Family-Mediated Exercises (FAME): An Exploration of Participant’s Involvement in a Novel Form of Exercise Delivery After Stroke

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Background: Family members and caregivers play a significant supporting role in the rehabilitation process after stroke, a role that may increase with the growing trend of providing stroke rehabilitation in the individual’s own home after discharge from the hospital. Objective: To explore the impact of family involvement in exercise delivery after stroke from the perspective of the individual with stroke and his or her family member. Methods: A qualitative research design was used in which in-depth semi-structured interviews were carried out with participants who had taken part in an 8-week family-mediated exercise program (FAME). A phenomenological theoretical framework and a grounded theory methodology were used to inform the data analysis. Results: Fifteen individuals with acute stroke and 15 designated “family” members participated in the study after completion of an 8-week, individually tailored, family-mediated exercise intervention. An overarching concept of patient-centeredness emerged after data analysis, which detailed the extent to which individuals with stroke and their families felt that their rehabilitation was enhanced by the active role of their families. Four key themes that expanded the concept of patient-centeredness were identified: personalized nature of the reported benefits, therapeutic value of the program, family involvement, and caregiver commitment to program. Conclusion: This research serves to increase our understanding of the role of family members in the rehabilitation process after stroke, particularly in relation to exercise delivery, from the perspective of the individuals with stroke and their family members. Key words: family involvement, physical therapy, qualitative research, rehabilitation, stroke recovery

Stroke is a major cause of death and acquired disability in all societies in which it has been studied. Approximately 16 million first-ever strokes occur in the world annually, causing a total of 5.7 million deaths.1 The true impact of stroke should not be considered only in terms of incidence and mortality rates but also in terms of disability, which often persists for a long time, sometimes permanently, after stroke.2 After a recommended initial hospital admission, up to 80% of patients are discharged home and many are dependent on informal caregivers, usually family members, to provide assistance with activities of daily living, including bathing, dressing, and toileting.3 The needs of these caregivers are inherently different from those of caregivers of individuals with progressive conditions such as Parkinson’s disease or dementia in that stroke is an unpredictable event that can be life changing. The sudden onset often does not allow family members sufficient time to prepare for the complex responsibilities of caregiving.4 Several interventions have been developed and tested to enhance family members’ transition into a caregiving role.5 These interventions commonly focus on providing information to care recipients and their caregivers about the particular health condition and its treatment5-8 or available community services.9 Other interventions target the caregivers’ needs by providing counseling and training in problem solving.7,10,11 Among the interventions that have
been evaluated, small to moderate reductions in caregiver burden and emotional distress and improvements in psychologic well-being and quality of life have been reported. Larger improvements have been observed in multi-component interventions including psychotherapeutic and psycho-educational elements that are specific and tailored to caregiver needs.

The experiences of caregivers of people with stroke have been widely researched. Studies have demonstrated that information and skills training that are required to implement physical care are among the most important predischarge needs identified by caregivers. However, to date, there is a lack of interventions designed specifically to provide caregivers with the skill set required to care for people with physical impairments after stroke. The TRACS (TRAining program for Caregivers of inpatients after Stroke) cluster randomized controlled trial (RCT) is currently underway, and its aims are to evaluate whether a structured, competency-based training program for caregivers improves physical and psychological outcomes for patients and their caregivers after disabling stroke. We recently completed an RCT (FAME – [Family-Mediated Exercise therapy] trial) that was designed to teach family members of people with stroke the skills to independently deliver an exercise program to their family members with stroke. To our knowledge, this was the first RCT to examine the impact of a rehabilitation model that facilitated active involvement of patients and their families in managing their recovery process in partnership with a physiotherapist. We demonstrated that an 8-week lower limb exercise program mediated by family members, in addition to routine physiotherapy, had a significant impact on recovery of impairment, activity, and participation. We also planned to complete a semi-structured interview with participants (person with stroke and their family member) to gain an understanding of their “lived in” experience of family involvement in the rehabilitation process. The aim of this study is to report on the qualitative element of the trial that explored the impact of the FAME intervention on individuals with stroke and their family members who participated in the exercise delivery.

