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## Barriers and facilitators to family participation in the care of their hospitalized loved ones

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### Abstract

This study's objective was to better understand family members' experiences in order to identify how healthcare organizations can facilitate their participation in the care of a hospitalized loved one. Eighteen individuals at the bedside of a hospitalized loved one were interviewed individually. Roles at the bedside and factors that facilitated their participation or represented barriers were examined. A qualitative analysis using a mixed inductive/deductive approach was performed. Reassurance and emotional support, as well as sharing information with the healthcare team emerged as main roles. Quality and timeliness of the information received about the patient's condition, prognosis and changes in medical condition, as well as information on how to participate in their care, were the factors most frequently evoked as facilitating participation. On the other hand, the need to improve communication channels and access to doctors were highlighted. Most family members having no prior knowledge or exposure to healthcare environments reported feeling overwhelmed in this foreign environment. Among the suggestions on how to improve their experience, having a well-identified contact person who liaises with them and who can instruct them on how to participate in care during hospitalization and back at home was frequently suggested. Furthermore, many mentioned that recognizing the experiential knowledge they have of the patient allows for more holistic care and contributes to improve both patient and family experience. Families need to be adequately recognized and supported and have access to information in a timely manner so that their contribution to their loved one's care is maximized and the burden associated with this stressful experience alleviated.

### Keywords

Patient and family-centered care, family experience, patient experience, qualitative methods, quality of care

### Introduction

In recent years, there has been a significant paradigm shift in healthcare regarding the role of family members and other significant others<sup>a</sup> in caring for their hospitalized loved ones. Healthcare professionals are increasingly aware of the role that the patient's family can play during hospitalization.<sup>1,2</sup> Indeed, their participation is crucial in a context where elderly patients represent a constantly growing proportion of hospital admissions, and where the development of ambulatory care has increased the frequency of trips to and from the place of care. Moreover, several benefits for the patient have been associated with increased family participation, including decreased stress and anxiety, lower delirium prevalence, shorter hospital stays, greater patient satisfaction and experience with care and a more proactive attitude towards their health condition.<sup>3-5</sup> While the growing attention to family members stems from the recognition of their natural caregiver role with the patient,<sup>6,7</sup> awareness of their vulnerability and needs during this trying time is also increasing.

In order to better understand the nature and importance of family participation during hospitalization, Li and colleagues<sup>8</sup> developed a typology of roles held by family members during an episode of care. These roles include being present at the bedside, providing support, ensuring that their loved one's needs are met, assisting them in daily activities and collaborating in care activities. As mentioned by these authors, family members may *act as a transmission belt* between the patient and the healthcare team. For example, they can clarify aspects of the patient's history, inform the care team of their loved ones' needs or pain he/she is unable to express verbally, detect complications early on, or ask the doctor for additional information on the patient's condition and explain technical terms or medical information to their loved one that he/she may not have understood.<sup>5,7</sup> Moreover, by ensuring that their loved one has the information and support they need to participate in decisions, participation of family members is essential to ensure that decisions respect the patient's values, preferences and needs. 1. Involving them in the patient's care would also ensure a better continuity of the roles they have towards him/her in their personal lives, which, in turn, may improve the overall hospitalization

experience for both the patient and family.<sup>10</sup> In addition to decreasing the patient's anxiety, participation of family members may also reduce their own anxiety and sense of helplessness.<sup>6,9</sup>

Laitinen and Isola<sup>11</sup> examined factors promoting or inhibiting participation of family members (or other significant others) in the hospital care of elderly patients. A questionnaire comprised of four open-ended questions was sent to family members identified by the patient as being their primary caregiver and returned by mail to the research team. Among the factors that encouraged participation, the most frequently mentioned were emotional support, coaching, and encouragement to be involved in care. Having more opportunities to talk to staff about different ways to help their loved ones, such as when and how to get involved during hospitalization, were among the factors that were deemed the most helpful. Other factors associated with increased participation were the patient and caregiver's health status, positive attitude and interest in getting involved, nurses' personal characteristics (more specifically being "humane" and cordial), as well as environmental or organizational factors such as a smaller distance between the home and hospital, flexibility of visiting hours, and fewer administrative complexities.

Welcoming family members and involving them in care processes is an important dimension of patient-centered care and patient experience. However, it appears to remain a marginal practice<sup>1</sup> as there is still a significant contrast between family members' "inactivity" during the hospitalization period and the active role they often have to take once the patient has returned home.<sup>7</sup> A study conducted in an intensive care setting in the US<sup>12</sup> found that while family members were generally very satisfied with the care provided, 17 to 20% of respondents rated communication, information and emotional support as poor. In 2014, our organization initiated a major change by prioritizing patient experience in its strategic planning for 2014-2020. Working to increase involvement of families in decisions and care was identified among the top priorities. Reasons for this were twofold. While there is a growing recognition of the importance of patient and family engagement in care, this dimension received the lowest scores in our organization's inpatient experience survey conducted the year before. So, in order to identify and support the implementation of essential actions to take, we decided to conduct a study to better understand the perspective of family members who were accompanying a hospitalized loved one in our organization.

