Integrated Funding Models Caregiver Experience Survey Final Report

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HEALTH SYSTEM PERFORMANCE RESEARCH NETWORK (HSPRN)

This report presents results from the Integrated Funding Model Caregiver Experience Survey conducted by the IFM Central Evaluation Team from the Health System Performance Research Network (HSPRN) at the University of Toronto.

Survey methodology

The IFM Central Evaluation Team aims to complete 10 surveys per IFM program per month. Patients were randomly selected from the list of patients provided by each IFM. Each IFM program obtained permission from patients prior to sharing the contact information with researchers at the University of Toronto. At the end of their bundle period, patients were mailed a package that included two sealed envelopes, one addressed to the patient and, beginning in October 2017, the other one to their primary informal caregiver, as well as an instruction letter that explained the contents of each envelope. The patient was asked to identify their primary informal caregiver and share the caregiver envelope containing the Caregiver Experience Survey (CES) with this individual. Telephone and electronic versions of the survey were also available if the caregiver preferred these other modes.

The survey included questions on: 1) the caregiver's health status; 2) their caregiving experience; 3) caregiver's burden / time spent caring for the patient and any costs incurred; and 4) the caregiver's background information. Questions were selected from a number of other surveys including the *Zarit Burden Interview*, *Mental Health Carer's Survey*, *Family/Friend Caregiver Survey*, *General Social Survey,* among others.

How to interpret the results

This report presents results for each program and pooled across all IFM. Positive responses are shown in varying shades of green, while neutral responses are in yellow and negative responses are in red. The percent positive response is also presented by a diamond-shaped point in the middle of each bar. For questions with four or five response options, the percent positive response is a combination of the two positive response options (e.g. completely or quite a bit; nearly always or quite frequently). For questions rating their experience on a scale of 1 to 10, the percent positive response is a combination of response options 7, 8, 9 and 10. A minimum of 5 responses were required per bar for privacy reasons.

The number of responses for each question is indicated by a number at the top of each bar graph.

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Section 1 - Experience during the Index Hospitalization

Figure 1. The proportion of caregivers who reported that healthcare professionals listened to their concerns about the patient, October 2017 - July 2018

Total percent positive was 68.5% and varied from 44.4% to 80.0% across the IFM programs.

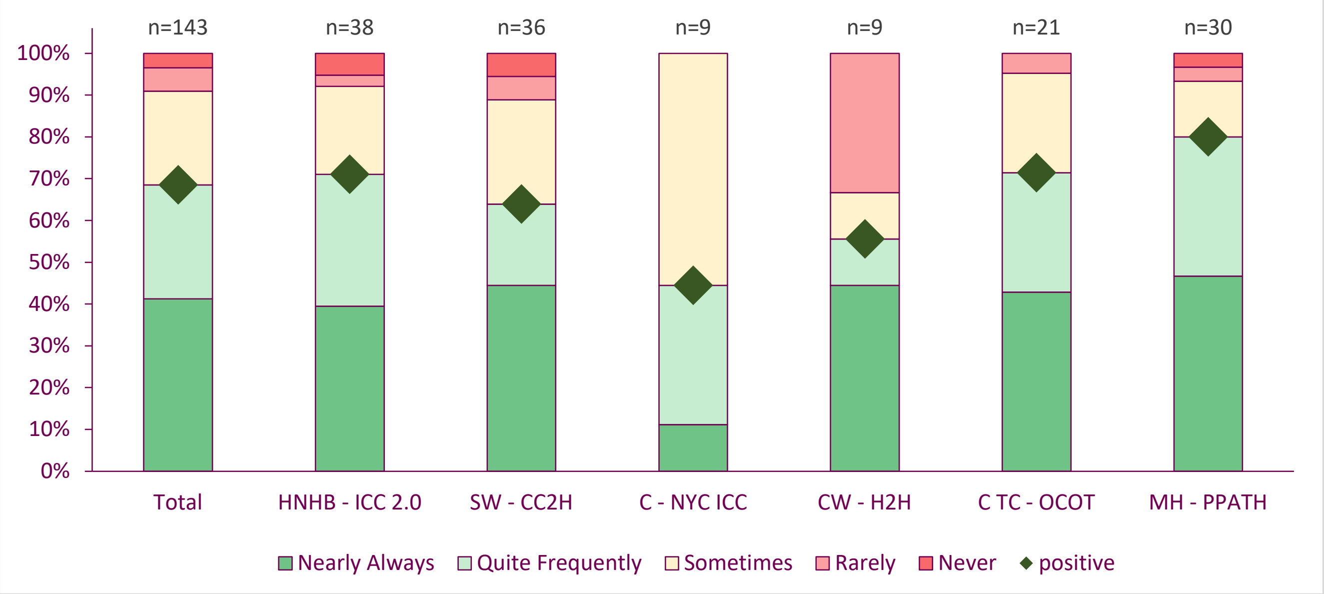


Figure 2. The proportion of caregivers who reported that healthcare professionals made them feel involved in decision making, October 2017 - July 2018

Total percent positive was 56.8% and varied from 33.3% to 66.7% across the IFM programs.

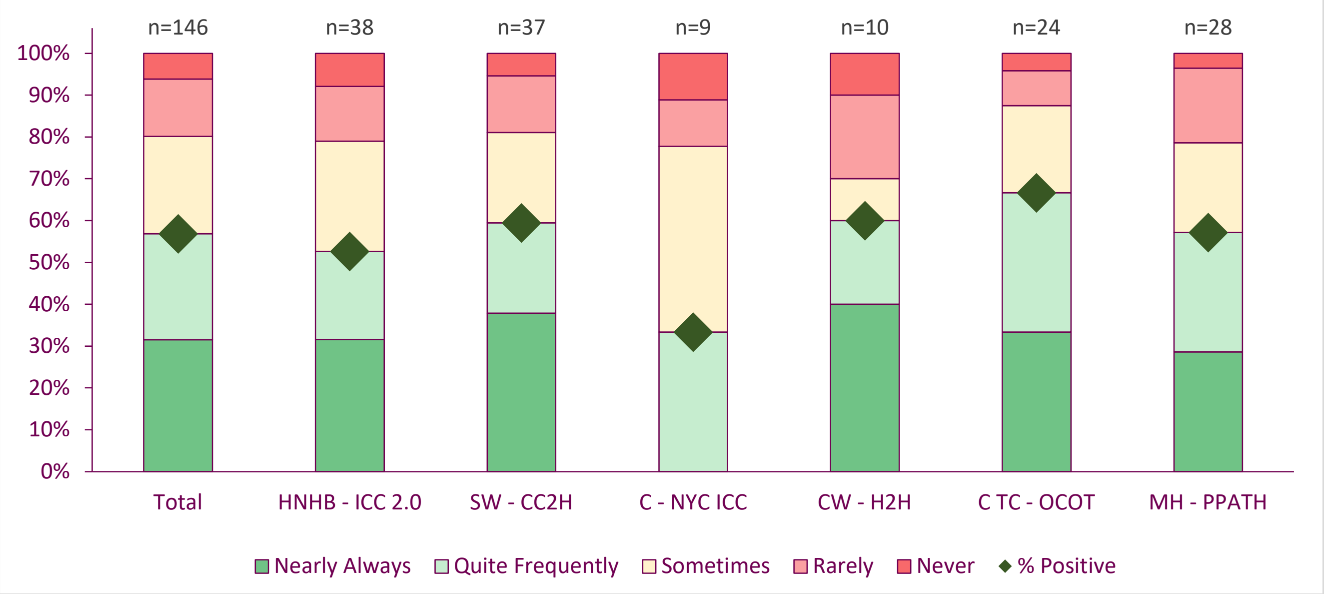
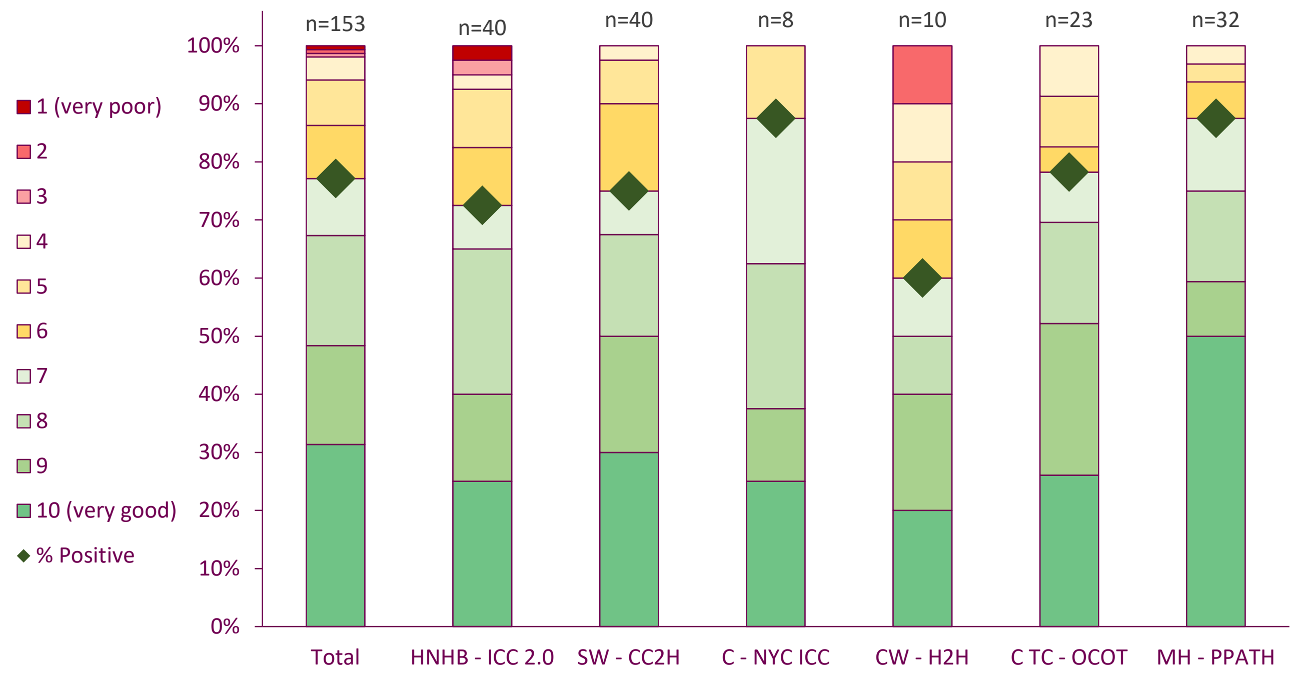


Figure 3. Caregiver rating of in-hospital care experience, October 2017 - July 2018

Total percent positive was 77.1% and varied from 60.0% to 87.5% across the IFM programs.



