VCH Community Engagement






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Client and Family Member Experience of Home Health Care

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About Vancouver Coastal Health - Home Health

We are facing a growing and aging population in British Columbia where incidences of chronic disease and disability are on the rise. Home and community care services provide in-home and community-based services support clients to improve their health and quality of life, and/or remain independent and safe in your own home for as long as possible.

Individuals with acute, chronic, palliative or rehabilitative health care need may require home and community care if they:

- Have been recently released from hospital and need short-term care while they recover;
- Have an ongoing, or chronic, health issue requiring more care than you or your family can provide;
- Have a health issue that is getting worse and need support to continue to live at home;
- Have a health issue that is making it impossible for you to continue to live at home safely.

Background on Home Health Redesign

The current service delivery model in Home Health does not fully meet the changing needs of BC's growing and aging population. To address this issue, Vancouver Coastal Health (VCH) is working with the Ministry of Health, other Health Authorities, and Accelerated Integrated Primary & Community Care (IPCC) initiative to revitalize our home health service model to better meet the needs of our clients. Home Health Redesign will focus on the processes, standards and tools to help staff use 'care management', every day, with every client, as an interdisciplinary care team.

"Care management is essentially an approach to coordinate and manage care across the continuum of health care systems for individuals with complex health conditions or disabilities. It's not an independent function or designated discipline – it's built into all health professionals' scope of practice."

Home Health Redesign is following a collaborative process that will include staff, clients and physicians to redesign our system to support care management. The first step is to better understand the needs of our clients and how we currently deliver services for all communities across VCH. VCH Community Engagement staff is supporting the Home Health Redesign (HHR) project team to incorporate patient and public engagement (PPE) in the redesign process with the support of Integrated Primary & Community Care (IPCC). VCH Regional Collaborative Practice is also conducting a review of staffing and care models for VCH services and facilities.

Engagement Process

In collaboration with the Integrated Primary and Community Care Team (IPCC) and the HHR project team, VCH Community Engagement designed a consultation process to capture the client's experience of VCH home health services. The objectives of the engagement were:

- To discuss the client and/or family member's experience of current home health services;
- To gather client and family suggestions for improvements as well as key elements that should be preserved because they are working well

This information will also serve the baseline measure when VCH evaluates its progress after changes are implemented.

The home health client and family consultation also capitalized on previous work that had been done such as the Richmond's Best Path Consultation in Richmond in July 2013 (n=6), the North Shore Home Support Client Satisfaction Survey in October 2012 (n=135) and the Roundtable consultation for George Pearson Redevelopment.

Methods and Participants

VCH home health services reach a variety of clients each with different needs so the consultation reached out to six key client populations:

- Clients living with chronic conditions (such as diabetes, kidney disease, high blood pressure etc.)
- Clients with acute/episodic health needs such as those who recently had surgery or had been in hospital)
- Adults living with a disability
- Seniors who required additional support to remain at home
- Palliative/end of life clients who would like to remain at home until the end of their life.

Family members often played a key role in initiating and managing care so they were also a key source of information. Participating family members represented a number of different relationships to the client (e.g. husband/wife, son/daughter). Priority for participation was given to clients and family members who currently receive or recently received (i.e. within the last six months) home health services so they could speak to their personal experience organizing and receiving care.

Frontline staff, case managers and IPCC champions were essential in the recruitment process. Frontline staff and managers identified clients and family members who use VCH home and community care services and who were willing and capable of participating. Because of the regional focus of this project, clients and family members were recruited from across VCH's region were consulted including Richmond, Sea-to-Sky Corridor (Whistler, Pemberton, Squamish), Sunshine Coast (Sechelt and Gibsons), North Shore, and Vancouver.

Since some home health clients have reduced mobility or are less comfortable speaking in groups so both one-to-one interviews and focus groups were offered to reduce barriers to participation. Anonymity was assured for all participant and a total of 36 people participated in the discussion groups and interviews. Interviews were arranged at times convenient to residents and family members and were offered in-person at a preferred location or by phone. Discussion groups were offered in eight different communities across the region. Interviews and discussion group participants were asked to complete short survey to capture some keys demographics about the client such as the client's age and gender; reasons why home health was set up; list of services used; how often services are received; and whether they are connected with a family physician. (See Appendix A for more details).

Key Themes

Seven main themes emerged from the discussion but the diversity in clients receiving home health care and their needs means that each theme has subtle nuisances reflecting this diversity. The themes from the discussions are presented below.

