

1 **Title:** Inclusion of relatives in stroke rehabilitation: Perception of quality of services they
2 received in the context of early supported discharged (ESD), in and out-patient services

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4 **Running head:** Quality of stroke rehabilitation services to relatives

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40 **Inclusion of relatives in stroke rehabilitation: Perception of quality of services they**
41 **received in the context of early supported discharged (ESD), in and out-patient services**

42 **Abstract**

43 **Background:** Relatives of stroke patients should be an integral part of the continuum of
44 rehabilitation services.

45 **Objective** was to describe their perception of the quality of the services they received in the
46 context of early supported discharged (ESD), in and out-patient rehabilitation services.

47 **Methods:** Descriptive study using the Quality of Services Questionnaire for Relatives post-
48 stroke (QSQR), completed online by relatives after the patient's discharge. It consists of 22
49 statements with respect to three subscales: 1) the training/instructions, 2) the information
50 provision and 3) the organizational process of the service offer. Space is allowed for free
51 comments and two open-ended questions. Quantitative data were analysed descriptively, and we
52 used a content analysis for qualitative data.

53 **Results:** One-third (30/90; 33.3%) of the sample is composed of relatives aged 55 and under,
54 with a majority (81%) of women and 51.3% of spouses. The training/instructions and
55 information provision were perceived positively with a mean % agreement at 85.0 ± 29.6 and
56 84.8 ± 22.4 respectively. The mean % agreement was 91.4 ± 17.8 for the organizational process
57 subscale. A significantly higher score ($p=0,03$; Kruskal Wallis test) was found for out-patient
58 services ($n=20$) as compared to ESD ($n=29$) or in-patient rehabilitation ($n=41$). Qualitatively, a
59 lack of involvement of relatives was mentioned as well as a lack of personalized information
60 about stroke and its consequences and provision of resources available. However,
61 communication between professionals, their availability and their professionalism were
62 appreciated.

63 **Conclusion:** Despite quantitative high scores, qualitative data allowed the identification of
64 concrete avenues for improvement to truly and systematically include relatives in stroke
65 rehabilitation.

66

67 **Keywords:** Stroke; relatives; rehabilitation; early supported discharge; training; information;
68 organizational processes

69

70 **Introduction**

71 Stroke is estimated to be the second leading cause of death worldwide, with an estimated
72 six million deaths in 2016 [1]. In Canada, approximately 400,000 individuals live with the
73 consequences of stroke [2]. In addition to the impacts on the individual and his or her daily life,
74 stroke also brings about changes for the people around the stroke survivor, the latter becoming a
75 caregiver or not. Thus, stroke is considered a "family disease" that affects not only the patient,
76 but also those close to him or her [3], which we therefore refer to as a relative and not a caregiver
77 per say as one does not have to provide care to be confronted to stroke consequences on own life.
78 The patient's relatives become important players in the rehabilitation process following a stroke.
79 Indeed, informal help from them is often sought quickly following this sudden event, even
80 though they may not have the necessary skills and knowledge [4]. Relatives are recognized as a
81 facilitating factor in providing help and support to their loved one with stroke [5]. Thus, in order
82 to fulfill this role, it is essential that relatives be considered not only as a source of information
83 by health professionals, but also as a client whose needs are to be assessed and who is likely to
84 require training, information and support [6]. This is called dual role leading to dual needs.
85 Stroke can lead to a negative impact on relatives' own level of participation [7] and on their
86 quality of life [8]. Specifically, the amount and duration of care provided to the stroke survivor
87 by relatives, the responsibilities associated with their new role, and the lack of time for self-care
88 and social activities would drain their physical, psychological, and social resources [9]. Among
89 family caregivers, 30 to 68% of caregivers are reported to have symptoms of depression or
90 anxiety following a stroke [10, 11]. A recent meta-analysis including 22 articles on the burden of
91 caring for relatives of people with stroke found that the gap between the abilities of the caregiver
92 and the needs of the person with stroke would lead to family burnout [12]. As a result, the
93 exhausted relative is more likely to experience health problems such as anxiety, depression,

94 cardiovascular disease and reduced quality of life [13, 14]. Caregiver anxiety, feelings of
95 inconsistency and depression have been shown to have a high relationship (effect size (ES) =
96 0.57 for anxiety; ES=0.48 for feelings of inconsistency and ES=0.64 for depression) with
97 caregiver burnout [12]. In addition, among the 3 025 patients and 2 887 family members who
98 were included into this metaanalysis, a moderate relationship was demonstrated between the level
99 of activity (ES=-0.39) and anxiety (ES=0.49) of the person who had the stroke and the
100 exhaustion of his or her family caregiver [12]. Moreover, relatives report that the
101 training/instructions and information they receive help reduce their stress and fear, which
102 justifies the importance of giving greater consideration to their needs [15].

