Decision-Making on Referral to Primary Care Physiotherapy After Inpatient Stroke Rehabilitation

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Objective: This study aimed to acquire insight into the decision-making processes of healthcare professionals concerning referral to primary care physiotherapy at the time of discharge from inpatient stroke rehabilitation. *Design:* A generic qualitative study using an inductive thematic analysis was performed. Semi-structured interviews were conducted following an interview guide. *Setting:* Secondary care centers in the Netherlands: neurology departments of nine hospitals and (geriatric) rehabilitation centers. *Participants:* Nineteen healthcare professionals (physiotherapists, specialist in geriatric medicine, physiatrist, physician assistant) participated in the study. All were involved in the decision for referral to primary care physiotherapy. *Results:* During the inpatient period, healthcare professionals gather information to form a complete picture of the stroke survivor as a basis for decision-making. The decision on referral is influenced by personal factors and home environment of the stroke survivor, organizational factors within the care setting, and the intuition and feeling of social responsibility of the individual healthcare professional. *Conclusions:* After inpatient rehabilitation, many elements are considered that may influence referral to primary care physiotherapy. Presently, there is no consensus concerning referrals. The final decision depends on the individual physiotherapist and care setting. Healthcare professionals mentioned the importance of movement behavior, although there is no consensus if secondary prevention is a primary task of the physiotherapist. More research is needed to identify risk factors for functional decline in order to develop a referral policy that addresses primary care physiotherapy to the right group of stroke survivors.

Key Words: Stroke/Rehabilitation—Decision-making—Physiotherapy—Primary health care—Patient discharge

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Introduction

Worldwide, stroke is a leading cause of death and disability.[1] Although incidence rates are expected to increase over the next few decades, survival rates are expected to improve. Consequently, more stroke survivors will have to learn to live with the consequences. After acute stroke care or rehabilitation, returning home is one of the primary goals for stroke survivors.[2] In the Netherlands, 65 % of stroke survivors return home immediately after acute hospital care.[3] The remaining 35% continue inpatient rehabilitation in a rehabilitation center (RC) or geriatric rehabilitation center (GRC) before returning home. Only 75% of this group returns home.[4]

One of the key disciplines involved in rehabilitation after a stroke is physiotherapy. Physiotherapy has been found to be beneficial to restoring and maintaining gait and mobility-related functions as well as improving activities of daily living (ADL).[5] This is essential for social reintegration.[6] Additionally, physiotherapy is beneficial in restoring motor functions and physical fitness[7] and contributes to secondary disease prevention.[8]

Physiotherapy starts within the first few days post-stroke in acute care[9] in the hospital and, if necessary, continues in a (geriatric) rehabilitation center or primary care. When patients are discharged from the hospital or rehabilitation setting, physiotherapy in primary care is taken into consideration to continue rehabilitation or to prevent functional decline. It is unclear on what basis referral to primary care takes place. In practice, some patients are referred, and others are not. Unfortunately, stroke survivors often feel abandoned from facility based care after discharge and have difficulties to re-engage in society.[10]

The stroke guidelines only give general instructions concerning stroke survivor and informal caregiver needs.[11–14] The recommendations on stopping or continuing physiotherapy are mainly based on consensus opinion and lack current evidence.

This entails the risk that people post-stroke are unnecessarily referred, or wrongly not referred. The Dutch Physiotherapy Guideline[15] leaves the decision to stop or continue treatment in the hands of the physiotherapist. Within the population post-stroke, a considerable variation exists in the risk for decline in ADL on the long term.[16] Factors that are associated with ADL decline are: ADL dependency, impaired motor function of the leg, insurance status, living alone, age $\geq$ 80, inactive state, impaired cognitive function, depression and fatigue. It is unclear if these and which other factors play a role in the decision to refer, and who takes the decision. The healthcare professionals that are involved in the decision-making, i.e. physiotherapists, physicians, and physician assistants, might have different considerations, intentions, and goals regarding patient referrals.

Currently, collaboration in networks between hospital, rehabilitation care and primary care needs improvement to support patient-centered care. One of the key elements to optimize this collaboration is communication.[17] In literature and in practice, there is no consensus on the organization and content of primary care in the chronic phase. Greater insight into the decision-making process could help healthcare professionals to make more-educated decisions with the aim to address primary care therapy to the right group of patients. Armed with this knowledge, the future of the physiotherapy care provided to stroke survivors returning home could be optimized. This contributes to more sustainable outcomes for people with stroke and possibly to a reduction of secondary complaints. Therefore, this study aimed to explore healthcare professionals' decision-making processes in hospitals and (geriatric) rehabilitation centers in referring patients to primary care physiotherapy at the time of discharge.

Methods

Design

The study was designed following a generic qualitative approach using semi-structured interviews.[18] The method and manner of reporting followed the Consolidated Criteria for Reporting Qualitative Research (COREQ).[19]

Participants

A purposeful sample of physiotherapists, physicians and physician assistants was selected from three hospitals, three rehabilitation centers and three geriatric rehabilitation centers in the Netherlands. Participants were eligible for this study if they 1) treat people with stroke, 2) work in a stroke unit, neurology department of a hospital or (geriatric) rehabilitation center and, 3) are involved in the decision to refer patients to primary care physiotherapy. All participants signed written informed consent forms before participating.

Data collection

Semi-structured interviews were conducted in February and March 2018 and lasted from 40 to 65 minutes. To ensure that all relevant topics were discussed, an interview guide was created (see Appendix 1) based on Guidelines and Best Practice Recommendations[12–15] as well as experts' knowledge. The main topics covered are given in Table 1. A pilot interview was carried out to test the interview guide prior to conducting the interviews. As the study evolved, the interview guide was adapted to explore emerging themes in the analysis.

