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How the Trivialization of the Demands of High-Tech Care in the Home is Turning Family Members Into Para-Medical Personnel

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This study analyzes the transfer of specialized professional activities from health care workers to patients and their family members in the context of the shift to ambulatory care for acute and chronic illnesses requiring hospitalization. Based on 119 semidirective interviews with patients released from hospital after early discharge and/or with the family members caring for them, and based on 26 focus groups and 9 individual interviews with health care professionals from hospitals and home care agencies in five regions of the province of Québec, this article raises the issue of the trivialization of professional care which underlies this transfer. This article also examines two stages in this trivialization: the preparation for discharge and the transfer of specialized activities. Theoretical and empirical implications include the need to better understand how health care workers support this transfer through a process of trivialization and the implications of this transfer for patients and their families.

Keywords: *home care; hospital discharge; ambulatory care; caregivers*

In Québec, as elsewhere in North America, the philosophy of ambulatory or community care, coupled with economic preoccupations over growing

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health care budgets in a period of economic restraint, have led to reduced hospital stays for many patient populations, resulting in longer periods of convalescence at home. This shift has been made possible thanks to medical innovations in both surgical techniques and postoperative care, making early discharge an option (Larsen, 1996). We are thus witnessing a spectacular increase in day surgeries and, more generally, in care that was previously only offered in a hospital setting being offered in the patient's home by public, private, or community home care professionals and even by the patients themselves or by members of their families. This change is considered by home care agencies as being very complex and necessitating new and specialized expertise for their nursing personnel (Kane, 1995).

Already, a large number of studies have demonstrated how earlier social policies aimed at deinstitutionalizing diverse populations (the frail elderly, people with mental, physical, or intellectual handicaps, people with mental illnesses) resulted in a transfer of care to families, with ever-increasing complex tasks being delegated to family members, in particular women (Brody, 1995; Chappell, Strain, & Blanford, 1986, Finch & Groves, 1983; Glazer, 1990; Guberman, Maheu, & Maillé, 1991; Stone, Cafferata, & Sangl, 1987). Indeed, the shift to ambulatory or community health care is but the latest in a long line of policy changes in health and social services, and as such it poses many of the same theoretical and conceptual debates that have existed since the first deinstitutionalization policies were implemented in the fields of mental health and physical disability.

These debates have included (a) the roles and responsibilities of different actors in health delivery including the public sector, the private sector, the nonprofit voluntary sector, the community and the family, and the specific role of the state; (b) the advantages and disadvantages of institutional versus community care and the specific role of families and homes as locations of care; (c) the professionalization and medicalization of many aspects of everyday life; and (d) the transfer of work from the waged labor market to the unpaid realm of the domestic sphere (Baines, Evans, &

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Neysmith, 1998; Glazer, 1990, 1993; Hooyman & Gonyea, 1995; Kane & Penrod, 1995).

These same debates are now linked to analyses of the shift to community care. However, what specifically characterizes the shift to ambulatory care and the concomitant early hospital discharge is the dispensing of relatively complex and often technical nursing and medical care, care requiring training and supervision (IV treatments, pain control, feeding by tubes, wound treatment, catheters, etc). This has given rise to what has been called high-tech home care (Kaye & Davitt, 1995). Although these treatments may be assumed by professional home care staff, preliminary research indicates that these activities are increasingly being transferred to patients and their family members (Binney, Estes, & Humphers, 1993; Côté et al., 1998). Already in 1990, Glazer (1990) described the multiple medical and nursing activities that had been transferred to caregivers in the U.S. context:

> Family caregivers "practice" nursing and medicine, monitoring patients for everything from reactions to change in medication to medical crises requiring emergency readmission to hospital. Women use high-tech equipment to deliver treatments for acute and chronic conditions and to treat systemic infection and cancer. They supervise exercises and give mechanical relief to patients with breathing disorders, feed by tubes those unable to take food orally or digest normally, give intramuscular injections and more tricky intravenous injections and monitor patients after antibiotic and chemotherapy treatments. (p. 488)

Indeed, there seems to be little systematization and regulation regarding the nature of the care that can be transferred, the characteristics and skills of the person to whom they are being transferred, or the conditions necessary to ensure a safe and secure transfer. Questions of professional accountability and quality of care appear to be glossed over. The ease with which medical professionals have delegated highly complex medical and nursing activities, activities which they refuse to delegate to other semiprofessional groups (nurse aides, home care workers, etc.), to untrained family members raises the issue of the trivialization of the transfer.

Shortened hospital stays mean that patients often leave the hospital in a very vulnerable state, and having to administer relatively complex care at home poses a series of problems for the patients, for their families, and for service providers. Among these, our previous exploratory study (Côté et al., 1998) found (a) unequal and even absent hospital follow-up; (b) coordination problems between hospitals and home care services; (c) insufficient support from overworked home care services lacking the resources to answer to the needs of the patients; (d) caregivers, in particular women, overwhelmed by the caring work; (e) patients with access to neither family members nor private help; and (f) absence or inadequate training and supervision of caregivers assuming complex professional care.

This situation raises serious moral and legal problems and accountability issues in the case of complications, errors, or accidents. It also generates much insecurity and anxiety for both the patient and the caregiver and raises the questions of the quality and safety of the care being delivered and of its equitable and universal access (Côté et al., 1998; Daniels, 1995; Guberman & Maheu, 1999).