103 According to Canadian best practices, family members must be an integral part of the
104 continuum of services [16, 17]. It emphasizes the importance of involving relatives throughout
105 the rehabilitation, reintegration, and transition to the community of individual who have had a
106 stroke and to provide them with the information and support they need. In order to offer services
107 centred also on the needs and expectations of relatives, an assessment of the social environment
108 is essential to be carried out. Indeed, relatives are part of the patient's social environment, which
109 is more dynamic and interactive than the physical environment [15]. A family-centred approach
110 would be ideal in stroke rehabilitation to consider family members as an integral part of the
111 continuum of services [18]. Viewing the family member as a client may make it easier for the
112 person with stroke to return home and live longer in the community [7], as family members are a
113 positive factor in stroke recovery [19].

114 Despite the establishment of these guidelines, relatives are currently not systematically
115 involved in the continuum of stroke services as they are not considered clients by health
116 professionals [6, 15]. In fact, variability in services provided to relatives was found where some

117 family members mentioned that they had not received services from the professionals, while
118 others reported being satisfied with the services they received, but would have liked them to be
119 delivered differently, without having to seek for information, education or support [6, 15].
120 Although the relatives' needs are known and the guidelines recommend including family
121 members in the continuum of services, it is clear that much work remains to be done to ensure
122 that they receive the services, support and information corresponding to their needs.

123 The objective of this study was to describe the perception of the quality of services
124 offered to relatives of stroke patients in the context of early supported discharged (ESD), in and
125 out-patient rehabilitation in various institutions of the greater Montreal area, Quebec, Canada.

126 **Methods**

127 **Study design**

128 This cross-sectional study used a mixt methods approach; quantitative close-ended
129 questions and qualitative content by-way of two open-ended questions and free-space for
130 comments to quantitative questions. This study was approved by the Research Ethics Board of
131 the affiliated Research Centre of authors. This manuscript was written to conform to the
132 STROBE guidelines.

133 **Study population**

134 The target population were relatives of stroke patients who have undergone rehabilitation
135 in one of the institutions or programs where *the Quality of Services Questionnaire for Relatives*
136 *post-stroke (QSQR)* had been implemented for quality improvement purposes. These different
137 settings invited the person with stroke to identify a relative upon admission to the rehabilitation
138 program. There were no specific inclusion or exclusion criteria. The institutions and programs

139 where the questionnaire had been implemented offer rehabilitation in the context of early
140 supported discharge (ESD), in-patient, or out-patient services.

141 **Setting**

142 Early supported discharge (ESD) consists of intensive interdisciplinary rehabilitation
143 offered 4 to 5 times/week at home and lasting approximately four weeks. It targets individuals
144 who have had a mild to moderate stroke presenting a stable health condition and who can
145 manage own medication by themselves or with the assistance of a relative. These individuals
146 should be motivated to receive rehabilitation services at home, be able to manage self-care and
147 dressing and yet cannot tolerate participating in out-patient services 2-3 times/weekly. In-patient
148 services target individuals who have had a moderate stroke, who need intensive interdisciplinary
149 rehabilitation offered daily in order to go back home. These individuals typically cannot yet live
150 at home although many of them do benefit of weekend passes. Both ESD and in-patient are
151 typically offered in the first few weeks post-stroke. Out-patient services consist of
152 interdisciplinary rehabilitation offered 2-3 times weekly, typically after discharge from ESD or
153 in-patient services, when the individual can live at home and travel to the rehabilitation centre to
154 receive services. It can sometimes also be offered to individuals who have had a mild stroke who
155 are not eligible to ESD or in-patient services as they can travel to the rehabilitation centre to
156 receive these out-patient services.

157 **Data collection**

158 An online bilingual (English and French) questionnaire has been created and
159 implemented in several health care institutions and programs in the greater Montreal area: The
160 *Quality of Services Questionnaire for Relatives post-stroke* (QSQR) (see Table 2 for complete
161 list of statements and supplemental file for the French version). The QSQR assesses the

162 perceived quality of services received by relatives of stroke patients. Statements were developed
163 based on a review of the literature [7] and further refined through three focus groups with stroke
164 rehabilitation clinicians representing acute care, inpatient and outpatient rehabilitation. The
165 questionnaire describes best practices (what should be expected) towards relatives of individuals
166 who have had a stroke in order to improve the quality of care and services offered to relatives.
167 This questionnaire was developed in French and English simultaneously. It consists of 24
168 statements. For statements 1 to 22, relatives respond using a four-level Likert scale ranging from
169 strongly agree to strongly disagree. For seven of these statements (training/instructions subscale),
170 a "*does not apply*" box is available since content is about training/instructions on how to manage
171 issues that may not be present in all clients. For each statement, a free-text comment box is
172 available and optional. The 23rd and 24th statements are open-ended questions. Statement #13 (...
173 *I think the information I received was incomplete*) is reversed in order to be able to detect
174 systematic respondents. A total % agreement score can be obtained by combining and adding
175 agree and totally agree responses x 100 / number of applicable statements. A score for each
176 subscale can also be calculated: training/instructions offered (7 statements), information
177 provision (10 statements) and organizational processes (5 statements) of the institution or
178 program. Demographic information (age, gender, and relationship to stroke survivor) for each
179 respondent was also collected through multiple-choice questions at the end of the online survey.