Interview procedure

The interviews were conducted by one researcher (MG) who is an experienced physiotherapist working in a stroke unit of a GRC. The interviews were digitally

Table 1. *Interview topics.*

The way the healthcare professional monitors progress and functioning of the patient during the inpatient rehabilitation
Procedure, initiatives and considerations on continuing physiotherapy in primary care at time of discharge to home
Goals that were intended to be achieved by referring to primary care physiotherapy
The influence on referral decision making of physical functioning, cognition, home environment, clinical assessment tools, cognition, sedentary behavior, secondary prevention, self-efficacy, the role of the informal caregivers, finance, E-health
Follow up in the inpatient setting after discharge to home
Feedback on referral and contacts with primary care

recorded and transcribed verbatim by the researcher or a research assistant. Summaries of the transcripts were sent to the participants to check the viability of the interpretation.

Analysis

To provide validity and rigor,[20] an generic inductive thematic analysis[18,21] was performed with the use of computer software.[22] Data and findings were discussed in research meetings (MG, RW and research assistants) to facilitate researcher triangulation and improve the reliability of the analysis. When all transcripts were coded, categories (i.e. potential themes) were identified by the researcher (MG). The codes were sorted and combined within the identified categories. Themes were defined and refined.[18] The analysis took place during data collection with the aim of using an iterative process to develop new theoretical ideas.[23] Sampling was stopped when saturation was reached on conceptual level. That was when no new concepts for categories could be identified. After that, two more interviews were conducted to verify saturation. Representative quotations from the transcripts were selected to improve trustworthiness and to strengthen the credibility.

Results

In total, 19 participants were interviewed. Study demographics are listed in Table 2. Participants reactions to the summary of their interview did not influence the content of the themes.

Emergent themes

Themes identified about the decision-making process on referral are presented in Table 3. Quotations which illustrate the themes can be found in the text as well as in Appendix 2.

I. Compiling information during admission to form a complete picture as a basis for decision-making

A complete picture of the person with stroke was formed by the healthcare professional during the

Table 2. *Demographic characteristics of the participants.*

Participant	Sex (M/F'')	Age	Profession	Setting	Experience with stroke (years)	Stroke patients treated per week
1	M	48	physician assistant	hospital	25	20
2	F	52	pt	hospital	30	6-10
3	F	28	pt	hospital	7	10
4	F	54	pt	hospital	33	10-15
5	M	39	pt	hospital	18	15-20
6	F	49	pt	hospital	25	10
7	F	27	pt	GRC^	5	12
8	F	54	pt	GRC	10	19
9	F	39	pt	GRC	17	19
10	F	32	specialist in geriatric medicine	GRC	1,5	15
11	F	52	pt	GRC	20	12
12	F	63	pt	GRC	42	12
13	F	27	pt	GRC	7,5	6
14	F	49	pt	RC˚	25	10-30
15	F	48	physiatrist	RC	18	15-20
16	F	63	pt	RC	40	10+
17	F	56	pt	RC	13	15
18	F	54	pt	RC	27	10-15
19	F	31	pt	RC(ª o.r)	9	10-12

M/F: Male/Female; pt, physiotherapist; ^GRC, Geriatric Rehabilitation Center; ˚RC, Rehabilitation Center; ªo.r, outpatient rehabilitation service.

Table 3. *Emerging themes and sub-themes.*

I. Compiling information during admission to form a picture as a basis for decision-making
II. Considerations on referral to primary care physiotherapy
1) personal factors of the stroke-survivor
2) home environment of the stroke-survivor
3) organizational factors of the institution
4) intuition of the healthcare professional
5) social responsibility of the healthcare professional
III. Taking the final decision

inpatient period via direct patient contact, clinical measurements, observations, multidisciplinary team members and family. Information was gathered about the domains of the World Health Organization's International Classification of Functioning, Disability, and Health (ICF),[24] and pre-morbid functioning, to establish rehabilitation needs and to estimate safe and healthy home functioning in case of discharge.

II. Considerations to refer to primary care physiotherapy

Referral to primary physiotherapy care was considered before discharge. All participants used measurement tools to guide their decision, but it became clear that multiple elements influenced the final decision:

> *Everything must be taken into consideration: age, how quickly a goal is reached, everything matters in this situation. It is not always necessarily clear, and you cannot always put it into words. (Participant 2, hospital, physiotherapist)*

1. Personal factors of the person with stroke

Shared decision-making was embedded into the routine of all participants, although participants expressed that not all patients had the ability to truly comprehend their situation. Patient progress concerning physical functioning and measurements as well as individual goals, plans, and expectations were evaluated and reviewed with the patient. Referral took place when the progress or decline of physical functioning based on ICF's activity and participation level was expected and support was needed. Although the prognosis based on research was considered, most participants said the final referral depended on the individual patient. A few participants were mainly guided by research:

> *Research points out that much recovery happens in the first three to four months up until the sixth month after a stroke. However, recovery can continue for up to two years, so I am not going to send someone home without guidance. (Participant 7, GRC, physiotherapist)*

The consequences that a stroke had on a patient's ICF level of body function and structure, such as contractures or pain, were sometimes a reason for referral. Participants from hospitals kept in mind that significant changes could happen in the acute phase after a stroke. Patients with small deficits and good coping skills were encouraged to first try to reach their goals by themselves.