Happy at Home

Home and community support services can help clients manage their own care while living at home. Most clients of the clients who were consulted expressed that they would like to recover from illness and injury, manage chronic conditions and live out final days at home so long as they are adequately supported.

"You have to be tough to be old. It's not easy being old, you can't be weak" – Client, Sea-to-Sky

"They are here to assist us to do the job" – Client, Vancouver

"Need to live independently as much as you can. I don't want to go into an institution" – Client, Vancouver

"My husband was only able to die at home because I used to be a nurse. We need more palliative care supports in our community since people who live here want to die here." – Family member, Sea-to-Sky

Navigating the System and Accessing Care

"It is a job to navigate the system" – Client, North Shore

"I don't know what I am eligible for. There are so many rules." – Clients and Family, all regions

Many clients and family members are not aware of what services are available nor what they are eligible for. Many voiced that it would be helpful to have clearly defined guidelines about services and eligibility criteria that clients and family could reference. Peers such as friends or family who had previous experience of home health care (as either client or former staff) often offered suggestions about how to better navigate the home health system such as information about what services are available, eligibility requirements as well as 'loopholes'.

"I heard about home health care from a friend who was a nurse and then I called to get a case manager for my mother but there isn't one number for intake." – Family member, Vancouver

Clients are connected to the home health care system through different mechanisms. Some participants were connected to services following a visit to the hospital while others received a referral from their family doctor, were self-referred or were assisted by a family member to initiate services. The timeline between initial contact, initial assessment and from to the start of home health services varied greatly depending on client's needs and urgency of services.

"I waited for over a year to get into the program. The program is not very often in my community and there is a waitlist." – Client, Sunshine Coast

Another issue for setting up services health care boundaries – within a single health authority as well as across health authority boundaries.

"I took me 60 days to get an appointment but the catchment area was the problem. I sit on the border of two primary health centers and I applied to the on which was closest so I could walk there. One month later they told me that I wasn't in their catchment area so I had to start the process all over again at the different primary health center. Why couldn't they have told me I wasn't in their catchment area when I gave them the application?" – Client, Vancouver

For many seniors, their services are subsidized by Veterans Affairs that further complicates the set up process. However, they also noted that this entitles them to additional support such as meal preparation and housekeeping support which they find very helpful.

"The case manager said she would be an advocate for us with Veteran's Affairs but in the end our daughter had to do figure out who pays for what etc. There was no one to help navigate through all the paperwork." – Client, North Shore

Client Involvement

Care Planning

"I gave a presentation to the care staff when I arrived so they knew what my condition [Parkinson's] was and what I needed of them" – Client, Vancouver

"Don't generalize clients; come with your eyes open. They know me well. They respect my independence and stubbornness" – Client, Vancouver

"Some staff need training on how to deal with seniors. They talk to you like you are idiots. Like you don't know anything" – Client, North Vancouver

Clients wish to be seen as an individual within the healthcare system but this requires health services to tailor services to the needs, preferences, and cultural values of the client. Care planning aims to put clients and/or family members on an equal footing with healthcare professionals, moving away from "doing to" to "doing with." A care planning consultation should feel like the "meeting of two experts" - the patient/client and their care team. However, there was substantial variety in how much clients and their families participated in care planning. The nuances of "care planning" are quite unique across the five key populations and different groups had different understanding and expectations of care planning. This could partially reflect type of services and the length of time clients had been connected to home care services. Nevertheless, many clients remembered having an initial assessment or annual meeting with their case manager but wasn't certain if this qualified as "care planning" since there was often limited input from clients and family on creating a "plan" on an ongoing basis.

Written Care Plans

"We had to create our own care plan." – Family member, Vancouver

Very few clients and families said that they have written care plan and for those that did have a written copy, they were not sure which health care professionals had access to it. Some families had created their own care plans because there were no tools or templates or support from health care staff to develop one. Family members suggested that a planning template that outlines a complete list of potential needs to consider who help them make arrangements to cover items such as laundry and housekeeping, safety modifications such as installing hand rails, moving furniture to prevent falls, enrolling in an emergency response system. Families and clients recognize that may these services may not be provided by VCH but are an integral complement to personal care and clinical services.

Choice and Preferences

Interviewer: How are you involved in the planning for the care you are receiving? How are your preferences, values/beliefs, traditions incorporated into your plan for care?
Client: "The problem is with your question; you have to make the service fit with what you want."