180 Data collection was conducted through the QSQR questionnaire, online with the *Survey*
181 *Monkey* platform. The questionnaire could also be answered in paper format. An invitation to
182 complete the questionnaire (including a link) was sent through email to patients' relatives at the
183 time of discharge by a staff member of the institution or program. Once received, relatives were
184 given the option of completing it on voluntary basis. The email included an introduction

185 explaining its purpose, that is to improve the quality of rehabilitation services offered to
186 relatives. Respondents were also informed that a comment section was available at the end of
187 each statement. They were asked to write a concrete example illustrating their level of agreement
188 and disagreement with the statement. A maximum of ten minutes was deemed necessary to
189 complete the questionnaire.

190 **Analysis**

191 Questionnaires with more than 50% of responses were included in the study (4
192 questionnaires were excluded as respondents quit answering too early on). We used descriptive
193 statistics such as mean (standard deviation) and frequency (%) to present the results. The mean
194 percentage of agreement for the total score and for the three subscales of the questionnaire was
195 also calculated. A percentage of agreement was described as low when below 75%, moderate
196 between 76 and 84% and high above 85%. The use of ANOVA (and its non-parametric
197 equivalent, the Kruskal Wallis test, since the sample size of the out-patients subgroup was
198 relatively small, =20) made it possible to test for the presence of a significant difference between
199 the scores according to the type of service offers. A thematic analysis of the data [20] was also
200 conducted for the qualitative comments/data. All free text comments were labeled with codes
201 which were further grouped into categories and themes. This coding process was realized by two
202 authors and results further discussed until consensus with first author who has experience in
203 qualitative analysis.

204 **Results**

205 The respondents (n=90) were varied in age (see Table 1) and were predominantly (81%)
206 female. More than half (51.3%) of respondents were the spouse of the stroke patient and more
207 than one-third were their child (31.6%). The questionnaire was completed with regards to

208 services received in the context of early supported discharged for 29 respondents, 41 completed
209 it for in-patient rehabilitation and 20 for out-patient rehabilitation.

210 The results for the whole sample on the QSQR are presented in Table 2. If we disregard
211 the reverse statement #13 (... *I think the information I received was incomplete*), the answer
212 'totally disagree' does not reach 10% for all the statements, while the answer 'totally agree'
213 exceeds 50% for 12/22 statements. For the whole sample (n=90), the quality of rehabilitation
214 services offered to relatives was perceived positively with a mean % level of agreement of
215 $86.2 \pm 20.0\%$. On average, the training/instructions offered matched best practices for a mean %
216 level of agreement of 85.0 ± 29.6 ; of 84.8 ± 22.4 for information provision and of 91.4 ± 17.8 for the
217 organizational processes (see Table 3). The total score mean % level of agreement for out-patient
218 rehabilitation (95.9 ± 8.2) was significantly higher as compared to in-patient rehabilitation
219 (81.1 ± 21.7) or ESD (86.8 ± 21.0) by relatives of people who have had a stroke (p ANOVA
220 value=0.02 and Kruskal Wallis test=0.03).

221 **Training/instructions offered**

222 The mean % level of agreement for the subscale Training/instructions offered was
223 significantly higher (p=0.04) for out-patient services as compared to ESD and in-patient
224 rehabilitation (see Table 3). Indeed, the percentages of agreement were high (i.e., between 90
225 and 100%) for all the seven statements of this subscale for out-patient rehabilitation (see Table
226 4). Both for ESD and in-patient rehabilitation, there was a high percentage of agreement for the
227 statement #2 regarding the time they were given to learn how to physically assist their loved one
228 safely in order to avoid injuries. In addition, the ESD obtained high percentage of agreement for
229 statements #4 and #6 about cognition and communication issues. However, for in-patient

230 rehabilitation, the percentage of agreement was low (i.e. 66.6%) for statement #5 relating to
231 long-term consequences of stroke, while it was moderate for the ESD.

232

233 ***Information provision***

234 The mean % level of agreement for the subscale Information provision was found to be
235 similar ($p=0.06$) when comparing ESD, in-patient and out-patient rehabilitation (see Table 3).