In analyzing the move from the hospital to the home, Ruddick (1995) questions the ideological dichotomization of home and hospital and suggests that more home-like hospital units may be preferable to many home situations. Levine (1999) raises issues of assessing family capacity and patient needs and problematizes the concept of family responsibility. She also raises questions about the dominant view held by health care professionals and managers that family care must be understood mainly from the perspectives of benefits to the patient and economic gains of the system, thus pushing other family members and their well-being off the agenda.

The introduction of managed care within the new mixed economy of care, wherein several welfare states such as Canada have retreated from the universal provision of services (Coyte, 2000), also leads to overlooking the impacts of care provision on family members by raising expectations of family involvement in the provision of care (Levine, 1999).

THEORETICAL FRAMEWORK

Glazer (1993) has already analyzed this transfer as a new labor process aimed at eliminating waged workers and replacing them with unpaid women (and some men) in families. For policy makers and health care managers, this transfer is meant to result in increased worker productivity and a reduction in health care costs. It is also supported by the ideological underpinnings of the deinstitutionalization and the self-care movements, which promote community and lay care over institutionalization and professional care as in the best interests of patients (Abel, 1991; Binney, Estes, & Ingman, 1990; Briar & Ryan, 1986).

This article examines how health care professionals participate in this transfer and advances that the trivialization of caring work is one of the motors of this process. As Glazer (1993) points out, technology includes knowledge, procedure, and material. Knowledge includes not only how to perform the procedure but understanding the reasons the treatment is being given, the likely or possible negative effects of the treatment and what to do if they occur, and how the equipment functions and what to do if it malfunctions. Transfer of knowledge cannot be reduced to learning a simple technique.

Indeed, the trivialization of the implications of transferring complex and technical professional activities to family members is a reflection of the general trivialization of all domestic labor. Critical and feminist analyses of the domestic sphere have documented how domestic labor has been rendered invisible and is not perceived as work (Luxton, 1980; Malos, 1980; Oakley, 1974). Domestic activities have often been reduced to "a simple addition of splintered tasks, having no links, no specific relation to production and without their own logic or goals" (Vandelac, Bélisle, Gauthier, & Pinard, 1985, p. 17).

In the same way, caregiving by family and friends has been characterized as being spontaneous and improvised and as lacking evaluation mechanisms and underlying perspective or theory (Guay, 1984). It is taken for granted that caregivers are ready to help others, be it through love or obligation, and that they automatically possess the necessary resources and skills to do so, at least in the vast majority of situations. This vision would lead us to believe that the care by a family member in the context of the home is somehow innately learned, requires little organization, and is basically simple to do or even simplistic. It would seem that once activities leave the public sphere of waged labor to enter the private sphere of the family, their very nature changes (Guberman & Maheu, 1992; Saillant, 1991).

Several feminist theorists (Haicault, 1994; Saillant, 1998) suggest that family members, in particular mothers, have been dispossessed of their knowledge and know-how with regard to lay medical care. This process was gradual over the first 60 years of the 20th century (at least in Québec), and by the 1960s, the medical professionals had completely taken over. Since then, families have become increasingly dependent on an impressive array of experts who impose their own norms such as efficiency and who tend to normalize treatment, whereas traditional family care practices have been largely forgotten and discredited (Saillant, 1999). With the implantation of community care polices, families have had to be taught institutional practices of medicine and nursing, thus widening the domestic space to the integration of the medical institution.

However, people are rarely as submissive to expert prescriptions as the professionals would like to think, leading to a large number of studies on patient compliance or, in fact, noncompliance (Conrad, 1987). As Schön (1983) has pointed out, nonprofessionals do not base their practices on standardized professional theories but on reflection-in-action of their particular situation. Cresson (2000), in a study of lay care practices by women in the family, found that attempts by professionals to transmit their knowledge were based on miscomprehension, including the idea that professionals are knowledgeable and that lay people are ignorant. The criteria that they use to judge successful transfer include understandability, usefulness, and exactitude of information, whereas mothers judged the transfer on the basis of whether information was sufficient, satisfactory, and had answered their questions.

According to Arras and Dubler (1995), the transfer of care to the home has led to a rearrangement of the traditional medical hierarchy. Doctors remain in the hospitals and their offices, whereas nurses, social workers, and para-medical professionals grapple with establishing new types of relationships with patients and their families who “have legitimate and powerful interests deriving not only from the fact that they are now on their own turf, but also from their active participation in the delivery of care” (p. 13).

However, as described by Twigg and Atkin (1994), services are negotiated among patients, families, and health care workers rather than allocated by professionals, although the power relationships between professionals and lay people are unequal with professional discourse having more authority. As Twigg and Atkin state, “Part of the power of practitioners lies in their capacity to teach appropriate expectations and responses to clients and patients” (p. 29). The new relationships between medical professionals and family members in the context of high-tech home care are currently being negotiated, and the results have not all been played out.

This article is based on findings from an empirical study on the impacts of the transfer of complex and technical care to the home carried out in Québec, Canada. Its aim is to more closely examine the process of how professionals tend to trivialize this care, a process that begins at the hospital and is continued in the home by home care professionals.

