed as a necessity, as stated by this director: "Our system could never work without informal care. Seventy per cent of care in the community is done by informal [sources]." In the absence of sufficient family involvement, participants stated that client choices to stay at home would be unmet. As such, one specialist referred to a "huge expectation" of family care "if patients want to stay at home."

As a client choice, being at home was then constructed as a client and family responsibility. One health agency's newest document supporting the "home is best" philosophy (Fraser Health Authority 2011) relates a fictional example in which an older, hospitalized client (Marjorie) wants to go home. The latent message is that keeping Marjorie at home respects her wishes, and that this is the moral imperative.

Family members were constructed as primary care providers by participants, with home health as supplementary or supporting, "assisting them to do for themselves." Participants contrasted home health roles against "paternalistic" approaches involving "doing for," "taking over" or "rescuing" families. One manager described one family caregiver as a "martyr" and "overburdening herself." This woman injured herself providing care; while she was recovering from surgery, the agency needed to send two workers to lift the client. The family wanted this care

to continue after the caregiver's recovery because she received medical advice not to lift the client. The manager suggested that this situation turns the health agency into the primary care provider, which is untenable and unfair to other clients, citing the need for fiscal responsibility and for home health to avoid taking on long-term responsibility.

Some participants spoke of increasing expectations of family responsibility as connected to service cutbacks, deficit recovery situations and restrictive home support guidelines. As an example, reduced home support hours have been accompanied by "a stronger expectation that family is the primary [care provider] and home support really is just to support what the family is able to offer." In contrast, other participants described family involvement as a founding cornerstone of home care philosophy, reflecting the value of independence that should be institutionalized regardless of resources. One director suggested that "we all have a responsibility for managing our health, and for self-care. It's not the system's responsibility."

Communicating messages of family responsibility

The companion video for the recent "home is best" initiative in one health agency (Fraser Health Authority 2011) states, "we don't rely just on family to provide [care at home]." Nonetheless, participants in the present study explained how expectations of responsibility are communicated to families in multiple ways. For instance, one director described how nurses communicate agency expectations by speaking of family members as "primary caregivers." Another director stated: "Something we push [families to do] is to take responsibility, and that's part of our discussions." A clinical specialist spoke of "unspoken expectations" that if family were present, it was assumed they would provide care (unless they said otherwise).

Participants described how home health emphasizes the primary responsibility of family caregivers in public materials, particularly through the language of home health's "supplemental" role (as representing the organizational position). One director expressed: "A lot of our policies say these services are to supplement the care provided by the family. So it embeds into the policy that there is a responsibility that rests with the family." The provincial HCC document referred to by one participant states: "Services complement and supplement, but do not replace" both self- and family care (Ministry of Health Services 2007: 1). This phrase, or similar ones emphasizing non-replacement, are echoed in three regional documents (Fraser Health Authority [no date]: 1; Interior Health Authority 2007: 3; Vancouver Island Health Authority 2009: 4) and one caregiver handbook (Fraser Health Authority 2005: 42).

In the caregiver handbooks, family members are encouraged to perform a wide variety of care tasks, but also to ask for and accept support from others (e.g., "It begins with doing all you can for yourself, and then learning to accept help, when help is needed"; Fraser Health 2005: 38). However, there is relatively greater weight placed on asking for help from informal rather than formal sources. One HCC guide describes care tasks that home support cannot provide, suggesting to the client, "There are many things we cannot do for you. This is where your family, friends and neighbours can help" (Vancouver Island Health Authority 2009: 19).

Participants spoke about how family involvement in all levels of care, or at least “as much as they are willing and able to do,” was promoted by skilled practitioners. One specialist stated: “The nurses and other staff are really skilled at, at least getting [families] to provide the care that they are able and willing to provide.” One director described how she coached staff to promote empowerment and family involvement through asking such questions as: “Why are we doing that if there’s family there and able to do that?” She also hired nurses skilled in teaching, mentoring and encouraging families.

Promoting family involvement in practice was described by participants as consisting of developing relationships; teaching care tasks; reassuring and negotiating with families; convincing families that agency involvement may harm their independence or empowerment; educating them about home health’s role and limitations; and emphasizing the benefits of family care. For instance, one director expressed: “As a rule, we do not present family involvement so much as a responsibility but sort of a blessing.” Benefits mentioned included those for the client (death at home, quality of care, autonomy) and family (quality time, bonding, self-efficacy, skill development for future self-care).

Professionals’ perceptions of available family support were described as influencing client need assessments and determinations of access to services. For instance, one HCC document states that service needs are determined not only by client symptoms and well-being, but “the support available through family, friends and close community ties” (Fraser Health Authority [no date]: 3). One director explained that if two clients with similar assessed clinical need have different family networks, the more networked client will receive less formal service. This approach is explained by this participant with reference to fiscal responsibility and system sustainability in the context of an aging population.