"Who decided that I only get one shower per week? I sit in a wheel chair all day and I would like more showers" – Client, Vancouver

Even when preference, values and beliefs were expressed, many clients and family members felt that their influence was restricted by the rules and eligibility requirements and they wished for greater power to shape their pathway through services.

Moreover, some communities did not have adequate supports to be able to accommodate client's preferences when it was expressed. For example, participants in rural communities (Sunshine Coast, Sea to Sky cooidor) the preference to die at home cannot always be supported due to supports and resources available.

"Our community nurse is amazing. She does everything she can to support the patient to pass away at home. Not everyone can have this option". – Client, Rural VCH

Accountability

In addition to creating care plans, it is essential to ensure that these plans are followed so that services are indeed responsive to clients' preferences. Clients and family members also need clear guidelines on how to raise concerns so that can be addressed in a timely and respectful manner. The gender of the care staff arose as a concern from a number of family members and clients. One client said that sometimes the agencies sent a male care worker but her care plan says only female staff. Similarly, some male clients prefer male workers since they don't want women other than their wife seeing them naked or because a male staff member share similar interests and could provide some social interaction. Most importantly, one client expressed that she could not remove a staff member who makes her feel uncomfortable but that there was no mechanism for her to remove him – even after she lodged a complaint.

Strengthening protections from abuse and neglect, including improved protections for those who report care concerns or complaints to have them taken seriously, and have them handled in a respectful and timely fashion.

Self Management

Clients were asked series of questions about self management including:

- Do you feel confident managing your condition?
- Has a health care professional discussed self-management with you (e.g. medications management, signs and symptoms to look for, what to do if issues arise)?
- What does self- management mean to you? Do you want to "self manage" or have more control management your condition?

There are different understandings of what self-management means and desire to "self-manage." As part of this consultation, interviewers noticed that 'self management' resonated more with clients living with a disability or chronic condition but did not resonate with most seniors. For example, many frail seniors do not relate to the concept of self management since their experience centered around the idea of staying at home and is less associated with their specific medical conditions; however, clients with a chronic disease understood the idea of self management but had differing desire to self manage their condition. Overall, health care needs to better understand each individual client understands of the term "self management."

"Self management? You mean you want us to act like adults" – Client, Vancouver

"How can we manage their condition if we don't understand our condition?" – Client, Sunshine Coast

"I'm a self manager. I set my own plans and work with my doctor. He asks me what my body says." – Client, Vancouver

"I am confident to manage my condition. The Healthy Heart program gave me the confidence to go back to the gym. Heart monitors help me to identify what I needed to stay safe." – Client, Sunshine

Financial Implications

"Money allotment determines the services you get. I help the system work for me." – Client, Vancouver

Many clients with high physical needs strongly felt that they would like more direct control over the care they receive. They spoke highly of the Choice in Supports for Independent Living (CSIL) program which is a direct funding model of self-managed home support which gives the client greater flexibility, choice and autonomy to manage home support services.

As the home is the workplace is the client's home, there can also be implication for equipment. One client who lives in shared care in the community described that she needs to purchase an expensive ceiling lift because of new Workers Compensation Board (WCB) requirements. While the client realizes the importance of workplace safety for staff, there was no financial support for the newly required equipment that she needed to purchase in order to continue receiving the services she needed to live independently in the community. There is a need to identify and publicize information on equipment options, with purchase and installation costs and available funding sources.

Family Involvement and Caregiver Supports

"I don't want to disturb my son because he is busy and has his own life." – Client, Vancouver

"Many family calls me but they live in Europe… My friends help when they can." – Client, Sea-to-Sky

"The care workers will call me if there is something up with my dad." – Family member, Vancouver

Family members were often key in implementing services and advocating for client but different family members are involved in different ways and different intensities. Many family members felt they need more information not only about health issues but a wide range of topics that are encompassed within their role as "caregiver" such as information about adult day centers, end of life planning, Representation Agreements and money matters). Family members stated that they valued the VCH caregiver support groups and would welcome more opportunities for support.

Providing care most often involved helping parents. Within the interviews and discussion groups, there were subtle differences between family caregivers who were children of the client and those where it was a spouse who was the primary family caregiver.

Caregivers must often provide care under complex circumstances, often balancing the concerns of their own immediate families, their careers, and their responsibility for elderly caregiving. Seeking support and maintaining their own health are key to managing their role as a caregiver. Using respite care before caregivers become exhausted, isolated, or overwhelmed is ideal, but all family members interviewed mentioned how hard to get respite care. Scheduling also posed challenges when home support was not offered on weekends or statutory holiday and family caregivers were expected to fill in.