236 The vast majority of statements of this subscale obtained a high percentage of agreement with
237 the exception of statements #14, 15 and 17 about providing a list of websites or resources and
238 informing on specific risk factors in the context of ESD and in-patient rehabilitation (see Table
239 4). Furthermore, more than one-fifth of the respondents agreed with statement #13, *I think the*
240 *information I received was incomplete.*

241 **Organizational Processes**

242 The organizational processes subscale obtained high mean % level of agreement for all
243 three types of service provisions (see Table 3). Specifically, respondents had a positive
244 perception of the organizational process in the context of outpatient rehabilitation as an
245 agreement score of 100% was obtained for all statements of this subscale, with the exception of
246 statement #21 on the level of involvement in decision making in preparation for discharge where
247 two of the 18 respondents disagreed with the statement. Moderate agreement was obtained also
248 regarding involvement in decision making in preparation for discharge (statement #21) both for
249 ESD and in-patient rehabilitation, and regarding the transition to the next level of care (statement
250 #22).

251 **Qualitative results**

252 The 320 comments from the 90 participants were grouped under six themes: 1)
253 Multidisciplinary work, 2) Communication between professionals and relatives, 3) Professionals'
254 approach, 4) Information provision and training/instructions offered by health professionals, 5)
255 Involvement of relatives and 6) Continuum of care (see Table 5). Several suggestions for
256 improving the quality of services offered to relatives were also raised by them. One relative
257 mentioned: "*More time from the centre's staff for exercise and walking assistance (rather than*
258 *relatives)*" (in-patient rehabilitation), another reported: "*Systematically meet them when the*
259 *patient arrives*" (in-patient rehabilitation). It was also suggested by relatives to offer groups for
260 them: "*Possibly have a special session for relatives of people who have had a stroke.*" (ESD) and
261 "*Having a group for single caregivers to share problems and challenges we face*" (in-patient
262 rehabilitation).

263 **Discussion**

264 The objective of this study was to describe the perception of the quality of services
265 offered to relatives of stroke patients in the context of early supported discharged (ESD), in and
266 out-patient rehabilitation in various institutions of the greater Montreal area, Quebec, Canada.
267 Although quantitative scores were high in general, qualitative data revealed variability in
268 services offered which support the added value of using a mixt-methods design in research [21]
269 but also for quality improvements purposes. The use of crowdsourcing [22], an inclusive method
270 to gain online feedback on services, ensured to collect a variety of experience which was
271 apparent concretely in the qualitative data collected. Indeed, subthemes highlighted both positive
272 and negative experiences relating to relatives' involvement into their loved one stroke
273 rehabilitation. These results are in coherence with findings from the literature where perceived

274 needs of relatives were investigated through individual interviews and focus groups [6]. Indeed,
275 one major issue that emerged was that relatives did not feel legitimate to receive services for
276 themselves [15]. Hopefully, their legitimization will be improved with last update of the
277 Canadian Stroke Best Practice Recommendations on the topic of Transitions and Community
278 Participation [16] where learning needs and the delivery of support and education now
279 systematically focus also on caregivers and families in addition to those of people with stroke.
280 An emphasis can also be found in these recommendations on the importance of involving all
281 members of the interdisciplinary team. Indeed, some of our respondents criticized that they could
282 only interact with one member of the interdisciplinary team, namely the social worker. However,
283 when looking at the statements' content of the QSQR, more specifically to the
284 Training/instructions offered subscale, it is clear that all members of the interdisciplinary team
285 should be involved in this training. There is also high level evidence of the benefits of
286 caregivers' training on both relatives' quality of life and their loved one who had a stroke [5, 23].

287 Another issue beside feeling legitimate to receive services was the necessity for relatives
288 of seeking for information [24]. A gap in information provision was also observed as
289 information, when provided, was not systematically offered both verbally and in a written format
290 [25]. Furthermore, lists of recognized website [26] and of community resources were not
291 systematically provided. The use of a questionnaire where level of agreement with statements
292 describing best practices enabled to document those gaps in services provisions. The use of a
293 satisfaction questionnaire, typically used in quality improvements initiatives, would not have
294 done so [27]. Indeed, when asked what they appreciated the most, many relatives highlighted
295 health professionals' professionalism, their kindness, attitudes and punctuality.

296 Interestingly, we found a significant difference in favour of out-patient rehabilitation for
297 total score and training/instructions offered subscale, as compared to early supported discharged
298 (ESD) or in-patient rehabilitation. Similarities between ESD and in-patient rehabilitation
299 experiences for relatives can be explained partly by the fact that both are offered relatively early
300 post-stroke as they belong to the same phase on the stroke continuum whereas out-patient
301 rehabilitation typically follows either ESD or in-patient rehabilitation. Therefore, we could
302 hypothesize that the higher score obtained for out-patient rehabilitation are partly due to a
303 repetition of training/instructions already offered in the context of ESD or in-patient
304 rehabilitation leading to a greater exposure favouring retention [28]. Furthermore, the fact that
305 out-patient rehabilitation is offered later in the stroke journey allowing for more time for
306 relatives to deal on a daily basis with these authentic situations, that is the various consequences
307 of stroke, probably contributed to these higher scores as relatives had to find strategies on their
308 own, building their confidence and thus their competence level [29]. However, there may also be
309 a true difference in the quality of services offered to relatives in favour of out-patient services as
310 clinicians often told us, anecdotally, that they did not purposely deliver training nor provided
311 information as they felt their clients (including their relatives) were not ready to receive it, even
312 though Canadian stroke best practices insist of doing so at all phases of the stroke continuum
313 [16] as the specific needs may change with time [30].

