



# Ethical issues relating to the inclusion of relatives as clients in the post-stroke rehabilitation process as perceived by patients, relatives and health professionals<sup>☆</sup>



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## ABSTRACT

**Objective:** To document the ethical issues regarding the systematic inclusion of relatives as clients in the post-stroke rehabilitation process.

**Methods:** A two-phase qualitative design consisting of in-depth interviews with relatives and stroke-clients (Phase 1) and three focus groups with relatives, stroke-clients and health professionals (Phase 2). Data was audio recorded. Transcribed interviews and focus groups content were rigorously analyzed by two team members.

**Results:** The interview sample was composed of 25 relatives and of 16 individuals with a first stroke whereas the three focus group sample size varied from 5 to 7 participants. Four main themes emerged: (1) overemphasis of caregiving role with an unclear legitimacy of relative to also be a client; (2) communication as a key issue to foster respect and a family-centered approach; (3) availability and attitudes of health professionals as a facilitator or a barrier to a family-centered approach; and (4) constant presence of relatives as a protective factor or creating a perverse effect.

**Conclusion/practice implications:** The needs of relatives are well known. The next step is to legitimize their right to receive services and to acknowledge the combined clinical and ethical value of including them post-stroke. Interdisciplinary health care approaches and communication skills should be addressed.

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## 1. Introduction

Stroke consequences for relatives have been known for many years [1]. Indeed, after stroke, an important proportion of relatives experience burden [2–4] and depressive symptoms [5,6] while facing challenges in resuming daily activities and social roles (participation) [7,8]. Even when the stroke is minor [9] or when the relative is younger (middle-aged) [10], qualitative studies reported

issues with quality of life especially pertaining to family life and persisting even six months post-stroke. Where do health care systems stand for these people almost 40 years later? In 2007, relatives still reported feeling alone, and lack of coordination characterized the services they received [11]. The needs of relatives in relation to their dual role of caregiving and client [12] are now better defined [13], but the effectiveness of intervention provided to them remains mixed [14]. However, in most cases, offering information, training and support makes common sense as Rodgers and collaborators [15] pointed it out in a review of the topic. Relatives wanted to receive information on all aspects of stroke care and services and to be involved in decision making, but reported difficulty obtaining information about the emotional consequences of stroke [15].

To overcome these difficulties in offering adequate and timely services to relatives, a family-centered approach [16] would appear necessary. Accordingly, the individual who has had a stroke

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**Table 1**  
Characteristics sought in the three targeted populations under study.

	Relatives	Stroke clients	Health professionals
Inclusion criteria	Showing a presence since the stroke	First stroke episode	Having worked with a stroke clientele for at least two years
Exclusion criteria	Inability to communicate in French		
Diversity sought		Age Stroke severity Discharge destination	Discipline Working milieu

(so called ‘stroke-client’) will not be the only one considered as a client, the only one ‘admitted’ to receive health care and services but the “family unit” will. Thus, a major change in stroke clinical practice would be to systematically involve relatives as clients. From an ethics standpoint, this represents a shift from a parentalistic-paternalistic paradigm, in which practitioners alone make decisions regarding the well-being of patients [17] to a family-centered approach, in which the needs and preferences of all members of the family unit are equally considered [16]. This paradigm shift, in which relatives are included in health care and services and their needs are closely taken into account, may be desirable, even inevitable, but necessary entails a new set of ethical issues (e.g., decisions related to the destination and timing of discharge). According to the Collins dictionary, definition of *ethical* is “in accordance with principles of conduct that are considered correct, esp. those of a given profession or group” [18]. But when health professionals are equally considering needs of individual who have had a stroke and those of their relatives, what is the correct way to intervene? Indeed, how much weight should be given to the wishes of relatives, especially when these wishes are in contradiction with those of the stroke client or the treating professional? By documenting perceived gaps between actual and desired services received by relatives [19], we wanted to further explore how all those involved into a paradigm shift toward a family-centered approach perceived what would be the morally correct way to behave toward relatives. This would clarify how to implement interventions to better inform, educate and support relatives to meet their needs.

Thus, the main objective of this study was to document the ethical issues involved in the systematic inclusion of relatives as clients in the rehabilitation process, from three perspectives: that of relatives, individuals with a first stroke (stroke clients), and health professionals. This paper reports the qualitative data based on these perspectives in five Canadian urban settings.

## 2. Methods

### 2.1. Study design

A two-phase qualitative design of a phenomenological orientation was used [20]. Phase 1 consisted of in-depth interviews [21,22] with relatives and stroke clients in order to document their perceptions of actual and ideal services received by relatives both in acute care (Time 1) and in in-patient or out-patient rehabilitation (Time 2). Space was allowed to express lived experience relating to health services as well as individuals perception of relationships with health professionals including how they wished these to be in an ideal world, a world without time or resources constraint. Only those who actually received formal rehabilitation services were interviewed at both times, four to six weeks following discharge, allowing patients to resume their normal activities and having the necessary hindsight to comment on actual and ideal services. Phase 2 consisted of three focus groups [23], in which results from Phase 1 were discussed with other relatives, stroke clients, and health professionals. The second phase enabled a form of validation of results and analysis with other participants [24] presenting similar

characteristics (relatives and stroke-client). It was also decided to hold a focus group with health professionals although they were not individually interviewed to expand meanings and application of results to their clinical reality. This focus group was planned to be held at the very end of the data collection process.

### 2.2. Samples

Three populations were targeted by the study: (1) relatives defined as the individual who has shown a presence with the patient since stroke, (2) individuals who have had a first stroke (stroke-clients) and (3) health professionals working with a stroke clientele. Table 1 illustrates inclusion and exclusion criteria and the diversity sought to maximize the scope of lived experiences. As relatives were recruited by way of approaching stroke-client, we assumed that the diversity of stroke-clients would result in a similar diversity for relatives. Although we did recruit some dyads (relative-patient), this was not an inclusion criterion. Targeted sample size for Phase 1 was 20 in each group with approximately half being referred to rehabilitation for a total of  $n = 60$  interviews to ensure data saturation [22] whereas targeted sample size for focus groups of Phase 2 were 5–7 participants per group [23]. Health professionals were recruited with the help of local on-site research coordinator not involved in the study. The research coordinator advertised the study to all members of stroke team and interested individuals would contact the research assistant of the study who would further validate eligibility to participate.

### 2.3. Recruitment

Participants of Phases 1 and 2 were recruited from three acute care hospitals. Participants of Phase 2 were also recruited from two rehabilitation centers to mirror the continuum of care. For both phases, eligible individuals were contacted by a research assistant from the occupational therapy discipline to explain the purpose of the study and to schedule an appointment either for an interview (Phase 1) or focus group (Phase 2). Interviews of Phase 1 were conducted by two occupational therapists (MT and JB) while focus groups were led by principal investigator (AR) with one of the occupational therapist who did most of the interviews of Phase 1 and who was in charge of leading data analysis (JB). Individual interviews lasted less than 1 h while 2 h period was used for each focus group. The research protocol of the study underwent a provincial multicenter procedure ensuring that the ethics committee of each establishment involved in recruitment approved the study.

### 2.4. Data collection

An interview guide was used in Phase 1 to facilitate the conduct of individual interviews while enabling the emergence of spontaneous, unanticipated content. The interview guide was developed following a rigorous process: (1) drafting of initial questions (by MT with the collaboration of AR) based on a literature review on the topic of the provision of services to relatives post-stroke (conducted by AR); (2) review by research

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