Adult day care and seniors centers was seen a great resource to support families but participants were unsure what the criteria are, whether it would be suitable for their loved, who is accountable for the day care and what is offered at adult day centers.

Care Coordination

"Our main contact [the case manager] was off for 2 long periods of time, we didn't know who was taking care of us." – Family Member, North Shore

"The client is the coordinator" – Client, Vancouver

"At first they wanted us to have all sorts of people coming in and out… even someone to do the cooking, but I still like cooking so we had to fine tune what was actually needed." – Client, North Shore

Most clients and family members felt that once they worked through the initial process of setting up care and working a few kinks care was reasonably well coordinated within isolated services but that care was not well connected between different parts of the system.

Regular Staff

"I have had a enough nurses to fill this room" – Client, Vancouver

Health authorities are challenged to adopt staffing practices that promote the consistent assignment of staff to residents, retention of staff, and reduce of staff turnover. While friendly, respectful, capable care workers are an invaluable asset in providing high quality home care services, participants stressed the importance of the relationship between the home care staff and the person receiving services. One participant said that having the same responsible and respectful person deliver the care regularly builds "an invaluable relationship." Family members and clients could cite a number of other benefits of familiar staff such as:

- Increased feelings of comfort for client and family;
- Consistent follow through and communication on the plan of care;
- Increased likelihood of noticing subtle changes in health;
- Creation of predictable routines (especially important for frail seniors).

Many participants felt that when casual staff covers for regular staff, they do not know details about client's history or routine and sometimes they do not have access to the care plan.

"The casual staff does not have the blackberry that has the care plan on it." – Client, Vancouver

"My dad doesn't like people coming to the house so we've set up keypad on the back door so that the staff can let themselves in. But when casual staff or new staff comes, they often ring the front door bell because they don't know this and my dad won't let them in." – Family Member, Vancouver

Scheduling

"The home support schedule is not flexible: if want to go to concert I have to make sure I am home at a certain time. The handy dart doesn't always show up. I lead an active life. " – Client, Vancouver

"When I first moved into Shared Care, I got the earliest time slot to get up because that was what was available. But I'm older now and need more rest but no one will change care times with me." – Client, Vancouver

"Allow sufficient time for people receiving care to be treated as people, not 'tasks to be done' "– Family member, North Shore

To be effective, home care services need to balance consistency and flexibility. Clients and family members emphasized that is essential that care is offered seven days per week including statutory holidays otherwise family members personally have to fill the gap in service or hire private care. Clients and family appreciate advance notice about when care staff will be coming each week so

that they can plan their schedules in advance. Demand for client care is heaviest in morning and evening which can create scheduling issues. Many seniors benefit from consistent daily schedules but other clients felt that home health care dictates their schedule unnecessarily (i.e. what time to get up, when to bathe, when to go to bed) and there is limited ability to make adjust care to accommodate extracurricular activities or personal choice.

"Sometime it would be nice to stay up a bit later but my wife has a hard time putting me to bed from my chair." – Client, Vancouver

A number of participants said that the care staff often arrive ten minutes late and/or leave ten minutes early to get to their next appointment because the staff rely on public transit instead of having their own cars. One family described that they have worked around this by booking a 90-minute timeslot instead of 60 minutes for the first visit in the morning because the clients' morning routine is not rushed.

Communication

Communicating effectively with patients and families is a cornerstone of providing quality health care. Home health clients and family members feel that they are the epicenter of the communication, keeping the different branches of their health care team informed. This role is especially true for family physicians that are not well connected with the home health team. Because of the disconnect between different members of the care team, clients and family have to repeat themselves. Many participants felt that the communication book works well to relay tasks between home care staff and mobile devices facilitate access to the care plan for home care workers.

Troubleshooting Issues

"I can ask our case manager about anything and she will help navigate" – Family member, Vancouver

When participants were asked if they knew who to contact with questions or concerns, most participants responded that it depended on what type of issue needed to be addressed. Clients and family members felt that they would benefit one person who is leading the clients care team acting as a knowledgeable point of contact to answer their questions, help them navigate the system and troubleshoot any concerns. Moreover, a few family members indicated that once services were established, they were "afraid to bring up issues for fear of rocking the boat" because the were worried that services would be cut back because of eligibility or other prerequisites.