314 **Strengths and limitations of the study**

315 The mixt method design [21] and the use of a questionnaire presenting statements of what
316 to expect rather than questioning about satisfaction [27] represent strengths of the study. The
317 sample size (n=90) and the comparison of different types of rehabilitation services offers are also
318 a strength although the different subsamples were not represented equally in each of the service

319 offerings. In addition, a large amount of missing or non-applicable data was obtained for some
320 statements, which represents a limitation of the study. Finally, qualitative comments need to be
321 interpreted cautiously since their number was limited without consideration of the
322 representativeness of the larger sample.

323 **Conclusion**

324 Overall, the quality of services offered to relatives of stroke patients is perceived
325 favourably, which demonstrates that the guidelines are currently being implemented in health
326 care institutions and programs in the greater Montreal area. However, some gaps remain and
327 need to be addressed by health professionals in order to improve the quality of services offered to
328 relatives. Indeed, with respect to organizational processes, the lack of involvement of relatives
329 across the continuum of care was raised as problematic. Also, relatives had to search and seek for
330 the information themselves, pointing out a gap in the information provision. The provision of
331 recognized websites and community resources would be a solution to counter this problem. Our
332 results identify concrete areas for improvement for healthcare professionals working in the field
333 of stroke, such as encouraging the rapid integration of relatives into the continuum of care and
334 shared decision-making [31], and offering groups and training for additional assistance to
335 relatives.

336

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Table 1: Characteristics of respondents according to various rehabilitation services offered (n=90)

	Early supported discharged N=29 N (%)	In-patient rehabilitation N=41 N (%)	Out-patient rehabilitation N=20 N (%)	Total sample N= 90 N (%)
Age group				
45 years old and less	3 (10.3)	10 (24.3)	1 (5)	14 (16.8)
46-55 years	8 (27.6)	4 (9.8)	4 (20)	16 (19.6)
56-65 years	7 (24.1)	12 (29.3)	4 (20)	23 (28.4)
66-75 years	6 (20.7)	8 (19.5)	6 (30)	20 (24.7)
76 years and more	3 (10.3)	1 (2.4)	4 (20)	8 (9.8)
Gender				
Women	21 (72.4)	27 (65.9)	16 (80)	64 (81)
Men	5 (17.2)	8 (19.5)	2 (10)	15 (19)
Relationship with individual who have had a stroke				
Child	7 (24.1)	14 (34.1)	3 (15)	24 (31.6)
Spouse	15 (51.7)	13 (31.7)	11 (55)	39 (51.3)
Brother/sister	1 (3.4)	3 (7.3)	0 (0)	4 (5.2)
Parent	0 (0)	2 (4.9)	3 (15)	5 (6.6)
Other relative	1 (3.45)	2 (4.9)	1 (5)	4 (5.2)

Note: Sample sizes may vary due to missing data.

Table 2: Perception of relatives (n=90) regarding the training/instructions offered, information provision and organizational processes using the Quality of Services Questionnaire for Relatives post-stroke (QSQR)

During the episode of [ESD, in or out-patient] rehabilitation services received related to my relative/friend's stroke...	Totally agree N (%)	Agree N (%)	Disagree N (%)	Totally disagree N (%)
Training/instructions offered				
1)... they took the time required to teach me how to offer my relative/friend support without tiring myself out.	50/80 (55,6)	19/80 (21,1)	7/80 (7,8)	4/80 (4,4)
2)... they took the time required to teach me how to safely help my relative/friend physically and avoid injuring myself or my relative/friend.	53/80 (66,3)	19/80 (21,1)	5/80 (5,6)	3/80 (3,3)
3)... they took the time required to explain the changes in my relative/friend's mood and behaviour and teach me how to handle them in my daily life	43/77 (47,8)	22/77 (24,4)	6/77 (6,7)	6/77 (6,7)
4)... they took the time required to explain my relative/friend's cognitive problems (such as changes in memory, concentration, judgement, etc.) and teach me how to handle them in my daily life.	51/80 (56,7)	18/80 (20)	9/80 (10)	2/80 (2,2)
5)... they took the time required to discuss the possible long-term consequences of the stroke on my daily life and ways to handle them.	40/80 (44,4)	22/80 (24,4)	12/80 (13,3)	6/80 (6,7)
6)... they took the time required to explain my relative/friend's language difficulties and teach me strategies to communicate effectively.	40/57 (44,4)	10/57 (11,1)	7/57 (7,8)	0/57 (0)
7)... they took the time required to explain my relative/friend's problem with swallowing and teach me how to manage it safely.	26/45 (28,9)	11/45 (12,2)	3/45 (3,3)	5/45 (5,6)
Information provision				
8) ... I received personalized information in response to my needs and questions.	57/87 (63,3)	24/87 (26,7)	5/87 (5,6)	1/87 (1,1)
9) ... the information was given to me verbally and in writing.	48/87 (53,3)	28/87 (31,1)	7/87 (7,8)	4/87 (4,4)
10) ... the information was given to me in words I could easily understand.	61/86 (67,8)	22/86 (25,6)	2/86 (2,2)	1/86 (1,1)
11) ... I received the information or was given the training when I needed it.	49/82 (54,4)	26/82 (28,9)	4/82 (4,4)	3/82 (3,3)
12) ... they answered my questions when I needed it.	63/88 (70,0)	21/88 (23,3)	4/88 (4,4)	0/88 (0)