Revised personal assistance guidelines referred to by one participant further support this model, wherein one criterion for delegating a task to a home support or community health worker is that “there is no other person in the client’s support system to do the task” (Ministry of Health Services 2008: 8). Clients are also encouraged to purchase private services if needed. Such an approach implicitly views informal care (and private purchase) as a substitute for formal care. In contrast, one agency claims publicly that “care provided by family members is ... not a substitute for formal supports in the home” (Fraser Health Authority 2011: 12).

Flexibility and appropriate system intervention

Some participants qualified expectations of family responsibility or suggested that their practical application could be flexible, as in “family involvement is what they decide is enough or not enough”; “different families are capable of doing what they can”; “it’s very important that we don’t overburden the family”; and “to expect to empower them to the point where they actually deliver the physical care may not be accomplished.”

In part, an emphasis on flexibility involved recognizing challenges involved in caregiving. Some participants expressed that it is not always possible for families to provide certain levels of care (e.g., they may live away or be estranged, have health problems, work full time or have young children). Caregiving strain was also noted, as in: “We need to let them off the hook

when they've reached their limit and allow them to resume their role as the wife/husband or daughter, and not the caregiver." One caregiver handbook states: "Being a caregiver does not mean doing it all – all the time" (Fraser Health 2005: 50), particularly when there are challenges; it suggests that families discuss involvement preferences with healthcare teams. Lastly, one clinical specialist emphasized respecting non-involvement: "Sometimes I would almost say, 'If only they would be able to be more involved ... it would just help so much.' Yet, this is not my journey."

As a less dominant theme, some participants described exceptions when providing support is necessary. One specialist stated: "The client's primary care provider is, in addition to their family, in the system, the home care nurse." A manager likewise suggested that the self-care model could not be applied universally; nurses should make individual assessments, and the system should provide care that families cannot (though as a result, home death may not occur).

Nonetheless, other participants characterized some professionals as being inappropriately overinvolved and paternalistic (believing they hold primary responsibility for clients), "taking over" rather than helping families do it themselves. As such, one director believed that promoting family responsibility requires practice standardization and restructuring "so that there isn't the same structure that people are reporting to, with the sense [of] 'new eyes, new ears, new questions.'"

Reference to flexible expectations of family was more predominant in talk and text about clients with terminal illness. Some participants suggested that expectations of self and family responsibility were less strongly applied in these situations, where the approach involves providing more support or making more "waivers or exceptions." More intensive services are usually available for defined, short-term palliative situations. The provincial HCC guide describes palliative services as focusing on symptom management, "so that those facing death and their loved ones can devote their energies to embracing the time they have together" (Ministry of Health Services 2007: 6). The provincial end-of-life framework (Ministry of Health Services 2006) also includes home care nurses (i.e., not only family members) in its definition of primary caregivers. As one director stated, for chronic clients or those with longer/more ambiguous terminal trajectories, "we don't want to ... promote a dependence upon us"; home support hours are more limited, and more financial costs are family responsibilities. Further, one specialist described organizational attempts to "tighten up" the current six-month prognosis criterion for palliative designation "because [palliative services are] really meant to help people die at home, not for long-term support."

Dissonance between system and public expectations

Participants commonly described family expectations of system responsibility as incongruent with organizational realities. Indeed, an emphasis on family responsibility in text and talk may partly reflect agencies' attempts to manage public expectations about available HCC services, particularly since these may differ considerably from in-patient services (which are covered under the *Canada Health Act*).

Families' expectations were often characterized as inappropriate, for example: "Their expectations of the system probably far exceed what we can honestly provide." One director heard frequent complaints from families that the agency was "downloading" and placing too many expectations on families; she described these as reflecting inappropriate expectations. A manager spoke about conflict over who "owns the situation," suggesting that families expect the health system to do "everything for everybody." A specialist further implied that some families, rather than being grateful for formal services as a "bonus" to help them provide care, view it as an entitlement. Another director described how public expectations conflict with policy directions favouring de-institutionalization: "When clients and families take their loved ones to acute [care], they think, 'Granny's been driving us nuts. They'll take care of her. They'll place her.' Not so much. Basically, we are moving to more of a 'home first' philosophy." Concern about dissonance between system and public perceptions led some participants to emphasize public education about services, and practitioner negotiations with families.

Participants believed that high expectations were related to such factors as denial of impending death, culturally specific beliefs or isolation from the dying process (i.e., resulting in low self-efficacy) and an older, paternalistic healthcare culture and previous acute care experiences that generate a sense of entitlement, especially among assertive families with high levels of wealth or education. When families resist responsibility for particular tasks, their expectations were described as needing to be negotiated and managed, for example, by explaining the limitations of formal services ("If they don't know what that limitation is, they don't know how much they're responsible for").