Connections across the Health Care Spectrum

Home care encompasses a broad range of services and environments often between different levels of health care and care settings. Many clients experienced the separation or isolation of primary care from the hospital and home care sectors. Participants stated that the lack of communication and coordination between hospitals, family doctors and home care is a significant barrier and it results in a home health system that is reactive not proactive.

Connection to a Family Physician

"The doctors know what the nurse does but doesn't know what home support does" – Client, North Shore

"My son helped me get help for my feet. He set up foot care at the health center cause I can't reach my toes. My family doctor didn't know that the program was available. Not enough people know about the health unit." – Client, Vancouver

While all clients stated that they had a family physician, very few participants stated that their GP was aware of what services a client was receiving connected with the home care team or involved in home care planning. Many participants expressed that they did not think that their family doctor is not aware of what services are available in the community. Moreover, some family members suggested that not all clients see their family physician regularly enough to proactively identify changes in home care needs. While house calls have declined, several participants mentioned how much they valued home visits from their family doctor or when their family doctor came to visit them in hospital.

Acute Care Transitions

"Two different worlds between the hospital and community services you almost need a passport to go between the two" - Family member, Vancouver

"Services were not set up on discharge… no one said what was supposed to happen after surgery." – Family member, North Shore

"It took 2-3 weeks before my mom 'qualified for services.' Why can't clients come in and get pre-qualified before surgery?" - Family Member, Vancouver

Participants felt that they were particularly vulnerable to breakdowns in care when transitioning from hospital back to their home. Many participants felt that little attention was paid to client and family caregivers' needs during transitions in care and consequently, many felt poorly prepared for the transition home. Some family members suggested that home care services (including necessary paperwork and eligibility screening) needed to be set up before client leaves hospital and in cases of planned hospital visits, they felt that services should be set up before admission to prevent a lapse in care. In addition, communication of information across the health authority boundaries or between the acute and community system presents additional challenges for clients and family members when returning home from the hospital. Furthermore, clients and family members living in rural and remote communities strongly expressed the need for urban institutions to have a better understanding of what services were offered in their client's home communities before discharge.

Additional Supports

"House care would be helpful if it's a bad day for me but they can only provide personal care." – Client, Vancouver

"I still do all my own the grocery shopping and cooking but I need my friend to drive me into town or I take the bus to get there." – Client, Sea-to-Sky

"I can't leave the house; I need to find private caregivers to go on an outing." – Client, Vancouver

When asked for suggestions of how VCH could improve home care, many participants stated that they needed or would benefit additional non-medical home support services such as transportation, meals preparation, housekeeping, grocery shopping and companionship. For example, one senior did her own laundry in her kitchen sink because she did not have a laundry machine.

Community Resources

Acknowledging that these services many not be within the health authority scope, several clients and family members suggested that partnerships with local community would be a robust and

sustainable mechanism to provide these additional supports. For example, one client shared that many local churches will provide companionship and pastoral home visits to the individuals who are unable to attend church services. Many family members requested a list of services as well as catalogue of community resources such as community center and senior centers, meals-on-wheels programs and educational information on pertinent topics such as end of life planning, financial legal issues.

Guidelines for Private Care

"We are happy to pay to get extra things done like toe nails." – Family member, Vancouver

"There is no coordination for private care. We don't know who to hire, or how to access live in care, which providers are reputable care." – Family member, Vancouver

Some clients and family members supplemented their home care services with private care but felt that there was a lack of information and oversight for private care.

Next Steps

At the next stage of this project, staff will be consulted on their experience of VCH home health. Then Home Health project team will consider both the ideas and experiences of families, clients, and staff in future planning to better meet our clients' needs as well as offer them greater involvement in their care.

Participants greatly appreciated the opportunity to share their experience and they were also interested in ongoing information on how VCH progresses following the staff consultation around home health services.

Appendix A

Table 1. Region of Participants

Region	No of Participants
Sunshine Coast	1
Vancouver	18
Sea-to-Sky	7
Richmond*	7
North Shore	3