Section 2 – Experience with the Transition from the Index Hospitalization

Figure 4. The proportion of caregivers who were included in the planning for the patient's discharge, October 2017 - July 2018

Total percent positive was 58.5% and varied from 44.4% to 67.7% across the IFM programs.

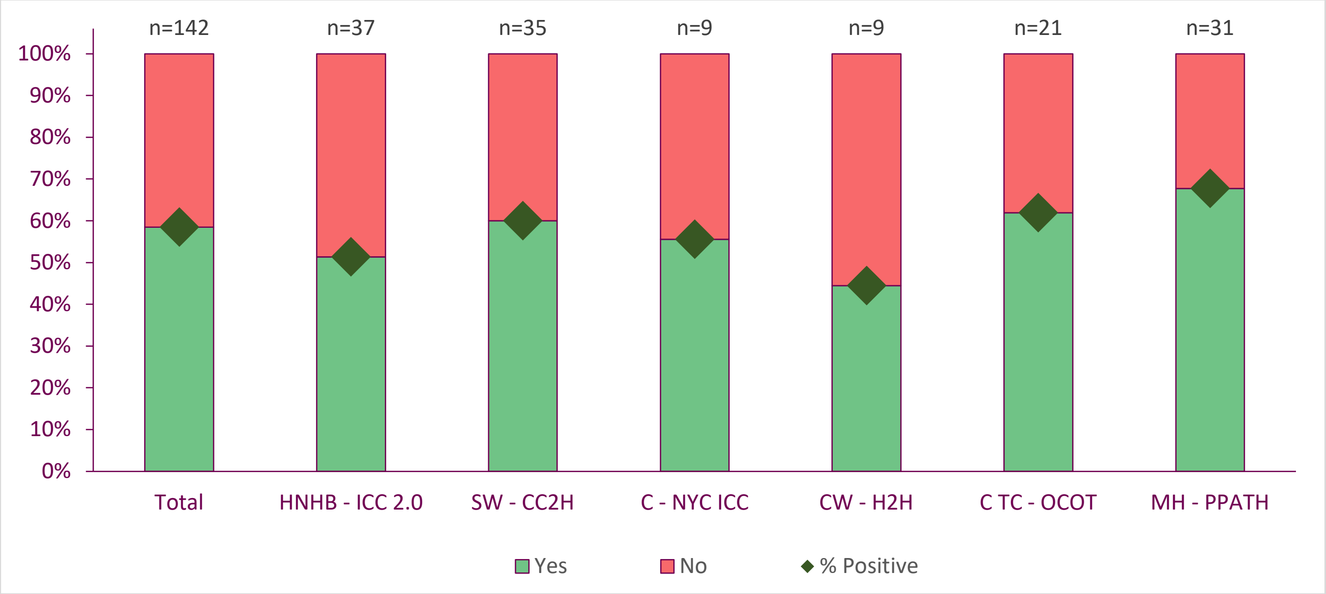


Figure 5. The proportion of caregivers who were asked by hospital staff if they were able or willing to help with the patient's care, October 2017 - July 2018

Total percent positive was 59.1% and varied from 51.5% to 71.0% across the IFM programs.

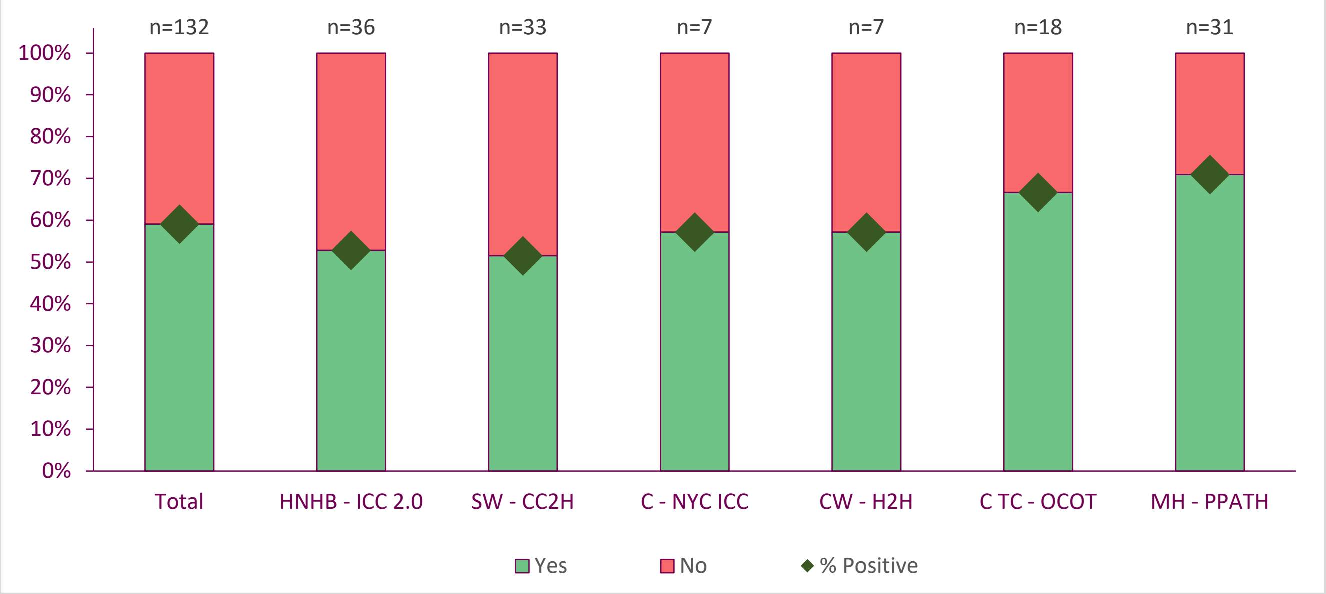


Figure 6. The proportion of caregivers who were given enough information on the patient's condition or treatment before leaving hospital, October 2017 - July 2018

Total percent positive was 72.1% and varied from 65.9% to 81.3% across the IFM programs.

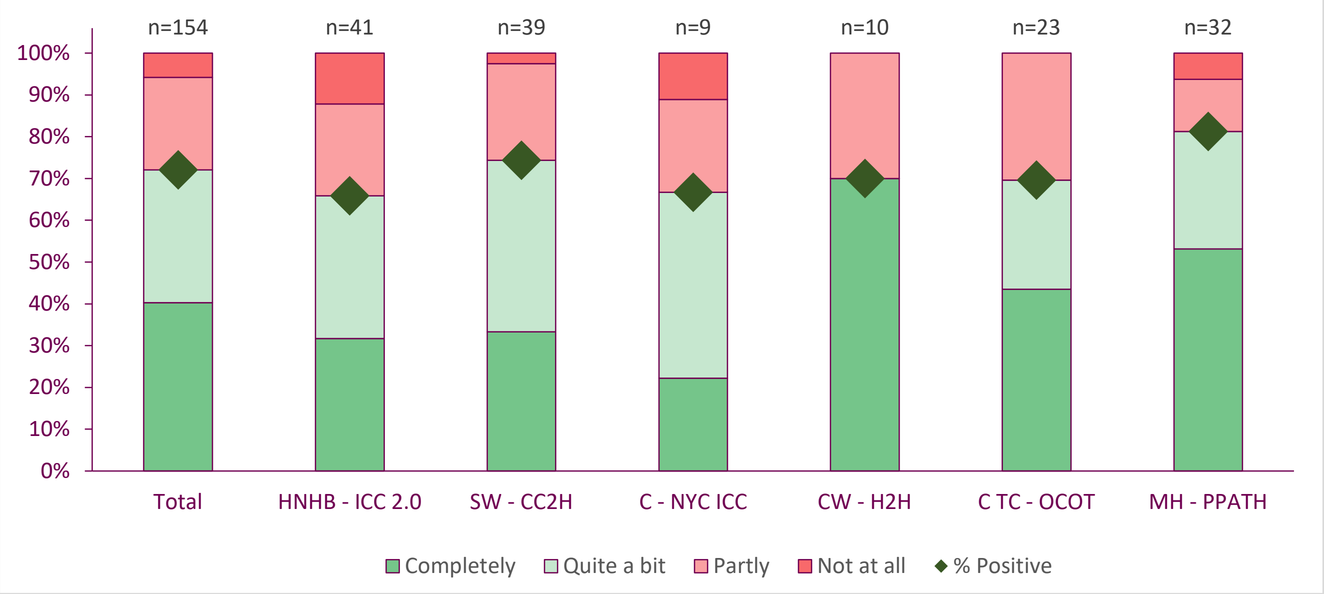
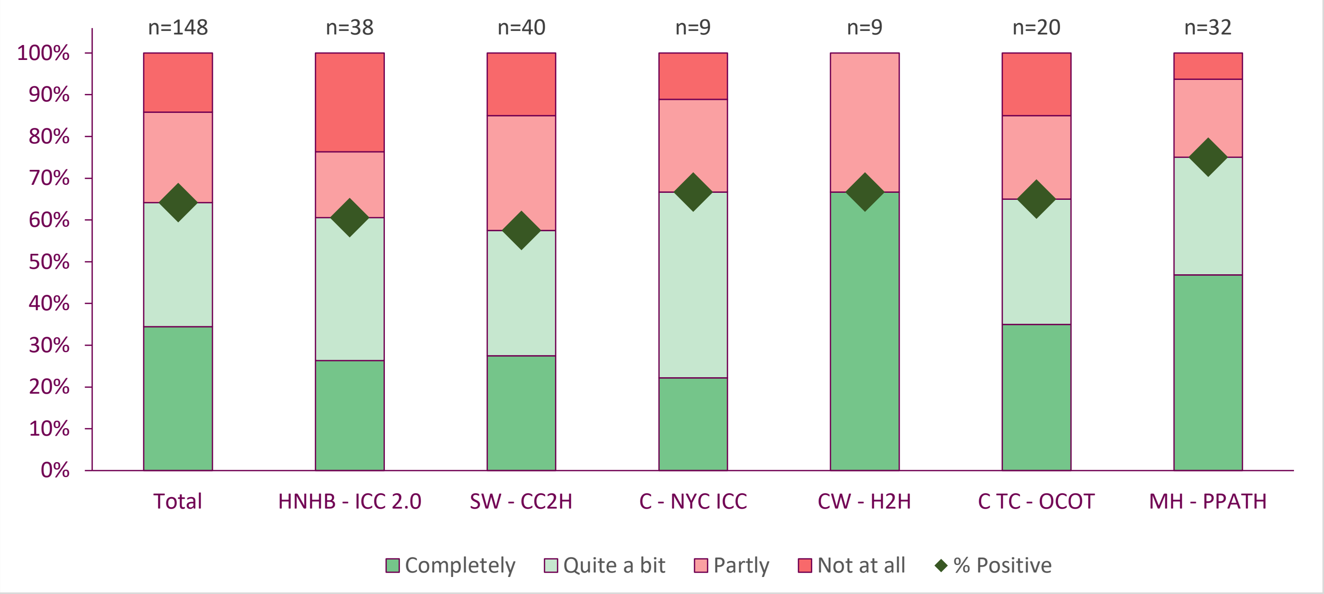