Arras and Dubler (1995) have extensively discussed the impacts of the transfer of high-tech care to lay people in the home, and our study corroborates these. However, the general position taken by the authors, and notably by Arras himself, is that the major limit to the transfer of high-tech care to lay people is the need to ensure that they give fully informed and free consent to assume these tasks. That is, not everyone should assume this care. However, the authors tend to assume that the transfer is a fait accompli or even a salutary modification in service delivery. As Arras (1995) states, “When things go well, high-tech offers the best of both worlds: state-of-the-art medical technology deployed in the privacy of one’s own home by loving family and friends” (p. xiv). What they do not argue is that perhaps nobody (when thinking of lay people) should assume much of this care, which rightfully belongs in the hands of professionals, or that, at the very least, there should be standards of what can and cannot be transferred.

We would advance that it is, in part, through a process of trivializing the knowledge, skills, and attitudes required to practice high-tech care that government, mangers, and professionals are justifying the disqualification and deprofessionalization of medical care, in particular nursing care and its transfer to lay persons. In this article, we will examine the perceptions and actions of the different players concerning the transfer and argue that this trivialization is at the heart of many of the problems being faced by families who are caring for a member after early hospital discharge.

METHODOLOGY

The research on which this article is based was one of social analysis aimed at describing and explaining the new sharing of responsibilities among persons released from hospital, their caregivers, and professionals in the home. More specifically, it sought to understand how sick people and their caregivers were managing this transfer: their difficulties, their questions, and their preoccupations. Analyzing this new sharing of responsibilities also meant examining the criteria and motivations that explain it and the possibilities of negotiating a different organization of care. This study is thus an analysis of social relations, of the organization of services and the way in which people experience home care.

The study is thus qualitative. To evaluate the division of responsibilities, to understand how it is arrived at and to identify people’s questions, needs and preoccupations were all objectives that called for a qualitative design. Our objectives required us not only to identify the different tasks but also to determine how they were shared. We also had to determine the perception of the different people involved in terms of their capacity to assume these activities, their feelings of competency and security, and their appreciation of the support they receive.

In qualitative studies, it is not the frequency of different situations or the respective weight of different variables that is of interest. Our sample is not statistically representative. Rather, we wanted to identify the largest variety of situations possible so as to have an overall view of the various difficulties posed by the transfer and of the different solutions put into place. It is qualitative research's capacity to develop a comprehensive analysis of the phenomenon being studied that integrates all of the situations studied that gives it its power of generalization (Glaser & Strauss, 1967; Strauss & Corbin, 1990).

The research is based on interviews with persons recently discharged from hospital and/or with their caregivers in five regions of the province of Québec, Canada. Five types of illnesses or conditions were chosen for the study because they were all areas where there had been a substantial reduction of hospital stay: hip fractures, antibiotic therapy by IV, chronic respiratory diseases, palliative care, and strokes. Clientele with these conditions were also chosen because they potentially required technical and/or complex and demanding medical and nursing care. However, the last condition, strokes, was added to the project quite late because we felt that we were not sufficiently seeing complex situations and because our hospital contacts suggested that we include this category. After verifying that this condition met the criterion of reduced hospital stay, it was included.

The in-depth personal interview with patients and their caregivers was chosen as the main method of investigation. By way of an open-ended thematic interview, we attempted to understand the circumstances and the contextual elements that were present throughout the process that led to a specific division of caring responsibilities at home. The interview guide employed by the researchers was developed from the major themes emanating from the research questions. The semidirective nature of the interview gave patients and carers certain freedom to develop as they wished different aspects of the interview guide while at the same time focusing the data collection on the areas of interest to the research.

Because the shift to ambulatory or community care involves returning people home more quickly, it also means a transfer of responsibility for care from hospital staff to home care personnel. To help us better understand all aspects of the processes involved and the dynamics between the different actors, we also interviewed hospital staff involved in discharge planning and home care staff as a complement to the information obtained from patients and caregivers. Focus groups were used with health personnel.

SAMPLE

A convenience sample of 119 patients and/or caregivers was referred to the research team by discharge nurses and other professionals in 10 different hospitals and rehabilitation institutions and in some home care programs in the five regions of the study. The sample included 64 men and 55 women of all ages, including 2 minor children. Almost half were over 65 (52 respondents), and 46 were between the ages of 40 and 64. Of the patients, 39 were referred because they went home with antibiotic therapy by intravenous, 31 had hip fractures, 29 had chronic pulmonary disease, 17 were in palliative care, and 3 had suffered strokes. It should be noted that the smaller samples for the last 2 conditions reflect the facts that it was much more difficult to recruit patients or family members in end-of-life situations, that stroke patients were included very late in the project, and that not all the regions were able to establish contacts with the appropriate hospital personnel for the referral of stroke patients. As well, several family members of stroke patients cancelled their interviews because of the intensity of care involved or a sudden deterioration in the situation of the patient. The majority of interviews were with the patients themselves, although in many cases the main caregiver or another member of the family was present for at least part of the interview. When the patients was unable to give the interview, particularly in the case of palliative care situations, but also in the cases where people had hip fractures or were suffering from pulmonary diseases, the primary caregiver was interviewed.

Interviews covered the history of the person’s illness or condition and their most recent hospitalizations, the discharge process and the preparation they received, the care they are receiving at home and those providing it, the help they receive from home care agencies, and the impacts of the transfer of care on the different areas of their lives.