The objectives of the present study were to (1) better understand the experiences of family members during hospitalization and (2) to identify factors that facilitated or, on the contrary, inhibited their participation in their loved one's care. More specifically, we aimed to understand what

is important to them with respect to participation, what their needs are, and the roles they play in the patient's life and wish to carry on during the hospitalization period.

## Methods

### *Participants*

Inclusion criteria - Potential participants had to have been present at the patient's bedside at least on two different days in order to have had some exposure to the situation. They also had to be able to express themselves in French or English and give written informed consent. Eighteen individuals (44% men, mean age 63 years)<sup>51-80</sup> were interviewed individually. The majority of participants were the patient's spouse (56%), the others were either an adult child (33%) or a sibling (11%). Participants were recruited from the following wards: surgical oncology (n = 6), neurology (n = 6), general surgery (n = 3) and short-term geriatric care (n = 3). Five refused to participate; given reasons were lack of time or interest, or because they did not want to leave the bedside by fear of missing the doctor's round.

### *Procedures*

Recruitment and interviews were performed by a member of our research team (MD). Recruitment was conducted on random days and at random times of the day. On recruitment days, the interviewer briefly met with the ward's head nurse, who pointed out which patients had a family member (or any significant other) at their bedside at that time. The participation of people whose family member had been admitted on the ward for less than 48 hours was not solicited. The interviewer then solicited participation of the family member after asking them if they had visited the patient regularly since his/her admission. We did not explicitly define what we meant by "regularly" but rather we later asked participants how often they had visited or had been present at their loved one's bedside in order to get a sense of how they themselves defined "regular presence". The interviewer explained the study and obtained written consent prior to the interview. Interviews took place on site, in a private office close to the patient's room. All interviews were audio taped. Average length of the interviews was 25 minutes, [range: 14-40 minutes]. An interview guide was developed based on main themes discussed in the literature on family participation and engagement and additional themes we wanted to explore.

### *Analyses*

The interviews were transcribed verbatim and thematic analyses were performed.<sup>13</sup> The QDA Miner® software was used to group themes and build a coding tree. We started from the following categories, which are a mix of categories from the literature on family members' roles<sup>8</sup> and participation to care<sup>11</sup> and additional categories explored in the present study: 1) current experience

regarding hospitalization; (2) roles in the patient's life during the hospitalization period;<sup>8</sup> (3) difficulties encountered in being involved in their relative's care and (4) aspects which facilitated their involvement;<sup>11</sup> (5) personal needs and (6) suggestions on how to improve their experience in relation with their loved one's hospitalization. The coding grid was developed progressively following an inductive approach from these broad categories.<sup>14</sup> As for the roles in the patient's life, we considered the typology developed by Li et al.<sup>8</sup> for a first categorization, which was subsequently adapted from our results. Considering the objectives of this exploratory study,<sup>15</sup> which were to better define the subject and help mark the reality to be studied in order to provide some benchmarks for more in-depth and targeted research, analyses of the interviews was begun during the data collection phase and a synthesis of the results allowed us to identify at which point data saturation was reached.

## Results

### 1. Roles of family members

Table 1 presents the different roles respondents played in the patient's life while he/she was hospitalized. The role that was mentioned the most frequently, and was judged as being the primary role, was to be present at the bedside and provide emotional support and reassurance. All participants reported sustained (several times a week, most of the day) presence at the bedside of their loved one. The majority (72%) considered themselves as being the main natural caregiver, and in most cases the only one, and five participants (28%) were family members taking turns at the bedside. As shown in Table 1, exchange of information between them and the medical team held a very important place for the participants, both in terms of perceived role, i.e., they felt they should stay informed in order to carry out their role, but also as an expressed need, i.e., they felt they needed to be informed of their loved one's health status in order to know what to expect psychologically and prepare accordingly. Participants regularly enquired about evolution of the patient's condition, treatment options, and treatment delivery. In turn, they also gave the care team information about their relative's current condition or medical history, met with doctors to answer questions or asked questions that the patient was not able or did not feel comfortable to ask. This role of "intermediary" between the medical team and the patient was held to varying degrees, depending on the patient's condition and communication needs. Relatives could also inform their loved ones about their condition or treatments, ensure that their needs were met, observe and interpret their behavior (especially in traumatology) in order to report this information to the medical team. As one participant at the bedside of his mother reported, "*I have a role of interpreter with the medical team, I can tell them what her behavior means, I am also her only landmark*". Participants

also reported having to take decisions when patients were not able to do so.