Table 2. Client vs. Family Participants

	No of Participants
Client	25
Family member	11

Chart 1. Age of Client

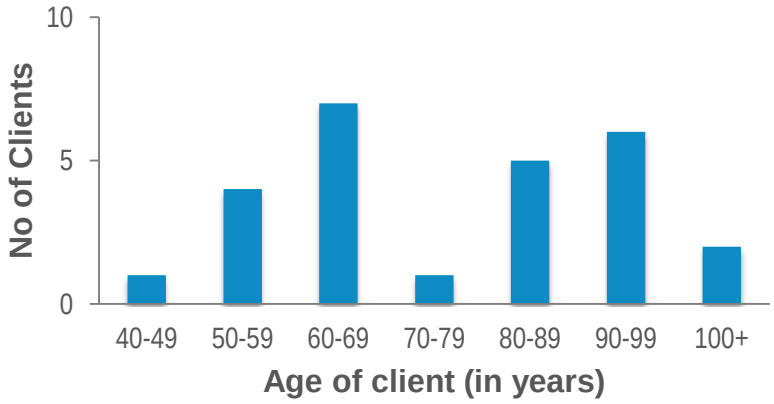

Chart 2. Gender of Client

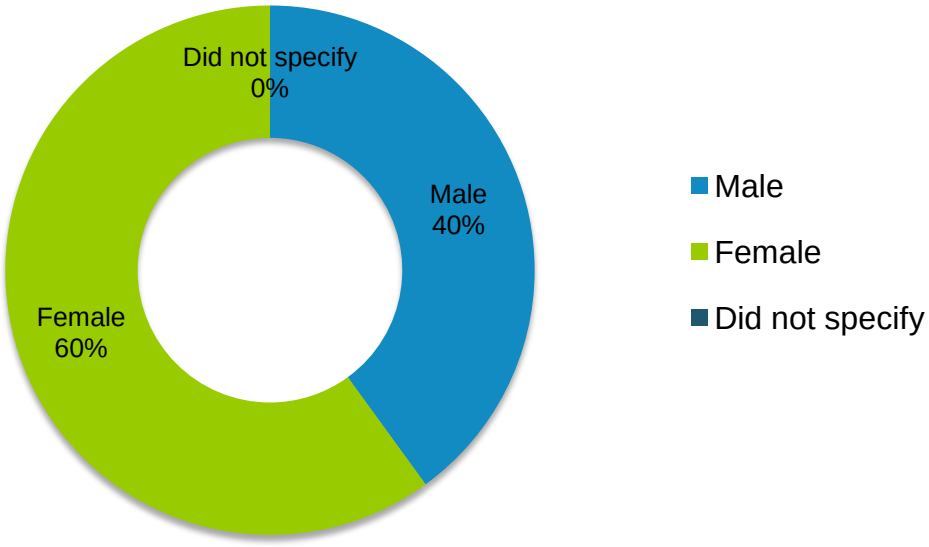

Chart 3. Reason for Receiving Care

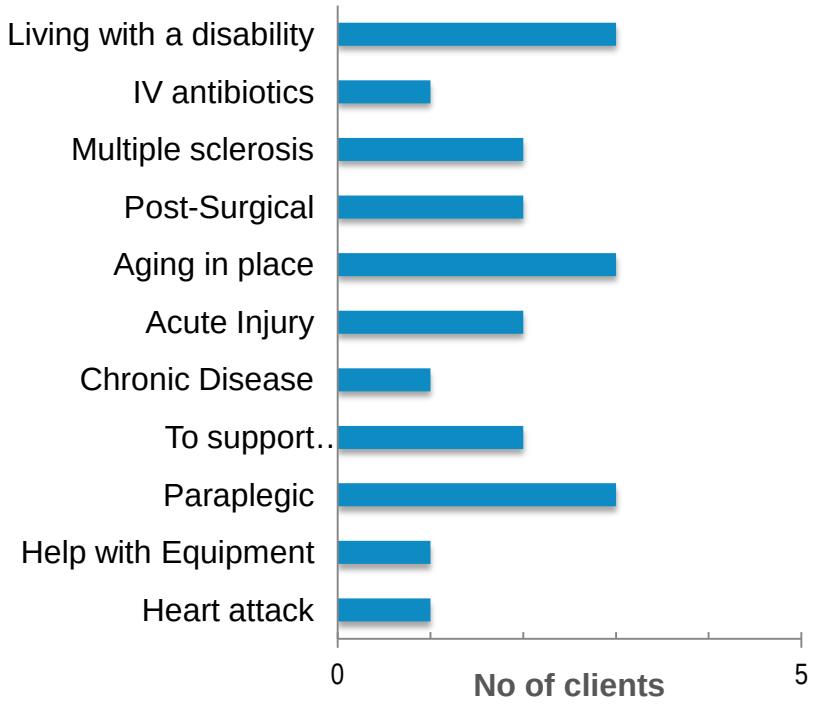

Chart 3. Type of Services Received