The participants considered a patient's safe movement and behavior and the patient's healthy activity level and lifestyle. They realized these might be influenced by cognitive impairments. Unsafe physical functioning was a reason for referral for RC/GRC participants. Hospital patients were referred to inpatient rehabilitation instead of primary care physiotherapy if there was any doubt about safety. All participants promoted physical activity although in hospitals, it had no priority due to the short length of a patient's stay. Participants determined if primary care physiotherapy support after discharge was necessary for a patient to return to (adapted) sports or to stay physically active. Participants disagreed on referrals when physical inactivity was due to cognitive impairments. There was disagreement concerning referrals made based on "secondary disease prevention" and lifestyle. Some participants expressed skepticism concerning the effectiveness of secondary disease prevention or believed that lifestyle programs did not belong in physiotherapy. Problems regarding self-efficacy were a reason to refer for half of the participants, although age and recurrent stroke were not.

2. Home environment of the person with stroke

The home environment includes the physical aspects of the house such as layout and presence of stairs as well as the social and cultural environment. Physiotherapy support was sometimes advised to help patients to adjust to physical functioning in their homes or to buffer the transition from ample assistance to none. Participants from RCs and GRCs referred with the aim of supporting and instructing the informal caregiver:

> *You feel that the spouse does not understand what needs to be done and there are cognitive problems. Is everything safe at home and will the patient do what he is supposed to do instead of what he is not supposed to do? (Participant 14, RC, physiotherapist)*

One participant pointed out to consider the referral to be a guide to good coping skills for people from foreign cultures.

3. Organizational factors of the care setting

The length of inpatient stays varied due to different criteria for discharge in each care setting. This influenced the frequency of referral. None of the investigated settings had a protocol concerning referral to primary care physiotherapy, except one RC: all patients were referred to primary care physiotherapy after discharge aiming

treatment, monitoring the transition to home, annual control or contingency:

In our stroke-service, we have said that all the patients recovering from a stroke . . . . should be standardly referred to physiotherapy in primary care. . . . If something comes up, a patient has a direct line to help. (Participant 18, RC, physiotherapist)

Among the settings, follow up consultations after discharge were organized in different ways. It varied from standard to incidental consultations at the physiatrist and/or neurologist to phone calls or a home visit of a nurse specialist to no follow up. Having a possibility of a follow-up consultation within the setting had a variable effect on the referral behavior. Half of the participants used the follow-up consultation as a sort of safety net to give delayed referrals if necessary. Others said that the existence of follow-up consultations did not influence their decisions. Due to short stay, participants working in hospitals had to make quick decisions. They took no risk and referred in case of doubt, except in cases where patients recovered very quickly.

4. Intuition

Although all participants made most decisions in a reasoned way, intuition played a part in decision-making. A combination of their observations and experience might have given them gut feelings concerning a patient's self-management skills and ability to cope at home.

If I can see that a patient can safely function independently, then I do not refer. But . . . . if I have doubts, however, they are based on my intuition and not on any numbers. (Participant 6, hospital, Physiotherapist)

Participants intuitively decided how to cope with unmotivated or stubborn patients. Intuition was also used in cases where maximum functioning seemed (almost) reached and where patients needed support in reaching their goals.

5. Social responsibility concerning efficiency and healthcare costs

Participants critically examined the usefulness, necessity, and efficiency of referrals. Most participants had some doubts about the knowledge and integrity of the primary care physiotherapist due to generalizing bad experiences and receiving no feedback after referring patients.

I do not know the expertise of my primary care colleague . . . . You must trust that these colleagues know what they are doing. We sometimes hear that people get a massage and walk around the table twice and it is done. (Participant 11, GRC, physiotherapist)

Although it did not stop them from referring, some participants tried to guide a patient to a specialized neurology physiotherapist. However, this kind of specialist was not always easy to find. Some of the care settings have set up a partnership with primary care physiotherapists specialized in neurology.

III. Taking the final decision

The percentage of patients referred to primary care depended on the individual participant and the care setting. Among the participants, the referral frequency varied from "always" to "no, unless":

I have colleagues who are quick to refer patients. In case of decline, they say a patient should go to a therapist. I am much more practical. I think . . . . when a patient has a mild problem . . . . not having too many problems functioning at home, or it costs him only a bit energy to do things himself than I am more prone not to advise physiotherapy. (Participant 5, hospital, physiotherapist)

The final decision concerning referral was usually made by the physiotherapist, often after a multidisciplinary team meeting. Sometimes a colleague or occupational therapist was consulted in case of doubt. The physician usually followed the advice of the physiotherapist. Most healthcare professionals referred patients to primary care physiotherapy for a short treatment period. The physiotherapists said to rely on prior decisions, however, they pointed out that feedback concerning referrals is lacking. Coincidental contacts they had with patients after discharge, were valuable to verify decision-making.

Discussion

The goal of the study was to gain insight into the decision-making process of healthcare professionals concerning referral to primary care physiotherapy when patients were discharged from inpatient stroke-rehabilitation. During the inpatient stay, the healthcare professionals gathered information which allowed them to form a complete picture of the patient as a basis for decision-making. At the point of discharge, the decision to refer to primary care physiotherapy depended on: personal and home environmental factors of the patient, organizational factors in the care setting, intuition and feelings of social responsibility of the healthcare professionals. Commonly, the physiotherapists made the decision to refer. In general, they could not evaluate their decision since they received no structural feedback from the primary care physiotherapist, the patient, or the physician after referral. Except in one RC, no protocol concerning referral to

primary care physiotherapy existed. Moderate confidence existed in the expertise of primary care physiotherapy. A specialized neurology physiotherapist in primary care was not always available.

The risk factors for decline as pointed out by Wondergem et al[16] were considered in the decision-making although disagreement existed on referral in case of cognitive disorders and sedentary behavior. Variation in referral policy among healthcare professionals as well as lacking the opportunity to evaluate the decision (not) to refer entail the risk that people post-stroke are unnecessarily referred, or wrongly not referred. Other researchers also found variation in post-stroke delivery of care after discharge and conclude therapist use after discharge might be underused[25,26] although these studies focused on all available follow-up services and not specifically on physiotherapy. Comparable to our results Kennedy et al[27] also demonstrated that healthcare professionals weigh clinical (personal and home environment) as well as non-clinical (organizational) factors when making decisions and many healthcare professionals had different opinions concerning decision-making about referrals.