Methods

FAME trial

The FAME trial was a single blinded RCT. Ethical approval was received for the study. Individuals with stroke were assessed for eligibility to participate in the FAME trial at 2 weeks after stroke onset, and those who had a diagnosis of a first unilateral stroke (confirmed by MRI or CT), had no impairment of cognition (score >23/30 on the Mini-Mental State Examination), were older than 18 years, were participating in physiotherapy, and had a family member willing to participate in the additional exercise intervention were eligible for inclusion. For the purpose of this study, family members were defined as family, friends, caregivers, or significant others who interacted with the person with stroke on a daily basis. Muscle strength, balance, proprioception, and cognitive function were assessed with the Orpington Prognostic Scale (OPS) to ensure that a homogenous population was recruited. The OPS is a clinically derived score that incorporates measures of cognitive impairment, motor deficit, balance, and proprioception. The score ranges from 1.6 (best prognosis/lowest level of disability) to 6.8 (worst prognosis/highest level of disability). Only individuals who achieved a score from 3.2 to 5.2 on the OPS at 2 weeks post stroke were included in the study. This cohort represents patients presenting with a moderate/severe deficit after stroke. After the provision of written informed consent, individuals with stroke and their designated family member were randomly assigned to a control group or an intervention group. Members of the control group (n = 20) received conventional, routine, or traditional levels of physiotherapy, delivered by the physiotherapy staff at the individual sites, for the duration of the trial. This group did not receive any additional structured physiotherapy intervention in the form of family-mediated exercises. Routine inpatient physiotherapy after acute stroke in hospitals and rehabilitation units in Ireland varies between and within centers. However, a previous study conducted with patients with acute stroke in the Dublin area and senior physiotherapists indicated that routine physiotherapy after acute...
stroke generally consists of physiotherapy every weekday for a period of 30 to 60 minutes.17 In the outpatient setting, the senior physiotherapists reported that routine physiotherapy generally consists of physiotherapy once a week for a period of 45 to 60 minutes. The FAME group (n = 20) also received routine therapy and 35 minutes of additional family-mediated exercise therapy daily for 8 weeks. The goals of the FAME program were to strengthen the lower limb through functional exercises, to achieve optimal stability and balance in sitting and standing, and to improve gait velocity. Exercises were designed appropriate to each participant’s ability. The methodology for the RCT has been described in detail elsewhere.18

Theoretical framework

A phenomenological theoretical framework and a grounded theory methodology were used to inform the data analysis of the qualitative component of this study. A grounded theory methodology within the framework of phenomenology is frequently used in rehabilitation research and in groups of individuals with stroke.4,16-22 The aim of a phenomenological theoretical approach is to set aside current knowledge and review concepts through the eyes of the individual experiencing them. Using this approach, researchers take the view that there is no correct answer, but that each individual has a range of subjective experiences. The aim is to identify, understand, describe, and maintain the subjective experiences of research participants and by doing so to develop new understanding.23,24 In this study, the purpose of the interview was to enhance the researchers’ understanding of the “lived in” experience of the FAME program from the perspective of the person with stroke and the family member and also to examine whether the program had influenced their perceptions of exercise and exercise delivery after stroke.

A grounded theory methodology assists in the development of theory and in grounding that theory in data.25,26 The concept behind grounded theory is that data gathering should not be influenced by preexisting theory, but, rather, theory should be derived from data. Therefore, in this study, the aim was to set aside current knowledge about the advantages, disadvantages, barriers, and facilitators to participation in a family-mediated exercise program after stroke and not to predetermine the likely experiences (either positive or negative) that participants (person with stroke and family member) might have from their involvement.

Interviews

After the trial, a semi-structured interview was conducted with the individual with stroke in the FAME group to acquire a sense of his or her experience in relation to the additional exercise therapy intervention. Interviews were also conducted with the designated family member. All interviews were conducted separately: therefore, only the interviewee and the person conducting the interview were present in the room at the time of interview. An independent experienced qualitative researcher (T.C.), not involved in stroke rehabilitation and unknown to the participants, conducted the semi-structured interviews. Before the interviews, this researcher discussed the proposed research with a person uninvolved in the study. This dialogue allowed the researcher to identify any preconceived notions and perceptions of the research and thus to recognize and address potential sources of bias. These presuppositions were then set aside or suspended so that the phenomenon could be explored and examined openly without preoccupation. 27