Figure 7. The proportion of caregivers who were given enough information on how to provide care or help the patient at home, October 2017 - July 2018

Total percent positive was 64.2% and varied from 57.5% to 75.0% across the IFM programs.



Section 3 – Experience Once Back in the Community

Figure 8. The proportion of caregivers who reported that members of the home care team were available when they needed them, October 2017 - July 2018

Total percent positive was 81.6% and varied from 66.7% to 100.0% across the IFM programs.

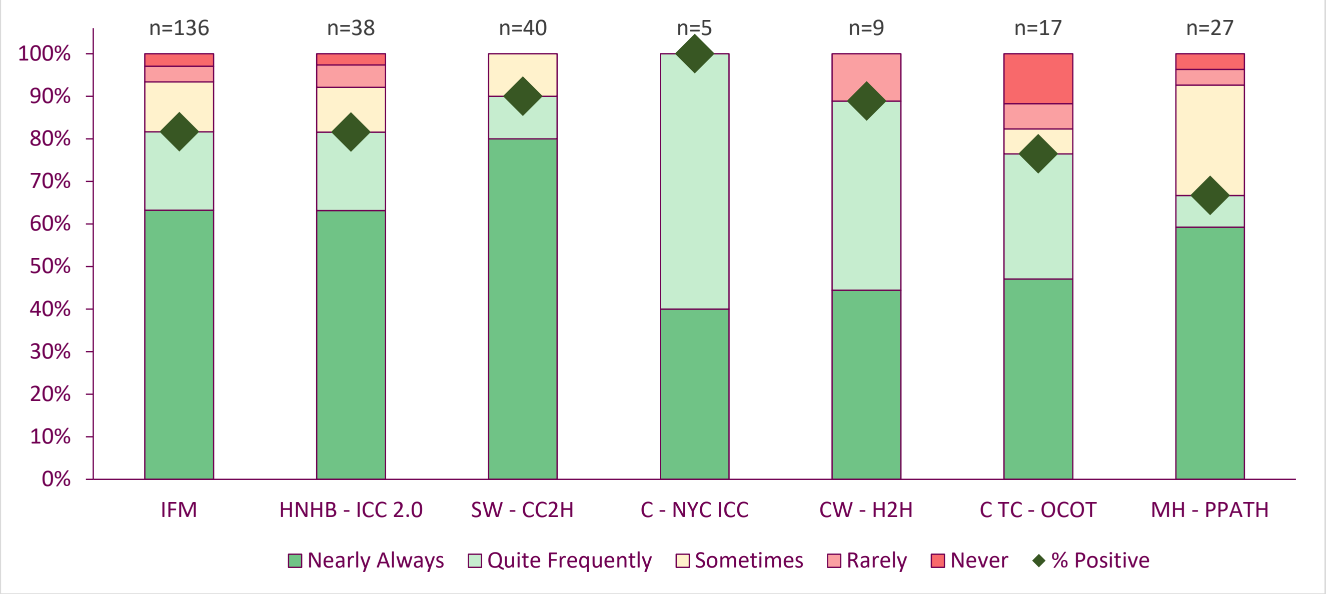


Figure 9. The proportion of caregivers who reported that home care visits were arranged in a manner that was convenient for them, October 2017 - July 2018

Total percent positive was 87.6% and varied from 83.8% to 100.0% across the IFM programs.

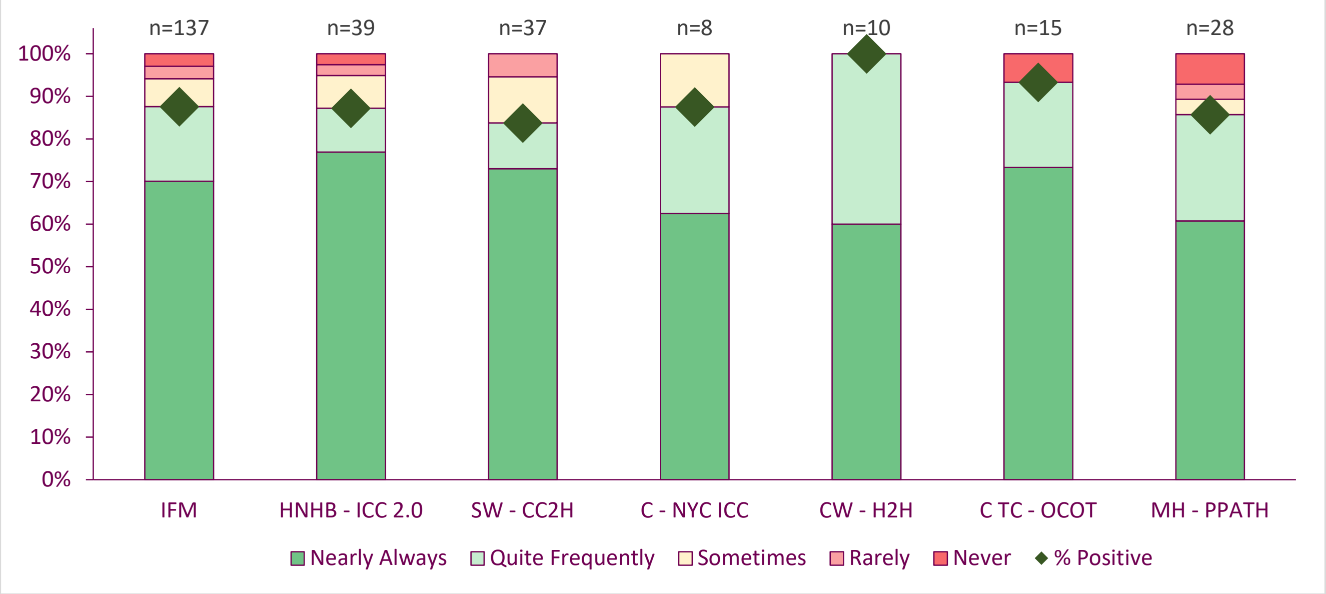


Figure 10. The proportion of caregivers who reported that the home care team seemed informed and up-to-date about the care the patient received in the hospital, October 2017 - July 2018

Total percent positive was 80.4% and varied from 70.0% to 86.5% across the IFM programs.

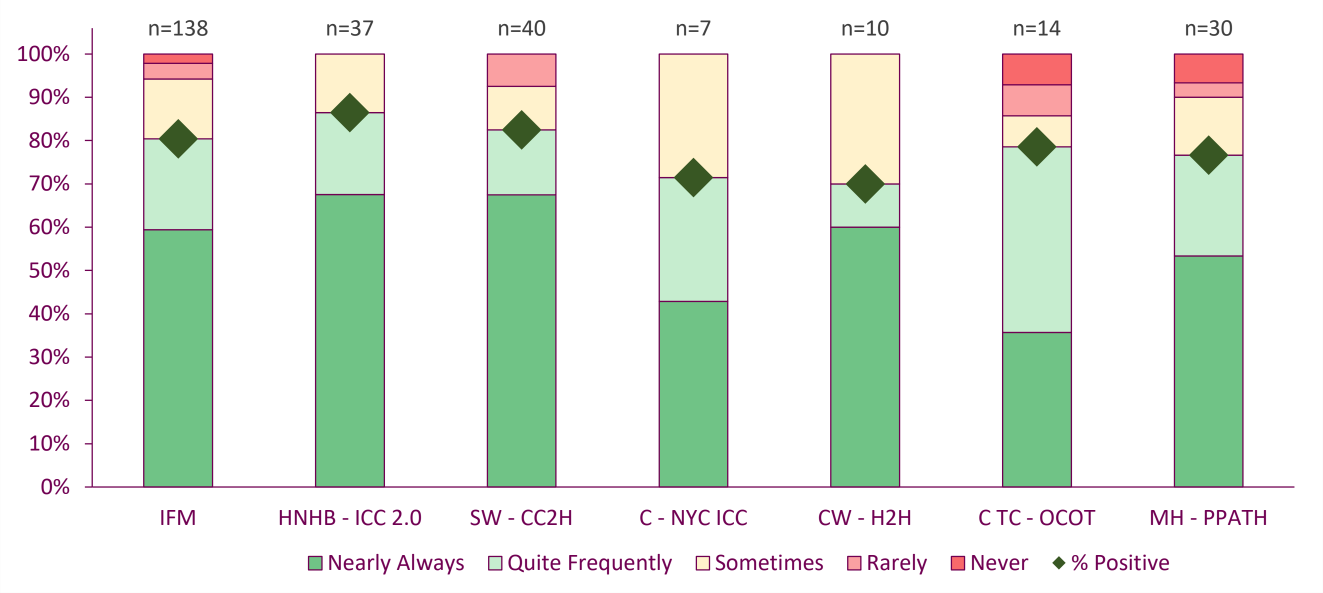


Figure 11. The proportion of caregivers who reported that the doctors or staff at the place where the patient usually gets medical care seemed informed and up-to-date about the care the patient received in the hospital, October 2017 - July 2018

Total percent positive was 80.6% and varied from 70.0% to 88.9% across the IFM programs.