#### 1.1. Participation in care

According to our results, participation in care varied greatly from one respondent to another. Some helped in all of their loved one's activities, others in certain ones only, while some still preferred not to participate in direct care. Caregiving activities that were mentioned by respondents were: helping the patient to sit up, get up and move around (or help the staff), help the patient eat and drink and help with daily hygiene (wash, bathe, brush their hair, dress) and other activities (e.g., massaging, speech therapy). Some participants reported that they acted as motivators to encourage the patient to adopt recovery promoting behaviors. Others reported sharing leisure time with the patient (e.g., sharing a meal, walking or going out in the yard, playing cards). To maintain the patient's connection with family life or life outside the hospital, some mentioned they made a point of sharing news of family members and friends and shared back information about the patient's condition with the rest of the family. Several of the people interviewed also dealt with various aspects of their loved one's life (finances, moving to another home, etc.). They were often the people in charge of the transitions between the hospital and the home.

### 2. Needs of family members

Given that they primarily focus on the needs of their hospitalized loved one, most participants had much difficulty identifying their personal needs, apart from the need to be informed as the patient's condition and prognosis progressed. According to some respondents, presence at the bedside increased their chances of having access to the information regarding their loved one, hence the need to be allowed access on the ward without many restrictions. As mentioned by some participants, information about the disease or condition from which their loved one suffered was another factor enabling them to take a more active role. Other needs that were evoked were to be reassured about the safety and the quality of care, be supported by the care team, have occasional respite, and be able to refer to a contact person from the care team, both during hospitalization and upon returning home. Participants whose homes were a greater distance away from the hospital also spoke about the need to have some help with accommodations.

### 3. Barriers and facilitators to participation (Table 2)

#### 3.1. Importance of information and communication

Information (or lack of information) emerges as an aspect of paramount importance. A majority of participants (n = 11/18) reported that the quality of the information they received about the patient's condition, prognosis, changes in his/her condition or treatment was one of the main factors that facilitated their involvement in care. Some

**Table 1. Perception of participants about their roles at the bedside**

<p><b>Theme 1: Presence and emotional support (n = 18)</b></p> <ul style="list-style-type: none"> <li><i>I am always with him. He feels more secure, less nervous, when I am there. I arrive at 9 AM, and leave around 6 pm.</i></li> <li><i>I have to be there because my husband cannot express himself. [...] He sees me as an interpreter. It is as if we were going to foreign country and couldn't speak the language, it reassures and calms him.</i></li> </ul>
<p><b>Theme 2: Enquiring about and sharing information with the medical team</b></p> <p>Enquiring about patient's condition update and treatment (n=5)</p> <ul style="list-style-type: none"> <li><i>I am spending all my days here because I want to have the opportunity to meet and speak with the doctors...</i></li> <li><i>I accompany her, I am her sister. I am a retired nurse... that's why I am here regularly ... to try to get as much information as I can in order to help out with treatments when she goes back home.</i></li> </ul> <p>Sharing information with the medical team / Taking part in meetings with the doctors and other clinical staff (n=5)</p> <ul style="list-style-type: none"> <li><i>I have just spent a lot of time with the doctor, she was asking a lot of questions and I think I gave her all the information she needed... this is so important so that they understand who she is, what she likes, what she is like.</i></li> <li><i>yes, [I always take part in encounters with the doctors]... because he cannot really answers questions...</i></li> </ul> <p>Watching the patient's behavior and changes in condition in order to inform the medical team (n = 3)</p> <ul style="list-style-type: none"> <li><i>[...] the fact that a family member can be there most of the time during the first week is very important. It helps reassure the family, it can help the staff who are overly busy, and answering emergencies all the time. We know the person best, we are able to see small signs that she is responding: she has just blinked, squeezed my hand [...]</i></li> </ul>