The interview questions were based in part on previous work in which family and caregiver involvement in physiotherapy was examined,17,28 together with elements that were considered relevant to the FAME trial in terms of examining the perception of participants and families about FAME therapy and outcome. Appendix 1 contains details of the questions that were used to guide the interview with the person with stroke and his or her family member. The interview schedule contained broad areas to be discussed and was revised as new topics were raised during the interview. In terms of the questions posed to the participants with stroke, the schedule shows that questions 1 and 2 were worded in such a way as to be more likely to elicit positive responses, whereas questions 5 and 7 were worded in a way to be more likely to
elicit negative responses. With reference to the interviews conducted with the family members, questions 1 and 2 were likewise designed to elicit more positive responses, whereas questions 3 and 5 were more likely to result in negative responses. The remaining questions were more open ended, eliciting neither more positive nor more negative responses. In all cases, only the interviewer and the study participant were present during the interviews to minimize any distraction or influence over the participant’s responses. Each interview took about 45 minutes to complete. In addition to the qualitative questions, each participant provided an overall evaluation of the program on a Likert scale of 1 to 5, with the anchors being “very dissatisfied” and “very satisfied.” All interviews were audio recorded by means of a digital voice recorder for later transcription.

Data analysis

All interviews were transcribed verbatim by one author (R.G.). All participants were assigned a code to ensure anonymity in the transcript. The transcripts were explored using a process of framework analysis. This form of analysis provides 5 systematic and visible stages to the analysis process; although the general approach is inductive, it facilitates the inclusion of a priori as well as emergent concepts during coding.29 In stages 1 and 2, transcripts were read in their entirety to acquire a sense of the whole, and patterns and themes were identified using line-by-line analysis and were documented. Stages 3 and 4 involved coding and charting the responses to facilitate the identification of recurrent patterns and themes. Finally, the suitability of the coding system was checked during the process of establishing inter-rater and intra-rater reliability and pursuing patterns both consistent and inconsistent with the codes defined. The codes were designed to be understandable definitions, which could be easily interpreted and used by other independent coders.

Inter-rater and intra-rater reliability were determined according to the methods described by Miles and Huberman.30 In terms of intra-rater reliability, R.G. rechecked the coding on an uncoded copy of the responses several days after the initial coding. Internal consistency is usually found to be in the region of 80%.30 Intra-rater reliability was found to be 95% for the responses (172 agreements from 180 agreements and disagreements) from the individuals with stroke and 93% (139 agreements from 150 agreements and disagreements) for the responses from their family members.

For the purposes of ensuring definitional clarity and reliability and assessing inter-rater reliability, 2 independent researchers were provided with the responses to each question in an uncoded format, and they independently coded the responses sequentially using the predefined codes. The coded transcript from these 2 independent coders was examined and compared with the questions that had been previously coded by R.G. Initial inter-rater reliability is usually reported to be in the region of 70%.30 Inter-rater reliability in this case was found to be 85% for the codes used to define the responses from individuals with stroke and 83% for their designated family members. After the examination of initial inter-rater reliability, a conflict resolution meeting was held to resolve all coding disagreements between coders. Two new codes relating to the description of the perceived benefits of the program from the perspective of the individual with stroke were identified and agreed upon by the 3 coders in an attempt to more accurately reflect the data presented. Thereafter, a fourth coder independently verified all the codes.

Results

Twenty people with stroke participated in the FAME intervention. Table 1 contains the demographic details of the participants. Fifteen participants completed the semi-structured interview after the 8-week FAME intervention. The remaining 5 individuals, who were allocated to the FAME group initially, were unable to complete the interview because of attrition from the program (n = 3) and refusal to complete the interview (n = 2). The family members of these participants were not contacted to participate in the interview. Interviews were conducted either in the hospital or in the person’s home. The semi-structured interview with the designated family member (n = 15) was also undertaken at 8 weeks, when the person with stroke had completed
the intervention. Each interview was conducted immediately after the interview with the individual with stroke at the same location. The designated family members consisted of 9 spouses or partners and 6 adult children.

After data analysis, an overarching concept of *patient-centeredness* emerged. This is not a new concept and has been identified among a range of health care professionals as client-centered practice, patient-centered care, and patient-focused care. Although these terms are used interchangeably, all have subtle differences, particularly with respect to the role of the patient in the process. Cott\(^3\) defines client-centered care as that which incorporates much more than goal setting and decision making between individual patients and professionals. Cott’s notion of client-centered care refers to an approach to the delivery of rehabilitation services that mirrors the needs of these individuals. This approach is grounded in a shift from an acute illness, curative model to one that recognizes the long-term life course of chronic illness or disability.\(^3\) This philosophy is particularly pertinent to our research on individuals with stroke. Our data illustrate the extent to which individuals with stroke and their families felt that their rehabilitation was individualized, personalized, and unique to them.