Figure 12. The proportion of caregivers who reported that somebody from the homecare team conducted an assessment of the supports they needed to help care for the patient, October 2017 - July 2018

Total percent positive was 69.7% and varied from 55.6% to 75.7% across the IFM programs.

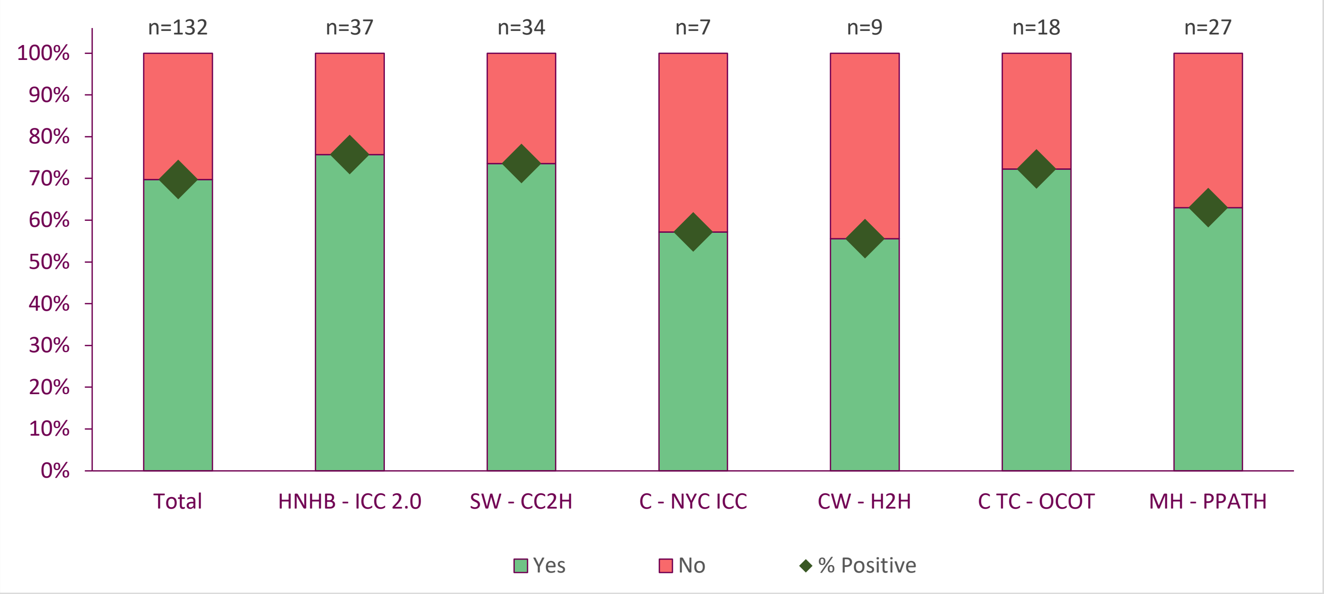


Figure 13. The proportion of caregivers who reported that somebody from the homecare team gave them information on caregiver support services (e.g. respite, caregiver support groups, educational seminars) or on how to care for themselves, October 2017 - July 2018

Total percent positive was 43.7% and varied from 22.2% to 58.8% across the IFM programs.

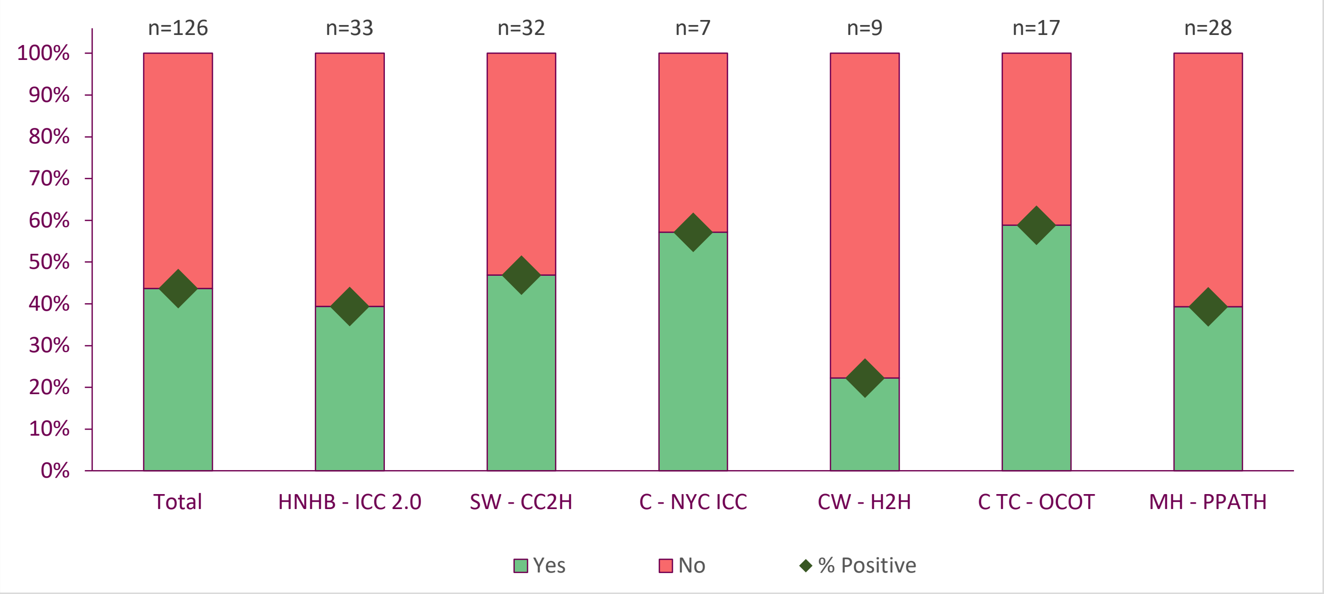
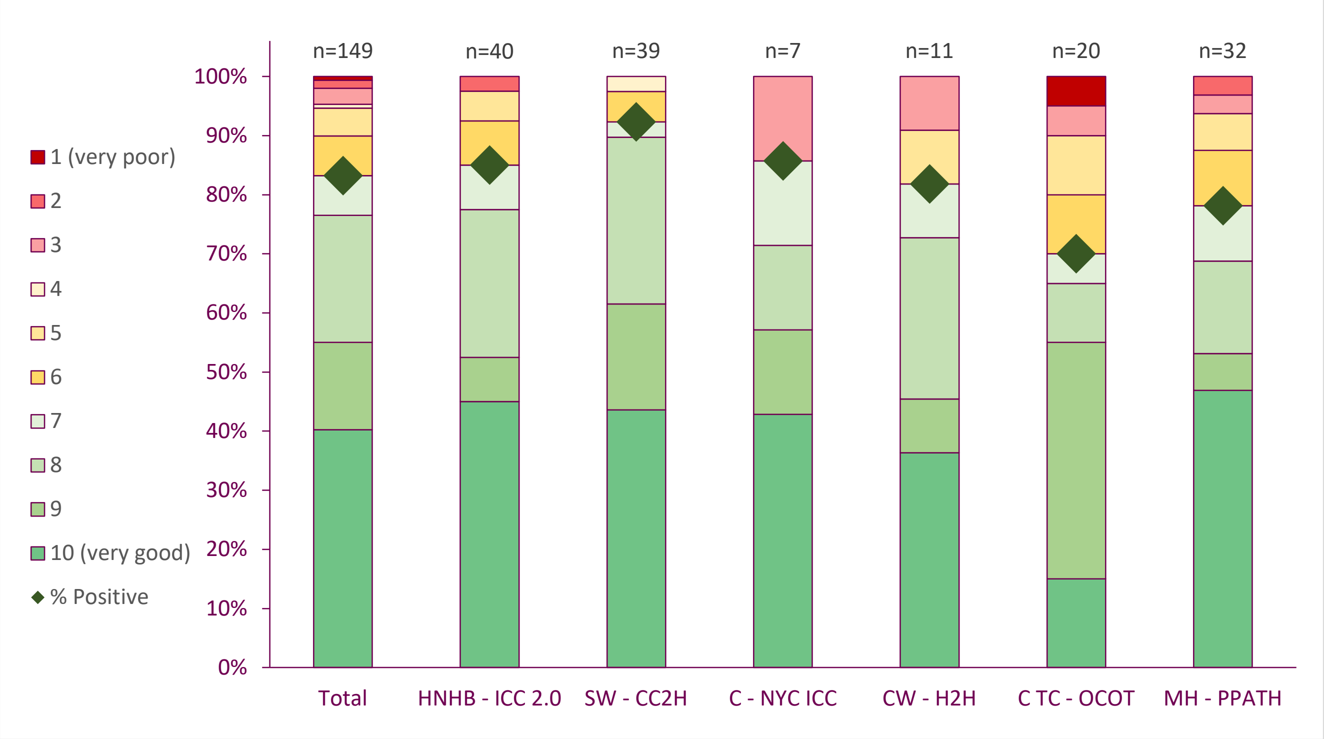


Figure 14. Caregiver rating of post-discharge home or community care experience, October 2017 - July 2018

Total percent positive was 83.2% and varied from 70.0% to 92.3% across the IFM programs.