Seventeen focus groups and seven individual interviews for people unable to attend the focus groups were held with hospital staff, and a total of 96 professionals took part. The interviews mainly questioned staff on discharge criteria and procedures, patient preparation, hospital follow-up after discharge, collaboration with home care agencies, and a general appreciation of the shift to community care. Nine other focus groups and two individual interviews, involving 51 people, took place with home care personnel. The themes discussed during these interviews included the transfer process, collaboration with hospitals, care provided by home care personnel at home, care provided by patients or their caregivers and the rationale for this division of responsibilities, the impacts of the transfer on patients and caregivers, and a general appreciation of the shift to community care.

ANALYSIS

All interviews were tape recorded and transcribed in their entirety. We applied the techniques of thematic content analysis (Bryman & Burgess, 1994; Dey, 1993; Strauss & Corbin, 1990).

First, we performed a preliminary analysis of themes and subthemes. This gave us a general overall picture of the material and allowed us to chose the most pertinent themes for further classification and to anticipate any difficulties in the analysis.

Second, we performed identification and codification of the units of sense or ideas. Last, we categorized the material.

We first coded the interviews on the basis of the themes that emerged from the data. This required several thorough readings of the transcriptions so as to identify the emerging themes and subthemes, their level of intensity, and their frequency of occurrence. For example, in studying data with regard to patient preparation for discharge, subthemes that emerged included transfer of knowledge from hospital to home and preparation for the unforeseen. After having satisfactorily developed our list of themes and subthemes from the initial coding of the material, we began establishing links between the various themes and organizing them in analytical categories. For example, the categories of preparation for discharge and division of labor in the home became linked through the analytical category of trivialization. These categories were questioned, revised, and readjusted until they obtained a satisfactory level of clarity, relevance, coherence, homogeneity, and exclusivity. We constructed our analysis by grappling with the meaning and signification of the categories and by comparing our analysis to other writings on this phenomenon.

Before presenting our results, we should make a brief statement on the organization of health care in Québec. Health care, including all medically necessary care in the home, is universal and free. Thus, most high-tech equipment is free, as is the professional support of nurses, social workers, rehab personnel, and other para-medical professionals. Homemaker services are also provided without charge, but access is so limited to these services that many people hire homemakers from the private sector or go without.

RESULTS

THE FIRST STAGE IN TRIVIALIZING THE TRANSFER: PREPARATION FOR DISCHARGE

Generally, hospital discharge is preceded by a period of preparation that can be more or less long and complex depending upon the nature of the patient's condition. Preparation can take different forms including learning techniques such as how to stick a syringe into a catheter, how to prepare an IV solution, how to clean a wound, or how to sterilize an area. In the case of hip fractures, preparation means learning how to do daily activities while compensating for the handicap. A second form of preparation consists of transmitting information including what symptoms to watch for, what precautions to take (such as getting enough rest), and what exercises to do. Information can be transmitted orally or in writing. Finally, preparation can take the form of simulating a return home. Despite the variety of methods used to ensure that the patient is well prepared for their return home, many of the respondents in our study were critical of the preparation they had received.

LACK OF SENSITIVITY TO THE IMPLICATIONS OF TRANSFERRING KNOWLEDGE TO THE HOME SETTING

One of the main issues raised by patients and caregivers was related to a certain lack of sensitivity on the part of hospital staff (an occasional exception being rehabilitation staff) to the implications of transferring care to a setting that is very different from a hospital. As one respondent stated, "They showed me. But being shown and doing it once you're home are two very different things." Performing a medical or nursing act in the hospital is very different from carrying it out in the home. In particular, the absence of on-going supervision and surveillance causes much anxiety for patients and caregivers alike.

As well, there appears to be a growing trivialization of medical and nursing activities themselves, and many professionals promote the idea that anybody is capable of performing quite complex and skilled activities with a minimum of explanation or with just a brief demonstration. This trivializes the degree of specialization of the care that is being transferred and the level of competency and the conditions that they require.

Although patients are shown how to perform certain activities and may even have practiced them in the hospital, many of these lessons are forgotten or are difficult to apply in the new setting once the patient is home and without medical supervision. One question asked, “Do you feel you were competent to give yourself the necessary care after discharge?” A respondent replied,

> In the beginning, no, because I couldn’t manipulate the needle and get it in [the catheter]. They had me practice sticking it into bottles and that went well. But actually working with the catheter, no. I had to learn that myself . . . . They told me, “You do this, you put that there . . . and that’s it. There’s nothing to it!” . . . . At the hospital you think ya, ya, it’s OK. And then you get home and you’re there and oh boy! Now, where does that go? How do you attach that? And you have your little manual, but at some point the manual . . . . To tell you the truth, I don’t even know where it is. (IV[1])

As mentioned previously, medical personnel often give the impression that many professional activities require little knowledge or training. This is seen in the following statement of a caregiver:

> They vaguely asked me, “Have you had any training or anything like that?” I answered, “I saw the woman from the home care department do it once.” The nurse replied, “Good, then now you’re capable of doing it.” (IV)

Returning home also means returning to daily life. It appears that hospital staff do not always realize to what extent certain equipment, such as IV lines, will handicap the patient’s mobility, and they consequently do not prepare patients for this reality. In one interview we asked, “And do you think that the people at the hospital were preparing you sufficiently to become aware of this context?” The respondent replied,

> I don’t think so. I don’t think people realize how much you use your arms. I don’t think so. You know, for a person to go to the grocery store and bring a bag of five pounds of potatoes or two liters of milk, it’s done, sure. For me, it was, uh-huh, I couldn’t do that. I had to assure that someone at the grocery store was going to deliver or somebody was going to drive me there and back. I had to depend on a lot of people for help. I don’t think the people in the hospital realize the limitations imposed on a person who has a pick-line. (IV)

When asked the same question, another respondent stated,

> When it’s really windy, you have to be careful. When you come in and sit down you have to pay attention to which side you put it, there’s always a cord hanging down you have to watch out for.