Four key themes that expanded the concept of *patient-centeredness* were identified, namely the personalized nature of the reported benefits, the therapeutic value of the FAME program, the role of family in rehabilitation, and the additional burden experienced by participants. Each key theme is illustrated by pertinent quotations to reflect the extent to which the FAME program was viewed as a positive experience. For the purposes of the data presentation, the responses from the individuals with stroke are identified with the abbreviation “PT,” and responses from family members are identified with the abbreviation “FM.”

### Personalized nature of the reported benefits

All participants expressed a strong sense of involvement in the FAME program. Notably, reported benefits were individual to each participant, which is not unexpected, given that each exercise plan was individual, specific, and tailored to the person’s needs after consultation with the family and the treating physiotherapist. The individual and personalized nature of recovery was evident in the responses from participants when they were asked what element of the FAME intervention was most beneficial. Seven respondents noted that a single element—such as the additional exercises, the family involvement in the exercises, or the visit from the physiotherapist—was the most beneficial part of the FAME trial.

*The additional exercises with my leg, that was the best.* [PT 08]

*My wife attended all of these sessions and she was taking things in…. [PT 14]*

Others noted that a combination of 2 or more elements of the FAME program was the most helpful for their recovery:

*Well I suppose it was the additional exercises and being helped by the family to do them you know. [PT 02]*

*I suppose X [FAME physiotherapist] visits were super but I think the exercises was the key to it all and the fact that they were explained so well and what the benefit was for me, where it was going to benefit me, was all explained so well, I had no doubts, no worries in doing them. [PT 10]*

These responses highlight the personalized nature of the reported benefits of the FAME program.

The majority of individuals with stroke (n = 10) indicated that participation in the trial was a positive experience, and 12 participants reported that it added a sense of structure to their daily

### Table 1. Baseline details of the FAME participants

<table>
<thead>
<tr>
<th>Variables</th>
<th>Control group</th>
<th>FAME group</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of participants</td>
<td>20</td>
<td>20</td>
</tr>
<tr>
<td>Mean (SD) age in years</td>
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<td>63.15 (13.3)</td>
</tr>
<tr>
<td>Gender</td>
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<tr>
<td>Male</td>
<td>7</td>
<td>13</td>
</tr>
<tr>
<td>Female</td>
<td>13</td>
<td>7</td>
</tr>
<tr>
<td>Type of stroke</td>
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<td></td>
</tr>
<tr>
<td>Hemorrhagic</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Ischemic</td>
<td>18</td>
<td>16</td>
</tr>
<tr>
<td>Side of paresis</td>
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<td></td>
</tr>
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<td>11</td>
</tr>
<tr>
<td>Right</td>
<td>14</td>
<td>9</td>
</tr>
<tr>
<td>OPS score (SD)</td>
<td>3.8 (0.8)</td>
<td>4.1 (0.7)</td>
</tr>
</tbody>
</table>

Note: FAME = family-mediated exercises; OPS = Orpington Prognostic Scale.
lives. This sense of structure allowed participants to take ownership of their recovery and their exercise routine.

It gave me a structure where I would have done my physio, but then that would’ve been it really, whereas I had this exercise program, it was structured, it was well thought out and it was you know, it motivated me again at 6 o’clock in the evening – I had something else to do. [PT 10]

It added a small bit of structure to my day actually, ’cause when you’re sitting around doing nothing, you have to drive yourself, motivate yourself to do these exercises and you might not do them if you hadn’t got the structure. [PT 11]

This sentiment was also expressed by the family members:

I would say it gave her extra focus, it gave her something to do with us apart from what she did with the physio’s at the time… . [FM 03]

It gave him something very definite to work on, you know and to do himself, because he likes to take control over things himself, so it gave him some control over what was happening to him. [FM 09]

I think even though he is very motivated, it kind of got him into a new kind of routine that had to be done. And you know when you went up in the evening time, no matter who was doing the work with him, it was “Ok, let’s do the exercises.” [FM 13]

These quotations illustrate the personalized nature of the patient’s recovery and the individual nature of the reported benefits, in keeping with the overarching concept of patient-centeredness, particularly with reference to the notion of delivery of rehabilitation services that mirror the needs of the individual.