The decision-making was shared with the patient as well as the family in all cases. Some healthcare professionals mentioned that certain patients simply could not comprehend or manage their own situation. Similar barriers concerning shared decision-making were identified by Armstrong.[28] All healthcare professionals stimulated and monitored capacities such as self-management and self-efficacy. They intuitively estimated these capacities for each patient. Research emphasizes the need to empower people recovering from a stroke to take an active role in managing their condition by taking advantage of self-management programs during rehabilitation.[29] This is proven to be beneficial to self-efficacy, quality of life and associated health outcomes.[29,30] The optimal timing of self-management programs depends on "the readiness of the patient" and the individual appraisal of the healthcare professional.[31,32]

The American Heart Association/American Stroke Association recommends physical activity to reduce the risk of recurrent stroke.[33] Alongside declined levels of physical activity, people recovering from a stroke are much more sedentary as compared to healthy peers.[34] Both of these behaviors, which are a part of movement behavior, are independent risk factors for recurrent stroke and all-cause mortality.[35,36] Nevertheless, although all healthcare professionals encouraged physical activity, there were different opinions about the contribution of physiotherapy to secondary disease prevention and sedentary behavior. Skepticism in the effectiveness of secondary disease prevention was pointed out, which was also found in other research.[37]

Most healthcare professionals considered risk factors for functional decline in the chronic phase, such as advanced age, cognitive disorders, depression, fatigue and physical inactivity but not all considered (prevention of) functional decline as a reason for referral. On the other hand, research points out that stroke survivors and their informal caregivers living in the community felt like they were left to their own devices by healthcare services when trying to cope with long-term stroke-related changes and decline,[10] which indicates the current referral policy of the healthcare professional might not meet the stroke survivors' long-term needs.

This study has strengths and limitations. It is the first Dutch study exploring the decision-making process concerning referral to primary care physiotherapy after inpatient stroke rehabilitation. Due to the large sample size, generalizability of a healthcare professional's view is plausible.[23] One weakness could be that the results are based on the health-care situation in the Netherlands, although the decision-making can be applied to other countries since the guidelines are similar. Another limitation of the study could be that mainly physiotherapists were interviewed and only a few physicians/physician assistants. However, during the sampling process, healthcare professionals indicated that they left the decision of referral up to the physiotherapist.

Based on the results of the current study, some recommendations can be made to improve decision making on referral to primary care physiotherapy. Stimulation of physical activity and prevention of sedentary behavior are the most important factors to consider for referral to primary care physiotherapy, to prevent decline in ADL and for secondary prevention. More research is needed to identify people with high risk for functional decline or recurrent stroke in order to generate a more substantiated basis for referral. To increase the confidence of the decision made, the physician should make it a point to share information about the follow-up examination with the multidisciplinary team to learn from the decisions that were made. Extending post-stroke care into the community using collaboration[38] between inpatient settings, primary care physiotherapy practices, and physical fitness opportunities could provide better health quality services concerning rehabilitation and safe sports environments.

We conclude that, after inpatient rehabilitation, many elements are considered that may influence referral to primary care physiotherapy. Presently, there is no consensus concerning referrals. The final decision depends on the individual physiotherapist and the care setting. Healthcare professionals mentioned the importance of movement behavior, although there is no consensus if secondary prevention is a primary task of the physiotherapist. More research is needed to identify risk factors for functional decline and recurrent stroke in order to develop a referral policy that addresses primary care physiotherapy to the right group of stroke survivors.

Ethical Considerations

For this study, WMO was not applicable. There are no conflicts of interest. This research did not receive any specific grant from funding agencies in the public, commercial, or not-for -profit sectors.

Declarations of Competing Interest

none.

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Appendix 1: Interview guide

Part 1. Demographics of the participant:

Age, occupation?

Years of experience with patients post-stroke?

How many patients post-stroke do you treat per week?

For physician / Physician assistant: What is your perception of physiotherapy (PT)?

Part 2. Impression of patient group/ procedures concerning discharge

What is the patient's level of functioning/impairment at time of discharge?

How do you monitor the progress? And the results?

Do you use any clinical measurement tools?

Level of functioning at discharge

Do you always feel confident that a patient has progressed enough by the time they are discharged? Please explain.

What is the dismissal procedure in your organization?

Who are involved in determining yes or no to physiotherapy after discharge? What is the time schedule? What actions are normally taken?

Which actions do you take regarding referrals to primary care PT? (consult patient or family, doctor, primary care PT? Write letters, conduct phone calls etc.?)

Do doctors and physiotherapists always agree on referrals?

If not, what do they disagree on?

Is the patient involved in determining whether to pursue primary care PT? In what way?

Do healthcare professionals and patients always agree on the referral or on the decision not to refer?

If not, what do they disagree on?

Do you ever consult a colleague about whether or not to refer a patient to PT?

If so, when? What difference does this consultation make to you?

At what moment in the rehabilitation process do you start thinking about whether or not to continue PT in primary care?

Are you inclined to refer or not to refer? Estimated ratio?

Part 3 Clinical reasoning:

What considerations do you have concerning referral; can you say something about that?

What are the typical characteristics of patients that are treated in primary care PT?

Do you keep in mind the following, and to what extent does each of these points play a role in the decision-making process?