At one point we asked, “And did they talk to you about these things at the hospital—how to function daily with all those cords and things?” The respondent (IV) simply said no.

THE CONTEXT AND THE CONDITIONS OF HOME

During activities aimed at preparing patients for discharge, the information given and the teaching are based on the context and the conditions of the hospital. However, homes are not set up like hospitals; they do not have the same layout or the same equipment. As one respondent stated, “We don’t have all the medicine, we don’t have all the instruments that we need like they do there.” It is thus difficult for some patients to transfer the teachings and to follow the advice of the hospital staff.

During one interview, a caregiver said, “Obviously they have machines which we don’t.” The patient added,

> I need a bigger apartment with more rooms so I could have a treadmill. They tell us to walk and do our exercises . . . but we’re missing half of the equipment they have there. There they have machines where you can adjust the weights. And they push us to exert ourselves more. And they tell us how to breathe and how to build up before exerting ourselves and when to breathe in and breathe out. As preparation for discharge they tell us to keep on doing what the physio showed us when we get home. But we aren’t equipped like they are. (COPD)

During one interview we stated, “And you said the bed which they had you practice climbing on to was lower than your own?” The respondent replied, “Oh, yes. It was a lot lower.” We then asked, “Did they ask you how high your bed was?” The respondent answered, “I told them I thought it was higher. I think it’s even higher than a hospital bed. Look how high that mattress is.” (HF)

LACK OF PREPARATION FOR THE UNEXPECTED

It appears that information given at the hospital is mostly technical and consists of explanations of how to perform various procedures. The emotions and the fears linked to assuming the responsibility for administering the care and the potential problems that may arise are often not addressed. One respondent stated, “We’re not made sufficiently aware of all that could happen.” Few patients were given any preparation for the psychological aspects of convalescing at home or for the difficulties they might encounter. Another respondent stated, “You get the positive side of things. ‘You can go home now. Your catheter is in, there’re no problems. Do what we told you and that’s it.’ No! That’s not it!” (IV)

Indeed, the training that patients received did not take into account the panic that many people feel when they suddenly find themselves all alone at home and they have to do a procedure or administer a treatment. The training also did not take into account what might happen if a crisis were to occur and the patient were not able to breathe. Touching on this subject, one respondent said, “It’s all fine and dandy when they’re showing you how to do it. But when you start to panic, that all goes by the wayside. You become stressed, you lose control.” We responded by leading, “And when you panic like that . . . . ” The respondent continued,

> Well, my pressure shoots up to 200, 250 . . . right to the top. When the ambulance guys saw me they said, “Sit down.” I said, “I’m seated.” But, I said, “Damn, I’m not being cared for, no one is taking care of me. And now you’ve had to come out again and I’m fed up with bringing you out.”

We then asked, “Were you prepared for these breathing crises before discharge?” The patient replied,

> No. No. Not at all. They simply told me to eat slowly, to take small bites, to eat things like stews or things mashed in the blender . . . . But they didn’t tell me there was a risk of choking, they didn’t tell me that I could end up choking, rolling on the floor. I thought I was a goner and they didn’t tell me about that. (COPD)

Speaking of dealing with an IV patient, one caregiver stated,

> You think it’s easy to inject someone, but when you’ve never done it . . . and then you try for the first time, you’re suddenly all thumbs. It’s hard! I really found it stressful! You can do it, but it’s very stressful. (IV)

With a similar view on the same topic, another respondent said,

> But even if you have the IV in the hospital you know that if anything goes wrong you can buzz the nurse and she’ll be there in two minutes . . . she’s on the same floor. But when you go home and you have that needle in you, you don’t have that comfort, so you forget. It’s normal you don’t remember, a person is tense. They might not take the time to go through all the information. (IV)

It is also stressful not to have sufficient information on what to do if something unexpected happens. One respondent said,

> They tell you, “Your catheter is in, your bandage has been changed, you have your medication, you have your things, the home care nurse will be in to see you.” But no, that’s not enough. We need to know what happens if the catheter comes unscrewed or if something is leaking, what’s causing it. Is it because it’s blocked? Or if it starts bleeding, after all, we’re talking about an open vein, it’s not a little thing an open vein. Where do you put pressure to stop the bleeding? What do you do? What if the post falls or you pull too hard on the line? What happens if I get caught up in the tubing and I pull the whole thing out? I mean there are all those things and I received no information on that. (IV)

Another respondent stated,

> I think that the patients should be sensitized to what might be happening , so that you don’t feel that there is something wrong. I mean maybe I’m not reacting well to the is pick-line and there is something wrong with me that I can’t lift my hand or bend my arm. I had to call and tell them, “Listen, this is what’s happening to me,” and talk to the nurse who said, “Yes, this is what you should expect and what you shouldn’t be doing.” But it would have been nice to know that in advance.(IV)

LACK OF INFORMATION OF THE EVOLUTION OF THE DISEASE OR THE CONDITION

The absence of information of the health status of the patient and the course of the condition is also a cause for anxiety. One respondent said, “I was told nothing, neither was he.” Many informants believe that the sharing of information should be an integral part of discharge preparation and that training should not only focus on the task to be performed but also on the nature of the illness and its probable course. During one interview we asked, “There were no meetings with your wife, the doctor, the nurse and the social worker? There were no discussions?” The respondent replied,