Therapeutic value of the program

The second key theme within the patient-centeredness concept was therapeutic value. Individuals with stroke and their family members identified several benefits to themselves and each other as a result of participation in the program. These benefits were much broader than the physical outcomes alone. Individuals with stroke highlighted physical benefits such as improvements in physical impairments, balance, mobility and confidence:

… all of those additional exercises helped me develop a lot more strength in my legs, calves and thighs. [PT 02]

The program helped me with my balance, because I couldn’t… I wobbled all over the place in the beginning but I’m improving all the time at it, so it definitely helped me with my balance. [PT 03]

The additional exercises in the bed helped when I started to walk, I started to walk very quick after that… . [PT 12]

My confidence grew all the time, every time I made progress, my confidence improved. [PT 08]

Family members also felt that there were psychological benefits to the program, particularly in relation to levels of motivation and enthusiasm:

Since he’s been working on that program (FAME) his balance is a lot better you know, that has helped him so much, even his mindset has improved. [FM 07]

When X [FAME physiotherapist] came and put him into the program, the extra support and exercise was just great. Like, she continuously encouraged him and he believed he could do it… it was a massive help. [FM 11]

I think it helped him in a very big way. Like I thought, like X [FAME physiotherapist] gave him great enthusiasm to help him to move. Like I remember the first night that he was able to lift up his foot, it was only a tiny little bit, but he was so thrilled about that but it’s just, like there, and having the extra help, it just did, it meant an awful lot to have to be honest like, I think it really helped XX [husband]. [FM 14]

These comments also support the importance of patient engagement in rehabilitation by physiotherapists and other health care providers. For clients to become independent and autonomous in terms of exercise participation, they must receive education and support. In this case, it is perhaps the value of FAME physiotherapists that they empower and enable persons with stroke and their family members to develop independence.

Role of family in rehabilitation

Family involvement in exercise delivery was the kernel of the FAME trial. This was also highlighted by the participants during the interviews. However, the broader role of the family in rehabilitation was also highlighted in terms of what was both helpful and unhelpful about involving family members in the exercise program. Individuals with stroke identified family involvement in the program as a motivator to complete the additional exercises. A number of comments made by participants in this regard included the following:

… just having my mom and my sister and my brother there to motivate me. [PT 08]
Continued family involvement as motivation to continue with exercise after the FAME intervention was also mentioned by participants:

*Once my family would be around me and they could motivate, that would keep me going with the exercises.*  [PT 08]

*If I had [my wife] to keep motivating me, she is very good at this, I'd be motivated to keep it [exercise program] up….*  [FM 09]

Fourteen family members indicated that they would continue to encourage and assist their family member with stroke to exercise after completion of the study.

*Oh yeah, I've been with her for a walk everyday and I'll definitely continue with that.*  [FM 03]

*I think the whole exercise program is very good, the fact that it was a week of different things so one week you'd have one set, another week you'd have another set and it's just its great it makes you feel that you're doing something rather than just sitting beside the bed and being helpless to do anything.*  [FM 12]

Involvement of the family in the rehabilitation process was identified as a positive experience, particularly in relation to engagement in exercise and physical activity. This feeds into the overall model of patient-centeredness as one that acknowledges the long-term impact of chronic illness such as stroke and recognizes the key role that families play in the life course of the disease.

**Additional burden**

Caregiver burden was a component that was examined in the interviews based on previous research indicating that levels of strain experienced by families and caregivers of people with stroke should be monitored as part of routine poststroke care. 17, 32 Thirteen people with stroke and their designated family members reported that FAME did not add pressure to the family member's daily life. Two family members reported that FAME was an additional pressure in terms of a time commitment but viewed the intervention as a positive experience. This finding was also corroborated by the one of the individuals with stroke who reported that “Yes, absolutely, it took up their time… but they didn't mind… .”  [PT 15]

Satisfaction with the FAME intervention was also explored during the interviews. Overall, both individuals with stroke and their family members reported that they were very satisfied with the FAME program and were happy to encourage someone else in their position to participate in such an intervention:

*Absolutely, I would really and truly ‘cause I look at me and that’s that. I would encourage everybody who could possibly do it to do it.*  [PT 15]

*I think the additional program was very beneficial and I would be… I would have no problem recommending it to anyone else. Absolutely no problem whatsoever… .*  [FM 11]

These findings illustrate that both people with stroke and their family members did not perceive the FAME program to be an additional source of burden to themselves or each other and were happy with the support and information they received throughout the trial.