- ICF's levels: impairment, functioning, participation.
- Cognition
- Clinical measurement tools that are recommended by stroke guidelines or other measurement tools?
- how much weight do measurement tools carry in the final decision-making process?
- Informal care / social network?
- First or recurrent stroke?
- Secondary disease prevention?
- Use of e-health?
- Financial aspects: reimbursement from health insurance
- Sedentary behavior during admission, the inpatient stay or when the patient had a history of sedentary behavior? Is a patient specifically asked about his plans to be active / exercise at home?
- Self-efficacy?

What best characterizes patients who are not being referred to primary care PT?

What makes you decide whether or not to refer?

Is this decision based on objective standards? Measurement tools? If so, which ones? What are the cut-off points?

Do you follow your gut feelings? Can you elaborate on this? For instance, what gives you bad or good feelings concerning a referral?

Do you ever have doubts about whether or not to refer?

If so, why?

If not, why?

Do you make a conscientious choice as to which primary care physiotherapist you refer to?

Do you have faith in the primary care physiotherapists?

What goals do you set when you refer a patient?

If you do not refer:

Do you have these patients come back to you for a check-up later? Do you give them any advice as to when physiotherapy should be resumed?

Does having an outpatient clinic within your own organization influence your decision to refer to primary care PT? If so, how?

At what point do you check to see if a patient recovers well at home on their own?

Have you ever provided feedback as to whether the decision to refer or not to refer was a good choice? Is this necessary, do you think?

We have come to the end of the interview. Thank you for your time. Do you have anything that you would like to add?

Appendix 2: Quotes

I. Gaining information during admission to form the picture

I see the patient every day, so I look how he functions and what changes there are. . . . in with an acute stroke, changes can go in all directions. If I notice significant changes, I re-test him. Furthermore, it is a matter of looking, judging, observing and writing the electronic record . . . . we exchange information with occupational therapy, and I read the nurses' files and I ask them: " how is this patient getting on?" because the nurses are involved in mobilizing the patient several times a day if he can't move independently . . . . If necessary, you talk to the physician . . . . And family, they know the patient, we need their input: Is he acting differently here compared to when he is at home, how does he react when they are there? (Participant 4, hospital, physiotherapist)

II. Goals and considerations to refer to primary care PT

1)personal factors of the person with stroke:

It is always about someone who maybe mobile in a different way and is otherwise safe or functioning than just a number would lead you to believe. (participant 4, hospital, physiotherapist)

Some reduced joint mobility in a paretic arm is a consequence of the condition and doesn't necessarily need to be treated if it doesn't lead to pain or further functional problems. (Participant 15, RC, physiatrist)

Sometimes there are slight coordination problems but that's it. Then, it is debatable whether a patient with a mild stroke should go to physiotherapy at once. If you have coordination problems after a mild stroke, especially in your preferred hand then you a.) work with that hand all day long because you know it will help and b.) realize that the situation can change after just three or four days and you can't really know on day one what the situation will be a week later. (Participant 4, hospital, physiotherapist)

The available adapted sports activities are suitable for people with minor or no motoric disorders. I think that if someone just has to keep on walking, he or she should go to individual physiotherapy. Of course, I suggest to the [primary care] *physiotherapist to advise the patient to do structured activity to remain active in the future. After discharge from inpatient rehabilitation, the step to independent sport is way too big for many people. (Participant 17, RC, physiotherapist)*

No matter how minor a stroke may be, it is always an eye-opener and people come to realize that perhaps their lifestyle isn't the right one. Some people decide that now is the time to change something, but I question whether anything is going to happen. So, I'm inclined to encourage someone to work out and go where there is someone who can explain how to safely enjoy working out and what the physical fitness standard is. (Participant 4, hospital, physiotherapist)

I wouldn't necessarily push a patient who was already in the last stages of recovery and working out well to go to a physiotherapist after suffering another stroke. If someone understands what needs to be done in terms of exercise and all was going well, I would consult with them to determine if exercise is something that they could do themselves or if they would need guidance again. Going through the whole process of physiotherapy is very challenging for some people. (Participant 4, hospital, physiotherapist)

2) Home environmental factors

Here, we exercise in a hospital situation and not in the home situation. So, it is really good if there is someone who can go into the home and see what is happening. Stairs here are different than the stairs found in a home, for example. What happens when someone must get into the bathtub or out of bed? What happens once a patient tries to go outside? In the traffic? How does someone manage? (Participant 6, hospital, physiotherapist)

In our facility, there is always a treatment team for patients but when they go home, their support system is suddenly very small. So, to make the transition easier, I am quick to refer. (Participant 11, GRC, physiotherapist)

You are in the acute phase; patients must train themselves and there is so much change happening so quickly. You can inform care providers but in three days, everything could be different. (Participant 5, hospital, physiotherapist)

I also have patients who lay in bed and are pampered by family members, which is the case for many cultures. You still try to tell them that this is exactly what shouldn't happen. This is an issue that should be quickly addressed by care givers in hopes of changing the home dynamics of a patient and thus improving recovery. (Participant 6 hospital, physiotherapist)

3) Organizational factors

Nowadays, the philosophy of the government is, in principle, to send everyone home. However, I see that this has changed. People that I used to think couldn't go home I see going home now. (Participant 9, GRC, physiotherapist)

In our organization the inpatient period is short [on average 4-6 weeks] *so actually I want to refer everyone because*

they are in the middle of their rehabilitation process. (Participant 13, GRC, physiotherapist)

[about follow-up consultation as a safety-net]

If we decided not to refer and it went wrong, we hear it in the follow-up consultation after six weeks. If than, if we did wrong, it isn't too late to go back and try something else. At this point, we refer a patient to physiotherapy. (Participant 1, hospital, physician assistant)