> No, no, no, there weren’t, none at all. It’s as clear as that, nothing, silence, that’s all there was. Any discussions we had were at our instigation because we wanted to ask questions and we weren’t getting any answers. In terms of the nurses, they were all very nice, all competent, but, medically speaking, they weren’t able to give me any more information than what was in my file. (PC)

LACK OF CONSIDERATION FOR THE DIFFERENT STAGES OF PREPARATION AND THE PATIENT'S CAPACITY TO INTEGRATE INFORMATION

In many cases, there seems to be no analysis of what is essential information that must be transmitted before discharge or of how much or what kind of information the patient is able to take in and what information could be given at home as part of the work of home care personnel. Hospital staff does not seem completely aware of the patients' capacity to absorb new knowledge and information. Sometimes, if patients do not pose questions, they do not have access to all the necessary information. But for many patients, it is difficult to know what to ask before having lived through the situation, as the following passage suggests.

We asked, "And did you try and ask those questions at the hospital?" The respondent replied, "They didn't come to mind the first time." When asked why, the respondent continued, "Because I didn't think I was going to live through what I lived through. It was new." (IV)

Often patients are not in a mental or physical state to integrate all the information, and it seems that staff does not always verify how much they have understood. During one interview we lead with the following statement: "So you said it's different when you were at home than when you were at the hospital." The patient replied,

> Well there's that danger when you are at home that you might forget what you have heard so there's that tension of being on your own and how you might forget what you heard. If you heard something only once, it doesn't always penetrate in the hospital. You are very foggy if you are there for a long time. It goes in and out of your ears and you'll nod and say yes and they will think you understand but . . . . In the hospital . . . I could have given a great impression that I was fully capable of doing everything and I could be the biggest klutz and not be able to follow any of their instructions and they never would have known. (IV)

In addition, one caregiver stated,

> You have to understand. Her illness is progressing and the doses of narcotics are increasing. Sometimes when she has an appointment with the doctor to change her dose, I can't be there.

The patient then stated,

> Often it's volunteers who take me or sometimes even a taxi. So, I'm alone and I'm under the effects of the medication so my mind isn't always clear.

> When I get home, he asks me what I'm supposed to take and all I can say is—well there's that and that and that.

The caregiver then said, "She doesn't remember," and the patient added, "I don't remember, I'm not sure." (PC) Another respondent said,

> I forget if they told me to be careful about certain things. I remember we had discussions, I remember the exercises. But the doctor and the nurse told me too many things . . . . When I was at the hospital, many doctors came to see me but I forget most of the things they told me. (S)

This brings one informant to the conclusion that the information which patients are given in the hospital has to be verified by home care personnel once the patient is home. Speaking of hospital workers, we asked one respondent, "She didn't go over it with you?" The respondent replied,

> She does, like I said, but in the hospital situation a lot of times you just nod yes, yes, yes . . . but once you're home, when your environment changes your whole frame of mind changes and adjusting to being at home is a big adjustment. Even the chemical reaction in the body is different, I found that even in myself. So like I said, it would be necessary to go over that information thoroughly once you get home. I must have read that pamphlet ten times. (IV)

This respondent also feels that the patient should always be accompanied by a family member or friend when information is being transmitted:

> My husband didn't like that he had to hear everything from me. He would rather have arranged to be there when they discussed these things, that they schedule a time convenient for him too. It's hard at a hospital when they have to act so quickly and when they want me to be back home at a certain time. But I think it would have been good . . . maybe he should have called. I'm just thinking now . . . . But it would be good to have the spouse or the close family member also to know what's going to happen and what are the medications, side-effects, for their security and for the patient's security. I think that would be advisable and my husband would have appreciated it.

Another respondent stated,

> When I was in the hospital I was next to many elderly patients and could overhear the doctors or the nurses giving instructions that they really couldn't fully comprehend. And the children would come to visit and then the instructions were not given the way I heard them given and I acted to interpret them correctly to the family members. But I'm just wondering . . . maybe the hospital doesn't involve that part of the family enough.

THE SECOND STAGE OF TRIVIALIZATION: THE TRANSFER OF COMPLEX AND TECHNICAL CARE TO PATIENTS AND CAREGIVERS

After release from hospital, exactly what care activities are being transferred to patients and their caregivers? Well, just about everything. Patients and their family members are practicing nursing, social work, nutrition, occupational therapy and physiotherapy, and even medicine as more and more professional activities are being shifted to the home and transferred to family members, thus confirming earlier American findings (Glazer, 1990).

In almost all cases, it is expected that patients or their caregivers check symptoms and auto-diagnose reactions to medications and treatments and the deterioration of health status including diagnosing infections, levels of pain, and so on. Patients or their caregivers must decide when to call for help, who to call, and when to return to the hospital. This implies a capacity to mobilize resources correctly, a knowledge of the health system, and a familiarity with how to orient oneself within it. As well, it is generally assumed that the majority of patients, and more so their caregivers, will assume all the activities of daily living required during convalescence.

The assumption that lay people have the knowledge, competencies, and conditions to perform all these tasks is another form of trivialization of the complexity and specialization of these medical and para-medical activities. Indeed, although some of the activities assumed by the family are perceived of and can be considered as easy or simple, many are relatively specialized and complex.