<p><b>Theme 3: Respecting the patient's values and preferences and responding to his / her needs</b></p> <p>Making decisions when the patient is unable to do so (n = 2)</p> <ul style="list-style-type: none"> <li><i>[I am] involved in decisions for her ... She cannot make decisions (in her present state).</i></li> </ul> <p>Ensuring that staff meet the patient's needs of (n = 3)</p> <ul style="list-style-type: none"> <li><i>I did that when he was more confused and agitated because of the medication. He did not think of ringing the bell to call for help or if he needed something.</i></li> </ul> <p>Helping the patient in his / her daily activities and collaborating in certain care or services (n = 11)</p> <ul style="list-style-type: none"> <li><i>[...] I help her with meals, help her get up, help her change, dress, and sit in her chair. Many times the nurses have told me: we are going to hire you ... I think I am more helpful than a bother (laughs).</i></li> <li><i>[...] I help wash his teeth, apply creams, small things like that, he likes that it is me who does it. And the staff is overwhelmed. So whatever I can do ... I am a good soldier, but I need things to be explained, if you explain things clearly: I do it! [...]</i></li> </ul>
<p><b>Theme 4: Motivation and encouragement</b></p> <p>Motivate the patient to adopt behaviors that are more conducive to recovery (n = 4)</p> <ul style="list-style-type: none"> <li><i>I am her motivator. [...] My mother is impressed by the doctors. So when she is lying in bed and the doctor asks her to raise her right leg. My mom, she almost doesn't lift it. So I say: "Mom, stop being embarrassed ... Raise your leg, come on, raise it higher, you can do it."</i></li> </ul>
<p><b>Theme 5: Typical family or social functions</b></p> <p>Maintaining links with out-of-hospital life (n = 4)</p> <ul style="list-style-type: none"> <li><i>[...] I try to talk to him about what's going on in our friends and family members' lives to keep him connected. I tell him about our son who came for four days. [...] I do not want him to disconnect [...], because it is not an easy environment here at the hospital... The days are similar. So that's it, I'm trying to keep him connected.</i></li> </ul> <p>Engaging in meaningful and pleasant activities (n = 2)</p> <ul style="list-style-type: none"> <li><i>Now she sleeps less, so we "have a picnic together", we eat in the room. I bring my lunch, I eat with her.</i></li> <li><i>I try to compensate by trying to have her play cards and other games. I try to make her talk through games</i></li> </ul> <p>Taking care of non-medical aspects of life (n = 2)</p> <ul style="list-style-type: none"> <li><i>So all that is financial [I take care of], but also take the appointments. I take care of everything in the background ... they wanted to send her to a transition care home ... she will not return to her home ... I took care of administrative stuff.</i></li> </ul> <p>Giving news to family and friends (n = 2)</p> <ul style="list-style-type: none"> <li><i>[...] everyone wants news. Because everyone expects to have information. [...] there are his mother, his brothers, his sisters, friends. You have to inform people and explain how to behave with him. And you're the resource person for all these people.</i></li> </ul> <p>Supporting an older parent at the bedside of his or her spouse (n = 1)</p> <ul style="list-style-type: none"> <li><i>[...] we are also there for Mom. Mom is 85 years old. She has been staying at a hotel across the hospital for one month now. We're from Rimouski [a region outside of the Quebec region]. So it's terribly difficult for her too.</i></li> </ul>
<p><b>Theme 6: Transition from Home to Hospital and vice versa</b></p> <p>Transport the person and his / her personal belongings from home to the hospital and vice versa (n = 3)</p> <ul style="list-style-type: none"> <li><i>In addition, I bring her clothes home I wash it and I bring it back.</i></li> <li><i>[...] my husband doesn't drive. [...] Then I accompanied him, stayed with him all the time.</i></li> </ul>