**Discussion**

The aim of this study was to explore the experience of an additional exercise intervention on the individuals with stroke and their family members. FAME was delivered by designated family members to individuals with acute stroke after the family member had received training from a physiotherapist. The interviews examined the subjective experience of the program from the perspective of the individual with stroke and his or her designated family member. The main concept that emerged from the interviews was one that we have called patient-centeredness. We believe this is consistent with the philosophy of client-centeredness described by Cott. 31 Although the themes that emerged in these interviews do not cover all aspects of client- or patient-centered rehabilitation as described by the author, 31 issues such as individualization of rehabilitation, active participation in goal setting and decision
indicate that the majority of family members did not find that the FAME program added pressure to their daily lives. The difficulties that caregivers face in managing people with stroke in the community have been cited as a contributory factor to caregiver strain, social exclusion, and isolation. In the past, studies have focused on interventions to support caregivers of persons with stroke by providing additional information and education, counseling, emotional support, or help with accessing services by means of information packages or meetings with social workers, specialist nurses, or family support workers. However, these interventions have been shown to have little impact on individuals with stroke and to result in only modest improvements in psychological and social measures in caregivers. This lack of effect may be due in part to the inability of some of the measures chosen to capture change as a result of the interventions; furthermore, few interventions took into account the physical demands of caring for individuals with physical deficits after stroke. Collaborative “hands on” interventions, such as the FAME program, with the family and informal caregivers from the outset can serve to highlight areas of difficulty for caregivers and implement the necessary support to assist caregivers in this regard.

Several family members detailed that the additional exercise program allowed them to become more involved in the rehabilitation process and make a “real” contribution toward the individual’s recovery. These sentiments have also been reported in other studies. The majority of family members were happy to assist in the delivery of exercises and were willing to assist and encourage their family member with stroke to continue to exercise after completion of the program. It is important to recognize that family members and caregivers play an important supporting role in the rehabilitation process, a role that may increase with the growing trend of providing stroke rehabilitation in the individual’s home after discharge from the hospital. Therefore, it is imperative that family members be involved and, more importantly, be comfortable with all aspects of the multidisciplinary rehabilitation of people with stroke from the outset.

The FAME program provided caregivers with skills essential for the day-to-day care of their family member with stroke, including demonstrations of the proposed exercises included in the program and supervised practice of a variety of activities including manual handling, transfers, and walking. The findings from the interviews indicate that the majority of family members did not find that the FAME program added pressure to their daily lives. The difficulties that caregivers face in managing people with stroke in the community have been cited as a contributory factor to caregiver strain, social exclusion, and isolation. In the past, studies have focused on interventions to support caregivers of persons with stroke by providing additional information and education, counseling, emotional support, or help with accessing services by means of information packages or meetings with social workers, specialist nurses, or family support workers. However, these interventions have been shown to have little impact on individuals with stroke and to result in only modest improvements in psychological and social measures in caregivers. This lack of effect may be due in part to the inability of some of the measures chosen to capture change as a result of the interventions; furthermore, few interventions took into account the physical demands of caring for individuals with physical deficits after stroke. Collaborative “hands on” interventions, such as the FAME program, with the family and informal caregivers from the outset can serve to highlight areas of difficulty for caregivers and implement the necessary support to assist caregivers in this regard.

Several family members detailed that the additional exercise program allowed them to become more involved in the rehabilitation process and make a “real” contribution toward the individual’s recovery. These findings have also been reported by other authors. Carr and Shepherd and Kalra et al note that the involvement of family members and caregivers in rehabilitation from the outset can lessen fears that caregivers may have about their ability to cope at home. Kalra et al also suggest that the use of a structured program of activities under professional supervision during inpatient rehabilitation may serve to empower consenting informal caregivers in their future role by teaching them appropriate skills. Two family members reported that involvement in the FAME program added pressure to their daily lives in terms of a time commitment. However, they viewed their participation in the additional exercise program as a positive experience. This finding is not surprising, because work and family commitments
had been cited as a limitation in the participation in physiotherapy. These findings illustrate the need for the careful consideration of family members who are appropriate candidates for participation in such an intervention after stroke.