The case of a 61-year-old woman, who was living alone and was interviewed because she had IV antibiotic treatment at home, gives us a good picture of the complexity of care being assumed by some patients. Besides administering her own IV treatments with a pick-line apparatus running directly to her heart, she also does her own clapping to remove pulmonary secretions, self-administers insulin injections, verifies her level of glycemia, and gives herself inhalotherapy treatments. Each of these operations is complicated and requires a fair amount of preparation so that she has to devote a large portion of each day to her care.

For example, her IV treatments are particularly demanding and involve manipulating syringes, needles, and bags of antibiotics as well as disinfecting the material and the site. She must be rigorous and highly concentrated and correctly follow the order of the various operations and control the intensity of the drip. As she explains,

> You have to be precise. That means you can take 2 or 3 minutes, but not 5 or 10. So at 7 a.m., you begin preparing your things, disinfecting, washing, and organizing everything so that it be ready at 8 a.m. for your treatment. You have 1, 2, 3 . . . 3 needles to use. Then you prepare your IV bag for the next day and then you count the drops. 6 drops every 15 seconds. It's not easy. Not at all. At first I had 5, 4, 7 . . . but I finally mastered it . . . . I couldn't see an elderly person doing it. You have to constantly verify things. You can have bubbles in the line which can be dangerous. Not the little ones, but they can become bigger if you just leave them. So you're constantly checking, you have to be really concentrated.

Not all patients and caregivers are involved in this type of care; many have home care nurses who assume these responsibilities. But a significant number of patients and caregivers, many of whom are elderly, are being asked to assume complex nursing and technical tasks themselves. Also, many other factors, besides the technique itself, contribute to the complexity of assuming these activities, including (a) the frequency and duration of treatments (a treatment that takes 2 hours and is given every 6 hours), (b) multiple preparations, (c) ensuring a sterile environment, (d) following strict protocols, (e) coordinating a multitude of medications, and (f) coordinating the delivery of medications. No standards seem to exist as to what can be transferred to the home or under what conditions care can be transferred. Also, different home care nurses have various expectations regarding the transfer. Another form of the trivialization of the transfer is the lack of consideration for the context in which care is given when it is given at home.

THE HOME: A COMPLEX ENVIRONMENT

It is somewhat disconcerting to imagine an activity taking place in the hospital and then displacing this same activity to the home. In the hospital, patients are put into hospital gowns on beds with sheets which are often changed daily. The patient is in a supposedly sterile environment. Diet and medications are completely controlled by hospital staff. Indeed, a patient who asks to keep and self-administer his or her medications is refused. An interdisciplinary professional team is present, and when any one member is confronted with a problem (leaking IV tube, patient discomfort, apparatus malfunction), the members of the team are backed up by specialists (IV technicians, specialized doctors, technicians, etc.) and by a team of people responsible for the organization of the instrumental activities of daily living (meals, bathing, toileting). Staff members are generally dressed in some form of uniform and must wear gloves, and sometimes masks, when entering a patient's room.

Now transfer this to the home setting. The patient comes home and puts on the pajamas they were wearing before hospital admission. They move freely from room to room, hug and kiss family members, and handle the family pet. Having lived on hospital food for the past week, they are ready for home cooking. Their caregiver quarrels with them as he or she feels responsible for ensuring that the patient follow the diet outlined by the hospital. In the excitement of returning home, the patient forgets to take his or her morning medications. A day after returning home, the patient has trouble with his or her IV catheter. The IV pole is squeezed in between the bed and the night table, and there is almost no room to move because of the addition of a small side table that is used to lay out equipment. The patient frequently gets caught in the line and loosens the catheter in his or her vein. When it starts bleeding at the site, the home care nurse has already come and gone. What to do? The caregiver makes an adjustment. He or she is abused for hurting the patient, but the IV starts to flow again and the bleeding stops. There is another dispute between patient and caregiver concerning hygiene around the IV. What does keeping a sterile area mean? Can the dog sit on the bed? Does the caregiver have to wear gloves? Are these questions important enough to disturb medical personnel for answers? Who should be called, the hospital, the home care nurse, or the 24-hour medical-information line? Indeed, transferring care to the home raises questions about the complex environment of the home and its appropriateness as a site of complex technical medical and nursing activities.

A PHYSICAL ENVIRONMENT

Hospital discharge policies do not always fully take into consideration the fact that the conditions of care at home are likely to be as variable as the homes in which care takes place. Conditions are also dependent on the socioeconomic situation of the occupants and the material conditions of the home.

Homes are not hospitals, and not all of them lend themselves to nursing care activities. Some are too humid or too dry, too hot or too cold for the patient's condition. The food available may or may not conform with the patient's dietary needs. Homes do not have space for equipment or are lacking appropriate equipment, and standards of cleanliness vary greatly. Equipment can be awkward and hard to manage in the home. In many cases, spouses are forced to sleep on the couch because of cumbersome electronic IV equipment or catheter lines. Lamps become stands for IV bags when the local community health centers do not have enough poles. And what about homeless people? What are their conditions for convalescence?