[Having a safety-net] *. . . . means that I take some more risks . . . . a patient who was very sportive says that he can't wait to exercise again . . . . If I have any doubts, if he will manage it by himself, I advise him to try it. I will hear how things are going at the follow-up. (Participant 17, RC, physiotherapist)*

4) Intuition

I always try to see each patient as an individual. I try to understand the individual and see how his life works and determine what in his life isn't working. The referral is thus dependent on the patient's personality and here is where I need to use my intuition. I can't subject a patient to thousands of questionnaires to figure out exactly who the patient is. Instead, I have to rely on my intuition to figure out what kind of person I have here and how he is going to deal with things. How will he cope and be self-reliant? I must rely on my intuition . . . . There is a lot of reliance on intuition, guessing and experience. So, intuition is certainly a factor. You try to test your objectives, but you still have another element that gets factored into the situation, be that your feeling or your intuition or whatever. (Participant 4, hospital, physiotherapist)

5) Social responsibility concerning efficient training and healthcare costs

because I feel that you also have a social responsibility not to burden the community with the cost of years of physiotherapy. I am a person who writes an authorization for physiotherapy, also for chronic indications, that I find necessary after a brain injury. However, I always write the indication for a year. If I am asked to write another authorization after one year of physiotherapy, I always reconsider the situation to determine if it is really necessary. (Participant 15, RC, Physiatrist)

Sometimes I will even write a referral letter with special stipulations. I don't want a patient to have a massage or have a shoulder treated a certain way by someone who doesn't know what he is doing. If someone with a hemiplegic shoulder goes to a sports physiotherapist, then beware. I don't trust it and so I will indicate 'only for fitness' on the referral. I still find it scary, but I restrict treatment to a specific goal and the rest doesn't need to be treated. (Participant 14, RC, physiotherapist)

Too often I hear stories from patients when I ask them 'have you ever had physiotherapy?' They answer 'yes, yes, someone always came to my house.' I ask further 'what did you do then?' 'Yeah, I did this and then I sat down and stood up a couple of times and that was it.' Since you don't have any idea what kind of experience outside people [physiotherapists in primary care] *have, I think that patients should just be treated in a rehabilitation center. This is simply because it is a matter of experience and a more functional approach. Often there are better facilities, but this isn't always an option. (Participant 3, hospital, physiotherapist)*

Sometimes we hear stories about the quality of physiotherapy [in primary care] *and what people complain about. (Participant 1, hospital, physician assistant)*

That's why it is also important that we work together with physiotherapists [in primary care] *to make it easier to transfer patients and it allows us to build up trust. It is about trusting and letting go. (Participant 14, RC, PT)*

III. Taking the final decision

In effect, the physiotherapist treating a patient determines what is necessary. This physiotherapist knows if a patient is ready or if he needs more physiotherapy and I can trust this. I'm not going to question it. (Participant 15, RC, Physiatrist)

I find it unfortunate that you never know if your advice was correct or not. So, it would be really beneficial to know how well a patient recovers. (Participant 19, hospital, physiotherapist)

I had a woman once who was doing really well in my care, especially motorically. I really thought that she didn't need any further physiotherapy and I didn't concern myself with it. I didn't have to write a referral and I didn't have to discuss anything with a doctor, but the woman did come back here for outpatient speech therapy and psychological treatment. So, the woman went home and walked a lot. Then it turned out that she started going to a gym, but she couldn't pace herself. She went way too fast. There was guidance at the gym, but no one knew that this woman was recovering from a stroke. Then I thought, this was someone who was recovering well but I should have monitored her much more closely. (Participant 13, GRC, physiotherapist)

References

1. Benjamin EJ, Blaha MJ, Chiuve SE, Cushman M, Das SR, Deo R, et al. Heart disease and stroke statistics-2017 update: a report from the American heart association.