Section 4. Impact of Caregiving (Burden, Time, $)

Figure 15. The proportion of caregivers who feel stressed between caring for the patient and trying to meet other responsibilities for their family or work, October 2017 - July 2018

Total percent never or rarely stressed was 48.1% and varied from 18.2% to 77.8% across the IFM programs.

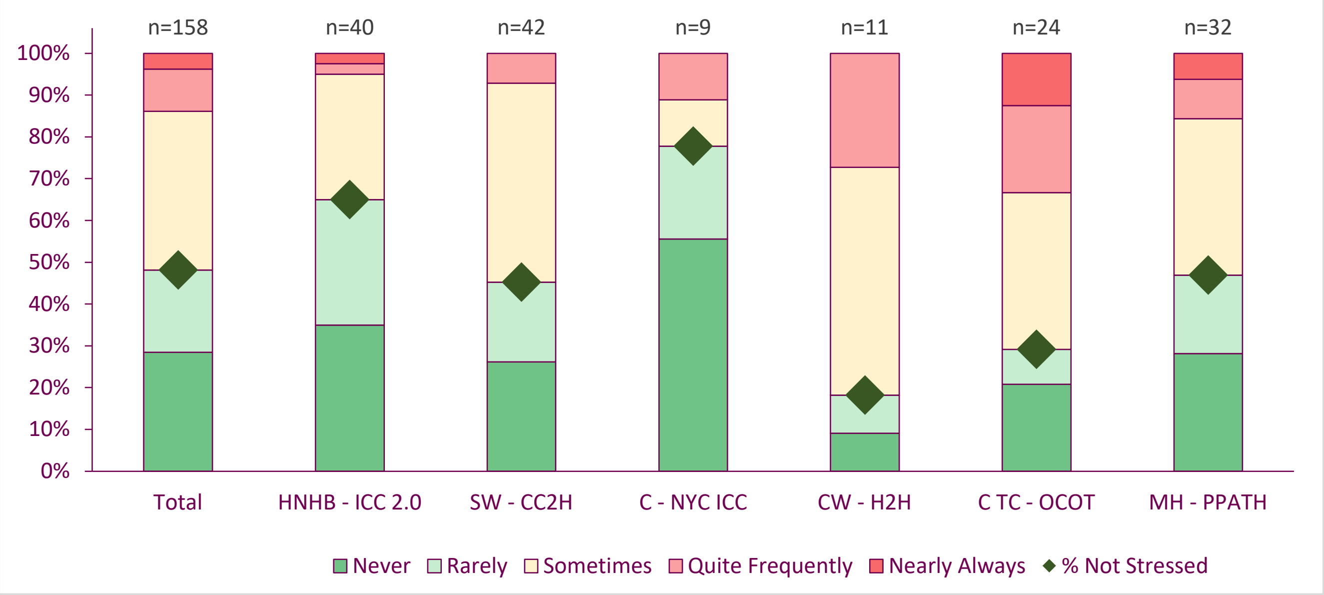


Figure 16. The number of hours of help the caregiver provided to the patient in an average week since the patient was admitted to the hospital, October 2017 - July 2018

Approximately, 55% of caregivers reported spending more than 10 hours per week helping the patient.

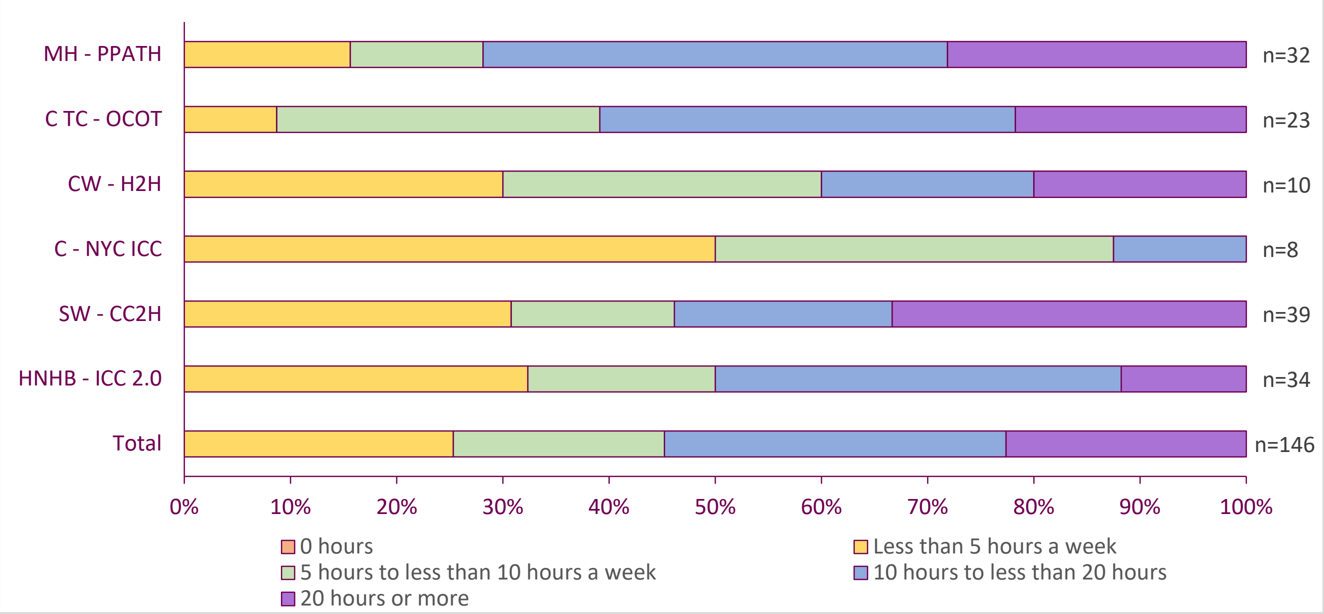


Figure 17. The amount of money spent by the caregiver and patient on prescription or non-prescription drugs for the patient's use since the patient was admitted, October 2017 - July 2018

Over 66% of caregivers reported spending some (>$0) money on prescription drugs for the patient's use.

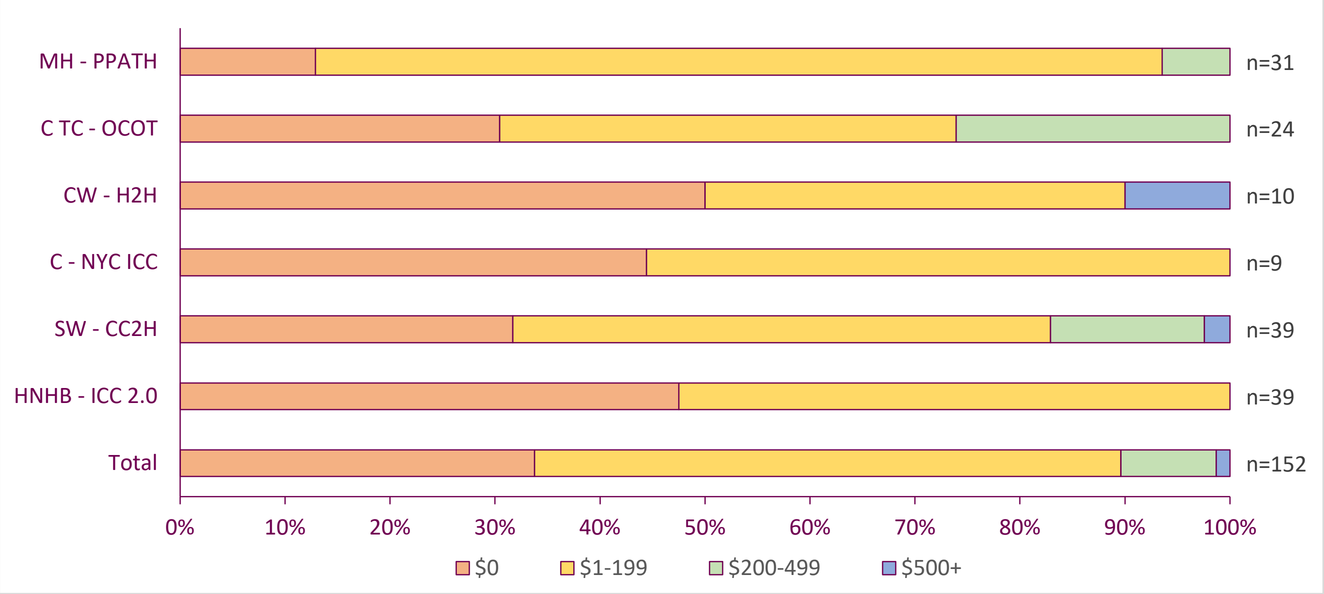
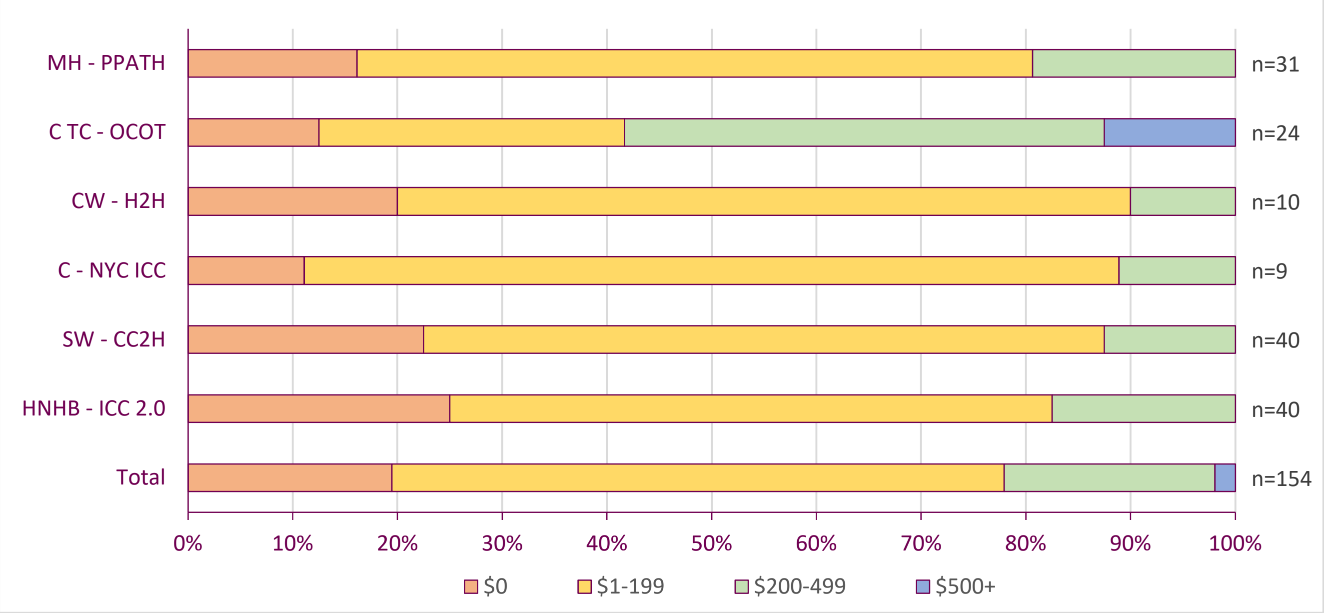