13) ... I think the information I received was incomplete.	10/82 (11,1)	8/82 (8,9)	16/82 (17,8)	48/82 (53,3)
14) ... they gave me a list of recognized Websites so I could get additional information on strokes in general and on the rehabilitation options available to us.	31/76 (34,4)	23/76 (25,6)	15/76 (16,7)	7/76 (7,8)
15) ... they told me what a risk factor is, about my relative/friend's specific risks and the best ways to reduce the risk of having another stroke.	34/78 (37,8)	25/78 (27,8)	11/78 (12,2)	8/78 (8,9)
16) ... they took the time to listen to what I had to say about the changes in my personal life since the stroke.	43/80 (47,8)	27/80 (30)	6/80 (6,7)	4/80 (4,4)
17) ... they gave me a list of resources available in my community that can provide respite, help and support if I feel I need it.	44/82 (48,9)	19/82 (21,1)	12/82 (13,3)	7/82 (7,8)
Organizational processes				
18) ... I received support when I needed it.	49/82 (54,4)	26/82 (28,9)	4/82 (4,4)	3/82 (3,3)
19) ... the health professionals* were available to answer my questions within a reasonable amount of time	61/84 (67,8)	22/84 (24,4)	1/84 (1,1)	0/84 (0)
20) ... the health professionals* were consistent in what they said and did not contradict each other	62/83 (68,9)	18/83 (20)	1/83 (1,1)	2/83 (2,2)
21) ... I participated in making decisions about preparing for discharge.	46/78 (51,1)	18/78 (20)	7/78 (7,8)	7/78 (7,8)
22) ... the transition between the [type of services offered] and home or next level of care and services was done within a reasonable amount of time.	41/79 (45,6)	26/79 (28,9)	7/79 (7,8)	5/79 (5,6)
Open-ended questions				
23) What could we do better to improve the quality of services for close relatives/friends of people who had a stroke?				
24) What did you appreciate most in the services for close relatives/friends of people who had a stroke?				

*The term "health professionals" includes all types, such as a physician, specialist, nurse, nursing assistant, social worker, pharmacist, physiotherapist, occupational therapist, speech therapist, neuropsychologist, etc., but EXCLUDES maintenance staff, orderlies and attendants.
Note: The results represent the percentage of agreement of the respondents. Sample sizes vary due to missing data or statements that were not applicable (Q1 to Q7 included). % takes into account these missing data or not applicable answers by dividing frequency/90, i.e. total sample size.

Table 3: Overall perception of the training/instructions offered by health professionals, information provision and the organizational processes according to the context of stroke rehabilitation

	ESD N=29	In-patient rehabilitation N=41	Out-patient rehabilitation N=20	p value for intergroup differences using Kruskal Wallis test	Full sample N=90
Training/instructions offered	86,7 ± 30,0	78,1 ± 32,3	95,7 ± 19,2	0,04	85,0 ± 29,6
Information provision	83,8 ± 22,7	80,3 ± 25,8	95,3 ± 6,3	0,06	84,8 ± 22,4
Organizational processes	90,4 ± 17,9	88,7 ± 20,9	98 ± 6,2	0,14	91,4 ± 17,8
Total Score	86,8 ± 21,0	81,1 ± 21,7	95,9 ± 8,2	0,03	86,2 ± 20,0

ESD = Early supported discharged

Note: The results represent the mean percentage of agreement of the respondents.