Circulation [Internet] 2017;135(10):e146-e603. https://doi.org/10.1161/CIR.0000000000000485. Mar 7 [cited 2018 Apr 19]Available from http://www.ncbi.nlm.nih.gov/pubmed/28122885.
2. Pollock A, St George B, Fenton M, Firkins L. Top ten research priorities relating to life after stroke. Lancet Neurol [Internet] 2012;11(3):209. https://doi.org/10.1016/S1474-4422(12)70029-7. Mar 1 [cited 2018 Jun 12]Available from http://www.ncbi.nlm.nih.gov/pubmed/22341029.
3. Revalidatie na beroerte | Hartstichting [Internet]. [cited 2017 Dec 10]. Available from: https://www.hartstichting.nl/hart-en-vaatziekten/beroerte/revalidatie-na-beroerte
4. American Heart Association American Stroke Association. Impact of Stroke (Stroke statistics) [Internet]. 2016 [cited 2018 May 30]. Available from: http://www.strokeassociation.org/STROKEORG/AboutStroke/Impact-of-Stroke-Stroke-statistics_UCM_310728_Article.jsp#.Ww7YWEiFOM8
5. Therapy-based rehabilitation services for stroke patients at home. Cochrane Database Syst Rev [Internet]. 2003 Jan 20 [cited 2018 Apr 19]; Available from: http://doi.wiley.com/10.1002/14651858.CD002925.
6. Blömer A-M V, van Mierlo ML, Visser-Meily JM, van Heugten CM, Post MW. Does the frequency of participation change after stroke and is this change associated with the subjective experience of participation? Arch Phys Med Rehabil [Internet] 2015;96(3):456-463. https://doi.org/10.1016/j.apmr.2014.09.003. Mar 1 [cited 2018 Jun 11]Available from http://www.ncbi.nlm.nih.gov/pubmed/25264108.
7. Veerbeek JM, van Wegen E, van Peppen R, van der Wees PJ, Hendriks E, Rietberg M, et al. What is the evidence for physical therapy poststroke? A systematic review and meta-analysis. PLoS One [Internet] 2014;9(2):e87987. https://doi.org/10.1371/journal.pone.0087987. [cited 2017 Nov 8]Available from http://www.ncbi.nlm.nih.gov/pubmed/24505342.
8. Lennon O, Galvin R, Smith K, Doody C, Blake C. Lifestyle interventions for secondary disease prevention in stroke and transient ischaemic attack: a systematic review. Eur J Prev Cardiol [Internet] 2014;21(8):1026-1039. https://doi.org/10.1177/2047487313481756. Aug 11 [cited 2018 Apr 19]Available from http://journals.sagepub.com/doi/10.1177/2047487313481756.
9. Langhorne P, Bernhardt J, Kwakkel G. Stroke rehabilitation. Lancet (London, England) [Internet] 2011;377(9778):1693-1702. https://doi.org/10.1016/S0140-6736(11)60325-5. May 14 [cited 2017 Nov 8]Available from http://www.ncbi.nlm.nih.gov/pubmed/21571152.
10. Pindus DM, Mullis R, Lim L, Wellwood I, Rundell AV, Abd Aziz NA, et al. Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services – a systematic review and meta-ethnography. Woloschak GE, editor. PLoS One [Internet] 2018;13(2):e0192533. https://doi.org/10.1371/journal.pone.0192533. Feb 21 [cited 2018 Jun 17]Available from http://dx.plos.org/10.1371/journal.pone.0192533.
11. Stroke rehabilitation in adults | Guidance and guidelines | NICE. [cited 2018 Jun 13]; Available from: https://www.nice.org.uk/guidance/CG162/chapter/1-Recommendations#planning-and-delivering-stroke-rehabilitation
12. Cameron JI, O'Connell C, Foley N, Salter K, Booth R, Boyle R, et al. Canadian stroke best practice recommendations: managing transitions of care following stroke, guidelines update 2016. Int J Stroke [Internet] 2016;11(7):807-822. https://doi.org/10.1177/1747493016660102. Oct 28 [cited 2018 Feb 28]Available from http://journals.sagepub.com/doi/10.1177/1747493016660102.
13. Lindsay MP, Gubitz G, Bayley M, Hill MD. Phillips S and SE. Canadian stroke best practice recommendations overview and methodology. On behalf of the Canadian stroke best practices advisory committee and writing groups. [Internet]. Ottawa. Ontario Canada: Heart Stroke Foundation, Canada 2014. [cited 2018 Feb 28]. Available from http://www.strokebestpractices.ca/wp-content/uploads/2014/08/CSBPR2014_Overview_Methodology_ENG.pdf.
14. Stroke Foundation. Clinical guidelines for stroke management 2017. Melbourne Australia. [Internet]. [cited 2018 Feb 28]. Available from: https://informme.org.au/Guidelines/Clinical-Guidelines-for-Stroke-Management-2017
15. Veerbeek JM, Weegen van EEH, Peppen van RPS, Hendriks HJ. KNGF Richtlijn Beroerte. 2014.
16. Wondergem R, Pisters MF, Wouters EJ, Olthof N, de Bie RA, Visser-Meily JMA, et al. The course of activities in daily living: who is at risk for decline after first ever stroke? Cerebrovasc Dis [Internet] 2017;43(1–2):1-8. https://doi.org/10.1159/000451034. [cited 2018 May 22] Available from http://www.ncbi.nlm.nih.gov/pubmed/27750246.
17. Borcherts J, Van Vree F, Goossens P, Groeneveld I, Arwert H, Meesters J, et al. Passende zorg en substitutie in zorgnetwerken voor mensen met een CVA. 2018. Available from: https://www.basaltrevalidatie.nl/cva-netwerken/site/assets/files/10047/eindrapportage-passende-zorg-en-substitutie-in-zorgnetwerken-voor-mensen-met-cva-def.pdf
18. Braun V, Clarke V. Qualitative Research in Psychology Using thematic analysis in psychology Using thematic analysis in psychology. Qual Res Psychol [Internet] 2006;3(2):77-101. https://doi.org/10.1191/1478088706qp063oa. [cited 2017 Nov 5]Available from http://www.tandfonline.com/action/journalInformation?journalCode=uqrp20.
19. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Heal care J Int Soc Qual Heal Care [Internet] 2007;19(6):349-357. https://doi.org/10.1093/intqhc/mzm042. Dec 16 [cited 2017 Sep 29]Available from https://academic.oup.com/intqhc/article-lookup/doi/10.1093/intqhc/mzm042.
20. Morse JM, Barrett M, Mayan M, Olson K, Spiers J. Verification Strategies for Establishing Reliability and Validity in Qualitative Research. Int J Qual Methods [Internet] 2002;1(2):13-22. https://doi.org/10.1177/160940690200100202. Jun 30 [cited 2018 May 6]Available from http://journals.sagepub.com/doi/10.1177/160940690200100202.
21. Thomas DR. Method notes a general inductive approach for analyzing qualitative evaluation data. Am J Eval [Internet] 2006;27:237-246. https://doi.org/10.1177/1098214005283748. [cited 2018 May 6]Available from http://journals.sagepub.com/doi/pdf/10.1177/1098214005283748.
22. NVivo 11 for Windows | QSR International. United Kingdom, London.
23. Holloway I WS. Qualitative research in nursing and healthcare [Internet]. 3rd ed. Malaysia: Blackwell