Figure 18. The amount of money spent by the caregiver and patient on other expenses resulting from the patient's health issues, such as transportation and parking, since the patient was admitted, October 2017 - July 2018

Over 80% of caregivers reported spending some (>$0) money on other expenses such as parking and transportation.



Section 5. Caregiver Comments

Respondents were able to share any additional comments about their experience, either at the end or, for telephone surveys, throughout the survey. For telephone surveys, responses were transcribed as the respondent spoke. Square brackets are used to indicate any words that were not transcribed verbatim at the time of the survey and have since been inserted.

HNHB – ICC 2.0

1. **[Final Comment]** *“The Province of Ontario has been announcing enhanced support programs to keep the elderly in their homes rather than assisted living facilities BUT I have asked the local PSW system, the family doctor, the hospital discharge staff and other caregiver friends where and what support they can give and all my mother gets is two showers per week. All other support to remain in her home is through a paid cleaning lady (once/month for $50) and a former PSW worker (4hr/wk for 3 visits @ $25/hr) her home support is through her son (me) for home maintenance and paid private services +/- $500/mo provincial/municipal support is non-existing. The province has DECEIVED the public about additional help for the elderly - SAD!!”*

2. **[Final Comment]** *“All our contacts were very professional and courteous and appropriately helpful. A very good experience with all contacts.”*

3. **[Final Comment]** *“Just general concern for my wife, as she has several ongoing health issues.”*

4. **[Final Comment]** *“What will happen to our healthcare system when I am 65 years old?”*

5. **[Final Comment]** *“Everyone was very helpful at the hospital. All nurses/home visits have been helpful & included me in conversations.”*

6. **[Q24]** *“I am the home care team.”*
   [Final Comment] *“My brother suffers from COPD & Type I diabetes, he also has some mental health issues. My problem is to get him to comply to outside help. House keeper only. I cook for him, drive him, laundry so he can stay in his apartment at my expense, which is okay.”*

7. **[Final Comment]** *“The Brant Community Health System along with the Homecare teams need a lot more work. The problem being that the right hand never knows what the left hand is doing. One person would say one thing and the next wouldn't know anything about it. Therefore, this system still has bugs. Once you work them out and everybody's on the same page, I'm sure this will be a valuable and workable system. All of the staff on the homecare team were wonderful and kind to the patient and good at what they do, just not aware of what the other one was doing. Hopefully, you can work this out. Thank you.”*

8. **[Final Comment]** *“The Brantford GH was excellent for my husband's care. The meals, however, could improve. We had homecare & they were very good, except the dietitian, she was here for about 10 mins & explained the different diets he should be on & said any amount of sugar is alright (wrong) but the salt issue was explained.”*

9. **[Final Comment]** *“For the first 3 days of my husband's hospital stay, I was with him most of the day and night (except for trips home to retrieve clothing, meds and his CPAP machine). Procedures, test results and med use were explained to both of us and we opted to take advantage of the integrated comprehensive care program. I lost contact with medical personnel when my husband was*

transferred to a ward that was closed due to a flu outbreak. During the outbreak, the hospital provided free phone service but they failed to notify the patients (and consequently, family members) when the "phone service" was terminated - I had much difficulty trying to reach my husband. Otherwise, he received excellent care during his hospital stay. The home care team was fantastic (other than 2 canceled nurse visits). The nurses were supportive and informative. The physiotherapist suggested "gentle exercises". The occupational therapist evaluated and approved of my husband's mobility and safety devices (years ago, when he had both hips replaced, he purchased a walker, rollator, scooter, cane, crutches and a bath bench and he installed shower bars and porch handrails.) Now that I have arthritis, the bars and handrails are beneficial for me too. Since we already have these aids, I answered $0 to question 36. I also answered $0 to question 37 because the government assistance and our private medical insurance covered the prescriptions. As my husband's caregiver, the person who helped me the most was the dietitian. In fact, we asked [them] to return for a second 2-hour visit so I could have her assess my new and healthier shopping and cooking methods which are important for both of us (his heart condition necessitates a low sodium diet, for example). I wish all this help was available years ago when I was my mother's primary caregiver after she suffered a stroke."

10. **[Final Comment]** *"[Their] stay was pleasant and the care exceptional. From ER (Zone 1) to B6, the healthcare providers were kind, confident in their treatment, and always took the time to answer any questions. Although [the patient] has a heart problem, he is capable of doing everything for himself."*

11. **[Final Comment]** "*The ICC Programme has been excellent help for me and my husband. It was comforting to know there was someone I could call for answers to any health concerns that might arise. The nurses, physiotherapist and dietitian were all most pleasant and provided much valuable information to best help my husband, and therefore, me!! Good programme!!"*

12. **[Final Comment]** *"The patient was put on a diabetic needle in the hospital. He was sent home without how to do it. I called a neighbour who helped him. He was put on CCIC who had my very ill husband going with me to a clinic on Colborne St that night 8:20 PM to have his intravenous bag replaced in a bad snow storm. The 2nd bag in clinic the next AM in a storm. It was so hard on both of us that a nurse came and told me we should have been with CCAC. I was doing everything for him and told CCAC would be in touch - no call. His appt with heart specialist told me to call them, give Dr. name, to get me help NOW. Nurses were great. He got help with showers. I was told I had 4 hours a week. Some came which got me out, some 25 min late. I took extra time at 3 hour and was told 1 hour expected. They canceled without telling me."*

13. **[Final Comment]** *"Sometimes it can be very stressing and I seem to never get all the work and things done."*

14. **[Q45]** *"Cannot say - no longer visit family, no longer volunteer, no longer pursue leisure activities. I have contracted with VON for 3 hours of respite on Thursdays. That is the only relief I get."*

[Final Comment] *"Program was fine for my mother. Offered nothing for me. As sole caregiver, I desperately need respite services. CCAC/LHIN would not deal with me as long as my mother was a participant in this program. Program was fine for my mother but why did it end? She is 92.5 years, has CHF and mid-stage dementia. I would be surprised if she lives to see 2019. Continuity of care would have been appropriate and appreciated. After 2 months, her condition remains and is even worse."*

15. **[Final Comment]** *"In the hospital the doctors took her off her blood pressure medication and this made her pressure rise to a dangerous level. The pain clinic she was going too picked it up and refused further treatment until she brought under control. Our family doctor is now endeavouring to bring it under control so she can return to her pain treatment. This should never have happened."*

16. **[Final Comment]** *"Caregiving is not an easy experience and is more complicated if you are emotionally involved rather than in a nurse/patient relationship for example."*

SW – CC2H

17. **[Q6]** *"When he was in hospital I didn't have time because I was there all day. I was exhausted. Because when I was there I had to do his bed, I had to take care of him. My husband thinks I give him too much, that I do too much for him and it gets on his nerve, its not my fault, I just worry a lot. He wants to control a little bit more (ie dress himself). Let's say I try to help him, he gets upset because I'm always after helping him. He says he wants more space. He's [Age Redacted] and I'm [Age Redacted]. He's [Country Redacted], and I'm [Country Redacted], he's an introvert and I'm outgoing. He doesn't realize that the way he talks to me, he doesn't realize. He has an infection now. I went and bought him something to cover and he got mad because it was expensive. But I cannot return it. Would you prefer if someone helps you, he said 'No'. It seems like he has to tell me what to do. Emotionally I get very, very tired. I'm already on anti-depressants, but sometimes I have panic attacks. You never know when it goes. Emotionally I'm not."*
    [Q8] *"Lately quite frequently."*
    [Q9] *"I know what to do. I'm very conscientious."*
    [Q12] *"They give me all of his medications. They took good care of him. The nurse came, but I had a hard time with him he wanted to go to [Redacted] to work."*
    [Q14] *"Somebody came and asked for that service. She said if you don't want it, you have to sign something, they will find someone else who wants it."*
    [Q15] *"I think maybe the nurse asked."*
    [Q16] *"Because I knew he had heart failure."*
    [Q17] *"They gave us after."*
    [Q20] *"The agency was good care, but the hospital was busy. But last week because the patient had a little (inaudible) he didn't want to have needle. Do you mind if someone else comes to talk to your husband. I understood that as them not wanting to care for the patient. A counselor came to the patient. Asked the patient "do you want us to take care of you?" Another doctor told us that he was going to die."*
    [Q21] *"We can talk to them if they have something."*

[Q22] *"At the beginning they come in to take his blood pressure, but now with Saint Elizabeth they are very up to date. I don't want him to go to the hospital."*
[Q23] *"If I call the doctor he won't answer. He used to be a good doctor. It was one doctor I was upset about and he did not do anything."*
[Q24] *"They used to write everything on their computer every time they came. Saint Elizabeth wrote everything by hand."*