Table 4: Level of agreement with each statement of the QSQR in the context of early supported discharge (ESD), in-patient and out-patient rehabilitation (Sample sizes vary due to missing data or not applicable statements)

<i>During the episode of [ESD, in or out-patient] rehabilitation services received related to my relative/friend's stroke...</i>	ESD N=29 N (%)	In-patient rehabilitation N=41 N (%)	Out-patient rehabilitation N=20 N (%)	Total sample N=90 N (%)
Training/instructions offered				
1)... they took the time required to teach me how to offer my relative/friend support without tiring myself out.	23/26 (88.5)	27/35 (77.1)	19/19 (100)	69/80 (86.3)
2)... they took the time required to teach me how to safely help my relative/friend physically and avoid injuring myself or my relative/friend.	23/25 (92.0)	33/39 (84.6)	16/17 (94.1)	72/81 (88.9)
3)... they took the time required to explain the changes in my relative/friend's mood and behaviour and teach me how to handle them in my daily life	19/23 (82.6)	27/34 (79.4)	19/20 (95)	65/77 (84.4)
4)... they took the time required to explain my relative/friend's cognitive problems (such as changes in memory, concentration, judgement, etc.) and teach me how to handle them in my daily life.	24/26 (92.3)	27/35 (77.1)	18/19 (94.7)	69/80 (86.3)
5)... they took the time required to discuss the possible long-term consequences of the stroke on my daily life and ways to handle them.	20/25 (80.0)	24/36 (66.6)	18/19 (94.7)	62/80 (77.5)
6)... they took the time required to explain my relative/friend's language difficulties and teach me strategies to communicate effectively.	18/19 (94.7)	19/24 (79.2)	13/14 (92.9)	50/57 (87.7)
7)... they took the time required to explain my relative/friend's problem with swallowing and teach me how to manage it safely.	12/15 (80.0)	15/19 (78.9)	10/11 (90.91)	37/45 (82.2)

Information provision				
8) ... I received personalized information in response to my needs and questions.	24/27 (88.9)	38/41 (92.7)	19/19 (100)	81/87 (93.1)
9) ... the information was given to me verbally and in writing.	22/27 (81.5)	35/41 (85.4)	19/19 (100)	76/87 (87.4)
10) ... the information was given to me in words I could easily understand.	24/26 (92.3)	39/40 (97.5)	20/20 (100)	83/86 (96.5)
11) ... I received the information or was given the training when I needed it.	25/26 (96.2)	34/40 (85.0)	18/19 (94.7)	77/85 (90.6)
12) ... they answered my questions when I needed it.	28/28 (100)	36/40 (90.0)	20/20 (100)	84/88 (95.5)
13) ... I think the information I received was incomplete.	6/26 (23.1)	7/36 (19.4)	5/20 (25.0)	18/82 (21.1)
14) ... they gave me a list of recognized Websites so I could get additional information on strokes in general and on the rehabilitation options available to us.	16/24 (66.7)	21/35 (60.0)	17/17 (100)	54/76 (71.1)
15) ... they told me what a risk factor is, about my relative/friend's specific risks and the best ways to reduce the risk of having another stroke.	20/27 (74.07)	24/34 (70.6)	15/17 (88.24)	59/78 (75.6)
16) ... they took the time to listen to what I had to say about the changes in my personal life since the stroke.	23/25 (92.0)	29/36 (80.6)	18/19 (94.7)	70/80 (87.5)
17) ... they gave me a list of resources available in my community that can provide respite, help and support if I feel I need it.	16/23 (69.6)	27/39 (69.2)	20/20 (100)	63/82 (76.8)
Organizational processes				
18) ... I received support when I needed it.	22/25 (88.0)	33/37 (89.2)	20/20 (100)	75/82 (91.5)
19) ... the health professionals* were available to answer my questions within a reasonable amount of time	26/26 (100)	37/38 (97.4)	20/20 (100)	83/84 (98.8)
20) ... the health professionals* were consistent in what they said and did not contradict each other	25/26 (96.2)	35/37 (94.6)	20/20 (100)	80/83 (96.4)

21) ... I participated in making decisions about preparing for discharge	17/21 (80.9)	31/39 (79.5)	16/18 (88.9)	64/78 (82.1)
22) ... the transition between the [type of services offered] and home or next level of care and services was done within a reasonable amount of time.	17/22 (77.3)	30/37 (81.1)	20/20 (100)	67/79 (84.8)

Table 5. Respondents answers to open-ended questions and free-text comments grouped under six main themes, with subthemes and verbatim excerpts