Limitations of the study

This is the first study to explore the impact of a “hands-on” family-mediated exercise intervention from the perspectives of the person with stroke and the family member who mediated the exercise delivery. The use of a qualitative method of enquiry enhanced the FAME study by permitting the inspection of aspects of the FAME program that were not accessible through quantitative measurement alone. The conduct and analysis of the interviews focused on the participants’ subjective experiences and interpretations of their involvement in the FAME study. Through close examination of these individual experiences, the researcher captured the subjective experience of the additional exercise program. It is important to acknowledge that the results of the FAME trial and the findings from these interviews can only be generalized to those patients with physical deficits after stroke who meet the inclusion criteria specified in the study.

In addition, there is a possibility that satisfaction with the program was linked with the participant/physiotherapy encounter, and questions posed during the semi-structured interviews may have prompted responses that were acceptable rather than accurate. However, all interviews were conducted by an independent person unknown to the participant, thus reducing the risk of bias. Furthermore, one author (R.G.) delivered the additional exercise intervention. Although the same protocol—in terms of family training and supervision—was followed for each participant, the possible influence of therapist motivation, may have affected the overall findings in the interviews. Finally, 5 participants and their family members were not interviewed because of attrition from the program (n = 3) or refusal to be interviewed (n = 2). Two families refused to be interviewed because they were uncomfortable with the process of a separate interview by a person who was unknown to them. This may have resulted in selection bias in the sampling, but it was deemed unethical to contact these individuals.

Conclusion

This study explored the impact of a rehabilitation model that facilitated active involvement of patients and their families in managing their recovery process in partnership with a physiotherapist. The overarching concept of patient-centeredness was a key finding from the study and has important clinical implications. First, rehabilitation encompasses much more than simply dual goal setting and decision making between patients and clinicians. There is a need for health care professionals to focus on a rehabilitation model that reflects the needs of the individual. This study also serves to enhance our understanding of the role of family members in the rehabilitation process after stroke, particularly in relation to exercise delivery. There is a need for additional multidisciplinary intervention studies that focus on the needs of caregivers and patients as they move through the stroke recovery process. Such strategies will increase the ability of caregivers and patients to adapt to the life-changing event of stroke by optimizing health outcomes and quality of life.

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REFERENCES


APPENDIX 1

Interview Guide

1. Individual with stroke

Question 1: Do you think that the additional exercise program helped you in any way? In what ways do you think the program has helped you? Can you give some examples?

Question 2: What part of the program did you think was most beneficial?

Question 3: What motivated you to continue and complete your exercises now that you have completed the program?

Question 4: What do you think would help or facilitate you to continue with your exercises?

Question 5: Do you think that the program added pressure to your daily life?

Question 6: Do you think that your family member/friend [NAME] was happy to assist you with the program?

Question 7: Do you think that the program added additional pressure to your family member/friend [NAME] daily lives?

Question 8: Would you encourage someone else in your position to undertake this program?

Question 9: Can you rate your satisfaction with the program on a scale of 1 to 5? (1 = very dissatisfied, 2 = dissatisfied, 3 = neither satisfied nor dissatisfied, 4 = satisfied, 5 = very satisfied)

Question 10: Finally, is there anything further you wish to say or add to what you have already said?

2. Family member

Question 1: Do you think that the additional exercise program helped [NAME] in any way? In what ways do you think the program has helped them? Can you give some examples?

Question 2: What part of the program did you think was most beneficial?

Question 3: Do you think that the program added additional pressure to [NAME] daily life?

Question 4: Do you think that you will continue to assist or encourage [NAME] to exercise now that the study has been completed? What do you think would help you to do this, for example, keeping the exercise diary and having it checked regularly by the physiotherapist?

Question 5: Do you think that assisting with the exercise program added pressure to your daily life?

Question 6: Would you encourage someone else in your position to undertake this program with their family member/friend with a stroke?

Question 7: Can you rate your satisfaction with the program on a scale of 1 to 5? (1 = very dissatisfied, 2 = dissatisfied, 3 = neither satisfied nor dissatisfied, 4 = satisfied, 5 = very satisfied)

Question 8: Finally, is there anything further you wish to say or add to what you have already said?