Table 2. Facilitators and barriers to family participation to care. Themes and examples of quotes.

<b>Theme 1: Importance of receiving information on prognosis and condition changes (n= 18)</b>
<p><b>Clear and timely information received on the patient's condition, prognosis and treatment (n = 11)</b></p> <ul style="list-style-type: none"> <li>• <i>I did not expect that within 24 hours, I would get all this information ... The doctor even wanted to show me the MRI pictures. [...]</i></li> <li>• <i>We received information [...] It is a big thing for us, because in front of the disease, very often, we feel we are in the dark. Here, our experience was that we could easily have some answers to our questions.</i></li> <li>• <i>I find that doctors explain a lot now. Formerly, doctors decided everything themselves. It's not like that anymore [...] It's clear that if I want to be useful, I need to be informed.</i></li> </ul> <p><b>Difficulty to meet doctors and get information from them (n = 6)</b></p> <ul style="list-style-type: none"> <li>• <i>I had difficulty getting answers to my questions about the evolution of her condition [...].It's been almost a week since I've had any news.</i></li> <li>• <i>Because you do not know when he (the doctor) comes around. If you're here all day, you may have a chance to see him, but otherwise you just can't</i></li> </ul> <p><b>Difficulty to know who to turn to for information (n = 3)</b></p> <ul style="list-style-type: none"> <li>• <i>One becomes confused... with the hierarchy of job titles in a hospital, especially in these emotional moments. [...] It has happened to me often. I do not who to turn to for information. [...] There is no one who is truly identified. I asked the housekeeping staff news about my father.</i></li> </ul>
<b>Theme 2: Information and education on how to care for the patient vs. lack of information</b>
<p><b>Received useful education on how to care for the patient (n=7)</b></p> <ul style="list-style-type: none"> <li>• <i>They showed me where things were [...]. And they said to me, "Take what you need." It is much less complicated than having to wait for us and you can do it when it is best for her.</i></li> <li>• <i>We appreciated the nurse who gave us all kinds of instructions and the meetings with other specialists (physiotherapist, occupational therapist and a person who talked to us about anaesthesia). They gave us a document that informs us about the steps before the operation, the day of the operation, the next day and after...</i></li> <li>• <i>[...] and three days later, we were trained on what a stroke is.</i></li> </ul> <p><b>Lack of information on how to care for the patient (n = 3)</b></p> <ul style="list-style-type: none"> <li>• <i>I help her eat, they showed me how to do that...but how to lift her up in her bed, it took some time before they showed me how to do that.</i></li> </ul>
<b>Theme 3: Staff attitude and support: Respectful and supportive vs. not</b>
<p><b>Staff commitment and professionalism (n = 7)</b></p> <ul style="list-style-type: none"> <li>• <i>Despite the circumstances, it was a great experience. All the nurses, the care attendants, even the housekeeping staff in the rooms, everyone is nice. They take care [...] I tell them often it's not a job you have, it's a calling.</i></li> <li>• <i>I found the staff extraordinary. I found they worked hard and had pleasant moods. [...]. People are very professional. I think they are well trained to meet all sorts of people. I have never felt I disturbed, [...] I have only good things to say about them.</i></li> <li>• <i>As a human being, we like to know the facts. I found that they had a very diplomatic attitude... They spoke openly and frankly, but in a very delicate way.</i></li> </ul> <p><b>Support by the medical team (n = 2)</b></p> <ul style="list-style-type: none"> <li>• <i>And there they will help us to find a care home. That was greatly appreciated. They also took away the burden of telling my parents that my mom was going to a care home and would not be able to return to her home.</i></li> </ul> <p><b>Lack of openness and courtesy of some staff members or healthcare professionals (n = 3)</b></p> <ul style="list-style-type: none"> <li>• <i>Some people ... at one point were more reluctant that I participate in care...they made me feel as if I was in their way ...</i></li> </ul>
<b>Theme 4: Recognition of the role and knowledge of family members and their preferences vs. lack of recognition</b>
<p><b>Recognition of the caregiver role and their preferences (n = 7)</b></p> <ul style="list-style-type: none"> <li>• <i>The staff thanked me for being here. [...] I told them that if they explained to me what to do, I would do it.</i></li> <li>• <i>For example, they [the staff] asked me at the beginning of his stay: "Will you wash him?" [...] I felt free to take decisions. They do not tell me: "do this, do that." But rather: "If you want, you can do this, but if you do not want to, you do not have to", I do not feel forced to do some tasks or care.</i></li> </ul> <p><b>Lack of personalization of care and services (n = 3)</b></p> <ul style="list-style-type: none"> <li>• <i>Care staff is on the front line. [...] [...] But sometimes they apply what they have learned in a somewhat uniform fashion. For a natural caregiver like me [...] this is not always suitable.</i></li> <li>• <i>It affects me to see that they do not view him, his daughter or his wife, with their own needs. [...] He's like a number, he's not LC, native of B, doctor for 40 years. His identity is gone. [...] I think it's not normal</i></li> </ul> <p><b>Lack of consideration of knowledge of family or relatives on patient (n = 2)</b></p> <ul style="list-style-type: none"> <li>• <i>... we must, of course, respect the clinical aspect, the competence of the physician. [...] But it took time for the doctor to trust me ... and to take my [the caregiver] knowledge more into account. I have been taking care of my husband for 5 years. I know him.[...] Perhaps to consider the knowledge of the loved one sooner, may help treat the patient better.</i></li> </ul>

(continued next page)