Themes and subthemes	Verbatim excerpts
Multidisciplinary work	
Excellent teamwork and atmosphere	<i>The workers did excellent teamwork (in-patient rehabilitation)</i> <i>I appreciated and liked the communication between the departments and the collaboration of the teams and their professionalism (out-patient rehabilitation)</i> <i>The workers worked in a very friendly atmosphere! (ESD).</i>
Lack of cohesion	<i>Nobody was on the same page (ESD)</i>
Access to only one health professional	<i>We were never met by any other health professional other than a social worker (in-patient rehabilitation)</i> <i>At the risk of repeating myself, the only person who really supported me and listened to me was the social worker, thank you very much [name of professional] (in-patient rehabilitation).</i>
Access to many health professionals	<i>Everyone was telling us about it (ESD)</i>
Communication between professionals and relatives	
Verbal information only	<i>Just verbally (in-patient rehabilitation)</i> <i>Verbally only (ESD)</i> <i>Never in writing, only quick verbal answer when I had specific questions (in-patient rehabilitation)</i>
Written documentation	<i>Documentation and lots of explanation (ESD)</i> <i>In writing when we weren't there in person, both when we were there [verbally] (ESD)</i>
Access to team meetings	<i>I had the privilege of attending information meetings which taught me a lot (in-patient rehabilitation)</i> <i>Clear explanations at the Intervention Plan meeting" (in-patient rehabilitation)</i>
Use of video and phone	<i>I was able to attend sessions, taking videos to show techniques (in-patient rehabilitation)</i> <i>Telephone conversations (in-patient rehabilitation),</i>
Use of the stroke patient	<i>No other than my mother, who was a bit confused about what had happened (ESD)</i>
Language or internet as barriers	<i>No one seemed to know anything. It also didn't help that all the staff were French and did not speak very much English (in-patient rehabilitation)</i> <i>No, we don't have internet (ESD)</i> <i>I don't use internet (ESD)</i>
Adapted language	<i>Vocabulary understandable, thank you (ESD).</i>
Professionals' approach	
Professionalism	<i>Their kindness, openness, acceptance (ESD)</i> <i>Dedication, empathy and kindness (out-patient rehabilitation)</i> <i>Punctuality of all (in-patient rehabilitation)</i> <i>The human approach of all the staff wow!! (in-patient rehabilitation)</i>

Inadequate approach such as not taking the time	<i>Nurse's questions were too direct, and somewhat depressing (ESD)</i>
Lack of availability	<i>Take the time no, but we discussed it (in-patient rehabilitation) commenting on statement #1</i> <i>However, we had many questions that we had no one to ask (in-patient rehabilitation)</i> <i>Always able to see the professionals... otherwise it's more complicated (in-patient rehabilitation) commenting the statement #8</i>
Accessibility to professionals in answering Q24 (what appreciated the most)	<i>The accessibility and availability of all health professionals (ESD)</i> <i>Their availability and understanding (out-patient rehabilitation)</i> <i>I find that you respond efficiently and quickly to our concerns (out-patient rehabilitation)</i> <i>We were informed of the changes every day (ESD)</i>
Information provision and training/instructions offered by health professionals	
Lack of information	<i>At first it was very difficult to get any answers. No one seemed to know anything [...] (in-patient rehabilitation)</i> <i>More detailed information to the family regarding the type of stroke, health consequences, prognosis, and more information about exercises, etc [...] we got nothing in this regard and could have really benefited from it. (in-patient rehabilitation).</i> <i>No, and I would have needed it [information on community resources] ... and since I'm alone and I have to pay for two adults. (ESD)</i> <i>Resources have not been recommended in case of need (in-patient rehabilitation).</i>
Seeking as a key strategy	<i>...often you have to be there at the right time and at the right place to meet the professionals who are working with your loved one. [...] (in-patient rehabilitation)</i> <i>I have done research on the internet (ESD)</i>
Negative impacts of incomplete or no information	<i>We felt very much in the dark about my mother's condition for much of the time she was there. We were left to figure out the majority of information on my mother's condition by observation during our visits. (in-patient rehabilitation)</i>
Lack of personalization, depth or timing in the information provision	<i>It was mentioned casually to "keep an eye" on her coughing while eating... (in-patient rehabilitation)</i> <i>Quite late (in-patient rehabilitation) commenting on statement #11</i>
Involvement of relatives	
Lack of involvement in decision making for discharge	<i>Not there in person. No-one called. (ESD)</i> <i>We had no choice but to be informed. (in-patient rehabilitation)</i> <i>I came in and they said it was the last day she went through the objectives. I had NO say (out-patient rehabilitation)</i>
Appreciation of involvement	<i>We work like a team, me and them and my brother (ESD)</i>
Burden of involvement	<i>I enjoyed being involved in the care provided. However, I felt that I was being asked to help to compensate for a lack of resources. (in-patient rehabilitation)</i>
Focus on stroke patient	<i>The focus was on the patient, not the caregivers. (ESD)</i>

Continuum of care	<i>At the same time, I did not feel that there was any support for the partner of the patient. I understand that the most important is for the patient to receive the... he needs to be able to get back on his feet however, there should be an extension to that service to help the partners get through the journey. (in-patient rehabilitation)</i>
Lack of follow up	<i>No teaching or follow up when I brought back feedback that she had been coughing a fair amount during meal time on more than one occasion. (in-patient rehabilitation) She offered to follow up with us regarding resources, tablet apps., etc. but we never heard back from her before my mother was discharged. (in-patient rehabilitation)</i>
Lack of transition or wrong timing	<i>There should be a more gradual transition between the two phases without interruption of service" (in-patient rehabilitation) Too early [the transition] (in-patient rehabilitation) Clearer follow-up for after; And for the leave (which was too fast in my case -24hrs) and for the necessary support. [...]" (in-patient rehabilitation) Longer home services" (ESD)</i>