18. **[Final Comment]** *"When my husband was taken to the hospital, he was treated great. The doctors and nurses were very helpful, they told me what to expect and what to look for. During his stay, they answered all questions and they treated us, the family, with respect. I am so happy that they were there for us during and after his visit. Thank you all so very much. Best regards, [Name redacted]"*

19. **[Final Comment]** *"2 nurses involved were very helpful to explain any concerns with a caring attitude. PSWs were on time & explained as best they could if patient has concerns feeling not great that day. - Respiratory techs only had 2 visits. More businesslike rather than what her needs were, very disappointed in Pro Resp Company for I had to deal with who was paying for O2. Explained government funded no charge. [Date Redacted] patient phones company to ask question about oxygen & were notified they were just preparing invoice - "Surprise" - not satisfied with this company right from start!"*

20. **[Q23]** *"The family doctor didn't get the information soon enough."*
    [Q25] *"Towards the end of homecare I said there were no suggestions on help I might need or could have used. At times, I felt overwhelmed and almost exhausted."*
    [Final Comment] *"I assumed all the questions referred to after [patient]'s discharge. I would like to say that even when he was in the hospital, I felt he needed help because there was not enough time for nurses to help toilet him and help with personal care. Expenses - while in hospital, the family spent money on parking because we felt someone should be at the hospital with him all day, in shifts. Since being home, I've had to provide a lot of care initially. It's getting more manageable now because he can do a lot for himself."*

21. **[Final Comment]** *"Initial time in ER waiting for an admission bed was uncomfortable (34 hrs). Nurses/staff were considerate and collaborative with me. Great connect to home program. Mostly excellent staff visiting. We did find scheduling unpredictable and erratic at times but understand that it could be hard to maintain with changing client needs. We both felt she was well supported and knew how to manage her new lifestyle with heart failure."*

22. **[Final Comment]** *"Just for information, I was diagnosed with multiple myeloma in 2015. Since that time, it is actually my wife that has been the caregiver. At this point, my situation is stabilized. So, at this point, my wife and I, I would guess, are both patients and caregivers! We really appreciate the opportunity to participate in this survey. Thanks, [Name redacted]."*

23. **[Final Comment]** *“We were and are pleasantly surprised by the care received during this crisis in our lives. surprised because we have always heard complaints about health care. We could not have asked for better care either in the hospital or at home*.”

24. **[Final Comment]** “The home care team visits were a big help to us. They helped us sort out the medication initially and helped my husband establish a routine to treat his heart condition which he follows closely. Without the team's help, we would have had great difficulty treating my husband's heart condition. I was very impressed with the service they provided.”

25. **[Final Comment]** *“I wouldn't call myself a caregiver, just a concerned daughter. Both my brother and I, who lives close as well drive about 20-25 min by car to visit mom and take her to necessary appointments, etc. She was quite able to drive herself before her medical issues arose in [Date Redacted]. I check on her a few times daily by phone and am at every hospital visit. CC to Home has been amazingly supportive of her and us.”*

26. **[Final Comment]** *“The EMS care in ambulance saved [patient]'s life. The doctors and nurses were professional and updated meds and stabilized her. The aftercare was great. This has been a Godsend as I was overwhelmed. I myself did not have the information on how to care for her. She needed people who could answer her concerns and assess her. I wholeheartedly approve of this homecare.”*

27. **[Final Comment]** *“My mother received excellent care*.”

28. **[Final Comment]** *“It has been a good experience*.”

29. **[Final Comment]** *“As well as partner being ill, I am ALSO responsible for my widowed mother who is 72 and having health issues. The survey asks for responses for my partner but I am dealing with 2 individuals. I too am on disability for MS and am trying to deal with my own issues. I am coping and hope there will be help for me when I bottom out. There are no children etc., for me. My point being that if my partner did not have my assistance, his outcome would have been very different.”*

30. **[Final Comment]** *“Mom does pretty well on her own, but this last visit brought to my attention all the care and need she may need in the future, thanks to the input of the CHC program.”*

31. **[Final Comment]** *“The care on the 5th floor cardiac ward at UH was very good. My mother finally received a proper diagnosis, treatment, and subsequent follow-up care. She continues to be monitored closely and I believe the home care team taught her the necessary routine to keep her from more hospital stays. We are very appreciative of the care she received.”*

32. **[Final Comment]** “*We praise the nursing staff that cared for [the patient]. The majority of them were fantastic. The doctor was difficult to deal with at times. We weren't shown the actual CT scan on screen or given the written report. Both my husband and myself are fully aware of understanding the reports and viewing the image. We are still confused as to why she died so quickly. We didn't request an autopsy.”*

33. **[Final Comment]** *"He was a great patient - easy to care for."*

34. **[Q18]** *"Weekends were bad. Phone not answered!!"*

35. **[Q18]** *"Outstanding!"*
    [Q27] *"Outstanding!"*
    [Final Comment] *"The care my husband received while a patient for 4 weeks in University Hospital was excellent! Unfortunately, it took 2 trips to the emergency (one by ambulance) and call time (he was sent home with congestive heart failure - our family doctor [redacted] LHIN also failed him will NOT providing the necessary tests and referrals to diagnose his illness. We could not have managed upon his discharge from the hospital without the support of 'Connecting Care to Home". Thank you!"*

36. **[Final Comment]** "*I answered this based on last hospital stay...he had been in twice before in 6 weeks prior to last stay without having been offered any post hospital support. Only on the third admittance when I was distraught and determined he was not leaving hospital till he was better, were we offered the connecting care at home support. It is a great program but has since stopped and he still isn't stable, so wish it could have gone on longer."*

37. **[Final Comment]** *"The programme was effective and helpful. May require more info my heart condition going forward. Not all answers always available. Seems like wait and see or guessing at situation."*

38. **[Final Comment]** "*Both [Patient Name Redacted] and myself were very pleased with the care given upon his return home. All of the team members were professional, kind, and knowledgeable. I found some of these questions kind of hard to answer because [Patient Name Redacted] makes his own decisions with regards to his health issues."*

39. **[Final Comment]** *"The help has been a relief. Especially the bathing help through Paramed. Help with Dr. appointments, transportation in the winter months would be greatly appreciated. Summer time we bus. Winter is hard on both of us. She is [age redacted] and I am legally blind."*

C – NYC ICC

1. **[Q5]** *"This survey is in response to [Patient Name Redacted]'s 2nd admission to the hospital in less than 3 weeks. At that time, I was moderately anxious and depressed, but by his 3rd admission on [Date Redacted], I was much more anxious and depressed."*
   [Q12] "*I was included in the planning for the patient discharge, but this program was not what we felt would benefit my husband the best. We begged to have him sent to a Rehab program. This was his second admission in a very short time. He was de-conditioned. He never came back to himself even after the first admission. He had no appetite and tired easily. He did not have his usual sense of humor, verve that was his normal self. He had no appetite. We said this to the Health Care Team but they refused to consider Rehab for him and he was back in the hospital on [Date Redacted]."*
   [Q14] *"I was given some pamphlets, but no one talked to me about support services and no social worker talked to me."*

[Q18] *"During this stay, especially, it was not easy to talk to the doctor as he was never around. He would visit my husband very early in the morning."*
[Q19] *"Homecare - After my husband was discharged, the nurse came to our home twice. The second visit was 2 days before his 3rd admittance to the hospital. There was a student nurse as well as the RN, however, only the student nurse took his vitals. Once again, I told them that he was not eating, was easily tired and was not his usual self. They asked if there was any weight gain, which of course there wasn't as he wasn't eating. However, 2 days later, at the clinic, it was discovered that he was suffering from Congestive Heart Failure. Even at the clinic, I got some resistance and was questioned about his attendance there as well as visiting his doctors, but once she realized his health problems, she did go into action and ordered blood tests and contacted his doctor. From there he was taken straight to emerge and was admitted."*
[Q28-Q32 Time Spent Helping the Patient] *"Upon the 2nd admittance, the number I have provided are approximately correct. However, on the 3rd admittance, the numbers increased drastically. For personal care, I provided upwards of 25 hours a week. For scheduling and coordinating, close to 10 hours a week. As well, my children and family and friends assisted on numerous occasions providing upwards of another 10 hours a week."*
[Q39] *"At the second admission, there was no out-of-pocket extra physical health service but on the third admission, we had a private physical therapist as the hospital was providing minimal therapy and even missed some days."*
[Q40] *"Since he was in the hospital for 6 weeks on the third admission, my family incurred several hundred dollars in parking fees. As well, the geriatric psychiatrist said that a TV would be very beneficial to his mental state of mind, so I also incurred a large expense for TV rentals."*
[Final Comment] *"You will only receive the caregiver's report as my husband died on [Date Redacted] at North York General Hospital. There is one question you have not specifically asked and that is to do with the patient's comfort during his stay. My husband had a large wound on his right foot. Debridement was necessary to remove dead skin. He also had bed sores and only after 4 weeks' stay was given an air mattress to sleep on."*

2. **[Final Comment]** *"[Patient Name] had a viral infection that affected her heart. When she was admitted her ejection factor was 39%. She was given very high doses of metropril (100g) and her ejection factor went to 16%. The cardiologist made her an appointment at Toronto General Hospital. She had to be discharged and I had to transport her in our private vehicle downtown Toronto, where that out dated drug was stopped, and very small doses of meds were started. She quickly started to improve with these other meds."*
3. **[Final Comment]** *"Hospital stay was well organized and aftercare support by visiting nurse was outstanding."*

4. **[Final Comment]** *"My physical & emotional health has suffered since the patient was admitted to NYGH. I have been under my physician's care, namely anti-anxiety meds when needed. As well, my BP readings were high, so it was necessary to monitor them plus alter my meds. As I suffer from osteoarthritis, the inflammation in my joints flared up due to ongoing stress. Living & coping with COPD on a daily basis is not only scary, it always presents an uncertainty. The assistance the patient has received from the Health Care Practitioners at NYGH has been extremely helpful and greatly*

appreciated. We are both doing our best to cope and understand this invasive disease. It appears that our lives revolve around hospitals, doctors, nurses, and medical appointments now. However, life could be much worse and we are thankful that our health care system is so supportive."