**Table 2. Facilitators and barriers to family participation to care. Themes and examples of quotes. (continued)**

<p><b>Theme 5: Visiting and caregiver presence policies: Open vs. restrictive</b></p> <p><b>Openness of staff to presence of family at the bedside (n = 8)</b></p> <ul style="list-style-type: none"> <li><i>I always wanted to stay with him. And they did not kick me out. They're not strict on that."</i></li> <li><i>They give us the opportunity to stay all day, that's good ... I can come at the time I want.</i></li> </ul> <p><b>Restrictive policies in emergency or intensive care units (n = 2)</b></p> <ul style="list-style-type: none"> <li><i>In the emergency ward, the security guard arrived and told me I had to leave"... Visitors are allowed ten minutes every hour on the hour in emergency wards. [...], "Please tell me what's going on with my wife" [...] "I will not leave [as long as I do not hear from her]". So the security guard came back, this time with a nurse who asked me to leave again, and go to the waiting room and wait for the next hour"... this is something terrible to ask of a close family member.</i></li> </ul> <p><b>Lack of clear policies (n = 1)</b></p> <ul style="list-style-type: none"> <li><i>When you are a very close family everyone wants to know: "Can I go or I should better not". "Can it be tiring for her?" Are there too many visits? not enough visit? I admit it was not at all clear for us.</i></li> </ul>
<p><b>Theme 6: Physical comfort: comfortable environment vs. uncomfortable or missing</b></p> <p><b>Adequate space and equipment (n=5)</b></p> <ul style="list-style-type: none"> <li><i>The physical environment is good. There is a family room. It's nice, it's beautiful [...] At first, he slept a little more. So I went to the living room, I went to eat, I had some rest.</i></li> <li><i>At the emergency ward when I arrived, I had to stay with my father because he was completely lost. And I stayed two-three hours standing there, I would have appreciated having a chair or even a stool.</i></li> <li><i>In the room, you have no privacy, for example, when the other patient has visitors, or when you are trying to sleep, or the person next to you is crying. We had 5 different roommates, you adapt, and they have to adapt too.</i></li> </ul>
<p><b>Theme 7: Coordination and continuity of care: well organised vs. not</b></p> <p><b>Having a contact person or liaison nurse (n = 2)</b></p> <ul style="list-style-type: none"> <li><i>For amyotrophic lateral sclerosis, we have MC, who is a nurse resource-person. If there is anything that does not work well, we can refer to her and she will move things forward. This is a big asset. There should always be someone like that [...]</i></li> </ul> <p><b>Lack of coordination (n = 2)</b></p> <ul style="list-style-type: none"> <li><i>I found that when you're hospitalized for a specific problem, it's like the rest of your body did not exist. He needed to change dressings, but it was not done in the hospital.</i></li> </ul>
<p><b>Theme 8: Personal characteristics of the caregiver and the patient</b></p> <p><b>Availability and wish to be present at the bedside (n=3)</b></p> <ul style="list-style-type: none"> <li><i>I'm here every day from 8:30 am to 8:00 pm. I walk in the corridor and everyone knows me, says hello. They are used to seeing me [...] When I'm not here, and my husband wakes up, [...] the staff seeks me quickly"</i></li> <li><i>Of course there are some people who would let the staff take care of him/ her. For my part, I wanted to take care of her. They did not force me. Sure, at one point they were used to it, they knew I would take care of her.</i></li> </ul> <p><b>Already having a caregiver role at home (n = 2)</b></p> <ul style="list-style-type: none"> <li><i>(help with daily care and activities): I did it when I was there (in the hospital) as I do at home ... It's normal for me. I see myself as a natural caregiver</i></li> </ul> <p><b>Enquiring personality, quick learner (n = 1)</b></p> <ul style="list-style-type: none"> <li><i>I naturally like to know what is going on. I like to know what happens. I can recall all that they have said so far ... Medicines, illnesses. I can learn quickly in general</i></li> </ul> <p><b>Knowledge of the healthcare environment (n = 5)</b></p> <ul style="list-style-type: none"> <li><i>I think it makes it a lot easier to know a little bit about how things are done in the healthcare. I think that for someone who is not familiar with this environment, it must be very difficult. If there is something I do not really understand, I can get the information from the right people.</i></li> <li><i>My niece said to me: " I do not know the health system. They can tell me anything, you best be there. "</i></li> </ul> <p><b>Handicap, age, education background (n = 3)</b></p> <ul style="list-style-type: none"> <li><i>I'm a little handicapped, I cannot help as much as I would like.</i></li> <li><i>My main obstacle is that I was raised like a guy. I think the 30-year-old men will stay at the bedside and feed their mother, but that's not part of my job (laughs). Not having a choice, I would, but seeing that the staff does it so well [...]. So I do other things..."</i></li> </ul> <p><b>Personal characteristics of the patient (n = 4)</b></p> <ul style="list-style-type: none"> <li><i>The staff seems to appreciate my spouse's character a lot perhaps that helps too. But again, I do not think we were disturbing people.</i></li> <li><i>My father is not easy to help, because he is so anxious and so stressed and terrified, it's hard, it's very hard.</i></li> <li><i>My father has an ill temper he is not easy to take care of.</i></li> </ul>

were impressed with the accuracy of the information and how it had been communicated to them, with diplomacy but frankness. Others pointed out the contrast between their actual experience and experience years back, when asking questions to the doctor was not something that people usually did, whereas now it appeared to some that “doctors make it their duty to inform relatives about their loved one’s condition and treatments”. Conversely, one-third of the participants (n = 6/18) spoke of a lack of information, mainly from the physicians, as a difficulty they experienced, and which represented a significant barrier to their involvement. Having difficulty meeting with the doctor, not knowing what to expect from the prognosis of their loved one or having “filtered or partial” information were other barriers. The difficulty of not knowing who to ask for information, and the difficulty in identifying the professional identity of the ward staff, was also highlighted by a few participants, one participant mentioned “this was so annoying and even distressing not to know who to turn to for information... I asked clinical information about my mom to the housekeeping staff a couple of times because all the staff’s uniforms look alike”.

According to most participants, receiving clear, structured information on how to deal with their hospitalized loved one, including concrete ways to help him/her with daily activities and how to collaborate with the care team, greatly facilitated their involvement. Usefulness of structured information on the disease, via brochures and crash courses, was also highlighted by a few respondents. Participants also appreciated the medical team’s support on how to communicate sensitive information about their condition and prognosis and, in some cases, on the difficult task of informing their loved one that they would not be able to return to their home, or on how to look for and select specialized accommodations for their loved one. Having a resource person regarding specific conditions (for example, amyotrophic lateral sclerosis in one case) or a nurse in charge of coordinating discharge from the hospital and continuity of care at home was greatly appreciated from participants in this situation. The nursing staff’s general attitude, their investment and professionalism, their courtesy and their good mood were commended and mentioned by several respondents as factors that greatly influenced their experience at their loved one’s bedside. Recognition of their knowledge and of their natural caregiver role, taking into account their preferences in the performance of various care-related tasks was also identified as a very helpful factor.