A PSYCHOLOGICAL ENVIRONMENT

For many people, returning home means returning to normal, to a state of wellness. There is the perception that one is sick in the hospital, and going home means being better. This mindset leads to much difficulty in accepting the limitations of apparatuses and care procedures. As well, patients have difficulty coping with the fact that they are convalescing and cannot do all of the things they are used to doing at home. These restrictions in the hospital do not have the same signification. It is normal not to be able to carry on with one’s regular activities in the hospital, but the home is another matter.

A SOCIAL ENVIRONMENT

Conditions and care at home are dependent on the social situations of patients and their families. The level of care is often dependent on the capacities and competencies of family members. But family dynamics include situations of alcoholism and drug addictions, mental illness, abuse, negligence, and violence, all which we met in the research. These situations raise the question of the limits of ambulatory care in situations of extreme poverty or marginalized populations, although the policy is promoted as universal.

Another aspect of the social nature of the home is the fact that life goes on at home. Too often, patients are solicited by the different activities of daily living, child care, housework, and so on, and end up trying to juggle these responsibilities with their care and convalescence. Both patients and hospital staff tend to underestimate the difficulties that the former will face each day as they attempt to return to their normal routine while having to assume self-care in a state of fragile health. And sufficient home care services are not put into place to compensate for these handicaps, forcing patients to overextend themselves.

Indeed, many patients have had some disagreeable surprises when they come home with equipment adapted for the hospital setting but not tailored to the context of homes and daily life. People with IV equipment quickly realize they have limited mobility, which was normal in the hospital but which is seen as abnormal at home, where they expect to take part in daily activities.

The same is true for caregivers who must integrate patient care into ongoing family life, juggling work schedules, school schedules, recreation, and hobbies. Just the management and feeding of visitors can become a burden that interferes greatly with daily living.

A LAY ENVIRONMENT

But perhaps the most unsettling aspect of the transfer of care responsibilities to patients and their families is the anxiety and insecurity of assuming this care without sufficient supervision and emergency backup. In the hospital, you have an emergency call button if something goes wrong. But what replaces this button when you are being cared for at home? Indeed, the home is psychologically, and sometimes physically, very far from immediate help in the case of an emergency or an unforeseen development. The majority of patients and caregivers assuming complex care felt alone and abandoned, causing high levels of stress and anguish and conflicts within couples and within families.

As one caregiver stated,

> It's a huge responsibility. You think, what if something were to happen and you don't know what to do. Who's going to live with that on their conscience for the rest of their life. Not the hospital. Not the nurse. Not the guy with the pencils trying to save money. It's the person who will have had to live through that.

Many respondents felt that supervision and control from home care nurses was lacking, that professionals were difficult to reach, and that appropriate services were not always accessible.

Finally, the question of the quality of care in these circumstances has to be raised. In many cases, patients or caregivers stopped or skipped treatments, modified doses, took initiatives with broken equipment, and took other risks when professionals were not available.

CONCLUSION

Our data reveal that this transfer of responsibility to patients is underscored by a growing trivialization of medical and nursing activities that now, it seems, can be accomplished by anybody. Medical and nursing activities are presented as being easily understood and easily performed by lay persons. But there are professional activities that until now have been reserved for specific corporate groups and that could not be delegated to other professional groups. And yet, they are now easily entrusted to patients and their caregivers.

Based on our study, we raise serious questions about the legitimacy of the transfer of high-tech care to the family. It would seem that in Québec, decisions to orient health care in this direction were not based on changing philosophical orientations or evidence-based studies that demonstrate the superiority of this mode of providing high-tech care. Rather, the principal rational appears to be one of cost-cutting and fiscal restraint.

To that extent, it appears imperative to call for a moratorium on the delegation of all professional acts until such time as clear guidelines are established as to what can appropriately be assumed by lay people, as to which lay people can do it, and as to under what circumstances it can be done. If, after analysis, certain acts are deemed compatible with a transfer to lay people, questions will have to be raised about their professional nature and the possibility of their transfer to semiprofessionals (nurses, aides, homemakers). Indeed, this latter scenario might provide an interesting alternative that both relieves family members of the burdens and responsibilities of care and that remains within the system's ability to pay.

In cases where the assumption of high-tech care by family members is deemed appropriate, we would suggest that the following conditions are needed to ensure a successful transfer of responsibility. First, before hospital discharge, a complete assessment of the patient and family situation should be undertaken jointly by hospital and home care evaluators. Second, patient and family preparation for discharge should be treated as a genuine training process that begins at the hospital and that continues at home. This training must be given systematically and must take into account the concerns of the patient and the family. It should also be given in a context that is conducive to the assimilation of teachings that must be more than technical but that must also include global knowledge about the treatment, about the patient's condition and prognosis, about possible side effects and possible problems which might arrive, and about emotional aspects linked to the affective relationship between patient and family. Third, families should be supported by mechanisms ensuring that all home care patients have 24-hour access to medical personnel. Finally, the transfers should be seen in the reality of the context and the conditions and logic of the domestic sphere and should be adapted to the environment of the home.

If the debate around the mixed economy of care and the sharing of care between the various social actors is to advance, there must be a redefinition of what it means to offer professional care in the context of the home. However, if the specific logic and conditions of the home are not recognized, this care will continue to be trivialized and transferred inappropriately to the detriment of patients and their families.

NOTE

1. Quotations are coded to ensure anonymity. The codes are as follows: *IV* for patients receiving treatment by intravenous; *COPD* for chronic pulmonary disease; *S* for stroke; *HF* for hip fractures; and *PC* for palliative care. Quotations from interviews held in French have been translated by the authors.

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