Discussion and Conclusions

Examining organizational positions on family responsibility is a challenging task, given that individual staff may interpret policy and practice directives in differing ways. This study could have been strengthened by using a larger sample of a wider range of organizational positions (e.g., including home care nurses), though larger samples often limit the extent of rich, in-depth data for analysis.

In these data, dying at home was constructed as a client choice, and service limitations and family responsibility as an almost natural consequence of this choice. Overall, of course, care at home is a positive trend with the potential to enhance client well-being. However, practitioners need to be cautious in universally promoting it in all cases, an approach that can create situations whereby staying at home – and, by default, family caregiving – becomes less of a choice and more of an imperative. Ultimately, service access decisions remain under the control of professionals and administrators. Will client choices to stay in hospital, or enter residential care, be respected equally as the choice to stay at home? Will the family's choice of their level of care involvement be considered? With a few exceptions, the texts and talk remain silent in this regard.

An emphasis on choice in the context of organizational constraints can reflect a process called "responsibilization" (Burchell 1996; Rose 1996), wherein government concerns (i.e.,

de-institutionalization, cost containment) become institutionalized within taken-for-granted individual choices. These individuals (and their families) are then viewed as needing to take responsibility for the outcomes, and caregiving becomes interpreted as a private family concern (McDaniel 2004). From a critical perspective, this process aligns with economic and political goals of many contemporary governments. Values of choice, independence and both personal and family responsibility in home care practice and policy can support task transfer to families (Funk et al. 2011; Purkis et al. 2008; Ward-Griffin 2001). In this process, the role of cost constraints is obscured, and families who provide inadequate levels of care may be blamed for incorrect moral choices.

In Canada and other developed nations, healthcare budgets are under increasing scrutiny; climates of constraint in fiscal and human resources align with practice frameworks supporting independence and empowerment. Attempts to minimize institutional costs have led to increasing reliance and demand on home care services not protected under the *Canada Health Act*. Over time, there has been curtailment or a lack of expansion of public home care services in British Columbia (McGrail et al. 2008; Penning et al. 2006), as elsewhere.

In this context, there is an increased reliance on and expectations of families to take primary responsibility for care, as reflected in these findings. While there may be positive benefits for families who desire greater involvement, there is also potential to increase care burdens. The Canadian Caregiver Coalition maintains that family caregiving should not be viewed only as “a substitute for public responsibility in health and social care” (Canadian Caregiver Coalition 2008: 3).

Nonetheless, many healthcare organizations tend to view families as a substitute for formal services. Further, participants (and policies) in this study constructed formal services as supplementing but not replacing family care, implicitly assuming that providing formal services risks replacing family care. However, evidence indicates that formal services do not in practice erode either family or self-care (Penning and Keating 1999; Penning 2002).

That expectations of family responsibility are often implicitly gendered was not mentioned in the texts or interviews; the reality of gendered care provision is obscured under the neutral term “family.” Women provide the majority of family care and tend to face higher expectations for the amount, extent and quality of care they provide as well as their emotional investment in the role (Aronson 1992; Calasanti and Slevin 2001).

Further, both text and talk remained silent regarding how socio-economic resources can constrain some families’ abilities to manage care responsibilities by purchasing services privately. The federal Compassionate Care Benefits program (introduced in 2004) reimburses some wages lost when caring for a family member, yet coverage is restricted to six weeks, to persons normally eligible for employment insurance benefits (e.g., in the paid labour force) and only in situations of diagnosed terminal illness.

Though many family members welcome care involvement, there are ethical concerns that some “may be pressured into assuming a role they feel unprepared for” (CHPCA 2004a: 7) or not fully understand what is involved when they make the choice (Stajduhar and Davies

2005). Both the Canadian Hospice Palliative Care Association (2004a,b) and the Canadian Caregiver Coalition (2008) emphasize the importance of informed choice about care involvement, open discussions and the provision of supportive services. Staying and dying at home, while potentially beneficial, should not be idealized as a universal good, because it can also involve negative outcomes for caregivers (Canuscio et al. 2002; Chentsova-Dutton et al. 2000; Fredman et al. 2008; Stajduhar 2003). Training of home health workers and professionals should strive to promote nuanced understandings of family involvement and empowerment (along with skills in reflexivity, critical thinking and dealing with moral distress).

Future research should clarify public expectations of the roles and responsibility of subsidized home health services. There should also be public discussion about the roles of clients, family members, communities and governments in home-based care, towards “a clearer delineation of social responsibility and family responsibility” (CHPCA 2004b: 14). The input of the public and caregiver advocacy groups will help ensure that families are adequately supported as well as have opportunities for care involvement where they are able and willing to contribute.

ACKNOWLEDGEMENTS

This analysis was supported by a postdoctoral fellowship from the Canadian Institutes of Health Research (CIHR). Interview data originated from a study led by Dr. Kelli Stajduhar, funded by CIHR.

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Home Healthcare and Family Responsibility: A Critical Discourse Analysis of Talk and Text

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