### 3.2. Access and physical environments

While flexible access to the ward was commended by some “They give us the opportunity to stay all day, that’s good ... I can come at the time I want, that really helps”, restrictive visiting hours, especially at the emergency ward and intensive care units, were pointed out as important barriers and quite stressful and frustrating for some respondents. For

example, a respondent whose spouse was admitted in the emergency ward reported: “People are allowed only ten minutes every hour in emergency wards. [...] this is something terrible to ask of a close family member.” A participant also mentioned that the lack of clear policies and guidelines for visiting hospitalized patients made it difficult to plan and further instruct family members about when they could come and help out or visit. Other difficulties with access included lack of appropriate furniture for caregiver to rest (lack of chairs in the emergency wards and other units). Insufficient adapted equipment, such as wheelchairs for transportation inside and outside the hospital, were also mentioned. Problems related to parking space in terms of cost, and sometimes inadequate or insufficient space and accommodations for people from outside the city were mentioned by several.

### 3.2. Personal characteristics

Several participants mentioned that their own personal characteristics influenced their participation in different care activities and influenced their level of involvement, including having a caregiver role at home or feeling close to the patient. Physical disability, older age, gender and education were mentioned by some participants as being factors that would probably interfere with involvement. Being constantly present at the bedside, which brought about a certain familiarity with the staff, was mentioned as greatly facilitating participation. The willingness to help, being proactive, having some knowledge or past experience of the healthcare environment, were also mentioned as being important enablers. As one participant pointed out, “knowing how things are done in the healthcare system makes it much easier to get involved and obtain information from the right people. It can be much more difficult for someone who feels lost in this impressive environment”. Personality characteristics of the patient were also mentioned by some participants as favoring or impeding their involvement.

## 4. Family members’ suggestions on how to improve experience and encourage participation

We also asked participants to share their suggestions on how the organization could facilitate and encourage their participation in care during the hospitalization of a loved one. Suggestions are summarized in Figure 1.

## Discussion

The aim of this study was to better understand the experience and needs of family members in order to identify how our organization can facilitate their participation in the care of their hospitalized loved one and help improve their experience at the bedside. Our results add to the evidence by refining our understanding of factors associated with family participation. Through in-depth analyses of 18 family members’ perspectives on participation to care, we have pinpointed factors that facilitated or impeded their implication and connected



**Figure 1. Participants' suggestions on how to facilitate family participation**

<p><b>1) IMPROVE COMMUNICATION</b></p> <p>Improve the transmission of information about the patient's condition</p> <ul style="list-style-type: none"> <li>• Have access to a schedule of doctor visits, paper or through web application;</li> <li>• Have access to a well-identified contact person who liaises with the family;</li> <li>• Have access to an easily accessible (web) application informing the family of relevant clinical information regarding the patient.</li> <li>• Implicate family members in the care plan or clinical discussions</li> <li>• Increase ease of identification of the personnel: different uniforms for different categories of personnel to help better identify who is who</li> <li>• Invite staff to present themselves and state their function as they enter the patient's room</li> </ul>
<p><b>2) EDUCATION REGARDING HOW TO HELP WITH CARE OF THE PATIENT WHILE IN HOSPITAL</b></p> <ul style="list-style-type: none"> <li>• Receive structured information on how to participate in care</li> <li>• Receive information (either written or verbal) on how to help the patient in his or her daily activities, how to communicate difficult information, how to manage extended family visits,</li> <li>• Systematic face to face encounter with a nurse or doctor to plan how to best help or how to help the staff to take care of the patient in a personalized way.</li> <li>• Increase the coordination and continuity of care between the hospital and the home through access to a designated resource person who knows the patient's story</li> <li>• Receive written information on how to care for the person and what signs to watch for, when to come back if needed, etc.</li> </ul>
<p><b>3) PROMOTE MORE HUMANE CARE (MORE HOLISTIC VIEW OF THE PERSON)</b></p> <ul style="list-style-type: none"> <li>• Increase the recognition that family members know the patient very well and hold information that will help personalize care (experiential knowledge)</li> <li>• Personalize the hospital stay- enquire about who is this <i>person</i> and inform care staff about the patient's likes and preferences</li> <li>• Involve family members in care plans</li> </ul>
<p><b>4) IMPROVE PHYSICAL COMFORT FOR THE CAREGIVER (HELP THEM FEEL WELCOMED)</b></p> <ul style="list-style-type: none"> <li>• Provide adequate furniture (ex., comfortable chair, coth) in patient rooms and waiting areas</li> <li>• Provide adapted equipment (ex., wheelchair)</li> </ul>

those with their perceived roles towards the patient and with their own needs during this stressful period. As with the results of others,<sup>6,7,9,10,16-18</sup> one of the points that emerged in our study is the paramount importance of communication. Our results further showed that the need to receive accurate, clear and transparent information, as the condition of their loved one evolves, was deemed essential for all respondents. In directly asking respondents to share their views on how our organization can facilitate their involvement in their loved one's care, this study was able to identify specific actions and processes to target in order to improve family members' experiences during hospitalization (see Figure 1). Specific suggestions included increased access to doctor rounds, for example through

paper or Web schedules made available to family members, and access to a designated contact-person. Some authors recommend systematic involvement of a family member during doctor rounds or to involve the family in the shift change at the bedside.<sup>6</sup> Our results rather suggested that what appeared of upmost importance for family members in our sample was that the information be made available to them on a regular and consistent basis, regardless of the chosen means of communication.