CW – H2H

40. **[Q14]** "*They gave me stuff on the patient. They told me that they were sending somebody home, and they gave me a pump and wanted me to do it, I preferred them do it."*
    [Q18] "*I can't remember. Its not the best place to go, I'm getting it confused for when he went to the hospital for an accident."*
    [Q20] "*We did need them and one time didn't want to come over, and I told them that we would phone someone, and that prompted them to come. They were all pretty good. They put a needle in the corner of his arm in the hospital that started to leak and asked them to come back, they cleaned him up but didn't change the needle. The nurses didn't want to come but later fixed it all up and were pleasant."*
    [Q23] *"I don't think they were, I think we told the doctor about it."*

41. **[Final Comment]** "*Well, you know, it just blows my mind that they have all these wards that are empty that they can't use. When you go there you are lined up and we were there last time for 7 hours in between tests for blood work. When I had pancreatitis for 12 hours and 6 hours. I feel sorry for the old people. They don't have rooms for you. You don't complain because you just want to get out of there. Nurses aren't informative enough. A minute is not 3 hours. They could be more honest. One time, I went in there and they lost my file and went charging around and looking for it. They don't want to make changes, so they set the ground rules. The hospital is a company and it depends how they run it. I don't know what is wrong with this hospital."*

C TC – OCOT

1. **[Final Comment]** "*I am exhausted. As an only child, I am her caregiver. Her health has been deteriorating and I worry. I get anxious and depressed. I work full time and I am extremely tired sharing myself between my work and my mom. I don't have time to take care of myself. I cannot afford to hire a person to take care of her at least 2h daily and I am obsessed that I don't do enough for her."*

2. **[Final Comment]** "*There is a critical lack of nursing staff in North York Hosp. My husband was a patient three times in 2017 and I ended up doing the nursing - everything from bathing to changing the bed to correcting medication. Spent more time searching for nurses when calls not answered. My heart goes out to patients who have no one to advocate for them. Some families hire PSW to be with their loved ones because they work - this is wrong! More nurses are needed - the ones they have should be spending more time with patients and much less time at desks and on computers!"*

3. **[Q10]** "*Social worker - Never; Doctor - Sometimes; Nurses – Good"*
   [Q11] "*Just with one nurse."*

[Q12] *"Just get told."*
[Final Comment] *"Disappointed in social work at NYGH."*

4. **[Final Comment]** *"Caregiving requirements were minimal as patient was transferred to St. John's Rehabilitation Centre for inpatient rehab. If this had not happened, home care requirement would have a huge requirement and time commitment. After being discharged from inpatient rehab, patient was between 95-100% self-sufficient.*

5. **[Final Comment]** *"My mother received outstanding care at NYGH. (She has since died; I requested that memorial donations be made to that hospital.) The stroke ward was SPOTLESS, well-managed & respectful. I could always find a nurse to help me. Doctors kept me informed. Prov. Physio people were great. The specialists were great. Our experience with Providence Health Care was not nearly as positive. Several of the constantly changing nurses were disrespectful and/or ignored her desires. The hallways were crowded with equipment. The room & her tray were unclean. Had I not been as diligent a health advocate, she would have been even less well off there. I would NOT recommend Providence."*

6. **[Final Comment]** *"1) Excellent follow up provided by Providence Health Care. 2) I found that the many tests that my wife had to undergo were at times somewhat confusing until the doctors reached an answer to her medical condition. We were both somewhat relieved when a diagnosis was finally reached. 3) I visited my wife on a daily basis to assist her as well as to help nurses wherever possible."*

7. **[Q13]** *"They didn't give me all the contacts - my mom needed rehab but they didn't give me that contact."*

8. **[Q20]** *"Sunnybrook rehab team was available."*
   [Q21] *"Rehab schedule was convenient."*
   [Q22] *"The rehab team were well informed."*

9. **[Final Comment]** *"There would be no one to look after this patient if I were not off work due to an injury. The health care after the hospital is terrible in this province. The way that a person is tested to see if they should be on their own care is appalling to me. When you ask an Alzheimer patient where they have lived for 60 years is a pretty easy answer. But if you ask what day or year they don't know. So you people sent Alzheimer patients home when you shouldn't, and you people should be liable for their health & well-being."*

10. **[Final Comment]** *"Stressful because of the unknown!"*

MH – PPATH

1. **[Final Comment]** *"It has been tough and very challenging to be the primary caregiver and only caregiver for the family and the patient. We have two young kids without any immediate family nor*

relatives in Canada that's why it was hard for me to balance my time and responsibilities for the whole family. I was not able to do much household activities and groceries for almost a month because of all the responsibilities and care I needed to do for my family. Work schedule was also affected, although my company agreed to provide me a modified schedule. I was close to applying for a stress leave at work. The new caregiver EI benefit was only approved recently and it would have been convenient if this was available sooner. My priority is to care for my family but I wasn't completely off from work otherwise I would not get paid."

2. **[Final Comment]** "*It was a difficult time, Trillium staff was very experienced and supportive."*

3. **[Final Comment]** "*V.O.N told us not to do one [of] the exercises that hospital had given us. No contact concerning rehab physical therapy. I have called but we have not heard back, 7 weeks now. When there was bleeding at the hospital, the nurse did not call the doctor as it was through the night. Next day, the doctor was not pleased as to how much bleeding there was and he had not been contacted. This was his chest [illegible] that was bleeding."*

4. **[Final Comment]** *"Everything was set up nicely!"*

5. **[Final Comment]** *"Staff at the hospital were good and professional, but everyone always seemed to be too busy and rushed. Support for caregiver at the hospital was non-existent. For staying overnight, I made sure to get a private room by paying extra, and when asking about being able to be down overnight, was told I was likely to have a chair which extended by a foot. The home care team when contacted by phone on the day we came home (4 days after operation) as my husband has atrial fibrillation, asked me to measure pressure and heart beat as if I have training! Also on other days their advice? "Go to the emergency, see the family doctor, etc." I don't need a home team to tell me that after waiting on the phone for half hour."*

6. **[Final Comment]** *"Called at 01:00 approximate time to get advice. Patient was in bed & relaxed. I am a retired nurse. the patient has >200 heart rate. He had NO symptoms. I used a stethoscope to monitor his heart rate. After 40 minutes, the heart rate decreased to a more acceptable 150-180 regularly/irregular heart rate. I decided to call for advice at this time (St. Elizabeth Nurse). She advised and I agreed to stay home as it was asymptomatic. I was quite worried through the night. Since I felt it was gone I never notified the cardiologist until 2 weeks later when booking an appointment. The office ordered a 24hr monitor for 2 weeks. Should I have taken my husband to emergency department that night?"*

7. **[Final Comment]** *"Head nurse was not empathetic and hard to speak to. Patient could not rest after the surgery and was having [illegible] dreams and hallucinations. Nobody explained this to me. My husband was very stressed - even after discharge. Voluntary individuals were good, as well as day nurse - I never got to see or talk to the head nurse - only came to see the therapy people 2 days before discharge - not very helpful. The St. Elizabeth service was OK. However, they only followed up once. Hospital did not send discharge info to family doctor."*

8. **[Final Comment]** *"My husband had a triple bypass. I was a bit anxious the first few days after his release because of his pain and recovery. But overall, I feel I handled it very well. I had a lot of help and support from family members - don't think I could have kept up with everything alone."*

9. **[Final Comment]** *"I feel my husband was discharged too soon following cardiac surgery. His legs were edematous above his knees. Since discharge from Trillium, he has had 3 re-admissions with fluid overload."*

10. **[Final Comment]** *"I would like to compliment every single nurse in the coronary surgical intensive unit, the short stay unit, the [names redacted] from the angiogram unit, [names redacted] from the coronary unit. They were very professional and their care was exemplary. The most helpful on the floor was the young gentleman from housekeeping. I rate him over the floor nurses. My husband vomited all over himself, the bed and floor and no one came and assisted me except for housekeeping. Being an RN, I was very disappointed at the care rendered. The nurses from the floor should use the nurses from the unit as role models."*

11. **[Final Comment]** *"Based on my experience as being the sole caregiver for my mother, I wish that the hospital staff (doctors and nurses) could have educated me more. It would have been helpful to have an idea on what is "normal" or what to expect in regards where incisions would be, how the surgery would be (breaking breast bone), the extreme pain that my mother would have experienced. There were instances where I felt that the medication doses were not kept up accordingly and a lot of times I had to request for more meds to manage my mother's pain. I'm unsure if it was because I was there that the doctors and nurses weren't giving my mom the consistent check up in maintenance of her personal hygiene and maintenance of pain. We had to ask daily when she could either bathe or if someone could assist me in showing me how to care for her incisions while cleaning her up. 3 days after the surgery, they sent someone to assist her - but, that person ended up giving me a rag and told me what to do. It was very frustrating. Also, the bed sheets were not changed regularly and we had to consistently request for it before someone considered doing it. It came to a point where we had to ask the nurse for new sheets and changed the sheets ourselves while my mom was using the washroom. It was very inconsiderate and disappointing when meals would be issued. No one would even ask if she needed help. Considering the extremity or pain and unable to use her arm properly with having a broken breast bone. The entire stay at the hospital, my mother was having issues with bowel movement. The only time I felt they cared about having her use the washroom, was the morning of discharge. They finally gave her a depository, which I felt was only given because they wanted her to leave. The same morning, you could tell that they were rushing to discharge her. We could see and hear that they were waiting for the room, as they had an elderly man outside waiting in the hallway with a divider. Overall, considering that this is a major surgery, the aftercare at the hospital could have been way better. It's a difficult time for the patient and family. We aren't the professionals and don't know what to expect or what is 'normal'."*