Publishing; 2014. p. 146-147. https://scholar-google-nl.proxy.library.uu.nl/scholar?hl=nl&as_sdt=0%2C5&q=-Holloway+I%2C+Wheeler+S.+Qualitative+research+in+nursing+and+healthcare%2C+&btnG=.
24. WHO | International Classification of Functioning, Disability and Health (ICF). WHO [Internet]. 2018 [cited 2018 May 26]; Available from: http://www.who.int/classifications/icf/en/
25. Putman K, De Wit L, Schupp W, Baert I, Brinkmann N, Dejaeger E, et al. Variations in follow-up services after inpatient stroke rehabilitation: a multicentre study. J Rehabil Med [Internet] 2009;41(8):646-653. https://doi.org/10.2340/16501977-0385. [cited 2018 Feb 25]Available from https://medicaljournals.se/jrm/content/abstract/10.2340/16501977-0385.
26. Freburger JK, Li D, Johnson AM, Fraher EP. Physical and occupational therapy from the acute to community setting after stroke: predictors of use, continuity of care, and timeliness of care. Arch Phys Med Rehabil [Internet] 2017. https://doi.org/10.1016/J.APMR.2017.03.007. Apr 4 [cited 2018 Feb 28]; Available from https://www-sciencedirect-com.proxy.library.uu.nl/science/article/pii/S0003999317302204.
27. Kennedy GM, Brock KA, Lunt AW, Black SJ. Factors influencing selection for rehabilitation after stroke: a questionnaire using case scenarios to investigate physician perspectives and level of agreement. YAPMR [Internet] 2011. https://doi.org/10.1016/j.apmr.2011.11.036. [cited 2018 May 30]; Available from https://pdfs.semanticscholar.org/9c41/a1749d2c8ce7dfe4819878603ca5f7cb404f.pdf.
28. Armstrong MJ. Shared decision-making in stroke: an evolving approach to improved patient care. BMJ [Internet] 2017;2(2):84-87. https://doi.org/10.1136/svn-2017-000081. Jul 1 [cited 2018 Jun 14]Available from http://svn.bmj.com/cgi/doi/10.1136/svn-2017-000081.
29. Jones F. Strategies to enhance chronic disease self-management: How can we apply this to stroke? Disabil Rehabil [Internet] 2006;28(13–14):841-847. https://doi.org/10.1080/09638280500534952. Jan 7 [cited 2018 May 23] Available from http://www.tandfonline.com/doi/full/10.1080/09638280500534952.
30. Jones F, Riazi A. Self-efficacy and self-management after stroke: a systematic review. Disabil Rehabil [Internet] 2011;33(10):797-810. https://doi.org/10.3109/09638288.2010.511415. Jan 27 [cited 2018 May 23]Available from http://www.ncbi.nlm.nih.gov/pubmed/20795919.
31. Wray F, Clarke D, Forster A. Post-stroke self-management interventions: a systematic review of effectiveness and investigation of the inclusion of stroke survivors with aphasia. Disabil Rehabil [Internet] 2018;40(11):1237-1251. https://doi.org/10.1080/09638288.2017.1294206. May 22 [cited 2018 May 23]Available from http://www.ncbi.nlm.nih.gov/pubmed/28271913.
32. Jones F, Livingstone E, Hawkes L. Getting the Balance between Encouragement and Taking Over' - Reflections on Using a New Stroke Self-Management Programme. Physiother Res Int [Internet] 2013;18(2):91-99. https://doi.org/10.1002/pri.1531. Jun 1 [cited 2018 Sep 19]Available from http://doi.wiley.com/10.1002/pri.1531.
33. Furie KL, Kasner SE, Adams RJ, Albers GW, Bush RL, Fagan SC, et al. Guidelines for the prevention of stroke in patients with stroke or transient ischemic attack: a guideline for healthcare professionals from the American Heart Association/American Stroke Association. Stroke [Internet] 2011;42(1):227-276. https://doi.org/10.1161/STR.0b013e3181f7d043. Jan 1 [cited 2018 May 23]Available from http://www.ncbi.nlm.nih.gov/pubmed/20966421.
34. English C, Healy GN, Coates A, Lewis L, Olds T, Bernhardt J. Sitting and activity time in people with stroke. Phys Ther [Internet] 2016;96(2):193-201. https://doi.org/10.2522/ptj.20140522. Feb 1 [cited 2018 Sep 19]Available from https://academic.oup.com/ptj/article-lookup/doi/10.2522/ptj.20140522.
35. Biswas A, Oh PI, Faulkner GE, Bajaj RR, Silver MA, Mitchell MS, et al. Sedentary time and its association with risk for disease incidence, mortality, and hospitalization in adults. Ann Intern Med [Internet] 2015;162(2):123. https://doi.org/10.7326/M14-1651. Jan 20 [cited 2019 Mar 16]Available from http://annals.org/article.aspx?doi=10.7326/M14-1651.
36. Matthews CE, George SM, Moore SC, Bowles HR, Blair A, Park Y, et al. Amount of time spent in sedentary behaviors and cause-specific mortality in US adults. Am J Clin Nutr [Internet] 2012;95(2):437-445. https://doi.org/10.3945/ajcn.111.019620. Feb 1 [cited 2019 Mar 16]Available from https://academic.oup.com/ajcn/article/95/2/437/4576797.
37. Walkeden S, Walker KM. Perceptions of physiotherapists about their role in health promotion at an acute hospital: a qualitative study. Physiotherapy [Internet] 2015;101(2):226-231. https://doi.org/10.1016/J.PHYSIO.2014.06.005. Jun 1 [cited 2018 Jun 14]Available from https://www.sciencedirect.com/science/article/pii/S0031940614000789.
38. Britnell M, Lowe-Lauri M. What works. Partnerships, networks and alliances. Glob lessons Trends [Internet]. UK 2016. [cited 2018 Jun 14]. Available from https://assets.kpmg.com/content/dam/kpmg/pdf/2016/04/what-works-partnerships-networks-alliances.pdf.