Family-presence policy authorizing a caregiver to stay for prolonged periods of time at the bedside was also deemed very helpful and appreciated. Other suggestions included having easy access to handy information, such as caregiver

presence policies and how and when they can communicate with the care team, and to more general information (e.g., hospital visiting hours, cafeteria opening hours and information about accommodations nearby).

The lack of clear indications given to families about how and when they can participate in the care of their hospitalized loved one was a major obstacle highlighted in our study, and this is also in line with others.<sup>8, 18, 19</sup> Most participants reported feeling overwhelmed in what they qualified as a *foreign and hostile* environment. Our results further suggested that if there are no procedures to ensure that opportunities for participation are offered to natural caregivers by the care team, involvement will often depend on the personal characteristics of family members, for example, having a proactive personality and the ability to impose their will to get involved. In addition, several participants mentioned that their role and knowledge of the patient was recognized and valued by the care team, however others mentioned that this point needed improvement in order to promote and deliver more holistic and humane patient care, make families feel welcomed at the bedside and value their experiential knowledge.

Taken together, our results and those of others<sup>20</sup> suggest that care teams can play an important role in facilitating the involvement of family members and should be trained to proactively offer opportunities to participate and support natural caregivers' participation. However, it is important to evaluate family member's wishes and capacity to participate in care from the outset. While some will want and be able to participate in direct care as much as possible, others will not, but can still provide information about the patient, take care of transitions from the hospital and the home and, just by being present, allow patients to maintain a connection with the outside world. Feeling involved in the care process can alleviate helplessness and may foster a sense of usefulness for caregivers and other family members and facilitate their adaptation to this stressful life situation.

Major hospitalization of a loved one is often a dramatic experience. Family members' emotional needs may be great during that time, however these are often forgotten.<sup>18</sup> Our results clearly show this and go further in highlighting that family members could not easily identify their own needs during that period, mostly because they were so focused on their loved ones. While some respondents spoke of the experience of intense stress and fatigue, it was hard for them to identify how they could, or wished, to be supported during this trying time. It would therefore be important to offer spontaneous psychological support to caregivers, for example through active listening, or by encouraging them to take some time to rest.<sup>9</sup> An interesting suggestion included organizing a space where they could rest, on or near the ward, without fearing they

might miss the doctor's round or important information about changes in their loved ones' condition.

These results need to be interpreted in light of some limitations. Although we felt saturation of the data was reached, our results cannot be extrapolated to other care settings. It is possible that additional or different results could have been observed on other wards or units, such as obstetrics for example, where family members may have different needs. Nevertheless, our main results are in line with those of other studies in intensive care or emergency settings. While the strategy of meeting with participants on the ward has proven to be effective for recruitment purposes, limitations may be associated with this methodology. It is possible that additional information may have been collected if participants had had more time to reflect on the interview questions beforehand. It is also possible that a selection bias may have influenced or results. In recruiting participants who were present on a regular basis, the views of those who were not may have been overlooked. Finally, given the small number of participants recruited on each ward, we did not carry out analyzes by ward type. Based on the present results and those of others, it would be interesting to carry out analyses by type of health issue and intensity of care (intensive care, re-adaptation, general) in order to better delineate specific needs of family members and what actions can be carried out by healthcare organizations and care teams to encourage and support family members' participation and lessen their emotional burden.

In conclusion, this study allowed us to collect rich and detailed information about the perspectives of our patients' family members who were at their bedside, which will help our organization prioritize actions to encourage and support their participation to care. Results, with an accent on participants' suggestions, were presented to our organization's clinical leadership committee and our board of directors' service quality committee, who retained several of those ideas as possible levers to improving patient and family experience through welcomed and facilitated contribution to the care of a loved one. For example, results from this study were an important lever to encourage our organization to join the *Better Together Campaign*, which encourages organizations to welcome family members 24/7 at the bedside.<sup>21</sup> Finally, the fact that these ideas resulted from an open conversation with our clientele resonated more strongly with leadership committees and will likely accelerate implementation of some of the suggested initiatives.

## Footnote

a. The terms “family” or family members will be used alone from here on, in order to alleviate the text; however we wish to remind the reader that, in the present context, it will encompass other significant others and friends which may not have family ties per se, but who are identified as such by the patient.

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